Understanding the Experience of Loss, Grief and Bereavement for Staff Supporting Persons with Intellectual Disability and Dementia: An Hermeneutic Inquiry

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SUMMARY

This thesis describes research which explores the experiences of loss and grief for frontline staff who support persons with intellectual disability and dementia. It is presented in two phases. Phase one was a funded project which explored the education and training needs of staff supporting persons with intellectual disability and dementia. An educational intervention was designed and delivered to the services who took part in phase one.

The research methodology utilised in phase one was qualitative descriptive. The research methods used were focus group interviews. The analysis of phase one was thematic analysis.

Arising from the findings in phase one, it emerged that grief was potentially a key area of concern for frontline staff who supported this population. Consequently, a deeper exploration of these experiences of staff grief became the central question for this thesis.

The data from phase one were re-analysed utilizing a philosophical Hermeneutic approach guided by the writings of the philosopher Gadamer. Individual interviews were conducted to deepen the data for phase two and the re-analysed data from phase one was merged with it.

The study populations were drawn from a cross section of six intellectual disability services and one specialist palliative care service in the republic of Ireland.

The analysis of phase two was therefore undertaken using an interpretative approach in line with a Hermeneutic methodology.

The data was organised using computer assisted qualitative research software (NVivo 7) to demonstrate an audit trail.

There was a total population of sixty eight participants in the study.

The findings indicate that frontline staff supporting persons with intellectual disability and dementia do experience loss and grief, that this experience is complex and is influenced by their existing worldview of what it is like to work in intellectual disability care. Furthermore, bereavement support is an important factor for them as professionals in this specialty, both from a receiving and a giving perspective.

CHAPTER 1 – SETTING THE SCENE

1.1 Introduction

This chapter introduces the reader to the background and context of a funded project from which the thesis emerged. This is phase one of the research to be presented in this thesis. Phase one is presented in chapters one and two. This chapter includes the background and context to the project which was to investigate the educational needs of staff who support persons with intellectual disability (ID) and dementia. Chapter one reviews the literature on ID care, palliative care and dementia care. As a team member on this funded project (phase one) I developed an interest in the researching of the experiences of grief for frontline staff in ID care (phase two). Phase two is presented in chapters three to ten.

1.2 Background

1.2.1 Introduction

This funded project (phase one) was designed in response to the World Health Organisation's (WHO 2000) recommendations that the needs of older people with ID ought to be included in policies and approaches designed for the betterment of all older people. Furthermore, that access to the full range of health services be assured, and that developed countries take a lead in such provision to guide such progress in developing countries (Hogg et al. 2000). On a national level, the Irish National Disability Authority (NDA) extends this ideal and recommends that additional services for people with ID need to be developed in order to address the existing gaps in services (NDA 2001, 2010). Equity of access to healthcare is a key concern for individuals living within the island of Ireland as highlighted in the Department of Health and Children's Quality and Fairness health strategy report (DoHC 2001a). In the pursuit of such improvements, the NDA (2001, 2010) further recommends that evidence from the national intellectual disability database (Kelly & Kelly 2010) be incorporated into service delivery and resource allocations. International reports such as the 'Convention on the rights of persons with disabilities' (UN Enable 2008) and the National report of the Health Service Executive and Irish Hospice Foundation (HSE/IHF 2008) 'Palliative Care for All ; Integrating Palliative Care into Disease Management Frameworks' are requiring that people with disabilities have a choice of where to live and die and for persons with

dementia to be able to access palliative care equally with other persons with non-malignant terminal conditions. Influenced by these reports, policy documents and recommendations from the above bodies, this project (phase one) was designed to improve the care of older persons with ID, in response to the documented current and predicted increase in the number of ageing persons noted in the national disability database (Kelly & Kelly 2010). It was furthermore designed to encourage an expansion of palliative care services to this population. Finally, it was designed, in particular, to address the needs of persons with end-stage dementia in ways which are encouraged by the WHO and which will be exemplary for other nations.

1.2.2 Current Demographics and Challenges for ID Services

There is a change in the demography of persons living with ID. The biggest proportional increase over the next decade will be in persons aged 50 years and over (Kelly & Kelly 2010). In addition to the benefits that accrue from a longer life, there is also an increased risk of age-associated chronic illnesses, including Alzheimer's dementia (McCarron & Lawlor 2003 ; Tyrrell et al. 2001). This is particularly evident in persons with Down syndrome, as there is general agreement that up to 15–45% of persons with Down syndrome over the age of 40 have a diagnosis of dementia, the risk of which increases significantly with age (Prasher & Krishnan 1993). Due to the pre-existing disabilities and the lack of established memory clinics and of appropriately-trained personnel, the difficulty of assessing for and establishing a diagnosis of dementia becomes a unique challenge in ID services. Defining the terminal stage of dementia and its duration in persons in the generic population is a challenge (Sachs et al. 2004; Ghiotti 2009 ; Evans 2009) and this is even more so in persons with ID (McCarron & Lawlor 2003). This challenge is further confounded in the ID services where a lack of preparedness for, and understanding of, the course of advanced dementia and end-of-life concerns, still exists (McCallion & McCarron 2004).

The growing numbers of ageing persons with ID and with the dual diagnosis of ID with Alzheimer's dementia are challenging the ID services delivery (Janacki & Dalton 2000 ; McCallion et al. 2005). Without new approaches to meet the needs of this emerging population, there is a danger that the benefits they have accrued from health and community participation to date will be reversed in old age. Traditionally, the ID service system has been underpinned by a philosophy the major emphasis of which has

been on the empowerment of individuals, the promotion of skills acquisition, and the building of individual independence. The realisation of the highest level of community presence is also of great importance. These concepts will always remain important components of the ID care agenda; however, this approach may be less helpful when supporting persons with ID to cope with increasing disability and the inherent decline evident in dementia. The lack of experience of service providers in regard to issues related to an ageing population, potentially results in inappropriate approaches to care being prolonged or futile. Furthermore, persons with intellectual disabilities may be transferred from their 'home' inappropriately if the service does not consider that it can support an 'ageing in place' philosophy due to lack of resources (McCallion & McCarron 2004 ; Tuffrey-Wijne et al. 2005 ; Tuffrey-Wijne et al. 2007).

As the intellectual disabilities service system copes with growing numbers of ageing persons together with subsets of persons with dementia and other terminal illness, they are also challenged with training needs and the creation of opportunities for persons to receive palliative care on site. There are strong desires within the intellectual disabilities service system to preserve rights and maintain community living for people with intellectual disabilities, regardless of terminal or chronic illness (McCallion & McCarron 2004 ; Tuffrey-Wijne et al. 2005 ; Tuffrey-Wijne et al. 2007 ; McCarron et al. 2008).

1.2.3 Challenges for Palliative Care Services
Palliative care nurses may lack knowledge and skills in communicating with persons with ID (Tuffrey-Wijne 2002). Therefore staff need to explore their respective abilities to provide palliative care to this ageing population. Parker and colleagues (2005) have identified that education, training and support for staff in aged care facilities are central to their being able to utilise principles and practice of palliative care with individuals with non-malignant conditions. The Report of the National Advisory Committee on Palliative Care (DoHC 2001b) acknowledged that there was an existing emphasis on palliative care delivery to persons with cancer (95% of recipients). It was recognized that palliative care approaches that were developed from cancer and AIDS models may not translate easily into useful information for care planning for broader groups of frail elderly persons (Lynn & Adamson ; 2003 Abbey 2004). However, persons with prolonged terminal illnesses such as dementia need to be able to access palliative care

and optimal end-of-life care on an equal basis to those with illnesses which are supported within the current provision of palliative care (HSE/IHF 2008).

If the extension of palliative care to generic populations with chronic conditions such as dementia is complex, then the extension of such approaches to persons with the dual disability of ID and dementia is potentially even more difficult. There appears to be a lack of understanding of the unique issues in the care of persons with ID and advanced dementia. There also exists a lack of sharing of the resources and perspectives available in palliative care provision. Furthermore, more work needs to be done on how the prevalent palliative care approaches may be modified to meet more adequately the needs of persons with ID and dementia (McCallion & McCarron 2004; Ryan & McQuillan 2005). In response to these concerns, this project was conducted with a view to making it possible to address issues such as equity, access and service delivery, all of which are concerns of the NDA (2001, 2010) and of the Department of Health and Children (DoHC) (Quality and Fairness Health Strategy 2001a). This project also made it possible to address the recommendations of the DoHC that palliative care ought to be extended to persons with ID (DoHC 2001b : 11), be integrated into community settings, involve community-based practitioners (DoHC 2001b : 88), and be more influenced by the perspectives of patients and families (DoHC 2001b : 52). End-of-life care models exist in the hospice and palliative care specialty, but they primarily address chronic illnesses such as cancers and are only being applied to Alzheimer's dementia within the last decade (Corr 2002).

The extension of such existing palliative care services is challenging, as there is a lack of empirical data on the palliative care needs of persons with ID as a vulnerable and at-risk population (Tuffrey-Wijne 2003; Ryan & McQuillan 2005). The range of levels of ID may mean that there are different needs and different abilities to be accommodated in decisions about care. The ability of the persons themselves to make such decisions is a key component of current palliative care models. To meet the palliative needs of a person with an ID, it is necessary to have close collaboration and interdisciplinary work between the ID and specialist palliative care services. Such collaborative work has been recommended to enhance individuals' understanding of the unique needs of persons with ID (DoHC 2001b ; McCallion & McCarron 2004 ; McCarron et al 2008).

1.2.4 Bringing Services together

This project (phase one) engaged experienced staff from both ID services and specialist palliative care services. The research sought to broaden the existing definitions of palliative care in order to include persons with ID and Alzheimer's dementia. The outcome of this project has potential relevance to the care of all persons with advanced dementia. The engagement of the specialist palliative care staff with the ID staff was also designed to facilitate both services to gain a deeper understanding of the challenges and possibilities in both specialty areas. A key goal was to establish a model for a collaborative working relationship between a specialist palliative care provider and a number of ID providers, which may be potentially replicated locally, nationally and internationally.

This research project on the manner in which palliative care and end-of-life care can be delivered to this population was timely and important for this population in Ireland, because of the ever-increasing number of persons with the dual diagnosis of ID and dementia and because of the significant challenges to the ID services (McCarron & Lawlor 2003) and to specialist palliative care services (Ryan & McQuillan 2005). A list of the publications related to this study (phase one) is presented in Appendix 1.

1.3   Context

In order to provide a context, it is important to outline how ID services have evolved. It is also important to understand the changing trends in ageing within these services and how this and, in particular, the dual diagnosis of ID and dementia are impacting on services provision and care. Furthermore, it is important to understand the evolution of palliative care responses, including the efforts being made to respond to the challenges posed by ageing persons with non-malignant conditions, dementia and ID. Finally, for the purpose of the project, it was important to outline what has already been identified as some of the education and training deficits in these contexts of health and social care for these populations. The following sections of this chapter therefore overview literature from ID, dementia and palliative care specialties and highlight the education and training issues identified prior to the project.

1.4   Intellectual Disability Care

1.4.1 Brief history and overview of intellectual disability care in Ireland

People with ID in the early 19th century were seen as 'a problem' (McCormack 2004). Facilities for such 'idiotic' children were established to differentiate them from the mentally ill in the late 19th century. In Ireland, the Stewart Institute was established in Dublin in 1869 for these children (McCormack 2004). ID care was a primitive and under-resourced specialisation, as the children were perceived as incurable. This under-resourcing was in terms of accommodation, personnel and professional involvement (McCormack 2004). The model of care provision was a custodial model with a biomedical approach to care (Sheerin 2000). From the early part of the 20th century, ID care in Ireland was provided predominantly by religious orders (Sheerin 2000). In the ID residential services, many carers had no formal qualification and they worked for low pay (McConkey 2004). Within the multidisciplinary team of these services, the nurses and consultant psychiatrists are the only staff who can achieve a formal professional qualification with specialist knowledge and skills in ID care. The numbers of paid carers have increased over the last 20 years, replacing the largely volunteer staff who were previously in these services. This has happened because the numbers of patients have increased, and the individual care needs have increased, as persons with ID are living longer (Janacki 2001 ; McCarron 2002 ; McCarron et al. 2005b ; McCallion & McCarron 2004 ; McConkey 2004). Teamwork is required when caring for a person with ID (McConkey 2004). He writes that recruiting people to work in ID services is a crucial starting point in selecting people with the qualities needed to care for this population. He further states that these qualities cannot be acquired or learned easily (McConkey 2004; 35). In the 1960s, developments came about in the preparation, training and education of professionals to work with ID services which were increasing in number.

One of the effects of this growing specialisation of professionals in these services was the disempowerment of the family. Services had care planning meetings without family consideration or inclusion. The parents' role re-emerged in the mid-20th century because the institutions providing care came under scrutiny worldwide. Persons with ID remained largely invisible owing to the way they were institutionalised, until public

awareness grew significantly when famous people had children with ID (Redmond 2004). Legal challenges followed and parent associations developed in Ireland: NAMHI (The National Association for Mental Handicap Ireland) was established in 1961 (Redmond 2004 : 124). The first parent and friend associations began to emerge in Ireland and so did some awareness of the need to include persons with disabilities in legislative terms, which occurred with the passing of the Private Members' Bill on Disability in Dáil Éireann in 1961 (McCormack 2004 ; 19). Following these developments, in the mid-20th century the recognition that persons with ID had recreational needs and rights was also growing, and social clubs to support such activities were established. Large institutions started to close down in the 1970s and 1980s, and small community-based units were preferred.

1.4.2. *Changes in philosophy of care*

The assumption that people with special needs could not have their needs met in ordinary settings was being challenged in the late 20th century by people like Wolfensberger (1970) and O'Brien (1980) and by papers from the King's Hospital Fund which promoted the idea that "people with disabilities have ordinary needs but often need support in having their ordinary needs met" (McCormack 2004; 15). The human rights debate is ongoing here in Ireland, where people with ID should be entitled to state services in equal measure with all persons. This issue of human rights was part of a challenge by Synnott in 2000 for access to education for her son, and some significant changes have happened in the last decade in relation to this issue (McCormack 2004 : 22).

The shift to accord legal rights to persons with ID is slow, tenuous and ongoing (Quinlivan 2004: 296). The report of the commission on the status of people with disabilities (1996) heralded the move from a charity model of care to people with ID, to a rights-based model. The Irish Constitution (Law) can be interpreted by the courts as the supreme legislative instrument, but its wording is weak on equality (Quinlivan 2004: 297). The Irish Disability Act of 2005 is seen only as a step in the right direction and does not fully support a rights-based policy model. "Human rights are not just about protection against power – they are also crucially about restoring power to the person," (Quinn and Bruce 2004 : 317). "Justice is primarily a principle", but the legal systems place low value on distributive justice; achievement of rights is a matter of pressure

politics and not a matter of principle (Quinn & Bruce 2004: 318).

The creation of a society that values difference is difficult because of the inequalities inherited from the past (Quinn & Bruce 2004). However, the United Nations (1994 ; 114) Article no. 11 upholds that the needs of each individual are equal. Moreover, international human rights law rests on four connected basic human values (Quinn & Bruce 2004; 320): dignity, autonomy, equality and social solidarity. Two other major reports – 'Report of the Commission of Inquiry on Mental Handicap' in 1965, and 'Needs and Abilities' in 1990 – have explicitly shaped the development of services for persons with ID in Ireland (Sheerin 2000).

Noonan Walsh and Conliffe (2004) state that there have been many changes in caring for people with ID in Ireland over the last two decades, owing in large part to our membership of the European Community and to the changes in policy and practice which that membership has brought us. In particular, the aim of the European Social Policy for social inclusion for all citizens is guiding, or provides the impetus for, a shift from a social care model for persons with ID to a human rights model. In 1984, government policy in Ireland stated that persons with ID needed kindness and understanding, not anti-discriminatory legislation (Noonan Walsh & Conliffe 2004). While legislation is important, Kendrick (2005) would support the idea that increased government action ought not to be seen as the panacea in its own right in the Irish context. He advocates for strong social movements which bring people to decisions, commitment and action, and can challenge established ways and in time become the trigger for governmental action.

Ireland has supported community living in principle since 1990 (Noonan Walsh et al. 2004: 279), and policy has recommended that residential care was for persons with severe and profound intellectual disabilities or for those with complex needs. There exists much variation on how services are provided, and the demand for full-time residential places is growing (Noonan Walsh et al. 2004; Kelly & Kelly 2010). Group homes and campus residences are two forms of ID service provision for adults which still exist in Ireland (Noonan Walsh & Gash 2004).

1.4.3   Challenges for future care

As persons with ID live longer, they are at risk of developing age-related diseases such as dementia (Noonan Walsh & Conliffe 2004). In the ID population, older people with Down syndrome (DS) are at greater risk of developing dementia (Janicki et al. 1996: 375). The increasing ageing population of persons with ID (Janicki & Dalton 2000) is putting demands on the ID service providers to develop capacity and to provide support for longer lifespan and for the challenges which this brings (McCarron & Lawlor 2003 ; Noonan Walsh & Conliffe 2004 : 143). A report on the status of people with disabilities in Ireland in 1996 showed that they were the neglected citizens of Ireland. Some policy and practice improvements have resulted from the recommendations of that report (Noonan Walsh 2004). The National Disability Authority advisory paper (2010) identifies that supporting independent living within the community has been the direction of policy over the last two decades.

A major challenge for staff who are caring for this population in the 21st century is how to include the client's wishes in the support they need, and how it can be delivered in the changing structures. The evolving model of service to persons with ID has been described by McCormack (2004) as a model which hands back power to individuals and families, which is community-based, holistic and individualised. He acknowledges that this approach will be a greater challenge for persons with severe or multiple disabilities.

Therefore, the task facing ID services in the new millennium is to put emphasis on citizenship, equal opportunities and on human rights (McConkey 2004). Professional services cannot easily replace the family; however, by replacing bigger organisations with small ones which share the characteristics of the family, a best model of care will develop. Such characteristics are that the service is small-scale, local, personal and committed (McConkey 2004: 38). A steady increase in persons with intellectual disabilities over the age of 35 years has been observed in the national intellectual disability database (Kelly & Kelly 2010). Over the next ten years, the biggest proportional increase in people with ID is likely to be in the over-50 age group, the group at increased risk of dementia. In spite of these demographic trends, policy and service provision for this population is lacking (McCarron et al 2008). The Health Service Executive (HSE 2011) has published the working group report which clearly proposes a new model of support which ought to be established in the community for

persons living with disabilities. However, there appears to remain a gap between policy and provision in spite of more than a decade of investigation of service provision for persons with disabilities (Tubridy 1995 ; HSE 2009 ; NDA 2010 ; Keogh 2011).

Although there are established group homes in the community for persons with ID, McKechnie (2006) reports that anecdotal evidence still exists that there remain difficulties in obtaining adequate healthcare from general practitioners. This greatly compromises the person's chances of having a seamless service when it comes to long term dementia care, a factor which is already identified as a major challenge for the generic dementia population (Nolan et al. 2006).

People with intellectual disabilities are confronted with the same life and death issues as everyone else, and how these are managed can vary depending on the understanding and experiences of their carers (McKechnie 2006). When staff are challenged to care for persons with a terminal illness such as dementia, this may be difficult for some carers in the postmodern world where death and dying might not be talked about (Dodd et al. 2005).

1.4.4   Intellectual disability and dementia

As a result of increased longevity, persons with learning disabilities have become subject to the diseases of the rest of the population (Black & Hyde 2004, Gates 2006). This population now has an increased risk of age-associated chronic illnesses including Alzheimer's dementia (Prasher 1995 ; McCarron & Lawlor 2003 ; Tyrrell et al. 2001 ; Noonan Walsh & Conliffe 2004 ; Hatzidimitriadou & Milne 2005). The prevalence of dementia in adults with ID other than Down syndrome has been reported as 15.6% in persons aged 65-75 years, 23.5% in persons aged 65-84 years, and 70% in persons aged 85-94 years (Cooper 1997). This reflects a higher incidence than that of the general population. However, others (e.g. Janicki & Dalton 2000) report rates of prevalence similar to that of the general population. In particular the incidence of Alzheimer's dementia in persons with Down syndrome exceeds that of the general population who do not have an ID (Prasher & Krishnan 1993 ; Janicki & Dalton 2000 ; Tyrrell et al. 2001). The increasing population of persons living with the dual diagnosis of ID and dementia (Wilkinson & Janicki 2005) are requiring more time to be spent on their care as the illness progresses (McCarron et al. 2002, 2005).

To date, a significant number of these older persons in Ireland live in an ID care setting (Noonan Walsh & Gash 2004 ; Keogh 2011), but these placements in ID services may not be available in the future, owing to the increased life expectancy of current residents (McCarron & Lawlor 2003). Those with a dual diagnosis of ID and dementia are bringing significant challenges to the ID services (McCarron & Lawlor 2003). The need to develop appropriate services to cater for this population in Ireland was highlighted by McCarron (1999). An Irish study involving 285 subjects with Down syndrome reported an age-specific prevalence of dementia at 5.7% in persons aged 40-50 years, 30.4% in persons aged 50-60 years, 41.7% in persons aged 60-70 years, and 50% in persons over the age of 70 years (Tyrrell et al. 2001). There is also evidence that people with Down syndrome experience an early and more abrupt decline in memory, behaviour, work skills and day-to-day functioning. It is also critical that ID services are aware that, regardless of Down syndrome, ageing itself carries a known risk for dementia (O'Shea 2007). Given the changing ageing demographics of persons with ID, their changing care needs must be anticipated and planned for. Because of the growing ageing population with ID and dementia, service providers will need to develop aged care facilities and dementia-specific facilities which will meet the needs of individuals and ensure person-centred care (McCarron & Lawlor 2003).

In a literature review on adults with an ID and dementia, Jokinen (2005) concluded that the literature sourced was predominantly concentrated on the biomedical, assessment and diagnostic aspects of dementia in the person with ID. Most of the literature was published in America and the United Kingdom. Some dementia care guidelines for persons with ID and dementia were identified within the literature (McCallion 1999), and one Irish paper was cited: McCarron and Lawlor (2003). Jokinen (2005 ; 334) believes that many of the guidelines for caring practice in this ID and dementia population are drawn from the existing caring practice for the general population with dementia, and that these guidelines may not be applicable to those with an ID as they were developed for persons in different circumstances and environments. Schalock et al. (2002) state that quality of life for persons with ID is within a social construct; it is multidimensional and has complex person-environment interactions. Furthermore, transferring persons with ID to dementia care services is not best practice for this population as issues arise in relation to such relocation to the detriment of the person and carers (MacDonald et al. 2004). Indeed transferring persons with intellectual

disabilities to generic health care settings can result in death due to a lack of basic understanding of the unique needs of the person by health care staff (O'Neill 2006 ; Mencap 2007 ; HSE 2009). Small group homes for people with ID may be well suited to provide good-quality end-of-life care for those with ID and dementia (Chaput 2002). Family systems therapeutic approaches could also be adopted for ID care models for this population (Forbat & Service 2005:429).

Tuffrey-Wijne (1998) suggests that there may be many reasons why residential care homes for intellectually disabled persons may be unable to care for a resident with a terminal illness. These reasons include a lack of resources or a lack of knowledge and skills to provide intensive physical nursing care. Commitment of the team in these settings along with collaboration with outside agencies are seen as essential if this terminal care is to be provided for the person in his/her own 'home'. An advantage of keeping persons in a setting where staff know them very well is that these staff can report subtle changes in their condition which would otherwise be missed (Tuffrey-Wijne 1998).

As stated, many services are poorly prepared to meet and respond to the diagnostic and care needs of people with ID who are at risk of dementia or have dementia. Even more challenging is the response to the care of the person with end-stage dementia. Medical complications associated with dementia are inevitable as the disease progresses. Alterations in feeding, mobility and continence, combined with the development of seizures and marked personality and mood changes, result in the dementia becoming a complex physical, emotional and social condition which requires specialist nursing and terminal care (Prasher 1995 ; McCarron et al. 2005). A terminal stage has been confirmed which presents with a clinical picture of severe intellectual deterioration, marked personality and mood changes, loss of sphincter control, seizure activity, immobility with hypertonia, and complete loss of self-care skills (Prasher 1995 ; Cosgrave et al. 2000 ; McCarron et al. 2005a).

Ongoing longitudinal work and statistics drawn from one Irish service provider identifies some of the critical implications of the increasing care challenges associated with Alzheimer's dementia. In 1993, at the Daughters of Charity Service, in preparation for a longitudinal study, 80 women with Down syndrome were identified who at that

time were aged over 35 years. They were then periodically assessed and followed up over a 12-year period. In 1993, 9% (7) of the women were assessed as having symptoms of dementia. In 2006 (notwithstanding that some deaths from the sample population had occurred over this time), 80% (64) were diagnosed with dementia. Currently within the Dublin (Ireland), region, at the Daughters of Charity Service there are 48 women with Down syndrome and Alzheimer's dementia, and 13 out the 31 community group homes of this service are currently supporting at least one person with dementia; five of these homes support two to three people with dementia. Given the increasing ageing demographics of the population served by the Daughters of Charity Service, and the use of age-specific prevalence rates for dementia in persons with Down syndrome, it appears that in five years there will be 30 more clients with this diagnosis, and that in ten years this will have increased to 51. Out of the current 31 community group homes, 23 are likely to be supporting persons with dementia (McCarron et al. 2005b).

Despite these pressing concerns, responses to Alzheimer's dementia issues to date have tended to be reactive rather than proactive, and the ID services system is just beginning to address these concerns. The impact on family carers is at an even earlier stage of response (McCallion et al. 2005). For service providers, staff and families, these are new care situations and there is a need for an evidence-based model for services if a resolution is to be realised, if institutionalisation and re-institutionalization is to be avoided, quality of life to be maintained, and costs contained. Help is also needed with day-to-day care issues when dementia is present.

There are also opportunities and efforts to support 'ageing in place', and there is a growing interest in understanding the role of specialised units for people with ID and Alzheimer's dementia (Janicki et al. 2002 ; McCarron et al. 2005b). Supporting 'ageing in place' requires that the environment is suitable and that the staff are adequately educated in regard to good dementia care (Watchman 2008). There have been some important developments in Ireland. Three are as follows: the establishment of the first special residential unit for persons with Down syndrome and Alzheimer's dementia at St. Michael's House services; the first postgraduate diploma to prepare clinical nurse specialists in ID and Alzheimer's dementia at Trinity College Dublin; and the organisation of an ID and Alzheimer's dementia Memory Clinic at the Daughters of Charity Services. Research is also exploring the characteristics of models of service to

maintain persons with ID and Alzheimer's dementia in the community (Janicki et al. 2002 ; McCallion et al. 2005 ; McCarron et al. 2005a). One particular concern that remains is how best to address end-of-life care issues for persons with ID and advanced dementia; this will necessitate the ID services and the specialist palliative care services working and learning together. Since the completion of phase one of this study the postgraduate diploma referred to above has been replaced by an MSc Dementia and the following papers have been published in relation to the supporting of persons with ID and advanced dementia (McCarron et al 2008 ; Fahey-McCarthy et al 2009 ; McCarron et al 2010, 2011).

1.5   Dementia Care

1.5.1   *Approaches to care for persons with dementia*

The term dementia refers to a group of diseases characterised by a progressive decline in mental functioning accompanied by deterioration in motivation and in emotional and social behaviours; it is a terminal illness (O'Shea 2007). In the general population, Alzheimer's disease is the most prevalent dementia (O'Shea 2007).

Contrasting ways of understanding dementia have existed to date. Dementia has been viewed as a neuro-psychiatric condition, a neurological condition, and a normal ageing state (Downs et al. 2006). In a study of GPs by the Dementia Services Information and Development Centre, Dublin, it appears that people still see dementia in Ireland as a normal part of ageing, and therefore patients present late in the illness (Cahill & Clark 2006). Approaching dementia care from a neuro-psychiatric perspective, treatment was aimed at the person, and the family was not usually included in the care; furthermore, this approach placed the person in the category of psychiatric illness (Downs et al. 2006). This approach remains the dominant explanatory model in western society and assumes that "the person with dementia has little agency, control, awareness or insight" (Downs et al. 2006; 209).

Dementia viewed as a neurological condition acknowledges that persons have a chronic illness, and that given the progressive nature of the illness, a palliative approach to their care will be required in order to maximise their quality of life and comfort (Downs et al. 2006). In our viewing dementia as wear and tear of our systems, not as a disease, the

person does not become a patient or a victim and remains valuable and integral to the family: no professional help is required (Downs et al. 2006). While this might be a preferable approach, these authors caution that this may not benefit persons if some of their nutrition and hydration needs are not met. These approaches to understanding dementia do not pay attention to the psycho-social needs of the person as addressed by Kitwood (1990, 1993, 1997), and Kitwood & Benson (2005). More recently there is increasing emphasis on understanding the person with dementia within a citizenship model of care (Bartlett & O'Connor 2007 ; Baldwin 2008).

1.5.2 Person-centred care

In dementia care, the concept of rementing was introduced in 1990 by Kitwood, who developed the approach of person-centred care following Rogerian psychotherapy (Kitwood 1997 ; Kontos 2005). The concept of 'rementia' is linked to the re-framing of dementia and that an individual's decline can be slowed or indeed s/he can be enabled to regain cognitive function, ability in the right circumstances of good dementia care (Baldwin & Capstick 2007). Kitwood created a formal method of evaluation of persons with dementia in formal settings which is termed dementia care mapping and such dementia care mapping is being used to some extent within ID services. In a small study by Jaycock et al. (2006), they demonstrated that this approach could be a useful tool to support future practice improvement and person-centred planning.

The concept of personhood, according to Kitwood (1997), is found in three discourse sources. These are transcendence, ethics and social psychology. Transcendence is concerned with Being in itself, sacred and to be revered. Ethics is concerned with the fact that each person has an absolute value and is always seen as an end and never as a means. Social psychology provides an understanding of personhood associated with self-esteem. Kitwood (1997: 8) defines personhood as the "the status bestowed upon one human being by others in the context of relationship and social being". He states that this implies recognition, respect and trust. He says that nowadays the concept of personhood is reduced to two criteria, namely autonomy and rationality, and that this excludes people with "serious disability from the personhood club" (Kitwood 1997:9). Post (1999) argues that putting emphasis on these two criteria is erroneous and that personhood should be linked strongly to the experience of feelings and emotions and the ability to live in relationships. Kontos (2005) challenges the definition of personhood

proposed by Kitwood and Benson (1995) which supports the view that there is a steady erosion of selfhood in the person throughout the trajectory of dementia. Kontos (2005) states that there is an embodied selfhood which manifests as the bodily reactions of the person and exists from the pre-reflective state of the individual, and which therefore remains intact in the person with dementia throughout the trajectory of their illness.

Maintaining personhood, according to Kitwood (1997: 19), is both a psychological and neurological task. He highlighted that the standard paradigm of care was based on a medical, disease-based model which fed into a negative view of dementia with no cure and no help. He recognised that in reality there were many social factors involved and that a radical improvement was required in the culture of care (Kitwood 1997: 42). Person-centred care or person-centred planning is also central to good ID care (Gates 2006). Indeed Kitwood (1997: 55) acknowledged that there was some transfer of knowledge and expertise in more positive approaches in the care of dementia from the ID sector and in hospice care. An important aspect of palliative care is caring for the person spiritually (Finlay & Jones 1995). Kitwood (1997: 55) believed strongly that a view of personhood when caring for a person with dementia should reveal a moral obligation and be valid in terms of psychology that focused on experience, action and spirituality and remained fully compatible with neuroscience. On-going debate and reflection on the critical importance of supporting personhood for the person with dementia permeates the literature (Sabat et al. 2011).

The first positive intervention in dementia care was called "reality orientation" in the 1950s (Kitwood 1997; Kontos 2005). This was followed by validation therapy (which affirmed the experience of dementia in the person), resolution therapy (which placed emphasis on empathy and communication) and reminiscence therapy (which affirms the inner world of the individual) (Kitwood 1997). Reminiscence therapy and validation therapy are the cornerstones of social therapeutic dementia care (Downs 1997). Biographical knowledge is important alongside reminiscence therapy, and this knowledge will be important in the future care of the person with dementia in relation to their identity within person-centred care (Kitwood 1997). Kitwood believes that significant developments have occurred, such as providing human contact and pleasurable stimulation to the senses which bypass cognitive approaches almost entirely, e.g. aromatherapy, massage, snoezelen. Kontos (2005), however, argues that

while these therapies provide ways of communicating with persons who are cognitively impaired, they largely cast the needs of the person in a psycho-social framework which assumes that the personhood of the person with dementia is to be situated only in the social context of meaning, and excludes bodily manifestations of personhood which persist in severe cognitive impairment. Embodied selfhood must be acknowledged by carers if true person-centred care is to be delivered, especially to persons with severe cognitive impairment as seen in dementia (Kontos 2005).

Kitwood (1997) identified five care issues in relation to the person with dementia, namely comfort, attachment, inclusion, occupation and identity. He believed that a person needs comfort in times of distress and loss. Even in dementia, people require to be attached and in relationships. Being included means being part of a group, and if this need is not met then the person can go into decline or retreat. Occupation is to be involved, and if this need is not met then the person's abilities can atrophy. Identity provides esteem and consistency where others around them can provide respect. Kitwood (1997:87) believes that if all these five elements of care were provided, it could be deemed good care. It is interesting that he used the term "palliative care" for this emerging model which broadly encompasses the improvement of the life of the person coping with dementia. In this new person-centred culture of care, Kitwood (1997:87) noted that improvements seemed to be reaching a ceiling which he believed was not because of structural inadequacies or lack of staff but was instead due to the limited interactive capabilities of staff. This was particularly true where physical care was not demanded.

In health care, Nolan (2000) states that it is important for nursing care in particular to make person-centred care visible. Caring is viewed as an interpersonal relationship between nurse and patient, and knowledge of a person is imperative to the development of a meaningful caring relationship (Nolan 2000). Liaschenko (1997) identified three types of knowledge which are important in establishing a good nurse-patient relationship: case knowledge, patient knowledge and person knowledge. Case knowledge embraces knowing about the biomedical aspects of the person; patient knowledge is knowing about the context. In particular, person knowledge involves understanding the person's 'biographical life' and would appear to be more important in long-term relationships. Although this theory is written in the context of care of the

elderly, it may apply to other long-term situations such as intellectual disability. Kitwood (1997) also refers to the importance of a carer's having this biographical knowledge of the person being cared for, in order to protect the individual's personhood.

In a conceptual analysis of person-centred care, Slater (2006) identified in the literature that there was inter-changeability between the terms person-centred, client-centred and patient-centred care. This complicated matters such as the power differentials between 'carer' and 'cared for', and the author concluded that clarification of the term may need to be considered for future debate. The complexity of the concept of personhood and its articulation in practice was also identified in an overview of the literature on person-centred care (McCormack 2004). Person-centred care remains difficult to define (Brooker 2007) and difficult to introduce in practice Rosvik (2011 ; Kirkley 2011), albeit that it is recognized as central to preserving the personhood of the person with dementia (Kelly 2010). In Ireland, the Health Information and Quality Authority, (HIQA, 2009) has identified person-centred care as a standard required for residential care for older persons, and Cahill et al (2012) have reiterated it as a primary standard of care for all persons with dementia.

Kitwood (1997:60) believes that when the physical needs of the persons with dementia are met, there remain other needs which are the enabling of the exercise of choice, the use of persons' abilities, the expression of their feelings, and their living in the context of relationships. In summary, he defines good dementia care as "a series of high-quality interactions, taking place in the context of stable and secure relationships" Kitwood (1997:97). Later authors identified that person-centred care had furthered the debate and the new culture of care for persons with dementia (Nolan et al. 2002), but also identified that greater attention needs to be paid to the inter-subjectivity of dementia and the relational aspects of care.

1.5.3 Relationship-centred care

Critiques of person-centred care have emerged (Adams & Gardiner 2005). The models of dementia care known as dementia care triads involve at the very least three people: the person with dementia, the informal carer and one or more health and social care professionals (Adams & Gardiner 2005). It is acknowledged that relationships extend

beyond three people to include other people involved in the care of the person. Dementia care triads are models of relationship-centred care, which was first described by Tresolini and Pew-Fetzer (1994). This approach to care embraces the fact that relationships are a central factor in health care. In particular the relationships recognised are those between the practitioner, the patient, the patient's community and other practitioners (Tresolini & Pew-Fetzer 1994). These authors consider health care as essentially a human activity which is given meaning by people within relationships. Nolan et al. (2001) acknowledge that person-centred care has had a far-reaching impact on care, but it is not enough to consider individuals without considering their relationships, as these are crucial to determining a person's quality of life. Relationship-centred care has an important part to play in situations where relationships are developed over long periods of time, such as in care homes (Nolan et al. 2006a). Therefore this approach to care is surely important in ID care settings where staff frequently know the clients over a period of many years. The central importance of relationships to good dementia care is recognized and more recent definitions of person-centred care include the recognition of the importance of relationships for the person with dementia (Nay et al 2009). The supporting of relationship-centred care between residents, relatives and staff in long-stay care settings improves the care environment and experience for all concerned (Nolan et al 2006a; Brown-Wilson et al. 2009).

1.5.4 Barriers to improving dementia care

Historically, low status is one of the most damaging aspects inherited by carers of the elderly – particularly carers of elderly persons with dementia, who often carry the stigma of the client (Kitwood 1997). This led to the general consequence of low self-esteem and a general sense of powerlessness in bringing about any positive change in the care of the person with dementia. Another barrier according to Kitwood (1997) was that the condition remained the territory of psychiatry, whereby the power and prestige remained with the medical profession whose concern about personhood and the interpersonal process of caring were not strong. Commercial pressures existed within the old culture where pharmaceutical companies held excessive sway. There could still be the same pressure nowadays to opt for the old culture for economic reasons, where medication is seen to be preferable to investment in personnel (Kitwood 1997). The public policy for persons with dementia in the general population in Ireland is to

facilitate their continued living at home for as long as is possible and practical (Report of the Working Party on Services for the Elderly 1988). However, there is a lack of co-ordinated services to deliver a seamless service of care to persons with dementia in the general population in Ireland (Cahill et al. 2003 ; Nolan et al. 2006b ; Cahill et al 2012). Furthermore, a lack of access to specialist diagnostic facilities to aid GPs was a factor in rural communities, and a lack of community supports was a factor in urban and rural practices (Cahill et al. 2006). O'Shea and O'Reilly (1999) in their Action Plan for Dementia advocate a social model of dementia care, which focuses on keeping the person in their community and is person-centred in maintaining personhood in line with the philosophy of Kitwood (1997). However, O'Shea (2006) identifies that the full resources necessary to implement the Action Plan for Dementia (O'Shea and O'Reilly 1999) have not been provided. Despite the lack of policy direction on good dementia care, the HSE in Ireland and the Irish Hospice Foundation are more aware of the matter and are committed to developing frameworks which will include palliative care for persons with dementia (HSE/IHF 2008). There are strategies for dementia in place in England (DoH 2009), Scotland since 2010 and Northern Ireland since 2011 (Alzheimer Society 2012). Wales have developed National dementia plans which guide care delivery there (Alzheimer Society 2012). The most recent development in Ireland has been the launch of the 'Creating Excellence in Dementia Care, A Research Review for Ireland's National Dementia Strategy' (Cahill et al 2012).

1.6   Palliative Care

1.6.1   Introduction and overview

There are many definitions of palliative care, all of which integrate psychological (emotional), social, physical and spiritual care of the person and family (Abu-Saad 2001, DoHC 2001b). The WHO (2002) defines palliative care as:

an approach that improves the quality of life of patients and their families while they face the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychological and spiritual. (WHO 2002)

The philosophy of palliative care embraces two broad goals: effective symptom control and maintaining quality of life (Abu-Saad 2001). The practice of palliative care

developed from the modern Hospice movement of the 1960s, and the terms 'hospice care' and 'palliative care' are sometimes used synonymously (Abu-Saad 2001). The term 'hospice' in medieval times described a place of shelter for pilgrims or travellers (Council of Europe 2003). The original hospice or care offered to the dying in Europe was initiated by Mme. Jeanne Garnier in France at the end of the nineteenth century. The first hospice care offered to the dying in Ireland was also initiated at the end of the nineteenth century by the Irish Sisters of Charity (Council of Europe 2003, O'Brien & Clark 2005). However, management of the physiological aspects of pain and symptoms at the end of life were hampered by a lack of knowledge regarding the nature of such symptomatology and a lack of appropriate medications (Council of Europe 2003). Developments in drug therapies, along with greater understanding of the psychosocial and spiritual needs of persons who were dying, paved the way for the development of palliative care services as they currently exist (Council of Europe 2003). The evolution of the new hospice and palliative care movement is attributed to Dame Cecily Saunders, who opened St. Christopher's Hospice in London in the middle of the twentieth century (Council of Europe 2003). The important objectives of care stressed by Dr Saunders were: "care of the patient and family as a unit, an interdisciplinary team approach, the use of volunteers, a continuum of care that included the home setting and follow-up of family members after the patient's death" (Abu-Saad 2001:5).

Palliative care is a philosophy of care which may be applied in all care settings, and no one model of palliative care provision is applicable in all care situations (Council of Europe 2003:21). Palliative care is viewed more as a continuum now (Abu-Saad 2001:11). This approach demonstrates that the comfort and supportive measures of palliative care are there throughout the trajectory of the illness and increase as active interventions (disease-specific therapy) decrease. It also demonstrates the importance of bereavement care within this continuum of palliative care.

Doyle (2003:151) states that people working in specialist palliative care have no monopoly on 'caring and concern', as many doctors and nurses in other areas of practice are as eager to provide the terminally ill with the best possible care. Therefore he concludes that the principles of palliative care, which he identifies as "attention to detail, patient-centred holistic care, team caring, honesty in all dealings with patients and superb communications", ought to be taught to all medical students as integral to all

care delivered to patients (Doyle 2003:151). He sees the universal education of medical and nursing students in this care as the future of good palliative care. He cautions against losing some of the uniqueness of 'care' within palliative care, especially if it is regarded as just another speciality and if students regard it as nothing more than good pain and symptom management. The uniqueness of care he refers to is that death is anticipated and not viewed as a medical failure. In addition, that staff accept uncertainty and communicate honestly, that it is ethically challenging, non-judgemental care which values both a dignified death, and an equality of access to individualised care for all.

Doyle (2003) states that it is unjustified of palliative care to claim to be uniquely based on a holistic approach to care, as many other specialties are in a position to claim to be equally sensitive to such an holistic approach. However, he questions whether other specialities are as sensitive to the spiritual care of patients. Finlay and Jones (2007) clarify that the palliative approach emphasises the importance of psychosocial and spiritual care and includes caring for family and domestic carers. All clinicians ought to use a palliative approach as a core skill to care for all patients with incurable conditions, and to access specialist palliative care when required, to ensure the best quality of life for them (Finlay & Jones 2007). Doyle (2003) questions as to whether caring professionals are sensitive enough to cultural issues of care. By this he is speaking of the three broader cultural issues of time, autonomy and authority. Therefore, in any palliative care training programmes, Doyle (2003) believes there must be recognition of the importance of these three broad cultural issues as well as the spiritual issues.

1.6.2   Palliative care in Ireland

The National Health Strategy of Ireland (1994) recognised the importance of developing structured palliative care services in order to improve the quality of life of persons with a terminal illness. National policy recommendations for palliative care in Ireland were published in the Report of the National Advisory Committee on Palliative Care (DoHC 2001b). This report highlights that "The goal of palliative care is the highest possible quality of life for both patient and family" (DoHC 2001b:20). The family is defined as "any person who is significant to the patient" (DoHC 2001b:21). Palliative care is increasingly recognised as a core component of the role of all health care personnel (DoHC 2001b ; O'Connor & Aranda 2003) and as a vital aspect of all health care (Council of Europe 2003).

Palliative care may be delivered at three levels (DoHC 2001b). The first level involves using a 'palliative care approach', where all staff in a general setting should have core knowledge and skills of palliative care which they use when caring for a person with a life-threatening illness or a person who is dying. They consult with specialist palliative care experts on issues about which they do not possess specialist knowledge (DoHC 2001b). The second level involves using specialists when palliative care interventions are required for symptom management, such as radiotherapy. This is referred to as general palliative care (DoHC 2001b ; Council of Europe 2003). The third level is when specialist palliative care is delivered by staff who are qualified in palliative care and give this care from a palliative care specialist practice setting (DoHC 2001b ; O'Connor & Aranda 2003). The Health Service Executive (HSE) in Ireland has introduced a Transformation Programme which emphasises the management of chronic illnesses associated with ageing (HSE 2007). In response to this, the HSE/IHF (2008) report on the Extending Access Study investigated the palliative care needs of non-malignant conditions. The three conditions chosen for this study were chronic obstructive airways disease, chronic heart failure, and dementia. Three organizations have had the responsibility for the strategic developments in palliative care in the republic of Ireland. These are the Irish Hospice Foundation, the Irish Association of Palliative Care and the National Council for Specialist Palliative Care (Cooley et al 2010). The most recent development in relation to palliative care in Ireland is the establishment of An All Ireland Institute of Hospice and Palliative Care for the whole island of Ireland in 2010. This institute will now provide the strategic direction for future research, education, policy and practice in best practice palliative care and end-of-life care (aiihpc.org).

1.6.3   Access to specialist palliative care

Specialist palliative care is accessed by patients with cancer (95%) more commonly than by patients with any non-malignant condition (DoHC 2001b). A key recommendation of this report is that specialist palliative care should be considered for people with intellectual, physical and sensory disabilities (DoHC 2001b:48). There is minimal reference to persons with disabilities, but the report states that further research is required to identify their needs, and that links should be made between the service providers for these populations and the specialist palliative care services in order to promote a quality service for all (DoHC 2001b:48) within the principles and philosophy

of palliative care.

In a baseline study, the Irish Hospice Foundation (IHF) identified that there is still a very low level of palliative care service delivery to individuals with a diagnosis of non-malignant conditions (IHF 2005). However, there is an explicit inclusion of access for patients with non-cancer diagnosis in many of the specialist palliative care services listed in the Irish Association of Palliative Care directory of services (IAPC 2005). Palliative care is emerging for persons with non-malignant conditions such as motor neuron disease, HIV/AIDS, and more recently for patients with end-stage disease of general system aetiologies (DoHC 2001b : 24).

1.6.4   Palliative care for an ageing population

Palliative care may be a suitable framework of care for older people (Currow & Hegarty 2006) with or without cognitive impairment, who are living at home or in long-stay care (Hallberg 2006). Hallberg (2006) states that they may require symptom management to maintain their quality of life and they need their social network maintained. Furthermore, he states that their awareness of their impending demise puts pressure on nursing staff to talk to them about their needs around death and dying, (a central task in palliative care). There is continuing concern about the specific needs of older persons at end-of-life in long-term care (Froggatt & Payne 2006 ; Brazil et al.2012). Parker et al. (2005) concluded from a study in Australia with non-cancer residents in aged care facilities that they were not usually referred for palliative care and that pain and symptom management was inadequate. They suggest that a palliative care approach in this context would be effective, provided that a link nurse or doctor was available and that this model of care would be supported further by active liaison with a palliative care specialist who would provide interventions and advice on occasion when required. Link nurses with such specialist knowledge are welcomed in nursing home settings (Waldron et al. 2008) and influence practice (Cotterell et al. 2007). In the most recent Irish study on implementing palliative care for persons in the last year of life, it is a recommendation that further research is important to identify the benefit of a GP or nurse-facilitator post to enhance palliative care in the community (IHF/HSE/ICGP 2011). Internationally the world health organization have identified palliative care for older persons as a health priority and have directed recommendations for policy and practice (Davies & Higginson 2004).

1.6.5   Palliative care and dementia

In the general ageing population, there is discussion regarding the need to provide palliative care for persons with dementia (Solomon & Jennings 1998, Panke & Volicer 2002). Hospice services in the United States have provided hospice-at-home care for persons with late stage Alzheimer's disease (Solomon & Jennings 1998). Abbey (2003) argues that during the terminal stages of common illnesses experienced by the ageing population, for example Alzheimer's disease, the care provided ought to be informed by 'sound' palliative practice. She does not explicitly elaborate on what she means by this, but stresses the importance of encompassing good communication in this practice and she highlights the need to keep good written communication as a means of protecting the individual's 'personhood'. Clear documentation regarding the individual ensures that "personhood is not lost" (Abbey 2003 : 314). Understanding the person's past is vital to planning the person's future – what they would like. This concept of maintaining personhood supports good dementia care (Kitwood 1997 ; Sabat et al. 2011). Early care-planning early is important for the care of the person with dementia, as are the assessing and the managing of pain in end-stage dementia (Abbey 2003). Both of these issues are important components of good palliative management. The maintaining of comfort for the person is of central importance in their palliative care, and the provision of dignity to the older person with palliative care needs, requires knowledgeable, observant, caring nurses as part of the multidisciplinary team (Abbey 2003). Again, the recognition that teamwork is important in palliative care overlaps with a team approach, which is required to meet the many care needs of a person with dementia and with an ID. Palliative care according to Hughes (2006) takes families and friends of the person seriously and is therefore very suitable for persons with dementia.

Lynn and Adamson (2003) identified that in America the health care and community services were not organised to meet the needs of persons with a progressive illness and disability such as dementia. They recognised that such patients had to navigate a fragmented and uncoordinated health care system. This was also identified by Nolan et al. (2006) in an exploratory study undertaken in Ireland. Lynn and Adamson (2003) also identify that because the progression of dementia is unpredictable, the model of hospice care developed in America in the 1970s does not apply well to persons with chronic illness trajectories. They recognised that patients with chronic terminal illnesses such as dementia blurred the distinction with regard to their requiring palliative care if that is

perceived as turning away from conventional (active) care – because this person will commonly require a mix of both kinds of care, particularly in the early stages of their illness. An International Expert Advisory Group Report on Palliative Care in Ireland (IEAGRPC 2006) acknowledges that people should be able to access specialist palliative care depending on their needs and irrespective of their diagnosis.

In a systematic review by Coventry et al. (2005 : 226) into predicting the appropriate timing of palliative care for older adults with non-malignant life-threatening disease, they concluded that there is inadequate evidence to support the notion that specialist palliative care is the most preferred or appropriate model of choice for this population. In the review, there were three studies associated with dementia care. These were all quantitative studies. Qualitative research may be important to explore this complex population who have complex human, social, psychological and relational needs. Solomon and Jennings (1998) argue that hospice palliative care is appropriate and should be available for persons with dementia, especially at the terminal stage of the disease. They believe that the reason families and heath care professionals may hesitate to introduce palliative care for this population is that they feel it would be ethically wrong. They cite some concerns of relatives and health care workers, who view palliative care as the abandonment of the patient, (not treating them actively) and have concerns about tube-feeding (artificial feeding) as to when or whether to initiate it.

People with dementia have received sub-optimal end-of-life care, according to Sachs et al. (2004 : 1057). They identify certain barriers which they consider to be responsible for this. These include the unpredictable nature of the illness, issues with assessment and management, and the fact that dementia is not identified as a terminal illness. Furthermore, in the United States a person has to be certified by a physician as having a six-month life expectancy before they can be considered for hospice care and this complicates the introduction of palliative care for the person with dementia (Sachs et al. 2004). Professionals and family have difficulty viewing dementia as a terminal condition, and the identification of the terminal phase of this illness remains a challenge (Sachs et al. 2004 : 1058). Solomon and Jennings (1998 : 137) state that palliative care is medically, ethically and legally a better option for the person with dementia when the benefit-to-burden ratio is better with palliative care rather than with life-prolonging treatment. Social care models focus not only on medical needs but equally on the person

and their family's social, psychological and spiritual needs (Solomon & Jennings 1998). It is important in the overall care-planning that certain choices in treatment and management of the person with dementia should be seen as points along a continuum. Such an approach allows care not to be regarded "as a series of disconnected medical crises" (Solomon & Jennings 1998:142). Planning such a continuum of care ensures that a person's care is individualised and that their comfort and dignity are maintained.

There is an emerging debate in the literature on palliative care for persons with dementia (Solomon & Jennings 1998 ; Panke 2002 ; HSE/IHF 2008 ; MacConville 2011), and on palliative care for persons with intellectual disabilities (Ryan & McQuillan 2005). This debate recognises that all persons living with an illness which is considered to be progressive and will ultimately end in death should be able to access palliative care, at least insofar as a palliative care approach is adopted to care (DoHC 2001). The challenges appear to be concerned with the referral process and what is the appropriate time to start palliative care, particularly with those conditions and illnesses with a long and unpredictable course or duration, which is true of dementia and Alzheimer's disease. McCarron et al. (2005) have identified that there are increasing and different care needs required throughout the course of living with dementia. They identified that there are increasing nursing care needs when the person has mid-stage dementia and that this increases at the late stage of dementia. Therefore provision of palliative care and 'the best' end-of-life care or terminal care for this population is becoming a reality now for the ID services (McCarron et al 2010 ; McCarron et al. 2011). There is active discussion by the World Health Organisation and Alzheimer's Disease International on dementia as a health care priority (WHO/ADI 2012). In particular, end-of-life care for persons with dementia is seen as a priority of care (NHS 2010).

The old approach of viewing dementia as a neuro-psychiatric condition did not give special consideration to end-of-life care, and indeed further isolated the person from accessing services such as specialist palliative care (Downs et al. 2006). A person-centred approach used in dementia care and a palliative approach to care are both concerned with the maintaining of a quality of life for persons, with their support with living until they die, and by one's making sure that the families, carers, and persons close to the patients are included in their care (Downs et al. 2006). Mahon & Sorrel

(2008) identified that a palliative care approach to persons with Alzheimer's dementia ought to include three components. These are (1) aggressive symptom management (decreasing suffering), (2) assistance with decision making (a component of enhancing quality of life), (3) optimal end-of-life care (providing comfort and compassion in dying).

A common theme central to developing or providing hospice care for patients with advanced Alzheimer's is the avoidance of transferring the person to hospital when an acute medical problem presents, which may be a key burden to the person (Solomon & Jennings 1998). Staff of the care setting must develop the ability to care for dying patients on site (Solomon & Jennings 1998). Staff in ID settings who will be caring for persons with advanced or end-stage dementia desire to have such ability if they are to be able to keep the person in their own service and not transfer them unnecessarily to hospital (McCarron et al 2008).

1.6.6 Palliative care and intellectual disability

The need to consider palliative care for persons with an ID is now receiving some attention (Blackman & Todd 2005 ; Ryan & McQuillan 2005). Palliative care seeks to "respect individuals for whom they are" (O'Brien 2001 : 4 ; DoHC 2001b). This philosophy of care is equally important in the care of persons with dementia (Kitwood 1997) and in the care of persons with ID (Gates 2006). Countries with well-developed palliative care services are beginning to recognise that some groups in society do not have equitable access to palliative care. One such group includes those with learning disabilities (Doyle 2003 ; DADHC 2004). There is one reference in the Irish report that persons with an ID will need to be considered as a population requiring palliative care (DoHC 2001b). This report states that the principles of palliative care apply to all patients with advanced progressive disease regardless of aetiology and in all care settings (DoHC 2001b).

The WHO (2002) highlight in their key principles the fact that palliative care is appropriate early in the course of an illness. The University of Sydney review (DADHC 2004) reports the difficulty which still exists in relation to the initiation of palliative care for persons with an ID, and report that staff in ID services do not normally hold palliative care skills. In a study by Ng and Li (2003), a lack of knowledge of effective

communication with the dying person and a lack of knowledge regarding bereavement support were identified among carers of persons with ID. Ryan and McQuillan (2005) acknowledge that the needs of persons with ID are not being met by current palliative care services. The integration of primary care services in Ireland is sub-optimal according to the International Expert Advisory Group Report on Palliative Care in Ireland, and general practitioners have limited experience or training in palliative care (IEAGRPC 2006). This finding is reiterated in a recent report on behalf of the Irish Hospice Foundation, the Health Service Executive and the Irish College of GP's (IHF/HSE/ICGP 2011).

Many of the ID services in Ireland are currently, and may in the future, be dependent on their having a general practitioner (GP) as a key person in the multidisciplinary team who are caring for the person with dementia or Alzheimer's disease. This will also be the case if the person with ID and dementia is being cared for at home. Therefore the on-going establishment of primary care teams as proposed by the State's Quality and Fairness health strategy (GOI 2001) is urgently required to improve both communication and the delivery of care to this population (IEAGRPC 2006). In a recent report for the Alzheimer society of Ireland MacConville (2011) identifies the central role which GP's have in the future care of persons with dementia in the community. The centrality of the role of the GP within the primary care team in community is re-iterated in the report 'Primary Palliative Care in Ireland' which was a joint programme between the Irish Hospice foundation, the Health Service Executive and the Irish College of General Practitioners (2011).

Ongoing team building is recognised as an important component for optimal functioning of teamwork in the Irish context of delivering palliative care (Rowe, Keating & Walsh (2005). Abu-Saad (2001) distinguishes between a multidisciplinary team and an interdisciplinary team. Interaction between team members in a multidisciplinary team, where one professional is highest in rank, is of secondary importance in palliative care. In an interdisciplinary team, however, where the identity of the professionals is superceded by the identity of the team, the interaction process is vital to success (Abu-Saad 2001:8) as the team itself is the vehicle for action.

1.7   Training Needs

Education and training deficits were identified from the literature prior to the development of an educational intervention in phase one (Fahey-McCarthy et al. 2009). This literature was sourced in relation the support of persons with the dual diagnosis of ID and dementia who will require palliative care and end-of-life care. Some recent literature is also included to highlight that the debate about educational deficits is on-going.

1.7.1   Knowledge and skills of caring for a person with intellectual disability

Lack of knowledge of the needs of persons with intellectual disabilities by staff in general acute medical settings was identified as leading to diagnostic overshadowing and unexpected and unexplained deaths in England (MENCAP 2007). Sometimes nurses lack understanding or knowledge of ID, which impedes their care-giving in community practice (Tuffrey-Wijne 1998). Lindop and Read (2000) identified that since the move to community living in England (by persons with ID), district nurses now have to provide care to more of this population and that they needed greater understanding and knowledge about caring for them. The need to be able to interpret non-verbal communication and utilize alternative communication strategies, as well as the assessment and management of pain, are identified as the two major areas of educational need to efficiently care for this population (Tuffrey-Wijne 1998 ; Lindop & Read 2000). Staff in ID settings need training and education about ageing persons with ID (McCarron & Lawlor 2003 ; Mc Carron et al 2008). Staff need to be facilitated to compare and contrast care in the medical and social models of care (Solomon & Jennings 1998). For staff in ID settings, there is an additional need for training and education regarding the ageing of persons with ID and the implications of care for a person presenting with symptoms of dementia (McCarron & Lawlor 2003). As persons with ID experience terminal illness and approach their end of life, this poses further challenges for the staff in ID settings. Hospice and other palliative care staff must also be equipped to understand the care of persons with ID (Doyle 2003 ; McCallion & McCarron 2004 ; Mc Carron et al 2008 ; Fahey-McCarthy et al 2009 ; McCallion et al. (2012).

1.7.2 Knowledge and skills of caring for a person with dementia

Sachs et al. (2004 and Parker et al. (2005) identified a need to train people who are going to care for persons with dementia. Regarding the care for the general population with dementia, McCallion et al. (1999) reported that care assistants in nursing homes themselves identified educational needs in relation to understanding dementia, communicating with clients with dementia, and the managing of behavioural issues associated with dementia. Good-quality and sensitive interactions between carers and individuals with dementia is essential for good care (Kitwood 1997).

In particular there is a need for staff to understand the need for early planning of care for the person with dementia (Sachs et al. 2004 ; MacConville 2011 ; Cahill et al 2012). Such planning is important in order to connect the care of the person with the trajectory of the illness, and to ensure that the quality of care at early, middle and late stages is linked. While the diagnosis of dementia in persons with ID is complex for many reasons, and the up-skilling of staff from ID services for the assessment and the support of the person with dementia is crucial, so also is on-going education of other staff and family on the needs and care issues for the person to improve the care of this population in the long term (McCarron & Lawlor 2003 ; McCarron et al. 2008). It is interesting to note that the first recommendation of MacConville's (2011) study recognizes that dementia education of a wider care audience within society, such as ambulance workers, police and legal professionals, is important at this time.

Another important issue in the care of a person with dementia is teamwork: "Caring involves the actions of people who are resourceful and aware, who can trust each other and work easily as a team" (Kitwood 1997:103). This view encourages in-service training, addressing teams to ensure shared goals and moving the content of training beyond the theoretical (Kitwood 1997). A new culture of care emerges that does not pathologise dementia. In the longer term, fostering changes in the culture of care requires both resourcing and training of staff: it is "essential to have a properly trained work-force at all levels, and care assistants need to be equipped not only for essential physical aspects of their work but also for psychological tasks, in particular, developing those skills of interaction" (Kitwood 1997:142). Indeed skilled communication remains a challenge for staff supporting persons with dementia (Mac Conville 2011).

1.7.3   Knowledge and skills of culturally competent caring

Ireland now embraces a multicultural healthcare context. Such developments generate a need to deliver culturally competent care (Tuffrey-Wijne 1998). Culture impacts on every facet of a person's being (Tracey & Ling 2005). In Ireland, the term non-national is used to describe persons from other countries and cultures (Tracey & Ling 2005). In considering the development of an educational intervention, it was necessary to consider the needs of such a multicultural workforce in order to include culture-specific content. Equally it was important not to reduce the topic of cultural care to a 'recipe approach' (Tracey & Ling 2005:172) or to reduce persons from one culture to a stereotype, i.e., that they have identical beliefs and values (McCallion, Grant-Griffin & Janicki 1997). Indeed, immigrants may choose to assimilate and adopt the values and beliefs of the host country (McCallion et al. 2007). The acknowledgement of the individuality of persons is therefore important when addressing such educational needs.

Broad culture-specific issues have previously been identified in relation to terminal illness. These issues encompass disclosure, breaking bad news, advance care-planning, and the locus of decision-making (Searight & Gafford 2005). In the last 40 years "the North American culture advocates explicit disclosure of cancer diagnosis and frank planning for end-of-life care" (Candib 2002:213). This approach may not be acceptable to other cultural groups, e.g., cultures that place higher value on family connectedness than on individual autonomy and may value life at all costs over an easy death. Explicit examples quoted by Candib (2002) are that some cultural groups would not tell a person that they are dying but would offer encouragement with regard to treatments and generate hope. Another example is that some cultural groups do not discuss a terminal diagnosis with the older person who is experiencing symptoms but would discuss such issues with the family members. The family then assists with the decision-making process. However, it is important to acknowledge that within ethnic groups there are also considerable variations (Searight & Gafford 2005). Educational interventions must therefore take cognizance of the potential range of ways in which culture may influence beliefs and behaviours of carers who are caring for persons with terminal illness and who are faced with the processes of decision-making and end-of-life decision-making for the person with a terminal illness.

In the ID context, McConkey (2004:35) identified that new staff members rely heavily on verbal communication; yet asking excessive questions may actually make situations more complex. This is potentially compounded within a multicultural workforce. McCallion et al. (1997) identified that professional staff in ID services may not be sufficiently sensitive to cultural differences and influences and may, in particular, fail to recognise the strengths in other cultures. Therefore, culturally-appropriate care respects and recognises the contributions of everyone involved. "Education is the key to the provision of culturally appropriate care," as noted by RNACPC (2001:45).

1.7.4 Knowledge and skills of palliative care

Staff in ID services do not normally possess palliative care skills or qualifications (DADHC 2004). Tuffrey-Wijne (1997) identified a clear lack of literature with regard to the palliative care needs of persons with ID, and suggested that collaborative working between ID nurses and palliative care nurses could improve care for this population. Staff in ID settings may be unprepared for the family dynamics and the emotions involved when caring for someone with a terminal illness (Tuffrey-Wijne 2002). Staff may wish to talk about death and dying but they may not have the expertise in practice (Tuffrey-Wijne 2002 ; Ryan et al. 2010). Working collaboratively with specialist palliative care services would potentially allow exchange of expertise such as truth telling and the explaining of the progression of illness in malignant conditions (Tuffrey-Wijne 2002). Carers in ID services need to be educated about what to report to the palliative care team, and what to expect about the progression of the disease or illness (Tuffrey-Wijne 2002 ; Todd 2004). Therefore they need to understand the condition (diagnosis) and what to expect (prognosis), and how to interpret any important changes which could, for example, indicate pain (Tuffrey-Wijne 2002).

A study by Whittaker et al. (2007) on the educational needs of care assistants, regarding their knowledge of palliative care, identified that few thought palliative care started at diagnosis, others were unsure, and most thought palliative care referred to end-of-life care and was delivered only to those with cancer. They considered that palliative care was of most benefit in the last hours or days of life. Results indicated that staff needed an end-of-life training programme (Whittaker et al. 2007). These findings are consistent with the findings from phase one of this study (McCarron et al 2008). In the Whittaker

(2007) study training needed to focus on the philosophy and principles of palliative care due to the limited awareness of staff; it needed also to focus on practical care such as oral care and nutrition, all of which are aspects of quality care. However, they needed more training in psycho-social, spiritual care and how to meet cultural needs too.

They also needed to be able to support a person on a syringe driver, to know about safety issues and positioning, and to be confident in delivering non-pharmacological pain-relief measures. Frontline staff and their skills determine the quality of care delivered (Whittaker et al. 2007). In earlier literature Solomon and Jennings (1998) identified that medical and nursing staff should be trained in the pharmacological and non-pharmacological management of pain and other symptoms to improve palliation. In the more recent studies in Ireland staff explicitly identified that they needed to feel more confident in supporting the person with this symptom management at end-of life (McCarron et al 2008 ; IHF/HSE/ICGP 2011).

The National Report of the Advisory Committee on Palliative Care (DoH&C, 2001) recognises that all staff dealing with people with advanced progressive disease need specific training in communication skills; this mirrors the best care practice which the above writers on dementia care and ID care have identified for their populations. Tuffrey-Wijne (2003 & 2005) identified that people caring for persons with the dual diagnosis of ID and dementia had serious concerns regarding communication issues and symptom assessment.

There is increasing emphasis on the need to provide palliative care to persons with end-stage dementia in order to prevent unnecessary transfer to hospital (Solomon & Jennings 1998 ; Chang et al. 2005 ; IHF/HSE 2008 ; McCarron et al 2008). Chang and colleagues (2005) found a lack of knowledge of palliative care and a lack of access to specialist palliative care services for these patients. Both studies identified that training and education in palliative care ought to be developed and delivered by multidisciplinary teams (Solomon & Jennings 1998 ; Chang et al. 2005). Fisher (2005) recognises that educationalists, policy makers and practitioners need to collaborate to develop equitable palliative care services for all persons. There are certain issues to be considered (when does active intervention cease?), for institutions of long-term care if they are to change from medical models of care for end-of-life dementia patients to ones providing comfort care and palliative care (Solomon & Jennings 1998). Ongoing team

building is also recognised as an important issue for optimal functioning of teamwork in the Irish context of delivering palliative care (Rowe, Keating & Walsh 2005).

Education is important for the future direction of palliative care in Ireland (Larkin 2005 ; Cooley et al 2010). The All Ireland Institute of Hospice and Palliative Care will provide strategic direction for future palliative care education in Ireland (aiihpc.org).

1.7.5   Knowledge of and skills in addressing nutrition, hydration, and pain concerns
Feeding difficulties and challenges experienced as part of end-stage dementia care by persons with ID mirror those difficulties described in the generic care literature in persons with Alzheimer's dementia (Norberg et al. 1994 ; Biernacki & Barratt 2001 ; McCarron & McCallion 2007). Lack of ability to self-feed, the difficulty of one's holding food in the mouth, concerns about chewing and swallowing, agitation and distress, spitting, and food inhalation or aspiration - all culminate in stress for the person, the family and staff (McCarron et al. 2003). Staff may find it difficult to watch someone they know and care for who is now unable to eat or drink, and they describe feelings of guilt and remorse when faced with this (Service 2002).

Again, within the generic care literature there is little evidence to support the use of tube feeding in persons with advanced dementia (Mitchell et al. 1998 ; Finucane et al. 1999 ; Volicer 2005). Perceived benefits of tube feeding in persons with advanced dementia, such as preventing malnutrition, reducing risk of pressure sores, preventing pneumonia, promoting comfort, and improving functional status, have not been upheld in the reported research (Finucane & Bynum 1996 ; Finucane et al. 1999 ; Volicer, 2005).

Therefore staff need to understand when a palliative care approach ought to be introduced for the person with dementia and to begin to develop the language which allows them to debate when the burden of an intervention outweighs the benefit. Furthermore, staff ought to be prepared to know when collaboration with specialist palliative care personnel may benefit the person in relation to their delivering the best end-of-life care.

The assessment of pain in persons with cognitive impairment or ID is problematic (Regnard et al. 2003, 2006). The assessment of pain in patients with Alzheimer's dementia appears to be even more complex (Regnard et al. 2006). Specialist palliative

care services may need to recognize that the assessment instruments used for the general population for both pain and nutrition needs, are rarely helpful (McCallion & McCarron 2004 ; McCarron & McCallion 2007).

1.7.6   Knowledge and skills of terminal illness, death and dying

Staff in ID services are now being challenged more frequently to care for persons with terminal illnesses (Blackman & Todd 2005). Staff in ID settings were unprepared educationally to care for the dying (Tuffrey-Wijne 2003); even when they had experiences of deaths, they struggled to give end-of-life care to the best of their abilities, instead providing lots of love and personal care (Todd 2004).

Staff have often had little or no experience of death and dying, and the fact that these staff need support in coping with caring for persons with terminal illness (Tuffrey-Wijne 2005, 2007) and end-of life care (Sachs et al. 2004 ; Forbat & Service 2005,) suggests that overcoming barriers to good end-of-life dementia care includes education of staff who care for this population. Furthermore it requires skilled communication from key professionals to assist families with the emotional and psychological challenges in their making decisions regarding end-of-life issues for persons with dementia (Sachs et al. 2004).

People need to understand that at the end stage of dementia, refusal of food and drink is a "natural part of the dying process" (Solomon & Jennings 1998:138). These authors reiterate the need for people to be in a position to discern when the intervention is beneficial or burdensome, and thus to be able to make decisions regarding the quality of care delivered within a palliative care approach. To this end, staff need to be introduced to an understanding of ethical dilemmas in practice for the person with dementia, advanced dementia and ethical decision making (Purtillo & ten Have 2004).

Communication about death and dying can be difficult for staff (Solomon & Jennings 1998 ; Ng & Li 2003). To communicate with relatives about death and dying is also an issue (Whittaker 2007). Care assistants may be young and have limited experience of death (Tuffrey-Wijne 1998). Staff should be prepared for issues such as what to do if the person dies while one of them is on one's with him/her; also staff should be trained in care issues like bathing, skin care, and oral care (Tuffrey-Wijne 1998). Meeting

cultural issues is important; therefore checking with family with regard to, for example, the religious issues of the dying person needs to be considered (Tuffrey-Wijne 1998). Staff in long-stay care settings must be able to care for dying patients (Solomon & Jennings 1998). Some of the educational needs of staff identified by these authors were: knowledge of what is ethically and legally permissible, clinical skills in pain relief and comfort measures, communication skills in interpersonal and intrapersonal relationships among staff and between staff and families (Solomon & Jennings 1998). Some important deficits in knowledge remain in relation to nurses' understanding of the distinction between foregoing life-sustaining medical treatment and assisted suicide, and of nutrition and hydration withdrawal. A significant number of physicians did not have sound knowledge of narcotic use in terminal care (Solomon & Jennings 1998). Palliative care in nursing homes for persons with advanced dementia remains sub-optimal (Mitchell et al 2004). Dying may not be recognized in this population in the nursing home (Mitchell et al 2004 ; Molloy & McQuillan 2012). Furthermore, General Practitioners (GP's) may lack knowledge and skills in recognising the dying process (Watson et al. 2006).

1.7.7   Knowledge and skills of facilitating grief and loss

Dodd et al. (2005) identified the need to train staff to support the grieving process for people with intellectual disabilities. They furthermore identified a gap in policy provision in relation to bereavement in the ID services surveyed in their Irish study (Dodd et al. 2005). It is important to include persons with ID in the dying of significant others in order to facilitate their grieving (Meeusen-van de Kerkhof 2006). In a study by Todd et al. (2004), clients were not informed that they were dying, the staff seemed to make this decision not to tell them early on, and this decision was not reviewed. Bereavement issues may be different in dementia (Sachs et al. 2004); therefore, supporting this grief is important for families and carers. Education and training of staff at senior level appear to be necessary to support change in practice (Sachs et al. 2004). Staff had formed relationships with the residents and needed to deal with their own grief (Whittaker et al. 2007). Solomon and Jennings (1998) also highlight the complexity of bereavement and grief issues for relatives of persons with dementia who experience mourning along the trajectory of the illness and long before the person actually dies (Boss 1999, 2011). A lack of knowledge about bereavement support was identified in a study with carers of persons with ID (Ng and Li 2003). Finally, grief can be

disenfranchised for the person and his/her carers (Doka 2004).

1.7.8   Knowledge of end-of-life care

There are a variety of frameworks designed to support a comfortable death for persons in the last days and hours of life. They are referred to as integrated care pathways. One of these is the Liverpool care pathway developed by specialists in cancer palliative care (Ellershaw & Wilkinson 2003). Watson and colleagues (2006) identified barriers to the introduction of this integrated care pathway for persons living in nursing homes in the last days of life. These barriers included a lack of knowledge of palliative care medication and symptom management, a lack of preparation of the staff for the approaching death, staff's not recognising the dying process, a lack of multi-disciplinary team working, a lack of confidence about talking about death, and a lack of ability or willingness to change established work practice. One important point raised in this study was that for an integrated pathway of care to work efficiently there needs to be "*a diagnosis of dy*ing" made, and therefore nurses, carers, families and GPs need to work together to make this decision (diagnosis) (Watson et al. 2006:237). Standards for best practice end-of-life care for persons with dementia have been developed in Ireland (Cahill 2010). In England the palliative care/end-of-life care needs of persons with dementia are included within their end-of-life care strategy: prioritizing high quality care for adults at end-of-life (DoH 2008).

It was also found to be difficult to get GPs to collaborate on the introduction of the integrated care pathway (Watson et al. 2006). In a study by Oberle and Hughes (2001) on ethical decision-making on end-of-life care and whether doctors and nurses perceive or approach these decisions differently, the authors found little evidence of the care-versus-cure distinction between the two. In the IHF/HSE/IGPC (2011) study the GP's identified ethical decision-making at end-of-life as an educational priority for them. Ethical or "moral distress experienced by nurses and doctors could be reduced by cross-disciplinary discussion and mutual recognition of the burden carried by the other" (Oberle & Hughes 2001:714).

1.8   Summary of Literature Reviewed for Phase One

In the review of the literature on ID care, dementia care, palliative care and end-of-life care, it appears that there are similar philosophies underlying them, and equally that

there are overlapping training needs identified for those caring in these specialist areas. A theme very central to all is the respect for the individual and the maximizing of his/her quality of life. In the three care settings of ID care, dementia care and palliative care, the caring relationship between carers and patient/client may be – and usually is – of some significant duration. This is very true for the ID residential settings and long-stay dementia settings. It may be true in palliative care settings with illnesses such as motor neuron disease, HIV or paediatric life-threatening illnesses, as these conditions usually have a longer illness trajectory than malignant diseases in the adult population. The clear distinction between the delivery of a palliative care approach or the utilization of specialist palliative care for ageing persons, persons with dementia and persons with ID is not explicit in the literature. A lack of explicit distinction between palliative care and specialist palliative care in many reports continues to add confusion to the situation. However, this matter appears to be receiving greater clarification in later reports (HSE/IHF 2008). Indeed, the proposal that end-of-life care is a better term to be applied to older persons living in acute and long-stay institutions is now debated in Ireland (O'Shea et al. 2008).

It is clear that experts in the specialist areas recognise that staff need specific knowledge of the specialty area and of the skills to initiate evidence-based practice. Staff in ID care settings require an understanding of practice and principles of palliative care, especially skills and knowledge in end-of life care (Wilkinson 2005). Staff from specialist palliative care require skills and knowledge in working with people with ID, especially in relation to communication issues which impact on the process of assessment (Tuffrey-Wijne 1998, 2002 ; Ryan & McQuillan 2005 ; McCarron et al 2008).

Teamwork is necessary in all three settings in order to provide optimal care, as it is acknowledged that no one individual in the multidisciplinary team can have all the necessary knowledge and skills to care fully for the patient on their own. The history of caring for all of the populations has had, and continues to have, elements of voluntary unpaid care. Although the research population in this project (phase one) were paid carers (staff), future research and educational developments with families and volunteer carers will need to be considered.

1.9   Conclusion

This chapter introduced the reader to the background and context of a funded project - (phase one) which was designed to explore the education and training deficits of staff supporting persons with ID and dementia. The broad literature on ID care, dementia care and palliative care was presented to give the reader a glimpse of the similar philosophies existing across the three and the existing gaps as they are identified at this present time in realizing optimal care for this population particularly at end-of-life. The next chapter overviews the project (phase one) and findings.

CHAPTER 2 – OVERVIEW OF FUNDED PROJECT (PHASE ONE)

2.1   Overview of Project – Phase One

2.1.1   Introduction

This chapter describes the funded research project. This is Phase One of the research presented in this thesis. Phase One was conducted to explore the experiences of paid staff in supporting persons with ID and dementia. The overall objectives of the phase one were to identify any education and training deficits that staff may have in relation to caring for this population, and to design, deliver and evaluate an educational intervention to meet these deficits.

2.1.2   Research aims

The aims of this phase one were:

1. To explore the experiences of staff in intellectual disability and specialist palliative care settings, their experiences of caring for persons with intellectual disability and dementia from diagnosis to death, and to extrapolate their perceptions of when or how the person required 'palliative' care.

2. To identify the gaps in education and training needs of the staff in relation to the care required.

3. To deliver and evaluate an educational intervention to staff from the intellectual disability services and from the specialist palliative care service.

2.1.3   Methodology

Qualitative research is now more commonly used in health care research and more commonly used to provide evidence for practice (Bailey et al. 2002). A qualitative descriptive approach was used to guide the project (Sandelowski 2000). Qualitative descriptive research naturally draws on naturalistic enquiry – the study of phenomenon in its natural state. It is, therefore, of more value and importance to a study where the obtaining of straightforward information from people with regard to their concerns about a service, is the focus of inquiry (Sandelowski 2000:337). The purpose of this

investigation was (1) to identify any education and training deficits of staff who were caring for or who had cared for persons with ID and Alzheimer's dementia, and (2) to develop, deliver and evaluate a training intervention to address these needs.

2.1.4   Study population

There were a total of fifty-seven participants in phase one. Fifty were from intellectual disability service providers in the greater Dublin area of Ireland. Seven were from one specialist palliative care service in the same catchment area.

2.1.5   Ethical conduct

Ethical approval from all the participating bodies in this study was received following due process. All research activity associated with the study was in accordance with the regulations of the University of Dublin, Trinity College (TCD) guidelines for the conduct of research studies (2002). The overall ethical approval for this research was granted by the Faculty of Health Sciences Committee TCD to the Principal Investigator. See Appendix 2. Access to the research sites was initiated by the principal investigator, and due process was followed by the research assistant (author of this thesis). All participants were afforded care in line with best ethical practice which reflected the ethical principles of beneficence, non-maleficence, autonomy and justice as outlined by Beauchamp and Childress (2004) and in line with the Declaration of Helsinki research on human participants (1989). All participants were assured of anonymity: each would be given an identification number which would be known only to the researcher.

2.1.6   Data collection

Fourteen focus group interviews were held to collect data. Focus group interviews were chosen for this study because they provided an opportunity to bring people together who had particular expertise and experience (Krueger & Casey 2000). A reflective journal was maintained in order to enhance the data and to assist the analysis. The data collected captured the experiences of the staff who were currently delivering or had delivered care to this population during their illness and up until their death. It was evident from reading and listening to the first three transcripts and from reflection on the visits that there were potentially 'culture-specific issues' emerging among staff in relation to end-of-life care. Therefore, four of the ID sites were revisited where there were staff from different cultural groups. The study explored the perceived education

and training needs of these staff and their perceptions of palliative care for this population.

2.1.7 Data analysis

Data analysis was initially undertaken manually and completed by using a computer-assisted qualitative data analysis software (CAQDAS) program called NVivo 7 (QSR International 2006). A combined approach was used to maximise a more thorough analysis. Qualitative content analysis was used, as it is most suitable for descriptive qualitative research and it is naturally oriented to presenting a summary of the data (Sandelowski 2000). Codes were generated from the data and systematically applied throughout analysis.

2.1.8 Findings

The data from this research were analysed thematically, and five themes emerged. These are listed in table1.

Table. 1 Themes from Phase One

Desirable care for the person with intellectual disability and Alzheimer's dementia
When should palliative care start
Communication skills
Death and dying
Modification of practice

Theme 1: Desirable care for the person with intellectual disability and Alzheimer's dementia.

At all times, staff articulated that they wished to care for persons with dementia within the ID services. They stressed that this was home for these persons and that they wished to keep them at home whenever possible and surrounded by people who were familiar to them. They acknowledged that they were unsure as to whether persons in the late stages of dementia knew where they were or recognised staff or peers, but they had witnessed individuals deteriorating and being very distressed when they were moved out of their usual environment. They generally appeared to manage to care for the person in the early and middle stages of the dementia in the same way as they had cared

for him/her prior to its onset, especially in settings where they were caring for one person with dementia at a time. They recognised that the living environments in many situations were not conducive to the supporting of a person with dementia, and they described the type of environment that they would wish the person to have. The logistics of caring for a person with dementia in smaller units and homes were also problematic. In the middle stage of dementia there were health and safety issues for staff to consider for persons and their peers. While persons with dementia were mobile it was important to keep them safe and secure in the building, but this meant on many occasions that the freedom of other clients was curtailed if doors had to be kept locked or kitchen facilities were made inaccessible.

Staff realised that early planning of care was important for the person with dementia. However, a lack of diagnosis of dementia appears to cause much of the ensuing frustration for staff, who could not put a plan of action in place to initiate a team approach to care, or look at future planning without this formal diagnosis. Multidisciplinary team care was recognised as essential in the care of a person with dementia. Nurses and carers provide most of the day-to-day care of the clients. The staff with the most experience of dementia care explicitly stated that nursing staff were necessary in the care setting to provide care for persons with dementia once they started to develop health care needs or swallowing difficulties. Staff from the specialist palliative care service recognised that they did not necessarily have expertise in managing dementia, and thought that the ID services should work closely with the generic dementia services in relation to dementia care.

Theme 2: When should palliative care start?

Many of the staff from the ID services considered that palliative care would begin when persons were at a late stage of dementia, when they were physically very unwell. Others directly equated the start of palliative care with the placement of a PEG (percutaneous endoscopic gastrostomy) tube in the person to maintain his/her nutrition and hydration, or with the need for pain and symptom management. A minority of the staff debated the idea that they were delivering palliative care from the time the person first showed decline, because they were providing comfort care from then onwards. ID staff in general had not thought about accessing specialist palliative care for someone with dementia, but in the interviews they began to ponder this. Some staff considered that the

delivery or initiation of palliative care was only for people with malignant disease or motor-neuron disease. There was a mixed response to the issue of whether staff in ID services had a role to play in bereavement care of the families of clients who had died. Follow-up visits by relatives were made after the deaths of clients, and staff welcomed them and provided informal support to the best of their abilities.

Person-centred care, to include excellent psycho-social care, was evident across the ID sites, and this was explicitly commented on by specialist palliative care staff as a particular strength of the care-giving witnessed in such settings. The need to meet the spiritual care of the person with dementia or of their relatives was not strongly evident in the findings. The specialist palliative care staff felt that they had a limited input and that what they had to offer over and above symptom management would be some expertise in how to approach decision-making, particularly ethical decision-making, e.g. about nutrition and hydration at the end of life. Staff from specialist palliative services were anxious that if staff in ID services provided a palliative approach to care within their own service, they would also know when to access the specialist palliative care level-three expertise. Staff at all ID sites stated that they would want support from specialist palliative care services if pain and symptom management in the care of the person with dementia was an issue.

Theme 3: Communication skills

Staff from the ID services expressed feelings of discomfort about talking with others about dementia, death and dying. They felt challenged when talking with other professionals, and they lacked confidence when dealing with colleagues, families and peers of the client. This was especially so for staff who had limited experience of caring for clients with dementia. In the focus groups, staff were beginning to wonder whether clients would understand and whether they ought to talk to them about the dementia. Staff were beginning to talk to the peers of the person about dementia, because they were aware that peer education was reducing anxiety and inappropriate behaviours within the living environments. Staff recognized that they required particular skills in communication within the ID setting; they also reported that because they knew the clients for so long (over many years) that they were able to understand them and be their advocate when necessary when dealing with other agencies or with multidisciplinary teams. Staff reported their belief that people in the generic services do

not understand the needs of persons with an ID in the first place, and that if they have the dual diagnosis of ID and dementia, then they will be understood even less.

Theme 4: Death and dying

Staff on some sites considered that the clients knew that they were dying and that clients with severe and profound disability knew when someone was dying. Generally, staff in the ID services identified that families needed support when the person was dying. Services varied in the amount of formal contact they kept, and much depended on the relationship that the family had with the service before their relative died.

There was a mixed response with regard to the location of where the person with dementia should have end-of-life care. Some wanted a unit for end-of-life care, others debated its effectiveness or appropriateness. Services where there were units to cater for persons at the end-of-life or when dying stated that these were not suitable for persons with dementia should they be ambulant, agitated, or noisy. Staff reported very positive experiences of their witnessing good deaths in patients with dementia in services where there was privacy for the person and relatives, and where the person was comfortable and then died peacefully. Staff also had some knowledge and skills of palliative care and had developed working relationships with specialist palliative care services in these situations. Conversely, staff reported that they had negative experiences where their clients died without these conditions being in place. Good deaths were not exclusive to the services described above, as staff appeared to have coped with uncomplicated deaths across the services without distress.

Throughout the dying trajectory, staff across all services included the peers of the person in the whole process of events around the client's dying and death, and included them in all rituals as far as possible after the death. This inclusion of the person's peers appeared to happen, not because the staff knew that it was theoretically good to include them in order to facilitate their own grieving, but rather because of a sense that they were family, and that if you were at home your family would be around and involved in everything. Some staff explicitly highlighted that the peers of the person needed bereavement support; others said that they thought that they did not understand and so did not need bereavement support. In services where they were beginning to give serious thought and consideration to this matter, they were reflecting back on cases and

beginning to wonder whether changes in client's behaviour were in fact unresolved grief issues for the client.

Some cultural issues arose from this study in relation to patient autonomy, understanding of palliative care practice, attitudes to death and dying, talking to the person about dying, and rituals at time of death.

Staff had three main areas of concern regarding some clinical skills during end-of-life care. These skills were: siting a subcutaneous line, assessing pain and distress, and understanding and managing syringe drivers.

Staff identified ethical issues such as a lack of policies in place for decisions about resuscitation, nutrition and hydration at the end of life, and inappropriate versus appropriate use of PEG feeding in a person with advanced dementia.

Theme 5: Modification of practice

Staff across all sites recognised the need for training and education with regard to dementia and Alzheimer's disease in order to understand the condition from physiological, social, emotional and practical perspectives. Staff reported the difficulties they experienced when assessing the person with Alzheimer's dementia. In one site the staff were unaware of any tools available to assess for dementia in this population. Staff recognised that their role was changing from one of teaching new skills to the person (client) , to a role of supporting someone losing skills because of their dementia. Staff spoke about the difficult decisions which had to be made about the well-being of persons in relation to moving them from their 'home', when it was no longer possible to manage them because of their increasing need for more nursing care and resources. The staff did not explicitly identify these decisions as ethical in nature, but displayed ethical distress (Purtillo 1999) when they spoke about how difficult it was to get a consensus across staff concerning the right time for the client to be moved, or when staff resisted prolonged respite for clients – believing that they ought to be 'at home'.

They were perturbed that clients had died very quickly in outside agencies after their having been transferred from their care. Expert feeding is a skill required when the person develops feeding difficulties, and care staff, in particular, reported being fearful about feeding persons with dementia when they had significant swallowing difficulties. There was no explicit acknowledgment in the interviews that staff may require more

training in feeding technique, for example in relation to PEG feeding. However, there appeared to be some gap in the staffs' knowledge about the benefits and burdens associated with this intervention in persons with advanced dementia.

Staff across all sites identified that the care of these clients with advanced dementia takes time and resources. The staff wanted to deliver quality care but recognised that this is difficult because of all the other pressures around their looking after other clients

Staff from both ID services and specialist palliative care services acknowledged that they shared similar philosophies of care. During discussion about quality of life for the patient within the specialist palliative care service, a distinction was made that, in ID services, the staff maintain quality of life for the person by ensuring maximum independence, but that in the palliative care context it was about maintaining the person's comfort. This comfort was mainly defined in terms of the medical management of symptoms by the specialist palliative care staff.

Staff in seven of the focus groups explicitly stated that there was a need for staff (nurses and carers) to have a knowledge and skill basis in ID care in order to be able to understand and care for someone with an ID.

A more comprehensive exploration of these themes is to be found in the report 'Supporting Persons with Intellectual Disability and Advanced Dementia: Fusing the Horizons of Intellectual Disability, Palliative and Person-Centred Dementia Care' (McCarron et al. 2008). For this report, written for the funding bodies of this project phase one), these five themes were collapsed into two major themes, (1) building upon services' history; and (2) supporting comfort and optimal death.

An executive summary of this report is available at: *http://www.nursing-midwifery.tcd.ie/assets/research/pdf/Fusing-Horizons-Exec-Summary.pdf*

2.2 Training intervention

2.2.1 Introduction

The development of a curriculum should not only be comprised of the ideas of the curriculum-planning group, but also reflect, through the team members, the ideas and beliefs of those whom they represent (Oliver & Endersby 1994). The educational philosophy of a course development ought to be in line with the philosophy of the educational climate and with the relationships between students and educators. Lack of consultation may potentially lead to lack of ownership on the part of those expected to implement the course. The participation of practitioners in day-to-day care is crucial to the process (Oliver & Endersby 1994). Knowles (1984) acknowledges that andragogy concerns the art and science of teaching adults; it implies that students are central to their own learning, take an active part in their own learning, have a more equal relationship with the teacher, and accept responsibility for their own learning. It is important to consider an andragogical approach to training in situations involving adult learners (Howard 1999). Benner (1984) identified that intuition was a distinguishing feature of the expert practitioner, and authors like Schon (1983) subsequently identified that reflection and reflective learning allowed access to this tacit knowledge or intuition. It was evident that the enhancement of communication skills between teams and within teams was imperative to the delivering of improved end-of-life care. Reflective teaching and team-teaching were primarily used as methods of teaching to enhance the acquisition of new knowledge and communication skills (Oliver & Endersby 1994, Tresoloni & Pew-Fetzer 1994).

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2.2.1 Planning of the education and training intervention

The findings in the literature with regard to the deficits in knowledge and skills in ID care, palliative care and dementia care settings were largely mirrored in the findings of phase one. The training needs were identified from the themes developed. These themes were identified on the completion of the analysis of the focus group interview data, and in collaborative discussions with academic and practice experts from the specialist areas of ageing, intellectual disabilities and specialist palliative care. Many of the staff who practise in intellectual disability and specialist palliative care services have long and varied life and professional experiences which they brought to the learning situation.

This experience was respected. To engender confidence in the use of intuitive knowledge (tacit knowledge) was a goal of the training.

The design of the intervention was also influenced by the needs of adult learners. Therefore, an andragogical (adult learning) approach influenced by Knowles (1980 & 1990) was used to develop the training intervention. Reflective learning and case scenario discussions and debate were central to the teaching and learning experiences of the participants. This approach was imperative for the facilitation of all the participants to come to a deeper understanding of the strengths and weaknesses of their existing care practices; this approach would also help them to face some challenging developments for future practice.

Furthermore, the needs of a multicultural workforce and client mix were kept in mind when developing the educational intervention in the light of globalisation, and due respect was afforded to the participants' cultural values and belief systems within such training. Finally it was also important to develop a course of study which could be refined by the services and submitted for accreditation as a short course or as a module to the relevant national educational and professional training bodies, such as the Higher Education and Training Awards Council, An Bord Altranais (The Irish Nursing Board), The Medical Council, or any other professional organization responsible for the approving of courses of study.

2.2.2   Pilot

A pilot training intervention was developed and delivered on two occasions in two different ID service locations. Attendance was open to all staff of the ID services who were participating in the project and to the specialist palliative care provider. An evaluation of this pilot intervention was conducted among the participants and the personnel who were delivering the course. Following this evaluation, the course of study was further refined and an educational intervention was developed for the services.

2.2.4   Overview of the educational intervention

The educational intervention (Trainers Manual) which was developed has two major elements:

1. A Trainer's Manual (including a CD with all of the PowerPoint presentations for the course.

2. A self-directed Student Workbook (in hard copy and on a CD in PDF format).

The Trainer's Manual (including the PowerPoint presentations on CD) is for the use of the staff who will teach the course (facilitators) within the services. The self-directed workbook is for participants who undertake the course of study; it contains student exercises along with the handouts and reading lists of the educational sessions.

2.2.5   Trainer's manual

An introduction in the Trainer's Manual offers guidelines on how the course may be developed within the services. These guidelines include the duration of the course, student effort, and content. It is designed to be user-friendly so that facilitators can have some flexibility in adapting it to their own work settings. This manual is designed in sessions. There are 20 classroom sessions in this study (see Fig 1). In sessions 1-18, participants are presented with some theory and background on various topics and some short student exercises to facilitate learning in the classroom. Session 19 is when all participants present a reflective piece of work (from their diary), in order to share learning with their peers. Session 20 is an evaluation session to allow the participants to give feedback on the delivery and content of the course and to record the learning achieved. As the sessions are all designed to stand alone, individual sessions can be delivered at any time.

Fig 2.1. Educational Intervention

	Educational Intervention
Session 1	Welcome & Introduction
Session 2	Reflection, Reflective practice, Diary & Workbook
Session 3	Introduction to the History & Philosophy of Intellectual Disability Care
Session 4	Alzheimer's Dementia in Persons with Intellectual Disability
Session 5	Health Co-morbidities in the Person with Advanced Dementia
Session 6	Understanding Person-centred Care in persons who are deeply forgetful
Session 7	Introduction to the History & Philosophy of Palliative Care
Session 8	Fusing the Horizons of Care
Session 9	Ethics, Decision-making and the person with ID and Dementia
Session 10	Influences of Culture in approaching Illness, Dementia and Healthcare
Session 11	Death & Dying ; exploring own values and beliefs
Session 12	Loss, Grief & Bereavement
Session 13	Loss, Grief & Bereavement in ID care
Session 14	Breaking Bad News – Some Important principles
Session 15	Communicating about Loss , Dementia, Death & Dying with persons with ID
Session 16	End-of-Life Care, the last 24-48 hours
Session 17	Teamwork & Collaboration
Session 18	Syringe Drivers
Session 19	Feedback from Reflective Diaries/Workbook
Session 20	Evaluation & Close

2.2.6   Self-directed workbook

The workbook is intended to support self-directed learning by the participants who undertake the sessions within the course. The workbook contains additional exercises for the participants to do in their own time after each classroom session is completed. This assists the participants to identify their level of knowledge and to begin to reflect on their care practices. The content of a number of the sessions will challenge individuals to think about their daily work situation and how they currently care for persons with dementia and advanced dementia. The exercises are designed to encourage the participants to think about the theory that they have received in the classroom, and to consolidate their learning after their attendance at the sessions, by their engaging in exercises on their own and by additional reading which they do in their own time. The workbooks will be used in conjunction with a personal notebook and a reflective diary. The instruction before each exercise will indicate whether the exercise will be done in

the notebook or in the reflective diary. The workbook, notebook and reflective diary are personal documents and belong to the individual student. Participants can reflect on any aspect of their practice where they refer to caring for a person with dementia or advanced dementia. In keeping with an adult educational approach, the course participants are expected to take individual responsibility and to make independent decisions on how and when to undertake these exercises in their own time.

2.3   Conclusion

This research study interpreted the perceptions of staff from a cross section of ID service providers and a specialist palliative care service in the Republic of Ireland, in order to gain an understanding of their educational and training needs as health and social care workers in their caring for persons with advanced Alzheimer's dementia. Their preparation for their delivering of this care in terms of their educational and training needs was analysed, and an educational intervention was designed and delivered in a pilot course to these services. The objective of the educational intervention was to improve the staffs' preparedness for their role and ultimately to increase staff awareness about how to improve the delivery of appropriate care, in particular end-of-life care, to this population.

Following an evaluation of the pilot educational intervention, it was refined and returned to the services which took part in the research. This facilitated them to continue to deliver an introductory educational intervention that would prepare staff better for their caring for persons with ID and advanced dementia. It is designed as an in-service educational intervention to be delivered by staff from within their own service setting. Some initial training has been provided on how to implement the intervention in practice; further training for facilitators is pending. Feedback is very positive to date from the staff who are familiar with the training manual. Two specialist palliative care services have also used this educational intervention to develop their own educational initiatives for their services.

The next chapter will introduce the reader to phase two and to the research question which emerged and which will be explored in the remainder of this thesis.

CHAPTER 3 – DEVELOPING THE RESEARCH QUESTION (PHASE TWO)

3.1   Introduction

In the process of analysing the data from phase one, it became apparent that staff recognised a deficit in their skills in relation to their caring for a population with a terminal illness. Furthermore, staff encountered an increasing number of people dying in their services, which required them to cope with such situations on a regular basis. The data suggests that the frontline staff (nurses, social leaders and carers), who provide the 24-hour care, experienced feelings of loss and grief as they encountered the person with dementia deteriorate and die. It is apparent from the findings in phase one that staff wish to deliver end-of-life care to their clients in the ID settings (McCarron et al. 2008). In order to provide quality end-of-life care, staff will be expected to incorporate and deliver a palliative approach to care (DoH&C 2001 ; HSE/IHF 2008 ; Davies (WHO) 2004) in situ (at home). An inherent aspect of the delivering of such an approach involves the utilization of the philosophy and principles of palliative care to include the supporting of their clients in coping with loss, grief and bereavement. Furthermore it will be important that staff understand and know how to engage in self-care activities when they are professionally supporting persons with loss and grief. Thus, there is a need to identify the constituents of loss, grief and bereavement in this care setting. Therefore, the data from the focus group interviews in phase one were reanalyzed within a Gadamerian hermeneutic framework in order to extract the content which related to any perceived experiences of loss, grief and bereavement. The rationale for the utilizing of this methodology will be described in chapter four.

3.2   Background and Context

Longevity in persons living with an ID has increased (McCallion and McCarron 2004) and those individuals are at risk of their developing age-related diseases such as dementia (Prasher 1995 ; McCarron and Lawlor 2003 ; Tyrrell et al. 2003 ; Noonan Walsh & Conliffe 2004 ; Hatizidimitriadou & Milne 2005). The journeying (or caring trajectory) with individuals with dementia is paved with losses for the individual and for his/her significant others (Panke and Volicer 2002 ; Doka 2004 ; Holley & Mast 2009). Significant others are those persons who matter to the person (client). In the family home context, the parents and siblings (unpaid carers) are commonly regarded as being

the significant others for the person with ID. In the ID Service settings, the staff (paid carers) live with the person in a close, family-like context, and as a result, they often become the significant others for the person.

In the settings where the person has been resident since childhood, staff may have had, in reality, more day-to-day knowledge of that person than the kinsfolk of the person. There is a recognition that unpaid caregivers experience multiple losses when caring for significant others over a prolonged period of disability or illness (Lamers 2002). However recognition of loss for health care workers or for paid carers on the death of a patient is often considered to be disenfranchised (Lamers 2002 ; Doka 2004). Disenfranchised grief refers to grief that is not openly acknowledged or legitimized (Doka 1989). Dementia is a terminal illness (Panke 2002). "Death is an ultimate experience of loss" (Smith 1988:159) and as such, the caring for a person with this terminal illness may potentially culminate in this ultimate experience for both paid and unpaid carers.

3.3   Rationale

Traditionally, staff in the ID services were enabling persons with ID to maximise their potential by continually teaching them new skills. Now they are challenged to care for a population who are ageing and who are dying and the staff need support to cope with their supporting of persons with terminal illnesses (Tuffrey-Wijne 1998). Staff prefer the person with dementia to die in their care (McCarron & McCallion 2004 ; McCarron et al. 2008 ; Fahey-McCarthy et al. 2009) and to deliver optimal end-of-life care to them (McCarron et al. 2008). Such optimal care requires the staff to acquire new knowledge and skills in collaborative models of care between existing specialist palliative care services and the ID services (McCarron et al. 2008). Collaborative models of education and training are recommended (DoH&C 2001b) and such a model was developed in Ireland from the project as outlined in phase one (Fahey-McCarthy et al. 2008). In the UK, the National Network for Palliative Care of people with learning disabilities and the Foundation for people with Learning Disabilities encourage and support such developments (Dodd et al 2003 ; Tuffrey-Wijne et al. 2005).

3.3.1 End-of-life care for persons with intellectual disability and dementia

The philosophy of care within ID care services was to support an individual to live life as fully as possible; professional carers were not providing support to people through illness and towards death (Blackman and Todd 2005). However, with an ageing population, the paid care staff within the ID services are now being challenged more frequently to provide this additional care to the person with a terminal illness. The transition from the supporting of persons to live their life as fully as possible to their supporting them through illness and death, may be very difficult for staff (Blackman and Todd 2005). However, with the ageing process and the associated co-morbidities comes the challenge for staff to re-evaluate their role in caring for this population. The philosophy of "ageing in place" whereby the person with an ID lives in one place and grows old and dies in his/her 'home', was strongly upheld in the ID services which took part in the project in phase one (McCarron et al. 2008). However, the complex physical, social and psychological challenges involved in the caring for a person with dementia, (particularly in mid and end stages), may result in adverse effects for the client, for other clients/peers and for staff and may raise questions as to whether ageing in place can be supported within these settings (McCarron et al. 2008, 2009). Should the person have to return from a community setting to live within a residential institutional setting, this results in the loss of community living for him/her and of associated loss for the paid carers who expected to keep him/her indefinitely in his/her 'home'. Staff in phase one of this project struggled to cope with this and kept clients for much longer than they really were resourced to do. This resulted from the emotional bonds which they had with the clients and their sense of failure in their not being able to care for them when they believed that the clients were at their most vulnerable.

3.3.2 Palliative care and end-of-life care

Caring for the dying and supporting a 'good death' is a central task of palliative care practice (WHO 2002 ; Gibson et al. 2008 ; Griggs 2010). The goal of palliative care is to achieve the best quality of life for patients and their families (DOH&C 2001 ; WHO 2002 ; Davies & Higginson (2004)). This same goal is also central to ID care (Gates 2006) and Dementia care (Kitwood 1997). To define 'quality of life' is complex (Nota et al. 2006) and needs further research particularly in relation to persons with intellectual disabilities (Petry et al. 2005). Therefore, staff who support persons with intellectual disabilities encounter additional challenges in relation to their maintaining

the best quality of life for their clients who develop dementia. This includes their supporting persons in their decline and death. In the smaller units in particular, (four to five clients in a house), where staff have made great efforts to create 'family' type structures, it seems inevitable that close bonds develop over time between certain clients and staff. Potentially, this can result in the experience of loss and grief for staff and requires further exploration in order to gain an understanding as to whether staff are to be supported in their efforts to give support to the clients. It is furthermore acknowledged that *"caregiver grief is a viable concept for study in the larger body of Alzheimer's disease research"* (Marwit & Meuser 2002:764).

The World Health Organisation have also highlighted that the assessment of bereavement for persons with dementia and their significant others is an important issue in developing appropriate palliative care for this population (Davies and Higginson 2004). It is with this background, context and rationale that phase two was developed.

3.4   Research Aim, Objectives and Question- Phase Two

3.4.1   Aim:

The aim of phase two was:

- To gain an understanding of the experience of loss and grief for nurses and frontline carers when they are supporting persons with ID and dementia.

3.4.2   Objectives:

The objectives of phase two were to:

- extrapolate data which explicitly or implicitly identified/described experiences of loss, grief and bereavement from the focus group data in phase one.

- reanalyse this data using a Philosophical Hermeneutic approach

- further explore the experiences of loss and grief for frontline staff who support persons with intellectual disability and dementia by the collection of further data with individual interviews.

- analyse and merge the data from phase one and phase two to describe a new understanding of the phenomenon under investigation

3.4.3   Research question:

The research question is:

What is the experience of loss and grief for frontline staff (nurses and carers) when they

are supporting persons with intellectual disability and dementia?

3.5   Literature review

3.5.1   Introduction

The literature in this review overviews key theories of loss and grief. The theories of "anticipatory grief" and "disenfranchised grief" are also explored. Anticipatory grief is experienced potentially by persons caring for others with a known terminal illness. Furthermore, disenfranchised grief may potentially arise because staff who work in ID services may experience disenfranchisement in their grieving a client. The concepts of loss and grief are reviewed in relation to professionals, family carers, dementia and ID. Literature was sourced through databases, personal, academic and public libraries. Key search words used were: "loss and grief" in combination with "professional", "nurse", "carer", "dementia" "intellectual disability", "learning disability" and "mental retardation". The retrieval of literature in relation to ID proved challenging due to the multiplicity of terms applied internationally by carers and professionals to represent persons with congenital/acquired cognitive disabilities.   There was no earliest date applied in the search but literature included is from the early 20th century to April 2012.

3.5.2   Loss and Grief

Loss may be broadly divided into the two categories; that of physical loss and psycho-social loss (Rando 1993). While it is possible to experience a psycho-social loss without a physical one, Rando (1993:21) argues that it is impossible to experience the opposite. Therefore, when an individual experiences the death of any loved one there will be the potential for multiple losses to manifest in bereavement such as physical, psycho-social and secondary losses (Rando 1993:22). Grief is the process of one's experiencing the psychological, behavioural, and social reactions to the experience of the loss (Rando 1993, 2000). Grief as a reaction to loss transgresses all aspects of individuals' lives as professional carers, as well as the lives of those for whom they care (Doka 2004 ; Goldsworthy 2005). The phenomenon of grief was first described by the psychoanalyst Freud (1915). Following this, Eliot (1932) described typical somatic and psychological reactions to grief. A classic study by Lindemann (1944) described the normal reactions to grief as experienced by survivors of a major fire in Boston and suggested that grief-work could potentially be completed in weeks. Later theorists refuted this and suggested

that grief work may potentially take years (Bowlby 1980 ; Parkes and Weiss 1983 ; Sanders 1989) or indeed a lifetime (Klass et al. 1996). These authors have explored loss and grief in order to define normal or uncomplicated grief versus complicated or unresolved grief in efforts to increase understanding and generate theories of grieving. The term 'complicated grief disorder' is interchanged with abnormal grief, pathologic grief, atypical grief and pathological mourning (Zhang et al. 2006). This is to highlight that, potentially, grieving is always complex and to state that it is pathologic may underestimate the complexity of the process for any one individual. Authors have undertaken concept analyses of grief (Cowles & Rodgers 1991, 1993, 2000) ; Cowles (1996). However, the concept of grief is especially difficult to measure (Reed 2003 ; Fulton 2003), but is acknowledged as a universal phenomenon experienced by humans (Meuser 2001 ; Reed 2003). Grief is perceived as "*an intra-psychic reaction to loss of indeterminate duration and intensity in which its expression is a function of both individual and social elements*" Fulton (2003 : 344).

3.5.3   Grief Theories

Some of the more familiar theories of grieving have been described as follows. Attachment theory (Bowlby 1969, 1973, 1980), Stage theory (Kubler-Ross 1970), Tasks of mourning (Worden, 1991), Anticipatory grief (Lindeman 1944 ; Parkes 1972/82 ; Rando 1993), and Continuing Bonds (Klass et al. 1996). Stroebe and Schut (1995, 1998, 1999) proposed a dual model of coping with loss where bereaved people oscillate between the mixed feelings of emotions and that of coping.

Bowlby's attachment theory (1969, 1973, 1980) explains how relationships formed early on in life between the child and a primary caregiver (usually a parent) can influence later separation and loss (bereavement) experiences for the child as s/he matures. This theory outlines four discreet phases which can occur after a person experiences a loss through death. These are a) numbing, b) yearning/ searching, c) disorganisation and d) re-organisation. Such a theory offers a linear framework which potentially implies that the experience of loss is a process with an end once the re-organisation phase occurs.

Kubler-Ross (1970), working as a clinician proposed a five-stage model which sees persons experiencing five distinct stages through which they progress when coming to

terms with their own dying. These are a) denial, b) anger, c) bargaining, d) depression and e) acceptance. This theory could also be interpreted as linear. However, not all of the stages had to happen to resolve grief or indeed they did not have to occur in the order in which they are presented in the theory. Furthermore, anyone could experience any stage more than once in their experience of coping with loss. This 'stages' model again served as a possible model to understand a process.

Worden (1991) proposed that for healthy grieving to occur, the bereaved individual/s had to undertake certain tasks. These include a) accepting the reality of the loss, b) working through the pain of grief, c) adjusting to the environment in which the deceased is missing and d) emotionally relocating the deceased and move on with life.
 All of these major theories of grief/bereavement explored the idea that the purpose of grief is to sever the bonds with the deceased in order to assist the bereaved to make new attachments referred to by writers such as Bowlby (1981) and Parkes (1972) as the 'resolution of grief'.

However, Klass et al. (1996) challenged these existing theories of grief and developed a theory that the bereaved integrate the dead person within their lives and continue to maintain the bond between themselves and the dead person. Therefore the previously presented 'stage' theories were challenged by a theory of 'continuing bonds'. Other authors concur that continuing a bond with the deceased person facilitates grieving (Fisher 2001 ; Benore & Park 2004). It is more generally accepted today that despite the permanence of physical separation, the bereaved can nevertheless be emotionally sustained through a continuing bond to the deceased (Field et al. 1999). Therefore, there is now a belief that continuing a bond with a deceased person can be considered "normative in mourning and can be integral to successful adaption to bereavement" (Field 2006:709). However, the continuing of a bond with the deceased can also be maladaptive if the bereaved do not acknowledge the reality of the death and that the physical relationship has ended and has been replaced by a representational one (Field 2006). Continuing bonds can be expressed in different ways. In earlier research by Field et al. (1999), behaviours such as 'keeping possessions of the deceased' were associated with increased levels of grief whereas 'sensing the deceased's presence' was not. In a later study by Field et al (2003), it was the intensity of the bonding rather than the expression which influenced the level of the grief which was experienced. Schut et al.

(2006) conducted studies to measure the conceptual overlap between continuing bonds and grief and concluded that continuing bonds are in themselves an intrinsic aspect of grief.

In a more recent revision, Klass (2006) identifies that other authors have misrepresented his theory of 'continuing bonds'(Klass et al. 1996), in that they have implied that continuing bonds facilitates healthy grieving and do not acknowledge the many complexities inherent in the theory. In particular, Klass (2006) acknowledges the importance of considering the social and communal nature of continuing bonds when exploring their impact on grief.

Devita-Raeburn (2004) proposes that the theory of continuing bonds is an important element in the grief of siblings as siblings' whose identities are intricately connected because they share similar histories, so that when one sibling dies, the survivors essentially lose part of themselves. Klass (2006) concludes that when we ask if continuing bonds leads to healthy grieving, that we are being too simplistic and that future research needs to develop better strategies to measure the multiple roles which continuing bonds can play in grief, and how these bonds change over time.

Theories can serve as models to facilitate some theoretical understanding of the grieving process. However, the concept of grief is complex and the understanding of the experience for an individual in terms of the use of a model may not capture the uniqueness of that experience (Moules 1998).

Long term illnesses can give rise to complicated grieving for the person or for his/her significant others due in part to the unpredictable nature of the illness and to the difficult decision-making that may be required along the course of the illness (Rando 1993). The experience of prolonged loss and its impact on caregivers has received limited attention to date (Sanders et al. 2008). The existing models of grief are not necessarily applicable to health professionals (Papadatou 2000). The subjective experience of grief in response to a loss (death) needs to be understood as it is directly related to the investment of the professional in the relationship (Papadatou 2000). This may be an important component in one's understanding of the grief experienced by frontline carers working in ID services as they work very closely with the client over a prolonged period of time,

regularly spanning many years. Strobe et al. (2001,2002) challenge whether there is a need to redefine grief and our understandings of grieving and they suggest that individual differences in the experience and process need to be explored. Strobe (2001) suggests that in the extension of current knowledge, coping and caring need further exploration in relation to studying the grieving process.

3.5.4 *Anticipatory Grief/ Anticipatory Mourning*

The term anticipatory grief was first described by Lindeman (1944) as the term applied to the grief experienced by persons prior to the possible death of another person. It can be described as the grief experienced in anticipation of an impending loss (Casarett et al. 2001). The term anticipatory grief was coined to distinguish it from the grief experienced following the occurrence of a death. However, the reactions to anticipatory grief can mirror the grief reactions experienced after an actual loss has occurred (Knott & Wild 1986). Studies on parents of children with terminal illnesses identified that grief reactions could take place weeks before the actual death (Fulton 2003). These studies concluded that anticipatory grief remained an "*elusive subjective experience not readily amenable to quantification* " (Fulton 2003 : 345). Studies from the 1970's and more recently demonstrated that the experience of anticipatory grief did not shorten the mourning period or decrease the intensity of mourning for the bereaved (Jacob 1993 ; Simon 2008). Furthermore, the experience of anticipatory grief may be helpful or harmful depending on the duration of the time a person was in the state of anticipation or on other factors (Rando 1984). Such experience of grieving before the actual death of a person may potentially benefit those who are anticipatory grievers in that they may have undertaken some of their grief reactions (grief work), in preparation for the ultimate loss through death. The experience of a prolonged grieving period before this ultimate loss, can also become a burden for some people who potentially become more stressed as a result.

Anticipatory grief was also the subject of some controversy as to whether it existed as a phenomenon (Corr et al. 1997). Anticipatory grief can be difficult to conceptualise because of its multi-dimensional complexity (Rando 1986, 2000). This complexity according to Rando (1986) is because this grief has two perspectives (that of the person dying and the grief of those emotionally involved with the person. Furthermore, the losses experienced by the person have time elements in that when someone is dying

they have experienced losses because of the illness (past abilities), they experience on-going losses (present abilities) and they have future losses to consider (life). Rando (2000) has renamed the concept of anticipatory grief as 'anticipatory mourning'. In a critique of these concepts Fulton (2003) states that this new definition expands on Lindeman's original one. He further identified that there remain problems of conceptualisation, definition, measurement and validity in the research attempts to explore the concepts of anticipatory grief or anticipatory mourning. Some of these difficulties arose form the fact that studies into anticipatory grief were conducted within a psycho-analytical paradigm and did not pay sufficient attention to the socio-psychological and socio-cultural influences on the experience of grief (Fulton 2003). Anticipatory grief in relation to dementia is discussed below.

3.5.5 Loss and Grief : Dementia

Grief in dementia care may be anticipatory as it relates to present and anticipated losses prior to actual death (Rando 1993 ; Meuser & Marwit 2001 ; Doka 2004). To know that an individual is going to die because she/he has a terminal condition has the potential to put family members into a state of anticipatory grief (Doka 2004 ; Clukey 2007). The trajectory of dementia is paved with many losses (Loos & Bowd 1997 ; Kuhn 2001 ; Doka 2004 ; Oppenheimer 2006), which give rise to grief as a universal response (Walker & Pomeroy 1996). The individual loses many cognitive and psychomotor abilities which give rise to loss of occupation and which can ultimately lead to the loss of one's identity.

There are many studies reporting on caregiver burden, stress and depression in dementia care-giving, but few apart from Doka (2004), Adams & Sanders (2004) and Boss (1999, 2011) report on grief, which may be an important but overlooked experience of the care-giver experience (Meuser & Marwit 2001 ; Adams & Sanders 2004 ; Marwit & Meuser 2005 ; Sanders et al. 2008). Walker & Pomeroy (1996) suggested that depression reported in dementia care-giving may indeed be normal grief reactions rather than depression. Indeed, studies have identified anticipatory grief in Alzheimer's dementia family care-givers (Theut et al. 1991 ; Loos & Bowd 1997). The phenomenon of social death has been attributed to persons with dementia (Sweeting 1991). Anticipatory grief was found to be a component in the family carers of persons with dementia who perceived them as socially dead. (Sweeting 1991).

A psychometric inventory to measure dementia care-giver's 'real' grief has also been developed and modified (Marwit & Meuser 2002, 2005). The care-givers in all of these studies were family care-givers. In the study by Sanders et al. (2008) high, medium and low levels of grief were measured in the care-givers and identified that multiple factors contribute to the experience of grief. The themes of "yearning for the past", "feeling isolated" and "feeling guilty" were identified in the grief reactions of the participants in the study by Sanders et al. (2008:x). The impact of anticipatory grief on care-givers of persons with dementia may be particularly tragic (Holley & Mast 2009). This has been sparsely investigated to date but the limited number of studies which have investigated it, have found that anticipatory grief impacts on caregiver burden in dementia care (Marwit & Meuser 2002, 2005 ; Holley & Mast 2009), and that the acknowledging of this and the providing of appropriate support for the care-givers may be required for their managing the burden of caring. They conclude that grief is an understudied but important aspect of such a care-giving experience. There is a dearth of literature addressing anticipatory grief in the ID care sector; however, from my initial work on phase one, I was very aware that staff were saddened to watch their clients deteriorate and lose the skills for which they had worked so hard to achieve.

3.5.6 Ambiguous Loss

The theory of Ambiguous Loss was first described by Boss (1999). She described two types of ambiguous loss. The first type is when persons are "perceived as physically absent but psychologically present" (Boss 1999:8). Examples of this are missing persons or possibly separated persons and adopted persons. The second type of ambiguous loss is when persons are "perceived as physically present but psychologically absent (Boss 1999:9). Examples of this are persons with addictions, chronic mental health conditions and Alzeimer's disease (Boss 1999). In her research with families of persons with Alzheimer's who were "there but not there", she discovered that the families were more distressed than the families who had suffered a "more ordinary loss" (Boss 1999:16). Boss (1999) talks about ambiguous loss as loss without closure and thus mourning cannot commence and she uses the term 'frozen grief' throughout chapter one of her book to describe this. Furthermore, Boss (1999) recognises that it can be a challenge for healthcare workers to support families who are

experiencing ambiguous loss. Furthermore, ambiguous loss can affect the person being cared for as well as the carer (Boss & Couden 2002).

In the case of staff working in ID care, they are the frontline carers but they equally fulfil the role of family for the person within residential care. Therefore, the staff in these circumstances may experience ambiguous loss themselves and require support with this. Ambiguous grief can be experienced because of the pull-tug of the 'goodbye without leaving' phenomenon which occurs as the carers of the person with dementia experience the many losses along the trajectory of the illness. Furthermore, the challenges of not knowing whether the person is 'absent or present, dead or alive' complicates the relationship between him/her and the carer. Ultimately the carers' grief is compounded as they struggle to support the person with advancing dementia. Such an endurance of ambiguous loss can become physically and psychologically exhausting (Boss 1999, 2001, 2011). Boss (2011: 1) defines ambiguous loss as "a unique and devastating kind of loss" which is "unclear, has no resolution and no closure". Loss and ambiguity are identified by Boss (2011) as core elements of being human because presences and absences are experienced in every relationship and she considers that these two phenomena merge into the experience of 'ambiguous loss' for carers of persons with dementia. However, many people manage both loss and ambiguity throughout normal living. Boss (2011) in the following quotation sums up the dilemma for persons with dementia, their carers and significant others who support them from diagnosis to death. *"Regardless of its cause, dementia's ambiguous loss can debilitate even the healthiest of us. This is the struggle: making sense of a nonsensical situation. You come to realise that life is dramatically altered. Your loss is great, but there is no sympathy card; no one sits Shiva or holds a wake"* (Boss 2011:5).

3.5.7 Disenfranchised Grief

Disenfranchised grief as a concept was first put forward by Doka (1989:4) as:

"...the grief that persons experience when they incur a loss that is not or cannot be openly acknowledged, publicly mourned or socially supported".

This concept of grief enabled clinicians and researchers to validate grief which had not previously been acknowledged (Corr 2002). Lamers (2002:183) argues that health-care

professionals "rarely grieve the death of patients", and "usually do not participate in funerals or in mourning rituals for deceased patients". This statement relates to health care staff working in general care situations. Moss & Moss (2002:205), however, speaking about staff in long-term care of the elderly settings state that: *"Disenfranchised grief occurs when staff members perceive that their loss is not legitimised and that their relationship with the deceased does not entitle them to feel or express grief".* They conclude that staff are *"not kin"* even though they may have had a lengthy relationship with a patient and that they use family metaphors when talking about him/her. They conclude that staff have: *"no lifelong ties with the resident"* and that they had always seen the resident as dependent (Moss & Moss 2002:202).

Grief is disenfranchised for parents who lose a child with a disability and enfranchisement of that grief can be facilitated by occasions like a day of remembrance as this marks the loss and recognises the child (Todd 2007). Similar disenfranchisement of grief may potentially arise for professional carers when adults with disabilities die. The staff in phase one of the current study had spent many years caring for their clients within intimate relationships of trust and friendship (close family like structures). The grief of staff in ID may be regarded as being disenfranchised when they feel that they are expected to act 'professionally' and do not receive emotional support from the service at the time of the death (Todd 2004). Where there was a poor history of family (kinsfolk) involvement in the clients' care (in phase one), this made end-of-life decision-making difficult. The carers considered themselves as 'like family' if they had worked and lived with the person, and had known him/her very well.

Lack of recognition of the emotional impact of the death on staff by management's filling his/her bed almost immediately compounded by the use of insensitive language which did not respect the person's existence, can be difficult for staff (Todd 2004). The institution's policies and procedures can compound disenfranchised grief of staff where rules and tasks dominate the culture of the work situation and the general environment does not support an overt grieving process (Landers 2002). This bureaucratic framework emphasises physical and medical care while the psycho-social needs in relation to death and dying are secondary to these (Moss & Moss 2002). In an organisational context, Eyetsemitan (1998:471) proposes that the concept of 'stifled grief' is equivalent to: *"any recognised grief which is denied it's full course"*.

Organisations may recognise that employees sustain losses (through death), but they do not appear to understand that relationships (or attachments) between the bereaved and the deceased matter greatly for the support potentially required by the employee (Eyetsemitan 1998). Such disenfranchisement in the workplace can 'extend and worsen the grief process' (Bento 1994:36). The caring for persons with terminal illness and who are dying is becoming an increasing part of health care in the ID services. Staff desire to do it well and will need to reach out to other services to assist them to provide optimal care at end-of-life. Todd (2004) suggests that important and critical support from the field of specialist palliative care will be required. It is increasingly being recognised that health-care staff may experience disenfranchised grief when they have to support others and it is not acknowledged that the death is significant to them or has had an impact on them (Wilson & Kirshbaum 2011).

3.5.8 *Professional Grief*

Papadatou (2000; 62/3) identifies that there are six major losses experienced by professionals in healthcare. These are 1) the loss of relationship where there was a 'special bond' formed with a patient, 2) loss due to empathy with the pain and suffering of the patient's family, 3) loss of sense of self-efficacy as a professional, 4) loss in relation to one's own personal beliefs, 5) unresolved or anticipated losses and 6) facing one's own mortality. It would appear that any or all of these losses could have been experienced by the staff in phase one. It has become increasingly recognised that staff working with dying patients experience grief (Sanders & Valente 1994 ; McNamara et al. 1995 ; Papadatou 2000, Gannon & Dowling 2011). Wilson & Kirshbaum (2011) identify that if patients have multiple hospital admissions and build up relationships with staff, that the deaths of such patients can have a profound effect on the staff. Little attention has been paid to the grief of staff working in long-term care settings and supporting the older population even though such staff regularly encounter the deaths of clients (Gannon & Dowling 2011 ; Osterlind et al. 2011). In a study into the experiences of hospice nurses and the stresses which they experienced in their work, McNamara et al. (1995:241) identified that nursing the dying is stressful and that staff have to cope with their own grief when their patient dies, "*having willingly given of themselves in relationships of fleeting but intense intimacy*". It may be argued that nursing and social care staff who support persons with ID build up intensely intimate

relationships because of the nature of the personal care required; these relationships are not fleeting but frequently are over many years (Turner 2004).

Redinbaugh et al. (2001) state that a profound sense of grief can arise in health care professionals who have persistent exposure to patient deaths. Such grief can be associated with occupational stress and burnout (Redinbaugh et al. 2001), or with grief overload (Bruce 2007). The concept of professional burnout was traditionally used in a generic sense and the focusing on such phenomenon may lead to a lack of recognition of what are in effect grief reactions (Papadatou 2000). Indeed, given the increasing prevalence of dementia in the ID services as highlighted in Chapter One and the new challenges which caring for this population is putting before staff, such professional burnout or grief reactions are possible.

Much of the work of hospice nurses which gives rise to stress is directly related to the sensitive nature of their work and a part of this embraces the grieving processes of the patients, their families and their significant others (McNamara et al. 1995). The supporting of the clients through death and dying in the ID setting, places demands on the staff to support the clients in the first place and to support their kinsfolk too if they have any. As important as this is, there is the expectation that staff equally have to provide support to the peers of the person with dementia who are in effect the 'family' who live together with the staff on a day-to-day basis. Read (1998) who writes on the palliative care needs of persons with 'learning disabilities' discusses the need to support carers in the community setting. While she does not explicitly identify that they need support with their experiences of loss and grief in their caring role, she identifies that they need psychological support with managing their fear and anxiety around caring for persons who are terminally ill. Studies measuring the stress levels of nurses working exclusively with dying patients show varying results (Foxhall et al. 1990). The possibility that a patient might die alone can create a sense of grief in the health-care worker (Redinbaugh et al. 2001). In the focus-group interviews in phase one of the current study, staff prided themselves that clients did not die alone in their service. Staff dealing with the care of the dying, which can be emotionally demanding, can further exhaust their resources for their coping with grief and sorrow (Redinbaugh et al. 2001).

Staff who work with the dying ought to be educated and facilitated to be able to take care of their own emotions associated with caring for the dying (Redinbaugh et al. 2001). Historically, nurses were not expected to demonstrate their own grief (Speck 1978). Määttä (2006) identifies that nursing and research literature explicitly and implicitly convey the need for nurses to keep a distance between themselves and their patients. Nurses may indeed be expected to walk a "tightrope" between showing empathy, keeping a distance and demonstrating feelings appropriate to a given scenario (Määttä 2006:9). In their examining the dynamics between community nurses and their patients, Öresland et al. (2006) describe how the nurse uses two identities when in the home of the patient. One identity is as the 'guest' and the other identity is as the 'professional'. As the 'guest', the relationship is of an equal status and is of a private nature, while as the 'professional', the nurse takes on a role of authority in the relationship. In the study by Öresland et al. (2006), the nurses realised that they had to make a choice as to which identity they held and they also realised that they could not hold both at the same time. Sanders and Valente (1994) stressed that a balance needs to be achieved between emotional detachment and emotional attachment in order for the nurse to care for self. Although the nurse grieves as an individual, the grieving process is validated when acknowledged within a team context (Sanders and Valente 1994). Indeed there is a need to articulate the emotional demands on the professional among the members of the team in order to manage strong emotions arising (Speck 1978).

The acknowledgment of grief reactions may not occur because of the culture of the organisation or of the culture of the profession (Speck 1978). Not all people need grief therapy intervention as they use their own coping strategies very effectively (Worden 1991 ; Schut et al. 1993 ; Jordan & Neimeyer 2003 ; Prigerson 2004). Healthcare professionals can share similar grieving needs to family and patient (Bruce 2007). Such grief impacts as a result of the healthcare professional supporting the person through suffering and death (Bruce 2007). Some of the issues which give rise to these feelings of loss and grief arise from the reality that attachment occurs when the healthcare worker enters into an empathetic role with the client thereby investing in the client and when the client dies there is a loss experience (Bruce 2007).

Katz and Johnson (2006) explore the notion that healthcare professionals working with dying patients experience countertransference experiences. Countertransference

experiences were first described by Freud (1959) as the unconscious processes involved in raising the carer's (analyst's) inner unresolved conflicts when treating the client which were seen to impede the therapeutic relationship between carer (analyst), and client. However, Katz and Johnson (2006) contend that such countertransference experiences are a natural emotional response between carer and client and are integral to all helping relationships. They propose that the work of a professional working with the dying is "extremely personal in nature" (Katz and Johnson 2006:6). They furthermore acknowledge that it is difficult for staff to accompany clients who are suffering and that therefore the staff can become "professional or objective" in order to avoid these deeper feelings (Katz and Johnson 2006:15). 'Being with' the person is more challenging than 'doing for' the person (Katz and Johnson 2006:17).

Palmer & Howart (2005) recognise that primary healthcare professionals need an acknowledgement of their grief for clients and need support in this grief/bereavement.

In a study examining nurses' reaction to a patient's death by suicide, Valente & Saunders (2002) conclude that nurses need support to grieve and that this may be facilitated by increasing the nurses' own awareness of their own mortality, their own reactions and their taking time to work through their grief. In the general healthcare setting, it is acknowledged that nurses have more extensive contact with patients than any other member of the healthcare team (Costello 2001). However, there remains a scarcity of research articles on the subject of the effects of patient deaths on staff (Wilson & Kirshbaum 2011). Literature on professional carers (non-nurses) in health and social care could not be sourced but carers in the current study also spent equally extensive contact time with the clients.

3.5.9   *Loss and Grief in Intellectual Disability*

In the course of the reviewing of the literature, it appears that there is a paucity of literature on the experience of staff grief in ID care. There is also a paucity of literature on grief and bereavement in persons with intellectual disabilities (Clements et al. 2004). However, some literature is emerging in this area (Clute 2010). In contrast to staff working in general healthcare settings, staff in the ID services have lifelong ties with the resident if that person has been in their service since early childhood. In the social model of care, this person would be perceived to be as independent as possible. In the ID services, grief is surely a challenge for staff when clients have spent a lifetime

together and then one of their peer-group dies. In this context, one may argue that care-giving staff may experience what Kastenbaum (1969) describes as 'vicarious grief' where they identify with a surviving resident who was a long-term friend or room-mate of the deceased.

Historically, ID services provide behaviour modification and skills training which do not recognise loss and mourning needs (Kauffman 1994). It is acknowledged that persons with ID can potentially experience a range of losses throughout their lifetime (Clements et al. 2004). However there are certain issues which can potentially complicate grief reactions for this population. Firstly, the subject of death can be kept secret from people with intellectual disabilities (Blackman 2003 ; Clements et al. 2004), but it is known that they can and do grieve losses (Blackman 2003, Dodd et al. 2005, Meeusen-van de Kerkhof et al. 2006). Persons with profound ID tend to sense 'something is wrong' from the reactions of others and from among other things, the atmosphere of the house (Meeusen-van de Kerkhof et al. 2006). Indeed in the phase one interviews staff spoke of the times when the most profound intellectually disabled clients in their care changed their behaviours during the times when the deaths of their peer was imminent. One example was that they became very quiet (whereas their normal behaviour was noisy), as if they sensed something was happening in the house and they needed to be quiet. When the mourning needs of clients with intellectual disabilities are neglected, their grief is disenfranchised (Kauffman 1994). In a study in the UK conducted by Raji & Hollins (2003), it was highlighted that people with intellectual disabilities are socially excluded from bereavement and funeral rites. In an Irish study exploring attitudes to ID and bereavement, the staff did not hide illness and death from clients with intellectual disabilities and included the peers of the dead person in all aspects of the rituals surrounding death and immediately after death e.g. funeral rites (Dodd et al. 2005). In phase one of this study, it was also evident that staff included the peers of clients in all end-of-life rituals over which they had control and supported the grief of peers to the best of their ability as anyone would in his/her trying to relieve the suffering of another person.

Recent studies investigating staff attitudes to clients with ID who were dying, suggest that staff in these services want their client to die in their 'own home' and actively attempt to keep other services at a distance in the belief that they themselves are more

knowledgeable and more sympathetic to this client group (Todd 2004; Fahey-McCarthy et al. 2008). However, it was also evident that although staff may be more knowledgeable about the supporting of a person with ID, (i.e. their providing lots of love and personal care), they are often unprepared educationally to care for the dying and struggle to give end-of-life care (Todd 2004).

Therefore, I consider that staff in these services need to acknowledge their strengths and limitations in relation to their supporting persons who will die in their care. Indeed, the need to explicitly recognise the existing expertise of staff when introducing palliative care within a setting, is a finding in recent research in community long-term care settings (Brazil et al. (2012). The literature identifies that professional grief is a reality when dying persons are being supported. I believe, for the reasons highlighted in the literature in relation to grief experiences of staff who form long-term close relationships, that grief is an important area to be researched for staff in the field of ID care because such relationships are the very essence of the speciality.

3.6   Conclusion

This chapter outlined the background, context and rationale for this research. The research question, aim and objectives were outlined. An overview of the literature which was reviewed for the research question was presented. Loss, grief and bereavement are complex phenomena. The management of grief is complex and there are reasons why the management of professional grief, and in particular the grief of professionals in an ID care setting, may be even more complex. In this study, there is an added complexity for the reason that there is potentially a need to identify grief which can exist over a longer trajectory with caring for someone with Alzheimer's dementia. The next chapter outlines the research methodology.

CHAPTER 4 – PHILOSOPHICAL FRAMEWORK & METHODOLOGY

4.1 Introduction

This chapter outlines the research methodology, and justification for the approach taken. The philosophical standpoint which guides this study is that of Hans Gadamer. While a variety of philosophical bases are possible, this chapter will explicate and justify a Gadamerian philosophical approach for this study. An overview of the history of Hermeneutics, Hermeneutic inquiry and some of the key theorists and concepts of modern hermeneutics is given. Finally, a description of my understandings of the key concepts of Gadamer and their application to this study is presented.

4.2 Methodology

4.2.1 History of Hermeneutics

The word 'Hermeneutics', since its emergence in the seventeenth century, has been used to refer to the art or science of interpretation (Grondin 1994). Prior to this, hermeneutics was embedded implicitly throughout the history of Philosophy (Ramberg & Gjesdal 2005 ; Lawn 2006). The word Hermeneutics is derived from the two Greek words 'hermeneuein and hermeneia' which are the verb and noun in the English language 'to interpret' and 'an interpretation' (Palmer 1969, Byrne 2001). The word has two sources; one from the Greek God Hermes (messenger to the Gods), and the other refers to hidden or secret knowledge (Lawn 2006:150). Grondin (1994) outlines that a modern history of hermeneutics is a construction and that up until the seventeenth century the discipline did not have a name.

Historically, Hermeneutics was concerned with finding meaning in the written word and was originally the method used in analysing sacred texts in the 17th century in order to illuminate the meaning within them (Palmer 1969 ; Packer 1985 ; Benner 1985 ; Dowling 2004 ; Lawn 2006); it was further concerned with the identification of these meanings for religious leaders in order to explain to others how to live good Christian lives (Byrne 2001). In later times, hermeneutics was generalised to wider textual interpretation (Palmer 1969 ; Packer 1985 ; Malpas 2003 ; Lawn 2006). Palmer (1969) outlines that hermeneutics has been defined historically in six fairly distinct ways. These are 1) the theory of biblical exegesis, 2) general philological methodology, 3) the

science of all linguistic understanding, 4) the methodological foundation of Geisteswissenschaften (humanities and social sciences), 5) phenomenology of existence and of existential understanding and 6) the systems of interpretation, both recollective and iconoclastic, used by man to reach meaning behind myths and symbols.

Interpretation is, according to Palmer (1969:9) "the most basic act of human thinking". The task of interpretation must be to make something which is unfamiliar in meaning into something intelligible (Palmer 1969). Meaning, interpretation and understanding are central tenets embedded in a Philosophical Hermeneutic enquiry (Geanellos 1998). Their mergence generates a new horizon (viewpoint), one that allows the researcher and the reader of research to gain a new understanding of the phenomenon under enquiry. The possibility of creating meaning, interpretation and understanding, calls for involving individuals who have experienced the phenomenon which is under investigation. Participants become part of the creative and interpretative process, where life experiences are brought to consciousness and expressed in dialogue. This commences the process of meaning, understanding and interpretation (Geanellos 1998).

Meaning is context specific and explanatory interpretation creates awareness that the explanation is contextual or from one horizon, therefore the explanation is made from an already existing horizon of meanings called pre-understandings (Palmer 1969). The merging of the two horizons both of the text and of the reader must be considered a basic element of all explanatory interpretation (Palmer 1969). To interpret the text, the interpreter "must pre-understand the subject and situation before he can enter the horizon of its meaning and this allows him to enter the magic circle of its horizon; the hermeneutical circle" (Palmer 1969:25). A certain pre-understanding is needed for communication to occur and that understanding is altered in the act of interpretation (Palmer, 1969).

Translation makes individuals more aware of how words actually shape our perceptions or view of the world (Palmer 1969:27). There are always two worlds, the world of the text and the world of the reader, therefore there is always a need to translate (Palmer 1969:31). The two concepts of a hermeneutic circle and of pre-understandings are important concepts in modern hermeneutics (Ramberg & Gjesdal 2005). The hermeneutic circle allows the researcher to methodically look between the parts within

the data and the whole of the data. Following this, the integration of the researcher's existing pre-understandings with the understandings of the participants facilitates a new interpretation to be made.

"Early hermeneutics resembled a technical theory, and as a rule such theory was of much less universal application than present-day philosophical hermeneutics" (Grondin 1994:3). The philosopher Gadamer, influenced by earlier philosophers such as Heidegger, developed 'Philosophical Hermeneutics' which embraces a broader approach to understanding than that of the taking of a traditional hermeneutical approach; it was defined as a procedure or technique to interpret texts (Lawn 2006). In philosophical hermeneutics, understanding is derived from personal involvement by the researcher in a reciprocal process of interpretation dependent on the person's experience of his/her being human (Spence 2001 ; Gadamer 2004 ; Lawn 2006).

4.2 2   Major philosophers of Modern Hermeneutics

Some of the key early theorists in the developments of early modern hermeneutics (post enlightenment), were Dannhauser, Spinoza, Ast, Chadenius and Wolf who all developed rules for accurately interpreting biblical, legal and classical texts (Lawn 2006:45). Ast and Wolf, in particular, were influential on the development of the early modern hermeneutics developed by Schleiermacher (Palmer 1969), who was a German philosopher and theologian and to whom the title of father of Modern or Romantic Hermeneutics is attributed (Palmer 1969; Grondin 1994; Lawn 2006). The key theorists of later modern hermeneutics included Schleiermacher and Dilthey, (Palmer,1969 ; Grondin 1994 ; Lawn 2006), Heidegger and Gadamer (Palmer 1969 ; Lawn 2006), and Droysen (Grondin1994). Augustine (354-430), a theologian and philosopher had 'a significant influence on contemporary hermeneutics' (Grondin 1995 ; Moules 2002) and he influenced the work of later philosophers such as Heidegger and Gadamer (Palmer 1969 ; Grondin 1994).

Schleiermacher was the first to articulate a coherent concept of a universal hermeneutics, that is, hermeneutics not related to any one particular text (e.g. Biblical, Historical), but to linguistic meaning in general (Ramberg & Gjesdal 2005). Schleiermacher, while having dedicated much of his life to developing hermeneutic 'methodology' by exploring the laxer (automatic) versus the stricter (systematic)

practices of interpretation, failed to publish his completed work which may have been because of his untimely death at the age of 60 years (Grondin 1994). Following Schleiermacher, Wilhelm Dilthey (1833-1911), as a philosopher spent his career attempting to establish the "epistemological legitimisation of the human sciences as sciences" (Grondin 1994: 85). Following on Schleiermacher's work, Dilthey was among those philosophers who were exploring how to 'justify the humanities within a university system based upon the Enlightenment ideals of critical reasoning and rationality' (Ramberg & Gjesdal 2005:7). Although Dilthey, as a young man, appeared preoccupied with the history of hermeneutics, it was not until 1900 that he explicitly focussed his work on hermeneutic methodology (Grondin 1994). Dilthey saw in hermeneutics "the foundation for 'Geisteswissenschaften' (i.e. all of the humanities and social sciences – all of the disciplines which interpret expressions of man's inner life") (Palmer 1969:98).

Heidegger (1889-1976) in his seminal work 'Being and Time' further explored the relevance of the ancient discipline of hermeneutics to the human sciences, especially its appropriateness to the study of human action (Packer 1985). Dilthey's most important contribution to hermeneutics was that 'he grounded hermeneutics in a general theory of human life and existence' (Ramberg & Gjesdal 2005:8). Influenced by Schleiermacher and Dilthey (among others), Heidegger developed his hermeneutics in the 1920's by proposing an ontology of factical life (Palmer 1969, Grondin 1994, Ramberg & Gjesdal 2005). This was termed the hermeneutics of facticity (our own specific being) (Grondin 1995). His earlier life was concerned with hermeneutics as understanding (Grondin 1995). To Heidegger, understanding is not something individuals do or fail to do; rather, it is what we are (Ramberg & Gjesdal 2005). His was an ontology of 'being' or 'Dasein' (Palmer 1969, Grondin 1995). His hermeneutics was concerned with finding a "method of going behind and to the root of western conceptions of being" (Palmer 1969).
 In particular Heidegger was concerned with understanding man's 'historical being-in-the-world'. Heidegger's hermeneutics challenged the traditional function of theoretical philosophy of his time, which sought to grasp the "totality of the world" but which frequently yielded results which "appeared irrelevant to practical concerns of our 'Dasein'" (Grondin 1995:55).

While the historical development of hermeneutics is interesting, it is not without its limitations. Primarily, these earlier philosophers did not develop a unified conception of hermeneutics, hence hermeneutic reflection remained peripheral to philosophy in the nineteenth century with most of the writings of Dilthey and Schleiermacher being published posthumously by their students. Heidegger, however, regarded hermeneutics as being central to philosophical concern (Grondin 1994). In his later life, however, after his publication of 'Being and Time', he ceased to concern himself explicitly with hermeneutics (Moules 2002 ; Ramberg & Gjesdal 2005), and with the debates about understanding, interpretation and the hermeneutic circle (Ramberg & Gjesdal 2005). However, his student, Hans-Georg Gadamer fully accepted the ontological turn in hermeneutics and further developed the ideas of his mentor Heidegger (Ramberg & Gjesdal 2005). These ideas included "pre-understandings", the "hermeneutic circle" and the "theory of horizons" (Caputo 1987:95). Ultimately, the historical developments in hermeneutics retain two foci (Palmer 1969). These are the theory of understanding in a general sense and the exegesis of linguistic texts – the hermeneutic problem. The task of bringing the text into understanding is at the heart of hermeneutics (Palmer 1969) and hermeneutic method (Geanellos 1998).

4.2.3 Key Tenets of Hermeneutic Inquiry re. Meaning, Understanding and Interpretation

An hermeneutic method of understanding is suited to the disciplines within the humanities (Palmer 1969). There are central tenets of hermeneutic inquiry in relation to the exploration of meaning, to the gaining an understanding of, and towards the formation of an interpretation of a phenomenon. These are now discussed under prejudices/pre-judgements or pre-understandings, dialectic and the hermeneutic circle. The main philosophers who influenced Gadamer were Schleiermacher, Dilthey and Heidegger.

4.2.4 Prejudices/pre-judgements or pre-understandings

Schleiermacher believed that some understanding occurred automatically between the reader and the text (laxer hermeneutic practice), but that to understand other cultures requires the reader to be open (Moules 2002). He considered that this is only possible if the reader systematically examines his/her own prejudices, thereby ensuring their lack

of influence on the process and on the outcomes of interpretation (stricter hermeneutic practice) (Moules 2002 ; Ramberg & Gjesdal 2005). One of the central tenets of Gadamer's (2004) philosophy was that understanding was only possible "with historical awareness" and inevitably such knowledge carried prejudices or pre-understandings (Fleming et al. 2003:115 ; Gander 2004). Tradition embraces a shared history, language and culture which influences individuals' understandings (Geanellos 2000). The concept of historicality was also central to Dilthey's hermeneutics (Palmer 1969). Dilthey's historicality refers to the fact that meaning is always horizontal, stretching into the past and into the future; man's self-understanding is dependent on his understanding the past and on his understanding of how his worldview influences his future (Palmer 1969). Dilthey believed that a real transposition can take place between humans because of a mysterious process of mental transfer which can happen because of a shared likeness between the mental experiences of being human (Palmer 1969). Like Schleiermacher, Dilthey considers this transposition as a reconstruction of the experience of others in terms of their worldview (social-historical worldview) (Palmer 1969). While Dilthey was concerned with trying to find a methodology for hermeneutics in his earlier life, he appears to have experienced a tension between his 'scientistic' efforts and an emerging realisation that hermeneutics was a philosophic endeavour when trying to understand historicity (Grondin 1994:89). Understanding always happens in the context of previous experience or history, and hermeneutical consciousness is, for Gadamer, one's being aware of this history and its influence on our worldview or 'horizon' (Malpas 2003 ; Gander 2004). The horizon is the perspective of seeing something from one viewpoint or worldview (Lawn 2006). Gadamer considered that tradition (history) is passed on through a complex and ever changing fabric of interpretations which become richer over time (Ramberg & Gjesdal 2005) and that an interpreter can never know a historical work as it originally appeared to the writer because context is important. This is captured by Gadamer (2004) when he states: *"When we try to understand a text, we do not try to transpose ourselves into the author's mind … we try to transpose ourselves into the perspective within which he has formed his views .. we try to understand how what he is saying could be right"* *(Gadamer 2004:292).*

4.2.5   Dialectic

The role of dialogue in hermeneutic inquiry is central to understanding and interpretation (Gadamer 2004). Gadamer's approach to truth-seeking is close to that of Socratic enquiry where truth is reached by means of dialectic rather than methodically (Palmer 1969:165). Historically Schleiermacher had proposed that dialectic meant the art of mutual understanding (Palmer 1969, Grondin 1994). Such understanding is made possible by the interpreter re-enacting the author's intended meaning, involving a process of reconstruction. Bonteko (1987) describes this process as involving a) the clarification of language (grammar and syntax), and b) context (author's life details). Thus Schleiermacher made a distinction between the grammatical interpretation (syntactical meaning) and the technical (Grondin 1994), which was also (later) referred to as the psychological interpretation (the author's intent) of a text (Lawn 2006).

Gadamer acknowledged that Schleiermacher's move to a general hermeneutics was an important development in the history of hermeneutics but was critical about his idea of psychological interpretation. Gadamer (2004) regarded that psychological interpretation placed overemphasis on the subjectivity of the author, while neglecting the productive role of the interpreter (Lawn 2006). For Gadamer, *"...the process of understanding a text is not achieved by making the interpreter invisible in the face of the author's psychology*" (Gadamer 1989:191); rather it involves dialogue that is dependent on a collective version of understanding between interpreter and text (Lawn 2006).

Gadamer considers that Schleiermacher focused on the expressive dimension of language without regarding the power within language itself to disclose the truth. The whole question of truth and what is truth within a text is important to Gadamer, *"...truth is not method but what happens in dialogue"* (Lawn 2006:3). The truth within a text for Gadamer is*, "...its power to throw light on matters at issue"* (Lawn 2006:50) and that such matters at issue concern existential matters of life and death and are culture specific. Gadamer ascribes truth to the truth of human self-understanding (Ramberg & Gjesdal 2005 ; Binding & Tapp 2008).

 Gadamer developed a robust dialogic approach to his hermeneutics and grounded '*understanding in the linguistically mediated happening of tradition'* (Malpas 2003:1). Gadamer further placed emphasis on the dialectic implied in hearing and considered

that once you heard something there was an obligation to respond (Gadamer 2004). In an attempt to engage in the processes outlined above, Gadamer considered that this was not feasible without some form of engagement, which involves one's becoming immersed within the Hermeneutic circle.

4.2.6   The Hermeneutic Circle

For Schleiermacher, the hermeneutic circle was concerned with understanding the parts of the text in relation to the whole of the text, thereby keeping hermeneutics as an important tool to understand philology (Ramberg & Gjesdal 2005). Schleiermacher makes the hermeneutic circle the "…heart of his theory of interpretation" (Lawn 2006:46). In his case, the circle involved moving between the grammatical and the psychological explication (Bontekoe 1987). Heidegger, however, regarded the hermeneutic circle as an interplay between the self-understanding of the reader and his/her understanding of the world which makes the task of hermeneutics an existential task (Ramberg & Gjesdal 2005). Gadamer's (2004) concept of the hermeneutic circle was similar to that of Schleiermacher, in that for Gadamer (2004: 291) '*…the whole must be understood in terms of the detail and the detail in terms of the whole*'. Gadamer (2004) regards this as a circular relationship, that is rooted in our "being-in-the-world", thus describing an aspect of the ontological structure of understanding. Every interpretation is constructed from the readers' anticipations of understanding, their traditions and prejudices. Such construction and reconstruction are undergoing constant revisions in a search for coherence between the parts and the whole (Grondin 2002).

4.2.7   Hermeneutics or Phenomenology

Philosophers such as Husserl, Heidegger and Gadamer developed philosophies which are used to underpin research methodologies (Fleming et al. 2002). Husserl (1859 - 1938) founded the philosophical method known as phenomenology (Beyer 2003). His work was placed in the traditional logic of his time and this provided a "…traditional scientific approach with its associated assumptions of objectivity and neutrality" (Fleming et al. 2002:114). He may be regarded as a ghostlike figure within the history of hermeneutics (Moules 2002) or as the person who opened the door to hermeneutics (Grondin 1995). Confusion exists within the literature as to whether phenomenology and hermeneutics are one and the same thing (Fleming et al. 2002). Both potentially

provide approaches to the understanding of embedded knowledge (Dowling (2004). Phenomenology seeks to understand a person's lived experience in terms of commonalities and shared meanings (Dowling 2004), while Hermeneutics is concerned with how language influences human understanding and knowledge (Byrne 2001). The close links between phenomenology and hermeneutics has resulted in an interchangeability of the terms in some of the literature (Byrne 2001 ; Dowling 2004). However, there are different philosophical beliefs between the two approaches (Byrne 2001 ; Moules 2002) and they encompass various schools of thought and methodologies (Dowling 2004).

Central to Husserl's development of understanding of a phenomenon, was the belief that all prejudice is eliminated in the interpretation process (Fleming et al. 2002). Heidegger, however, considered Husserl's definition of phenomenology to be *"…burdened with categories of natural science, namely the idea of certainty and absolute clarity"* (Fleming et al. 2002:114). Husserl was concerned with the concept of "knowing". Heidegger, however, was concerned with the concept of understanding (Fleming et al. 2002).

Some authors refer to Gadamer's hermeneutics as 'phenomenological hermeneutics' (Bontekoe 1987 ; Binding & Tapp 2008). This is because hermeneutics can be considered as a school of phenomenology (Dowling 2004); furthermore while phenomenology can exist without hermeneutics, there can be no hermeneutics without phenomenon (Moules 2002).

Hermeneutics is described as both a philosophy and a research method/science of textual interpretation (Geanellos 1998). Byrne (2001) states that because of the interchangeability of terms that it is up to the researcher to clarify what s/he means by them when developing a research framework. For the purpose of the current study I have chosen to use Gadamerian hermeneutics, (philosophical hermeneutics), to underpin this inquiry. While Gadamer incorporates components of hermeneutics already explored by earlier philosophers of modern hermeneutics, (i.e pre-understandings and the hermeneutic circle), he builds on these with his theory of horizons. This results in my reporting an understanding of a phenomenon (loss, grief & bereavement) which has a merged understanding arising from the participants' understanding and from my

existing and developing understandings. Healthcare practitioners may choose interpretative phenomenological approaches because from experience they know that colleagues prefer these approaches to research (McCormick & Downer 2012). Packer (1985) proposes that a valuable contribution of the taking of an hermeneutic approach to understanding an action is that the action may be understood as its having a semantic organisation rather than its being logical or causal in nature. By the use of a hermeneutic approach, the researcher does not only engage in rich description (as in pure phenomenology), but rather acknowledges that the phenomenon occurs in an eventful, on-going and emergent way (Jardine 1992). Therefore I did not undertake a phenomenological study which reports what the participants say about the phenomenon. I am reporting on a Gadamerian hermeneutic inquiry and presenting a new understanding of a phenomenon (loss and grief), which represents a fusion of my understandings merged with the understandings of the participants.

The ID services are facing new challenges with the ageing populations. It is important to gain a deeper understanding of the issues for services in order to begin to understand the issues from their own perspectives (or from their existing horizons of understanding). These include, for example, how the staff feel about their supporting a client with an ID, how they experience the ethos of care within an ID care setting, how the experience of their supporting an individual with ID is impacted upon when the client develops dementia, and ultimately how they cope with the demise of the client. This horizon of understanding may also be regarded as the practical understanding of the person, and hermeneutics is concerned with the practical every-day experiences of a person's life (Packer 1985). Only the staff themselves can explain what it is like to support this population within the ID services. Only the staff who have experienced loss and grief while they were supporting these persons, can describe these experiences from their own worldview of their working in ID care settings/services. During the interviews and in my reading/listening to the texts of the interviews, I was engaged in dialogue, asking questions and trying to clarify understandings. In essence, it involved my becoming engaged in the hermeneutic circle of understanding, merging my own horizons of understandings with those of the participants. Gadamer developed the philosophical hermeneutic approach of Heidegger (Palmer 1969), by introducing reflection into interpretation or understanding.

By my using a Gadamerian approach in this study, it allowed such reflexivity to inform the interpretation (Gadamer 1989), thereby merging my already held understandings with those expressed by the participants. Such reflexivity occurred throughout the study and continued to inform the analysis up to and including the write-up process. Such reflexivity allowed me to fuse my own horizon of understanding and tradition, coloured by my own history with the horizons of the participants. For this research those horizons were the personal experiences of my supporting individuals who developed dementia and my experience of grief both at a professional and on a personal level.

4.2.8   *Why Hermeneutic methodology for this study?*

There is a dominance in the utilising of methodologies of scientific rationalism (Lawn 2006). While this may be considered to be efficient for exploring scientific and technologic discovery, it may jeopardise some other methods of exploring truth and understanding. Hermeneutics is concerned with the manner in which language influences human understanding and knowledge (Byrne 2001). The primary concerns of hermeneutics according to Geanellos (1998) are the gaining of understanding and the interpretation of phenomena. Increasingly, nurses are using the philosophy of hermeneutics to inform interpretive research (Geanellos 1998 ; Larkin 1998 ; Roche-Fahy & Dowling 2009 ; McCormick & Downing 2012).

Kitwood (1997) who is a key seminal writer regarding dementia and good dementia care, states that the investigative skills required in research are not those of a detached researcher but those engendered by commitment and engagement. During the focus-group interviews described in phase one, I witnessed the staffs' becoming visibly emotional when speaking about their clients with ID who had developed dementia; and how painful it was to watch them deteriorate and die. This sadness was subsequently apparent both implicitly and explicitly in the analysis of that data. It reminded me of my own existing worldview and understanding of what it was like to watch an individual whom I loved and admired lose his ability to recognise those of us who loved him. That finding from the participants impacted on me as a researcher. As I shared memories with the participants, a fusion of my own horizons was merging with their horizons. Examples of such events will be in the text of the next chapter or within appendices which will be highlighted in the next chapter.

This process generated for me the research question for this thesis. (What is the experience of grief for frontline staff in their supporting persons with ID and dementia?). Formulating the research question can be the first stage in the formulation of 'a method' in an hermeneutic enquiry (Fleming et al. 2002).

Tradition embraces a shared history, language and culture which influences our understandings (Geanellos 2000). Knowledge of the history of care of persons with an ID remains unknown to many (Atkinson et al. 2003). Staff in the ID services in this study shared some common histories, language and cultures within their philosophies of caring. The data collected from these staff were captured on tape and transcribed into text. This text in effect was 'literary work' as it captured the very rich experiences of people who chose to support persons with ID and dementia. "*Understanding a literary work is not a scientific kind of knowing which flees from existence into a world of concepts; it is an historical encounter which calls forth personal experience of being here in the world*" (Palmer 1969:10).

This method of understanding therefore is suited to the disciplines within the humanities (Palmer 1969). Furthermore, Hermeneutics is a method of analysis which emphasises historical and socio-cultural influences on qualitative interpretation (Byrne 2001); therefore in the interpretation process, attention was paid at all times to the significant changes which have occurred in the philosophies of supporting persons with ID, from those of custodial care to the current liberational approaches to care.

4.2.9   Why Gadamerian Philosophical Hermeneutics for this study?
Gadamer is the chosen philosopher guiding this study. He was a German philosopher whose long life spanned the twentieth and twenty-first centuries (1900 – 2002), (Malpas 2003 ; Grondin 2003 ; Lawn 2006). The philosopher Gadamer expanded the work of Husserl and Heideggar and offers: *"an interpretive approach to understanding, that is central to research in the human sciences"* (Binding & Tapp 2008).

Gadamer's work can be divided into four main areas which are a) philosophical hermeneutics, b) dialogue within philosophy, c) engagement with literature, poetry and art and d) practical philosophy (Malpas 2003). His academic contributions ranged from aesthetics to theology (Malpas 2003). His seminal work Wahrheit und Methode (Truth

and Method 1960) marked an important event in the development of modern hermeneutical theory (Palmer 1969). This work critically reviewed modern aesthetics and also Heidegger's 'theory of historical understanding'. Following this, Gadamer proposed a "…new philosophical hermeneutics based on the ontology of language" (Palmer 1969:162). Understanding in the Gadamerian sense is not conceived as a subjective process of man over an object, but rather the way of being of man himself (Palmer 1969 ; Malpas 2003). Gadamer's hermeneutics is a philosophical effort to understand the ontological process in man (Palmer 1969).

The recognition of the significance of the researcher, the importance of historical understanding and of a clarification of a fusion of horizons (viewpoints), are important developments in Gadamer's hermeneutic theory (Palmer 1969). Gadamer's fusion of horizons refers to the way the researcher interprets the text and the way their horizon of understanding meets the horizon of the text (Geanellos 1998). This process occurs when the reader enters into a dialogical relationship with the history in the text (Gander 2004 ; Ramberg & Gjesdal 2005). The achieving of such a fusion of horizons entails a tacit capacity on the part of the interpreter to make exemplary interpretations and judgements (Ramberg & Gjesdal 2005). One of the central tenets of Gadamer's philosophy is that understanding is only possible "with historical awareness" and, inevitably, such awareness carried prejudices or pre-understandings (Fleming et al. 2003:115 ; Gander 2004). Therefore, the acknowledging of such pre-understandings, according to Gadamer, is fundamental to one's allowing understanding to occur (Geanellos 2000 ; Malpas 2003 ; Gadamer 2004). The visiting and revisiting of one's own pre-understandings is an important component of interpretation within the hermeneutic circle and within Gadamerian hermeneutic inquiry (Malpas 2003).

Furthermore, the reclaiming of repressed or forgotten ideas is also important in the using of Gadamer's hermeneutics (Lawn 2006). Therefore, one's engaging in reflection is an important process throughout the research study as this facilitates the reclaiming of these ideas . In philosophical hermeneutics, understanding is derived from personal involvement by the researcher in a reciprocal process of interpretation dependent on the person's experience of being human (Spence 2001). Palmer (1969) states that as a result of Gadamer's work, hermeneutics is put at the centre of ontological and epistemological questions because understanding itself is defined as ontological or epistemological.

During the process of interpretation, the interplay between ontological and epistemological understandings becomes apparent (Geanellos 1998). This interplay is recognised by Buker (1990) as important in the moving forward of research. Gadamerian hermeneutical enquiry involves dialogue, and interpretation permeates every activity, with the researcher's having to consider the cultural, social and gender implications of such interpretation (Kock 1999).

Research which utilises a Gadamerian hermeneutical approach is concerned with achieving a deep understanding of a phenomenon (Fleming et al. 2002). Of particular relevance here is Gadamer and *"his exploration of dialogue and conversation as an inherently human mode of understanding"* (Binding & Tapp 2008:121). Loss and grief are inherently human experiences and this methodology allowed an exploration through dialogue to attempt to understand this phenomenon for staff who support persons with ID and dementia.

4.3   Conclusion

Chapter Three outlined the research methodology. An overview of Hermeneutics and hermeneutic methodology was presented. The research methodology used was a philosophical Hermeneutic approach guided by the writings of Gadamer**.** The influences of history, tradition and culture are all influences which I consider to be intrinsically important in my attempting to create an understanding and an interpretation of meaning in the field of ID care. To date there is no literature in Ireland on the experiences of loss and grief for staff who support persons with ID. This methodology was suited to the exploration of this phenomenon as it allowed a genuine dialogue to happen, as identified by Gadamer (2004); it also allowed the emergence of a new 'fused' understanding of loss and grief for these staff who had bonded so closely with the persons in their care.

The next chapter will present the research methods utilised in the study.

CHAPTER 5 – RESEARCH METHODS

5.1   Introduction

In this chapter a justification of the study methods and the decisions made in operationalising the study to support the chosen methodology are presented. The sampling methods are provided. The study participants are identified and procedural stages of data collection, data management, data analysis and issues relating to trustworthiness are described. Ethical and consent issues are also discussed in this chapter.

5.2   A Gadamerian-Based Research Method

Existing methods proposed for phenomenological or hermeneutical research studies have been identified by researchers (Colaizzi 1978 ; van Manen 1984 ; Diekelmann 1992 and Koch 1995, 1996). However, there is often no clear differentiation made in the literature between hermeneutic and phenomenological research (Fleming et al. 2003). Fleming et al. (2003) recognise that such methods, referred to above, do not do justice to a Gadamerian Philosophical study and therefore propose the following five stages of the research process as being of value in the framing of the methods of such a study. Table 5.1.

This framework was used for this study as it provided a systematic approach which I believe facilitated greater reflection throughout the process.

Table 5.1 Developing a Gadamerian-Based Research method (Fleming et al. 2003)

Deciding upon a Research Question
Identification of Pre-understandings
Gaining Understanding through Dialogue with Participants
Gaining Understanding through Dialogue with Text
Establishing Trustworthiness

5.3 Stage 1 - Deciding upon the Research Question

The process of my deciding on the research question for this study is described in Chapter Three. In brief, the original data from the focus group interviews in phase one were re-analysed in a process of secondary analysis. Secondary analysis of data occurs when the researcher analyses again the data which was collected for previous research (Jacobson et al. 1993 ; Polit, Beck & Hungler 2001). The data in phase one had been analysed primarily to identify education and training needs of staff who support persons with intellectual disability and dementia. "The aim of a secondary analysis is to address new research questions by one's analyzing previously collected data" (Long-Sutehall et al. 2010 : 336). Commonly, secondary data analysis may be conducted by another researcher (Devine 2003). However, in this study I had collected and analysed the original data so I was already aware of the context and common themes in that data. An important issue to resolve in secondary data analysis is the match between available data and the new research question (McArt & McDougal 1985). I already knew that the data contained reports from staff who reported various cognitive, behavioural and affective experiences which clearly related to the losses experienced by themselves and by the clients with ID and dementia. Therefore, I was now looking to explore the experience of loss, grief and bereavement for these staff. My new research question was "What are the experiences of loss, grief and bereavement for staff in their supporting of persons with ID and dementia?" By the utilising of a Gadamerien hermeneutical approach in this secondary analysis, this data were re-coded with interpretations made and then documented. The process is represented diagrammatically in Fig 5.1 below.

Fig. 5.1 Process of deciding on Research Question

Existing Horizon or worldview of researcher and participants

Phase One
Identifying training needs of staff supporting persons with ID and dementia

Pre-understandings of researcher

Reflection of researcher and Fusion of Horizons of researcher and participants

Existing New Horizon or worldview of researcher and participants

Phase Two
Research Question – *What are the experiences of loss, grief and bereavement for staff supporting persons with ID and dementia?*

Pre-understandings of researcher

5.4   Stage 2 - Identification of Pre-understandings

"True hermeneutic endeavour requires interpretation drawing on the researchers pre-understandings from their tradition or history" (Geanellos 2000:115).

In this hermeneutic study I have endeavoured consistently to continue to make explicit my pre-understandings or prejudices as outlined in the Gadamerian approach (Gadamer 2004). These pre-understandings have included my professional and personal

experiences of life. I had an existing horizon of many years of what it was like to nurse in general settings, in specialist settings such as paediatrics, theatre, HIV/AIDS, palliative care and in the care of the elderly. My personal life horizons were informed in the roles of a daughter, a sister, a wife and a mother. In particular my significant influences relevant to this research, which coloured my horizon of life, were the experiences of my caring for my elderly parents, one of whom had dementia, and my enabling my father to live and die at home despite a healthcare culture which pathologised dementia. In more recent years my experiences have included the supporting of other family members and friends who have cared for someone whom they loved who had dementia. I also have close family who currently live with dementia. I have reflected on what it might be like to have dementia. Appendix 3. Finally, a significant life experience which constantly colours my horizon of life is that I live with the experience of loss, grief and bereavement as a mother (Fahey-McCarthy 2003).

Prior to my commencing phase one, I had limited experience and knowledge of the supporting of persons with ID. As a paediatric nurse, children with ID were admitted for short term orthopaedic procedures but they normally had a nurse from the ID service accompanying them; the paediatric nurses in the hospital had minimal input in their day-to-day care apart from the general surgery care. I have had a number of extended family, friends and acquaintances who had young children and young adults with an ID. I held some powerful negative childhood memories of discussions I heard in relation to an extended family member being 'sent', as a baby, to a service for the 'mentally handicapped'. The event was discussed in terms of the infant's being 'incarcerated' and that the parents had abandoned their infant with 'mongolism'. Therefore, I had a very limited understanding (worldview) of these ID services. I furthermore had very limited experience of knowing older adults with ID either in a general social sense or in professional practice. Therefore this life experience (existing worldview) impacted on my current prejudices (pre-understandings) at the outset of this study.

Researchers have to be socialised into a tradition if they want to understand the meaning of the situations which they are studying (Gadamer 2004). Therefore, in preparation for this research two placements in ID settings were arranged for me by the principal supervisor of this research. As a result of these experiences, I had a changed horizon of

understanding and a different set of prejudices following those placements. I discovered that there was an intensity about that work which I had never previously contemplated. I had a new horizon which was informed by my exposure to the services and to the personnel therein who included clients and staff. I had a new understanding of the daily routines, the nature of the work and more importantly the nature of the relationships which staff had developed with clients in their care (Fahey-McCarthy 2006). It is important to clarify that in Gadamerian hermeneutics, prejudices do not necessarily denote negatively-held beliefs but can also be positively-held views or beliefs (Malpas 2003 ; Gadamer 2004). Furthermore, it is possible for individuals not to be aware of all of our prejudices (Moules 2002) and this is why hermeneutic research may benefit the researcher who is working in professional disciplines, if by visiting our beliefs results in changes for the better in our practice (Binding & Tapp 2008).

From my placements within ID settings, I gained a new understanding of the world of supporting persons with ID and what it was like to support these persons when they developed dementia and died in these services (McCarron et al. 2008). I furthermore gained invaluable insight and understanding of the ethos and philosophies of care in ID services from my speaking with academic colleagues who worked in ID specialty. I also spoke with many staff and clients from a range of ID settings throughout the first two years of this research project. I also immersed myself in reading and in talking with experienced people who have practice and research knowledge of working with people with intellectual disabilities and dementia, both nationally and internationally. This preparatory work and groundwork carried out while I was interfacing with the staff and clients in intellectual disability services and specialist palliative care services, facilitated my emerging understanding of their respective worldviews of what supporting persons with ID and dementia actually was like. Added to this were the challenges to my already held pre-understandings in relation to this population. I began to see the world of ID care from the inside and in reflection realised that I had held a very limited view of that world up until that time. (Appendix 4).

In summary, some of my pre-understandings at the outset of the study were:

I understand that dementia is a terminal illness with a long disease trajectory. Furthermore, I know that if people with dementia are supported with the appropriate

provision of care which they need within a person-centred or relationship-centred philosophy of care, that they enjoy a better quality of living and dying.

I understand death and dying as a continuum of living. Furthermore, the experience of loss and grief is very personal and human beings have a breadth of resilience to endure and survive great suffering. Bereavement may create social isolation for individuals but this isolation can be reduced by the compassion of others.

I had limited understanding of ID as described above.

5.5 Stage 3 - Gaining Understanding through Dialogue with Participants

5.5.1 Participants

Hermeneutic enquiry is not validated by numbers but by how completely the topic has been examined and how the understanding of the topic under study becomes extended (Moules 2002:28). In keeping with a hermeneutic approach, it was important to ensure that the participants had experience of caring for persons with ID and dementia so that the data generated were richly informed from that particular experience or viewpoint, (their horizon of understanding of the caring for a person with ID and dementia). Purposeful sampling is more commonly used in qualitative studies (Morse 1989, Miles & Huberman 1994 ; LoBiondo-Wood & Haber 2006 ; Creswell 2007) and supports the methodology. Advice and practical assistance was sought from an experienced researcher/academic who already had significant knowledge of the services and who was familiar with a rich resource of staff with the relevant experience of supporting this population. Therefore, all of the participants chosen both for the focus-group interviews and for the individual interviews had this richness of experience. In order to gain a broader understanding across the ID services and settings, the sample was drawn from staff working in a variety of ID out-of-home care settings. Similarly, the specialist palliative care staff worked across the in-patient, day care and community palliative care settings of their own service.

5.5.2 Sample

A total of sixty eight participants were interviewed between phase one and phase two. In phase one there were fifty seven participants in the focus-group interviews. Fifty were from intellectual disability services and seven were from a specialist palliative care service.

Fig. 5.2   Total Participants of Phase One

Participants of Phase 1
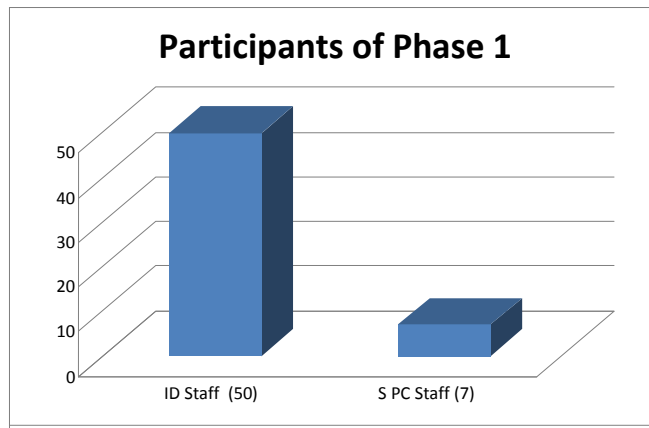
Of the total of fifty staff from the intellectual disability services there were twenty nine nurses, seventeen carers, three doctors and one social worker.

Fig. 5.3   Participants of ID Services Phase One

Participants ID Services Phase 1
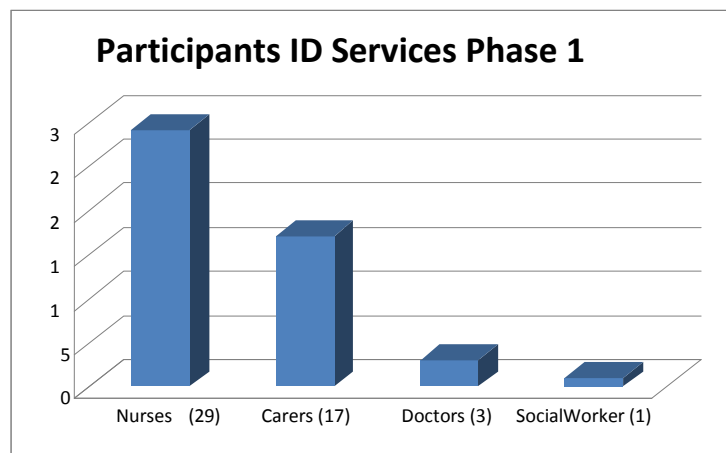
Of the seven staff from specialist palliative care, there were five nurses and two doctors.

Fig. 5.4   Participants of Specialist Palliative Care Services Phase 1

Participants SPC Services Phase 1
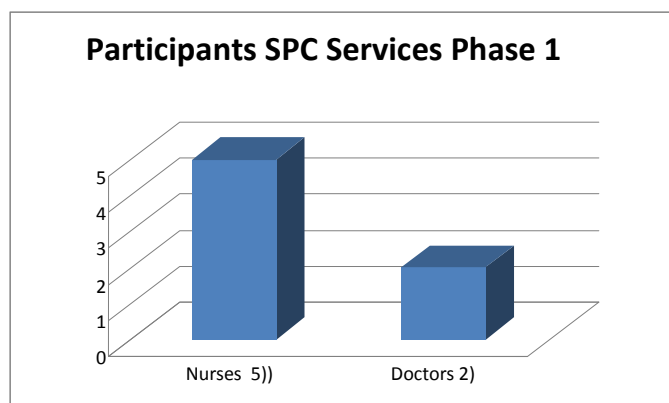
When the data from phase one (57) were subjected to secondary analysis, the staff from the specialist palliative care service did not explicitly identify issues of loss, grief and bereavement for themselves in relation to their delivering specialist palliative care support to this population. However, they explicitly stated that they recognised specific issues in relation to the experiences of loss, grief and bereavement for the staff in ID services who supported this population. There was explicit and implicit evidence of loss, grief and bereavement identified by the staff working in the ID services in relation to their caring for persons with dementia.

Furthermore, this loss, grief and bereavement experience was expressed by the nurses and carers (social/care staff). Although the non-nursing (Medical and Social Worker) staff acknowledged that the grief in this setting (ID) was different because of the long duration of relationships between client and paid worker, they explicitly stated that in their opinion the impact of loss, grief and bereavement was potentially greater on nurses and carers than on the other members of the multi-disciplinary team (MDT). They attributed this to the fact that the nurses and carers spent considerably more time on a daily basis with the clients and provided more intimate personal care for them than did the other MDT members.

Therefore, further purposeful sampling was used for the individual interviews with eleven frontline staff (nurses and carers) from the ID services in order to deepen my understanding of their personal/professional experiences of loss and grief when they were supporting persons with ID and dementia. These eleven staff worked across the six ID sites which had already taken part in phase one and all of them had experience of working on average between 10 and 20 years with persons with ID and dementia. The eleven participants in the individual interviews worked in ID settings. Nine were nursing staff and two were carers.

Fig. 5.5   Participants of ID Services Phase 2

Participants ID Services Phase 2
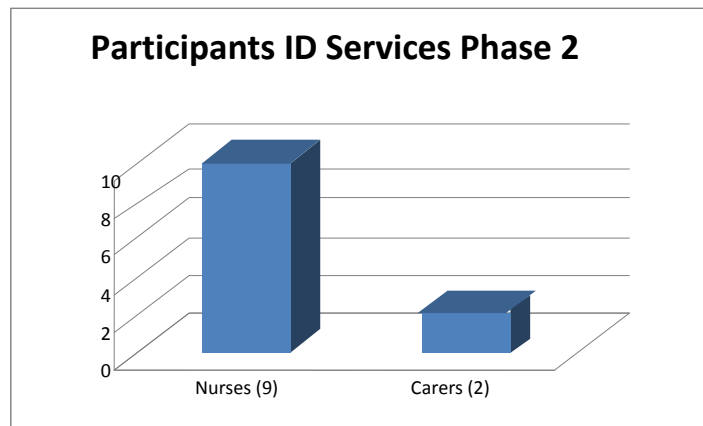
The overall sample of phase one and phase two was sixty eight participants.

Fig. 5.6   Total Participants of Phase 1 & 2

Participants of Phases 1 & 2
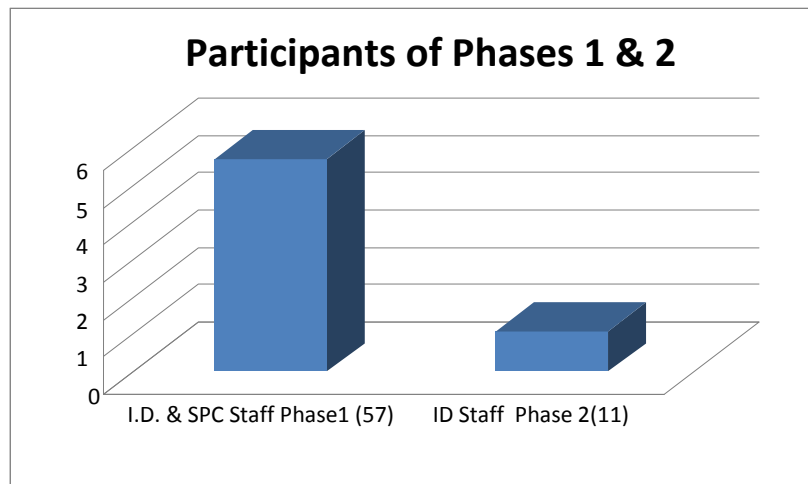
5.5.3   Research sites

The participants were from six ID service providers in Ireland. Five of these providers were Voluntary Organisations and one was a Statutory Organisation. Each was a major service provider for persons with an ID with client numbers ranging between 400 and 1,400 across the services (NAMHI 2003). All six services provide a variety of out-of-home placements for persons with dementia including community group homes, campus group homes, institutional/residential type settings, and one dementia-specific group home. One of the residential type settings had a specialist facility to support people who were terminally ill and who required intensive nursing support, palliative and end-of-life care. Within this facility, a number of staff had undertaken specific

training in palliative care. A number of the campus group homes were described as ageing-specific and were primarily supporting persons who were more frail. All of these ID services are at various stages of the development of services to meet the needs of the ageing populations and of the co-morbidities of ageing persons.

5.5.4   Inclusion criteria – Focus Groups

The inclusion criteria set for the focus groups for staff from the ID services were that they:

- Were currently caring for a person with dementia or had cared for an individual with dementia within the previous 12 months. In the initial communications with the ID services, it emerged that a number of the clients had died more than 12 months previously. However, from speaking to the staff on the telephone, it was apparent that their memories of the experiences of their supporting these clients were still very vivid and that they were anxious to take part in the study.

- Were working in the service for at least one year. This was originally considered important to ensure that the staff member had adequate experience to be able to talk in depth regarding that experience. The population who volunteered had, on average, 20 years experience of working in ID settings.

- Consented to participate in the study.

The inclusion criteria for the focus group interviews for staff from specialist palliative care service were that they:

- Had experience of working with persons with ID and, preferably, that they had worked with persons with ID and dementia.

- Consented to participate in the study.

5.5.5   Inclusion criteria – Individual Interviews

The inclusion criteria set for the individual interviews for staff from intellectual disability services were that they:

- Understood the nature of the study and volunteered at the focus group interviews to explore, at a future time, to discuss their personal experiences of loss, grief and bereavement in relation to their supporting a person or persons with intellectual disability and dementia.

- Consented to participate in the study.

5.5.6 *Gaining Access and Recruitment of participants Phase 1*

Although there is a National Intellectual Disability database in Ireland (Kelly & Kelly 2010), which registers persons requiring or receiving ID services, it does not include diagnostic categories. Currently, it is not known how many people there are with ID and dementia in Ireland. However, the principal supervisor of this study has extensive personal and professional knowledge of ID services and had previously undertaken significant longitudinal research in dementia within ID in Ireland (McCarron et al. 2002, 2010). Therefore, she was in a position to advise which ID services had experience of caring for persons with ID and dementia.

At the outset of data collection, I received contact names of gatekeepers who were willing to support the study and to recruit research participants in these ID services and in the Specialist palliative care services. Information sheets and letters of invitation to participate in this study were duly circulated. Once a service agreed to participate, I telephoned or emailed the gatekeepers and arranged to forward them the full study information pack, the interview schedule and the consent forms so that potential participants would have these at least two weeks to peruse same before the date of interviews. The gatekeepers approached staff within their services who had experience of caring for persons with ID and dementia and invited them to volunteer to participate in focus-group interviews. Once they had arranged volunteers, they communicated with me electronically or by telephone, then mutually acceptable venues, dates and times were agreed for the focus-group interviews.

It was more acceptable to staff that I travelled to their workplaces to conduct the interviews. Staff from across the multi-disciplinary teams (MDT) were invited to participate. However, within the first six focus-group interviews at the ID services, all of the participants attending were nurses and care staff only. As ID care is delivered by MDT's within these services, it was important to consider ways of recruiting other members of the multi-disciplinary team in order to extrapolate a range of the wider experiences. The principal supervisor again communicated with some senior medical staff who had significant experience of caring for persons with ID and Dementia and two further interviews were arranged involving medical and social care staff from the

ID services. These two interviews consisted of two and three persons respectively as they could not come together to form one focus-group due to logistical reasons.

In the specialist palliative care service there is also a multidisciplinary team delivery of care. There were a limited number of staff in this specialty who had experience of delivering specialist palliative care to someone with an ID; there was even a smaller number of staff who had cared for persons with the dual diagnosis of an ID and dementia. This determined the staff who volunteered for the focus-group in the specialist palliative care setting and this focus-group was comprised of medical and nursing staff.

5.5.7   Gaining Access and Recruitment of participants Phase 2

Participants from ID settings in the focus-groups (phase one), clearly articulated feelings of sadness and loss when recalling clients who had developed dementia and had declined or were declining in health and/or who had died. When asked at the focus-groups if they wished to explore this experience further in an individual interview, a number volunteered to be re-interviewed individually in order to deepen the data explicitly on these experiences of loss, grief and bereavement for them in relation to their supporting persons with ID and dementia. It was of note that Irish staff volunteered and no non-Irish staff volunteered to be re-interviewed. It is beyond the remit of this thesis to speculate as to why this was the case but this could be pursued in further research.

Therefore, access to the participants for the individual interviews was by direct contact. I telephoned or emailed them when phase one was complete and they confirmed that they were willing to be re-interviewed in one to one interviews. I then arranged a mutually acceptable venue, date and time.

5.5.8   Data collection - Focus Group interviews

All focus group interviews in phase one were arranged for the convenience of the participants. One interview was conducted off site for the convenience of the group. All of the other interviews were held on-site in the six ID services and in the specialist palliative care service. The original data collected from the focus group interviews was very rich as it brought people together who had a particular expertise. This is an

advantage of this method (Krueger & Casey 2000 ; Stewart et al. 2007). That expertise was comprised of the knowledge and skills in specialist palliative care and knowledge and skills of ID staff in caring for persons with ID and dementia (Alzheimer's disease). The focus-groups provided an opportunity for participants to discuss this experience from their own perspectives (world-views). Indeed focus-group interviews may be used in healthcare research to investigate emotive issues or existential questions (Stewart et al (2007). Such existential questions and strong emotional reactions may emerge for nurses when dealing with terminal illness and patients dying in their care (Marchessault 2012). The participants from ID services are now increasingly being challenged with such questions and these questions are central to the daily experience of the participants from specialist palliative care services.

The ideal size of a focus-group in non commercial topics is 6-8 participants (Krueger & Casey 2000); however, if the questions are meant to gain a deeper understanding, as they were in that study, then this is best accomplished with smaller numbers. Small focus-groups or mini focus-groups can be used for this 4-6 participants if they have a lot of or prolonged experience of a phenomenon (Krueger & Casey 2000). A minimum of four people and a maximum of eight were requested to be recruited in each group. On the day of the interview the number actually in attendance depended on resource issues and client care always took precedence. The focus-groups therefore varied between two and eight members in each one. A total of fourteen focus-group interviews were facilitated involving fifty seven participants. Thirteen focus-group interviews were held across the six ID service providers and one focus-group interview was held with multidisciplinary staff working in a specialist palliative care service.

A rich dialogue was encouraged and the opening question asked the participants to talk explicitly and freely about their experiences of caring for persons with ID and dementia. The following discussion in the interview focussed on the good and the bad experiences and why the participants deemed the experience to be good or bad. The participants were asked about what they considered to be palliative care and when they thought a palliative care approach ought to be introduced for these clients. Finally, participants were asked to identify any education and training needs (if any) they perceived were present in their organisation. A focus-group guide was used. (Appendix 5).

The dialogue in the first two focus-groups became concentrated very quickly on end-of-life care as this was when staff experienced new challenges in their existing practice of supporting this population. On my reflecting on each interview, I modified my interview technique while still retaining a similar structure. I gradually focussed in sooner, (in the interviews which followed), on care of these clients in the late stages of dementia and at the end of their lives as this was of most concern for the staff.

The key characteristic of the information/data gathered from focus-groups is the insight (data) produced as a result of the interaction between the participants in the focus group (Gibbs 1997 ; Krueger & Casey 2000 ; Polit et al. 2001 ; Stewart et al. 2007). The collaborative nature of the focus-group interview enabled the participants and myself to come to a collective understanding of their experiences and concerns in their supporting of persons with advanced dementia. It provided the opportunity for participants to discuss experiences from their own perspectives while at the same time enabling multi-disciplinary team members to gain new insights into each other's perspectives during the interview and come to new understandings in relation to the understanding of the needs of the person with dementia.

Although the research methodology chosen for phase one was qualitative descriptive in nature, on reflection, I had been engaging in an interpretative process as I proceeded with analysis of the data and while it was being coded to identify the educational deficit themes. Furthermore, some fusion of existing horizons of the participants with my own horizons was occurring within the focus-group interviews. I was interpreting their conversations by reference to my existing understandings of ID settings and what the ethos of care was like within an ID service. The hermeneutic analysis was a matter of my re-visiting my interpretations of my codes and to develop my understanding as I originally undertook secondary analysis of the data. (Appendix 6).

Because I had had basic training in group psychotherapy and working as a nurse counsellor, I had significant experience and expertise in conducting groups, in interviewing techniques and in managing issues of sensitivity in clinical and educational settings However, the managing of the focus-group interviews, within a research context, effectively required me to develop additional skills. At some sites there were individuals who attempted to dominate the conversation because they had more

experience of the phenomenon under question (and therefore had more to contribute) or there was a possible power balance relationship between managers and sub-ordinates. I was aware from the outset of the potential conflict with these issues; therefore a pro-active approach to managing this situation was adopted. The establishment of clear grounds is recommended in focus-groups (Gibbs 1997 ; Polit et al. 2001 ; Krueger 2002 ; Holloway & Wheeler 2010). The laying of ground rules for participants and the building of rapport and the acknowledgement of a genuine interest in the experience of each participant in the group, facilitated exploration of the issues concerned. An example of a ground rule was to establish with the participants, prior to the interview, that no one would discuss issues identifying clients or carers outside of the interview. Probing and clarification was determined by interviewer sensitivity to issues emerging in the interview (Gibbs 1997), and this facilitated greater in-depth exploration without influence or direction.

Although I had the focus-group guide and sample questions I did not use these rigidly because a conversation cannot be planned but must be allowed to flow. I use humour naturally as a coping strategy so, inevitably, I found that once I could use this strategy within the interview, a change occurred and the shared commonality of my having a nursing background (with the participants), and my having cared for persons with dementia, all helped to break down any perceived/anticipated communication barriers. My general sense during all of the interviews was that the staff welcomed the opportunity to share their experiences and, indeed, I perceived that they were eager to know that I had heard clearly the nature of their experiences. All interviews were recorded and transcribed. The planned interview times were to be of one hour minimum and one and a half hours maximum. In practice they varied between forty and eighty minutes.

In conclusion, the primary analysis of the data (phase one) was used to identify the Education and Training needs of staff as described in Chapter One. The secondary analysis was conducted on this data (phase one) to extrapolate the information directly related to the experiences of staff in relation to personal and professional loss and grief when supporting clients with ID and dementia. These new understandings appeared context specific and therefore I considered that in keeping with the methodology, it was important to explore the worldview of staff from within the care setting of ID.

Following this, a broad topic guide was generated in keeping with the methodology (Gadamer 2004). This was undertaken in preparation for returning to the research sites to interview staff individually in order to deepen my understanding regarding their experiences of loss and grief in their supporting this population.

5.5.9 *Data collection - Individual Interviews*

Following the secondary analysis of the data from the focus-group interviews, individual interviews were conducted. In preparation for the individual interviews I engaged in reflection in regard to my own history of supporting persons with dementia and my personal and professional experiences of loss, grief and bereavement. Such reflexivity is important prior to engaging with others in an interview context so that the researcher gains an understanding of his/her own positions and interests and how these may potentially influence the research process (Primeau 2003). Such self-reflection may be viewed as a responsibility of the researcher prior to conducting qualitative research interviews (Streubert Speziale & Carpenter 2007). I telephoned each individual and we agreed a mutually convenient meeting place which was a quiet area without interruptions. The choosing to have the interviews at a time and place convenient to the participants is conducive to facilitating them to be more relaxed and enables them to share important information (Streubert Speziale & Carpenter 2007).

The individual interviews allowed me to return to a self-selecting sample of the participants and to engage in more depth with discussions about their understandings of their experiences of loss and grief while they supported persons with ID and dementia. A new topic guide, which was developed from the broad themes on loss and grief identified from phase one, was used to ascertain what staff considered to be the nature and experience of loss, grief and bereavement (if they did), in relation to their supporting the person with ID and dementia. Appendix 7. A topic guide is useful to ensure that the questions I wanted to ask were really asked (Polit & Beck 2006). However, the nature of the individual interview was conversational in keeping with Gadamerian methodology. The interviews were broadly guided by the three world views outlined in the topic guide to ensure that the research question and the aims and objectives would be met.

In order to understand how staff experienced loss, grief and bereavement in their work environment, I decided that I wished to understand their 'worldview' as it existed for them in the ID setting. My questioning technique was open-ended to allow participants an opportunity to describe more fully their experiences and understandings. My opening questions were asking the participants why they choose to work with persons with an intellectual disability and what this experience was like for them. Such a worldview is informed by the social, historical and cultural influences on the service. Furthermore I wanted to understand their worldview of loss, grief and bereavement within the worldview of ID care. Therefore, I asked them what their understandings of loss were for the persons in their care. Following this I asked about their understanding of loss, grief and bereavement for the person with dementia and how they experienced these phenomena personally and professionally.

Philosophically, conversations can produce different forms of knowledge (Kvale & Brinkmann 2009). In classical philosophy, knowledge which is represented in research interviews, may be known as 'doxa' or knowledge which describes the participants' opinions and experiences; knowledge can be known also as 'epistme' which is the knowledge that arises from questioning more deeply these held opinions or beliefs (Kvale & Brinkmann 2009). In the individual interviews, I wished to deepen my understanding of the worldview of the participants who supported persons with ID and dementia, thereby generating more 'epistme' knowledge within the interview. I engaged in a genuine conversation as described by Gadamer (2004) which meant that I listened carefully to the participants and demonstrated respect for them as persons as well as potential informants in my approach to them. I ensured that they were comfortable and that we were at eye level without any barriers between us (e.g desk). By my asking more questions of the participants, I challenged their opinions and they began to ask themselves what influenced their opinions; this, on occasion, generated for them more insight into their own existing understandings. It also allowed the participants and myself to begin a fusion of our collective understandings in the conversation (interview), and which was in keeping with the chosen methodology.

All interview times varied between forty and eighty minutes. All interviews were digitally recorded with participants' permission and then transcribed verbatim.

5.6   Stage 4 - Gaining Understanding through Dialogue with Text

5.6.1   Data Analysis - Introduction

Collection and analysis of data proceed concurrently with qualitative research and is reflexive in nature (Miles & Huberman 1994 ; Horsburgh 2003). Analysis commenced in the interviews because I generated epistemic knowledge as described above. Following the interviews, I became very familiar with the original data as a result of my engaging hermeneutically with the audio tapes and the written transcripts over a period of many weeks/months, in a process of immersion. This immersion is regarded to be of great advantage when analysing the data because the researcher knows the content so well (Krueger and Casey 2000). In philosophical hermeneutic methodology, the researcher can analyse the interviews by engaging with the texts (transcriptions) and by paying attention to prejudices from his/her own tradition and history (Kvale & Brinkmann 2009). The sites of the interviews were allocated numbers chronologically from interview to interview. In the focus-groups this number was followed by the interview number; finally a number was allocated to each participant as he/she spoke in the interview.

5.6.2   Data analysis - Approach

To gain understanding within a Gadamerian study is a complex task. The understanding of a phenomenon and the understanding of the researcher changes over time (Fleming 2003). Changes in pre-understandings are happening all of the time and they influence each new interview (dialogue). Therefore, my questions and reflections were attempts to verify my understandings all throughout the research study. In my consideration of some of the existing analysis frameworks (Colaizzi 1978 and van Manen 1984) I decided that a staged approach suggested by Fleming et al. (2003) would be more suitable to guide me in a systematic approach to data analysis as it gave me a structure with which to proceed. See Table 5.2.

Table 5.2 Approach to analysis of a Gadamerian study (Fleming et al. 2003)

Step 1	**Gaining understanding of the whole text** – examination of the interview texts to gain an understanding of the whole
Step 2	**Detailed analysis of text** – Detailed investigation of text to expose its meaning for understanding of the subject matter and the identification of themes

Step 3	**Expansion of the unity of the understood sense** –
	Relating the detailed investigation of the text in step 2 back to the whole thus expanding its meaning
Step 4	**Representing shared understandings** –
	Identification of passages that seem to represent the shared understandings between researcher and participants

Computer-assisted qualitative data analysis software (CAQDAS), cannot interpret the meaning of the data; therefore the researcher must have a comprehensive knowledge of the data to operate an effective analytical process. A manual analytic process once completed can be transferred into a computer-assisted qualitative data analysis software package. Therefore, the organisation, the management, the storage and retrieval of the data was transferred into NVivo 7 (QSR International 2006). It was also possible for me to re-visit my interpretations and memos (reflections) and to elaborate them because my horizon of understanding was changing; furthermore I was able to confirm my understandings as I proceeded with writing the findings. By my using such a system, I was enabled to provide some of the appendices in this thesis for the reader in order to demonstrate some of my developing horizons of understanding.

Initially, data analysis for both the focus-group and the individual interviews was undertaken manually. In this study, I undertook the data collection and transcription and was immersed in the data for many months, listening to and reading/re-reading the interviews and transcripts. My reflective thoughts were recorded in field notes immediately after each interview and at other times during the analysis of the data. Key brief summaries of such reflections were documented as memos in the computer-assisted software (NVivo 7, QSR International 2006). An example of a memo captures how it became evident to me that staff considered themselves to be in relationships with their clients in ID settings – which were special and similar to the complexities of 'family structures' in many ways. Therefore as I reflected on this, I merged reflective thoughts I held (my interpretations of what were stored as 'nodes' or units of understanding, in the computer assisted software), in order to regroup my ideas as analysis proceeded. This was a process of challenging my assumptions. Appendix 8. At a later date I reflected further on what the concept of family was within ID care. Appendix 9.

Further reflections concerned the conduction of the interviews, the discussions with the participants, the clients (whom I observed), the sites and ethos of care which I witnessed. This enabled me to plan from one interview to the next and develop a questioning technique which assisted the analysis of the data in the transcripts when they were revisited. Such a technique helped me to further reflect on the meaning in relation to contextual issues, prejudices and to my existing and developing worldview as it was fusing with the worldview of the participants. I was always particularly impressed with the ethos of care. (Appendix 10).

5.6.3   Step One – Gaining understanding of the whole text

This step one entails and examination of the interview texts to gain an understanding of the whole. It is important to remember that in a philosophical hermeneutical study guided by Gadamer, the text refers to all material collected over the course of the study. This includes the taped interviews, the written transcripts, my reflections, comments /memos which were made post reflection on my own prejudices. The data collected for the project (phase one) were re-analysed in light of the research question i.e. *What are the experiences of loss, grief and bereavement for staff supporting persons with intellectual disability and dementia?*. In the primary analysis of that data, it was evident that the staff working in ID settings were explicitly making statements regarding their distress and sadness. It was evident also that loss and grief experiences were implicit in the transcripts across the trajectory of the long-standing relationships between staff and clients and between clients themselves. All of the data already grouped under themes/codes (units of understanding of the phase one, referred to as free nodes and tree nodes in the computer assisted software), and which related directly to loss and grief were identified and grouped in NVivo. A manual search was then conducted on the transcripts while the tapes were listened to again to identify any broad references to losses not necessarily associated with death but with any separation or perceived loss; then new codes (free nodes) were generated with their interpretations (definitions) and stored in NVivo. (Appendix 11).

This manual analysis was undertaken while I was reading the transcripts and simultaneously listening to the audio recordings. I re-read my original interpretations of the codes within the nodes and themes and then either decided that my original

interpretation still held or to amend my interpretation in some cases to reflect what I now considered to be my understanding of what was said by the participants , this now merged with my own understanding of the phenomenon. Topics as they arose were documented in the margins of the transcripts. These topics became new codes in the transcripts (nodes in the computer assisted analysis). This resulted in the development of the topic guide which was alluded to in section 5.5.9 and used in the individual interviews.

In phase one focus-group interviews, the staff from the specialist palliative care service and the non-Irish staff in the project did not explicitly or implicitly identify issues of loss, grief and bereavement for themselves in relation to their involvement with persons with ID and dementia. Therefore, the greatest volume of data relating to the experience of loss, grief and bereavement in relation to this population were collected from the more experienced Irish staff in the ID services.

The individual interviews were transcribed verbatim and again transferred to compact discs. This allowed me to engage with the texts and to listen to the audio recordings simultaneously. I also continued to maintain reflective accounts during this time. A manual analysis as described above was repeated with this data. This step one of the analysis or gaining understanding of the whole text (all data phase one and phase two), was my overall understanding after the initial reading and listening to the texts and of my reading my collective reflections from all of the interviews. It was necessary to gain an understanding of the 'whole' or a broad understanding of the phenomenon of loss and grief across both the focus group interviews (phase one) and the individual interviews (phase two) prior to moving on to step two of the hermeneutic analysis. My understanding was that loss, grief and bereavement were being experienced in the ID setting and that it may be being contained instead of being managed. (Appendix 12).

5.6.4   Step Two – Detailed Analysis of text - the Hermeneutic circle and reflection
Step two of the analysis entailed a detailed investigation of all text to expose its meaning for understanding of the subject matter and the identification of themes. Gaining a detailed analysis of the texts and collective reflections involved my engaging with the text in each individual focus-group interview and with each individual interview and then my coding each one systematically. This process was primarily

inductive with my own prejudices (my existing horizon of understanding), and influenced the content of each of the codes as I created them. On many occasions I coded units of analysis under multiple codes. The analysis of the 'parts' or the 'specifics' was an important part of the process in keeping with the chosen methodology and it was a difficult task. The 'parts' were my coding of phrases and my creating annotations and memos in NVivo and also how I made interpretations of what constituted important groupings such as the free nodes or tree nodes. An example of a memo is in Appendix 13. In keeping with the methodology (horizons of understanding) and my topic guide I decided to group the findings (clusters of nodes) as I understood them under three 'worldviews' of the participants. This was consistent with the topic guide. These worldviews were 1) worldview of ID, 2) worldview of loss and grief in ID and 3) worldview of bereavement in ID. (Appendices 14, 15 & 16).

In keeping with the methodology, it was important to remember that language as a medium for understanding includes spoken and unspoken language. The reflective writing after each interview captured as much of the unspoken data as possible. I maintained a reflective diary throughout this study which contained entries from the time of my placements in ID settings prior to data collection; also included were the entries from pre and post interviews from the ID services and the specialist palliative care service. Such reflection continued until the submission of this thesis. I made entries of my impressions of the services after each placement and after each interview. These included reflections on the venue, the ethos of care I witnessed, the clients, the staff, and anything which was deemed of interest about the event. On my reading over or on my adding to this diary, I was entering and leaving the hermeneutic circle and in this process of my attempting to understand the whole in light of the parts and the parts in light of the whole, I was developing my understanding of what were the experiences of the staff combined with my own experiences, and making an interpretation of the meaning to be found there.

The hermeneutic circle refers to the engagement of the researcher in a cyclical way between parts of the text and the whole of the text. My using a tape recorder ensured that the dialogue was recorded accurately (Holloway & Wheeler 2002, 2010). A digital recorder was used which meant that the recordings were easily transferred to my personal computer. Following the transcription of these recordings, the two sources of

data allowed me to look at text or listen to words either together or separately. My being able to play the interviews over again and again provided me with the opportunity to get to know the data very well and to identify who was saying what. As I have a particularly good voice recognition ability, it was relatively easy to match most of the participants' identities with the voice and with the words.

My engaging with the hermeneutic circle allowed me to develop my understanding as I went on to expose my own pre-understandings and began to merge my changing horizons of understanding with those of the text (i.e. the words of the participants). In the process of interpretation, the interplay between my ontological and epistemological understandings became apparent (Geanellos 1998). I consistently immersed myself in the text both by the reading and the re-reading of the written word and also by listening to the oral words (audio tapes). I also added to my reflections and kept field notes for reference to enhance analysis. This was all in an effort to arrive at an interpretation which was as fully informed from my developing horizons of understanding and from those in the language of the participants.

Staff, working in ID services, work in partnership with individuals to improve their autonomy as identified by Moulster & Turnbull (2004). My pre-understandings of ID nursing were those commonly held by general nurses as described by Turnbull (2004). Within the hermeneutic circle I continued to reflect, as I continued with my analysis, on the uniqueness of this discipline of nursing and how the role of the nurse in ID is encompassing a changing healthcare role. One particular aspect of their work valued by ID nurses is that they can form long-standing and meaningful relationships with their clients as identified by Turner (2004). I witnessed these meaningful and longstanding relationships of staff with clients repeatedly on my visits and I continued to experience them throughout the language of the texts and tapes. These bonds developed strong emotional ties and on occasions staff members developed particularly special relationships with clients. Such close bonds were severed on the occasions when individuals became separated. There were many potential separations which arose for the nurse/carer and for the client along the trajectory of life for the person with ID and dementia. Firstly, the person (client) may not have been able to stay in his/her 'home,' should human, financial or physical resources dictate that it became unsuitable for them due to their changing needs because of the progressing dementia. This was the first

possible separation from the staff who had effectively become their day-to-day family. Also, in a care setting for persons with ID, their peers are part of this family unit. With the further cognitive decline of the person with progressive dementia, the staff and peers also experienced a different separation. Staff sometimes talked about the fact that they had lost them well before they actually died. The ultimate separation came with the demise of the person. All of these separations or loss of relationships culminated with experiences of loss, bereavement and grief for those left behind.

In the process of my exploring all of the above, I endeavoured to fuse my own horizons of understanding (professional experience and personal experience) with the horizons of understanding of the staff in the ID settings. This was done by entering the hermeneutic circle (bringing horizons of understanding together), to arrive at a fused interpretation of the experience of loss and grief for the staff when they are supporting a person with ID and dementia throughout the trajectory of their illness and at the time of their death. My revisiting the reflections allowed me to explore and challenge my already held pre-understandings about the care of persons with ID, about the care of persons with dementia, about experiences of loss and grief and resulted in my existing understandings being challenged. All of this resulted in new and emerging understandings for me. (Appendix 17).

5.6.5   Step Three Expansion of the unity of the understood sense- Fusion of Horizons
This step involved my relating the detailed investigation of the text in step 2 back to the whole (step one), thus expanding its meaning. By my engaging in this process, (entering and leaving the hermeneutic circle), many different horizons of understanding were explored. As an individual coming from outside of the specialty, I found it difficult to understand the many possible structures and practices across the ID services. Care is managed in different ways across the services involved in this study. Persons with dementia may be living in any of the available settings within the service, for example in a residential setting on a campus, in a community house, in a designated care of the elderly unit or in a designated palliative care or end-of-life care setting. The ID services support a policy of 'ageing in place' which aims to keep a person in the environment in which s/he has lived within the service for the duration of their life. This place where the person lives is his/her home. Therefore, tension exists for staff who wish to support a policy to which they have strong commitment (keeping the person at home) and their

desiring to give the person with dementia the best possible care in life and at the time of their death. Some of the community settings have nursing staff and care staff (or social care staff). Other community settings have no nursing staff. Therefore if the person requires nursing care it may inevitably mean that s/he will be transferred out of his/her home to another part of the service where there is nursing care available or to an outside service. This difficult decision to do the best for the person at the end-of his/her life, was one major source of the experiencing of loss and grief by staff and one which I could identify with from my own personal life experiences. This is an explicit example of an occasion where my own horizon was being fused with that of a participant. I have been directly involved in this decision-making process and could identify with the dilemmas being discussed. (Appendix 18).

5.6.6   Step Four Representing shared understandings

Step four of analysis involves the identification of passages that seem to represent the shared understandings between researcher and participants. These new understandings and changed horizons of understanding all informed the analysis and interpretation of the data collected and supported the choice of this methodology. Central to such an approach to the analysis of text, I endeavoured to understand the meaning in the text by engaging in a fusion of horizons of understanding; these are the horizons of understanding of myself and the horizons of understanding of the research participants. In this study I endeavoured to interpret what were the understandings of the frontline staff in their supporting of persons with an ID and dementia. Such an approach to analysis allowed an interpretation of the fusion of horizons of care from the different perspectives of the frontline staff in ID and from my own experiences (pre-understandings). After my experiences in interviewing staff in the ID services and by reflecting on these, I developed a greater understanding of the care that they delivered and I had a changed horizon on that (Fahey-McCarthy 2006). Reflection on observed episodes of care continued to inform me in my interpretation of the words of the participants when they talked about the care they desired to give to their clients. I did not know what challenges end-of-life care posed for these services. In my analytic journey, I teased out the overlap of understandings about loss and grief and how this was experienced by the frontline staff in their supporting persons with ID and dementia. This resulted in a fusion of horizons of understandings (Gadamer, 2004) which gave rise to the interpretations as presented throughout the findings in chapters six, seven and

eight. The interpretations are supported with identified passages (quotes) throughout these chapters. The writing of interpretations was very challenging.

5.7 Establishing Trustworthiness

5.7.1 Trustworthiness in a Gadamerian study

Many proponents of flexible qualitative research avoid the terms validity and reliability (Robson 2002). Therefore, the term trustworthiness is used for this study. The importance of pre-understanding being incorporated in the analysis of text is highlighted by authors writing about hermeneutic enquiry (Geanellos 1998 ; Geanellos 1999 ; Binding & Tapp 2008). The personal experiences of the researcher are not considered an impediment in hermeneutic research methodology; rather the values of the researcher provide a context for meaning for the readers (Byrne 2001). Therefore, in the analysis I merged and amended my interpretations with the memos I made in NVivo thus making transparent how from reflection I changed my interpretations over time (Byrne 2001). Such reflection and self-awareness are important aspects for the researcher in an hermeneutic enquiry "involving human experience" (Gadamer 2004 ; Binding & Tapp 2008:128). A central concern of Gadamer in understanding is to see the existential meaning of the object for one's own life and future (Palmer 1969). Examples from my reflective diary provided evidence of such personal growth as I engaged with the topic within the transcripts during analysis.

Fleming et al. (2003:115) identified that while Gadamer offered invaluable insight into how a researcher could gain deep understanding of texts, and that he also recognised that a systematic approach was required, he did not however offer a method for doing so. Although there may not be a method given in hermeneutic enquiry, there is an expectation that the researcher is guided in how to proceed (Moules 2002). Gadamer (2004) states that one cannot proceed without one's being guided by the topic. The topic may be more fully understood by the use of Gadamerian enquiry through the dialectic of question and answer within a genuinely open conversation (Binding & Tapp 2008). The purpose of such enquiry is not to report the experience of the participant but rather to report on the subject matter (topic) (Moules 2002 ; Gadamer 2004 ; Binding & Tapp 2008) and to create a new understanding of the topic (Gadamer 2004). In Gadamerian terms three levels of conversation are possible between people engaging in conversation

(Binding & Tapp 2008). The first level in research terms may be where the researcher regards the participant purely as an informant; the second level could be where the researcher and the participant are competing or striving for counter-argument but reciprocity is not achieved (Binding & Tapp 2008). The third level, however, entails that both researcher and participant remain open to the possibilities within each other's worldviews (Binding & Tapp 2008). Conversation, according to Gadamer, is "a process of coming to an understanding" and that it belongs to every true conversation that each person opens himself to the other and truly accepts his point of view as valid and transposes himself into the other to such an extent that he understands, not the particular individual, but what he says" (Gadamer 2004:387). A genuine conversation according to Gadamer (2004:385) *"is never the one that we wanted to conduct .. ..as no one knows in advance what will come out of a conversation".*

Central to my use of a Gadamerian approach were my attempts at all times to enter into a genuine conversation with the participants, firstly in the interview and again when I read and re-read the transcripts of the interviews. I have endeavoured to demonstrate explicit examples of how I engaged in a genuine conversation which arose out of a genuine relationship between the participants and myself (in the interviews and in the transcripts) throughout the analysis, the presentation of findings and the write-up processes. Finally Koch (1996) suggests that in order to strengthen rigor (trustworthiness) in hermeneutic methodology, it behoves the researcher to visit the philosophical literature. Therefore I have familiarised myself with the concepts of Gadamer and the application of his philosophical hermeneutics within hermeneutical research methodology from the translated version of his magnum opus 'Truth and Method' (second revised edition 2004) and from other philosophical writings. "Trustworthiness is re-conceptualised in hermeneutic research and part of its trustworthiness is believability" (Moules 2002:32). Gadamer (2004) states that there are multiple interpretations and none are finite but some ring more true. Therefore it is up to any individual reader to make a judgement as to the believability of the findings presented in this thesis. Another reflection of rigor according to Moules (2002) is to demonstrate that the research is consistent with the philosophical framework chosen. This, in the case of Gadamer, means that I do not claim my interpretations to be the 'truth' but rather that I have tried to achieve the best interpretations throughout my conversations and readings of the texts (transcripts).

5.8 Ethical Considerations

5.8.1 Ethical conduct

The ethical conduct of research is an important issue for the researcher because "the conduct of research itself has to be subject to the practice of the intellectual and moral habits intrinsic to the conduct of research" (Gregory 2003:15).

All research activity associated with this study was in accordance with the regulations of the University of Dublin, Trinity College Guidelines for the conduct of research studies (2002). All of the participants were afforded care in line with the best ethical practice which reflects the ethical principles of Beneficence, Non-maleficence, Autonomy and Justice as outlined by (Beauchamp and Childress 2004) and in line with the Declaration of Helsinki research on Human participants (1989). Some of the key components which demonstrate good ethical conduct in this study are now presented.

5.8.2 Ethical Approval

Ethical approval for the study was obtained from the Ethics Committee at the Faculty of Health Sciences, Trinity College Dublin. (Appendix 16).

5.8.3 Access to Sites and Ethical Approval

Ethical approval was obtained from the Ethics Committee and/or the Board of Management of each of the seven participating sites.

Gatekeepers were used at the various sites to distribute initial letters of invitation and also information sheets about the study to the appropriate personnel at the various sites.

5.8.4 Consent, Anonymity and Confidentiality of Participants

Codes of ethics which guide research with human subjects, stress the importance of voluntary-informed consent by the participants (Gregory 2003). Informed consent implies that the participant has had full information given to him/her which includes any reasonable or foreseeable issues (risks/benefits) which allow the participant to make a decision to take part in the study or not. All participants were provided with the research study information, interview guide and consent form at least two weeks before taking part in the study and were given clear information that they were participating voluntarily; they could withdraw at any time if they wished, without any penalty.

Written consent to participate in the study was gained from all participants at each interview and the researcher was available to answer any questions about the research at the beginning and end of each interview. Contact telephone and e-mail details of the researcher were also provided to the participants together with the study information and consent forms. Staff volunteered themselves after the focus groups for the individual interviews. Therefore, verbal consent was obtained at the outset of each individual interview.

All participants were assured of anonymity by my stating that each individual participant would be given an identification number which would be known only to the researcher. They were informed that the names of any individual/s i.e. clients/service users who might be discussed at the interviews would be changed in the transcriptions in order to protect client/service user anonymity. An initial would only be used in quotes which would not reflect the first letter of the client's/service user's real first name.

The participants were further assured of confidentiality in respect of their own names and of the name of their Organisation in any presentation of the findings from the study. In all interviews ground rules were laid down regarding the confidentially of information discussed during the interview.

5.8.5 *Beneficence, Non-maleficence, Autonomy and Justice*

I was aware that the participants were likely to have had both positive and negative experiences in their supporting persons with dementia across the various settings and that the recalling of this experience could be an emotionally challenging experience for them. I have undertaken training in counselling and in grief therapy, therefore I felt confident that I could support a participant if s/he became upset during an interview. On occasions where staff were showing any early signs of their becoming emotionally upset, I immediately offered to terminate the interview. Staff in all interviews looked visibly upset on occasion when they recalled their experiences and relived their feelings of grief about clients whom they had supported with dementia. Some cried or appeared to be visibly trying not to cry in the focus-group interviews. Staff more often cried openly in the individual interviews or when there were two or three present. I consistently facilitated their expressions of grief during the interviews to the best of my

ability. I furthermore followed up one participant who was crying profusely in the individual interview by phoning the participant to have a discussion about the issues which had arisen in the interview. S/he reassured me that s/he did not need any formal assistance in dealing with grief issues. Five of the eleven individual interviewees stated that they had benefitted from their talking about their feelings of loss and grief in the interview because they said they would not feel comfortable sharing some of these feelings (sadness, loss, grief) with other staff at their workplace.

Language is the medium of understanding according to Gadamer (2004); therefore careful use of language was deemed appropriate at all stages of this study. I was already aware of my existing prejudices (pre-understandings) and I was anxious not to offend anyone with my lack of knowledge of their professional ways of working. Therefore, I strove to use language in relation to the research study which, I believed, sufficiently explained such a study in the language of nursing practice and caring. I wished to acknowledge and respect an existing level of understanding of terminology used within nursing practice. Such terminology was used in the study information documentation, in the interview schedule and on the consent forms at the outset and in all of my encounters with the staff through correspondence, telephone communications and in person throughout the study. I was very aware when in the practice area that I was an 'outsider'. I did not wish to appear insensitive to the fact that staff were giving me their attention and time. One pre-understanding which I held in my memory was of previous visits over many years to the practice setting as a nurse tutor (academic), where I received defensive welcomes on occasion as if I were arriving from the school to discover or highlight bad clinical practice. Therefore, I consistently stressed to the participants that they were the experts who had invaluable information to give me about their experiences of caring for the population in this study. Furthermore, I stressed that there were no right or wrong answers but that I was seeking to understand their experiences as they saw them.

5.8.6   *Storage of Raw Data*

All data were stored and will be destroyed in keeping with the Data Protection (Amended 2003) Act (GOI 2003). All tapes and transcripts were available to the researcher only and to her supervisors on occasion, (for expert review), and were kept safe and secure with computer password protection. All tapes and transcripts that had

any participant or client/service user identifying features were replaced with case numbers/initials and site and visit codes.

5.9   Conclusion

Chapter five outlined the research methods used and the approach taken to analysis and the ethical conduct of the study. The research methods were a combination of a re-analysis of data collected from focus-group interviews, of a primary analysis of data collected from individual interviews and of reflection. All of this was conducted and guided by my using a Gadamerian hermeneutical approach. The topic guide was used to group concepts, ideas and interpretations informed by hermeneutic philosophy. The interpretation produced three overarching thematic worldviews. Each worldview will now be individually presented and discussed in the next three chapters.

CHAPTER 6 – WORLDVIEW OF SUPPORTING PERSONS WITH INTELLECTUAL DISABILITY/DEMENTIA

6.1   Introduction

In order to be able to begin to understand the experiences of loss and grief for staff who support persons with ID and dementia, I consider that it is important to begin to try to understand their worldview of what it is like to support this population in the first case. Therefore, this chapter presents the findings which comprise Theme One – Worldview of supporting persons with ID. This theme was developed from the combined re-analysis of the focus group interviews from chapter one and the analysis of the data from the individual follow up interviews. In keeping with a Gadamerian hermeneutic representation the findings are described in terms of worldviews of the research participants fused with that of the researcher. Each theme, sub-theme and category will have an interpretation presented for it. Inevitably this incorporates my interpretation, of an existing and a developing understanding of (supporting persons with ID and advanced dementia), as a result of an analysis of what the participants said about this phenomenon during interviews.

6.2   Theme 1 - ID Worldview of supporting persons with intellectual disability and dementia/advanced dementia

Interpretation: Worldview of the supporting of persons with ID and dementia refers to the nuances inherent in this type of care. To support a person with ID is a unique experience. To work in this 'world' brings a certain satisfaction. Key aspects of what it means are articulated in the findings but equally there is difficulty in one's articulating what is at the core of his/her job satisfaction. To support persons with ID is in itself a primary achievement, and when the person developed dementia it appears that the commitment by his/her carer deepens. The centrality of relationships and bonds of attachment appear to deepen also.

There were two sub-themes described by participants in this theme. These are:
- Valued Relationships
- Ethos of care

6.3   Valued Relationships

Interpretation : Valued relationships refers to the intricacies in the relationships which were developed in the ID care setting. Relationships between the participants and the clients, between the clients themselves and between the participants and the kinsfolk of clients, develop over the years spent together. The stages of development of relationships are unique, and yet many of the stages share commonalities between residents. Valued relationships become more intimate and covert over time, to the extent that "bonds" are formed of varying degrees between carers and clients.

This sub-theme places high importance on the centrality of relationships and how these are formed and fostered within ID care. There are four categories:

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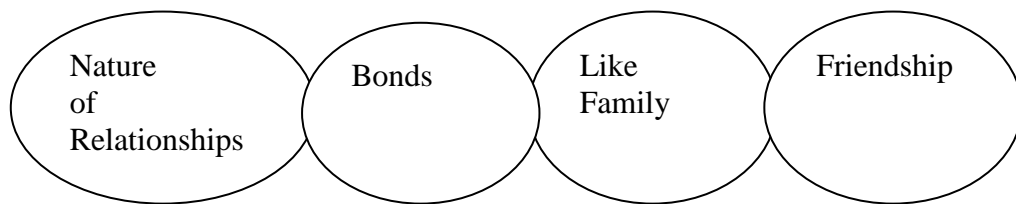
6.3.1   Nature of Relationships

Interpretation : Nature of relationships refers to the many nuances of the making of and the maintaining of relationships within the world of ID care. Such forming and maintaining of relationships can be, and often is, complex. Relationships can be of short, medium and long term duration, which in turn is influenced by the carer, those being cared for and the ethos of care within the organisation. Relationships between clients and participants in the ID setting were of a long-term duration.

Some participants had spent more time with the clients while they were in their care than their kinsfolk did as captured in the following quote:

> *.. our people are with us ten.. fifteen, twenty years .. you know.. like the families haven't been with them that long .. you know .. I've known them from what.. three or four years of age .. 1.3.2*

In one service participants knew the clients across the different facilities of that service. They had started out as young professionals knowing the client as a child and now years later as an adult. They regarded it as growing-up together. Hence in one way, almost a sibling relationship was potentially established as captured in the following quote:

> *...would have grown up with him you know they saw him through his day service and the pre-school and saw him going through school and then back through the adult services and into the community residential so they.. a lot of people around would have grown up with… 1.2.3*

It was often perceived that the supporting of a person with ID and the nature of the relationships between participants and client was 'not work' but 'a way of life'. This is captured in the following quote:

> *.. it's more to it than professional .. It's your whole life .. it's a different story .. it's a different field that we're working in .. the women are part of our life.. it's a holistic .. we're not treating an illness .. 1.3.5*

Inevitably if staff and clients are going to be living together over many years then it may be expected that bonds will be made among them.

6.3.2 Bonds

Interpretation: Bonds refer to the many types of attachments which participants made with clients. They made closer relationships with some clients rather than others and they felt stronger bonds of attachment with some clients. Bonds may be invisible and do not need a "voice" to acknowledge their presence or existence. The onset of illness, or the diagnosis of dementia can enhance the "strength " of the bonds. Bonds are not confined to the life of the client, but rather continue after death.

Shared humanity refers to the nuances inherent in 'being human'. Human beings are part of one species. The power of reflection is unique to humans. Although some participants supported persons with ID, on occasion, they questioned as to whether these clients had the capacity to actively 'reflect'. However, the participants acknowledged a certain bond with the person with ID which was beyond explanation. This bond resembles a spiritual experience intertwined with the experience of belonging

to the one human race. On occasion this was an invisible bond and expressed by one participant in the following quote:

.. even though I don't understand why that can't be and like how come that happened to X .. it doesn't em .. I suppose I would have a notion that that's the way he is and though I'm looking at his body that's not the important thing .. and sometimes people get too hung up on the idea that .. his body is there and it just happens to be .. and I personally think that we happen to be spiritual beings .. and human experience. Some people think it's the other way around. So I think he has the same contribution to life .. he's as important as anybody else and just because you know his physical body can't do this or because his physical body looks a certain way doesn't personally bother me..3.5.1

Participants recognised the shared humanity that they experienced when working with persons across the spectrum of severity of ID. They found that communication happened at an affective level and language was not necessary in the relationship. This aspect of their work was meaningful as demonstrated below:

... people with an ID don't decide I'm going to be nasty to you or make your day awkward. It's very much they're so thankful for what you do for them. The level of communication can be at a feeling base. It's not just when somebody says thanks because sometimes they're not able to say it .... I like the approach of caring for somebody who doesn't have the words. Like some people say when you work in a client group would you not like to get feedback? It's basic again and it is nice to have a conversation but you can still talk to somebody even if they can't hear you .. even if they can't talk back.... 3.1.5

Language was not a necessity and participants did not always know whether clients understood the situation. For example, when a participant moved on to another service or left a particular part of the service to work in another area. However, the special bond they had with the client would be deeply renewed with the client if they went back to visit the client and s/he reacted to him/her personally with a smile or some eye contact. This typified a particular bond between client and carer. The most vivid descriptions were when they said that irrespective of whether the client still recognised them when they had advanced dementia, the participants were delighted to think that the clients

eyes 'lit up' when the participants member visited them. The following quote captures this bond:

> *...sometimes they have a good connection with some other staff .. they mightn't be their key worker ... or sometimes it could be another staff member whom they are particularly fond of. Their eyes light up when they see them or something! 3.1.1*

Participants spoke about their relationships in terms of their becoming attached to clients over time. It appeared that such attachments could be quite significant both to the participants and to the clients. As the person was declining with dementia s/he required more personal and intimate support which increased the time spent in each other's company. Participants spoke about the difficulty of breaking this bond of attachment. In a situation where the person is deteriorating cognitively the participants appeared to be striving hard to maintain the bond between them on a very personal level rather than on a professional level. The emotional challenge on a personal level when the relationship changes between participants and clients is evident in the following quote:

> *You live with them practically.. Because we know them so long It is, they're part of your family in a way.. It's not a work relationship, it's I know this person this number of years, you can't, I mean you'd want to be ice cold to be able to detach yourself. 10.1.2*

Furthermore, participants identified that they also had bonds of attachment with the kinsfolk of the clients and that these bonds are important to recognise in the ID setting. The following quote captures this point:

> *There is much more attachment there. Much more attachment with the families and we need to be very mindful of that 7.1.1*

It was becoming apparent very early on in the interviews that participants considered themselves to be supporting their clients within family-like philosophies of care.

6.3.4   *Like Family*

Interpretation: 'Like family' constitutes all of the complexities which are inherent in family dynamics which are shaped by many factors. It embraces one's being with the person '24/7' for many years. It includes having ups and downs, good days and bad

days with moods, arguments, falling out of favour, kissing, making-up and loving again after such events.

Some examples of 'being like family' were when participants included clients in their own family circle at special family events, almost like an older sister or an auntie figure. The following quote demonstrates this:

> *.. Like a lot of the patients like are here for years, and you are the only one like ... I suppose you are like their family to some of them.. one lady .. she came to my wedding, she's like a family member 12.1.1*

It is evident from the above that when participants referred to themselves as 'family' that they readily interchanged the notion that they were part of the client's family and the client was part of theirs. Indeed many stories were related outside of the interviews of the many Christmases or other occasions when a participant took a client home to their own family home.

Participants made the point that not only are they working with them but indeed they are living with them in a family context and in a family setting. This referred to living in a community house where there was one staff member and four to five residents comprising a family unit and operated like any family in the community. They lived as independently as possible like a family in every other house in that community. This routine of family life is captured in the following quote:

> *...maybe that's a family situation you know not everybody always gets on in a house you know so you have your differences and whatever. But I think the common bond is there that they all have been together for so long and they are comfortable in each other's company and you know they can have their quite times and whatever. 3.12.8*

A few participants grappled with the notion of family versus paid carer in the lives of clients especially when talking about clients who did not have kinsfolk. These participants believed that although they were paid carers they needed to be something more to these clients. The following quote demonstrates this:

> *.. but we are paid to be here .. to a lot of them here ..you are all they've got. You really are, some of them are blessed to have family and visitors and stuff*

and others aren't and its them that you know, you need everything you've got ..
out of you for them. 1.2.1

Participants in the long established ID services especially considered that they knew the clients better than their kinsfolk did, because they have had more contact on a day-to-day basis than many of those family members. Participants across all sites acknowledged that families ultimately had the legal right to make decisions regarding the person's welfare and health care but on occasion considered that they ought to have some input in this decision making. They considered that they knew the client better and therefore were more aware of the person's wishes, likes and dislikes. The following quote below was made by a participant who knew that a lady loved her food but in a recent hospitalisation her kinsfolk made the decision to have a per-cutaneous endoscopic gastrostomy tube (PEG) inserted.

> *Although sometimes you wonder should staff still have some kind of say because*
> *I mean if you've been 20 something years with a client and you know them fairly*
> *well, you probably see them a hell of a lot more than their family ever did.*
> *10.1.1*

That participant experienced great distress that when the lady was home again with the ID service, they could no longer feed her orally and watch her delight in savouring the taste of food she loved so much – ice cream. Maybe this is akin to the situation of decision-making within a dysfunctional family context where siblings may not agree on the best course of action for a person who is declining with dementia.

Participants also related 'like family' within the extended family unit, i.e. that they had a familial relationship with the client and with the client's own kinsfolk which reflected that 'extended family'. Furthermore, an important element in the 'like family' concept is the context of care for the person with ID and dementia. Participants explicitly wanted to clarify the difference between their supporting of a person in an ID setting versus the supporting of someone in another health care setting. The following quote is from a participant in an ID service where clients are younger and have transferred in from their own family home. Their kinsfolk are very much included in their day-to-day activities.

.. The relationship that you've had with the service user and also the relationship you've had with the family.. because it's not like a general hospital where you have .. or a nursing home. There's a lot of involvement here .. it's twenty-four seven this place is open – now we seldom have visitors at night except there's .. It's very much a family here still .. no matter what way you look upon it.. 2.1.1

While participants reflected on the similarities between different family structures, they also thought about the internal relationship within their family unit of care. They debated whether a hierarchy existed in the family they formed. Some participants reported that informal hierarchies existed in relation to how the clients perceived the roles of nurses and carers. The following quote demonstrates this:

I suppose .. it's supposed to be not hierarchical.. but it wouldn't always be like that…   the clients would always, like if the clients need to go to the toilet they would ask the care staff, they would wait, they are very like they wouldn't ever ask a nurse. They'd be like that.3.12.1

The notion of whether nurses were nurses or family was summed up nicely when one participant described her role in the following quote:

I suppose you feel appreciated more, you are not just a nurse ... and you are providing something, a huge part of their life, not just from a nursing point of view. You are providing a full world for them like you know ... It's not just the clinical nurse, you are not just the number like, I think you are more like a family/nurse.3.3.10

That participant looked very satisfied when she coined the term family/nurse. It emphasised the fact that there exists a familial bond first and a practitioner with a skill set as second to that in the relationship between client and nurse.

Some participants felt that the relationship between client and nurse/carer was akin to a parent-child relationship where the participant was the parent figure. The following quote demonstrates this:

you have the parent role with it definitely, without a doubt. Because you are, you are involved in all parts of their life you know.   There will be good times and

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bad times everything you know the upsets everything, so you really are, you are in the parent, you are fulfilling that parent role for them definitely. 3.7.1

On the other hand some participants had mixed reactions as to whether they had a parent-child or child-parent relationship with clients. The complexity of this situation within the relationship is captured with this quote:

… I would see them more like a mother figure than me as the mother figure. And I would often say that and any of them that would have no family I'd always say aren't you like my granny, won't you mind me.   And they like that sense of oh yeah you know they'll mind me because they have the mother instinct, everyone of them and you can see that. So they would see me as the child even though they know that I'm the boss. So there's that sense of it. But I'd never see me as the mother figure. 3.10.1

There were many complexities with this notion of being 'like family'. Participants in the ID services which were established many years ago referred more frequently to themselves as 'like family' than participants from the more recently established ID services. In the older established services, the clients were of an older population and there was less kinsfolk involvement in a general sense for a variety of reasons.

Participants felt that they were contradicting themselves because on the one hand they felt that they were not 'family' because to be 'family' they would be more emotionally involved with the clients; on the other hand they could not avoid being emotionally involved with the clients and therefore they felt they were part of a 'family' unit. The following quote captures this point:

I suppose I think as I said earlier when you are working with somebody for so long you know you are actually, you are, you are part of their family really in a sense. I know I keep saying okay we are not, you know, not supposed to be seen as overly emotionally involved and everything. 3.12.8

The notion that they behaved 'like a family' and also like 'friends' was articulated particularly in the community residential setting where the numbers were smaller. This is captured in the following quote:

> *... eh, I suppose going back to the family bit, we are actually like a family here and you know we have great craic among ourselves and everything.   And you know we are, we are great friends in the whole house the whole lot of us. 3.12.1*

Being in a family does not exclude the possibility that some members of the family will also be friends.

6.3.5   Friendship

Interpretation: Friendship refers to relationships made between individuals and among the staff, peers, kinsfolk and the clients in the ID setting. Friendship implies an intimacy in a relationship albeit that the relationship may be platonic. Friendships develop between persons and among people of different ages, from different social, cultural, religious backgrounds and different educational backgrounds. Friendships may occur spontaneously when individuals are in close proximity with each other and if there is a sharing of common interests, values and beliefs. Equally friendships may occur when individuals feel comfortable in each other's company and no words can describe why this is so.

Although some participants had earlier identified that they could perceive themselves in relationships similar to parent and child, some participants clearly did not perceive themselves to be a parent figure but rather as a friend. One participant commented:

> *... Yeah I wouldn't like to think that I would think that way as a parent because I probably… I think she's very much a friend .. 3.11.1*

Age did not appear to influence friendships and a variety of combinations were visible in the ID settings. Activities shared as friends were: having a coffee, shopping, attending social events. Sharing experiences such as reading a magazine and laughing at it's humour or admiring current fashion and style were also activities shared between and among clients and participants. The experience of the ordinary every day things that friends would share appeared to distinguish the relationship. The following quote demonstrates this:

> *... but I suppose yeah I'd have a great respect of where she came from I would, like she'd be very, very loving person and would enjoy life and likes to get out for a coffee and likes relationship with the staff and you know.   Em, she would probably be my particular sort of friend as you say.3.11.1*

Unique friendships existed between care participants and clients and between nurses and clients but one nurse participant commented that clients understood the hierarchy and would report issues of concern to nurses but would talk more personally with the care staff. The care staff were perceived by the clients to be their friends as demonstrated by the following quote:

> *A lot of our ladies cling more to the care staff, the care staff, or their main carers, they are their main support, they would have the chat. They LOVE the care staff.   The carers are their friends, you know… 3.9.1*

There was a sense that friendship could exist within the 'extended family' framework in the residence similar to any family context in the general community. This is captured in the following quote:

> *More friends than anything else, just one lady in particular like she has a family like but she'd be very fond of them and like the staff and she kind of, everything goes through us like, she sees us as her family too like and that's nice ... 3.1.13*

There was a distinct sense that the formation of friendships between participants and clients was inevitable within the ID care setting as opposed to any other healthcare setting. This is demonstrated in the following quote:

> *.. yeah definitely you build up friendships. That's what we would be is friends like.   Like what you have here you'd never have in any other setting, I don't think you would anyway 3.10.1*

Again the longevity of the relationship influenced the formation of these bonds of friendship. Participants recognised that there were clients who were more vulnerable and needed their friendship as demonstrated in the following quote:

> *I think that's how friendships form, it's hard to, you wouldn't automatically become best friends with one of them who you know have loads of family ... It's who you bond with you know, we have a very, very good chat with them like… need it more than we'd know they need it like…   They know us so long you see. 3.10.1*

Some participants questioned the nature of what friendship means and while they acknowledged that friendships happen, they began to question what was the essence of friendship between 'carer' and client. They debated whether friendship was dependent on the level of ID of the person as demonstrated in the following quote:

> *Em yeh .. but it does depend eh .. .. friendships happen if you're in an area and depending on someone's level of ID I think it's easy to form a friendship .. if someone doesn't communicate with you .. is it a friendship?.. 3.5.1*

In summary of sub-theme 'Valued relationships, it is evident that the most important issue for participants supporting persons with ID is the 'nature of relationships' which are defined by their longevity of years spent together and the very nature of their professional work. Furthermore, bonds of affection are made among staff and clients who are resident in ID settings. To be 'like family' to the person with ID is inherently challenging for staff due to the many complexities within the definition of family. The forming of 'friendships' with persons with ID were perceived as inevitable in the course of the work and proved equally challenging to define.

6.4   Ethos of Care

Interpretation: Ethos of care refers to the distinction of an organisation in relation to the values inherent in its operation. It may or may not reflect the attitudes and values expressed in its mission statement. It is the spoken and unspoken atmosphere which is 'almost tangible' at an organisational and personal level when one visits an organisation. It can evoke negative or positive responses. The ethos of care in ID care 'felt special'. There was a certain calmness in the working environment. There was no rush to complete tasks or activities. The client was first and foremost the important person in the organisation.

There were four categories in the sub-theme 'Ethos of Care'. These were 1) Person-centred care, 2) Ordinariness of care, 3) Meaningful work and 4) Changing expectations.
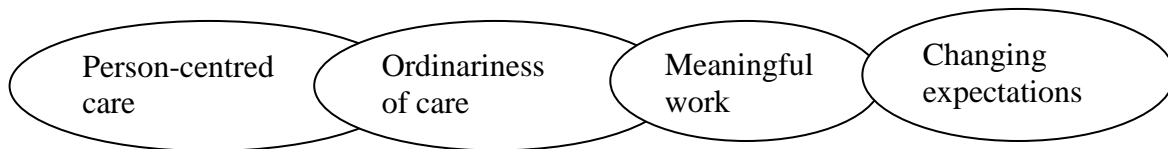
6.4.1   Person-centred care

Interpretation: Person-centred care refers to delivering individualised and well-planned care. Such care requires that the care-giver knows the client intimately. When such care is delivered to an individual, it serves to protect his/her identity. Person-centred care embraces the values inherent in one's respecting the person and preserving his/her dignity.

Participants delivered personalised and individualised care to clients and ensured that the preferred activities of the person were continued well after their decline into advanced dementia had been established. If someone enjoyed shopping trips then they were taken 'out shopping' whether they did or did not know what to shop for anymore. The well-being of the person was always central to such decisions.

Participants consistently paid great attention to the individual and his/ her personal needs as demonstrated in the following quote:

> *And I suppose always looking at the person and I suppose it's the person-centeredness thing as well ... 3.10.7*

Person-centredness as a concept had always been an implicit part of the ethos of ID care and support but was now being explicitly addressed in care planning. They referred to person-centred care as being more actively prominent in the services of recent years as demonstrated in the following quote:

> *I remember when I was in X 20 years ago, it was very task orientated.. We definitely have become more person centred .. We've a wider view of how people develop .. not as closed as 25 yrs ago where the view was they can only do so much .. 3.4.6*

Within the delivery of person-centred care, a great sense of dedication to the well-being of the client was discussed by the participants. Dedication refers to attention to the duty of care of staff in the ID setting. Dedication may require great attention to detail and one-to-one attention in a care-giving context. It may furthermore require an individual

to go beyond the call of duty or to pursue a unique investment of oneself in another person. Staff gave time, energy, commitment, and dedication to the client which was well beyond their job description/role or call of duty. Examples of this were their visiting clients outside of their work rotas, their coming in when deaths occurred without any time given back, the attending of funerals, their taking clients out or to their own homes for special occasions and continuing to visit clients after they had left their service. This is demonstrated in the following quote:

> *we come in on our days off, I would come in on my days off because you know we trained with them…   like we had come in numerous times .. people could be shopping for clients on their days off, people bring the people out on their days off... 3.3.10*

The participants discussed their dedication by the use of the term 'for the love of the client' as demonstrated in the following quote:

> *… but still there's very, very good staff.   Very, very caring staff and I suppose they are here for the love of the service users first and foremost and if they can sort of be there a couple of minutes earlier to give a hand it's an unspoken thing that just happens.   You might never get thanks for it but you know it would be just there…3.2.11*

It was evident form participants that they were not explicitly asked to give of their time. Rather, that it was of a voluntary nature as described in the following quote:

> *No one expects you to come in, you just do it for yourself like.   Nobody ever says like you know we'd like you all to come in…   you just come in. 3.2.12*

When they advocated for person-centred care for the clients, there was an inherent belief by the participants that the upholding of the dignity and respect for the person with ID was paramount. Respect and dignity refers to the upholding of the values central to the protection of the inherent moral worth of another person. To demonstrate respect for a person is to value difference, while the upholding of a person's dignity is to afford him/her respect.   Participants protected the moral worth of the person irrespective of the person's ability to understand or communicate with the staff member. The desire to respect persons with ID and to treat them with dignity is demonstrated in the following quote:

.. staff would say for Christ sake H (own name) he can't hear you.. But I've no problem it didn't matter to me and again em if you talk .. I remember working with someone with a particular care assistant who asked me is it ok that I talk to J (client with profound ID) and I said of course it is!.. 13.3.1

This wish to respect persons and to treat them in a dignified manner lasted throughout their life and up to their death. They recognised that if persons could no longer reside at 'home' where they had resided for years because of a lack of resources, that it was matter of respect to give them comfort in their decline with dementia. While they struggled to let the person be moved, they recognised that a more comfortable death could be achieved and that this ultimate act was upholding the dignity of the person. The following quote demonstrates this:

.. we hadn't the facilities first of all to look after her and it was the last few weeks that she was going to be here.   And I just said for her own dignity and respect and everything, you know I said why can't we have her somewhere more comfortable.. 13.3.6

This determination to respect the person's dignity was carried through while they caring for the person at end-of-life. The desire to give an aesthetic environment in spite of an ever on-going reduction in resources in one service is evident in the following quote:

You'll go and rob a bunch of flowers .. they (management) know that… Make the place nice, just because they're dying .. You would like someone to do it for you .. 13.3.3

This determination to respect the person and his kinsfolk continued after the person's demise. It was always the way the participants spoke in a tone of voice which gave the interviewer this sense of respect that participants had for their clients. If a client was moved to another part of the service and died, they appreciated being able to bring the person back for the waking period. They perceived this as a mark of respect to the person, to the staff and to the kinsfolk of the person. This is demonstrated in the following quote:

Well em in terms of respect for the man. That's where he grew up. He was going back to a familiar environment. Staff ... were ... twas like the finished business ...

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yeh who'd looked after him and sort of seen him laid out ... and like as it was his last time there ... and of course for his family. If like say you've brothers and sisters say coming in ... say they know bungalow number X ... they don't know bungalow Y em and I just think its important for them. I think it's enough for staff ... obviously for relatives to cope with somebody dying ... likewise staff ... without them having to feel like well oh no I have to come over to a strange place .. or a different environment for to pay my respects ... rather than to have them in a place where ... a few weeks ago I was showering him ... a few weeks ago I was bringing him for a walk ... a few weeks ago I was doing whatever. And all those memories are taken away from you ... (said very quietly!) and I don't think that should be done... 13.3.7

Person-centred care then embraced supporting the individuality of the person with ID and protecting his/her moral worth as a person by the provision of dignified and respectful care to him/her. Much of this care or support was necessary to enable the person to life as full and as healthy a life as possible. 'Ordinary care' was more commonly discussed by the participants as the requirement to uphold this person-centred care described.

6.4.2 *Ordinariness of care*

Interpretation: Ordinariness of care refers to the nuances of providing care which is largely invisible in ID care settings. Caring about someone embraces thinking about that person and his/her needs. This ordinary care is the 'taken for granted care' which ensures that a person's elementary/fundamental needs, as identified in 'Maslows Hierarchy of needs', are satisfied. This care allows a balance or harmony to exist for the person being cared for. Participants cared for and supported their clients when they met their ordinary 'activities of daily living' by their ensuring that they were clean, warm, nourished, safe and happy. Ultimately, this ensured that their clients were comfortable physically, psychologically and socially. This was the 'bread and butter' of the care they delivered every day and night to persons who either could not do these activities for themselves or needed varying degrees of support in achieving them.

Such 'ordinary' care was very important to the participants and central to their judgement of how well they did their job. In the most uncomplicated of terms

participants said they were 'just caring for them'. This is evidenced in the following quote:

> *I suppose get them up in the morning and bring them to their activations and bringing them back and feeding them and putting them to bed.   Just caring for them.. 3.1.12*

Although there was an 'ordinariness' about what participants did, there was also an intensity about the support delivered to the person. This intensity is captured in the following quote:

> *I suppose like that even when somebody would be, its nearly, its back to your whole day that that person is comfortable and they are you know.. need a drink or don't need a drink, that their pad is changed, all them things that is very much go, go, go, you are very involved… 3.2.11*

In principle, participants appeared to like delivering this support in a social model of care rather than a health-focussed model of care. They recognised that having an ID did not mean that the person was sick. This is captured in the following quote:

> *It's basic things that are so important. You give them their food .. you wash them .. you make sure that they don't have any pressure areas ..and its very immediate . I like it .. the idea that you're not trying to make somebody better as such. Like they have an ID .. that's the way they are.3.5.1*

In order to support persons with ID within this social care model participants recognised that teamwork was important. Teamwork refers to the realisation that no one professional can adequately meet all of the needs of the person with ID. Each member of the multi-disciplinary team has a specific role to play for the well-being of the person. Teamwork ensures that different roles and responsibilities can be exercised for the well-being of the client. The different strengths of expert knowledge and skills can be combined to benefit the client. Regrettably, some services do not have as broad a range of multi-professional teams to provide care as others do and the participants in these services recognise that the client misses out because of this.

Participants recognised that effective teamwork was imperative and acknowledged that without it they felt unsupported as demonstrated in the following quote:

> *.. obviously we are relying on each other and maybe that's a good scenario when everybody gets on well and it's a good team that you have but if you haven't got that good dynamics in that team then there's no real support at all.3.1.11*

Some participants who came from working in non-ID settings identified that they had stayed working in the ID settings particularly because of that very ethos of teamwork which permeated the ID service. This is captured in the following quote:

> *I like the teamwork, less hierarchy in the ID service they're more open and you can get .. there's a better atmosphere.3.1.11*

Finally, in this category of 'ordinariness of care', the participants demonstrated a heightened sense of responsibility towards their clients as they delivered support in their daily practice. Responsibility refers to the taking seriously of responsibility for the well-being of another human-being. It potentially includes the taking-on the duty of being guardian, advocate and companion for the client. It resembles parenting / guardian role, where boundaries may be crossed for the benefit of the client. It is potentially an onerous task. It embraces a possible combination of emotions such as fear and excitement but equally can give a sense of satisfaction if taken seriously.

Participants took on a serious responsibility to undertake the role of advocate for the clients in the small ordinary daily choices one needs to make. This could be in the making of the choice of what clothes to buy which would be the choice of the client him/herself is he/she could choose as evidenced in the following quote:

> *.. you're their advocate . they can't make choices. You are trying to support them with their choices cos they're not able. You think ahead .. you think outside the box . You think what would they like? You think ahead like what they'd like for Christmas. What they'd buy .. where .. all the nice little things you do.. 3.1.12*

Although, the participants discussed an ordinariness about their work, they visibly appeared to have great pride in this aspect of care and to the difference they made to the client's life.

6.4.3   Meaningful Work

Interpretation : Meaningful work refers to the implication that working in ID care has a particular impact on the staff. Meaningful work is very satisfying. To have an occupation is important for the well-being of a person. To have an occupation potentially brings physical, psychological, social and emotional satisfaction to an individual. Paid employment brings financial benefit which pays the bills. It is possible to do a job because an individual enjoys it rather than for the remuneration. Indeed many health and social care workers are inadequately remunerated for the work which they do. There was a strong sense of satisfaction and fulfilment for participants in relation to how their work with people with intellectual disabilities gave them such fulfilment and meaning in their professional role. There are no categories under this sub-theme.

Participants spoke about the satisfaction and enjoyment they derived from their work as captured in the following quote:

> *I enjoy working with them. I think they (service users) are great to nurse, they're very pleasant and it's just a lovely environment to work in as well. So I don't think I could ever go back to general (nursing)! 3.6.1*

This also captured the sense of fulfilment which the participants experienced and described when they discussed the special nature of their work. The following quote demonstrates this:

> *Yeah very fulfilling, even now in the post that I have like that I'm not hands on contact where I'm coming in and out and in and out and I suppose its been a couple of days with cutbacks and that that we've been out on the floor and I suppose its been great. With all the madness of shortage of staff and everything but actually getting back out there and sort of being in the thick of it is great.3.2.11*

Participants felt that the clients appreciated them including those clients who had no verbal skills. This is captured in the following quote:

Em, I suppose… like they never say thanks to you but they can do something for you like you know.   em, a lot of them do, they would be very vocal, I suppose its like a guardian angel and I suppose they can smile, you know, that kind of thing, it's nice like. You know that they appreciate it like.3.2.12

Participants also had a closeness with the clients with profound ID and spoke movingly about the rewards they received such as a smile or some facial reaction by the client which indicated recognition when the participant returned after a period of absence. This is demonstrated in the following quote:

It's holistic because the most profound here have a personality when you get to know them .. that's the reward that we get. You go in and you get a smile and or you see the recognition in their faces when you come back off holidays and you know they've missed you. You know they've been looking around. You know even when you get your hair cut they notice.3.1.3

Participants described, with depth of feeling, the satisfaction that they derived from their working with this client group and the positive impact it has on their own well-being.

I enjoy what I do and there's a great sense of satisfaction ... you make a greater difference to the peoples lives... personally what the residents have done for me is greater that what I could ever do for them I like looking after these people. The thing is .. I can't say this to my employer but I'd do it for nothing! .. .3.5.1

Participants also found it difficult to articulate exactly what they liked about their work with persons with ID.

I don't know, it's probably very simple, I think they are probably, .. there's no what your car is, there's no.. you know, like you get on and we are kind to each other. Sort of a better understanding than some people have for, it's hard to put into words.. 3.11.1

Participants felt privileged to be working in such a situation and clearly considered the setting to be the home of the client.

.. there's none of this we are here to mind you .. it's their home!.   I suppose it's a privilege for me opening the door in the mornings and come in and help them like....3.10.1

The satisfaction and pride which participants derived from their work was palpable in the discussions. However, they were also conscious that in spite of improvements in the ethos of care towards more person-centred care, there are changes in practice which could jeopardise this quality of care.

6.4.4   Changing Expectations

Interpretation: Changing expectations refers to the ever-changing demands which are being made in the workplace of ID care settings. Change brings new demands which may be comfortable or uncomfortable. Change requires people to adapt to a new way of being/doing. Participants were faced with changes in the 'ethos' of caring due to the bureaucratic nature of the delivery of services over the years.

On the one hand, participants saw the positive changes within the ethos of caring for persons with intellectual disabilities.

There are differences. In the old days, in the past em I hate saying it but … very custodial care – protect, mind, medicate, manage, contain.. didn't look outside the box. Now it's looking at everything, how we can help the person .Old managing meant manage that ward, make sure nobody goes miss.. manage the ward.. 3.6.2

Others believed that the ethos of care remained fundamentally similar but acknowledged that the increasing trend to be more 'hands off' because of the demands for paper-trails.

Em .. .. .. I think the caring role is much the same but I think it's sort of .. I think it's more business like now. There's not as much fun in it. It's very regimental. And em you know after a while it's a routine. You don't tend to get that nowadays. Staff .. It's like staff coming now – its twelve hour shifts? .. Bathing so many people .. the chances are they are going to have a hands off approach .. the reason being is that there is so much paperwork and they can't get to sort of look after the clients. And then the care staff then are left to do it. So personally

I think the care ... t'was more the atmosphere has changed and I think it has changed for the worst.3.5.5

These changes are happening at a time when there are changing demographics in these services. Staff will be required to spend more time in their supporting of people with ID who are ageing and have terminal illnesses such as dementia.

6.5   Conclusion

This chapter presented theme one – Worldview of Care in ID. It explored how participants perceive their world and what is important to them in living in that world as professionals supporting people with ID and in particular in supporting people who subsequently develop dementia. The establishment of close relationships between participants and clients is the main issue identified. Secondly the participants identified that there was something special about the ethos of care when supporting this population. The participants also agreed that their work was meaningful even though they struggled with identifying clearly some of the key reasons why this was so. Finally they spoke about the positive and not so positive changes occurring in their world from a practical and philosophical perspective. Theme two – Worldview of loss and grief for staff in ID settings will be presented in the next chapter. Theme two is the substantive theme of this thesis.

CHAPTER 7 – ID WORLDVIEW OF LOSS & GRIEF

7.1   Introduction

This chapter presents the findings which comprise Theme Two – ID Worldview of Loss and Grief. This theme was developed from the combined re-analysis of the focus group interviews from chapter one and the analysis of the data from the individual follow up interviews. In keeping with a Gadamerian hermeneutic representation, the findings are described in terms of worldviews of the research participants fused with that of the researcher. Each theme, sub-theme and category will have an interpretation written for it. This inevitably incorporates the researcher's interpretation of an existing and a developing understanding of the phenomenon of what 'loss and grief looks like' in the world of ID as a result of an analysis of what the participants said about this at interviews.

7.2   Theme 2 - Worldview of Loss and Grief in supporting persons with Intellectual Disability and Dementia

Interpretation: Worldview of loss and grief in supporting persons with ID and dementia attempts to describe the experience of staff supporting this population. It can potentially be difficult to describe an understanding of loss or grief. The experience for staff is different on some occasions depending on the many intrinsic and extrinsic factors. Feelings of loss accompany any transition and staff in ID care experience separations from clients for a variety of reasons during their careers. Loss through death was infrequent in some services but it is increasing in general in ID as the clients are ageing and developing terminal illnesses such as dementia.

In supporting clients with ID participants were doing so in order to support them to learn new information and skills and how to maximise their abilities. With an ageing population and clients developing terminal illnesses (dementia), staff were now having to begin to explore a changing worldview with ID care. Losses were occurring for the clients with dementia and losses were occurring for the peers living with them and for

the staff who were supporting them. The experience of their grieving these losses was becoming apparent.

There were four sub-themes:
- Complex Grief
- Emotional Impact
- Disenfranchised Grief
- Coping strategies

7.3 Complex Grief

Interpretation: Complex grief refers to the intricacies of the grief experience in ID care. It is difficult to know whether grief is ever "un-complicated". Existing theories of grief attempt to provide a framework to individuals to explain 'normal' grieving. The nature of being human and having the ability to reflect allows individuals to try to fit their grieving into frameworks in order to make sense of the process of grieving. However, there is always the potential for variables to complicate an individual's grief.

Variables can complicate grief. Some of the variables within the ID care setting were: 1) To have a meaningful and long relationship with the person, 2) the complex nature of caring for someone with dementia, 3) the participants own philosophies about loss and grief.

In the sub-theme of 'complex grief' there were three categories:

Maintaining Relationships   Nature of the Illness   Personal Grief
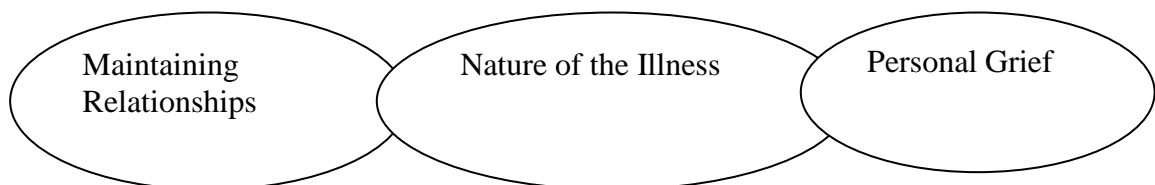
7.3.1 Maintaining Relationships:

Interpretation: The maintaining of relationships refers to the attempts staff made to keep the relationship or bond with clients after they were separated. Maintaining relationships can be challenging in any relationships. It takes commitment and energy to maintain relationships. Usually a sense of reciprocity is expected. Such reciprocity may

be difficult if there is a physical, geographical or cognitive separation between two persons. As relationships are central within intellectual care settings, the maintaining of links between staff who were familiar with the client, even if they are moved out of their 'home', was of paramount importance. Home in this context was the place where the client would have lived for the most part of his/her lives within the ID services. The bonds of attachment which staff made with clients were threatened when the they were diagnosed with or suspected of having dementia. The tension between holding on to the person and letting go of the person was palpable in the interviews and in the transcriptions.

Participants identified the difficulty of anticipating a break in that bond between themselves and clients because of such attachment. The loss of this attachment was challenging as captured in the following quote:

> .. There would be, people would be very closely attached to the client. They would have been with them for the last 2 or 3 years, they know the client very well, in some cases some of the staff might be more attached than other staff because they are more intimately involved. They would obviously be quite challenging for them, they know the person involved.. 1.7.2

Some participants felt that they had an investment of 'self' in the clients' life and when they left the service or a client moved away that they 'lost a part of themselves'. This is captured in the following quote:

> I find you become very attached to them yourself .. like the years that they're here ..you kind of have a bond with them as well like .. you're letting go some of you as well like .. 1.5.3

Although many participants spoke openly about forming relationships and attachments to clients, some of them identified that staff can become too emotionally attached. Therefore some services moved staff around annually to prevent such close attachments as demonstrated in the following quote:

> Yeh because people were becoming too attached! It was you know nearly like they were the only people in the unit that person and this is the only person.. it's like come on now we need to pull back and especially with the nature of the illness that they will decline… so yeh we change them every year so people don't

get too emotionally attached you know and that keeps people at bay .. some people can get obsessional about it. .....PAUSE ......It's not healthy .. it's not good for the service user or its not good for the carer.3.1.1

This moving of staff may be interpreted as contrary to good dementia care where the maintenance of relationships is important in supporting the well-being of the person especially as their dementia is advancing. However, it was evident that participants struggled with this, especially when it came to supporting the client with issues around the experience of loss and grief as demonstrated in the following quote:

Certain personalities take on that route (supporting grief and loss?). it's more to do with personality and you as a person than anything else you know. It's just that .. it's not that we try to discourage relationships .. we don't cos they need the relationships because we're the people they see all the time you know .. but it's just to get the balance right you know. The balance is important you know. 3.1.1

Participants considered that for a broad range of reasons, persons with dementia ought to be cared for within the ID service and within an environment which would benefit them best in terms of their changing needs. However, they recognised that as the overall care needs of the client increased they were having to consider whether they could deliver in their home the care they desired to give or whether they had to consider moving them to a more suitably resourced environment which would enhance their care. They wanted the person to be moved once only and to another unit within the ID setting, not to an outside or non-ID setting such as a hospital or nursing home. They considered that the person would not be understood or as well cared for outside of an ID setting. This is captured in the following quote:

I think the letting go thing.., normally in general nursing you are dealing with people for a 3 or 4 week period ..whereas in our form of nursing you are dealing with them for 4 or 5 years. we see that all the time.. That the people (staff) that are so good just find it really, really hard you know, that sense of ownership.. 7.1.1

The notion of ownership was strong even between the different settings within the same ID service. Participants from the community settings found it equally difficult to move the person back into residential care as demonstrated in the following comments:

But the staff find it very hard to let… let go… 10.1.3

Oh you do. 10.1.1

Ah yeah. 10.1.2

In particular, one issue which upset participants when they did eventually move the person was that they no longer felt able to 'care for' the person because the staff in the other setting were now doing that. Although the participants were all from the same ID service, the participants felt helpless that they could not continue supporting the person. There appeared to be an unspoken expectation that the staff from the 'old' setting stopped being actively involved with the person as captured in this quote:

Once the client moves on we're nearly cut off.. 10.1.1

Participants desperately wanted to keep in as much contact with the daily lives of the person should s/he be transferred but found it logistically impossible. Their sense of loss was palpable as demonstrated in the following quote:

It's just physically impossible to get around to doing it because you've other needs in the house and there are things going on but you actually feel the loss sometimes.. 10.1. 3

Some participants felt guilty that they were reneging on the person with whom they had formed a close attachment. This is captured in the following quote:

.. so its very sad in a way cause you've sorta said we'll be with you and everything and yet you're not able to look after them anymore and they have to be moved .. and while it's for their general good .. on a personal level it's kinda .. especially when you obviously get attached to the ladies you know and .. 3.1.5

Participants acknowledged that they did let go, even if reluctantly, when they no longer felt that it was in the best interests of the client. They still acknowledged that this was very difficult to do and that they had to suspend their own emotional turmoil to cope with same. This is captured in this quote:

We knew her so well.. just to see her slipping you know.. you understand the illness but its so hard as a carer. It really is hard to let go… but you do.. but there's a sadness in you .. you want to make sure that that letting go is the least painful for the service user and you're inclined to shelve what you are feeling ..3.5.2

It was important for participants to maintain that bond with the clients when they were facing their demise, so that someone familiar to them would be with them when they were dying, whether that was within the ID service or out in a hospital. Any time they spoke about having had a death on a unit they inevitably said it was no problem if it was an uncomplicated death and that staff were present. The fact that the person did not die alone and that there was someone there with them who knew them was important to participants. The following quote was said with a sense of satisfaction:

.. it was just a gradual thing ..so staff were with her every day and there was none no problem .. no problem .. she still died .. but like staff were there.. (3.1.7)

While participants were saddened that clients had to be moved away from their home, they stayed in contact with them. They actively followed clients when they were transferred to non ID outside places of care. Participants on one site were upset that the client was not receiving the person-centred care which he had when he was with them. The participants went to visit him in their own time, again demonstrating commitment beyond the call of duty and more in line with a filial love for the person. Participants spoke of the client with implicit or explicit language or feelings of 'love'. Filial love equates to parental love - is conditional but captures a particular type of committed dedicated love. The person had particular likes which were not being attended to as far as they were concerned so they continued to visit him every day until he died in order to meet these needs:

.. he was transferred to a nursing home near his own home .. and em like that again the day services and his home staff would just have kept going every day (2.1.2)

Although participants seemed to accept that they were no longer the primary carers when someone was transferred to another setting within the ID service itself, they continued to visit with clients for years even when those clients no longer recognised

them because of advancing dementia. They also considered it important to bring old friends along in order to keep the peer relationship alive. This contact was maintained in spite of the fact that they said it was difficult because of the extra resource issues especially around staffing. This is captured in the following quote:

> *..a good few years now. .. About 2½, nearly 3 years and they still visit on a regular basis..* (*10.1.3*)

In early or mid-stage dementia, participants did not want clients transferred within their own service even for short periods and actively ensured that the clients returned to their own 'home' as quickly as possible. The bonds of time which the participants had established with clients were palpable when they spoke about how difficult it was to let them go even for these short breaks. There was humorous banter between participants as they discussed the advantages and disadvantages of transferring people for respite breaks within their own organisation. It was possible to send the person with ID/AD to another part of one service for more one to one attention during an acute medical crisis. When participants stated that they could take clients to such units and give them more of this one to one attention, the participants from the home site stated in a half joking but at the same time serious manner:

> *You could .. yeh .. you'd have to get through the door first ! 1.3.7*

This friendly 'tug-of-war' among the participants continued if the person was transferred with both sides believing that their setting was the best for the person. While the staff in the home of the person accepted that s/he would get this one to one attention if moved, they made a concerted effort to ensure that s/he came 'home' as soon as possible again. The following quote demonstrates that they went to extraordinary lengths to bring the person home:

> *.. but you know like I have one in particular there not so long ago and I had to fight .. I was going "ah no" she can go home next week .. they just took her back to her unit! she was gone back to her own .. she was gone back to her home that week-end.. (while the staff member was off duty).1.3.5*

Over the trajectory of the illness, participants also bonded with the kinsfolk of the person with dementia. They supported the person together. Participants appeared to

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experience a shared sense of loss with the kinsfolk of the person as demonstrated in the following quote:

> *the staff would have been very distraught, you know, maybe distraught is a bit strong but they would have been very, very upset and I suppose there would have been very close relationships… that families would be coming down so therefore they would know the staff quite well. 3.11.1*

Participants also recognised that they had issues around maintaining relationships with the kinsfolk of the person with dementia. They particularly spoke about their sadness that they lost connection with them after the person died as demonstrated in the following quote:

> *We just had a great relationship with him .. and with his family. His sisters used to come visit every day. One sister used to come every day. So you see if you're building .. if you're seeing someone for three years and you're seeing them people three times a week you do build up a relationship with them and with K, like I mean .. so I was a bit sad I suppose because that whole connection with the family was gone .. 3.1.1*

In summary, the participants endeavoured to keep the relationship/s among themselves and persons with dementia and their significant others as intact as possible in spite of the varied circumstances which were experienced in their having to move them from their 'home'.

7.3.2 *Nature of the Illness*

Interpretation: The nature of the illness refers to the trajectory of the illness that is inherent in dementia. The nature of the onset, diagnosis and progression of dementia is fraught with uncertainty and this is more complex when the person has an existing ID. There are many complexities in the caring for someone with dementia, and there are challenges for the client and the staff. Multiple losses are incurred by the person with dementia and their carers. There is unpredictability about the nature of the course of the illness which impacts on the experience of loss.

The loss of skills of the person and the loss of a familiar place ('home') were of particular concern in relation to experiences associated with loss and grief. Equally the losses associated with advancing dementia were of concern. This category had three sub-categories.

Losing Skills	Loss of familiar environment	Unpredictability of the illness
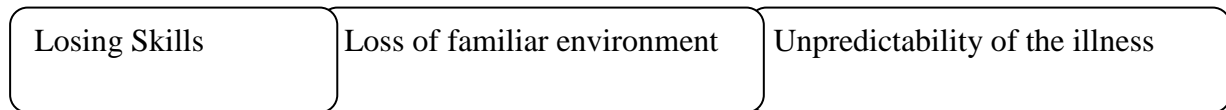
Losing Skills
Interpretation: Losing skills refers to the decline in the abilities and functional capacity of the person with advancing dementia. Cognitive decline in the person with dementia gradually erodes the memory of the person's being able to remember how to recognise family and friends, how to execute many psycho-motor skills or how to react in an emotionally appropriate way on occasion.

To observe an individual who was able to 'do' something, lose that ability, can be experienced with feelings of sadness, hopelessness and helplessness. In the ID setting participants had been with the client up to twenty years in some cases and had taught him/her many skills over that time. Now they were watching this individual lose those hard earned skills much more rapidly than they had acquired them. This is captured in the following quote:

> *had regressed nearly to the childhood stage really and that's quite difficult to watch.. 10.1.5*

In the focus group interviews, participants often started to share their experiences of working with a particular client. They did not always explicitly identify that they were experiencing sadness when remembering the person but they spoke in a quiet gentle manner and looked sad when saying:

> *.. when she came to us first she had the album with everybody and you'd say where's mammy or where's Tom, Dick or Harry and she'd point.. now you'd hand it to her and she looks at you as if what's .. that's gone .. it's gone you know .. 1.3..5*

Participants reminisced among themselves about clients and how they were sad to observe them experiencing such loss of independence. This is captured in the following quote:

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.. he was so active before .. 1.6.3

.. yeh ..he was so independent like, he was a free spirit .. you know.. he could come and go ..and all that .. and it was terrible sad to see it .. 1.6..4

I remember going back a good few years I was on nights and he would go from one side (of the service) to the other and you know he would know left from right (how to get around the grounds). That's how as independent as he was .. he was able to do a great deal .. but in a short space of time he lost that ...1.5.1

The direct impact on the participants was palpable and they admitted that they cried on occasion when they witnessed the obvious deterioration of the client, perhaps the social death. This was evident from this comment:

Depending on the nature of the dementia two and three quite notable stages – person going, person still there but struggling, the person you knew – little mannerisms, they lose them.. that's very sad .. there are times when you cry .. It's hard .. only a year ago I was taking her to a Shopping centre carrying out her assessments, her ability to buy her bits and pieces – now she's in a wheelchair and she doesn't recognise me anymore! 1.2.1

Participants also felt sorry for the losses experienced by the kinsfolk of the person in relation to this loss of skills and the perceived social death. This captured in the following quote:

..looking at them they are losing more and more as they go along .. skills and all sorts of things that they had ..even from 6 months ago, so the loss of their independence and all that they were to their families and the family are beginning to feel that they've lost them at this stage and that's huge. I feel a lot of brothers and sisters and parents feel – well he's not there anymore.   That loss for them is very different, they are not dead yet.. they are still there to them. 1.6.1

In summary, this loss of skills for persons as their dementia advanced was felt deeply by participants and kinsfolk.

Loss of Familiar Environment

Interpretation: Loss of familiar environment refers to the 'move' of the person with dementia from their 'home' to another environment when they could no longer be supported at 'home'. The most familiar environment for an individual is usually his/her home. For any person to be removed from his/her home to a new one is disorientating. For the person with cognitive decline (dementia), this may be very disorientating and invoke negative consequences. These negative consequences may be experienced by the person with dementia and also by those most directly affected by the move. These include family or significant others in the life of the person. In the ID care setting, staff may be the significant others who experience this loss and grief.

Regrettably, it was necessary to move clients from their 'home' (familiar environment), because of their changing needs (advancing dementia care needs). This was one such loss which the participants experienced for the client and for themselves when the client was moved. Participants also perceived that transferring clients to outside agencies after spending a lifetime in their service was of no possible benefit and could be potentially traumatic for the client. The following quote captures this:

> *I don't think they would benefit from that. .. Because they are in that place for how many years now and how they have been there for a long time, they will get confused if you change their environment .. 2.3.2*

Some participants recognised that it was also traumatic for staff when such change happened as evidenced in this quote:

> *.. And where people will have worked alongside someone on a unit for a number of years and then move .. (looked at the floor and spoke very quietly and looked sad) .. 3.11.1*

In summary the participants perceived that observing of the loss of skills and the physical loss of the person from their care to be a potential loss and grief experience.

Unpredictability of the illness

Interpretation: Unpredictability of the illness refers to the changing nature of the illness that does not necessarily allow for the trajectory to be anticipated. As with any long-term illness, there is an increasing immobility with repeated health and well-being

events requiring medical and inter-disciplinary management. The anticipation of the worst outcome (the client's demise), of any acute event such as a chest infection where there may be a transfer to a hospital may generate a sea-saw of emotional reactions associated with the recovery (or not) of the client.

This unpredictability of whether a client would be ill again or whether s/he would die on any given occasion after a health crisis continues throughout his/her life with dementia. Participants struggled to come to terms with this continuous threat of illness and the on-going struggle of the person to survive. The following quote captures a common finding:

> *.. she was getting one chest infection after the another, she was rushed in .. into hospital and she would nearly have a bronchospasm & she'd have you know aspirate pneumonia and she'd be sent in to X(Hospital) and then you'd think this is it she's not going to make it then she'd rally and she'd come back and you'd sort of say oh my God she's still with us, you know that sort of way ..*
> *1.2.1*

In acknowledging the long trajectory of the illness, the participants spoke about the impact on themselves as they watched the client decline. After every acute episode the client had deteriorated – more of him/her self was lost and s/he would never be the person s/he was before the event. There was a sense of unreleased emotion as captured in the following quote:

> *..Yeh and that's another aspect of it we know this client and been with them and then we see them going into the dementia and going down like you know but it's a long road and its very hard at times to… its like they're our own really and truly we've known them so long and we've been with them or around them and then to see them going down ... (tears in eyes) 2.1.1*

Participants working in the purpose built unit for persons with Alzheimer's dementia, described how the unit was originally expecting to have persons transferred in and that they would die within six months to one year. However, they found that in practice the clients lived much longer. This finding was mirrored across all of the services and is captured in this quote:

I suppose the length of people being here was a lot longer than we ever expected ... there was people moved in to the unit and died 2 or 3, 4 years later where they were only expected to be here for 6 months or a year and they actually…. I suppose .. so when they hit the terminal stage it went on for much longer than any of us ever expected it to.... 5.1.2

In summary, the participants were travelling a long and unpredictable road with their clients and they were struggling with the inevitability of death from a terminal illness with an unknown trajectory and with the challenge to maximise the quality of living for their clients. During this journey the participants were experiencing loss and grief at a conscious or unconscious level and this was potentially influenced by their own previous experiences of personal loss.

7.3.3   Personal Grief

Interpretation: Personal grief refers to the unique personal experiences of staff in relation to loss and grief. Personal grief will usually be experienced by all persons at some time in their lives. Professional carers may or may not have experienced personal grief during their career. Grief is experienced by the individual in his/her own unique way. The impact of personal grief may or may not influence how staff experience professional grief. Staff who work in ID may potentially find it more difficult to distance their 'personal self' from their 'professional self' because of the nature of the relationships they form with their clients.

The participants spoke about how their own experience of loss, grief and bereavement helped them to be able to talk about death with other colleagues. They furthermore recognised that the experiencing of grief and coping with death is a reality of life as captured in this quote:

I have lots of experience of loss and grief in my life…. …can't make it go away. I find it works if you're very supportive. I try to tell staff that 'believe it or not you are going to go on from this (experience of death). This is important that you go through this! And you'll grieve from it! This is life and this is what happens'. 3.2.1

Furthermore, participants also explicitly stated that in addition to their experiencing personal grief it was beneficial to have undertaken education on loss, grief and bereavement. Such education was of personal use to process personal grief and subsequently useful to support others professionally. This is captured in this quote:

> *On a personal note I lost my mother when I was a child. I was only x yrs of age and my father reared us. But when I was doing the care of the elderly course in y and part of the course was grief and that sort of thing. A workshop thing and it was the first time in years 20 yrs that I opened up and felt that that pain... That helped me you know to help others 3.4.1*

In summary, the sub-theme 'complex grief' presented how the maintaining of meaningful relationships for the person with dementia, the nature of the illness and the potential losses associated with it and the influence of personal grief can complicate the experience of grief for staff in the workplace.

7.4 Emotional Impact

Interpretation: Emotional impact refers to the many emotional reactions experienced by staff as they supported the person with ID and dementia. How an individual expresses or represses emotions may be personality driven, culturally driven, gender driven or otherwise. However, suffering, observing someone close suffer or the event of a close death may often legitimise a reason to publicly display emotions such as sadness, relief, anger. These emotions may be experienced at different times from diagnosis of dementia up until the demise of the client. These responses may be triggered by events (real or imagined) in which potential separation from the client or a severing of the relationship is anticipated. Strong emotional responses may be experienced for staff in ID (because of their close relationships) when they witness a person 'suffering' or declining with a debilitating illness.

In the sub-theme of Emotional Impact there were two categories:

Sadness   Mixed emotions
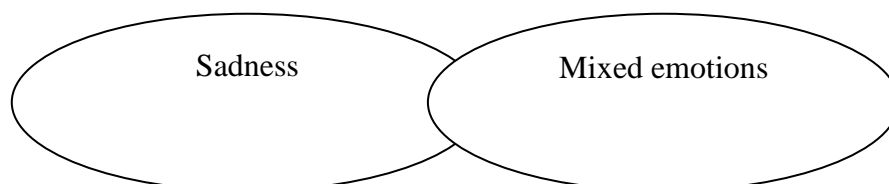
7.4.1   Sadness

Interpretation: Sadness is an emotion which can be experienced with any loss and does not have to be associated with death only. It can be experienced for one's own losses and for the losses experienced by and for others. A powerful experience of sadness may overwhelm a person. This overwhelming experience of sadness may be expressed in crying, withdrawal or may be covertly experienced in silence. The extent varies in intensity and duration; however, these are unpredictable.

The strongest emotional response in the interviews was one of sadness at the perceived suffering of the person with ID who was declining with dementia. This resulted in a tension which brought about emotional reactions and a tension between 'not crying' and 'crying' as they struggled to watch their perceived suffering of the person with dementia. The following quote captures this emotion:

> *Very sad, very sad, very sad .. and you know that that's the nature of the illness and you try to be very clinical about it and you are .. 'this has happened now and that's the way it is .. so .. but it doesn't stop you feeling… and it's different at times.. and you're reluctant to admit it. You feel you're a staff member and above all that.. but you don't. But there are times when you feel really really sad.3.6.2*

Suffering refers to the participants perceptions that the person with ID and dementia was in physical, social, psychological, emotional or spiritual pain. Physical suffering is usually visible; very often pain, whether physical or emotional may be the source of suffering. To observe an individual suffering may impact on caregivers and generate strong emotional responses.

Participants questioned the possibility that the clients with dementia suffered physically and emotionally as they declined. They felt helpless because they perceived that they had done their best to protect the person from physical or emotional hurt/harm all of their time working with them over the years; now they were doubly vulnerable with the dual diagnosis of ID and dementia.

Participants expressed the raw emotion of grief in the light of what they perceived was this suffering of the person in the days before their demise. This is captured in this quote:

> *You come away and you're physically sick.. you wonder what suffering ... you're grieving that and you're grieving the loss of the person .. she was some character .. wonderful (smiles brightly)..3.2.1*

The tension as to whether to cry or not to cry was evident in the discussion in the interviews. This tension which participants felt was about whether to display their raw emotions when they were next to tears. Whether an individual is a 'crier' or a 'non-crier' may become evident to him/herself at some point in the individual's own personal growth when s/he identifies his/her own strengths/weaknesses, coping mechanisms and personality traits. It may not matter if an individual cries at a social event such as a film or a wedding. Crying can benefit an individual by releasing emotions. Crying can fulfil a range of emotions such as joy, sadness, relief, suffering or frustration. However when an individual enters the workforce there may be social or professional mores which dictate whether it is acceptable for him/her to show emotions or to cry 'on the job'. Participants in this study experienced a constant tension between experiencing the strong emotional impetus to cry and the need to balance this reaction with not crying.

Participants reported surprise that very experienced staff whom others did not expect to display emotional responses, had on occasion cried when they realised that they could not support the client's needs and were traumatised by this because they felt at a loss and experienced the loss of the person from their life.

> *.. staff who would be regarded as hardened staff were actually crying in a particular unit where somebody .. it was a unit for people with dual diagnosis and they felt .. the service didn't have the support a person needed and the person was transferred down the country back down to his catchments area and staff – male staff – in particular were crying 3.5.1*

Participants were taken by surprise that they had such a strong reaction as crying when they knew themselves to be non criers. Reflecting on it, they acknowledged that the bonds of affection which they shared probably influenced the reaction as demonstrated in this quote:

I tend not to get upset in front of people.   I don't think I ever, I never thought I'd let it get in on me, I think one of them affected me the most. So much so that my family even saw it.   That it really affected me and it wasn't till I went home after the funeral that I absolutely lost it, I got so upset. I lay on the bed and I roared, absolutely, I was like what is wrong with me why can't I stop crying.. That never happened to me before and since I've been here you know I'd say at this stage 80 deaths but just one individual in particular that really, really now affected me I suppose. I don't know why, I suppose I was very attached to her 3.10.1

There was an acknowledgement by some participants that tears were going to be inevitable as part of the supporting of this population as they aged, developed dementia and died in the services. The following quote captures this:

.. sometimes you are just crying because you are just exhausted and sometimes because you don't know where to turn really.   But you know I know there's going to be more tears put it that way and you know I suppose we'll just have to cross that bridge when we come to it really.. 3.8.1

Other participants could feel the benefit of sharing the grief overtly with the kinsfolk of the person. They considered it beneficial to be able to express their grief rather than to repress it as demonstrated in this quote:

.. if I'm crying .. I didn't hide .. I didn't feel there was any problem with me crying. It didn't upset me. It didn't make me feel bad that I was crying. Absolutely not ..and I actually felt in sympathy with the family and with the woman .. so I didn't feel at all! (that there was a problem with crying). I think it was actually good... 3.6.1

Experienced participants who had witnessed many deaths were still finding it difficult to cope with the grief and loss experienced after some of those deaths. They became very emotive when recalling the event and what it was like to realise that someone you cared for so deeply had died. The realisation came when they were breaking the news of the death to a family member. This death had occurred years before this interview but the emotions were still very raw. This participant said:

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.. I was actually realising it was real, you know, because you put on this cap ..
put up this block.. it's your job to do this.. I'll never forget that as long as I
live.. had to ring and tell her brother over the phone..   And it was so hard
because it was the first time I was actually saying it .. (crying+ in the interview)
3.2.2

The experience of feeling sad and or crying therefore was experienced across all sites and for a variety of reasons associated with the supporting of persons with dementia. The overwhelming emotion expressed was sadness but there was also expression of other emotions which will be briefly presented below.

7.4.2   Mixed emotions

Interpretation: Mixed emotions refers to the range of emotions apart from sadness which was experienced by staff in ID settings. It is possible to experience many emotions at once: 'crying with happiness' or 'guilty and relieved'. Emotions come unexpectedly and it takes practice from childhood into adulthood to learn how to manage them appropriately.

While sadness and the tension of crying/not crying were the overwhelming emotional responses, other emotions were also expressed. These included anger and frustration, helplessness and moral distress, guilt, emptiness and relief.

The participants expressed anger about the person with dementia being transferred to hospitals to die. This participant was angry about a client who was known previously not to have liked change in his life. S/he said this in an angry tone:

Because I don't see what staff in a general hospital could do for him. You know
in all honesty. You know he has brothers and sisters who come in to visit him
and it doesn't seem right for X like you know I mean he's going through enough
and like say he has a lucid moment in hospital and he's thinking where the hell
am I now? And there's nobody there to reassure him or nobody there for to like
sort of say certain things to him that would have been important to him during
his life.3.5.1

The participants also felt helpless on occasion and experienced moral distress when they could not (because of resource issues), cater for the person's needs at end-of-life. Some participants lived with this moral distress for at least two years after the death of the client. One participant said:

> *So that to me nearly killed me. I was so upset over that because I felt that we had let her down, that she had been in care all her life and that the last few days that she had here that we weren't able to do anything for her properly. I thought that was, that to me now was my grief. And it took me a while to get over that. I feel to this day just, it should never ever have happened .. 3.7.1*

This helplessness led to feelings of guilt when the participants made a decision to move the person, even though they knew intellectually that it was in his/her best interests.

> *... it's an awful guilt trip ..1.3.1*

Participants experienced an emotional 'emptiness' when the client died which they found difficult to articulate as noted in the following comment:

> *If any of them get sick or they die it's like losing one of your own like .. now we're not going down the corridor bawling crying .. but there's an emptiness there and it takes a long time .. you never forget them certainly. But there's a sort of a .. it's a void! .. 3.4.1*

Crying was not always as a reaction to the loss of the person or the relationship. On this occasion the participant cried with relief that the person was no longer suffering as they perceived him/her to be:

> *.. but I actually cried with relief 3.6.1*

In summary, the participants experienced a range of emotional reactions in their supporting of persons with dementia which are similar to the emotions associated with experiences of loss and grief in general.

7.5   Disenfranchised Grief

Interpretation: Disenfranchised grief refers to the nuances associated with grief that is not publicly legitimised in the ID care setting. When an individual has died it is accepted, in most situations and cultures, that grief is potentially experienced by

individuals who were significant to the person who died. Who/what determines who was significant to the dead person may be dictated by social, cultural mores. Whether a professional paid carer is deemed significant in a given society or culture may be varied from one culture/sub-culture to another. Furthermore, it may be questionable as to whether an organisation or professional body would view it appropriate for a healthcare/social care employee to grieve publicly for a client who dies in his/her care. Historically, professional training encouraged a private/public or personal/professional divide to be maintained by the healthcare worker in his/her clinical practice. Furthermore, kinsfolk of a person with ID may have diverse opinions of whether paid carers are significant but can publicly share their grief together.

In the sub-theme of Disenfranchised grief there were two categories:
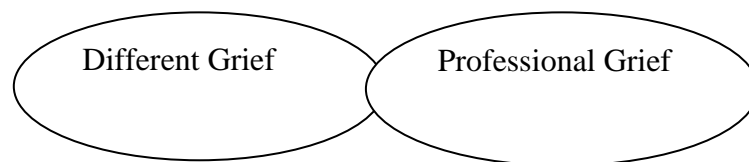
7.5.1   Different Grief

Interpretation: Different grief refers to the nuances of what is different in the ID setting. The debate about who is significant to the person with ID who lives in a care setting is interesting. Nurses and carers deliver 24hour care in these settings. They live, eat and sleep in the one house in community settings. They know each other's mannerisms, likes and dislikes in food, clothes, hobbies and in many more aspects of their daily lives. When one member of the unit becomes ill, changes identity (dementia) and/or dies, the remaining members of that unit experience changes in the make-up of the relationships at the very least. These changes generate emotional responses and ultimately generate grief reactions for that transition from what was to what is now. Each such occasion is a unique situation and potentially a unique grief experience because of the centrality of unique relationships within this setting.

The participants acknowledged that there may be such grief in ID settings as evidenced by the following quote:

Probably because they build up more relationships with them because if you're in a general hospital you don't really get to know anybody. D'you know. People die and they're gone within the hour. It's different in ID because you know the people, you've built up a relationship with them. You probably know them for more than a year so of course there's going to be more grief issues… 3.1.1

Participants working in an ID care setting perceive themselves as in a different role to that of their working in a general health care setting when it comes to dealing with the death of a person. This is evidenced in the following quote:

I remember like the first time I actually laid out a body in general and the difference like it was just, this was in ICU and all of a sudden a person died. I didn't know him, I barely knew his name, I had to ask what his name was, you know, it was so different… I think it's so much more personalised and you know it means a lot more I think, you know to provide a good death… but you know I think here it's so different. That's why I think the job is so different…3.10.1

The grief may remain invisible in the world of one's supporting a person with ID who develops dementia. If grieving is disenfranchised, then it will go unnoticed by many. Participants who support persons with ID who develop dementia, potentially experience losses associated with the person's decline, their own reactions to observing and coping with this decline and to the ending of a relationship with the person (move away or death). The following quote captures the potential invisibility of this grief:

Yeah, em its hard like when you are out there on the floor, it is, its very hard and .. I suppose you are there what 39/40 hours a week you know spending most of every day in work. So it can be hard. It can't not affect you I don't think. 3.11.1

The inevitability of grief reactions was felt albeit that at an intellectual level participants were aware that overt grieving would not be an expectation of the organisation in which they worked in. This is evident from the following quote:

Well because of the area you work in personally … you will grieve, that's the simple thing about it, you will like …we are told you can't here. It would be frowned on if you are upset because somebody died, at all, but it happens anyway, it still happens. Because you do build up a relationship with

people.3.9.1 (knew client 20+ yrs from std to cnm2) I must have had it about 30 years, worked with her, 3.6.1

Furthermore participants in ID care are heavily involved in all of the organisation and management of the person's funeral following his/her death. Because their own grief may be invisible they may experience a feeling of an anti-climax at the end when they perceive an expectation from the organisation to continue in their role as if no death has occurred. This is evidenced by one participant who said:

I had arranged this lady's funeral, I had done everything, readings, and I did everything and I think it was the build up of that and if you are doing something like that on your own, we arranged mass books, choir, we arranged speakers, I wrote a piece on her, I rang the priest to inform him what she was like because he wanted to talk about her. Made sure people knew and they were at the funeral all that and we had senior staff crying their eyes out, you are not supposed to, you go and bury the lady, come home and then suddenly find you are at a loss. She's gone and you are after being…, it's like arranging a wedding you do all this arranging and there's nothing there at the end of it. It's like an anticlimax thing but that's the loss for me, they are not there at the end like.. 3.10.1

The participants had identified in the previous chapter that they held different 'family like' relationships with clients in the ID services. Filial grief refers to the grief staff experienced as if they were in the role of a parent with the person with ID. Historically, the ID services took the child into care to support him/her and inadvertently pushed* (*methaphor) the parents away because the services perceived themselves to have the expertise to improve the life of the child. The culture of 'children in hospital' (non-ID), was also to advise parents not to visit the child in short-term stays as it was regarded as too upsetting for the child when the parent/s visited and then had to go home and leave the hysterical child behind. In the ID setting for long term-care this may have potentially resulted in staff becoming replacement parent-figures. However, most parents naturally try to protect their child from harm. Staff in ID care, although knowing theoretically that it is not encouraged in the philosophy of care to act like a parent, may inadvertently assume the parental role in order to protect the person they see as as a vulnerable child.

Some participants spoke of the client in terms of his/her being almost like their child, even though the person was an adult/ a mature adult. They related like a parent to him/her and did not want to sever the links they had with their 'child'. One participant commented:

> *I was working 10 years in y unit (care of the elderly/ dementia) I was promoted. I was very lonely leaving .. there was a few were my babies and I was leaving them and I was really lonely. I kept going back and forward and then I thought that's that you can't keep going back .. 3.3.1*

Some participants recognised that grief reactions could re-emerge at a much later date if they were not expressed at the time of the death.

> *I've seen it with other staff in the community and a lady might pass away in a house it's what happens afterwards. It's not,.. sometimes the death itself and the immediate time afterwards is nearly the easy bit in a sense. Because you just have to get on with it and get over those few days. But it sometimes happens it might be six months down the line something might happen I think and would, something very simple or you mightn't sleep or there could be something that just kind of creeps up on you. It's a very strange thing.. 3.8.1*

Sibling or friend grief refers to the grief staff experienced as if their brother/sister or friend had died. Within families siblings can assume roles of responsibility, care and concern or indeed the opposite. Indeed, siblings may feel obliged to look after each other, especially if parents are absent. Many friendships evolve and become the family an individual chooses for oneself. Therefore, the grief for a friend may be experienced as similar to that of the grief experienced for a sibling depending on the nature of the relationship.

Some participants used sibling terms for the clients and perceived that as they lived together as family units that this bond was similar to what may be experienced in their own family context. Participants observed among themselves that these 'sibling' relationships developed between carers and clients and that the grief reactions mirrored what they considered may be the reactions among siblings in an ordinary context. One participant commented:

.. one of our care staff P .. she is like a sister to her, I pity her that day ..the whole day she was crying 2.3.1

Grieving for a friend also arose together with sibling grief reactions. Participants recognised that once the person died, they had lost more than the person from their lives. They had lost the friendship as captured in this comment:

I suppose its where you lose that friendship more so, you know, you know someone is going to, they are at the end and they are going to die and you think you are prepared but its the loss of the friend, of the actual relationship that you've had with them. But it's not until they are gone that you know that it's the relationship that you had with them that, my understanding of the loss would be. It's not that they are not there, it's that friendship that you've built up with them .. I think... 3.10.1

In addition to filial, sibling and friend grief, peer grief was identified by participants as a grief which can be disenfranchised. Peer grief refers to the grief potentially experienced by a client from the ID service when another client from the 'unit' dies. The clients live together in an ID setting and they belong to a common club. The club, which supports them because they have an ID. Often they may have come in together around the same time to the service and become lifelong friends/colleagues. They live in these 'family' units for many years. Whether peers are considered family when the person dies in relation to experiencing grief reactions, is potentially complex.

Participants in some sites acknowledged that peer grief could be disenfranchised as noted in the following quote:

... yeh and it's a grieving process for them as well .. and often they're forgotten about as well in the whole thing .. 2.1.1

However, participants acknowledged that when a client dies, the family unit where they live is disrupted and the remaining clients are exposed to the experience of the loss of one of the group members.

No, it's more that somebody.... It's more somebody has departed from a group of people - peers 3.9.1

Participants across the sites had different opinions about whether the peers, (of the person with dementia and who was dying or had died), experienced grief and grief reactions. In general, participants considered that peers with mild to moderate ID could experience grief as stated in this quote:

> .. they suffer.... some more than others .. (3.1.5)

Some participants considered that the extent to which grief and loss was experienced by peers was limited. This was particularly evident in the context of peers with severe to profound ID or when they were late stage dementia. Such consideration arose from their view that their clients would not understand illness, death and dying and therefore that they did not have loss and grief needs to be met.

> ..I suppose .. it depends on the ability you have .. you're caring for .. but I mean as of now .. the ability of ours (moderate - severe ID) .. they don't understand .. they're quite happy to do their own thing .. they seem to be very independent and they seem to be immune .. 6.1.1

However, other participants were beginning to re-visit their opinions about clients with severe or profound ID and whether they experienced loss and grief. This is captured in the following quote:

> .. well it's amazing .. the lads sense it or whatever it is .. whatever it is .. there's a silence around the place .. it's amazing .. honestly .. (6.1.4)

Some participants were actively reflecting on whether the peers had unrecognised grief as demonstrated in this quote:

> .., I would have worked in the largest unit and the ladies would have been quite exposed to death and dying over the years of other ladies that would have lived alongside them. and sometimes I nearly felt it was how they dealt with it was very matter of fact. Whereas sometimes I just wondered did we have it properly understood.. 3.11.1

Watching the peers of the person grieving for their 'friend' who is alive but because of their cognitive decline does not interact with them anymore, was challenging for some participants. This quote demonstrates this:

Yeah, oh god its so, I'd have to walk away now. Because for them its not, they are like, they think she's dead in the bed because it's not the person they remember sharing the rooms and having the fights with, having their dinner with every evening. And to see them trying to rationalise it around the bed and their carer and staff who have been in that house for 30 odd years .. It's so sad to see that, you know, I suppose we feel their loss, they've lost their friends already, it's very, very obvious to see that. It's very hard to witness it, it's horrible. 3.10.1

Furthermore, participants recognised that if there were special bonds of friendship between the dead person (or the person who has been moved out) and another client, then the remaining client can be deeply affected.

But I was saying, R, that time she got really ill and she had to leave us they were very upset over it but particularly M because M would have been her closest friend in the house.. 3.7.1

In summary, the category of 'different grief ' explored the findings which demonstrate that grief in ID can be different from grief in other healthcare settings, it can be invisible and it can be experienced as a loss within a family dynamic or within a friendship dynamic for staff and peers of the person who dies.

7.5.2 *Professional Grief*

Interpretation: Professional grief refers to the acknowledgement that as paid health and social care workers, the staff experienced grief for clients. Professional education and training can be undertaken to acquire cognitive and psycho-motor skills. It is more challenging to educate and train individuals in professions in the affective domain. Counselling skills can be taught in anticipation of an individual being required to support a client in coping with loss and grief. However it is not until an individual is faced with a situation which challenges his/her emotional reactions that the individual knows how s/he will cope. Therefore staff, when faced with the death of someone with whom they have had an emotional bond with dies, potentially may experience emotional reactions.

The participants appeared to feel an obligation (perceived or real), to maintain a professional decorum in relation to their personal reactions when they were experiencing feelings of loss and grief. They appeared to work hard at not crying in front of kinsfolk even though they felt very sad. However, in the interviews some participants cried when remembering occasions of the deaths of the person. The following quote captures such an occasion:

> *...   I don't know, I honestly don't know.   As I said ..that stuff is normal.. I think if you took that way it would be abnormal, you know, because when you are that close you have to be upset anyway.   But you do remain professional because that is your job. So you do remain, because you have to be the support for the family...   (Crying) ... sorry I don't know where that came from .. 3.2.2*

The participants spoke about the tension of one's being and one's behaving as a professional doing a job and then having to keep a professional distance as taught in training college versus being involved closely in a more personal way because they have a bond with the person. This is captured in this quote:

> *... that's what I was taught in college, you know, you don't, you are not in a sense supposed to but you just do.   But when you are here like you are involved in every aspect of somebody's life and even I suppose if someone is deteriorating especially with dementia they are really fading away in front of you...   this is somebody you've cared for, for 12 years ...3.8.1*

This tension in the effort to keep a professional distance and to manage an emotional involvement was repeated by participants across settings time and again. The following quote demonstrates this:

> *From a work point of view something similar but it's because you have to be professional about it and you always have to be seen to be not overly emotionally involved and that's the whole thing about this job.   You try to be professional in your approach to everything you do but its the type of job that you do get drawn in and you do, you cannot just be one person, you know, you are the whole package.   And you have to, if you weren't' emotionally involved in some respects you wouldn't be doing the job simple as, if you weren't passionate about it or if you didn't really care you wouldn't be here. So I suppose when it comes to loss and that you have to be seen that you are being I*

suppose that you are dealing with it professionally and you know I suppose correctly in a way to the outside world but inside it's a different story again.. 3.7.1

The participants acknowledged that irrespective of the professional relationship, they grieved for the loss of the person and the relationship which they had with the person. One participant commented:

.. and because you're professional like I mean I think it's ok no matter who somebody is em you know for to sort of grieve. And you don't suddenly sort of have . you knew somebody .. sort of a bullet vest .. that's to protect me from all that's coming at me .. 3.5.1

On occasion participants were taken by surprise that they were overcome with an unexpected emotional response. The following quote reflects this:

.. I don't know where it came from ..but I would, I would put on this exterior and I think that's why it surprised me that I got so upset over that woman dying.3.10.1

Some participants felt that they could cry for a client who had died, in the presence of a few of their health/social care peers. However, they did not appear to acknowledge explicitly their grief to others outside of their own immediate work setting/unit. This is evident in the following quote:

Like there's a lot of people and you just don't have that conversation with them.. (how you feel about a client's death). They wouldn't know what you are talking about and they wouldn't be able to cope with it. Em you know so you have to keep it to yourself. 3.5.1

In summary, participants experienced disenfranchisement of their grief because the experience of loss and grief and is experienced differently for staff who work in ID settings from that experienced in other settings. Furthermore, professional grief is complex in these settings due to the close personal relationships between clients and staff.

7.6   Coping Strategies

Interpretation : Coping strategies refer to the many ways staff used a range of strategies to help them when they experienced feelings of loss and grief. Individuals use coping strategies throughout their lives in order to manage many stressful situations. Coping strategies may include hope, denial, humour, music, work and many more. The human condition is very resilient and individuals may employ a range of coping strategies in diverse ways in order to avoid or reduce pain whether physical or psychological.

Participants coped individually and collectively with the challenges of their supporting persons with dementia and advanced dementia up until their death. Although in some services there was no discussion that dementia was a terminal illness, the participants knew that the person was declining both physically and cognitively and they appeared to employ a range of different coping strategies which could be divided under three categories. In the sub-theme coping strategies, there were 3 categories:
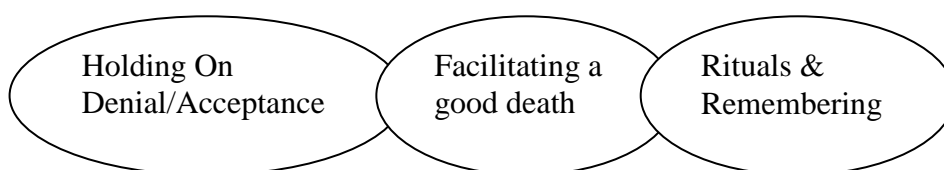
7.6.1   *Holding on/ Denial/Acceptance*

Interpretation : Holding on/denial/acceptance refers to the tension experienced by staff who did not want the client to be taken from their setting. It was closely aligned to the denial of the fact that the person ought to be moved and the acceptance that the person was declining and needed support which could not be provided. Potentially, there may be many reasons why an individual may not wish to let go of a familiar situation. A familiar situation or routine may be comfortable and comforting. One's holding onto something which is familiar may be easier emotionally and a denial that the situation ought to change is one way of facilitating that holding on.

The participants did not want to let go of the clients until they absolutely believed that they could not give them the support and care that they required with safety and comfort. Therefore they employed lots of strategies for holding onto the client.

There were many examples of when participants all along the trajectory of the dementia resisted thinking about the need to move a client to another setting even within their own service. They did not actively look to have the client moved. However, coming up to end-stage dementia when the client's care needs were increasing and human and other resource issues were challenged, participants would begin to consider that, in the best interests of the client, they probably ought to consider a move.

A participant (manager) reported at one site that she knew that when staff said they could no longer cope with caring for a person with dementia in that setting because of a lack of resources and health and safety issues, that it was probably six months or more before that when they found that they could not cope and were at breaking point when they admitted it. This was in a community care context and the following quote demonstrates the point:

> *.. my experience is that if you said to the nurse would you like us to take M and bring her somewhere else, you know, for the end- stage.. they would probably say no .. even though they are very overworked and over-stretched providing care to everybody else who doesn't have dementia on the unit.. 1.7.1*

Some participants found that the prolonged trajectory of dementia facilitated their using a denial mechanism to cope with the inevitable, (that the client was terminal). They avoided thinking about the person's death and admitted that it may possibly be a coping mechanism in order to avoid the feelings of sadness and grief. The following quote captures this:

> *I think because he is dying in such a regular basis (over a long period of time) you don't think too much about that. Em I think you're being prepared sort of in terms of grieving sort of .. you know when he eventually will die but you don't .. well for me personally I don't tend to think about that. Like I'm aware it will happen..3.5.1*

On occasion some participants were looking after the person for so long and coping with the acute episodes where they had repeatedly anticipated their demise, (and instead the person recovered), operated on a denial mechanism to cope and were then taken by surprise when the person died. The following quote demonstrates this:

> *I think probably with one or two I would have denied .. and one had come back from the brink so many times that you thought she will .. she'll come back again. And when it did happen it was a shock because we didn't really expect it. So I think there is an element of denial yeh. There was one in particular a long time beforehand. But the element of denial is definitely there.. 3.6.1*

Alternatively, some participants realised that when death was inevitable that they ought to accept that it was better for the suffering of the person to come to an end. The following quote demonstrates this:

> *I suppose when it (death) happens then .. it's the element that, that's it then. That's death, you are sort of not wanting it to go on any longer so they don't have any longer suffering but at the same time when it does happen that sort of, I suppose its nice the best possible care has been given and they have remained at home and with their family and remained among friends/peers, I suppose those things 3.11.1*

Some participants acknowledged that because the client had been dying over a prolonged time that it was acceptable that they died and that they had had enough. The following quote captures this:

> *.. people I've worked with for a long time, that's the most.. But it's almost okay that they died because they had been dying for so long..   Sometimes it's okay, they've had enough, they don't deserve .. 3.9.1*

In summary, coping mechanisms are employed by staff to manage their emotional reactions to loss experienced while supporting persons with dementia. These coping mechanisms mirror those used by bereaved individuals in general.

7.6.2   To Facilitate a good death

Interpretation: To facilitate a good death refers to the general views which staff held in relation to maximising good end-of life care and support at the time of death for the person with ID and dementia. The hospice movement brought to public awareness the knowledge that individuals ought to be afforded the experience of dying with dignity. What determines a good death may be determined at a societal, cultural or individual level. As health and social care professionals, there may be expectations to facilitate a 'good death' for clients. What this means in practice may put demands on staff to question what they do and what they can do to support the person with a terminal illness and who is dying in their care.

The participants considered that a 'good death' was an important aspect of their care for the person with dementia. Senior nursing participants placed emphasis on the fact that they coped with their emotional reactions by their ensuring that they facilitated a 'good death' for the client. Aspects in the provision of a good death were identified as the providing of good physical, emotional, medical and spiritual care. Participants aspired to the ideal within the reality of the resources at their disposal. One important aspect of end-of-life care for one participant was that no-one ought to die alone. The following quote demonstrates this:

> *You don't want them to be on their own, that's one thing I fought for and thank god I've gotten it, that I will not have anyone die on their own.3.9.1*

In one ID service, a participant recalled that when she had realised that her client was possibly dying in an acute hospital setting, she arranged for him to be transferred back to the ID service because she wanted him to die 'at home' with staff around him who knew him. This was considered an important aspect of care for this person as demonstrated in this quote:

> *He was dying .. I said goodbye and we brought him out on a stretcher and got him back. Thank God we brought him back .. and it was when he got into the bed you thought oh my God (said with relief) you know and then he died at two o'clock that night. 3.10.1*

All nurse participants and experienced carers said that when the client was dying they believed that they could give the required 'basic nursing care' and that dying was the same for any client irrespective of their diagnosis. This was in relation to one's providing comfort for the person and medical attention and symptom management if or as required. Many nurses considered that they had the knowledge and skills required for caring for the dying. General nurses, and experienced ID nurses particularly, stated this as captured in the following quote:

> *I think we have the capability of caring for the dying .. 4.2.3*

In some sites where there was reasonably good and established medical support provided to the ID service and where they had extensive experience with deaths, the participants clearly did not consider that the end-of -life care of someone with a diagnosis of dementia /Alzheimer's was any different from end-of-life care for anyone else. This is captured in the following quote:

> *Well their end of life care at the end of the day is the same as anyone's end of life care. They are not any different to any other clients, whether they have CA or any other illness. The end of life is the same for every single one of them because at that stage of the game you know everyone is on par. So the end of life issues is an issue for us all.. with them all,.. 3.2.3*

In one interview participants described how they had consciously decided to create a 'family' situation for a client when they surrounded her with the people (staff and other clients) whom the participants perceived to have mattered to her in her life and they "locked out" anyone else from the service so that the significant chosen people only, would be with her when she died. The following quote captures this:

> *But at the end I knew she was about to go and I made us all, they were all in, everyone of the girls were in that day and we all sat around the bed and held her until she left and I think about, must have been about half an hour after she had died I informed them in the office.   I was in trouble for it but I didn't want anyone involved in it because I felt that we were her family, any other family could make a decision like that so I told nobody she was that bad and we sat there, they knew(staff), she was passing, she was like.. but staff really appreciate it to this day, they'd say it. Now I explained to her why I did it and she was fine, I was like but I could not, ... we needed that half hour, and the rest of them*

(clients) knew as well, yet we did not, not one of them stirred they all knew. We sat there. (laughing at the memory of defying the system!) All of the women in the unit as well. It was the only time I've ever done that. 3.3.10

Some participants (nurses) felt more control over the facilitating of a good death because they had additional training in end-of-life care and had the confidence to deliver care which managed the persons pain and symptoms. The following quote captures this:

I can manage their pain and their agitation. I can make sure they're comfortable. I can do something. You see and doing is a great way of alleviating .. or .. I suppose addressing your grief issues ..you know .. I can do something and as long as I can help to make them comfortable and they're peaceful. That to me is a good outcome .. and that's how I deal with it.. 3.1.1

In relation to the supporting of clients with dementia who were dying in their care, participants had had time to come to terms with their gradual decline. Furthermore, they also got solace from their being present with the person at the time of death and that the person died in their care. This is captured in the following quote:

... but staff saw the gradual .. and staff were with her right up until the end.. so there wasn't that major tear at the heart you know when they go somewhere else to die and you're called you know the last .. 1.3.5

In a service which was now delivering end-of-life care for people in the ID setting, participants were furthermore now very satisfied that they were providing after death care. This is captured in the following quote:

...it's worked out .. you know . cause at the start we were like ..oh no ..we'll have nobody laid out here .. but it was actually worse seeing them laid out in the funeral home. .1.5.3

Participants from the services where there was an end-of-life care units and the staff had basic knowledge and skills in palliative care described their experiences of persons dying in very positive terms. In one of these units where there was individual rooms and space and families were usually involved a participant said that the care was so good

that it would be the setting she would wish for her own family members if they were dying.

7.6.3   Rituals and Remembering

Interpretation : Rituals refers to the many aspects of care which staff employed before, during or after the death of persons in their care and which related to the demise of the person. Rituals may be considered important as rights of passage. They can be employed in relation to the coping and the enabling of the expression of grief pre or post the death of the person. Rituals may be culture specific and indeed sub-cultural specific. This may prove important in a multicultural health and social care workforce and within the particular world of ID care. Participants engaged in rituals in all of the services but there were some changes in practices which were causing them concern.

Interpretation: Remembering refers to another coping strategy utilised by staff to manage their grief. Remembering someone who has died is inevitable for the bereaved (unless it is actively suppressed). It is increasingly recognised, in developing theories of grief, that it is important for healthy grieving that the bereaved actively remember the deceased person and learn how to re-integrate them back into their lives within a new understanding.

In regard to rituals, some participants, from the long established services, found that some of the rituals that they had previously found useful to cope at the time of deaths, were now disappearing. This is captured in the following quote:

> *we used to do, well we don't do it anymore but we used to all line the avenue*
> *you know we would go out and stand in the avenue when the hearse would be*
> *going out.   But we don't do it anymore now.   There's not as many ladies or*
> *staff now .. 3.9.1*

Furthermore participants were disappointed that new staff in the organisation were not following older customs and this bothered them as stated in the following quote:

> *And I couldn't get over it, she was in 3 different units in this service and because*
> *it was at tea time nobody bothered. So and so's funeral, are you not going to go*
> *to it, maybe you should go up, you'd be encouraging them to go.   I just felt this*

was at tea time so it doesn't fit into the routine.   So nobody bothered pushing them, that personal touch whereas years ago if the team, you know, if there was a funeral to go to, its probably an old thing as well, but I just, I couldn't believe it. I was thinking about it and it bothered me and afterwards when I came out of the church I felt, I felt disgraced to say, we are losing our personal touch here. And it bothered me .. 3.9.1

A number of participants described how they coped by 'doing' and described themselves as more logical than emotional. They tidied away the belongings of the person and found this helpful in managing their feelings of loss.

Of course there is and for some people it's about going to the funeral, for some people it's not. Some people need to go to the funeral for closure. Actually another thing that puts closure on it for me is em .. putting all their things away (said quietly). Packing their room up. That brings closure. I'm a more practical person as opposed to being an emotional person. Yes. 3.6.1

Perhaps reflective of the theories of Klass et al. (1996), when clients died, staff across all sites endeavoured to continue the bonds with the deceased. On some occasions the service erected a special garden seat in memory of the person and this was used by staff as a place to visit with the peers of the person to remember the person and to hold them close in their memories. However, the most common way staff attempted to keep the bond alive was via the medium of photos of the deceased being displayed in prominent positions in their workplace.

Participants across all sites spoke about their own strategies of remembering the clients. There was a positive energy to remember the relationships which they had with the person. In all of the ID services the participants had photos of the deceased clients in places of prominence. They used these photos to talk about the clients among themselves and with the peers of the client.

Like you still never forget them like .. there's always little things in your unit that you .. we've pictures of them all that we have over the years ..you know ..1.6.1

Participants used the photos of the deceased regularly for many years.

> *if you miss someone and you say when did she die? And you'd be trying to think, did she only die last year, did she die the year before. So I'd refer back to the picture, I suppose I'm always up looking at the board. 3.9.1*

This use of photos to share memories among staff and peers and on occasions to introduce new staff to the deceased members of the unit was repeated time and again across the services. In some instances the participants actively sat down as a team when the opportunities arose and talked about the deceased clients. This happened in a unit where end-of-life care was common.

> *But then what we always do like is we sit around the table and we'll always talk about the person (who has died). That's extremely important .. even afterwards we'll always talk about people .. regularly about people who have passed away .. and you know what they did and you know different stories that you have you know and .. I like it when people ask about .. when people passed away and you just tell them how it is . and that's really important like .. we don't forget about the person we .. it's now they're gone now and that's it! It's so not that way.3.1.1*

Furthermore, in all of the services there were events to remember the client in a more formal way. These events were for staff and peers in some settings and included inviting back the kinsfolk in other sites. It was becoming more common to invite kinsfolk back. The following quote is a sample from one participant:

> *We do have a months mind and we are planning to have an anniversary, a one year anniversary around Christmas time where people come back together for Christmas mass 1.7.1*

In summary, the conduct of rituals and the remembering of the deceased was recognised by participants as important in facilitating their coping with their experience of loss and grief. In doing this they were actively expressing and engaging in continuing bonds with the deceased person.

7.8   Conclusion

This chapter presented theme two – Worldview of loss and grief experiences of staff working in ID care. It explored how participants perceive loss and grief as professionals supporting people with ID and in particular in supporting people who subsequently develop dementia. The complexity of the grief is the main issue identified. Secondly the participants identified that the experience of loss and grief is particular within ID care. The participants also agreed that professional grief was inherent/intrinsic in their world view from the nature of the separations which they encountered with clients over the years and now it was recurring due to the nature of supporting more persons with terminal illnesses such as dementia. This world view of loss and grief was influenced by their experience of bereavement following the deaths of clients . The third theme – Worldview bereavement for staff in ID settings will be presented in the next chapter.

CHAPTER 8 – ID WORLDVIEW OF BEREAVEMENT SUPPORT

8.1 Introduction

This chapter presents the findings which comprise Theme Three – ID Worldview of Bereavement Support. While the experience of loss and grief for staff was being explored, it emerged that their experience was influenced by their subsequent experience of bereavement support which they encountered on a personal and professional level following the death of a client. This theme was developed from the combined reanalysis of the focus group interviews from chapter one and the analysis of the data from the individual follow up interviews. In keeping with a Gadamerian hermeneutic representation, the findings are described in terms of worldviews of the research participants fused with that of the researcher. Each theme, sub-theme and category will have an interpretation written for it. This inevitably incorporates the researcher's interpretation of an existing and a developing understanding of the phenomenon of what 'bereavement support' looks like in the world of ID as a result of an analysis of what the participants said about this at interviews.

8.2 Theme 3 – Worldview of Bereavement Support in ID Care Settings

Interpretation: Worldview of bereavement support in ID care settings refers to the opinions staff held about such support. Bereaved individuals are commonly part of a family, a community, a society, a cultural network and potentially benefit from receiving sympathy or empathy from others for their loss. Within any scenario bereaved persons may also be supporting other bereaved in relation to the same loss (sibling, parent, child, friend). Some individuals do not require any specific professional bereavement support to process their grief and others may require such support.

Participants described the bereavement support which they gave, received and perceived to be desirable. There were three sub-themes:

- Supporting Bereavement
- Being supported in Bereavement
- Seeking Bereavement Support

8.3   Supporting Bereavement

Interpretation: Supporting bereavement refers to the support staff provided to anyone within their world of ID care when those persons were experiencing loss. This loss was usually (but not exclusively), in relation to the death of a client rather than to other losses experienced in practice. As an individual anyone may or not have the natural ability to provide bereavement support to others when they experience the death of someone significant to them. Commonly to be present to bereaved persons is an important starting point. One's actively listening and remaining non judgemental in such situations are other valuable behaviours inherent in supportive care for bereaved persons. There may be an expectation that health and social care workers have the requisite knowledge and skills to provide this support when a death occurs. In reality, without specific training in this specialty, staff do their best to ease any suffering which they perceive is being experienced, by clients, colleagues, kinsfolk.

All participants reported their having given support to others after a death occurred. Participants spoke about feeling obliged to support others with their feelings of loss and grief after a death.

There are three categories:

Colleagues   Kinsfolk   Peers

8.3.1   Colleagues

Interpretation: Colleagues refers to any fellow workers alongside whom the staff in the study worked as professional paid staff in the ID setting. Inevitably, a team of paid workers support those persons with ID who live in residential care. Within this study, nurses and carers were the team members interviewed. They provide 24 hour frontline care and make more intimate platonic relationships with clients because of the personal nature of their work in their supporting of the person with activities of daily living. Collegial support may be an important element when people work as part of a team. but in bereavement work this collegial support may be all the more important in ensuring

that individual workers feel able to be vulnerable in relation to their expressing emotions which may arise during bereavement experiences in the work setting.

Participants supported each other emotionally and practically within their respective smaller units of work. In particular the more experienced nurses or carers provided bereavement support for junior nurses and care staff. This is evident in the following quote:

> *But yeah I suppose from a professional point of view like you know I'm the one that can fight for the staff, you know the last three deaths this year I was on and I had very young staff on with me.   Two of them in my arms roaring crying because they'd never, you know they had become so attached, these were young girls who had become so attached to the ladies like I did when I was that age like you know.3.10.1*

Although nurses and carers supported each other to the best of their ability, they acknowledged that they needed more help to deliver this confidently and efficiently. This is captured in the following quote:

> *.. and staff who are very upset .. and I do feel I need more support to do it (support staff emotionally) properly.. 3.6.1*

8.3.2   Kinsfolk
Interpretation: Kinsfolk refers to the blood relations of the person with ID, excluding the peers of the person in the care setting. Although, the kinsfolk of some of the clients in ID care settings may not have had a close relationship with the person who has died, they nevertheless may require varying degrees of bereavement support. Such support can be different depending on the actual need of the kinsfolk.

Participants considered that practical support such as the providing of a place to stay to be near the deceased person may be an important element of bereavement support. This is evident in the following quote:

> *I suppose probably in a nursing position out there because you are there to support the family, ...only families being very, I suppose I would have felt very much anything you could do for the family if it meant staying the night or little things that would have meant a lot, anything at all to sort of ease their time as*

well and its their last time with the person, that it would be as special as possible or as dignified as possible.. 3.11.1

Bereavement support for the kinsfolk in the way of the arrangement of annual remembrance events was a reality in most of the services. Participants appeared to value the continuing of the relationships as evidenced in this quote:

.. have a thing here at Christmas for all the people who have passed away .., the relatives come back .. gives you time to reflect on them .. cause often times you think oh that's the family gone but actually it doesn't we've kept in touch with all the family (smiles).. 1.5.1

Furthermore, participants identified that they had a role in supporting the kinsfolk of the person who died as a professional and also identified that they needed to demonstrate empathy to the kinsfolk. They also acknowledged that it was good to demonstrate their emotions to kinsfolk, especially if they had a relationship with them over time. This is captured in the following quote:

Yes and we are aware of that. It is foremost in our minds. But you have to acknowledge that sometimes it's quite tough. Depends on where you're at.. how you are feeling on that particular day .. but you do .. you do feel very sensitive. Every death is different. You maintain that professionalism and you don't let the shutters down. Especially with families .. as they need you to be strong .. They need you to be there for them.. but they also need you to weep with them. They need you, you know, to acknowledge what they're going through and they like to feel that you've not em ..3.2.1

Ultimately, participants were aware that the kinsfolk need a particular form of bereavement support once their family member with ID dies and that they do not necessarily meet that need as an organisation yet. The participants understood that life for the deceased person and his/her kinsfolk had centred around the ID service and therefore the bereaved family members were suddenly isolated from all that that entailed once the person had died. The kinsfolk in a sense had bonded with the ID service personnel too. The personnel had become part of their extended family as well as the person with the ID. This is evidenced in the following quote:

> *... families it was the families that had been bereaved that came.. So we are*
> *trying to ask them what it is that they want us to do to help them. We do feel we*
> *could be more assertive in giving them support ..because they don't fall into the*
> *normal category of bereaved people.. (7.1.1)*

The supporting of kinsfolk of the person who died was expected by the service, but participants had mixed feelings about the role that kinsfolk played in the life of the person who sometimes only appeared when the person was dying. This was a challenge for participants as evidenced in this quote:

> *.. like a lot of emphasis go on the families, like.. I probably said that at the*
> *beginning, a lot of back up for the families and we're willing to have that .. but*
> *the people that are with them more often than the families are us.. and we are*
> *not allowed to grieve, we give the support to the family, even though at the end*
> *of the day the family maybe see them 3 times a year, you know what I mean, and*
> *they are there at the end .. 3.2.2*

Anticipatory grief and the need for bereavement support prior to the demise of a person may occur in terminal illnesses such as dementia. Participants were sensitive to the fact that on occasion families may not wish to accept that the client had a terminal illness. The participants on all sites re-iterated that they would respect the wishes of kinsfolk and this meant that if relatives did not want to talk about illness and death, then participants would respect that. This is demonstrated in this quote:

> *.. I know in our situation we have one lassie now with Alzheimer's and her*
> *family does not want to talk about end of life issues. They will deal with things*
> *as they arise, they do not want to talk about end of life.. (3.2.2)*

Participants across the sites therefore perceived a need to support kinsfolk of persons with dementia but also respected the need for sensitivity in knowing when it would be inappropriate to do so.

8.3.3 Peers

Interpretation: Peers refers to the other persons with ID who resided with the person with ID and dementia within the care setting. Identification with a group of people brings the identity of belonging to a peer group. The clients living in these settings all

have a common identity of living with an ID. Membership of a sub-culture of this peer group was having the dual diagnosis of ID and dementia. There was a lack of consensus across the sites as to the extent to which peers were affected by the death of a client and/or needed bereavement support.

The participants initiated supporting actions for the peers if they considered that the peers demonstrated a change in behaviour such as becoming upset because the client with dementia was declining with advancing illness. Such support included spending more time with them as evidenced in this quote:

> .. *we have only six people in the house and they seem to be ok .. it hasn't been an issue for us .. if someone gets upset and we think it's because someone is ill and in bed we talk to them and support them .. (4.1.3)*

The participants appeared to feel that they were the primary people to provide bereavement support to the other clients and they were now beginning to initiate plans about preparing the other clients for the demise of the person with dementia. This need to prepare the peers of the person is captured in this quote:

> *And you know it's going to, I know it's going to happen E (name) .. sooner than later but we had a meeting here with the girls and I was saying look we'll have to start thinking and getting them ready for it because you know they are going to be devastated and you know really how, it's the fall out afterwards E (name) sometimes is the worst.3.8.1*

In a site where clients had severe and profound ID, the participants attempted to facilitate the grieving of peers of the person by ensuring that rituals and respect afforded to a dying or dead person were honoured. In all sites, participants included the peers of the dying person in as many aspects of the death, dying and post death rituals as possible as evidenced in this quote:

> *the majority of them died here like so you were here for the whole process and you got your chance to say goodbye ..and the other men could come in and out like and pray at the bedside .. so you went through the whole process with them and then when the person does die .. the room isn't touched for a certain amount of time and then when the room is being cleared out ..the boys are in and out of the room ..it's automatic for people here .. 6.1.4*

Participants also felt a responsibility to put the grieving of peers ahead of their own feelings of grief but acknowledged that from experience, now they understood the need for self-care. This is captured in the following quote:

> *And then you have the ladies grief, their grief is massive and like you could have 10 ladies and each one would handle it very, very differently.   But we as staff take on the role of minding that grief.. and you forget about your own for a little while. That's where there could be a build up, you know, because again I would encourage them to cry because I think it's like a release of the initial emotions that I don't seem to be able to let go off straight away.. 3.10.*

Participants recognised that due to the increase in clients who will be experiencing loss and grief there will be a need to support them and that they will need extra knowledge and skills to do so. This need to be better prepared to provide bereavement support is captured in this quote:

> *bereavement too .. we could always benefit from more training about bereavement .. we are going to have more people with dementia and dying so it would be important to have more knowledge and skills to deal with it ... 4.1.1*

In summary, the participants supported the bereaved peers of the person with dementia before and after the death. They did this intuitively and recognised that they could benefit from education and training to be able to do this more confidently.

8.4   Being Supported in Bereavement

Interpretation: One's being supported in bereavement refers to any support which the staff received or did not receive when they were experiencing loss and grief in their work setting. Bereaved individuals describe how people avoid them or do not know how to give them eye contact after they have endured a loss of someone through death. Others report that some individuals say inappropriate things to them because they do not know what to say. Because they worked in a close environment with colleagues and clients it meant that participants were confronted with sharing the experience of the loss of the person together. Their working within a professional environment brought some expectation that grief was recognised and attempts made to provide bereavement

support to each other. However such support was not always received from upper levels within the organisation.

There were three categories.

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( Collegial )( Organisational )( Client )
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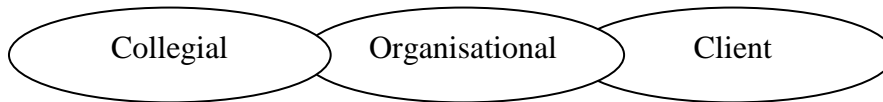
8.4.1   Collegial Support

Interpretation: Collegial support refers to the support participants received from their fellow health and social care colleagues pre-death of a client, at the time of death or after a death occurred. Nurses and carers provided bereavement support to each other, to clients and to kinsfolk as already described. Such support was reciprocated among themselves when participants described how they supported each other and received support in their grief from colleagues.

Experienced nurse participants recognised the need to talk about their feelings of loss with colleagues if they could or with close family as evidenced in the following quote:

> *You have to know how to talk. I think it would be more healthy if people were more confident in how to talk to somebody. I talk to S (colleague/friend) and she talks to me. I can offload which we have done. You do with a close colleague, even with a family, a sister, we'll talk together. A problem shared is a problem halved you know.3.3.1*

The above quote highlights that participants working in these settings who are experiencing more deaths, realise that they need to self-care. These experienced participants also felt that although they support more junior or inexperienced staff, that they may not get support themselves within the workplace. One participant commented:

> *Yes. Yeh you feel as a nurse I feel personally that I've more personal supports because I know the more overall picture and I like the idea that I can give support then to other people... Now that may not happen the other way around. 3.5.1*

Participants explicitly recognised that care staff often are even more disenfranchised in not being supported with feelings of loss and grief when clients are transferred out.

> *Whereas with care staff em it's just not there at all. I don't think even the organisation is aware of the importance of having it (grief support) there for staff. Because it does affect them and in some cases/places depending on the area you would experience more like sort of loss in terms of even the person's transferred or the person dying… … but staff who would be regarded as hardened staff were actually crying in a particular unit where somebody .. it was a unit for people with dual diagnosis and they felt the service didn't have the support a person needed and the person was transferred down the country back down to his catchment area and staff – male staff – in particular were crying. But like there was nothing .. there was no supports there for staff and I think I hear that throughout the service. That was like sort of major.. 3.5.1*

In some services the participants availed of bereavement support from the Pastoral Care staff in the service to support them in supporting peers and colleagues with loss after a person with dementia was transferred out of her community house back into residential care. The following quote captures this:

> *We got a lovely, N is our, she's involved with bereavement counselling here and I organised for N to come down just after R left and we had like a little service, it was based on friendship and that you know because they are not with is you are still her friend you know (laughing) but anyway, so anyway N came down and it was really to let them know that she, she was still going to be there you know. But she wasn't with us here. (crying)…3.8.1*

The Specialist Palliative Care participants in particular recognised that the grief experienced by staff working in ID could resemble the grief of a 'family member' because of the usually long standing relationship with the client or service user. These specialist palliative care participants recognised that the ID staff therefore may need bereavement support.

> *.. staff in Intellectual disability would need that support more because of the nature of their relationship with the person .. they have had years together .. 9.1.1/2*

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However, participants resisted seeking formal bereavement support on occasions from within their own service. In one site it was stated that nurses, in particular, did not access bereavement support for themselves when clients died. Such bereavement support was available as a training course and counselling service but the participants continued to cope together in the local unit where the person died. This is evidenced in the following quote:

> *We have had specific bereavement training courses for both staff and clients within the organisation as a total ..but because most of the staff on the unit are nurses and nurse trained I think ..their preferred way is to use peer support for it, peer support to help them through with the grieving process. .. 7.1.1*

8.4.2   *Organisational support*

Interpretation: Organisational support refers to the bereavement support received from anyone who was in senior management positions and who was seen to represent the organisation for which they worked at a macro-level. Participants across the sites in this research were working with relatively large organisations. Participants working within large organisations can potentially feel isolated from the headquarters geographically if it is far away or, psychologically, if they do not meet members of senior management on a regular basis. Furthermore, the participants work within a fairly autonomous role in the day to day care of persons with ID with their day beginning and ending in the presence of the client/s whom they support. In some ways, the staff can remain an invisible cog in the wheel of the success of the organisation while they expertly support the person with ID.

There was a sense of frustration on occasion when experienced participants perceived that management did not realise the impact of a death on staff in a unit. They were upset that management did not acknowledge the impact of the death and felt that it was just another person dies and now there is a bed available for someone else. A reaction is captured in the following quote:

> *.. we would, say N passed away, ... ah thanks very much.   And that's the response you get…*

The participants felt that the fact that they have considerably more involvement with the person in ID when they die than staff have in general settings, that this goes largely

unnoticed by the management personnel in the bigger organisation. Their intense involvement in planning and their being involved in all aspects of the funeral is an extension of their caring role when the person dies. In view of their bond of time together they felt personally bereaved but perceived that because their grieving is disenfranchised both within and outside of the ID setting, that they are not supported in their bereavement. This is evidenced in this quote:

> *..in a general hospital when someone dies and is gone they don't have anything to do with them .. they don't even know where Mr Mac in bed three has been buried or gone .. where we go to funerals .. we organise funerals .. organise the mass.. we organise everything .. and then you're meant to go back to work and it's all over and get on with your day .. 3.1.7*

There were established formal bereavement counselling support available for clients which participants could avail of also should they wish to pursue it. However they perceived this bereavement support to be more for the clients as evidenced in the following quote:

> *.. certainly within the organisation there is an offer .. people are able to go for outside counselling .. it doesn't happen within the unit .. nobody needs to know about it .. the service itself would promote a bereavement training course for staff to go on it if they want .. A lot of it would focus towards the service users and how they can cope with bereavement .. but there again there is the opportunities for staff ..1.5.1*

In some services, in recognition of the increasing frequency of deaths of clients, there was formal bereavement training being developed. Participants were recognising that this would be an important part of professional development. The following quote demonstrates an example of this:

> *.. so of course there's going to be more grief issues. I think this organisation is responding to that now and are more aware of it especially with the new booklet they've done up and the bereavement training sessions. I think they're important that all the staff go on them. Certainly all the staff here need to go on them.. 3.1.1*

Participants in some sites reported positively that ID services are improving in relation to their recognition of the concept of grief and that the environment is becoming more supportive of bereavement. This is evidenced in the following quote:

> *I think in the ID sector we are only beginning to come to terms with loss and grief .. we're doing things a little bit better. I think we're more acknowledging of the loss .. we've become more empathising. Now what happens when someone dies .. we give time to grieve and I think that's good .. the whole idea of loss has become more acknowledged .. management have become more aware and understand much better than they did yrs ago. And I think the whole thing of staff and acknowledging .. definitely ID are getting better compared to when I started. There is a totally different and much more a supportive network.. 3.6.1*

Support can come in many formats and participants were appreciative of subtle support and were looking for sensitivity from the organisation to the experiences of deaths of clients in their care and to the effects these have on staff. The following quote captures this:

> *.. things that can be so subtly done and nicely as we go along.. You don't even realise its being done but you are being helped without knowing you are being helped. In a professional yet caring manner that yet when it actually comes and goes ..it's not a case of another off the list.. great .. it's a different, you still get your chance to grieve and cry but you are not.. hard done by .. no that is the wrong word, you are not left like you are not cared about ..   That someone does care, you know.. 3.2.2*

Participants perceived the organisation to be insensitive when a new client was moved too quickly into the living space of a client who recently died. However, the needs of the participants to be supported in bereavement were being recognised by the organisation.

> *...as soon as the person died the bed was nearly warm by the time Joe Bloggs was moved into the bed. It's very, very tough on staff to have to deal with that in this setting, its not an acute setting. So it was very tough for staff to deal with that. sometimes you could nearly be resentful of the person who is being moved into the bed for a short period of time, you know, its human nature. 8.1.2*

In the services where death was becoming a common occurrence, participants acknowledged that management have improved their awareness of the impact of deaths on staff.

> *.. the whole idea of loss has become more acknowledged .. management have become more aware and understand much better than they did yrs ago. And I think the whole thing of staff and acknowledging .. definitely ID are getting better compared to when I started. 1.3.1*

In summary, organisational support in relation to the bereavement of staff is an area of concern to participants. As ID services are experiencing more deaths, they are being challenged to recognise that staff are grieving and that there is a need to be sensitive to this. Some services are developing policy and practice which acknowledges the emotional impact of deaths of clients on the staff and are responding with sensitivity and also actively pursuing education and training for staff to be able to provide bereavement support to surviving clients. Some of the services also have bereavement support available to the staff but the participants in this study were not availing of it or felt that it was not suitable for their needs.

8.4.3   Client supporting bereavement

Interpretation: Client refers to the persons with ID who resided in the service. Human beings have the capacity to reflect. That is, humans can think about their thoughts and expand their understanding. Some clients across the services had experienced bereavements of their own. Usually it was the death of a parent. Therefore they had their own world view or understanding of bereavement.

On the occasions of personal bereavement for participants, some clients supported them in their own personal grief experiences. Participants placed huge value on the 'genuine nature' of this support given to them by their clients. An example of this was when a participant's sibling died suddenly and when he returned to work, a client took him by surprise when he came to him to sympathise with him. This participants found that gesture very supportive and still reflects on it although it was many years ago. This is evidenced in this quote:

> *Em.. He was more perceptive. He wasn't' saying it for any particular reason em.. whereas sometimes staff would like offer their condolences .. but they're*

doing it because that's what you say or do. Whereas he was saying it .. although it was upsetting at the time .. God I thought that was so thoughtful, the way he was able to say it. He wasn't like I'll wait until Y (own name) is on his own. He just came out and said it. I like that because it's more like sort of innocence what he said and he could touch you at a level that staff hadn't touched me at. Even to this day I think it's nice that he was able to do that. 5.3.1

Another participant recalled that when her own mother died, a client started to ask her questions about her mother and started to share her memories of her (client) own mother, offering the participant consolation that both mothers were now doing similar things together in heaven. Again the nurse found this very supportive in her own grief process.

.. she had this picture nearly of them in heaven and like her mother would have known the ropes and you know mammy was going to be the new kid on the block and its strange but I found it.. I'll never forget it either, I just thought it was the nicest, her image of what was happening.. it was lovely like.. 3.11.1

The above quote was said while the participant was smiling with the memory which demonstrated that she still found solace from that encounter. This sharing of a similar experience between the two participants and their client whom they did not expect to be able to understand their grief, demonstrates the bond which can be shared by the common experience of the death of someone significant.

8.5   Seeking Bereavement Support

Interpretation: Seeking bereavement support refers to the support staff would like to receive when they are experiencing feelings of loss and grief particularly when a client died. As professional caregivers, there may be an expectation that staff automatically cope with and manage grief reactions. However, in reality, any bereaved person whether in a professional or personal role desires at some level an acknowledgement of the loss that has occurred and opportunities to explore events and memories. Participants described as the bereavement interventions which they would like to receive when they were experiencing loss and grief.

This particularly concentrated around their grief in regard to the death of a client. They experienced a void and appeared to be able to share this with immediate colleagues at some level but not with senior staff within the organisation. In this sub-theme there were three categories:

Acknowledgement   De-Briefing   Reassurance

8.5.1 Acknowledgement

Interpretation: Acknowledgement refers to the need staff had to be made visible in relation to their experience of a loss as a professional. To give acknowledgement to an individual is to give respect to the person. This acknowledgement may be great or small or interpreted by the individual receiving it as great or small. However, to be acknowledged is to be rewarded in some way for an achievement. Staff in the ID settings invest themselves in their work which is often invisible by the very ordinariness of it. Therefore to have this investment of self in another person's living and dying surely is important to staff.

Participants needed to have their grief acknowledged when a client died. In particular they identified that it was important that the relationship they had with the client was acknowledged. This relationship comprised of the care, the commitment, the investment and the support they provided in the overall care that they delivered to the client.
Some participants considered that there was no acknowledgement of their bereavement and this would be an important starting point. This need to be acknowledged is captured in the following quote:

> So I don't know, I think, I think maybe we need to be acknowledged at the end ..
> It took me about 4 or 5 months even before I could talk about it. And em that
> was it we just kind of got on with it then. You know but I really don't think, I
> think you are very much left to your own devices here when something happens
> afterwards to pick up the pieces and you know you get on with your own stuff
> yourself privately and you support the ladies the best way you can.3.8.1

Interestingly, in a service where deaths are becoming more usual, the participants felt that the acknowledgement from management of their care for the dying person was now not being acknowledged although it used to be when deaths were less common. This is evidenced in this quote:

> ..I try, I try my best. I would hate to think that the staff go home upset, because if I go home upset I'd hate if anyone else did that because I'd rather you know, I brought it up to management from here our own unit .. and it's not just an appreciation… it's just an acknowledgement, I think staff need that.. 5.3.1

It appears evident from the above quote that nurses perceived that the carers had a particular bond with the clients.

Some nurse manager participants felt that acknowledgement of the investment of frontline staff (nurse and carers) was important but that they lacked the skill set themselves to support bereaved staff. This is evidenced in this quote:

> .. there have been four deaths in one particular house and that takes its toll and I think these people (frontline staff) need something someone to come over and talk to them.. because I haven't that skill yet I wouldn't take it on. I think it should be acknowledged. I actually was thinking of that today .. these people (staff) … do so much…. 3.3.5

Participants may get some acknowledgment from local management in their own unit but they still craved this acknowledgement from the higher management of the organisation. This is captured in the following quote:

> .. not just management on the ground but acknowledged from the top down out there they (frontline staff) would feel they were doing a good job. I think that a huge support need and if they (staff) are not going to get that they are going to feel hard done and they'll feel they have worked for with this person for 4 or 5 years with somebody and no acknowledgement at the end.5.3.1

On occasion, participants felt acknowledged when there was direct communication given to staff for a job well done from upper management.

> .. but that did change a while ago because when that p[person when he died .. the director .. he was very good he said you looked after him well he was laid

out well. Sort of that like a change. He (the director of the service) was involved in it! And even say the cnm2 like she said to all the staff that we did the best we possibly could and all the staff were actually included .. do you want to do a prayer of the faithful? do you want to do this .. so that was nice cos prior to that like the .4.3.1

Nurse participants were aware that while they might receive acknowledgement for their support of a client through death, that, carers might not receive such acknowledgement on occasion.

.. the care staff have been there on a regular basis getting that person up and then suddenly then when the death happens it's like sort of well you know we are not going to acknowledge the care that you've given that person or somebody to make a remark say E (carer) was very good to Y (client).2.3.1

Participants considered that direct communication from senior management was important. A telephone call did not satisfy this need for acknowledgement as evidenced in the following quote:.

… and then (management) did ring the nurse in charge and said to tell the staff they did very well but I personally think he should have come over .. you know it isn't like somebody's downstairs and they come up here. They pick up the phone and ring say F and she comes out and tells you and again I found that annoying because If I'd got no message at all .. it would have been easier to cope with. 7.3.1

Nurse and Social care Manager participants, knew from personal experience of loss and grief in the workplace, that in principle such personal support from senior management would increase staff moral. This is captured in this quote:

When you sit down with staff its important to acknowledge.. I have expressed that staff need support with loss and grief both work related and personal. Such support strengthens the staff.. 6.3.1

In summary, participants do receive some acknowledgement of their investment of themselves in their relationship with the deceased client. However, the experience is not

universal. Participants considered that care staff were less acknowledged than nurses in relation to this.

8.5.2 De-Briefing

Interpretation: De-briefing refers to the need expressed by participants to have formal sessions after the clients death among the staff who supported the person in his/her demise, in order to explore the facts of the case. Health and social care professionals receive education and training to prepare them for their work. There may be expectations that as professionals, staff know the correct procedures and practices in any given scenario. However, when new and unexpected challenges present themselves, staff may be in the position of doing their best while at the same time not being totally confident that they are delivering the best care. Furthermore, when staff have expertise, they too may benefit from re-visiting a scenario and understanding what was good or bad about it in relation to their own professional practice.

Participants spoke about their need to have a formal de-briefing about the client after his/her death. This de-briefing would be for the persons directly involved in the care of the client. Such de-briefing could occur pre death or post death of the client.

Participants identified that being able to sit down purposefully to talk about the person who had died and especially to talk about the relationship they had with the client may assist the bereavement process. This is captured in the following quote:

> *... sit down and all talk about it. I've seen it in H (another heath care setting) and it was lovely, at the time they used to bring staff in and talk to them and just whether they wanted to speak or not she could drag a piece out of them, but it was so nice, its almost reflective scenarios and if people felt like talking about someone who just passed they could and the relationship they had with them. we don't have that here. 3.10.1*

Experienced nurse participants recognised that time-out periods for de-briefing were important for staff while the person was dying. This is captured in this quote:

> *You know, I try and do it with my staff, I'm not a professional counsellor or a professional, I don't know what areas to hit on, am I hitting right or wrong areas because I don't know what is going on with people's personal lives. I don't think I should have to you know do it, but I do try and do it, in the morning if someone is dying get all the staff to sit down and how do you feel and*

*you know if someone wants to talk about it. Time out, you know, because we
don't have a little prayer room or a little room we could do that properly in and
I think that's what's lacking. It might help even me and the staff to overcome,
the feelings like are huge, its massive emotions you feel. Because it's like that,
it's like losing part of your family like .. 3.10.1*

Some nurse participants equated the de-briefing to that which happens at an emergency
situation in a general health setting (cardiac arrest), where all those present are given a
clear understanding of the event and the management of the event.

*I remember in general, from a medical point of view if you were involved in an
arrest every person involved would be sat down by the doctor or consultant and
debriefed about what you know how good we did the job or whatever, there was
no more we could do for this person if they had been successfully resuscitated
they would have you know had no quality. Everything was explained to you ,..
3.5.1*

Experienced participants also recognised the 'felt' need for their own de-briefing from
more senior management. Interestingly such opportunities were afforded by
management when the first deaths occurred in the ID service. However as death became
more of a common occurrence this support declined and ceased as evidenced in this
quote:

*Oh I wouldn't mind my manager to ring me up and say 'I'll come down to the
unit' and maybe spend an hour or two here ..but now if somebody dies here
you'd be lucky if you get a call. 5.1.3*

In summary, participants would welcome opportunities to be de-briefed at a local level
about the end-of-life care they were providing for their clients. In addition they were
beginning to consider the possibility of gaining reassurance from specialist palliative
care in relation to the end-of-life care for clients with dementia.

8.5.3 Reassurance

Interpretation: Reassurance refers to the need expressed by staff to be told by more
expert staff that they had delivered the best end-of-life care available to them to the
dying person. Furthermore, emotional responses experienced in grief can be confusing,

erratic and overwhelming. Reassurance that an individual 'did his/her' best may serve to answer some questions to reduce or manage the confusion associated with grief.

Again, participants described their need to receive reassurance that they had delivered the best care possible to the person and that what they had delivered had been good care. This could include the de-briefing element described above but extended beyond it in so far as it encompassed the need of participants to be re-assured by other professional/s with more expertise that they had done a good job and had given the best care to the person including a good death. This is captured in this quote:

> *So you know even as much as for the palliative care ward specialist you know even who could call it, its very hard to, but I suppose the little bit of comfort in the fact that she said you know if that lady was beyond in the * (*hospice) they wouldn't be doing anything different than what we were doing, which was you know, it was sort of good to hear because I suppose people were feeling, you were getting that negative vibe as well.   And I suppose it had probably left its mark for me even now that we are prepared that you know we don't end up in that sort of position again… 3.3.1*

Finally, in relation to supporting persons with ID and dementia, it can be more difficult to assess the person for discomfort/pain and this may further increase the distress for nursing staff. The following quote captures this challenge for participants:

> *.., especially when like we've clients with Alzheimer's and they sometimes have very long, long drawn out deaths like that they are, you are trying to get a hold on their comfort measures, breathing. It's just not.. it's hard to watch you know and frustrating because you are nearly trying to breath for them. it's not that it's a horrible death but usually they get a handle on them but it's still distressing, seeing somebody trying to breath or gasping for a breath.   And it's worst when they can't tell you.   3.8.1*

Participants from specialist palliative care also acknowledged the difficulty in assessing the person with the dual diagnosis of ID and dementia for pain and symptom management.

In summary participants from ID needed re-assurance that they had given the best end-of-life care to the person with advanced dementia who died in their care. This re-assurance was typically desired from a specialty such as specialist palliative care. Some services had informal links to such a service and some did not. It appeared that although they may have utilised an informal phone contact for advice prior to the death that in general they did not have any contact with the specialist palliative care service after the death.

8.6   Conclusion

This chapter presented theme three – Worldview of Bereavement Support in staff in ID services. It explored how participants perceive their world and what bereavement looks like in that world for professionals after their clients with ID and dementia die. Participants identified, that they, as frontline staff provided bereavement support to their colleagues, the peers and the kinsfolk of the deceased person. The participants also acknowledged that they received bereavement support both on a personal and a professional level from colleagues, clients and the organisation in varying degrees. The participants clearly identified a desire for specific bereavement support from senior management within their organisations. They furthermore desired reassurance from staff or services with specialist knowledge and skills in supporting the dying patient such as specialist palliative care services. The next chapter will present a discussion of chapters six, seven and eight and offer conclusions and recommendations for practice.

CHAPTER 9 – HERMENEUTIC CIRCLE OF DISCUSSION

9.1   Introduction

This chapter presents the discussion of the findings of chapters six, seven and eight. The discussion is conducted under the three themes or worldviews of the participants. These are

1) Worldview of supporting a person with ID and dementia,
2) Worldview of loss and grief
3) Worldview of bereavement.

9.2   Theme 1: Worldview of Supporting a Person with Intellectual Disability and Dementia. A Hermeneutic circle of discussion.

Theme one is now discussed in relation to the literature available on the supporting of a person with ID and dementia. The discussion within the hermeneutic circle means that the parts and the whole of understanding continue in a discursive way.

The sub-themes within this worldview are used as major headings to focus the discussion and the categories are discussed within these sub-themes. The sub-themes are 1) Valued relationships and 2) Ethos of care.

9.2.1   Valued Relationships

There were five categories in this sub-theme of 'valued relationships'. These were 1) the nature of the relationship, 2) the bonds made in the care setting, 3) the family-like relationship formed, 4) the friendships made and 5) the experience of sharing common human experience between staff and client.

Nature of relationship:

An essential element in maintaining the well-being of persons with intellectual disabilities is the presence of meaningful relationships (Knox & Hickson 2001); such maintenance of relationships is also espoused by Kitwood (1997) as central to good person-centred care. The relationships between persons with ID and the staff may be of a long duration, over many years. McCarron et al. (2011), in a recently published large scale Nationwide study of older adults with and ID in Ireland reported that 41% of

participants interviewed had lived in their current setting for more than 20 years. It was evident in the current study that the longevity of relationships led participants to identify that the making and sustaining of relationships with clients was a natural and an important development which appeared to be central to their worldview of what it really is to be working with persons with an ID. Turnbull (2004) suggested that nurses working with people with ID place central importance on this relationship. Participants in the current study evidently saw themselves as part of the clients' social network, along with 'the kinsfolk' of the person (if they had family) and with the peers who lived with them in the ID setting as evidenced in chapter six. This supports findings such as Robertson et al. (2001), where fewer than a third of 500 people with ID, living in various settings, had people other than staff, family members and other people with ID in their networks. Similar findings were reported by McCarron et al. (2011) where one in four adults reported meeting their family once a year or less, and family contact declined with increasing age and in persons with a more severe to profound ID. Additionally almost 80% of adults reported their seldom engaging in activates with friends outside their home and generally relied on staff for such engagement. The relationships in the Robertson et al. (2001) study were enhanced through what appeared to be occurring as the 'fusion of the two worlds' – that of the world of the client and that of the staff member.

Service practices potentially have influence on the social networks of persons with ID (Robertson et al. 2001). Five of the six services in the current research study were long established ID services with a more institutional history. Therefore participants and clients were closely intertwined in each other's lives without large social networks. In the final report of disability policy review of the Department of Health and Children (Keogh 2011), it reports that 90% of services, (day and residential) are provided in congregated settings. Less institutional settings are more likely to have larger social networks, and include family members and /or non disabled persons (Robertson et al. 2001; McConkey et al. 2003 ; Keogh 2011). Earlier studies reported that people in dispersed community housing, have few non learning-disabled in their social network and are happy with their existing relationships with other intellectually disabled people (Gregory et al. 2001). Ager et al. (2001) reported that persons with ID, when transferred from residential care to living in the community, had increased community involvement. However, Srivastava (2001) argued that dispersed housing has resulted in

more isolation of people with ID. Indeed some participants in the current study reported that they believed some of their clients had become more isolated when they were moved out from larger residential living to smaller community houses. Also, people with ID who were moved out from long stay hospitals into the community did not have continued contact with those left in the hospitals (McConkey et al. 2003). Ultimately while deinstitutionalisation as a process is broadly associated with increased social networks, there appears to be literature supporting a range of findings in regard to persons with ID (Ager et al. 2001 in HSE 2011).

 The National Disability Authority advisory paper (2010) identifies that the supporting of independent living within the community has been the direction of policy over the last two decades. The Health Service Executive (HSE 2011) has published the working group report which clearly proposes a new model of support which ought to be established in the community for persons living with disabilities. This is described a "…*simple in approach but will significantly challenge the system to deliver it…*" (HSE 2011: 4). In summary there appears to remain a gap between policy and provision in spite of more than a decade of investigation of service provision for persons with disabilities (Tubridy 1995; HSE 2009 ; NDA 2010 ; Keogh 2011).

In the current study, the participants were also shocked at how quickly clients died after they were moved to other non-ID institutions. This was demonstrated to be the result of the staff in the non ID services not understanding how to communicate with persons with ID or how to assess their needs (McCallion 1999). Previous research in Ireland in relation to nursing home care has also attributed this to a lack of understanding of the needs of the person with an ID and to communication difficulties encountered by staff in generic care settings (O'Neill 2006; HSE 2009). The severing of established relationships and its impact on staff is discussed in theme two below.

In relation to the support of the person with dementia, it is well acknowledged that relationships are an important aspect of protecting the identity and well-being of a person (Kitwood 1997 ; Adams & Gardiner 2005 ; Kontos 2005), and of improving his/her quality of life (Nolan et al. 2001). The kinsfolk or significant others of the person with dementia in a home context can fulfil this supporting role, and the participants in the current study working in ID services fulfilled this role. Consequently, the acknowledging and the nurturing of these relationships and their role in the

maintaining of the personhood of the person with ID and dementia is of paramount importance. Some relationships of a 'special nature' were reported by participants in the current study and are now discussed under the category of 'bonds'.

Bonds:

It was evident that the participants in the current study created strong bonds of attachment with some clients. Indeed, as seen from the quotes in chapter six the participants frequently used the term 'very attached' in an effort to stress these bonds of attachment. Bowlby's attachment theory (1969, 1973, 1980) explains how relationships formed early on in life between the child and a primary caregiver (usually a parent) can influence later separation and loss (bereavement) experiences for the child as they mature. In the current study, the participants potentially created, sustained and maintained bonds of attachment influenced by their own personal histories; again, a fusion of the personal history of the client and that of the staff member occurred. There is little research to date on health-care professionals' attachment styles and whether this influences their occupational wellbeing; that which is available is inconclusive (Hawkins et al. 2007).

In the current study there were key worker systems in many of the ID settings and these key workers worked very closely with the client acting often in 'loco parentis'. Consequently, very strong bonds and attachments were made and fostered between clients and staff. This appeared to facilitate what Kitwood (1997) refers to as person-centred dementia care. The value inherent in this relationship with the person underpinned what participants considered as an essential pre-requisite to good dementia care. They knew the person intimately and the person's every need could be anticipated. However, in some settings the value inherent in this relationship between participants and clients were not acknowledged and understood and there appeared to be conflicts and confusion as to the supporting of the 'best interests' of the person. Rather than nurturing these relationships, management at times thought it better that staff be rotated because it was considered to have a protective element for both the client and staff; they also thought that it prevented the client from becoming too attached to staff, or the staff from becoming too attached or close to the client.

While this may be acknowledged by the management as healthier for relationships among staff and persons with ID, there needs to be a re-thinking of this for the benefit

of the client who develops dementia because of the important role that the relationship with the carer holds in relation to the maintaining of the persons personhood and identity. Findings from the current study indicate a need for a much greater understanding within the field of ID on the nature and value inherent in 'relationship-based dementia care'. There is also a need to understand strategies to improve support for and nurture these relationships, as well as strategies to support staff should this relationship end.

Like Family:

Internationally, article 19 of the Convention on the rights of persons with disabilities (UN Enable 2008) recognises that all persons with disabilities have equal right to live in the community and to have the opportunity to choose where and with whom they live. In the United Kingdom, the White Paper of 1971 advocated the replacement of the term Hostel to 'Home' and that substitute family groups within a family atmosphere ought to be created (Atkinson 1989). However , the benefits of community living with respect to improved quality of life for people with an ID is well documented (see for example, Heller et al. 1998) United Nations and other declarations (UN, 2006) . Despite this understanding, the social engagement of adults with an ID with the community remains poorly understood. For example Verdonschot et al. (2009), in a review of studies published between 1996 to 2006, suggests that many studies provide a poor definition of community participation, and furthermore they are generally restricted to persons with a mild ID. However, both this review and a more recent review by Kozma, (2009) on the transfer of persons from campus to community settings, conclude that while people with an ID who have moved from segregated settings into the community are more connected than people who remain in more segregated settings, those living in the community continue to remain poorly connected with their communities. In the current study, as stated earlier, participants identified with this finding.

However, it is acknowledged that professional services cannot easily replace the family, but that the replacing of bigger organisations with small ones which share the characteristics of the family, could potentially promote the development of a best model of care. Such characteristics are the service is local, small scale, personal and committed (McConkey 2004:38). Morse (1991) considers the concept of commitment versus caring to be an important one in the examining of the nurse's role when with his/her

patient. This concept of commitment is also examined by Holst et al. (1999) when exploring the nurse-patient relationship between nurses and their clients with severe dementia. There was undoubtedly a strong commitment from the participants of the current study towards their clients with ID. This commitment appeared more consolidated once the client developed dementia and began to need more support to enhance his/her quality of life. The participants strove to maximise the abilities of the person and sought actively to continue the person's individual routine psycho-social activities despite increasing difficulties to do so as the person declined.

Atkinson (1989) poses the question as to whether ID services can provide a 'real home'? She argues that while residential homes can simulate aspects of home life, they cannot be 'real' homes as compromises will have to be made between the needs of individuals, the needs of the group and the needs of the organisation. She observed in her study of residential homes that those which supported a philosophy of supporting the individual person's needs reflected more of a 'real' home and those which supported more collective group needs reflected mini-institutions. However, staff from both residential situations used the 'family' analogy when they talked about the supporting of persons within a residential setting. Defining what constitutes family is also challenging. Families have been described for research purposes as complex because of their possible 'dynamic webs of multiple perspectives, multiple roles and multiple influences' (Martin & Cole 1993:186). In the current study, participants described all of these dynamic webs as they explored their own relationships with clients within their ID care settings. The participants also used the 'family analogy'.

In their proposing a new model and framework of institutional end-of-life care in Ireland for the older person dying in hospitals and in long-term care settings, Payne et al. (2009) stress the importance of extending the understanding of family to include friends and significant others. In addition to the analogy of 'family' the participants in the current study used the analogy of 'friends'. Friendship will be discussed later. Therefore, in any ID residence, any or all of the residents and staff are potentially the 'significant others' to the person with dementia. Evidence from research, together with the accounts of disabled people themselves, also suggest that the relationships between professionals and disabled people are varied (French and Swain, 2001). Thus, it could be expected that the experience of grief is equally varied. Therefore, as in any family

context in life, there may be staff who grieve, clients who grieve those who do not grieve and potentially different expressions of grieving in any of the settings where clients are dying in ID services. Bereavement reactions may potentially be determined by whether recognition of grief is acknowledged and whether it is facilitated or repressed.

Friendship:

At the best of times, to develop relationships and human friendships can be complex (Duck, 1992; Caroline, 1993). In the world of ID, it appears to be even more complex. Paid professionals have long been identified as important in the network of friendships of adults with intellectual disabilities (Amado 1993 ; McCarron et al. 2011). Staff/families need to foster all aspects of the personal skills required in the developing and in the maintaining of friendships (Grant et al. 2005). Such skills include sharing and connecting. Therefore, the role of staff in facilitating friendships for people with ID is important. Grant et al. (2005) stress the need for person-centred planning to be exercised so that the individual's needs are met in the facilitation of relationships/friendships. *"Friendships cannot be made for other people, people choose their friends"* (Grant et al. 2005:480).

Time spent together is an important part of one's developing a friendship (Jobling & Cuskelly 2002). Many of the participants interviewed for the current study were senior staff who had worked for up to thirty years in a service. Therefore, many participants knew some of the clients very intimately since they had spent a lot of time together over the years. Lutfiyya (1991) carried out a small study to explore the meaning of friendship between persons with and without learning difficulties. There were twelve pairs of friends in the study and one point of note was that most of them had met while in a staff/client relationship. In a concept analysis of friendship by Caroline (1993), she concluded that close friendships had a voluntary and enduring nature without social or legal norms and that there is reciprocal exchange which includes intimacy and love. Participants in the current study often spoke of the 'love' which they felt for clients within the client-staff relationship. That relationship was one of concern, care and responsibility towards the person. When I spoke with many staff who currently work or have worked in ID care, both in the study and otherwise, they identified that they all had made friends with clients over the years. Becoming friends and knowing someone

intimately in these settings surely challenges the experiences of loss for staff and clients when separation from one another occurs. Loss and grief are discussed in theme 2 in 9.2.

Although the above acknowledges that friendships occur between staff and clients in ID settings, authors such as Grant et al. (2005) state that staff in the work context cannot usually be considered friends of their clients in the fullest sense of the word; that people with ID are usually perceived as a concern in their own right and unable to share emotions or provide support to others in times of need. They qualify this by stating that friendships sometimes happen between client and staff member but usually this is when the staff member leaves the work setting and no longer has the role of caregiver to the person with ID. This was the case with some participants in the current study but it was not the case with all. There were also participants who were still supporting persons whom they considered as friends and they included these persons (clients) in their staff occasions and in their major and personal major family occasions such as weddings, Christmas, Special occasions; they did this on an on-going basis. In line with my findings, the report of the first results from the intellectual disability supplement of The Irish Longitudinal study on Ageing in Ireland, provides evidence that points strongly to the fact that many of the population surveyed engage in these social activities with staff and peers (McCarron et al. 2011).

In a small study of four people with intellectual disabilities, Knox & Hickson (2001) found that they identified two types of close friendships which they made. These were 'boyfriend/girlfriend' or 'good mate'. Interestingly, although the clients identified staff as friends in Knox & Hicksons (2001) study, they did not identify staff as 'close friends' or 'good mates'. However, the fact that the persons with ID considered staff as friends supports the finding that friendships happen. Friendships may be covert and therefore such friendships need acknowledgement in experiences of separation and loss so that the experience of grief does not become disenfranchised.

Friendships are often nurtured by sharing common concerns (Grant et al. 2005). The sharing of experiences such as 'grief' may bring about a sharing of thoughts, feelings, and values which might not otherwise be shared and it deepens the relationship to one of 'soul mates' (Grant et al. 2005). It was evident that the participants in the current study were more aware of death and the possible impact of a client's death on his/her peers. Therefore, they were now beginning to share some of these thoughts and feelings

described above between themselves and their clients. This may imply for the future that new and deepening levels of friendship will be developing as grief becomes a shared human experience between professional carer and client in these settings.

Shared humanity:

Health and welfare professionals need to work with disabled people as allies which means relinquishing their professional power (French and Swain, 2001).

The participants in the current study in ID settings, appear to be in a stage of 'opposition' and 'apposition' in terms of relationships – which heightened the potential complexity of any grieving process. They were walking a tightrope between maintaining two of the mutual relationships described by Morse (1991). These were a) and b).   a) The *connected relationship in which the nurse views the 'person/patient' as a person first and a patient second*. In this relationship the nurse will take on the role of advocate readily and break rules to 'go the extra mile'. The participants identified that they had a strong role as advocate for the client and this is recognised in ID care in the literature (McConkey 2004 ; Turnbull 2004 ; Gates 2006). Acting as advocate, the participants in the study frequently worked to keep the person with advanced dementia 'at home' for as long as possible and if possible to keep them at home to die. In this way they were attempting to keep the relationship close and attempting to manage their own loss and grief experiences with the client. The second role (b) the *over-involved relationship where the relationship develops beyond the professional relationship and becomes a more personal relationship*. Morse (1991) recognises that this latter type of relationship carries a high emotional demand on the nurse and that both of these relationship profiles (1 & 4) develop in longer term relationships. Such long-term relationships are commonplace in ID settings as demonstrated in the current research study. Therefore, there is a high emotional demand made on the staff (nurses and carers) which can impact on their experiences of loss and grief when supporting clients over many years.

Participants identified a sense of shared humanity with their clients. They saw the person beyond the disability irrespective of whether the person had mild or profound ID. They recognised the commonality of being human beings sharing a home together. This is reflected in the literature where service users in a study by Marquis & Jackson (2000) reported that they felt understood and accepted when staff shared life

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experiences with them; this sharing outside of the paid work context also allowed the service users to experience friendship and family dynamics within their relationship with staff. The service users valued the quality of interactions with staff who responded to them as individuals rather than responding to their disability (Marquis and Jackson 2000). A major theme from Marquis and Jacksons (2000) study was - 'Human serving – more than doing a job'. Within the current study, it was evident that participants did more than their job. In relation to loss and grief, they went beyond their job on every occasion when a client was dying or had died. In all of the services they were totally involved in all arrangements for the removal, funeral and in the follow-up services provided by the Service for families and peers. More often than not much of these activities were done in the staff members' own time. Furthermore, participants acknowledged a personal growth for themselves when they experienced this common humanity in their supporting of a person with ID and this is reflected in the literature (Welsh 2004).

The seminal work of Morse (1991) describes four types of relationships which can develop between nurse and patient in a general (non ID context). These are 1) clinical relationship, 2) therapeutic nurse-patient relationship, 3) connected relationship and the 4) over-involved relationship. In the first two relationship models, the individual is seen as patient first and as person second. In the latter two, the person is seen as person first and patient second. In the current study I consider that the participants did not overly identify with the clinical or therapeutic nurse-patient relationships described by Morse (1991). They regarded the client (person) first and only considered the client a patient when s/he had health care needs By virtue of the nature and longevity of the relationships connected relationships were made consistently. Connected relationships occur according to Morse (1991:458) either when the staff and patient have been together long enough to have passed the clinical and therapeutic relationships or the process of developing a connected relationship is accelerated to meet the 'patient's extreme needs'. In the connected relationships the staff are perceived to have gone that 'extra mile'. The participants in the current study demonstrated going the extra mile as described in chapter six. In the over-involved relationships, the staff relinquish their 'impersonal professional relationship' (Morse 1991:459). This 'walking the tightrope' between keeping a professional relationship and a personal relationship with their clients is described later in Theme two.

Strong bonds of attachment were made among participants and clients in the ID settings of this study. The resulting relationships of intimacy and a shared humanity potentially run the risk of staff experiencing disenfranchised grief if the nature of such relationships are not recognised and that subsequently the staff are not facilitated in their loss and grief as desired.

9.2.2   Ethos of care

There were four categories in this sub-theme. These were 1) person-centred care, 2) ordinariness of care, 3) meaningful work and 4) changing expectations.

Person-centred care

Person-centred care is recognised as an important aspect of good dementia care Kitwood (1997 ; Kontos 2005). Person-centred care is a term commonly used but it can be difficult to articulate (Brooker 2007). Participants did not talk too much explicitly about their delivering of person-centred care but in my observing the support and care given to clients, it was evident that considerable thought was put into the delivering of very personalised care to each individual. The participants displayed great dedication to their upholding of the dignity of the person and to respecting his/her personhood as recognised within good practice for supporting persons with dementia. Indeed the goal of utilising person-centred care for persons with dementia can be to preserve their personhood (Kelly 2010). Participants in the current study went to a lot of effort to ensure that staff who did not know a client well, were orientated to that client's needs, to ensure that the person's likes and dislikes were accommodated. In this way they were endeavouring to protect the client's identity and ultimately his/her personhood.

The current service provision of disability services in Ireland continues to be influenced by a professionalised health and social model which continues to aim support towards group settings and not towards individuals (HSE 2011).   Therefore implementing meaningful individualised person-centred care remains a challenge for services. Such challenges to an ethos of care require sustained efforts towards changing the culture of an environment and are not a one off event (McCormack et al. 2010).

More recent definitions of person-centred care recognise the importance of interdisciplinary working and recognition of relationships (Nay et al. 2009).

Nolan, Keady and Aveyard (2001) recognise that while person-centred care has done much to advance care, that relationship-centred care ought to be recognised as important in improving a persons' quality of life. Although relationship-centred care (Tresoloni and Pew-Fetzer 1994) was not explicitly identified by participants in the current study, the central importance of relationships in good dementia care is highlighted by writers such as Kitwood (1997), Oppenheimer (2006) and Nay (2009). However, although not explicitly discussed in the interviews, it was evident that the participants across all sites did collaborate with other professionals, kinsfolk and with any other person deemed important with regard to good decision-making in relation to supporting the person with dementia. Dementia care triads involve including the person with dementia, the informal carer and the professional carer (Adams and Gardiner 2005). It is evident in the literature that such relationship-centred care may be even more important where long-standing relationships are formed (Nolan et al. 2006). Hughes et al. (2006:200) acknowledge the importance of relationships for persons with dementia in 'filling some of the gaps' which are created with advancing decline and communication difficulties, stating that the families/friends are the safe keepers of the person's identity. As stated earlier, participants in the current study, because of their long-standing relationship with the person, were fulfilling this dual role on occasion for the clients whom they supported as their dementia progressed.

Ordinariness of care

The practice of custodial care for persons with learning disabilities in hospitals and large institutional settings began to change from late 20th century following the work of people such as Wolfensberger (1970) and O'Brien (1980). The work of these authors, together with papers from the King's Hospital Fund, promoted the philosophy of "people with disabilities have ordinary needs but often need support in having their ordinary needs met" (McCormack 2004:15). Indeed the participants in the current study spoke of the 'ordinariness' of their day-to-day work in terms of meeting the client's basic physical/physiological needs in relation to activities of daily living (eating, drinking, personal hygiene, social). The participants identified a common sharing of their ordinary needs with those of the client. Taylor (1991 ; 1998) observed this ordinary sharing oneself as a nurse as a human-being with a patient, as being central to the nurse's sharing a common sense of his/her own humanity with patients in his/her

care. Reflection on the therapeutic role of ordinariness of the nurse may lead to a re-conceptualisation of the nurse as a 'person' within the nurse-patient relationship (Taylor 2006).

In addition to the experience of the ordinariness of supporting the clients in ID, the participants spoke about the need for teamwork. Participants understood that the supporting of persons with dementia was optimised when they could deliver a multi-disciplinary team approach to their care. In some services there was such a team but in others there were nurses and carers on-site; there was visiting medical support only for medical management of health issues. Participants in the current study already recognised that good teamwork among frontline staff was important in the supporting of persons with ID. The person with the dual diagnosis of ID and dementia requires staff to have knowledge and skills to work both inter-professionally and intra-professionally within and outside of their own ID services as the dementia progresses (McCarron et al. 2008). Effective and efficient teamwork is recognised as being imperative in delivering high quality dementia care (Kitwood 1997) and high quality palliative care (DoH&C 2001 ; Abbey 2003 ; Rowe, Keating & Walsh 2005) along the trajectory of the illness and at end-of life (Tuffrey-Wijne 1997 ; Ryan & McQuillan 2005 ; McCarron et al 2008).

The participants in the current study acknowledged that the supporting of the person with dementia required a team approach from within the ID service itself and also an extended multidisciplinary team collaboration between themselves and services such as general practitioners. The expertise of specialist palliative care was seen to be important in relation to the planning and the delivering of improved end-of-life care. Interestingly, no participant across any site spoke about their requiring support from specialist dementia care services. One ID service did have significant expertise in dementia care within their service. It appeared that the other services depended on their visiting medical staff from general practice or psychiatry/psychology for such support. However, the specialist palliative care participants in the focus groups in phase one, identified that they would require the support of dementia specialist services to manage any referral of a person with dementia as they did not have this expertise as evidenced in the report of the findings from phase one (McCarron et al. 2008).

Finally in the ordinariness of their daily work and as members of a team the participants took their responsibility of advocate for the person very seriously. They appeared very protective of the clients whom they supported and tried to ensure that other staff, whom they perceived did not know the client as well as they did, were made fully aware of the client's wishes and preferences. Advocacy in nursing is not without its critics as to whether it ought to be commended or not (Dooley & McCarthy 2005).

However, advocacy requires the practitioner to know the: *"values in living that seem to be recognised universally as fundamentally important or essential to human and humane living"* (Liaschenko 1998:12).

I consider that the participants explored these values as they worked with their clients in trying to make sense of their living and dying. This relationship of a shared humanity was explored in the previous sub-theme of valued relationships.

Meaningful work

Although participants found it difficult to articulate why they worked in ID care, they spoke with passion when trying to say why they loved their work. Their work gave them meaning. This ability for humans to search and find meaning appears to be a strong primary motivator as described by Frankl (2004).

> *"Mans search for meaning is the primary motivation in his life… this meaning is unique" and can only be fulfilled by the person himself. "Man is able to live and die for his ideals and values Frankl (2004: 105).*

Meaningful work fulfils a person's desires (Ó Murchú 2007). All of the participants spoke of making a deliberate decision to work with people with ID. Some participants went into this work purposefully and others did not. In every case they continued to care for this population because they got something special back from working with people with ID. This is reflected in the literature by Turnbull (2004) who testifies that many people go into learning disability nursing because of their desire to work with this population rather than to 'nurse'. The majority of the participants in this study were working in these services between 10 and 30 years and portrayed a sense that they genuinely enjoyed their work and would not change it. This wish to stay, and the fact that they appeared to love what they were doing were often stated despite an ever existing lack of human and practical resources in practice.

Participants stated that they 'loved' the clients and spoke about the tough decisions that they had to make on occasions such as moving the client with dementia out of their 'home' when the time came that they (staff) could no longer support the person due to inappropriate resources and environment. Participants really struggled with the difficulty of their making of a decision 'out of love' for the client to let him/her go to another area of the service where the participant knew the client would receive more one-to-one care. While this expression of love may appear unusual in a professional-client relationship, it also reflects the vulnerability of human relationships and understanding as highlighted in Victor Frankl's (2004) *'Man's Search for Meaning',* persons can find meaning through love:

> *"Love is the only way to grasp another human being in the innermost core of his personality" ... no one can become fully aware of the very essence of another human being unless he loves him.. . By this love the 'lover' is enabled to see the essential traits and features of the beloved and even more see the potential within himself which ought to be actualised.* (Frankl 2004: 116).

Perhaps the love participants have for clients in ID care is akin to filial love (Read & Wuest 2007), whereby the staff have a strong sense of responsibility to the clients as if they were in a parent-child relationship particularly where the client is older than the staff member. Alternatively, maybe the love is of 'charity' or agapé (Lewis 1960) which brings forth caring regardless of circumstances. Whatever the type of love between participants and clients, loving someone is a precursor to the pain of separation when the love is changed through loss and death (Parkes 2006). Grieving may be potentially disenfranchised if the staff member cannot openly acknowledge s/he had such feelings of love for a client.

In relation to reciprocity, participants in the interviews spoke of the feedback they had received from clients as being important to them and that they got a lot back from clients. This point is mirrored in Lutfiyya's (1991) study of the reciprocal nature of such relationships. Such reciprocity between participants and clients surely impacts again on the nature of the experiences of loss and grief when these are experienced in the relationship. Participants were more commonly supporting a population with terminal conditions such as dementia. Compassion fatigue as described by Sabo (2006) can become a feature of caring for persons who are in pain, seriously ill and dying. In

relation to the supporting of a person with a chronic condition, it is described as the loss of ability by the staff to: *"provide the same level of compassion to patients, families as they once did"*. Wilson & Kirshbaum (2011:560).

I do not consider that the participants experienced this phenomenon of compassion fatigue in this study. They had been supporting the person with an ID within a social-care model for many years. Although they inevitably support the person within a health-care model in advanced dementia, the participants continued to uphold the ethos of the social model. It was evident that participants considered the relationship between themselves and the client as central within the combined health-care/social-care model .

From my reflections on this study, I consider that the relationship between the staff member and the person with ID differs from that of any relationship between other professionals and patients who do not have ID. At the outset, there is a relationship of equals in a shared humanity where value judgements appeared to be absent. Although there could be the perception that the person with the ID may be the vulnerable one in the relationship with the carer, there appeared equally a vulnerability in the carer as s/he struggled to articulate the reasons as to why s/he derived satisfaction from her/his work. I furthermore believe that there was an unspoken spiritual dimension to the relationship between participants and their clients which was part of the 'shared humanity' presented in chapter six. In contrast to a relationship of equals, I consider that there is also an unequal one which is defined by the fact that one person does not have a label of ID and s/he is operating in a professional capacity and is being financially remunerated for providing support to the other.

Changing expectations
Participants commented on the increasing bureaucratic nature of their work and that they had more paperwork now. They reflected on how they had more time to spend with the clients previously. However, the reality is that the client with the dual diagnosis of ID and dementia requires more time-giving as they decline with the dementia (McCarron 2003). Therefore, if staff are being expected to deliver a palliative approach to care, this will inevitably place a greater expectation from them that they will be able to deliver on all of the principles of palliative care espoused by the WHO (2002). This is in addition to what they already deliver within a person-centred context. An important

aspect of this care is to support the person with loss and grief. Furthermore, there will be the need to support the significant others (peers, family, other staff and themselves) of the person who has a terminal illness. Such support demands time and a specific skill set. Recent research in Ireland identifies that staff recognise that clients with ID experience loss, grief and bereavement (Ryan and Dodd 2011).

Dawson (2004) refers to the journey which staff and clients make in ID care as a Journey 'from dependence to independence'. Indeed staff in the current study also spoke of 'being on the journey of dementia' with the client. In the next section in theme two in this chapter this issue of journey is demonstrated as it relates to the feelings of loss which staff experience when supporting a client from independence back to dependence again.

There is a desire by participants to deliver person-centred care while recognising an 'ordinariness' about their care and about their wish to continue to find meaning in their work during a time of significant change in the cultural or organisational climates of their employment. Various frameworks have been proposed that attempt to capture the intricacies of Work ethos. Furthermore, the term person-centred care pervades the literature and policy documents in ID care, care of the older person; it is included in much of the care plans written for these populations. However it is also recognised that it can be a difficult concept to articulate and to implement in practice.

In summary, theme one– Worldview of supporting a person with ID and dementia, a hermeneutic discussion has now been presented and supported with findings from chosen literature. The key findings of 1) Valued Relationships and 2) Ethos of Care were discussed in relation to how these two categories are interpreted as important within the worldview of the participants of the current study.
Theme two – Worldview of Loss and Grief will now be presented.

9.3   Theme 2: Worldview of Loss & Grief - Hermeneutic circle of discussion

Theme two is now discussed in relation to the literature available on loss and grief for staff who support persons with ID and dementia. The discussion within the hermeneutic circle means that the parts and the whole of understanding continue in a discursive way. The sub-themes within this worldview are used as major headings to focus the discussion and the categories are discussed within these sub-themes. The sub-themes are 1) Complex grief, 2) Emotional impact, 3) Disenfranchised grief, and 4) Coping strategies.

9.3.1   Complex Grief

There were three categories in this sub-theme. These were 1) maintaining relationships, 2) the nature of the illness and 3) personal experiences of grief.

Grief was complex in the first case by the participants' identifying that the relationships which were formed among persons with ID and secondly between staff and the clients were broken due to many transitions over the years. The grief and loss therefore was perceived as different to other grief experienced in other health & social care settings. Furthermore, participants readily identified the concept of professional grief as a phenomenon which they experienced in practice.

Maintaining Relationships

To maintain the relationships between themselves and the client until s/he died was something participants endeavoured to do despite the difficulties which arose as the dementia progressed. This commitment to their maintaining relationships was given emotional, psychological and physical energies as they struggled to keep the clients 'at home' to die. Communication between nurses and clients with advanced dementia is complex (Holst et al. 1999 ; Doka 2004). Within the nurse-patient relationship, each confirms the other's identity. The client confirms the nurses personal identity and professional identity and the nurse confirms the client's personal identity (Holst et al. 1999). According to Holst et al. (1999), when the patient is unable to confirm the nurse's identity (personal and professional), because of his/her cognitive decline, this can lead to feelings of helplessness on the part of the nurse. This phenomenon of feeling helpless was reported time and again by the participants in the ID settings in my research study. Their helplessness was sometimes due to their being able to do nothing

more for the client, and sometimes because they did not know whether they could do more or not. When clients were moved because of resource issues the participants wanted to remain connected and involved in their care. This was also true for relatives of persons with dementia in the general population in an Irish study (Argyle et al. 2010). However, it was not often logistically possible for the participants in the current study to remain involved in the client's care and this potentially complicated their experience of loss and grief for them. Furthermore, they were grieved by their witnessing the grief of other staff (usually the less experienced) and the grief of the peers of the client in the original setting (home) after the transfer. This phenomenon of one's having said goodbye when the person left and then saying hello at visits, potentially re-enforced the feelings associated with ambiguous loss (Boss 1999) for the participants, colleagues and the peers of the person transferred. There is a dearth of literature on the personal grief experienced by staff working with clients with ID.

Nature of the illness

Dementia has a long trajectory from diagnosis to death and the phenomenon of loss is an inherent part of that experience for the person with dementia and for those who support the person. Grief in dementia care may be anticipatory as it relates to present and anticipated losses prior to actual death (Rando 1993; Meuser & Marwit 2001 ; Doka 2004). To know that someone is going to die because s/he has a terminal condition has the potential to put family members into a state of anticipatory grief (Doka 2004; Clukey 2007). Some participants in the current study acknowledged that they dreaded the death of the client and looked sad when they reflected on his/her life with them together. Other participants said they wouldn't think about it until it happened. The road of dementia is paved with many losses (Loos & Bowd 1997; Kuhn 2001 ; Doka 2004 ; Oppenheimer 2006). Participants in the study identified the many losses for the person and found it very difficult to watch her/him losing hard earned skills over a short period of time.

Many participants did not talk about their experiencing feelings of loss and grief until the client was in the mid or late stages of dementia. They spoke about the loss of occupation for the client when s/he could no longer travel independently to a place of work because of his/her cognitive decline and inability to remember where to go or how to return home. They also spoke about the loss of independence for the client when s/he could no longer carry out any personal care. Finally they spoke about their loss of the

relationship and how that impacted on them as staff. Inevitably, the participants had long-standing relationships with the client with dementia. In a study with paediatric staff, such long-standing and close relationships between staff and their patients was central to the grief response experienced (Plante & Cyr 2011). The nature of the relationship between the bereaved and the deceased is central to the grief experience (Fulton 2003 ; Johansson 2012). The many losses and the anticipated many goodbyes during the period of supporting a person with dementia may result in ambiguous loss (Boss 2011). The participants in the current study found it very difficult to cope with this ambiguous loss particularly when the person had advanced dementia or was at the end-of-life. They repeatedly saw the person succumb to infections and become moribund. They anticipated the death of the person each time and said goodbye when the person was transferred out to a hospital or another unit. Then the person recovered and returned to their care again.

Participants made a distinction between the grief they experienced for persons with dementia and the grief they experienced for clients who died suddenly. Caring for persons who are dying may not be stressful in itself but the nature of the relationship between nurse and patient matters – for example a young or favourite patient (Alexander & Ritchie 1990; Hinds et al. 1994). In the current study participants expressed greater sorrow for young patients who died suddenly. They felt that the person was too young to die and that the person with dementia had at least lived a full life and his/her death came as a relief from suffering. In a study by two key theorists, on the impact of patient death on healthcare staff, Kubler-Ross & Worden (1977) surveyed 5000 staff in healthcare settings and described a trend that nurses were more emotionally impacted upon with the deaths of young patients of their own age and gender. An experienced male carer in the current study who was perceived by his colleagues as a 'tough guy', spoke of the effects which the sudden death of a young man had had on him in the early years of his career in ID. He was recalling the traumatic effect this had on him although it was now many years after the event. There is a dearth of literature on the grief experienced by professional carers.

Inevitably most participants in the current study identified the experience of loss directly with the death of a client. It was only staff who had reflected on their personal and professional experiences and who had a deeper understanding of loss such as any

significant transition during life who identified other experiences of loss. The experience of personal loss and grief was recalled by many participants.

Personal grief

A factor which may complicate the grief experience for carers who support persons with dementia is their own personal experience of anticipatory grief and how that influences their overall reaction to the impending death of their loved one (Oppenheimer 2006). In the current study, personal experiences of loss and grief and how these influenced the participants' coping with the demise of clients, were evident. Some senior participants referred to learning by personal experience as learning from the 'university of life'. In one's reflecting on one's own way of grieving, one can understand better one's own coping mechanism (Fahey-McCarthy 2003). Anticipatory grievers may have the opportunity to explore some of their emotional reactions to impending loss when they know someone is going to die (Rando 2000). The participants who reflected on their own personal experiences, could relate their reactions and coping styles to how they managed their grieving. Some recognised that they were 'doers' and suppressed their emotional responses; others were thinkers and expressed emotional responses. Interestingly, the personal grief history of healthcare staff surveyed by Plante & Cyr (2011) did not influence the intensity of their grief response. However, there were strong emotional responses by staff to the death of a child which were similar to those of a parent at the time of the death. Participants grieved for clients to whom they had become attached and loved.

9.3.2   *Emotional Impact*

There were two categories in this sub-theme. These were 1) sadness and 2) mixed emotions.

The emotional toll on staff may be a covert part of the cost of caring, and the need to balance emotional reactions and to develop improved ways of protecting self is seen by Bailey et al. (2011) as important for staff who support dying patients. Participants in the current study felt that they could demonstrate their grief and could cry in front of colleagues and even in front of the kinsfolk of the client. However, only some participants did this. There were two occasions when participants cried copiously during the interviews. This was when they were recalling the death of a client with whom they

had had a substantive bond. Plante & Cyr (2011) similarly found this with staff who supported children who died in their care. In the current study, the participants were unable to articulate what was special about the relationship but they just identified that they had had a unique relationship with him/her.

It was evident that participants experienced emotional reactions during the course of their supporting the person with dementia throughout their decline and death. Sadness was the emotion most strongly expressed. In a large study by Rickerson et al. (2005) across six healthcare institutions in the USA, the greatest grief responses in staff were in those who had long and close relationships with patients. Participants in the current study had very long-standing relationships with their clients as is the nature of ID care. In a study by Rickerson et al. (2005), crying and feeling sad were the most common emotional responses to patient deaths. In the current study, the participants experienced physical and emotional symptoms and the most common reactions were also feelings of sadness and crying or the tension of one's not crying. Such responses were commonly in relation to the fact that they perceived that the client was suffering. This suffering could have been of a psychological, physiological or emotional nature. This was usually referred to when they were observing a client coming towards the end of his/her life. The literature on suffering is conceptually confusing with much of the literature on suffering within healthcare concentrated on physical suffering; there is some concern about its possible impact on staff (Morse 2001). To watch a patient suffer may increase the grief of healthcare staff (Bruce 2007). The participants in the current study were certainly saddened to watch what they perceived as their client's suffering. They were most anxious about physical suffering for the person i.e. the experience of physical pain. They also found it difficult to watch the person linger.

 On other occasions, participants who did not cry during the interview but instead made strong emotionally-laden statements about how angry or annoyed they felt because they were not there for the clients when they died. This happened because they were off duty and they were not told about the death until they came back to work. The reaction of anger is recognised as a normal reaction to grief (Kubler-Ross 1970). This strong emotional response appeared to be as a result of their being unable to say goodbye to the client as they were neither at the death nor at any of the rituals of the funeral/burial. The process of saying goodbye is important in facing a loss (Read & Wuest 2007). In

dementia care the process of saying goodbye is further complicated by the fact that there may be multiple 'goodbyes' (Boss 1999, 2011). Therefore the participants who were denied this process appeared to remain emotionally upset even many years after the death. The participants in the current study discussed feelings of grief when they perceived that they were unable to give the highest quality of care to the person. This is a phenomenon also identified by Parkes (1999).

In a study by Sanders et al. (2008) family carers recognised that their grief was compounded by unresolved guilt. A significant source of this guilt in the Sanders et al. (2008) study was the removal of the person with dementia from his/her home to a long-term care placement. This guilt was also reported by the participants in the current study as they felt that they had ultimately let down the person with dementia at that final time when the person needed them the most. This is again mirrored in Loos & Bowd (1997) and in a recent Irish study by Argyle et al. (2010) when family members felt guilt because of the institutionalisation of their relative.

Evidently, some of the participants identified that they were more 'thinking' than 'emotional' beings and that they coped with the deaths of clients by being very practical and used a coping strategy of 'doing' (organising funeral, putting away belongings, tidying room). Morse (2001) proposes a model of suffering where the person suffering goes between two distinct states of being. These are emotional suppression (enduring) and emotional suffering (emotional expression). The emotional suppression/enduring states are when the sufferer is able to function and carry on with the day-to-day activities. In the emotional suffering/expression state the sufferer is filled with sadness, needs to express it and will recognise the meaning or significance of the loss. Participants spoke of the need to be/remain professional even though they may have been very close to the client who died. It may be argued that participants in the current study who described themselves as being more practical, were in those circumstances, in an enduring state as described by Morse (2001); therefore they were donning their professional identity to be able to keep emotions in check and to be able to function in performing the day-to-day activities expected of him/her.

However, some participants described themselves as 'more practical' and engaged in 'doing' activities like tidying away, packing belongings, and did not feel the need to

express emotions but, unexpectedly some days or weeks later, broke down in tears. This phenomenon of one's experiencing delayed emotional reactions and staff's experiencing unexpected grief reactions out of the context of the actual death, was also identified by Papadatou (2000). In the ID settings the staff are heavily involved in all aspects of the arrangement of the funerals for the clients. In the current study this was mostly without the client's kinsfolk for a variety of reasons. The participants, whom I consider were in enduring states of bereavement as described above, were senior nursing/social staff who had the major role of organising, liaising, communicating and supporting others at the time and afterwards. Although this may be exacerbating the emotional impact on staff, it appeared that this role was also very important for the participants. The deep sadness experienced by the participants, mirror those in Clukey (2007) when examining experiences of family caregivers of persons dying from chronic illnesses in a hospice. This re-iterates the close 'family like' bonds which the staff have with the clients in ID services.

Sanders and Valente (1994) stressed that a balance needs to be achieved between 'emotional detachment' and 'emotional attachment' in order for the nurse to care for self. The emotional toll of one's 'being' with a person is more challenging than one's 'doing' for the person' (Katz and Johnson 2006:17). The term emotional labour is used by Bailey et al. (2011a) to describe the investment of emotions of a nurse caring for persons who are dying. Fortinash & Worret (2004) and Bailey et al. (2011a) recognise the importance of the investment of the therapeutic self of the nurse with clients who are dying and the need to balance emotional labour and emotional intelligence (Bailey et al. 2011a). The investment of the therapeutic self fosters the development of the relationship between nurse and patient (Bailey et al. 2011a). Such fostering of relationships occurs naturally within the ID settings due to the very nature of the work.

9.3.3 Disenfranchised grief

There were two categories in this sub-theme. These were 1) Different grief and 2) professional grief. During the analysis of the data, it was apparent that staff were experiencing disenfranchised grief as first described by Doka (1989) and later recognised in relation to dementia (Doka 2004). This disenfranchised grief, I consider, was a component of ambiguous loss as described by Boss (1999). The grief experience

was different because of the specialty - the intellectual disability care setting. Furthermore, carers of and persons living with dementia may be disenfranchised in their grief. Finally, the staff can experience disenfranchisement in their own grief as professional carers for their clients as they witness them declining with advancing dementia.

Different Grief

Staff were sad and missed clients when they were moved out (because they had progressive care needs and they did not have the resources to keep the person 'at home'), and this was compounded by their witnessing the peers of the person grieving. Marlow & Martin (2008) in a small study of six family carers reported that an intensification of closeness occurred between persons with ID and their family after a diagnosis of a terminal illness. They termed this 'interlocked companionship' (Marlow & Martin 2008:345). I consider that the participants in the current study displayed this interlocked companionship on many occasions. They wished to keep the client at home and went to great length to do this even when the person was in advanced dementia and they were really under pressure because of a lack of human resource or unsuitability of accommodation. This intensification of closeness, I consider, is why they found it so extraordinarily difficult to let them go either to, a) other agencies for acute admissions(hospital), b) to another service (nursing home or another part of their own service) or c) to die. This intensity of reaction by a family member to the diagnosis of a terminal illness in a person with ID reported in Marlow & Martin's (2008) study is also documented in earlier literature (Tuffrey-Wijne 2002).

In the ID settings, losses other than death can be commonplace when clients and staff have to move from one setting to another. If these separations between clients and staff are not perceived as experiences of loss, then there is the potential for their being disenfranchised. In one small study, ID clients reported sadness at their leaving home and entering institutions; also when they left those institutions and went to live in community settings, they missed family when moving in and missed friends when they moved out (Senescall (1997). Likewise, it was reported in the findings of this thesis that staff mourned the loss of clients who moved away from services over the years and also felt similar loss when they as staff moved away from one work setting to another and left clients behind.

If staff are socialised into a culture of keeping death secret from people with intellectual disabilities (Blackman 2003; Clements et al. 2004), even though it is known that they can and do grieve losses (Blackman 2003, Dodd et al. 2005, Meeusen-van de Kerkhof et al. 2006), then they may not have acquired the skill set to support persons who are dying. While participants in the current study attempted to support people from the 'university of life', they appeared vulnerable as to whether they were supporting people adequately. This was on the one hand because of a lack of a vocabulary to talk about death and dying and also the lack of clarity as to whether the clients could comprehend discussing such matters. This lack of being educationally unprepared to care for the dying, resulted in their struggle to provide knowledgeable end-of-life care (Todd 2004).

Senior nurse participants, appeared to feel the responsibility to support junior nurses, carers and clients. In the settings where there was no nursing staff, the senior care staff participants felt the need to support the more junior staff and the other clients in the residence. In principle, staff in the ID services perceive that they understand the needs of persons with ID better than generic services and wish to deliver end-of-life care (Todd 2004 ; Fahey-McCarthy et al. 2008).

In phase one also, it was evident that participants included the peers of clients in all end-of-life rituals over which they had control and supported the grief of peers to the best of their ability as anyone would in his/her trying to relieve the suffering of another person. This is reflected in literature from another Irish study (Dodd et al. 2005). Grief can be disenfranchised for healthcare staff who support persons with dementia and/or ID and who recognise the needs of the kinsfolk and attempt to support them in their grief in their daily routine (Parkes & Prigerson 2010).

Professional Grief

Participants in the current study acknowledged that they experienced grief for clients who had died and to whom they had provided support as 'professional' or paid carers. Such grief is acknowledged in the literature (Sanders & Valente 1994 ; McNamara et al. 1995 ; Papadatou 2000 ; Bruce 2007 ; Gannon & Dowling 2011). These authors recognise that healthcare staff experience grief which is similar to the grief experienced when any close relationship or bond is severed. The more recent literature on staff grief

in long-term care of the elderly settings, has identified that little attention has been paid to such grief experiences (Gannon & Dowling 2011, Osterlind et al. 2011). Wilson & Kirshbaum (2011) identify that if patients have multiple hospital admissions and build up relationships with staff, that the deaths of such patients can have a profound impact on the staff. However, they also identify that there still remains a scarcity of research articles on the subject of the effects of patient deaths on staff (Wilson & Kirshbaum 2011).

Loss of the relationship is a component of the overall experience of loss (Papadatou 2000). Some senior nurse participants in the current study who had delayed grief reactions such as 'bursting out crying' weeks after a death of a client, described how they were the persons within their own family who always supported others in grief. There can be an expectation that the nurse in the family can cope within a professional role in his/her giving comfort to all of the other members of the family (Crawley 1985). Whether it helps nurses/carers to have experienced personal bereavement in order to support others in their professional capacity in relationships with patients, is not certain (Hayslip & Leon 1992). McNamara et al. (1995), in a study of hospice nurses identified that professional grief occurred after nurses had had a relationship of intense intimacy. These relationships in specialist palliative care settings are usually of short duration in comparison to those between nurse/carer and client in the ID settings, who can have intense relationship over many years (Turner 2004). Although, there is an increasing number of persons ageing and dying in the ID services, I do not consider that they are at the same risk of profound grief (Redinbaugh et al. 2001) or of grief overload as identified by Bruce (2007); this phenomenon arose in staff who were persistently exposed to deaths of patients. Staff in the ID settings support other residents alongside the person with dementia and therefore not all of their population have terminal illness; they have to continue to support a very active social model of care for all of their population. However, grief reactions among staff will potentially become more common when they experience the various losses while they support an ageing population who develop dementia.

In the general healthcare setting, it is acknowledged that nurses have more extensive contact with patients than any other member of the healthcare team (Costello 2001). Literature on professional carers in health and social care could not be sourced but

carers in the study central to this research also spent equally extensive contact time with the clients. Historically, nurses were not expected to demonstrate their own grief (Speck 1978) and nursing and research literature explicitly and implicitly conveys the need for nurses to keep a distance between themselves and their patients (Määttä 2006). While this may be identified as important in general nursing, this may be very difficult to do in ID care, where the nature of developing relationships between professional paid workers and clients is inherently central to providing the best support to clients.

In the Öresland et al. (2006) study of community nurses, they describe how the nurse uses two identities when in the home of the patient. One identity is as the 'guest' and the other identity is as the 'professional'. As the 'guest', the relationship is of an equal status and is of a private nature, while as the 'professional', the nurse takes on a role of authority in the relationship. In the study by Öresland et al. (2006), the nurses realised that they had to make a choice as to which identity they held and they also realised that they could not hold both at the same time. This is akin to the ID settings in the current study because participants identified themselves as 'the guest' and said the care setting was the home of the client. Therefore the nurse/carer is challenged to find a balance between the two identities. I consider that the challenge is greater when the client develops dementia and as they progress into advanced dementia, as the nurse/carer swaps the social care model of care more and more for the health-care model of care.

I further consider that, in particular, it becomes more difficult for the carers who feel more helpless when the healthcare model engages. Their experience is more like that of family carers in Adams & Sanders (2004) study where feelings of grief were identified as more intense/common when their relative was in the advanced stages of dementia. The carer participants in the current study reported and appeared more helpless than the nurse participants, because of their lack of understanding of the patho-physiology of advancing dementia and their lack of skills in managing end-of-life pain and symptom control for the person. It is recognised in the literature that the non-nursing staff have specific educational needs as highlighted in chapter one of this thesis (Whittaker et al. 2007).

Healthcare professionals may share similar grieving needs to family and patient (Bruce 2007). Such grief impacts as a result of the healthcare professional,s supporting the person through suffering and death (Bruce 2007). Some of the issues which give rise to these feelings of loss and grief arise from the reality that attachment occurs when the

healthcare worker enters into an empathetic role with the client thereby investing in him/her but when the client dies there is a loss experience (Bruce 2007).

9.3.4 Coping Strategies

There were three categories in this sub-theme. These were 1) holding on and denial/acceptance, 2) facilitating a good death and 3) rituals and remembering.

Holding on, Denial and Acceptance

Not all people need grief therapy intervention as they use their own coping strategies very effectively (Worden 1991 ; Schut et al. 1993 ; Jordan & Neimeyer 2003 ; Prigerson 2004). Participants in the current study identified that they utilised a range of coping strategies in response to their feelings of loss and grief for clients.

In the first case participants wanted to hold on to the person with dementia for as long as possible in his/her usual residence (home). They ideally desired to support the person in his/her home until s/he died. They employed sustained and enduring efforts emotionally and physically to do this until they had to concede from exhaustion from such efforts. When the person with dementia was transferred physically from his/her home, the participants continued to try to hold on to the psychological ties with him/her. In a study of accident and emergency nurses Bailey et al. (2011b) identified that they were trained to preserve life in that setting and that they could develop coping mechanisms to help them cope with sudden deaths, where they did not identify with aspects of the patient's personhood. These authors conclude that these coping mechanisms cannot be utilised in the care of patients dying a slower death. Therefore, these coping mechanisms could potentially be destructive to good dementia care where the preservation of the personhood of the person with dementia is central to delivering good care (Kitwood 1997).

Staying close to the person then, is an important aspect in the support of the person with dementia; the tug of holding on versus letting go is challenged all through the trajectory of the illness. It can be difficult for staff to accompany a person whom they perceive is 'suffering' and this can prompt staff to stay 'professional' or 'objective' in order to manage those feelings (Katz and Johnson 2006:15). Furthermore, in the advanced stage of dementia when the person succumbs to repeated infections and recovers, the staff repeatedly say goodbye and hello and experience the state of

ambiguous loss described by Boss (2011). This holding on and letting go is described by Diwan et al. (2009:359) as *"years of living and reconciling with the loved one's chronic illness".*

The tension in one's trying to hold on psychologically to the person is in itself, potentially challenging when the person is changing with advancing dementia. This is compounded when there is also a threat of physical separation for staff. Their desire to do what is best for the client is persistently challenged as they debate the decisions to be made in relation to end-of-life care for him/her.

Facilitating a good death

Staff who care for the dying, which may be emotionally demanding, can further exhaust their resources for coping with grief and sorrow (Redinbaugh et al. 2001).

To facilitate a good death was an important element for participants in the current study and this appeared to help them to cope with the death. In particular, the nurse participants reported that it supported them in their grief to know that they had made the client's death comfortable and dignified and that they had met his/her particular needs. The possibility that a patient might die alone can create a sense of grief in the health-care worker (Redinbaugh et al. 2001). Families also, do not wish a patient to be alone at the time of death (Goodridge et al. 2005). Furthermore, family carers may experience guilt if they are not present at the time of death which complicates their grief (Stajduhar et al. 2010). In the current study, participants particularly prided themselves in the fact that clients did not die alone in their service. The participants fulfil the combined roles of health/social care worker and 'family' carer for the clients so this combines the possibility that they are more than likely to experience the same as those presented for family carers and healthcare staff in general settings.

The concept of a good death can include aspects of care which are commonly viewed as necessary to achieve a comfortable death. A good death scale to measure these was developed by Schwartz (2003). However, what might be perceived as important by staff, families or clients across different care settings may be different from one setting to another depending on client's needs (Gibson et al. 2008). It is important then to obtain the opinion of staff supporting a particular population in a particular setting as to what they perceive to be a good death (Gibson et al. 2008). The participants in the

current study were experienced practitioners and had experienced client deaths in the ID settings. There was a general consensus among the participants as to what constituted a good death for their clients.

The theme of 'relationships' was central to research conducted by Mac Conville (2004) into an exploration of care of the dying in Ireland. It is inevitable that relationships of varying intensities will develop between those 'caring' and those being 'cared for', when professional staff enter into the living and dying of the patient/person. Mac Conville (2004) identified that boundaries can become blurred for specialist palliative care staff in these relationships with patients, as the staff are not the patient's friends but are there in a professional capacity. This is where a challenge exists for staff who work in ID as they live alongside the person with end-of-life care needs within a close family-like structure. They are not just visiting the person and staying for an hour or two. Participants in the current study consistently re-iterated this.

Some participants acknowledged that keeping busy by 'doing' was their coping strategy. This may be perceived as an avoidance of emotional pain (Katz and Johnson 2006). Others reported a mixture of acceptance of the death as a relief from suffering and the denial of the fact that the person had dementia and that dementia is a terminal illness. Froggett (1995) identified that Hospice nurses used various coping strategies to reduce their emotional involvement with patients, (professional distance), but she acknowledged that the nurses were unable to do so all of the time.

Rituals and Remembering

To remember the person after s/he had died may be an important element in the facilitating of the grief of staff (Molloy & McQuillan 2012). Participants in the current study remembered the deceased clients informally as in talking together spontaneously in the care setting about their memories of the person, or more formally, by arranging/attending memorial events such as an annual mass. All of the services had various approaches in the way they actively remembered the clients who had died.

It is now more generally accepted that despite the permanence of physical separation, the bereaved can nevertheless be emotionally sustained through a continuing bond to

the deceased (Field et al. 1999). Continuing a bond with a deceased person can be considered "normative in mourning and can be integral to successful adaption to bereavement" (Field 2006:709). In the current study, the participants appeared to be attempting to continue the bonds with the deceased and appeared also to find solace in this. They spoke lovingly of the person/s whom they had as part of their family in the unit. Field et al. (1999) found that certain types of continued bonds (e.g., keeping possessions) were associated with increased levels of grief, whereas another (sensing the deceased's presence) was not. In the current study it was not evident that any personal possessions of the deceased were kept by either staff or peers. However, sensing the deceased's presence was very possible when staff or peers spoke about the person when their memory was triggered for some reason. In a state of healthy continuing bonds, the bereaved can mentally evoke the representation of the deceased as a "safe haven," or comforting presence, when under duress (Field et al 2005). In the current study, the participants fondly remembered the deceased clients as 'comforting presence's' among themselves and among themselves and the peers of the person who had died.

Continuing bonds with the deceased can play an important role in sustaining the identity of the bereaved through enabling them to maintain a sense of continuity amidst the flux of change required in accommodating to the new life situation without the deceased (Field 2006). The utilisation of the theory of continuing bonds in the context of ID care in this current study appeared to give staff such an opportunity for the continuity of 'a bond' among themselves and also to give them such opportunities to share this bond with the peers of the person who were grieving/potentially grieving. Both staff and peers may have lived for many years with the deceased person, effectively as a family unit. The use of continuing bonds to support them in grief therefore may be beneficial and similar to that found in sibling grief (Devita-Raeburn, 2004 ; Packman et al 2006).

The participants, furthermore, used the theory of continuing bonds in a healthy fashion with kinsfolk of the deceased when opportunities presented themselves. In another study on long-term outcomes of a sample of bereaved participants, those with higher grief scores (on the Texas Revised Inventory of Grief, TRIG; Faschingbauer, 1981) retained closer continuing bonds (on the CBS) than those with lower grief scores (Field

et al. 2003). These authors concluded that ''the bereaved's extent of continuing bonds use rather than the type of expression is the more important factor associated with bereavement-related adjustment''(Field 2003 : 115). In the current study, such intensity was not evident; it seemed that intuition was at the centre of the participants actions to support themselves and the peers/kinsfolk.

The theory of continuing bonds is complex (Klass 2006), and continuing a bond with the deceased can also be maladaptive if the bereaved do not acknowledge the reality of the death and that the physical relationship has ended and been replaced by a representational one (Field 2006). In the current study, all of the participants acknowledged the reality of the death and the ending of the physical relationship and the continued representational relationship. They furthermore supported each other and the peers and kinsfolk of the deceased to the best of their abilities from their own knowledge base and life/professional experiences.

Schut et al. (2006) conducted 3 studies together with experts in grief, the general public and bereaved persons and non-bereaved persons to examine the conceptual overlap between grief and continuing bonds and concluded that "it is even possible that continuing bonds is an intrinsic aspect of grief" (Schut et al. 2006:764). They furthermore suggested that previous studies where it was reported that continuing bonds lead to better or worse adaptation to bereavement may have drawn invalid conclusions. In the current study, I would concur that the efforts of participants to establish/maintain continuing bonds with the deceased clients was an intrinsic aspect of their experience of grief. I furthermore consider that it provided a positive mechanism for them to support themselves and the peers/kinsfolk of the deceased clients in their care.

The kinsfolk and the peers of the deceased person were formally invited back to the service for the occasion. The participants in the current study included the peers in all of these various events. Their taking part in rituals around the funeral was also important for staff. Indeed this 'intuitive inclusion' of staff and peers in all aspects of the rituals around death and dying and inclusion in funerals in an Irish context of ID service provision is documented in research findings (Dodd et al. 2005). Further discussion on bereavement is included in section 9.3 below.

Although the nurse grieves as an individual, the grieving process is validated when acknowledged within a team context (Sanders and Valente 1994). Teamwork is inherently a part of the ID care philosophy. Participants in the current study valued this teamwork when supporting the client at end-of-life. Indeed there is a need to articulate the emotional demands on the professional members of the team in order to manage strong emotions when they arise (Speck 1978). Therefore, the sharing of feelings of loss and grief among the team who supported the person in life and death may be of importance in order to facilitate the development of emotional intelligence to enable the practitioner to manage grief (Bailey et al. 2011a).

In conclusion, theme two – Worldview of loss and grief in ID care, a hermeneutic discussion has now been presented and supported with findings from chosen literature. The key findings of 1) Complex grief, 2) Emotional impact, 3) Disenfranchised grief and 4) Coping strategies were discussed in relation to how these four categories are interpreted as important within the worldview of the participants of the current study. Theme three – Worldview of bereavement support will now be presented.

9.3 Theme 3: Worldview of Bereavement Support - Hermeneutic circle of discussion

Theme three is now discussed in relation to the literature available on bereavement for healthcare staff in general, and in particular for staff supporting persons with ID and dementia. The discussion within the hermeneutic circle means that the parts and the whole of understanding continue in a discursive way.

The sub-themes within this worldview are used as major headings to focus the discussion, and the categories are discussed within these sub-themes. The sub-themes are 1) supporting bereavement, 2) being supported in bereavement, 3) seeking bereavement support.

9.3.1 Supporting bereavement

Participants across all sites automatically supported the kinsfolk and peers of persons with dementia as they struggled to come to terms with their experiences of loss along the trajectory of the illness, at their death and following the death. They equally provided this support to each other as colleagues in the workforce.

As discussed earlier, there may be an expectation that health and social care workers have the requisite knowledge and skills to provide bereavement support to persons experiencing loss. Such expectation of participants in the current study to provide this informal bereavement support was evident across all sites. Formal bereavement support is found to be lacking for families/ carers or their patients pre and post death in both general and psychiatric hospitals and particularly lacking in the long term stay settings (NCAOP & IHF 2008:117).

Furthermore, carers of persons with dementia may be affected by anticipatory grief (Doka 2004 ; Holley & Mast 2009) and by the experience of ambiguous loss (Boss 2011). I consider that participants in the current study experienced both anticipatory grief and ambiguous grief as they supported their clients with dementia. Evidently, they knew that their clients were going to die and attempted to prepare for this personally and also to prepare the peers and the kinsfolk in most circumstances. Some did this more confidently than others. Furthermore, they struggled with the repeat occasions when they said goodbye to the client when they were hospitalised and the subsequent

experiencing of saying of 'hello' when the client returned to their care from the acute setting of the hospital.

Staff who work with the dying ought to be educated and facilitated to be able to take care of their own emotions associated with caring for the dying (Redinbaugh et al. 2001). In ID care settings also, staff need training in the provision of grief support to clients (Dodd et al. 2005). Participants in the current study felt an expectation to support clients in the process of grieving. This was more in the support of the peers of the person with dementia. They felt that they gave support to their clients and colleagues in a way that they would give support to a friend who was grieving. The majority of the participants lacked confidence in their ability to deliver knowledgeable bereavement care.

There is on-going and emergent literature that persons with ID experience loss (Clements et al. 2004 ; Ryan & Dodd 2011), and experience grief (Blackman 2003 ; Dodd et al. 2005 ; Meeussen-van de Kerlehof et al. 2006 ; Clute 2010). The participants in the current study had mixed perceptions as to whether persons with ID experienced grief or not but there was a general consensus that persons with mild ID were more likely to experience it. They were beginning to reflect more during the interviews as to whether their clients with moderate, severe and profound ID were neglected in their being supported with grief issues. Some participants had undertaken courses in palliative care or in bereavement therapy and they were more confident that they were better prepared and able to provide appropriate and effective bereavement support.

There is less literature on the grief experiences of staff; perhaps their bereavement becomes disenfranchised because they are still expected to support families during the bereavement period (Payne et al. 2009). To be able to manage their own grief will be a challenge for staff in such circumstances within ID care settings where they form such close relationships with clients. The participants in the current study provided informal bereavement support to the kinsfolk of their clients who died. They intuitively offered them a welcome back to the service for informal visits because they recognized that family carers of persons with ID can be disenfranchised in their grief by their being abandoned by the service once the client has died (Ng and Li 2003).

In summary, participants across most sites routinely felt an expectation to give bereavement support to the peers and kinsfolk of their clients with dementia. They delivered such support to the best of their ability. Some had confidence in this because they had undertaken education in palliative care or bereavement courses. Others felt confident enough because of their own life experiences. Others still lacked confidence about their supporting of bereaved persons. Participants also supported each other with bereavement but because this support had a reciprocal nature it is presented in section 9.3.2 below in order to avoid repetition.

The bereavement support which participants received will now be presented.

9.3.2 Being supported in Bereavement

Staff who have invested much of themselves in the care of the dying have to cope with their own grief when their patient dies (McNamara et al. 1995). The participants in the current study had invested much time, care and commitment to their clients with ID and dementia over many years and it was evident in the study that they experienced grief.

There were different levels of bereavement support received across the services in the current study. The nurse and carer participants supported each other in an informal collegial sense across all of the services. Senior staff ought to have a role in the anticipation and recognition of the effects of loss on junior staff and to support them in coping with grief (Parkes 1999). The senior nurse participants in the current study recognised the grief of junior and less experienced staff and they provided this bereavement support to junior colleagues or carers who had little experience of deaths. Nurse participants considered that care staff had potentially more need for bereavement support because of their very close relationship in advanced dementia. Collective grieving may be important in the supporting of the grieving process especially if a staff member had a close relationship and the client dies when they are not on duty (Papadatou 2000). Some participants in the current study did experience strong emotional reactions such as anger and guilt when this happened; these could be interpreted as normal grief reactions.

The culture of the organisation can facilitate or prevent staff grief responses (Speck 1978 ; Eyetssemitan 1998). However, little attention has been paid to the grief of staff working in generic long-term care settings and who are supporting the older population (Gannon & Dowling 2011 ; Osterlind et al. 2011).

Across the services, participants in the current study reported that the organisations were becoming more aware of loss and grief issues at the macro level. Things were changing in relation to, for example, filling the bed of a deceased client. Senior management were now aware of the need to give the staff on a unit time to grieve before they moved another client into that room. However, in some of the services involved in the current study, participants in sites where deaths were occurring more frequently, felt that they managed their own grief within the units because no one outside of their units perceived their grief.

This finding was repeated on many occasions, as participants worked together within their own units to support the dying person and they did not appear to want to reach out to anyone outside of their own unit because they were 'coping as a family' and they did not want to bring outsiders in unless they really had to do so. However, one of the conditions of effective teamwork is that one person has overall responsibility for the decisions which the team makes (Randall & Downie 2007). Participants in the current study had informal links with specialist palliative care. Some had well established relationships and could access specialist palliative care for advice on symptom management at end of life. None of the ID services had a formal link person to communicate with specialist palliative care at the time of the study. None of the participants had availed of any formal bereavement support for themselves.

Some of the services were actively pursuing training in loss, grief and bereavement for staff in the service. Some criticism was levelled by participants that the training was theoretical, 'a power-point presentation', and that a more experiential approach may be of more value. In the educational intervention designed in phase one of this study, emphasis was placed on reflective learning and an andragogical approach to learning (Fahey-McCarthy et al. 2008, 2009). Reflective learning, is an important approach as it facilitates the learner to understand his/her own personal qualities and how these influence him/her as a practitioner. In recent research conducted in the development of a palliative care model for persons with dementia in Ireland, reflective practice was intrinsic to the process (MacConville 2011). Reflective practice is also seen to be an important component to improve end-of-life care within a long-term care setting (Molloy & McQuillan 2012).

Participants felt supported by their organisations at the time when a client was actively dying in that they would have extra staff provided at that time. This was to ensure that the staff who knew the client were relieved from caring/supporting others in the unit and were facilitated to be able to stay with the dying person and to attend funerals.

An interesting finding was that participants in the study appreciated the 'empathy' demonstrated by their clients with ID to the participants' own grief. There was a certain genuineness felt about the effort clients made to communicate their bereavement support to a participant when s/he (the participant) experienced a personal loss or death of a significant person in his/her life. No literature could be found to support this finding.

The participants had clear ideas about the support they desired and these will be presented now.

9.3.3 Seeking Bereavement Support

Participants in all sites had similar ideas about the type of support which they desired after they experienced a death of a client. They sought acknowledgement of their relationship with the client and they sought support for their grief by way of de-briefing of the end-of-life care of the client. Furthermore, they sought this reassurance from reliable sources that they had given the client a good death.

The participants across the sites identified that they would value some acknowledgement of their personal investment as well as their professional investment in the life of the deceased. This investment of self is important to acknowledge in the grief reaction as greater investment potentially lengthens the grieving process (Papadatou 2000). Acknowledgment of the grief of staff and subsequent support thereafter is important in facilitating grief resolution (Palmer & Howart 2005). The acknowledgment of grief reactions may not happen because of the culture of the organisation or of the culture of the profession (Speck 1978). I would not think that the culture or 'ethos' of care within ID settings as described in chapter five reflects an un-caring culture of care. Instead, the living person with ID is supported by staff within an ethos of care, concern, respect and responsibility in all aspects of his/her well-being.

The supporting of persons living with a terminal illness such as dementia requires a re-thinking of the professional ways of working for frontline staff in this specialism.

In the current study, there appeared to be a need by frontline participants to have feedback from the Senior Management of the organisation and this was explicitly needed in the form of direct human contact and not a telephone call from the office. Participants needed to feel valued and recognised as individuals who were personally connected with the deceased client and that senior staff realised that his/her death mattered to the participant. The participants did not want monetary appreciation but they seemed to crave an appreciation of their investment in the client and to have it recognised in a personal way.

Staff who form relationships with the residents, need to deal with their own grief (Whittaker et al. 2007). The explicit support that participants identified that they would like in a practical way, was in the form of de-briefing. Although in most sites the participants would informally discuss the care of the dead person among themselves, they appeared to want a more structured approach to this de-briefing. The use of Death Reviews as described by Malloy & McQuillan (2012), where staff are facilitated in a constructive manner to reflect on the end-of-life care which they delivered to a person and to engage in remembering the relationship which they had with the person, may be one way of providing this de-briefing. This reflective process may facilitate discussion on the skill set of the staff who delivered this care and enable an identification of any skill set which could be improved for future similar situations. Furthermore, the symbolic nature of naming the person and lighting a candle at the beginning of such a review, followed by the extinguishing of the candle at the end of such an occasion gives the staff who were in a relationship with the deceased an opportunity to say goodbye to the person/s.

Although all of the participants in the current study spoke about remembering the client and having informal sessions to remember him/her over time, I consider that they did not share their mourning of the person together. One participant in particular in the current study who cried profusely during the interview had never been afforded an opportunity to openly mourn a client whom she sat with when s/he died many years before. This participant had had opportunities to remember the person among other staff who reminisced about him/her. However, s/he had not had one opportunity to share her

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emotional pain. I have found in my past professional life that rituals such as lighting and extinguishing a candle as described by Molloy & Mc Quillan (2012) provide an opportunity to engage with the spiritual or sacred dimension of giving closure to a relationship and helps staff to let go some of their emotional pain in relation to patients whom they mourned.

 Increasing nurses' awareness of their own mortality, their own reactions to grief and the importance of taking time to work through their grief is recognised as an important element of supporting grief in relation to sudden patient deaths (Valente & Saunders 2002). There is further evidence that if staff are educated on theories of grief and coping strategies within a safe and supportive environment that they benefit personally and collectively in relation to their ability to manage grief (Fessick 2007) and bereavement McCreight (2004). The importance of keeping this approach as informal as possible may be important as nurses appear to prefer an informal support structure over a formal one (McCreight 2004 ; Rickerson 2005).

The participants in the current study consistently valued both informal opportunities to reflect and learn and also formal sessions. Some participants as stated earlier had undertaken specific bereavement education and utilised it in practice to educate colleagues informally. Interestingly, the nurses explicitly did not value education and training from non-nursing personnel. They perceived that these non-nursing personnel did not know from experience what it was like to support people in dying and therefore all of the knowledge being imparted was too theoretical.

There may be cultural considerations of whether staff value formal or informal education on loss and grief (McCreight 2004) a Northern Irish study, and (Rickerson 2005) an American study. Ultimately, there appears to remain a desire to mix formal bereavement support approaches with informal ones (Aycock & Boyle 2009).

Participants stated that in addition to de-briefing at a local level, that they would value the reassurance from staff who were expert in care of the dying i.e. specialist palliative care staff. This reassurance appeared to be desired after the death of the person and gave them the evidence that they had done all that they could for the person in line with best evidence based end-of-life care. Nurses can appear to feel they managed their grief better if they ensured that the patient had a good death (Sanders and Valente 1994), and

this was also a finding in the current study. The utilisation of a palliative care approach in ID settings is very desirable. Staff ought to have core knowledge and skills of palliative care which they use when caring for a person with a life-threatening illness or a person who is dying and to be able to consult with specialist palliative care experts on issues about which they do not possess specialist knowledge about (DoHC 2001b ; IHF/HSE 2008 ; MacConville 2011). Indeed, in phase one of the current study participants could clearly articulate where their knowledge gaps were and the educational intervention was developed to meet these (Fahey-McCarthy 2009). Incorporated in this core knowledge would be knowledge and skills on such issues as breaking bad news and talking about loss/grief and death/dying. One of the recommendation in the End-of-Life care for older people in acute an long-stay settings in Ireland (2008:192) does explicitly state that

> *"bereavement support for families, staff and patients should be central to the culture of care within acute and long-stay care settings".*

It is interesting that in the recent exploration of a possible model of palliative care for persons with dementia in the general population that bereavement support is not discussed for the person. However, it is recognised that the carers of the person with dementia ought to be supported in bereavement throughout the trajectory of the illness and after the demise of the person (Mac Conville 2011). The participants in the current study considered that the client's level of ID and whether they perceived them to be experiencing grief determined whether they required such support. Generally this support comprised ensuring that the client was not experiencing sadness.

In summary, theme three – Bereavement support has been presented as a hermeneutic discussion has now been presented and supported with findings from chosen literature. The key findings were discussed in relation to how they are interpreted as important within the worldview of the participants of the current study. The areas identified are that the participants would value more of an acknowledgement of their investment in the life and death of the client, they would like more formal de-briefing after the death and they would like a reassurance that they had given the best possible end-of-life care in relation to symptom management.

9.4   Conclusion

The discussion in this chapter on the findings was done in close alignment with the current literature and theory on the history and philosophy of caring within ID care, person centred dementia care, palliative care, end-of-life care, loss, grief and the bereavement experiences of healthcare workers. The final chapter will now be presented which will outline my own conclusions from the study.

Chapter 10 – A New Horizon of Understanding of Loss, Grief and Bereavement for Frontline Staff in ID Settings

10.1 Introduction

This chapter outlines my own conclusions as drawn in an attempt to interpret hermeneutically my understanding of the experiences of loss, grief and bereavement shared with me in this research. This is the fusion of the horizons of the understanding of loss, grief and bereavement of the interviewees with my own original understanding of these phenomena and with the new understanding which I now have. The merging of these understandings was undertaken within the hermeneutic circle of analysis.

10.2 The experience of grief for staff

Grief is a very personal experience. I am not at all sure that any individual's grief can be fully accessed or understood by another or that research can begin to answer the question of what grief really feels like for any individual or group of individuals. However, what I have attempted to explore and to interpret (by my engaging in an hermeneutic enquiry which is influenced by the philosopher Gadamer), is, I believe, an understanding of the phenomena of loss, grief and bereavement as experienced by staff who collectively supported persons with ID and dementia and who subsequently died in their care. This interpretation incorporates my own understanding of loss and grief merged with my interpretation of what I believe the participants in the current study attempted to articulate; it also incorporates my analysis and reflection on the texts from the data generated.

All of the participants found it very difficult to actually verbalise their own understandings of their experiences of loss, grief and bereavement. Some did it better than others and these were staff who had more of the vocabulary to express thoughts and feelings about loss, grief and bereavement. They had this 'language' either because they had personal experiences of grief and had reflected on their own existential issues in relation to these, or because they had reflected on transitions which had occurred in

their own life's journey. Others had the language to express themselves because they had undergone professional training or had significant professional experience of death and dying. Some obviously had both personal and professional experiences to draw on. There is no doubt but that the participants in this study experienced both psychological, somatic and emotional reactions to the decline and demise of their clients (whom they remembered vividly throughout the interviews). Such was the strength of some of their memories that they still cried during the interview/s, even though the deaths had occurred many years previously.

In the individual interviews when asked an open question about what loss and grief meant to participants, the majority of respondents associated loss and grief with actual death. The only participants who explicitly identified loss and grief outside other than the experience of someone dying, had undertaken grief and bereavement training and they identified a wider repertoire of loss experiences such as leaving the place of employment, clients leaving a setting or other changes in living arrangements. These experiences of loss revolved around the loss of the relationship between the nurse/carer and the client.

In some of the services, nurses stated that the clients have closer relationships with carers as they perceive the nurses are in a hierarchy above the carers and therefore they (clients) confide more in the carers. Therefore, when the client dies the carers are more affected by the deaths. One participant who had been a carer for many years and then undertook nurse training, recalled that as a carer s/he found it more difficult to cope with his/her feelings when the clients were dying or after they had died. The reasons given were that, as a nurse, one felt more empowered because one had more knowledge about the dying process or could get it more easily from other colleagues such as specialist palliative care staff. Furthermore, as a nurse one had more control over the outcomes in relation to one's facilitating an optimal death, particularly in complex end-of-life scenarios, where pain control (physical pain) could be achieved by the nurse who was co-ordinating care between appropriate professionals.

In the bigger picture (or the 'whole' in hermeneutic enquiry), it appeared that carers were more affected by the deaths of the clients. However, in the smaller picture (or 'parts' in hermeneutic enquiry), nurses were equally deeply affected by some deaths. In

the two interviews where two participants cried openly, one was a carer and one was a nurse. I believe that the centrality of the relationship between the participants (nurse or carer) and the client was the greatest influence on the experience of loss, grief and bereavement for the interviewees. Across all interviews they recalled different experiences and recalled different relationships so there was no common denominator as to their grief experience. Some considered the relationship to be one of friendship, others considered the relationship to be akin to that of a parent and child (this could be where the participant was either parent or child and the client the other), yet others considered the relationship to be that of professional carer and client.

While, most commonly, the relationship had been of a long duration (many years), there were some occasions where the relationship was more akin to that developed at a hospice - short and intense where the participants got to know the client and family very well over weeks or on occasion over days. This happened when the person was transferred for end-of-life care to another part of the ID service where the human and practical resources were available for such care.

Participants debated the advantages and disadvantages of the 'Key Worker rotation' system which was operational in some of the services. They could understand that it could be of benefit either for the carer/nurse or the client, in that no one member of staff became so attached to a client that either of them would be adversely affected when a separation occurred. There appeared to be little, if any, consideration of what effects this system of working could have for the person with dementia in some services.

The continuing grief felt after the ending of a special relationship was described by Papadatou (2000:65) as *"a stirring that never stops"*. I am not interpreting this as chronic grief but as an enduring feeling of the loss of a relationship that once was. I met a senior nurse some weeks ago who participated in my original interviews five years ago; she has moved from one service to another. A number of staff with whom she worked in the previous service have also moved. They still mourn together some of the clients with dementia whom they supported in the previous service. I think that there are elements of the relationship which impact on the grief which endures for staff working with persons with ID.

The relationship between the paid professional carer (whether social carer or health carer or nurse) and the person with ID has a certain potential for common components. The relationship is usually one of longevity, intimacy, vulnerability, humanity. The person going in to work in the ID service may or may not have experience of having a previous relationship with a person with an ID. In their working role they form relationships with the clients which will bond them in varying intensities like all of human relationships. From my observations and reflections on the data which I collected, I believe that the relationship which the participants developed with the person with ID is unique. Relationships change over time and I believe that this happened with participants in the study. However, I perceive that participants were changed as a result of working closely with this population in particular. I think that participants were very sad to witness the clients developing dementia. Some participants spoke of the 'double whammy' and that the person did not deserve to get dementia after his/her having already lived a life with an ID. They struggled to hold on to the person with whom they had developed the relationship. I think there is something unique about the relationships I was told about, which brought about changes in the staff as they reflected on life for the person with ID. I think that when the person developed dementia, the participants deepened their reflections on the very meaning of life for their clients and for themselves. Some could do this more eloquently than others.

Furthermore, the participants had to balance the personal relationship which they had with the client with the professional relationship between themselves and the client. As individuals we experience grief differently and I believe that the participants were a reasonably representative sample of the many ways people grieve internationally. The ultimate cost of the relationship changing over time and ending in the physical sense in death resulted in a unique grief experience for the staff member. An attempt to capture this is presented in Figure 10.1

Figure 10.1 – A Unique Grief
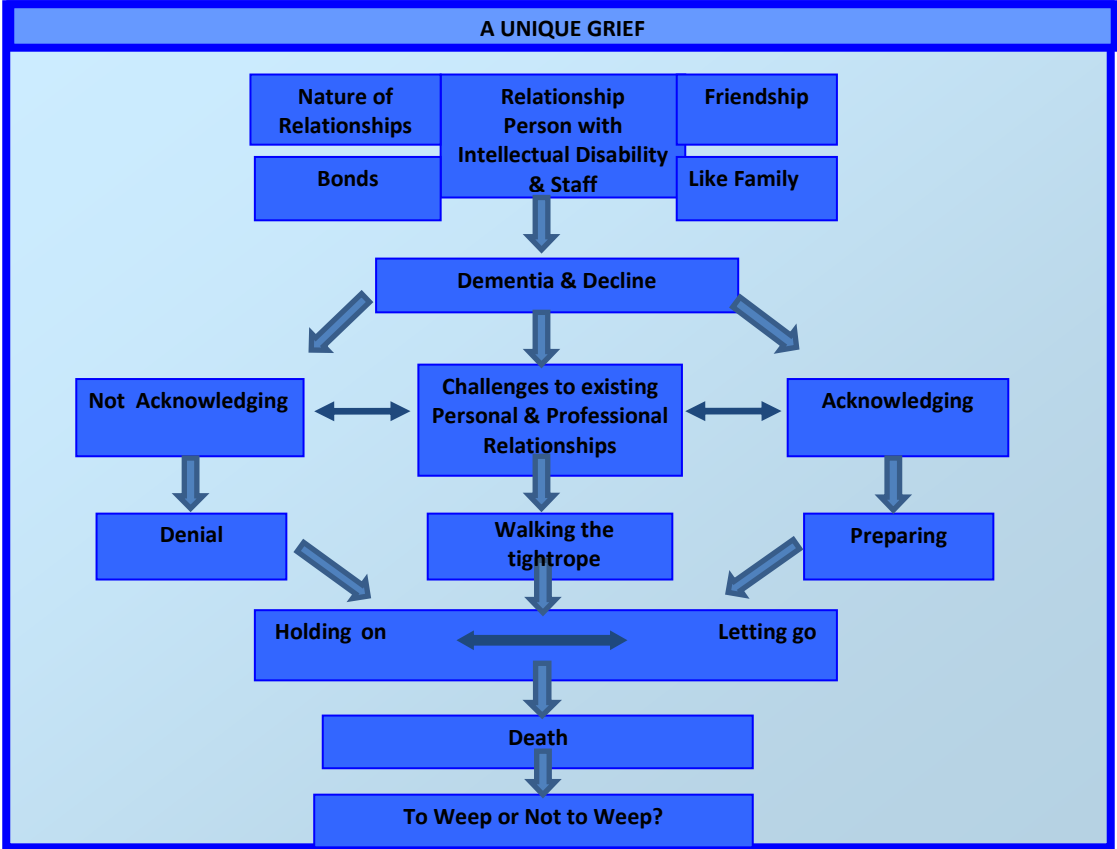
10.3   Understanding palliative care in the context of intellectual disability care

To explore the meaning of loss and grief is an inherent part of supporting a person within a palliative care approach. Much of the support provided by the staff to clients with dementia/advanced dementia was consistent with the delivering of a palliative care approach in many respects. It is well recognised in the literature that there is overlap with much of what is central to the philosophy of palliative care within the philosophy of person-centred care. Much of what was recognised as good in a person-centred care approach was observed in the philosophy of ID care. The challenge for the ID services is to support an ageing population who are developing terminal illnesses. The current study was exploring loss and grief for staff who were supporting one population living with a terminal illness, namely dementia. Therefore, this concluding discussion

concentrates on the challenges for staff as they move towards the provision of an approach to care which best suits this population. An approach to care which must embrace the best of what is already known about a supportive approach to care or about a palliative approach to care or about an improved approach to end-of-life care. Inherent in the provision of any model of care will be the requirement of staff to have a skill set which allows them to support both persons with dementia and their significant others in order to prepare them for decision-making about living and dying and to be able to support people effectively and confidently (clients, colleagues and kinsfolk of the person with dementia), with their experiences of loss, grief and bereavement.

The WHO (2002) defines palliative care as an approach that "*improves the quality of life of patients and their families who face the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychological and spiritual*".
I believe that grief reactions include physical, psychological and spiritual reactions. Therefore the grief of staff (who are also family of the person with ID), ought to be recognized in the first place and strategies should be developed to support them appropriately in the management of same.

In general, the utilisation of a palliative care approach embraces the upholding of the eight principles of palliative care espoused by the World Health Organisation (WHO 2002).

10.3.1 Principles of palliative care:
- the relief of pain and other distressing symptoms
- the affirmation of life and acceptance of dying as a normal process
- the intention to neither hasten or postpone death
- the integration of psychological and spiritual care of the person
- the support of patients to enable them to live as actively as possible until death
- the support of family to help them to cope with the illness and the bereavement
- a team approach to meet patient and family needs
- enhance the best quality of life for the person, positively influencing their experience of illness

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- applicable early in the course of illness in conjunction with other therapeutic interventions.

(WHO 2002)

10.3.2 The relief of pain and other distressing symptoms, the affirmation of life and acceptance of dying as a normal process, and the intention to neither hasten or postpone death.

I think that the first three principles above are the daily routine for staff working in specialist palliative care (SPC). This specialist health service provider is expert in the provision of support and care to people diagnosed with a terminal illness and who are referred to them.

In relation to the first principle, SPC have developed an expertise in the approach to and in the management of total pain, i.e. pain of a social, psychological, physical or spiritual nature. Throughout the interviews in the current research, participants from ID acknowledged that they really did not know whether their clients with dementia had pain or not. The nursing and care staff participants within ID services were those who were more intensely involved in the day-to-day care of the dying person. Experienced nursing and care staff participants in the current study appear to have developed their own intuitive coping strategies and felt competent to deliver the necessary nursing care required to look after someone dying who did not explicitly require pain or symptom management. When participants had concerns about pain assessment and management, these concerns were more prominent in regard to persons with advanced dementia, or when the person was at the end of life (in the terminal phase of the illness or when they were actively dying). Services who had developed working relationships with specialist palliative care, valued this co-operative working because of the expertise in pain and symptom management.

In relation to the second principle, SPC deliver care to people who are living but are living in a knowledge that they are facing their imminent death. These staff engage in communication about death and dying, loss and grief in their day-to-day work and therefore have expertise in the vocabulary required to engage with patients and their significant others who live with a terminal illness and face their demise. Traditionally staff working in ID care have been caring for the 'living' person who is younger and who has no reason to explore the realities of death and dying. Many of the participants

in the current study had limited confidence to discuss death and dying and loss and grief with ease. Staff in ID settings will require this vocabulary if they are going to be confident in appropriately supporting more clients who will face an anticipated death.

In relation to the third principle, SPC staff have an expertise in regard approaching decision-making at end-of life. Participants from ID in the current study, had experiences of the deaths of clients on all six service sites with just one site having limited experience of death. They are now being challenged with the decisions regarding end-of-life decision-making and will have to consider this in their approaches to advance care planning. There is a need for staff to understand the distinction between interventions which benefit the client and those which become a burden for the client with ID and dementia with complex end-of-life needs. This is clearly an area where the collaboration between specialist palliative care services and the ID services would be of paramount importance.

10.3.3 *The integration of psychological and spiritual care of the person.*

In relation to this principle SPC staff will be routinely comprised of pastoral care staff and psychology staff to integrate these aspects of care for their patients. Psychology and psychiatry services were available across the ID services and were accessed as deemed necessary. Participants from all ID sites were very conscious of meeting the psychological needs of their clients in their day-to-day care. They delivered a person-centred approach to care and they continued to meet the needs of the individual person with dementia as the person declined and was not able to communicate his/her needs anymore. They endeavored to keep their clients comfortable and free from emotional pain. They constantly tried to keep their clients happy. I did reflect that, in their attempts to keep their clients happy, they may not have been facilitating them to experience grief on occasions. In the services where there was an existing religious influence/ethos, attention to the spiritual care of clients was delivered. Dedicated pastoral care staff were appointed to support clients and staff. In other services, it was dependent on the participants to identify whether spiritual care was delivered or not. There was no systematic assessment of spiritual needs. This would not be an unusual in my experience all throughout my career as a nurse in general nursing.

10.3.4 The support of patients to enable them to live as actively as possible until death and enhance the best quality of life for the person, positively influencing their experience of illness.

In relation to these two principles, I consider that they overlap. Staff in ID care give care which embraces person-centeredness as stated and this enhances the individual client's quality of life. Therefore I believe that this principle is well upheld. Indeed the specialist palliative care participants who were interviewed in phase one of the current research acknowledged that staff in ID care are probably the best of all specialties to give this person-centred care. Indeed, it was evident that the clients with dementia and advanced dementia were being facilitated on a daily basis to keep up whatever abilities and interests that they had. This included taking them out frequently on occasions such as going shopping, going to social events, or other activities until the person no longer benefited from such events. This was usually decided by the carers when they believed that the person was more traumatized by some event. In regard to these non-medical interventions, participants recognized when the social/therapeutic intervention became a burden instead of a benefit to the person. Once, this phase of care was over, the participants continued to ensure that their clients lived as actively as possible until their death by ensuring their inclusion in any activities (which they enjoyed), within the residential setting. They were especially good to facilitate the long-term memories of residents with dementia through the use of the established therapies like reminiscence and life story books. This was the execution of the 'ordinariness of care' within a person-centred approach; they knew that they did this well.

10.3.5 The support of family to help them to cope with the illness and the bereavement
I believe that this is the principle which is an important challenge, and which is identified in this thesis because it is the one which explicitly identifies the need to support others to understand dementia as a terminal illness; it also identifies the need to provide bereavement support to these 'others'. In the WHO (2002) principle above, the term family is used and can be interpreted narrowly by services as blood relatives of the person who has the terminal illness. However, as time evolves the definition of 'family' is influenced by societal norms and mores; therefore health and social care workers have to define who exactly 'family' is for any client in their care. I am aware that specialist palliative care assess very carefully who the family are in close collaboration with the person being supported in their service. Specialist palliative care support the

family as defined by the person but these definitions of 'family' vary from client to client.

I have used the term 'kinsfolk' in the findings to refer to the blood relatives of the person with dementia. I have used the term significant others to capture any persons who matter in the life of the person with dementia. In ID care, the staff and the other clients in any residence who live together are effectively, in a practical way, a family unit. Therefore supporting family in bereavement in this context becomes complex. In all sites the participants in the current study supported the kinsfolk of the person with ID and dementia in many ways. They befriended the kinsfolk, they provided advice on many aspects of the person's health and well-being. They demonstrated by their actions, their love for the clients and they provided professional advice how to best support a person with an ID. There were differences across the services in the levels of support given or in the personnel who provided that support to the families (kinsfolk). This is an area which will challenge the existing provision of support to 'family'. The participants, as has been demonstrated throughout this thesis, are as much the family of the person with dementia as are the peers living in residence with them. The particular challenge for staff is that they will be expected to continue to provide the bereavement support to kinsfolk and peers of the person; but who will provide the bereavement support to them?

10.3.6 A team approach to meet patient and family needs

Multi-disciplinary team working is embedded in the delivery of specialist palliative care. In the current study the different services had differing combinations of 'team' members within their services. Some services had access to multi-professional team members who supported the person with dementia across a spectrum of care. However, in the current economic climate there was much frustration felt by participants in the ID services where these multi-professional teams were diminishing. This is a further challenge if these frontline staff are expected to deliver a palliative care approach and they cannot access a physiotherapist or an occupational therapist to support such an approach. In relation to the supporting of grief, some services had grief support mechanisms in place. The emphasis would be at the end-of-life and more concentration on the support of the grief of the peers and kinsfolk of the person who was dying was evident.

10.3.7 Applicable early in the course of illness in conjunction with other therapeutic interventions.

The dilemma of when to adopt palliative care for the person with dementia is well recorded in the literature. Equally the participants interviewed in this study were uncertain as to when a palliative care approach ought to be introduced. In fact they were unsure as to whether persons with dementia were a group of people who would warrant palliative care except for its introduction at the terminal stage of life.

Participants in one site stated that they coped fairly well with deaths in their units because they were used to deaths occurring in such units. It was stated that staff probably get over it (the death) more quickly because there are all the other clients to look after. The fact that they had experience of death appeared to be enough for them being able to cope with it. This service had significant experience of deaths occurring in general units for older people and experience of a limited number of deaths of persons with dementia. What they reported as most stressful about the end-of-life care for persons with dementia was the issue of appropriate resources being made available to keep the person comfortable.

Randall and Downie (2006) offer a critique of palliative care which can be taken to mean specialist palliative care. They argue that there is increasing conflict between the philosophy of palliative care as reflected in the WHO (2002) definition and practice. For them the concept of total pain (Richmond 2005) that underpins palliative care has shifted towards use of a series of assessment tools as templates that reflect a more reductionist approach and based on the values and assumptions of the healthcare professionals. Moreover, these tools are perceived as interventions in their own right. Randall and Downie (2006) offer a counter definition for palliative care is

> *..the care of patients whose disease is incurable and is expected to cause death within the foreseeable future. The aims of treatment are to minimize pain and other symptoms, and to prolong life, but with a minimum of burdens and risks as assessed by individual patients and professionals working together (Randall and Downie 2006:224).*

Their definition and critique was, not surprisingly scrutinised and ultimately questioned as relegating palliative care specialists to symptomatologists (Jeffrey 2006). Nonetheless, they foreground tensions and conflicts within the specialist palliative care community. Randall and Downie (2006) may believe that specialist palliative care has become more reductionist as described. However, the ID participants in the current study remain truthful to the principles as espoused by the WHO (2002).

10.4   Mediating a palliative care approach while walking a tightrope

I believe that a major challenge for the staff in ID will be to stress the continuation of the education process for themselves about what a palliative care approach entails for the person with dementia (and any other terminal condition). Evidently, the challenge for these staff will be to identify the cross over between good person centred care, which is already at the core of what they do best in practice, and to identify where the gaps are in relation to broadening their care, not only care for the living (without threat of death), but to care for those who are living and facing a known demise because they have a diagnosis of a terminal illness.

This work gives a major source of meaning to these participants and they found their work very rewarding. I believe that the work that frontline staff do in ID care is invisible. I believe further that their work is surely akin to the care which parents give children with or without an ID; or to adult children with ID in the home setting, albeit that no-one is probably capable of loving a child like his/her parent loves him/her. Interestingly, my first conversations with my own colleagues in the academic world who came from ID care always frowned upon any comments I made at those times. In the collegial world of ID, when I spoke about parent-child analogies, I would visibly observe the body language of those colleagues and on occasion they articulated their views that the use of such analogies were a 'no no' in the ID care world.

Inevitably, in the research, although the participants knew that they avoided this analogy (parent-child relationship), they too, at a human level, appeared to take on a protective stance often voiced as 'being an advocate' when they spoke about the

vulnerability of their clients journeying with dementia. The complexity of relationships was evident.

For the nurses and carers in this study, walking the tightrope between their supporting of the clients as paid professionals and their balancing the relationships on a personal level between selves and clients was evidently a very real phenomenon. In relation to their coping with their experiences of loss and grief when a client died, I believe it was marginally more difficult for carers than it was for nurses.

Staff need to continue to be involved in the support of the person in the decision-making concerning end-of-life after being transferred to other site/s even within their own service. This was identified for as an important aspect for carers of persons with dementia in the general population in a recent Irish study (Argyle at al 2010). The staff in ID also need to be included in death and dying rituals for the person if they are transferred.

Finally I conclude that grief is a solitary journey and the majority of people find their own way to live with it without requiring professional help. As the parent of child who is dead I received much solace from the theory of 'continuing bonds' (Klass et al.1996). I consider that the participants in the current study were coping with their grief within that theoretical framework. They consistently integrated the deceased clients into their living families in the services by keeping their memories alive in all of the various ways that they strived to do so. In one service all new staff were formally introduced to the deceased members of the family by being brought systematically around to their photos and being told practically all of their life story so that the person would not be forgotten in that unit. The disenfranchisement of the grief of the participants across the services was evident. I consider that the invisibility of their work contributes to this disenfranchisement.

10.5   Strengths and Limitations

Strengths

- A key strength of the study was that the participants had a wealth of experience of supporting persons with ID and dementia and therefore had an established worldview of this experience.

Limitations:

- It was a small study with 68 frontline staff from within one particular geographical area in the Republic of Ireland.
- The participants in the individual interviews were self-selecting participants which could mean that they had an agenda? (e.g. highlighting the lack of support/resources)
- The participants were drawn from a homogenous cultural group (Irish & Caucasian)
- In relation to the methodology, Gadamer's writings were all translated from German which puts another layer in the subjective interpretation of the translator and researcher.
- The Marwit & Meuser (2002) inventory to assess anticipatory grief was not utilised.

10.6   Conclusion

Staff across the ID settings in this research want to deliver care to this population who have the dual diagnosis of ID and dementia until their death. The staff believe that they have developed such a bond with them over the years that they ought to keep them at home, surrounded by family within the ID service, to die. The support of people with a terminal illness requires that the staff have a particular knowledge base and skill set. Part of this includes one's being able to support the person to cope with the physiological, social, emotional reactions to loss and grief and to support significant others in bereavement. Another part is the care for 'self' when one is supporting people in bereavement. I believe that staff working in ID care have additional self-care needs

because of the intensity and long duration of relationships between themselves and clients.

Nurses and carers appear to have different experience of loss and grief. The difference may be that nurses have extra knowledge about theories of death and dying and also have an additional skill base which allows them to 'do' tasks which support a comfortable or 'Good' death. Therefore, nurses potentially may feel more empowered when they support persons who need end-of-life care. Carers on the other hand, as was reported by the nurses in this study, make more personal intimate relationships with clients in ID care settings and make close bonds of a very personal nature. Furthermore, they may not have the theoretical knowledge or skills (experience) of facilitating grief and loss, which, may facilitate them to process grief appropriately after the death. I think the participants from ID in the current study had developed the 'friendly professional' role with the client which reflects an authentic approach to the ideas of palliative care (Randall & Downie 2006:213). In other words, palliative care begins and ends with the relationship forged between the patient and healthcare professional. The antithesis of such a relationship is one in which the healthcare professional remains aloof or focused on particular symptoms in a way that diminishes the recognition of total pain. Relationships between nursing and care staff, and clients in my research reflected immersion in the principles of palliative care even though the term was not part of everyday language of ID care.

Finally, I would like to recall that Elizabeth Kubler-Ross (1975), when she wrote about death and dying following her original interviews and observations with dying patients, identified that in order for persons to explore existential questions about their own living and dying, they needed to feel a part of their past present and future.
This must also be true for those who care for persons facing their demise.

> *"In order to be at peace, it is necessary to feel a sense of history, that you are part of what has come before and part of what is yet to come" Kubler-Ross 1975:167.*

The methodology chosen for this study mirrored these sentiments as the researcher has a past, a present and a future and has contemplated many issues in relation to previous, current and anticipated losses during the completion of this thesis.

10.7   Recommendations

Education:

Arising from the findings of this study staff ought to be educated in the understanding of dementia as a terminal illness which would benefit the person being supported within a palliative care approach from diagnosis to death. This would embrace staff having a clear understanding of the theory and application of the principles and practice of palliative care to their own context. The utilisation of the training pack developed in phase one would facilitate this.

Research:

An evaluation study of the use and impact of the training intervention developed in phase one needs to be undertaken in the ID services in order to ascertain the educational and practice outcomes to date particularly in relation to the impact of training of staff in the support of clients, colleagues, kinsfolk and selves with loss, grief and bereavement.

Practice:

Staff placement in specialist palliative care services would increase staff awareness in relation to optimal end-of-life care, supporting persons/significant others and staff with loss, grief and bereavement.

Strategies ought to be initiated for continuing communication between staff/peers from 'home' site and staff in new accommodation post transfer to nursing homes/ other sites.

10. 8   Glossary

For the purposes of this thesis these terms were used:

Frontline staff: The term frontline staff interviewed referred to two categories of persons working in ID services. These were registered nurses and professional carers.

Carer: The term carer refers to a person employed as a paid professional carer within the ID services. These persons may have had different titles in their workplace as many terms are used. They are not registered nurses.

Registered Nurses: The term nurse refers to any staff member whose name was held on any register of the Professional body for the Regulation of Nursing in Ireland, An Bord Altranais. There are four divisions of nurse referred to in this category. These were Registered General Nurses (RGN's), Registered Nurses in Intellectual Disability (RNID's), registered Psychiatric Nurses (RPN's) and Registered Children's Nurses (RCN's).

Kinsfolk: The term kinsfolk was used in the findings instead of family to describe the natural next-of-kin blood family of the person with an intellectual disability (and dementia).

Client/s: The term client/s refers to a person or persons with an intellectual disability who resided in any of the intellectual disability services of the study.

Service User/s: The term service user/s was used instead of client/s in some of the intellectual disability services.

Peer/s: The term peer/s refers to the other persons with intellectual disability who were resident with the person with intellectual disability and dementia.

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APPENDICES

Appendix 1 **Publications from Phase One.**

Fahey-McCarthy, E., McCallion, P., Connaire, K. & McCarron, M. (2008) *Supporting persons with intellectual disability and advanced dementia: Fusing the horizons of care. An Introductory Education and Training programme.* Trainer's Manual. Dublin : Trinity College Dublin.

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Appendix 2   Ethical Approval – Phase One

THE UNIVERSITY OF DUBLIN

TRINITY COLLEGE

FACULTY OF HEALTH SCIENCES

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Dr Mary McCarron
School of Nursing & Midwifery
24 D'Olier Street
Dublin 2

Wednesday, 05 April 2006

Study: A palliative care model for supporting person's with intellectual disabilities and advanced dementia

Dear Dr McCarron

Further to a meeting of the Faculty of Health Sciences Ethics Committee 2006, we are pleased to inform you that the above project has been approved without further audit.

Yours sincerely

Professor Chris Bell
Chairperson
Faculty of Health Sciences Ethics Committee

Schools of the Faculty:

Physic (Medicine), Dental Science, Physiotherapy, Occupational Therapy, Clinical Speech and Language Studies, Radiation Therapy, Nursing and Midwifery

Appendix 3   **Personal Reflection on Dementia**

As I have now experienced supporting people with dementia over many years I have asked my self what must it be like to be living in that world. At the outset I consider that it must engender fear. I used to hate when my father asked in his lucid moments "what happening to me child?" I had deeply admired and loved him all of my life. I admired his strength both physically and mentally. I admired his deep spiritual, non-judgemental and compassionate nature. He lived with dementia for 3years and died as he lived – quietly and simply. My husband was stunned to realise that his most precious belongings were his claddagh wedding ring and his watch.

I wonder if I will live quietly and simply should I be diagnosed with dementia? As dementia is increasingly being prioritised as a health concern internationally, and there is emphasis on early diagnosis I would probably know I had it early in its progression and I would be able to start planning ahead. As I am an anticipatory griever I would want to grieve in anticipation of the many losses before me. That would be important to me as I like to be in control! I think I would be fearful because that control will be taken away from me. However, I know that by being able let go in anticipation of the particular loss I can cope better. Being an anticipatory griever does not make me miserable and not able to enjoy life. I am a number seven in the Enneagram personality type so I laugh through my pain.

In order to remain in control when challenged with dementia it would be important to keep communication with the significant people in my life. I have already started this conversation with them. Apparently they perceive that a crèche would be a more suitable place for me rather than "an old folks home" because of my childlike qualities!.

I do not see dementia as all negative for myself. Maybe I will like the fact that others will take control for me if or when I cannot make decisions for my own well-being. The benefit of an early diagnosis will be that I will have spent all the money while I was in control.

Appendix 4   Emerging Understandings from Phase One

Having cared personally at home for a parent in the old culture of care where dementia was pathologised, it was refreshing to witness person-centred care as described by Kitwood (1997) being delivered to the clients in the ID services in this research study. My general sense of intellectual disability nursing prior to this research was that they had it easier than nurses in other disciplines. I remembered that they didn't look busy or overworked when they accompanied their clients to general hospital for acute medical paediatric care. They behaved and looked relaxed even when there was an urgent event or episode on the ward. I believed at the time when I was preparing for the placements that I was going to observe nurses sitting and holding someone's hand and that there would be no intensity of 'nursing' activity.

I knew from listening to colleagues in Intellectual Disability nursing that they provided much social and psychological care to clients. What I had not appreciated however was that Intellectual Disability nursing could be so physically demanding. I observed many examples where clients were immobile and unable to meet their own activities in relation to eating, drinking, washing, elimination. I observed consistently that I never noted adverse odours in relation to incontinence even though many of these persons were permanently doubly incontinent. Their skin integrity and general cleanliness of person, clothes, personal effects were always impeccable. In the first few interviews I reflected on whether I was being shown selective areas of the services only. However, as I went to the sites I made bonds with staff and I was encouraged to visit other areas of all services at random. My observations of this care described above was mirrored again and again. This care which I observed, impressed me as I reflected on it. It was delivered in a dignified and person-centred way. Staff generally had known the individuals before their onset of dementia and continued to talk about the person from that previous knowledge of knowing him/her, his/her likes and dislikes, their personality and their behaviours. There was a very holistic sense to the care they delivered.

The data collected to date indicates strongly that staff wish to deliver this care to include end-of-life care and they want to improve the quality of this care within the Intellectual Disability service. They appear to be very aware of the experience of loss for themselves and for their clients who have dementia as the illness progresses and people die. They appear to struggle with how to cope with their emotional reactions as a professional workforce. The staff from the Specialist Palliative care service wish to extend their expertise to persons with Intellectual Disability and to improve their quality of care at end-of-life in partnership with the ID services. They perceive that they have a very narrow input around supporting staff with symptom management and decision-making re. end-of-life care. They also perceive that staff in ID settings have more issues around experiencing and managing grief reactions because of the nature of the relationships between staff and clients in ID. 06/12/2006.

Appendix 5   **Focus-Group Interview Guide**

Welcome.

Introductions.

Check all members of group received the study information.

Obtain written consent.

Advise/remind that the session will be audio taped – check all members ok with this.

Some key questions will need to be asked in order to achieve the research aim and objectives of Phase One. Sample questions which were asked are below.

Questions:

Q. Can you tell me about any experiences you have had with caring for a person with intellectual disability and dementia?

Prompts   *what was the experience like?

                 *What/when were the greatest challenges for you?

                 *Could the experience be improved?

Q. Do you consider that there is a place for Palliative care for a person with dementia?

Prompt   *why?

                 * What is your understanding of a palliative care approach to care?

                 *When would it be suitable to introduce a palliative care approach for clients with dementia?

Q. Do you believe that your organisation needs training in palliative care for persons with intellectual disability and dementia?

Q. Can you identify three key/major areas that you would like to have addressed in an educational training programme for your organisation to enhance/further enhance end-of-life care for this population.

Appendix 6 **Sample - Re-visiting interpretations of the themes and categories**

Writing interpretations is proving more challenging than I thought. I am inclined to write a description of the category within the theme rather than to tease out the possible meanings behind the words. I can only come to an interpretation if I explore my current understanding of the phenomenon and by reflecting on how this understanding is informed. This is an example of how my interpretation of ethos of care developed.

Ethos of care (1st draft)

Interpretation: Ethos of care refers to ……. The ethos of care in intellectual disability care 'felt special'. There was a certain calmness in the working environment. There was no rush to get things done.

I was describing what I had experienced and I had not reflected on what were the possible meanings I could apply to the word ethos or to the word care. After reflection a new understanding is written.

Ethos of care (Final draft)

Interpretation: Ethos of care refers to the nuances of an organisation in relation to the values inherent in its operation. It may or may not reflect the attitudes and values expressed in its mission statement. It is the spoken and unspoken atmosphere which is 'almost tangible' at an organisational and personal level when one visits an organisation. It can evoke negative or positive responses.

Appendix 7   **Topic Guide for Individual Interviews**

Topics arising from phase one:

1. Working in ID setting - world of ID support and care

2. Loss and grief - working with persons who develop a terminal condition (dementia)

3. Bereavement - coping strategies/reactions to deaths of clients

Examples of questions:

> As a Gadamerian approach needs to conversational it is not possible to predict where a conversation may go. However, I wanted to guide the conversation in attempting to gain an understanding of what the worldview of supporting a person with intellectual disability was first and then to attempt to capture an understanding of what staff perceived as loss and grief in that world. Finally, I wanted to try to understand how their experience of bereavement in that world was perceived. Therefore from those three topics I started the conversation with a broad question such as:

"Can you tell me what it is like to work with persons with intellectual disability?"

A conversation would follow on this topic until an appropriate time to ask:

> **"what do you understand by the terms loss & grief ?"**

Again a conversation would follow to discuss the topic broadly and then to focus more specifically to discuss an understanding of loss and grief in the ID setting. In particular, the conversation would then be directly related to the experience in relation to the person with dementia. The final topic of how bereavement is experienced when clients who develop dementia die in the ID setting was a third important question to conclude the conversation. This question was:

 "What is it like when the person with intellectual disability and dementia dies?"

Appendix 8   Merge of nodes – challenging assumptions

As I reflected on my visits, the data collected and my changing understanding (horizon of knowing) I was manually concept mapping. I used NVivo at the beginning to manage the volume of data and this allowed me to merge nodes (units of understanding) as my understanding was developing.

LOG: 5:54 pm, 4/28/06. : Merged with Copy of node (F 17). when staff spoke of the client as 'own' know them intimately. like family ?unconditional love 'special relationship' (1 Node)

Issues highlighted about the relationship between staff and client were the length of relationship, the staff knew clients from infancy, through childhood and into adulthood. They exuded a sense of satisfaction at the very least that they had watched the client achieve milestones along the way. There was sadness at seeing the clients develop dementia states and losing skills…
? this overlaps with the node 'effects on staff. The relationship mirrors a parental relationship with an unconditional love for the client who needs protection and nurturing, empowering and enabling?13-12-05 Like paediatric nursing the staff reported out of duty involvement with clients!

LOG: 5:53 pm, 4/28/06. : Copy of node (F 17) .
LOG: 10:23 am, 5/12/06. : Merged with Copy of node (F 24). this is meant to be the same as F8!! I need to merge these once I learn how! 12-12-05 'ID is best' (1 Node)
LOG: 10:23 am, 5/12/06. : Copy of node (F 24) .any references from staff that it is desired and best to care for the client within the ID service provider site.12-12-05. have copied node 24 into this 11/05/06

Note: NVivo was only used as a storage and retrieval system from 2007.

Appendix 9   Example of a reflection - Who is family?

Who has best interests of person re. healthcare decision making?

First observations

There was no reference to any formal team approach to include family in decision making. However it appeared that the nursing and care staff had a good relationship with family members if they were in contact with the client. **dec05.**

Later observations

may06 now after 6 different sites issues around family(kinsfolk) differ. Some of the services had well established inclusion of family (kinsfolk) in all matters of the person's well-being on a frequent and regular basis. Other services did not have regular family involvement due to a complexity of reasons and the family may only have been involved at crises times e.g when the person was suddenly hospitalised.

The legal situation is that the kinsfolk make decisions on the healthcare decision making for the person with intellectual disability. However many staff feel they know the client better than their family do and believe that outside agencies (Hospitals) in particular, make decisions with the family for the person without considering the person's known needs as they (the id staff) know them! Staff in ID setting feel that as they know them better they should be included in the decisions too but feel excluded and frustrated on occasion.

Person-centred care is known to be beneficial for persons with dementia. However relationship-centred care progresses on person-centred care and recognises that at least a triad of client, healthcare personnel and significant other (e.g family) is involved in the delivery of effective care to the person with dementia. The dilemma for staff in the intellectual disability services then may be to define who family are for the person because they often referred to themselves and indeed the peers of the person in the setting as the 'family' of the person. The lived as a family in a setting which was purposefully designed to imitate family living. It seemed that the staff lacked the knowledge and the confidence to be involved in advising the kinsfolk when it came to decision making and furthermore acknowledged that it was legally the prerogative of the next of kin to make ultimate decisions for their loved one. If relationship centred care is to be utilised for the person then who the healthcare person is and who the significant other is may be a challenge for staff in ID. The heath care may be removed to an outside source (hospital) and then the triad is outside of the ID service and too often the staff felt that they were unrecognised in the care and management of the person when they were outside of their ID setting.

Appendix 10   Memo - Site x visit x Ethos of care

Very nice environment, quiet, calm, aesthetic, nice furniture, paintings, newish equipment e.g. complex wheelchairs, walkers etc in room (sitting room) nice fresh décor.

Warm and cosy sitting room with fruit in bowl on table. Flowers in vase.

Staff welcoming even though they appeared to be busy as they had a number of clients requiring full nursing care and had just finished a round of feeding residents, washing them and changing them.

The bedbound clients were in their rooms, a general impression was the unit was reasonably well resourced with appropriate beds, equipment, staffing etc, the clients on observation appeared physically very well cared for, all clean, shaved, skincare, oral care, eye care, grooming, clothing all impeccable.

General sense of comfort and no obvious distress on the part of clients observed during the visit. This is a unit dedicated to persons with palliative care needs at the moment. There is no definite plan to develop it up as such and for this purpose. The unit has developed more in response to the needs of quieter personality type people some of whom have also developed illnesses such as dementia.

Mature staff on unit and there for some years. Know clients very well. Appear to have close relationships with them.
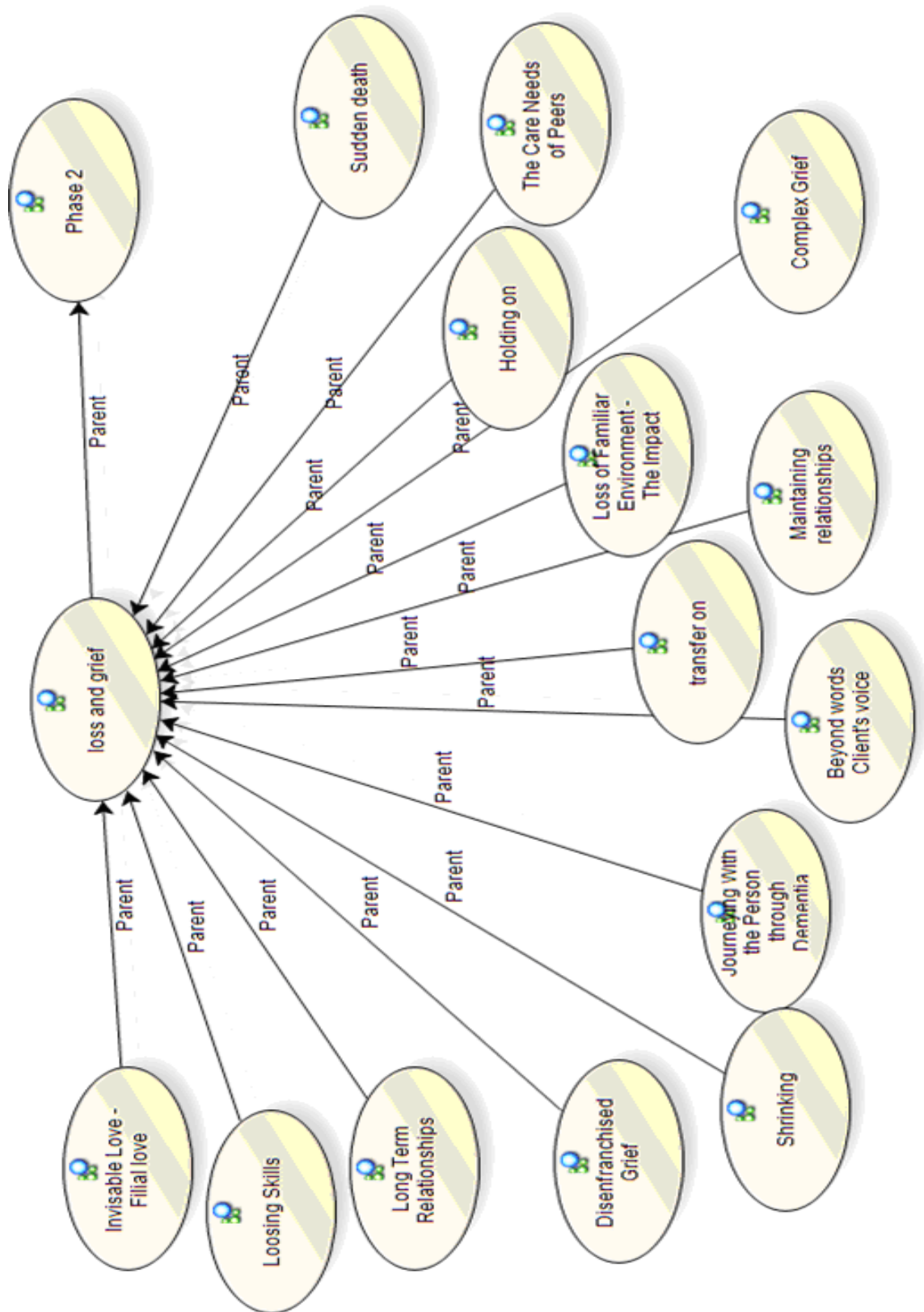
Appendix 12   Reflection Site x visit x Experience of grief for staff

I felt that this interview was almost like a therapy session. A bereavement therapy session. This was my fourth time meeting one of the staff members present and she had experienced a significant number of deaths of residents. She became very emotional when recalling a recent experience and cried uncontrollably for a few minutes. Because of having experience in supporting grieving persons, I did not feel uncomfortable with the situation. I felt a change in my role from the interviewer/researcher to one of friend or counsellor. She had just recently undertaken a bereavement/transition course which I felt had probably allowed her to open up some of her grieving process/reactions for a first time. We talked for a few minutes about the possible grief issues there may be for staff when people they have known for a long time die.

My general impression of this person when I met her originally in the working situation was that she portrayed a tough exterior 'professional' stance when in the public forum but in observing her in the one to one client encounters she displayed a gentleness/kindness and closeness to the clients in her care which belied that tough image presented as 'the professional'. She knew me from a few brief encounters and smiled broadly when we met anytime since I first met her.

I took this event as a positive sign that she accepted me as someone she could now be vulnerable with in the presence of her other colleagues. I felt privileged that she was able to be vulnerable here and portray a more private persona and in a way she was trusting me. We continued with the interview as she said that was ok. However, even thought I wanted to get answers to my specific questions I continued to be aware that the entire interview was more a therapeutic session for this member of the group and therefore I had to remain sensitive and supportive of this person throughout the process.

My General sense was that the nursing staff want to care for the person with ID/AD in their own unit until death and believe that they can do it provided that they would have some staff with a level of specialist knowledge and skills'(people trained in palliative care re symptom management e.g pain+_)' available for advice or support if the person was in distress/pain.

We had a de-briefing after the interview and this person had good insight into her strengths and weaknesses and coping mechanisms so I did not have any concerns about this person on leaving the site. I did discuss this event at this interview with one of my supervisors.

Appendix 13   Example of a memo from NVivo.

There was a very strong response from staff when asked if they thought non ID services understood their clients and their needs. The staff believed that non ID services did not understand ID clients and their needs. In site 1 all staff reacted to this, care staff and nursing staff. They were frustrated that they had lost some resources and that they had an uncertain future in relation to what was happening on the site in relation to relocation of clients.12-12-05. In site 2 equally they stated that ID was best and appeared delighted to report that even the Dr didn't transfer a client to hospital because he felt that the care they would get in the ID service was better! Also they explicitly stated that they looked after the clients better re. skin care, personal hygiene than outside health services e.g hospital, nursing home.13-12-05

Appendix 14   **Theme 1 World View of Supporting Persons with ID**

Appendix 15   **Theme 2 Worldview of Loss & Grief in ID**

Appendix 16   **Theme 3 Worldview of Bereavement in ID**

Appendix 17　　　　　**New and emerging understandings – Phase Two**

Now that I am more familiar with intellectual disability care I have a developing understanding of the lives of the person with ID and his/her carer. It was very difficult for me to understand how the structures or hierarchy operated within the different services. It was completely different from general nursing structures and hierarchy. It was in effect entering a whole new world. There was a great sense of community and autonomy among the workforce.

I had always thought that if my daughter had lived with an intellectual disability that I would never have her in any ID service. Now I could begin to possibly re-consider that after witnessing the dedication of staff to those in their care. Something special seems to happen between the staff and the clients. I do not like the term 'client' but the word patient was rarely used (even when someone was sick and in a nursing/medical unit). Another term used in some services was 'service user'. Again a term which I find to be clinical and cold. I had held an understanding of ID services as almost like hospitals where people were admitted and stayed for a lifetime.

I was now beginning to understand that these services were the home of the clients and the place of work of the staff. Therefore, staff were always visitors and there was a different dynamic between client and carer. This emerging understanding of the service being home to the client allowed me to begin to think differently about where the client ought to die. Where one dies is not only of concern to the person but it is also of concern to those who love that person. I was beginning to understand that staff loved their clients in these settings in a familial sense at the very least. They were the advocates for what they understood to be the best choices for those they supported who were unable to choose freely for themselves.

Appendix 18 **Example of Merging of Horizons of Existing and Developing Understanding - Gadamer**

" A person trying to understand a text is prepared for it to tell him something. That is why a hermeneutically trained consciousness must be, from the start, sensitive to the text's alterity. But this kind of sensitivity involves neither "neutrality" with respect to content nor the extinction of one's self, but the foregrounding and appropriation of one's own fore-meanings and prejudices. The important thing is to be aware of one's own bias, so that the text can present itself in all its otherness and thus assert its own truth against one's own fore-meanings".(Gadamer 2004:271)

> *"oh I know it's going to happen Elizabeth, (that the client will die), but I just can't bear to think about it" (participant 2.8.1)*

I listened to participants recounting their experiences of feeling sad when they watched the clients lose 'hard earned' skills, those of one's being able to go to work each day, to travel independently and to look after their own personal hygiene. I vividly recalled my previous experiences and how I had adjusted to the losses experienced by myself, family members and patients who declined with dementia. I remembered the struggle to 'hold on' and 'let go' which the participants described. The feelings of frustration when the relationship was changing because of the cognitive decline which impacted on their taken for granted communication. I could identify with the feelings of helplessness and their desire to 'make things better'. I also remembered and reflected on my own coping mechanisms and compared and contrasted how the staff used similar strategies. In my knowing that I am an anticipatory griever, an that that had assisted me in coping, I had to remain open to the fact that anticipatory grief may not manifest for many participants even though they had a forewarning of death for their clients with dementia. (20/11/2011).

Appendix 19   Ethical Approval – Phase 2

THE UNIVERSITY OF DUBLIN

TRINITY COLLEGE

SCHOOL OF MEDICINE

FACULTY OF HEALTH SCIENCES

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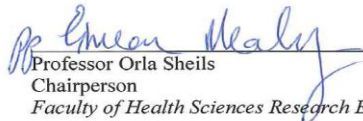24 D'Olier St.,
D 2

8th June, 2010

Original Study title: A palliative care model for supporting person's with intellectual disabilities and advanced dementia.

Dear Prof McCarron,

I can confirm that Prof Orla Sheils granted an extension for the above study on 17th April, 2008. The new extension was to explore the loss and grief experiences for staff supporting this population.

The above study was approved by the Faculty of Health Sciences Ethics Committee in 2006.

Yours sincerely

Professor Orla Sheils
Chairperson
Faculty of Health Sciences Research Ethics Committee