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PSYCHOSOCIAL ADAPTATION TO LOWER-LIMB AMPUTATION
DURING THE YEAR FOLLOWING REHABILITATION:
A LONGITUDINAL AND QUALITATIVE ANALYSIS

VOLUME I

By

Olga Horgan



**A thesis presented to the University of Dublin for the degree of Doctor of
Philosophy**

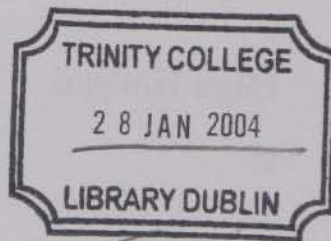
Trinity College Dublin
2003

PSYCHOLOGICAL ADAPTATION TO LOWER-LIMB AMPUTATION

THROUGH THE YEAR FOLLOWING REHABILITATION

A LONGITUDINAL AND QUALITATIVE ANALYSIS

VOLUME I



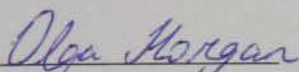
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DECLARATION

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Olga Horgan

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Psychosocial Adaptation to lower-limb amputation during the year following rehabilitation: A longitudinal and qualitative analysis

By

Olga Horgan

A wide variety of factors are associated with the process of physically and psychologically adjusting to an amputation. These are: demographic factors, including age, sex, marital status, education; personality factors and coping mechanisms; amputation-related factors, including time since amputation, amputation level, cause of amputation, phantom-limb pain, stump pain; and environmental factors, including social stigma, barriers to mobility, and available social support systems. This longitudinal study was conducted to examine the impact of these aspects on reactions to amputation and on psychosocial adaptation to changes that occurred during the year following lower-limb amputation and rehabilitation. In examining these interrelationships, semi-structured interviews were conducted with predominantly middle-aged and older adults with a lower-limb amputation. Participants were interviewed a maximum of four times, with the first interview being conducted while they were in rehabilitation, and subsequent interviews taking place in their homes throughout the following year. A grounded theory approach was taken in analysing interview data. Livneh's (2001) conceptual framework for studying psychosocial adaptation to chronic illness and disability was taken in examining the impact of demographic, social, personal, and amputation-related factors on adjustment to amputation. Over the year, a model of psychosocial adjustment emerged from the interview data and was explored in terms of reactions to the amputation, learning to walk, adapting to the prosthesis, phantom limb and stump pain, body-schema and body-image changes, lifestyle changes and limitations, social changes, and self and identity changes. A model of coping with these changes also emerged from the interview data and was explored in terms of emotional, cognitive, and behavioural approach and avoidance coping. It is contended that the longitudinal pattern of adjustment to amputation supports, to some extent, stage theories of adjustment to acquired disability. In addition, it is suggested that the patterns of change observed throughout the year suggest that the period after rehabilitation may reflect the end phase in these stage theories of adaptation to disability. The implications of these findings for rehabilitation and psychological well-being in adjustment to disability are also discussed.

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A person who undertakes an investigation of the world should be aware of the physical, mental, and psychological challenges that are faced in the process. The physical challenges that are faced include the need for physical fitness, the need to be able to stand for long periods of time, and the need to be able to handle the physical demands of the work. The mental challenges that are faced include the need to be able to handle the mental demands of the work, the need to be able to handle the mental demands of the work, and the need to be able to handle the mental demands of the work. The psychological challenges that are faced include the need to be able to handle the psychological demands of the work, the need to be able to handle the psychological demands of the work, and the need to be able to handle the psychological demands of the work.

CHAPTER 1

LITERATURE REVIEW

The purpose of this literature review is to provide a comprehensive overview of the current state of research on the physical, mental, and psychological challenges that are faced in the process of undertaking an investigation of the world. The review is organized into three main sections: physical challenges, mental challenges, and psychological challenges. Each section provides a detailed overview of the current state of research on the challenges that are faced in the process of undertaking an investigation of the world. The review also identifies the key areas of research that need to be addressed in order to improve the understanding of the challenges that are faced in the process of undertaking an investigation of the world.

A person who undergoes an amputation of the lower limb(s) is faced with many physical, social, and psychological challenges. Some of the physical challenges that are faced include reduced mobility, adjusting to an artificial limb, learning to walk, and adapting to an altered body-schema. Some of the social challenges that are faced include becoming more dependent on other people for assistance, experiencing difficulties in accessing public places, maintaining friendships despite these problems, dealing with other people's reactions when they notice that the person they are talking to has an amputation. Finally, some of the psychological challenges that are faced include maintaining emotional well-being in the face of all of these challenges, using and/or developing appropriate coping methods, and adjusting sense of self and identity to incorporate all of the physical and social changes that have occurred.

In the present chapter, descriptive studies on the incidence and prevalence of amputation, causes of amputation, and level of amputation are reviewed. Following this, rates of physical adjustment to amputation and an artificial limb are reviewed and factors associated with such adjustment are examined. These factors are discussed in terms of two main categories: amputation-related or individual-related. Amputation-related factors include prosthetic referral, level of amputation, number of amputations, phantom limb pain, and stump pain. Individual-related factors include pre-amputation physical functioning, physical and cognitive functioning, and age. Following this, psychological adjustment to amputation is reviewed in terms of depression, anxiety, body-image anxiety, social functioning and social discomfort, and sense of self and identity and its relationship with physical limitations. Factors associated with adjustment are then discussed in terms of three main categories: Amputation-related factors, sociodemographic factors, and personality attributes and coping modes. Amputation-related factors include cause of amputation, level of amputation, time since amputation, phantom limb pain, stump pain, and aspects of the prosthesis. Sociodemographic factors include gender, age, education/socio-economic status/income, and marital status/social support. Following this, extrapersonal adjustment to amputation is discussed in terms of rates of employment, type of employment, factors associated with employment, and satisfaction from work. Finally, an examination of reactions and responses to amputation is conducted, and a discussion on whether this process could best be described as a "grief" reaction or "coping" response concludes the chapter.

AMPUTATION TRENDS

Incidence and Prevalence of Amputation

The incidence of amputation varies quite significantly amongst Western nations. One Swedish study reported that the incidence of amputation in the Motala Hospital catchment area was 42 per 100,000 of the population, per annum (Kald, Carlsson, and Nilsson, 1989). A study conducted in the U.S.A. found that the incidence of amputations in 1995/1996 was 12.28 per 100,000 for amputations performed at the level above the knee and 12.65 per 100,000 for amputations performed at the level below the knee. One of the most comprehensive studies comparing amputation rates across different nations was carried out in 2000 by the Global Lower Extremity Amputation Study Group. Results of this worldwide study revealed that the highest amputation rates across ten sites were in the Navajo area, USA. In this region, the rate of amputation, per annum, for all amputations in men was 49.5 per 100,000 of the population. The lowest amputation rates were in Madrid, Spain. At this site, it was found that the equivalent amputation rate for men was only 3.6 per 100,000 per annum. Figure 1.1 shows the results of this study for seven other sites in the United Kingdom, U.S.A., Taiwan, and Italy.

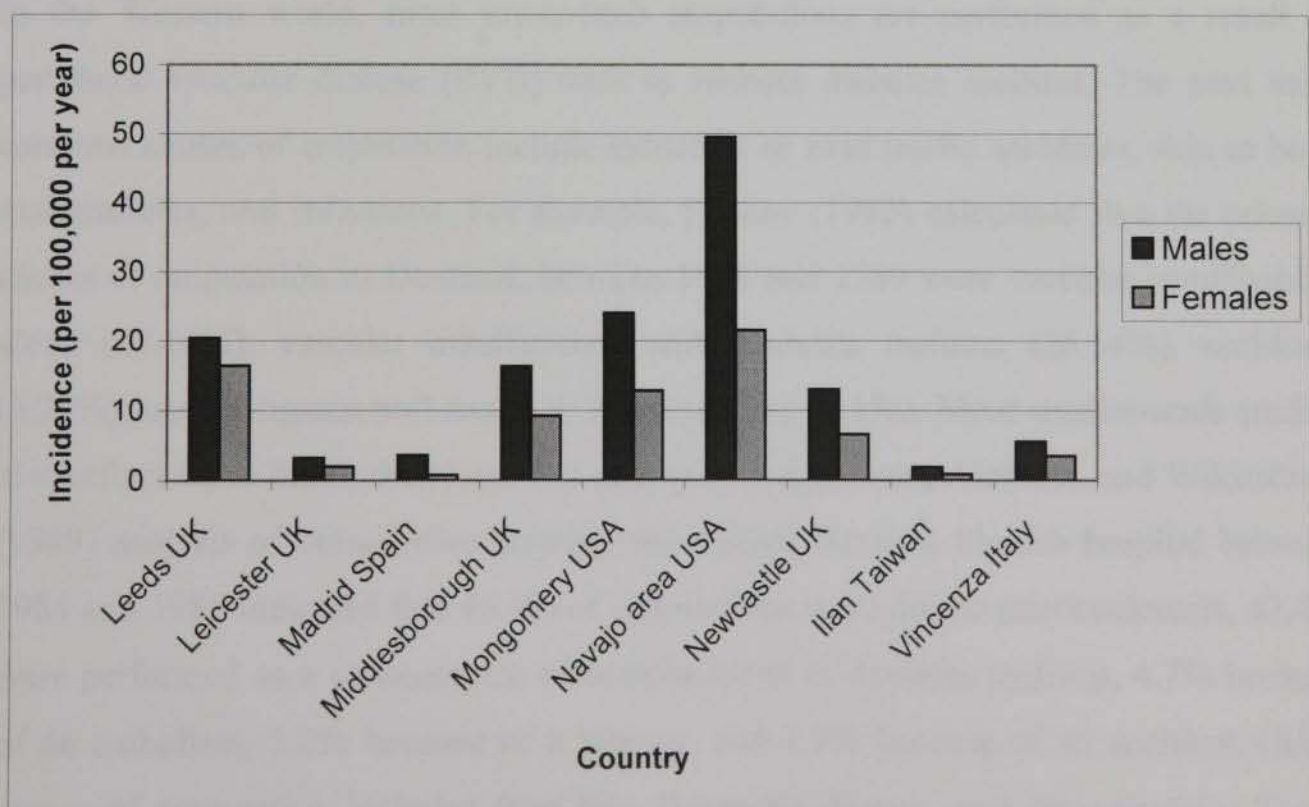


Figure 1.1: Age adjusted incidence of *all* major amputations for men and women in 9 international sites (Adapted from the Global Lower Extremity Amputation Study Group, 2000)

In Ireland, there are no statistics regarding the incidence and very few statistics regarding the prevalence of amputation in the population. However, an estimate of the number of people with amputations in Ireland was made by Keane (1994), who calculated that between 1961 and 1993, as many as 6,918 people attended limb-fitting clinics in various locations around the country, including Dublin, Cork, Galway, Donegal, and Sligo. Keane (1994) estimated that between 1984 and 1993, the new people that were being referred for rehabilitation assessment for the first time represented 85% - 90% of all new amputations performed per annum. If most people with newly acquired amputations are referred to a rehabilitation clinic for assessment, therefore, it could be estimated that the figure of 6,918 represents 85% to 90% of the total number of amputations performed in Ireland between 1961 and 1993. To place these data in some form of context, these figures are relatively small compared to what has been observed in other countries. For example, Lavery, van Houtum, Armstrong et al. (1997) found that in the U.S.A.'s state of California, the number of amputations performed in 1991 alone totalled 8,169. In Denmark, Ebskov (1992) reported that between 1978 and 1989, 25,767 lower-limb amputations were performed.

Causes of Amputation

In the Western world, most lower-limb amputations are performed as a result of peripheral vascular disease (PVD) with or without diabetes mellitus. The next most common causes of amputation include industrial or road traffic accidents, skin or bone malignancies, and infections. For example, Ebskov (1992) calculated that the primary causes of amputation in Denmark between 1978 and 1989 were vascular insufficiency alone (68.10%), vascular insufficiency with diabetes mellitus (26.54%), accidents (4.20%), and malignant soft tissue or bone tumours (1.1%). Most smaller-scale studies also reflect these broad divisions. For example, Pohjolainen, Alaranta, and Wikström's (1989) analysis of consecutive amputations carried out in a Finnish hospital between 1984 and 1985 indicated that 46.4% of amputations were due to arteriosclerosis, 42.4% were performed as a consequence of complications of diabetes mellitus, 4.7% because of an embolism, 3.2% because of a tumour, and 1.7% because of an accident. Other causes of amputation included frost-bite, Buerger's disease, and osteomyelitis. These broad causes reflect the fact that the majority of people with lower-limb amputations are

aged 60 years and over. In this age-group, 85%-95% of amputations due to vascular problems with or without diabetes mellitus (Pernot, de Witte, Lindeman et al., 1997).

Level of Amputation

Depending on the severity of disease and/or injury, major lower limb amputations can be performed at several levels. These include partial foot, whole foot (Symes), trans-tibial or below-knee (BK), knee disarticulation or through-knee (TK), trans-femoral or above-knee (AK), hip disarticulation (HD), and hemipelvectomy. The two most common levels of amputation are BK and AK, with BK rates being up to twice as frequent as AK rates. For example, Francis and Renton (1987), in Britain, reported that of 85 consecutive amputations performed over a four-year period, 65% were BK and 29% were AK. Similarly, another British study conducted by Campbell, Kernick, St. Johnston et al. (1994) remarked that of the 228 amputations performed over a five-year period, 65% were BK and 32% were AK. Although one notable exception to this ratio has been noted (Pohjolainen et al., 1989), long-term analyses of amputation levels confirm an increase in the number of BK amputations performed relative to AK amputations over the last twenty years (Ebskov, 1992; Cutson and Bongiorno, 1996; Fletcher, Andrews, Hallett et al., 2002).

Several studies have reported a relationship between level and cause of amputation. For example, it has been found that amputations due to diabetes mellitus tend to dominate foot-level and BK amputations (Ebskov, 1992; DeLuccia, De Souza Pinto, Guedes et al., 1992). Amputations for uncomplicated vascular disease and gangrene are predominantly performed at either BK (43%) or AK level (45%) (Ebskov, 1991). Amputations due to thrombosis and embolism are at significantly higher levels, with only 23.3% being performed at foot-level and 72% being performed at AK level. Finally, amputations performed as a result of neoplasm malignancies constitute 53% of all hemipelvectomies and less than 1% of foot to AK levels (Ebskov, 1992).

A relationship between level of amputation and patient age has also been reported in the literature. Three studies have found that the number of BK amputations decreased and the number of AK amputations increased with age (Ebskov, 1991; Mandrup-Poulsen & Jensen, 1982; Inderbitzi, Buettiker, and Enzler, in press). For example, Ebskov (1991)

reported that patients who had amputations at foot level were younger than those who had amputations at BK level, who in turn were younger than those with amputations at TK level, who were younger than those with amputations at AK level.

PHYSICAL ADJUSTMENT TO AMPUTATION

Post-amputation functioning

In examining the measurement of post-amputation functioning, an important methodological issue must be noted. A review of studies assessing mobility in people with amputations revealed that comparison across studies is not often possible because several measurement scales and questionnaires have been used to assess rehabilitation outcome (Rommers, Vos, Groothoff et al., 2001). Furthermore, the length of time between amputation and assessment has varied across studies; while some studies have looked at functioning six-months post-amputation, other studies have looked at functioning up to five years post-amputation, and others have used a cross-sectional design. Moreover, often the literature does not distinguish between people who have completed a rehabilitation programme and those who were not referred for prosthetic fitting. Bearing these issues in mind, and for the purpose of this literature review, I have grouped studies together on the basis of time since amputation that the assessments were carried out.

Studies assessing function at discharge from rehabilitation

Several studies have assessed functioning following discharge from a rehabilitation institution (Traballesi, Brunelli, Pratesi et al., 1998; Harris et al., 1991; Rommers et al., 1996; O'Toole, Goldberg, Ryan et al., 1985; Jensen and Mandrup-Poulsen, 1983). In terms of prosthesis use at this time, rates across studies have varied. For example, Rommers et al. (1996) reported that 83.9% of those with unilateral amputations and 60% of those with bilateral amputations had been successfully fitted with a prosthesis at discharge. Jensen and Mandrup-Poulsen (1983) reported that 76% of their sample were using their prosthesis at discharge, with 17% and 59% using their artificial limb for indoor use and outdoor use, respectively. Traballesi et al. (1998) found that just over 90% of their sample were able to walk with a prosthesis and that 45.8% and 44.4% had

reached what they called “good” and “partial” autonomy, respectively. Using broader criteria for assessing rehabilitation success, Harris et al. (1991) remarked that 89% of those referred for rehabilitation had reached their rehabilitation goals at discharge (for example, independent transfer for independent living, ambulating with a walker, independent walking), which included 73% of those aged 80 years and over and 66% of those with bilateral amputations.

Studies assessing function 5-6 months post-amputation

Several studies have also examined rehabilitation outcome and functioning five to six months post-amputation (Grieve and Lankhorst, 1996; Johnson, Kondziela, Gottschalk et al., 1995; O’Toole et al., 1985; Panesar, Morrison, and Hunter, 2001; Francis and Renton, 1987). In terms of prosthesis use, Francis and Renton (1987) found that six months after amputation 19% of their original sample of 84 people had died, 28% did not use a prosthesis, 7% only used their prosthesis occasionally, 13% used their prosthesis for walking indoors only, and 29% used their prosthesis for walking indoors and outdoors. In terms of functioning, findings have been somewhat mixed. O’Toole et al. (1985) found that six-months after leaving a rehabilitation hospital, levels of independence (as assessed using the PULSES) had decreased and need for social supports had increased since admission to the rehabilitation hospital. Similarly, Grieve and Lankhorst (1996) found that compared to pre-amputation functioning, a low-functional outcome at six months post-amputation was associated with increased scores on the Sickness Impact Profile (SIP) and decreased scores in physical functioning, social functioning, activities of daily living, and communicative functioning. On the other hand, Panesar et al. (2001) found that although the Functional Independence Measure (FIM) did not indicate any change in function between discharge and six-month follow-up, the Amputee Activity Scale showed that improvements had been made in terms of walking, ability to remove the artificial limb, lower use of walking aids, and reduced use of a wheelchair. Part of the problem in interpreting these findings is that the scale of ratings in indexes of ability/disability may be too broad to detect subtle changes in functioning (Feinstein, Josephy, and Wells, 1986). Therefore, any changes that had occurred may not have been indicated in the FIM and may have been too small to make any impact on the SIM. According to Panesar et al. (2001), the Amputee Activity Scale is a more appropriate instrument to measure daily functioning

than the FIM, as it examines actual levels of activity rather than the amount of support that a person requires to carry out an activity.

Studies assessing functioning 1-2 years post-amputation

Functioning one to two years post-amputation has generally focused on the extent of prosthesis use and contexts in which the prosthesis is worn (e.g. McWhinnie et al., 1994; Pohjolainen, Alaranta, Kärkkäinen, 1990; Uiterwijk et al., 1997; Pohjolainen and Alaranta, 1991; Steinberg, Sunwoo, Roettger et al., 1985; Kald et al., 1987; Weiss et al., 1990). At one year follow-up, Uiterwijk et al. (1997) found that out of a total cohort of 123 patients who had a limb amputated, 59% were using a prosthesis. McWhinnie et al. (1994) found that out of a total cohort of 96 patients who had a lower-limb amputation, only 47% were using a prosthesis for indoor (11%) and outdoor use (36%). Weiss et al. (1990) reported that out of a total cohort of 97 patients who had an amputation 15 months previously, only 36% had some level of ambulation.

In terms of only those who had attended a rehabilitation hospital, Pohjolainen et al. (1990) reported that 89% continued to use a prosthesis at one-year follow-up. Of these individuals, 79% used their prosthesis to walk indoors only, while 60% used it for ambulation both indoors and outdoors. Similar findings were observed by Pohjolainen and Alaranta (1991), who reported that at one year follow-up, 95% of people with BK amputations and 76% of people with AK amputations continued to use their prosthesis. At 10.5 months follow-up, Christensen et al. (1995) reported similar results. They found that 94.5% and 70% of people with BK and AK amputations, respectively, continued to use their prosthesis for either indoor use only or for both indoor and outdoor use. At two-years follow-up, rates of prosthesis use declined somewhat. For example, Steinberg et al. (1985) found that full-time prosthesis use was evident in 75% of those with BK amputations, 50% of those with AK amputations, and only 33% of people with bilateral amputations. Similarly, Kald et al. (1987) reported that 62% of people who had been referred for rehabilitation continued to use their prosthesis on a daily basis at two-years follow-up.

Studies assessing function 5-years post-amputation

A relatively smaller number of studies have assessed functioning in people with amputations at five years follow-up (e.g. McWhinnie et al., 1994; Helm, Engel, Holm et al., 1986). McWhinnie et al. (1994) followed 96 people with lower-limb amputations for a total of five years. Of the 54 who had been prosthetically fitted shortly after amputation, 31 were still alive at the final follow-up. Of this 31, approximately 50% were continuing to use their prosthesis for indoor or outdoor use. Out of the total sample, however, those continuing to use their prosthesis represented only 17%. More successful rehabilitation rates were reported by Helm et al. (1986). These researchers followed 257 people over a five year period. At the final assessment, 107 were still alive, 78 of whom had been prosthetically rehabilitated. Of this 78, 75% continued to use their prosthesis on a daily basis. Out of the total sample, however, those continuing to use their prosthesis represented only 23%.

Overall, in examining rehabilitation rates it is clear that when looking at rehabilitation for total samples, success rates are generally poor. For example, out of a total sample of people who had undergone a lower-limb amputation, Uiterwijk et al. (1997) found that only 59% were using a prosthesis at one year post-amputation. Similarly, McWhinnie et al. (1994) reported that only 47% of their original cohort was using a prosthesis one year post-amputation. At five years, total sample prosthesis was as low as 17% (McWhinnie et al., 1994) and 23% (Helm et al., 1986). Despite these poor overall success rates, however, when prosthesis use amongst those who have been referred for prosthetic rehabilitation only is assessed, success rates appear to be significantly more favourable. For example, discharge use of prosthesis amongst those who have been sent for rehabilitation ranges from 75% to 90% (Jensen and Mandrup-Poulsen, 1983; Rommers et al., 1996). One and two year prosthesis use rates amongst rehabilitated people appears to remain relatively constant for those with both BK and AK amputations. For example, Pohjolainen and Alaranta (1991) and Christensen et al. (1995) found that approximately 95% and 75% of people with BK and AK amputations, respectively, continued to use their prosthesis one year post-amputation. By five years post-amputation, prosthesis use appeared to have fallen somewhat (McWhinnie et al., 1994), although prosthetic use amongst five-year survivors was reported to be as high as 75% in one study (Helm et al., 1986).

PHYSICAL FACTORS ASSOCIATED WITH ADJUSTMENT TO AMPUTATION

Amputation-Related Factors

Prosthetic Rehabilitation

Following an amputation, not all patients are referred for rehabilitation. In fact, rates of referral for prosthetic rehabilitation tend to range between 17% and 65% of all people who have had a lower-limb amputation (Rommers, Vos, Groothoff et al., 1996; Harris, van Schie, Carroll et al., 1991). Rommers et al. (1996), for example, examined rates of referral and prosthetic rehabilitation amongst people with lower-limb amputations in the north of the Netherlands. Retrospective chart analyses revealed that between 1987 and 1991, only 17.64% of the 1,037 patients who underwent a lower-limb amputation were admitted to a rehabilitation centre. Similarly, Campbell et al. (1994) analysed referral rates, during a five-year period, amongst British people with lower-limb amputations and found that only 52% of an original sample of 210 patients were referred for prosthetic fitting.

Factors associated with prosthetic referral: Mortality

One of the predominant reasons for low referral rates to rehabilitation is the high mortality rate amongst people with newly acquired amputations (Fletcher, Andrews, Butters et al., 2001; Houghton, Taylor, Thurlow et al., 1992; McWhinnie, Gordon, Collin et al., 1994; Christensen, Ellegaard, Bretler et al., 1995; Campbell et al., 1994; Pell and Stonebridge, 1999). In general, postsurgical mortality during hospitalisation ranges from 10% to 30% (Cutson and Bongiorno, 1996; Campbell et al., 1994; Condie, Jones, Treweek et al., 1996; Kald et al., 1987; Mandrup-Poulsen and Jensen, 1982). Longer-term mortality rates are very high in the first year post-amputation and then begin to fall during the second and subsequent years. Ebskov (1996), for example, reported that during the first and second years following amputation, mortality was 8.4 times and 4.13 times higher than the expected mortality, respectively. Pohjolainen et al. (1989) reported that 2 month, 1 year, and 2 year mortality rates were 27%, 40%, and 59%, respectively, thus indicating a survival curve with an initial sharp fall and a more gradual decline thereafter. Similarly, Mandrup-Poulsen and Jensen (1982) and Jensen (1983) reported an initially steep mortality curve whereby 34% of the sample had died

during the first year post-amputation. Subsequently, they found that the mortality curves ran parallel to that of the control population and, after some years, converged towards the curve of expected mortality.

In their analysis of 100 sequential deaths of patients who had been referred to a limb fitting centre in Scotland, Stewart and Jain (1992) found that just over half of these deaths were due to myocardial infarction and heart disease. Other common causes of death were carcinomatosis, bronchopneumonia, and stroke. Similar findings were observed by Moran, Buttenshaw, Mulcahy et al. (1990), although the primary cause of death in their sample was bronchopneumonia, with myocardial infarction being the second most common cause of death. Adunsky, Wershawski, Arad et al. (1997) reported that one-third of the deaths in their sample were due to cardiac problems, with thromboembolic causes (28%) and sepsis/infection (26%) being other frequent causes of mortality.

Several risk factors for increased mortality have been observed in the literature. Age and level of amputation are among the primary factors associated with in-hospital and one-year mortality (Ebskov, 1996; Ebskov, 1991; Mandrup-Poulsen and Jensen, 1982; Moran et al., 1990; Pell and Stonebridge, 1999). In terms of age as a risk factor, Moran et al. (1990) found that patients who died during hospitalisation were significantly older than survivors (78 years vs. 71 years). In terms of level of amputation as a risk factor, Ebskov (1996) reported that during the first year post-amputation individuals with a Symes amputation were at a 5.39 times greater risk of dying than the general population of their age, individuals with a BK amputation were 7.59 times more likely to die, and those with an AK amputation were 13 times more likely to die. Since age and amputation level are already associated with each other, assessing the relative mortality risk of age versus amputation level can pose difficulties. Using logistic regression over a two-year period following amputation, Pell and Stonebridge (1999) reported that although both age and amputation level were significantly associated with mortality, age was an independent predictor of death at 30 days, 6 months, 12 months, and 2 years post-amputation. On the other hand, Jensen (1983) determined that primary amputation level was the most determining factor for death rate, whereas age had only secondary influence on the long-term chance of survival. It has been argued that amputation level

is associated with an increased risk of mortality because an individual requiring an AK amputation has more widespread disease than a patient requiring a BK amputation (Stewart and Jain, 1992; Pell and Stonebridge, 1999). Thus, an AK amputation is an indicator of disease severity associated with death, rather than a direct risk factor for mortality. Using multivariate logistic regression analyses, Mandrup-Poulsen and Jensen (1982) combined both age and amputation level in assessing mortality risk. These researchers reported that an 85-year-old with a BK amputation, a 70-year-old with a TK amputation, and a 50-year-old with an AK amputation all run a 15% risk of mortality within thirty days post-amputation.

The presence of other illnesses have also been implicated in increased mortality rates amongst people with amputations. Weiss, Gorton, Read et al. (1990) found that mortality rate in their sample was associated with multiple postoperative complications and frequent comorbid medical conditions. Similarly, Mandrup-Poulsen and Jensen (1982) reported that in-hospital mortality was primarily related to the occurrence of somatic complications. Although neither Harris et al. (1991) nor Stewart and Jain (1992) reported any difference in the immediate mortality rate between those with and without diabetes mellitus, DeLuccia et al. (1992) found that patients with diabetes had a risk of late mortality six times higher than that of non-diabetics over a five-year period.

Factors associated with prosthetic referral: Age

Significant associations have been found between age and lower prosthetic rehabilitation referral rates (Fletcher et al., 2002, 2002; Pohjolainen et al., 1989; Christensen et al., 1995). For example, Fletcher et al. (2001, 2002) reported that patients aged over 85 years were significantly less likely to be considered for prosthetic fitting than patients under 85 years. Similarly, Christensen et al. (1995) reported that out of 105 people with lower-limb amputations, 59% were not given a prosthesis. The mean age of those not fitted was 73.5 years, whilst the mean age of those fitted was 63 years for AK and 64.5 years for BK amputations. However, age has already been found to be associated with a higher mortality level (Moran et al., 19990), greater number of AK amputations (Ebskov, 1991), and higher number of comorbid medical conditions (Clark, Blue and Bearer, 1983), all of which are contraindications to prosthetic fit in their own right. Thus, when considering age as a variable in prosthetic rehabilitation, Clark et al.

(1983) stress the fact that age in itself is not an absolute contraindication to prosthetic fit. In support of this, they cite some anecdotal evidence that patients aged 90 and above have been fitted and successfully trained with a prosthesis.

Factors associated with prosthetic referral: Level and type of amputation

Other variables associated with referral for prosthetic rehabilitation are level and number of amputations. Patients with AK and bilateral amputations are significantly less likely to be referred for prosthetic fitting than are patients with BK amputations (Fletcher et al., 2001; McWhinnie et al., 1994; Uiterwijk, Remerie, Rol, et al., 1997; Fletcher et al., 2002; Pohjolainen et al., 1989). For example, Fletcher et al. (2002) reported that out of 292 patients with lower-extremity amputations, only 13% of those with AK amputations compared to 37% of those with BK amputations were fitted with a prosthesis. Similarly, Pohjolainen et al. (1989) found in their sample that only 18.4% of people with AK amputations compared to 51.3% of people with BK amputations received a prosthesis. In terms of those with bilateral amputations, McWhinnie et al. (1994) reported that a second amputation was one of the reasons why 43% of their sample were considered unsuitable for prosthetic fitting.

Level and type of amputation are considered barriers to prosthetic fitting primarily because significantly more energy is required to operate an AK prosthesis or bilateral prostheses than a BK prosthesis (Waters, Perry, Antonelli et al., 1976; Huang, Jackson, Moore et al., 1979). Huang et al. (1979), for example, found that compared to people without amputations, younger people (aged less than 40 years) with BK amputations required 9% more energy to walk, those with AK amputations required 49% more energy to walk, while those with bilateral AK amputations required 280% more energy to use their prostheses while walking. Although level and number of amputations are not direct contraindications to prosthetic fitting, these variables combined with comorbid medical conditions [see below] often make it unfeasible and unsafe for some people to attempt such a physically demanding task as prosthetic rehabilitation (Clark et al., 1983).

Factors associated with prosthetic referral: Medical comorbidities

In addition to mortality, level of amputation, and number of amputation, the presence of other medical comorbidities are often cited as reasons for low prosthetic referral rates (Condie et al., 1996; Fletcher et al., 2001; Harris et al., 1991; Campbell et al., 1994; Clark et al., 1983). In their study of 189 participants with lower-limb amputations, for example, Fletcher et al. (2001) reported that 60% were not referred for prosthetic fit for reasons which included the presence of cognitive deficits, cardiovascular disease, and poor skin integrity of the contra lateral or amputated limb. Harris et al. (1991) and Campbell et al. (1994) both reported that the occurrence of cardiovascular accident or stroke was a determining factor in considering candidates for rehabilitation. Clark et al. (1983) list several health complaints that should be considered before determining the appropriateness for prescription of a prosthesis. These include severe cardiopulmonary disease, severe and/or multiple neurological deficits, threatened gangrene of the contra lateral limb and poor stump healing. These writers suggest that in view of the increased energy required to operate a prosthesis, these comorbid medical conditions, particularly cardiac problems, might represent a relative contraindication to prosthetic rehabilitation.

Amputation Level

Once a person has been referred for prosthetic fitting, several other amputation-related factors can impact on their physical adjustment to amputation. One such factor is amputation level (Houghton et al., 1990; Pohjolainen et al., 1990; Uiterwijk et al., 1997; Helm et al., 1986; Steinberg et al., 1985; Hagberg, Berlin and Renström, 1992; Jensen and Mandrup-Poulsen, 1983). Hagberg et al. (1992), for example, examined rehabilitation outcome in 24 people with BK amputations, 18 people with AK amputations, and 17 people with TK amputations. They found that those with BK amputations were significantly better at putting on their prosthesis than those with either TK or AK amputations. In addition, while daily use of the prosthesis was recorded in 96% of the BK sample, only 76% of the TK sample and 50% of the AK sample used their prosthesis on a daily basis. Since they found that significantly more people with AK amputations made no use of their prosthesis than those with either TK or BK amputations, they concluded that a higher level of amputation resulted in a significantly lower level of rehabilitation. Steinberg et al.'s (1985) study found similar results amongst participants with BK and AK amputations. At 22 months follow-up, they

reported that although 75% of the BK sample continued to use their prosthesis, only 50% of the AK sample were still full-time prosthesis users. Generally, use of an AK prosthesis is associated with poorer rehabilitation success because it requires more energy to operate (Huang et al., 1979), because people with AK amputations tend to be older than those with BK amputations (Ebskov, 1991; Mandrup-Poulsen and Jensen, 1982), and because older people with amputations tend to have a higher number of medical comorbidities (Clark et al., 1983).

Because age, medical comorbidities, and level of amputation tend to co-occur, determining the most important factor in rehabilitation success can be difficult. Interestingly, however, two studies have reported no influence of amputation level on rehabilitation success (Lavan, 1991; O'Toole et al., 1985). Lavan (1991), for example, examined the rehabilitation outcome in 20 older, Irish people with amputations and found that over 90% used their prosthesis regularly and that the majority were competent in almost all activities of daily living. In addition, Lavan reported that there was little difference in the degree of functional competence between people with BK and AK amputations, with the exception of climbing stairs. Similarly, O'Toole et al.'s (1985) study of 60 people admitted to a rehabilitation hospital found that neither amputation level nor presence of diabetes mellitus had an influence on functional status. Instead, they reported that age was the most important determining factor in mobility.

Bilateral amputation

People with bilateral lower-limb amputations present a particular rehabilitation challenge. The major cause of bilateral lower-limb amputation is obstructive arterial disease with diabetes mellitus being present in many cases (De Fretes, Boonstra, Vos et al., 1994; Volpicelli, Chambers, Wagner et al., 1983). While the overall prevalence of bilateral amputations ranges between 21% to 33% of all people with amputations (Pernot et al., 1997), the rate of prosthesis referral for this group has been reported to be as low as 11% (Pohjolainen et al., 1990) and as high as 53% (Harris et al., 1991). Rates of successful rehabilitation in people with bilateral lower-limb amputations have ranged from 41% shortly post-discharge (Volpicelli et al., 1983) to 26% in cross-sectional studies with a mean follow-up time of 1.8 years. (Datta, Nair, and Payne, 1992).

In rehabilitating patients with bilateral amputations, age, level of amputation (Volpicelli et al., 1983), comorbid medical conditions (Thornhill, Jones, Brodzka et al., 1986), and mortality risk (Datta et al. 1992) each play a significant role. Volpicelli et al.'s (1983) study demonstrated the importance of age and level of bilateral amputations (as an index of disease severity) in predicting rehabilitation outcome. In this study, the functional outcome of patients with either bilateral AK or TK amputations, bilateral AK and BK, or bilateral BK/Syme amputations were compared. When results for the amputation level groups were considered separately, it was found that only 5% of the bilateral AK/TK group, while 79% of the bilateral BK/Symes group could walk. On the basis of these findings, it was concluded that patients' age at the time of the second amputation (younger or older than 60 years) and the extent of systemic disease were significantly related to ambulatory status. In fact, while 75% of the younger group, who had amputations predominantly due to trauma, had been rehabilitated, only 37% of the older group, who had amputations predominantly due to vascular disease, had been rehabilitated with a prosthesis.

Thornhill et al.'s (1986) study indicates the importance of particular medical comorbidities, over and above age, in determining rehabilitation success of people with bilateral lower-limb amputations. In their study, retrospective analyses of the outcome of older people with amputations due to vascular disease was compared with the outcome of relatively younger people with non-vascular-related amputations. Minimal functional use of bilateral prostheses for periods ranging from 5 months to almost 16 years was only 51% in the younger, non-vascular group compared to 71% in the older, vascular group. Further analyses indicated that the non-vascular group had a 67% rate of psychosis and a 78% rate of alcoholism, whilst the dysvascular group had several comorbid conditions, including diabetes, hypertension, cardiac disease, and blindness. Therefore, these results would appear to suggest the relative contribution of particular medical conditions over and above the effect of age.

Generally, as with people with unilateral amputations, survival rates for those with bilateral amputations is quite poor. For example, one study (Inderbitzi et al., in press) noted that in-hospital, two-year, and five-year mortality rates for people with bilateral amputations were 12%, 38%, and 69%, respectively. Some relationship between

mortality and use of prostheses in those with bilateral amputations has been found (Datta et al., 1992). A follow-up study of 41 consecutive patients, with a mean age of 66.8 years, revealed that individuals who had abandoned using their prostheses survived for an average of four years and four months, while those who continued to use their prostheses survived for three years and five months only. According to Datta et al. (1992), this finding could be explained by the fact that use of bilateral prostheses would place an additional strain on already compromised cardiorespiratory systems.

Phantom Limb Pain

Another amputation-related factor that could impact on rehabilitation outcome is phantom limb pain. Following the amputation of a limb, many people experience the sensation that the whole limb, or discrete parts of it, are still present. This sensation, termed 'phantom limb' by Weir Mitchell (1871), can either be perceived as painless or painful. Several longitudinal studies have been conducted examining the incidence, intensity, frequency, duration and qualitative descriptions of phantom limb pain (PLP). A longitudinal study of people with amputations primarily due to vascular disease (Jensen, Krebs, Nielsen et al., 1985) revealed decreasing PLP prevalence rates of 72%, 65% and 59% at 8 days, 6 months, and 2 years post-amputation, respectively. Somewhat different PLP rates were found by Nikolajsen, Ilkjaer, Krøner et al. (1997a), who reported increasing rates of 67%, 68% and 75% at the respective follow-up times of 1 week, 3 months, and 6 months post-amputation. Finally, relatively unchanged rates of PLP were found by Carlen, Wall, Nadvorna et al. (1978) and Steinbach, Nadvorna, Arazi et al. (1982). Carlen et al.'s (1978) initial study of 73 people with combat-related amputations, who were assessed one to six months following amputation, found that 67% complained of PLP. Five years later, Steinbach et al. (1982) reported that 69% of the 42 who were still available for follow-up were still experiencing PLP.

Etiological explanations for phantom pain – peripheral nerve factors

Several lines of evidence suggest that mechanisms in the periphery, that is, within the stump and spinal cord, are involved in the initiation or maintenance of phantom limb pain. For example, phantom limb pain is significantly more frequent in people with long-term stump pain than in those without persistent pain (Jensen, Krebs, Nielsen et al., 1983, 1985; Nikolajsen, Ilkjaer and Krøner et al., 1997). In addition, percussion of

the stump or stump neuromas can induce stump or phantom limb pain (Nyström and Hagbarth, 1981), and injection of substances into the neuromas that either increases or decreases sodium conductance can increase or decrease levels of phantom limb pain (Chabal, Jacobson, Russell et al., 1989). Changes occurring within the spinal cord following amputation are also hypothesised to be involved in phantom limb pain. For example, it is known that when peripheral nerves are severed, several physical and neurochemical changes occur in the dorsal root ganglion; the result being that transmission of nociceptive information is amplified (Cook, Woolf, Wall, et al., 1987). Despite this, and other, evidence suggesting that peripheral factors play a role in triggering phantom limb pain, the fact that pain can occur without stump pathology (Jensen and Rasmussen, 1994) and that phantom limbs can occur without nerve damage in people with congenital-related amputations (Melzack et al., 1997) suggest that that stump and spinal cord mechanisms are not the only factors involved in occurrence of phantom limb pain.

Etiological explanations for phantom pain – central nervous system factors

In a series of articles, Melzack (1990, 1992, 1995) has argued that phantom limb pain originates from what he termed the “neuromatrix,” a genetically hard-wired network of neurons that creates the person’s sense of body awareness or body schema. Normally, the neuromatrix engages in repeated, cyclical processing between the thalamus and the cortex and between the cortex and the limbic system to produce the “neurosignature,” an individual’s pattern of sensory processing that has his or her unique body schema as its output. Melzack (1990, 1995) argued that after an amputation, burning phantom limb pain occurs because even though the neuromatrix no longer receives modulating inputs from the amputated limb, it remains active for that region of the body and produces an abnormal signature pattern that produces the experience of a burning sensation in the limb. He also hypothesised that cramping and shooting phantom pain occur because of repeated messages from the action-neuromatrix to move muscles in the absent limb. As these messages remain unfulfilled, they increase in strength with the result that cramping or shooting pain is felt in the phantom limb.

Because neuromatrix theory encompasses a very broad framework, it is difficult to come up with definitive evidence either for or against it. Melzack (1995, 1990) himself

has stated that he cannot imagine how all of the disparate signals within the brain come together to produce the neurosignature. On the other hand, he has cited several animal studies, in which reduced phantom pain has followed after the neurosignature has been blocked by injecting a local anaesthetic into a discrete area, as providing support for his theory (Melzack, 1995, 1990). Empirical support for a genetically hard-wired neuromatrix underlying the body schema is provided by studies reporting that individuals born without a limb can still experience phantom limb pain and phantom limb sensation (Weinstein and Sersen, 1961; Weinstein, Sersen, and Vetter, 1964; Saadah and Melzack, 1994; Melzack, Israel, Lacroix et al., 1997; Gallagher, Butterworth, Lew et al., 1998). Having never had a limb where the phantom is felt, it is argued that the body schema for the absent limb must emerge from a genetically laid down pattern in the brain. However, recent brain-imaging studies which did not find any incidence of phantom limb sensation or phantom limb pain in adults with congenital limb absence (Flor, Elbert, Mühlnickel et al., 1998; Montoya, Ritter, Huse et al., 1998), have claimed that experience, for example trauma to the residual limb, rather than genetic factors, may be responsible for these experiences of phantom limb pain. Although psychological studies of body image (e.g. Pucher et al., 1999) and case studies of phantom limb in stroke patients (e.g. Halligan, Marshall and Wade, 1993) have used neuromatrix theory as a framework to explain their findings, this evidence can be perceived as indirect and *ad hoc* only. Further indirect evidence has been provided by brain imaging studies showing cortical correlates of phantom limb movements and pain (Ersland, Rosén, Lundervold, et al., 1996; Rosén, Hugdahl, Ersland et al., 2001; Rosén, Willoch, Bartenstein et al., 2001) and by neurological studies examining the relationship between cortical reorganisation and phantom limb pain (Flor, Elbert, Knecht et al., 1995; Grüsser, Winter, Mühlnickel et al., 2001a), which have generally interpreted their findings as consistent with the neuromatrix theory that pain and the body schema comes from a distributed network involving regions of the cortex and the subcortex.

Recent theories of phantom limb pain are currently examining its relationship to referred sensations and cortical reorganisation. Referred sensations, which are phantom limb sensations induced in the phantom limb by stimulating another part of the body, have been documented since the 1950s (Cronholm, 1951). However, Ramachandran,

Rogers-Ramachandran, and Stewart's (1992) study of referred sensations in three people with upper-limb amputations marked a resurgence of interest in this topic. These writers suggested that sensations referred to upper-limb phantoms by stimulating trigger points on the face and around the amputation stump could be due to an invasion of adjacent somatosensory areas into deafferented regions that previously served the now amputated limb. Several studies and case reports subsequently confirmed the phenomenon of referred sensations in people with upper-limb amputations (e.g. Halligan et al., 1993, 1994; Yang, Gallen, Schwartz, et al., 1994; Knecht, Henningsen, Elbert, et al., 1995, 1996; Knecht, Henningsen, Höhling et al., 1998; Doetsch, 1997; Borsook, Becerra, Fishman et al., 1998; Grüsser et al., 2001a). Generally, these studies indicated that although there is a distinct topographical relationship between the trigger points and the sensation referred to the phantom limb shortly after amputation, this relationship breaks down over time such that there is no discernible pattern observed between those areas on the body, specifically the face and chest, that elicit phantom sensation and the site of the elicited upper-limb phantom sensation (Ramachandran et al., 1992; Halligan et al., 1994; Doetsch, 1997; Knecht et al., 1998). The particular relevance of these findings for the occurrence of phantom limb pain is that a positive correlation between cortical reorganisation and the number of referred sensations for painful stimuli has been found (Knecht et al., 1995, 1996, 1998a; Grüsser et al., 2001a).

Concurrent with the above studies, many researchers using transcranial magnetic stimulation and neuroelectric source imaging found extensive reorganisation in both the motor cortex (Hall, Flament, Fraser, et al., 1990; Cohen, Bandinelli, Findley et al., 1991; Pascual-Leone, Peris, Tormos, et al., 1996; Chen, Corwell, Yaseen, et al., 1998; Rörich, Meyer, Niehaus et al., 1999; Dettmers, Adler, Rzanny, et al., 2001) and somatosensory cortex (Yang et al., 1994; Elbert, Sterr, Flor, et al., 1997) following amputation. Converging lines of evidence now indicate that this reorganisation is associated, to some degree, with phantom limb pain. For example, several studies using a variety of brain imaging techniques have found high, positive correlations between phantom limb pain and somatosensory and motor cortex reorganisation (Flor et al., 1995, 1998; Grüsser et al., 2001b; Knecht et al., 1996; Lotze, Flor, Grodd et al., 2001; Dettmers et al., 2001; Karl, Birbaumer, Lutzenberger, et al., 2001). In addition, a direct link between the two phenomena has been established by the finding that elimination of

PLP following an anaesthetic to the stump co-occurs with a reduction in cortical reorganization (Birbaumer, Lutzenberger, Montoya et al., 1997). Moreover, it has been found that use of a myoelectric prosthesis is associated with significantly less PLP and cortical reorganisation than use of a cosmetic prosthesis (Lotze, Grodd, Birbaumer et al., 1999) and that prevention of cortical reorganisation by training participants to discriminate stimuli applied to the amputation stump is associated with significantly less PLP (Flor, Denke, Schaefer, et al., 2001). Although these studies all point to associations among phantom limb pain, somatosensory reorganisation, and referred sensations, it must be remembered that the mechanism of reorganisation is still open to debate (Chen et al., 1998). In addition, it should be noted that not every person with an amputation experiences mislocalization (Halligan et al., 1994), that not every study has found a relationship between PLP and reorganisation (Schwenkreis, Witscher, Janssen, et al., 2001; Grüsser, Winter, Schaefer, et al., 2001b), and that one of the studies pointing to a relationship between cortical reorganisation and phantom limb pain (Lotze et al., 1999) has been criticised on the basis of flawed statistical analyses (Kooijman, Dijkstra, Geertzen et al., 2000). Moreover, because significant levels of somatosensory reorganisation have been found prior to amputation (Grüsser et al., 2001a) and because cortical reorganisation is also related to chronic and acute pain in the absence of amputation (Knecht et al., 1998b), the results of those studies that have assessed the relationship between post-amputation reorganisation and PLP may be confounded by pre-amputation levels of pain. Therefore, although the evidence points to some relationship between phantom limb pain and cortical reorganization, the precise causal nature of this association is not certain.

Influence of phantom limb pain on rehabilitation

Findings regarding the influence of PLP on prosthesis use and rehabilitation outcome have been mixed. Most earlier studies concluded, without having conducted research specifically aimed at investigating the question, that the experience of PLP was a debilitating one which caused major problems in the everyday and work lives of people with amputations (e.g. Sherman and Sherman, 1983; Sherman, Sherman and Parker, 1984). In addition, a more recent study by Pohjolainen and Alaranta (1991) reported that at one-year post-amputation follow-up, the occurrence of phantom pain was negatively associated with walking distance and walking time. However, several recent

studies have concluded that phantom limb pain causes disturbance to a minimal number of people only. For example, Houghton, Nicholls, Houghton et al.'s (1994) survey reported that only 22% of their sample thought that PLP interfered with their rehabilitation. Wartan, Hamann, Wedley et al. (1997) found that 68% of respondents with PLP did not seek treatment because their pain was not severe enough, frequent enough, or had disappeared entirely. Gallagher, Allen, and MacLachlan (2001) found that 63.5% of their sample did not think that phantom pain interfered with their daily lives during the previous week, while 19.7% remarked that it had interfered only "a little bit." The remaining 16.8% of respondents remarked that their phantom pain interfered moderately, a bit, or a lot in their daily lives. Finally, a series of recent studies (Smith, Ehde, Legro et al., 1999; Ehde, Czerniecki, Smith et al., 2000) revealed that back pain caused significantly more problems in the lives of their respondents than did phantom limb pain and that the majority of people with PLP fell into the two categories of either low pain intensity/low disability and high pain intensity/low disability (Ehde et al., 2000). In fact, Ehde et al. (2000) went so far as to conclude that phantom limb pain is "not particularly bothersome" in the lives of people with an amputation. In conclusion, then, these findings would appear to suggest that while the majority of people with amputations do not experience severe or debilitating phantom pain, its occurrence in a significant minority may interfere with prosthesis use, walking, and overall rehabilitation.

Stump Pain

In comparison to phantom limb pain, stump pain is defined as pain experienced in the residual body part that has not been amputated (Davis, 1993). According to Davis (1993), stump pain is commonly caused by six mechanisms. The most common cause of stump pain is improper fit of the prosthesis; that is, if the prosthetic socket is too tight, too loose, or if the rims or trim lines of the prosthesis are inappropriate. The second cause of stump pain is neurogenic pain; for example, the formation of neuromas or nerve bundles on the end of the stump. The third cause of stump pain is arthrogenic, that is, arising from a joint or its surrounding soft tissues. In people with BK amputations, this would be the knee-joint, and in people with AK amputations, this would be the hip joint. The fourth cause of stump pain is pain associated with the sympathetic nervous system. The fifth cause of stump pain is referred pain from the facet joints, the

sacroiliac joints, the piriformis muscle, or from various myofascial conditions. Finally, the sixth cause of stump pain is due to abnormalities of the stump skin; for example, scarring and infection.

Longitudinal studies of older people with amputations (Jensen, Krebs, Neilsen et al., 1983; Nikolajsen et al., 1997) have shown that over time, the prevalence and intensity of stump pain tends to decrease. For example, Jensen et al. (1983) found that the prevalence of stump pain in their sample, aged 69.8 years on average, decreased significantly from 57% of patients eight days post-amputation to 22% of all patients six months post-amputation. In addition, Nikolajsen et al. (1997) reported that intensity of stump pain, measured on a 100-point visual analogue scale, decreased from 15.5 at one week post-amputation, to 7 at three months post-amputation, and 4.5 at six months. However, cross-sectional studies examining stump pain prevalence and intensity in younger subjects, aged an average of 45 to 49 years have yielded different results (Gallagher et al., 2001; Smith et al., 1999). For example, Gallagher et al. (2001) reported that 48.1% of their sample had experienced stump pain during the previous week, and Smith et al. (1999) found that 76.1% of their sample had experienced stump pain during the previous month. In terms of stump pain intensity, Gallagher et al. (2001) reported that 13.1% described their stump pain as mild, while 47.8% found their pain discomforting, and 26.1% found it distressing. In Smith et al.'s (1999) study a larger percentage described their stump pain as mild (37%), while moderate and severe levels of stump pain were experienced by 23.9% and 38.1% of subjects, respectively.

In terms of the extent to which stump pain interferes with individual lifestyles, Gallagher et al. (2001) reported that stump pain interfered with daily living either moderately, quite a bit, or a lot in 39% of their subjects. In addition, Smith et al.'s (1999) respondents perceived their stump pain as being significantly more bothersome than either phantom pain or back pain. Although the influence of stump pain on rehabilitation outcome has not been extensively studied, the available research on this topic has indicated a negative relationship between stump pain and satisfactory rehabilitation (e.g. Clark et al., 1983; Smith, Horn, Malchow et al., 1995; Miller, Speachley, Deathe, 2001; Pezzin, Dillingham, MacKenzie et al., 2000; Steinbach et al., 1982; Pohjolainen and Alaranta, 1991; and Marshall, Jensen, Ehde et al., 2002). In older

people with amputations, stump complications and poor stump healing are contraindications against rehabilitation referral (Clark et al., 1983). In addition, amongst older people, Pohjolainen and Alaranta (1991) found that increased stump pain was associated with reduced outdoor walking and reduced walking distance. Moreover, Miller et al. (2001) found that one of the factors associated with having fallen on a prosthesis was stump pain. Associations between stump pain and rehabilitation have also been reported amongst younger people. For example, in their five-year follow-up study of younger participants with combat-related amputations, Steinbach et al. (1982) found that a greater number of stump pathologies was associated with decreased satisfaction with rehabilitation outcome. In addition, Gallagher et al. (2001) found that respondents with stump pain had a significantly poorer adjustment to their physical limitations than did respondents without stump pain. Moreover, Smith et al. (1995) reported that 75% of their respondents, aged 36 years on average, could only walk a certain number of steps a day, after which their residual limb would hurt.

Overall, therefore, on the basis of the above literature, it would appear that stump pain occurs more often in younger people with amputations, rather than in older people with amputations. Regardless of age, however, stump pain can interfere with adjustment to the prosthesis and rehabilitation outcome.

Individual Factors

Pre-amputation functioning

It is interesting to note that the majority of the above studies examining rehabilitation success rates and prosthesis use did not take into account pre-amputation functioning and mobility. Nevertheless, this factor has been found to relate to post-amputation prosthesis use and mobility in a number of studies (e.g. Uiterwijk et al., 1997; Helm et al., 1986; Johnson et al., 1995). Uiterwijk et al. (1997), for example, followed 123 people with lower-limb amputations from hospitalisation, to discharge, to one year later. They found that not only was poor pre-operative mobility associated with one-year mortality rates, but that having a prosthesis at one year (59%) was associated with a higher level of pre-amputation walking ability. Similarly, Johnson et al. (1995) examined the charts of 120 men with BK amputations and found that pre-amputation

and post-amputation mobility shortly after discharge were highly correlated ($r = .52, p < .001$). In terms of general functioning, Helm et al. (1986) used multiple regression analyses and found that five-year post-amputation functioning was significantly associated with pre-operative levels of dependence. Specifically, poorer functioning was related to higher levels of dependence pre-amputation.

Physical and Cognitive Functioning

Other individual factors associated with rehabilitation success are physical health and cognitive functioning (Hanspal and Fisher, 1997; Steinberg et al., 1985; Weiss et al., 1990; Pohjolainen and Alaranta 1991; Johnson et al., 1985). In examining the importance of medical factors, Johnson et al. (1995) conducted quite an extensive investigation into the relative influence of physical health on post-amputation mobility. These researchers reported that the mean number of concurrent medical problems experienced by the 120 people with lower-limb amputations in their sample was 1.75 (range 0 to 4). In addition, they found that number of post-amputation medical problems and mobility was significantly correlated. Although the mean post-amputation mobility score for patients with one to three medical problems was the same, the score for patients with no medical problems was at least one grade higher. In general, the two main medical problems that independently influenced mobility were cardiac disease and stroke. Other medical problems, including diabetes and peripheral vascular disease, influenced mobility in combination with other conditions. In considering the influence of both medical problems and cognitive functioning, Hanspal and Fisher (1997) assessed the latter in 32 men and women using the Clifton Assessment Procedures for the Elderly at 2-4 weeks and 8-14 weeks post-amputation. They found that when medical conditions were controlled for, intellectual status accounted for approximately 20% of the variance in mobility scores. In patients without comorbid medical conditions, intellectual status accounted for as much as 85% of the variance in mobility. Steinberg et al. (1985) also recognised the importance of both cognitive function and health status in determining prosthetic rehabilitation. They found that 22 months after undergoing discharge from rehabilitation, 75% and 50% of people with BK and AK amputations, respectively, continued to use their prosthesis. In addition to age being associated with non-use of a prosthesis, Steinberg and colleagues reported that non-use was usually due to mental deterioration or concurrent medical disease.

Age

Several studies have implicated age as an important factor in determining rehabilitation outcome at five months, one-year, and five-year follow-up (e.g. Grieve and Lankhorst, 1996; McWhinnie et al., 1994; Pohjolainen et al., 1990; Trallesi et al., 1998; Pohjolainen and Alaranta, 1991; Helm et al., 1996; Johnson et al., 1995; Steinberg et al., 1985; Narang, Mathur, Singh et al., 1984). Grieve and Lankhorst (1996), for example, found that lower scores on the Sickness Impact Profile were associated with age over 60 years at five months post-amputation. At one-year post-amputation, Pohjolainen et al. (1990) found that of the 8% of their sample who used a wheelchair only, 80% were aged over 60 years. Similar results were found by Pohjolainen and Alaranta (1991), who followed 125 people referred for limb fitting for a one-year period. They found that age was negatively associated with walking distance, walking time, amount of indoor walking, increased need for aids in ambulation, and decreased use of a prosthesis. Finally, at five-years post-amputation, age was found to be negatively associated with both general function (Helm et al., 1996) and level of mobility (McWhinnie et al., 1994).

PSYCHOLOGICAL ADJUSTMENT TO AMPUTATION

Depression

Depression is one measure of psychosocial adaptation to amputation that has been used extensively. Shortly after amputation, depression has been reported by some patients as being the reason for decreased use of prosthesis (Jones, Hall and Schuld, 1993) and lower levels of mobility (Gerhards, Florin and Knapp, 1984). Amongst people with long-term amputations, depression has also been associated with higher levels of activity restriction (Williamson, Shulz, Bridges et al., 1994), increased feelings of vulnerability (Behel, Rybarczyk, Elliott et al. 2002), and poorer self-rated health (Rybarczyk, Nyenhuis, Nicholas et al., 1995).

Research examining the prevalence of depression in people with amputations has had mixed findings. While some studies have found no evidence of increased depression amongst people with amputations (e.g. Fisher and Hanspal, 1998a,b; Breakey, 1997), others have concluded that they have a particular vulnerability to developing depressive

symptomatology (Hill, Niven, Knussen et al., 1995; Kashani, Frank, Kashani et al., 1983). In examining the literature, it is difficult to draw any firm conclusions with regard to these findings. Most studies examining this issue have been cross-sectional in design, thus utilizing responses from people who have had their amputations at different ages, for different lengths of time, and for different reasons (e.g. Behel et al., 2002). In addition, as prevalence and symptoms of depression can vary across different age-groups (Papassotiropoulos and Heun, 1999), determining the occurrence of depression amongst people with amputations is fraught with difficulties. Furthermore, authors across studies have varied in their methods of assessing depressive symptoms, with the result that many studies are, therefore, not comparable. Furthermore, those studies that have used the same instrument to assess depression have given different norm figures for rates in the general population, thus making their conclusions non-comparable across studies using similar methodologies. In view of these difficulties, then, for the purpose of this review, I have grouped studies examining prevalence of depression in people with amputations on the basis of the mean time since respondents had their amputation(s).

Depression one to two-years post-amputation

Comparatively few studies have examined rates of depression amongst people shortly after amputation or up to two years post-amputation. Amongst younger people, some depressive symptoms have been observed during the post-amputation hospitalisation period (Randall, Ewalt and Blair, 1945; Shukla, Sahu, Tripathi et al., 1982b). For example, Randall et al. (1945) reported that although most of their military sample had remarked that they felt lucky to be alive, depressive reactions were common enough amongst these participants. In their study of consecutively admitted patients, Shukla et al. (1982b) noted that 40% had symptoms of depression as assessed by diagnostic interview. Amongst older participants, high levels of depression have been found at the beginning of a rehabilitation program (58% using the Geriatric Depression Scale), and substantially lower rates of 12% have been found at discharge from rehabilitation (Schubert, Burns, Paras et al., 1992). Although they measured “psychological distress” rather than depression *per se*, similar findings were reported by MacBride, Rogers, Whyllie et al. (1980). In this study, they found that General Health Questionnaire scores

significantly fell between admission to and discharge from a rehabilitation unit, with the result that scores indicative of 'caseness' reduced from 75% to 47% of the sample.

Amongst people who were, on average, eighteen months to two years post-amputation, some depressive symptoms have been noted (Bodenheimer, Kerrigan, Garber et al., 2000; Caplan and Hackett, 1963; Thompson and Haran, 1984). Caplan and Hackett (1963), for example, described 58% of their 12 participants as depressed at eighteen months post-amputation. In addition, Bodenheimer et al. (2000) reported that on the Beck Depression Inventory, 30% of their sample scored above the cut-off score for depressive symptoms. Somewhat contradictory findings were reported by Thompson and Haran (1984), who examined psychosocial functioning in people with newly acquired and established amputations who had been prosthesis wearers for one to two years. They found that although only 13% of their sample reported feeling depressed following their amputation, almost half were at risk of psychiatric illness according to their General Health Questionnaire (GHQ) scores. Interestingly, several researchers have commented on this phenomenon. MacBride et al. (1980) reported that many of their participants admitted to their rehabilitation unit were unwilling to express distress in front of visitors for fear of upsetting them. Similarly, Parkes (1975) described how the participants in his study appeared to be under social pressure not to appear distressed about their amputation, but to appear optimistic and brave in front of others. Thompson and Haran (1984) suggested that participants in their study showed a "heroic cheerfulness" and a tendency to deny their emotional problems. Rogers, MacBride, Whyllie et al. (1977-78) noted these phenomena in the amputation group meetings they chaired as part of their rehabilitation program. They found that amongst people with newly acquired and established amputations, depression was a 'taboo' subject that was rarely mentioned. In fact, when depression was mentioned, it was predominantly as something that was retrospectively, rather than currently, experienced. These authors were of the opinion that the tone of these rehabilitation meetings was unrealistically positive and that participants did not want to admit to any negative or depressive emotions.

Depression two to ten years post-amputation

Compared to the one- to two-year depression rates discussed above, many studies examining depression amongst people who have had their amputations between two and ten years did not find elevated rates of depression amongst these individuals. In fact, only two studies did report higher rates of depression amongst people with amputations compared to the general population (Rybarczyk, Nyenhuis, Nicholas et al., 1992; Williamson et al., 1994). With both studies using the Center for Epidemiological Studies Depression Scale (CES-D) as an indicator of depressive symptomatology, the proportion of those scoring above the cut-off point was 23% (Rybarczyk et al., 1992) and 21% (Williamson et al., 1994). The fact that the only two studies in this period that found higher rates of depression both used the CES-D requires some comment. A study by Papassotiropoulos and Heun (1999), which used the CES-D with older populations, found that 27% of the sample scored above the cut-off score for depression, even though a clinical interview found that only 3.5% of the sample was actually depressed. On this basis, they concluded that the CES-D has a false-positive rate of 90.1%. Bearing in mind that 27% of Papassotiropoulos and Heun's (1999) participants appeared to be depressed according to CES-D scores, it could be argued that the participants in Rybarczyk et al.'s (1992) and Williamson et al.'s (1994) studies did not show particularly elevated rates of depression. In fact, it is only when one compares their findings with that of the norm rates discussed by these authors (Rybarczyk, al., 1992; Williamson et al., 1994), that is 10.7% and 15% in older adults, respectively, that one could consider their findings to be indicative of a high prevalence rate of depression.

The remainder of the studies with participants who had their amputation an average of two to ten years did not show particularly high rates of depression. One qualitative study of 19 people who had lost their limb one to five years previously found that only two had required treatment for depression post-amputation, a reaction that was also explained on the basis of their social circumstances (Furst and Humphrey, 1983). Moreover, according to participants of this study, their initial reaction of sadness to the amputation soon gave way to optimism with their concurrent physical improvement (Furst and Humphrey, 1983). A quantitative study by Marshall, Helmes, and Deathe (1992) using the Millon Clinical Multiaxial Inventory found no evidence of depression amongst middle-aged people who had their amputation an average of eight years

previously. Another quantitative study by Frank, Kashani, Kashani et al. (1984) reported mean Beck Depression Inventory scores of 6.5 amongst their sample, which was significantly below the cut-off point of 10 for indicating 'caseness'. Furthermore, these authors found no difference between a norm group and people with amputations in scores on the Symptom Checklist-90. Finally, using the Hospital Anxiety and Depression Scale (HADS) with patients aged an average of 65 years, Fisher and Hanspal (1998a), reported that only one person scored in the clinical range for depression. Moreover, the mean depression score in this study was 2.9, which was significantly below the cut-off score of 8 for indicating possible caseness.

Depression ten to twenty years post-amputation

Contrary to the findings above, only two studies (Breakey, 1997; Fisher and Hanspal, 1998b) have found low rates of depression amongst people who were ten to twenty years post-amputation. Breakey (1997), for example, found that amongst individuals who had had amputations an average of 17 years, rates of depression were low as assessed by the Generalized Contentment Scale. In addition, Fisher and Hanspal (1998b) reported that of their sample of 107 people with amputations, only 1 person scored in the clinical range for depression. On the other hand, the remaining four studies that have examined rates of depression in people who are ten to twenty years post-amputation have indicated somewhat higher rates of depression (Hill et al., 1995; Behel et al., 2002; Rybarczyk et al., 1995; Williamson and Walters, 1996). Of these studies, three used the CES-D, reporting rates of depression that ranged from 22.4% to 28% (Williamson and Walters, 1996; Behel et al., 2002; Rybarczyk et al., 1995). In the light of the above discussion regarding the CES-D and the fact that one study investigating its validity found comparatively high rates of depression using this instrument in a population sample of older adults (Papassotiropoulos and Heun, 1999), it could be argued that the findings reported by these authors are not necessarily indicative of high rates of depression. The remaining study reporting high rates of depression used the GHQ-28 and found that 30% exceeded the cut-off for moderate to severe levels of distress (Hill et al., 1995). This rate is higher than reported GHQ-28 norms of 24% and 8% amongst unmarried and married older men, respectively (Grundy and Sloggett, 2003).

Depression twenty to thirty years post-amputation

To date, there are few studies examining rates of depression amongst people with long-term amputations. Two studies have examined this amongst people who had their amputations an average of 20 to 30 years previously. Both of these reported rates that were consistent with those of the general populations. Dunn (1996), for example, used the CES-D amongst predominantly male respondents who had their amputation(s) an average of 20.36 years previously. She found that 18.2% of respondents scored above the cut-off point of 16, a rate which is lower than (Papassotiropoulos and Heun, 1999) or slightly over (Williamson et al., 1994) published norms. Gerhards et al. (1984) examined rates of depression amongst people who had their amputation an average of 30 years previously. They found that 16% could be considered to be suffering from severely depressed mood; a rate which they concluded consistent with the general population of that age-group.

Depression: Conclusion

In reviewing these studies of depression in people with amputations, a somewhat clear picture emerges. Studies of those with newly acquired amputations indicate that a depressive reaction is quite common in the initial phase of an amputation, although it could be argued that this is a normal reaction to losing a limb rather than a depressive reaction *per se*. Following the initial post-amputation stages, depression has also been found in people who are two years post- amputation. However, rates of depression seem to decrease again between two and ten years post-amputation, with only those studies using the CES-D indicating increased rates. Between ten and thirty years post-amputation, findings are mixed, with some studies indicating elevated rates of depression and others indicating normal rates of depression. In interpreting these findings, again, it is interesting to note that most of those studies which have found elevated rates of depression have used the CES-D, an instrument which has been shown to have high false-positive rates of depression amongst older individuals. In conclusion, then, when one discounts studies using the CES-D, depression in people with an amputation appears to be high immediately and between one to two years post-amputation. Following this, however, rates of depression appear to decrease to what is found in the general population.

Anxiety

Anxiety is another potential measure of psychosocial adjustment to amputation. Unlike the mixed findings that have been reported in terms of the prevalence of depression in people with an amputation, the findings regarding anxiety appear to be more straightforward. Studies on people up to one year post-amputation suggest that levels of anxiety are increased during this period (Randall et al., 1945; Shukla et al., 1982b). Randall et al. (1945), for example, reported that using Rorschach tests, 67% of the 100 soldiers in their study had free-floating anxiety. Similarly, Shukla et al. (1982b) reported that 53% of their younger participants indicated symptoms of anxiety shortly after amputation and during hospitalisation.

The remaining studies that have examined anxiety in people who had their amputation an average of two to twenty years have found no difference between these individuals and the general population in levels of anxiety (e.g. Bodenheimer et al., 2000; Fisher and Hanspal, 1998a, 1998b; Frank et al., 1984; Marshall et al., 1992; Weinstein, 1985; Breakey, 1997). Using the State-Trait Anxiety Inventory (STAI), Bodenheimer et al. (2000) found that amongst individuals who had their amputation for an average of two years years, mean scores were within the range for the normal population. Weinstein (1985) also used the STAI, and reported no significant differences between controls and older individuals who had their amputation for an average of 5.73 years. Fisher and Hanspal (1998a,b) used the Hospital Anxiety and Depression Scale and reported that although 10.75% of their sample scored within the clinical range for anxiety an average of 9.7 years post-amputation, only 3.7% of people who had an amputations for an average of 13.9 years scored within the clinical range. In summary, therefore, it would appear that anxiety is likely to be somewhat increased in the period immediately after and up to one year post-amputation. After this, however, anxiety levels appear to fall to those that are observed in the general population.

Body Image Anxiety

Adaptation to a changed body image is another potential mediator of psychosocial adjustment to amputation. One definition of "Body Image" is that it is "the combination

of an individual's psychological experiences, feelings and attitudes that relate to the form, function, appearance and desirability of one's own body which is influenced by individual and environmental factors" (Taleperson and McCabe, 2002; pg. 971).

In the general literature examining the relationship between disability and/or disfigurement and body-image anxiety, findings have been mixed. Some studies have found no relationship between disability and body-image anxiety (e.g. Ben-Tovim and Walker, 1995), while other studies have found significantly high levels of body-image anxiety amongst people following surgically altering procedures (Henker, 1979), burn injuries (Fauerbach, Heinberg, Lawrence et al., 2002; Fauerbach, Heinberg, Lawrence et al., 2000), scleroderma (Benrud-Larson, Heinberg, Boling et al., 2003) and mastectomy (Al-Ghazal, Fallowfield, and Blamey, 2000). Moreover, these and other studies have indicated that body-image anxiety is associated with poorer adjustment in terms of physical functioning (Fauerbach et al., 2000) and psychological well-being (Fauerbach et al., 2000, Al-Ghazal, Sully, Fallowfield et al., 2000; Benrud-Larson et al., 2003).

In the amputation literature, earlier papers briefly described the occurrence of body-image anxiety in people with an amputation (e.g. Friedmann, 1978; Furst and Humphrey, 1983; Frierson and Lippmann, 1987). Subsequent papers have since indicated that body-image distortion (Bhojak and Nathawat, 1988) and body image anxiety can, indeed, exist among some people who have an amputation (Rybarczyk et al., 1995; Breakey, 1997; Fisher and Hanspal, 1998b). Moreover, such anxiety has been found to be associated with depression (Rybarczyk et al., 1995; Breakey, 1997), quality of life (Rybarczyk et al., 1995; Breakey, 1997), lower self-esteem (Breakey, 1997), and higher levels of general anxiety (Fisher and Hanspal, 1998b).

Social Functioning and Social Discomfort

Social functioning is another potential mediator of psychosocial adjustment to an amputation. In addition to having to cope with physical limitations and the impact that these can have on social functioning (Pohjolainen et al., 1990), individuals have to adjust to the fact that they appear 'different' from other people. In the eyes of people who do not have an amputation, they may now appear 'disabled' and, in the words of

Goffman (1963), members of a 'stigmatised' group. Such perceptions of 'stigma' can sometimes lead to disabled people being treated differently by non-disabled people because the latter may make assumptions about all aspects of the individual's personality and functioning (Goffman, 1963). For example, people without a disability can sometimes make the erroneous assumption that a disability is the core aspect of the person's personality and functioning, rather than just one facet of his or her life (Dunn, 2000). In addition, people without an amputation are liable to assume that the occurrence of the amputation was a negative occurrence for the individual (Rybarczyk et al., 2000). In view of this, it has been reported that many people without disabilities ignore those with disabilities for fear of saying the wrong thing or because of experiencing general anxiety and unease in their presence (Gething, 1991).

In support of this, experimental studies (Kleck, 1969; Kleck, Ono and Hastorf, 1966) have indicated that people with simulated disabilities, specifically, a simulated amputation, are treated differently by those without any visible impairment. For example, Kleck et al. (1966) found that when a person with a simulated amputation conducted an interview with students, members of the latter group showed elevated physiological arousal as assessed by galvanic skin response. Moreover, those who expressed discomfort in the presence of the 'person with an amputation' terminated the interview sooner than those who did not express discomfort. In Kleck's (1969) subsequent study, students were required to teach Origami to a confederate either with or without an 'amputation.' Those who appeared to have an amputation were given significantly greater social distance by the students on the first trial, but not on the second trial. Interestingly, students in the study formed a more positive impression of the 'disabled' confederate than of the non-disabled confederate. According to Kleck (1969), the formation of a more positive impression may have been due to the tendency in society to be kind to 'disadvantaged' individuals. Newell (2000) argues that such 'kindness' may actually be an attempt on the part of non-disabled people to reduce anxiety upon seeing a disabled person and to establish a sense of dissimilarity from the latter.

In view of these findings that individuals without a disability are likely to treat those with a disability differently, it is no surprise that people with an amputation have also

reported such experiences (Gallagher and MacLachlan, 2001; Furst and Humphrey, 1983; Rogers et al., 1977). In their qualitative study, for example, Furst and Humphrey's (1983) participants remarked that other people often appeared embarrassed upon realising that they had an amputation. In support of Dunn's (2000) assertion that non-disabled individuals are likely to over-emphasise the role of the disability in the individual's life, Furst and Humphrey (1983) also found that individuals naïve with respect to an amputation rated people with amputations as being highly misfortunate compared to themselves, while individuals with an amputation rated themselves as being only marginally less fortunate after their amputation than before. Out of six disabilities, people with an amputation and their spouses rated a leg amputation as being the least severe, while naïve participants rated an amputation as being the second most severe of the disabilities listed. Participants in Gallagher and MacLachlan's (2001) study remarked that at times, other people had reacted to their amputation with shock and sometimes patronising behaviour. In addition, a small number remarked that they had sometimes been asked what they perceived as demeaning questions about their capabilities. Similar experiences were discussed by participants in Rogers et al. (1977-1978) rehabilitation groups, who found that others tended to react to them with feelings of awkwardness, avoidance, sympathy, and unwanted assistance. In dealing with such behaviour, those who had had their amputation for relatively longer periods remarked that having a sense of humour was important in dealing with such reactions.

In view of the fact that people with amputations are functionally restricted (Pohjolainen et al., 1990) and sometimes treated differently by others (e.g. Gallagher and MacLachlan, 2001), the findings regarding the impact of an amputation on social functioning have been mixed. Some studies have found that amongst younger, middle-aged, and older people with amputations, no significant differences in social functioning or levels of social discomfort have been found when compared to the general population (Smith, Horn, Malchow et al., 1995; Kegel, Carpenter, Burgess et al., 1977; Peters, Childs, Wunderlich et al., 2001; Weinstein, 1985). For example, Smith et al. (1995) found that participants in their study did not score any differently from general population norms in terms of Social Functioning, as assessed by the SF-36 Health Status Profile. Using a different measure, Peters et al. (2001) found no difference between people with diabetes with and without an amputation in social functioning as

assessed by the Sickness Impact Profile. Weinstein (1985) used the Discomfort Scale for measuring a sense of discomfort in interpersonal situations and reported no difference between older people with an amputation and randomly selected hospital visitors.

Contrary to the above findings, however, some social problems amongst people with an amputation have been reported (Nissen and Newman, 1992; Pell, Donnan, Fowkes et al., 1993; Pezzin, Dillingham, MacKenzie, et al. 2000; Schoppen, Boonstra, Groothoff, 2001a,b). Amongst older people with an amputation, Nissen and Newman (1992), for example, found that although their participants did not appear to have any difficulties in maintaining social relationships, they did experience some difficulties in participating in social activities. Similarly, Pell et al. (1993) reported that their participants reported significantly more problems with social isolation compared to controls on the Nottingham Health Profile. Amongst younger people with amputations, Burger and Marinček (1997) found that almost half of their participants visited friends and relatives less frequently since their amputation and that approximately two-thirds were less likely to go to the cinema, theatre, sport events, library, dances, and shows. Pezzin et al. (2000) found that their participants scored significantly poorer on Social Functioning, as assessed by the SF-36, than the general population. Similarly, Schoppen et al. (2001a) reported that individuals with an amputation scored significantly lower than controls on the Social Functioning subscale of the RAND-36.

Although it is difficult to assess the relative contributions of functional limitations, social discomfort, and perceived social stigma to overall social functioning, one study did find a direct link between activity restriction and social discomfort (Williamson, 1995). In this study, older people who experienced a sense of public self-consciousness were significantly more likely to report being restricted in caring for others, doing household chores, going out shopping, visiting friends and maintaining friendships. This finding was observed regardless of gender or age (Williamson, 1995). The relationship between social discomfort and decreased social functioning could also be mediated by depression. Two studies have found that perceived social stigma and social discomfort are significantly associated with increased levels of depression amongst people with amputations (Rybarczyk et al., 1992, 1995). In Rybarczyk et al.'s (1995) study,

perceived social stigma was measured by asking respondents to endorse having experienced being treated by others in ways that reflected stereotypical negative attributes of disabled people. In Rybarczyk et al.'s (1995) study, social discomfort was assessed using three questions examining avoidance of social contact and distress associated with being asked about the amputation. Both studies revealed that perceived social stigma and social discomfort significantly contributed to scores on the CES-D in separate regression analyses. Since depression is associated with increased physical disability in older adults (Bruce, Seeman, Merrill et al., 1994; Penninx, Deeg, van Eijk et al., 1999), social discomfort and perceived stigma could therefore impact on reduced physical and social activities indirectly as well as directly.

Identity, Self, and Limitations

Following an amputation, individuals must adapt to changed physical and social functioning and incorporate these changes into a new idea of self and self-identity. In this way, changes in physical functioning, limitations, and self-identity are closely related. In his paper examining the similarities between bereavement and limb loss, Parkes (1975) briefly touched upon this topic. He remarked that in the early phases, the person with an amputation feels mutilated, empty and vulnerable. As time passes, however, the individual discovers how well he or she can cope with the newfound limitations and restrictions. This ongoing process of discovery and accomplishment is what influences the person's final view of him/herself. Despite Parke's (1975) comments, to date there has been no research conducted on the relationships among functioning, limitations, and identity in people with amputations. Thus, to gain some insight into these relationships, the general literature on adjustment to illness and disability can be used to suggest possible ways in which individuals with newly acquired amputations develop a sense of self and identity to incorporate their altered body functioning, body image, and identity.

Leventhal, Idler, and Leventhal (1999) argue that the impact of a disabling chronic illness focuses attention on physical activities and bodily functions that were previously taken for granted by the individual. A disruption of previously automatic tasks, including walking and dressing, now become central to the self-concept and present a possible threat to notions of the self. These disruptions raise such questions as "Who am

I?” and “What am I becoming?” and create a pressure on the individual to redevelop a different, physically changed self. This process of reformulating the self and identity is influenced by conceptions of the illness itself and by previous self-concepts, functioning, and achievements. For example, Leventhal et al. (1999) remark that individuals who have raised a healthy and happy family will probably react differently in incorporating physical and social changes into a new self-concept than those who have not.

Another theory examining the relationships among physical functioning, limitations, and self-identity is that of Corbin and Strauss (1987). These writers argue that when a person becomes ill, the body’s appearance and ability to perform an activity are radically altered, with the result that ideas of body failure “strike at the core” of the individual. As a result, the very foundations of his or her existence are shaken, and a new concept of self has to emerge. According to Corbin and Strauss (1987), the degree to which one’s self-identity is affected by these changes depends on the number and importance of the aspects of the self that have been lost, the possibility of their recovery, the person’s ability to discover new ways around the limitations imposed, the ability to overcome their limitations, and the ability to accept and come to terms with the losses. In short, Corbin and Strauss (1987) argue that the person faces the task of building a new concept of self around his or her new found limitations.

In examining the time course of such identity changes in the light of body alterations and physical limitations, Morse (1997) conducted a review of qualitative studies on self-concept and illness and synthesised the results into a five-stage model entitled “Responding to Threats to Integrity of the Self.” In the first two stages of this model, (1) *Vigilance* and (2) *Disruption: Enduring to Survive*, the acute stage of the illness overshadows any sense of identity disruption or change. In the third stage, (3) *Enduring to Live: Striving to Regain Self*, individuals are forced to recognise the physical changes and loss of function that they have experienced, and they begin work to restore as much of their physical function as possible. In the fourth stage, (4) *Suffering: Striving to Restore Self*, the individual is now beginning to recognise the effects of what has happened and he or she begins to struggle with grief and mourning for what has been lost. At the same time, individuals in this phase start to hope and set realistic goals for

themselves. However, despite learning to live with setbacks and difficulties, they often refuse to accept their limitations and attempt to work towards a more complete recovery than is considered possible. According to Morse (1997), it is only in the fifth stage, (5) *Learning to Live with the Altered Self*, that the person comes to accept his or her body and the limitations it now brings. They learn to realise that life will never be the same again, while at the same time, revaluing their lives and learning to appreciate different things. Their focus shifts more to the inner person rather than to the external, outer body. In addition, they re-evaluate their goals, modify their careers, and learn to accept the consequences of the changed body and self. At this point, the individual has incorporated physical changes into a new self-identity and has learned to “live with the altered self.”

FACTORS ASSOCIATED WITH PSYCHOLOGICAL ADJUSTMENT

Amputation Related Factors

Cause of amputation

As a potential mediator of psychological adjustment to amputation, Whyllie (1981) anecdotally described differences in reaction between those who lost their limb as a result of trauma and those who lost their limb due to vascular disease. According to these reports, people with trauma-related amputations are more likely to display denial, while people with vascular-related amputations are more likely to show anger and hostility immediately after the amputation. Despite such anecdotal reports, only one study (Gerhards et al., 1984) has indicated that cause of amputation, in the sense of being convinced as to the necessity of amputation, was associated with lower levels of depression post-amputation. The remaining studies examining the relationship between cause of amputation and psychosocial outcome have found no effect of amputation cause on psychiatric symptoms (Shukla et al., 1982b), anxiety (Weinstein, 1985), depressive symptoms (Kashani et al., 1983; Williamson and Walters, 1996; Rybarczyk et al., 1992), activity restriction (Williamson, 1995), or social discomfort (Weinstein, 1985).

Level of amputation

In examining the relationship between amputation level and psychological well-being, the previous observation that amputation level is an important factor in predicting

rehabilitation success (Houghton et al., 1992; Pohjolainen et al., 1990; Uiterwijk et al., 1997; Helm et al., 1986; Steinberg et al., 1985; Hagberg, Berlin and Renström, 1992) must be acknowledged. For example, Hagberg et al. (1992) found that prosthesis use decreased as level of amputation increased. Similarly, Steinberg et al. (1985) found that although 75% of those with BK amputations in their sample continued to use their prosthesis, only 50% of those with AK amputations were still full-time prosthetic users. Earlier, it was explained that because significantly more energy is required to operate an AK prosthesis than a BK prosthesis (Waters et al., 1976; Huang et al., 1979), higher levels of amputation can affect rehabilitation success. It is perhaps no surprise, therefore, that in examining levels of activity amongst middle-aged and older people with amputations, Williamson (1995) and Williamson et al. (1994) reported that individuals with AK amputations were significantly more likely to be restricted in daily activities than those with a BK amputation. Interestingly, however, Williamson (1995) found that when public self-consciousness was also included in analyses, high levels of this variable were more important in predicting activity restriction than amputation level.

Despite the fact that AK amputations are associated with poorer rehabilitation outcomes and higher levels of activity restriction, AK amputations have not been found to be associated with increased levels of anxiety (Weinstein, 1985), social discomfort (Weinstein, 1985), general psychiatric symptoms (Shukla et al., 1982b), depression (Behel et al., 2002), or adjustment to amputation (Tyc, 1992). Interestingly, the one study that did find a relationship between amputation level and psychological outcome revealed that individuals with a BK amputation were more likely to be depressed than those with an AK amputation (O'Toole et al., 1985). In explaining this finding, O'Toole et al. (1985) suggested that because individuals with BK amputations are less severely disabled in terms of functioning than those with AK amputations, they may be in a better position to compare their functional abilities with their premorbid abilities and, as a result, be more sensitive to the differences between themselves and able-bodied individuals. Similar findings and explanations have been put forward in other studies on disability. Minchom, Ellis, Appleton et al. (1995), for example, found that children with more severe disabilities associated with spina bifida tended to have higher levels of self-esteem and global self-worth than those with less severe disabilities. These writers

explained this finding by suggesting that people could become more distressed about having less severe disabilities because they are closer to functioning at what they perceive to be 'normal' levels. On the other hand, those with more severe disabilities are further away from functioning 'normally' and, as a result, find it easier to psychologically adjust to and accept the fact that they cannot function the same as other people.

Time since amputation

Time since amputation is another factor that could mediate the relationship between amputation and psychological adjustment. Several studies have reported no relationship between time since amputation and depressive symptoms (Behel et al., 2002; Rybarczyk et al., 1992) or general psychiatric symptoms (Thompson and Haran, 1984). When an effect of time since amputation has been found, the findings have indicated that increased time since amputation is associated with a more favourable outcome. For example, Rybarczyk et al. (1995) reported that an increased length of time since amputation was associated with a better perceived *quality of life* in terms of leisure and social time, family life and relationships, and overall quality of life. Livneh, Antonak and Gerhardt (1999) found that *depressive* symptomatology tended to decrease and that *acceptance of disability* (amongst older people) increased with time since amputation. Frank et al. (1984) reported an interaction between age and time since amputation, such that older people tended to improve in psychological functioning, as assessed by the Beck Depression Inventory and the SCL-90, with longer time since amputation. However, younger people tended to worsen with longer time since amputation.

In examining the relationship between *body image* and time since amputation, only one study (Breakey, 1997) found no relationship between body image anxiety and time since amputation. On the other hand, general qualitative studies on body-image following physical disability (Taleperos and McCabe, 2002; Norris et al., 1998) and amputation (Gallagher and MacLachlan, 2001) have indicated that acceptance of a changed body-image occurs with time. In their longitudinal study, for example, Norris et al. (1998) found that individuals who had experienced a significant change in physical appearance or function, including amputation, went through three phases in adapting to a changed body-image over the course of eighteen months. In the first

phase, participants were faced with the initial shock of having to adapt to the altered body-image. Following this, they entered the second phase of 'wishing for restoration' in which they engaged in efforts to disguise their changed shape and altered functioning. For people with an amputation, this meant hiding the fact that they had an amputation by using appropriate clothing and wearing the prosthesis in all situations. In the third and final stage, entitled 'Reimagining the self,' participants realised the implications of their loss, recognised their altered body-image, and incorporated the physical changes into their lives and into a changed definition of identity and self-image (Norris et al., 1998).

Phantom Limb Pain

Another potential mediator of psychological adjustment to amputation is phantom limb pain. Early psychodynamic explanations of phantom limb pain perceived it as evidence of psychopathology in people with amputations (Frazier, 1966; Kolb, 1954; Weiss, 1958; Simmel, 1959). As part of these earlier psychogenic theories, it was argued that phantom limb pain may be more likely to occur in amputated parts that were of greater importance to the individual's body image (Weiss, A. 1956; Frazier and Kolb, 1970; Solomon and Schmidt, 1978). Thus, S. Weiss (1958) put forward a theory of 'denial through activity,' in which he claimed that phantom limbs were due to the individuals' narcissistic demands to maintain their limbs and that phantom pain served the unconscious function of convincing people that their limbs were still present. However, recent theories of phantom limb have argued that phantom limb pain is *not* a sign of denial or psychological dysfunction in people with amputations. In his review, for example, Katz (1993) outlined several reasons as to why phantom limb pain could not be due to denial of limb loss, including the fact that phantom pain can occur in individuals who have not lost their limbs (Melzack and Loeser, 1978) and that individuals who appear to have successfully adapted to their amputations continue to experience phantom limb pain for years afterwards (Simmel, 1959).

More recent studies have examined the impact of phantom limb pain on psychological functioning, rather than on perceiving phantom pain as evidence of psychopathology. Throughout the literature, PLP has been cited as responsible for the occurrence of *body image anxiety* following amputation. Lindesay (1985) suggested that the increased

incidence of head and neck pains found amongst his patients with phantom pain indicated a role for body image in phantom pain. Since an amputation can cause a serious disruption to a person's body image, and since the head and face are important areas in self-presentation, anxieties about body-image disruptions may exacerbate and prolong phantom limb pain and refer pain to those other areas of the body, such as the face and neck, which are important in self-presentation. Despite these suggestions, to date, only two studies have actually reported any significant relationship between body image anxiety and PLP. Without speculating as to the precise direction of the relationship, Pucher, Kickingger and Frischenschlager (1999) found that participants with phantom pain were significantly more likely to draw intact body image drawings than were participants without phantom pain. In addition, Whyte and Niven (2001a) found that body image anxiety items from the Beck Depression Inventory accounted for 16 percent of the variance in phantom pain intensity.

Besides body image anxiety, phantom limb pain has also been associated with several other cognitive and/or emotional outcomes post-amputation. A relationship between phantom limb pain and the occurrence of stress has been established. For example, several studies have cited psychological stress, upset or "excitement" as precipitating or aggravating phantom pain (Jensen et al., 1983, 1985; Sherman and Sherman, 1983, 1985; Steinbach et al., 1982; Pilowsky and Kaufman, 1965; Bailey and Moersch, 1941). Furthermore, it has been noted (Sherman, 1994) that experiencing phantom pain shortly after an amputation can be extremely anxiety-provoking and that explaining the nature of these sensations to patients results in much reduced pain severity. Supporting these reports of a stress-phantom pain relationship, one longitudinal, diary study (Arena, Sherman, Bruno et al., 1990) found that almost three-quarters of their sample experienced some relationship between *stress* and phantom pain intensity, such that stress either preceded, followed, or coincided with increases in phantom pain levels.

Although the above findings indicate some relationship between stress and phantom limb pain, the findings relating depression and anxiety to such have been mixed. Some cross-sectional studies (Whyte and Niven, 2001a; Hill, 1993; Lindesay, 1985) have found an association between duration or occurrence of phantom pain and depression. However, others have found no difference between those with and without such pain

and levels of anxiety (Fisher and Hanspal, 1998a) or depression (Fisher and Hanspal, 1998a; Katz and Melzack, 1990; Parkes, 1973). These mixed findings indicate the difficulties in determining the precise nature of the relationship between phantom pain and psychological distress. The general literature on pain and psychological functioning has reported a positive association between chronic pain and depression (Haythornthwaite, Sieber and Kerns, 1991; Doan and Wadden, 1989; Haley, Turner, and Romano, 1985), a finding which researchers have tended to support (Lindesay, 1985; Sherman et al., 1987). Furthermore, although most studies have not reported high levels of depression and anxiety amongst the general population of people with an amputation (Fisher and Hanspal, 1998a,b; Breakey, 1997; Frank, Kashani, Kashani et al., 1984) the general depressive reactions experienced by some individuals shortly after having an amputation (Randall et al., 1945; Caplan and Hackett, 1963; Turgay and Sonuvar, 1983; Shukla, Sahu, Tripathi, et al., 1982a; Kashani, Frank, Kashani et al., 1983; Frierson and Lippmann, 1987) make it difficult to assess the unique role of normal or depressive reactions to having an amputation in the occurrence and intensity of PLP. Overall, the conclusion appears to be that people with an amputation have the same level of psychological functioning as the general population (Sherman et al., 1987) and that chronic phantom limb pain is affected by stress, anxiety and depression in much the same way as are other chronic pain syndromes (Sherman, 1994).

Stump Pain

Another potential mediator of psychological adjustment to amputation is stump pain. In terms of the general literature on pain and depression, there are two possible mechanisms whereby stump pain could be associated with psychological well-being. In the first instance, stump pain could be directly associated with depression. In support of this, the general literature on pain and psychological well-being indicate that pain and depression tend to co-occur (Haythornthwaite, Sieber, and Kerns, 1991; Geerlings, Twisk, Beekman et al., 2002). In their cross-sectional study, for example, Haythornthwaite et al. (1991) reported that compared to non-depressed patients, depressed patients reported greater pain intensity, greater interference in their lives due to pain and more pain behaviours, including affective distress behaviours. Although it is difficult to ascertain the direction of this effect, one longitudinal study (Geerlings et al., 2002) confirmed that although the relationship between pain and depression was bi-directional, the percentage of individuals who went on to develop depression was more

than three times higher in those who had initially reported pain than in those who did not have pain at baseline. In this way, then, it could be argued that stump pain is directly associated with psychological well-being in terms of a direct effect on depression.

Another mechanism whereby stump pain could impact on psychological well-being is via its impact on activity levels. Previously, it was observed that stump pain is associated with a less satisfactory outcome in rehabilitation (e.g. Clark et al., 1983; Smith, Horn, Malchow et al., 1995; Miller, Speechley, Deathe, 2001a; Pezzin, Dillingham, MacKenzie et al., 2000; Steinbach et al., 1982; Pohjolainen and Alaranta, 1991; and Marshall, Jensen, Ehde et al., 2002). For example, Pohjolainen and Alaranta (1991) found that increased stump pain was associated with reduced outdoor walking and reduced walking distance. Moreover, Gallagher et al. (2001b) reported that respondents with stump pain had a significantly poorer adjustment to their physical limitations than did respondents without stump pain, and Smith et al. (1995) reported that the majority of their participants could only walk a certain number of steps a day, after which their residual limb would begin to hurt.

As a result of the negative impact of stump pain on mobility and rehabilitation and the resulting activity restriction, individuals could become frustrated, depressed, and/or anxious. In the general literature, a relationship between activity restriction and depressed affect has been found (e.g. Williamson and Schulz, 1995; Williamson, 1998). For example, Williamson and Schulz (1995) reported that in their longitudinal analysis, activity restriction at baseline was associated with depressive symptoms eight months later, particularly among younger participants. In the literature on people with amputations, Williamson et al. (1994) reported that activity restriction mediated the relationship between depression and the number of hours a day the prosthesis was worn, income adequacy, and satisfaction with social contacts. Although no study has examined the mediating effect of activity on stump pain and depression, the above findings would appear to suggest that as stump pain severely restricts adjustment to limitations and mobility (e.g. Gallagher et al., 2001b; Pohjolainen and Alaranta, 1991), the resulting activity restriction could act as a mediator between stump pain and psychological well-being.

Prosthesis

Another potential mediator of psychological adjustment to the amputation is the prosthesis. In adjusting to the physical limitations that the amputation brings, the prosthesis can help individuals regain mobility and independent functioning (e.g. Grieve and Lankhorst, (1996). Since activity restriction and depression are interrelated (Bruce, Seeman, Merrill et al., 1994; Penninx, Deeg, van Eijk et al., 1999), the use of a prosthesis could be an important tool and mediator between disability and emotional well-being.

In adjusting to an altered body image, the prosthesis could also act as a buffer against body image anxiety. In 1947, Wittkower suggested that in addition to serving functional needs, the prosthesis also acted as a tool to conceal the amputation and to restore a 'normal' or 'intact' body image to the individual (Wittkower, 1947). Subsequent papers have verified these ideas qualitatively (Gallagher and MacLachlan, 2001a; Norris, Kunes-Connell, and Stockard-Spelic, 1998), quantitatively (Murray and Fox, 2002; Yetzer, Rose-de Young, Nuñez et al., 1998), and anecdotally (Friedmann, 1978). For example, in their study of 44 lower-limb prosthesis users, Murray and Fox (2002) found that amongst women, increased body-image anxiety was associated with lower levels of satisfaction with their prosthesis, in terms of overall ratings, aesthetic aspects, and weight. Amongst men, increased body-image anxiety was associated with decreased use of the prosthesis and lower levels of prosthesis satisfaction in terms of overall ratings, functional aspects, and weight.

Sociodemographic Factors

Gender

In terms of *psychological well-being* following amputation, most studies have found no relationship between gender and psychosocial outcome. For example, gender of respondent has not been related to either activity restriction (Williamson, 1995) or acceptance of disability in older or younger people with people with amputations (Bradway et al., 1984; Tyc, 1992). Shukla, Sahu, Tripathi et al. (1982b) found no effect of gender on general psychiatric symptoms in their sample of people with recent amputations. Furthermore, neither Behel et al. (2002), Rybarczyk et al. (1992), nor

Williamson and Walters (1996) found any relationship between respondent gender and depressive symptomatology in people with more long-term amputations. Where effects of gender on psychological outcome have been found, they have tended to be in favour of men rather than women. These studies have reported that women are more likely to experience depression (Kashani et al., 1983), to score significantly worse on emotional adaptation to role changes (Pezzin et al., 2000), and to perform worse on a measure that includes an assessment of emotional adaptability (O'Toole et al., 1985).

In terms of *body-image* anxiety, the effect of gender is inconclusive. Throughout the general literature on body-image, it has been found that women tend to be more dissatisfied with their bodies than do men (Cash and Henry, 1995) and that physical appearance is more important for women than it is for men (Öberg and Tornstam, 1999). Although only one study suggested that women may be more prone to body-image anxieties following amputation than men (Furst and Humphrey, 1983), the remainder of the studies that have examined body-image anxiety in people with an amputation have not assessed differences by gender. The only paper that conducted general analyses on the basis of gender (Murray and Fox, 2002), did not indicate whether women scored lower than, equal to, or higher than men in terms of body-image anxiety.

Age

Another potential mediating factor in psychological adjustment to amputation is age. In examining the relationship between age and *psychological well-being* post-amputation, findings have been mixed. Using the CES-D, Rybarczyk et al. (1992) and Behel et al. (2002) found no relationship between age and depressive symptoms. Using the Diagnostic and Statistical Manual II (DSM-II) diagnostic categories, Shukla et al. (1982b) also reported that age had no effect on a range of psychiatric symptoms, including depression and anxiety. However, where age effects on psychological well-being have been found, the direction tends to be in favour of older people rather than younger people. For example, using the HADS, Fisher and Hanspal (1998b) found that younger age was significantly associated with higher levels of anxiety. Using the SCL-90, Frank et al. (1984) found that younger people with amputations scored significantly higher on subscales examining depression, anxiety, hostility, paranoid ideation,

psychoticism, Global Severity Index, and Positive Symptom Distress index. Using the CES-D, both Dunn (1996) and Williamson et al. (1994) reported that younger people scored significantly higher in terms of depressive symptomatology. According to Dunn (1996), the relationship between age and depression may be mediated by activity restriction. In support of this, Williamson and Schulz (1995) found that restriction of routine activities because of pain and illness was relatively more distressing in younger cancer patients than in older cancer patients. If this is the case, then younger people with amputations could also become more distressed as a result of activity restrictions than older people with amputations.

In terms of the impact of age on *body image*, the general literature has been mixed. Some studies on older women's' body image have found positive (Loomis and Thomas, 1991; Öberg and Tornstam, 1999), negative (Davis et al., 1994), and no association with age (Cash and Henry, 1995; Janelli, 1986). In older men, fewer studies on this topic have been conducted, although two older studies did report no relationship between age and body-image (Sidney and Shephard, 1979; Plutchik, 1971). The picture becomes more complicated when considering the relationship between age and disability. Some studies have indicated that those who acquired their disability at a younger age are more likely to experience body-image anxiety than those who acquired their disability at an older age (Ben-Tovim and Walker, 1995; Benrud-Larson et al., 2003). In terms of younger people with amputations, anecdotal reports indicate that adolescents often report feeling self-conscious about their body image and are upset and bothered when people stare at them or ask them questions about their amputation (Tyc, 1992). However, empirical studies of body-image in people with amputations have found no relationship between younger age and body-image anxiety (Breakey, 1997; Fisher and Hanspal, 1998).

One possible reason as to why no significant differences in body-image anxiety have been found between older and younger people could relate to the instruments used to measure body-image anxiety. In general, instruments measuring body-image anxiety in people with amputations have tended to be single scale, unidimensional measures incorporating anxiety related to physical functioning and physical appearance. [e.g. 21] However, a recent paper on body-image satisfaction in middle-aged and older adults

(Reboussin, Rejeski, Martin et al., 2000) has indicated that for people in this age-group, body satisfaction is comprised of two factors, Body Function and Body Appearance. Results of this study revealed that amongst middle-aged and older adults, Body Function was more important in predicting psychological well-being than Body Appearance. Taking into account that body satisfaction involves two-factors in older individuals, therefore, it could be argued that no significant age differences in the overall scores on body-image assessments were found because these two factors were not considered separately in overall body-image assessments. Thus, on these instruments, older adults may have indicated greater concern with functional aspects of body-image, and younger adults may have indicated greater concern with appearance aspects of body-image. However, because the factor structure of the instruments was not explored, these differences in responses may have gone unnoticed and overall scores could have been somewhat similar.

In terms of *activity restriction*, only one study (Williamson, 1995) found no relationship between age and this factor in correlational analyses. However, several other studies have implicated age as an important factor in determining rehabilitation outcome at five months, one-year, and five-year follow-up (e.g. Grieve and Lankhorst, 1996; McWhinnie et al., 1994; Pohjolainen et al., 1990; Trallesi et al., 1998; Pohjolainen and Alaranta, 1991; Helm et al., 1996; Johnson et al., 1995; Steinberg et al., 1985; Narang, Mathur, Singh et al., 1984). Grieve and Lankhorst (1996), for example, found that lower scores on the Sickness Impact Profile were associated with age over 60 years at five months post-amputation. At one-year post-amputation, Pohjolainen et al. (1990) found that older age was associated with use of a wheelchair, rather than a prosthesis.

Education/Socio-economic status/Income

Other potential variables that could mediate the relationship between amputation and psychological adjustment are educational level, socio-economic status, and income level. Although Shukla et al. (1982b) found no relationship between education level and the occurrence of psychiatric symptoms in their participants, Pezzin et al. (2000) found that amongst their sample of younger people, having a high school education was associated with greater levels of bodily pain than having lower levels of education. In addition, having a college-level education was associated with a significantly better

outcome on physical role functioning than was a lower level of education. Interestingly, although socioeconomic status has not been found to be related to the occurrence of psychiatric symptoms (Shukla et al., 1982b) or child and adolescent adjustment to amputation (Tyc, 1992), income adequacy was found to be significantly related to activity restriction (Williamson et al., 1994). That is, individuals with lower levels of income were more likely to be restricted in their activities. Despite this, however, income level of people with amputations has not been found to be related to depressive symptoms (Behel et al., 2002).

Marital Status/Social Support

In examining the role of social support in adjusting to amputation, the specific type of it that is received is important. According to Vaux (1988), social support consists of three theoretically distinct constructs, including support network resources, supportive behaviour, and support appraisals. Of interest in the rehabilitation context are the latter two aspects; supportive behaviour and supportive appraisals. Supportive behaviours are defined as those acts generally recognised as helping efforts on the part of others (Chwalisz and Vaux, 2000). On the other hand, support appraisals are the subjective evaluations of an individual's supportive relationships (Chwalisz and Vaux, 2000). Interestingly, while helping behaviours tend to be deleterious in adjusting to disability, support appraisal is associated with more favourable outcomes. In the general literature, for example, it was found that solicitous spouse responses (i.e. offers of assistance, taking over tasks, and shows of concern) to expressions of pain were associated with greater levels of pain and disability (Turk, Kerns, and Rosenberg, 1992). Similarly, in the amputation literature, it was found that in addition to coping responses, solicitous spouse responses at one month post-amputation were associated with increased levels of depression and phantom limb pain interference, while perceived social support was found to have the opposite effect (Jensen, Ehde, Hoffman et al., 2002).

To date, the vast majority of studies that have included social support as a potential mediator between amputation and psychological outcome have tended to measure perceived social support (i.e. support appraisals). These studies have all drawn similar conclusions regarding its beneficial effects. In young children and adolescents, social support was found to have a direct effect on general adjustment to amputation (Tyc,

1992). In their qualitative study, Furst and Humphrey's (1983) participants remarked that one of the factors promoting a successful rehabilitation post-amputation was the existence of family support. Several quantitative studies have found that increased social isolation (Thompson and Haran, 1984) and lower levels of perceived social support are associated with lower perceived quality of life (Rybarczyk et al., 1995) and higher levels of depressive symptomatology (Rybarczyk et al., 1992, 1995; Williamson, 1995; Williamson et al., 1994). The general literature on the mechanism by which social support enhances psychological well-being has tended to revolve around two theories: the *buffer effect* model claims that social support mediates the relationship between stressful life events and psychological distress, and the *direct effect* model states that social support has a positive effect on psychological well-being regardless of the stress process (Chwalisz and Vaux, 2000). To date, however, there have been no studies examining the mechanism by which social support assists adjustment to amputation.

Personality Attributes and Coping Modes

Personality

Surprisingly, very few studies have examined the impact of personality factors on psychological adjustment to amputation. Although the role of motivation in adapting to the physical sequelae of an amputation has been discussed (e.g. Caplan and Hackett, 1983; Clark et al., 1983), the impact of motivation on adjusting to psychological sequelae has not been empirically investigated. Nevertheless, Gerhards et al. (1984) noted that several pre-amputation personality factors were important in determining rehabilitation success. For example, they found that being a risk taker and an extrovert prior to the amputation was associated with lower levels of depression. In addition, having been socially active and an extrovert before the amputation was associated with better levels of social integration post-amputation. Moreover, Dunn (1996) noted that having an optimistic disposition and a higher level of perceived control over disability were associated with lower levels of depression and higher levels of self-esteem. This finding was explained by the fact that respondents who were high in dispositional optimism would be more likely to search for a positive meaning in their amputation. Upon finding such meaning in the amputation, these individuals would gain a greater sense of control over the event and over the ensuing disability. Such control over the

event and the disability would subsequently lead to a greater sense of coherence and self-esteem.

Coping

Coping is another potential mediator of outcome following amputation. The majority of studies examining coping with amputation have focused on the relationship between coping mechanisms and phantom limb pain (Jensen et al., 2002; Pucher et al., 1999; Machin and Williams, 1998; Hill, 1993; and Whyte and Niven, 2001b). In a diary study involving 89 individuals with a lower-limb amputation, Whyte and Niven (2001b) reported that amongst those who experienced phantom limb pain, coping strategies included distraction, relaxation, seeking social support, exercise, manipulation of the stump, and drug/alcohol use. In a smaller study of 26 British World War II veterans, Machin and Williams (1998) reported differences in coping strategies between people who lived with a spouse and people who lived alone. Although the most common strategy adopted by both groups was accepting the pain, individuals who lived with a spouse also tended to use distraction techniques or emotional expression as means of coping with their pain. On the other hand, individuals who lived alone were more likely to seek emotional support for their pain and to adopt problem-solving techniques. More detailed analyses of coping with phantom limb pain were conducted by Hill (1993) and by Jensen et al. (2002). Using the Coping Strategies Questionnaire, Hill (1993) found that amongst younger people with trauma-related amputations, catastrophizing responses to pain significantly contributed to the variance in pain reported and psychological distress. Further support for the role of catastrophizing was provided by Jensen et al. (2002), who found that catastrophizing at one month post-amputation was associated with depression, pain intensity, and pain interference at this time and with depressive symptoms and pain interference five months later.

The remaining papers on coping with amputation have examined the relationship between coping and general adjustment to amputation. Some researchers have focused on particular coping scales to examine their association with psychological outcomes (e.g. Livneh, Antonak, and Gerhardt, 2000; Livneh, Antonak, and Gerhardt, 1999; Gallagher and MacLachlan, 1999). Livneh et al. (2000) concluded that the coping efforts of people with amputations were not meaningfully different from those used by

people without any type of physical disability. Thus, they reported that people with an amputation had coping responses that reflected three general dimensions including: (a) Active/confrontive coping versus passive/avoiding, (b) Optimistic/positivistic versus pessimistic/fatalistic, and (c) Social/emotional versus cognitive. Relationships between similar coping strategies and psychological well-being have been reported by Gallagher and MacLachlan (1999) and by Livneh et al. (1999). For example, in their study of 44 people with lower-limb amputations, Gallagher and MacLachlan (1999) found that higher levels of psychological distress were associated with increased use of an Avoidance coping strategy. An interaction effect was also observed, such that individuals who had both higher levels of Seeking Social Support *and* lower levels of Avoidance coping also had higher levels of psychological distress. In a series of regression analyses, Livneh et al. (1999) reported several relationships among coping strategies and general adjustment to amputation, depression, and anxiety. Overall, adjustment to amputation was associated with higher levels of Active Problem Solving, lower levels of Cognitive Disengagement (for example, denial and mental disengagement) and lower levels of Emotion-Focusing (for example, venting emotions, wishful thinking, and social withdrawal). In addition, anxiety was associated with higher levels of Cognitive Disengagement, and depression was associated with lower levels of Active Problem Solving and higher levels of Emotion-Focused and Cognitive Disengagement.

Other researchers examining coping with amputation have based their investigations on major theories from the general literature on the use of reality negotiation, positive illusions and social comparisons in coping with health and illness (e.g. Dunn, 1994; Taylor and Lobel, 1989; Thompson, 1985; Taylor and Armor, 1996). According to these researchers, negative life events, including trauma and illness, frequently cause the person to look for a positive meaning in the event and to rely on positive illusion, or reframing, to cope with the event outcome (Dunn, 1994). In the general literature, a series of studies and reviews by Taylor and colleagues (e.g. Taylor, Wood, and Lichtman, 1983; Taylor and Brown, 1988; Buunk, Collins, Taylor et al., 1990; Taylor and Lobel, 1989; Taylor and Armor, 1996) have indicated that when people become ill, they tend to re-evaluate the event and their circumstances as having some positive meaning for them. According to Taylor et al. (1983), mechanisms by which individuals

construe positive meanings include making social comparisons with others in less fortunate circumstances, selectively focusing on attributes that give them a greater advantage, perceiving something beneficial to have occurred in the event, creating a hypothetical worse world, and manufacturing normative standards of adjustment that make their own adjustment appear to be exceptionally good. Other researchers (e.g. Snyder, 1989; Elliott, Witty, Herrick et al., 1991) have used the term *reality negotiation* to explain this process, whereby individuals use particular cognitive strategies to promote positive beliefs about the self under threatening situations, including trauma and illness.

To date, two studies (Dunn, 1996; Gallagher and MacLachlan, 2000a) have utilised these ideas in examining how people cope with their amputation and its psychosocial sequelae. For example, Dunn (1996) examined the relationship between finding positive meaning in the amputation and psychological well-being in people with predominantly traumatic amputations. Just over three-quarters of the respondents found something positive to have occurred to them as a result of their limb loss. Such positive events supported the findings of Taylor et al. (1983), in that participants in this study also used techniques involving social comparisons, perceiving side benefits, imagining worse situations, and forgetting negative aspects of the amputation. Moreover, it was also found that finding positive meaning following the amputation was related to lower levels of depressive symptomatology (Dunn, 1996). Gallagher and MacLachlan (2000a) similarly found that perceiving something positive to have happened as a result of the amputation was associated with significantly higher self-ratings of health and physical capabilities, better adjustment to limitations, and lower levels of athletic restrictions. In general, such positive thoughts included the belief that the amputation had resulted in increased levels of independence, had led to a changed attitude towards life, had been character building, had improved coping abilities, had eliminated pain, and had led to an improved lifestyle.

EXTRAPERSONAL ADJUSTMENT

Employment

Rates of Employment

Since the majority of people who undergo an amputation are older than 60 years (Pernot et al., 1997), and because younger individuals with amputations are more likely to have acquired their amputation as a result of accident or injury, (Pernot et al., 1997), the vast majority of studies examining the impact of amputation on employment have been conducted on people with trauma-related amputations. Although several studies have provided rates of employment following amputation (e.g. Whyte and Carroll, 2002; Millstein, Bain and Hunter, 1985; Pezzin et al., 2000; Hill et al., 1995; Pohjolainen et al., 1990; Schoppen et al., 2001, a,b), it is difficult to interpret these findings as they have utilized samples from different countries and with different mean lengths of time since amputation.

Overall, rates of employment post-amputation have shown that employment has decreased by as little as 11% in a Canadian study (Millstein et al., 1985) to as high as 47% in a British study (Hill et al., 1995). In examining these findings, it is interesting to note that the two results indicating the smallest decrease in employment of 11% in a Canadian study (Millstein et al., 1985) and 19% in a Finnish study (Pohjolainen et al., 1990) were measured shortly after the amputation(s) had occurred. On the other hand, the two rates indicating the highest drop in employment of 39.7% in an American study (Pezzin et al., 2000) and 47% in the British study (Hill et al., 1995) were measured a mean time of seven to twelve years post-amputation. Interestingly, there was a subsequent drop in employment rates between thirteen years post-amputation in a British study (Whyte and Carroll, 2002; 31.5% drop) and nineteen years post-amputation in a Dutch study (Schoppen et al., 2001b). The low rate of employment decrease in Millstein et al.'s (1985) and Pohjolainen et al.'s (1990) study could be explained by the finding that these rates were measured shortly after amputation. Throughout this period, people with amputations may have returned to work unaware of whether their amputation would prevent them from continuing in their current employment. As time passed, however, they may have dropped out of their current

employment because of their amputation, decided to change to more suitable work, or decided to retire. Thus, the large increase in unemployment measured up to twelve years post-amputation may reflect this period of employment instability and change, in which individuals were changing jobs and attempting to find suitable work through periods of unemployment. Following this, the relatively lower rates of unemployment measured after this period of instability may reflect a more settled time in which individuals found suitable employment and were less likely to be unemployed and still seeking appropriate work.

Type of Employment

Although one study reported that the number of weekly hours worked was comparable in people with and without amputations (Schoppen, Boonstra, Groothoff et al., 2002), many studies have indicated that after amputation, the type of work significantly changes to employment that is more administrative (Schoppen et al., 2001a), less physically demanding (Pezzin et al., 2000), or more sedentary (Millstein et al., 1985) roles. For example, Millstein et al. (1985) reported that although 65% of the original working sample had been offered their pre-amputation jobs, only 21% actually returned to these jobs. The other participants changed from jobs that involved machining, processing, product fabrication, and construction to service jobs, clerical positions, sales, and managerial positions. Whyte and Carroll's (2002) results support this finding. In addition, they found that individuals in professional positions tended to remain within this type of employment after their amputation, whilst those in manual employment who changed jobs tended to find work in nonmanual occupations.

Factors associated with employment/unemployment

Amputation-related factors associated with unemployment include phantom pain and stump pain (Whyte and Carroll, 2002; Millstein et al., 1985; Dawson and Arnold, 1981), upper-limb amputation rather than lower-limb amputation (Millstein et al., 1985), above-knee amputation rather than below-knee amputation (Hettiaratchy and Stiles, 1996; Millstein et al., 1985), and wearing comfort of the prosthesis (Schoppen et al., 2001a)

Individual factors associated with unemployment post-amputation include female gender (Millstein et al., 1985; Whyte and Carroll, 2002), older age at the time of the amputation (Schoppen et al., 2001b), lower levels of education (Pandian and Kowalske, 1999; Schoppen et al., 2001a), other physical and/or health problems (Dawson and Arnold, 1981; Pezzin et al., 2000; Schoppen et al., 2001b), and living in a rural area (Hettiaratchy and Stiles, 1996).

Satisfaction from work

Only two studies have examined levels of perceived satisfaction from work in people with amputations (Gerhards et al., 1984; Schoppen et al., 2002). Gerhards et al. (1984) reported no difference in satisfaction between people with and without amputations. However, Schoppen et al. (2002) found that compared to controls, people with amputations were significantly more satisfied with their employment. In fact, 70% of those with amputations judged their work life as 'good', compared to 54% of those without amputations. In general, individuals with an amputation reported fewer hindrances in work caused by the failures of others and fewer hindrances caused by temperature fluctuations. Any dissatisfaction with their employment was associated with the presence of comorbid illnesses and the desire for better modifications in the workplace. According to Schoppen et al. (2002), the higher rates of satisfaction among people with an amputation could be due to several factors, including autonomy in the workplace, job control, relationships with colleagues, and a perception that work is more valuable.

REACTIONS AND RESPONSES TO AMPUTATION

Reaction to Amputation

Overall, individuals with an amputation are faced with adapting to several changes and losses. One of the biggest changes that people have to adjust to following an amputation is loss of physical function and independence. In the early post-amputation stage, people with lower limb amputations are faced with difficulties in mobility (Francis and Renton, 1987) and in carrying out activities of daily living (Jones et al., 1993). At the same time, they have to adapt to an image of themselves without the amputated limb

while reconciling three images of their body: before the amputation, without a prosthesis, and with a prosthesis (Rybarczyk et al., 2000). It has also been suggested that following an amputation, the individual loses a sense of him or herself as a complete, intact person with an immutable body boundary and is faced with the realisation that he or she has a disrupted, violated body image (Parkes, 1975).

In addition to coping with these changes in physical function and body-image, individuals also have to face the fact that they may now be seen as “disabled” and part of a “stigmatised” group in society (Goffman, 1963). The general literature to date has indicated that individuals with a physical disability often experience negative reactions from others, with the result that they may begin to avoid social contact (Thompson and Kent, 2001; Kent, 2000). In the literature on people with amputations, it has been found that some experience a sense of discomfort in public interactions with others and that such discomfort is associated with increased levels of depression (Rybarczyk, Nyenhuis and Nicholas, 1992). In support of Goffman (1963), Rybarczyk et al. (1992) argued that such social discomfort may have been a response to the “stigmatising” social cues given by nondisabled individuals in their environment. Williamson (1995) also noted levels of public self-consciousness amongst older people in her study. She reported that this was directly associated with restrictions in caring for others, going shopping, visiting friends, and maintaining friendships.

Various reactions to these functional, physical, and psychological challenges have been described in the short-term and in the long-term. In fact, several authors have described common reactions to amputation during the pre-operative period (MacBride et al., 1980; Bradway et al., 1984; Friedmann, 1978), immediately post-operatively (Randall et al., 1945; Bradway et al., 1984; Friedmann, 1978; Parkes, 1975; MacBride et al., 1980; Gallagher and MacLachlan, 2001a; Lundberg and Guggenheim, 1986), during rehabilitation (MacBride et al., 1980; Randall et al., 1945; Friedmann, 1978; Parkes, 1975; Lundberg and Guggenheim, 1986; Bradway et al., 1984) and long-term (Furst and Humphrey, 1983; Parkes, 1972, 1975; Parkes and Napier, 1975)

In the *pre-operative phase*, just after individuals have been told that an amputation is required, several reactions have been observed. According to Friedmann (1978), most

people who require an amputation because of an injury or accident often experience little reaction to being told that this is the case. At this stage, they are not aware of their situation or surroundings and are not in a position to process the information given to them. On the other hand, people who need an amputation as a result of vascular disease or on-going illness often show signs of relief that a solution to their suffering has been proposed and that their pain is coming to an end. Nevertheless, both MacBride et al. (1980) and Bradway et al. (1984) indicate that even though most vascular patients are in extreme pain at this time, an anticipatory grief reaction is common amongst these individuals. Furthermore, concerns about the future and about coping with an amputation are also common (Bradway et al., 1984). According to MacBride et al. (1980), 40% of participants in their study regarded the pre-operative phase as the most upsetting time of the amputation process.

In the *post-amputation phase*, several distinct reaction stages have been observed. In the immediate post-operative period reactions have been mixed. Gallagher and MacLachlan's (2001a) participants remarked that this period had been marked by feelings of devastation and distress. On the other hand, Parkes (1975) remarked that participants with an amputation showed emotional numbness and a strong tendency to deny the emotional impact of their amputation. At the same time, some pining for what they had lost was observed. Amongst people who had lost a limb due to war conflicts, Randall et al. (1945) reported high levels of optimism. These researchers noted, for example, that participants in their study often remarked that they were lucky to be alive and, for the most part, showed few worries about the future. Similarly, MacBride et al. (1980) found that immediately post-amputation, many of the older people in their study admitted to being euphorically optimistic and encouraged about their futures. In fact, only 23% of their participants felt that the immediate post-operative stage of the amputation was the most upsetting phase of their ordeal.

Following the immediate post-amputation phase, an intermediate rehabilitation phase has been observed amongst those who are selected for prosthetic fitting and rehabilitation. According to MacBride et al. (1980), it is during this phase that the reality of their situation and losses begin to dawn upon patients. Upon being given a prosthesis to walk on, they realise that doctors' predictions that they would be "as good

as new” after a prosthesis were overly optimistic. Randall et al. (1945) reported similar findings amongst their younger, military sample. During the rehabilitation phase, their study participants revealed newly-formed doubts and uncertainties about their futures. Worries about adjusting to an amputation and others’ reactions to them also surfaced during this phase. In their review of the literature, Bradway et al. (1984) remarked that denial of the emotional and physical impact of the amputation is replaced by the beginnings of a grief reaction and pining for the losses that they are now beginning to recognise.

Once the patient is discharged from rehabilitation, another phase in their reaction to amputation begins (Randall et al., 1945; Bradway et al., 1984; Lundberg and Guggenheim, 1986). Despite the fact that these writers recognise the existence of this phase, to date, there has been no literature on the immediate post-rehabilitation period. Although Bradway et al. (1984) remark that the harsh realities of the disability are imposed upon the person with an amputation at this stage and that a marked decrease in supportive help is experienced, they cite Parkes (1975) and Randall et al. (1945) in support of this, both of whom do not give an in-depth discussion of the immediate post-rehabilitation phase in their studies.

Reaction to amputation as a “grief” or “coping” process

Earlier authors have described the overall psychological response to amputation as a grief reaction (Parkes, 1972, 1975; Parkes and Napier, 1975; Friedmann, 1978; Bradway et al., 1984). In comparing the reaction of people who had lost a limb to people who had lost a husband at 4-8 weeks and 13 months post-loss, Parkes (1975) noted that both groups showed typical grief reactions of numbness, denial of the loss, pining for what had been lost, showing preoccupation with thoughts about the loss, having difficulty in believing the fact of the loss, and avoidance of reminders of the loss. Thirteen months later, he remarked that both groups in his study had undergone a process of realisation whereby their existing models of the world had been altered to take into account the loss of limb or person. In an earlier paper, Parkes (1972) outlined this process of realisation as one involving two distinct stages. In the first stage, the realisation process begins, and the person reacts to the loss with the external urge to

recover the lost parts and an internal urge to protect the mental idea of the lost object. In the second stage, the realisation process moves towards unlearning the old mental model of the world and learning a new mental model of the world without the lost object. Throughout these stages, the person experiences anxiety, frustration, and depression as the old models are replaced by new models and as realisation of the loss is continuously brought home to the individual by external objects. Eventually, the new models develop to the point in which they are sufficient enough to match external reality. Parkes (1975) concluded that these phases are not clear-cut and that individuals tend to move back and forth between them whenever they are reminded of what they have lost. Eventually, however, a stage of mental reorganisation is reached and the individuals reach the end of the realisation process.

Although using bereavement theory to explain the process of adjustment to amputation appears to make intuitive sense, several writers have discussed problems with stage theories of grief in general (Bonanno and Kaltman, 2001) and, more specifically, with applying grief theories to adaptation to disability (e.g. Hewson, 1997; Wortman and Silver, 1989). For example, Wortman and Silver (1989) examined common expectations that following spinal cord injury, depression is inevitable, failure to experience distress is indicative of pathology, and that “working through” the loss is necessary. In their review, they concluded that the available empirical work fails to support, and in some cases, actually contradicts these common expectations. As an alternative to such grief theories, Hewson (1997) describes reactions to disability as a stress response, rather than as a grief response. In this way, she describes common ‘grief-like’ reactions of numbness, denial, or optimism in terms of coping mechanisms rather than as maladaptive responses to loss. In the present study, the applicability of “grief models” to psychological adjustment to amputation will be explored. To date, however, the validity of describing reaction to amputation as a “grief reaction” or as a “stress response” has not been investigated.

RESEARCH STATEMENT

The above review has shown that adaptation to amputation involves adjusting to a combination of physical and psychological changes. Physical changes that occur include loss of independence, difficulties in mobility, and problems in carrying out activities of daily living. Psychosocial changes that occur following an amputation include body-image alterations, self and identity changes, changes in social relationships, and employment and role changes.

Numerous studies reporting the functional outcome of people with amputations immediately after rehabilitation and throughout the subsequent year have been conducted (e.g. (Harris et al., 1991; Grieve and Lankhorst, 1996; Johnson et al., 1995). However, these studies are limited for several reasons. Firstly, they are not comparable with each other, as several different measures were used to assess function. Secondly, they have tended to neglect the impact of psychological and social variables on mobility and function, even though it is recognised that the two are closely related (e.g. Williamson et al., 1994; Bruce et al., 1994). Instead, the majority of these studies have used measures of rehabilitation success that include prosthesis use and physical measures of mobility only.

A large number of studies have been conducted on adaptation to psychosocial changes following amputation. For example, studies have commented on reactions to amputation in the immediate post-amputation period (e.g. Parkes, 1975; MacBride et al., 1980), during the rehabilitation phase (e.g. Randall et al., 1945; MacBride et al., 1980), and shortly after rehabilitation (e.g. Schubert et al., 1992). In addition, several researchers have used cross-sectional methodologies to examine psychological well-being in people with long-term amputations of varying ages (e.g. Williamson et al., 1994; Hill et al., 1995) and of varying etiologies (e.g. Behel et al., 2002). To date, however, there are no recent longitudinal studies examining psychological adjustment to amputation in the year following limb loss. Furthermore, with some notable exceptions (e.g. Furst and Humphrey, 1983; Gallagher and MacLachlan, 2000a, 2001) there are relatively few recent qualitative studies examining psychosocial adaptation to amputation. Although Parkes (1975) did conduct a qualitative study examining reactions and adjustment to

amputation, he covered only two time points shortly after and approximately one year after amputation. Thus, detailed analyses of psychological adjustment throughout the year were not presented.

Although longitudinal, qualitative studies on psychosocial adjustment to amputation are lacking, it is clear from the above literature review that a wide variety of factors have been found to be associated with the process of physically and psychologically adapting to an amputation. These factors include demographic factors of age, sex, marital status, education; personality factors and coping mechanisms; amputation-related factors of time since amputation, amputation level, cause of amputation, phantom-limb pain, stump pain; and environmental factors of social stigma, barriers to mobility, and available social support systems.

This study was conducted to examine the impact of these aspects on reactions to amputation and on psychosocial adaptation to changes that occurred during the year following lower-limb amputation and rehabilitation. Since very few studies have examined the experience of amputation throughout this period, it was thought that a qualitative approach would be more informative than a quantitative approach in examining adjustment during this period and in highlighting issues that are important to people undergoing this process. Livneh's (2001) conceptual framework for studying psychosocial adaptation to chronic illness and disability can be used to graphically illustrate the proposed outline and aim of this study. Figure 2.1 illustrates the proposed areas of research in the present study. In the present study, the Antecedent variables taken into account when exploring adjustment to amputation are the triggering events (e.g. cause of amputation) and contextual variables (including psychosocial status, environmental conditions, and biological status). Process variables that are explored in the present study include the reactions and responses to the amputation and the contextual influences, including amputation-related variables, sociodemographic characteristics, personality and coping modes, and environmental features. Finally, outcomes of adjustment to amputation are explored in terms of participants' subjective accounts and responses to questionnaires assessing psychological and physical functioning.

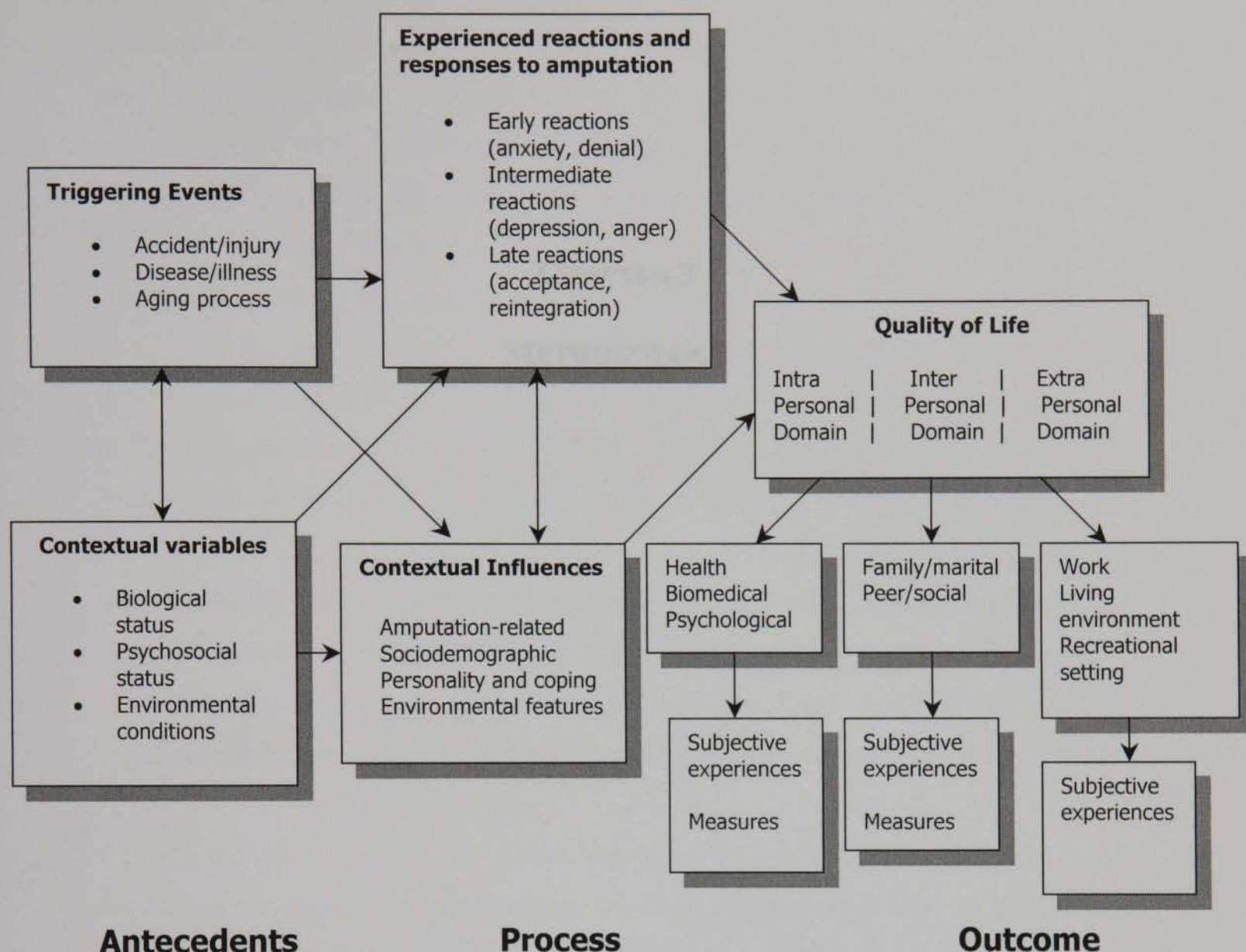


Figure 1.2: An illustration of the proposed framework for the present study, adapted from Livneh's (2001) conceptual framework for studying adaptation to chronic illness and disability.

In view of this framework, it is proposed that this study will describe the physical and psychological changes that people with an amputation have to face in the first year following rehabilitation. In addition, this study will examine their psychological adjustment to these changes in terms of depression, anxiety, and body-image anxiety. Furthermore, this study will highlight and discuss the amputation-related, demographic-related, and personality-related factors that appear to impact on the both the extent of and reaction to these changes. Overall, the study aimed to answer the following research question: "How do demographic factors, personality factors, and amputation-related factors impact on psychosocial adjustment to amputation during the year following rehabilitation?"

DESIGN

A longitudinal design was chosen as the most appropriate one to study physical and psychological adjustment to long-term use of the following rehabilitation, for several reasons. First, studies have been conducted on physical functioning following discharge from rehabilitation (Frost et al., 1978; Harris et al., 1977; Robinson et al., 1976; O'Leary, O'Leary, & ... and Member ... 1981).

CHAPTER 2

METHODOLOGY

... years post-discharge (McWhinney et al., 1975; Prochaska et al., 1978; O'Leary et al., 1977; ... and Agresti, 1974; ... et al., 1985; Kall et al., 1975; ... et al., 1987). However, although these studies are longitudinal in nature, they have not provided data on use of the following ... and ... they do not provide enough information for any detailed picture of physical functioning to emerge. Furthermore, the majority of these studies have only used very basic, non-validated measures. For example, only use of prosthetic use, functional impact of prosthetic ... physical factors in their physical functioning measures has not been explored.

Despite the large number of studies that have been conducted on psychological adjustment to amputation, the majority of these are cross-sectional in design (eg. Williams et al., 1974; Bell et al., 1987; Debot et al., 1982; Rymer et al., 1982, 1975). Moreover, although studies have attempted to investigate reactions to amputation in the immediate post-discharge period (eg. Fisher, 1971; Macfarlane et al., 1991), during the rehabilitation phase (eg. Brown et al., 1987; Macfarlane et al., 1989), and shortly after rehabilitation (Brown et al., 1992), there are no known longitudinal studies examining psychological adjustment to amputation during the year following rehabilitation. Although Fisher (1971) did conduct a longitudinal study comparing reactions of people who had had a limb amputated with a control group who amputated the lower limb 4-6 weeks and 17 months after the loss. Whilst a longitudinal design is only the appropriate one to investigate the year following amputation, it is limited by the fact that a control group is not possible in this regard as it is not possible to provide the best strategy for amputating prosthetic adjustment to limb loss in a control group. Furthermore, specifying the year post-discharge of the amputation is also a year

DESIGN

A longitudinal design was chosen as the most appropriate one to study physical and psychosocial adjustment to amputation, during the year following rehabilitation, for several reasons. Many studies have been conducted on physical functioning following discharge from rehabilitation (Traballesi et al., 1998; Harris et al., 1991; Rommers et al., 1996; O'Toole, Goldberg, Ryan et al., 1985; Jensen and Mandrup-Poulsen, 1983), five to six months post-amputation (Grieve and Lankhorst, 1996; Johnson et al., 1995; O'Toole et al., 1985; Panesar et al., 2001; Francis and Renton, 1987), and one to two years post-amputation (McWhinnie et al., 1994; Pohjolainen et al., 1990; Uiterwijk et al., 1997; Pohjolainen and Alaranta, 1991; Steinberg et al., 1985; Kald et al., 1987; Weiss et al., 1990). However, although these studies are longitudinal in nature, they have gathered data at one or two follow-up periods only and, therefore, they do not provide enough information for any detailed pattern of physical functioning to emerge. Furthermore, as the majority of these studies have used only single item outcome measures, for example, daily use of prosthesis, the longitudinal impact of other psychosocial factors on these physical functioning measures has not been explicated.

Despite the large number of studies that have been conducted on psychological adaptation to amputation, the majority of these are cross-sectional in design (e.g. Williamson et al., 1994; Hill et al., 1995; Behel et al., 2002; Rybarczyk et al., 1992, 1995). Moreover, although studies have commented on psychological reactions to amputation in the immediate post-amputation period (e.g. Parkes, 1975; MacBride et al., 1980), during the rehabilitation phase (e.g. Randall et al., 1945; MacBride et al., 1980), and shortly after rehabilitation (e.g. Schubert et al., 1992), there are no recent longitudinal studies examining psychosocial adjustment to amputation during the year following rehabilitation. Although Parkes (1975) did conduct a longitudinal study comparing reactions of people who had lost a limb with those who had lost a spouse, he only covered the time period 4-8 weeks and 13 months after the loss. Using a longitudinal design to study the adaptation to amputation during the year following amputation is in keeping with Livneh's (2001) proposal that longitudinal methods provide the best means for studying psychosocial adaptation to chronic illness and disability. Furthermore specifying the year post-rehabilitation as the critical period of study is also in accordance with his recommendations of appointing a certain time

period during which to examine reactions to chronic illness and disability (Livneh, 2001).

A qualitative approach to data collection was taken in this research. In general, the primary aims of qualitative research are to elicit meaning from individuals experiencing the phenomena under study, thereby gaining a richer and contextual understanding of their experiences (Lyons, 1999). As discussed in the introductory chapter, there are relatively few studies examining psychosocial adaptation to amputation from a qualitative perspective. Qualitative studies examining reactions to body-altering events (e.g. Norris et al., 1998) and illness (Corbin and Strauss, 1987) have been conducted. Furthermore, qualitative methods have been extensively used in research in other areas of health psychology, including redefining the self as a non-smoker (Brown, 1996), recovering and transforming oneself following liver transplantation (Wainright, 1995), and describing the experience of parents with HIV positive sons (Siegl and Morse, 1994). However, with some notable exceptions (e.g. Parkes, 1975; Furst and Humphrey, 1983; Gallagher and MacLachlan, 2000a, 2001) there are very few qualitative studies examining reactions and adjustment to amputation. Furthermore, apart from Parkes's (1975) research, no longitudinal qualitative studies examining psychosocial adjustment to amputation during the year following amputation have been conducted.

The general neglect of research into the personal meanings that individuals ascribe to their particular disabilities has been previously noted by some authors (e.g. Crisp, 2000; Dunn, 2000). In fact, it has been argued that many researchers in the area of disability and rehabilitation are "outsiders" who, in all probability, have no personal experience of disability. As a result, they are prone to making the erroneous assumption that people with disabilities are preoccupied with their physical states and that the disability is the sole focus of their lives (Dunn, 2000). In reality, however, "insiders" with the disability are more likely to perceive their situation as more favourable than outsiders (e.g. Hamera and Shontz, 1978; Mason and Muhlenkamp, 1978). Thus, using a qualitative research method in this study meant that individuals with an amputation were given the opportunity to express their unique and personal reactions to their amputation within the context of other aspects of their lives, including their social, family, and work lives. In keeping with qualitative methodology, questions were asked about the personal context of health and illness (Lyons, 1999), that is, the meanings of the amputation for the

individual, and their lived experience of having lost a limb. In using such a methodology, the “insider”, the person with the amputation, was the expert in the research programme. Therefore, every effort was made to prevent any of the researcher’s assumptions regarding reactions to amputation and the impact of the amputation on general lifestyle to colour the research outcome. Overall, use of a qualitative methodology served to redress the imbalance in the current literature in which quantitative methods are more prevalent. The previous use of qualitative research in health psychology (Brown, 1996; Siegl and Morse, 1994) and in the amputation literature (Gallagher and MacLachlan, 2000a, 2001) attests to the suitability of this approach for the current study. Moreover, the broad nature of the research question, “How do demographic factors, personality factors, and amputation-related factors impact on psychosocial adjustment to amputation during the year following rehabilitation?” lends itself particularly well to qualitative research. Since this research question was proposed in the absence of any prior assumptions as to what findings would emerge, a qualitative methodology that took into account demographic, personality, and amputation-related factors within the context of the individuals’ lives was considered the best methodology for this study.

The overall qualitative procedure for collecting and analysing qualitative data was Grounded Theory (Glaser and Strauss, 1967). According to this methodology, a broad research question is posed at the beginning of the research. Following this, data are collected to shed light on the research question and to explicate issues arising at the beginning and throughout the research process. The use of the words ‘Grounded Theory’ were originally chosen by Glaser and Strauss (1967) to reflect the fact that a theory explaining findings emerges from the data itself, rather than from any preconceived hypotheses or theories. Therefore, although a broad research question is stated at the outset of the study, the researcher does not propose any firm ideas about the direction in which the findings are expected to take. Thus, despite the fact that the researcher sets the original research agenda, emerging findings on the basis of participants’ narratives are expected to somewhat alter the research focus and subsequent interview questions. Since the research question is flexible and unconstrained by pre-existing theory, the findings are expected to emerge from participants’ lived experience and from the meanings they ascribe to their lives. In view

of the previously observed paucity of qualitative research on people with an amputation during the year following rehabilitation, the use of grounded theory was thought to be particularly suitable for studying this area. Because very little theory on adjustment to amputation during this period has been put forward in the literature, using a grounded approach, making the participants the experts in the research, and having their experiences set the research agenda was considered the best approach to take in exploring this heretofore neglected area.

SAMPLING AND PARTICIPANTS

Interviews

Participants were interviewed a total of four times. The first interview was conducted during their in-patient stay at the National Rehabilitation Hospital, Dún Laoghaire, Co. Dublin. The second, third, and fourth interviews were conducted in their homes at three, nine, and twelve months after the initial interview. (See Figure 2.1)

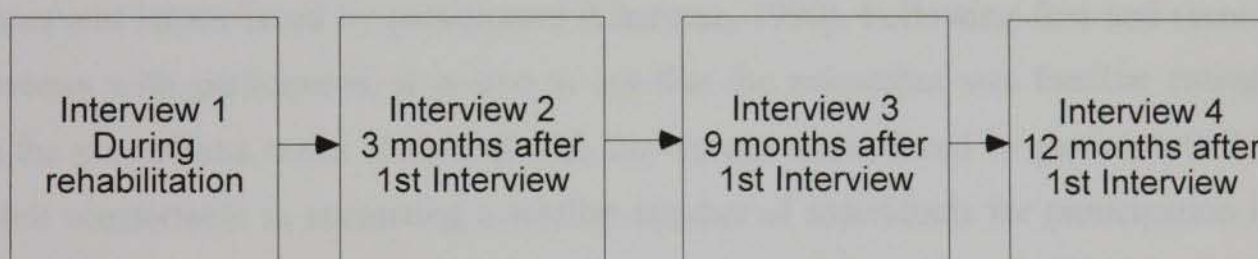


Figure 2.1: Interview stages

Sampling

The sampling procedure for data collection within Grounded Theory methodology is theoretical sampling (Strauss and Corbin, 1998; Pidgeon and Henwood, 1997; Charmaz, 1990). According to this procedure, research participants are specifically chosen to check, verify, extend, or eliminate theoretical categories. Although Strauss and Corbin (1998) recommend this procedure to be implemented from the beginning of the research procedure, theoretical sampling in this research was thought to be practical at the third interviews only. Theoretical sampling was not practiced during the first interviews because the longitudinal design of the study meant that a high number of sample

attrition was expected. Therefore, it was thought that interviewing all participants who met the study's inclusion criteria would mean that a sufficient sample size would be available to provide enough for theory generation one year later. Theoretical sampling was not practiced during the second interviews for similar reasons. At this stage of the study, the researcher was unsure as to how many individuals would be willing to continue with their participation in the study. Thus, all of the first-interview participants who were contactable were sent a letter inviting them to take part in the second stage of the study. Only three people did not want to be interviewed for a second time. Following second-stage interviews with the remaining contactable participants, the researcher was somewhat assured that there would be enough people in the study to generate theory throughout the subsequent interviews. Therefore, theoretical sampling was practiced at the third interview stage, with the result that only some of those who had been interviewed for a second time were asked to take part in the study for a third time. Use of theoretical sampling at this stage is in keeping with Charmaz's (1990) recommendations. According to this researcher, theoretical sampling is more appropriate after key concepts in the study have been defined. Thus, she contends that delaying focused theoretical sampling helps to foster an in-depth understanding of the realities and issues faced by participants (Charmaz, 1990). Following first and second interviews with participants, it is true to say that the researcher was familiar enough with the phenomena under study and with the various issues faced by participants that she felt comfortable in contacting a smaller number of individuals for participation in the third and fourth stages of the study.

Between 31st November 2000 and 19th October 2002 [less four months – see Ethical Considerations below], in-patients at the National Rehabilitation Hospital, Co. Dublin, who had been admitted for prosthetic fitting and training were approached and asked to participate in this study. Inclusion criteria for the study were: that they were aged 18 years and above, that they were attending the rehabilitation unit for the first time to obtain their first prosthetic limb(s), that they did not have their amputation for more than six months prior to admission for rehabilitation, and that they did not present to the rehabilitation unit with any cognitive impairment or psychotic disorder as detailed in their medical records.

Participants

During this period, 30 individuals met the above inclusion criteria. These participants were six women and twenty-four men. The mean age of the participants was 62.36 years (SD 10.81, range 38-80 years). The mean time since the most recent amputation had been performed was 4 months (SD 1.46, range 1-6 months). Eighteen of the participants were married, four were widowed, five were single and living alone, one was separated from his spouse but living with a partner, one was separated from her spouse and living alone, and one was single but living with a partner. Twenty-seven people had unilateral lower-limb amputations and three people had bilateral amputations. Of the unilateral amputations, 18 were above-knee, 8 were below-knee, and 1 was through-knee. Of the bilateral amputations, one was bilateral above-knee, one was bilateral below-knee, and one was bilateral above- and below-knee.

First Interview Participants

For the purposes of the first study, the interviews of twenty-four of these participants were analysed. Three interviews were not analysed because the quality of the tape-recording was too poor. Another three interviews were not analysed because the participants subsequently refused to participate in a second interview. The twenty-four participants whose interviews were analysed in the present study were four females and twenty males. Their mean age was 61 years (range 37 years to 80 years). The reasons for amputations were as follows: pulmonary vascular disease (PVD) = 9, diabetes = 9, accident = 2, clot/aneurysm = 2, ulceration of the leg = 1, cancer = 1. Twenty-two participants had unilateral lower-limb amputations, including fourteen above-knee amputations and seven below-knee amputations. Two participants had bilateral lower-limb amputations; one person had bilateral above-knee amputations and the other person had one above-knee amputation and one below-knee amputation. Some of the participants had concurrent medical problems that could impact on their rehabilitation. Two people were visually impaired, one man had arthritis in his hands, and one man had a heart condition. Table 3.1 outlines the characteristics of these participants in terms of age, type of amputation, time since amputation, and other notable characteristics that could impact upon their rehabilitation.

Second Interview Participants

Six participants were lost to follow up. MOB died shortly after he had left the National Rehabilitation Hospital. JL and PR had no fixed address when they had been interviewed during rehabilitation and, therefore, were non-contactable. Finally, JS, PM, and JW were in hospital when they were contacted again and were not physically well enough to participate in the interview. Overall, eighteen participants took part in Stage 2 interviews (See Table 4.1 for a description). These were four women and fourteen men. Their mean age was 60.61 years (range 37 to 72 years). The reasons for amputation were as follows: pulmonary vascular disease (PVD) = 6 diabetes = 6 accident = 2, clot/aneurysm = 2, ulceration of the leg = 1, cancer = 1.

Sixteen participants had unilateral lower-limb amputations, including eleven above-knee amputations and five below-knee amputations. Two participants had bilateral lower-limb amputations; one person had bilateral above-knee amputations and the other person had one above-knee amputation and one below-knee amputation. Some of the participants had concurrent medical problems that could impact on their rehabilitation. Two people were visually impaired, one man had arthritis in his hands, and one man had a heart condition. Table 4.1 outlines the characteristics of these participants in terms of age, type of amputation, time since amputation, and other notable characteristics that could impact upon their rehabilitation.

Third Interview Participants

Four participants were lost to follow-up. One participant, JMcG, had died in the months after his second interview. The other three participants, OMcK, CD, and GC could not be interviewed within the time period required by this study. As outlined in the Ethical Procedures section below, a new medical consultant in charge of Amputee Rehabilitation was appointed at the National Rehabilitation Hospital and withdrew permission for the study to be conducted until it had been put before the hospital's new ethics committee. As a result, the study was halted for a period of four months until it was subsequently passed by the ethics committee. Because of this time delay, OMcK, CD and GC were not asked to take part in a third interview, but instead, they were sent a letter thanking them for their contributions to the study and indicating that their participation was no longer possible due to time constraints. In keeping with theoretical sampling outlined above, one other participant, AOM, was not asked to take part in a

third interview because it was felt at this point that the data had been saturated and that her contributions, while interesting in themselves, did not yield any further insight into the process of adjustment to amputation.

Overall, thirteen participants took part in Stage 3 interviews. These were two women and eleven men. Their mean age was 58.69 years (Range 38 to 73 years) [See Table 5.1 for a description]. The reasons for amputation were as follows: pulmonary vascular disease (PVD) = 4 diabetes = 4 accident = 2, clot/aneurysm = 2, ulceration of the leg = 1. Eleven participants had unilateral lower-limb amputations, including seven above-knee amputations and four below-knee amputations. Two participants had bilateral lower-limb amputations; one person had bilateral above-knee amputations and the other person had one above-knee amputation and one below-knee amputation. Some of the participants had concurrent medical problems that could impact on their rehabilitation. Table 5.1 outlines these medical conditions.

Fourth Interview Participants

One participant, MMcC, did not want to participate in a fourth interview because he had just returned home from spending two weeks at the National Rehabilitation Hospital and was in the process of adjusting to a new artificial limb. As a result, he did not think that he would have anything new to contribute in an interview. Overall, twelve participants took part in Stage 4 interviews. These were two women and ten men. Their mean age was 58.23 years (Range 38 to 72 years) [See Table 6.1 for a description]. The reasons for amputation were as follows: pulmonary vascular disease (PVD) = 3 diabetes = 4 accident = 2, clot/aneurysm = 2, ulceration of the leg = 1. Ten participants had unilateral lower-limb amputations, including six above-knee amputations and four below-knee amputations. Two participants had bilateral lower-limb amputations; one person had bilateral above-knee amputations and the other person had one above-knee amputation and one below-knee amputation. Some of the participants had concurrent medical problems that could impact on their rehabilitation. Table 6.1 outlines these medical conditions.

Ethical Procedures

Informed Consent

Permission to carry out the study was given by the Ethics Committee of the Department of Psychology, Trinity College, Dublin and by the Ethics Committee of Trinity College's major teaching hospital, St. James's Hospital. Permission to conduct the study within the National Rehabilitation Hospital was given by the then consultant in charge of Amputee Rehabilitation. Upon being informed as to the nature of the study, this consultant did not believe that it needed to be put before the hospital's ethics committee. Potential participants were informed about the reason for the study, the nature of their participation, the likely duration of the interview, and the possibility that they would be asked to take part in future interviews over the coming year. They were then asked to give consent for participation in the study and for their interview to be tape-recorded. Subsequently, they were interviewed by their bedside in the rehabilitation unit.

Seven months after the study had begun, a new consultant in charge of Amputee Rehabilitation was appointed and withdrew permission for the study to be conducted until it had been put before the hospital's new ethics committee. As a result, the study was halted for a period of four months. When the study was subsequently passed by the ethics committee, it was agreed that remaining participants would be required to sign a written consent form indicating their willingness to continue to take part in the study *and* for their interview to be tape-recorded. Those individuals who were no longer taking part in the study were sent a letter which offered them the opportunity to ask any questions about their participation in the study.

Confidentiality

Participants were assured that their responses to questions were confidential and that they would not be disclosed to anyone outside the study group. They were informed that, if they wished, they could have transcribed copies of their interview. Data from each interview were stored on word documents, SPSS files, and NUDIST*4 files. Initials, rather than full names, were used to protect participants' identities. The interview tapes, questionnaire responses, and transcribed interviews were kept in a locked cabinet.

Participant Safety

Because some of the questions in the interview were thought to be of a sensitive nature, during the first seven months in which the study was conducted, the researcher informed her supervisor, a clinical psychologist, in the event that any participant appeared to be experiencing psychological difficulties. After the study had been passed by the National Rehabilitation Hospital Ethics Committee, it was decided that if any participants appeared to be experiencing any difficulties, the Consultant in Amputation Rehabilitation and the Senior Staff Clinical Psychologist at the hospital were to be informed. Participants were informed at the beginning of the study that they would be referred to these individuals if the researcher thought it necessary.

Remuneration

Participants were not remunerated for their participation in the present research.

DATA COLLECTION

Interview data were collected using Grounded Theory methodology (Glaser and Strauss, 1967; Corbin and Strauss, 1998). Originally, the term 'Grounded Theory' was chosen to express the idea that the theory emerges from the data itself, rather from any predefined research hypothesis. Within this framework, participants' own accounts of their social and psychological events were strongly emphasised (Pidgeon, 1996). On the basis of these narratives, and in keeping with grounded theory methodology (Corbin and Strauss, 1998), the researcher continuously refined her research questions to explore new avenues that had been suggested by participants' experiences. Similarly, issues that were initially deemed to be of interest to the researcher but that were not held to be of any importance to participants were not stressed throughout the interviews. In this way, the lived experience of participants' was emphasised and explored over and above the preconceived notions of what the researcher felt to be of relevance.

A series of questionnaires were used in the collecting the data. These questionnaires were used for two purposes. The first was to provide a guide in which to answer the research question: "How do demographic factors, personality factors, and amputation-related factors impact on psychosocial adjustment to amputation during the year following rehabilitation?". Similar to other grounded theory analyses that have used

questionnaires to assist in data collection (e.g. Anderson, Standen, and Noon, 2003; Hirschfeld, 2003), the questions in these instruments were used to provide a point of departure for exploring themes, rather than as devices to constrain the interviews. Therefore, although participants were administered these questionnaires throughout their interviews, items were interspersed with follow-up and open-ended questions on these issues and other issues of interest to the participant. The second reason as to why questionnaires were used to assist in data collection was to provide descriptive statistics regarding the characteristics of the participants in terms of their experiences of phantom pain (using the McGill Pain Questionnaire – Short Form), their adaptation to amputation and a prosthesis (using the Trinity Amputation and Prosthesis Experience Scales), body-image anxiety (using the Amputation Body Image Scale), and psychological well-being (using the Hospital Anxiety and Depression Scale). Because few studies have been conducted examining adjustment to amputation during the year following limb loss, it was thought that completed questionnaires could greatly contribute to the literature on adjustment to amputation and provide descriptive information on people during the year following their limb loss. Use of questionnaires for such purposes is consistent with several other research that has used grounded theory analyses (e.g. Gott and Hinchliff, 2003; Zhang and Verhoef, 2002; Green, Hayes, Dickinson et al., 2002).

Semi – Structured Interviews

Data was collected using a semi-structured questionnaire and an interview, which was tape-recorded. The average length of the first interviews was 40 minutes. The average length of the second and subsequent interviews was one and a half hours. Within psychological qualitative research, this interview format is amongst the most popular methods of data collection (Willig, 2001). With the aim of investigating the overall research question, the following topics were addressed: (1) The events leading up to the amputation, (2) Initial reactions to being told that an amputation was necessary, (3) Pain in the limb prior to amputation, (4) Current thoughts about having an amputation (for example, whether they felt they would get over their limb loss, their hopes for the future), (5) Current emotional well-being, (6) Current goals, (7) Phantom limb pain, (8) Stump pain, (9) Body Image anxieties, and (10) Initial reactions to seeing the prosthesis. During the second and subsequent interviews, these topics were also addressed. However, the events leading up to the amputation were discussed only when the

participants chose to introduce the topic. New issues introduced in the interviews included (11) Perceived progress and difficulties in learning to walk and (12) Emotional and physical adaptation to the prosthesis. Throughout the follow-up interviews, perceived changes and developments in these issues were discussed.

Guideline questionnaires for the semi-structured interviews

In following a semi-structured format, several assessment instruments were used to provide questions as a guideline. These instruments, which are outlined below, included the Trinity Amputation and Prosthesis Experience Scales (TAPES; Gallagher and MacLachlan, 2000; See Appendix 1), the TAPES-Revised (See Appendix 2), the Short-Form of the McGill Pain Questionnaire (SF-MPQ; Melzack, 1987; See Appendix 3), the Amputation Body Image Scale (ABIS; Breakey, 1997; See Appendix 4), and the Hospital Anxiety and Depression Scale (HADS; Zigmond and Snaith, 1983; See Appendix 5). Although all of the questions on the first three instruments, the TAPES, SF-MPQ, and ABIS were covered, participants were given the opportunity to expand on all of their answers, rather than adhere to the answer formats given. Thus, on the basis of their answers, further questions were asked and clarifications sought. At the end of each interview, the HADS was then administered in a structured format, in that participants were required to answer according to the rating scale provided. However, during administration of the HADS, they were given the opportunity to expand on and clarify their answers if they wished.

Demographic information

Participants were asked a series of demographic questions on (1) Age, (2) Number of amputations, (3) Time since amputation(s), (4) Reason for amputation(s), (5) Marital Status, (6) Number of children, (7) Employment status, (8) Home address and telephone number.

Amputation and Prosthesis Experiences

Trinity Amputation and Prosthesis Experience Scales (TAPES)

Throughout the second, third, and fourth interviews, psychological adjustment to a prosthesis, general satisfaction with the prosthesis, and social/functional activity restrictions as a result of the amputation were discussed using questions included in the

TAPES (Gallagher and MacLachlan, 2000b). These questions were not asked throughout the first interviews, because their emphasis on daily use of the prosthesis was not thought to be appropriate for people who were in the early stages of rehabilitation.

The Psychosocial Adjustment scale focused on: General Adjustment, Social Adjustment, and Adjustment to Limitations. The first topic, *General Adjustment*, examined the extent to which participants believed that they had adjusted to having an artificial limb, whether they accepted their artificial limb more with time, and whether they perceived their lives to be full despite having an artificial limb. The second topic, *Social Adjustment*, referred to the impact of the artificial limb on social situations in terms of whether participants felt comfortable with others' seeing their limb, talking about their artificial limb in social situations, and people asking about their artificial limb. The third topic, *Adjustment to Limitations*, assessed the extent to which participants had adjusted to limitations as a result of having an artificial limb, whether they felt dependent on others as a result of their limb, and whether the artificial limb interfered with their work lives

The Prosthesis Satisfaction scale focused on the following areas: Functional Satisfaction, Aesthetic Satisfaction, and Weight Satisfaction. The first section, *Functional Satisfaction* was used to discuss the extent to which participants were satisfied with the following aspects of their prosthesis: Reliability, Fit, Comfort, Usefulness, and Overall Satisfaction. The second section, *Aesthetic Satisfaction*, was used to address the extent to which participants were satisfied with the appearance, shape, colour, and noise of their prosthesis. Finally, the third section, *Weight Satisfaction*, addressed the extent to which participants were satisfied with the weight of their artificial limb. Participants were asked to indicate their level of satisfaction with these aspects of their prosthesis, providing explanations as to their current levels of satisfaction.

The Activity Restriction Scale focused on three areas: Functional Restriction, Social Restriction, and Athletic Restriction. The first topic, *Functional Restriction*, examined the extent to which participants were limited in functional activities, including walking half a mile, walking 100 yards, and climbing one flight of stairs. The second topic,

Social Restriction, addressed the extent to which individuals were restricted in their social lives as a result of their artificial limb. Thus, problems in visiting friends, maintaining friendships, working on hobbies, and going to work were discussed. The third topic, *Athletic Restriction*, examined the extent to which participants were restricted in engaging in vigorous activities such as lifting heavy objects, running for a bus, engaging in sport and recreation, and climbing several flights of stairs.

TAPES Revised Section

Because the TAPES consisted of questions designed to elicit participants' adjustment to wearing a prosthesis, rather than adjustment to an amputation *per se*, an additional section was added to elicit, throughout all of the interviews, individuals' reactions to having had an amputation. In exploring general adjustment to having an amputation, participants were asked to indicate the extent to which they agreed or disagreed with the following statements (1) "I will never get over losing a limb?", (2) "I feel I am the same person I was before I lost my limb?" and (3) "Because I have lost a limb, I feel that life will never be as good again?", (4) "I see my amputation as a challenge in life?" (5) I often think that there is always somebody out there who is worse off than myself?, and (6) "Since having my amputation, I feel deprived from leading a normal life?" In exploring social discomfort since the amputation, participants indicated the extent to which they agreed or disagreed with the following four statements: (1) "I find it easy to talk about my amputation?," (2) "Since my amputation, I am reluctant to interact with others?," (3) I don't care if anybody notices your artificial limb?, and (4) "I don't mind people asking me about my amputation?" Follow-up questions on these statements were given, and open-ended questions on any other issues of adjustment to amputation that were of concern or interest to the participant were given.

Phantom limb pain

General information on phantom limb pain was assessed with the following questions: "When did you first experience phantom limb pain?", "Did you find it distressing to experience phantom limb pain?" "Are you taking any type of pain-killers for your phantom limb pain?"

TAPES

The occurrence, frequency, and intensity of phantom limb pain (PLP) and the extent to which this interfered with participants' normal lives was assessed using questions included in the TAPES (Gallagher and MacLachlan, 2000). Occurrence of PLP was assessed by asking participants the question "Do you experience phantom limb pain?". Frequency of PLP was assessed by asking participants "During the last week, how many times did you experience phantom limb pain?" Duration of PLP was assessed with the question "How long, on average, did each episode of phantom limb pain last?" Intensity of PLP was assessed by asking participants to rate, on a five-point scale, the average level of phantom limb pain experienced during the last week. This intensity scale included the following points: Mild (=1), Discomforting (=2), Distressing (=3), Horrible (=4), and Excruciating (=5). The extent to which PLP interfered with participants' normal lives was assessed with the following question: "How much did phantom limb pain interfere with your normal lifestyle (e.g. work, social and family activities) during the last week?" Participants answered according to a five-point scale ranging from: Not at all (= 1), A little bit (= 2), Moderately (= 3), Quite a bit (= 4), and A lot (= 5). Follow-up questions on these responses were asked, and open-ended questions on any other issues of phantom pain that were of concern or interest to the participant were given.

Short-Form of the McGill Pain Questionnaire (SF-MPQ)

Descriptions of phantom pain were elicited using the SF-MPQ. This instrument was developed by Melzack (1987) in response to the need for an instrument that could be completed over a relatively short time-period, while still assessing for descriptions of pain, present pain intensity, and overall pain intensity. Based on the longer McGill Pain Questionnaire (Melzack, 1975), the SF-MPQ contains three separate sections.

Section one consists of 15 adjectives that can be used to describe the quality of pain experienced. These adjectives were chosen by Melzack (1987) on the basis that they had been endorsed by at least one-third or more of patients with either phantom pain, labour pain, menstrual pain, headache, post-herpetic pain, dental pain, cancer, arthritis, or low-back pain. Adjectives are divided into *Sensory* and *Affective* subscales. *Sensory* adjectives are: throbbing, shooting, stabbing, sharp, cramping, gnawing, hot-burning, aching, heavy, tender, and splitting. *Affective* adjectives are: tiring-exhausting,

sickening, fearful, and punishing-cruel. Participants indicated whether their pain resembled these words on the following scale: None (= 0), Mild (= 1), Moderate (= 2), and Severe (= 3).

The second section consists of a Visual Analogue Scale with the words “No Pain” on the left hand side of the line, and the words “Worst Possible Pain” on the right hand side. Participants are asked to mark a place on the line that best resembles their overall pain experience. The third section consists of a five-point Present Pain Intensity scale, in which participants are asked to rate whether they are currently experiencing *no pain* (= 0), *mild pain* (= 1), *discomforting pain* (= 2), *distressing pain* (= 3), *horrible pain* (=4), or *excruciating pain* (= 5). In the present study, only the first section of the SF-MPQ was used, as questions included in the TAPES were thought to be sufficient to elicit this information on PLP. Follow-up questions on these descriptive words were asked, and open-ended questions on any other issues of phantom pain that were of concern or interest to the participant were given.

Since its development, the SF-MPQ has been successfully used to measure several pain syndromes, including cancer pain (Dudgeon, Raubertas, and Rosenthal, 1993), chronic low-back pain, rheumatoid arthritis, and chronic headache (Morley and Pallin, 1995), pain in scleroderma (Benrud-Larson et al., 2003) and angina pain (Kimble, McGuire, Dunbar et al., 2003). Of relevance to this study, the SF-MPQ has also been used to measure phantom limb pain (Fisher and Hanspal, 1998a; Elizaga, Smith, Sharar et al., 2002).

Stump Pain

TAPES

The occurrence, frequency, and intensity of stump pain and the extent to which stump pain interfered with participants' normal lives was assessed using questions included in the TAPES (Gallagher and MacLachlan, 2000). Occurrence of stump pain was assessed by asking participants the question “Do you experience stump pain?”. Frequency of stump pain was assessed by asking participants “During the last week, how many times did you experience stump pain?” Duration of stump pain was assessed with the question “How long, on average, did each episode of stump pain last?” Intensity of stump pain was assessed by asking participants to rate, on a five-point scale, the average level of

stump pain experienced during the last week. This intensity scale included the following points: Mild (=1), Discomforting (=2), Distressing (=3), Horrible (=4), and Excruciating (=5). The extent to which stump pain interfered with participants' normal lives was assessed with the following question: "How much did stump pain interfere with your normal lifestyle (e.g. work, social and family activities) during the last week?" Participants answered according to a five-point scale ranging from: Not at all (= 1), A little bit (= 2), Moderately (= 3), Quite a bit (= 4), and A lot (= 5). Participants were asked follow-up questions and open-ended questions on their stump pain also.

Body-Image Anxiety

TAPES-R

Body-image anxiety following the amputation was explored on the basis of three items in the TAPES-R. Participants indicated the extent to which they agreed or disagreed with the following statements: "I always think about how I look to others", "I dislike the appearance of my amputated limb," and "Since my amputation, I have become more concerned about my physical appearance." Follow-up questions on these statements were given, and open-ended questions on any other issues of body-image that were of concern or interest to the participant.

Amputation Body Image Scale (ABIS)

During the second, third, and fourth interviews, the occurrence of body image anxiety was also assessed on the basis of questions in the ABIS (Breakey, 1997). Because many of the questions in the ABIS revolved around use of the prosthesis in daily situations, the fact that participants were only getting used to their prosthesis within a rehabilitation setting meant that these questions were not appropriate to use throughout the first interviews. The ABIS is a 20-item questionnaire measuring the affective aspects of body image anxiety and their behavioural and functional consequences. Affective aspects of body image anxiety were measured with such questions as "Because you have lost a limb, do you feel more anxious about your physical appearance in social situations than when you're alone?" Behavioural aspects of body-image anxiety were assessed with such questions as "When you're not wearing your prosthesis, would you avoid situations where your physical appearance can be evaluated by others?" Functional aspects of body-image anxiety were assessed with such questions as "Does it concern you that the loss of your limb impairs your body's functional capabilities in

various activities of daily living?" Finally, consequences of body-image anxiety on self-identity were assessed with such questions as "Does the loss of your limb makes you think yourself as disabled?"

The ABIS was considered the most suitable instrument from which to explore the occurrence of body-image anxiety for several reasons. Unlike another measure of body-image anxiety that was used with people with amputation(s) (Fisher and Hanspal, 1998b), this measure was specifically developed for use amongst people with lower-limb amputations and, therefore, included such amputation-specific questions as "Do you like the appearance of your stump anatomy?" Therefore, it was considered to reflect particular areas that could be of potential concern to people with amputations. Furthermore, compared to another measure of body-image anxiety in people with limb loss (Rybarczyk et al., 1995), the ABIS contains a wide variety of items assessing the affective, functional, and behavioural sequelae of body-image anxiety. Thus, questions assessing the effect of body-image anxiety on clothing, the role of the prosthesis in preventing body-image anxiety, and the impact of body image anxiety on social interaction self-identity were included in the ABIS. Follow-up questions to each of the items were asked, and open-ended questions on any other issues of body-image that were of concern or of interest to the participant were given.

General Health, Other Medical Problems, and Other Pain Experiences

TAPES

General health and physical capabilities were assessed by asking participants to rate on two five-point scales their answers to the following questions: "In general, would you say your health is: Very Poor (= 1), Poor (= 2), Fair (= 3), Good (= 4), or Very Good (= 5)" and "In general, would you say your physical capabilities are: Very Poor (= 1), Poor (= 2), Fair (= 3), Good (= 4), or Very Good (= 5)" Participants were given the opportunity to expand on and explicate their answers if they wished.

The occurrence of other medical problems was assessed using questions included in the TAPES (Gallagher and MacLachlan, 2000). Participants were asked "Do you experience any other medical problems apart from stump or phantom limb pain?" If participants did experience other medical problems, they were asked the question "Please specify what problems you experience." The duration of these problems was

assessed with the question “How long, on average, did each problem last?” The level of pain associated with these problems was assessed by asking participants to rate, on a five-point scale, the level of pain experienced as a result of these problems during the last week. This intensity scale included the following five points: Mild (= 1), Discomforting (= 2), Distressing (= 3), Horrible (= 4), and Excruciating (= 5). The extent to which these medical problems interfered with participants’ lifestyles was assessed with the following question: “How much did these activities interfere with your normal lifestyle (e.g. work, social and family activities) during the last week?” Participants answered according to a five-point scale ranging from: Not at all (= 1), A little bit (= 2), Moderately (= 3), Quite a bit (= 4), and A lot (= 5). Again, participants were given the opportunity to expand on and explicate their answers if they wished.

The occurrence of any other pain was assessed by asking participants the question “Do you experience any other pain that you have not previously mentioned? If participants did experience other pain, they were asked to specify this further. Follow-up and open-ended questions on issues of pain that were of interest to the participant were also asked.

Psychological Well-Being

The Hospital Anxiety and Depression Scale (HADS)

The HADS (Zigmond and Snaith, 1983) was used to measure psychological well-being in the study’s participants. This instrument consists of two seven-item subscales measuring anxiety (HADS-A) and depression (HADS-D). Responses to each item are scored on a four-point scale (range 0 to 3), with maximum scores of 21 on each subscale indicating a high level of anxiety and/or depressive symptoms. Although no definitive cut-off scores have been determined, cut-off scores of > 8 on each subscale are proposed to be indicative of ‘mild’ symptoms (Zigmond and Snaith, 1983; Bjelland et al., 2002), cut-off scores of > 11 are proposed to be indicative of ‘moderate’ symptoms, and cut-off scores of > 14 are proposed to be indicative of ‘severe’ symptoms (Zigmond and Snaith, 1983; Zigmond and Snaith, unpublished data cited in Johnston, Wright, and Weinman, 1996). Although some studies have proposed a higher cut-off score of 10/11 to be indicative of probable ‘caseness’ (Crawford, Henry, Crombie et al., 2001; Osborne, Elsworth, and Hopper, 2003), one large scale review concluded that the lower cut-off point of > 8 was successfully used by the majority of studies to indicate

'caseness' and that this point permitted satisfactory sensitivity and specificity levels (Bjelland, Dahl, Haug et al., 2002).

The HADS was considered the most suitable instrument for assessing psychological well-being in this study for several reasons. In a review of over 200 published studies from medical settings, it was found that the scale is generally well accepted by patients and non-patients, with many studies reporting response rates of 100% in well-motivated patients (Herrmann, 1997). Furthermore, in its development, Zigmond and Snaith (1983) did not include somatic symptoms of depression and anxiety, for example, dizziness and headaches. Therefore, it is suitable to be used amongst individuals with a physical illness, as symptoms of these comorbid medical conditions would not confound scores on the two subscales. In fact, the HADS has been extensively used to assess psychological well-being amongst several medical populations, including cancer patients (Fosså and Dahl, 2002; Osborne et al., 2003; Nordin, Berglund, Glimelius et al., 2001), patients with rheumatoid arthritis (Morley and Pallin, 1995; Sharpe, Sensky and Allard, 2001), and people with advanced terminal disease (Hotopf, Chidgey, Addington-Hall et al., 2002). Of relevance to the present research, three studies have used the HADS in assessing the presence of psychological symptoms in people with amputations (Carrington, Mawdsley, Morley et al., 1996; Fisher and Hanspal, 1998a,b). Carrington et al. (1996) reported median total HADS scores of 7 for people who had both diabetes and an amputation compared to 4 for people with diabetes only. Fisher and Hanspal (1998b) reported median HADS-A and HADS-D scores of 4 and 4, respectively, amongst a group of 97 people with amputations. In a second study, they reported mean HADS-A and HADS-D scores of 3.9 and 2.9 amongst 93 people with amputations, with only 11% scoring above the cut-off score for possible anxiety and less than 1% scoring above the cut-off score for possible depression (Fisher and Hanspal, 1998a).

Two large-scale reviews of the HADS (Herrmann, 1997; Bjelland et al., 2002) have supported the psychometric properties of this instrument amongst medical populations. Although some researchers have proposed a three-factor model of the HADS (e.g. Caci, Baylé, Mattei et al., 2003), the two-factor HADS-A and HADS-D solution originally proposed by Zigmond and Snaith (1983) has been supported in the majority of studies (Mykletun, Stordal, and Dahl, 2001; Bedford, de Pauw, and Grant, 1997; Herrmann,

1997; Bjelland et al., 2002). Moreover, in terms of the reliability of the HADS, Herrmann (1997) concluded that in several longitudinal studies, it showed excellent test-retest reliability, was suitable for presenting to participants at two-week intervals, and was sensitive enough to detect minimal changes in mood over time. In addition, internal consistency estimates (Cronbach's alpha) ranging from 0.80 to 0.93 for the anxiety subscale and from 0.81 to 0.90 for the depression subscale were reported in large-scale reviews (Herrmann, 1997; Bjelland et al., 2002). In terms of the HADS' concurrent validity, it was found to compare favourably with other questionnaires for anxiety and depression, including the Beck Depression Inventory (BDI), the State-Trait Anxiety Inventory (STAI), and the Symptom Checklist-90 (SCL) Anxiety and Depression Subscales (Bjelland et al., 2002). In terms of the HADS' discriminant validity, its ability to detect psychiatric cases has been found to be similar to that reported for other scales (Herrmann, 1997). Moreover, its sensitivity ratings range from 0.83 to 0.90 for HADS-D and HADS-A, respectively, and its specificity ratings range from 0.78 to 0.79 for both subscales (Bjelland et al., 2002). Although the HADS cannot be used to make a specific anxiety diagnosis or a diagnosis of major depression, it performs well in screening for possible cases of depression and anxiety (Herrmann, 1997; Bjelland et al., 2002).

In conclusion, the HADS was thought to be suitable for eliciting psychological symptoms from participants for several reasons. Its brevity and high acceptability amongst medical and non-medical patients gave it an advantage over other instruments, including the BDI, the STAI, and the SCL-90. Furthermore, because it was developed for use with medical populations, it was thought that participants' somatic symptoms (associated with amputation and comorbid medical problems) would not confound answers or findings. Finally, the factor structure, reliability, and validity of the HADS was found to be suitable in individual studies and large-scale reviews.

DATA ANALYSIS

Data were analysed according to Grounded Theory methodology. In keeping with guidelines provided by several authors (Glaser and Strauss, 1967; Corbin and Strauss, 1998; Pidgeon and Henwood, 1997; McLeod, 2001), a number of procedures were followed.

- (1) All interviews were transcribed *verbatim* by the researcher as soon as possible after they had been conducted.
- (2) Using NUDIST*4.0 (a software tool for analysing qualitative data), each interview was analysed as soon as possible after collection so that the researcher was made aware of emerging themes (McLeod, 2001; Corbin and Strauss, 1998). All interviews were analysed within their “stage” only. That is, all first interviews were analysed together, all second interviews were analysed together, all third interviews were analysed together, and all fourth interviews were analysed together.
- (3) The interview material was thoroughly read by the researcher. The process of ‘open coding’ was then conducted. According to Corbin and Strauss (1998), open coding is defined as the “analytic process through which concepts are identified and their properties and dimensions are discovered in the data” (pg. 101). Using this procedure, each line of the interviews was coded to at least one category that was labelled by the researcher on the basis of what was thought to be occurring in the piece of data.
- (4) The dimensions of each open code were explored. On the basis of this exploration, categories that were of a similar higher-order meaning were combined to produce higher-order categories (Strauss and Corbin, 1998).
- (5) These higher-order categories were explored, and connections between them were made using the technique of ‘axial coding’. According to Strauss and Corbin (1998), axial coding refers to the “process of relating categories to their subcategories, termed ‘axial’ because coding occurs around the axis of a category, linking categories at the level of properties and dimensions.” (pg. 123)
- (6) Throughout the analysis, a process of ‘constant comparison’ was followed (Strauss and Corbin, 1998; McLeod, 2001; Charmaz, 1990; Pidgeon and Henwood, 1997). In this way, the meaning of all categories were compared and contrasted with each other. Thus, categories that were initially thought to hold disparate meaning could subsequently be found to be part of a higher-order category and, therefore, linked together.
- (7) Throughout all stages of data analysis, ‘memos’ and ‘diagrams’ were made by the researcher in outlining the development of the theory.

INTRODUCTION

The first part of the introduction discusses the importance of the research and the need for a theoretical framework. It also discusses the research objectives and the research questions. The second part of the introduction discusses the research methodology and the data collection process. The third part of the introduction discusses the research findings and the conclusions.

CHAPTER 3

FIRST INTERVIEWS

The first part of the chapter discusses the preparation for the first interviews. It includes a discussion of the interview schedule, the interview questions, and the interview process. The second part of the chapter discusses the first interviews. It includes a discussion of the interview process, the interview questions, and the interview findings. The third part of the chapter discusses the analysis of the first interviews. It includes a discussion of the interview findings and the conclusions.

INTRODUCTION

After an individual has undergone a limb amputation, he or she may be referred for prosthetic fitting and rehabilitation. In general, rates of referral for such rehabilitation ranges between 17% to 65% of all people with a lower-limb amputation (Rommers, Vos, Groothoff et al., 1996; Harris, van Schie, Carroll et al., 1991). Factors associated with an increased likelihood of being referred include being younger (Fletcher et al., 2002, 2002; Pohjolainen et al., 1989; Christensen et al., 1995), having a below-knee amputation, (McWhinnie et al., 1994; Uiterwijk et al., 1997; Pohjolainen et al., 1989), and having fewer medical comorbidities (Condie et al., 1996; Fletcher et al., 2001; Harris et al., 1991; Campbell et al., 1994; Clark et al., 1983).

A number of physical factors have been found to impact on an individual's rehabilitation outcome and adjustment to amputation. One physical factor that is extremely important in determining outcome is the level of the amputation (Houghton et al., 1990; Pohjolainen et al., 1990; Uiterwijk et al., 1997; Helm et al., 1986; Steinberg et al., 1985; Hagberg, Berlin and Renström, 1992; Jensen and Mandrup-Poulsen, 1983). Because an above-knee prosthesis requires more energy to operate (Huang et al., 1979), because people with an above-knee amputation tend to be older than those with a below-knee amputation (Ebskov, 1991; Mandrup-Poulsen and Jensen, 1982), and because older people with amputations tend to have a higher number of medical comorbidities (Clark et al., 1983), learning to walk on an above-knee prosthesis can pose more difficulties for the user than learning to walk on a below-knee prosthesis. Another physical factor that is important in determining rehabilitation outcome is the number of amputations that a person has. Generally speaking, individuals with bilateral lower-limb amputations are much less likely to walk using their prostheses than are people with unilateral amputations (Volpicelli et al., 1983). Other physical factors that may influence rehabilitation outcome include age, physical health and cognitive functioning (Hanspal and Fisher, 1997; Steinberg et al., 1985; Weiss et al., 1990; Pohjolainen and Alaranta 1991; Johnson et al., 1985). In addition, phantom pain and stump pain have been found to affect rehabilitation outcome. According to some studies, both types of pain significantly interfere with an individuals ability to use his or her prosthesis and to walk long distances (e.g. Pohjolainen and Alaranta, 1991). In older people, for example, increased stump pain is associated with reduced outdoor walking

and reduced walking distance (Pohjolainen and Alaranta, 1991) and having fallen using the prosthesis (Miller et al., 2001). In younger people, a greater number of stump pathologies is associated with decreased satisfaction with rehabilitation outcome and significantly poorer adjustment to physical limitations (Gallagher et al., 2001; Steinbach et al., 1982).

A number of psychological factors are also related to adjustment to amputation. However, comparatively few studies have examined the association between such factors and adjustment during the rehabilitation period. To date, anxiety and depression are the most commonly examined measures of adjustment to amputation during this time. Reports on the occurrence of anxiety in the year following amputation indicate that it is likely to increase during this period (Randall et al., 1945; Shukla et al., 1982b). With regard to depression, some depressive symptoms have been noted in younger people with amputations during the initial hospitalisation period (Randall, Ewalt and Blair, 1945; Shukla, Sahu, Tripathi et al., 1982b). On the other hand, psychological distress and depressive symptoms have been found to substantially decrease in older people between the beginning and the end of a rehabilitation program (Schubert et al., 1992; MacBride et al., 1980).

Numerous other factors related to adjustment have been examined in people who have had their amputations for several years. For example, the relationships among social discomfort, social stigma, and activity restriction (Williamson et al., 1995; Rybarczyk et al., 1992), the relationship between body-image and depression (Rybarczyk et al., 1995), and the associations between coping mechanisms, personality, adjustment to amputation (Livneh et al., 1999; Gallagher et al., 1999; Gerhardt et al., 1984) have all been assessed in cross-sectional samples. In addition, the impact of amputation-related factors, including phantom pain, stump pain, and adaptation to prosthesis on psychological symptoms have been investigated in people with long-term amputation (Sherman, 1994; Lindsay, 1985; Whyte and Niven, 2001; Gallagher et al., 2001). To date, however, no investigation on the impact of these variables on adjustment throughout the rehabilitation period has been conducted. Furthermore, no qualitative analysis on the interrelationships among these variables and on the impact of the amputation on sense of self and identity during this time has been carried out.

Aim

- Using a qualitative methodology, the aim of the present study was to investigate the occurrence and interrelationships among amputation related factors (phantom pain, stump pain, prosthesis, learning to walk), coping mechanisms, reactions to amputation, psychological well-being, sense of self and identity, body-image anxiety, and social functioning during the rehabilitation period. In order to provide an initial starting point for exploring amputation-related and psychosocial-related factors, a series of questionnaires were administered throughout the interviews, and follow-up and open-ended questions were also asked to explore other these aspects and other issues of interest to participants.
- Using the questionnaire data above, the present study also aimed to provide descriptive information on the amputation-related and psychosocial-related characteristics of participants in order to indicate the representativeness of this sample.

METHOD

Procedure

As outlined in Chapter 2, semi-structured interviews were conducted with patients attending the National Rehabilitation Hospital for first time prosthetic fitting and rehabilitation. Patients were approached by the researcher and asked to participate in the present research. They were told that they may be asked to participate in follow-up interviews throughout the forthcoming year and given the opportunity to ask any questions that they had about the research. The interviews, which were tape-recorded, were based on health related, phantom pain related, and stump pain related questions included in the Trinity Amputation and Prosthesis Scales (TAPES; Gallagher and MacLachlan, 2000), the TAPES-R, the Short Form of the McGill Pain Questionnaire-Short Form (SF-MPQ; Melzack, 1987), and the Hospital Anxiety and Depression Scale (HADS; Zigmond and Snaith, 1983). Responses to items on these questionnaires were followed with probing questions assessing the reasons for their responses. In addition, participants were asked open-ended questions about their reaction to their amputation,

learning to walk, their current goals, their hopes for the future, their social support, and qualities of phantom limb pain.

All of the interviews were transcribed *verbatim* by the interviewer. The interviews were then analysed using QSR NUD*IST 4.0 for analysing qualitative data. In accordance with grounded theory methodology, open codes from the interviews were created using line-by-line analyses. These open codes were then used to create categories of higher-order concepts. On the basis of these categories' properties and dimensions, axial coding was then carried out to focus the results and draw the concepts together.

Inter-rater reliabilities were used to assess the validity of the categories. In order to test the validity of the *Amputation-Related Sequelae*, 20 examples from each of the subcategories were given to an independent rater. This rater was then asked to place each example into one of the following categories: Amputation-Related Sequelae, Social Sequelae, Body Image Sequelae, Identity Sequelae, Limitations Sequelae, and Other Worries. Initial ratings revealed that sixty-five percent of the examples were coded reliably. Subsequent discussions between the researcher and the independent rater resulted in maintaining the Identity, Social, and Limitations sequelae. However, it was agreed that they should be placed, along with the Body Image Sequelae, under the overall category of Psychosocial Sequelae. In this way, the interrelations among the three categories (that is, Identity, Social, and Limitations) could be preserved.

In order to test the validity of the *Appraisal* and *Coping* categories, 20 examples from each of the subcategories were given to an independent rater. This rater was then asked to place each example into one of the following categories: Appraisals of the Amputation and its sequelae, Cognitive Approach, Cognitive Avoidance, Behavioural Approach, Behavioural Avoidance, Emotional Approach, and Emotional Avoidance. Initial ratings revealed that seventy percent of the examples were coded reliably. The independent rater had placed many of the Appraisals examples (e.g. Social Comparisons, Benefits) into Cognitive Approach coping. Subsequent discussions between the researcher and the rater as to the rationale for Appraisals (See Summary and Discussion) resulted in the maintenance of the current categorical system. However, upward Social Comparisons with regard to walking were placed in Cognitive Approach coping. The reason why such comparisons were placed in Cognitive Approach, while

downward comparisons were placed in Appraisals, was because participants *explicitly* stated that use of upward comparisons helped them to cope with their doubts, fears, and uncertainties about whether they would be able to walk again. On the other hand, use of downward social comparisons were never explicitly or overtly described as coping mechanisms by participants. Instead, these comparisons merely appeared to reflect a process of assessing their situation in comparison with other people.

Participants

Criteria for inclusion in the study were that the individuals were aged 18 years and above, that they were attending the rehabilitation unit for the first time to obtain their first prosthetic limb(s), that they did not have their amputation for more than six months prior to admission for rehabilitation, and that they did not present to the rehabilitation unit with any cognitive impairment or psychotic disorder as detailed in their medical records. Between 31st November 2000 and 19th October 2002 (less four months – see Ethical Considerations, Chapter 2), 30 individuals met the study's inclusion criteria. Their demographic characteristics are outlined in Chapter 2.

For the purposes of the present study, the interviews of twenty-four of these participants were analysed. Three interviews were not analysed because the quality of the tape-recording was too poor. Another three interviews were not analysed because the participants subsequently refused to participate in a second interview. The twenty-four participants whose interviews were analysed in the present study were four females and twenty males. Their mean age was 61 years (range 37 years to 80 years). The reasons for amputations were as follows: pulmonary vascular disease (PVD) = 9, diabetes = 9, accident = 2, clot/aneurysm = 2, ulceration of the leg = 1, cancer = 1. Twenty-two participants had unilateral lower-limb amputations, including fourteen above-knee amputations and seven below-knee amputations. Two participants had bilateral lower-limb amputations: one person had bilateral above-knee amputations and the other person had one above-knee amputation and one below-knee amputation. Some of the participants had concurrent medical problems that could impact on their rehabilitation. Two people were visually impaired, one man had arthritis in his hands, and one man had a heart condition. Table 3.1 outlines the characteristics of these participants in terms

of age, type of amputation, time since amputation, and other notable characteristics that could impact upon their rehabilitation.

Name	Sex	Age	Amputation type	Reason for amputation	Time since amputation	Concurrent difficulties
AMcG	F	72	Right AKA	PVD	6 months	None
AOM	F	75	Left BKA	Diabetes	6 months	None
BN	F	55	Left BKA	Diabetes	6 months	None
CD	M	64	Right AKA	PVD	2 months	None
DOD	M	56	Right BKA	Diabetes	3 months	3 toes amputated on right foot
FF	M	66	Right AKA	PVD	5 months	None
GC	M	59	Right AKA	PVD & Arthritis	4 months	Arthritis in hands
GD	M	62	Right BKA	Diabetes	3 months	Kidney transplant; Heart problems
JL	M	46	Right BKA	PVD	6 months	None
JM	M	58	RAKA & LAKA	PVD	2 months	None
JMcG	M	69	Left AKA	Cancer	3 months	None
JS	M	53	Right AKA	Diabetes	6 months	None
JW	M	80	Left AKA	PVD	4 months	None
LB	M	71	Left AKA	Clot	1 month	None
MG	M	62	Left AKA	Complications of Aneurysm	6 months	None
MW	M	70	Right AKA	Ulceration of the leg	2 months	None
MMcC	M	62	Right AKA	PVD	3 months	None
MOB	M	73	Left AKA	PVD	4 months	None
NK	M	37	RAKA & LBKA	Diabetes	6 months, 1 month	Visually Impaired
OMcK	F	64	Right AKA	Diabetes	2 months	None
PG	M	48	Left AKA	Road Traffic Accident	4 months	Visually Impaired
PM	M	64	Right BKA	Diabetes	4 months	Heart Condition
PR	M	58	Right BKA	Diabetes	4 months	None
SC	M	38	Left BKA	Boat Accident	3 months	None

Table 3.1 : Describes the name, sex, age, type of amputation, cause of amputation, time since amputation, and concurrent medical difficulties of the participants. F = Female; M = Male; AKA = Above-knee amputation; BKA = Below-knee amputation.

RESULTS

Descriptive statistics of participants

A table and brief description of participants' scores on the questionnaire instruments are provided in Appendix 10. As these scores did not comprise part of the major results, they were not included in the main results section.

Qualitative Findings: A model of adaptation to amputation

Figure 3.1 is a pictorial representation of the findings that emerged from the interview data. The higher-order category "Amputation Sequelae" was comprised of two lower-order categories: Amputation-Related and Psychosocial-Related. Within the Amputation-Related category, the following topics were discussed: reactions prior to having an amputation, phantom limb-pain, stump pain, adapting to the prosthesis, and learning to walk. Within the Psychosocial-Related category, the following topics were discussed: reactions to changes in body schema and body-image, lifestyle changes and limitations, social changes, identity issues, and other worries that arose as a result of having an amputation (for example, family concerns, financial worries). In adjusting to these changes, individuals tended to appraise them within a context of "it could be worse." Such appraisals were made through Acceptance of the Amputation and its consequences, making social comparisons with others perceived to be in more challenging situations, making temporal comparisons of the self prior to amputation, seeing benefits in the situation, appraising the amputation as having minimal impact because of older age, and appraising the amputation as being less serious than a previous loss. Appraisals also included some mixed feelings and attributions for the amputation. After appraisals were made, a variety of coping mechanisms emerged from the interviews. These included Cognitive Approach methods of making social comparisons and looking ahead; Cognitive Avoidance methods of taking things from day-to-day and not thinking about problems. Emotional Approach coping methods included Emotional Determination, using Emotional Social Support, and turning to Religion. Emotional Avoidance strategies included joking about the amputation and hiding its emotional impact from others. Behavioural Approach methods included Taking Action to resolve a problem, using external resources to help coping with any problems, using practical social support. No Behavioural Avoidance methods were

observed throughout the first interviews. Overall, the structure of coping that emerged was similar to that of Lazarus and Folkman (1984) and Tobin, Holroyd, Reynolds et al. (1989).

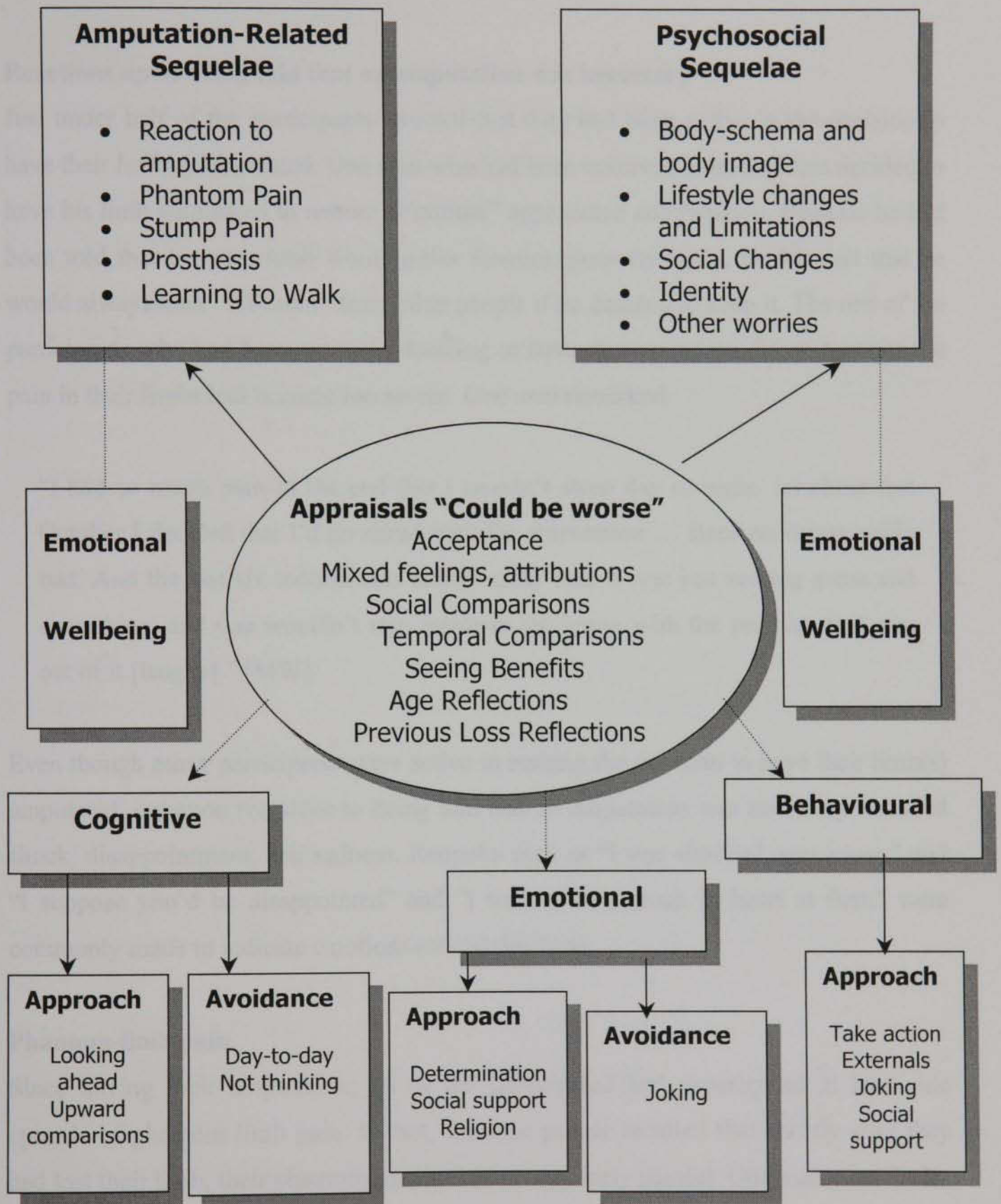


Figure 3.1: A pictorial representation of emergent findings. The broken lines between emotional well-being and amputation-related and psychosocial-related sequelae represent the preliminary relationships observed amongst these variables. Similarly, the broken line between Appraisals and coping mechanisms indicates that the greater the threat appraisal, the more coping mechanisms are required.

SEQUELAE OF AMPUTATION

Amputation-related sequelae

Reactions upon being told that an amputation was necessary

Just under half of the participants stressed that they had been active in the decision to have their limb(s) amputated. One man who had been involved in an accident decided to have his limb amputated to restore a “normal” appearance and function. Because he had been told that his own limb would never function properly again, he felt that that he would always look “different” from other people if he decided to keep it. The rest of the participants who had been active in deciding to have an amputation did so because the pain in their limbs had become too severe. One man remarked:

“I had so much pain in the end that I couldn’t sleep day or night. So about last October I decided that I’d go ahead with the amputation ... Because it was really bad. And the last six months was really, really bad. It was just turning green and everything, and you wouldn’t stay inside in the house with the perfume that was out of it [laughs].” [MW]

Even though many participants were active in making the decision to have their limb(s) amputated, common reactions to being told that an amputation was necessary included shock, disappointment, and sadness. Remarks such as “I was shocked, you know,” and “I suppose you’d be disappointed” and “I took it very much to heart at first,” were commonly made to indicate emotions around this time.

Phantom-limb pain

Since having their amputation, all of the participated had experienced at least one episode of phantom limb pain. In fact, fourteen people recalled that shortly after they had lost their limb, their phantom pain had been extremely painful. One man remarked:

“the pain was terrific, horrendous. It was unbelievable. I even asked the doctor is there such a thing that a person never sleeps again, because I used to look up at a big clock. I’d close my eyes for a minute, and I’d think five minutes was gone. Then I’d look at it, and it was only a minute.” [FF]

However, at the time of the present study, almost every participant indicated that their phantom pain had become either less frequent or less severe. In addition, seventeen people remarked that they had experienced either none or mild phantom limb pain during the previous week. One man (JMcG) described his phantom pain as “harmless ... not really a pain,” another man (MG) stated that his phantom pains were “very little, but not severe, darts ... mild, you know, so it could happen ten times a week and I wouldn’t take much notice of it. I just can take it, it isn’t a worry to me.” Only three of these individuals were taking prescribed medication for their phantom limb pain.

Although seven participants described their phantom limb pain as either discomforting or distressing, six maintained that the level or frequency of pain had decreased since their amputation. Five were continuing to take medication for their phantom limb pain (Neurontin or Tegretol), as they found it effective in controlling the intensity of their pain. One man had discontinued taking medication for phantom limb pain, and one never took medication for this phantom limb pain.

In general, the average duration of episodes of phantom limb pain that participants reported experiencing during the previous week was minutes or seconds. Most people had only experienced phantom limb pain once or twice during the previous week, although six people, three of whom experienced discomforting phantom pain, did indicate that their phantom limb pain occurred on a daily or nightly basis.

Only one man (DOD) felt that his phantom limb pain interfered with his daily living. When asked whether he found it emotionally and physically upsetting to experience phantom limb pain he said “it is because it interferes with your company, and you’re gritting your teeth, they’d be looking at you wondering what’s wrong with you.” The remainder of the participants, including six of those with discomforting or severe phantom limb pain, stressed that their phantom limb pain did not interfere with their daily activities.

Stump Pain

Only three people answered “yes” when asked whether or not they experienced stump pain. Of these individuals, AMcG noted that her stump pain was discomforting at times,

while the other participant, JS, said that his stump “starts to burn at times, like it was boiling water that was poured on it.” The other person with stump pain (JL) only experienced this as ‘mild’ while walking with his prosthesis. However, although the remaining individuals did not consider themselves to be experiencing stump pain *per se*, that is, they answered “no” when asked whether they experienced stump pain, almost all of them did admit that their stumps were tender or slightly discomforting at times. One woman, AOM, said “it’s not sore, but say now if something was to hit against me, that would hurt me ... it’s a little tender.” Another man (FF) reported that his stump was tender because he had two open sores on the stump that were not healing due to having methicillin-resistant *Staphylococcus aureus* (MRSA)¹. Yet another man, JM, said that he would have “a small little bit of pain. It wouldn’t keep you, it comes and goes. It isn’t stuck there the whole day, it just comes and goes.”

Adapting to the prosthesis

The majority of participants had no problem with either the comfort or appearance of their prosthesis. In fact, one man, MMcC, who was very pleased with the fit of his prosthesis, went so far as to call it “a work of art”. Nevertheless, eight out of the twenty-two participants remarked that their prosthesis was painful to use at the beginning. One woman, AMcG, had to have a new limb made for her because she could not wear her first one at all. She said of this prosthesis “it hurt me terrible, it seemed to be too long. It used to dig into me here in the groin, you know ... there were times when I felt like throwing it out the window.” Although this woman was the only person to have another prosthesis made for her, the other seven participants had similar experiences. One man, MOB, said of his prosthesis “it kills me, it’s sore in the groin,” and another man, PG, described wearing his prosthesis as “exhausting.”

Five people also disliked the appearance of their prosthesis. Terms such as “crude looking”, “a monster”, “unimpressive,” and “not a nice looking sight” were used to indicate such displeasure. One man, PG, remarked:

¹ MRSA is a bacterial infection that is acquired on wound sites. Its prevalence in the Republic of Ireland is estimated at 14 per 100,000 of the population (McDonald, Mitchell, and Johnson et al., 2003). It is the most common cause of surgical site infection in vascular patients (Naylor, Haes and Darke, 2001) and is often associated with a poor treatment outcome (Scriven, Silva, Swann et al., 2003).

“It’s a terrible looking yoke. When it’s on, you don’t notice it as much ‘cos you’re not looking down on it ... but in general, if I see someone else’s, and I look at it, I’ll say ‘Jesus, that’s a queer, ugly looking yoke.’” [PG]

Interestingly, the only five people in the study who admitted to disliking the appearance of the prosthesis were all included amongst the eight who experienced pain when wearing their artificial limbs.

Although some people were dissatisfied with the comfort and appearance of the prosthesis, it became clear throughout the interviews that almost everyone was extremely willing to adapt to their artificial limbs in order to restore a sense of “normality” to their appearance and lifestyle. For example, SC, who found his prosthesis uncomfortable, had originally chosen to have an amputation because he believed that this would make him look ‘normal’. JL, who also experienced pain when wearing his prosthesis said “It looks well when you see yourself, when you’re looking in a mirror.” PG, who particularly disliked the appearance of his limb, stated:

“I’m trying to accept it. It’s the way forward. What do I do? Throw my head against the wall and run off without it. That’s not going to help. This is for me and it’s for my family. The thing is basically a camouflage.” [PG]

In terms of ‘normal lifestyle’, most participants also believed that the prosthesis would go far in helping them get over their limb loss and restore functioning in everyday living. For example, one man, FF, remarked “I do miss my leg, but I expect I won’t miss it as much when I get my prosthesis. Another, GC, said “Once I get the new leg, sure, you’re home and dry, as good as ever ... it means I can stand up and walk around no problem.” Similarly, PM said that because of his artificial limb “it was a great thing to be able to stand up again straight and to start walking again. It’s a mighty thing, your independence is coming back again.”

One noteworthy finding from the interviews was that most of the participants were unsure about how successful they would be in meeting the challenge of adapting to the artificial limb. For example, AMcG did not know whether she would be able to adapt to it because her previous one had been too painful. She remarked:

“I’ll wait now until I get it and keep it for longer, you know, and see what happens. Because the one I had before, it hurt me terrible. So, I’ll have to wait and see with this one. It’s trial and error.” [AMcG]

Learning to walk

Learning to walk was fraught with difficulties in the early stages, with many people experiencing falls or being afraid of doing so. Four men had actually fallen since their amputation, three of whom required further surgery as a result. Of these men, PM, had experienced a particularly bad fall after his amputation. He said:

“I’d a few falls, and the day before I left the hospital, I went into the toilet, I’d one of them walking aids, and it tumbled over some way with me, and I hurt it [i.e. the stump] then, bursted two stitches and it bled ... I hurted it terrible, it was awful pain. The cold sweat came out through me. I felt awful sick.” [PM]

Regardless of whether they had fallen or not, many participants were continuously nervous of doing so. Fears of falling in public toilets, of falling while walking with crutches, or of falling while learning to walk on the prosthesis were expressed by several participants. However, despite the fact that some people had fallen since their amputation, and despite the fact that fears of falling were common, the goal of walking was uppermost in almost everyone’s mind at this stage of the study. Furthermore, most people were looking forward to mastering their artificial limbs and being able to walk again. Comments such as the following were common:

“Walking is my main goal ... my main aim is to get back on my feet and get good walking, that’s my main priority in life, ‘cos it’s the most important thing in my life. You have two legs, you take it for granted. I’ve only one and a half now. It’s going to be hard, but that’s all I’m thinking about.” [BN]

“I’m looking forward to getting a new limb, going home, and start walking again, you know, with or without sticks. At the moment, I’ll be glad to walk with the sticks. I’ll enjoy life again. I’ll enjoy the craic.” [PM]

With walking being the primary goal at this stage of their rehabilitation, almost everyone indicated that they were extremely motivated and determined to master their prosthesis and learn to walk again. Participants made such comments as “nothing will stop me from learning to walk” and indicated that they were “going to be the best” of their age and “do the very best” they could do to become mobile again.

Psychosocial Sequelae

Body-Schema and Body Image Changes

One issue that emerged from the interviews was that after losing a limb, participants had to adapt to a new body-schema. Evidence that such adaptation was required was found in the observations that some participants often ‘forgot’ that they had an amputation. As a result, they sometimes made efforts to use their amputated limb in routine behaviours that they would previously have used their limb for. Thus, falling out of bed or trying to scratch a phantom itch was a common occurrence for some people. The phenomenon of phantom limb sensation appeared to play a role in such ‘forgetting’. As one man remarked “You think you can use the leg, and it isn’t there to use. The sensation is there to use it, but it isn’t there. That’s how you fall over.” Another man explained:

“What happens is, you go to do something with it, like scratch your other leg in the bed. You go ‘Jesus, you can’t do that, you’ve none.’ Or taking your shoe off. You know the way you put your foot against the other shoe to take it off. I’m doing that every night. I say ‘Jesus, I’ve nothing there.’” [GC]

In addition to physically adapting to a new body schema, a small number of people admitted that in the beginning they had found it upsetting to look at their amputated limb and to come to terms with the absence of their leg. For a period after their amputation, three people recalled that they covered up their amputated limb when they had visitors. One man admitted to currently finding it difficult to come to terms, emotionally, with having a changed body-image. He said:

“It’s kind of a weird way to phrase it, but in some ways, I don’t believe that I don’t have the leg. I still get shocked if I look down and it’ll take me aback for a second ... it’s a little sad.” [SC]

In addition, seven people admitted to still feeling embarrassed about showing their amputated limb or about the fact that they would now be walking with a limp. One woman said that she had done a lot of swimming prior to her amputation but that she would be embarrassed getting into the water with only one leg. Several people remarked that they would not like other people to notice them limping. One man explained his self-consciousness as follows:

“I’d be shy, I’d be shy, yeah. I don’t see the embarrassment part, I’m gone over the line, I was at one side a few months ago, now I’m on the other, but I’d prefer if people didn’t know about it ... I don’t particularly like it [his amputated limb]. I’d like if there was something there instead of it, that I’d look more like the rest of people. I don’t like it being gone.” [DOD]

Although only seven people admitted to feeling embarrassed or shy about their amputation, many people seemed to perceive their prosthesis as a means of restoring a ‘normal’ body image and appearance. Remarks such as “I thought that it’d be more natural looking,” and “People wouldn’t know, you’d still have two legs showing,” were common amongst the participants. Therefore, although most of the participants did not appear to be self-conscious their body-image, such reliance on the prosthesis may have meant that participants were not, at this stage, adapting to a new body image because their hopes were pinned on the prosthesis to restore their previous body-image.

Lifestyle Changes and Limitations

In thinking about the implications that their amputation would have on their lives, most people were eager to stress that they would still be able to do many of the things they used to do. For example, one woman said “Basically, I’ve done almost everything I used to do, but in a wheelchair.” Similarly, one man remarked “I’ll do the same things when I get back on the road.” However, despite being kept to stress that they would still be able to do most things, the majority of people in the study also acknowledged that there would be some things that they could not do. One man discussed having to curtail his work and going to football matches. In addition, one woman talked about the difficulties she faced in working in her kitchen at home. Another woman explained how she felt about these limitations:

“I couldn’t even get out of the doorstep, and that to me was a big loss, because I lived on land, you know, farming. I worked full-time and I reared eight kids, so obviously I’ve been very busy all my life, and to think that all that’s been taken away from you, it’s a terrible loss.” [BN]

Although most people acknowledged that they would not be able to do everything they had previously done, only two people thought that their lives would not be as good again as a result. One of these individuals, FF, said:

“Ask anyone here, their lives are changed ... because, I mean, there’s so many places that I’d love to go [but] I haven’t the same ambition now. I’d say that I’d be more or less an encumbrance now. Maybe I won’t, I don’t know, but at this moment, I do feel that life’s not as good or it won’t be as good again.” [FF]

The remainder of the participants were either unsure of whether their lives would be as good, believed that their lives would be as good, or believed that their lives would actually be better. As one man remarked “It will be better. Sure, it can’t get any worse.” Those who were unsure about the impact of the amputation on their lives were withholding judgement until they saw how they fared on their artificial limb. For example:

“I would withhold judgement, really, on making any decision on the way I feel until I’ve tried them on [i.e. his artificial limbs] and see how successful that is. Because I don’t know how successful I’m going to be on the limbs, how much I’m going to be able to do, so I’ll just leave my mind open to it to see how it resolves.”[NK]

This theme of uncertainty with regard to the implications of the amputation and its subsequent impact on lifestyle was also observed in other aspects of the participants’ lives. For example, many of the participants were unsure about their living arrangements and future working situations. While they were in hospital, their family and friends were in the process of having their homes adapted to improve their accessibility. The uncertainties surrounding these processes and their financial consequences were also playing on participants’ minds. One man, CD, lived alone and

had to move to a new town because that was the only place in which he could find a suitable house. As a result, he was unsure whether he would be able to maintain the same circle of friends or go visiting as often as he used to before his amputation. Another man, NK, was in a similar situation. While he was in hospital, his wife was looking for a new, more accessible, home for them to buy. He admitted:

“The thing that would really worry me is the fact that I’m stuck here in the hospital and the whole burden shifts onto my wife. That she’s going to go out and find these houses, and look at the house, sell our house, transfer the furniture. It’s an enormous burden when there’s two people there, when it’s dropped onto one person’s shoulders, it’s an incredible strain ... I would get a little tense when I’d be thinking about the situation as regards the house because there wouldn’t seem to be one single body that’s got the answer.” [NK]

In many cases, the financial concerns that accompanied these adaptations could not be dealt with directly, as participants were also unsure as to what their working futures would be. Although twelve participants had been working prior to their amputation, only four of these were sure that they would be returning to the same jobs. The remainder did not know, at this stage, whether they would have to retire or find another job. Concerns about being able to get adequate insurance, being on one’s feet for prolonged periods, and being physically able for their jobs were commonly expressed.

Social Changes

None of the participants felt that, since having their amputation, they had difficulty talking about their limb loss with other people. However, an interesting division emerged in the group on closer inspection. The majority of participants who said they had no problem talking with others maintained this view throughout their interview, and half of these individuals clarified their opinions by stating that they were willing to talk about their amputation if it could help other people in their situation or if it could help students conducting research. However, eight individuals, despite indicating that they had no problem talking about their amputation, subsequently went on to indicate that they did, in fact, have some reserve in this area. Thus, some generally did not talk about their amputations, others were reluctant to talk about their amputations for fear of boring people, a small number found constant talking about their amputation annoying

in the sense that it was repetitive and prevented them from moving forward. Finally, one man felt that talking about his amputation was very dependent on the mood he was in at the time. He remarked:

“Sometimes you want to forget about it, get on with things. It keeps dragging you back to the time you had it done, and I’d rather keep going forward.” [GC]

Despite the fact that most people had no problem talking about their limb loss, about half of the participants noted that, at times, they were treated differently by others. In some cases, participants felt that they were being ignored or ‘talked over’ by others. In other cases, the reverse situation, receiving too much attention, was perceived. For example:

“If I’m with people, they’ll tend to say to my friends ‘How’s B. today?’ And I’m sitting here. And a few times I’ve jumped up, and I’ve said it to them ‘Look, I’m B., I’m the same B. Nothing’s changed. I’m better, in fact. All that’s wrong is I’m missing a bit of leg.’” [BN]

“You’re probably a target for people, you know, to express their feelings or their concerns to you. If I walked down normally, I probably wouldn’t be noticed, but if I went in a wheelchair, I would definitely be sticking out like a sore thumb.” [DOD]

In addition to being treated differently by others, almost every participant had some experience of finding it difficult going out and moving around socially. As a result of these experiences, most people felt extremely dependent on other people and were worried about being a burden on others. For example:

“Everywhere I go, I’ve to be taken out of the house, ‘cos I’ve only recently got a ramp, I’ve to be lifted out of the step, I’m not a light person, you know, then pushed out to the car ... they have to fold the wheelchair, put it in the car. You might only be going down the street. You’ve to get out again, they get the wheelchair out, then lift you up. And it’s an awful burden on anyone. They’re only glad to have me, but I feel it’s an awful burden.” [BN]

“If I go into a pub, and there’s not a toilet for a wheelchair, the toilets might have three or four steps. You’re feeling awful, you know, you have to ask your friends can you hold onto them or put your arms around their shoulder to get to the toilet. Very awkward, that.” [JL]

Because some people felt that they were being treated differently by others or that they were being too much of a burden on other people, five participants indicated that they were less willing to interact socially than they had been prior to their limb loss. Remarks such as “I have my pride,” “I’d be like a side-show,” and “I don’t want to be seen in the wheelchair” were made to indicate such reluctance. For example:

“This fella called in to me a couple of weeks ago. ‘Come on,’ he said ‘and we’ll have a couple of pints and any problem you have, I’ll help you out.’ I didn’t want to be imposing on people, I didn’t want to be an invalid ... I don’t like attention. I suppose I do have my pride. That’s why I wouldn’t go down to the local without my leg.” [MMcC]

“I was to go last Saturday night to a 25th wedding anniversary of a very close friend of mine, but when it came down to it my wife and I said ‘Look, I’m going to be the side-show at this thing.’ There was a big crowd going, they’d all be friends of mine and some I wouldn’t know. I didn’t want that ... they’d be saying ‘I think I’d better go over.’” [PG]

“I will not go out in the wheelchair ... I’ll go thirty miles away, I’ll go shopping there alright, but I won’t go in my locality. That’s all in my head, I know it is, but I just don’t want to be seen in the wheelchair.” [BN]

On the other hand, not everyone felt socially awkward as a result of being treated differently by others. Many of the participants described others’ reactions as kindness or as inexperience in dealing with disabled people. As one man said:

“Once or twice, they’d talk to your wife rather than to me. You’d think you were a mute. I’d just have to say ‘excuse me, I’m here, I can talk. It’s just the limb that’s

gone. But I think people just have a habit of that. They don't mean anything by it." [GC]

Furthermore, many people were delighted to receive so much attention from other people and found that this boosted their courage and self-esteem. As one man said "I was amazed at people I barely knew, they called to see me while I was in hospital, and all the mass cards I got." Thus, the majority of participants were extremely eager to resume their social lives and to continue on as they had been prior to their amputation.

Identity

An interesting finding emerged in the interviews with regard to what influenced people's assessments of whether they felt like the same person they had been prior to their amputation or not. In general, participants who tended to disregard their physical and social restrictions and limitations were more likely to feel like they were still the same person they had been prior to their amputation. These people focused more on what they could do and on how good they were feeling at the time. Some remarked that they felt like better people because they were no longer in pain. Others noted that although there were things they could not do, these limitations were irrelevant to who they were as a person. For example:

"I'm improved. I have no pain. And, you know, I would get cross when I had the pain ... the week before I came in, I was hardly eating at all. Now I'm back eating pretty good." [MW]

"Personality-wise, I'm the same. The only thing is that the activities I used to do, they have to be curtailed somewhat." [DOD]

On the other hand, participants who did not feel like they were the same person they had been prior to their amputation tended to focus on their limitations when describing their sense of how they had changed. Of the seven people who did not feel that they were the same person they had been prior to their amputation, five said that this was because there were many things they could now no longer do. All of these individuals were amongst the six people who now perceived themselves as 'disabled.' For example:

“I don’t think I’m a full woman now, because I can’t do what I used to do. I mean, I feel a full woman, but when you cannot hop up and go, you’re not a full woman, d’you know ... I’m disabled now for the first time in my life.” [BN]

“I feel different. When I had the leg I was able to do anything, run away, go upstairs, help people. Now, when I have the son here, I can’t help him that much. I won’t be as fast or anything like that. I’ll be slowing down alright.” [JL]

“I suppose you feel you’re not the full man, or whatever. Basically, what I am now, I’m disabled, or I’m not whole, what I wasn’t before.” [PG]

Other worries

In addition to having to cope with the amputation-related issues and psychosocial changes that emerged following the limb loss, many participants had to cope with other non-amputation-related illnesses and health worries. For example, sixteen of the participants experienced concurrent medical complaints, including diabetes, arthritis, asthma, heart problems, cancer, eyesight problems, kidney problems, and osteoporosis. Interestingly, despite the fact that over half of the participants experienced at least one other physical illness, only three people rated their overall health as fair, while the remainder rated their health as either good or very good. Only four people continued to worry about their other limb, two of whom admitted to worrying about their health in general. PG talked about his general health worries and his worries about his other limb:

“What I am worried about is weaknesses that are in my body. I don’t know what’s there. When my family were told by the doctor ‘nothing else can happen’, something else happened. For instance, I was okay, then I got a clot, then I got a urinary tract infection. I don’t know how serious they get, and these things can be a worry. When they talk about how I was on kidney dialysis, was there any damage caused to my kidneys? ... I worry that if I had a swelling in my brain, has it affected my reactions as well. I try not to think about the other leg at all, but when you’ve got pins-and-needles in it you worry.” [PG]

At the time of the interview, some of the participants were concerned about the effect of their amputation and its sequelae on their families. LB was concerned about whether his

wife and children and come to terms with his having had an amputation. Similarly, NK was worried that his wife was having difficulty accepting his amputation and that she was being put under too much strain by looking for a suitable house to buy while he was in hospital. Both GC and FF were worried about the physical burden placed on their wives by putting them in the position of having to bring them to places. PG was anxious about the effect that his accident and amputation had had on the emotional well-being of his family. He remarked:

“Whatever about me, I missed all this, I was out cold for nine weeks. But it’s to think of the effect it would have had on my family looking at me. My wife, especially, it must have been very traumatic ... my family seem to be good, but I might not see it. Because I wouldn’t be sharp enough to be looking at things, how they react. I’ve two lads, and they might be taking it hard, I don’t know.”[PG]

Since having an amputation, many people found themselves having concerns about money and finances. Although twelve people had been working prior to their amputation, only four were confident that they would be able to return to the same job. The other eight participants were either unsure that they would be able to work again or had decided to retire from work. Only those people who had been working prior to their amputation were concerned about the financial implications of their amputation. As one man said “there’s going to be so much expense. The prosthesis, the car. But you have no choice.”

EMOTIONAL WELL-BEING

During the course of the interviews, seven participants reported having felt somewhat depressed in either the run up to their amputation or prior to their rehabilitation. For example:

“One morning I woke up, and I knew I felt bad. Not sick bad, but bad mentally. I got up and it was too much trouble to put the kettle on. I didn’t want to know anyone, I didn’t want to see anyone. All I could do was cry. So, I knew it had to be depression. And I thought ‘well, Christ, if I haven’t suffered enough.’ ... And I was looking at that wheelchair, and I was bawling my heart out, you know. And

all that was bothering me was that I couldn't get a sledgehammer and make bits of it." [BN]

"Oh, I did feel down, of course I did. First time, now, when I knew I was going to lose it. The month of January was the worst month of the lot. I had the heart attacks and everything, and then I knew I'd lose the leg. I just wondered how I would cope, how I would manage." [PM]

Despite the fact that several participants had gone through periods of sadness or depression prior to or shortly after their amputation, none of the participants appeared to be currently experiencing any depressive symptoms and no one scored above the cut-off point for 'caseness' on the HADS-D. Furthermore, most participants appeared to be in a very positive frame of mind, seeing their current rehabilitation as bringing them one step closer to returning to their normal lives. In support of this, almost everyone commented on how happy they were to be in the rehabilitation hospital and on how pleased they were with being able to walk again. Furthermore, many talked about how they were looking forward to going home and spending time with their families. For example:

"At the beginning, I did feel 'this is the end of the world', but this has all changed, and I feel very positive now. Last weekend I brought the prosthesis home with me, and I walked around with it ... and I was delighted I did." [JMcG]

"I'm happy now, 'cos I've got as far as rehab. I'm in no pain, and they're doing everything they can for me. What more could I ask for. So I'm very happy today." [BN]

"I'm looking forward to going home at the weekends, which is very new to me. I look forward that that. Beyond that, I'm looking forward to going on holidays with my wife." [PG]

Despite the fact the none of the participants appeared to be particularly depressed at this stage of the study, three participants, PG, JL, and DOD scored above the cut-off point on the HADS-A, thus indicating the possible presence of clinical anxiety. All scores

were within the 'mild' range, according to standard cut off points²: PG scored 10, DOD scored 8, and JL scored 7. A closer look at PG's interview sheds some light as to why he may have been experiencing high levels of anxiety. He admitted to being currently worried about the effect of his accident on his family, his financial situation, and his health problems. In addition, he indicated that he did not feel like the same person he had been prior to his amputation and that, as a result, he felt somewhat disabled. Furthermore, because he sometimes felt self-consciousness and awkward in public, he occasionally avoided social interactions for fear of being the centre of attention and a burden on other people. Finally, he remarked that he was unsure about the future and whether his life would be as good again. The second participant with high scores on the HADS-A, JL, also admitted that he did not feel like the same person he had been prior to his amputation. In addition, he was uncertain about whether he would be able to find work again. Furthermore, he was one of the three participants who experienced stump pain at this stage and was one of the two participants who admitted to feeling a sense of regret over having agreed to an amputation in the first place. Finally, in social situations, he also felt that he was a burden on other people. The third individual with high HADS-A scores, DOD, differed from the other two in the sense that he continued to feel that he was the same person he had been prior to his amputation. However, he was the only person at this stage to indicate that his phantom limb pain interfered with his daily living. Furthermore, he was the only individual to remark that his general approach to life was that he always expected the worst to happen. In addition, DOD also experienced some body-image anxieties and indicated that he was reluctant to talk about his amputation with other people. As only three participants had high HADS-A scores, it is difficult to draw any firm conclusions as to why they may have been experiencing more severe symptoms of anxiety. However, perhaps their particular worries and reactions to their situation, which are outlined above, played some role in the development of anxiety symptoms.

COPING WITH AMPUTATION SEQUELAE

As the above analyses indicate, participants had to cope with many psychosocial and physical changes after their amputation, including phantom limb pain, stump pain, adapting to a new body shape, learning to walk, social and physical restrictions, and a

² Zigmond and Snaith (1983)

changing sense of self and identity. Despite being faced with these issues, most participants appeared to have high levels of emotional well-being and low levels of depressive and anxious symptoms. As suggested earlier, the emotional well-being found amongst these participants may be due to the fact that they perceived themselves as being almost over their ordeal and one step closer to resuming their normal lives. Another reason for the high levels of emotional well-being found at this stage could be due to their use of effective coping mechanisms against the particular adversities and stressors they faced. Through detailed analyses of their interviews, a model of coping emerged. This model, which is depicted in Figure 3.1, is headed by Appraisals of the Amputation. In general, sequelae of the amputation were generally appraised within a context of "it could be worse." This conclusion was drawn on the basis of comparisons with other people, comparisons with previous losses, reflections on the impact of the amputation on the basis of age, and perceiving something beneficial to have occurred as a result of the amputation. Other appraisals of the amputation included acceptance or rejection of it and its sequelae. Depending on the extent to which the amputation and its sequelae were appraised as threatening or non-threatening, participants engaged in three forms of coping: Cognitive, Emotional, and Behavioural. Cognitive Approach methods involved making social comparisons and looking ahead and thinking about problems to be faced. Cognitive Avoidance methods, on the other hand, involved taking things from day-to-day and not thinking about problems to be faced. Emotional Approach coping methods included Emotional Determination, using Emotional Social Support, and turning to Religion. Emotional Avoidance strategies involved joking about the amputation and hiding its emotional impact from others. Behavioural Approach methods, on the other hand, included Taking Action to resolve a problem, using external resources to help cope with any problems, and using practical social support. No Behavioural Avoidance techniques emerged throughout the first interviews.

Appraisals

Acceptance

Despite experiencing shock, sadness, and disappointment at being told that an amputation was necessary, almost all of the respondents perceived their amputation as being the “lesser of two evils”: Pain vs. No Pain and Life vs. Death. Remarks such as the following were common:

“When I seen the doctor that morning, he said to me ‘that leg’ll have to come off. You’re going to lose the leg.’ And I said ‘I don’t mind. The pain I had to put up with for a week or two.’ If I had a saw, I’d have cut it myself. Cut it off myself.”

[JL]

“I didn’t feel too bad. Well, I don’t think I had much of a choice, ‘cos it was going to kill me if it didn’t, with the gangrene, so, it didn’t really bother me all that much. I said ‘fine, carry on.’ So that was it. I think when you hit a brick wall, you’ve no choice. I just said ‘right, work away.’” [GC]

Because the majority of participants perceived the amputation as the “lesser of two evils,” the primary reaction to having the amputation was one of Acceptance. Many people made such comments as “What could I do?” and “There was no point in me fighting it, it would have gone through me” to indicate their acceptance of the situation and the necessity of having an amputation. For example:

“I was kind of shocked, you know. and then I just let them go ahead and do it, because there was no point in me fighting it, it would have gone through me, you know ...It happened very quickly, so I’d no time to really think, brood about it, having to lose it, you know that way. It just happened, and it’s gone. That’s it.”

[AMcG]

Because the amputation resulted in an end to the pain that most of the participants had been experiencing prior to their limb loss, another common initial reaction to having the amputation was one of uncomplicated relief. One woman remarked “When I first had the below-knee amputation, I felt that much relief that the pain was gone, I didn’t really mind. I didn’t really mind, because the pain stopped.” Similarly, another man said “It

was great relief. It was, no pain, like. Well, I had pain, but it wasn't the same pain that I'd had. And I had gone through it."

Mixed Feelings and Attributions

However, despite the fact that acceptance of the amputation and relief at an end to pain were common appraisals of the situation, some of the younger participants showed signs of mixed feelings, regret, or disbelief about having had the amputation. For example, a 56-year-old man indicated that even though he knew that an amputation was the only solution to his pain, he maintained that he had been prepared to put up with the pain to keep his foot. A 37-year-old man knew that the pain he was experiencing was interfering with his overall health and well-being and that only an amputation could prevent his health from deteriorating any further. However, he still did not want to lose his limb. He said:

"You've a whole mixed bag of feelings, you know. I mean, obviously, I didn't want to lose the leg. At the same time, when you're lying in bed, you're diabetic, and your blood sugars are running riot, you haven't really any choice in the matter whatsoever. Because if it's not going to heal up, what can you do about it ... it'll spread up your body and kill you, so you've no choice." [NK]

The two participants who showed signs of regret were a 46-year-old man and a 55-year-old woman. These people regretted having, in the midst of all the pain they were experiencing, told the doctors to remove their limbs. For example:

"I was in so much pain, d'you know, I was glad to see the back of the damn thing. Never thinking about long-term prospects, not being able to walk, and I was in so much pain at the time, I just wanted to get rid of it." [BN]

One 38-year-old man, who had chosen to have his leg amputated in order to maintain a "normal" appearance and gait felt a sense of disbelief about his limb loss. He experienced a shock whenever he looked down and saw that his leg was missing.

"Sometimes I'm transfixed, nearly, you know. I'll be just staring at it. I can't believe it, like ... It's kind of a weird way to phrase it, but in some ways I don't

believe that I don't have the leg, you know. I still get shocked if I look down, and it'll take me aback for a second." [SC]

Interestingly, the two participants who had received no prior warning that they were going to lose a limb, because they were unconscious when the decision to amputate was made, did not appear to have experienced any reaction to having had an amputation. One of the men wondered whether his loss would hit him at a later stage:

"I just woke up and the doctor told me that he had to take off the leg to save my life. So, I said "So be it, that's it." I'd no depression or felt sorry for myself so far. Unless it strikes me at some stage, I couldn't tell you, but it didn't strike me yet, anyway." [MG]

The other man felt that the loss only started to hit him when he came to the rehabilitation hospital, but that he did not think he had fully dealt with losing the limb:

"I don't remember anything. I think the first time it began to hit me was when I came here, actually. Because I'd heard so many other stories that I could have gone over the other side. I was aware which was the lesser of the evils, you know. You wonder how long it will last. The leg isn't exactly going to grow back or anything. But I probably have not dealt fully with the leg loss. But then again, have I dealt with nearly passing away? I don't know. I haven't fully realised the whole significance of the trauma, you know. I'm not too sure I want to know the whole significance of it either." [PG]

In conclusion, in terms of immediate and initial reactions to amputation, it is important to note that many participants felt instrumental in making the decision to have the amputation. In addition, the immediate and subsequent reactions to the amputations were dependent on reasons for having lost the limb in the first place. In almost all instances, the amputations were performed to end pain and suffering and to save the participants' lives. Consequently, most people accepted their limb loss as 'the lesser of two evils' and experienced relief that their pain was gone and that they were still alive. However, some departures from these reactions were also observed. Age and prior notification of amputation may have had some bearing on the initial reactions to losing a limb. Compared to the older participants, younger participants showed mixed feelings,

regret, and disbelief in the light of their amputation. Moreover, although the numbers are too small to draw any definite conclusion, it is interesting that only the two participants who received no warning prior to amputation did not appear to have experienced any reaction to the amputation during their first interviews.

Solace & Making Comparisons

Most participants appraised their amputation within a context of “it could be worse.” One in which such a conclusion was arrived at was by seeing some kind of solace in the situation, for example, by making such statements as “At least I still have ...” and by comparing their situation with that of other people perceived to be in more challenging situations. For example, in adjusting to having had a limb amputated, one man reasoned that it would have been worse to have lost an arm, rather than a leg. In adjusting to the physical limitations posed by her amputation, one woman looked back on what she had experienced during her lifetime and drew comfort from that. She remarked: “I just think of the good life I had. I was into swimming and walking and everything, you know, and I had it, so I don’t miss it.” In adjusting to their new self-identities as ‘disabled’, both FF and BN also saw some kind of solace in the situation. For example, FF remarked:

“I was thinking to myself for quite a while if I was to become disabled, I wouldn’t be able to draw, I wouldn’t be able to write. But now, I’m thankful for a lot of things. I’m thankful that it wasn’t a stroke I got. I can get up, I can go to the toilet, I can dress myself, shave myself, I can make my own tea, and I can use the walkers, so there’s a lot to be thankful for.”[FF]

Another way in which participants appraised their amputation within the context of “it could be worse” was by comparing their situation with that of others. For example, many of the participants with unilateral amputations compared themselves to younger people with amputations, with others in the hospital with bilateral amputations, or with people who had disabilities that they perceived as being worse. For example:

“Just over there, across, there’s a man. He had both legs amputated, and one is a bit higher than the other. And he’s a very jolly man. I have nothing to complain about. He had his wife and his three children in yesterday, and he’s a lot younger

than me. They have it tough, you know. I said ‘at least I’ve my family reared and they’re all out doing for themselves.’ So, I’ve a lot to be thankful for.” [FF]

“In the hospital I was in, there were four or five men, and five or six women, they can neither talk nor walk. And there’s one man, he’s over ninety, and he’s paralysed and he’s blind. And there’s another woman, she’s ninety-four, and she’s blind. When you see that, you think you’re not so bad.” [JW]

Another comparison that some participants made in putting their situation into a context of ‘it could be worse ...’ was between their own current emotional well-being and their pre-amputation well-being. These individuals noted that even though there were times when they felt sad or low, this was normal for them, as they had experienced such days when they had both of their limbs intact. As one man said “I’m coping pretty good. I had my ups and downs. Everybody does. But I used to have those prior to the accident.” Similarly, another man remarked “Sure, even before I lost the legs, you wouldn’t feel cheerful all the time. Say, ninety-five percent of the time I’d feel cheerful.”

Seeing Benefits

Another way in which individuals appraised their amputation within a context of “it could be worse” was through seeing something beneficial to have occurred as a result of having lost a limb. In appraising their status as ‘disabled’, for example, some participants focused on the benefits given to disabled people in Ireland. In appraising the impact of their amputation on their lives, many participants focused on the fact that they would now have a better quality of life, be in a better mood, and have no more pain. Furthermore, some people felt that they had become better people as a result of having an amputation because they were less stressed and had time to enjoy simple things in life. For example:

“I think life will be slightly better. Walking was always a bit of a hassle. Going out to a restaurant, you had to make sure there were no chairs in front because the straight leg used to hop up in the air. Even simple things like going to the toilet, the toilet had to be higher ... I’ll have a much better life than having the straight leg.” [GC]

“I was always a tense sort of person. That’ll never change, but I think from now on, I’m probably going to be able to accept things that I couldn’t before ... and I’ve learnt things about myself that I never knew I could do because I’d always been so busy before and the opportunity never arose.”[BN]

“If I say anything positive, I suppose I’m lucky in the sense that it has pulled me back from going on the way I was going. It made me realise there’s more to life than what I was doing up to now. It kind of woke me up a little bit.”[DOD]

Age Reflections

Another way in which participants appraised their amputation within a context of “It could be worse” was by reasoning that its physical and psychological implications were minimal because of their advancing age. Such age-related appraisals were evident in discussing whether they had any body-image concerns. As one man remarked “Sure, I’m not a young lad of twenty-one now, going out. If I was twenty-one again, it might be different. You’ve a different outlook on life when you’re seventy-one.” Many individuals also appraised their amputation as having a minimal impact on their lives because their older age had meant that their lives had been “slowing down” even prior to their amputation. Such appraisals were evident in responses that participants made when they were asked if they believed that life would ever be the same again. For example:

“I’m sixty-six now, anyway, and I was slowing down. At sixty-six you’re slowing down. There was a lot of heavy work, but I was liking the lighter work ... you wouldn’t understand it now, being a young person, but naturally enough, the older you get, you’re more confined to what you can do. I’ve accepted that.” [FF]

“I will have to curtail some of the things, which doesn’t bother me, because as you get older, you’ve to slow down anyway. You don’t do what you were doing when you were thirty-five. You don’t, so, I mean, you’ll accept that.”[MMcC]

Previous Loss Reflections

Another noteworthy way in which participants appraised their amputation within a context of “It could be worse” was through comparing its impact with that of a previous

loss or stressful event. One man remarked "I think you could dwell on it too much. I mean, it's only a limb and get on with life. Life is much too important to be fretting about these things." Another man, PM, considered the death of his wife as being more of a blow than had the loss of his limb. NK thought that the loss of his sight over ten years previously had prepared him for the experience of loss, thus limiting the impact of the amputation on his emotional well-being. He remarked:

"I would say the loss of the sight prepared me for a lot of it, because I think with a lot of people, it's simply the fear of the unknown, and it would be a much greater fear of losing your sight than losing your limbs." [NK]

Conclusion: Appraisals

Throughout the interviews, participants appeared to appraise their amputation as something that "could be worse." Generally, most people accepted their amputation as the "lesser of two evils," even though some people harboured feelings of regret over or blame for having lost their limb. Other people appraised the amputation and its sequelae as having a minimal impact on lifestyle, body-image, social well-being, and identity through comparisons with other people they perceived to be in more challenging situations, to have more serious disabilities, and to have more to lose because of younger age. Many participants appraised the amputation as non-threatening in seeing benefits that were gained as a result. Furthermore, several people appraised the amputation as having a minimal impact on lifestyle or body-image anxieties because older age meant that life was 'slowing down' anyway. Finally, the amputation was appraised as being less threatening or as having less impact than previous losses or stresses, including bereavements and loss of sight.

Cognitive Approach Coping

Looking Ahead and Thinking About Problems

One coping strategy that many participants employed during rehabilitation was looking forwards into the future towards life with an amputation, rather than backwards to life without an amputation. In this way, many participants were planning ahead to when they would be able to resume their previous lifestyles. For example:

“It’s all about focus and moving on, accepting the situation and making the best of what you have and what’s ahead of you.” [NK]

“I’m looking forward to the best and that’s it. I want to try to see can I go forward now and not backwards.”[CD]

Upward Social Comparisons

Interestingly, in appraising their amputation within a context of “it could be worse”, most of the participants used downward comparisons. However, the reverse comparisons were employed by almost everyone in coping with their limitations and having to learn to walk. Thus, many participants observed how other people with amputations were making excellent progress with walking, and they were using these observations to give themselves hope and courage to do the same. Because participants who used these upward comparisons indicated that their use increased their motivation to succeed and raised their hopes and expectations for the future, it was decided to place these comparisons within a Cognitive Approach coping strategy. For example:

“There’s a fella back at home, I suppose he’s going on eighty years, he spent two months in here. He’s able to go to the shop, and it’s over a mile from him. Sometimes he’ll have a stick, and other times he won’t. I couldn’t believe how good he is.” [AOM]

“I saw a man the other day, and he was walking up and down between the two rails, you wouldn’t think there was anything wrong. I couldn’t believe it. So, I said ‘jeepers, see what that man is doing, and I’ve only the one leg gone.’[JMcG]

“I saw a guy above in Galway, and I never realised he’d a limb. There he was in his van, and he came out and walked over to me. I nearly had a heart attack when he said he’d a limb. He said he had it fifteen years. You would never have known.” [JS]

Cognitive Avoidance Coping

Not Thinking About Things and Taking Things from Day-To-Day

One popular Cognitive Avoidance strategy included ‘not thinking’ about the amputation or its implications for the future or health concerns. For example, not wanting to know reasons for the amputation were common. In addition, not thinking about current health problems or how near to death some had been were other issues that a number of people preferred not to ruminate over. For example:

“I don’t know why I had the amputation above the knee. I didn’t ask, don’t want to know. It’s gone and that’s it. I never do talk about it. I never think about it. It’s gone, that’s it, make the best of what I have. I can be positive now, and I don’t brood on it.” [AMcG]

“I take things as they come. I never thought this would happen to me. I’m not wondering why it did happen. It happened to me and that’s it ... If you spent time thinking about it you’d get depressed, and I don’t want that.” [JM]

“If you worry about it, you’re only going to make a fool out of yourself, ‘cos you’re going to get sick from it and everything. There’s no use worrying about it. I hope it doesn’t happen, but there’s no use worrying about this other leg ... it’s like dying and all this crack. People worries about dying. Sure, you’re doing to die one way or the other, let it be short, let it be long. So what difference does it make? Sure, I often said ‘if you die this minute, there’s nothing you can do about it. That’s all, and life goes on as good as ever. No use worrying about it.” [PR]

Closely associated with the approach of “not thinking about the amputation” was the method of taking things “from day-to-day” without looking or thinking ahead about problems that could be encountered when adapting to the amputation or learning to walk. For example:

“I’m trying not to think too far ahead. My interest is to see if I can get walking again, and then I’ll make some decision about the car. I’m just looking from day to day, I’m not looking too far ahead. I’m too advanced in years for that.” [JW]

“I’ve to get used to walking, and I’ll take one step at a time. See how I get on and how I get on with the walking, and if I’ll be able to walk, then I’ll get a lift in a car or get a taxi for the time being. Take one thing at a time. That’s the way I look at it.”[JS]

Emotional Approach Coping

Emotional Determination

One common Emotional Approach coping strategy that was adopted by many of the participants during rehabilitation was that of Emotional Determination, which involved giving oneself a “mental talking to” in order to maintain high levels of determination and motivation in getting over the amputation and in adapting to its psychosocial sequelae. Generally speaking, this strategy is similar to the “fighting spirit” that has been described in cancer patients (Watson, Haviland, Greer et al., 1999). For example:

“If you lie under, it’s just like a motor car, if it breaks down and you don’t fix it, you’ll drive no more. So, the same thing with this. If you lie under the like of it, you’ll be dead.” [PR]

“It’s a change of life, a change of direction. You have to accept that and get on with your life and make the best of each day that’s ahead of you. And to sit here now and bemoan the lot, and look down at the loss of legs, and consider what I’ve lost, to me, it’s absolutely pointless because what you’ve lost, you’ve lost. You’ve got to look and what you can do and get on with life rather than sit back and bemoan your lot.”[NK]

“I won’t sit down and just cry about this thing. I’m not going to let it beat me, you know. And I’m not thinking about dying tomorrow or the next day. I’m thinking about getting up here, getting to hell out of this place.”[BN]

Emotional Social Support

Another common Emotional Approach coping method used by participants was use of Emotional Social Support to cope with the psychosocial sequelae of the amputation.

During rehabilitation, several people commented on how happy they were to have received get-well cards, letters, and telephone calls of support from neighbours and friends. In these cases, such displays of support boosted the individual's courage and spirit and helped them through the period of hospitalisation and amputation. In addition, visits from family members before and after their amputation went a long way towards lifting their spirits. For example:

"I used to get so many visitors every day, I was pure worn out. It made me realise how popular I was, the regard people had for me. So, I was on a high." [BN]

"I got wonderful support from my family. My wife stayed with me every night, and all the family used to come in and see me every day. So, that kept the heart up. They were brilliant, you know." [MG]

"My wife was phenomenal during all of this thing. She was absolutely fantastic. And the whole family were great ... The attitude of my kids was 'as long as you come home, we can get over you losing your leg.' That's a bit of a booster as well." [PG]

Interestingly, not every participant appeared to rely on Emotional Social Support in coping with the implications of their amputation. Two people indicated that they had not wanted to talk to anyone or seek anyone's advice after they had been told that they needed to have an amputation. Despite the fact that one man's brother had previously had an amputation and was undergoing a second one at the same time as he had lost his limb, he did not feel the need to discuss his amputation with him. Interestingly, both men were unmarried. They remarked:

"Sure, there was no good in talking to anyone about it. What was the point? I had to get the leg off and that was it ... I wouldn't expect anyone from my own side to visit. It's a long way to come, you know. It's seventy miles. I wouldn't be looking forward to them coming because I know they couldn't possibly make it." [CD]

"My brother didn't say anything about it, really. He was in the hospital when I was in, and he didn't know mine was gone either .. I won't be going home at the

weekend either. It's a long way down, and there's nobody there then. It's a long trip, so I don't know." [JS]

Religion

A small number of participants also turned to their religion in order to cope with the practical and psychological sequelae of their limb loss. For three people, in particular, religion appeared to be an important coping resource in coming to terms with having had an amputation and in finding daily support. For example:

"I say a few prayers every day, that's the way I look at it. I've great faith in the Mother of God, in the Blessed Virgin. So, I hope she'll hear my prayers." [LB]

"I don't say 'why me?'. That's the will of God. I do leave it to God, and I say God is good, and God will help me." [AOM]

Evidence of negative religious coping was observed in one man, who indicated that he felt angry with God at times for all the suffering he had experienced. He said that he often found himself asking of God "What did I do wrong?", a question which upset him greatly, as prior to his amputation, he had always considered himself to be a very religious person.

Emotional Avoidance Coping

Joking

During rehabilitation, both of the people who had acquired their amputation as a result of an accident used joking to preserve their emotional well-being and to present a positive front to other people. In this way, they avoided the expression of their true emotions and, instead, used joking as a means of covering up their true feelings. One man did not appear to be particularly upset about using this coping strategy, although he did think that maintaining this front hid from others the fact that he felt like a different person inside. The other man, however, was unsure as to how appropriate a coping strategy this really was. Because of maintaining such a front, he did not feel like he was the same person he had been prior to his amputation. Instead, he felt that he had become somewhat false. For example:

“I’m sure I’ve changed. I think outwardly I’ll tend to be the same. But inside I’m different. What I’m really thinking and stuff like that. Because a lot of times, this is always on my mind ... I don’t want them [i.e. his friends] to know about it. You know, you’re with your friends, and there’s one guy in the corner bringing everyone down. I don’t want to be that character, so I just fake it ... Overall, it’ll tend to make you feel better.”[SC]

“I was inclined to make a little joke of it really, trying to play it down. It’s one way of coping. I’m very aware of it. I say ‘Jesus, why am I telling the lads jokes, and I look down and then I look down and see my leg is gone ... I don’t know why I should be laughing. I’ve nothing to laugh about, and yet I am laughing ... I’m a little bit false. I’m trying to entertain everyone. I know I’m saying ‘there’s not a problem with me really.’ I was always kind of at that, but I’m forcing it a little bit now.” [PG]

This form of joking was placed in the Emotional Avoidance category because it was perceived as a “deflection” technique, whereby thoughts and emotions associated with the amputation were avoided and ignored, rather than faced and dealt with.

Behavioural Approach Coping

Taking Action

One Behavioural Approach coping strategy that was adopted by the participants was Taking Action of some kind to confront and solve a particular problem they were facing as a result of having had the amputation. For example, many participants were instrumental in ensuring that they could maintain their own independence, despite the fact that to do so could be quite difficult. One woman, BN, had been encouraged by her family to hire a woman as “home help” to take care of housekeeping work. However, she subsequently made the decision to let this woman go because she wanted to be able to do her own housekeeping without having to rely on others. Another participant, NK, was active in learning how to take care of himself, in that he requested and took a cookery class in the rehabilitation hospital so that he could make his own meals when he went home. He remarked “it was my suggestion, because it’s important to me, I’m a

very independent person, that I would still maintain those skills in cooking.” NK also described how he liked to be active in finding solutions to any problems he would encounter as a result of having lost the use of both his legs, as well as his sight. He said:

“There’s obstacles, but if you think about it, you can find a way around them. Every single day, when you’re blind, brings obstacles. And if you’re going to let them knock you down and keep you down, you might as well climb into a cauldron and put the lid on. You walk around them, you climb over them, or you jump them sideways. You find a way to get over them. And the legs will be no different, whether I’m standing on artificial ones or in the chair, I’ll just have to find a way around, to get on and lead my life.”[NK]

Many of the participants were also, at this stage, involved in developing new interests and hobbies in the light of the limitations imposed upon them by their amputation. For example:

“I’ve never once said I was bored, because you can always find something to do. Even if it was only a crossword. I’ve always wondered at people who say they’re bored. I’ll find something to do.” [AMcG]

“When I go home, I’ll have nothing to do. I could look out the window, but I have to make sure that I don’t do that. I have a computer, and I’m going to take a course and retrain. So, I think I can get things for me to do.” [SC]

Using External Resources

Another Behavioural Approach coping strategy was Use of External Resources. As discussed earlier, many participants appeared to be using their *prosthesis* as a way of coping with the limitations imposed upon them because of their amputation. In these cases, the prosthesis was perceived as a means to restore a ‘normal’ life and a ‘normal appearance’. In this way, the onus was placed on an external resource, that is, the prosthesis, to cope with some of the body image concerns and psychosocial sequelae of the amputation.

Joking

Another Behavioural Approach strategy that was used by several participants was joking about the amputation. In this way, joking served as a coping strategy to help foster social relations with other people in the rehabilitation ward and with health professionals. According to PR, for example, joking about having the amputation was often used by all of the patients in the hospital and “threats” to “break each others’ legs” were commonly used to lighten the mood of the other patients. In addition, joking served to ‘break the ice’ when confronting visitors and other people who did not have an amputation. For example, one man, MMcC, laughed about his amputation the next day with his consultant, informing him that he had removed the wrong limb by accident. Another man, JM, also joked about having lost both of his legs with visitors who came in to see him. He said “If I was still in the bed there, now, and somebody came in and sat on the bed, I’d let a roar and say ‘get up, you’re sitting on my toes.’ Things like that, I’d laugh about, you know.”

Unlike the previously discussed use of joking as an Emotional Avoidance technique, this form of joking was placed under Behavioural Approach coping because it was perceived as an active way of acknowledging the fact of having had an amputation and of making efforts to foster social relationships and help people feel at ease at meeting someone with an amputation for the first time.

Practical Social Support

Another Behavioural Approach method of coping that was used by most participants included the use of practical social support to overcome difficulties faced in dealing with physical and social sequelae of the amputation. Several participants commented on the help they received from neighbours following their limb loss, including offers to do shopping and to drive them to places out of walking distance. In addition, most of the participants relied on family members to help with mobility and to assist in daily living chores. However, a difference between accepting emotional and practical support became apparent, in that while participants had no difficulty accepting the former, they were sometimes uneasy about accepting the latter. Generally speaking, several participants remarked feeling guilty about the strain they were putting their wives or partners under in having to bring them around to places or do some of their household chores.

“I feel guilty at the wife, you know, with her having to do so much. But she’s plenty of help at the weekends, and there’s always one of the children, somebody home for their dinner.” [JM]

“It’s always at the back of your mind. The amount of stress and strain that my wife’s been under.”[NK]

SUMMARY

Amputation-Related Sequelae

During rehabilitation, neither phantom limb pain nor stump pain were perceived as a problem by the majority of respondents. In adjusting to wearing their artificial limbs, some people were dissatisfied with their comfort, and most of these people were also unhappy with their appearance. However, almost everyone appeared to be extremely willing to adapt to their artificial limbs. In fact, many people remarked that their artificial limbs would help in restoring a ‘normal’ appearance and functioning, and many perceived their limb as a major stepping stone on the way to a normal lifestyle. Therefore, despite the fact that some were dissatisfied with the comfort and/or aesthetic aspects of the limb, it was not considered a major obstacle in learning to walk by anyone in the study. On the contrary, participants continuously praised the usefulness of their prosthesis and the fact that it enabled them to engage in activities they would otherwise have been unable to do. Thus, it could be argued that their pleasure at being able to walk again may have been a more important gain than any discomfort experienced from wearing the prosthesis.

Psychosocial Sequelae

Although the majority of people in the study did not indicate that they experienced any body-image self-consciousness, seven people admitted to feeling some self-consciousness about having other people notice their limb or about the fact that they now walked with a limp. In terms of limitations, most people recognised the fact that they would not be able to do some of the things they used to do prior to their amputation. Despite this, they were eager to stress that there were still many things that they could do, and only two people believed that their new-found restrictions would

prevent their lives from being as good again. Many either felt that their lives would continue to be as good, while others believed that it would actually improve because their pain was now gone.

Individuals who felt that they were the same person they were since before their amputation did not perceive these restrictions and limitations as being associated with sense of self. Thus, even though they recognised their restrictions, they considered these irrelevant in determining sense of self. On the other hand, seven people did not feel that they were the same person they had been prior to their amputation. In most of these people, abilities and disabilities were closely tied up with their sense of self and self-identity. Therefore, because they could no longer do the same things they had done prior to their amputation, they perceived themselves as being different people. Moreover, since their identities were closely tied up with their abilities, not having these abilities any longer meant that they now classified themselves as 'disabled'.

In terms of the social impact of their amputation, most of the participants had no problem talking about their amputation, although eight people did indicate that they have some difficulties in talking about their amputation in the sense that talking about it was dependent on their mood at the time, that they did not often want to talk about it, that they were afraid of boring others, or that it kept them from moving forward with their lives. In addition, most participants experienced difficulties in navigating around places and in getting used to being dependent on other people as a result of their amputation. Because of these difficulties and the dependence that ensued, almost half of the participants felt embarrassed in social situations because they perceived themselves as being a burden on other people. Consequently, some people were less willing to interact with other people than they were prior to their amputation because they felt that they just 'weren't ready' to face others again, that they were a burden on others, or because they felt that they would be too much a centre of attention. However, it must be noted that in spite of the difficulties that some people were experiencing, the majority of participants had no problems interacting with other people, and even though they did perceive themselves as being treated differently by others, they did not feel self-conscious because of this. In fact, most people were looking forward to resuming their social lives again.

Although many people were optimistic about their futures during their rehabilitation interviews, some were unsure about whether their lives would be as good again. This theme of uncertainty was also evident in other aspects of their lives. Many were uncertain about their future living arrangements, where they would live, and what kind of alterations needed to be done to their homes. Furthermore, the financial implications of their amputation could not be directly addressed either, because most of the participants who had been working prior to their amputation were unsure as to their future working lives. While some were considering retirement, others were faced with decisions about what jobs they could now be suited for.

Emotional Well-Being

In terms of emotional well-being, seven participants remarked that they had periods of feeling 'down' or 'depressed' either in the run up to or shortly after their amputation. However, at this point in the study, no one appeared to be particularly depressed about their situations. Only three participants appeared to be somewhat anxious. Analyses of these individuals interviews indicated that they experienced a combination of body-image anxieties, worries about their future working lives, concerns that their lives would no longer be as good again, and a sense of being a different person to whom they had been prior to their amputation. Despite the fact that three people appeared to be experiencing high levels of anxiety, the predominant mood during rehabilitation was of optimism for the future. Most people were looking forward to learning to walk and going home to spend more time with their families and friends. Thus, it could be argued that because the participants were aware that their ordeal was almost over and that they were very near to resuming their previous lives, none of them appeared particularly depressed about their current situations.

Appraisals and Coping

Overall, participants appraised their amputation in a non-threatening light, with many taking the attitude that "it could be worse." The majority of people accepted that the amputation was a necessity and the lesser of two evils, although some of the younger participants indicated some mixed feelings or regret over having had the amputation. Furthermore, through comparing themselves with others perceived to be in more challenging situations, they came to the conclusion that their situation was not so bad. Reflecting on the fact that their lives were 'slowing down' and that an amputation

would affect a younger person a lot more than someone their age cast the amputation in a non-threatening light. In the light of their appraisals of the amputation, a range of Approach and Avoidance strategies based on Cognitive, Emotional, and Behavioural methods were used.

Cognitive Approach methods included thinking about problems ahead and making plans about how they can be resolved. Cognitive Avoidance methods included thinking about problems ahead, making plans about how they can be resolved, and making upward social comparisons. In the present study, the changes that were observed in use of upward social comparisons throughout the year [See Chapters 5 and 6], and the apparent use that participants made of such comparisons in maintaining motivation and determination [present chapter and Chapter 2] suggests that these comparisons were effortful, affected more than emotional well-being, and were context dependent, thus fulfilling criteria as coping strategies (Tennen and Affleck, 1999). The Cognitive Avoidance methods observed in the present study included: not thinking ahead and taking things from day to day. Emotional Approach methods included: giving oneself a 'mental talking to' to maintain motivation and courage, using social support for emotional reasons, and turning to religion. Emotional Avoidance methods included: joking about the amputation and its implications as a means of maintaining a 'positive front'. Behavioural Approach methods included: joking about the amputation to facilitate social interactions, taking particular steps or actions to overcome a problem, using external objects such as a car or prosthesis to overcome hurdles, and using social support for practical reasons. Behavioural Avoidance methods included engaging in tasks to distract one's thoughts away from the stressor. Use of these strategies was not in evidence throughout the first interviews.

DISCUSSION

These qualitative findings illustrate the importance and dynamic interplay of the various demographic, personality and coping, amputation, and environmental factors in psychosocial adjustment to amputation. Using Livneh's (2001) conceptual framework, questions regarding the impact of such *demographic* factors as age and marital status were raised during the course of this study. For example, it was observed that the younger participants tended to have more mixed feelings about their amputation than

did the older participants. Furthermore, appraising the amputation as having a minimal impact because of age was one of the most common ways in which participants appraised their limb loss as non-threatening. Finally, marital status may have impacted on some of the coping strategies that were adopted, in that unmarried people appeared less likely to have used Emotional Social Support than married people in the run-up to their amputation, even though their families may have been available to offer them such support. *Coping mechanisms* also appeared to have been important in facilitating participants' adjustment to amputation. Although most people tended to appraise their amputation within a context of "it could be worse", the two participants who acquired their amputation because of an accident were more likely to use an Avoidance strategy of joking about the amputation and hiding its emotional impact from other people. *Amputation-related* factors such as phantom pain, stump pain, and cause of amputation may also have been associated with adjustment to amputation. Even though phantom pain and stump pain were not perceived as a major problem by many people, the two people with increased levels of anxiety were among the few who did experience relatively higher levels of such pain. In terms of cause of amputation, it has already been observed that the two people with trauma-related amputations were more likely to use the Emotional Avoidance coping strategy of Joking about the amputation. Another example of amputation-cause possibly impacting on adjustment to amputation could be the observation that the two men who acquired their amputations while unconscious did not seem to have experienced any reaction to their limb loss. Finally, *Environmental* factors, such as barriers to mobility, were found to have impacted on learning to walk, using the prosthesis, accessing places, and participating in social gatherings. Furthermore, the sense of social stigma that some people felt as a result of having an amputation resulted in a small number avoiding contact with other people.

CONCLUSION

Overall, this qualitative study has illustrated that adjustment to amputation, during the period of rehabilitation, is a dynamic process involving interrelationships among demographic, personality, coping, amputation-related, and environmental factors. Although numerous studies have examined the impact of social discomfort and social stigma, and body image anxiety on adjustment to amputation (Williamson et al., 1995; Rybarczyk et al., 1992, 1995; Breakey, 1997), the findings of this study have indicated

that only a small number of individuals appear to have experience of this. Furthermore, only a small number of people were reluctant to interact with other people as a result of feeling this way. Moreover, although several studies have suggested that phantom limb pain and stump pain can have a significant impact on rehabilitation (Sherman et al., 1984; Pohjolainen and Alaranta, 1991), the findings of the present study have suggested that during rehabilitation, such pain is not considered to be a problem for most people. Finally, although a number of studies have looked at strategies for coping with adjustment to amputation (Livneh et al., 2000; Gallagher and MacLachlan, 1999) and phantom limb pain (Jensen et al., 2002; Hill, 1993; Whyte and Niven, 2001b) in cross-sectional samples, this qualitative study has described a model of coping in people who are only a few months after amputation. What is interesting to observe is that contrary to some perceptions that the amputation is a “disaster” for individuals and results in a high rate of depression, hopelessness, and psychiatric problems (Caplan and Hackett, 1963; Lundberg and Guggenheim, 1986; Shukla et al., 1982), the majority of participants did not seem to be experiencing high levels of psychological symptoms. On the contrary, most perceived their amputation as the “lesser of two evils” and appraised it within a context of “it could be worse.”

Introduction

During rehabilitation, it may be difficult for some people to deal with the reality of having an amputation and the loss of a limb. It is important to understand the needs of these participants and to provide them with the information and support they need to deal with this loss. However, people who have had an amputation may experience a sense of loss and it is important to understand the needs of these people and to provide them with the information and support they need to deal with this loss. On the other hand, some people who have had an amputation may experience a sense of loss and it is important to understand the needs of these people and to provide them with the information and support they need to deal with this loss.

CHAPTER 4

SECOND INTERVIEWS

It is important to understand the needs of these people and to provide them with the information and support they need to deal with this loss. In general, the majority of participants did not experience body image anxiety to any great extent. Moreover, although most people experienced difficulties in accessing social events, and many were aware that others were treating them differently, the majority of participants did not avoid social interactions because of these changes. In terms of amputation-related issues, neither phantom limb pain nor stump pain were considered to be major problems. Although some people were dissatisfied with the comfort of their new artificial limbs, almost everyone was willingly to accept them and become competent in walking on them. In view of these findings, it can be said that during rehabilitation the majority of participants were optimistic about their future and looking forward to returning home to their families, becoming independent again, and resuming their social lives.

Although the predominant issue during rehabilitation was one of optimism, the period immediately after rehabilitation has been described as a particularly difficult one (Glas, 1994; Morse and Collins, 1999). In leading the rehabilitation institute, counselors should be aware of the fact that it is not until about six to eight weeks after amputation that people begin to deal with some of the hopes that people have built up around their bodies (Baker, Eklak and Ford, 1998). For the first time, participants have to face the world as it is with an amputation. Therefore, he or she is exposed to the scrutiny of others (Collins, 1993) and to an increased possibility of feeling self-conscious about a changed body and altered social role (Rymer et al., 1992, 1993; Johnson, 1997; Fothergill, 1998). It is important to

INTRODUCTION

During rehabilitation, it was found that most people had accepted the necessity of having an amputation and appraised it within a context of "it could be worse." Many participants were aware that they would face limitations and restrictions in their daily lives. However, people who disregarded these limitations as unimportant tended to feel that they were the same person they had been prior to their amputation and were more likely to believe that their lives would be as good again. On the other hand, those individuals who focused on their disabilities, rather than abilities, were more likely to consider themselves as 'disabled', to feel like a different person, and to believe that their lives would not be as good again. In general, the majority of participants did not experience body image anxiety to any great extent. Moreover, even though most people experienced difficulties in accessing social events, and many were aware that others were treating them differently, the majority of participants did not avoid social interactions because of these changes. In terms of amputation-related issues, neither phantom limb pain nor stump pain were considered to be major problems. Although some people were dissatisfied with the comfort of their new artificial limbs, almost everyone was extremely willing to accept them and become competent in walking on them. In view of these findings, it can be said that, during rehabilitation, the majority of participants were optimistic about their futures and looking forward to returning home to their families, becoming independent again, and resuming their social lives.

Although the predominant tone during rehabilitation was one of optimism, the period immediately after rehabilitation has been described as a particularly difficult one (Glass, 1994; Morse and O'Brien, 1995). In leaving the rehabilitation institute, uncertainties about the future come to an end (Mishel, 1988), and as these uncertainties are brought to an end, so too are some of the hopes that people have built up around their futures (Babrow, Kasch and Ford, 1998). For the first time, participants have to face the world as a person with an amputation. Therefore, he or she is exposed to the scrutiny of others (Goffman, 1963) and to an increased possibility of feeling self-conscious about a changed body and altered social role (Rybarczyk et al., 1992, 1995; Williamson, 1995). Furthermore, he or she is

experiencing, for the first time, the day-to-day impact that the amputation has on daily lifestyles, and limitations and losses are faced for the first time (Morse and O'Brien, 1995). As a result of all the psychological and social changes that accompany the departure from rehabilitation, this period could be described as the time when the old identity and new identity as a person with an amputation will begin (Morse and O'Brien, 1995).

To date, there are several studies that have assessed physical functioning in people with amputations after they have been discharged from rehabilitation. Prosthetic use at this time tends to range between 75% and 90% for people with unilateral amputations (Traballesi, Brunelli, Pratesi et al., 1998; Harris et al., 1991; Rommers et al., 1996; O'Toole, Goldberg, Ryan et al., 1985; Jensen and Mandrup-Poulsen, 1983). In addition, the majority of people are able to walk with their prosthesis, and most tend to reach what has been called "good" or "partial" autonomy (Traballesi et al., 1998). Furthermore, using broader criteria for assessing rehabilitation success, the majority of people with amputations tend to have reached their rehabilitation goals at discharge (Harris et al., 1991), including independent transfer for independent living, ambulating with a walker, independent walking.

Although there are many studies assessing physical functioning following discharge from rehabilitation, there has been no research examining psychosocial functioning in the period immediately after rehabilitation. Thus, the present study aimed to redress this imbalance by examining psychosocial functioning during this period. Using a qualitative methodology, the following aims were formulated:

Aim

- To investigate the occurrence and interrelationships among amputation related factors (phantom pain, stump pain, prosthesis, learning to walk), coping mechanisms, reactions to amputation, psychological well-being, sense of self and identity, body-image anxiety, and social functioning during the rehabilitation period.

- To observe any changes that had occurred between the rehabilitation and post-rehabilitation period in terms of participants' amputation-related experiences, reactions to amputation, their psychological well-being, their coping mechanisms, sense of self and identity, body-image anxiety, and social functioning.
- To describe the amputation-related and psychosocial-related characteristics of participants in order to indicate the representativeness of this sample.

METHOD

Procedure

Three months after they had taken part in the Stage 1 interviews, participants were sent a letter [See Appendix 7] requesting their participation in a second interview on their psychological adjustment to their amputation and their prosthesis. Approximately three days after they would have received the letter, they were subsequently telephoned by the researcher, and if they were willing to take part in a second interview, a date was arranged on which the researcher would call to their homes.

The interviews were tape-recorded, and were based on questions included in the Trinity Amputation and Prosthesis Experience Scales (TAPES; Gallagher and MacLachlan, 2000), the TAPES-R, the Short Form of the McGill Pain Questionnaire-Short Form (SF-MPQ; Melzack, 1987), the Amputation Body-Image Scale (ABIS; Breakey, 1997) and the Hospital Anxiety and Depression Scale (HADS; Zigmond and Snaith, 1983). Responses to items on these questionnaires, as described in Chapter 2, were followed with probing questions assessing the reasons for their responses. In addition, participants were asked open-ended questions about their reaction to their amputation, learning to walk, their current goals, their hopes for the future, their social support, and qualities of phantom limb pain.

All of the interviews were transcribed *verbatim* by the interviewer. The interviews were then analysed using QSR NUD*IST 4.0 for analysing qualitative data. In

accordance with grounded theory methodology, open codes from the interviews were created using line-by-line analyses. These open codes were then used to create categories of higher-order concepts. On the basis of these categories' properties and dimensions, axial coding was then carried out to focus the results and draw the concepts together.

Inter-rater reliabilities were used to assess the validity of the categories. In order to test the validity of the *Amputation-Related Sequelae* categories, 10 examples from each of the sub-categories were given to an independent rater. This rater was then asked to place each example into one of the following categories: Amputation-Related Sequelae, Social Sequelae, Body Image Sequelae, Identity Sequelae, Limitations Sequelae, and Other Worries. Initial ratings revealed that ninety percent of the examples were coded reliably. Subsequent discussions between the researcher and the rater resulted in one hundred percent agreement.

To test the validity of the *Appraisal* and *Coping* categories, 10 examples from each of the subcategories were given to an independent rater who was then asked to place each example into one of the following categories: Appraisals of the Amputation and its sequelae, Cognitive Approach, Cognitive Avoidance, Behavioural Approach, Behavioural Avoidance, Emotional Approach, and Emotional Avoidance. Initial ratings revealed that eighty-five percent of the examples were coded reliably. Again, upward Social Comparisons with regard to walking were placed in Cognitive Approach coping. Similar to what was argued in the previous chapter, such comparisons were placed in Cognitive Approach because participants *explicitly* stated that use of these helped them to cope with their doubts, fears, and uncertainties about whether they would be able to walk again. Contrary to this, downward social comparisons were never explicitly or overtly described as coping mechanisms and merely appeared to reflect a process whereby participants assessed their situation in comparison with other people.

Participants

Six participants were lost to follow up. MOB died shortly after he had left the National Rehabilitation Hospital. JL and PR had no fixed address when they had been

interviewed during rehabilitation and, therefore, were non-contactable. Finally, JS, PM, and JW were in hospital when they were contacted again and were not physically well enough to participate in the interview. Overall, eighteen participants took part in Stage 2 interviews [See Table 4.1 for a description]. These were four women and fourteen men. Their mean age was 60.61 years (range 37 to 72 years). The reasons for amputation were as follows: pulmonary vascular disease (PVD) = 6 diabetes = 6 accident = 2, clot/aneurysm = 2, ulceration of the leg = 1, cancer = 1.

Name	Sex	Age	Amputation type	Reason for amputation	Time since amputation	Concurrent difficulties
AMcG	F	72	Right AKA	PVD	9 months	None
AOM	F	75	Left BKA	Diabetes	9 months	None
BN	F	55	Left BKA	Diabetes	9 months	None
CD	M	65	Right AKA	PVD	5 months	None
DOD	M	56	Right BKA	Diabetes	6 months	3 toes amputated on right foot
FF	M	67	Right AKA	PVD	8 months	None
GC	M	59	Right AKA	PVD & Arthritis	7 months	Arthritis in hands
GD	M	62	Right BKA	Diabetes	6 months	Kidney transplant; Heart problems
JM	M	58	RAKA & LAKA	PVD	5 months	None
JMcG	M	69	Left AKA	Cancer	6 months	None
LB	M	71	Left AKA	Clot	4 months	None
MG	M	62	Left AKA	Complications of Aneurysm	9 months	None
MW	M	71	Right AKA	Ulceration of the leg	5 months	None
MMcC	M	62	Right AKA	PVD	5 months	None
NK	M	37	RAKA & LBKA	Diabetes	9 months, 4 months	Visually Impaired
OMcK	F	64	Right AKA	Diabetes	5 months	None
PG	M	48	Left AKA	Road Traffic Accident	7 months	Visually Impaired
SC	M	38	Left BKA	Boat Accident	6 months	None

Table 4.1 : Describes the name, sex, age, type of amputation, cause of amputation, time since amputation, and concurrent medical difficulties of the participants. F = Female; M = Male; AKA = Above-knee amputation; BKA = Below-knee amputation.

Sixteen participants had unilateral lower-limb amputations, including eleven above-knee amputations and five below-knee amputations. Two participants had bilateral lower-limb amputations; one person had bilateral above-knee amputations and the other person had one above-knee amputation and one below-knee amputation. Some of the participants had concurrent medical problems that could impact on their rehabilitation. Two people were visually impaired, one man had arthritis in his hands, and one man had a heart condition. Table 4.1 outlines the characteristics of these participants in terms of age, type of amputation, time since amputation, and other notable characteristics that could impact upon their rehabilitation.

RESULTS

Descriptive statistics of participants

A table and brief description of participants' scores on the questionnaire instruments used are provided in Appendix 11. As these scores did not comprise part of the major results, they were not included in the main results section.

Qualitative Findings: A model of adaptation to amputation

Figure 4.1 is a pictorial representation of the findings that emerged from the interview data. It is similar to that observed in Chapter 3, with the exception of one strategy within the Cognitive Approach category. During rehabilitation, participants were found to engage in a strategy of Looking Ahead into the future without formulating any specific plans or goals. Throughout the second interviews, however, this strategy emerged into one in which particular goals and plans were thought about and formulated. Despite this, however, the structure of coping that emerged was again similar to that discussed previously by Lazarus and Folkman (1984) and Tobin et al. (1989).

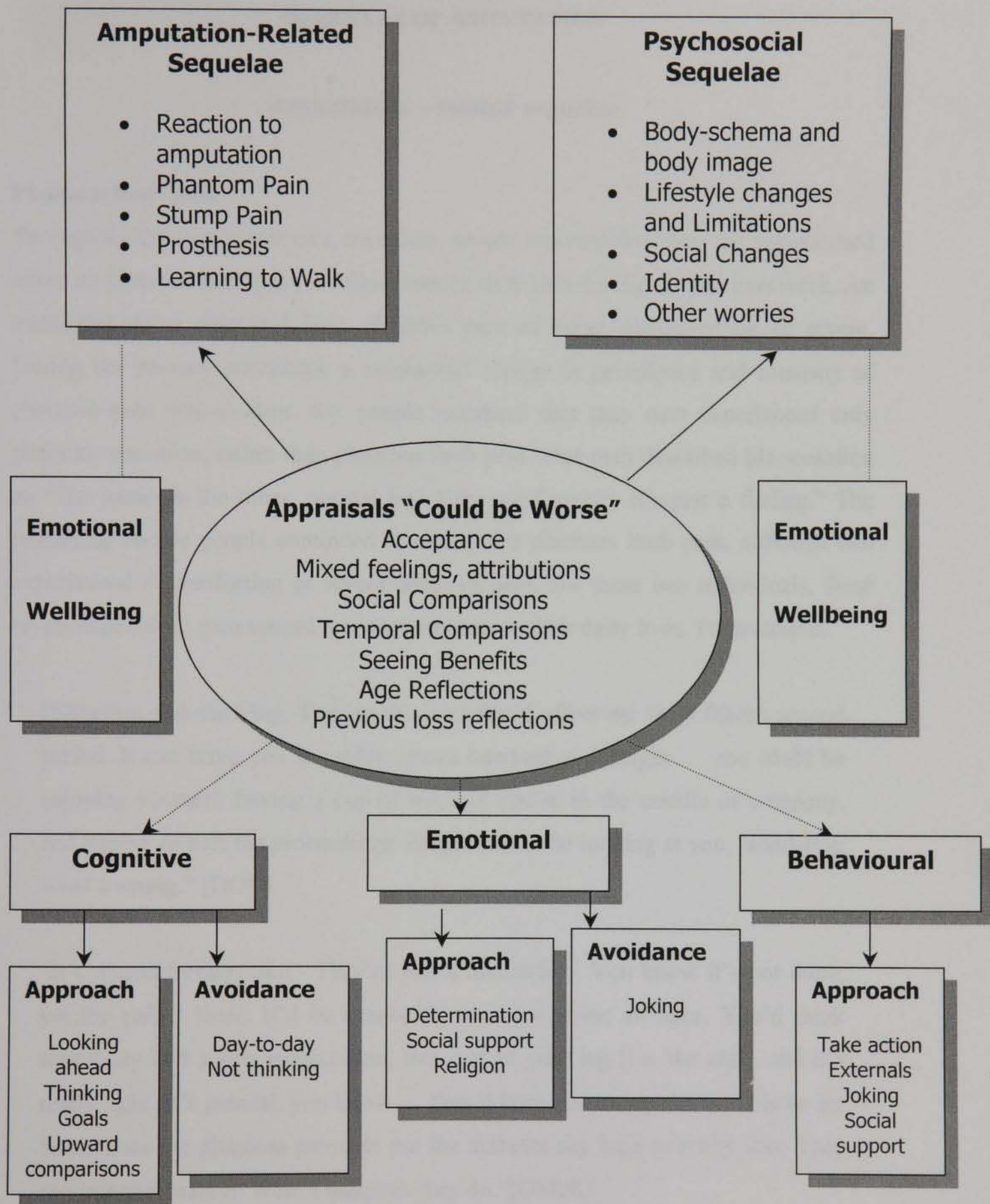


Figure 4.1: A pictorial representation of emergent findings. It is similar to Figure 3.1 with the exception of the Cognitive Approach coping strategy. In this model, the Looking Ahead category has evolved in Looking Ahead, Thinking About Problems, and Setting Goals.

SEQUELAE OF AMPUTATION

Amputation – related sequelae

Phantom limb pain

Throughout the first interviews, seventeen people reported that they had experienced either no phantom limb pain or mild phantom limb pain during the previous week. An additional seven described their phantom pain as either discomforting or severe. During the present interviews, a substantial change in prevalence and intensity of phantom pain was evident. Six people remarked that they now experienced only phantom sensation, rather than phantom limb pain. One man described his sensation as “The same as the other, normal leg. Very comfortable. It’s just a feeling.” The remaining twelve people continued to experience phantom limb pain, although two experienced discomforting or severe phantom pain. For these two individuals, these levels of phantom pain caused some interference in their daily lives. For example:

“Shooting and stabbing. They’re the ones that’d affect me for a fifteen second period. It can bring you to reality, it can interrupt you alright ... you could be enjoying yourself, having a cup of tea, and you’re in the middle of company, and you’ve to halt the proceedings. People would be looking at you, wondering what’s wrong.” [DOD]

“It’s discomforting, like. They’re just a discomfort. You know it’s not there, yet the pain’s there. It’d be constantly there for about an hour. You’d think somebody had a belt around here, this part of your leg [i.e. the calf], and it’s really tight. It’s painful, you know ... they’d keep you awake for an hour or so. Sometimes the phantom pains do put the diabetes sky high or really low. They can interfere with it. Well, I maintain they do.”[OMcK]

For the remainder of the participants, very little interference in daily living was noted. In fact, most of the participants remarked that they paid very little attention to their phantom pain because its duration was so short, its severity so mild, and its frequency

so limited. Thus, remarks such as “You wouldn’t know it was hardly there at all,” “It just passes, you wouldn’t take any notice of it,” were common. As one man said:

“The phantom pain I would have had originally, it would have been more like someone trying to put a needle right into the bridge of your foot or into your shin, and it could have been occurring every thirty seconds, and that could go on for hours on end. And now that doesn’t occur. I can honestly say over the last three months I haven’t had any bouts that would last any amount of time. You might just very briefly get a short shot of phantom pain, but that passes very quickly. It’s not anything that would give me any amount of aggravation. It just isn’t persistent.” [NK]

Stump Pain

During the first interviews, only three people indicated that they experienced stump pain. Nevertheless, most admitted to having some tenderness or soreness in the stump that they were willing to put up with as a normal consequence of amputation surgery. During the present interviews, however, half of the participants answered ‘yes’ when asked whether or not they experienced stump pain. For many participants, wearing the prosthesis was one of the main reasons as to why stump pain was occurring. For other people, problems with the stump itself were perceived as being the predominant cause of stump pain. For example:

“I have a little bit of tenderness all the time on the inside part. The outside part is getting, from lifting the leg, is getting hardened. But the back would be tender all the time. The prosthesis would hurt it during the day a bit.” [MG]

“They measured my stump one day, and it’s two and a half inches long. And people’s stumps are usually only about an inch long. And it’s causing me a lot of problems. My stump is so long, it’s bending under me when I wear the prosthesis, and it’s causing me a lot of pain. Instead of being down, it goes under, and all my weight is on this here. I’ve tried everything. Less socks, more socks. So, then, my leg was rubbing and it caused this big blister.” [BN]

Despite the fact that half of the participants experienced stump pain, only two people remarked that this interfered with their ability to walk and adapt to their prosthesis. The remainder of those who did experience stump pain perceived this as a ‘normal’ part of adapting to the amputation and to the prosthetic limb. As a result, they were not particularly troubled or bothered by this pain. Remarks such as “you’re bound to be sore,” and “you just accept it, it’s part of the cure,” were made to indicate expectations for stump pain at this stage.

Adapting to the prosthesis

During the first interviews, five people had admitted to disliking the appearance of their prosthesis shortly after their amputation. During the present interviews, only two people continued to be apprehensive about the way their prosthesis looked. One man, PG, had disliked his prosthesis from the beginning, describing it as a “set of bagpipes.” Even though he had got used to looking at it, he still thought it was a little frightening to see. The other man who disliked the appearance of his prosthesis, SC, remarked:

“When I first saw mine, I was thinking that I could make a better one with a couple of tools. I think it’s very unattractive. There are some very expensive ones, they have this skin they just roll on, and they have little toes and everything, where it looks like a leg. Whereas now, if I’m wearing the leg, and I take off my shoe and sock as well, there isn’t any toes really, it’s just like a mesh. It looks like a prosthetic leg. It doesn’t look like a leg at all. I don’t like looking at it.” [SC]

Despite the fact that only two people disliked the appearance of their prosthetic limbs, over half of the participants admitted to finding the prosthesis somewhat uncomfortable. In addition, many people were beginning to experience difficulties with the fit of their limb. One man, FF, continued to have an open wound on his stump as a result of MRSA. Because of this, he had eventually resolved after repeated attempts to wear the limb that this was not possible. Nevertheless, the remaining participants were able to wear their limb, despite finding it uncomfortable. For example:

“This prosthesis is giving me a lot of trouble now, in as much as it blistered my leg. Now, I’m in trouble. I can’t wear the prosthesis comfortably. I’m in pain today. If you had a blister and you took the skin off it, and you put anything on it, it’s going to be sore because it’s down to the flesh. Well, can you imagine all my weight on this leg, up against this, you know.” [BN]

“It seems to be a different fit every day. It doesn’t fit like a glove anyway. While it’s okay, it’s still not as much part of my stump as I’d like it to be. I can stand up and lift it, I can shake it, and it’ll move, you know. It’s not fitting as I’d like it.” [PG]

Despite the fact that almost all of the participants experienced comfort or fitting difficulties with their artificial limb, as many as eight people were willing to accept these problems. As one man remarked:

“It’s reasonably comfortable. Well, I don’t expect it to be totally comfortable, I’ll be honest with you. I don’t. I never expected that, because they said it’ll take time to get into it, so I presume that this is kind of a teething period.” [DOD]

Overall, therefore, almost every participant appeared to be very satisfied with their prosthesis at this stage. Remarks such as “It’s excellent. I’m a hundred percent, very, very pleased with it,” and “I think they’re fine. I would say I’d be very satisfied. They’re grand so far,” were commonly used to express overall satisfaction with the limbs. While it may appear somewhat contradictory to accept and be very satisfied with artificial limbs that ill-fitting, uncomfortable and somewhat unreliable, a closer analyses of the interviews offered some indication as to why this may have been the case.

In general, most participants were very grateful to have the limb because it enabled them to do things that they would not be capable of doing otherwise. Because of this gratitude, most participants perceived their prosthesis as a highly useful tool to assist them in their daily living. Furthermore, five people had come to see the prosthesis as a part of themselves. For example:

“I’m very glad to have it, no matter what. These are just teething problems. Without my leg, I couldn’t do things, you know. Without it, my life would be so much worse, you know. I’ve great praise for the leg, because it meant a new life to me. What would I have without it? ...That leg is a big part of me. Without that leg, I can’t get out of bed. So, it’s the first thing I do in the morning, I put on my leg.” [BN]

“I’m glad to have it. Very glad it’s there, and glad that science or technology has these things. It’s great, I’d give it full marks for usefulness. Thank God it’s there to use, you might be so limited. You can go out now, at least ... It’s very much a part of me alright. I do get used to it when I’m out, when I’m there and walking around. And in fact, I often look down at it and say ‘I wonder do people know that that’s not my leg. And they don’t really, you know.’” [PG]

“The prosthesis is the best thing that ever happened to me. I wouldn’t be fed up with it. Without it, I couldn’t manage at all. I’m able to drive the tractor now. Only for it, I’d be in the wheelchair. I’m thankful for that, not to be stuck indoors in the wheelchair ...It’s a part of me. I never leave it off. I put it on, I get up at a quarter to seven every morning, I go to bed about eleven o’clock. Then I take it off. I couldn’t be without it. I’d miss it.” [GD]

Because most of the participants were very glad to have their limbs, perceiving them as either ‘part of themselves’ or as tools to assist them in their daily living, they were willing to put up with the limb being uncomfortable and, at times, ill-fitting and unreliable. As a result, most people had fully adjusted to wearing an artificial limb, and some even went to far as to say that they felt ‘guilty’ for criticising any aspects of it. For example:

“I haven’t a fault at all with the leg. It’s not the leg’s fault that things are going like this ... I feel guilty criticising the leg, because without it, my life would be so much worse, you know. I’m very happy with the leg, because it’s not the leg’s fault. It’s the way I’m reacting to it, do you see.” [BN]

“I would have to give the leg full marks for satisfaction because anything that’s not right with it is my own fault, not the limb’s. And everyday, there is an improvement ... I would say ninety percent I agree that I’ve adjusted to wearing the artificial limb. You have to. You look forward to doing it, actually. Every day, every week, I look forward to being better next week.” [MMcC]

In reviewing their progress, two participants remarked that they coped a lot better with their limbs than they had previously thought they would. One of these participants, OMcK, remarked “I didn’t think I’d be able to do all I can,” while another, MW, revealed that he was doing “a lot better than he thought” he would. On the other hand, one person admitted that he found it more difficult to adjust to wearing the limb than he had anticipated. Furthermore, two participants were sceptical about whether they would ever totally come to terms with having to use an artificial limb. For example:

“I thought it’d be a doddle, because I was hell-bent on doing it. But it wasn’t that easy. It’s still not a hundred percent easy, but it’s getting easy. Like I don’t find any problem in running out to the car, and getting into it, and driving off, or any of that business. A little slower, but there’s very little I can’t do.” [MMcC]

“Physically, yeah, I’ve adjusted to it. There wasn’t too much change, besides just getting used to having it so high up on the inseam. It’s still uncomfortable, but it’s not too bad. But mentally, whether it’s this prosthetic or any prosthetic, it’d probably be the same, but this being my first one, it’s probably a little more because I went from having no prosthetic, not needing one, to having this thing in the corner. I’ve gotten used to it, but still, it isn’t easy, just, getting used to the whole idea of having a prosthetic.” [SC]

Learning to walk

During the first interviews, almost everyone appeared to be extremely motivated and determined to learn to walk on their prosthesis. Throughout the second interviews, it became apparent that such determination to walk had paid off for most participants. Although many continued to use their wheelchair for some occasions, including grocery shopping or attending large social gatherings, most people preferred to use

two crutches. Five people preferred to use just one stick when out walking, and two of these had above-knee amputations and were able walk short distances in their homes without any aid at all. Overall, only three people were displeased with their progress on their prostheses at this stage. One of these individuals, PG, felt that he had reached a “plateau” and that his progress was extremely slow. On the other hand, fifteen of the participants were pleased with their progress so far, with most of these noting an improvement in their walking every day. Compared to the three people who were dissatisfied with their progress, the majority of those who had noted an improvement tended to practice their walking every day. For example:

“Every day gets better, you know. Your body gets used to it. I remember when I came out first, if you walked a couple of hundred yards, you’d have to sit down, you’d get a pain across your back.” [GD]

“I’m getting on great. I can go up and down steps ... I can walk on grass now, which was hard in the beginning. But now, I can, I’ve improved a lot in that as well. And steps as well. I can go up a stairs and down a stairs. Walking half a mile would be easier. In the beginning, now, you would get tired after a short bit of walking, but now, what I’m doing, I don’t get tired.” [MG]

“I’m up at nine o’clock in the morning. I sit down and read a book or the paper, or watch television. And I’d go for a walk then. I might do two walks a day, if the weather’s like today. And I would walk down to the end of the street. I’d be out for more than an hour, nearly.” [LB]

Although most of the participants were pleased with their progress and noticed an improvement every day, it was clear that they still faced several obstacles in learning to walk. One such obstacle was a fear of falling and being nervous while walking. Since coming home from rehabilitation, three people had fallen. Of these three participants, two were not markedly affected by the fall, with one being more embarrassed than physically hurt. The third person, however, fell twice during her first week home from rehabilitation. These falls affected her confidence quite badly, with the result that she was extremely fearful of learning to walk. In the three months since she had come home from the rehabilitation hospital, she had only been out to

practice walking five times, and she was one of the three individuals who did not perceive herself as progressing well with the prosthesis. She tended to remain seated while at home and was extremely nervous of doing housework of any kind. Although only three people had fallen since rehabilitation, such nervousness of falling was evident in a number of participants who had not fallen. As one man remarked:

“The only thing I have to bear in mind is wait for the click of the prosthesis every time, before I put weight on it, because it’s a frightening experience. I have never fallen, but I had some near ones. And if I didn’t have crutches, two of them, I would have been down on that knee, down on the ground. And that is solid. That is titanium metal that’s in it. And there’s no doubt about it, if you hit the ground with that, I weigh thirteen stone, and there’s no give in that. I would smash my hip. And that terrifies me, because if that happened, God knows how long it would be, if I would be the same again. So, for that reason, I’m inclined to be overcautious.” [MMcC]

In addition to falling and being afraid of falling, participants faced other impediments that either prevented them from practicing on their prostheses or that made the learning process more difficult. These other obstacles included bad weather, walking on rough ground, and being in a crowd of people. One man, LB, remarked that the training he had received in physiotherapy had not been sufficient to prepare him for walking on the uneven paths in his neighbourhood. He said:

“The physiotherapists would tell you ‘look up straight when you’re walking.’ That was alright in the physiotherapy room, but there’s bad paths, and cracks in the paths, and in some cases, the paths slope out very much. I’d always keep my eyes partly down as well as up ... I would avoid a place now if it was rough, really rough, you know. My area here is limited. It’s only down the road, it’s a big wide road. If I go up this way and turn left, it’s a very busy street and the paths are roughish. I went around the block there once, but I wouldn’t be inclined to do it again.” [LB]

Psychosocial Sequelae

Body-Schema and Body Image Changes

Throughout the second interviews, it emerged that the majority of individuals accepted their changed body-image and did not appear to experience any embarrassment or self-consciousness as a result of losing a limb. These individuals had no problem with other people noticing their amputated limb, they did not dislike their physical appearance when not wearing their prosthesis, they had no difficulties in going out socially without their artificial limb, they were not embarrassed to be seen limping, and they wholeheartedly answered 'no' when asked whether they experienced any body-image self-consciousness following the amputation. For example:

"I do like the appearance of my amputated limb. I don't mind it. The grandchildren do be saying to me 'Nanny, why did you lose your leg?' And I do say 'Well, I've a false leg now, still two legs.' And they think it's funny. They do knock on it. They still love me. That's the main thing." [OMcK]

"Oh, I don't care if anyone notices my leg. Anyone that'll come, I'll pull up my pants and show them my limb. Many a one that comes in to see me. I'll say "do you want to see my limb?" And they say "Oh, my God isn't it great what they can do." [AOM]

Although the majority of participants did not have any feelings of body-image self-consciousness, it was apparent that six people did experience above average levels of embarrassment or self-consciousness, according to their ABIS scores, as a result of having an amputation. In descending order of their ABIS scores, these individuals were SC, PG, BN, MMcC, DOD, and FF. Most of these individuals indicated that they much preferred their appearance with their prosthesis on and that they would be extremely reluctant to interact with other people without it. Some also remarked that they would be embarrassed about the fact that other people might realise that they had an amputation or notice their prosthetic limb. Others were self-conscious about being seen walking with a limp. For example:

“I would not sit without my prosthesis at all. I’d be self-conscious. I would feel there was an awful lump missing and that people would be noticing, you know ... When I went into work. I was a little embarrassed because I was seen walking with the stick. Self-conscious, if you like.”[MMcC]

“I’d be conscious enough, even at the swimming pool now. It’s not that I mind. Well, I do, with some of the kids, you know. You’ll see their eyes. I don’t mind really, but it must, putting myself in that position a while ago, not even as a kid, even I wouldn’t be that *au fait* now, or that great, looking at people with one limb.”[PG]

“I’m very glad to have it [i.e. her prosthesis]. But I would be a bit conscious of it. You see, I keep trousers on now, just so no one can see it. I don’t want people to see it. I couldn’t take it off now, put it standing there, and people in the house. I wouldn’t do it. So, maybe the appearance of it does bother me.”[BN]

In assessing possible differences between participants with and without body-image self-consciousness, an interesting distinction between the two groups emerged. Throughout the first interviews, it was apparent that in the process of adapting to a new body shape, a small number of individuals sometimes ‘forgot’ that they had an amputation. Interestingly, the incidence of ‘forgetting’ increased at the second interviews, with as many as six people admitting to having such experiences. Of these six individuals, five were amongst those with high levels of body-image self-consciousness. Again, phantom limb sensation may have been responsible for some of this ‘forgetting’ about the amputation. Because these individuals continued to perceive their limb as being there and often tried to use it in everyday behaviours, they also experienced a sense of shock or sadness when they ‘suddenly realised’ that their limb was gone. Seeing themselves in photographs and noticing their reflections were some of the instances during which the reality of their limb loss was recognised. In describing such an experience, two men remarked:

“Sometimes, I’ll feel like the leg is moving the whole way down. And then you feel ‘Ah, it’s grand, things are not as bad as they are.’ But then you go to move

and you say 'Oh, shit, I don't have a leg' ... I got a fright recently, when I saw pictures of Christmas. In one of the pictures, I didn't have the prosthesis on, and I really got a fright. I'd the trousers on alright, but I'd taken the prosthesis off for some reason. I had the trousers on, and you could see the leg wasn't there. I thought I didn't look well, you know. That's not one of the pictures I'll be holding to keep." [PG]

"The few times that I have gone by the mirror, I've seen myself in it. I can do nothing about it, but you do get a little bit of a shock, there's no doubt, you get a little bit of a shock. There's no point in saying you don't. The shock doesn't last. It's just a twinge, and it's gone again ... I don't like the appearance of it. It's the only time it hits you that it's not normal to have it that way. It's not my happiest moment, looking at it." [FF]

On the basis of these findings, then, it would appear that those individuals who experience the sensation that the limb is still there are more likely to experience a shock when they see their reflection and realise that their body self-image does not match with their body-reality. Interestingly, almost all of these individuals experience body-image self-consciousness, in the sense that they dislike the appearance of their amputated limb, are reluctant to be seen by others without their prosthetic limb, and feel self-conscious about the fact that they now walk with a limp. It may be that the self-consciousness arises from the fact that these specific aspects of self-consciousness that they experience tend to highlight the incongruity between internal body-image and external reality.

Lifestyle changes and limitations

Similar to what had been observed throughout the first interviews, the theme of stressing abilities was still evident in the second interviews. Thus, even though all of the participants recognised that they were limited in what they could do, many stressed the fact that they could still go shopping, look after themselves at home, and do many jobs around their homes. In contrast to the first interviews, however, participants were more likely to admit feeling restricted and limited because of their amputation. Previously, the participants were unsure as to the implications of their amputation on their lifestyle and, therefore, they withheld judgement as to what their

lives would be like after rehabilitation. By this stage, however, they had returned to 'real life' after the hospital and, as such, were beginning to acknowledge the implications that the amputation was having on their lives. For the first time, remarks such as "curtailed," "restricted," and "handicapped" were commonly used to describe how they felt as a result of their limb loss. In addition, as many as seven people remarked that there were certain things that they missed being able to do and would love to do. For example:

"I can't go out. I have to wait until my wife is going, which is not handy at all. That's the only thing I'm a bit annoyed about. I really am confined to the house. Normally, if that was me, I'd be out, I'd bring a model airplane with me, and I could fly a model somewhere. But I can't do that, because I need a car to put the gear in. So, I'm handicapped that way, really." [GC]

"For the last two years, I've been in and out of hospital quite a lot, so I've been off work more times than I've been working. I miss that alright. I do miss the buzz at work and meeting work colleagues and that kind of thing. I miss the regularity of the whole thing, you know, getting up and going into work." [DOD]

"There are things I miss. Even going back to work again. I'll miss fitting the cameras and being a hundred percent involved, but I can't now, you know. On the fitting end of it, I'd miss it ... and I miss the dancing. I used to go dancing a lot. It was one of our hobbies." [MG]

One interesting feature to emerge from the interviews was the emphasis placed on abilities and limitations in determining whether life would be as good again. Those participants who felt that their lives would be as good again recognised their limitations but perceived these as unimportant in determining whether they felt deprived from leading a normal life or whether they felt they were experiencing a good quality of life. For example:

"I wouldn't accept that it won't be as good again. It mightn't be as good, in the sense that I can't achieve or do lots of things. I know I'm not going to be able to

do them, but good as in enjoying myself. I think it's going to be just as good. I think it is anyway.”[DOD]

On the other hand, participants who felt that their lives would never be as good again tended to focus on their restrictions and limitations as the predominant reason for thinking this way. For example:

“I feel like it's impossible [for life to be as good again], because I'll always have to worry about the prosthetic, and if a bolt comes loose or something breaks, then I can't walk, you know. It matters how I end up with the prosthetic and how I deal with it, but basically, no, I don't think it will be as good again.”
[SC]

Social Changes

Throughout the first interviews, it emerged that eight individuals had some reservations in talking about their amputation. At this stage, only three participants were continuing to feel this way. One man did not like having to discuss his medical history and the whole process leading up to the amputation. Another man disliked the fact that he had to keep repeating to others about what he had been through. The third man, SC, did not mind talking about his limb loss to friends, as this served to validate his experiences. However, he disliked it when strangers asked him about his amputation. He remarked:

“Loads of strangers come up to you. I'll be in the pub or walking down the street. They come up, they actually walk up, and they'll have this look of confusion ‘So, what happened to you?’ And I'm like ‘Do I know you?’ It's, like, ‘Get away from me, I don't know you.’ Because I think it's, basically, kind of rude. It's just like asking a person a private question that'd obviously be traumatic, asking them to relive it ... But there's actual times I like to talk about it, whether it's to relieve pressure, as it were, or, worst case, if it's to help people think of me as ‘Poor S.’ On the one hand, I hate it, but sometimes I think I feed on it. It's weird. It's bizarre, like. I might feel sorry for myself, and if someone else does too, it makes what I'm feeling legitimate.”[SC]

The remainder of the participants did not appear to have any difficulty talking about their amputations or artificial limbs. In fact, three people sometimes liked talking about their amputation, with two of these people, including SC, indicating that this served to validate their experiences and what they had been through.

Twelve people described at least one instance of being treated differently by other people since their amputation. Six people thought that they were being treated differently in the sense that others approached them now as if they were 'disabled.' In addition, six people had received pitying reactions from other people, three felt that they were being treated differently in the sense that were sometimes ignored or 'talked over' by other people, and two encountered embarrassed reactions from others. Two participants had particularly negative experiences of being mocked by others since their amputation. For example:

"Kids made fun of me once. They threw some ice at the windows. It was when we had all the snow. And it scared me. I thought the windows might break. So, I went outside, basically telling them, I was waving the cane 'Get out of here.' And they started making these, they were all walking like they were crippled. Calling me 'the cripple' or something like that. I came inside and threw the cane down. I was trembling a little bit. That was the first time I've ever had that. I've been made fun of as a kid, everyone has. But never as an adult. Never for being a cripple." [SC]

"People give you that, kind of, 'terrible sorry for your trouble' and all this pity, you know. Someone you wouldn't see too often, and then they'd see you, and they'd start commiserating with you. You'd think I was after dying." [AMcG]

"Some people would attempt to treat you differently. But it's up to you to nip that in the bud as well. There are those people, you get the classical 'Does he take milk in his coffee?' They've a tendency to talk to your wife instead of you, but it does tend to be more with strangers and with people you've encountered for the first time." [NK]

Although almost everyone had experience of being treated differently by others, most people did not appear to be particularly upset by this behaviour. For example, those participants who felt that others were too sympathetic or treated them as disabled felt that they were only trying to be kind and considerate. Furthermore, a number of participants explained other peoples' changed behaviour in terms of their lack of experience in interacting with people with disabilities. For example:

"I think they don't know how to treat you. Because they don't usually deal with disabled people, they don't know how to treat disabled people. I think maybe they want to stay at arm's length in case they say the wrong thing or do whatever it is." [PG]

"They'd treat you differently on the basis that you have an amputation or that you have a disability. They'd be more kind, that kind of a way. They wouldn't go and mock you or anything like that. It's just that they're considerate." [DOD]

"It's more [i.e. being 'talked over'] to do with them being awkward in dealing with someone who's disabled, because you can tell they're struck with 'What am I going to say?' If I make a joke of it, they'll laugh and they'll talk to you. It's just a matter of breaking the ice with most people." [NK]

In addition to being treated differently by others, almost everyone experienced difficulties in getting about socially, with half of the participants admitting that they were now limited in visiting friends as a result of their amputation. Similar to what had occurred shortly after their amputation, experiencing such awkwardness and difficulties in getting around socially meant that half of the participants felt increasingly dependent on other people since their amputation. Throughout the first interviews, this dependence on others was associated with perceiving oneself as being a burden in many participants. Throughout the present interviews five participants remarked that they felt this way. For example:

"The loss of independence isn't the nicest way to be, you know. People would say to you 'forget about it' or 'I'll do that' or 'come out of the way, someone

else'll do that.' It's very good natured of people to be like that, but it's just a bit frustrating not being able to do it." [DOD]

"When I'm sitting in the front of the car, I can manage a whole lot better. But I feel bad putting people out of the front of the car. They don't seem to mind. Whether they do, they don't say it. You see, able-bodied people don't realise. These are small things, but they're big things to me. Because not alone am I upsetting things, it's upsetting things for them as well. You wouldn't call it upset, but it's changing your way of going as well as mine ... you feel a burden." [BN]

Responses to experiencing these social changes were somewhat mixed. Almost everyone indicated that they still enjoyed going out socially since having their amputation. One woman, for example, said "I go to bingo three times a week with my daughter. I don't win much on it, but sure, it's a cheap night out, and you're with different friends every night you go, and sure, the crack is great. You get a good laugh and that, you know." However, despite the fact that most people still enjoyed themselves when they went out socially, as many as seven people admitted that they sometimes avoided interacting with others because of feeling a burden or dependent on others. PG, for example, remarked "It's a big effort going out, and I know that because of my condition a lot of people would be coming up out of courtesy and all." Similarly, BN said:

"Sometimes I feel so bad about being a burden, I'll say 'No, I won't go.' My daughter will come in and say 'Do you want to go for a run to the city?' And I'd be only dying to go, I'd love to go. But I'd say 'No, I don't feel like it.' She's happy enough because she thinks that's the way I feel inside. But inside, my heart is broken for want of going out. But I won't burden myself on anyone." [BN]

Identity

In terms of identity, similar findings to what had emerged throughout the first interviews were observed in the second interviews. In general, the majority of participants agreed that they were the same person they had been prior to their

amputation. For most of these people, their limitations were not important in defining their sense of identity. As one man remarked:

“Nothing has changed in my life. Although the limb is gone, nothing has changed otherwise. I’m still as happy-go-lucky as I was. I’m the very same. It doesn’t interfere with me at all. And I mean that. It really doesn’t bother me in the least. Now, there’s a few little things, sometimes you’d like to be a little faster doing things, but I wouldn’t let that get me down. I’m very contented, I must say.” [GC]

Only four people remarked that they did not feel like the same person they had been prior to their amputation. Similar to what had been observed during rehabilitation, these people tended to focus on their limitations and disabilities in concluding that they were not the same. Again, similar to what had been observed previously, these individuals were amongst the majority of those who considered themselves as disabled. For example:

“I still feel, I feel less the person than I was. Because I can’t jump out of bed now, like I used to. I can’t do this, I can’t do that. Even though I’m getting on great, I’m not the same person, of course I’m not. And I never will be the same person. But I’m doing the best with what I have. I’ll always be restricted. Even with the good leg, I feel I won’t ever be the same.”[BN]

“I don’t really feel like the same man. I try to be. I suppose I was always, well, I was always a great man to go for a few pints and go to a lot of matches. I can’t. I’m restricted ... and my wife. I don’t know, she seems great, but I wonder how she finds it. Am I the whole man I was? I don’t know. I worry about that. If we do decide to go back into business again, I’m restricted. I can’t do that. There’s so many things I can’t do now that I could do before ... I would be disabled, yeah.”[PG]

Other worries

In addition to having to cope with amputation-related issues and psychosocial changes that emerged following the limb loss, many participants had to cope with other non-

amputation-related illnesses and health worries. Overall, sixteen of the participants experienced concurrent medical problems, including excessive weight loss, diabetes, arthritis, asthma, heart problems, cancer, visual impairment, kidney problems, and osteoporosis. Despite the fact that almost everyone had at least one medical condition, only one man rated his current health as 'fair.' The remaining participants rated their health as being either 'good' or 'very good.'

Although most participants rated their health positively, some people did find that their concurrent medical problems interfered with their daily living, learning to walk, or using the prosthesis. For example, one woman who had lost too much weight following her amputation experienced great difficulties using her prosthesis as a result. Another man who had lost a toe on his intact leg because of an accident several years previously, now found it tiring to walk because he was putting too much pressure on this 'good leg' when using the prosthesis.

In spite of having concurrent health difficulties that interfered with their rehabilitation, only four participants were continuously worried about their health. One man, DOD, was worried about his intact leg and, as a result, he was reluctant to engage in activities he considered to be too strenuous. Another man, GD, worried about his heart, since he had suffered a heart attack while in hospital for his amputation. PG was worried about his eyesight and whether he would ever recover full use of his sight again. He discussed his health worries as follows:

"I am worried about my eyes. I do make an issue of my eyes alright. I want to believe it will come back, but I don't know ... And I am anxious about my health. I mean, I'm supposed to have hit the dirt four or five times. I think one of the references is 'there isn't an organ in that man's body that hasn't been hit.'" [PG]

In addition to having concurrent health difficulties and worries, participants also had to cope with managing the financial and practical consequences of their amputation. In terms of the financial implications, only six participants intended returning to work. Of these, three talked were concerned about coping financially since they were not yet

able to resume employment. One woman, BN, appeared to be struggling quite significantly. She remarked:

“In this day and age, I actually saw hunger since I had my leg off. I don’t look hungry, I know I don’t. But to keep my bills paid when I was getting seventy four pounds a week, I couldn’t buy food a lot of the time. Sometimes, when I hadn’t the price of groceries, I used to buy a bar of chocolate or a bag of sweets, which I shouldn’t eat, just to keep my blood count up. And in this day and age, to say that you were hungry, is ridiculous, and the boom that’s going on. I never had money, but at least I could live from week to week. I’m finding that a struggle now.” [BN]

Closely tied up with these financial difficulties were experiences of inefficient bureaucracy. Three people, in trying to claim benefits accruing as a result of the amputation, were often faced with having to negotiate their way through endless amounts of “red-tape” and disorganisation on the part of government and private officials. A small number were particularly upset because on numerous occasions they were asked to “prove” that they had lost a limb in order to claim their benefits.

“I knew I was only getting a percentage of what I should have been getting. They were saying ‘We have to see, we can’t give it to you yet. We have to see are you qualified.’ And yet, people have come here, seen my leg gone. I used to say ‘Do they think I’ve grown another bloody leg in the meantime? What can I do to prove I’m eligible? Besides show my half a leg again. So, as I said, I’m three and a half months waiting for that. There’s so many things. It’s no wonder I’m sitting here frustrated.” [BN]

Besides having to cope with the financial implications of the amputation, some participants were worried about family matters. One man, MMcC, was concerned about his wife’s, rather than his own, health because she had a long-standing medical history. Two men, PG and SC, wondered whether their wife/partner still considered them to be attractive after having lost a limb. One woman, OMcK, had separated from her husband since her amputation, stating that he had left simply because he did not

want to take care of her. Although she said that she had got over this shock, she did admit that she sometimes felt upset by his leaving. She remarked:

“He just didn’t want to look after me, you know. That was it. It just boiled down to that, after forty-five years of marriage. I do feel resentful towards him. He gave me no support. But sure, that’s all, now. I don’t feel tense all the time or anything. It’s just sometimes when I think back and that, you know. But sure, no matter. I’m coping. That’s the main thing.” [OMcK]

EMOTIONAL WELL-BEING

Throughout the first interviews, it was found that none of the participants appeared to be particularly depressed about having had an amputation. Throughout the second interviews, only one participant, SC, had elevated scores of 12 and 9 on the HADS-D and HADS-A, respectively, which indicated mild depressive and moderate anxiety symptoms. Analyses of his second interview indicated that it was only since he had come home from hospital that the reality of his situation ‘hit him’, and he began to realise the full implications of his limb loss. He remarked:

“[Since I left the hospital] The physical bit, is going fine. The mental bit, it’s gone back a little bit, I guess. Maybe it’s getting used to real life, you know, having to have a prosthetic and everyday life. Once you leave the hospital, that’s when it really gets you, like. ‘Cos it really dawns on you what life is going to be like.”[SC]

In addition to the fact that the implications of the amputation had only begun to hit him, he also indicated experiencing some grief-like symptoms, such as a sense of disbelief at the finality of his limb loss, wishing to say goodbye to his limb, and not wanting to give up wishing for his limb to return. He remarked:

“I’m still at the point where I feel like a little child having a tantrum, you know, wanting my leg back, you know. And it, it brings me down quite often thinking about it. It’s almost like there’s still hope that my leg’ll come back, which I

know is complete rubbish, but it's still kind of there, you know ... it's almost like I had this weird idea that if I give up hope of having my leg back that I'll never have it back, you know. Even though I know I'll never have it back, you know, ah, it's almost like I don't want to lose it yet.”[SC]

In keeping with the theme of loss and grief, SC talked about how he had never got the opportunity to “bury” or “say goodbye to his limb.” He remarked:

“I don't know if this has anything to do with anything, really, but when I first had it taken off, I was told that they hold on to it for months, you know, and you tell them what to do with it ... And so at first, I was like you know, “maybe I'll have the ashes, ‘cos I don't want the leg itself.” “I'll have the ashes and sprinkle them somewhere” just to, after watching these talk shows, you know, the term “closure,” and all this business, like you know. But as it turns out, immediately after the operation, they burned it with all the rubbish.”[SC]

Overall, SC's responses were indicative of his somewhat depressive mood. He did not feel like his life would ever be the same again because he would constantly have to think and worry about his limb loss. In addition, he no longer felt like the same person he had been prior to his amputation because he felt restricted and limited in his activities. Furthermore, he continued to experience body-image anxiety and often felt self-conscious about other people staring at him and noticing that he had an amputation.

The remaining participants in the study did not appear to be particularly anxious or depressed, a finding which was supported by their scores on the HADS-D and HADS-A. However, eight people did admit that since returning home from the rehabilitation hospital, they sometimes felt a bit ‘down’ despite being quite happy about their progress and about their lives to date:

“I do get depressed at times. It might be four days ago since I got depressed, maybe. It'd be some small thing that'd trigger it. It'd come from nowhere. Nothing in particular would trigger it off. It might be a glorious sunny evening, and you'd hear the birds singing, and you'll say ‘I'll go such a place’ and then

you think all of a sudden that you cannot go ... but thank God, I'm in good form, now. I would get pangs of depression, we'll say, now, about once a week. But even in normal circumstances, you can get depressed over nothing." [FF]

"Sometimes I can be down for a day, and I might be down for an hour. Sometimes I've been down, and my daughter or one of my sons would come and take me out, and that picks me up again ... But I mean, I'm not downhearted or anything." [BN]

"I do get down moments. I think everybody does. I think if anybody tells you they don't, they're telling you lies, you know. It's a big change in your life, and if you don't get down moments over it, there'd be something very wrong. But they don't tend to last. It isn't really part of my nature. I've never been a person that would be depressed and stay depressed for any length of time." [NK]

One reason for these increased rates of 'feeling down' since coming home from hospital could be the fact that with this return home, participants realised that they were still unable to do many of the activities or jobs that they wanted to do. While they were in the rehabilitation hospital, many were pinning their hopes onto the prosthesis as a means of restoring normal functioning. In returning home, they may have come to realise that 'normal' functioning was not possible, even with the help of the prosthesis. Thus, with the return home, as SC had noted, the day-to-day implications of having an amputation may have been brought to the fore. In support of this, as many as nine participants remarked that they did experience some frustration over their inability to do things they wanted to do. For example:

"My blood pressure had gone up. But I think it was just frustration. I said to the doctor 'Frustration, it is. I can't get out and do the things I want to do.' You'd say to yourself 'I'll try and do this,' and you'd realise you wouldn't be able to do it. And the poor dog would be sitting looking at me, wanting to get out, wanting me to take him out in the morning, and I couldn't. And that used to get me." [AMcG]

“It’s a bit frustrating that you’re still not able to do anything like what you were able to do before. Even to get stuff off the floor or things like that, or if I was to paint that door, for instance, I’d have difficulty in the bottom part of it. I’d have to sit down, rather than kneel down. So, I find that frustrating alright. There’s things I could do in the normal sense, that I have to get someone to do now.”[DOD]

“I’m getting on quite good, but I get restless somedays. I get very despondent at times. When I see the little jobs I’ve to do, that I cannot do. I’ve to pay somebody to do these jobs I love doing, especially out in the garden out there. I miss that. I miss that terribly.”[JMcG]

COPING WITH AMPUTATION SEQUELAE

At this stage of the study, participants were still faced with coping with many psychosocial changes that had occurred as a result of their amputation. Although levels of phantom limb pain had decreased since the first interview, participants still experienced stump pain and discomfort when wearing their artificial limb. In addition, they had to cope with learning to walk under a variety of circumstances, despite being afraid of falling and endangering their rehabilitation process. Health concerns, financial worries, family concerns, body-image changes, social changes, and identity-changes were also issues that participants had to adapt to at this stage of their rehabilitation. Despite being faced with all of these challenges, most participants did not appear to be particularly anxious or depressed. Eight participants did remark that there were times when they felt a bit ‘down’, and nine also admitted to sometimes feeling frustrated over their limitations. However, when asked directly about their emotional well-being, these participants did state that, overall, they felt emotionally good.

One reason as to why the majority of participants had high levels of emotional-well-being could be because their appraisals of the amputation were generally of Acceptance and of the attitude that “it could be worse.” Even after these appraisals, a wide variety of coping mechanisms were used by participants in coping with the

physical and psychological consequences of their amputation. Similar to what was observed throughout the first interviews, Amputation-Related Appraisals emerged that revolved around Acceptance, Mixed Feelings and Regret, and the thought that “It could be worse.” Generally speaking, participants put their amputation into such a context through comparing themselves with others perceived to be in more challenging or difficult circumstances, seeing something beneficial to have occurred as a result of the amputation, reflecting on their age when perceiving the implications of their limb loss, and comparing their amputation with other losses or stressors experienced in their lives. Despite the fact that the amputation was generally perceived within the context of “it could be worse,” some coping mechanisms were required to help deal with the emotional and physical consequences of the limb loss. These coping mechanisms included Cognitive Approach and Avoidance, Behavioural Approach, and Emotional Approach and Avoidance techniques. There were no Behavioural Avoidance coping methods in evidence throughout the second interviews.

Appraisals

Acceptance

Throughout the second interviews, the predominant reaction to having the amputation was one of Acceptance, with twelve people indicating that they felt this way. However, even though Acceptance was the primary appraisal of having lost a limb, it was not necessarily equated with “getting over” having lost the limb. For example:

“I’ve just got half a leg missing, and I could accept that all along. It was a tragedy that happened, but my leg’s gone and it’s not coming back. I’m not going to grow another leg. That’s obvious.” [BN]

“I’ve accepted the fact that the leg’s gone and that’s that. But you never get over losing your leg, that’s the way I see it. It’s a loss, but I accept it, you know. I’ve accepted it and that’s that.” [LB]

“I wouldn’t have my own limb back in the same condition as it was. And the amputation doesn’t bother me as much as some people might think. They say

‘Ah, Jesus, isn’t it rough?’ But I don’t look on it that way. It’s a fact of life. It has to be faced up to, has to be coped with ... I will probably never put it behind me one hundred percent. But I don’t brood on it. It doesn’t bother me.”[MMcC]

Acceptance was a common appraisal when taking into account the implications of the amputation on lifestyles and the resulting limitations and restrictions. In fact, over half of the participants indicated that these were simply things that they had to accept and get on with. For example:

“The doctor came back twice and checked me out. So, my blood pressure’s gone down again. I told him ‘I think it’s frustration, I can’t do some of the things I was able to do,’ you know. So, I’ve settled to that, now. You have to, you know. It’s hard, but you get used to it, accepting different little things.” [AMcG]

“There are always going to be things now that I will not be able to do that I could do before, simply because of accessibility. Like, I mean, cupboards and storage areas that are low down just cannot be reached. There’s no way I can do that ... There’s things like that you have to accept. They aren’t going to change. That’s the way it is. And I would accept those gladly.”[NK]

Acceptance of thinking that their lives would not be as good again was also a common appraisal. For example:

“Life will never be as good. Because this leg is always going to be in the way ... I won’t be able to do the things I want to do. So, I’ll always be restricted. Even with the good leg, I feel I won’t ever be the same. I accept that.” [BN]

“I wouldn’t expect my life to be as good. I couldn’t expect it to be, it’s as simple as that. I’d be enjoying things on a different scale, to be quite honest with you. Ah, sure, it’d be a different life altogether, but I’m used to it, and I don’t mind it.”[CD]

In examining these appraisals of Acceptance, it is worth noting that these were perceived by the researcher as evidence of participants' reflecting upon and acknowledging their amputation and the changes it brought. Their Acceptance appraisals did not, in any way, indicate a passive process of having resigned themselves to accepting their limb loss. Instead, their responses indicated that they had considered and thought about the implications of their amputation and had come to accept these.

Mixed Feelings and Attributions

Despite the fact that Acceptance was the predominant appraisal, mixed feelings were still in evidence in that some people felt somewhat bitter about having lost their limb and continued to think 'why me?'. Others blamed their doctors or themselves for not attending to their needs quickly enough. For example:

"I cried several nights, you know. It was more or less neglect with me. Ignorance and neglect. I got a sore toe and it went from bad to worse. I didn't go near a doctor because it wasn't too bad then. And it was too bad when I did go ... But I've accepted it now. There's no point in regretting it." [CD]

"You never could be a hundred percent over having lost your limb. I would, I think, be a bit naïve if I thought that I would be a hundred percent over it ... the amputation has left me in the position that I have a little bit of a chip in my shoulder as regards the doctor because I'd been going to him for years. I was smoking at the time, smoking heavy. This is what they told me in the hospital, that smoking was the cause of it. He checked my chest and everything, said that cigarettes hadn't any affect on me, but I think that he slipped up badly." [FF]

"I think 'why me?'. That's right. I often think about it. 'Why me?', but there's no answer for that one, either, there's no answer. I would think that about, maybe, once a month. When I'm here on my own." [GD]

"I feel a bit bitter. Why was it me? I tried to be straight all my life. Do the best I could. I had no enemies. And why, after working hard all my life why was I to be punished like this? And you say 'did I do anything awful wrong to deserve

this punishment?’ All these things go through your mind ... But I’ve accepted it. I’ve let go for a good while. What’s the use in holding that inside. That’s the way it is.” [JMcG]

Interestingly, the two people who hadn’t experienced any reaction to losing the limb, shortly after the amputation, continued to feel this way three months later. One of these individuals, MG, remarked “Nothing’s happened. It hasn’t hit me yet. It probably won’t now.” The other man, PG, said something similar:

“I haven’t reached what you might call a crossroads or whatever it is, yet. I’m always expecting one, you know, and yet I can’t identify it. Maybe there won’t be one.” [PG]

Solace and Making Comparisons

One way in which participants appraised their amputation was in a context of “it could be worse.” The conclusion that things could be worse was arrived at through finding solace in their situation, for example, by making such statements as “At least I still have ...” and by comparing their situation with that of other people perceived to be in more challenging situations. In appraising the fact that they had had an amputation eight participants focused on the fact that they were still alive and that they could have had more severe injuries. Furthermore, in appraising the impact of limitations posed by their amputation, ten participants found solace in the fact that there were still some activities that they were able to manage. For example:

“Previous to getting treatment for diabetes, you wasted away and that was that. There was nothing you could do about it. So, I suppose in that sense, I’m lucky to be alive and get to spend days I have with it, you know. That way, I’m kinda lucky, I think, if you could call it that.” [DOD]

“I could be an awful lot worse. I could have got a stroke. At least I’m able to get out of bed. I’m able to shower myself. I can get up with crutches and go as far as the car and drive off. I’ve an awful lot to be thankful for. Sure I’m not as bad at all, really and truly. I’m lucky. As I say, everything was going for me before

it happened, and things didn't disimprove that much since then. Just, I know that I have to live without a limb, but I could be a million times worse." [FF]

"I've done most of the things any human being could possibly do over the years. I know that. Okay, so I lost a limb, but I'm not immobilised by any means. And I can do most of the things that I want to do still. And those that I can't, it doesn't bother me, because I can't anyway, and there's no use in getting into a heap of depression." [MMcC]

Another way in which participants appraised their situation within a context of "it could be worse" was by engaging in non-effortful comparisons with others. Thus, these were perceived as appraisals, rather than coping mechanisms. For example, as many as six people noted having seen others with what they perceived as more serious illnesses or disabilities. Other participants compared themselves to younger people with amputations or with disabilities they perceived as more serious. For example:

"There was a chap in there in the rehab, and he had two amputations. He was blind as well. And it was amazing the way he could go. They are the people, I mean to say, when you see people like that, I say 'Sure there's nothing at all wrong with me.'" [FF]

"I see people worse than myself, you know. There's a little girl up there [i.e. in Dún Laoghaire], with her legs gone from here, you know. It must be an awful handicap. It must be very traumatic on her, a young girl of sixteen, that'd be looking forward to going to discos and that. Says I to myself 'I've my best dancing days done.' ... Sure, the way I look at it, I'm seventy now. When I see youngsters at that age, I wouldn't like to have it happen to me years ago. [LB]

"There's worse off than me, now. Young people especially. There was a young girl, she was over here from abroad working, and she had a stroke and was paralysed down one side ... when you see all young people and that, in car crashes and things like that, you'd be saying 'Well, I had my life,' you know. I'm sixty-four. I'm glad this didn't happen to me when I was young." [OMcK]

Another comparison that some participants made in putting their situation into a context of ‘it could be worse ...’ was between their own current emotional well-being and their pre-amputation well-being. These individuals noted that even though there were times when they felt sad or low, this was normal for them, as they had experienced such days when they had both of their limbs intact. Other temporal comparisons were made between current and previous lifestyles. For example:

“Sometimes I feel I’m coping well, not always. But I’m thinking that that’s fairly normal, you know. I’d say people with everyday life don’t always cope well, you know. They’d have a bad day, like. I used to have mood swings, everyone does to some degree. So, I can’t expect life to be perfect when it wasn’t perfect before.”[SC]

“I do miss the buzz at work and meeting the work colleagues and that kind of thing. I miss the regularity of the whole thing, you know, getting up and going into work. But then again, if I was to be cherry picking, there’s lots that I don’t miss either. There’s aggravation and things like that. I don’t miss that. It’s nice to get away from it. Before you came, now, this morning, there was someone looking for me, to do with work. It was grand. All I’d to say was ‘You’ll have to find someone else.’” [DOD]

Seeing Benefits

Another way in which eleven participants appraised their amputation within a context of “It could be worse ...” was by seeing something beneficial to have occurred as a result of having lost a limb. Five people focused on the fact that they were now free from pain; three people noted that they would not be alive if they had not had their amputation; another three participants remarked that they had gained new friends and had come to see the goodness in people since losing their limb; two people thought that moving around and getting to places had become a lot easier since their amputation; another two people noted that their amputation had brought their families closer together; two people felt that the amputation had changed their perspective on life and given them a better appreciation and sense of gratitude for what they did have. Finally, one man believed that he was now a better person because he had given

up work and thus had more free time and energy and more time to relax and think about his life. For example:

“I’m a better person, I would say. I understand people. I understand living an awful lot better. Because I was fully engrossed. When you’re running a business, you’re fully engrossed and you don’t have time to think. And you can’t plan anything, because there was so much, always, going on that you would be under pressure. But the pressure is gone now.” [FF]

“Only for I lost the leg, I’d be long ago dead. I would be. That’s one thing. I wouldn’t be alive. Because after removing my toes, I was gone, only for they took the other part to it. And thanks be to God, I haven’t looked back since. I’m improving every day. [AOM]

“I’ve no pain at all, whereas before, with the straight leg, if I went to a restaurant, I had to make sure I could get my leg under the table. It was very, very awkward. Now, I just pull the lever, and it bends, and there’s no problem at all. It’s a hundred times easier than having a straight leg. So, it’s great that way.” [GC]

“I think it’s probably brought the family closer together. Because the lad that was here a few minutes ago, he’s living in the town with a couple of lads. And any time he was off work, he was out. Now, he’d always bring you something and ask you if there’s anything you’d want. Before, he’d just come and pass no remarks. But he’s always ringing up. He rings every day to ask how I am ... and the other lads here. They’d never go without telling you they’re going. And they’d always make sure, between them, that there’s somebody here with me.” [JM]

“It makes you think about things differently, certainly, on a lot of levels, you know. I mean, it’d make you, as I said to my wife, there’d be very much to live for and enjoy the moment. Because you never know when things are going to change, or how they’re going to end. So, you’ve got to enjoy it for when it’s there. And I would say, if anything, it’s probably made me even more

determined in my outlook. When I decide to do something now, it gets done.”

[NK]

Age Reflections

Another way in which participants appraised their amputation within a context of “It could be worse ...” was by reasoning that its physical and psychological impact was minimal due to the fact that they were getting older anyway. As many as thirteen people thought this way when discussing the limitations posed by their limb loss. For example:

“I know my life won’t be as good, I won’t be able to do the work I was doing. Everybody’s the same, getting old. I don’t expect to be doing any work. But thank God, I’m great. Isn’t it great to be able to get up and walk around. As I said, I’m forgetting about the hard work. I’ve done my share of it. I’ll be seventy-five years, please God, at Christmas, if I’ll be alive. So, amn’t I great.”

[AOM]

“There’s very little that I can’t do now that I would normally do. But then, as you get older, I’m sixty-two now, you’ll settle for less than you did when you were twenty-five or thirty-five. So, I consider myself semi-retired now. My life is as full as I would expect it to be at sixty-two years old.” [MMcC]

Previous Loss Reflections

Another way in which five people appraised their amputation within a context of “It could be worse ...” was by comparing its impact with that of other stressors or traumas. One woman remarked that the more recent separation from her husband was a bigger shock than the loss of her limb. One man, JMcG, remarked that it was a bigger shock to be told that he had cancer than to be told that he had to lose a limb. Another man, GC, noted that his arthritis caused him greater concern than his limb loss did. Two men, PG and GD were more concerned about their health than their limb loss, with both being continuously worried about their eyesight. For example:

“I’ve more problems than the leg, because I got a kidney transplant, and I’m always thinking would it last, you know. That’d be more a bigger worry on me,

you know ... so I've had a lot of things that'd be more serious. The leg's different, you know, you're able to manage with the leg. I'm worried about my eyes as well. They'd bother me more than the legs. It's a bigger loss anyhow. You can rectify the leg, but you can't rectify your sight." [GD]

Conclusion: Appraisals

Similar to what had been observed throughout the first interviews, participants in the second interviews appeared to appraise their amputation as something that "could be worse." Generally, most people accepted losing their limb as the "lesser of two evils," even though an increased number indicated harbouring feelings of regret over or blame for having lost their limb. Other people appraised the amputation and its sequelae as having a minimal impact on their lifestyle and psychological well-being through comparisons with other people they perceived to be in more challenging situations, to have more serious disabilities, and to have more to lose because of younger age. In addition, many participants appraised the amputation as non-threatening because of the benefits they gained as a result, including the fact that they were still alive, that they had a better lifestyle, that they were free from pain, that they had become a better person, and that they had a closer family. Furthermore, several people appraised the amputation as having a minimal impact on lifestyle or body-image anxieties because older age meant that life was 'slowing down' anyway. Finally, the amputation was appraised as being less threatening or as having less impact than previous losses or stresses, including other health worries and family losses.

Cognitive Approach Coping

Looking Ahead, Thinking About Problems, Setting Goals

In the previous chapter, one Cognitive Approach coping strategy that emerged was that of 'thinking ahead' or 'looking forward' which was characterised by such thought processes as 'don't look back' or 'I must look forward to the future.' Throughout the second interviews, use of this particular cognitive coping strategy had somewhat evolved. Instead of 'looking forward' in a non-specific manner, eleven participants formulated particular rehabilitation goals, and four gave themselves a particular time

frame within which these goals could be achieved. Furthermore, six participants engaged in active thinking ahead about problems that they could face in the future. For example:

“I’d be looking ahead to improve myself in some way or another, you know. I’ll try it anyway, it’s as simple as that. I’m looking ahead so that I can walk without anything, simple as that. You can’t always have a walking aid.”[CD]

“It’ll take me twelve months to get over the whole thing really, you know, the anaesthetics and the shock and everything else. The shock to your system. Like, it’s only starting to ease down. The pain is starting to go and everything else, it’s getting used to your system and everything else. In twelve months I’ll be back. I’ll be in better form than I am now, like. I’ll feel stronger anyway, and get back more independence.” [JM]

“I was trying to figure out how would I get on the bus. One of the neighbours, she comes in, and she was saying they have wheelchair accessible buses ... and my brother’s children were over yesterday from San Francisco. They keep asking me to go over. And I’m saying to myself ‘Now, how would I get on a plane? How would I go over.’ Here I am, plotting and planning, you see.” [AMcG]

Upward Social Comparisons

In learning to walk with their prosthesis and adapt to limitations, six participants tended to use upward social comparisons. That is, they compared themselves with other people with an amputation and who had already rehabilitated successfully and were walking confidently on their prosthesis. These were considered as coping strategies, because they were perceived as effortful by participants. For example:

“I’m meeting people up there [i.e. the wheelchair centre] who have the same problems as me. They might have their legs twenty years or ten years or whatever. And if you didn’t know that they had false legs, you wouldn’t know it at all. So, that’s why I have great hopes for the future.” [BN]

“There’s a man near here, he was in the rehab in Dún Laoghaire as well. But he’s mighty. He can walk now without any sticks. I don’t know if I’ll be that way, now.” [JMcG]

Cognitive Avoidance Coping

Not Thinking About Things and Taking Things from Day-To-Day

A total of ten participants demonstrated at least one instance of using the Cognitive Avoidance strategies of ‘not thinking about things’ and ‘taking things from day to day’. Some participants used the former strategy in relation to their health. Others used the strategy in order to avoid confronting the implications of their amputation on their day-to-day living and future lifestyle. For example,

“The effects of the accident and medical operations I had after it, it would worry me, if I thought enough about them, but I don’t. Death would frighten me. That mightn’t be related to the leg, it might be related to the accident. You see, I don’t know what it’s like. I don’t want to. I like this side of the ground, and I was so nearly on the other side. And if you think about it a lot, it closes in, so it’s not something I think about a lot.” [PG]

“The only thing that I think of, as you get older, you’d be saying ‘What’s going to be the position?’ If you have your two limbs, you’re not too bad, but are you going to be dependent later on. What’s going to be your position a few years down the road if you still live. But you try to forget about it fairly fast. No good dwelling on it, because if you start dwelling on it, you’ll only get into depression.” [FF]

Closely associated with the approach of “not thinking about it” was the Cognitive Avoidance strategy of taking things from “day to day”. In using this strategy, participants did not think about the implications of their amputation for the future, but instead, they focused on their lives in the short term only. As one man said “I take things as they come. I think the worst thing you can ever do is worry about things. I try not to worry about anything.”

Emotional Approach Coping

Emotional Determination

One common Emotional Approach strategy that was used by many participants was that of Emotional determination. Generally, this strategy is similar to Watson et al's (1999) "fighting spirit", and involved giving oneself a mental "talking to" in order to maintain motivation and courage in coping with the amputation and in helping to maintain emotional well-being. For example:

"It's been a great challenge in my life. It's the worst thing that could ever have happened to me. But I didn't lie down. I've always been on top of it, and I've always been determined to beat it. It was never going to get me. When I say 'get to me', I was never going to sit in the chair for the rest of my life and say 'Well, you've lost a leg, now, B., sit there now until you die.' Because I'm hell bent on going forward all the time." [BN]

"You would have to say to yourself, you cannot sit back and say that you're not going to get better. You have to come along and be firm with yourself. You have to say to yourself 'I'll be better.' It's difficult enough to do it, but you have to. You cannot lie down under it." [FF]

"I don't get depressed, thanks be to God, or brood on it. I'm not that type. You just make the best of it and get on with it. Thank God you're still alive. I was never like that. I've seen people that wallow in self-pity. I can't. I can't do that."
[AMcG]

Emotional Social Support

Another Emotional Approach coping strategy that emerged from the second interviews was that of using emotional social support. As many as ten participants in the second interviews commented on how emotional support from family and friends was a great help in maintaining psychological well-being and courage. For example:

“Wherever I go, even to this day, I get a great welcome. People say to me ‘you’re a mighty feckin’ woman.’ Because I had problems in my marriage and everything, you know. And I get the finest of praise. Not that I want praise, but I don’t want degrading either.” [BN]

“[Since the separation from my husband] some of the children are on his side. They’re not speaking to me or anything. But I’ve the others to make up for that. They’re very good to me, that’s the main thing. All I’ve to do, if I feel like phoning them at night, I phone them and have a bit of a chat with them and that, my sisters and that ... I’m not getting upset now, as much as I was in the beginning. I’m getting great support from my family.” [OMcK]

Religion

Similar to what was observed during the first interviews, a small number of participants also turned to religion as an important Emotional Approach coping resource. Overall, five people used prayer and religion as a means of coming to terms with their amputation and its psychosocial consequences. One man had been on a pilgrimage to Lourdes and had found it a life changing experience. He remarked:

“It was an experience going to Lourdes. And I said a few prayers. Even though I suppose I should be better, but I believe that with the drug [he was on an experimental drug to treat his MRSA] and with prayer, faith we’ll call it, that I’m got as good as I am. I’ve more faith now than I used to. I don’t believe in miracles, I’m sad to say. But I believe prayer gives you comfort. Our Lady of Lourdes helped me. Now. That’s the only thing I can say. I definitely believe that there’s something in it. There is something. I cannot explain it to you.” [FF]

During the first interviews, evidence of negative religious coping was observed in one man who had blamed God for the fact that he had got cancer and had lost his limb. Throughout the second interviews, this negative coping was no longer to be found. Instead, he remarked:

“I’ve let go of thinking ‘why me?’ I accept it. Maybe it’s because I have great faith. I believe I have. I say a few rosaries. You do say to yourself ‘did I do

anything wrong to deserve this awful punishment. And then you say ‘well, that can be the will of God.’” [JMcG]

Emotional Avoidance Coping

Joking

Similar to what was observed throughout the first interviews, the two participants who had acquired their amputations as a result of an accident continued to hide their distress about their amputation from other people by “putting on a front” and joking about their limb loss. Throughout the first interviews, only PG had indicated that he sometimes found this strategy difficult to maintain. During the present interviews, it emerged that joking about the amputation was not ideal for either of the participants. SC discussed how he resented it when people tried to join in and make jokes about his amputation. The other man, PG, remarked that it became tiresome to maintain this front. At the same time, he kept it up because it made him feel better if other people thought he was coping well. For example:

“When I’m with my friends, even when I was in the hospital, I was always cracking jokes and stuff. It’ll tend to make me feel better. But every once in a while, they’ll crack a joke about it, you know, just making light of it. And I’ll laugh, but inside I’m thinking ‘that’s not funny. What are you talking about? I’m going to chop your leg off, so you can see what you’re laughing about.’” [SC]

“I’m still putting on a front and joking about it. I’m still doing that. It bothers me a bit, and I’m kind of relieved when they’re gone, I don’t have to put on a false front. But I will try not to leave the side down, for want of a better word. I’m not going to let people see that I’m down. I like people to say to me ‘Jeez, you’re great, you’re in great spirits, and you’re handling this really well.’ I like people to say that.” [PG]

Again, this form of joking was placed in the Emotional Avoidance category because it was perceived as a “deflection” technique, whereby thoughts and emotions associated with the amputation were avoided and ignored, rather than faced with and dealt with.

Behavioural Approach Coping

Taking Action

Another Behavioural Approach coping strategy that was used was Taking Action to resolve any problem that was encountered. In this way, participants not only thought about the barriers, obstacles, and social changes they faced, but they also took particular steps to address any social changes they were experiencing and remove any impediments in this regard. In adjusting to limitations in getting around to places, fourteen participants showed evidence of having taken some action to increase their mobility, including having cars adapted for driving and making adjustments to their homes for greater accessibility. One man, NK, discussed his reasons as to why he used the “Taking Action” strategy:

“I think you need to really empower yourself to a big degree. I mean, I organised my transport from day one, even out in Dún Laoghaire, getting home from here, getting back in. The same with work. I made the phone calls and stuff, because I always feel it’s better to do these things yourself. Because if you can do it yourself, why would you put it in someone else’s hands. That’s my way of coping with stuff, it’s to take over, take control of it, and go and do for myself whatever I can do ... I would be very independently minded. It’s not that it would cause me aggravation to accept help from others, but even if they were helping me, I’d still be thinking all the time ‘well, how do I get around this and do it myself?’ And usually, I find a way of doing it, you know.” [NK]

Earlier in the chapter, it was observed that many participants had experience of being treated differently by others, including being ‘looked over’, ignored, or pitied by others. Although many people accepted these reactions, four participants took some type of action to prevent others from treating them differently again and to maintain their social identities as fully capable individuals. For example:

“I wouldn’t accept that sort of pitying behaviour from others, because I think in many, many ways, you’re treated the way that you accept to be treated. I

wouldn't accept it. I'd rather have nobody talk to me than to treat me like that. So, I'd do something about it. I'd open my big mouth and do something about it. And if that didn't work, I'd say 'that's their problem, not mine.' It's always better to take it into your own hands and do something about it than just sit there. If you're going to be passive about it and just sit there, and let that go on and perpetuate, you know, it's going to cause you a lot of aggravation and stress, then you're stupid. You should be doing something about it." [NK]

Using External Resources

Many participants used External Resources in order to cope with aspects of their amputation. Similar to what was observed throughout the first interviews, ten people appeared to be using their prosthesis as a means of restoring a 'normal' body image and, thereby, coping with potential body-image anxieties. For example:

"I often look down at it and say 'I wonder to people know, now, that that's not my leg.' And they don't, really, you know, because it's camouflaged. They don't. And I am looking forward to the time when I can discard the crutches and walk, you know, without the aid of crutches, and walk as normal, as near as normal as possible. You know, I am looking forward to that alright." [PG]

Another External Resource that two participants made use of to maintain emotional well-being and cope with the psychosocial sequelae of their amputation was their employment. One man, JM, felt that when he returned to work, he'd be in a better position to socialise with other people around his home town. The other man, MMcC, remarked:

"If I hadn't to get back to work, it may have made a difference, because you feel 'well this is the scrapheap, now, anyway.' But psychologically, I didn't feel that way." [MMcC]

Joking

Similar to what had been observed throughout the first interviews, a small number of participants made jokes about their amputation as a means of fostering social relations and breaking the ice. In addition to joking about his amputation to "put on a front" to

other people, for example, PG often remarked that he would bring up his amputation first and make jokes about it to other people to put them at their ease. Similarly, AMcG remarked that she joked about her amputation to her family. She said:

“I can see the funny side of it now. I often say, when I’m standing on the one leg, I feel like a stork standing in a field. When my niece calls me ‘peg leg’, I can see the funny side, thank God.” [AMcG]

Similar to what was argued throughout the first interviews, this form of joking was placed under Behavioural Approach coping because it was perceived as an active way of acknowledging the fact of having had an amputation and of making efforts to foster social relationships and help people feel at ease at meeting someone with an amputation for the first time.

Social Support

Another Behavioural Approach strategy that thirteen participants used was Practical Social Support from their family and friends. Interestingly, a change in attitudes towards accepting practical social support was evident throughout the interviews. In the previous chapter, it emerged that several participants felt guilty about accepting practical social support from other people and felt somewhat conscious that they were putting others under some sort of a burden. Throughout the current interviews, however, this reluctance to accept practical social support appeared to have diminished somewhat. At this stage, only three participants remarked that they would rather be more independent and that they did not want to impose on others. One man remarked:

“I feel confined, I feel lack of freedom in that respect [i.e. that others have to bring him places]. They’d bring me anywhere I wanted to go, but I don’t want to be pulling at them all the time ... I feel it’s not fair on them, although they have no objection, they don’t mind at all. They offer more often. I never ask for assistance.” [JMcG]

It is interesting to consider why participants may, at this stage, have come around to accepting practical social support from their family and friends. One possible reason

for this change could be due to the fact that, compared to what was observed throughout the first interviews, most of the participants now recognised that they were limited in their activities and that there were now certain things they could no longer do. In fact, as was indicated earlier in this chapter, participants for the first time remarked that at times, they felt down and frustrated because of their limitations. With this realisation, they may have decided that that they had no other choice but to rely on their family and friends to help them with activities they were unable to do. As a result, feeling guilty about accepting such help would be counterproductive in the long-term. On the other hand, the decline in reluctance to accept Practical Social Support may also have been due to the fact that as participants increased in strength and walking ability [See Learning to Walk], they may have recognised that such Practical Social Support would not be necessary for much longer.

There was some indication, at this stage, that over-acceptance of Practical Social Support could be detrimental to rehabilitation progress. One woman, who had fallen shortly after she had returned home from the rehabilitation hospital, had only left her home on five occasions since. Within her home, she was also nervous of walking or engaging in any activities. With her brother watching her and helping her all the time, she never had the opportunity to address or get over these fears. She remarked:

“My brother watches over me like a hawk. Coming down in the morning, he’ll hear me going into the bathroom, and I carry a plastic bag, I put everything into it, glasses, cigarettes, the book. Everything I need. And when I come out of the bathroom, he’s standing waiting. He takes the bag, and he just walks down ahead of me. And when I’m going up at night, he’ll take the bag, and he’ll walk up behind me. He does my washing and ironing. He does everything.” [AMcG]

SUMMARY AND DISCUSSION

Amputation-Related Sequelae

The prevalence and severity of phantom limb pain decreased substantially between the first interviews and the second interviews. Shortly after amputation, the majority of participants experienced phantom limb pain, with seven people describing their

pain as discomforting. However, during the second interviews, only twelve people continued to experience phantom pain, with only two describing it as discomforting. This decrease in phantom pain in months post amputation has been observed in other longitudinal studies (e.g. Jensen et al., 1983, 1984) and may be explained by physiological or psychological mechanisms [See Chapter 7 - Discussion]. However, although phantom pain decreased after rehabilitation, the incidence of stump pain increased substantially during the same period. Reasons for stump pain were associated with increased walking (Davis, 1993) and included wearing the prosthesis and aspects of the stump itself, for example skin grafts and length of stump. Increased perception or reporting of stump pain may also have been due to the fact that expectations for pain (Arntz et al., 1990) were not so prevalent as they had been during rehabilitation. Despite the fact that half of the participants admitted to experiencing stump pain, only two people remarked that this interfered with their learning to walk and adaptation to the prostheses.

In the present study and similar to what had been found in the first interviews, many participants found the prosthesis uncomfortable and experienced difficulties with its fit or reliability. Nevertheless, almost everyone remarked that they were satisfied or very satisfied with their artificial limb. Interview analyses indicated that such satisfaction may have been due to the fact that most participants were very grateful to have their limbs, perceiving them as either part of themselves or as extremely useful tools that allowed them to achieve everyday tasks of daily living. In view of these findings, it could be argued that in terms of early satisfaction with and adjustment to an artificial limb, its perceived usefulness could be more important than experience of initial comfort, fitting, or reliability. As discussed in the previous chapter, this supports a study that has confirmed the relative importance of ability to walk with a prosthesis over comfort (Legro et al., 1999).

Overall, the determination in learning to walk that was observed throughout the first interviews appeared to have paid off by the second interviews. In fact, almost all of the participants were pleased with their progress in walking and perceived themselves to be getting on very well with their prostheses. This observation supports the primary importance of motivation, over aspects of the prosthesis itself, in adapting to a prosthesis and learning to walk (Grisé, Gauthier-Gagnon, and Martineau, 1993).

This progress was achieved, despite the fact that participants faced many practical obstacles in learning to walk, including a fear of falling, uneven ground, bad weather, and crowds. Although these environmental obstacles are often ignored in research on physical rehabilitation, the importance of these factors in learning to walk has been previously noted in one qualitative study on Irish people with amputations (Gallagher and MacLachlan, 2001).

Appraisals, psychosocial Sequelae, and emotional well-Being

Similar to what had been observed throughout the first interviews, most participants appraised their amputation within the context of "it could be worse." Thus, social comparisons with others perceived to be in more challenging circumstances, seeing solace and benefits to the amputation, and reflecting on its impact on the basis of age and other losses were common. However, compared to what was found during rehabilitation, wholehearted acceptance of the amputation as 'the lesser of two evils' had declined. Previously, it had been found that only younger participants seemed to have mixed feelings, regret, and disbelief about their amputation. Three months later, although acceptance of the amputation was still seen in the majority of participants, almost everyone at the second interview indicated experiencing mixed feelings about having had an amputation. Thus, some people remarked that despite accepting their limb loss, they would never fully get over their amputation. Others admitted that they were had some feelings of regret and self-blame over behaviours or actions that could have been responsible for their amputation. Yet others admitted to blaming other people for their amputation or feeling bitter about having had to lose a limb in the first place.

Compared to what was observed throughout the first interviews, similar findings with regard to sense of self and identity were found in the second interviews. In general, the majority of participants still considered themselves to be the same person they had been prior to their amputation. On the other hand, those who considered themselves to be different still focused on their limitations and on a sense of being 'disabled' in determining their sense of self and identity.

For the first time, however, participants did not focus on their abilities to the same extent as they had done during rehabilitation. Instead, many remarked that they felt

'restricted', 'curtailed', or 'limited,' while some admitted to missing particular aspects of their lives that they could no longer engage in. Furthermore, a number of changes were evident in their social interactions with other people. Many more people had experiences of being treated differently by other people in the sense that others were embarrassed to approach them, avoided them at times, mocked them at times, and treated them as disabled, ignored or 'talked over' them, or pitied them. Similar to previous observations, most participants were not overtly upset or distressed by these reactions, explaining them as kindness, as consideration, or as a lack of experience in dealing with 'disabled' people. However, even though the majority of participants appeared to still enjoy going out socially and interacting with others, there was a slight increase in the number of participants who sometimes avoided going out or interacting with others for fear of being a burden or overly dependent on others and for fear of receiving too much attention. Despite the observation that an increased number of participants avoided interacting with others, the proportion of those experiencing body-image anxiety declined. However, during rehabilitation and the present study, it was found that many people were continuing to use their prosthesis as a means of 'restoring' a normal body image. Thus, the decline in body-image anxiety observed in the present study could be due to the observation that aesthetic dissatisfaction with the artificial limb also decreased in the same period.

Overall, some of the above findings of the present study support the notion that the period immediately after rehabilitation is a particularly difficult one (Glass, 1994; Morse and O'Brien, 1995). After leaving rehabilitation, the observation that more people were recognising that others were treating them differently supports Goffman's (1963) theory that a person with a visible disability is exposed to greater public scrutiny. The finding that an increased number of participants were avoiding social interactions for fear of being a burden or appearing socially awkward also suggests that the greater perceived public scrutiny was associated with increased levels of social discomfort (Rybarczyk et al., 1992; Williamson, 1995). After rehabilitation, the increased emphasis on limitations and restrictions that was observed suggests that participants were coming face to face with the real-life impact that their amputation was having on their lifestyles. Thus, their limitations and losses were being addressed for the first time (Morse and O'Brien, 1995; Morse, 1997). Although the majority of people did not appear to be clinically depressed or anxious

as a result of these changes, one man did appear to be experiencing a grief-like reaction to his limb loss and appeared to be experiencing clinical levels of depressive and anxiety symptoms. Furthermore, just under half of the participants felt 'down' or 'frustrated' at times over their limitations and restrictions. It may have been the case that the greater number of mixed feelings with regard to having had the amputation were a reflection of these emotions. That is, with the realisation of the losses and restrictions that participants were facing, they may have been in a greater position to judge whether they would ever get over their limb loss or not.

Although the above findings support the notion that the period following rehabilitation is a difficult one, the observation that during this time, the proportion of participants experiencing body-image anxieties actually decreased is contrary to it (Morse and O'Brien, 1995). Furthermore, the finding that most people were still likely to feel like the were the same person they had been prior to their amputation does not support the theory that the period after rehabilitation is a time when an old identity as an 'able-bodied person' and a new identity as a person with an amputation is forged (Morse and O'Brien, 1995). The observation that many people were using their prosthesis as a means of restoring a 'normal' body-image supports previous findings (Norris et al., 1998), and the finding that aesthetic dissatisfaction and body image anxiety both decreased is in keeping with previous findings indicating a positive relationship between aesthetic satisfaction with a prosthesis and body-image anxiety (Murray and Fox, 2002). The finding regarding identities may reflect that fact that even though recognition of losses and limitations has occurred, individuals were still in the phase of attempting to 'restore the self' and had, therefore, not moved into the phase of 'learning to live with the altered self' (Morse, 1997; Morse and O'Brien, 1995).

Coping

Similar to what had been observed throughout the first interviews, Cognitive, Behavioural, and Emotional Approach and Avoidance methods were used by the majority of participants in coping with the physical and psychosocial implications of their amputation.

Consistent with the fact that the use of coping mechanisms is dependent on the individual's situational context (Tennen and Affleck, 1999; Holohan and Moos, 1987), the use of some coping strategies declined, while others increased. For example, use of joking as a Cognitive Approach method to foster social relations amongst health professionals and other people with amputations somewhat declined as participants left the hospital environment. Reluctance to accept Practical Social Support also declined during this period. This may have been due to the fact that after they had left the rehabilitation hospital, participants they were beginning to recognise their limitations and accept that there were certain activities they could no longer do. Recognition of limitations may have been accompanied by a recognition of the futility of feeling guilty about requiring help. Furthermore, the increases in physical strength and walking abilities that were occurring around this time [see Learning to Walk above] may have meant that they were aware that Behavioural support would not continue to the same extent for much longer. Thus, participants may have been more likely to tolerate receiving Practical Social Support.

One coping strategy that appeared to have evolved after rehabilitation was the Cognitive Confrontive coping strategy of 'thinking ahead'. During the first interviews, participants remarked that they were looking ahead as a means of coping with their amputation and its sequelae. However, they did not appear to have formulated any specific goals, beyond the overall goal of walking. Furthermore, they did not appear to have given themselves any time frame within which to achieve their goals, and very few appeared to have engaged in thoughts aimed at solving problems or obstacles they may have faced. Throughout the second interviews, participants were still looking ahead towards their futures. However, this time using the "thinking ahead" strategy they formulated specific goals, gave themselves specific time frames, and engaged in problem-solving thinking ahead to resolve some obstacles that could emerge in the future. This increase in use of 'Taking Action' is likely due to the fact that a return to community living after rehabilitation ended the uncertainty that many participants were facing with regard to their future lives (Mishel, 1988). As a result, participants were in a better position to formulate new goals that would be consistent with their physical abilities and environmental context.

CONCLUSION

Similar to what was observed throughout the first interviews, these qualitative interviews illustrate the importance and dynamic interplay of the various demographic, personality and coping, amputation, and environmental factors in psychosocial adjustment to amputation. Using Livneh's (2001) conceptual framework, the importance of personality factors and coping mechanisms, amputation-related factors, and environmental factors on adjustment to amputation were demonstrated. In terms of *personality* factors, for example, the importance of motivation in learning to adapt to an artificial limb was found to influence progress in walking, as those who were determined and who practised walking every day were more likely to be satisfied with their progress than those who were not motivated into practising on daily basis. *Environmental* factors were found to influence both physical and psychological adjustment to limb loss. For example, environmental barriers to physically adjusting to a prosthetic limb, including uneven ground, difficulties accessing places, and crowds, meant that some people could not practice walking as often as they wished. In addition, the difficulties experienced in accessing places meant that some participants preferred to remain at home, rather than go out socially, for fear of being a burden on others or the centre of attention. Environmental factors may also have been associated with the increase in mixed feelings that participants had with regard to their amputation; it was argued that because they had left the hospital, their return to the 'real world' had brought the impact of their amputation on their lifestyles and abilities to the fore. As a result, a greater number of mixed feelings with regard to having an amputation followed. At the same time, however, coping methods changed in accordance with this altered environment, in that more people began to look ahead and form specific goals in their heads in order to resolve some of the problems they were facing. In thinking about their accessibility problems, for example, many people had their cars adapted, while others realised the benefits of planning a proposed journey or outing well in advance. Finally, *amputation-related* factors may also have impacted on participants' physical and psychological adjustment to amputation. In terms of amputation cause, for example, the two men with trauma-related amputations continued to be the only two people who used the Cognitive Avoidance strategy of joking about their limb loss.

Furthermore, both men who were unconscious when the decision to amputate their limb was taken continued to think that they had not yet 'reacted' to having an amputation. Finally, the *demographic* factor of age as well as amputation cause may have had a joint impact on one man's adjustment to amputation. As one of the youngest participants, and one of the two participants with trauma-related amputations, one participant appeared to be experiencing a grief-like reaction to the loss of his limb and had appeared to have the highest anxious and depressive symptomatology.

Overall, this study has demonstrated the dynamic nature of adjustment to amputation. Between the first and second interviews, for example, phantom pain prevalence and intensity declined, while that of stump pain increased. As walking levels improved, the importance of environmental barriers to adjustment came to the fore in that these made accessibility to places difficult at times. As a result, many people felt dependent on others, and even though body-image anxiety decreased, there was an increase in the number of people who avoided interacting with other people. Furthermore, with the return home from hospital, barriers and restrictions were faced and, for the first time, a focus on limitations and disabilities became more prevalent than a focus on abilities. Even though most people continued to feel like they were the same person they had been prior to their amputation, those who did not feel this way perceived themselves as 'disabled' and cited their limitations and restrictions as being the cause of feeling different. With these environmental changes, coping mechanisms also changed to cope with additional challenges brought. Thus, many more people used a Taking Action Strategy in order to cope with the restrictions and limitations they faced. Furthermore, a new strategy of Planning Ahead with regard to specific goals emerged as participants became more aware of the barriers and restrictions that they were now facing.

INTRODUCTION

In the previous study, some of the findings supported the notion that the period immediately after rehabilitation is a particularly difficult one (Glass, 1994; Morse and O'Brien, 1995). After leaving rehabilitation, the observation that more people were recognising that others were treating them differently supported Goffman's (1963) theory that a person with a visible disability is exposed to greater public scrutiny. The finding that more participants were avoiding social interactions for fear of being a burden or appearing socially awkward also suggested that the greater public scrutiny was associated with increased levels of social discomfort (Rybarczyk et al., 1992; Williamson, 1995). After rehabilitation, the increased emphasis on limitations and restrictions that was observed suggests that participants were coming face to face with the 'real-life' impact that their amputation was having on their lifestyles. Thus, their limitations and losses were being addressed for the first time (Morse and O'Brien, 1995; Morse, 1997). Although the majority of people did not appear to be clinically depressed or anxious as a result of these changes, one man did appear to be experiencing a grief-like reaction to his limb loss and clinical levels of depressive and anxiety symptoms. Furthermore, just under half of the participants felt 'down' or 'frustrated' at times over their limitations and restrictions. It may have been the case that the greater number of mixed feelings with regard to having had the amputation were a reflection of these emotions. That is, with the realisation of the losses and restrictions that participants were facing, they may have been in a greater position to judge whether they would ever get over their limb loss or not.

Although the above findings supported the theory that the period following rehabilitation is a difficult one, the observation that during this time, the proportion of participants experiencing body-image anxieties actually decreased is contrary to this notion (Glass, 1994; Morse and O'Brien, 1995). Furthermore, the finding that most people still felt that they were the same person they had been prior to their amputation does not support the theory that the period after rehabilitation is a time when an old identity as an 'able-bodied person' and a new identity as a person with an amputation is forged (Morse and O'Brien, 1995). These observations may mean that even though participants were beginning to recognise their losses and limitations, and were having

more mixed feelings about having had an amputation, they were still in a phase of attempting to 'restore the self' rather than 'learning to live with the altered self' (Morse, 1997; Morse and O'Brien, 1995).

In view of this observation that in the immediate post-rehabilitation period, participants may have been in a phase of "restoring the self", this study aimed to explore whether any further changes in amputation-related and psychosocial-related changes would have occurred during the six months after their second interview. Thus, in the present study, the following question was asked: Since acceptance of amputation had given way to mixed feelings and an emphasis on restrictions and limitations in the second interviews, what implications would this have on physical rehabilitation, social lifestyles, perceptions of self and identity, body-image difficulties, and perceptions of limitations six months later? Therefore, the study's aims were:

Aim

- To investigate the occurrence and interrelationships among amputation-related factors (phantom pain, stump pain, prosthesis, learning to walk), coping mechanisms, reactions to amputation, psychological well-being, sense of self and identity, body-image anxiety, and social functioning approximately nine months after the rehabilitation period.
- To observe any changes that had occurred between the post-rehabilitation period and six months later in terms of participants' amputation-related experiences, reactions to amputation, their psychological well-being, their coping mechanisms, sense of self and identity, body-image anxiety, and social functioning.
- To describe the amputation-related and psychosocial-related characteristics of participants in order to indicate the representativeness of this sample.

METHOD

Procedure

Six months after they had taken part in the Stage 2 interviews, participants were sent a letter [See Appendix 8] requesting their participation in another interview on psychological adjustment to their amputation and their prosthesis. Approximately three days after they would have received the letter, they were subsequently telephoned by the researcher, and if they were willing to take part in a third interview, a date was arranged on which the researcher would call to their homes.

The interviews, which were tape-recorded, were based on questions included in the Trinity Amputation and Prosthesis Experience Scales (TAPES; Gallagher and MacLachlan, 2000), the Short Form of the McGill Pain Questionnaire-Short Form (SF-MPQ; Melzack, 1987), the Amputation Body-Image Scale (ABIS; Breakey, 1997) and the Hospital Anxiety and Depression Scale (HADS; Zigmond and Snaith, 1983). Responses to items on these questionnaires were followed with probing questions assessing the reasons for their responses. In addition, participants were asked open-ended questions about their reaction to their amputation, learning to walk, their current goals, their hopes for the future, their social support, and qualities of their phantom limb pain.

All of the interviews were transcribed *verbatim* by the interviewer. The interviews were then analysed using QSR NUD*IST 4.0 for analysing qualitative data. In accordance with grounded theory methodology, open codes from the interviews were created using line-by-line analyses. These open codes were then used to create categories of higher-order concepts. On the basis of these categories' properties and dimensions, axial coding was then carried out to focus the results and draw the concepts together.

Inter-rater reliabilities were used to assess the validity of the categories. In order to test the validity of the *Amputation-Related Sequelae* categories, 10 examples from each of the sub-categories were given to an independent rater. This rater was then

asked to place each example into one of the following categories: Amputation-Related Sequelae, Social Sequelae, Body Image Sequelae, Identity Sequelae, Limitations Sequelae, and Other Worries. Initial ratings revealed that ninety five percent of the examples were coded reliably. Subsequent discussions between the researcher and the rater resulted in one hundred percent agreement.

In order to test the validity of the *Appraisal* and *Coping* categories, 10 examples from each of the subcategories were given to an independent rater. This rater was then asked to place each example into one of the following categories: Appraisals of the Amputation and its sequelae, Cognitive Approach, Cognitive Avoidance, Behavioural Approach, Behavioural Avoidance, Emotional Approach, and Emotional Avoidance. Initial ratings revealed that ninety-five percent of the examples were coded reliably. Again, upward Social Comparisons with regard to walking were placed in Cognitive Approach coping.

Participants

Four participants were lost to follow-up. One participant, JMcG, had died in the months after his second interview. The other three participants, OMcK, CD, and GC could not be interviewed within the time period required by this study. As outlined in the Ethical Procedures section of Chapter 2, a new medical consultant in charge of Amputee Rehabilitation withdrew permission for the study to be conducted until it had been put before the hospital's newly established ethics committee. As a result, the study was halted for a period of four months until it was subsequently passed by the ethics committee. Because of this time delay, OMcK, CD and GC were not asked to take part in a third interview, but instead, they were sent a letter thanking them for their contributions to the study and indicating that their participation was no longer possible due to time constraints. In keeping with theoretical sampling outlined in Chapter 2, one other participant AOM, was not asked to take part in a third interview because it was felt at this point that the data had been saturated and that her contributions, while interesting in themselves, did not yield any further insight into the process of adjustment to amputation.

Overall, thirteen participants took part in Stage 3 interviews. These were two women and eleven men. Their mean age was 58.69 years (Range 38 to 73 years) [See Table 5.1 for a description]. The reasons for amputation were as follows: pulmonary vascular disease (PVD) = 4, diabetes = 4, accident = 2, clot/aneurysm = 2, ulceration of the leg = 1. Eleven participants had unilateral lower-limb amputations, including seven above-knee amputations and four below-knee amputations. Two participants had bilateral lower-limb amputations; one person had bilateral above-knee amputations and the other person had one above-knee amputation and one below-knee amputation. Some of the participants had concurrent medical problems that could impact on their rehabilitation. Table 5.1 outlines these medical conditions.

Name	Sex	Age	Amputation type	Reason for amputation	Time since amputation	Concurrent difficulties
AMcG	F	73	Right AKA	PVD	15 months	None
BN	F	56	Left BKA	Diabetes	15 months	None
DOD	M	56	Right BKA	Diabetes	12 months	3 toes amputated on right foot
FF	M	66	Right AKA	PVD	14 months	None
GD	M	63	Right BKA	Diabetes	12 months	Kidney transplant; Heart problems
JM	M	59	RAKA & LAKA	PVD	11 months	None
LB	M	72	Left AKA	Clot	10 months	None
MG	M	62	Left AKA	Complications of Aneurysm	15 months	None
MW	M	70	Right AKA	Ulceration of the leg	11 months	None
MMcC	M	62	Right AKA	PVD	12 months	None
NK	M	37	RAKA & LBKA	Diabetes	15 months, 10 months	Visually Impaired
PG	M	49	Left AKA	Road Traffic Accident	13 months	Visually Impaired
SC	M	38	Left BKA	Boat Accident	12 months	None

Table 5.1 : Describes the name, sex, age, type of amputation, cause of amputation, time since amputation, and concurrent medical difficulties of the participants. F = Female; M = Male; AKA = Above-knee amputation; BKA = Below-knee amputation.

RESULTS

Descriptive statistics of participants

A table and brief description of participants' scores on the questionnaire instruments used are provided in Appendix 12. As these scores did not comprise part of the major results, they were not included in the main results section.

Qualitative Findings: A model of adaptation to amputation

Figure 5.1 is a pictorial representation of the findings that emerged from the interview data. It is similar to that observed in Figure 4.1, Chapter 4, except for some changes within the Appraisals, Cognitive Approach and Cognitive Avoidance coping, and Behavioural Avoidance strategies. Within Appraisals, conflicted feelings with regard to having had an amputation were added. Within the Cognitive Approach category, Looking Ahead, Thinking About Problems, and Setting Goals changed to just Looking Ahead and Thinking about Problems. In addition, Upward Social Comparisons were no longer in use, and downward social comparisons appeared, for the first time, to be used explicitly as coping strategies rather than as appraisals of the situation. Within the Cognitive Avoidance category, use of Taking Things from Day to Day was no longer in evidence. Furthermore, within the Behavioural coping strategies, the Avoidance technique of engaging in distracting tasks was added. Again, despite the changes that were observed in coping between the second and third interviews, the hierarchical structure was again similar to that of Lazarus and Folkman (1984) and Tobin et al.'s (1989) models.

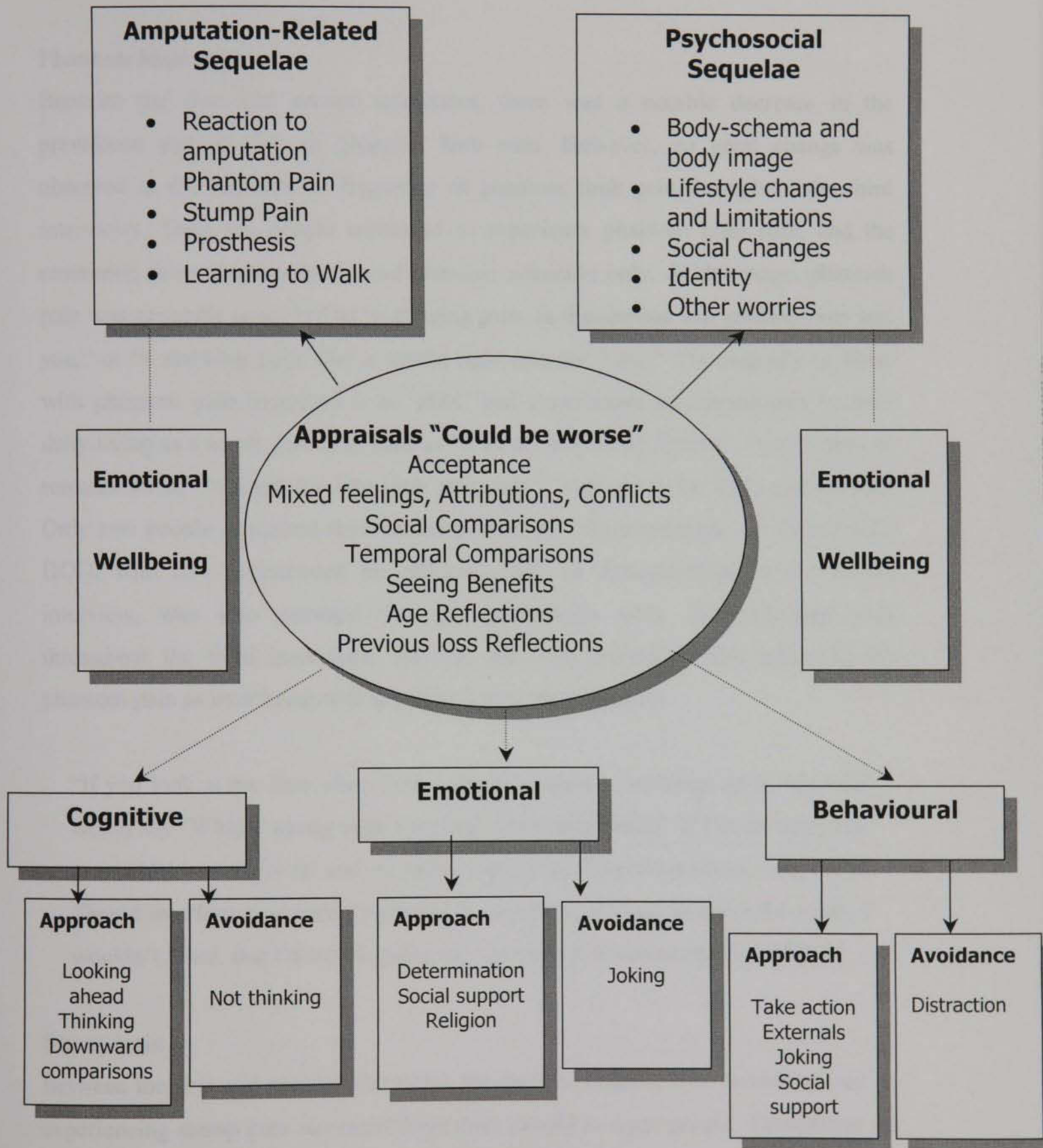


Figure 5.1: A pictorial representation of emergent findings. It is similar to Figure 4.1 with the exception of the Appraisals, Behavioural Approach, and Cognitive Approach and Cognitive Avoidance coping strategies.

SEQUELAE OF AMPUTATION

Amputation-related sequelae

Phantom limb pain

Between the first and second interviews, there was a notable decrease in the prevalence and severity of phantom limb pain. However, no great change was observed in the intensity or frequency of phantom limb pain throughout the third interviews. Thus, ten people continued to experience phantom limb pain, and the remaining three people experienced phantom sensation only. At this stage, phantom pain was generally described as “a stinging pain, as if someone was sticking pins into you,” or “a stabbing pain, like a needle right into the bone.” The majority of those with phantom pain described it as ‘mild’ and experienced no interference in their daily living as a result. Remarks such as “it’s only a nibbling feeling”, “you’d pass no remarks on it,” “I’d get the odd little stab only,” were made by these respondents. Only two people described their phantom pain as ‘discomforting’ or ‘distressing.’ DOD, who had experienced his phantom pain as discomforting at the second interview, was also amongst the two participants with ‘discomforting’ pain throughout the third interviews. He was the only individual who perceived his phantom pain as interfering with his daily living. He remarked:

“If you look at my face when I have the pain, there’s writhings on it. My wife would say ‘What’s wrong with your leg? Have you pains?’ If I’m in company, now, I’d try and get up and go away, out of the way somewhere, you know. They’d interfere moderately with me. In company, if I had to leave the room, I wouldn’t mind. But I’d avoid going into company if it was occurring.” [DOD]

Stump pain

Between the first and second interviews, the number of those who answered ‘yes’ to experiencing stump pain increased from three people to eight people. Throughout the third interviews, similar findings were observed in that six of the participants answered ‘yes’ when asked whether they experienced stump pain. Three people indicated that their prosthesis caused their stump pain, two men indicated that their

stump pain was caused by the way they lay on the residual limb at night, one man with stump pain remarked that it was often caused by 'overdoing it', that is, by walking too much. Although four of the participants perceived their stump pain as 'mild', two participants, DOD and SC, rated their stump pain as 'discomforting.' These participants were the only ones to perceive their stump pain as interfering with their daily lives. In fact, both individuals rated the level of interference from stump pain as being 'moderate' and both indicated that once stump pain occurred, they would have to stop walking and rest until it went away again.

Adapting to the prosthesis

Throughout the third interviews, it emerged that one participant, FF, was not using his prosthesis because he had undergone another amputation to remove an infection in his residual limb. Four participants had been given a new artificial limb because their previous ones had become too big for them. Another participant had been measured for a limb and was due to take it home the week of his interview. Two of those with new artificial limbs were satisfied with them, while two were dissatisfied. GD, who was dissatisfied with his new limb, thought it was still too big to fit properly, and the other man, SC, continued to get blisters if he wore his limb for prolonged periods. On the other hand, BN, was generally pleased with her new limb, despite the fact that she believed it to be too long. Similarly, MW was happy with his new prosthesis after he had had a sufficient period to 'break it in.' These two participants remarked:

"It didn't take me an awful long time to get used to it, because it was very comfortable. The other one was way too big. He'd tell me to put four or five socks on so you'd pack it as hard as you could to make it stay still and tight. Then it used to hurt me, because it was too tight. Then, when I got this, there was great comfort, and it just went on and stayed where I put it, and it was lovely. I suppose it took me, maybe a month to get used to, and I was as good as ever." [BN]

"It's pretty good now. I got it about two days before my daughter's wedding, but I wasn't too comfortable with it. So, I wore the old one for the day of the wedding. When I came back, I put on the new one, and I didn't put the old one

on since. It's a lot better than the last one. I haven't as much padding or anything, and it isn't as warm. The last one was very warm." [MW]

Throughout the first and second interviews, the number of people who were dissatisfied with aesthetic aspects of their artificial limb reduced from five to two people. Throughout the third interviews, however, the number of people who were dissatisfied with particular aesthetic aspects of their artificial limbs increased to four. The predominant reason for disliking the appearance of the prosthetic limb was because it was too 'artificial' or 'alien' looking. For example:

"I hate the appearance of it. It's an ugly looking thing. But I don't like to say that sometimes, because I'd have nothing without it. But I do hate the look of it. Hate it. It's so artificial looking. I'd cope with the stump, 'cos at least it's a natural part of me. But you couldn't expect a prosthesis to be as good anyways. I mean, it's an artificial thing." [BN]

"If you were to think about it, I suppose, you know, it's alien. I don't like the look of the damned thing. But you have to have it. If it's comfortable, you can walk with it, it doesn't come into it. So, I don't think I'd worry about the appearance." [MMcC]

One reason why more people were dissatisfied with aesthetic aspects of their prosthesis could be that increased use of the prosthesis in public places would mean that they had more opportunities to watch other peoples' reactions to their artificial limbs. As one man put it:

"It's when you get out more with them you notice. I hadn't been out before, I hadn't been out that much with them. When you have them a while, that's when you start to find out what the crack is with them. When I started wearing them, I thought they were great at first. But then, people started commenting at me, young friends of the family and that. They'd say 'they don't look right'. Then you'd start to think, like, if they know, what does a stranger know." [JM]

Throughout the previous interviews, it emerged that approximately half of the participants admitted to finding their artificial limb uncomfortable. Throughout the third interviews, this proportion increased to the extent that nine out of the thirteen participants rated their limb as being somewhat uncomfortable. Generally speaking, this discomfort stemmed from wearing the prosthesis for prolonged periods and from the fact that it tended to pinch the skin on the residual limb. Almost as many participants experienced difficulties with the fit of their prosthesis. Four people felt that their limbs had become too big, despite the fact that three of them were already wearing their second prosthesis. Another two participants remarked that their artificial limbs, rather than being too big, were in need of adjustment to fit more comfortably and “like a glove.” Finally, one man with cosmetic limbs was extremely unhappy with their fit because they did not sit well under his clothes and looked very unnatural. Despite having problems with the fit and comfort of the artificial limbs, the majority of participants were, again, either overall ‘very satisfied’ or ‘satisfied’ with their prosthesis. Only one man, JM, remarked that he was ‘dissatisfied’ with his cosmetic limbs, and the other two men were ‘neither satisfied nor dissatisfied’ with their artificial limb. Previously, this contradiction between ratings for satisfaction and ratings for comfort and fit were explained on the basis that many participants perceived their limbs as a part of themselves and were very grateful to have them for what they enabled them to do. This explanation may also explain the current contradiction between overall satisfaction and comfort/fit ratings. For example:

“It’s part of me, and it’s a part of my life. I mean, in the morning, now, that’s as much dressing to me, and even more so, than dressing. Because where can I go without my leg? In the morning, the first thing I do is put on my leg and my trousers. It’s a part of my life one hundred percent. That’s the way it has to be. Without it, I can’t function. I can go in a wheelchair, but by God, I’d want to be awful bad.” [BN]

A second possible reason for the observed contradiction between overall satisfaction and comfort/fit ratings could be that participants were aware that the fitting and comfort difficulties they were experiencing were, first of all, due to their stump shrinking rather than to the prosthesis itself. Recognising that the fitting difficulties

are not necessarily a 'fault' of the limb may make it easier to be content with it, since they were likely aware that they would soon be getting a new limb or limbs. In support of this, one woman said "The leg was lovely until now. It's not a fault of the leg as such that it's not fitting so great. It's my own leg that's shrinking." In addition four people who were due new artificial limbs, including SC, GD, LB and MMcC, remarked several times throughout their interview that they would be getting a new prosthesis within the next few months and that these were likely to be an improvement on their current limbs. As one man, MMcC, remarked, "My new limb is a lot easier to walk on than this one. It's a pound and a half lighter."

The above reasons explaining the contradiction between satisfaction and comfort/fit ratings for the prosthesis may also explain the finding that the majority of participants had adjusted to and accepted wearing an artificial limb. Remarks such as "I'm well used to it now", "I've got used to it now, it's a question of having to," and "very much so, I've adjusted. It's all a part of life, you've got to" were made by nine of the participants in indicating their acceptance of their artificial limb. Interestingly, the three participants who were 'dissatisfied' or 'neither satisfied nor dissatisfied' with their artificial limbs were the only three individuals who did not, at this stage, believe that they had fully adjusted to having an artificial limb. Even though they had gotten used to wearing their limbs, they had not fully adjusted to *having* to wear an artificial limb. Two of these individuals had acquired their amputations as a result of trauma.

"I suppose I'm thinking of it as a kind of quasi-friend, because it helps me walk, you know. There's times I mind it and times I don't, because I know it helps me walk. The times I don't like it, it reminds me of the accident and of what's missing. But I have got used to wearing it. I may not like it, but I've gotten used to it at least." [SC]

"I haven't got used to wearing the limb, I disagree. It's because of the make-up of it. It's awkward, and it's not normal. I can't get up and say 'Right, I'll get a cup of coffee,' because I can't get up, I'll spill this, spill that. All those things are gone, you know." [PG]

Learning to walk

Throughout the third interviews, only one person, AMcG, described herself as being ‘a little’ limited when it came to walking one hundred yards. The remaining ten participants with a functional prosthesis were not limited at all in walking this distance. In addition, six participants remarked that they would not be limited in walking half a mile, and two men, LB and SC, remarked that they would not be limited in walking a mile. In view of these self-rated limitations and abilities, only four participants remarked that they could feel themselves improving in their walking. These participants made remarks such as “I’m getting on great. I’m getting more used to it every day,” and “I’m definitely getting more mobile and more confident” in indicating their satisfaction with their rehabilitation to date. Similar to what had emerged throughout the second interviews, those participants who perceived themselves as having improved in their walking tended to walk more often on a daily basis than did those who did not think that they had improved.

The remaining participants felt that they had either disimproved in their walking, reached a ‘plateau’ in the sense that they were not getting any better in their walking, or were not improving fast enough. One man likened himself to “the marathon runner who gets to a wall.” One woman remarked:

“I’m not improving a lot. I find it a dead loss, walking. I’m no good walking long distances. I’m great around the house, and sometimes if I go shopping and that, I always have a walking stick in the back of the car, because if I’ve to walk any length, I’ve to lean on it ... I thought it was getting easier, and now I think because the leg is loose, I’m going down a bit now again. Not that much, but I just felt when I was coming up before, I seem to be going back a bit.” [BN]

These individuals did not manage to practise walking on a daily basis. Some people did not want to push themselves too far for fear of “encouraging more pain.” Other people simply could not find the time, energy, or motivation to practice. As one man said “when you get home from work, you’re not really in the mood for going for a swim or going for a walk or anything like that.”

Regardless of whether participants noted improvements or disimprovements in their walking, everyone faced obstacles in learning to walk. Similar to that found throughout the first two interviews, a fear of falling and nervousness in walking was prevalent. At this stage of the study, only one man had fallen within the last six months. This man, FF, did not have a functional prosthesis and had gotten “a few right good bangs around the house” while walking on his crutches. Fortunately, he had managed to fall on his intact limb and, therefore, had not injured himself any further. Despite the fact that only one man had fallen, six participants remarked that they were continuously afraid of falling. Similar to that found in the previous interviews, this fear of falling may have inhibited their progress on the prosthesis. For example, AMcG, who had fallen twice shortly after returning home from the rehabilitation hospital, still felt nervous when using her prosthesis. In the six months since the previous interview, she had only been outside her house to practice walking a total of five times. Furthermore, she was the only participant who, at this stage, perceived herself as being somewhat limited in walking five hundred yards. She remarked:

“I’m still nervous of falling, yeah. I don’t like to walk too far, now. The neighbours invited me in next door for a few drinks, but I was too nervous to go. I didn’t want the drink to be going to my head and I’d fall, you know.”

[AMcG]

The other six participants who were nervous of falling did not appear to be as limited as AMcG in their walking and rehabilitation. However, their fear of falling may have held some of them back, to some extent. As one man put it:

“You’re not as confident at doing things as you were, of course you’re not. Even walking, you’re afraid you’re going to slip on the roads if the ground is wet and things like that. You’re just more cautious. You’re a little bit curtailed.”[MMcC]

In addition to falling and being afraid of falling, participants faced other obstacles in practicing on their prosthesis and learning to walk. Similar to that found previously,

these obstacles included bad weather, uneven ground, walking on hills, and being in a crowd. For example:

“Even now, I hate being in crowds and things like that, because I don’t know where the leg is. I can trip over things and stuff like that. And just trying to manoeuvre it. I can’t twist on the ankle anymore, because it’s rigid.” [SC]

Another obstacle that some people had to face in learning to walk was overcoming health problems that interfered with their rehabilitation process. One man, FF, had osteoarthritis in his intact knee and felt that this could be a problem in learning to use his prosthesis. Another man, GD, had undergone a kidney transplant two years previously and was limited in engaging in strenuous work as a result. Two participants, PG and NK, faced considerable difficulties as a result of being visually impaired. PG also faced problems in his hip and with his weight. For example:

“The side effects of the accident, the sight and everything else are a big challenge as well. I could probably, maybe, walk along this room, and do all this kind of thing, but my eyes are going to play a big part in it, and maybe my hip down the road is going to play a big part in it. I often think ‘Okay, next week, I’m going to start on Monday, and I’m going to train three or four times a week.’ But I’m often afraid, am I going to cause fierce harm to my hip, am I going to cause harm to my hernias.” [PG]

Psychosocial Sequelae

Body-Schema and Body Image Changes

Throughout the second interviews, it was found that the majority of participants did not experience particularly high levels body-image self-consciousness, while six people experienced some embarrassment or self-consciousness as a result of having an amputation. Throughout the third interviews, it was found that the number of people with body-image self-consciousness increased to the extent that that seven people indicated experiencing some self-consciousness, a finding which was supported by their scores on the ABIS in that all of them scored above the mean of 24.

At this stage, therefore, those with no body-image self-consciousness were in a minority. One man explained his absence of consciousness as follows:

“I wouldn’t really be self-conscious at all. That sort of thinking doesn’t really come into my head. I suppose if I wasn’t already married or, you know, obviously hadn’t already a relationship with my wife, and if I was younger and single, then I would possibly think it, you know. ‘Bummer’, you know ‘I’m damaged goods,’ or something like that. I can imagine that. But it doesn’t really occur to me.” [NK]

The seven participants in the study with above average body image consciousness generally felt uncomfortable in several of the following areas: they did not like the appearance of their amputated limb, did not like their prosthesis being seen by other people, would not like to go out without their prosthesis on, did not particularly like other people knowing that they had an amputation, disliked the appearance of their stump, were somewhat bothered that they did not conform to society’s idea of normal appearance, and did not like to look at their reflection in a mirror. The two people who had trauma-related amputations, PG and SC, had the highest and second highest levels of body-image anxiety, respectively, according to their ABIS scores. The remaining individuals with above average levels of body-image anxiety (in descending order of ABIS scores) were BN, MMcC, DOD, JM, and JD. They explained their self-consciousness as follows:

“I wouldn’t be in company with other people without my artificial limb. I had to go out before without them, but I’d prefer not to. When you’re in Dún Laoghaire, you don’t take any notice, because everybody’s in the same position, but in an ordinary day, now, I wouldn’t go out without it, no, if I could avoid it. I don’t particularly like my physical appearance without my prosthesis. I wouldn’t like it.” [DOD]

“I would avoid situations where my physical appearance can be evaluated by others. Most of the time. When I’m wearing the prosthesis, I don’t like to be hopping around the place. I’ll try and avoid that most of the time. If I’m static,

I'm not too bad. But I'll avoid things, take the easy way out. I suppose I don't, as I say, want to throw my weight around. I don't use the wheelchair, and I look a bit clumsy hopping about with the stick." [PG]

"I've loads of skirts, because I've never worn trousers in my life. But you see where the joint is now, if I wore a skirt down here, and there's the slightest bit of wind, my skirt's going to blow, and that's going to be showing off the joints and that. And that's what I don't want. I mean, even though everybody that I know knows that I have a leg, I don't want everybody to see that I've got a false leg. I'm not ashamed of it or anything, but it's not very nice looking." [BN]

In looking at reasons as to why some participants experienced body-image self-consciousness, while others did not, two particular explanations could be put forward. The first explanation revolves around the prosthesis and its role in providing a 'normal' body image. Unhappiness with the aesthetic aspects of the prosthesis, particularly an appearance that was perceived to be artificial or unrealistic, would mean that the prosthesis could not function properly as a means of re-establishing a 'normal' appearance. As a result, body-image self-consciousness could ensue. Throughout the course of the first two interviews, it became apparent that many participants perceived the prosthesis as a means of restoring a 'normal' body image. This finding emerged throughout the third interviews also. In fact, six of the eight individuals with body-image self-consciousness were also amongst the eight individuals who indicated that their prosthesis made them look 'normal.' Furthermore, all of those who were unhappy with the aesthetic aspects of their prosthesis were amongst the seven participants with body-image self-consciousness. For four of these individuals, not looking 'natural', 'normal' or 'realistic' enough were the main concerns. For example:

"When you look down at this, it looks like a normal leg, because that has a moulded sponge over it, which is the shape of a normal leg. So, that's what you're looking at. You can look normal. I'd like my appearance most of the time with it on. I'd look very misfit without it on, wouldn't I? When my leg is there, the prosthesis, I don't feel any different." [MMcC]

“I want to leave them as natural as I can without having to do anything with them. If they were right, I shouldn’t have to do anything with them, only wear them. They look strange. Like, people would cop on straight away ‘there’s something wrong with him.’ ...I want them sitting nice, you know, so that people don’t pass any remarks on them.” [JM]

A second explanation as to why body-image self-consciousness was only experienced by some participants revolves around the issues of phantom limb sensation, ‘forgetting’ about the amputation, and experiencing a mismatch between perceived and actual body-shape. Throughout the second interviews, an interesting distinction emerged between those individuals with above average and below-average body-image self-consciousness. Those individuals who experienced phantom limb sensation were likely to ‘forget’ that they had an amputation. Furthermore, people who perceived the whole limb as being present also experienced a sense of shock or sadness when they suddenly ‘realised’ that their limb was gone. Interestingly, almost all of the individuals who experienced this sense of shock experienced body-image self-consciousness. This observation may also explain the findings of the third interviews. Of the five individuals who experienced phantom sensation, three remarked that they got a ‘shock’ upon seeing that they had an amputation. These individuals experienced high levels of body-image self-consciousness.

“The other day, my grandson hopped on the bed, and while I knew my leg wasn’t there, I felt like pulling it up. He was actually where the leg should be, and I was very conscious of him hurting the leg. I felt like ‘he’ll hurt my leg, ‘cos my leg is there.’ ... Actually, the first time I saw a picture of myself at Christmas last year, by accident, was with my grandson. I had my trousers on, but the leg was off. I got a fright. I don’t mind looking down at it, but if I see it in the mirror, I don’t like it.” [PG]

“You’d wake up in the morning sometimes, you’d think you were only dreaming. Then you realise that they’re gone. It’s a terrible shock, and it brings it on again, maybe. You’d dream you’re after being out somewhere, working or something. And you put down your hand and you feel that they’re gone. Then

you get a shock. It doesn't happen very often, but it does happen, you know."

[JM]

"It's a shock. When I'm dressing myself in the morning, I'd say it's a shock. Because I'd say to myself 'where's my other leg?' I'm not sure how I'd rephrase that. I'm different. I know I am. I don't like the look of it, I dislike the appearance of my amputated limb. It gives me a reminder each time. It's been the same since the beginning. I can compare with it. If I'd the two limbs gone it'd be different. But with the one, it's shorter. So, you'd usually be comparing it. I have to. It's there in front of you. It's a bit of a shock still. I'm not used to it yet." [DOD]

Moreover, of the two participants who admitted to previously, rather than currently, experiencing a sense of shock when they perceived that their limb was missing, both were amongst those individuals with above average body-image self-consciousness. They remarked:

"It would be rare I would get a shock, now, when I see it. I'm never happy to see it, but I don't know if it'd be a real shock *per se*. It was a shock in the beginning. It was so new, it was almost like I didn't believe it. It was a jolt, but part of me was thinking 'ah, sure, it's not real', but it's a not a big shock anymore, really. It'd probably be a bigger jolt if I looked and I had the leg back." [SC]

"The biggest shock I ever got in my whole life, when I got the leg off, was, you see, when you go back to the ward, you're sorta half asleep, you'd think you had your two legs. When I woke up and sat up in the bed, I thought the whole bottom was gone out of the bed. I couldn't feel anything. That was the biggest shock I ever got. I'll remember that clearly 'til the day I die. But it's gotten easier." [GD]

Lifestyle Changes and Limitations

Throughout the first and second interviews, most participants were keen to stress their abilities and the activities that they could engage in, even though they recognised that they were limited in the choice of what they could do. Throughout the third interviews, some changes in this regard emerged. Although most participants continued to recognise their limitations, an emphasis on abilities substantially declined. In fact, only four participants remarked that they could still do what they wanted to do, regardless of their amputee status. The remaining nine participants admitted that because of their amputation, there were things that they could not do. Thus, similar to what had been found throughout the second interviews, over half of the participants admitted to feeling 'limited', 'frustrated', or 'handicapped' as a result of their amputation.

"I used to grow nice vegetables. So, I decided to plant some more. That's some of the frustration. I find that I can't do what I used to do. It wouldn't have cost me a thought to grab the spade and go down and set up a plot, you know, and put potatoes into it or whatever. But I couldn't, and I had to pay a fella to dig it and rake it and seed it." [MMcC]

"I don't do any work now, apart from work around the house. It inhibits me alright. I'd feel like it would inhibit me that way, you know ... I'm handicapped, that's a description. It has hampered me." [DOD]

Similar to what was observed during the second interviews, it was found that people who believed that their lives would be as good again and that they were currently being fulfilled disregarded their limitations and restrictions. Instead, they focused on what could fulfil them at the moment, the benefits of their situation, and a general belief that life would be better. For example, one participant focused on the fact that he was free from pain and that his life would be "as good and better" as a result. Another man remarked that his life would be as good again because "life's what you make it, you could still have your limbs and not get on". Another man said:

“My life is full. It’s getting fulfilled all the time. Everyday, there’s something new happening and I can cope. Compared to six months ago, I feel much stronger, and I suppose, more fulfilled with the oul’ job and that, you know.”
[MG]

On the other hand, participants who felt that their lives would never be as good again, were currently unfulfilled, or were deprived from leading a normal life, focused on their limitations as a predominant reason for this. Overall, eight people were unsure or did not think that their lives would be as good again. Similarly, six participants were unsure or did not think that their current lives were fulfilling. A focus on limitations was a strong theme running through these thoughts. For example:

“My life is not a patch on what it used to be. Life will never be the same again. Sadly. But so much good has come out of it. My life would be as good, so long as I wouldn’t have to walk there. I can still do a bit of social life, I’m still doing the same things. I can visit my family. But I couldn’t do as much housework and this, that, and the other. Yeah. But I’m limited.”

“Oh, sure, it won’t be as good. It will be good, but it’s not going to be as good. I won’t be at everybody’s beck and call like I used to be before. People, now, wouldn’t ask me to do a job, and they would have asked me before. ‘Will I come such a place?’ or ‘Will I go such a place?’ They won’t ask me now.” [LB]

“My life isn’t full, to be honest with you. To the extent that I’m not on the same level as I used to be. Maybe that’s misleading to say it isn’t full. It is full in a sense. But it’s not to the same level as it used to be. That’s what I meant. It’s as good as I’m going to get it anyway. Things that I’d like to do, climb a mountain, I’m still very keen to do that. But I know I’m not going to be able to, so maybe that’s a lack of fulfilment in a way.” [DOD]

However, even though some people did not feel that their lives would be as good or as fulfilling again, they did not appear to be overtly upset about thinking this way.

Instead, acknowledgement of these limitations was marked by overall acceptance and an indication that they were incorporated into existing lifestyles. For example:

“I couldn’t do as much housework, like. Yeah, I’m limited, but I’m happy with my life. I accept it’ll never be the same. and if I could turn the clock back, of course I’d have my leg back. But I can’t. This is life.” [BN]

Social Changes

Throughout the first and second interviews, the number of people who had reservations in talking to other people about their amputation diminished from eight to three. Throughout the present study, the same number of people showed some reluctance in talking about their limb loss. Although all three participants remarked that they did not really have a problem *per se* in discussing their amputation, one man remarked that he did not like doing so because it made him feel different from others. The other two men both felt that when strangers asked them, it was an invasion of their privacy. DOD explained his reluctance to talk about his amputation as follows:

“I don’t like bringing it up. I just want to be the same as everybody else, walking down the street and walking about the place. I probably stick out a bit more than most people that wouldn’t have it, but I wouldn’t go out of my way to discuss it or anything like that. Even the man next door to me, he’s an amputee as well, but we don’t discuss it. I wouldn’t have difficulty talking about it, but I wouldn’t like it to be the centre of attention. I’d rather talk about the weather or a match or something like that.” [DOD]

The remainder of the participants had no difficulties with people asking them about their amputation or their artificial limb or in talking about what they had gone through. In fact, many of those who had no problem talking about their amputation indicated that they would like to talk about it if it could help others. However, although most participants experienced no difficulty in talking to other people about their amputation, ten people noticed at least once instance of being treated differently by others since having their amputation. For example, three people remarked that at times, complete strangers had approached them and asked them about their limb. Two

participants had experience of others treating them in a pitying way. Two people noticed that other people were sometimes embarrassed upon discovering that they had lost a limb. Another two people had experience of others being overprotective of them or wanting to do everyday things for them. For example:

“Maybe it’s in my own mind, but I’ve heard down in the pub ‘Oh, Jaysus, I heard MMcC had his leg off.’ I see fellas in the pub, you know, I’ve gone in there initially ‘Oh Jesus,’ you know ‘the poor so and so.’ I don’t want to be felt sorry for. They weren’t making an issue out of it, but I don’t want anybody giving me a sympathetic look or a sympathetic glance. I’m the same as I was before, but people are inclined to treat you differently because you’re slightly incapacitated or inhibited or whatever.” [MMcC]

“There was a young lad in work, there, last week in the canteen. And he said to me ‘Sir, do you want a bowl of soup? Did you have an accident? How did you hurt your leg?’ And I said ‘Well, I only wish. I’ve no leg.’ Well, I knew the poor fella felt like going through the ground. I suppose I felt I was making a big deal of it. Here’s me. I’ve no leg. I just didn’t break my leg playing football. It was an awful stupid thing to do, really. And I’ve done it once or twice. It embarrasses them as well.” [PG]

Only five people perceived these behaviours as being treated as though they were ‘disabled,’ and the majority of people were not particularly concerned or upset about being treated this way. In fact, similar to what had been found throughout the second interviews, every participant who noted that others were treating them differently in the sense of doing things for them felt that this was done out of kindness only. One man remarked that he was “delighted” to be treated in such a way. Another man, DOD remarked:

“It gives me a good feeling for people, rather than for myself. It’s nice to see that happening to you, especially young people that would say it to you. For myself, I don’t mind. I find it amusing at times, because that would have been my position prior to this, and I’d be thinking ‘I wonder what did people think of

me when I was doing that?’ Were they dying to tell me to shag off or something like that. But it amuses me. And it’s great to see, there are good people anyway.” [DOD]

In addition to being treated differently by others, many participants experienced difficulties in getting about socially. Similar to what had been found throughout the second interviews, half of the participants admitted that accessibility problems restricted them in visiting friends. As a result of these problems, four people noted that they were also limited in maintaining their friendships. One man remarked that he could no longer “dash into town on impulse to meet friends”. Another man, MMcC, indicated that he felt somewhat isolated since he had stopped socialising in his local pub. He remarked:

“I haven’t been to the pub in two months. It’s too awkward getting there and back, and she’s [i.e. his wife] not happy with it. It’d be only upsetting her, you know. She says “I’ll go down and get you a couple of cans of beer if you want it.” It’s not the same in the house. And then, if you’re not going down to the local, you miss an awful lot of tit-bits and that sort of thing. So, for that reason, I lost touch with it. I’ve lost touch with people there, now, because it’s a good two months since I was down there.” [MMcC]

In addition to being somewhat limited in visiting and maintaining friendships, eleven participants remarked that they felt quite dependent on others since their amputation. In the first and second interviews, this feeling of dependence on others was associated with feeling like a burden in eleven and five individuals, respectively. Six months later, however, it was found that only three people continued to feel like a burden on others.

During the first and second interviews, it had been found that although almost everyone indicated that they still enjoyed going out socially since having their amputation, several people admitted that they sometimes avoided interacting with others because of feeling dependent or a burden. Throughout the third interviews, the number of individuals who enjoyed going out socially had reduced to just six

participants. Of these individuals, one woman remarked that her time was so “taken up” that she only came home to “go to bed.” Similarly, one man remarked that he experienced no limitations in going to pubs and restaurants and that he “looked forward to it” regularly.

On the other hand, seven participants had some reservations in going out and interacting with other people. For some, feelings of being a burden and embarrassment meant that they sometimes avoided going out socially. Other participants avoided interacting with others because of problems with accessibility and awkwardness.

“In certain aspects, I would avoid interacting with others, yeah. Location, I suppose, would be the one thing, to get to a place. Or the facilities that would be there, you know, if there’s a downstairs bathroom or an upstairs bathroom. If it’s upstairs, I might find a reason not to go. I have said ‘no’ to going to places. Like, people would say ‘Do you want to me in T.?’ And I’d say ‘I’m doing something.’ That’d be my reason. I mightn’t be doing something, it’s just the inconvenience of getting there and one thing or another, you know.” [DOD]

“I would avoid situations, yeah. When I’m wearing the prosthesis, I don’t like to be hopping around the place. I’ll try and avoid that most of the time. At the wedding I was at, I didn’t get up that much really. Now, I’ll admit, it was the particular hall that was awkward in that we were sitting at the back of the hall. At the previous function, I got up and danced, but I didn’t at this one. I would avoid it. And I won’t go to that many matches, because it’s too awkward, you know, it’s extremely awkward. I’m reluctant to go out at the moment. I am, yeah. I tried it at the start, but I was full of beans at the start. But it wasn’t easy, and I wasn’t really enjoying it all that much.” [PG]

For the first time, it was observed that these difficulties in getting about socially induced feelings of embarrassment and social self-consciousness in three participants. One man explained why he felt this way:

“I just started to feel inadequate in the pub. Felt that people would look at you, like as if you were sitting in a wheelchair, they don’t look at you, they just look at the chair. That feeling began to creep on me, you know. So, I just stopped going. It wasn’t like that at the very start, but then after a while, my wife would be saying ‘I wish to God you wouldn’t be driving that car.’ She would offer to drive me around in her car, she’s quite agreeable to that. But I don’t want to be seen in front of the pub, creeping out of that little car instead of pulling up in my own.” [MMcC]

Identity

Throughout the first two interviews, the majority of participants indicated that they felt like they were the same person they had been prior to their amputation. These respondents were more likely to disregard their physical and social restrictions in answering this question than were participants who did not feel like the same person. Throughout the third interviews, it emerged that rather than the majority of participants feeling like they were the same person, only five people perceived themselves as being the same. Of these five, none mentioned their restrictions or disabilities when concluding that they felt the same.

On the other hand, four participants felt that they were not the same person they had been prior to their amputation, and another four gave a mixed response to this question in the sense that in some ways they were the same and in other ways they were different. Previously, it was found that physical restrictions were the most important factor in thinking that one was not the same person. At this stage of the study, however, consideration of personality became equally as important in concluding that identity changes had occurred. For example:

“I’m sick telling people, this part of me is the same as it ever was. I’ve half a leg missing, but they seem to think because I’m disabled now, that I’m not able to do the work I could do before. Even though I’m still me. They didn’t touch my brain. They didn’t touch my hands. I am the same person. Mentally, I’m a better person, but physically I’m not.” [BN]

“I suppose I’m the same person. I don’t think my personality has changed. Whether my attitude has changed, I don’t know. Ah, I wouldn’t be the same. In a way, I wouldn’t be the same. I hope I am here. I am with the lads here, now. I’ve no problem here, now, the house is running smoothly. But I just can’t do some things. I suppose I am the same person. I hope I am anyway.” [LB]

“I wouldn’t be the same person. No. I suppose I would have been much more happy-go-lucky, get on with it, bit of crack, meet you Friday for a few pints. And even though they’re giving me the okay to go in, I won’t go to that many matches, because it’s too awkward. It’s extremely awkward, like.” [PG]

“I’m not the same, I disagree. I don’t know if I’m better, stronger, weaker, whatever. But I’m not the same, I don’t think. I think I’ve gotten stronger and weaker all at the same time, like. It’s weird. Because the pain doesn’t really bug me too much anymore. It bugs me, but I’m not whining about it. But emotionally, I’m a bit more fragile.” [SC]

Similar to what was observed in the previous two interviews, people who did not feel like the same person were more likely to consider themselves as ‘disabled.’ In fact, of the seven participants who perceived themselves as ‘disabled’, five felt that they were no longer the same person they had been. Interestingly, the notion of how to ‘categorise’ or phrase their status as ‘disabled’ was raised by two participants who considered themselves as disabled and by one participant who did not. For example:

“Now I’m the handicapped guy. I know one other person without a leg and that’s it. When I do think of it, I would think of myself as handicapped, yeah ... but I usually don’t think of the word ‘handicapped’. I think of the word ‘crippled’. It’s more negative, you know. It’s an older word, whereas handicapped would be more politically correct. I’ll say ‘crippled’, I’ll think that to me, but if I was talking to others, I might say handicapped. If I had to choose, I’d probably say handicapped, because crippled does sound worse.” [SC]

“I don’t think of myself as disabled, no. What are we categorised at all as amputees? What are we? ... People would treat me as disabled, they’d let me first out the door and they’d be kind that way. That’s all. But I don’t feel disabled at all, no, no.” [MG]

Other worries

In addition to having to cope with amputation-related issues and the psychosocial changes that occurred following the amputation, many participants had to cope with other non amputation-related illnesses and health worries. Overall, ten participants experienced concurrent medical problems, including blood pressure, being overweight, diabetes, kidney problems, heart complaints, arthritis, visual impairment, stomach problems, and problems with the intact limb. Two people indicated that they continued to worry about their intact leg. One man discussed such worries:

“I lost the power of my other leg about eight weeks ago. I didn’t even realise what was going on, but my consultant said to me ‘I never saw a man so traumatised or surprised. Because you had come through the other one so well.’ I said ‘that was a different story.’ If the second one went, I was threatened. That was the end of the world. It really was. Because I couldn’t have people tending me hand and foot like I was a baby. I couldn’t live with that. Definitely, no. I doubt very much if I’d cope with that.” [MMcC]

Despite the fact that most participants had at least one medical complaint, only one man rated his current health as ‘fair’, one man rated his health as ‘fair to good’ and the remaining participants rated their health as either ‘good’ or ‘very good.’ Moreover, only four participants felt that their health problems interfered to some extent with their rehabilitation process.

Two participants continued to worry about the health and well-being of their wives. One man, PG, was worried about the strain his wife was under as a result of his amputation and another man, MMcC, was still anxious about wife’s physical health. In addition to these worries, a small number of participants had to cope with managing the financial and practical implications of their amputation. Previously, six

people had remarked that they wished to return to work. Of this six, two people had returned to work full-time and two people had returned to part-time work. One man had returned to work but retired some weeks later due to concerns about his intact limb, and one man continued to be unemployed. Interestingly, one participant who had previously thought that he would be unable to return to work went back to his job because he felt strong enough to do so. Regardless of whether they were unemployed or in full-time or part-time work, three participants indicated some concern over their financial status. One man, SC, in particular, was very uncomfortable about having to accept unemployment benefits and remarked that he should be “depending on” himself rather than on the State. In general, these financial difficulties were closely tied up with experiences of inefficient bureaucracy. Again, proving that one had an amputation to government officials was a matter of annoyance and frustration to some people. As one man remarked:

“One letter should do me, from Beaumont Hospital or from Dún Laoghaire. ‘This man has lost his two limbs.’ That should be the end of it. Send a copy off to whom it concerns. If they want to see me, then they can come back here. But they keep sending the form back, and sending it back. They make a mistake and then send it back to you. That’s all bull.”

EMOTIONAL WELL-BEING

Throughout the first interviews, three participants had mild anxiety symptoms according to their scores on the HADS-A. Although a number of people admitted to feeling somewhat ‘down’ shortly after their amputation, the overall mood was one of optimism during the rehabilitation period and none of the participants appeared to be particularly anxious or depressed, a finding which was supported by their score on the HADS. Throughout the second interviews, only one participant appeared to be experiencing a grief-like reaction to the loss of his limb, and his HADS scores indicated that he showed moderate symptoms of anxiety and mild depressive symptoms. Throughout the third interviews, the largest number of people to date had elevated scores on the HADS-A and HADS-D. In fact, three participants, PG, SC and DOD showed either mild or moderate anxiety symptoms and scored 12, 9, and 9

respectively on the HADS-A. In addition, two participants, PG and MMcC showed mild depressive symptoms and scored 9 and 8, respectively, on the HADS-D.

Analyses of these participants' interviews indicated that they tended to be experiencing a range of psychosocial difficulties at the time of this interview. All of these four individuals had above average levels of body-image anxiety according to their ABIS scores. In addition, all of them avoided interacting with other people at times because of feeling awkward or embarrassed about other peoples' reactions to them. Moreover, all of them believed that their lives were currently not full and that their lives would never be as good again. Furthermore, none felt like they were the same person they had been prior to their amputation, and in each case, personality, rather than physical limitations, was given as a reason for feeling different. Finally, two of these participants, SC and DOD, were the only two individuals in the study to experience discomforting stump pain that interfered, moderately, with their daily activities.

In talking about their current emotional well-being, MMcC and PG did admit to sometimes feeling 'down'. PG sometimes felt fed up or irritable with his family and often felt down because everything he tried to do was a "chore." MMcC, who had recently retired from work because he thought that he had been putting too much strain on his other leg, remarked that he missed being at work and chatting with his colleagues. Both men described feeling 'down' as follows:

"I don't want to say to myself 'I'm bloody sick of sitting here. I'm going to bed.' Or 'I'm going down to the pub, I'm going to get stoned drunk.' That's not going to improve matters, so I take it as it comes. There are bad days, but not that bad. You get an odd one. You just can't help it. You get up in the morning and you say to yourself 'Oh, another day.'"

"I'm kind of up and down ... some days you're sitting at home and you can't get up to make a cup of tea. It's awkward. And then you're out, and it's awkward. And you're awkward looking and it's awkward to get around. I've ups and downs still. I don't know why, but I was pissed off at home last night. I

don't know why. I do look forward to things, but then when it comes to the time to go out, I say to myself 'God, I don't want to move from here. We'll have to find a seat ...' Everything is a chore, you know. I still feel that way. I was at home the other day and I lost it with the young lad. And I felt down then for the day after getting on to him." [PG]

The three participants with elevated HADS-A scores also talked about feeling anxious or nervous at times. PG remarked that prior to his amputation, he tended to have been a nervous or anxious person anyway. Similarly, DOD indicated that his personality would have been somewhat anxious prior to his amputation and that he generally expected the worst to happen so that he would be prepared. SC's anxiety stemmed from thinking about his future, his working life, and being nervous about having another accident. He often felt 'down' about not having a job and was often worried about being in another accident. He remarked:

"I'm not working yet, I'm still trying to get artwork jobs, but I'm not trying as hard as I could. I'm not motivated for some reason. But it feels like it's hopeless. Why am I even doing it, like? It might just go down to depression a bit, like ... So, I'm a bit nervous about the future, because some of it's really annoying. And I'm worried about the leg and stuff like that. I'm a bit nervous, you know. Even when I'm riding the mountain bike and enjoying it, I'm always nervous about losing the leg off the pedal or crashing. I always think if I'm on the bike, I'm going to get under a car. All sorts of stuff I didn't used to worry about. I used to be very naïve, or maybe just normal, about accidents. You know, where you didn't used to worry about them. But I think about having an accident once again, another accident, fairly frequently."

Despite the fact that only four participants scored above the cut-off points for clinical anxiety and/or depression according to their HADS-A and HADS-D scores, another two participants also admitted that they sometimes felt 'down' or 'wound up'. Analyses of these participants' interviews indicated mixed positive and negative reactions to the psychosocial issues they were facing. For example, BN, who had an above average score of 5 on the HADS-A, but an average score of 2 on the HADS-D,

experienced some body-image self-consciousness since her amputation. Although she believed that her current life was full and that she was not deprived from leading a normal life, she did think that her life could never be as good as it had been prior to her amputation. Furthermore, she now perceived herself as 'disabled' and thought that even though her personality was the same as it had been, she was not, physically, the same person. Similar to BN, JM also experienced body-image self-consciousness. However, contrary to what BN believed, he did not think that he was currently leading a full life. Despite this, he did not think that he was being deprived from leading a normal life, and he believed that his life would be as good again. Furthermore, he continued to feel like he was the same person he had been prior to his amputation and did not consider himself as 'disabled.' JM's HADS-A and HADS-D scores were below average, at 2 and 1, respectively. Both of these participants admitted to feeling some moments of sadness or anxiety. JM, for example, remarked that "there's good days and bad days, from time to time." Similarly, BN admitted "There is odd days when you think 'Oh Christ, am I going to make it? This is an awful way to be living.' In moments, sometimes, you'd think that."

Interestingly, however, both of these participants remarked that compared to how they had previously felt in terms of emotional well-being, they were much happier and more content. JM compared his current emotional well-being with how he had felt six months previously and indicated that he felt much better. BN compared her current emotional state to how it had been while she was married and living with her husband and how it had been shortly after her amputation when she hadn't got her prosthesis. She remarked:

"I can honestly say, since I got myself sorted after the trauma of this thing, since just about I got the car and before that, I have peace of mind now. And it's the first time in thirty-four years of marriage, because I was in a rotten marriage. And I'm so happy today, it's unbelievable. I haven't got the worry that I had at one time. I could never envisage myself being this happy. I'm getting better and better every day. And every day, I look forward now to getting up in the morning, whereas before I got the leg, I couldn't care if I never got up. I'd get up and I'd put on a brave face, but what was I getting up for? I've been very

happy, now, getting there, since last June, since I got my first leg. Because after the depression of six months in the wheelchair, anything was better. I've such peace of mind and I'm so happy with myself, that if I won the Lottery tonight, it wouldn't make me any happier." [BN]

The remaining seven participants did not indicate feeling 'down' to any great extent. Analyses of their interviews indicated that the majority tended to respond positively to the psychosocial issues they faced. Six people felt that they were currently leading a full life, and five of them (AMcG, FF, MG, MW, NK) believed that their lives would be as good again. In addition, four people (AMcG, FF, MW, NK) believed that they were the same person or somewhat the same person (LB) they had been prior to their amputation, and four (FF, MG, MW, NK) also remarked that they did not perceive themselves as 'disabled.' One man, LB, remarked "thank God, I don't suffer from depression, I don't." Another participant, AMcG, noted that she was "never the type to get down, I don't think that way." NK responded in a similar way. He remarked that even though he would feel down on very rare occasions, this mood never stayed:

"I'd say my wife would suffer more of that [i.e. depression] than I would, you know. I think that's very much a personality thing. I mean, I never was a person that could. I just cannot remain depressed. If I got really depressed in the past, before I lost my sight or my limbs, I'd just take myself off to bed for the night, and get up the next morning, feeling fine. And that would happen very, very rarely. And it's the same with this. I don't have an awful lot of time for self-pity. And I don't really suffer it very well with other people ... it's just the way I am, I don't really get depressed and stay depressed." [NK]

COPING WITH AMPUTATION SEQUELAE

At this stage of their rehabilitation process, participants were still faced with many psychosocial changes that had occurred following their amputation. Although most participants experienced only 'mild' phantom and stump pain, most experienced some level of discomfort with their prosthesis. At this stage, over half of the participants were unhappy with the progress they had made in walking. Furthermore, levels of

body-image anxiety and social-self consciousness appeared to have increased. Although most participants did not appear to be particularly anxious or depressed as a result of these changes that had occurred, four people had elevated scores on either the HADS-A, HADS-D, or both, and three of these participants admitted to feeling down or anxious at times during their interview. Another two participants remarked that they sometimes felt down, even though they generally felt much better emotionally than they had before. Finally, seven participants did not appear to be particularly anxious and depressed according to either their HADS scores or their responses to the psychosocial issues they were facing.

In looking at these psychosocial issues, it is interesting to consider what coping mechanisms were employed by participants in helping them address and overcome these challenges. Furthermore, it is interesting to assess whether those individuals with depressive or anxiety symptoms tended to have different coping mechanisms than did those who did not appear particularly depressed or anxious.

One reason as to why the majority of participants had high levels of emotional-well-being could be because their appraisals of the amputation were generally of Acceptance and of the attitude that "it could be worse." Even after these appraisals, a wide variety of coping mechanisms were used by participants in coping with the physical and psychological consequences of their amputation. Similar to what was observed throughout the first interviews, Amputation-Related Appraisals emerged that revolved around Acceptance, Mixed Feelings and Regret, and the thought that "It could be worse." Generally speaking, participants put their amputation into such a context through comparing themselves with others perceived to be in more challenging or difficult circumstances, seeing something beneficial to have occurred as a result of the amputation, reflecting on their age when perceiving the implications of their limb loss, and comparing their amputation with other losses or stressors experienced in their lives. Despite the fact that the amputation was generally perceived within the context of "it could be worse," some coping mechanisms were required to help deal with the emotional and physical consequences of the limb loss. These coping mechanisms included Cognitive Approach and Avoidance, Behavioural Approach and Avoidance, and Emotional Approach and Avoidance techniques.

Appraisals

Acceptance

Throughout the first and second interviews, the predominant reaction to having an amputation was one of Acceptance. However, throughout the second interviews, these non-effortful feelings of acceptance were also accompanied, in some cases, by an increased number of mixed feelings, regret, and blame. Throughout the third interviews, it was found that only half of the participants, rather than the majority of participants, indicated that they Accepted their limb loss. For example:

“I’ve accepted it. I accepted it from day one. I’ve totally accepted it. I never cried over that leg. I just cried at the frustration of not being able to do things.”

[BN]

“You have to try and accept it as quickly as possible, because whatever is amputated, it’s not going to grow back. And there is life after an amputation ... I’m so long, now, like this. I’m a year. It’s me. This is me. If you’re sick or you get a cut, it heals, and you know it will be alright down the road. Or if you break your leg, it’ll heal. Mine won’t. It won’t come back. So, I get along, and I work on the prosthesis, and I hope.” [PG]

Mixed Feelings, Attributions, and Conflicts

Instead of the predominant appraisal to amputation being one of Acceptance, this reaction was now shared equally with mixed feelings as some participants appeared to regret having had the amputation and others appeared to blame their amputation on the failings of doctors or health professionals. For example:

“If they had of given me a chance to think about it, I probably wouldn’t have got off that leg. I remember the nurse saying to me ‘I wouldn’t agree to that, you’d want more time to think about it.’ I didn’t know what to think ... I wouldn’t have got it off if I knew as much as I do now. I often think about that, yeah. Maybe if they had waited. But they know, though. What would I know?”

But I think about it a lot. I walked into the hospital first, there wasn't a bother on me. And to come out like that. Sometimes it annoys me, alright." [GD]

"It's very easy to be wise in hindsight, but I definitely feel that the doctor I was attending here, he was treating me for arthritis up to the day before I went into the hospital. And even though I had mentioned it to him 'Could it be a circulation problem?', he said 'No way.' I think if I was treated for circulation problems, I would never have had an amputation." [FF]

In addition to the fact that some people appeared to show regret for having had an amputation, as well as a sense of blame toward their doctors, as many as six people were struggling with the concept of "acceptance" and "getting over" the limb loss. Thus, half of the participants indicated that were not quite over having lost their limb(s) and that they had not dealt successfully with their limb loss. For example,

"I wouldn't say I've dealt successfully with it. No, I wouldn't. I've dealt with it, if I may put it like that. But I don't think I've been very successful with it. I'm too impatient. I don't know. I suppose it is successful, the way I dealt with it. And I'll have to get over losing the limb. It affects your life, but I will get over it, yeah. I have to get over losing the limb. I know that." [DOD]

"I suppose you never will get over losing your limbs. It's hard to accept, but I've got over it. It's just hard to get over it. It's hard to get over it, losing any limbs. It's hard to get over, you know." [JM]

Two men explained why one could never get over losing a limb. According to SC, getting over the limb would incorrectly imply that he no longer cared about his leg. According to PG, getting over the limb could never happen. All that one could hope for would be to get on with life and readjust to living without the limb. Thus, accepting and adjusting to the limb loss did not mean that one would ever 'get over' losing a limb. For example:

“I don’t know if I’ll get over it. I hope I do. I hope I get over it. I might get over it. There’s different ways of getting over it. I would think that getting over it would mean I didn’t care, whereas I’ll always care. I have healed up and I’ve carried on with life, but I don’t feel like I’ve done what I could have done.”

[SC]

“If I was to advise people, I’d say it’s always new. I don’t think you’ll ever be an old amputee. I think of advice that somebody gave me in rehab one day. I met a guy who had an accident in 1977. He said ‘you never get over it, but you get on with it.’ From the point of view of giving advice, then, I’d say, you may not get over it. It is foolish to think you will get over losing a limb. But you get on with it. You try and readjust.” [PG]

Interestingly, the two participants who had experienced no emotional reaction upon being told that they had a limb amputated continued to feel this way. MG remarked that it “never really hit” him at all. Similarly, PG said:

“I don’t know if I can ever pinpoint when I knew about it. I can’t really, you know. I can’t remember getting a shock. The nearest I got to it was when I reported for assessment at rehab. Then I said ‘God, I have a problem. This is a really serious place to be going to.’ But I cannot remember any reaction to it.”

[PG]

Solace and Making Comparisons

One way in which participants appraised their amputation was in a context of “it could be worse.” The conclusion that things could be worse was arrived at through finding solace in their situation, for example, by making such statements as “At least I still have ...” and by comparing their situation with that of other people perceived to be in more challenging situations. In appraising the fact that they had had an amputation, three participants focused on the fact that they were still alive and expressed gratitude for what they did have. Moreover, in appraising the impact of their limitations and restrictions on their lifestyles, some participants reasoned that engaging in these activities would sometimes have been difficult or uncomfortable anyway. For example:

“I did, I suppose I do at times, ask ‘why did this have to happen to me?’ Sure, I suppose I have to accept it now. And that’s that. These things happen, must happen, to people. You know, I could be dead if the clot had to move. I’m lucky to be alive, I am, yeah.” [LB]

“At my age, I’ve a lot going for me. I’ve a wife, a nurse, and all the family were reared. And everything outside was well taken care of. Things kinda kept going. Cancer, stroke, I would think any of them would be terrible, would be a calamity. A stroke, I think, is the worst. So, losing a limb is not as bad.” [FF]

“Well, I’ll tell you, I’d rather it happened to me than it happened to anybody else in the house. If it happened to any of the children, you know. That’d be worse. A whole lot worse.” [JM]

“As regards giving up work, I didn’t look at the downside that much. I simply said ‘Well, at least I don’t have to get up in the mornings at five o’clock, go out and scrape off the ice off your car, and maybe slip in the process.’” [MMcC]

Another way in which participants appraised their situation within a context of “it could be worse” was by comparing their situation with that of other people they perceived to be in more difficult or challenging situations. As many as seven people compared themselves to others with disabilities they perceived as being worse. In addition, two participants compared their situation to that of younger people. For example:

“The people down in the wheelchair centre, they’ve got MS, Parkinson’s Disease. And my heart’s broke for them ... And do you know, I find myself to this day when I go down there, I’m not a great believer but I say ‘Well, if there’s a God above, I’m happy and I’m delighted that I’ve only half a leg missing.’ When I’ve seen what I’ve seen in rehab and then these poor devil’s here, I think I’m very fortunate just to have lost a leg.” [BN]

“I always think there’s someone worse off. Oh definitely. I do think of one chap. He’s gone to a home now. He’s in a wheelchair, and he won’t come out of it. And he’s only in his thirties. If I was in my thirties and that happened to me, I suppose I wouldn’t know what way I’d feel.” [LB]

In support of the aforementioned argument that such social comparisons are not coping mechanisms [But see Cognitive Approach – Social Comparisons, this chapter] because they are not effortful and used to enhance psychological well-being, some participants noted that making such comparisons had no effect on their emotional well-being. For example:

“I do think there’s someone else worse out there. I do. It doesn’t make any difference. There is, no matter how bad you are, or where you are, isn’t there always someone worse off. It doesn’t make you feel better. You just have more sympathy for the person. It doesn’t make any difference.” [GD]

“I do think there’s someone else worse off, but it never dawns on me, really. There is of course. But I’d never make it a consolation that there’s people worse off. You’d just think about it and that’s it.” [MG]

Another comparison that four participants made in putting their situation into a context of ‘it could be worse ...’ was between their current and pre-amputation emotional and psychosocial functioning. For example, one man reasoned that he had always had unfulfilled goals prior to his amputation and that not having the limb may not have made any difference to whether these goals were achieved or not. Two men reasoned that their emotional functioning was similar to how it had been prior to their amputation. Finally, one man concluded that his current body-image self-consciousness was similar to how it has always been. For example:

“There’s always going to be something out there that I want to do but can’t. But then again, when I was in good form, there were things I’d like to do, like cruise around the world. I wouldn’t be able to do that. So, these are goals that you can

dream of anyway. Having the leg and not having it doesn't mean I could have achieved it anyway." [DOD]

"I do find myself wound up alright. There's no point in telling you lies. There's good days and bad days. But there's people telling me that they're walking around and they have them themselves, that's what they tell me. And before, I would have good days and bad days. Yeah. I had them before." [JM]

"I always felt self-conscious. This doesn't make me feel any more so. I felt that way before that, you know. When we used to go to dances years ago, God, we had no courage. Absolutely none." [MMcC]

Seeing Benefits

Another way in which eleven participants appraised their amputation within a context of "It could be worse ..." was by seeing something beneficial to have occurred as a result of having lost a limb. For example, five people remarked that they were now free from pain, two participants thought that their artificial limb was better in terms of function than their amputated limb had been, two people felt that they had become more confident in themselves and found out more about themselves, two people believed that their quality of life had improved, two people thought that they had made new friends since losing their limb, and two people added that the financial benefits that accrued to them as a result of having had an amputation were somewhat beneficial. For example:

"I got rid of the pain. That means a lot. Got rid of the pain. Jeez, before they got rid of the pain, oh, when I think back. I told nobody about it. The pain was something else. I was walking that floor for a month before I went into hospital. I'd sneak out there, walk out there. I didn't know what was wrong with me. It's like winning the Lotto, as I told somebody, getting them off. The pain was big time. Because I told them in Beaumont, if they didn't take them off, I'd take them off myself. That's one good thing about it." [JM]

"I found me. I got out of a bad marriage. I've realised that life with an amputation could be a whole lot worse. But for me, it's been good. I've got

things now that I never had before the amputation. So much good has come out of it. I've found out so much about life. About myself. What I want out of life. I've got more confidence. I know what I'll be able to do out of life. And I'm going to aim for it ... and I can honestly say, since I got myself sorted after the trauma of this, that I have peace of mind now. And it's the first time in thirty-four years of marriage." [BN]

"Definitely, you're less stressed. You're relieved of the pressure, because running a business with a lot of different irons in the fire, and a hard day at labour, and wondering are you doing the right thing, it puts you under a fair amount of stress. Now, I'd say it's a lot less stressful. A lot less."

Interestingly, one man, SC, who remarked that having an amputation afforded him financial benefits, remarked that "the bad stuff would outweigh the good stuff." [FF]

Age Reflections

Another way in which participants appraised their amputation within a context of "It could be worse ..." was by reasoning that its physical and psychological impact was minimal due to the fact that they were getting older anyway. Previously, thirteen participants had used this strategy in appraising the physical limitations they were facing as a result of their amputation. At this stage, a total of seven participants appraised their limitations or their body-image changes in this way. Interestingly, objective age was not important in making such appraisals, as one of the youngest participants in this study, NK, appraised his body-image changes in this way.

"I don't know if I'd ever be able to run. I never tried it. I don't know. It mightn't be the leg that'd stop me. It might be old age that'd stop you running, you know. Old age has a lot to do with it. You'll find that yourself too, in years to come. Things you was interested in years ago, sports and things, you wouldn't be interested in now, one way or the other, you know." [GD]

"I know there's no blonde or brunette going to be looking at me now, not at my age. So, I don't worry about my appearance. I'd take as much care, though. I'd be clean and that going out." [LB]

“I wouldn’t really be self-conscious at all. That sort of thinking doesn’t really come into my head. I suppose if I wasn’t already married or, you know, obviously hadn’t already a relationship with my wife, and if I was younger and single, then I would possibly think it, you know. ‘Bummer’, you know ‘I’m damaged goods,’ or something like that. I can imagine that. But it doesn’t really occur to me.” [NK]

Previous Loss Reflections

Another way in which two people appraised their amputation within a context of “It could be worse ...” was by comparing its impact with the impact of previous stressors or traumas. GD remarked that the uncertainties and difficulties inherent in being a farmer meant that he was often more concerned about this aspect of his life, rather than his amputation. PG described how the loss of his mother’s furniture had been a bigger shock to him than his amputation:

“I don’t know if I can ever pinpoint when I knew about it. I can’t remember getting a shock ... But you know, my mother’s furniture was stolen recently, and it was very sentimental to me, and I was in a bigger shock about that than I was about my leg. Because it was sentimental. When I heard it was stolen, when I heard it was gone, I was in shock. I can’t remember being the same way about my leg, you know.” [PG]

Cognitive Approach Coping

Looking Ahead and Thinking About Problems

Throughout the first interviews, one Cognitive Approach strategy that emerged was that of ‘thinking ahead’ or ‘looking forward.’ This strategy was characterised by such thoughts as ‘I must look forward to the future,’ without formulating any concrete plans about particular obstacles or problems. Throughout the second interviews, this particular coping strategy had evolved into actively thinking ahead about particular, concrete problems that may have to be faced. Throughout the third interviews, only three participants indicated forward planning in this way. Furthermore, goal planning was not in evidence at this stage. For example:

“I do suss out in advance, if we’re going to go for a drink or whatever, I’ll make sure I know where I’m going, you know. I know in advance the hazards that are there, and things like that. I’d pick out doors first, and then pick out places and that.” [DOD]

“Obviously, in the past, where I could have went basically anywhere by bus or by train, that now takes a lot of forward planning. For example, if I’m going up to visit my parents, I’d have to ring forward to the station to make sure that the trains are coming in on the correct platform because, obviously, from the wrong platform, there’s no way of getting across without being physically carried. So, you have to do that sort of forward planning. And I can’t simply go into town with my wife and decide to jump on a bus coming home. I’ve to think and forward plan and basically use accessible taxis or else take the manual wheelchair.”[NK]

Downward and Upward Social Comparisons

During the first and second interviews, it was argued that downward social comparisons were appraisals of the situation, rather than overt coping methods, because they did not appear to be used for the purposes of maintaining psychological well-being. However, for the first time in the study, the two participants who had acquired their amputations due to trauma indicated that they *may* have been deliberately using social comparisons as a coping mechanism in that doing so helped them to bolster their self-esteem and emotions.

“It helps a little bit, to think that there are others worse off. When I went up to the rehab, I took the bottom part of my trousers off, because I wanted to walk in the hospital, because there was people just starting off, so they’re worse off, you know. They might have lost both legs, or just lost it, so they’re traumatised. And I wanted to walk around and show them ‘look at me, I have a prosthetic leg, and I’m just cruising around.’ And I made a point of minimising the effort. So, knowing there’s people worse off helps me, because I’m thinking ‘Maybe I can give them a hand’ or even walk up and say ‘How are you doing?’ and ‘Don’t worry. It’ll be alright.’ It makes you feel a bit more powerful.”[SC]

“I want to try and be positive. You see other people that are worse off than you ... I wouldn't think I'd be denying the seriousness of what happened. I think it's always there. Yes it is serious, and it's not that it's a consolation, but you do almost console yourself. You say 'there's somebody worse than me'. Or 'it could have been worse for me.' In my case, I got a second chance, you know. I know lots of kids that didn't get a second chance, much younger than me. They didn't. And I suppose you go along and say 'God, it's not too bad. I'm not doing too bad, like.'” [PG]

Throughout the first and second interviews, many participants used upward comparisons when learning to walk. That is, they compared themselves with other amputees who had already rehabilitated successfully and were walking confidently on their prosthesis. Throughout this stage of the study, these comparisons were not in evidence. Although three participants did note other people's superior progress with walking, each of these participants remarked that these people fared better because they were younger, had experienced more favourable circumstances, and had below-knee amputations rather than above-knee amputations. For example:

“I was in Dún Laoghaire and I saw a guy there that came from Loughlinstown hospital. He'd had brilliant physiotherapy in Loughlinstown and he came in great shape as regards accepting the limb. And he was nearly walking with no crutch in no period. He was fantastic. But he'd told me he'd had a great physiotherapist who'd told him all the things to be done. We'd had physiotherapy, but I'd a lot of things to overcome that way. He'd a big advantage.” [MG]

“I met a man briefly in the hospital. Very briefly. He's very good on the limb. He had it done the previous year. He came in to see me after I had my amputation, and you wouldn't think there was anything wrong with him. I don't know whether he had a stick or not, even. But he was a younger man than me, now. I think it depends on where you have the amputation. If you have an amputation just above the knee, or another inch above the knee, it'll make a difference.” [LB]

At this stage of the study, it would appear that upward social comparisons were not being used as a coping strategy in maintaining motivation to walk and adapt to the prosthesis. In fact, one man went so far as to say that he disliked being upwardly compared to other people with amputations, in particular, one man with bilateral amputations who has a high-profile in Ireland as a singer and a medical doctor. For example:

“Everybody tells me about Ronan Tynan. ‘Look at him, he’s great ...’ I’m sure there are ninety-nine Ronan Tynan’s, but I’d be thinking ‘Fucking Ronan, I don’t want to hear about Ronan. This is PG. This is a whole different scenario.’ I’m different, you know. I’d be saying, ‘well, is he above-knee or below-knee’, and if you’re below-knee it’s faster to recuperate, it’s faster to learn walking, you have the bend of your knee. When you’re above-knee, it’s a whole different ball game.” [PG]

Cognitive Avoidance Coping

Not Thinking About Things

Throughout the second interviews, ten participants demonstrated at least one instance of using the Cognitive Avoidance strategy of ‘not thinking about things’ and taking things from ‘day to day’ to help cope with problems or worries that arose. Throughout the third interviews, none of the participants appeared to be taking a ‘day to day’ approach. Furthermore, only two participants used the strategy of ‘not thinking about things.’ One man, MMcC, used this strategy when considering his retirement and remarked “there was no point in dwelling on it one way or another.” Another man continued to use this coping strategy in relation to his health problems. For example:

“I worry about what limit I went to and because every organ seemingly failed. It didn’t at the time shock me because I didn’t know about it. I know about it now. I’m learning all the time. Sometimes I don’t want to learn. You know what I’m saying, about reports and that. I went last Thursday, and the guy was talking about ‘your stroke’ and I was saying ‘no, you’re talking about the wrong guy.’ This is not me. And even when we had delved into it, it wasn’t me as far as I was concerned.” [PG]

Emotional Approach Coping

Emotional Determination

One of the most common Emotional Approach strategies used by five participants was Emotional Determination. In general, this strategy is similar to Watson et al.'s (1999) "fighting spirit" and involved giving oneself a mental 'talking to' in order to maintain motivation and courage and in helping to maintain emotional well-being. For example:

"There's no use in brooding on something you're not going to improve. Because if you start that business, it's going to get worse and the quality of life will deteriorate as a result. I'm aware of that, so I'm not going to let it get me down." [MMcC]

"I really don't have an awful lot of time for self-pity, and I don't suffer it very well with other people either. I just want to get up and get on with it, you know. I usually find something to occupy myself with. And if I'm sitting and really pondering it, looking at my life and thinking 'Oh, woe is me', that's rubbish. I don't know how much longer I've got to live, and I've got to get out there and enjoy my life as best I can." [NK]

"Okay, I'm holding on. I can stand on one leg. You get on with it. You do just get on with it. I make the best with what I've got. If you lie down under it, you've got no chance. I don't think people will. I don't think people will be stupid enough to lie down under it, because it's themselves they affect. No one else. By lying down, you're hurting no one but yourself." [PG]

Emotional Social Support

Another Emotional Approach coping strategy that six participants indicated using to maintain emotional well-being was Emotional Social Support. For example:

"There is odd days when you think 'Oh Christ, am I ever going to make it? This is an awful way to be living.' In moments, sometimes. And then when you go and get dressed up, people say 'Oh, God, B., for what you've been through,

you're looking mighty.' And it just gives you a bit of courage. I don't want compliments. I don't want people to be feeling sorry for me. So long as they pass a compliment, that's nice." [BN]

"As far as my wife's concerned, I'll be running in the Olympics next year, you know. But that's the way she is. I know it's all to keep me up, I do know that. But I'm happy enough with that as well. I'll go along with it. If I say something like 'Shite, this leg of mine, will it ever get right?' I hope to God she never comes back with a negative, or I don't know what I'd do. If she comes back with 'Oh, yeah, it looks like you're fucked,' I'll really fall down." [PG]

Religion

Throughout the first two interviews, it was found that Religion was an important coping resource for five participants. Throughout the third interviews, the two participants, of the original five, who remained in this study continued to indicate that religion was an important coping mechanism for them. For example, FF, indicated how he had used prayer in order to cope with the possibility (which eventually happened) that he would have to go for another amputation to help cure an infection he had in the bone. He remarked:

"It was at the back of my mind that I might need another amputation. It was at the back of my mind all the time. But I prayed a lot, which really helped. Prayer helped me a lot. We're in a different generation now, young people don't pray as much." [FF]

Emotional Avoidance

Joking

Throughout the first two interviews, the two participants who had acquired their amputations as a result of an accident had used the Emotional Avoidance coping strategy of joking about their amputation to hide their distress from other people and to "put on a front". Throughout the third interviews, only one participant, SC, continued to use this coping strategy. He discussed his use of joking as follows:

“I went to the rehab last week [i.e. in Dún Laoghaire], it’s part of the insurance claim. The woman there told me that she saw it now and she saw it earlier when I was actually there, that I had put on a face, laughing and joking. She thought I wasn’t coming to terms with the leg, yet. I knew I was like that. I don’t like to be depressing, you know, because it’ll bring other people down as well, you know. And that makes me feel even worse. So, I’d be looking out for myself. I pretty much new I was doing it. I can act like I’m cheerful when I’m not, and that can make me cheerful.”

Similar to what was argued throughout the first and second interviews, this form of joking was placed in the Emotional Avoidance category because it was perceived as a “deflection” technique, whereby thoughts and emotions associated with the amputation were avoided and ignored, rather than faced and dealt with.

Behavioural Approach Coping

Taking Action

One of the main Behavioural Approach coping strategies that was used by fourteen people throughout the second interviews was that of Taking Action to resolve any problems that were encountered. Throughout the third interviews, only seven people used this coping strategy, which involved taking specific action or steps to address and overcome physical limitations and obstacles. In overcoming mobility problems, one man made several attempts to resolve his difficulties by trying to cycle a bicycle, while another travelled on his own to prove to himself that he could do this. Furthermore, in overcoming difficulties with their artificial limbs, two people engaged in research and sought information from various sources to help inform them on how to get the best artificial limb. Moreover, in overcoming health problems, one person sought the advice of a dietician, while another began a course of physiotherapy at home in order to build up his strength.

Earlier in the chapter, it was found that many participants had experience of being treated differently by others in the sense that they were embarrassed upon noticing they had an amputation or tried to offer them unwanted assistance. Although most people accepted these reactions, two people indicated that they would take particular

steps to overcome these reactions. In dealing with overprotection, for example, NK said that he would always tell people “thank you, but I can manage myself.” In dealing with the embarrassed reactions of others, MG indicated that he would try to put these people at their ease. He described such an incident as follows:

“The first day I was in the swimming pool, some kids came in with their father, going up to the kids’ session. And they were saying to their Dad ‘that man has only one leg.’ I spoke to them straight away, so as not to be putting the father under pressure, in case he’d think I’d be upset when I’d hear them. I told them I’d only the one leg, and we got chatting. It’d be the father you’d feel pity for, that he’d be embarrassed. If it happened to me [i.e. with his children], I’d be telling them to stop.” [MG]

Using External Resources

Another Behavioural Approach coping strategy was use of External Resources in order to cope with aspects of an amputation. Throughout the second interviews, ten participants used their prosthesis as a means of restoring a ‘normal’ body image. Throughout the third interviews, seven participants still continued to perceive their prosthesis in this way. For example:

“I do like my overall appearance when wearing my prosthesis. It makes you look normal, as a normal able-bodied person. Most of the time I’d like my appearance, yeah. Since the prosthesis, I take it for granted, now. I don’t take any notice of my appearance.” [DOD]

Another External Resource that two people used in coping with their mobility limitations and restrictions was a car. As BN explained:

“The car is my absolute world. I had a struggle to buy that car moneywise, and I’m still paying for it. But if that car goes, I think I’ll just, you know, you say you’ll top yourself. Of course you wouldn’t. But I feel that car, now, it’s the best friend in the world I’ve had since I’ve been sick. I look at it every morning to make sure it’s there. But I just love to see it there and that it’s there if I want

it. Now I have a choice. If I hadn't that car, I wouldn't be as happy today as I am." [BN]

Finally, another External Resource that three participants used to maintain emotional well-being was their employment. The role of employment as an External Resource was illustrated by the remarks of one participant, SC, who discussed how finding a suitable job would help him cope better with his emotional problems and how he had often felt a sense of pride and self-esteem in his previous job. The three men who were working were very glad to be doing so and talked about how it helped them psychologically. One man remarked that he now felt 'fulfilled' as a result of returning to work, another noted that he felt more 'normal' with his return to work, and another was happy to be occupied during the day. For example:

"I was looking forward to going back to work. I was fed up with being house-bound. And I found it easy to adapt to a supervisory role. I'd no problems with it at all. I enjoy when I'm in working and looking for business, or whatever. That's my life. That's it, you know. I feel much stronger now. I suppose more fulfilled with the owl job and that, you know. The last time you were down, I was only talking about it. Now, I'm into it." [MG]

"It's great being back at work. Well, no, I don't enjoy it in the sense that it's work and all, but I'm delighted to be back. Part of the problem for me, it's been indicated to me that I'd be better off not back at work for the insurance claim that I might have. Which, indirectly, saddens me because financially it could cost me. But mentally and physically, I feel I have to get back. And I think it's good to have gone back." [PG]

Joking

During the first and second interviews, a small number of participants made jokes about their amputation as a means of fostering social relations and breaking the ice. Throughout the third interviews, only one reported using this Behavioural Approach strategy in coping with social interactions. He remarked:

“I played a funny joke. The priest’s housekeeper was at work the other day, and I said “My foot is very itchy, would you scratch it?” You see, I do catch people with the same crack as I did before. And when I’m in work, now, I do cross the artificial legs, just put them across. Do you know, it’s a bit of crack, you know.”

The role of joking as a Behavioural Approach coping mechanism in this instance could be called into question, however, as this participant indicated that such joking had been an integral part of his personality prior to his amputation. As he said “I was always that inclined, having the crack with people. That’s come back very quickly.”

Social Support

Throughout the second interviews, thirteen participants indicated that they used Practical Social Support as a coping mechanism. Throughout the third interviews, six participants indicated that they made use of this strategy in helping them deal with practical problems they faced.

Throughout the first interviews, several participants felt guilty about accepting practical social support from other people, and they worried that they were putting others under some sort of a burden. Throughout the second interviews, however, this reluctance to accept practical social support appeared to have diminished, and only three participants remarked that they did not want to impose on others. Throughout the third interview, this trend continued, and only two participants showed some discomfort about receiving Practical Social Support.

Behavioural Avoidance Coping

Distraction

During the third interviews, a small number of people indicated that they sometimes engaged in particular activities in order to distract their attention away from potentially distressing thoughts or emotions. For some people, Behavioural Distraction was used as a means of coping with upsetting feelings regarding the amputation. For others, this coping technique was perceived as a means of coping with or ‘forgetting about’ phantom limb pain. For example:

“You’d wake up in the morning sometimes, you’d think you were only dreaming. Then you realise that they’re gone [i.e. his limbs]. It’s a terrible shock, and it brings it on again, maybe ... It doesn’t happen very often, but it does happen, you know. But I’ll pass no remarks. Because I’ll hop into my chair, go in there where I watch television and that’ll be it.” [JM]

“I did get fed up with the wound not healing. I did, yes, naturally enough you’d get depressed at times. But there was so much going on. I would say I’ve a lot to be thankful for. My wife and my family, there was never a dull moment, so that’s a big thing. There was a lot of things going on at the time, I never really got depressed for more than a minute.” [FF]

“I know if I’ve been doing something here, now, I do a lot of baking and that, and the minute I’ve stopped doing it, the phantom itch is still there, but I haven’t thought about it because I’m busy thinking about something else. It’s all in your mind, you see.” [BN]

SUMMARY AND DISCUSSION

Amputation-Related Sequelae

The prevalence and intensity of phantom limb pain and stump pain remained similar to what had been observed throughout the second interviews. Thus, only two people experienced their phantom limb pain as ‘discomforting’ or ‘distressing’, and one person indicated that his phantom pain interfered with his daily living to some extent. Similarly, two people experienced their stump pain as ‘discomforting,’ with both of these individuals indicating that they would have to rest when the pain started, which meant that they were restricted in engaging in any activities it had resolved.

Similar to what had been observed throughout the first and second interviews, the majority of participants experienced discomfort and fitting problems with their prosthesis but remained generally satisfied with their limbs nevertheless. However, compared to what had been found throughout the second interviews, the number of participants who were dissatisfied with aesthetic aspects of their prosthesis had

increased. The main reason for disliking the appearance of the limb was because it was perceived as being too artificial or 'alien' looking. One reason as to why dissatisfaction with the appearance of the prosthesis increased could be because participants may have had greater exposure to others' reactions to the limb. In support of this, some participants in the study admitted that this, indeed, was the case, that they had become more self-conscious about their limb since they had noticed people looking at them. Because the evaluations of others' is an important element in self-evaluation (Thompson and Kent, 2001), perceived differences and negative reactions from others towards the limb may be responsible for the fact that there was an increase in dissatisfaction with aesthetic aspects of the prosthesis. Interestingly, many participants at this stage perceived the prosthesis to be 'a part of them' and 'a part of their lives.' Thus, it would make sense that any perceived negative evaluations of the limb would be taken 'personally' (Thompson and Kent, 2001).

Throughout the third interviews, it became evident that perceptions of progress in walking had somewhat altered since the previous interviews. In the second interviews, the majority of participants had indicated that they were happy with their rehabilitation. Six months later, however, only four people were happy with the amount of walking they could do, and seven people felt that they had either reached a plateau in their rehabilitation or were not improving fast enough. These observations could be due to the fact that participants' improvements in walking may have been accompanied by increases in their expectations. According to Fontaine (1974), any success that is attributed to a stable factor leads one to expect higher levels of success. Thus, participants' success in walking after rehabilitation may have meant that their expectations for walking increased throughout the year. In support of this, several participants indicated that although they were pleased with their progress so far, such comments as 'I'm trying to run before I can walk', 'I'm always aiming higher,' and 'My aim is to walk as naturally as possible' suggested that they were continually developing higher rehabilitation goals for themselves. Because definitions of success depend on what the expectations for achievement are (Podlog, 2002), the self-rated improvements in limitations may not have been sufficient to qualify as success according to participants' achievement goals.

Appraisals, Psychosocial Sequelae, and Emotional Well-Being

Similar to what had been observed throughout the first two interviews, most participants appraised their amputation within the context of "it could be worse." Thus, social comparisons with others perceived to be in more challenging circumstances, seeing solace and benefits to the amputation, and reflecting on its impact on the basis of age and other losses were common. Although acceptance of limb loss was still observed amongst some participants, only half of the participants indicated wholehearted acceptance in response to their limb loss. On the other hand, participants indicated having a greater amount of mixed feelings, regret, and blame when considering their amputation. In fact, five people did not feel that they were fully over having lost their limbs, three did not believe that they had successfully dealt with their limb loss, and two indicated either regret or blame of others for having had the amputation in the first place.

Compared to the second interviews, body-image self-consciousness increased according to ABIS scores. Seven participants experienced above average body-image consciousness in terms of the following areas: they did not like the appearance of their amputated limb, did not like their prosthesis being seen, would not like to go out without their prosthesis on, did not particularly like others knowing that they had an amputation, disliked the appearance of their stump, were somewhat bothered that they did not conform to society's idea of normal appearance, and did not like to look at their reflection in a mirror.

Compared to the first two interviews, participants were less likely to stress their abilities and more likely to report that because they had lost a limb, they could not engage in all of the activities they would like to. Furthermore, just over half of the participants remarked that they felt 'restricted', 'handicapped', or 'limited' in their daily lives. Interestingly, participants who disregarded their limitations tended to believe that their lives would be as good again, and in focusing on their abilities, they were more likely to perceive their current lives as fulfilling. On the other hand, those who focused on their limitations were either unsure of whether their lives would be as good again or believed that their lives would not be as good again. In addition, they were more likely to perceive that their lives were not currently fulfilling. Despite feeling this way, they did not appear overtly upset or distressed about this realisation.

Instead, they accepted these beliefs and appeared to incorporate these limitations into their daily lives. Nevertheless, for the first time in the study, the number of people who were happy to go out socially, with no reservations, had diminished to only half of the participants. Moreover, for the first time, three participants admitted to feeling embarrassed at their perceived awkwardness in social gatherings and at often feeling like they were the centre of attention.

Compared to what had been observed throughout the first and second interviews, only a minority of the participants considered themselves to be the same person. In fact, eight participants felt that either they were not the same person or that they were changed in some respects and different in others. Although previously, reasons for a changed identity predominantly involved restrictions and limitations, at this stage of the study, personality factors became equally important as physical factors in determining identity.

Coping

Similar to what had been observed throughout the first interviews, Cognitive, Behavioural, and Emotional, Approach and Avoidance methods were used by the majority of participants in coping with the physical and psychosocial implications of their amputation. Consistent with the fact that the use of coping mechanisms is dependent on the individual's situational context (Tennen and Affleck, 1999; Holohan and Moos, 1987), the use of some coping strategies declined, while others increased.

One coping strategy that declined in use was Taking Action. One reason as to why the prevalence of this coping method appears to have reduced is that previously, the main area in which action was taken by participants was in buying a car and learning to drive. At this stage of the study, five participants had either bought a car or had their existing cars adapted. Thus, there was no need for action to be taken in this area. Moreover, the fact that participants were more mobile due to increased practice at walking could also mean that they did not require any particular course of action to increase their mobility.

Compared to what had been observed during the first and second interviews, the use of upward comparisons were no longer used as coping strategies in learning to walk. This finding may reflect what Mussweiler, Gabriel and Bodenhausen (2000) called "shifting social identities" in response to threatening social comparisons. According to these authors, upward comparisons can result in lowered levels of self-esteem if this standard with which one is comparing oneself cannot be met. In order to protect self-esteem in the face of these threatening comparisons, people will emphasise the differences, rather than the similarities, between others, and thus the threat of seeing someone else doing better is reduced because the other person is not actually in similar circumstances. In the present situation, the dissatisfaction that participants were feeling over their perceived lack of progress in walking may have made them feel that comparing themselves to other people with amputations was not a helpful strategy, in that it only served to highlight the delay or impediment in their progress that many were perceiving. Thus, realising that other people who were doing better had more favourable circumstances could be a way of consoling oneself that progress was not as good as initially expected. Furthermore, participants' experience in having an amputation and continued practice on their artificial limb may have meant that, at this stage, they had become more aware of the potential difficulties they were facing and the implications of having an above-knee rather than a below-knee amputation. Thus, they may have come to realise that earlier comparisons with those who were younger or who had below-knee amputations were not realistic or feasible.

In the previous chapter, it was found that although many of the findings throughout the second interview supported the notion that the period immediately after rehabilitation is a particularly difficult one (Glass, 1994; Morse and O'Brien, 1995), some findings were somewhat contradictory to this idea. For example, the finding that body-image anxiety decreased during this period was not indicative of experiencing difficulties. Furthermore, the finding that most people were still likely to feel like they were the same person they had been prior to their amputation did not support the theory that the period after rehabilitation is a time when an old identity as an 'able-bodied person' and a new identity as a person with an amputation is forged (Morse and O'Brien, 1995). As a result of these observations, it was argued that individuals were still in a phase of attempting to 'restore the self' and had, therefore, not moved

into the phase of 'learning to live with the altered self' (Morse, 1997; Morse and O'Brien, 1995).

The significant psychosocial changes that occurred between the second and third interviews would suggest that this time, rather than the time immediately post-rehabilitation, reflects the period of greatest difficulty. In these months, body-image anxiety increased, reluctance to interact with other people increased, beliefs in being the 'same person' decreased, and beliefs that life would not be as good again increased. Concurrent with these events, mixed feelings about the amputation became more prevalent, and beliefs that one may never get over losing the limb were expressed. At this stage of the study, the highest number of people appeared to have clinical levels of anxiety and/or depression according to their scores on the HADS. This period, rather than the immediate post-rehabilitation period, may be the most difficult time for people because at this stage, the 'novelty' of being home from hospital is over, and the tasks of real-life are finally faced. This would explain why satisfaction with progress in walking declined, since participants had become 'used' to walking, and pleasure in socialising regardless of obstacles and awkwardness decreased because, as some people put it, "it became too much of an effort."

Although this period does reflect some psychosocial difficulties, there is evidence that people were moving toward a phase of 'learning to live with the altered self' (Morse, 1997). Many people, instead of wholeheartedly accepting their limb loss, recognised that they may never "get over" an amputation, even though they were learning to "get on with it" and "live with it." Furthermore, although most people accepted their limitations, they were not particularly despondent about these restrictions. Instead, they discussed how they incorporated these limitations into their daily lives and got fulfilment from what they could achieve and could do. At this stage of the study, however, people appeared to be struggling to a greater extent with identity issues. With most people believing that they were no longer the same person they had been prior to their amputation, they had moved on from the phase of 'restoring the self'. However, the emphasis on disabilities and limitations in defining the self would appear to suggest that they had not yet incorporated their old identity into a new self as a person with an amputation. Nevertheless, for the first time, an equal emphasis

was given to personality in defining sense of self, thus suggesting that this merge may occur sometime in the near future. Furthermore, the finding that some people were struggling with definitions of 'disability' and 'handicap' would suggest that issues of identity were being worked through at this time.

CONCLUSION

Similar to what was observed throughout the first and second interviews, these qualitative interviews illustrate the importance and dynamic interplay of the various demographic, personality and coping, amputation, and environmental factors in psychosocial adjustment to amputation. Using Livneh's (2001) conceptual framework, the importance of personality factors and coping mechanisms, amputation-related factors, and environmental factors on adjustment to amputation were demonstrated. In terms of *personality* factors, for example, two of the three participants with clinically significant HADS-A scores indicated that they would generally have been quite anxious individuals prior to their amputation. *Environmental* factors were found to influence both physical and psychological adjustment to limb loss. For example, environmental barriers to physically adjusting to a prosthetic limb, including uneven ground, difficulties accessing places, and crowds, meant that some people experienced difficulties in using their prosthesis. In addition, the difficulties experienced in accessing places meant that some participants preferred to remain at home, rather than go out socially, for fear of being a burden on others or the centre of attention. For the first time, perception of social stigma was evident in three of these individuals. Environmental factors may also have been associated with the increase in conflicted feelings that participants had with regard to their amputation; with their return to the 'real world', the impact of their amputation on their lifestyles and abilities may have been brought to the fore. As a result, wholehearted acceptance of the amputation diminished, while conflicted feelings regarding acceptance of and adjustment to an amputation emerged. Coping methods also changed in accordance with this altered environment, in that fewer people began to plan rehabilitation goals ahead, possibly because they felt they had reached their highest possible level. In addition, use of Upward social comparisons was no longer in evidence as many people, who were displeased with their progress, began to note that others with superior walking progress had more favourable circumstances. On the

other hand, use of Downward social comparisons appeared to be used, for the first time, as coping mechanisms by the two people with trauma-related amputations. *Amputation-related* factors may also have impacted on adjustment to amputation. In terms of amputation cause, for example, the two men with trauma-related amputations continued to be the only two people who used the Cognitive Avoidance strategy of joking about their limb loss. Furthermore, both men were amongst the four with clinically significant HADS-A and HADS-D scores, and both men were the only two who indicated using Downward social comparisons as coping mechanisms. Finally, the *demographic* factor of age may have had an impact on adjustment to amputation. As was observed throughout the first two interviews also, many of the older participants appraised their amputation as having less of an impact on them than if they were younger.

Overall, this study has demonstrated the dynamic nature of adjustment to amputation. Between the second and third interviews, for example, perceptions of progress in walking had altered such that only a minority of participants continued to be happy with their progress to date. In addition to the observation that levels of body image anxiety increased during this period, the number of people who had no reservations in interacting with others socially were now in a minority for the first time. Furthermore, a small number of people admitted to feeling a sense of social stigma as a result of having an amputation, and more people than previously were likely to emphasise their disabilities and limitations over their abilities. In terms of identity and sense of self, changes were also observed between the second and third interviews. For the first time, the majority of participants now felt that they were not the same person they had been prior to their amputation because they were different in terms of physical functioning or personality.

Along with the changes in psychosocial sequelae, coping mechanisms also changed in dealing with the altered challenges. As limitations, identity changes, and social difficulties were faced, an increased number of mixed feelings and conflicts with regard to having an amputation were observed. In addition, as participants became more used to their environments and their lifestyle changes, the need for Planning Ahead and Setting goals became less of a necessity, and the use of Taking Things on

a Daily Basis disappeared. Furthermore, as they became more used to walking with an artificial limb and familiar with having an amputation, their use of Upward Social Comparisons declined. Finally, as two participants consistently showed clinically significant levels of anxiety and depression, they demonstrated using Downward Social Comparisons as a coping strategy for the first time.

CHAPTER 6

FOURTH INTERVIEWS

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In the previous study, some of the things we found that the people who were doing this work were doing it because they were interested in it. They were doing it because they were interested in it. They were doing it because they were interested in it.

Although the people who were doing this work were doing it because they were interested in it, they were also doing it because they were interested in it. They were doing it because they were interested in it. They were doing it because they were interested in it.

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INTRODUCTION

In the previous study, some of the findings suggested that the period between three months and six months post-rehabilitation reflects a time of greatest difficulty for people. In these months, there was an increased ambivalence about having had an amputation, and a greater number of participants indicated that they may never get over losing their limb. Furthermore, body-image anxiety increased, reluctance to interact with other people increased, beliefs in being the same person decreased, and beliefs that life would not be as good again increased. At this stage of the study, the highest number of people appeared to have clinical symptoms of anxiety and/or depression according to their scores on the HADS. These psychosocial difficulties may be due to the fact that at this stage, the 'novelty' of being home from hospital was over, and the task of real-life was finally faced. This may explain why satisfaction with progress in walking declined, since participants had become 'used' to walking, and pleasure in socialising regardless of obstacles and awkwardness declined because, as some people put it, "it became too much of an effort."

Although this period does reflect some psychosocial difficulties, there is evidence that people were moving toward a phase of 'learning to live with the altered self' (Morse, 1997). Many people, instead of wholeheartedly accepting their limb loss, recognised even though they may never "get over" an amputation, they could and were learning to "get on with it" and "live with it." Furthermore, although most people accepted their limitations, they were not particularly despondent about these restrictions. Instead, they discussed how they incorporated these limitations into their daily lives and got fulfilment from what they could achieve and could do. At this stage of the study, however, people appeared to be struggling to a greater extent with identity issues. Most people believed that they were no longer the same person they had been prior to their amputation, and the emphasis on disabilities and limitations in defining their sense of self would appear to suggest that they had not yet incorporated their old identity into a new identity as a person with an amputation. However, for the first time, an equal emphasis was given to personality in defining sense of self, thus suggesting that this merge may occur sometime in the near future. Furthermore, the finding that some people were struggling with definitions of 'disability' and

'handicap' would suggest that issues of identity were being worked through at this time. In view of these observations, the aims of the present study were:

Aim

- To investigate the occurrence and interrelationships among amputation-related factors (phantom pain, stump pain, prosthesis, learning to walk), coping mechanisms, reactions to amputation, psychological well-being, sense of self and identity, body-image anxiety, and social functioning approximately one year after the rehabilitation period.
- To observe any changes that had occurred between nine and six months after rehabilitation in terms of participants' sense of self and identity, as well as other amputation-related and psychosocial sequelae.
- To provide descriptive statistics on the characteristics of participants one year after their amputation.

METHOD

Procedure

Three months after they had taken part in the Stage 3 interviews, participants were sent a letter [See Appendix 9] requesting their participation in a final interview on psychological adjustment to their amputation and their prosthesis. Approximately three days after they would have received the letter, they were subsequently telephoned by the researcher, and if they were willing to take part in a fourth and final interview, a date was arranged on which the researcher would call to their homes.

The interviews, which were tape-recorded, were based on questions included in the Trinity Amputation and Prosthesis Experience Scales (TAPES; Gallagher and MacLachlan, 2000), TAPES-Revised, the Short Form of the McGill Pain Questionnaire-Short Form (SF-MPQ; Melzack, 1987), the Amputation Body-Image Scale (ABIS; Breakey, 1997) and the Hospital Anxiety and Depression Scale (HADS; Zigmond and Snaith, 1983). Responses to items on these questionnaires were

followed with probing questions assessing the reasons for their responses. In addition, participants were asked open-ended questions about their reaction to their amputation, learning to walk, their current goals, their hopes for the future, their social support, and qualities of phantom limb pain.

All of the interviews were transcribed *verbatim* by the interviewer. The interviews were then analysed using QSR NUD*IST 4.0 for analysing qualitative data. In accordance with grounded theory methodology, open codes from the interviews were created using line-by-line analyses. These open codes were then used to create categories of higher-order concepts. On the basis of these categories' properties and dimensions, axial coding was then carried out to focus the results and draw the concepts together.

Inter-rater reliabilities were used to assess the validity of the categories. To test the validity of the *Amputation-Related Sequelae* categories, 10 examples from each subcategory were given to an independent rater. The rater then placed each example into one of the following categories: Amputation-Related Sequelae, Social Sequelae, Body Image Sequelae, Identity Sequelae, Limitations Sequelae, and Other Worries. Initial ratings revealed that ninety three percent of the examples were coded reliably. Subsequent discussions between the researcher and the rater resulted in one hundred percent agreement.

In order to test the validity of the *Appraisal* and *Coping* categories, 10 examples from each of the subcategories were given to an independent rater, who then placed each example into one of the following categories: Appraisals of the Amputation and its sequelae, Cognitive Approach, Cognitive Avoidance, Behavioural Approach, Behavioural Avoidance, Emotional Approach, and Emotional Avoidance. Initial ratings revealed that ninety-two percent of the examples were coded reliably.

Participants

One participant, MMcC, did not want to participate in a fourth interview because he had just returned home after spending two weeks in the National Rehabilitation Hospital and was in the process of adjusting to a new artificial limb. As a result, he

did not think that he would have anything new to contribute in an interview. Overall, twelve participants took part in Stage 4 interviews. These were two women and ten men. Their mean age was 58.23 years (Range 38 to 72 years) [See Table 6.1 for a description].

Name	Sex	Age	Amputation type	Reason for amputation	Time since amputation	Concurrent difficulties
AMcG	F	72	Right AKA	PVD	18 months	None
BN	F	55	Left BKA	Diabetes	18 months	None
DOD	M	57	Right BKA	Diabetes	15 months	3 toes amputated on right foot
FF	M	66	Right AKA	PVD	17 months	None
GD	M	62	Right BKA	Diabetes	15 months	Kidney transplant; Heart problems
JM	M	58	RAKA & LAKA	PVD	14 months	None
LB	M	71	Left AKA	Clot	13 month	None
MG	M	63	Left AKA	Complications of Aneurysm	18 months	None
MW	M	70	Right AKA	Ulceration of the leg	14 months	None
NK	M	38	RAKA & LBKA	Diabetes	18 months, 13 months	Visually Impaired
PG	M	48	Left AKA	Road Traffic Accident	16 months	Visually Impaired
SC	M	38	Left BKA	Boat Accident	15 months	None

Table 6.1 : Describes the name, sex, age, type of amputation, cause of amputation, time since amputation, and concurrent medical difficulties of the participants. F = Female; M = Male; AKA = Above-knee amputation; BKA = Below-knee amputation.

The reasons for amputation were as follows: pulmonary vascular disease (PVD) = 3, diabetes = 4, accident = 2, clot/aneurysm = 2, ulceration of the leg = 1. Ten participants had unilateral lower-limb amputations, including six above-knee amputations and four below-knee amputations. Two participants had bilateral lower-limb amputations: one person had bilateral above-knee amputations and the other person had one above-knee amputation and one below-knee amputation. Some of the participants had concurrent medical problems that could impact on their rehabilitation. Table 6.1 outlines these medical conditions.

RESULTS

Participant characteristics

A table and brief description of participants' scores on the questionnaire instruments used are provided in Appendix 13. As these scores did not comprise part of the major results, they were not included in the main results section.

Qualitative Results

Figure 6.1 gives a pictorial representation of the findings that emerged from the interview data. It is similar to Figure 5.1, with the exception that the Emotional Avoidance Joking category was no longer included. Furthermore, the Behavioural Avoidance technique of Distraction was also no longer in evidence. Similar to what has been previously noted, the hierarchical structure of coping that emerged throughout the final interviews was similar to that observed by Lazarus and Folkman (1984) and Tobin et al. (1989).

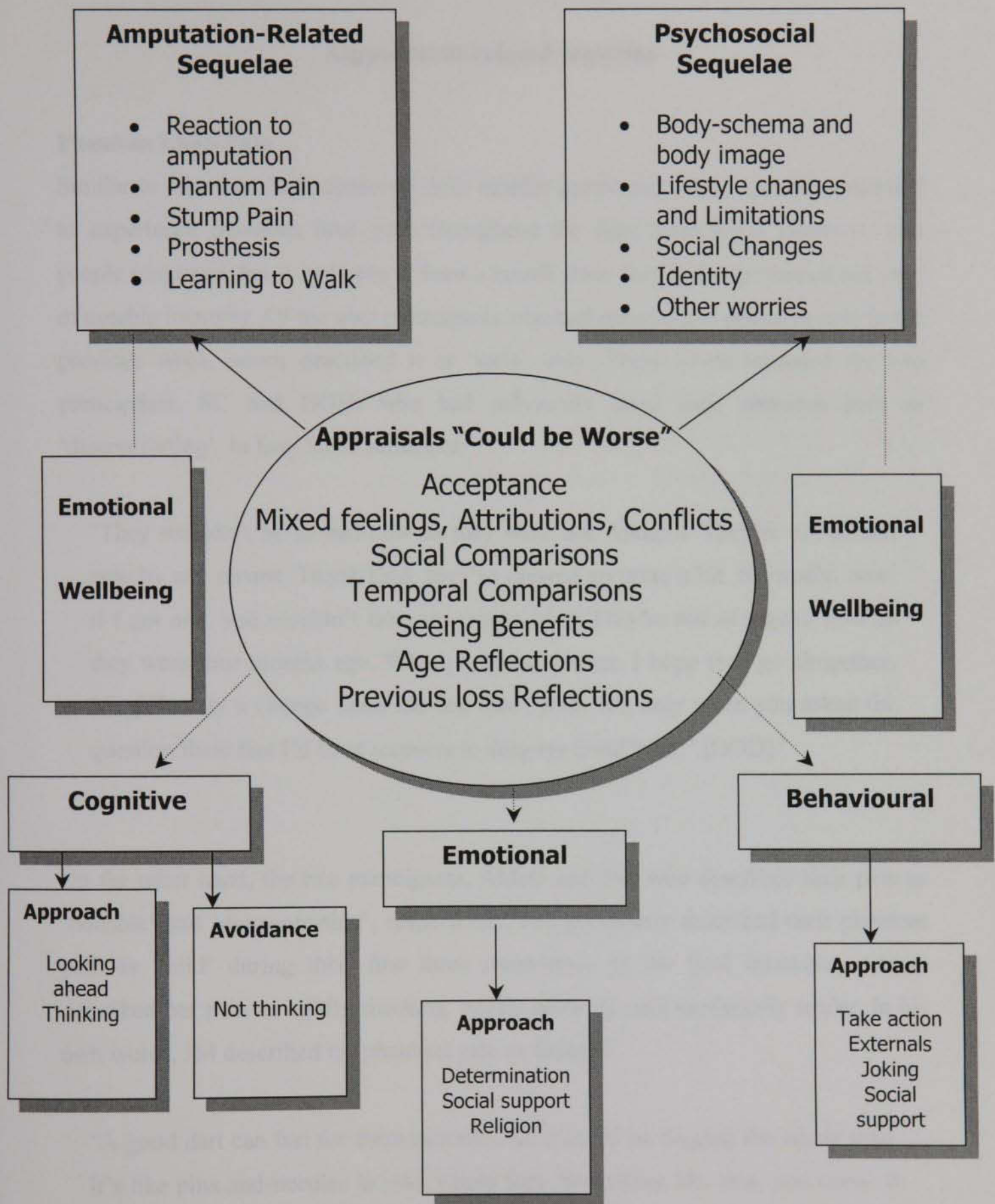


Figure 6.1: gives a pictorial representation of the findings that emerged from the interview data. It is similar to Figure 5.1, with the exception that the Emotional Avoidance Joking category was no longer included. Furthermore, the Behavioural Avoidance technique of Distraction was also no longer in evidence.

SEQUELAE OF AMPUTATION

Amputation-related sequelae

Phantom Limb Pain

Similar to what had been observed three months previously, eleven people continued to experience phantom limb pain throughout the final interviews. However, two people remarked that it had been at least a month since they had experienced any pain of notable intensity. Of the nine participants who had experienced phantom pain in the previous week, seven described it as ‘mild’ only. These seven included the two participants, SC and DOD, who had previously rated their phantom pain as ‘discomforting’. In fact, DOD remarked:

“They wouldn’t be as bad now as they were last Autumn. They’re not as bad now by any means. Thank God, they’ve cleared up quite a bit. Normally, now, if I got one, you wouldn’t take any notice of it. They’re not as regular now as they were four months ago. Which is grand for me. I hope they go altogether. It’s definitely a change since the last time, yeah. It’s only when you asked the question there that I’d have recourse to drag my mind back.” [DOD]

On the other hand, the two participants, AMcG and JM, who described their pain as ‘horrible’ and ‘discomforting’, respectively, had previously described their phantom pain as ‘mild’ during their first three interviews. At the final interview, AMcG described her pain as mildly shooting, mildly gnawing, and moderately tender. In his own words, JM described his phantom pain as follows:

“A good dart can last for three minutes, but it could be digging the whole time. It’s like pins-and-needles in your whole foot. Something like that, you know. It can be horrible, I’ll tell you the truth, now. It’s okay now, but when you do get it, it’s horrible. It’s something you can do without. It can happen two or three times throughout the night. It’d waken you up, you know.” [JM]

Of these seven participants with ‘mild’ phantom limb pain, six felt that their pain caused no interference in their daily lives. One man described such pain as “a flash that wouldn’t linger”, while another said his “just passes, it doesn’t interfere with anything.”

Overall, two people, SC and JM, felt that their phantom pain interfered with them somewhat, with both indicating that sometimes it could prevent them from falling asleep.

Stump Pain

Throughout the second and third interviews, half of the sample experienced stump pain. Throughout the final interviews, only three people continued to experience such pain. Of these three, GD described his as ‘mild’, AMcG described hers as ‘discomforting’, and SC described his as ‘distressing.’ The main cause of stump pain in these individuals was removal of the artificial limb, wearing the artificial limb, and poor skin quality on the residual limb. Only SC remarked that stump pain interfered with his daily living. He explained:

“If I whack the leg on something, whenever I whack it, that’ll be sore. When I walk, I bring the leg right up. I have to whack the prosthetic to bring it up, so, it’s the whacking bit that does it. It prevents me from walking. I either have to not walk as far and rest. Then once I’m home, I might have to take it off. Then, I’m either stuck home, and if it’s raining and I have to go out, I have to use a stick, so it’s tricky, then.” [SC]

Adapting to the prosthesis

At the time of the third interviews, four participants had been given a second artificial limb. By the fourth interviews, a number of changes had occurred to several people. Two more people, DOD and PG, had been given a new prosthesis. Both men were somewhat pleased with their new limbs, despite the fact that PG’s limb had not been finished off aesthetically. He had mixed feelings with regard to this limb: although it was safer than his previous prosthesis, it was also a little bit more awkward to use. He

described it as a “bit more cumbersome than the other one” and felt that everything was “a bit slower” when using this limb.

Despite the fact that SC had been given a new prosthesis several months previously, he had been forced to return to using his first prosthesis because stump surgery that he had undergone in the previous three months meant that this second prosthesis no longer fitted. He was a little disappointed at having to go back to wearing this limb, which was more painful to use than the previous one had been. He called this move a “step back in a way.” Finally, one man, FF, had returned to the National Rehabilitation Hospital in Dún Laoghaire. He was, at this stage, in the process of adapting to a second prosthesis after an MRSA infection and a subsequent re-amputation on his residual limb had prevented him from adapting to his first prosthesis. He was very happy with his new prosthesis and remarked that he felt “lost without it” when it had been taken away for minor adjustments.

Throughout the third interviews, four people were dissatisfied with aesthetic aspects of their prosthesis. By the final interviews, however, only two of these individuals continued to be unhappy with the appearance of their artificial limb. SC, who was commenting on his first prosthesis, had previously indicated dissatisfaction with its shape and general appearance in his first two interviews. At the final interview, he had not altered his opinion in any way. He described it as “an awful looking thing,” and said that if he had a choice, “it would not look like that at all.” BN, who was consistently dissatisfied with the appearance of her limb, remarked:

“It’s too dark. It’s a rotten colour. They gave me these tights to go over them, and I wouldn’t buy that colour tights anyway. They’re an awful colour. And the shape is terrible. Even though I’ve got long skirts down to the ankles, I’ve this fear that some day there’ll be a wind out and it’ll blow it up, and they’ll see the shape of the leg. That’s such an eyesore that leg, it really is, compared to my own.” [BN]

Similar to previous observations, over half of the participants admitted to finding their artificial limbs uncomfortable at times. For example, PG often felt his limb hurting

him in the groin and admitted that he was “not happy with the comfort element of it.” In addition, neither BN nor SC could walk for prolonged periods, because their residual limb would become too sore. According to SC, for example, it hurt every time he took a step because it had become too big.

Throughout the third interviews, seven participants were dissatisfied with the fit of their prosthesis. Throughout the fourth interviews, five participants remained dissatisfied with this aspect of their limbs. Three people felt that they had become too big, despite the fact that two were wearing their second prosthesis. Another person felt that his limb was generally too awkward and ill-fitting, in the sense that it was uncomfortable and not moulded to his shape. Another person thought that his artificial limb was in need of adjustment so that his gait could be improved. Despite the fact that over half of the participants were dissatisfied with the comfort and/or fit of their artificial limb, the majority were still either ‘very satisfied’ or ‘satisfied’ with their prosthesis when asked to rate this on a five-point scale. In fact, only SC was ‘dissatisfied’ with his limb, while PG and JM were ‘neither satisfied nor dissatisfied’. These three men expressed aesthetic, comfort, fit, or usefulness problems with their prosthesis, their ratings are fairly explicable.

Since there were four people who were satisfied or very satisfied with their limb, despite experiencing aesthetic, comfort and/or fit problems with it, this apparent contradiction must be examined. As explained previously, this contradiction may be due to the fact that most participants who had problems with their limb were, nonetheless, very grateful to have it because it enabled them to do things they would otherwise be incapable of doing. Furthermore, many participants perceived their artificial limb as a highly useful ‘tool’, and three people perceived it as being a part of themselves. For example:

“I would hate to take the leg off and stay up for an hour after taking it off. I leave it on until the very last. It’d be like, if you left on one shoe and sock and took off the other shoe and sock and walked around with one foot barefoot. You’d feel it. I feel lost today, completely, since they’ve taken it down for adjustments. I hated having to go down to physio today without it. Most

definitely, it's a part of me now. When I say I miss it so much, it's unbelievable." [FF]

A second possible reason for the observed contradiction between comfort, fit, and satisfaction ratings could be that participants were aware that these difficulties were due more to their stump shrinking than to the prosthesis itself. As one man said "it's not a fault of the leg. It's your own leg shrinking." Recognising that the fitting difficulties were not necessarily a 'fault' of the limb may have made it easier to be content with it, since participants were aware that they would be getting a new prosthesis within the next few months. In fact, one woman, BN, remarked as much when she said "I know that better things are coming. I don't think I'd like to have a leg like this all the time. But I can do with it because I know that better's coming."

The observation that people recognised the uses of their limb, were grateful to have it for what it enabled them to do and perceived it as part of themselves may also explain the finding that ten of the participants had adjusted to and accepted wearing an artificial limb. As one man said, wearing the prosthesis was "just like having your shoes and your trousers on." Only two participants, PG and SC, continued to feel that they had not fully adjusted to wearing their artificial limb. Throughout the third interviews, they did not seem to have adjusted to *having* to wear an artificial limb. Throughout the final interviews, PG's reservations about his limb appeared to be more about problems he was having with their comfort and fit. On the other hand, SC, was having mixed feelings toward his limb in that there were times when he liked it and times when he hated it. For example:

"I've not adjusted to it As I was saying to the girl I deal with where my limb was made, I said 'C., at the moment, I'm certainly not happy. If your ears were red over Christmas, it was me talking about you, because I fucked and blinded at times. Because this cuts me at the back and it hurts up in the groin. You've done your lot, now, and if this is the best you can do, and if this is the best I can get, I'll have to stick with it. However, if there's something better available, I'll go after that.'" [PG]

“I’d probably have a little more ways to go in terms of adjusting to having an artificial limb. It’s almost like a toy, you know, as a child, if you have a favourite toy, it’s not part of you, you know. There’s times when I think of it warmly, as it were. But there’s times when it’s just, like, ‘Oh, that rotten thing. I have to put that stupid thing on.’” [PG]

Learning to Walk

By the end of the third interviews, only one person described herself as being ‘a little’ limited when it came to walking one hundred yards, six participants remarked that they would be somewhat limited in walking half a mile, and eleven participants remarked that they would be limited a lot in walking more than a mile. Throughout the fourth interviews, an interesting finding emerged, in that perceived limitations appeared to increase. At this stage, four participants now felt that they would be ‘a little limited’ in walking one hundred yards, seven participants thought that they would be somewhat limited in walking half a mile, and none of the participants felt that they could walk over a mile. In examining the increase in perceived limitations between the third and fourth interviews, two explanations can be put forward. The first of these is that participants did, in fact, disimprove in their walking between the third and fourth interviews. When asked about whether they could perceive an improvement in their walking, six participants remarked that they had not improved since the previous interview. For example:

“I don’t think I’m going to improve any better than I am. I don’t think so, balance-wise anyway. I’m at my limit. That’s as good as I can get. I tried, but I think that’s the limit as far as I can go. I reached it, possibly, the last time you would have been here. What I have difficulty with is things on the ground. Stooping and that. I can’t do it.” [DOD]

“I’ve taken a step backward, you know. Because of the operation and everything, I’m kinda back about, maybe, a year ago or something like that. I’m a lot stronger, physically, I would think. But just because I’m back on the old leg and I’m waiting on a new leg, it’s almost like I’m stronger and wiser, but back to where I was a year ago.” [SC]

“I’m still not happy with my progress. My progress is slow. It’s extremely difficult because of the other problems. I kind of take one step forward and sometimes two back. So, then, I have to take three forward again. So, there hasn’t been a huge change, no.”[PG]

However, the explanation that participants objectively disimproved since their previous interview is unlikely, given the finding that their use of sticks and crutches had decreased quite substantially since the second and third interviews. Thus, another explanation can be put forward as to why participants perceived themselves as more limited in their walking throughout the fourth interviews. As the length of time since their amputation increased, participants’ expectations for walking may have concurrently increased. Throughout the first interviews, it was evident that they were delighted to be mobile and learning to walk again. Therefore, they may not have been as critical in judging their limitations in walking. However, with the return of their physical strength and greater practice on the artificial limb, their expectations for walking may have increased and they may, at the same time, have become more self-critical about their abilities and limitations. In support of this, two participants indicated surprise when progresses, which they had not observed, were pointed out to them. Furthermore, three of the four participants who did not feel that they had improved in their walking over the last few months did concede, when asked, that they had come on quite a long way since their amputation. For example:

“I’d forgotten that I’d wanted to walk with only one crutch. I didn’t think it’d be possible before. Well, it’s coming to pass now. I can walk with one and without much of a limp. But you are handicapped with the prosthesis because you can’t bend your toes. That’s why you’ll have a bit of a limp.” [MG]

“It’s better than going back, maybe, twelve months. It’s a big change for me to be able to get up and walk around ... looking back at fourteen months ago, when I was in the wheelchair, I was doing everything in the wheelchair. The days were long, you couldn’t get out. I wasn’t going anywhere then. So, then, recapping on what I was fourteen months ago, then I’m doing okay.” [DOD]

Regardless of participants' self-rated limitations at walking particular distances, analyses of their responses indicated that those who perceived an improvement in their walking were more likely to practice walking regularly. As one man said "the more you walk, the more competent you get on it." Conversely, those who did not perceive themselves as having improved were less likely to practice walking on a regular basis. Again, for some, it was finding the time and energy to practice that was difficult. For others, it was their health difficulties or the environmental obstacle of having to practice on uneven ground or in the dark that prevented daily walking with the prosthesis.

Similar to what had been observed throughout the previous interviews, a fear of falling was found amongst half of the participants. Since the previous interview, two men had fallen while walking over the last three months. PG had fallen unexpectedly in his home and said that his "leg just went from under him." SC fell after having been asleep and 'forgetting' either that he was not wearing his artificial limb or that his limb had been amputated. He described this experience as follows:

"When I came home from the last stump operation, I was just so tired, and I lay on the couch. About an hour later, the postman rang the bell, and I jumped up off the couch. I must have taken one step with the long leg and then the next step with the no leg. And I hit the stump on the ground, just dead on. I got on the crutches and went out, and he had a box or something for me. He was wanting to talk, but I was bleeding, wincing, 'I can't talk. I've got to go.' ... It must have been just because I was startled. I must have thought I was wearing the leg. Maybe I thought I still had it. I don't know." [SC]

In addition to having fallen while walking, the participants who predominantly used wheelchairs had also fallen while in their chair. Neither of them indicated that they had been upset by these incidences. NK, who had fallen onto a busy road while trying to avoid a crowd of people remarked "I didn't get particularly hurt or ravelled. I'm just thankful there weren't any buses coming down or it could have been a very

different story.” Similarly, JM, who had fallen in his garden said “I didn’t hurt myself anyway, you know. I was lucky enough. Thanks be to God I didn’t bang my head.”

Similar to what had been found throughout the previous interviews, this fear of falling may have inhibited people’s progress on the artificial limb. In fact, many of those participants who were nervous of falling were reluctant to try walking without any crutches or sticks. As one woman said:

“That time I walked with no sticks, you get a kind of a fear that you’ll fall and damage the good leg or hip, you know. So, that way, you’re careful. It makes me that bit more careful, you know.” [AMcG]

In addition to falling and being afraid of falling, participants faced several other environmental obstacles in adapting to their prosthesis and learning to walk. Similar to what had been observed previously, these obstacles included bad weather, uneven ground, walking on hills, and being in crowds. GD explained the difficulties he experienced in crowds:

“If there was a funeral now, a person you knew, I couldn’t go to it because of the steps and the crowd, you know. You just wouldn’t go. I’d try and avoid going to big funerals, because of the crowds, pushing, and steps and everything else. If you were coming in on your own, and there was a few people, you’d be alright. But not with the crowds you’d see at funerals.” [GD]

Another obstacle that some participants had to face while learning to walk was concurrent health problems. Both NK and PG continued to feel that their visual problems posed obstacles in learning to walk. Moreover, FF confirmed his earlier suspicion that his osteoarthritis could affect his rehabilitation. Because of this condition, he had been advised to walk using a fixed-knee prosthesis rather than a free-knee prosthesis. Another participant, DOD, remarked for the first time that his eyesight was a problem when walking in the dark and on uneven ground. He also added that the amputation of toes on his intact limb affected his balance somewhat.

Psychosocial Sequelae

Body-Schema and Body Image Changes

Between the second and third interviews, the number of people who experienced above-average body-image self-consciousness, according to their scores on the ABIS, increased from six to eight individuals. Throughout the final interviews, five participants continued to experience above average body-image self-consciousness, while seven people did not show any signs of feeling this way. One man, NK, explained his views on the futility of feeling self-conscious about having an amputation. He remarked:

“Anyone who feels self-conscious, they’re adding a lot of stress and worry to themselves that they don’t really need to. Because at the end of the day, what does it matter what a stranger thinks of how you look. They’re hardly going to express it to you. And if they do, I would say the problem is their’s and not yours.”

The remaining five participants indicated above average body-image self-consciousness according to their ABIS scores. These participants, in descending order of their ABIS scores were PG, SC, DOD, BN, and GD. These participants showed anxiety in several of the following areas: they disliked the appearance of their stump, thought that they must have four limbs to be physically attractive, did not like their artificial limb showing, did not want others noticing that they had an amputation, disliked the appearance of their amputated limb, avoided looking into mirrors, preferred their appearance with the prosthesis on, were concerned that they did not conform to society’s idea of ‘normal’ appearance, and were continuously anxious about their overall appearance. Two participants explained feeling self-conscious as follows:

“The way I look at it, I’m still conscious in ways. Every day I meet people, and they’re saying ‘How are you today, B.?’” And they’re used to seeing me, now, in trousers, which I never wore in my life. And now, I’d feel conscious again if I went back to skirts. I’ve tried wearing a skirt a couple of times, but then they go

back into the wardrobe. Can't wear it. You see, it's this consciousness that people are watching you all the time. I don't want to go out yet with that leg, there. I'm not happy with the shape of that leg. And even though I've long skirts down to the ankles, I've this fear that some day there'll be a wind out, and it'll blow it up, and they'll see the shape of the leg." [BN]

"It's unlikely that I'd wear shorts or anything like that. I don't know if I would. I would do it, but that would be taking into account that I could be able to walk much better. That I wouldn't be like the Hunchback of Notre Dame, humping along, and then in your shorts, you know. I would be conscious of walking that way. I'd like to think that I'd get back to somewhere as near as normal walking. I'd like if people didn't notice, that I'd have a little limp like I'd only hurt my ankle or something." [PG]

In looking at reasons as to why some participants experienced body-image self-consciousness, while others did not, two particular explanations were put forward throughout the third interviews. This first explanation proposed that a reliance on the prosthesis to provide a 'normal' appearance and unhappiness with aesthetic aspects of the prosthesis could mean that it was not functioning properly as a means of re-establishing a 'normal' body-image and body-image self-consciousness could ensue. Throughout the fourth interviews, this explanation was partly valid. For example, both participants who were unhappy with aesthetic aspects of their prosthesis, BN and SC, were amongst the five participants with above average body-image self-consciousness. In addition, both participants who indicated that they wanted their prosthesis to give them as natural an appearance as possible, PG and DOD, were also amongst the four participants with above average body-image anxiety. However, because the individuals in these two groups did not overlap, all that can be concluded is that disliking aesthetic aspects of the limb could be associated with greater body-image anxiety. Furthermore, having a desire to appear 'normal' could also be suggestive of body-image anxiety, regardless of whether or not the artificial limb helps establish such normality.

A second explanation as to why body-image self-consciousness was only experienced by some participants revolves around the issue of phantom limb sensation, 'forgetting' about the amputation, and experiencing a sense of 'shock' when suddenly realising that the limbs are gone. It was argued that those individuals who tended to perceive their whole limb as being present were more likely to experience a shock when they 'realised' they had an amputation. Because mental body-image was not a match for perceived body-shape, participants did not like to be faced with any reminders about this incongruence and, therefore, self-consciousness ensued. Throughout the fourth interviews, this explanation was partly valid. Of the five participants with mild or severe body-image self-consciousness, three were currently experiencing phantom limb sensation, and two participants had previously but no longer did experience phantom sensation. Thus, at this stage, experience of phantom sensation may not be implicated in body-image self-consciousness. However, getting a shock upon realising that one had an amputation was still experienced by three of the five participants with above average body-image anxiety. For example:

"It's frightening, to be honest with you. I get a fright when I see it. When I see it, I do say 'Where's the rest of it?' It's cut off from here. Then I cover it up. I don't like it." [DOD]

"I haven't got used to the image of myself without the prosthesis, no. It still shocks me the odd time. I don't have a big mirror I look in at home, but if I go to rehab or where I get my limb made, they've got a big mirror and I've to sit there and take my limb off. And I see the limb is gone. Now, that's not nice for me. It shocks me every time." [PG]

"If I wasn't wearing the leg, I always cover it up. But if I'm in the house, I see it all the time. If I was out in public, it would seem a bit weird. Like 'That's actually me.' Even now, I look at it with wonder, or shock. It's like 'I can't believe it's actually gone.'" [SC]

Interestingly, one man, JM, who had previously experienced above average body-image self-consciousness and a sense of shock upon realising that he had lost both his

limbs remarked that since his previous interview, he had seen himself for the first time in a photograph without his artificial limbs on. He said that had gotten a shock initially, but had then adjusted to being able to see this picture. Throughout his final interview, he remarked that he no longer experienced this sense of shock and that he no longer felt self-conscious about his body image. He said:

“I never looked in a mirror in my life since I had them off. I didn’t see myself until I saw a photograph of myself. I got a bit of a dart, but that’s it. It’s gone now. And somebody said to me ‘That’s not the way we see you. We see you, talking to you, not looking at your appearance.’ So, once you hear that, it’s okay. It was a little bit of a shock the first time I saw it. It lasted about five or ten minutes. Then I thought ‘That’s it. Good luck. Go on and forget about it.’”

[JM]

As JM was getting over his self-consciousness, he remarked that he was planning to give up wearing his artificial limbs altogether. He explained his wish to do this as follows:

“As time goes on, I’ll probably stop wearing the artificial limbs altogether. Like, I’ve nothing to be ashamed of. What happened to me was through sickness, nothing else. I was shy at the start, now, meeting people. But it’s all gone now, you know. They see you once, they’d look at you once, and that’s all. It’s funny when you think of it, people where I live know I lost my limbs. They know I’ve lost my two legs. Yet, they see me at mass when I’ve the two sitting here. So, who’s coddling who? Am I coddling them? They know I lost the limbs. And they pass no remarks.” [JM]

Lifestyle Changes

Throughout the third interviews, participants were less likely to emphasise their abilities and more likely to emphasise their disabilities and limitations. Similar findings were observed in the present study in that only three participants believed that having an amputation did not prevent them from doing anything they wanted to do. These people remarked:

“I can do practically anything. I can get up. I can go out. I can drive the car. I can go anywhere I like. I can cut the grass. I’m able to do that. And that’s what I was going to retire to do anyway. And I can do accounts and things like that. So, that isn’t going to affect me. I expect to be able to do all I want to do.” [FF]

“If I get my car and get the go-ahead and get back to work, you know, it’ll be great. Because it’s great to have somewhere to go in the mornings, even if it’s only for two or three hours. I’ll come back again, go into the garden, or go fishing, or do whatever I like. That’s all I want, you know. I’ll be doing all the things I used to be able to do, you know.” [JM]

The remaining nine participants felt that because of their amputation, to some degree, there were things that they could no longer do. Again, similar to what had been observed previously, half of the participants remarked that they felt ‘limited’ or ‘restricted’ as a result of having an amputation. For example:

“I can’t, say, get out there and jump in the car and go somewhere. I can still go out and get into my car but it would only be to go to a house, you know. I used to go to friends of mine and I’d go out in the fields, walk across the fields, now. I could walk into a field, but it would have to be a level field. Not an ordinary field, where there’d be animals, or where there’d be footprints, heavy footprints. That’d be quite dangerous now.” [LB]

“I’m restricted a bit alright. I’m restricted from what I used to be able to do, definitely. The limb is more restricting than the eyes, yeah. For climbing stairs or going up a hill or jumping over a wall or anything like that. You really have to pick where you have to go for a bit of a stroll or a walk. You don’t want to be running up and down the banks or rivers or things like that. You’re not able to. It is a restriction that way.” [DOD]

Similar to what had been observed throughout the previous interviews, the belief that life would be as good again was associated with a disregard for these limitations and

restrictions. Only three people believed that their lives would be as good again, and these were the same three who felt that they could do whatever they wanted to do, regardless of their amputation. In responding to this question, JM said “life is what you make it, so it will be as good again,” FF remarked that his life would be improved because he had mastered the first episode of his rehabilitation and now knew what his future held. MW also felt that his life had improved because he was no longer in pain and could sit at ease and enjoy himself.

On the other hand, the nine people who either did not think that their lives would be as good again or were unsure about how to answer this question tended to talk about their limitations and restrictions when considering this question. For example:

“I’m not sure about as good. I certainly wouldn’t be able to do what I used to do, or anything like it. I’m going to be restricted, I know that. But that’s a thing I’ll have to accept. It’s going to be difficult, I know that. I get frustrated at times.” [DOD]

“Ah, no, there’s a big difference. There’s a lot of things that aren’t possible. It’s just more restricted, it’s as simple as that. It’ll never be as easy as it was with your normal limbs, never will be. But it’s liveable. You can work away with it and you can do an awful lot. But it just would not be the same. It can’t ever be the same.” [NK]

“Well, life won’t be as good, no. I mean, I have restrictions now that I didn’t have before. I used to be able to go out and run for a bus. Do different things. Gardening, and walking the dog.” [AMcK]

Interestingly, despite the observation that most people were unsure about or did not think that their lives would be as good again, only three people found their current lives unfulfilling, while the majority of participants believed that their current lives were fulfilling. In answering this question, a focus on abilities, rather than on disabilities, was again noted. Thus, remarks such as “It’s as full to the best of my ability” (LB) and “I can make it as full as I like. It’s up to myself to do what I can”

(DOD) were given in responding to this question. What is interesting about this finding is that it suggests that even though most people felt that their limitations and restrictions meant that their lives would no longer be as good as they had been, they could still find fulfilment in what they were able to do. Thus, contrary to what had been observed throughout the third interviews, in which limitations were stressed, and most people did not feel that their lives were fulfilling, the final interviews would suggest that people had come to accept their restrictions and incorporate them into a life that they could still find fulfilling, regardless of whether they felt it could ever be as good again or not. One participant remarked on this:

“I’m doing what I want to do, but it couldn’t be as much as I used to do at one time. But I’m happy enough. I agree I’m deprived, but only in inverted commas. I’m doing what I want to do, but it’s not the life that I want to lead. I’m just doing the best I can with what I have, if that makes sense to you. My life is as normal as it can be, with a false leg. In fact, it’s better than I’ve seen a lot of people’s. It’s not the life I’d choose, of course. And I am deprived, I told you that. Doing normal, everyday things that people do. I can’t do them. So, of course, I’m deprived from leading a normal life. But I’m happy enough with that ... You just accept it, and get on with it, you make the most of what you have, like.” [BN]

Social Changes

In the third interviews, the number of participants who were somewhat reluctant to talk about their amputation and prosthetic limbs had decreased to three individuals. In the final interviews, two participants indicated that they would have some reservations in talking about their limb loss to others. One of these individuals, DOD, indicated that he disliked talking about his amputation because he felt it would only bore other people if he brought it up continuously. The other individual, SC, was reluctant to bring up his limb loss for fear of bringing his friends ‘down.’ Although he had no trouble talking about it if he was asked, he did not like to be the first person to introduce the topic. He explained:

“I feel a bit awkward, because it can really bring the party down. It’s like ‘Oh, by the way, let’s talk about my amputation’. If they want to know about it, I don’t mind talking about it, but I would feel awkward just bringing it up. I kinda like talking about it, but I feel I don’t want to bring everyone down. Some people hear about it and they get really quiet and stare and the floor, and they’re like ‘Oh, jeez, what do we talk about now?’ But if people want to talk about it, I don’t mind.” [SC]

Despite the fact that the majority of participants had no difficulty in talking to other people about their amputation, eleven people noted at least one instance in which they were treated differently by others. For example, six participants felt that other people were often overprotective of them and that they were being treated as though there were ‘disabled.’ Three people had experience of others being embarrassed upon realising that they had an amputation. One woman thought that even though most people had been kind to her since her amputation, some had treated her in what she perceived as a pitying way. Another individual, SC, remarked that since he had removed the outer foam from his prosthesis, he had noticed that others tended to stare more at him. His reaction to this depended on the manner in which they were looking. Participants described these reactions as follows:

“Some people, they say ‘Oh, God, you’re finished,’ you know. I don’t think I’m finished at all. But I’ve come across people like that many’s a time. I don’t know are they ignorant, are they just cheeky, or whether they don’t care.” [BN]

“I met a nun, she’s a lovely person, now. She said ‘Did you get another hip done, L.?’ And I said I got my leg off. ‘Oh, God,’ she said. She nearly collapsed. She has a red face, and her face got redder. ‘Oh, God, I didn’t know that now, no one told me that. Oh, God, that’s terrible,’ she says. ‘It isn’t,’ I said ‘I could be dead. I could be in the wheelchair a lot of the time, like a lot of young men are.’ And then she said ‘Ah, I know, but you were so active a fella, you used to be down here, and you used to be flying around.’ ‘Well, it’s gone now, Sister, but I’m still around.’ She felt embarrassed, I’d say, for asking. A few people did. I’ve met umpteen fellas that I wouldn’t meet normally. And

they'd say that to me, 'Did you get a hip done?', and I'd have to tell them. And they'd all get a shock with it. A bigger shock, now, than you'd imagine. They're more or less sorry for asking me." [LB]

Two participants, NK and DOD were sometimes bothered about the fact that others treated them as 'disabled' at times. NK felt that constant efforts to help him were "irritating" and sometimes "patronising". In addition, DOD remarked that he would feel self-conscious and the centre of attention when other people were rushing to help him, while all he wanted was to "be the same as everyone else." However, despite being bothered at times by this attention from others, both of them, and the other four participants who sometimes felt that they were being treated as if they were disabled, understood that people were only being kind towards them. DOD explained:

"I can see where they're coming from. And I would be one of the first, had it been the other way around, to do the same thing, to open the door for someone. It'd be good manners anyway to do that ... I'd have been the same way with people, but I wouldn't have been overprotective of them." [DOD]

In addition to being treated differently by other people, half of the participants remarked that they often experienced accessibility problems or difficulties in getting out socially. Although these problems had previously meant that many people felt limited in maintaining or visiting friends, this was not the case in the present study. In fact, ten participants remarked that they had no problems in maintaining their friendships and eight people did not feel that they were limited in visiting friends. As one man, FF, stated "I wouldn't even have the slightest limitations in the line of maintaining friendships. I call to people, they call to me at home, when I go home at the weekend. I meet people all the time, so I don't have the slightest problem." However, four people did feel that they were somewhat limited in visiting friends, two of whom indicated that they were restricted in maintaining their friendships as a result. SC and NK explained why they felt this way:

"You would be limited by accessibility basically. Most houses, the major problem would simply be them not having toilet facilities that are accessible.

And most of them are houses that would have at least one or two steps going up to them. I would get up, maybe, one step or down one step, no problem, with the crutches. I certainly wouldn't attempt going up two or three together. It's too much of a balancing act with the two legs being amputated." [NK]

"I'd be limited a little in visiting friends. The same with maintaining friendships because it's a bit harder to get around. I might be more inclined to stay at home, because if they're all going to a big party in a pub, a big crowded pub, I'd be, like, 'I don't know if I want to go.' I used to go out a little bit more, but it was when I lived on the island, and there isn't really anything else to do. But I have to think more, now. Because even with the really nice leg on, I can't walk as steady as I used to, even without any drink on me. So, if I'm out, I have to think of that. I can never just not think about it." [SC]

Although most people did not feel that they were limited in maintaining or visiting their friends, as many as eight participants felt somewhat dependent on other people as a result of having an amputation. Although such a feeling was held by the majority of participants, this did represent a small decline from the eleven people who had felt dependent on others throughout the third interviews. Moreover, similar to what had been observed previously, only three people continued to feel self-conscious about being a burden on others despite feeling more dependent. Throughout the third interviews, it was found that half of the participants were somewhat reluctant to interact socially because of the difficulties they experienced in accessing places and because they sometimes felt like a burden. Throughout the final interviews, however, a substantial change was observed in that only two participants indicated that they avoided interacting with others. PG did so because of his health problems and because of awkwardness and difficulties in getting out socially. The other man, SC, did so because of the difficulties in getting around to places. PG, explained:

"I've curtailed a lot of my activities. It's not just because of the limb, it's because of my eyes and my stomach as well ... I'm quite happy at home with my family and my wife, it's not a great problem there, you know. But I'd like sometimes to go out. The reason I'm not going out socially, is because socially

for me means eating more and drinking more and that doesn't agree with me ... I also gave up going to matches. My eyes, again, prevent me. I have to be sitting at a particular angle, in a particular area to follow it. If there's crowds, I have to be careful going in and out. I can't always get disabled tickets. Even though I have contacts enough, I got sick of bumming from them, to be honest. I just got fed up. I said 'I'll leave it.'" [PG]

The remaining ten participants indicated that they had no problem interacting with other people. For example, JM, remarked "When I go into the town, you can't get me home. Because I go out meeting people and that." Similarly, FF said "I've gone to two weddings since, and I hadn't got my prosthesis. And I'm looking forward to going places."

Identity

Throughout the third interviews, it was found that only five participants perceived themselves as being the same person they had been prior to their amputation. In answering the question, they disregarded their limitations and restrictions. Throughout the final interviews, nine people felt that they were the same person they had been before their amputation. In concluding that they felt the same way, personality, rather than limitations, were mentioned as reasons. In fact, although six of those participants who indicated that they felt like the same person also recognised that having an amputation prevented them from doing things they wanted to do, remarks such as 'Personality-wise, I'm the same, yeah' (DOD) and "I don't think it's altered me as a person" (NK) suggested that restrictions and limitations were not important for these people. Instead, a sense of identity was comprised of personality only.

Although a smaller number of participants considered themselves to be somewhat changed since their amputation, similar to what had been observed throughout the third interviews, limitations and personality factors were equally important in considering this issue. Of the three participants who felt somewhat different, one participant mentioned personality factors, one participant mentioned physical limitations, and one participants mentioned both. For example:

“I don’t feel like the same person. I think everyone changes after traumatic things. It might be very mild change, you know, but maybe I whinge a little bit more. Maybe my skin isn’t quite as thick as it was. Like, certain films will make me a little tearier than I might have been. I’m a little bit more thin-skinned with sad things like that. The accident makes me feel really mortal, you know, I could lose a limb or an arm, and then what would I do?” [SC]

“I feel I’m the same person, but I have to be different because of this. I’m still me. Yeah, I’m still the same person, but with differences [laughs]. I got a bad spell when all this was going on, but I’m back now, in great form. I’m not the same person, physically, you know. But mentally, I am.” [BN]

“I’m not by a long shot, the same person. I mean, I would have been very involved socially, very much involved in sport, sporting organisations, sing-song on a Saturday night. The lads would be up and down the house for a bit of crack. That’s all gone. My personality has been subdued somewhat, I suppose. People would say I was the life and soul of the party, in that way, I would always like to go out and get involved. Now, I don’t because I’m limited in that, you know. I don’t think I can afford to get back to being the same person. Physically, I can’t afford to do that. I’m not going to be like I was before. I can’t.” [PG]

Throughout the first three interviews, participants who felt that they were not the same person they had been prior to their amputation were amongst the majority of those who considered themselves to be disabled. Throughout the final interviews, all three participants who did not feel like they were the same person they had been prior to their amputation also considered themselves to be disabled. For the first time, however, six of those who considered themselves to be the same person also considered themselves to be ‘disabled.’ Thus, compared to previous findings in which the majority of those who perceived themselves as disabled also considered themselves to have changed, the majority of those who perceived themselves as disabled also perceived themselves as being the same person.

This finding can be interpreted in light of the observations that throughout the third and fourth interviews personality factors, rather than limitations, began to become more important in considering whether identity had changed or remained the same. Thus, it could be argued that regardless of whether participants perceived themselves to be limited or not in what they could do, they could still be 'disabled' but still remain the same individual with the same personality.

Other worries

As well as having to cope with amputation-related issues and the psychosocial changes that were occurring as a result of the amputation, many participants had to cope with other non amputation related illnesses and health worries. Overall, ten participants experienced concurrent medical problems, including blood pressure, being overweight, diabetes, kidney problems, heart complaints, arthritis, visual impairment, stomach problems, and problems with the intact limb. Three participants indicated that they continued to worry about their intact limb. For example, GD had a bypass in his intact limb that had stopped working a few weeks previously. He explained:

"I got a bypass in my other leg, and it's stopped. I don't know if it's okay, to be honest with you. They're watching it, but they didn't try to get the bypass going. See, when the bypass stopped, I went in to get it checked, see if it was alright. They kept me in, and they were going to carry out surgery to free the bypass, but because it was getting blood, they said they'd leave well enough alone. If anything went wrong, I was to go back to them. I think about it now. It would be a worry, alright." [GD]

Despite the fact that most of the participants had at least one medical complaint, only one man rated his health as 'fair.' The remaining participants rated their health as either 'good' or 'very good.' Moreover, only four participants perceived their health problems as interfering with their rehabilitation process. For example, NK and PG continued to feel that their visual problems posed obstacles in learning to walk. Moreover, FF confirmed his earlier suspicion that his osteoarthritis could affect his rehabilitation. Because of this condition, he had been advised to walk using a fixed-

knee prosthesis rather than a free-knee prosthesis. Finally, DOD, remarked for the first time that his eyesight was a problem when walking in particular terrains and that the amputation of toes on his intact limb affected his balance.

Previously, it was found that in addition to having concurrent health worries, a small number of participants were faced with managing the financial and practical implications of their amputation. At the present stage of the study, three participants were in full-time employment and two participants were in part-time employment. The only person to indicate any financial concerns was the one participant, SC, who remained unemployed and looking for work. Interestingly, the other participant who had previously had financial concerns indicated that she no longer worried about such matters. Since the previous interview, she had taken up some part-time work teaching crafts. Furthermore, she no longer felt too embarrassed to ask her family to help her out when needed.

Previously, it had been found that these financial difficulties were closely tied up with experiences of inefficient bureaucracy. Throughout the third interviews, two participants, JM and PG, had such experiences. At the present stage of the study, only one participant remarked having to deal with such bureaucracy in trying to get benefits due as a result of her amputation. This participant was not working in any form of employment and had not indicated any financial concerns. She had been waiting for months to get a grant from the local authorities to build a ramp from the front door of her house that would enable her to go out in her wheelchair.

One participant continued to worry about the impact of his amputation on the health and well-being of his family. He was concerned about the amount of driving his wife had to do and was worried that he was putting her health at risk because of this. Furthermore, he continued to be worried about the psychological health of his wife and family and the effect that his accident had on his children's futures. He remarked:

“The lad at home, he's not great. He's extremely temperamental and very nervous. This only came out recently, every time we get into a car, he's a nervous wreck. While he's at school, he can't relax. He knows his mother is

doing all the driving, and if I go into hospital, he gets very nervous. And my second daughter, she was doing her leaving when I had the accident and completely threw in the towel. She did okay, but she could have done better. I missed out on being there for those two ... I feel as well, now, that I mightn't have the same control with them." [PG]

EMOTIONAL WELL-BEING

Throughout the third interviews, four people scored above the cut-off point on the HADS-A and/or HADS-D. Throughout the fourth interviews, SC continued to have elevated HADS-A scores of 8, suggesting mild anxiety symptoms. In addition, PG continued to show mild anxiety and depressive symptoms according to both subscales of the HADS. He scored 8 on both the HADS-A and the HADS-D.

Analyses of these participants' interviews indicated that they tended to be experiencing a range of psychosocial difficulties at the time of this interview. Both participants were the only two participants to remark that they had not yet adjusted to wearing an artificial limb. Furthermore, both had the first and second highest scores on the ABIS. In addition, both were the only two who sometimes avoided interacting with other people because of perceived awkwardness and difficulties in getting around socially. Neither believed that their lives were currently full nor that that their lives would be as good again in some respects. Furthermore, both men were amongst the three individuals who did not feel like they were the same person they had been prior to their amputation and in each case, personality factors rather than physical limitations, were given as a reason for feeling different. Finally, SC was the only participant in the study to experience 'distressing' stump pain that interfered 'moderately' with his lifestyle.

In discussing their current emotional well-being, both PG and SC admitted to feeling down and/or irritable at times. Interestingly, SC noted that his depression had become less severe throughout the year, a statement that was somewhat supported by his HADS-D scores. In the first and second interviews, his HADS-D scores were 6 and 9, respectively. However, in the third and fourth interviews, his HADS-D score was 5 at

both times. Nevertheless, although his HADS-D score of five would be considered within the ‘normal’ range, he did exhibit some depressive symptoms. For example:

“I’m a little bit more thin-skinned with things that are sad. It’s usually films, or if I’ve hurt myself. If there’s a film with a father and his boy, and the father dies, because mine did, I’ll be like ‘Ah, jeez, that’s terrible,’ you know. Which is awful. The film ‘Field of Dreams’, that’ll get me going, you know. It’s like turning on a faucet ... But I think from a year ago, I’ve perked up a little bit. I used to have a little bit of depression with this whole thing, but it’s more of a milder thing. I don’t really notice it. Whereas it used to be more like a stabbing pain, rather than something milder.” [SC]

“There’s enough pressure on my wife, it would be very remiss of me, very unfair of me, to start feeling sorry for myself. I do at times, but then she knows it at times. Then I go away, and I kick the fucking presses and I say ‘Right, come on. Snap out of it.’ That happens once a month, maybe, or once a fortnight. It did the other night for something. I can’t remember what happened. I knew I had to go for a walk, and then it got too late. And I kinda got pissed off, and I got annoyed because my wife didn’t show great enthusiasm for going out ... I suppose I get a bit down alright. I mean, as things go, I can’t have more than six years where I’m working, because I’m not going to be promoted. They told me that. It’s because of my injury. These things get to you, alright. I mean, my class have all been promoted, but I won’t be promoted. I’ve a class reunion in two weeks, and I’m a little bit disappointed because they’ve all been promoted, and I haven’t.” [PG]

Both SC and PG also talked about feeling anxious or nervous at times, a finding that was supported by their elevated HADS-A scores. In both cases, feeling vulnerable as a result of their accident was cited as one of the main reasons for feeling anxious. For example:

“I am worried about my wife and all the driving she’s doing. The car is nine months old, and there’s thirty thousand miles on it. That’s why I had the

Mercedes in the first place when I had the accident, because it was safer with all the driving I was doing. But all these things are there all the time, and I'm not out of the woods yet, I suppose. I do think that lightning can strike twice, so I'd be thinking 'Don't get too happy with yourself and watch your step.' Yeah, apprehensive I'd be." [PG]

"I worry about the accident, just being hurt, those kind of things. Because I never used to worry about that kind of stuff. I'd be jumping around, having a good time, and I never worried about being hurt. I always thought I'd never get hurt. And then, being hurt like this. If I'm going to cross the street there, not every time, but every once in a while, there'll be a car coming up, and I could picture what it would actually feel like to be caught under the car and get run over. Yesterday, like, I had this mental dream that stayed with me, of trying to get on the boat, and then the rope lets loose and my leg was still off, and it was this leg, the one with the prosthetic, and it got caught in the pier, and I was still on the boat, and something has to give way. The dream doesn't really end. It ends right there, really, not knowing what happens. I was kind of a nervous wreck." [SC]

Despite the fact that only two participants showed symptoms of depression and/or anxiety according to HADS-A and HADS-D scores, it is important to note that another two participants, DOD and BN, admitted to sometimes feeling 'down' and 'frustrated' at times about not being able to do things. Analyses of these participants' interviews indicated mixed positive and negative reactions to the psychosocial issues they were facing. For example, both participants were amongst the five individuals with above average body image anxiety, according to their scores on the ABIS. Although both felt that their current lives were fulfilling, they believed that their lives would only be somewhat as good again and that they were, in some ways only, deprived from leading a normal life. Finally, even though both participants felt like they had maintained the same personality they had prior to their amputation, BN remarked that while she was mentally the same, she was still physically different. Both of these participants admitted to feeling some moments of sadness or frustration about their limitations. For example:

“Sometimes I get down now, even though life is good. You think ‘Well, nobody wants me. Nobody cares.’ But they do care about me, and they’ve accepted me now that I can’t do the things that I used to do. They still love me as a mother, but I feel useless because I cannot do the things and help them like I used to. I just get down the days when it’s sore, and I’m only fed up when I can’t get out. It’s the feeling of helplessness, because even though I’m only new to this, I was never sick a day in my life before.” [BN]

“I’m probably doing better than I thought. But at the same time, I probably won’t ever be back up to where I was. Emotionally or otherwise, physically or otherwise. I won’t ever get back up to that level. That’s the one thing you have to accept, much as I dislike it ... it’s frustrating at times. It isn’t nice, having to leave things for others that you can’t do yourself.” [DOD]

Despite the fact that BN admitted to feeling down at times, she remarked that she now felt much better than she had done previously and that, on the whole, she was very happy with her life. In addition, one man, JM who had previously admitted to feeling ‘down’ about himself, was also currently very happy with his life. Both remarked:

“I’ve had so many downers, so much crying, so many trips to the hospital. And I’d thought ‘If this is life, I’d rather be dead.’ The day I joined the wheelchair association was one of the best days of my life. Number one, it got me out of the house, which was very good for me because I was in a bad state of depression at the time. And I got to know people and got to know the real me ... And now this time, eighteen months later, life is very good to me, and I’m very, very glad to be alive, d’you know. I’m very happy with my life.” [BN]

“I know what I have now, and I’m accepting it, and I’m happy to have what I have. There’s people with everything are not as happy as I am. Like, people with money, and all they’re worried about is making more. I don’t care if I hadn’t a penny. That’s the difference, you know. I’m happy enough, now, with the way I am. If I go into the garden or go into the glasshouse, I’ll be quite

happy there. I'm happy as Larry, you know. It's up to yourself what you do, you know." [JM]

Overall, eight participants did not indicate feeling 'down' or 'anxious' to any great extent. Interestingly, most of these participants tended to respond positively to the psychosocial issues they faced. Only one of these experienced above average body image anxiety and did not feel that his current life was full (GD), while the remaining seven participants did think that their lives were currently fulfilling. Moreover, none of the eight participants felt that they were currently being deprived from leading a normal life, and five of them believed that their lives would be as good again (FF, JM, MW, NK, and MG) or somewhat as good (LB). Finally, all of them felt that they were the same person they had been prior to their amputation. Two of these participants described how they had never experienced any sadness or depression as a result of their limb loss. They remarked:

"I'm lucky in the fact that I would be a very positive person. I never really did suffer from being depressed. At any stage of my life, if I got depressed, I'd go to bed. The next morning I'd get up, full of beans, and that would be it, I'd be grand. I would just be a fighter by nature. I would just say 'No, I'm not going to lie down and let this beat me.' I just wouldn't do it ... It's just the way I am. Being negative and depressed would just really annoy me, because you know, there's so much to live for." [NK]

"No way, I never felt down. Once I had the leg off, it was perfect. I'd no pain, really. That was a big thing, now. I lost a lot of blood alright, and they had to take me back up to intensive care for a day. And then I came back down, and I haven't looked back since. In my situation, I had to do it. There was no other way out, and I felt very comfortable doing it. So that was it. I never got down or depressed about it." [MW]

COPING WITH AMPUTATION SEQUELAE

At this stage of their rehabilitation process, participants were still facing a number of psychosocial changes that had occurred following their amputation. Although most participants experienced only 'mild' phantom pain and very little stump pain, just over half of the participants experienced some discomfort with their prosthesis, and just under half of the participants experienced problems with its fit. At this stage, four participants did not feel that they had improved in their walking and five participants experienced moderate to severe body-image self-consciousness. Compared to the previous findings, however, levels of social self-consciousness appeared to have decreased somewhat to the extent that most participants who perceived themselves as being treated differently explained this as kindness or consideration. Moreover, most participants did not appear to be particularly anxious or depressed as a result of the changes that had occurred. Nevertheless, one participant showed 'mild' anxiety symptoms according to his HADS-A and interview responses. In addition, another participant showed 'mild' depression and anxiety symptoms according to his HADS-A, HADS-D, and interview responses.

In looking at these psychosocial issues, it is interesting to consider what coping mechanisms were employed by participants in helping them address and overcome these challenges. Furthermore, it is interesting to assess whether those individuals with depressive or anxiety symptoms tended to have different coping mechanisms than did those who did not appear particularly depressed or anxious.

Appraisals

Acceptance

Throughout the final interviews, acceptance was a common way in which many of the psychosocial aspects of the amputation were appraised. For example, four participants indicated that they accepted their changed body-image, two people accepted the fact that their artificial limbs were not always comfortable, and one man indicated that he accepted his health problems. For example:

“I don’t care if anyone notices that I’m limping. I did, but not now. I’ve been awful embarrassed about things, but I accept it now, and people tell me how great I am, and this, that and the other, so it boosted me up. I don’t care now, now. I think I’m lucky to be walking at all ... I’m beginning to accept myself now for what I am, because I know I’ll never be any different. I’ll always be fat, but there’s nothing I can do about it now.” [BN]

“I’d a bad heart. I only had it in the last couple of years. I’d a heart attack in Beaumont hospital, the time I was in it. A mild heart attack. But I get on with life. If you’re going to go, you’re going to go. It’s as simple as that, you know.” [JM]

Similar to what had been observed throughout the third interviews, only half of the participants indicated that they had accepted their limb loss. For example:

“I’ve put it behind me now. There’s nothing can be done about it. I’m not going to grow another pair of legs. They’re not going to get another pair of legs and fit them to me, unless they’re artificial ones. So, you just have to accept that and do what you can with whatever’s left in your life to live and enjoy it the best you can.” [NK]

“I took it from the word go. I took it, alright. That was it, you know. And I’ve come from it now and that’s it. Not to look back. And that was the attitude. So, I just accepted it.” [MG]

Mixed Feelings and Attributions

Instead of the predominant appraisal of the amputation being one of acceptance, this was now shared equally with mixed feelings, as many participants indicated that even though they accepted losing their limb, they may never get over this. Throughout the third interviews, some participants indicated that ‘getting over the limb’ would imply that they no longer cared about their lost limb, a situation which they did not think could happen. Throughout the final interviews, this suggestion was supported by the

observation that some people continued to miss their limb, even though they had accepted it was gone. For example:

“I still miss it. I’m still looking for it, you know. When you grow up with your legs for that length of time, it’s what you’re used to. I don’t think I’ll ever be in a position where I could adapt to measuring things without it. I’m still doing the same things as if I had the leg, you know.” [DOD]

“I’ve accepted losing the limbs, but you’d miss them. You’d miss them, you know. You take so much for granted. You never think it could happen to you. It’s as simple as that, like, you know. You get the reminders every day, but I don’t let it worry me anymore.” [JM]

“Right now, I really miss it, like. I don’t think about it all the time, but it’s almost like an underlying kind of thing. Like ‘Jeez, I wish I had it back.’ Maybe in twenty years, when I’ve had the leg, when I’ve been an amputee for twenty years and that’s all I can recall, it’ll be different ... I think with being totally comfortable with it, I might have twenty years to go.” [SC]

Thus, because of the conscious or unconscious awareness that the limb was gone and because some people continued to miss their limbs in their daily living, participants indicated that even though they had accepted losing their limb, they may never actually ‘get over’ this. BN and NK explained:

“I’ll never get over losing a limb. But I’ve accepted it. Which is good. What’s the difference? ... The thing about it is, no one wants to be like this. Who’d want to be like this if they had a choice? But I’m happy, because I think I’ve come out good. I’ve adjusted to this, and I don’t know any other way to live now. But of course I’d love to have my leg back.” [BN]

“It’s a peculiar sort of question [i.e. Will you ever get over losing your limbs?] I mean, it’s always there at the back of your mind, when you get undressed at night, or when you get up in the morning that they’re not your legs any longer. I

wouldn't say it causes me any grief or problem or anything. When the actual legs are off, I would think about it. But as I say, I'm well over the thought of losing the limbs." [NK]

In addition to having mixed feelings about acceptance and 'getting over' the limb loss, two participants continued to blame others or to harbour feelings of guilt over having lost their limb. One woman, BN, remarked for the first time that she blamed her doctor for her amputation. One man, GD, sometimes blamed himself for losing his limb. He remarked:

"It never gets easier. Sometimes you blame yourself. Where did you go wrong? I neither drank nor smoked. The doctor said to me "Ah, if you hadn't smoked or drank that wouldn't have happened to you." But when I told them that I never smoked or drank, they go off with themselves. No answers. They're only using the diabetes then." [GD]

Not everyone blamed others for their amputation. One participant, FF, who had previously blamed his doctor for his amputation throughout his earlier interviews indicated that he no longer felt this way. This time he remarked "You can't be going around and saying it was their fault. If it happens, it happens. You're not going to avoid fate." The other participant, PG, was asked to allocate blame in the court case he attended as a result of his accident. He remarked:

"I was in court this week, and what helped me a little bit this week, was that I wasn't held responsible for the accident. The guy came down my side of the road, I flashed him, and he didn't go. I know he didn't mean it either. The judge asked me did I feel strongly about a custodial sentence for the guy involved. I said 'I certainly don't.' And she said 'You can thank Mr. G. now that you're not going down. Because you were going down.'" I certainly wouldn't want anyone to go to jail. And I said in court 'I believe that it was totally accidental.' He just fell asleep. Ah, he's a young lad with a child and going to jail is not going to bring my leg back. " [PG]

Similar to what had been found throughout all of the previous interviews, two men, PG and MG, did not appear to have experienced any particular reaction to having lost a limb. In fact, both men maintained that their limb loss had not ‘hit them’ and that they can never remember experiencing any of the emotions of shock, sadness, disappointment, and grief that the other participants remembered having. Even though it could be argued that lack of preparation prior to amputation could be associated with a worse reaction to limb loss, throughout their final interviews, both men suggested that the absence of any reaction on their part may have been due to the fact that the decision to have their limbs amputated and the operation itself were done while they were unconscious. They remarked:

“I took it from the word go. I was very sick when I found out my leg was taken off. It meant nothing. I was sick anyway, so I accepted it like that. And I said ‘What about it?’ you know. Maybe that’s why it didn’t bother me so much. It didn’t bother me that I mightn’t get better, you know. Maybe the way it happened made a difference. The decision was taken away from me.” [MG]

“I didn’t react. And I’ve often wondered did I react to the leg. I didn’t as such, like. I can’t remember sitting down and crying. It’s not that I don’t cry. I do, like, and I can react ... I think it arose one day [i.e. that he’d had an amputation] because I kept telling my brother that I couldn’t lift my leg. Eventually he said ‘But you haven’t got a leg. Your leg is gone, P. There’s no leg there. You lost your leg in the accident.’ I’d been told several times, but I wasn’t listening. It didn’t sink in. As far as I was concerned, my leg was still there. I just couldn’t cross it over the other one. I was relaxing in hospital. Glad to be alive after all, but I didn’t know I’d lost my leg. So, I was spared that much, as against somebody who has a problem on a Wednesday, and they lose their leg the following Tuesday.” [PG]

Solace and Making Comparisons

One way in which participants appraised their amputation was in a context of “it could be worse.” The conclusion that things could be worse was arrived at through finding solace in their situation, for example, by making such statements as “At least I still have ...” and by comparing their situation with that of other people perceived to

be in more challenging situations. In adjusting to the fact that they had had an amputation, six participants reasoned that they were still alive or that they could have had a more serious illness. As PG said “I’ve been fortunate, lucky and unlucky all in one go. I could quite easily not have got a second chance.” In adjusting to the limitations and restrictions they were experiencing as result of their amputation, four participants focused on what they still had and on what they could still do. GD, for example, remarked “I’m lucky that I have the work I can do. I’m my own boss. I can come in when I want and go out when I like.” Finally, in adjusting to a changed body-image, one woman reasoned that it “was a small price to pay” in that she was still alive and able to move around.

Another way in which a total of seven participants appraised their amputation in a context of “it could be worse” was by non-effortfully comparing their situation with others they perceived to have more severe disabilities. Two participants also compared themselves to younger people. One woman remarked:

“I’ve seen people worse off. In the rehab. Car crashes, strokes, terrible cases. It makes you think ‘God, what have I got to be moaning about.’ There’s always someone else worse off than yourself. Really, really bad, you know. There was one girl there, now, and she couldn’t even move her fingers. She smoked, and she had to have a little device where they could put it into her hand. She was only in her thirties. There was a good few like that. It was terrible. So, it makes you feel thankful for what you have.” [AMcG]

Another comparison that two participants made in appraising their amputation within the context of “it could be worse ...” was comparing themselves in terms of physical and emotional functioning before and after their amputation. One participant concluded that he was the same person, emotionally, that he had been prior to his amputation. The other participant, on the other hand, felt that she had improved as a person. They remarked:

“I’ve come to terms with the limits now, no comment on it. What I say to myself is, I was often fed up with working when I had two legs. And I look at

that now and say 'I'm not limited.' That's a good thing to put in front of you, is that there are good days and bad days when you're perfectly healthy. You would be fed up with work and you would be fed up with yourself, do you know what I mean?" [MG]

"Before I had the leg off, I was a tense sort of person, but it was the life I was living. Since I've come on my own, and I used to get those real panic attacks, oh, they were dreadful. I don't have panic now. Nothing. I'm very brave altogether. I'd face anything. Oh, I've come on in leaps and bounds. Even while you've been coming here, there's been an awful change in me." [BN]

Finding benefit

Another way in which nine participants appraised their amputation within a context of "It could be worse ..." was by seeing something beneficial to have occurred as a result of having an amputation. For example, three people remarked that the amputation had brought their families closer together; three people thought that they were better people for having gone through the experience; two people indicated that they were now free from pain; and one person felt that her quality of life had improved substantially. For example:

"My sickness, I was so bad, it brought the family fierce close together. And they're close since that because they got an awful fright, you know. Losing a limb didn't mean anything to them. It was getting over the sickness was a big thing. Now, with the lads, they're definitely closer to you alright." [MG]

"I've a better attitude to life now. We were sitting in the yard there, now. Some people might take that for granted, but I'd just be delighted to be there, you know. Simple things are good enough now. Even money doesn't bother me anymore. Once I have my health now. Your health's your wealth. Last Sunday, we went for a spin, which before would have been unheard of. We wouldn't have had time to go for a spin. I'd be going nowhere, and I still wouldn't have had time. That never happened before. It's a different attitude to life now." [JM]

“I’m a better person, I would say. You can relate to other people, we’ll say, let it be age or moods. It’s hard to describe it. You can get more intimate with people, your understanding would be better. You can relate to them and listen to their, sometimes trivial, complaints better because you’ve gone through so much yourself. When you hear a person saying there’s something wrong with them, you can listen to them and have sympathy for them, and sympathise with them. Whereas if you don’t experience pain or anything like that, you don’t know what people are talking about.” [FF]

“My outlook on life is different. Better. I don’t worry about things that I used to do. I used to worry about piddling things, nonsense. I used to worry so much about everything. I worried because I couldn’t pay this, I couldn’t pay that. I was a constant worrier. But you see, the one thing this has taught me now is that there’s a lot more to life than worrying about things you cannot do. What’s the point in worrying about it? I’ve accepted I can’t do it, and that’s it.” [BN]

Interestingly, one man noted that it was quite difficult to see anything positive to have come out of his amputation. Giving the matter more thought, he thought of one beneficial event but still concluded that, overall, the negatives outweighed the positives. He remarked:

“Can’t say there’s anything particularly positive. Hard to see what would be positive out of losing your legs. I suppose one thing is that we’ve relocated into town and we’re in a better position than we were as regards the house and accessibility to facilities, and entertainment, and town, and also to getting to work. That’s probably the one benefit to come out of it. But I mean, most of the result would be negative. Okay, you minimise the negativity. Obviously, I get on and do whatever I want to do with my life as much as I can do.” [NK]

Age Reflections

Another way in which five participants appraised their amputation within a context of “it could be worse ...” was by reasoning that the impact of the amputation on their lives was minimal because of their older age. For example:

“You say to yourself, you’ve got your full life behind you ... I would say it would take way longer for a younger person to accept it. But I’d say if they accepted it, they could do wonders.” [MG]

“I wouldn’t feel more anxious about my physical appearance. My age would govern that to a point, you know what I mean. Like, a young person like yourself there, now, or if I was young I suppose I would feel self-conscious. I wouldn’t go into a pub haphazardly dressed now or anything like that, but Sunday night, now, I’ll go up. I wouldn’t get worried about it.” [LB]

Previous Loss Reflections

Another way in which two participants appraised their amputation within a context of “it could be worse ...” was by comparing their amputation with other losses or stressors they perceived as being more serious. For example, GD remarked that experiencing a bereavement was “a lot worse than losing a leg.” In addition, PG indicated that his sight difficulties were worse than having an amputation. He said:

“My eyes upset me. That keeps my mind off the limb loss. With my sight, I think I’d be more effective on the limb as well. Things wouldn’t be as difficult. My sight would be more important, you know.” [PG]

Cognitive Approach Methods

Looking Ahead and Thinking About Problems

During rehabilitation, one Cognitive Approach coping strategy that emerged was that of ‘thinking ahead’ or ‘looking forward.’ This strategy was characterised by such thoughts as ‘don’t look back’ or ‘I must look forward to the future,’ without formulating any concrete plans about particular obstacles or problems. Throughout the second and third interviews, this strategy evolved into actively thinking ahead about particular, concrete problems that may be faced. Although several people adopted this strategy shortly after rehabilitation, only three people continued to use this approach by the third interviews. By the end of the year, only one person indicated using such a strategy. For example:

“What I do is, I plan out the work I have to do a little bit better and work to suit the way I am, you know. I need three levels to do things. Over my head, the balance isn’t great. If I go back, I could go backwards or forwards, you know. But at, we’ll say, chest level, I’m grand. And then, as I say, I’ve to plan it out if I’ve to stoop. I’ve to sit down and drag myself along the ground. It’s just to plan it out.” [DOD]

Social Comparisons

Although it has previously been maintained that Social Comparisons are Appraisals, rather than effortful coping strategies specifically used to increase emotional well-being, two people indicated during their third interviews that they sometimes deliberately used downward social comparisons as a coping mechanism. Interestingly, although SC had been one of these individuals, he indicated at his final interview that use of such social comparisons sometimes had a negative effect on his mood. He remarked:

“it makes me feel a little better, like ‘Oh Jeez, it could have been worse.’ But often, it makes me feel sad that someone else doesn’t have any legs or doesn’t have any arms, or cancer, whatever, like.” [SC]

During the first two interviews, upward social comparisons had been used by many people in adapting to their prosthesis and learning to walk. Throughout the third interviews, however, these comparisons were not so much in evidence. Although three participants did note other people’s superior progress with walking, each of them remarked that these people fared better because they were younger, had experienced more favourable circumstances, and had below-knee amputations rather than above-knee amputations. Throughout the final interviews, only one man compared his walking to another person with an amputation who appeared to have rehabilitated successfully. Again, this man indicated that the person he was comparing himself to had more advantages than he had. He remarked:

“My neighbour next door, he has the same problem as I have, only his left foot is gone, and he has a prosthesis as well. But I can see him walking much better

than I can. But he has a full foot on the other leg, which to me sounds way better if you can have it. I've toes missing on my other foot." [DOD].

One reason as to why upward coping strategies were no longer in use is that experience in having an amputation and continued practice on the artificial limb may have meant that participants at this stage had become aware of the potential difficulties they were facing and the implications of having an above-knee rather than a below-knee amputation. Thus, they may have come to realise that earlier comparisons with younger or below-knee amputees were not feasible. In support of this, four participants remarked that since their amputation, they had learned more about their limitations and what they needed or required with regards to their prosthesis. For example:

"I can ask questions now about the prosthesis, because I'm familiar with one, do you know what I mean? Before, I was ignorant of everything and just took what I got. But now I can ask 'Can I get a lighter one?' or 'What type of belt is that?' and things like that." [MG]

Cognitive Avoidance Methods

Not Thinking About Things

Throughout the third interviews, only two participants appeared to use the Cognitive Avoidance strategy of 'not thinking about things' to help cope with issues or worries that arose as a result of having an amputation. Throughout the fourth and final interviews, two participants used this coping. The general conclusion with regard to using this Avoidance method was that fretting or worrying about their problems would not help or resolve them. For example:

"I often said to my wife 'It's the eternity for my leg. It's never, never going to come back, no matter how long I live,' you know. The leg is gone and that's it. Something like that. I don't like to think too deep into it, but that's as near, and when I start thinking that deep, I switch off. That's going off down to the next stage and that, you know." [PG]

“I’d worry about things a lot before. But not as much now. Because I realise that I’m not going to change things by worrying about them. If you’d told me that twenty years ago, I wouldn’t have believed you, I’d think worry was a great thing, you know, that you’re going to solve everything by it. You’re not. You’re not going to solve it.” [DOD]

Emotional Approach Methods

Emotional Determination

One of the most common Emotional Approach strategies was Emotional Determination. In general, this strategy was similar to that observed by Watson et al. (1999) in cancer patients and involved giving oneself a mental ‘talking to’ in order to maintain motivation and courage and in helping to maintain emotional well-being. Throughout the final interviews, four people used Emotional Determination in coping with thoughts about having had an amputation, in coping with the limitations and life changes that had occurred after their amputation, and in maintaining courage and psychological well-being. For example:

“It’s all up to your attitude. I mean, if you want to sit there, you could sit there. But I just couldn’t. I’ve always been such an active person. And I couldn’t take that. I couldn’t take that at all. So, it’s all about attitude ... One day, I just said to myself ‘Well, B., this is you. Like it or lump it. Get on with it ... I’m determined this thing is never going to beat me, you know. I’ve such a great attitude, and I’m so determined. I say ‘No matter what happens, that leg will never beat me.’ And unless I really have to give in, that leg will not beat me.” [BN]

“One way I’d look at it is say ‘Well, this happened to me. You don’t know how many more years you’ve got left. Maybe you’ve got a second chance at it.’ I’m damn sure I’m going to enjoy it, the best I can, every minute of it. So, that’s just the way that it is, and that’s all there is to it. What’s behind you is behind you, you know. And what’s there in front, you should be getting on and taking it on. And enjoy it the best you can. Every day brings new challenges. Either you let them get on top of you and murder you, or else you just get on and think your

way around them ... I would just be a fighter by instinct, by nature. I would just say 'No, I'm not going to lie down and let this beat me.' I just wouldn't do it. I've absolutely no time for self-pity." [NK]

"Nobody takes your leg off for fun. It's extremely serious, and it's normally taken off to save your life, or if you've had an accident. The reason is, they're saving your life anyway, and it's not for fun. So, try and get on with it. It's certainly not easy. So, you just have to weather the storm for a while." [PG]

Emotional Social Support

Another Emotional Approach coping strategy that five people used in maintaining emotional well-being and courage following their amputation was Emotional Social Support.

"A wee lassie came into work one day, and she nearly died because she saw me there. She hadn't seen me in twelve months. She was delighted to see me there. And it's great, you see, children can be very, very hard. But thanks be to God, I've never come across any of them yet. And that gives you a boost, you know, to get back into that circle again. And once I get back in there with the help of God, I'll be flying." [JM]

"People tell me how great I am, and this, that and the other. So, that boosts me up ... I am a soft sort of a person. I would feel hurt if they said something about me, but I haven't come up against that. My friends and that, they've been awful good to me. Very understanding. Very helpful." [BN]

"It was a bit of a hard battle alright, the last fourteen months. And you have to believe, well, people would encourage you, and this was great. I didn't think I could be as mobile as I am." [DOD]

Religion

Throughout the third interviews, two participants indicated that religion was an important coping mechanism for them. At this stage of the study, three participants, FF, LB, and JM, indicated using religion as a means of coping. Of these three

individuals, JM mentioned religion as a coping strategy for the first time in the study. Since he had been on a pilgrimage to Lourdes, he indicated that he felt much more at ease in social circumstances and he no longer felt as self-conscious about his body-image. In talking about Lourdes, he said "It was a really great experience. It helped me a lot, you know, getting back into the circle again, you know." In this case, therefore, it would appear that religion served as a social support as well as an external resource.

Emotional Avoidance

Joking

Throughout the third interviews, only one man appeared to use the Emotional Avoidance strategy of joking about his amputation in order to hide his distress from other people and to "put on a front." Throughout the final interviews, this "deflection" strategy did not appear to be used by anyone.

Behavioural Approach Coping

Taking Action

Throughout the third interview, seven people used a "Taking Action" coping strategy, which involved taking particular steps or actions to overcome any physical limitations or obstacles that were faced in daily living. Throughout the final interviews, four people used this strategy in developing new interests and activities; two people used this strategy in testing their limits and restrictions, and one person used this strategy in finding out all he could about getting the type of prosthesis he wanted. For example:

"I'm going to build a greenhouse. I put the foundation down yesterday. It's only a small yoke. It's not going to flood the market with plants now or anything like that. But I'll plan it out and get a few tomatoes and cucumbers. There'll be always something to do in it, or I'll make something to do, to occupy my mind. It'll be a bit of an achievement, and it'll keep me going until Christmas." [DOD]

"Just for the chance, there, yesterday, I was over with my workmate, and I climbed two steps of a ladder. Just to see could I, and I could. I could stand. I

don't know how long, but I could stand it. And I felt great, would you believe that. I was on a high." [MG]

Earlier in the chapter, it was found that most participants had experience of being treated differently by others in the sense that people were overprotective of them or were embarrassed upon realising that they had an amputation. Three participants used a Taking Action strategy in dealing with these reactions, one of whom stated:

"If they really stare and just keep staring and don't look me in the eye or just like stare at the leg. I just wanna smack them. 'Who taught you to do that?' like, you know. Ages ago, one guy was just staring and staring and I just walked up and said 'Quit it, quit staring, it's rude', and he's like 'Oh.' He just snapped out of it all of a sudden." [SC]

Using External Resources

Many participants used External Resources in order to cope with various aspects of their amputation. Throughout the third interviews, seven participants perceived their prosthesis as a means of coping with body-image anxieties and restoring a 'normal' body image. Throughout the final interviews, only three people indicated that they perceived their prosthesis in this way. One man, PG, remarked:

"When I get this limb right, I'll get the gait right, it will be better. It's a more natural type of walk, you know. Even when my wife and I went for a walk at night and I'd ask her 'How's the walk?' She said 'Not too bad.' It looks more natural. With the other one, I've a full limp, you know. The prosthesis helps you look fairly normal." [PG]

Throughout the third interviews, three participants had used their employment as a means of maintaining emotional well-being. Although these participants had adjusted to being back at work by the final interviews, one participant who had returned to part-time employment indicated that throughout his rehabilitation, returning to work had been his main goal and that this had kept up his courage and motivation. Since returning to work, his confidence had increased. He remarked:

“The confidence I have now is in getting back to work and getting my car and getting out. From the word go, I set up my goals. And from the word go, my goal was to get back to work. And that’s what has me going so far. And to get a car. My goal from the word go, when I lost the first limb, was to get back to work. And when I lost the second one, ‘By Jesus,’ I said ‘I am going back.’ It was not when am I going back. It was ‘I am going back.’” [JM]

Joking

During the final interviews, only one man indicated that he used joking as a Behavioural Approach method in order to foster social relations and to ‘break the ice’ about having an amputation. He remarked:

“The first thing I told a woman, she was going in for an amputation, she’s only about fifty, ‘Here’s one thing,’ says I ‘You must remember when you get off the leg, you won’t be able to play any more football.’ So, that broke the ice, straight away.” [JM]

This form of joking was placed under Behavioural Approach coping because it was perceived as an active way of acknowledging the fact of having had an amputation and of making efforts to foster social relationships and help people feel at ease at meeting someone with an amputation for the first time.

Practical Social Support

Throughout the third interviews, six participants indicated that they used Practical Social support in helping them cope with practical problems they faced as a result of their amputation. Throughout the final interviews, four participants indicated using this strategy. As LB remarked: “I would depend on my wife and the lads here to do a job for me. Maybe I might be a bit lazy myself, I should go up and do it. I’d get up and do it myself, but I wouldn’t refuse help.”

In one participant’s case, it appeared that too much practical support may have been counterproductive. AMcG remarked that her brother continued to do everything for

her around in their home, and as a result, she had not tried and was outwardly discouraged from attempting any activities. She remarked:

“My brother still does everything for me. Every blessed thing. I can’t even set the table. He won’t let me. He’s nervous, I think. He’s real overprotective. Brings me breakfast in the morning. And he opens up the blind in the windows, and he’ll give me the weather forecast. He does every blessed thing. My laundry and all. Irons the blouses better than I’d do them myself. The whole lot. I don’t know whether I’d be able to do them. I haven’t even tried.” [AMcG]

Throughout the first interviews, it was observed that several participants felt guilty about accepting practical social support from other people, and they worried that they were putting others under some sort of a burden. Throughout the second and third interviews, however, this reluctance to accept practical social support appeared to have diminished, with only three and two participants, respectively, remarking that they did not want to impose on others. Throughout the final interviews, similar findings were observed in that only three participants indicated that they did not want to put others under a burden.

SUMMARY AND DISCUSSION

Amputation-Related Sequelae

The prevalence and severity of phantom limb pain remained similar to what had been observed in the second and third interviews, with eleven people continuing to experience phantom limb pain to some extent. The majority of these individuals experienced their pain as ‘mild’, while two people described it as ‘discomforting’ and ‘horrible’, respectively. One of the individuals with ‘mild’ pain and the person with ‘horrible’ pain indicated that their pain interfered ‘a little bit’ and ‘moderately’ in their lives to the extent that it sometimes prevented them from sleeping. Although the rate of phantom limb pain was similar to what had been observed three months earlier, the number of individuals who experienced stump pain diminished between the third and fourth interviews from six to three. Levels of stump pain for these three were ‘mild’, ‘discomforting’ and ‘distressing’, respectively. Only one man, SC,

indicated that his stump pain 'moderately' interfered with his daily living in that when it occurred, he would either have to use a cane when walking or abstain from walking altogether.

Dissatisfaction with aesthetic aspects of their prosthesis decreased from four participants to two participants. However, many people continued to find their limb uncomfortable, and almost half remarked that they were also experiencing fitting difficulties with it. Despite experiencing such problems, nine people were either 'satisfied' or 'very satisfied' with their artificial limbs, and the majority indicated that they had adjusted to wearing their prosthesis. Similar to previous explanations for this contradiction, it was argued that for these individuals, the perceived usefulness of the limb and gratitude for what the limb enabled one to do may have been more important in determining overall satisfaction than either comfort or fit. In addition, the contradiction between overall satisfaction and comfort/fit ratings could be due to the fact that participants were aware that the fitting difficulties were not due to the leg itself, but rather, to their stump shrinking. The fact that they were due to have a new limb within the next few months may have meant that they were more willing to tolerate the disadvantages of the prosthesis because of its inherent benefits.

In terms of walking, participants' self-rated limitations increased throughout the fourth interviews. Thus, four participants now felt that they would be 'a little limited' in walking one hundred yards, seven participants perceived themselves as 'a little' or 'a lot' limited in walking half a mile, and no participants felt that they could walk over a mile without limitations. These observations could be due to the fact that participants' improvements in walking may have been accompanied by increases in their expectations. That is, with increased expectations, they may have become more critical about their progress. Thus, even though they may have objectively improved, their sense of achievement from walking may not have been the same with increased critical judgements. Regardless of whether participants perceived themselves to have improved in their walking or not, however, almost every individual faced at least one significant obstacle throughout their rehabilitation. Such obstacles included a fear of falling, walking on difficult terrain and hills, bad weather, or health problems.

Appraisals, Psychosocial sequelae, and Emotional Well-Being

Similar to what had been observed throughout the third interviews, Acceptance of amputation was only observed amongst half of the participants. Instead, over half of the participants, including three of those who had accepted losing their limb, indicated that they may never entirely get over losing a limb. General reasons for thinking this way appeared to revolve around the fact that they still missed their limbs and were continuously reminded, on a conscious or unconscious level, that their limb had been amputated. Despite the fact that many people had mixed feelings about having lost their limb, most people continued to appraise the amputation within a context of "it could be worse." For example, most participants thought that at least one positive event had occurred as a result of their amputation. Furthermore, most people compared themselves to other people they perceived to be in more difficult or challenging situations, and some perceived the impact of the amputation on their lives as minimal because of their older age or because they had experienced other losses or stresses in their lives.

Throughout the final interviews, five people continued to experience body-image self-consciousness. Although such consciousness was associated with aesthetic dissatisfaction with the prosthesis throughout the previous interviews, only two of those with above average body-image self consciousness were dissatisfied with aesthetic aspects of their prosthesis. Nevertheless, the role of the prosthesis in body-image anxiety is still indicated in some respects, as another other two people with above average body-image anxiety were the only two to indicate that they wanted their prosthesis to give them a 'normal' appearance.

Throughout the second and third interviews, experiencing phantom sensation was associated with a sense of 'shock' upon realising that one had an amputation. Both of these experiences were also associated with above average levels of body-image anxiety. Thus, it was argued that while phantom sensation is being experienced, it is more difficult to incorporate the physical reality of an absent limb into the mental body-schema. In this way, phantom limb sensation may prevent the individual from mentally adjusting to an altered body-image, with the result that participants with phantom sensation experience a shock when they realise that their mental body-image

does not match their perceived body-shape. Because of this, the areas of self-consciousness that they indicated (e.g. not wanting to look in the mirror, not wanting to be seen without the prosthesis, not wanting others to know they have a prosthesis) could serve to stress the incongruence between the mental and perceived body-shape. Throughout the final interviews, this explanation was partly valid. Three of the participants with above average body-image self-consciousness experienced phantom limb sensation. However, only one of these was amongst the three participants who continued to experience a shock upon realising that they had an amputation. Thus, phantom sensation is not necessarily associated with either body-image anxiety or experiencing a sense of shock. However, the three participants who experienced a shock upon recognising their amputation were amongst the five with above average body-image self-consciousness. Furthermore, one man who had previously experienced both body-image anxiety and this sense of shock remarked that he no longer experienced either. Thus, experiencing a shock may be associated with body-image anxiety. It could be argued that each of the areas of body-image self-consciousness experienced by those with above average body-image anxiety serve to stress the incongruence between body image and perceived body-shape.

Similar to what had been observed throughout the third interviews, participants were less likely to stress their abilities and more likely to stress that because of their amputation, they could not engage in all of the activities they would like to. In addition, many described feeling 'restricted' or 'limited' in what they could do. Those who focused on these limitations and restrictions were amongst the nine participants who did not think or were unsure about whether their lives would be as good again. On the other hand, a focus on abilities or disregard for limitations was associated with thinking that life would be as good again, that life was currently fulfilling, and that there was no deprivation from leading a normal life. For the first time, however, the majority of participants believed that their lives were fulfilling, despite the fact that many believed their lives would not be as good again. In coming to this conclusion, it was evident that even though restrictions and limitations were recognised, they had been incorporated into participants' lifestyles so that a focus on abilities became more important than a focus on disabilities.

Similar to previous findings, only a small number of participants were sometimes reluctant to talk about their amputation. Furthermore, participants continued to experience 'pitying' reactions from others, strangers staring at them, others being embarrassed upon discovering their amputation, or others rushing to do things for them. In addition to being treated differently by other people, half of the participants sometimes experienced difficulties and accessibility problems in getting out. As a result, four people felt that they were limited in visiting friends, and two thought that they had greater difficulties in maintaining friendships. Although many of the participants also felt dependent on other people, for the first time in the study, the number of those who felt dependent on others decreased. Moreover, despite the fact that three people had admitted to feeling socially awkward and embarrassed throughout the third interviews, such experiences were not in evidence throughout the final interviews. Furthermore, compared to the finding three months earlier that six people were reluctant to interact with other people because of their amputation, only two participants continued to feel this way at the final stage of the study. The remaining ten participants indicated that they enjoyed going and socially and meeting others, despite the accessibility problems and difficulties they faced.

Participants' sense of self and their sense of self

Compared to what had been observed throughout the third interviews, the majority of participants now considered themselves to be the same person. For the first time, restrictions and feeling 'disabled' were not important determinants of identity. Thus, many of those who considered themselves as 'disabled' also considered themselves to be the same person they had been prior to their amputation. Moreover, of the three people who did not consider themselves to be the same, personality factors were equally as important in assessing sense of self as were physical factors.

Participants' sense of self and their sense of self

Overall, most of the psychosocial difficulties that participants were experiencing in the previous study appeared to have somewhat abated. Although some people continued to experience body-image anxieties, most people felt that their lives were currently fulfilling, despite thinking that they may never be as good again. In this way, a focus on abilities and what one could do were brought to the fore in determining fulfilment. In addition, the majority of people, once more, believed that they were the same person they had been prior to their amputation, regardless of their

restrictions and limitations. Moreover, with dependence on others appearing to decline, with most people, again, enjoying participation in social activities, and with fewer people thinking that their friendships were suffering as a result of their limitations, their social lives appeared to have resumed and improved. In keeping with the finding that psychosocial difficulties appeared to have declined somewhat, participants well-being appeared to improve according to their scores on the HADS and according to their own thoughts on their emotional well-being. The only two people who continued to have some difficulties were the two younger participants who had acquired their amputation as a result of trauma.

Based on these findings, it would appear that at the final stage of the study, participants were well on their way to 'learning to live with the altered self' (Morse, 1997). For the first time, restrictions and limitations were no longer important in determining either sense of self and identity. Furthermore, considerations of restrictions and limitations were disregarded in thoughts of whether life was currently fulfilling. Overall, these findings suggest that throughout the final interviews, participants had made significant steps towards adjusting to their amputation and incorporating its sequelae into their lifestyles and sense of self.

CONCLUSION

Similar to what was observed throughout the first, second, and third interviews, these qualitative interviews illustrate the importance and dynamic interplay of the various demographic, personality and coping, amputation, and environmental factors in psychosocial adjustment to amputation. Using Livneh's (2001) conceptual framework, the importance of personality factors and coping mechanisms, amputation-related factors, and environmental factors on adjustment to amputation were demonstrated. *Environmental* factors were found to be influence both physical and psychological adjustment to limb loss. For example, environmental barriers to physically adjusting to a prosthetic limb, including uneven ground, difficulties accessing places, and crowds, meant that some people experienced difficulties in using their prosthesis. In addition, the difficulties experienced in accessing places meant that some participants preferred to remain at home, rather than go out socially,

for fear of being a burden on others or the centre of attention. Environmental factors may also have been associated with the increase in conflicted feelings that participants had with regard to their amputation; with their return to the 'real world', the impact of the amputation on lifestyles and limitations was brought to the fore. Thus, wholehearted acceptance of the amputation diminished, while conflicted feelings regarding acceptance of and adjustment to an amputation emerged. However, a shift in values appeared to have occurred such that personality factors became much more important in determining a sense of self than 'disablement' factors. Furthermore, an emphasis on abilities and on current fulfilment became more important in determining quality of life than restrictions and limitations. These findings reflect Wright's (1983) theory of adjustment to disability, in which previous values that were held prior to the disability are subordinated, while new emphasis and values are placed on what one can do, and sense of self and personality are more important.

Amputation-related factors may also have impacted on adjustment to amputation. In terms of amputation cause, for example, the two men with trauma-related amputations were the only two people with clinically significant HADS-A and HADS-D scores, and both men, again, had the highest body-image anxiety according to scores on the ABIS. Furthermore, both men were also the only two people to indicate that they had not yet adjusted to wearing their artificial limb. Finally, the *demographic* factor of age may have had an impact on adjustment to amputation. As was observed throughout the first three interviews also, many of the older participants appraised their amputation as having less of an impact on them than if they were younger. Furthermore, in addition to the fact that the two men with trauma-related amputations appeared to have a relatively poorer adjustment to amputation, it could be argued that their younger age may also have been a factor in this adjustment as well as the cause of their amputation.

Overall, this qualitative study indicates the dynamic nature of adjustment to amputation in that several changes were again observed in the three months since the previous interviews had taken place. Analyses of interview data revealed several changes in amputation-related and psychosocial factors. These changes in stump pain, body-image anxiety, adjustment to limitations, lifestyle, and identity indicate that the

process of adjusting to an amputation is a complex one that involves a dynamic interplay of demographic, personality and coping styles, and amputation-related factors. In choosing a qualitative, longitudinal methodology, the nature of these changes over time can be explained and interpreted within context of the individuals' lives and experiences.

CHAPTER 7

DISCUSSION

CHAPTER 7

DISCUSSION

CHAPTER OUTLINE

This chapter discusses cross-sectional and longitudinal findings of each of the amputation-related and psychosocial-related sequelae of amputation.

AMPUTATION-RELATED SEQUELAE

Phantom Limb Pain (PLP)

Retrospective reports on the prevalence and intensity of phantom pain immediately after amputation revealed that it had been quite intense, with many people using words such as 'horrible' and 'terrible' to describe their pain experiences during this time. Shortly afterward, however, they remarked that there was a subsequent decline in phantom pain that continued until three months after their rehabilitation. After this, the prevalence and intensity of phantom pain appeared to be fairly constant throughout the remainder of the year such that only one or two people continued to experience severe or discomforting pain. The remaining respondents used words such as 'harmless' or 'it's nothing, really' to describe their pain experiences during this time.

The observed reductions in and subsequent stabilisation of phantom limb pain prevalence and intensity are consistent with previous findings (e.g. Jensen et al., 1983, 1985; Carlen et al., 1978; Steinbach et al., 1982). For example, Jensen et al. (1983, 1985) found that rates of phantom pain in their study reduced from 72% to 65% between eight days and six months post-amputation, but had only declined by 6% up to two years later. Similarly, Carlen et al. (1978) and Steinbach et al. (1982) found that rates of phantom limb pain did not significantly change between six months and five years post-amputation. Physiological and psychological mechanisms may explain the initial post-amputation decline and subsequent levelling off.

In examining physiological reasons as to why phantom pain reduced, it is possible that prescribed medications did not play a significant role. Overall, only eight participants indicated that they were taking medication for their phantom pain at the beginning of the study. However, phantom limb pain rates and intensities reduced

regardless of whether medication was being taken or not. Other physiological explanations for the initially observed reductions in phantom pain revolve around current research on the relationship between phantom limb pain and neural plasticity. Several studies and case reports have confirmed the phenomenon of referred sensations in people with upper-limb amputations (e.g. Halligan et al., 1993, 1994; Yang, Gallen, Schwartz, et al., 1994; Knecht, Henningsen, Elbert, et al., 1995, 1996; Knecht, Henningsen, Höhling et al., 1998; Doetsch, 1997; Borsook, Becerra, Fishman et al., 1998; Grüsser et al., 2001a). In general, referred sensations are phantom limb sensations which are induced by stimulating another part of the body (Cronholm, 1951). It is thought that these referred sensations are due to an invasion of adjacent somatosensory areas into deafferented regions that previously served the now amputated limb (Ramachandran, Rogers-Ramachandran and Stewart, 1992). Interestingly, these studies and case reports have shown that there is a distinct topographical relationship between the trigger points and the sensation referred to the phantom limb shortly after amputation. However, this relationship breaks down over time such that there is no discernible pattern observed between those areas on the body, specifically the face and chest, that elicit phantom sensation and the site of the elicited upper-limb phantom sensation (Ramachandran et al., 1992; Halligan et al., 1994; Doetsch, 1997; Knecht et al., 1998). The particular relevance of these findings for the occurrence of phantom limb pain is that a positive correlation between cortical reorganisation and the number of referred sensations for painful stimuli has been found (Knecht et al., 1995, 1996, 1998a; Grüsser et al., 2001a). If the phenomenon of referred sensations is to be taken as an index of cortical reorganisation, then the breakdown in the topographical relationship between trigger points and the referred sensation would suggest that, over time, cortical reorganisation settles down and becomes undiscernible. If cortical reorganisation is associated with phantom pain (Knecht et al., 1995, 1996, 1998a; Grüsser et al., 2001a), then its occurrence in the first months following amputation is likely to be associated with intense phantom pain. Furthermore, its 'settling down' may be associated with the observed finding that phantom pain settled down for most people in the later months after their amputation.

Two psychological explanations for the observed reduction in rates and intensity of phantom limb pain revolve around the relationships among emotional stress, anxiety

and pain. Experiencing an amputation is a traumatic event for any individual (Friedmann, 1978), and findings in the present study have indicated that during this time participants had to cope with a variety of emotional reactions and social and physical changes. Moreover, the period shortly after return from rehabilitation is also described as a stressful period (Glass, 1994), and findings in the present study have revealed that this phase is characterised by adaptation to a prosthesis, limitations, and lifestyle changes. Long-term memory of the events leading up to the amputation has been found to relate to the occurrence of phantom limb pain (Angrilli and Köster, 2002). Furthermore, psychological stress, upset or “excitement” have been widely cited as precipitating or aggravating phantom limb pain (Jensen et al., 1983, 1985; Sherman and Sherman, 1983; Sherman et al., 1984; Sherman and Sherman, 1985; Steinbach et al., 1982; Pilowsky and Kaufman, 1965; Bailey and Moersch, 1941). Thus, because the events prior to amputation are likely to be fresh in participants’ minds shortly after amputation, and because the first few months after amputation and rehabilitation are likely to be stressful for individuals, their phantom pain is likely to be exacerbated during this period. However, after the initial post-amputation and post-rehabilitation phases, participants’ lives were shown to become more routine as they were adapting to their prosthesis, learning to walk, and becoming more mobile. The restoration of a new order to their lives would suggest that the psychological and lifestyle conditions that could potentially provoke anxiety, and phantom pain as a result, would decline.

The second psychological reason for the reduced reports of phantom limb pain in the latter half of the year in the present study revolves around participants’ cognitive responses to phantom pain itself. The overall experience of phantom pain shortly after an amputation is an extremely anxiety-provoking experience (Sherman, 1994a), an observation that several participants made in the present study. In fact, some participants retrospectively reported that after they had questioned a doctor or a nurse about their phantom pain, they were much relieved and noted a subsequent decrease in their pain. Since increased stress and catastrophising thoughts about phantom pain are associated with increased levels of such pain (Arena et al., 1990; Hill, 1993; Jensen, M., et al., 2002), again, adaptation to experiencing phantom pain, reassurance that the pain was normal, and reducing phantom pain due to the aforementioned

psychological and physiological factors may have further maximised conditions in which pain could decrease.

Regardless of the intensities of phantom limb pain, it did not appear to interfere with the daily lives of the majority of respondents throughout the year. In fact, only one or two people thought that their phantom pain impeded, to some extent, their social activities or affected their quality of sleep. This finding is consistent with those of several other studies investigating the effect of phantom limb pain on daily living. For example, Randall et al. (1945) contended that phantom pain was not as important an aspect of amputation as is general adjustment to amputation. Parkes (1973) reported that none of his sample regarded phantom pain as a major cause of persisting disablement. Steinbach et al. (1982) found that phantom pain was not associated with degree of disability, employment or change of profession. Wilkins et al.'s (1998) study of children with amputations reported that phantom limb pain either did not interfere or caused little interference with daily activities. Houghton et al.'s (1994) survey indicated that only 22% of respondents believed that their phantom pain interfered with their rehabilitation. Wartan et al. (1997) found that 68% of those with phantom pain did not seek treatment because the pain was not bad enough, frequent enough, or had disappeared entirely. Gallagher et al. (2001) found that the majority of their respondents rated their phantom pain as interfering "not at all" or "a little bit" in their daily lives. Finally, a series of studies comparing bothersomeness ratings of phantom pain with stump pain and back pain (Smith et al., 1999; Ehde et al., 2000; Jensen, M., et al. 2001) revealed that back pain caused significantly more problems in the lives of respondents than did phantom limb pain (Jensen, M.P. et al., 2001). In fact, Ehde et al. (2000) went so far as to conclude that phantom limb pain is "not particularly bothersome" and that future research should concentrate on the impact that such pain has on the person's quality of life and future functioning.

Stump Pain

During rehabilitation, most of the participants admitted to experiencing some discomfort in the stump. Interestingly they did not perceive this as "stump pain" *per se* at this stage. Instead, they appeared to accept this discomfort as something to be expected and, as such, nothing to be particularly bothered about. Three months and nine months later, however, participants were much more likely to indicate 'yes' to

experiencing stump pain. At these stages, some participants remarked that the pain was bad enough to wake them up at night, while others claimed that banging the stump, stump skin grafts, walking on the stump, or over-use of the prosthesis caused or aggravated their pain. Nevertheless, by the end of the year, the number of individuals who experienced stump pain decreased again so that only three participants continued to report having such pain. Overall, even though rates of stump pain showed an initial increase during the first three quarters of the year and a decline thereafter, at most, stump pain was experienced by only half of the participants.

When they were interviewed during rehabilitation, it had been an average of four months since their amputation. Thus, the low reported rates and intensities of stump pain at this time are consistent with previous reports (Nikolajsen et al., 1997; Jensen et al., 1983). In explaining these initial low rates, two explanations can be put forward. First of all, participants' expectations for discomfort while learning to walk may have played a role. In previous studies, it was found that individuals who were anxious about experiencing more pain prior to a pain event actually reported lower levels of pain following the event (Arntz, van Eck, and Heijmans, 1990). In another study examining post-surgical pain, accurate information about expected pain levels prior to an operation were associated with lower levels of reported post-surgical pain (Wallace, 1985). Furthermore, in an experimental study examining the relationship between cognitive variables and expected pain, underprediction of pain was associated with higher levels of catastrophising, and catastrophising about the pain was associated with higher levels of emotional distress (Sullivan, Rodgers, and Kirsch, 2001). In the present study, participants' realistic expectations of pain post-amputation and pain associated with learning to walk may have been associated with their initially reduced pain reports. Because they expected pain while wearing their prosthesis, they may have been more likely to make realistic appraisals about expected pain and less likely to catastrophise their pain experience.

A second reason as to why participants experienced minimal stump pain at the beginning of the year could be the influence of distraction and anxiety on reported pain (e.g. James and Hardardottir, 2002; Janssen and Arntz, 1996; Arntz and DeJong, 1993; Al Absi and Rokke, 1991). During their rehabilitation, participants were faced with a variety of tasks, the foremost being learning to walk with a prosthesis.

Learning to use a prosthesis is a daunting task that requires an intensive use of energy (Huang et al., 1979; Waters et al., 1976) and concentration (Miller et al., 2001). While learning to walk, some participants remarked that they were anxious of falling, a finding which has been reported in other studies (Miller et al., 2001). Such intense focus on learning to walk may have meant that participants were distracted from attending to pain associated with wearing the prosthesis, a suggestion which is in keeping with previous reports on the effect of distraction on perceived pain (e.g. James and Hardardottir, 2002; Janssen and Arntz, 1996). Furthermore, anxiety directed towards falling, rather than towards the source of pain, may have distracted individuals away from stump pain. This suggestion is consistent with experimental findings that anxiety relevant to the source of pain exacerbates pain reports, whereas anxiety directed away from the source of pain reduces pain reports (Al Absi and Rokke, 1991). Thus, focusing on learning to walk and being anxious about falling may have distracted the participants attention away from experiences of stump pain.

Although these factors may have kept rates of stump pain at a minimum in the beginning, they may not have been sufficiently present during the first nine months after participants returned home from rehabilitation. In support of this, none of the participants indicated that they 'expected' to experience stump pain in the months following rehabilitation. Thus, while they were willing to tolerate pain in the early stages of their rehabilitation, the continuation of discomfort may have become bothersome after a while. Furthermore, the effect of distraction in minimising stump pain may also have diminished during the nine months following rehabilitation. Despite the fact that individuals continued to have a fear of falling, they improved in their walking and in their use of their prosthesis [see Learning to Walk below]. Thus, the intense focus on walking that was present in the beginning, and that likely distracted attention away from stump pain, is not likely to have been present during the later stages of the year.

In addition to the fact that factors associated with reduced stump pain had decreased, factors associated with increased stump pain may have increased in the nine months following rehabilitation. During this time, participants were engaging in increased walking distances [See Learning to Walk below]. At the same time, several people

were either given a new prosthesis or were being measured for a new limb because their existing ones had become too big. Since extended use of the prosthesis (Davis, 1993), fit of the prosthesis (Davis, 1993) and prolonged walking (Smith et al., 1995) are all associated with increased levels of stump pain, risk factors for stump pain had obviously increased during this period.

The decrease in stump pain towards the end of the year may have been due to the fact that, at this stage, participants had become more used to wearing their artificial limb and had recognised their limits in walking. In support of this, respondents were keen to stress during the early stages that they were 'testing their limits' in walking. Towards the end of the year, however, some remarked that they now knew what their capabilities were and did not want to expand on these much further. With such recognition of limitations, participants' reduction in offending activities would have caused a subsequent decrease in stump pain.

Overall, the main causes of stump pain in the present study included banging the stump, wearing the prosthesis, and walking. These are among the six most common causes discussed by Davis (1993). Regardless of the rates of stump pain that were experienced, however, only one or two participants indicated that such pain interfered with their learning to walk. These individuals indicated that whenever they experienced stump pain, they had to rest, which thus prevented them from engaging in activities they would otherwise be doing. The manner in which stump pain interfered with participants' lifestyles has been previously reported. Amongst older amputees, for example, Pohjolainen and Alaranta (1991) found that increased stump pain was associated with reduced outdoor walking and reduced walking distance. Amongst younger people with amputations, Steinbach et al. (1982) reported that a greater number of stump pathologies was associated with decreased satisfaction with rehabilitation outcome. In addition, Gallagher et al. (2001) found that respondents with stump pain showed significantly poorer adjustment to their physical limitations than did respondents without stump pain. Moreover, Smith et al. (1995) reported that 75% of their respondents, aged 36 years on average, indicated that they could only walk a certain number of steps a day, after which their residual limb would hurt.

Adapting to the Prosthesis

Throughout the course of the study, aesthetic satisfaction with the artificial limb varied considerably. During rehabilitation, most people indicated that they were happy enough with the appearance of their artificial limb(s), although a number of people remarked that they had been shocked upon seeing it for the first time. Remarks such as 'it's a monster', 'it's a terrible looking yoke,' and 'it's crude looking' were made by some people to describe their initial reaction to their prosthesis. Although the number of people who disliked the appearance of their artificial limb dropped considerably three months later, displeasure with its appearance increased again nine months after rehabilitation. At this stage, some participants made reference to the fact that it was 'unnatural' or 'alien' looking and that other people could recognise that they were wearing an artificial limb. Indeed, remarks such as 'It's not me, it's a prosthetic leg,' and 'I hate the look of it, it's so artificial looking,' were made by some participants to reflect their displeasure with the aesthetic aspects of the limb at this stage. Nevertheless, by the end of the year, most participants had come to accept the appearance of their artificial limbs once more. The overall consensus appeared to be that even though its was not totally satisfactory, it was better than not having a limb at all. As one woman said 'I hate the appearance, it's terrible looking. But where would I be without it?'

These longitudinal findings with regard to aesthetic satisfaction with the limb could reflect Kendall and Buys' (1998) model of adaptation. During rehabilitation, many participants remarked that they were shocked at the appearance of their artificial limb upon first seeing it, with some indicating that they had expected it to restore a 'normal' appearance. According to Friedmann (1978), a shocked reaction to seeing the prosthesis for the first time is not uncommon; prior to seeing their first limb, individuals often have the belief that it is going to make them look 'normal' and 'the same as before.' (Friedmann, 1978). Upon seeing the limb, however, such beliefs are shattered, and the person is faced with the reality of learning to adapt to an uncomfortable and unnatural looking *artificial* limb. Consistent with Kendall and Buys' (1998) model, the schema that participants had developed of themselves with the new leg may have collapsed when they were confronted with their new limb. During rehabilitation, then, they may have been forced to realise the inadequacy of

their old schema and, as a result, were faced with developing a new schema incorporating themselves wearing an *artificial* limb. The observation that displeasure with the appearance of the artificial limb subsequently decreased three months later is consistent with the notion that at this stage, a new schema incorporating the artificiality of the limb and displeasing aspects of its appearance had been developed. Thus, participants at this stage would have been more likely to accept the appearance and other cosmetic aspects of their prosthesis.

The subsequent increase in displeasure with aesthetic aspects of the prosthesis could be due to the convergence of a number of events. At this stage in the year, participants were becoming more confident in their walking and, therefore, may have been less likely to focus on mechanical aspects of the limb [see Learning to Walk below]. Furthermore, because participants had more experience of participating in social activities [see Social Changes below] they had more opportunities to experience the reaction of others towards their limb [see Social Changes below] and were realising the differences between their artificial limb and others people's intact limbs. In support of this, some participants in the study admitted that this, indeed, was the case, that they had become more self-conscious about their limb since they had noticed people looking at them. Because the evaluations of others is an important element in self-evaluation (Thompson and Kent, 2001), perceived differences and negative reactions from other people towards the artificial limb may be responsible for the fact that there was an increase in dissatisfaction with aesthetic aspects of the prosthesis. Interestingly, many participants at this stage perceived the prosthesis to be 'a part of them' and 'a part of their lives.' Thus, it would make sense that any perceived negative evaluations of the limb would be taken 'personally' (Thompson and Kent, 2001). At this stage, therefore, another schema of the prosthesis, incorporating the reactions of others, would have to be developed (Kendall and Buys, 1998) in order to cope with perceived negative reactions. The finding that displeasure with aesthetic aspects of the prosthesis had decreased again by the end of the year could reflect the fact that, at this stage, such a schema had been formulated. This schema may have come about because participants began to focus on their gratitude towards the limb and for the mobility it afforded and its uses and benefits. Thus, comments such as 'I hate the appearance, it's terrible looking. But where would I be without it?' could

reflect the fact that displeasure with aesthetic aspects of the limb are not important in the overall schema of accepting and adjusting to the limb. As a result, the appearance of the limb would not be important in overall assessments.

In terms of the functional aspects of the prosthesis, most participants remarked that throughout the year they were continuously experiencing problems with its fit and/or comfort. During rehabilitation, for example, remarks such as 'exhausting', 'it hurts me terribly,' and 'it's sore in the groin,' were made to indicate the levels of discomfort that they were experiencing. Such discomfort with the limb continued throughout the year. In the later months, fit problems also were a problem for many. In the months after an amputation, the stump shrinks considerably, with the result that the prosthesis that is fitted in the early stages often becomes too big. Because of this, almost half of the respondents were using their second artificial limb by the end of the year and, therefore, had undergone the task of physically adapting to two limbs.

Despite the fact that most respondents experienced problems with either the fit or the comfort of the artificial limb, overall satisfaction with it/them remained very high throughout the year. During rehabilitation, participants remarked that they were extremely willing to adapt to their prosthesis, with many indicating that learning to walk on it was the only way forward. With walking being their primary goal at this stage, participants were extremely willing to put up with the discomfort because of the gains in mobility that the limb would afford. Following rehabilitation, most participants remarked that even though their limb was uncomfortable, it enabled them to do so much that they would otherwise have been unable to do. Phrases such as 'It's a great invention,' 'I'm very grateful to have it,' and 'I wouldn't be without it,' were made by most of the respondents in explaining their overall satisfaction with their prosthesis. Therefore, even though the limb was uncomfortable and, at times, ill-fitting, the gains in mobility and independence were enough to outweigh the functional disadvantages of the prosthesis. By the end of the year, remarks such as 'it's a part of me' or 'it's an extremely useful tool' were made to indicate satisfaction with and acceptance of the limb.

In adapting to a prosthesis, the primary importance of motivation, over aspects of the prosthesis itself, has been previously discussed on the basis of informal discussions with people with lower-limb amputations and with professionals associated with the rehabilitation of people with amputations (Grisé, Gauthier-Gagnon, and Martineau, 1993). According to these researchers, satisfaction with aspects of the prosthesis is only the sixth most important factor for establishing and enabling artificial limb use in the early stages, while physical health status and motivation are the most important factors. In this study, therefore, willingness to overlook the discomfort of the prosthesis at this stage may have been due to participants' primary goal of learning to walk and re-establishing functional independence.

Although there are no studies examining psychological adaptation to a prosthesis during the year after rehabilitation, one study of people who had their artificial limb for a number of years has confirmed the relative importance of ability to walk with a prosthesis under varying conditions, over comfort while standing and sitting (Legro, Reiber, del Aguila, et al., 1999). In the present study, participants continuously praised the usefulness of their prosthesis and the fact that it enabled them to engage in activities they would otherwise have been unable to do. Thus, it could be argued here that their pleasure at being able to walk again may have been a more important gain than any discomfort experienced from wearing the prosthesis. Interestingly, however, Legro et al. (1999) also reported that fit of the prosthesis was the most important aspect of the prosthesis, thereby being more important than ability to walk with the prosthesis. Although this finding contradicts the present observations, it must be noted that respondents in the present study knew that their limbs would only fit in the short term (due to stump shrinkage). Therefore, in the light of the overall utility of the prosthesis, they may have been more willing to tolerate a limb that was ill-fitting in the short-term because they were aware that this was a short-term measure only.

Learning to Walk

During rehabilitation, walking was perceived by almost every participant as being their primary goal. Remarks such as 'I intend to master it,' 'Walking is my priority', and 'I look forward to moving on it,' were made by the majority of individuals, thus indicating their high levels of motivation. Three months later, this determination in

learning to walk appeared to have paid off, in that almost every participant was very pleased with his or her progress to date. Such comments as 'I'm getting on great,' 'every day gets better,' and 'your body gets used to it' were made to illustrate progress so far. This finding supports previous studies indicating that motivation is one of the most important factors in rehabilitation (Clark et al., 1983; Grieve and Lankhorst, 1996; Friedmann, 1978; Grisé et al., 1993).

Six months later, however, an interesting finding emerged. Although objectively, participants' remarks about their limitations in walking indicated that they had improved during this period, their perceived satisfaction with progress to date actually declined. Furthermore, by the end of the year, it was found that in addition to declining levels of perceived satisfaction, actual objective self-ratings about limitations in walking increased. Thus, by the end of the year, remarks such as 'I don't think I'm going to improve any more,' 'I've taken a step backwards,' and 'I've reached a plateau' were voiced.

These observations could be due to the fact that participants' improvements in walking may have been accompanied by increases in their expectations. According to Fontaine (1974), any success that is attributed to a stable factor leads one to expect higher levels of success. Thus, participants' success in walking after rehabilitation may have meant that their expectations for walking increased throughout the year. In support of this, several participants indicated that although they were pleased with their progress so far, such comments as 'I'm trying to run before I can walk', 'I'm always aiming higher,' and 'My aim is to walk as naturally as possible' suggested that they were continually developing higher rehabilitation goals for themselves. Because definitions of success depend on what the expectations for achievement are (Podlog, 2002), the self-rated improvements in limitations may not have been sufficient to qualify as success according to participants' achievement goals. Thus, what may look like success to an "Outsider" is not success according to the "Insider" who is setting the goals.

The subsequent increase in self-rated limitations that was observed towards the end of the year could also be due to changing definitions of success. In addition to the fact

that success depends on expectations for achievement (Fontaine, 1974), success has also been defined according to the emotion of 'feeling good' after a goal has been reached (Podlog, 2002). Throughout the first interviews, it was evident that participants were delighted to be mobile and learning to walk again. Thus, these feelings of happiness and delight at walking again may have been sufficient to engender feelings of success. However, as success leads to an increase in expectations (Fontaine, 1974), abilities that were pleasing three months after rehabilitation may not have been so satisfying one year later. As a result, participants may have become more critical in judging their limitations at walking toward the end of the year and may not have felt so successful or unlimited in walking distances they had earlier managed. In support of this, some participants indicated surprise when progress that they had not observed was pointed out to them by either the researcher or by a health worker. In addition, a number of individuals who thought that they had not improved over the previous three months did concede that they had, in reality, come a long way since the previous year. Furthermore, one participant contradicted herself when commenting on her progress. Although she did not feel that she had become any better using her prosthesis, she later indicated that she did feel more confident in walking on it. This temporal variation in perceptions of success may reflect Kendall and Buys' (1998) model of adaptation to physical illness and disability. Throughout the year, achievements in walking and adapting to the prosthesis meant that schema or criteria for success were continually being developed and reformulated. Thus, adjustment to walking limitations was very much dependent on individuals' success schemas, the latter of which were dependent on their past and future goals and expectations.

Overall, in learning to walk, participants had to overcome several psychological, personal, and environmental obstacles. One of the biggest psychological obstacles to face was a fear of falling. A fear of falling while learning to walk on a prosthesis is not unusual (e.g. Rogers et al., 1977-78; MacBride et al., 1980; Miller et al., 2001a,b). In the present study, a small number of participants had fallen shortly after their amputation and had required further surgery as a result. Throughout the year, falling incidences continued to be reported by a number of participants, while many of the remaining individuals, despite having never fallen, reported that they had experienced

a few 'near misses' using crutches and/or learning to walk on their prosthesis. Thus, several people admitted to experiencing a continuous fear of falling throughout the year. This observation supports previous findings that a fear of falling was experienced by just under half of those with a lower limb amputation (Miller et al., 2001a). Although almost everyone continued walking on their prosthesis despite these fears, one woman who had fallen shortly after leaving the rehabilitation hospital was extremely reluctant to use her prosthesis afterwards. Furthermore, her brother, whom she lived with, was also keen to do most of the housework so that she would not have to be mobile on her limb [See Social Support below]. It is interesting that in the present study, although almost everyone had a fear of falling, only one participant appeared to be reluctant to walk because of these fears. This is contrary to Miller, Deathe, Speechley et al.'s (2001b) finding that fear of falling, in the presence of objective balance instability, is associated with reduced mobility and social activities. In the case of the individual in this study, her brother's insistence on preventing her from engaging in any activities may have been a bigger factor in impeding her rehabilitation than her fear of falling. In the general literature on social support, the influence of solicitous responses and overprotection of others has been previously found to negatively influence progress in rehabilitation (Vaux, 1988). In the present study, then, such social support, combined with a fear of falling, may have been responsible for this particular participant's reluctance to walk.

Some of the personal obstacles that participants had to face while learning to walk included comorbid health problems. Most participants in the present study had at least one comorbid medical condition, including visual impairment, diabetes, arthritis, heart complaints, and weight problems. The impact of comorbid medical conditions on mobility following amputation has been discussed previously (Steinberg et al., 1985; Weiss et al., 1990; Pohjolainen and Alaranta 1991; Johnson et al., 1985). In keeping with this literature, a number of individuals commented that these health problems interfered, to some extent, with their ability to walk and to adapt to their prosthesis. Visual impairment for example, interfered with the rehabilitation of two participants, one of whom could only use his artificial limbs indoors, as his need for a white cane outdoors precluded use of crutches in ambulation. Being overweight and underweight were also problems for a number of people; one woman was too

underweight to carry her prosthesis effectively and, therefore, found it too heavy and cumbersome to practice on. Having arthritis interfered with rehabilitation of two individuals; one man had severe arthritis in his hands and shoulders that made carrying a crutch very difficult, while another had arthritis in his intact knee that made walking difficult and painful.

Some of the environmental obstacles that participants faced in learning to walk included rough ground, crowds, and bad weather. To date, very little research on the impact of these environmental conditions on rehabilitation with an amputation has been considered. However, in Gallagher and MacLachlan's (2001) qualitative study, people with lower-limb amputations voiced similar environmental concerns. In this study and the present study, the potential danger posed by wet floors, the effect of hot weather on the stump, and being nervous of falling in wet, icy, or windy weather were discussed. Most of those participants who had fallen throughout the year had done so on floors that were wet and/or tiled. In addition, several times throughout the study, participants indicated that they could not practice walking due to poor weather conditions or because the ground outside was too uneven. Furthermore, many participants chose to remain home from events they otherwise would have attended because they did not want to walk amongst crowds. According to the respondents, walking in a crowd was extremely difficult, because they were unable to see the ground they were walking on and because people surrounding them could knock against them and cause them to lose their balance or to lose their crutches. Gallagher and MacLachlan (2001) argued that these practicalities emphasise the restrictions that people with amputations face on a daily basis and heighten the awareness of people who have had an amputation to the importance of the environment in their rehabilitation.

PSYCHOSOCIAL-RELATED SEQUELAE

Body-schema and body-image changes

Throughout the year, feelings of self-consciousness about body-image varied considerably. During rehabilitation and up to three months later, body-image anxiety was experienced by a small number of individuals. Nine months after rehabilitation,

there was an increase in the number of people with body-image self-consciousness. By the end of the year, the amount of body image consciousness slightly diminished, such that most of the same people continued to experience such self-consciousness. However, although most of the same people remained self-conscious at the end of the year, some small changes in attitudes toward the prosthesis as a means of concealing the amputation were becoming evident. For example, one man who used bilateral cosmetic prostheses indicated that he would eventually stop wearing his limbs altogether because he was aware that using them 'fooled' nobody, that everybody knew his limbs were amputated, and that they served no real purpose for him. Two other participants, even though they were reluctant to be seen in public without their prosthesis, started to wear their artificial limbs without the covering foam. Even though they disliked the appearance of their artificial limbs and would not be seen in public without them, they were not concerned that the narrow bar made their limbs look very noticeable to other people.

The increases in body-image anxiety between three months and nine months after rehabilitation, and the change in attitudes toward the end of the year, are in keeping with Norris et al.'s (1998) grounded theory study of re-imaging the self after body-image disruption. In their study, they found that over an 18 month period, individuals went through three phases of adjustment to changes in body-image; the phase of body-image disruption, the phase of wishing for restoration, and the phase of re-imaging the self. In the phase of *wishing for restoration*, many of their participants who had amputations indicated that they relied heavily on their prosthesis as a means of restoring their appearance and hiding the reality of the amputation to other people. In the phase of *re-imaging the self*, individuals abandoned their attempts to conceal their body-disruptions and, instead, incorporated these changes into a new self-image (Norris et al., 1998). In the present study, individuals with body-image anxiety also used their prosthesis as a means of restoring a 'normal' appearance and concealing the amputation from others. Similarly, by the end of the year in the present study, a small number of those who experienced body-image anxiety appeared to be relinquishing their reliance on the prosthesis as a means of alleviating body-image anxieties.

In explaining the varied temporal pattern of body-image anxiety, the role of social interactions in exacerbating body-image anxieties may play a role. Previously, the relationship between aesthetic dissatisfaction and social interaction has been discussed [see *Adapting to the Prosthesis* above]. In explaining the increase that was observed in body-image anxiety between three and nine months post-rehabilitation, a similar explanation can be put forward. That is, the increased social interactions that participants engaged in during this time would likely have exposed them to increased public scrutiny. In Western culture, individuals with a disability do not conform to Westernised body-image ideals (Stone, 1995). Therefore, increases in social interactions are likely to have exposed individuals to a greater number of perceived negative evaluations on the part of others [See *Social Changes* below]. Because body-image is partly comprised of the evaluations of others (Thompson and Kent, 2001), then participants' body-image consciousness is likely to have increased concurrently with their increase in social interactions. The finding that some participants avoided social interactions towards the end of the year due to public self-consciousness supports the notion that they were aware and conscious of public scrutiny.

The role of the prosthesis in alleviating and exacerbating body-image anxiety must also be noted. Several authors have previously talked about the fact that many people with amputations use their prosthesis to restore a 'normal' body image (Friedmann, 1978; Wittkower, 1947). Furthermore, a recent study (Murray and Fox, 2002) has confirmed the importance of the prosthesis in preventing body-image anxiety, in that people who were satisfied with the aesthetic, functional, and weight aspects of their prosthesis were significantly less likely to experience body-image anxiety than those who were dissatisfied with these aspects of their prosthesis. In the present study, many participants indicated that they expected their prosthesis to restore a 'normal' body image. Remarks such as 'it makes me look more 'normal',' and 'I like my appearance with it on. I don't look any different' indicate the hopes that respondents had with regard to their artificial limb. In addition, analyses of responses to questions about body-image anxiety indicated that the majority of those who were anxious in public would be extremely reluctant to be seen outside without their artificial limbs, that they preferred their appearance with their limb on, and that they avoided looking at themselves in the mirror without their artificial limb. Because such hopes were

pinned on the prosthesis to restore a 'normal' body-image, then it is not surprising that the largest increase in body-image anxiety co-occurred alongside the largest decrease in aesthetic satisfaction. That is, between the three months and nine months after rehabilitation, both aesthetic dissatisfaction and body-image anxiety increased quite a lot.

The role of body-schemata and experiences of 'shock' in some people's experiences of body-image anxiety must also be noted. During rehabilitation and throughout the year, many people were in the process of adapting to their altered body schemas. According to Head (1920), neural representations or schemata serve as guides to help localise body stimuli and to steer responses and changes in posture. In the present study, it was evident that such schemata were continuing to operate. Even at the end of the year, some individuals were still 'forgetting' that their limb had been amputated and would try to walk on their amputated limb or use their limb in behaviours that they would previously have used it for. According to Gallagher et al. (1998) the continuation of such schemata even after limb amputation lends support to the theory that all of our limbs are represented in an innate body-schema that is developed prior to birth and built upon with experience during our lives. In the present study, an interesting finding with regard to 'forgetting' about the absent limb, phantom sensation, and body-image anxiety emerged. Up to nine months after rehabilitation, individuals who tended to 'forget' that their limb had been amputated, and who experienced the phantom sensation that the limb was still present, often experienced a shock when they looked down or looked into a mirror and saw that their limb was absent. If body-image, in this instance, is defined as "the picture of our own body which we form in our mind ... the way in which the body appears to ourselves" (Schilder, 1935), then the experience of shock upon noticing one's reflection or appearance seems to suggest that these individuals' mental representation of their body-image had not adjusted to incorporate their amputation. What is interesting in the case of these individuals is that they were also more likely to experience higher levels of body-image anxiety and consciousness up to nine months post-rehabilitation. Analyses of their responses to questions about body-image anxiety indicated that they disliked looking into a mirror without their prosthesis on, were reluctant to be seen in public without their prosthesis on, and did not like to look at their residual limb(s). In

the case of these individuals, the observed relationships among phantom sensation, 'forgetting', body self-image and body-schema may be as follows: If phantom limbs are experienced because the body schema has not had a chance to catch up to the new body shape (Simmel, 1956), and if body self-image is associated with body schema (Shontz, 1990), then the occurrence of a phantom limb may have been important in maintaining the mental illusion that the limb was still there and in preventing the individual from developing a new internal body-image and body-schema. Because the formation of an adapted internal body-image was delayed, then the experience of 'forgetting' and 'shock' upon noticing the amputation would have served to highlight the incongruence between internal and external reality. Thus, participants' body-image consciousness may have stemmed from a wish to avoid reminders that the limb is gone (for example, looking into the mirror without a prosthesis, being seen in public without a prosthesis) and the unpleasant sensations associated with them.

By the end of the year, the relationships among phantom sensation, shock, and body-image anxiety had altered. At this stage, there was no association between phantom sensation and experiencing a shock upon noticing the absent limb. Nevertheless, those who experienced a shock upon 'realising' that their limb had been amputated continued to be amongst those with above average levels of body-image anxiety. As noted earlier, the neurological mechanisms for phantom sensation and phantom pain are continuously undergoing changes during the months following an amputation (Ramachandran et al., 1992; Halligan et al., 1994; Doetsch, 1997; Knecht et al., 1998). Therefore, the reduction in phantom sensation may be due to changes in neural mechanisms underlying its occurrence. Thus, although body-image anxiety continued to occur towards the end of the year, this was only associated with experiencing a 'shock' upon noticing the amputated limb. It is interesting to note that with the reduction in phantom sensation came a modification in attitudes towards using the artificial limb to restore a 'normal' body image.

Overall, the longitudinal pattern of body-image anxiety in the present study supports Kendall and Buys' (1998) model of adaptation to physical illness and disability. The increase in social activities between three and nine months after rehabilitation meant that individuals would have become increasingly conscious of the public scrutiny of

others. With the concurrent realisation that the aesthetic aspects of the artificial limb were not satisfactory, increased levels of body-image anxiety ensued. Furthermore, because the body-schema had not adapted to the loss of the limb, internal body-images had also not adapted to external reality, thereby aggravating or adding to experiences of body-image self-consciousness. Toward the end of the year, however, body-image anxieties appeared to diminish slightly. Moreover, a number of individuals appeared to be in the process of incorporating the amputated limb into their internal body-image, in that they no longer seemed to rely on the prosthesis as a means of concealing their limb loss. Therefore, mental schema of the self without a limb may have been beginning to develop in some individuals with body-image anxieties, thus indicating that their schemata were beginning to change and incorporate body-image changes.

Lifestyle Changes and Limitations

During rehabilitation, most of the participants recognised the fact that they would not be able to do some of the things they used to do prior to their amputation. At this stage of the study, however, they were also eager to stress that there were still many things they could do. Thus, despite recognising their limitations, only two people believed that the restrictions on their activities would mean that their lives would not be as good again. Most of the remaining participants felt that, despite the fact that their current lives were unfulfilling, their lives would continue to be as good or would improve because their pain had now ended.

The initially held beliefs that life would be as good again contradicts previous reports that the initial recognition of limitations following an acquired disability is associated with a grief-like reaction (Morse, 1997; Parkes, 1975). Recognition of limitations, instead of causing distress and grief in participants, was accompanied by a shift in focus to abilities. It could be argued that the absence of grief-like reactions may have been due to the fact that participants were an average of four months post-amputation, and past the acute grieving period (Bonanno and Kaltman, 2001). It could also be argued that the failure to find grief-like reactions in the current study simply means that such a reaction is not universal following disability and loss (Kendall and Buys, 1998; Wortman and Silver, 1989; Hewson, 1997). In fact, some writers argue that

reactions following loss represent a stress response (Hewson, 1997), rather than a grief response.

If the emphasis on abilities, rather than disabilities, reflected a stress response (Hewson, 1997), participants may have been keen to stress their abilities during rehabilitation because they were engaging in positive “illusions of mastery” (Taylor and Brown, 1988). According to this perspective, exaggerated perceptions of control and mastery are characteristics of normal human thought that are facilitated by cognitive-processing mechanisms that distort incoming information in a positive way. Such positive illusions are particularly beneficial in maintaining mental health and well-being following a threatening event (Taylor and Brown, 1988; Taylor and Armor, 1996). In the present study, therefore, the threat that the amputation posed to participants’ functional abilities may have precipitated the ‘positive illusion’ that abilities would not have changed. Alternatively, the focus on abilities rather than disabilities may reflect a process of ‘restoring a sense of self’, which has been described in Morse’s (1997) model of adaptation to illness and disability. According to this model, once the acute crisis of an illness has been resolved, the individual is forced to recognise the physical changes and loss of function that have occurred. At this stage, he or she tries to restore as much physical function as possible and, at times, refuses to accept limitations and attempts to work towards a more complete recovery than is considered possible.

Although many people were optimistic about their futures during rehabilitation, some were unsure about whether their lives would be as good again. This theme of uncertainty was also evident in other aspects of their lives. Many were uncertain about their future living arrangements, where they would live, and what kind of alterations needed to be done to their homes. Furthermore, the financial implications of their amputation could not be directly addressed either, because most of the participants who had been working prior to their amputation were unsure as to their future working lives. While some were considering retirement, others were faced with decisions about what jobs they could now be suited for. Uncertainty is generally believed to be a central feature of any illness experience (Babrow, Kasch, and Ford, 1998). Although many conceptualisations of uncertainty in illness have been

proposed, Mishel's (1988, 1990) uncertainty in illness theory (UIT) is particularly informative in the present study. In UIT, uncertainty is defined as the "inability to determine the meaning of illness-related events" (Mishel, 1988). Thus, individuals are unable to predict the outcome of events or assign value to any particular event or object. Contrary to the predominant perceptions in the literature that uncertainty in illness is always negative and to be avoided (Babrow et al., 1998), Mishel's (1988, 1990) theory would suggest that participants' uncertainty is not necessarily harmful to their psychological well-being. Instead, her theory suggests that uncertainty following amputation could be appraised as negative or positive, depending on its cause and its likely outcome. In the current study, participants were most likely uncertain about their futures or the impact of limb loss on their lives because they had no prior experience of living with an amputation. In support of the proposition that uncertainty is not necessarily detrimental to psychological well-being, the majority of participants who were unsure about their futures did not appear overtly anxious regarding their futures (an observation supported by their HADS-A scores). Perhaps because their main goal and focus was learning to walk, they did not wish to be distracted by focusing on future uncertainties that may never come to pass. Alternatively, because most participants were happy to be rehabilitating and optimistic about their futures, uncertainties offered them the opportunity to think positively about their functional abilities and lifestyles (Babrow et al., 1998).

After participants left the rehabilitation hospital, their views on the impact of their amputation on their lifestyles underwent a significant change, and during the course of the year, two interesting longitudinal patterns were observed. The first pattern was that the initial belief held by the majority, which proposed that life would be as good again, was held by only a minority of participants by the end of the year. Analyses of responses indicated that those who did not believe that their lives would be as good again were more likely to focus on their limitations and their restrictions. Remarks such as 'curtailed', 'limited,' or 'hampered' were used in expressing these thoughts and several mentions were made of activities that participants missed doing and would otherwise have been able to do. On the other hand, those individuals who *did* believe that their lives would be as good again tended to focus on their abilities and on what they could do. Comments such as 'It'll be different, but it'll be as good,' and 'I

can't do some things, but I'm not far off it,' were made to indicate that limitations were not the main priority in determining whether life would be as good as it had been prior to the amputation. Similar findings to this were observed by Albrecht and Devlieger (1999) in their qualitative study on quality of life in people with disabilities. According to these researchers, participants who had a self-rated quality of life as "good" illustrated a 'can do' approach to life. This reflected a process whereby limitations and disabilities were acknowledged rather than denied. However, these limitations were irrelevant in determining life satisfaction. Rather, a sense of fulfilment and achievement were attained from engaging in activities one could do to the best of one's ability.

The second longitudinal pattern to be observed was that despite the decrease in beliefs that life would be as good again, perceptions of living a full life actually increased throughout the course of the year. In examining the responses of those who were being fulfilled in their lives, an emphasis on getting enjoyment out of what one could do and finding a sense of achievement in one's abilities was apparent. For example, comments such as 'It's not as full as it was, but it's as full as it can be, to the best of my ability,' and 'I get fulfilment from the things I can do,' were made by participants in explaining the ways in which they gained enjoyment from life. Although it may appear contradictory to an outsider that one can believe that life will never be as good again and, yet, still feel fulfilled, it became apparent throughout the year that participants had recognised and accepted their limitations and had worked around them to gain fulfilment. Therefore, even though they recognised that their lives were not up to the same level they had been before their amputation, this no longer mattered or coloured perceptions of fulfilment in life. Therefore, in spite of the limitations, life was good. It may not be as good as it was before, but it was still good. This theme was expressed by almost every participant throughout the year, with such remarks as "I'm limited, but I'm happy with my life. I accept it'll never be the same, and if I could turn the clock back, of course I'd have my leg back. But I can't. This is life" being made to indicate such beliefs.

This observation that levels of fulfilment in life were increasing throughout the year, despite the belief that life would never be as good again, indicates that respondents

were moving toward what has been described by Morse (1997) as 'learning to live with the altered self.' In Morse's model, this is the final stage of adaptation to disability and is characterised by an acceptance of the consequences of the experiences and the knowledge that life will never be the same again. Instead, life is revalued, different goals are set, and different achievements are appreciated. Such changes also reflect the end phases in stage-theories of adaptation to disability (Livneh and Evans, 1984; Antonak and Livneh, 1991), in which acceptance of limitations and restrictions is followed by adjustment, whereby such limitations are incorporated into a new life with the disability.

Social Change

Throughout the year, participants described several experiences of being treated differently by others in social situations. Some people reported being 'talked over' or ignored, some reported that others were often embarrassed upon meeting them, and some recalled receiving pitying reactions or too much attention or kindness from others. The differential treatment of people with amputations by those with no visible disabilities has long been documented in the literature (e.g. Kleck et al., 1966; Kleck, 1969; Furst and Humphrey, 1983; Gallagher and MacLachlan, 2001; Rogers et al., 1977). In their qualitative study, for example, Furst and Humphrey's (1983) participants remarked that other people often appeared embarrassed upon realising that they had an amputation. Similarly, participants in Gallagher and MacLachlan's (2001) study remarked that at times, other people had reacted to their amputation with shock and sometimes patronising behaviour, while a small number remarked that they had sometimes been asked what they perceived as demeaning questions about their capabilities. Furthermore, Kleck and colleagues (Kleck, 1969; Kleck et al., 1966) found that people were more likely to terminate contact with individuals with a visible disability sooner, even though they were also more likely to rate them more favourably. Helping and kindness toward individuals with disabilities has been discussed at length in the literature (e.g. Newell, 2000). It is argued that such 'kindness' may actually be an attempt on the part of non-disabled people to reduce anxiety upon seeing a disabled person and to establish a sense of dissimilarity from them.

Despite noting that they were being treated differently by others, participants were not particularly bothered about these reactions. Instead, most people explained these behaviours as the result of kindness or inexperience in dealing with disabled people. “Outsiders”, that is, people without a disability, would explain the observed reactions of ‘ignoring’, ‘talking over’ and excessive kindness as reflecting stigmatised behaviours. On the other hand, it is interesting to observe that “Insiders” did not perceive these reactions as such. One explanation as to why they did not perceive such behaviours as stigmatising is that admitting to discrimination could increase feelings of powerlessness, while minimising or denying discrimination protects self-esteem and gives a greater sense of control over the situation (Ruggiero and Taylor, 1997). However, the notion that participants’ responses to others’ reactions merely reflects a coping mechanism against perceived discrimination serves to perpetuate the notion that those with disabilities *must* be discriminated against and that the behaviour of others *must* reflect a process of stigmatisation. By interpreting all behaviours towards those with disabilities as being rooted in their disability, the “Outsider” is taking the view that the disability is the sole concern or defining feature of the individual and his/her interactions with others (Dunn, 2000). On the other hand, by listening to the “Insiders” perspective, others’ behaviours may actually reflect what the person perceives it to reflect; namely, human kindness and a lack of experience in dealing with disabled people.

In addition to being treated differently by others, most participants experienced difficulties in access to and getting around places. One participant, for example, had to buy a new house in order to be close to a wheelchair accessible bus-route. Several participants described difficulties encountered in public houses and restaurants; specifically, toilet facilities were not suitable or access was limited because of stairs or steps. Because of these environmental difficulties that were posed in accessing and getting around places, participants often found themselves dependent on others for assistance throughout the year. In the present study, the majority of people did not feel that their friendships had suffered as a result of having an amputation, while some people even remarked that they had gained friends since losing their limb. However, some people did feel that they had become restricted in visiting and maintaining friends. These difficulties faced by people with an amputation in accessing places,

participating in social activities, and maintaining friendships has been outlined previously (Nissen and Newman, 1992; Burger and Marinček, 1997; Pezzin et al., 2000). For example, Pezzin et al. (2000) found that their participants scored significantly poorer on a measure of social functioning than did the general population. Burger and Marinček (1997) found that almost half of their participants visited friends and relatives less frequently since their amputation and that approximately two-thirds of the sample was less likely to go to the cinema, theatre, sport events, library, dances, and shows.

Because of awkwardness and difficulties faced in accessing and navigating around places, embarrassment about feeling dependent on others and about being the 'centre of attention' in social situations was initially high, although this dropped significantly throughout the year. Two explanations for the observed reductions can be put forward. The first explanation is that the reduction in embarrassment reflects real individual and environmental changes. As walking levels improved [see Learning to Walk above], objective dependence on others is likely to have decreased. Furthermore, as the length of time that participants had been at home increased, it is likely that friends and community acquaintances became more used to interacting with them and no longer showered them with attention. The second explanation for the reduction in embarrassment about feeling the 'centre of attention' and dependent on others may reflect a process of accommodation and adaptation to an altered social environment. According to stages models of adaptation to disability (Livneh and Evans, 1984; Antonak and Livneh, 1991), the individual eventually reaches a stage in which he or she acknowledges the changes that have occurred as a result of the disability and, subsequently, he or she accommodates this into what becomes an adapted lifestyle, taking into account the limitations and changes that have occurred. Initially, being dependent on others and the focal point of attention in social situations was likely a changed environmental circumstance that was not part of participants' schema for social activities. By the end of the year, however, they may have altered their schema to take into account that dependence was something to be accommodated to. Indeed, it was noted above [Lifestyle Changes and Limitations above] that by the end of the year, most participants had learned to accept the restrictions that the amputation imposed on their lifestyles. Therefore, with a

recognition and acceptance of these limitations may have come an acceptance of being dependent on others in social situations. Thus, adjustment to these changed social circumstances, embarrassment about being the centre of attention may have ensued.

Although embarrassment about being dependent on others and being the centre of attention diminished, avoidance of social interaction actually increased between three and nine months after rehabilitation and subsequently fell again. Certainly, as has been found in other studies (e.g. Williamson, 1995), it could be argued that feelings of social embarrassment and self-consciousness may have played some role in avoidance of others nine months after rehabilitation. However, because embarrassment about being the 'centre of attention' actually decreased while avoidance of interactions increased, social discomfort cannot totally explain this finding. A closer look at the data suggests several reasons as to why the observed finding occurred. First of all, the previously observed finding that body-image anxiety increased and aesthetic satisfaction with the prosthesis decreased during this period could explain why participants sometimes avoided social interactions [See *Adapting to the Prosthesis and Body Schema and Body Image Changes* above]. Second of all, the fact that most participants had been in hospital for extended periods prior to their amputation may have meant that they had initially been enthusiastic about returning to their social lives, regardless of the practical difficulties it caused. However, once they had experienced difficulties in accessing and navigating around places, their initial enthusiasm may have waned. In support of this, several people in the study commented that when they first left rehabilitation they were 'very enthusiastic' and 'delighted' about getting back into their previous social scenes. However, consideration of their limitations, awkwardness in getting to places, and other health problems meant that they subsequently became more reluctant to go out socially because of these restrictions. The finding that, by the end of the year, such reluctance to interact with others significantly diminished again may also reflect a process of acceptance and accommodation in adjustment to disability (Livneh, 1986; Antonak and Livneh, 1981). As there was a slight shift in body-image anxiety [See *Body Schema and Body Image Changes* above], and as participants were beginning to acknowledge and accept their limitations, individual and environmental barriers to social participation may not have seemed so important.

Identity

The longitudinal findings with regard sense of self and identity showed an interesting pattern. During rehabilitation, the majority of participants remarked that they felt like the same person they had been prior to their amputation. Throughout the year, however, the number of people who continued to feel this way diminished to such an extent that they were in a minority nine months after rehabilitation. However, between nine months and the end of the year, a dramatic turn-around was observed, such that the majority of participants now felt like they were the same person they had been prior to their amputation.

Interestingly, for the first half of the year, consideration of limitations and being 'disabled' were important determinants of self-identity. Thus, individuals who focused on their restrictions and who considered themselves to be 'disabled' no longer felt like they were the same person they had been prior to their amputation. Personality considerations were not considered important determinants of identity at this point. On the other hand, people who considered themselves to be the same person disregarded their limitations and restrictions. Instead, they focused on their abilities, did not perceive themselves as 'disabled', and looked at positive aspects of their amputation, such as living a pain-free life. Nine months after rehabilitation, personality factors became equally as important as disablement factors in considerations of self and identity. Therefore, as well as being more likely to think of themselves as 'disabled' and physically restricted, those people who no longer considered themselves to be the same person mentioned how their personalities had changed. One man, for example, considered himself less 'happy-go-lucky' than he had been, while another knew that his personality had changed in the sense that he was more fragile in some ways and stronger in others. Interestingly, by the end of the year, having a 'disabled' identity was no longer important in considerations of overall identity and the perceptions of being the same person or not. Thus, the majority of people now considered themselves to be the same person they had been prior to their amputation, even though many also considered themselves as 'disabled.' Furthermore, those who no longer felt like they were the same continued to focus on their personalities, as well as on their physical limitations, in assessing whether they felt the same or different.

The finding during rehabilitation that most people believed that they were the same person prior to their amputation may be explained by two different processes. First of all, the beliefs in feeling like the same person may reflect participants' inexperience of living in the world with an amputation. Because of this inexperience, they would have no experience of feeling different in any way and would, therefore, continue to feel like the same person they had been. Second of all, feeling like the same person during rehabilitation may reflect Morse's (1997) fourth stage of adaptation to physical illness and disability. Up until this stage and prior to rehabilitation, participants were focused on recovering from their physical illness. Therefore, they did not have time or sufficient energy to focus on the implications of their amputation for themselves and their sense of self and identity. During rehabilitation, however, individuals were in the process of healing their physical selves and, therefore, may have been in the fourth stage of 'striving to restore the self' in which individuals may refuse to accept or acknowledge the implications of their physical disabilities, or their 'damaged self', and they may work towards a more complete recovery than is considered possible (Morse, 1997; Morse and O'Brien, 1995). Therefore, in keeping with this phase, participants may have been believed that they were the same person, despite their amputation and subsequent limitations.

The changing pattern in identities and shifting focus from physical limitations to personality considerations occurred after participants left the rehabilitation hospital and began to live in the world with their amputations. Thus, they were faced with living with the implications of their amputation on their lives. Their change in focus from physical limitations to personality has been observed in previous studies of psychosocial adaptation to illness and disability. In Morse's (1997) fifth stage of adaptation, 'Learning to live with the altered self', she notes that after attempts to restore the self, people then learn to accept the consequences of their experiences and revalue their lives and their priorities. With reference to identity, she reports that people become better able to "recognize the inner person rather than focus on the external body of the other." This changing pattern in identities and shifting focus from physical limitations to personality is also reflected in Beatrice Wright's (1983) acceptance of loss theory. According to Wright (1983), this shifting focus reflects a process in which the importance of the body or the physique in defining one's sense

of value is subordinated relative to other aspects of the self, including personality and abilities. In the present study, then, participants began to disregard their physical limitations in determining a sense of self. Nine months after rehabilitation, most people did not feel like they were the same person they had been prior to their amputation; these feelings were associated with a focus on limitations and feeling 'disabled'. However, by the end of the year, the majority of people recognised their 'disabled' status but did not consider this to be important in defining a sense of self. On the other hand, the continuation and maintenance of personality and social relationships became more important.

In examining the pattern of identity change and considerations, it could be argued that the course reflects a pendular form (Yoshida, 1993). In this model, identity reconstruction following traumatic injury (in this case, spinal cord injury) is a process in which identities swing back and forth like a pendulum. The pendulum depicts five predominant identity views that people swing from: the former self, the supernormal identity, the disabled identity as total self, the disabled identity as an aspect of the total self, and the middle self. Certainly, in the present study, aspects of most of these identities were observed throughout the year. The *former self*, for example, is the 'core' person that forms the basis for reconstruction. In this case, the 'core' person may reflect identity during the rehabilitation phase. With most people feeling like they were the same person they had been prior to their amputation, ideas of the former self were still pertinent. The *disabled identity as an aspect of the total self* means that the 'disabled' identity represents just one aspect of the person; people consider both their nondisabled and disabled aspects of the self in varying proportions. By nine months, this identity was evident in many people. Although they recognised their limitations and disabilities, personality factors were also important in considerations of identity. The *middle self* occurs when a person moves closer to the middle of the pendulum. In this identity, there is a recognition and acceptance of limitations and what is called a 'collective disabled consciousness.' What this means is that other people with similar disabilities are considered in decisions made regarding social interactions and everyday life. In the present study, this 'collective disabled consciousness' was evident in a small number of individuals. One woman, for example, became heavily involved in campaigning for disabled rights.

Overall, the process of identity reconstruction in the present reflects a dynamic interplay of continuity and change. When a person becomes ill or disabled, their life-story is interrupted (Corbin and Strauss, 1987). For a period following the amputation and rehabilitation, participants' sense of self and identity was disrupted. By the end of the year, however, continuity appeared to have been restored and considerations of 'feeling the same' were voiced by the majority. Overall, what assisted in restoring continuity was a value change where physical abilities were made subordinate to personality and social factors.

COPING WITH PSYCHOSOCIAL SEQUELAE OF AMPUTATION

Throughout the course of the year, it was apparent that participants coped with a variety of physical and psychological changes that occurred as a result of their amputation. With regard to physical changes, they had to cope with physical restrictions and limitations, adapting to a prosthesis, learning to walk, and coping with phantom pain and stump pain. With regard to psychological changes, participants were faced with incorporating a new 'disabled' identity into their sense of self, adjusting to social limitations and social changes, and body-image anxieties. Despite having to face these changes, the majority of participants appeared to maintain high levels of psychological well-being. In the case of the present study, such well-being may have been maintained because (a) the events were not appraised as stressful or because (b) effective coping strategies were put in place to deal with events that were appraised as stressful.

A Model of Coping

Over the course of the year, a number of appraisals and coping mechanisms were identified. On the basis of these findings, a model of coping with psychosocial sequelae of amputation was developed (see Figure 3.1) In the first step of the model, a process of *Appraisal* takes place, in which the amputation and events are appraised and given a threatening or non-threatening meaning. This involves making appraisals of the amputation itself, making comparisons with others perceived to be less fortunate, making comparisons with the self prior to and during adaptation to the amputation, seeing something beneficial to have come out of the amputation and its

sequelae, seeing solace in the situation, and assigning meaning and level of seriousness to the event on the basis of age and previous experiences. In this model, *Appraisals* were not considered to be coping mechanisms per se. Instead, they were considered necessary precursors to and determinants of the actual coping mechanisms used by participants in the study. The placement of Appraisals at the top of the model is based on several considerations. It has previously been contended that the structure of coping generally falls into three categories: Problem-focused, Emotion-Focused, and Appraisal-Focused (Endler and Parker, 1990; Cox and Ferguson, 1991; Paterson and Neufeld, 1989). According to these authors, Appraisal-Focused Coping *does* include a process whereby individuals re-evaluate the stressful event, find something positive to have come out of the event, minimise the seriousness of the event, and compare their situation with that of others perceived to be less fortunate. However, although re-evaluating the stressful event, finding something positive to have come out of the event, minimising the seriousness of the event, and making comparisons are confirmed as Event Appraisals, the role of such appraisals as actual coping mechanisms has been called into question. According to Tennen and Affleck (1997, 1999), for example, finding benefit in the situation and making social and temporal comparisons do not consistently fulfil the three criteria of coping mechanisms: (a) that they are effortful; (b) that they affect more than emotional well-being, and (c) that they change in predictable ways in response to situational demands. Furthermore, to perceive Positive Reappraisals of a stressful event as coping mechanisms is to take an "Outsider" assumption that the event *must* have been *re*-appraised, because to perceive something positive or beneficial to have come out of the amputation or to see oneself as better off than others *must* reflect effortful processing rather than an appraisal of current reality (Dunn, 1994). That is, in assigning Positive Appraisals to coping mechanisms the assumption is being made that the amputation is something that *must* be coped with, and "Outsider" interpretations are being imposed onto "Insider" perceptions of reality. Such assumptions are evident in the previous literature examining adaptation to physical illness and disability. For example, Taylor and colleagues (Taylor and Armor, 1996; Taylor and Lobel, 1989; Buunk, Collins, Taylor et al., 1990) have discussed the use of downward comparisons as a coping mechanism used in adapting to physical illness. Bulman and Wortman (1977) have described 'benefit finding' as a coping mechanism used in adjustment to spinal cord

injury. In the amputation literature, ascribing the “Outsider” perspective is evident in several writers’ references to how people with amputations “deny” experiencing any emotional reaction to their amputation and always try to maintain a “positive front” before others (e.g. Friedmann, 1978; Turgay and Sonuvar, 1983; Caplan and Hackett, 1963; Thompson and Haran, 1984). In these studies, the absence of emotional reactions are seen to be at variance with traditional grief models of adjustment (e.g. Parkes, 1975) and indicative of a process of denial or repression of emotions. In the present study, however, demonstrating a positive attitude is *not* thought to be representative of denial or emotional repression. Instead, it is perceived to be an accurate representation of reality on the basis of the “Insider’s” perceptions and appraisals of the situation.

In addition to the fact that Positive Appraisals are ascribed to the “Insider’s” perspective, placing Positive Appraisals at the top of the coping model is consistent with Lazarus and Folkman’s (1984) model of stress and coping. According to this model, event appraisals are of primary importance in determining whether coping mechanisms are needed or called for. If the event is perceived as non-threatening or non-challenging, then there is no need to use any coping mechanism. If, on the other hand, the event is perceived as threatening or challenging, then coping resources are needed to manage the implications of the event for emotional and physical well-being. Placing Positive Appraisals at the top of the model is also consistent with Elliott, Kurylo, and Rivera’s (2002) dynamic model of adjustment to disability. According to these authors, the appraisal of the event is of primary importance in adjustment to disability because it has considerable influence on subsequent reactions to disability and on subsequent methods of coping.

In the present model, appraising the event as positive or negative precedes the Cognitive, Behavioural, and Emotional coping mechanisms that were used by participants. The use of a broken line in Figure 3.1 between Appraisals and Cognitive, Emotional and Behavioural approaches indicates the indirect relationship between Appraisals and the coping approaches. The extent to which a person has a positive appraisal of their situation will inversely influence the extent to which a person uses the cognitive coping approaches. The categorisation of Cognitive, Behavioural, and

Emotional coping strategies has been described previously. According to Wills (1997), for example, Behavioural Strategies involve engaging in particular activities or strategies to resolve the problem faced, and Cognitive Strategies involve directing thoughts in such a way that the implications of the event are considered and ways of overcoming them are thought about. Emotion-focused coping is used to regulate the affect or emotions surrounding a stressful event (Lazarus and Folkman, 1984). In the present study, and compared to previous categorisations in which Cognitive and Behavioural categories are perceived as actively addressing the problem (Stanton and Franz, 1999), each of the Cognitive and Behavioural Coping mechanisms were categorised as being either Approach-oriented or Avoidance-oriented. Furthermore, compared to previous categorisations that have tended to perceive Emotion-Focused methods as predominantly avoidant and maladaptive (Stanton, Danoff-Burg, Cameron et al., 1994), this study focused on both Approach and Avoidant techniques within this category. Therefore, in Approach-oriented coping, the problem or stressor was acknowledged and Cognitive, Behavioural or Emotional strategies were put into place to deal with its implications. In Avoidance-oriented coping, the problem was also acknowledged, but Behavioural, Cognitive, or Emotional strategies are used to avoid dealing with its implications. This sub-division of coping into Approach and Avoidance categories is consistent with previous reports that these two strategies actually represent higher-order factors that subsume both Problem- and Emotion-Focused Coping and both Behavioural and Cognitive Coping strategies (Stanton and Franz, 1999; Wills, 1997). Thus, in the present study, participants were seen to use Cognitive, Behavioural, and Emotional methods in dealing with and avoiding the problems or stressors at hand.

Cognitive Approach methods included thinking about problems ahead, making plans about how they can be resolved, and making upward social comparisons. In the present study, the changes that were observed in use of upward social comparisons throughout the year, and the apparent use that participants made of such comparisons in maintaining motivation and determination suggests that these comparisons were effortful, affected more than emotional well-being, and were context dependent, thus fulfilling criteria as coping strategies (Tennen and Affleck, 1999). The Cognitive Avoidance methods observed in the present study included: not thinking ahead and

taking things from day to day. Emotional Approach methods included: giving oneself a 'mental talking to' to maintain motivation and courage, using social support for emotional reasons, and turning to religion. Emotional Avoidance methods included: joking about the amputation and its implications as a means of maintaining a 'positive front'. Behavioural Approach methods included: joking about the amputation to facilitate social interactions, taking particular steps or actions to overcome a problem, using external objects such as a car or prosthesis to overcome hurdles, and using social support for practical reasons. Behavioural Avoidance methods included engaging in tasks to distract one's thoughts away from the stressor.

Appraisals

During the course of the year, it was evident that every participant positively appraised the meaning of their amputation and its psychosocial sequelae. Such positive meanings were evident in their downward comparisons with others, in the fact that they perceived something beneficial to have happened as a result of the amputation, in their acceptance of the amputation and its sequelae as necessary, and in their assessment of the implications of the amputation in terms of its perceived seriousness and their own developmental stages.

Appraisal of Limb Loss: Acceptance and Adjustment

Upon being told that an amputation was necessary, participants recalled feeling shocked, disappointment, and sad. In almost all instances, the amputations were performed to end pain and suffering and to save participants' lives. Thus, despite experiencing the above emotions, most people also remarked that they accepted the limb loss as 'the lesser of two evils.' Therefore, immediately after the amputations had been performed, participants recalled feeling a sense of relief at an end to their pain and expressed the sentiment that they were 'lucky to be alive'. At the time of the first interviews, therefore, most people accepted their limb loss as a necessity and were determined to make the best of their rehabilitation and their future lives. Some admitted to periods of feeling 'down' shortly after their amputation but remarked that these feelings had dissipated since entering rehabilitation. Interestingly, however, these high levels of acceptance of the amputation were not maintained throughout the year. Despite the fact that participants continued to perceive their limb loss as the 'lesser of two evils' three months after they had left the rehabilitation hospital,

respondents at this stage and throughout the following year also indicated having mixed feelings about losing their limb. For example, at each of the interview stages, some remarked that they would never fully get over losing their limb, others admitted to missing their limb, and some carried feelings of regret, self-blame, blame of others, or bitterness. With the increase of such mixed feelings throughout the year, there was a corresponding decrease in total acceptance of the limb loss. In fact, compared to the finding that the majority of respondents wholeheartedly accepted their limb loss shortly after their amputation, only half of the respondents continued to do so by the end of the year. Despite such mixed feelings, many respondents were keen to stress that losing a limb was something you 'learn to live with' rather than 'get over'. Thus, they remarked that they were making the best of their situation and living full lives to the best of their abilities. Therefore, although unquestioning acceptance of the situation appeared to have dissipated, a process of Adjustment to having an amputation appeared to have unfolded throughout the year.

Participants' retrospective accounts of shock, disappointment, and sadness upon being told that an amputation was necessary are consistent with previous reports in the literature (Gallagher and MacLachlan, 2001; Butler, Turkal, and Seidl, 1992). According to Livneh and Evans (1984) and Antonak and Livneh (1991), shock and depression are two normal reactions to disability and a pre-requisite to subsequent adaptive reactions of acknowledging and adjusting to the disability. Thus, in the period prior to amputation, participants' accounts of their reactions appear to indicate a 'normal' pattern of adjustment. The finding that most people saw their limb loss as 'the lesser of two evils' and that many experienced a sense of relief at an end to their pain has also been previously reported (Caplan and Hackett, 1963; Gallagher and MacLachlan, 2000; Randall et al., 1945; Friedmann, 1978). Given that the majority of participants had experienced long periods of hospitalisation prior to amputation, such a reaction to being told that an amputation is necessary is not surprising. Indeed, Friedmann (1978) has previously noted that people with long-term vascular problems have had a long time to prepare themselves for the possibility that they may lose a limb. As a result, by the time they are informed about the necessity of the amputation, they have weighed up the advantages and disadvantages to losing a limb and are aware that, in many cases, it is a life-saving procedure.

Some participants continued to regret having their amputation, making such statements as 'If I'd known what I'd have to face, I would never have agreed to it,' or 'I'd never have agreed to an above-knee amputation.' Although regret remained fairly constant throughout the year for the small number of individuals who felt this way, research to date would suggest that these feelings may dissipate with time (Gilovich and Medvec, 1995). Because these respondents were regretting an action (i.e. having given permission for their limb to be amputated), rather than an inaction, several cognitive processes are likely to play a role in decreasing the emotional pain of this regrettable action over time (Gilovich and Medvec, 1995). One such cognitive process is that the consequences of the regrettable action can prime the individual to think of a greater number of associated silver linings or benefits (Gilovich and Medvec, 1995). In the present study, analyses of Appraisals illustrate that perceiving benefits to having had an amputation do, indeed, play a major role in coping with limb loss [See "It Could be Worse: Solace and Social Comparisons below].

Many participants continued to blame themselves or others for their amputation during their rehabilitation and throughout the following year. Three studies have found that blaming others for the experienced disability or illness is associated with poorer psychological adjustment in the short-term (Bulman and Wortman, 1977; Taylor, Lichtman and Wood, 1984; Thompson, 1985). Although self-blame has been reported to be associated with a positive psychological adjustment to physical disabilities in the short-term (Hanson, Buckelew, Hewett et al., 1993) and long-term (Schulz and Decker, 1985), other studies have reported no long-term relationship between self-blame and acceptance of disability (Heinemann, Bulka and Smetak, 1988). Thus, in the light of the above findings, it is difficult to draw any conclusions as to the long-term impact of blame on adjustment to amputation. However, the fact that only one of the participants (BN) who exhibited depressive or anxious symptomatology throughout the study blamed anyone else for their amputation, would suggest that in this research, attribution of responsibility was not associated with psychological well-being.

“It could be worse”: Solace and Social Comparisons

Throughout the year, most participants put their amputation into a context of “it could be worse” by looking at what they still had or what they could still do in their lives, regardless of their amputation. Therefore, the overall meaning of the amputation and the implications that it had on their lives was considered in the wider context of their whole lifestyle. Putting the amputation into a context of “it could be worse” by focusing on what they still had and on what they could still do is similar to the previously observed findings in which participants were keen to stress their abilities, rather than their limitations, in assessing their overall quality of life. Just as Albrecht and Devlieger (1999) observed in their qualitative study on quality of life in people with disabilities, a sense of achievement and fulfilment in the present study were attained from engaging in activities one could do to the best of one’s ability. Moreover, participants in the present study also looked at and considered what they had, rather than what they had lost, in evaluating their lives and assessing the meaning of the amputation for their lives.

Participants also put their amputation into a context of “it could be worse” by making social comparisons, that is, by comparing themselves with other people whom they perceived to be in more difficult or challenging situations. Thus, some compared themselves to people who had had a stroke or cancer. Individuals with one amputation compared themselves to others with bilateral amputations or upper-limb amputations. Many compared themselves to younger people whom they had seen in the rehabilitation hospital and who were paralysed following road traffic accidents or who had lost multiple limbs as a result of illness.

Participants also put their amputation into a context of “things could be worse” using temporal comparisons. In this way, they compared their current situations with how they had been prior to their amputation or at an earlier period shortly after their amputation. Comparisons between the present and their lives pre-amputation tended to reflect continuity, rather than change. On the other hand, comparisons between early post-amputation and current functioning tended to reflect improvements or downward comparisons.

The use of temporal and social comparisons has been extensively documented in the health psychology literature (Buunk and Gibbons, 1997). In general, temporal comparisons that reflect continuity over time are said to bolster a person's self-esteem under threatening circumstances (Rickabaugh and Tomlinson-Keasey, 1997). In addition, downward temporal comparisons are said to be gratifying because they reflect an improvement over time (Wilson and Ross, 2000). On the other hand, reports investigating the relationship between downward social comparisons and psychological well-being have been mixed. Whereas some studies have found that comparing oneself with others who are perceived to be worse off is associated with lower self-esteem and psychological well-being (Buunk, Collins, Taylor et al., 1990; Michinov, 2001), some researchers have reported positive relationships between downward comparisons and psychological well-being (Taylor et al., 1983). The discrepancies observed in the literature may be explained by the fact that downward social comparisons increase well-being when the person is comparing him/herself on a dimension that will not worsen, and they will decrease well-being when the person is comparing him/herself on a dimension that may worsen (Wood and VanderZee, 1997). In the present study, there was no relationship between downward social comparisons and psychological well-being in that during the year, people who showed both normal and elevated HADS-A and HADS-D scores continued to compare their situation to that of others perceived to be worse off. The lack of relationship between social comparisons and psychological well-being in the present study supports Tennen and Affleck's (1997) contention that social comparisons do not represent a coping mechanism. As a coping mechanism, social comparisons would be expected to have some impact on psychological well-being (Lazarus and Folkman, 1984) and to change in predictable ways as situations change (Tennen and Affleck, 1997). However, the lack of relationship between social comparisons and depression or anxiety and the fact that the type and prevalence of comparisons remained stable throughout the year would suggest that they served no particular purpose with regard to mental health in the present study. Instead, it could be argued that the preponderance of social comparisons in the present study is simply a reflection of how the amputation is appraised and put into the context of total lifestyles. In support of this contention, a number of participants remarked that they did not explicitly use social comparisons as a coping mechanism. Although some people remarked that comparing themselves to

worse off others did help them put their situation into context, other people remarked they never used such comparisons to make them feel better about themselves. As one man said, he'd "never make it a consolation that there's people worse off."

Seeing Benefits

Positive appraisals of the amputation and its psychosocial sequelae were also demonstrated in people's perceptions that something beneficial or positive had happened to them as a result of their limb loss. Throughout the year, many participants reported that the amputation had resulted in a reprioritisation of their lives and a greater appreciation for their friends and family. In addition, some people indicated that since their amputation, they had become better people in the sense that they were less stressed and anxious, more compassionate and empathic, better listeners, and more confident in themselves. Furthermore, many reported that their quality of life had improved in that they were now free from pain and able to move around and socialise better than they had been prior to their amputation.

In the present study, most of those who perceived benefits during rehabilitation and three months later continued to do so throughout the year following their rehabilitation. Finding benefits in adversity have been reported by people experiencing a wide range of losses or traumas, including bereavement (Noelen-Hoeksema and Davis, 2002), loss of home (Thompson, 1985), and chronic illness (Tennen and Affleck, 1999). To date, two studies have also reported benefit-finding in people with amputations (Gallagher and MacLachlan, 2000; Dunn, 1996). What is interesting to observe is that the types of benefits reported in the present study, including a reprioritisation of life, having a greater appreciation for family and friends, and becoming a better person have been reported across all of these studies, regardless of the loss or trauma experienced.

Previous cross-sectional and longitudinal studies have found significant relationships between finding benefits and psychological well-being (Tennen and Affleck, 2002; Thompson, 1985; Dunn, 1996; Gallagher and MacLachlan, 2000). In the present study, however, there did not appear to be a strong relationship between perceiving benefit and psychological well-being either prospectively or concurrently. Throughout

the year, one of the participants, PG, who showed elevated anxiety and depressive symptoms continued to perceive benefits as a result of his amputation. He remarked that since losing his limb, he was now able to spend more time at home with his family. Of the two participants who believed that the negative consequences of the amputation far outweighed the positive consequences, only one man, SC, showed depressive or anxiety symptoms throughout the year.

The theoretical background and explanations as to the functions of benefit-finding may shed some light as to why no relationship between benefit-finding and psychological well-being were observed in the present study. Some researchers believe that psychological well-being is associated with finding benefits because the latter can be construed as a coping strategy (Tedeschi, Park, and Calhoun, 1998) or as a process of "selective evaluation" (Taylor et al., 1983). In construing benefit-finding as a coping process, the person is assumed to be actively searching for a positive meaning or benefit to what has happened to them in order to restore a sense of meaning to their lives (Janoff-Bulman, 1992). In construing benefit-finding as "selective evaluation", the positive appraisal of the benefits from an adverse situation or loss can help the individual to adapt to the perceived threat and loss (Taylor et al., 1983). However, several researchers have argued that finding benefits does not necessarily or always reflect an active coping process or process of evaluation (Tennen and Affleck, 1999; Tennen and Affleck, 2002). According to these authors, benefit-finding may actually reflect a process of genuine growth or transformation as a result of role and developmental changes. After a person has undergone a loss or trauma, their work and family roles may undergo a profound change. As a result, they may experience a developmental shift such that they take on a different position or role within the family and their social spheres. This developmental shift may then bring with it real benefits that had heretofore not been present. (Tennen and Affleck, 2002). In the present study, most of the amputations were performed as life-saving operations, with the result that many participants felt that they had been close to death prior to their amputation. Following the limb loss, many participants left work and had more time to spend with their families. Furthermore, while they had been sick and recuperating, they were often showered with attention from friends and neighbours and given the opportunity to experience other peoples' kindness at first hand. In view

of these changes that occurred surrounding the amputation, it is perhaps not surprising that the amputation would serve to reprioritise their lives and that they would recognise the benefits that occurred. This interpretation of benefit-finding is consistent with an “Insider” approach to research (Dunn, 2000) in which the participants’ perceptions of benefits are taken as reflections of real and actual change, rather than as reappraisals of unbearable or difficult situations. In interpreting their reports of benefits as reflections of real transformation and change, there would be no reason to assume a relationship between psychological well-being and perception of benefits. That is, if the benefits are reflections of real change, and *not* attempts to improve or sustain well-being, then they should not have any direct association with mood. To the extent that the benefits are, by nature, more favourable, they may only be associated with psychological well-being as a “side-effect” only (Tennen and Affleck, 1999).

Age Reflections

Throughout the year, many participants indicated that they did not perceive their amputation as having a huge impact on their lifestyles because of their older age. Therefore, accompanying the aforementioned downward comparisons with younger people, many participants indicated that their advancing years meant that their lives were “slowing down” anyway and that body image concerns were a thing of the past. Interestingly, such appraisals of limitations on the basis of age increased between the first and second interviews and subsequently declined thereafter.

Several studies have confirmed that younger and older adults associate ageing with a greater preponderance of declines than gains (Heckhausen and Krueger, 1993; Heckhausen, Dixon, and Baltes, 1989; Heckhausen and Brim, 1997). In addition, one qualitative study of older adults confirmed that the most common expectations of ageing included declines in physical and social functioning (Sarkisian, Hays, Berry et al., 2001). Such lowered expectations are associated with increased levels of satisfaction because they are easier to realise in one’s own functioning (Baltes and Baltes, 1990). In the present study, it can be argued that expectations of ageing were associated with lower levels of threat appraisals. Because declines in older age were expected, the physical limitations posed by the amputation were not perceived as a

threat or as having as great an impact on lifestyles than if the amputation had occurred at an earlier age. Interestingly, these findings are somewhat contradictory to previous findings on adapting to limitations of old age. Other authors have argued that in order to minimise the threat posed by advancing years, many older adults engage in a process of “social downgrading”, comparing their functioning favourably against similar aged adults whom they perceive to be in a worse off situation (Heckhausen and Brim, 1997). In the present study, however, participants did not put themselves in a more favourable position than same-age peers. Instead, they embraced age-related limitations in putting their amputation-related limitations into a developmental context. Thus, embracing age, rather than amputation, may mean that they still perceived themselves as functionally equal to other adults of the same age. One reason as to why age-related appraisals increased between the first and second interviews could be due to the previously observed finding that during rehabilitation, participants were unaware of the limitations they could face in the future. In the months following rehabilitation, however, their uncertainties regarding the implications of their amputation diminished, and they subsequently experienced their amputation-related limitations first-hand. Therefore, because the threat of limitations only emerged after rehabilitation, the age-related appraisals of the threat were only required during this time. As participants adapted to their limitations [see *Adaptation to Limitations* above], threat appraisals would no longer have been required to the same extent.

Previous Loss Reflections

Throughout the year, a small number of people consistently appraised their amputation as significantly less upsetting or threatening than previous losses or threats they had or were currently experiencing. One woman indicated that the recent separation from her husband was a bigger shock than losing her leg. Similarly, one man rated the death of his wife as much more upsetting than his amputation. Another participant described how the loss of his sight many years previously had prepared him for losing his legs. Finally, some people rated their current health worries as being far more worrying than their limb loss.

These analyses, in which participants perceived previous losses and concurrent worries as having a greater impact than loss of the limb, indicate the importance of taking an “Insider” approach (Dunn, 2000) to research on adaptation to amputation. These accounts in which other losses are perceived as more upsetting negate popular “Outsider” beliefs that the amputation or disability is the sole focus of the individual (Furst and Humphrey, 1983; Dunn, 2000). Instead, they serve to emphasise the fact that the implications of the amputation are assessed by “Insiders” within the context of their whole lives, past and present. In taking such a perspective, individuals in the present study made relative, subjective judgements as to the importance or consequences of their amputation on the basis of their previous or current life experiences.

Appraisals – Summary

Overall, participants’ Appraisals tended to place their amputation into a non-threatening context. Throughout the year, appraisals of the amputation as the ‘lesser of two evils’ meant that most people initially accepted the necessity of the amputation. Although wholehearted acceptance of the amputation subsequently diminished throughout the year, most people appeared to be appraising the amputation as something that had to be ‘lived with’ and incorporated into their lives. Most people perceived something beneficial to have occurred in their lives as a result of having an amputation and they put their amputation into a context of ‘things could be worse’ by focusing on what they still had and by comparing themselves with other people they considered to be in more threatening or challenging situations. Furthermore, many people considered their amputation in the light of their current age and concluded that because of their advancing years, the impact of the limb loss on their lifestyle would be minimal anyway. Finally, several people compared their limb loss to other stressors and losses that they had or were currently experiencing and concluded that these events were more stressful or worrying than their amputation had been.

In view of the fact that none of these appraisals were associated with psychological well-being, and that most of them did not change in frequency throughout the year, their role as appraisals, rather than coping strategies, is supported (Tennen and Affleck, 1999; Lazarus and Folkman, 1984). As appraisals, then, they represent the first stage in the coping process. The next stage of the coping process involves the use

of particular strategies in order to deal with amputation-related events that *were* perceived as potentially threatening or stressful.

Cognitive Approach Coping

Upward Social Comparisons

Interestingly, although the majority of social comparisons were in a downward direction, upward comparisons were evident during the first half of the year when participants compared themselves to other people with amputations who were doing extremely well in learning to walk. During the second half of the year, however, use of upward comparisons reduced significantly, and participants tended to focus on other people's dissimilarities, rather than on their similarities. Thus, a focus on other peoples' level of amputation, the length of time since they had their amputation, and the favourable circumstances in which they learned to walk was evident in the later half of the year.

In explaining the diminishing prevalence of upward comparisons throughout the year, several explanations can be posited. First, the dissatisfaction that participants were feeling over the lack of perceived progress in their walking in the latter half of the year may have made them feel that comparing themselves to other people with amputations was not a helpful strategy, in that it only served to highlight the delay or impediment in their progress that many were perceiving [See Learning to Walk above]. Thus, realising that other people who were doing better had more favourable circumstances could be a way of consoling oneself that progress was not as good as initially expected. Second, experience in having an amputation and continued practice on the artificial limb may have meant that participants, at this stage, had become more aware of the potential difficulties they were facing and the implications of having an above-knee rather than a below-knee amputation. Thus, they may have come to realise that earlier comparisons with younger and/or below-knee amputees were not feasible or realistic. Overall, the changing pattern of upward comparisons reflects what Mussweiler, Gabriel and Bodenhausen (2000) call "shifting social identities" in response to threatening social comparisons. Although upward comparisons may provide information and foster hope and optimism, they can also result in diminished self-esteem if this standard cannot be met by the person making the comparisons.

Thus, in order to protect self-esteem in the face of these threatening comparisons, people tend to emphasise the differences, rather than the similarities, between others. As a result, the threat of seeing someone else doing better is reduced because the other person is not actually in similar circumstances.

Downward Social Comparisons

Throughout the third interviews, downward social comparisons appeared to be used for the first time as deliberate coping mechanisms. Both men who acquired their amputations as a result of trauma appeared to compare themselves with others they perceived to be in worse off situations in order to help them cope with the emotional implications of their amputation. At this stage of the year, both showed elevated HADS-A and/or HADS-D scores. Thus, the appearance of social comparisons as Cognitive Approach coping mechanisms for the first time could be because the increased distress they were feeling required the use of such mechanisms (Lazarus and Folkman, 1984). Interestingly, however, one of these men indicated by the end of the year that such comparisons were not always helpful in maintaining emotional well-being, as it sometimes made him feel sad to see others in worse off situations. This finding that downward comparisons can be associated with a negative effect on psychological well-being has previously been documented (Taylor and Lobel, 1989). In the present study, the use of downward comparisons in someone who had described himself as more 'thin-skinned' and 'more easily upset' since his amputation could easily be maladaptive, since looking at others perceived to be in worse off situations could be emotionally upsetting to someone feeling more vulnerable.

Thinking, planning and making goals

During rehabilitation, participants used a Cognitive Approach method of looking ahead to the future and to a time when they could resume their employment, hobbies, and activities. At the stage, their predominant goal for the future was learning to walk. Broad statements such as "It's all about focus and moving on," and "I'm looking forward to the best" were prevalent at this stage, while no specific or concrete plans or goals were set.

Throughout the second interviews, use of this cognitive approach method of thinking ahead changed somewhat. Instead of "looking forward" without formulating specific

plans, over half of the participants had formulated particular rehabilitation goals for themselves, a number of people gave themselves a particular time frame within which these goals could be achieved, and some engaged in thinking ahead about barriers or obstacles they may face in accessing places and getting around socially. Throughout the remainder of the year, however, such thoughts about future obstacles and goals diminished substantially such that only a small number of individual continued to think about rehabilitation goals, barriers, and obstacles to walking.

The use of optimistic thoughts about the future and goal planning as effective coping strategies in health and rehabilitation have been outlined previously (Oettingen and Mayer, 2002; Nair, 2003; Elliott, Uswatte, Lewis et al., 2000). In general, it is argued that the success of a rehabilitation programme depends on the setting of meaningful life goals for the individual (Nair, 2003). Furthermore, low goal instability and an ability to formulate flexible and appropriate goals for the future can significantly and positively effect rehabilitation outcomes (Elliott et al., 2000). In the present study, participants during rehabilitation thought about their futures and activities they were likely to continue, without formulating or setting any firm rehabilitation goals or plans to achieve this. Despite the fact that specific goals were not set at this stage, such optimistic thoughts and expectations about the future are associated with high levels of motivational effort and achievement (Oettingen and Mayer, 2002). In general, the absence of firm goals for the future at this stage would be expected, since participants' uncertainties regarding their future functional abilities (Mishel, 1988), and the fact that their daily goals were being set by the rehabilitation team (Elliott et al., 2000) would mean that they had neither the experience nor the need to set firm goals for the future.

The large increase in concrete planning that was observed three months later would also be expected, since a return to community living and a change in uncertainties would mean that new goals consistent with physical abilities and environmental contexts would have to be developed. The subsequent decline in goal setting and planning ahead during the remainder of the year is consistent with the previously observed finding that individuals felt that they were reaching a 'plateau' in their walking and were becoming familiar with their limitations [See Learning to Walk and

Lifestyle Changes and Limitations above]. In reaching a plateau, their expectations for future success in goal achievement may have diminished (Fontaine, 1974), with the result that their motivation for setting and maintaining new goals may have diminished. Furthermore, in becoming familiar with their physical abilities and limitations, their need for planning ahead and thinking about environmental obstacles and barriers may also have declined. Thus, in keeping with the characteristics of coping mechanisms, the need for planning ahead and setting goals changed concurrently with personal and contextual change (Lazarus and Folkman, 1984; Tennen and Affleck, 1999).

Cognitive Avoidance Coping

Not thinking about the problem and taking things from day-to-day

During rehabilitation, many participants engaged in thought suppression with regard to health concerns, the reason for their amputation, and the implications of their amputation for the future. Closely associated with the approach of “not thinking about things” was the method of taking things from “day-to-day” without looking ahead about problems that could be encountered when adapting to the amputation or learning to walk.

Three months after rehabilitation, thought suppressions and approaching life on a daily basis were still used by over half of the participants in coping with their health worries and the implications of their amputations on their lifestyles. However, during the remainder of the year, there was no evidence that participants were continuing to take a “day-to-day” approach to life. Furthermore, thought suppression and “not thinking” about health worries were only evident in two participants during the third interviews and two participants by the end of the year. An interesting finding to emerge was that at the beginning of the year, there was no relationship between use of this Cognitive Avoidance approach and psychological well-being. Towards the end of the year, however, those who continued to use this technique appeared to have relatively higher anxiety and/or depressive symptoms according to their scores on the HADS-A and HADS-D. At the third interviews, two men, PG and MMcC, indicated that they used thought suppression to avoid thinking about their concerns, one of whom showed elevated HADS-D scores, the other of whom showed elevated HADS-

D and HADS-A scores. At the fourth interview, PG continued to engage in thought suppression and continued to show elevated HADS-D and HADS-A scores. In addition, DOD admitted to suppressing his worries at this time, and showed mild anxiety symptoms at the third interviews and borderline clinical anxiety symptoms at the final interview.

The high rates of the Cognitive Avoidance strategies of thought suppression and taking things on a daily basis during the first two interviews are consistent with the findings of Livneh et al. (1999) who found higher rates of Cognitive Disengagement strategies in people who had their amputations for relatively shorter periods of time. These current findings may be explained on the basis of contextual factors. During rehabilitation, a high state of uncertainty prevails in that participants are unsure about the shape of their future lifestyles, limitations, and roles (Mishel, 1988). At this stage, being in rehabilitation would mean that they are not in a position to alter or tackle this situation. Since Avoidance techniques have been found to predominate in situations in which the individual has no control over (Folkman and Lazarus, 1980), then use of a Cognitive Avoidance strategy would seem to be appropriate in this instance. Furthermore, since Avoidance of thoughts regarding the future or the amputation would help participants to maintain focus on their main goal of walking [See Learning to Walk above], it could be argued that in this instance, use of Cognitive Avoidance is a useful strategy (Klinger, 1975) and, therefore, would not be associated with poor psychological well-being. The high prevalence of thought suppression and “taking things on a daily basis” during the three months following rehabilitation could also reflect a lack of control over the situation. As discussed previously, the period immediately after rehabilitation can be highly stressful and overwhelming (Glass, 1994). During this time, participants for the first time were faced with the task of adapting to and living in the world with an amputation. Thus, Cognitive Avoidance of thoughts not directly associated with this adaptation process may have protected participants from becoming overwhelmed with unwanted or unnecessary cognitions.

The dramatic reductions in thought suppression and approaching life on a daily basis that were observed in the latter part of the year may reflect the fact that at this stage, participants were in a better position to think about and process their anxieties and

worries because their overall uncertainties regarding the implications of their amputation were being resolved, and their walking was objectively improving. Consistent with this theory that suppression of thoughts was coming to an end, anxieties and worries about the prosthesis, body-image, and social avoidance surfaced to the greatest extent in the third interviews [See Body Schema and Body-Image Change, Social Change, and Adapting to the Prosthesis above]. Thus, with an end to thought suppressions came a concurrent increase in other worries and concerns. The finding that Cognitive Avoidance was associated with anxiety and depressive symptoms in the latter half of the year has been previously observed: in the general literature on coping, these techniques are argued to be associated with poorer psychological outcome because they prevent the individual from directly dealing with the source of the stressor using behavioural techniques (Penley, Tomaka, and Wiebe, 2002). In the literature on adjustment to amputation, Avoidance techniques have been associated with poorer adjustment to amputation (Livneh et al., 1999) and higher levels of emotional distress (Gallagher and MacLachlan, 1999). Thought suppression, in particular, has been associated with the development of post-traumatic stress disorder in motor vehicle accident victims (Ehlers, Mayou, and Bryant, 1998) and with the maintenance of obsessive thoughts, depression, anxiety, and insomnia (Beevers, Wenzlaff, Hayes et al., 1999). According to Beevers et al. (1999), thought suppressions are associated with poorer psychological adjustment because of an “ironic process” in which the unwanted thoughts produce a preoccupation with the very thoughts that one hopes to suppress. In the present study, thought suppressions were used by two participants at the end of the year, one of whom was among the two people who had an amputation as a result of trauma. Throughout the year, this man continuously remarked that he did not like to think about the implications of his accident or the fact that he had almost died.

While we cannot draw any definitive conclusion regarding the impact of this man’s accident on his psychological well-being, his thought suppressions are consistent with previous findings on trauma (Ehlers et al., 1998) and with previous findings that have related Avoidance techniques to people who have had amputations due to trauma (Gallagher and MacLachlan, 1999).

Overall, therefore, the findings with regard to Cognitive Avoidance techniques of thought suppression indicate that in the short-term, this approach was used by the majority when circumstances of uncertainty prevailed. For most of these individuals, this was not associated with poorer psychological outcome, possibly because it maintained their focus on the task of walking and adapting to living with an amputation, and possibly because they subsequently addressed their thoughts and worries when the former goals were being fulfilled. For a small minority of individuals, however, thought suppression was associated with poorer psychological adjustment. Although no firm conclusions can be drawn as to the reasons why these people continued to suppress their worries, the fact that one of the men had his amputation as a result of a traumatic accident could be associated with his use of this Avoidance technique.

Emotional Approach

Emotional Determination

Throughout the year, a small number of participants demonstrated a particular Emotional Approach style called “Emotional Determination.” This strategy involved giving oneself a “mental talking to” in order to maintain levels of motivation, courage, or determination to cope with the amputation and its physical and psychological sequelae. To this end, statements such as “You can’t just lie under it,” or “You just have to get on with it” were common at all points throughout the year.

Because such Emotional Determination was maintained throughout the study, the question arises as to whether this is a coping strategy *per se* or a particular style of personality. In adjusting to stress, it has long been recognised that personality and context both influence the coping process (Holahan and Moos, 1987). However, the distinction between particular coping strategies as personality styles or as situational-dependent coping states has never been fully delineated (Tennen and Affleck, 1997). As a coping strategy, Emotional Determination fulfils two of Tennen and Affleck’s (1997, 1999) criteria: it is deliberately effortful, and it affects more than emotional well-being. However, its use has not changed in predictable ways throughout the year, but instead, has been maintained more or less throughout. Therefore, it could also be conceived as a personality style. As such, it could reflect cognitive hardiness (Kobasa,

1979), which describes a state in which individuals believe they can control or influence their events, perceive change as a challenge rather than as a threat, and have a commitment to activities, their interpersonal relationships, and to their lives. Furthermore, it could also reflect an internal locus of control (Rotter, 1966), which is a personality trait that is used to describe an individual who believes that he or she has personal control over the events in his/her life. In analysing participants' responses, it can be concluded that it is both an Emotional Approach coping mechanism and a personality style. For some individuals, it was deliberately used as a means of maintaining well-being, but it was also perceived as part of their personality. As one man put it, he was a "very positive" person anyway. Similarly, another man described himself as a "fighter by instinct." For other people, it was apparent that this style was deliberately used as a coping mechanism only. These individuals made such remarks as "you try and get on with it, but it's certainly not easy," and "it's difficult to do it, but you cannot lie down under it," in indicating that such Emotional Determination was a coping mechanism only.

It is interesting to observe that the distinction between Emotional Determination as a coping style or a personality trait serves to differentiate those with high and low levels of psychological well-being. In general, those individuals who demonstrated that Emotional Determination was a personality trait indicated that they had a positive outlook at all times (for example, NK and GC). On the other hand, those individuals who used Emotional Determination as a coping style admitted that they found it hard to maintain this at times. Furthermore, they also admitted to periods of 'feeling down' throughout the year or consistently had elevated scores on measures of depression or anxiety (for example, BN, FF, and PG). According to several authors (e.g. Penley et al., 2002; Lazarus and Folkman, 1984) use of Emotional coping styles would tend to be associated with higher levels of emotional distress. This is because these coping styles are harnessed to cope with distressing emotions associated with a stressful event. Therefore, the fact that BN, FF and PG deliberately used Emotional Determination *and* indicated that this was difficult at times, *and* indicated that they experienced periods of 'feeling down' or appeared anxious or depressed would suggest that for these people, this was a coping strategy. On the other hand, the fact that NK and GC indicated that they were generally positive or determined individuals

and did not appear depressed or anxious throughout the study supports the view that for these people, Emotional Determination was a personality trait.

Religion

Throughout the year, a small number of participants consistently indicated that they used their religious beliefs to cope with their amputation and its sequelae. At the end of the year, one additional person indicated using religion to cope with his amputation for the first time during the course of the study. Some people focused on religion to give sense and meaning to their amputation and their lives. In this way, they indicated that because their amputation was the will of God, it was easy to accept having had an amputation and to move on with their lives. As one woman put it "I don't say 'Why me?' That's the will of God. I do leave it to God, and I say God is good, and God will help me." Some participants indicated that they found support and a means of coping with their amputation through prayer and attending religious services and pilgrimages. For example, one man remarked "I believe prayer gives you comfort ... I definitely believe that there's something in it." During the year, two participants attended a religious pilgrimage to Lourdes, both of whom remarked that the experience had been wonderful and had given them renewed faith and courage to cope with their amputation and its sequelae.

The use of religion as a means of coping with health-related stress has been extensively studied (Siegel, Anderman, and Schrimshaw, 2001; Harrison, Koenig, Hays et al., 2001). Some researchers have argued that because illness and disability are only partly amenable to problem-solving coping strategies, they are particularly likely to elicit religious coping strategies (Koenig, George, and Siegler, 1988). Despite the fact that religion is sometimes associated with passive coping, it tends to be empirically associated with active or Approach strategies (Pargament, Olsen, Reilly et al., 1992), possibly because it involves a recognition, rather than an avoidance, of the stressor. According to Siegel et al. (2001), there are three main ways through which religion can influence adjustment to illness: (a) as a means of providing an interpretive framework for meaning, (b) as a means of improving coping resources, including sense of control and self-esteem, and (c) as a means of facilitating access to social support and promoting social integration. In the present

study, each of these mechanisms may have played a role in facilitating coping amongst participants using religion. As discussed above, some participants in this study focused on religion as a means of giving a sense of meaning to their amputation and their lives. Others indicated that they found support and a means of coping with their amputation through attending religious services and pilgrimages. Yet others remarked that they put a lot of faith in prayer, thus suggesting that access to an omnipotent God through prayer and faith may have made them feel that they had a powerful ally in helping them deal with their situation (Dull and Skokan, 1995).

Because of the aforementioned mechanisms through which religion is used to cope with life stressors, religious coping tends to be associated with positive psychological adjustment (Siegel et al., 2001; Harrison et al., 2001). In the present study, those individuals who continuously used religious coping appeared to have high levels of psychological functioning. Although one man, JM, did admit to feeling 'down' at times, he only commented on using religion as a coping mechanism at the end of the year, by which stage, he remarked that he had never felt better and that he was a changed man in terms of personality and the life he was now leading. Although the numbers are too small to draw any firm conclusion, it is interesting to note that of the three people who focused on religion and who were studied for the duration of the study, two of these (JM and FF) were amongst the few who remarked that their amputation had led to a better quality of life and that they were now better people for having gone through it.

Another interesting finding with regard to religious coping is that during rehabilitation and three months later, one man appeared to be struggling with negative religious coping. Negative religious coping occurs when one blames religion for one's troubles, become angry with, or loses faith in it. Such negative coping is associated with poorer psychological and physical adjustment (Siegel et al., 2001; Fitchett, Rybarczyk, DeMarco et al., 1999). In the present study, this man became upset during rehabilitation and remarked that he often blamed God and thought "Why me?" when trying to find a meaning for his cancer and his amputation. Three months after rehabilitation, he appeared to be coming to terms with his ordeal and to be finding a

reason for his illness. Although he died shortly after his second interview, he appeared to have come to terms with his amputation and to have found peace in his religion.

Joking – Emotional Avoidance and Behavioural Approach

During rehabilitation, joking about aspects of the amputation were common amongst participants. After rehabilitation, however, the use of joking as a coping strategy declined significantly such that by the end of the year, only one man appeared to be still making jokes or finding humour in his situation. In examining participants' joking responses, it became apparent that they were using humour to cope with a variety of situations and for a variety of reasons. Many people used humour as a means of fostering social relationships with fellow patients and as a means of 'breaking the ice' with those who did not have amputations. For example, one man remarked that in the rehabilitation hospital, they often joked about "breaking each others' legs" to lighten the mood of the other patients. Another man commented that if a visitor came in to see him and sat on the bed, he'd "let a roar and say 'get up, you're sitting on my toes.'" Other people used humour as a means of making light of their situation and of minimising the seriousness of their amputation. For example, one woman remarked during the year that she often felt "like a stork standing in a field," while another man who was confined to a wheelchair commented that in work, he'd never get tired because he'd be "sitting down the whole time." In addition to using humour to foster social relationships and to make light of the situation, two people in particular also used humour and joking as a means of concealing their distress and buoying their mood. These people remarked that "putting on a front" to other people helped them to feel better about their situation, even if they did not always feel happy at the time. As one of these participants said "I can act like I'm cheerful when I'm not, and that can make me cheerful."

The above uses of humour in coping with social interactions and emotions have been described elsewhere. In a qualitative study examining uses of humour in medical interactions, Francis, Monahan and Berger (1999) concluded that humour in these circumstances generates positive emotions among members of an interacting group by bonding them together. Similar to what was observed in the present study, these researchers noted that patients often joked about their illnesses in such a way that health care providers could not participate, thus fostering in-group cohesion. Because

of these social effects of humour, and because use of humour in coping with stress has been found to be associated with more enjoyable social interactions with others (Nezlek and Derks, 2001), it has been argued that in this way, humour serves as an active problem-focused strategy that is used to cope with potentially stressful social situations (Lefcourt, 2002). In the present study, then, using humour to foster group cohesion and to 'break the ice' with people who have not had amputations could be described as behavioural-approach coping strategies.

In the present study, humour was also used by participants in ways that are consistent with avoidance emotional coping (Abel, 2002; Lefcourt, Davidson, Shepherd et al., 1995). One way in which humour was used in the present study as such a strategy was through "perspective-taking humour" (Lefcourt et al., 1995). When people use perspective-taking humour as a means of coping with the emotional aspects of the situation, they are "distancing" themselves from the negative experiences by taking themselves and their experiences less seriously (Lefcourt et al., 1995; Abel, 2002). In the present study, comments such as "feeling like a stork" and "you're sitting on my toes" could be interpreted this way. In addition to fostering social relationships through humour, these comments also served to distance participants from their situations and to give them a different perspective on their amputation. Another way in which a small number of participants used humour in a manner consistent with Emotional Avoidance coping was by "denying" their low affect and maintaining a positive front in front of other people. Thus, in addition to fostering social relations (thereby serving an approach behavioural coping function), joking with others functioned as an Emotional Avoidance coping method. It may be that for those two participants who used joking as a means of putting on a front to others, the social enjoyment that accrued from acting this way may have been sufficient to raise their mood (Kuiper and Martin, 1998; Nezlek and Derks, 2001). However, the value of humour for these individuals may be called into question, since one admitted to finding it tiring to maintain a positive front for others, while the other was often annoyed when his friends participated in his jokes about his amputation. He remarked that when this happens "I'll laugh, but inside I'm thinking 'that's not funny. What are you talking about? I'm going to chop your leg off, so you can see what you're laughing about.'" In this instance, then, even though his humour served to facilitate

social relations and to enhance his mood, the fact that he did not like his friends to join in the jokes indicated that he may also have been using humour to maintain distance from other people. As a result, their joining in his joke was neither appropriate nor appreciated (Francis et al., 1999).

During the year, use of humour as an Approach Behavioural coping method possibly decreased because participants were becoming more accustomed to socially interacting with their amputation [See Social Changes above]. Thus, the need to foster in-group relationships with other people with amputations and to “break the ice” with people may not have been perceived as challenging situations to cope with anymore. In using humour to foster social relationships, there did not appear to be any relationship between this coping method and psychological well-being. Towards the end of the year, however, the use of humour as an Avoidance Emotional coping method appeared to be associated with psychological well-being. During the year, the two participants who used humour as a means of “putting on a front” (i.e. avoidance emotional coping) both experienced symptoms of psychological distress. For example, SC, who indicated using this technique during the first three interviews, had high anxiety and depressive symptoms three months after rehabilitation and continued to have high anxiety symptoms for the remainder of the year. The other participant, PG, who remarked “putting on a front” during the first two interviews showed elevated depressive symptoms during rehabilitation and elevated depressive and anxiety symptoms during the latter half of the year.

These findings are contrary to previous studies that have found positive associations between use of humour and positive mood (Nezlek and Derks, 2001; Abel, 2002; Kuiper and Martin, 1998). However, these studies have tended to measure humour coping as an Approach coping technique to foster favourable social interactions. When humour is taken used as an Avoidance technique to “deny” negative emotions, then the observed finding of a negative relationship between psychological well-being is consistent with reports in the literature indicating a negative relationship between Avoidance coping and psychological functioning (Lazarus and Folkman, 1984; Carver et al., 1989; Livneh et al., 1999). Furthermore, the finding that both of the participants who used Avoidance Emotional coping were the only two people to have

acquired their amputations due to trauma is consistent with the findings of Gallagher and MacLachlan (1999), who reported that such techniques were more prevalent amongst people with trauma-related amputations. Generally speaking, avoidance Emotional coping strategies are thought to be maladaptive in the long term because they prevent the individual from actively addressing and dealing with the problem or emotions they are currently experiencing (Penley et al., 2002). In the present study, then, “putting on a front” to others may have been emotionally tiring and prevented them from addressing their distressing emotions. However, although this is a plausible explanation, it must also be noted that there may be no causative relationship between use of humour and negative relationship. The observed use of humour by the participants in this study may simply have been what they perceived as an effective means to “hide” their low mood from others. That humour and depressed mood were associated does not necessary indicate that the Avoidance technique fostered poor psychological functioning. As has been discussed earlier, Emotional Avoidance techniques are likely to be more common amongst people high in emotional distress anyway (Lazarus and Folkman, 1984).

Social Support – Emotional Approach and Behavioural Approach

During the year, Emotional and Behavioural social support was used by the majority of participants in coping with the emotional impact of the amputation and its practical implications. Emotional support was generally given to participants by their family and friends and remained fairly constant throughout the year. It was usually observed in the form of encouragement and, according to participants, served to maintain or increase their self-esteem and confidence in psychologically adjusting to their amputation. Individuals who commented on receiving such support were generally very happy with it. For example one man remarked that it was “a bit of a booster” that his children did not care about his limb loss and just wanted him to come home; one woman remarked that it gave her “a bit of courage” when friends and family remarked on how well she was coping.

A different pattern of results emerged for instrumental or Behavioural social support. During rehabilitation, most participants remarked that they required a lot of practical help from their families and friends in terms of accessing places, moving around the

house, and engaging in everyday activities. Although they had been happy to accept emotional support, many of those who commented on Behavioural support indicated that they felt guilty or uncomfortable about accepting such help. Remarks such as "I hate the burden on my wife," "I feel guilty at the wife," and "It's not fair on them," were made to indicate the reluctance that most people felt about accepting practical help at this stage. Throughout the rest of the year, however, an interesting finding emerged. Three months and nine months after rehabilitation, feelings of dependence on others continued, and the need for instrumental help generally stayed the same, but the sense of discomfort and guilt about receiving such help diminished. By the end of the year, the need for instrumental help appeared to have decreased, and only four participants indicated requiring such help. Furthermore, only two participants continued to dislike accepting such help from their family and friends.

The differential findings with regard to Emotional and Behavioural Approach coping with social support indicates the dynamic nature of the relationship between social support and recovery from physical illness (Wilcox, Kasl, and Berkman, 1994). In the present study, Emotional Social Support was maintained throughout the year and was much appreciated by all of those participants using it. In general, social support has been cited as a beneficial emotional resource in coping with illness because it may provide the individual with a sense of self-esteem, prevent him/her from ruminating on the problem, or motivate him/her into making efforts to overcome the problem (Jung, 1984). On the other hand, instrumental (i.e. Behavioural) social support has been found to have both positive and negative effects on physical and psychological well-being (Penninx, van Tilburg, Boeke et al., 1998; Dunbar, Ford and Hunt, 1998). According to Dunbar et al. (1998), for example, instrumental social support may cause distress in some individuals because they feel that their social relationships are unequal and that their self-esteem is being threatened. In the present study, such feelings may have been in operation when most participants in receipt of Behavioural social support commented on feeling guilty or uncomfortable about accepting such help. The finding that these feelings of guilt about accepting Behavioural social support decreased throughout the study, and the observation that the need for such support also declined shortly afterward is consistent with reports indicating the role of longitudinal, contextual, and illness-related factors in the use of coping mechanisms

(Terry, 1994; Wilcox et al., 1994). In the present study, participants became less anxious and uncomfortable about accepting instrumental support after they had left rehabilitation. This may have been due to the fact that during this time, they were beginning to recognise their limitations and accept that there were certain activities they could no longer do [See Lifestyle Changes and Limitations above]. Accepting limitations may have been accompanied by a recognition of the emotional futility of feeling guilty about requiring help. Furthermore, the increases in physical strength and walking abilities that were occurring around this time [see Learning to Walk above] may have meant that they were aware that Behavioural support would not continue to the same extent for much longer. The observed finding that, at the end of the year, such support was only required by a minority of participants supports this idea.

Despite the overall indication that use of Behavioural Support declined throughout the year, one participant continued to rely almost exclusively on such support in her everyday activities. According to this individual, her brother actively discouraged her from engaging in any activities, with the result that she rarely practiced walking on her prosthesis and had only left the house on a couple of occasions since leaving the rehabilitation hospital. This negative aspect of Behavioural Social Support has been discussed in the literature (Vaux, 1988). In some cases, overprotection on the part of carers or family members induces what has been called “imposed dependency” such that the individual is not permitted to be independent even though he or she is perfectly capable of being so (Gignac and Cott, 1998). Such imposed dependency and overprotectiveness has been found to impede recovery after illness (Vaux, 1988) and, in the case of people with amputations, increase disability associated with phantom pain (Jensen et al., 2002).

Overall, there did not appear to be any relationship between use of Emotional social support and psychological well-being. Individuals who did appear to have anxious or depressive symptomatology were amongst those who praised their family and friends for the support and encouragement they gave them. In addition, those individuals who did not seem to need Emotional support did not appear to be experiencing any psychological distress. Although this finding is contrary to the majority of the

literature indicating that Emotional support has either a direct or buffering effect on the relationship between stress and well-being (Cohen and Wills, 1985), there are some indications that not everybody requires social support to maintain positive well-being (Wilcox et al., 1994; Jung, 1984). Furthermore, not every research paper has found a relationship between provision of Emotional Support and psychological well-being (Jung, 1984). Because the impact of Emotional Support is mediated by a variety of situational and personality factors (Terry, 1994; Symister and Friend, 2003), it is likely that the small number of participants in the present study precludes a detailed investigation into the myriad of factors associated with the impact of Emotional Support on Well-Being.

Although Behavioural Social Support caused some discomfort and guilt in participants at the beginning of the year, only one person expressing these feelings appeared to be particularly anxious or depressed at this time. Thus, contrary to findings in which Behavioural Support is associated with psychological well-being (Wilcox et al., 1994; Penley et al., 2002), no such relationship was observed in the present study. However, because such support has been found to be associated with less disability in longitudinal analyses (Wilcox et al., 1994), it cannot be ruled out that in the present study, participants' decreased need for Behavioural Support was associated with the high levels they were receiving from the beginning of the year.

Behavioural Approach Methods

Taking action

One of the main Behavioural Approach methods of coping that was used throughout the year was that of Taking Action to resolve particular barriers or obstacles that were faced. During rehabilitation, Taking Action was used by only a small number of people as a means of maintaining independence, keeping occupied, and learning how to cope with activities of daily living. Three months after rehabilitation, however, use of Taking Action as a coping strategy increased to the extent that the majority of participants were seen to use this method in dealing with other peoples' reactions towards them and in improving their mobility and accessibility. Although use of the Taking Action coping strategy diminished somewhat throughout the rest of the year, it was still in use by just over half of the participants in developing new interests and

activities, coping with prosthesis problems, health problems, other peoples' reactions towards them, and mobility issues.

The increase in use of Behavioural Approach strategies in the months following rehabilitation supports the idea of coping strategies as context dependent (Terry, 1994; Lazarus and Folkman, 1984; Holohan and Moos, 1987). Whilst attending the rehabilitation hospital, most participants were solely focused on adapting to their prosthesis and learning to walk again. In addition, many were unsure as to the kind of obstacles they were likely to face once they had left the hospital and resumed their normal lives. Because of this, and the fact that there were not many opportunities for taking action while in hospital, it is not surprising that most people did not use Taking Action as a coping strategy during this time. After rehabilitation, however, the uncertainties about obstacles and barriers were beginning to end, and participants were beginning to realise what problems they faced and what needed to be acted upon. Therefore, during the months after rehabilitation, many began to look at ways in which they could resolve transport problems, deal with other peoples' reactions, improve their accessibility to places, and engage in other activities and hobbies to keep occupied. Once these problems had been resolved to some extent, then the need for such coping strategies would not be so pressing or necessary. Thus, the observed decline in use of Taking Action makes sense in the context of the situations that people were likely to be facing.

Overall, there did not appear to be any relationship between use of Taking Action as a coping strategy and psychological well-being. Individuals who had low and high scores on the HADS-A and HADS-D were found to use the Taking Action strategy throughout the year, regardless of their psychological well-being. Although these findings are inconsistent with previous findings that use of Problem-Solving strategies (such as Taking Action) are associated with improved physical and psychological health (e.g. Holohan and Moos, 1987; Folkman and Lazarus, 1988; Aldwin and Revenson, 1987), they are consistent with the results of a meta-analytic study on the relationship between health and coping (Penley et al., 2002). According to these authors and other researchers, the lack of relationship between Problem-Solving strategies and psychological well-being may be moderated by the perceived

effectiveness of the strategy (Penley et al., 2002; Falkum, Olff and Aasland, 1997). That is, if participants are continually engaging in an unsuccessful Taking Action strategy, then this could decrease any positive effect it may have on emotional well-being. This could explain the findings in the present study. Of those who used Taking Action as a strategy, but continued to have high HADS-D and HADS-A scores throughout the year (i.e. DOD, SC, and PG), some failures in their efforts were noted. For example, DOD tried to improve his accessibility problems by applying for a Driver's License, but discovered that his eyesight had deteriorated to such a degree that he was not permitted to drive. He also tried to improve his mobility by cycling, but also found that this was too difficult. Another man, PG, made various attempts to contact different organisations that could help him solve the problems he was experiencing with his prosthesis, but he was having no luck with these efforts and was referred back to the original company that had made his prosthesis. Another man, SC, made several attempts to find new activities and employment, but these had not been successful. As a result, he indicated that he was continuously frustrated and upset about these failed attempts. On the other hand, of those who used Taking Action as a strategy (e.g. MG, NK, JM, FF, BN) failures in their attempts were less obvious. Even though one man, FF, was battling an methicillin-resistant *Staphylococcus aureus* (MRSA)¹ infection in his stump throughout the year, his efforts to improve his mobility and accessibility were highly successful, such that he was able to drive a car and engage in some gardening. The remaining participants were also successful in their attempts to cope with others' reactions, improve their accessibility, find new employment, or return to their old jobs.

Use of External Resources

Throughout the year, many participants indicated using External Resources in order to cope with some of the psychological and physical implications of their amputation. One external resource that people used to cope with transport problems was a car. For these people, the car was a valued resource in helping them to maintain their independence and desired mobility.

¹ MRSA is a bacterial infection that is acquired on wound sites during hospitalisation. Its prevalence in the Republic of Ireland is estimated at 14 per 100,000 of the population (McDonald, Mitchell, and Johnson et al., 2003). It is the most common cause of surgical site infection in vascular patients (Naylor, Haes and Darke, 2001) and is often associated with a poor treatment outcome (Scriven, Silva, Swann et al., 2003).

Another external resource that participants used to cope with body-image anxieties was their prosthesis. During rehabilitation and throughout the year, many people indicated that they were relying on their prosthesis to restore a 'normal' body image. Overall, such use of the prosthesis reached a high point three months after rehabilitation and declined thereafter.

Another external resource that a number of people used to enhance self-esteem and self-concept was employment. During the year, six people had returned to full-time or part-time work. Most of these people indicated that this return had helped them to maintain their levels of self-esteem and well-being.

The importance of a car in maintaining independence following acquired disability has been documented previously. For example, participants in Albrecht and Devlieger's (1999) study remarked how their ability to drive and use their cars served to empower them and give them a sense of control over their bodies and minds. The importance of the prosthesis as a means of helping people to cope with body-image anxieties has also been observed (Murray and Fox, 2002). In fact, these researchers reported that individuals who were dissatisfied with the aesthetic aspects of their prosthesis were more likely to experience body-image anxieties, a finding which was also observed in the present study. Finally, the beneficial effect of a resumption of employment following acquired disability has also been found (Chapin and Kewman, 2001; Saunders, Leahy, Frank, 2000). For many people, employment is seen as a means of getting increased access to social support (Aquino, Russell, Cutrona et al., 1996) or as a means of increasing self-concept (Chapin and Kewman, 2001; Saunders et al., 2000). In the present study, the beneficial effects of employment in maintaining psychological well-being is supported by the finding that the two people who had to retire as a result of their amputation (DOD and MMcC) showed elevated depressive or anxiety symptoms. Furthermore, the one participant who was unsuccessfully looking for work (SC) showed increased psychological symptoms and implicated his unemployed status in these emotions. This man remarked that his previous job had given him a certain status in the community he had lived in and that being employed in artwork would not engender as much a sense of pride. Nevertheless, because he

remained unemployed during the year, he remarked that this often brought him down because he was constantly worried and feeling guilty about it.

Behavioural Avoidance

Distraction

Throughout the year, a small number of people indicated that they sometimes engaged in particular activities in order to distract their attention away from potentially distressing thoughts or emotions. For some people, Behavioural Distraction was used as a means of coping with upsetting feelings regarding the amputation. For others, this coping technique was perceived as a means of coping with or 'forgetting about' phantom limb pain.

In general, Behavioural Avoidance techniques are generally used when it is not possible to use Approach techniques to deal with and resolve the problem being faced (Lazarus and Folkman, 1984). This would appear to be the reason why such techniques were used in the present study, as participants using Behavioural Distraction were faced with aspects of their amputation that they had no direct control over: phantom limb pain, limb loss, and poor stump healing. Participants' use of Distraction in coping with phantom pain is consistent with previous reports on the beneficial effects of distraction on general pain (McCaul and Malott, 1984) and phantom limb pain (Whyte and Niven, 2001b; Machin and Williams, 1998). For example, Whyte and Niven (2001b) reported that one of the most common strategies of coping with phantom pain in their study was distraction. Similarly, Machin and Williams (1998) found that individuals who lived with a spouse, rather than alone, also tended to use distraction techniques or emotional expression as means of coping with their pain.

Participants' use of Distraction to cope with distressing thoughts associated with the amputation is explicable in view of the fact that their limb loss was not something that could ever be reversed. Because there were no Behavioural Approach techniques that could possibly be engaged in to resolve this problem, Distraction from distressing thoughts could be more helpful than continuously ruminating on the problem. However, two of the participants who used such techniques (FF and JM) admitted to

feeling 'down' at times during the year. Although no direct link between use of Distraction and 'feeling down' can be posited, this finding supports the notion that use of Distraction is associated with decreased psychological well-being, perhaps because those who are more psychologically distressed, in the face of stressors that cannot be altered, require more Distraction techniques (Lazarus and Folkman, 1984).

EMOTIONAL WELL-BEING

In discussing the psychological well-being of participants throughout the year, it was decided to focus only on the responses of those individuals who had participated in at least three of the interviews. This decision was made because it was thought that two interviews did not provide a sufficient time period to perceive longitudinal relationships among coping style, personality disposition, and responses in those who had only completed two interviews.

In examining emotional well-being in the present study, it was found that many participants (NK, MG, AMcG, AOM, LB, GD) did not appear to be experiencing any psychological difficulties in adjusting to their amputation and artificial limb. On the other hand, a minority of participants (FF, JM, BN) admitted that they sometimes experienced periods of 'feeling down' or 'anxious' even though they did not have elevated depressive or anxiety symptoms according to their responses on the Hospital Anxiety and Depression scale. Furthermore, another group of people (PG, MMcC, SC, and DOD) during the year indicated that they felt 'down' or 'anxious' about certain aspects of their lives, and these individuals *did* show elevated scores on the Anxiety and/or Depression subscales of the HADS. While PG and SC showed elevated HADS scores throughout most of the year, DOD had elevated anxiety scores at two times points during the year, and MMcC had elevated depression scores at one point during the year.

In general, analyses of the responses of individuals who did not appear to be experiencing any psychological difficulties throughout the study revealed that at all times, they generally had positive thoughts regarding their present and future lives and they tended to believe, most of the time, that they were the same person they had

been prior to their amputation, that their lives were currently fulfilling, and that their lives would be as good again. In addition, none of these individuals appeared to be experiencing any social difficulties with regard to their amputation, and none decided to forgo interacting with other people because of feeling socially awkward or uncomfortable. Moreover, none indicated experiencing any body-image anxieties as a result of having an amputation.

On the other hand, analyses of the responses of individuals who indicated that, at times, they felt 'down' or 'anxious' revealed a different pattern of responses. Those with elevated HADS scores tended to respond negatively to questions regarding their selves, their futures, and their amputation. Therefore, they tended to believe that their lives would never be as good again, that their lives were not currently fulfilling, that they were 'disabled' and limited in what they could do, and that they were no longer the same person they had been prior to amputation. Furthermore, they tended to experience moderate to severe body-image anxiety and to remark that their social lives had been curtailed, to some extent, as a result of awkwardness in getting to places and feeling a burden. Individuals who did not have elevated HADS scores, but who also felt 'down' or 'anxious' at times, also experienced body image anxieties and some avoided social interactions, at times, because they felt awkward or a burden in certain circumstances. In addition, they also tended to respond negatively to questions regarding their futures and their amputations, although they did so to a lesser degree than those with elevated HADS scores.

Three interrelated factors may explain why some people consistently responded positively to their situation, while others had periods of feeling 'down', and others indicated continuous psychological difficulties. The first factor that could explain these findings is *personality disposition*. Although no measures of personality were included in the present study, three of the four people who had elevated HADS scores (SC, PG, DOD) indicated that prior to their amputation, their personalities had been particularly depressive, anxious, or pessimistic. Conversely, individuals experiencing no emotional distress indicated that their optimistic personality style was an asset in coping with the implications of their amputation.

Optimists expect that good things will happen to them in their current and future lives (Scheier and Carver, 2002). In the present study, participants with no depressive or anxiety symptoms believed that their lives would be as good again, that their lives were currently fulfilling, and that they were the same people they had been prior to their amputation. Overall, an optimistic disposition has been associated with numerous favourable outcomes in medical populations, including lower levels of distress in patients undergoing treatment for early-stage breast cancer (Carver, Pozo, Harris et al., 1993) and increased psychological well-being and better self-rated quality of life in patients recovering from coronary artery bypass surgery (Scheier, Matthews, Owens et al., 1989). According to Scheier and Carver (2002), one of the main reasons as to why optimists appear to have increased psychological functioning following adversity is that they tend to engage in Approach coping techniques, rather than in Avoidance coping techniques. Thus, while optimists report a dispositional tendency to rely on active, problem-solving coping, pessimists report a tendency to disengage or “deny” their problems.

In the present study, use of such *coping strategies* associated with optimistic versus pessimistic personalities could explain the observed differences in psychological well-being between those who did and did not experience ‘depressive’ or ‘anxious’ periods. Moreover, the extent to which coping strategies were used and experience of *trauma* could differentiate those who felt ‘down’ or ‘anxious’ but with low HADS scores from those who felt the same way but who had elevated HADS scores. In general, those individuals who did not appear to have any psychological difficulties did not use any Avoidance coping strategies throughout the latter half of the year. Instead, they used Cognitive, Emotional, and Approach methods of Thinking and Planning Ahead, using Religion, Determination, and Taking Action with successful outcomes.

On the other hand, those individuals who experienced periods of feeling ‘down’ or ‘depressed’ without having elevated HADS scores used Avoidance coping to some extent, despite using Approach methods with some success. For example, FF used the Approach coping strategies of Emotional Determination, Religion, and Taking Action. BN also used Emotional Determination as well as Taking Action and External

Objects (i.e. her car). JM used Religion, Behavioural Joking, and Taking Action at various points throughout the year. However, all three of these individuals indicated that, at times, they relied on the Avoidance method of Behavioural Distraction to take their mind off distressing thoughts about their amputation and their lifestyle.

What differentiated these individuals from those with elevated HADS scores is that the latter tended to predominantly use Avoidance strategies at all points throughout the year. When they used Approach techniques, these were often unsuccessful. For example, PG, MMcC, and DOD were the only two who engaged in thought suppression during the last two interviews, a coping strategy that has previously been implicated in the development and maintenance of depression or anxiety (Beevers et al., 1999). Furthermore, both SC and PG were the only two participants who engaged in Avoidance Joking as a means of concealing their distressing emotions and “putting on a front” for other people. Moreover, although PG, SC, and DOD engaged in Taking Action Approach coping, none of their efforts in resolving the particular problems they faced were particularly successful. Interestingly, SC and PG were the only two individuals to lose their limb as result of a trauma, and in general, it has been found that people who undergo a traumatic event are more likely to experience psychological distress (Mohta, Sethi, Tyagi et al., 2003) for longer durations (Zlotnick, Warshaw, Shea et al., 1997). In addition, they are more likely to use Avoidance coping mechanisms and less likely to use Approach coping (Jeavons, 2000; Jeavons, Horne, and Greenwood, 2000).

Although *personality disposition, coping style, and experience of trauma* are all implicated in the development of psychological distress in the present study, the relative importance of each is difficult to determine. The experience of persistent psychological distress in the two people who lost their limb due to trauma is consistent with previous reports indicating a heightened risk of emotional problems in those who have experienced traumatic events (Mohta et al., 2003). Moreover, their predominant use of Avoidance coping is also consistent with reports that such coping strategies are more common amongst victims of trauma (Jeavons, 2000). As discussed earlier Avoidance coping is generally associated with a poorer psychological outcome than is Approach coping because the former method maintains rather than resolves the

problem (Penley et al., 2002). However, because both of these individuals with histories of trauma also indicated that their personalities had been depressive or anxious prior to their limb loss, this could suggest a dispositional vulnerability to developing depression or anxiety. Furthermore, because the other man who experienced anxiety throughout the year (i.e. DOD) also indicated that his personality was of a pessimistic nature, then the role of *personality disposition* in the development of persistent psychological symptoms could be more important than the role of *coping mechanisms*. In further support of the role of *personality*, the causative nature of Avoidance coping in psychological symptoms cannot be established in the present study because many participants who did not have psychological symptoms actually used such methods at the beginning of the study. Further support for the role of personality is the indication that those who were not experiencing psychological distress tended to have optimistic views about their futures, whilst those who felt 'down' or 'anxious' at times were not so hopeful about their present or future lives. Thus, in support of the view that personality disposition is important in determining coping strategies (Holoan and Moos, 1987), it could be argued in the present study that personality dispositions were of primary importance in determining the predominant modes of coping that were used (Carver and Scheier, 2002). In this way, both *personality* and *coping methods* combined influenced psychological well-being throughout the year. This conclusion supports that of Furst and Humphrey (1983), who reported that the spouses of people with an amputation had concluded that personality was the most important factor in adjustment to an amputation.

CHAPTER 8

CONCLUSION

PSYCHOSOCIAL ADJUSTMENT TO AMPUTATION

Overall, the longitudinal pattern of adjustment to amputation observed in the present study supports, to some extent, stage theories of adjustment to acquired disability, including limb loss (Livneh and Evans, 1984; Livneh, 1986; Antonak and Livneh, 1991). With regard to these stages of adjustment, these authors argue that adjustment to acquired disability occurs only after the following psychological reactions are experienced: shock and anxiety, bargaining and denial, depression and internalised anger, externalised aggression, acknowledgement and acceptance, and final adjustment. According to Antonak and Livneh (1991), Reactions of Depression, Internalised anger, Shock, Anxiety and Externalised hostility are thought to be necessary precursors to experiencing Acceptance and Acknowledgement.

Consistent with stage-theories, reactions of Shock, Disappointment, and Sadness were recalled in the present study by participants prior to their amputation. However, reactions of depression, withdrawal, internalised anger, and externalised aggression were not noted amongst the majority of respondents, and only one participant appeared to be experiencing a grief-like reaction during his first two interviews. The fact that mourning, depression, withdrawal, internalised anger and aggression (Livneh and Evans, 1984; Antonak and Livneh, 1991) did not appear to be experienced by everyone in the present study may be due to the fact that participants had undergone their amputation an average of four and seven months at the time of the first and second interviews, respectively. Although it is notoriously difficult to determine the average length of grief reactions, suggested durations have varied from six months to one year (Bonanno and Kaltman, 2001). Thus, with participants being an average of four to seven months post-amputation in the earlier stages of the study, the typical grief reactions described by Parkes (1975) may have already occurred and been resolved. Similarly, such psychological reactions as externalised aggression, internalised anger, denial, and bargaining may have already occurred by the time participants had entered rehabilitation. If this is the case, then rehabilitation may mark the beginning of the last stages of adjustment to disability.

Support for this idea, that rehabilitation marks the beginning of Acceptance and subsequent Adjustment, is found in the longitudinal patterns of Appraisals of Amputation, Adjustment to Lifestyle Changes and Limitations, and Identity changes. During rehabilitation, most people accepted their amputation as the 'lesser of two evils.' Such acceptance was accompanied by participants' general belief that life would continue to be as good as it had been previously, that they were the same person they had been prior to their amputation, and that they would not be faced with many social and physical limitations. However, following rehabilitation, a shift in all of these attitudes was evident throughout the year. Overall acceptance of the limb was subsequently followed by some mixed feelings, doubts, guilt, and blame. Furthermore, the belief that life would again be as good as it was previously began to be replaced by thoughts that this may not be the case. Furthermore, a focus on restrictions and limitations in physical and social functioning began to become more prevalent and more and more people began to equate a changed identity with feeling 'disabled' and limited. By the end of the year, however, another shift in these beliefs was evident. Although wholehearted acceptance of limb loss did not occur, most people indicated that they had put their amputation behind them and that they had learned to live and enjoy their lives, despite the fact that they may never fully get over losing a limb. In keeping with this changed attitude, limitations and restrictions were not perceived to be important in determining whether life would be as good again. Furthermore, such restrictions were no longer important in their sense of self and identity, and instead, personality became more important in assessments of self, rather than restrictions. Thus, most people now indicated that although they were 'disabled', they were still the same person they had been prior to their amputation.

These patterns of attitude change may reflect the end phases in stage-theories of adaptation to disability (Livneh and Evans, 1984; Antonak and Livneh, 1991), in which Acceptance of disability is followed by Adjustment. At the beginning, acknowledgement and acceptance of the amputation were very much in evidence among participants. During rehabilitation, however, they would have had no experience of living in the world with an amputation, and, therefore, they would have had no opportunity to incorporate the fact of having lost a limb into their lives outside the hospital. Following rehabilitation, however, they began to live in the world

Adjustment to Lifestyle changes, Social changes, and Identity changes occurred [See below].

INTERRELATIONSHIPS AMONG VARIABLES – LIVNEH'S (2001) FRAMEWORK

Throughout the duration of the study, it was evident that the effect of amputation-related, contextual, and personal factors on Adjustment to amputation were interrelated at all stages. Using Livneh's (2001) model to explicate these interrelationships, it was observed in the study that the Triggering Event (cause of amputation) was associated with Contextual Influences (Coping, Presence of comorbid illnesses, and Sociodemographic characteristics). Thus, people who had their amputation due to trauma were more likely to use Avoidance coping and Downward Social Comparisons as coping mechanisms. On the other hand, people who had their amputation due to disease were more likely to be older and to appraise their amputation as non-threatening and as having minimal impact because of their advanced age. Regardless of amputation cause, however, both groups were likely to experience comorbid medical problems.

Contextual Influences (Amputation-Related Variables, Personality Attributes and Coping Modes, and Environmental Features) were all interrelated and associated with Intrapersonal, Interpersonal and Extrapersonal Functioning. In terms of Amputation-Related variables, individuals with phantom limb sensation were more likely at the beginning of the study to 'forget' they had an amputation and experience a shock upon noticing their absent limb. Experiencing such a shock was associated with increased body-image anxiety. Furthermore, individuals who were displeased with aesthetic aspects of their prosthesis were more likely to experience body-image anxiety and to avoid social interactions with other people for fear of appearing awkward or being a burden on others. Length of time since amputation was also associated with perceptions of success in learning to walk, as longer duration since amputation was associated with feeling that one had reached a 'plateau' and that no more improvements could be gained. In terms of Personality Attributes and Coping Modes, individuals who were optimistic appeared to be more likely to use Approach coping and less likely to have psychological difficulties throughout the year. On the

other hand, people who used Avoidance coping were more likely to have periods of 'feeling down', to have negative thoughts about their amputation, to avoid social interactions, and to experience body-image anxiety. Overall, the use and extent of particular coping mechanisms varied throughout the year, with some being more prevalent during and shortly after rehabilitation, and others remaining constant throughout the year. In terms of Environmental Features, some individuals who encountered barriers and obstacles in accessing places were more likely to avoid socially interacting with others for fear of being a burden on others. Furthermore, some people who perceived that others were evaluating their prosthesis negatively were more likely to experience body-image anxiety and to avoid interacting with others as a result. In addition, Environmental Features such as uneven ground, slippery surfaces, and crowds were likely to put people off from practicing walking or engaging in social activities.

Experienced Reactions and Responses to the Amputation were associated with Intrapersonal, Interpersonal, and Extrapersonal functioning. The individual who appeared to be experiencing a grief-like reaction during the year had relatively high levels of psychological distress. Furthermore, the above described movement from Acceptance of amputation to Adjustment to amputation was associated with alterations in body-image anxiety, social activities, assessments of self-identity, and a shift in value change in which the importance of the physique and physical abilities became subordinated to personality factors. With the move from Acceptance to Adjustment, body-image anxieties were likely to rise and fall as different social encounters were made and attitudes towards the prosthesis changed. In addition, values placed on physical abilities underwent a shift as limitations were accepted and incorporated into a new self-identity and lifestyle.

CLINICAL IMPLICATIONS OF THE STUDY

Implications for Physical Rehabilitation

The *Amputation-Related* findings with regard to phantom pain, stump pain, learning to walk, and adapting to the prosthesis all have implications for the rehabilitation of people with amputations. Contrary to what has been observed in much of the earlier

literature on pain associated with amputation (e.g. Sherman et al., 1984; Pohjolainen and Alaranta, 1991), phantom pain and stump pain interfered with the lives of only a minority of participants, and only a small number were forced to stop walking when this pain started. However, as most of the studies that have reported a relationship between pain and interference have been conducted using cross-sectional populations (e.g. Smith et al., 1999; Gallagher et al., 2001), it could be argued that such pain becomes bothersome at a later stage of adjustment to amputation. Thus, although participants may not complain too much of phantom limb or stump pain in the early stages of adjusting to a prosthesis, there is the possibility that such pain may become more troublesome in later years.

The finding that many participants were not happy with their progress by the end of the year may also have implications for their rehabilitation. In the rehabilitation literature, it has been found that when goals are not reached, rehabilitation key workers will alter their expectations for goal attainment in a downward direction (Stanley and Standen, 2001). Similarly, in the present study, a small number of participants indicated that because they felt they had reached a 'plateau' they were no longer setting walking goals and felt that they could progress no further. Because of these observations, and because self-ratings of functional limitations actually increased towards the end of the year, participants' motivation to keep practicing on their prosthesis could be affected.

The role of environmental barriers and fear of falling in the present study may also have implications for rehabilitation. Throughout the year, most participants indicated that they faced several environmental obstacles that they would not have been prepared for during rehabilitation. Such obstacles included rough ground, crowds, and access difficulties. In addition to facing these obstacles, many participants remained nervous of falling throughout the year. In some cases, this may have prevented them from practicing to the best of their ability, and, therefore, impeded their progress on their prosthesis. In view of these obstacles, rehabilitation training could include classes to prepare individuals for such environmental obstacles.

The findings regarding the role of the prosthesis and factors associated with adjustment to an artificial limb also have implications for physical rehabilitation.

without their limb and thus were faced with role changes, identity changes, limitations, restrictions, and social changes. During the year, the above summary indicates that these changes were incorporated into their over self-concepts and lifestyles. If adjustment is defined as the incorporation of limitations into a new life (Livneh, 1986), it would appear that on the basis of the dynamic responses to limitations, lifestyle changes, and self-identity indicate that this occurred in the majority of participants.

Overall, this cognitive shift from acceptance of amputation to adjustment to amputation may be explained using a non-linear model of adjustment to disability (Kendall and Buys, 1998) According to Kendall and Buys (1998), acquiring a disability means that the person's existing schemas for understanding the world are no longer adequate. Initially, however, he/she is too overwhelmed by his/her situation to develop new schemas, and, therefore, the old ones are maintained for some time after the disabling event. However, with repeated exposure to the environment, new schemas can be developed, revised, modified, and restructured. As a result, a more realistic approach to life eventually emerges. This process is not linear, and it is argued that throughout the reconstruction phase, the individual is likely to oscillate between adjustment and maladjustment to the disability until satisfactory schemas have been developed and a point of equilibrium has been reached. In the present study, individuals initially accepted their amputation because they perceived it as 'the lesser of two evils' and something that was necessary to save their lives. At this stage, they had no experience of living in the world with an amputation and, thus, had no real knowledge of the impact of an amputation on their psychosocial functioning. However, with their departure from the rehabilitation hospital and their re-emergence into the 'real world', they were faced, for the first time, with the physical and emotional consequences of living with an amputation; an event which has previously been documented as daunting (Glass, 1994). Thus, their initial acceptance of the amputation had to be revised and new schemas of themselves in the world without a limb had to be developed. As a result, it is not surprising that they no longer wholeheartedly accepted their amputation and that feelings of blame, regret, and loss began to emerge. At the same time, the recognition of limitations, abilities, and changes that occurred throughout the year brought a shift in value changes so that

Throughout the study, most people appeared willing to tolerate an ill-fitting and uncomfortable prosthesis in the early stages because they were grateful to the limb for what it enabled them to do, because they expected to experience some discomfort in learning to walk, and because they were aware that the fitting problems were because their stump was shrinking, rather than because the artificial limb was poorly fitted. However, the aesthetic qualities of the prosthesis appeared to be very important to participants, in that many who were dissatisfied with the appearance of their artificial limb experience above average body-image self-consciousness. In the early stages of rehabilitation, therefore, it would appear that satisfaction with the limb depends predominantly on the usefulness of the limb and what it enables one to do, rather than on comfort and fit. However, the appearance of the limb was very important to most people. Because many indicated that they wanted their prosthesis to restore a 'normal' appearance, its aesthetic qualities were very important in helping people adapt to their limb.

Implications for psychological adjustment to amputation

The process of adjustment appears to involve coming to terms with a changed identity, social circumstances, lifestyle changes, and limitations. However, although two people consistently appeared to be experiencing psychological difficulties, and some people admitted to feeling 'down' at times as a result of having an amputation, a grief reaction was only observed by one participant in the study. Although this may be due to the fact that grief reactions had already occurred in these individuals, their retrospective accounts of the immediate post-amputation period and their interviews during rehabilitation and throughout the year did not seem to indicate a grief reaction to losing a limb. Thus, contrary to popular belief that a grief-reaction is a necessary precursor to adjustment to loss (Wortman and Silver, 1989), the findings of this study imply that a grief reaction may not be a universal reaction to losing a limb. Furthermore, although periods of sadness and anxiety were observed among participants throughout the year, the majority appeared to appraise their amputation within a context of "it could be worse", and thus, most appeared to have accepted and adjusted to having lost a limb. Thus, contrary to previous observations that limb loss was almost always followed by crises and psychiatric symptoms (Shukla et al., 1982;

Lundberg and Guggenheim, 1986), the findings of this study would seem to imply that this is not necessary the case.

The observation that the two people with trauma-related amputations appeared to have poorer adjustment their limb loss and to use more avoidance coping methods than the remainder of the participants has clinical implications. This finding underscores the importance of observing individuals with trauma-related limb loss to assess their adjustment to their amputation and to assess their use of appropriate coping mechanisms.

The observation that personality and coping strategies were important in adjusting to amputation has clinical implications. That is, the finding that people with high levels of emotional determination generally described themselves as 'fighters' or 'optimistic' individuals, while those who experienced psychological symptoms described their previous personalities as 'anxious', 'pessimistic', or 'depressive' indicates the importance of assessing particular personality styles as well as particular coping styles in people who have lost a limb.

The observed interrelations among the multiple variables associated with adjustment to amputation suggests that it is a dynamic process that unfolds over a period of at least one year. Demographic factors, personality and coping styles, and amputation-related factors are all important in determining the manner in which this adjustment unfolds. Because of this, physical, social and psychological factors are equally important in both physical rehabilitation *and* psychological adjustment to amputation. The interrelations among all of these variables indicate that the relative importance of each cannot be underestimated or assessed in isolation.

LIMITATIONS OF THE STUDY

Although the study purports to look at psychosocial adaptation to lower-limb amputation, its findings are only applicable to those who has undergone rehabilitation after a lower limb amputation. As observed in Chapter 1, only 17% to 65% of all people who have had a lower-limb amputation are referred for rehabilitation

(Rommers, Vos, Groothoff et al., 1996; Harris, van Schie, Carroll et al., 1991). Thus, the findings of this study are not applicable to those 35% to 83% of people who are not referred for rehabilitation and are not given the opportunity to adapt to wearing an artificial limb. Further study needs to be conducted into the psychological adjustment to amputation of people who have not been referred for limb fitting or for physical rehabilitation.

The fact that some people were unable to continue their participation in this study due to repeat hospitalisations and that three people did not wish to participate in a second interview further limits the generalisability of the findings. This means that the observations in the present study may only apply to those individuals who were physically strong and rehabilitating successfully. Furthermore, it could be that those who wished to continue participating in the study were feeling particularly happy or psychologically well to participate and, therefore, represented a high-functioning subsample of those who have been referred for rehabilitation.

Although the longitudinal and qualitative nature of this study permitted extensive research into the contextual, personality, and amputation-related variables associated with adjustment to limb loss, the small number of participants in the study precluded any statistical examination of the interrelationships among the various aspects studied.

Finally, because the first interviews were conducted an average of four months after amputation, it was not possible to explore reactions prior to the amputation and immediately after an amputation. Thus, it was not possible to gather any evidence to support or refute traditional stage models of adjustment to illness and physical disability (Livneh and Evans, 1984).

