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Maintaining Wellness in Fibromyalgia

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1.1 Declaration

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1.3 Summary

Fibromyalgia is a chronic pain condition characterized by widespread musculoskeletal pain, fatigue and multiple tender points. It is a common, multidimensional disorder that is associated with complex symptomatology and relatively poor treatment outcomes. For a large number of patients, fibromyalgia is associated with pain, fatigue, sleep dysfunction, stiffness, depression, anxiety and cognitive disturbances. This thesis examined the experience of patients living with a diagnosis of fibromyalgia, with the aim of producing an empirically supported, theoretically informed, self-management intervention. The research focused on the subjective experience of patients with fibromyalgia which informed the development and subsequent delivery of a wellness based intervention to this cohort of patients.

Chapter 1 presented a general introduction to fibromyalgia, its aetiology, pathophysiology, and diagnosis. The many psychological aspects of living with the condition and varied treatment options available to patients were also detailed in this chapter.

Chapter 2 examined the subjective experience of living with fibromyalgia. In order to capture the patients' perceptions of support, their illness and its treatment a qualitative approach was deemed most suitable. Qualitative data obtained through focus groups, and analysed using a descriptive and interpretive framework revealed that fibromyalgia has a substantial negative impact on the patient's lives regardless of gender and that patients living with fibromyalgia may benefit from general healthcare support in relation to the validation of their illness experience and from psychological

support that may serve to promote knowledge, acceptance, facilitate active coping strategies and reinforce their adaptive, health promoting behaviours.

Chapter 3 aimed to investigate the impact of a WRAP® informed wellness Intervention on the self-management of fibromyalgia. The chapter provided an overview of the Recovery Model, WRAP® and Goal Setting Theory. The study utilized a pre-post longitudinal evaluation of a seven week Wellness in Fibromyalgia Intervention. In addition, the study provided a comparison study between two groups: a Wellness in Fibromyalgia intervention group ($N = 78$) and a comparison group ($N = 50$). Post-intervention interviews were completed with a sample of participants ($N = 10$) 12 months after completing the intervention. Analysis of the longitudinal data demonstrated that overall, the Wellness in Fibromyalgia Intervention had a positive impact on measures of self-efficacy, pain acceptance, activities engagement, impact of illness and internal control. Physical functioning scores and total number of feel good days differed across time points with a significant decrease observed on each of these subscales over the course of the intervention. In the comparison study, the Wellness in Fibromyalgia Intervention had significant effects on measures of self-efficacy, activities engagement and internal control. No significant changes occurred for physical functioning, days missed from work, pain willingness, matter of chance, powerful others having control, doctors having control or other people having control.

Chapter 4 described how post intervention interviews with a sample of participants ($N = 10$) were analysed using a descriptive and interpretive approach in order to understand the views of those participants in terms of their experience of receiving a WRAP® informed intervention for the management of their condition. The

analysis proposed five categories – Most Significant Illness Adjustment, Least Significant Illness Adjustment, Maintaining Wellness through WRAP®, Meaning of Wellness and Programme Review.

Chapter 5 integrated the findings from previous chapters in this thesis and discussed the implications, both theoretical and clinical; of employing a WRAP® informed intervention in the management of fibromyalgia. Limitations of the research were considered and avenues for future study were suggested.

1.4 Table of Contents

1.1 Declaration	ii
1.2 Acknowledgements	iii
1.3 Summary.....	v
1.4 Table of Contents	viii
1.5 List of Tables.....	xii
1.6 List of Figures.....	xii
1 Chapter 1: General Introduction to fibromyalgia and treatment options available to patients.....	1
1.1 Introduction.....	1
1.2 Fibromyalgia: An Overview	6
1.2.1 Aetiology	6
1.2.2 Pathophysiology.....	13
1.2.3 Diagnosis	13
1.3 Psychological Aspects of Living with Fibromyalgia	17
1.3.1 Psychological Well-being	18
1.3.2 Mood Disorders.....	19
1.4 Pain related Fear Avoidance.....	22
1.5 Impaired Cognitive Function	25
1.6 Treatment Options	28
1.6.1 Psychological Therapies	28
1.6.2 Pharmacological Interventions	38
1.6.3 Physical Treatments	40
1.6.4 Complementary and Alternative Medicine (CAM) Treatments.....	45
1.7 Multidisciplinary Treatments	48
1.8 Areas for future research	49
1.9 Conclusion	52
2 Chapter 2: The Subjective Experience of Male and Female Fibromyalgia Patients in an Irish Population: A Qualitative Study	55
2.1 Introduction.....	55
2.1.1 Gender Differences and Pain	57

2.1.2	The Current Study	59
2.2	Method	61
2.2.1	Participants	61
2.2.2	Focus Groups.....	62
2.2.3	Procedure	62
2.2.4	Data Analysis	64
2.3	Results	66
2.3.1	Treatment	66
2.3.2	Experience of Fibromyalgia.....	71
2.3.3	Perceived support	75
2.4	Discussion	77
2.4.1	Limitations.....	83
2.4.2	Future Study.....	84
2.4.3	Conclusion.....	84
3	Chapter 3: Maintaining Wellness in Fibromyalgia Intervention.....	86
3.1	Introduction.....	86
3.1.1	Recovery.....	87
3.1.2	Wellness Recovery Action Plan (WRAP®)	91
3.2	Goal Setting Theory	93
3.3	Study Aim and Hypotheses	96
3.3.1	Longitudinal Study	96
3.3.2	Comparison Study	97
3.4	Methods	98
3.4.1	Design.....	98
3.4.2	Participants & Procedure	98
3.4.3	Power Analysis	101
3.4.4	Intervention	101
3.4.5	Measures.....	105
3.4.6	Data analyses	108
3.5	Results	113
3.5.1	Participants	113
3.5.2	Longitudinal Study Data Analyses	116

3.5.3	Comparison Study Data Analyses	129
3.6	Discussion	142
3.6.1	Clinical implications.....	149
3.6.2	Limitations.....	150
3.6.3	Future Research	152
3.6.4	Conclusion	154
4	Chapter 4: Overall Impact of the Wellness in Fibromyalgia Programme and Suggestions for Change	156
4.1	Introduction.....	156
4.2	Methods	159
4.2.1	Participants & Procedure	159
4.2.2	Data Analyses	162
4.3	Results	163
4.3.1	Illness Adjustment.....	163
4.3.2	Programme Review	177
4.4	Discussion	180
4.4.1	Limitations.....	187
4.4.2	Conclusions	187
5	Chapter 5: General Discussion.....	189
5.1	Summary of the Research	190
5.2	Implications of Research	192
5.2.1	Theoretical Implications.....	198
5.2.2	Clinical Implications	205
5.3	Limitations.....	206
5.4	Future Research	210
5.5	Conclusion	212
6	References	213
7	Appendices.....	265
7.1	Appendix 1: Ethical Approval Letters	265
7.2	Appendix 2: Information Letter For Chapters 2, 3 and 4	270
7.3	Appendix 3: Consent Forms For Chapters 2, 3 and 4.....	274
7.4	Appendix 4: Debriefing Letter For Chapters 2, 3 and 4.....	278

7.5	Appendix 5: Questionnaires For Chapter 3	282
7.6	Appendix 6: As Treated Analysis Results.....	289
7.7	Appendix 7: Focus Group Transcripts For Chapter 2	313
7.8	Appendix 8: WRAP® Workbook.....	337
7.9	Appendix 9: Lesson Plans	415
7.10	Appendix 10: Copeland Centre Values and Ethics	421
7.11	Appendix 11: Interview Transcripts For Chapter 4	422

1.5 List of Tables

Table 2.1: Domains, Categories and Meaning Units.....	66
Table 3.1: Components of the Wellness in Fibromyalgia Programme.....	103
Table 3.2: Participant demographics	114
Table 3.3: Descriptive Statistics for Intervention (N = 78) and Comparison Groups (N = 50) across time points time	119
Table 4.1: Domains, Categories and Meaning Units.....	163
Table 7.1: Participant demographics	292
Table 7.2: Descriptive statistics <i>for Intervention (N = 48) and Comparison Groups (N = 43) across time points</i>	296

1.6 List of Figures

Figure 1.1: Fibromyalgia Diagnostic Criteria (Source Adapted from Wolfe et al., 2010, p. 607).....	16
Figure 1.2: The fear-avoidance model of pain (Source Adapted from Vlaeyen & Linton 2000, p. 9).....	25
Figure 3.1: Relationship Among Assigned Goals, Self-Set Goals, Self-Efficacy and Performance. (Source Adapted From Locke and Latham, 1990, p. 72)	95
Figure 3.2: Participant Enrolment, Allocation, Follow up and Analysis - Intervention Group	110
Figure 3.3: Participant Enrolment, Allocation, Follow up and Analysis - Comparison Group	111
Figure 3.4: Mean Self-efficacy Scores for Intervention Group at Time 0, Time 1, Time 2 and Time 3. Error bars represent standard deviations.....	117
Figure 3.5: Mean Chronic Pain Acceptance Scores for Intervention Group Time 0, Time 1, Time 2 and Time 3. Error bars represent standard deviations.....	118
Figure 3.6: Mean Total Activities Engagement Scores for Intervention Group Time 0, Time 1, Time 2 and Time 3. Error bars represent standard deviations.....	120

Figure 3.7: Mean Fibromyalgia Impact Scores for Intervention Group Time 0, Time 1, Time 2 and Time 3. Error bars represent standard deviations.....	122
Figure 3.8: Mean Impairment Scores for Intervention Group Time 0, Time 1, Time 2 and Time 3. Error bars represent standard deviations.....	123
Figure 3.9: Mean Physical Functioning Scores for Intervention Group Time 0, Time 1, Time 2 and Time 3. Error bars represent standard deviations.....	124
Figure 3.10: Mean Number of Days Missed from Work for Intervention Group Time 0, Time 1, Time 2 and Time 3. Error bars represent standard deviations.....	125
Figure 3.11: Mean Number of Feel Good Days for Intervention Group Time 0, Time 1, Time 2 and Time 3. Error bars represent standard deviations.....	126
Figure 3.12: Mean Internal Control Scores for Intervention Group Time 0, Time 1, Time 2 and Time 3. Error bars represent standard deviations.....	127
Figure 3.13: Illustration of the interaction between time and group for Total Self-Efficacy Scores. Error bars represent standard deviations.....	130
Figure 3.14: Mean Pain Acceptance Scores at Time 1, Time 2 and Time 3. Error bars represent standard deviations.....	131
Figure 3.15: Illustration of the interaction between Time and Group for Activities Engagement Scores. Error bars represent standard deviations.....	133
Figure 3.16: Mean Fibromyalgia Impact Scores at Time 1, Time 2 and Time 3. Error bars represent standard deviations.....	134
Figure 3.17: Mean Impairment Scores at Time 1, Time 2 and Time 3. Error bars represent standard deviations.....	135
Figure 3.18: Total Number of Feel Good Days at Time 1, Time 2 and Time 3. Error bars represent standard deviations.....	137
Figure 3.19: Illustration of the interaction between Time and Group for Total Internal Control Scores. Error bars represent standard deviations.	138
Figure 7.1: Participant Enrolment, Allocation, Follow up and Analysis - Intervention Group	290
Figure 7.2: Participant Enrolment, Allocation, Follow up and Analysis - Comparison Group	291
Figure 7.3: Mean Self-efficacy Scores for Intervention Group Time 0, Time 1, Time 2 and Time 3. Error bars represent standard deviations.....	293

Figure 7.4: Mean Chronic Pain Acceptance Scores for Intervention Group Time 0, Time 1, Time 2 and Time 3. Error bars represent standard deviations.....	294
Figure 7.5: Mean Activities Engagement Scores for Intervention Group Time 0, Time 1, Time 2 and Time 3. Error bars represent standard deviations.....	295
Figure 7.6: Mean Fibromyalgia Impact Scores for Intervention Group Time 0, Time 1 Time 2 and Time 3. Error bars represent standard deviations.....	297
Figure 7.7: Mean Impairment Scores for Intervention Group Time 0, Time 1, Time 2 and Time 3. . Error bars represent standard deviations.....	298
Figure 7.8: Mean Number of Feel Good Days for Intervention Group Time 0, Time 1, Time 2 and Time 3. Error bars represent standard deviations.....	299
Figure 7.9: Mean Internal Control Scores for Intervention Group Time 0, Time 1, Time 2 and Time 3. Error bars represent standard deviations.....	300
Figure 7.10: Illustration of the interaction between Time and Group for Self-Efficacy Scores. Error bars represent standard deviation.....	303
Figure 7.11: Mean Pain Acceptance Scores Time 1, Time 2 and Time 3. Error bars represent standard deviations.....	304
Figure 7.12: Mean Activities Engagement Scores Time 1, Time 2 and Time 3. Error bars represent standard deviations.....	305
Figure 7.13: Mean Total Score on FIQ Time 1, Time 2 and Time 3. Error bars represent standard deviations.	306
Figure 7.14: Mean FIQ Impairment Scores Time 1, Time 2 and Time 3. Error bars represent standard deviations.....	307
Figure 7.15: Mean Number of Feel Good Days- Time 1, Time 2 and Time 3. Error bars represent standard deviations.....	308
Figure 7.16: Mean Internal Control Scores Time 1, Time 2 and Time 3. Error bars represent standard deviations.....	310

1 Chapter 1: General Introduction to fibromyalgia and treatment options available to patients.

1.1 Introduction

In order to understand the concept of illness, health and recovery it is worthwhile to start with disease. Modern medicine is so focused on the understanding of disease and fighting illness that one seldom stops to think about the ultimate goal, namely, health. Yet, as Gadamer (1996) illustrates, illness cannot exist without health. It presupposes health insofar as it is the loss or disruption of health. However, the attempt to define health is frequently confronted with an elusive target. An individual is most healthy precisely when they are least conscious of their health, and thus competent to engage in various activities. Whilst the concepts of 'health', 'mind' and 'body' vary considerably across time, place and culture, they play a fundamental role in the experience of being human.

It is difficult to establish a single, universally acceptable account or definition of health, as many of the definitions currently in existence are surrounded with much controversy. The World Health Organisation (WHO, 1946) put forward a definition which has been widely quoted. They defined health as a state of complete physical, social and spiritual well-being and not simply an absence of illness. However, this definition is one which has come under increased scrutiny and some criticism as the notion that health must be more than merely an absence of disease is rapidly gaining support. The definition has also been criticised for representing an unrealistic goal (Boorse, 1977), nevertheless, it does emphasise the holistic nature of health involving body and spirit, along with physical and mental state, and social and psychological

variables. More recently, Marks, Murray, Evans and Willig (2000) revised this definition provided by the WHO and deemed health to be a state of being with physical, cultural, psychosocial, economic and spiritual attributes, not simply the absence of illness.

Defining chronic illness is an equally complex task. Within the literature, the term chronic illness is frequently mentioned in contrast to acute illness. In more general terms, however, chronic illness refers to an incurable illness which is characterised by slow onset or progression and a long duration (Lubkin & Larsen, 2006). An individual with a chronic illness may cycle between periods of mild improvement and relapse, the illness is therefore commonly seen as a lifelong affliction. Chronic illness presents itself in many forms, ranging from cardiovascular disease (CVD), diabetes, and cancer, to chronic pain conditions such as rheumatoid arthritis (RA), muscular sclerosis (MS) and fibromyalgia. While each of these illnesses are significantly different from one another in terms of their aetiology and treatment, they share one common feature and that is their ability to produce untold disruption to the diagnosed patient. Despite this, health and chronic illness have the potential to coexist; however, this coexistence is heavily dependent upon processes and attributes possessed by the individual and their ability to employ these appropriately in the individualized attempt to live with chronic illness and stay well.

Chronic pain conditions represent considerable psychological and physical impairment to the individual and are associated with psychiatric and medical comorbidities. The cost to the patient can be psychological, social or economic, consequently pervading all aspects of the patient's life. Evidence suggests that such

conditions also represent a considerable economic burden to society (Spaet, 2009) as they are associated with the increased utilization of healthcare and non-healthcare resources, and can have a detrimental impact on family, social and vocational relationships, and the overall quality of life of the patient (Preece & Sandberg, 2005). From a psychological theory perspective, early models of pain (e.g. Descartes, 1664; Von Frey, 1895; Goldschneider, 1920) described pain within a biomedical framework as an automatic response to an external factor; suggesting that pain is caused by tissue damage, it is an automatic response to an external stimulus, it has no single cause and that psychology has no causal influence and is involved only as a consequence of pain (e.g. anxiety, depression or fear). Such simple stimulus-response models of pain showed no role for psychology. However, psychology has now been shown to play a critical role in the understanding of pain and this has been based on several observations.

In recent times, it has been observed that medical treatments for pain (e.g. surgery, medications) were for the most part only useful for the treatment of acute pain. Such treatments appear to be ineffective for the treatment of chronic pain, thus suggesting that there must be additional factors involved in the pain sensation which is not included in the simple stimulus-response models. Such an observation suggests variation between individuals; perhaps it is this variation that indicates a role for psychology in the pain experience (Ogden, 2007). Melzack and Wall (1965, 1982; Melzack, 1979), developed the gate control theory of pain (GCT), which represented an attempt to introduce psychology into the understanding of pain. This theory suggested that, although pain could still be understood in terms of a stimulus-

response pathway, this pathway was complex and mediated by a network of interacting processes. The gate control theory of pain therefore served to integrate psychology into the traditional biomedical model and not only described a role for psychological causes and interventions, but also allowed for psychological causes and interventions. As a model of pain, it has afforded practitioners and researchers the opportunity to examine the intricate relationship between psychology and pain and the place psychologically based treatment options holds in the management of many complex conditions.

Chronic diseases are long-term conditions, lasting more than six months, involve some disability or functional impairment and are usually incurable. Many of these conditions are caused by lifestyle factors and other determinants of health including diet, physical inactivity, tobacco and alcohol consumption, accidents and other environmental factors (Department of Health and Children, 2014). Chronic disease is an international concern with incidence rates increasing dramatically (Helmick et al., 2008). An increase in the number of studies in the area of chronic pain has been observed in the past two decades, reflecting both the increasing incidence rates and interest in the subject matter (Branco et al., 2010) and it is estimated that by 2020, the number of adults in Ireland with chronic diseases will increase by around 40% (Balanda, Barron & Fahy, 2010). Factors such as the increase in incidence rates and the profound impact of illness on this cohort of patients are commanding the attention of both researchers and healthcare professionals. For researchers, it has posed many challenges due to both the steady increase in incidence rates and the findings that deem the origins of chronic pain to be multifaceted. Chronic pain

diseases, for example, osteoarthritis, rheumatoid arthritis, multiple sclerosis, polymyalgia rheumatica and fibromyalgia, are presently among the most frequently diagnosed illnesses by practitioners (Diez, Bravo & Victor, 1999). A postal survey of 3136 people conducted through GP practices with a representative community-based sample of Irish adults by Raftery et al. (2011), where measures were obtained for socio-demographic variables, physical and psychological well-being, depressive symptoms, the presence of pain, pain severity, pain-related disability and illness perceptions showed the prevalence of chronic pain to be 35.5%. The most commonly reported site of pain was the lower back (47.6%); however, multiple pain sites were common with over 80% reporting the presence of pain at more than one site. 12% were unable to work or were on reduced work hours due to pain and of those with chronic pain, 15% met the criteria for clinical depression compared to 3% of those without pain. The study emphasised that pain is a prevalent health problem in Ireland and is associated with significant psychological and functional disability. Responses were received from 1204 people.

After osteoarthritis, fibromyalgia is the second most commonly diagnosed chronic rheumatic disorder (Clauw, 2014). Fibromyalgia can develop at any age, including in childhood, and the prevalence rate of 0.5-5% is similar across countries, cultures and ethnic groups (McBeth & Jones, 2007). Unlike many other chronic illnesses; it is devoid of any biological markers, however, it, like any chronic illness has a significant impact on those diagnosed with the condition. An overview of the condition, its aetiology, pathophysiology, diagnosis, psychological impact and treatment options will be discussed in the current chapter.

1.2 Fibromyalgia: An Overview

The term 'fibromyalgia' was first used by Hench in 1976 (Häuser, Bernardy, Arnold, Offenbächer & Schiltewolf, 2009) and in 1990, the American College of Rheumatology (ACR) published its first classification criteria for the disorder (Wolfe et al., 1990), which was subsequently reviewed in 2010 (Wolfe et al., 2010). Fibromyalgia is a complex and often debilitating chronic pain condition. Its defining characteristic features are persistent pain, pain that is neither localized nor strictly regional- but rather gives an impression of `being all over, and a general sense of distress. Patients frequently report accompanying symptoms such as fatigue, sleep disturbance, non-restorative sleep, numbness and/or tingling, cognitive difficulties and an observation of several inordinately tender points at specific body sites which are associated with enhanced pain sensitivity (Wallace, 1997).

1.2.1 Aetiology

The exact aetiology of fibromyalgia remains unknown. An interaction of psychosocial and biological variables in the triggering, development and predisposition of the condition has been proposed (Oliveira & Costa, 2012), and numerous studies have sought to identify factors that may be linked to disease onset. In a review article, Eich, Hartmann, Muller and Fischer (2000) evaluated the role of psychosocial factors in the development of fibromyalgia and findings supported the view that psychosocial factors can be relevant at different etiological levels and can be classified into predisposing, triggering, and stabilising. Alternatively, Van Houdenhove and Egle (2004) postulated stress as playing a key role in the pathogenesis of fibromyalgia, placing emphasis on the relationships between adverse life experiences,

stress regulation, and pain-processing mechanisms. Van Houdenhove, Egle and Luyten (2005), highlighted, from an etiologic point of view, studies regarding the role of adverse life events, and lifestyle factors and negative childhood experiences, Bennett (2005a) examined the role of genetics and Moldofsky (2008), examined the role of sleep abnormalities. Each of these proposed factors will be discussed.

1.2.1.1 Genetics

A genetic study by Bennett (2005a) suggests the possibility of an increased prevalence of specific genotypes of neurotransmitters and their receptors in fibromyalgia. Bennett concludes that polymorphisms of genes in the serotonergic and catecholaminergic systems are linked to the pathophysiology of fibromyalgia. There appears to be some genetic and familial factors that play a role in fibromyalgia. The frequency of fibromyalgia among the first-degree relatives of patients with fibromyalgia and rheumatoid arthritis were 6.4% and 1.1%, respectively. The median number of tender points among the first-degree relatives of the fibromyalgia patients was 17 out of maximum of 18, whereas the median number of tender points was 12 out of 18 among the relatives of rheumatoid arthritis patients (Bradley, 2009).

According to Buskila and Neuman (2005) it is likely that several genes are working together to initiate fibromyalgia. More recently, further evidence has suggested that genetic factors may play a role in the pathogenesis of fibromyalgia. A meta-analysis of 21 studies examining the possible link between onset of the condition and genetics by Lee, Choi, Ji and Song (2012) demonstrated the 5-HT_{2A} receptor 102T/C polymorphism is linked to susceptibility to fibromyalgia. Longitudinal studies have also been conducted examining the link between various factors,

including lifestyle behaviours that have been found to predict future development of the condition. Evidence pertaining to genetics remains inconclusive and further genotype research is needed.

1.2.1.2 Sleep Abnormalities

Sleep disturbance is a prevalent feature of fibromyalgia. The American College of Rheumatology (ACR) criteria for the classification of fibromyalgia identify sleep disturbance as a primary associated symptom of the condition (Lineberger, Means & Edinger, 2007). Researchers report that 70-90% of patients with fibromyalgia experience some form of sleep disruption (Rao, & Bennett, 2003). Mork and Nilsen (2012), in an 11 year longitudinal study of 12,350 fibromyalgia patients, indicated sleep difficulties to be a predictive factor in the onset of the condition. Several researchers (Clauw & Crofford, 2003; Lineberger et al., 2007; Moldofsky, 2008) indicate that sleep disturbance is among the more common symptoms reported by fibromyalgia patients, reporting that the majority of these patients present with sleep difficulties. Patients with fibromyalgia report early awakening, less hours of sleep, difficulty falling asleep and taking more medications for sleep than healthy controls (Clauw & Crofford, 2003). Martínez-Lavín, Hermosillo, Rosas and Soto (1998) showed that compared to controls, patients with fibromyalgia may also have significantly lower heart rate suggesting that this diminished heart rate may also contribute to sleep disturbance, non-restorative sleep and the subsequent onset of fatigue. According to Moldofsky (2008) patients with fibromyalgia perceive their sleep to be light and un-refreshing regardless of how long they sleep

Numerous self-report studies have been conducted in which fibromyalgia patients were asked to give an account of their experience of sleep disturbance and its effect on quality of life. Theadom, Cropley and Humphrey (2007) suggested that sleep quality in patients with fibromyalgia was significantly predictive of pain, fatigue, and social functioning. These results support previous findings (Agargun et al., 1999; Nicassio et al., 2002) that poor sleep was associated with increased pain and fatigue in patients with fibromyalgia. Polysomnographic studies lend support to such subjective reports of fibromyalgia patients by confirming excessive wake time, the intrusion of waking-like alpha frequencies into non-rapid eye movement sleep, and increased arousal to be common among fibromyalgia patients (Linebarger et al., 2007).

Sleep disturbance is a common feature of fibromyalgia. Although numerous studies have focused on the different aspects of sleep in fibromyalgia, no clear consensus has been reached concerning the exact role poor sleep has in relation to this condition. Patients with fibromyalgia themselves report difficulties with sleep however researchers remain unaware of whether sleep disturbances are part of a biological predisposition for fibromyalgia or whether fibromyalgia itself interferes with sleep (Moldofsky, 2008). There is however, objective evidence that abnormalities in the sleep structure of fibromyalgia patients does exist therefore adding credibility to the subjective complaints of this cohort of patients.

1.2.1.3 Traumatic Life Events

In relation to past experiences, Dell'Osso et al. (2010) showed that lifetime exposure to potentially traumatic events, in particular loss events, increased the severity of illness and decreased the health related quality of life in fibromyalgia

patients ($N = 70$). Goldberg et al. (1999) examined the relationship between traumatic events in childhood in 91 patients with fibromyalgia, myofascial pain and chronic facial pain. Fibromyalgia patients reported the highest rates of childhood physical and sexual abuse. Walker et al. (1997) compared patients with fibromyalgia to patients with rheumatoid arthritis and reported fibromyalgia patients had significantly higher rates of victimization. In this study, the severity of the trauma experienced was correlated with measures of illness adjustment, psychiatric distress, physical disability and quality of sleep in patients with fibromyalgia but not in patients with rheumatoid arthritis.

In stark contrast, a number of studies have found no difference in rates of physical or sexual abuse in patients with fibromyalgia when compared to healthy controls (Alexander et al., 1998; Taylor, Trotter & Cuska, 1995). Ciccone et al. (2005) attempted to resolve the inconsistent findings concerning the role of abuse. They conducted a community-based study in which they compared patients with fibromyalgia and depression, patients with fibromyalgia and no depression, controls with only depression, and healthy controls and failed to find increased fibromyalgia symptoms in the abused versus non-abused patients with fibromyalgia.

Physical trauma has also been proposed as having a role in fibromyalgia onset. McLean, Clauw, Abelson and Liberzon (2005) assessed whether a road traffic accident was a possible trigger to the onset of fibromyalgia. They concluded that a motor vehicle collision was capable of triggering fibromyalgia, but not through direct injury. Instead, they proposed that such an event could act as a possible stressor that when

combined with other environmental and/or biological factors, which may trigger the onset symptoms.

Though many studies have attempted to establish a causative link between the onset of fibromyalgia and some type of trauma, be it physical, sexual or emotional, research to date has failed to indicate any clear connection. There appears to be conflicting research regarding the role abuse may have in the development of fibromyalgia.

1.2.1.4 Stress

Fibromyalgia is frequently viewed as a stress disorder (Johnson, 2008). Several researchers have implicated psychosocial stress as a risk factor for musculoskeletal pain (Bongers, Kremer, & Laak, 2002; Linton, 2000). Pain experienced by patients with fibromyalgia has been shown to escalate with emotional stress (Van Houdenhove & Egle, 2004). The mechanisms by which stress is related to the pain in fibromyalgia are however, poorly understood. A review by Johnson (2008) established that sympathetic nervous system axes and disturbances of the Hypothalamic-Pituitary-Adrenal (HPA) axis may explain some of the symptoms associated with fibromyalgia.

According to Thompson, Lettich and Takeshita (2003) cortisol hormone levels are typically elevated in patients with fibromyalgia. This type of elevation is normally associated with hyper arousal, however, conversely, a study by Catley, Kaell, Kirschbaum and Stone (2000) demonstrates this may not be the case in fibromyalgia patients as it emerged that elevated levels of cortisol in 21 patients with fibromyalgia could not be connected to any on-going or acute stressor.

Nilsen et al. (2007) examined the relationship between mental stress-induced autonomic activation and pain in patients with fibromyalgia compared to healthy controls and patients with chronic shoulder/neck pain. Participants completed a stressful task for 60 minutes. Physiological recording were obtained for heart rate, blood pressure, and respiration frequency before, during, and after the stressful task and a comparison of the physiological responses with the subjective reports of pain was made. Abnormal cardiovascular responses and a negative association between the heart rate response and the pain which developed during the stressful task were observed in participants with fibromyalgia. The authors hypothesized that these results, along with similar findings (Cohen et al., 2001; Kelemen et al., 1998) suggest a lower stress-induced pain reduction for patients with fibromyalgia (Nilsen et al., 2007). Although the research suggests that stress has a function in fibromyalgia, the exact nature of this relationship remains uncertain. Further studies are needed to determine the role stress has in the development and maintenance of fibromyalgia.

Many theories pertaining to the aetiology of fibromyalgia have been presented in this section and there are many more in existence. Forseth, Husby, Gran and Førre (1999), in a study of 214 patients that had a 5 year time frame between assessments, found back pain to be a predictive factor of fibromyalgia. In 2010, Mork, Vasseljen and Nilsen examined obesity combined with inactivity in an 11 year study of 15,990 patients. This study found that when combined, obesity and inactivity are predictive factors in the development of the fibromyalgia; Choi, Knutsen, Oda, Fraser and Knutsen (2010) in a study ($N=3,136$) spanning between 25 and 26 years, identified smoking as a predictor of the development of fibromyalgia. Each of the studies cited

serve to increase knowledge in relation to the many variables, both biological and environmental that are thought to play a part in the development of fibromyalgia and their findings have enhanced knowledge in relation to the aetiology of this complex condition. However, it remains clear that further research is required to establish the exact aetiology of this complex condition.

1.2.2 Pathophysiology

Many factors are associated with the pathophysiology of fibromyalgia but the relationship remains unclear. The functional changes observed in patients with the disorder include reduced reactivity of the hypothalamus-pituitary-adrenal-axis to stress, reduced reactivity of the hypothalamus, disturbances in neurotransmitters such as serotonin and dopamine, and increased pro-inflammatory and decreased anti-inflammatory cytokine profiles (those produced by cells involved in inflammation) (Sommer, 2012). Prolonged exposure to stress inducing life events may also contribute to these functional changes (Bradley, 2009; Van Houdenhove et al. (2005).

1.2.3 Diagnosis

The diagnosis of a chronic illness is typically permanent; however, some chronic diseases afford patients a period of remission. For example if the inflammation markers utilised in the diagnosis and monitoring of rheumatoid arthritis (RA) are no longer evident, the individual is said to be in remission from RA. A diagnosis of fibromyalgia however, is a permanent one in the sense that a person may present with a small number or even no fibromyalgia symptoms for a period or an increase in symptoms during other periods. For example, problematic fibromyalgia

symptoms may become more apparent during periods of excessive physical exertion and/or mental stress and may relent or decrease during periods of better health or tranquillity (Katz, Wolfe & Michaud, 2006). Diagnosis of fibromyalgia is mainly based on a combination of physical examinations, laboratory evaluations such as MRI to exclude other conditions such as MS and patient history (Peterson, 2007; Wolfe et al., 2010).

As a chronic pain condition, fibromyalgia has been fraught with ambiguity in diagnosis, uncertainty in understanding of the pathophysiology behind its many complex symptoms, and difficulties that physicians face in managing it competently. In the past, chronic widespread pain was its defining feature, however, fibromyalgia is also associated with psychological conditions such as anxiety and depression (Thieme, Turk & Flor, 2004) and physical conditions such as Irritable Bowel Syndrome (IBS; Sperber et al., 1999); though not all patients will experience all of the associated symptoms or conditions. The diagnostic criteria of the American College of Rheumatology (ACR) have gained worldwide acceptance as the prevailing definition of fibromyalgia. These criteria define fibromyalgia as chronic pain (i.e., pain for more than 3 months) in multiple parts of the body, i.e. pain in the axial skeleton (cervical spine or anterior chest or thoracic spine or lumbar spine), and pain in the right and left sides of the body, and pain above and below the waist, and pain on palpation of at least 11 of 18 defined tender points (Wolfe et al., 1990). The 1990 ACR criteria required tender point examination, they also created the invalid impression that fibromyalgia is a peripheral musculoskeletal disease with the pathology centred on the tender points which subsequently emerged as the most characteristic feature of

fibromyalgia. Since then, understanding about the underlying pathophysiology of this complex pain syndrome has evolved and the need to develop new diagnostic criteria has grown. Recently, there has been increasing recognition of central pain sensitization as the underlying neurobiological basis that explains most of the fundamental systemic symptoms (Wolfe et al., 2010).

In 2010, the American College of Rheumatology (ACR) published new fibromyalgia diagnostic criteria suitable for the primary care setting that incorporated both peripheral pain and somatic symptoms (See Fig. 1.1). The 2010 ACR criteria are aimed at simplifying the diagnosis of fibromyalgia and being suitable for use in primary care practice without requiring a tender point examination which formed a key part of the original criteria from 1990. An additional objective of the revised criteria was to recognize the importance of the numerous non-pain symptoms of fibromyalgia, such as perceived cognitive impairment (“fibrofog”), fatigue, and sleep disturbance, in making the diagnosis (Garg & Deodhal, 2012).

Fibromyalgia is a complex condition making this a challenging disorder to both diagnose and treat (Peterson, 2007). The aetiology of the condition remains unclear, and while current research has added to our knowledge of fibromyalgia, additional studies are required. The invisibility of its many symptoms and its impact on both the physical and emotional state of the patient are both problematic and distressing, and the fluctuating characteristics of fibromyalgia and the fluidity of its many intricate symptoms make the treatment of the disorder a complex issue.

A patient satisfies diagnostic criteria for fibromyalgia if the following 3 conditions are met:

- 1) Widespread pain index (WPI) ≥ 7 and symptom severity (SS) scale score ≥ 5 or WPI 3–6 and SS scale score ≥ 9 .
- 2) Symptoms have been present at a similar level for at least 3 months.
- 3) The patient does not have a disorder that would otherwise explain the pain.

Ascertainment

1) WPI: note the number areas in which the patient has had pain over the last week. In how many areas has the patient had pain? Score will be between 0 and 19.

Shoulder girdle, left	Hip (buttock, trochanter), left	Jaw, left	Upper back
Shoulder girdle, right	Hip (buttock, trochanter), right	Jaw, right	Lower back
Upper arm, left	Upper leg, left	Chest	Neck
Upper arm, right	Upper leg, right	Abdomen	
Lower arm, left	Lower leg, left		
Lower arm, right	Lower leg, right		

2) SS scale score:

- Fatigue
- Waking un-refreshed
- Cognitive symptoms

For the each of the 3 symptoms above, indicate the level of severity over the past week using the following scale:

- 0 = no problem
- 1 = slight or mild problems, generally mild or intermittent
- 2 = moderate, considerable problems, often present and/or at a moderate level
- 3 = severe: pervasive, continuous, life-disturbing problems

Considering somatic symptoms* in general, indicate whether the patient has:

- 0 = no symptoms
- 1 = few symptoms
- 2 = a moderate number of symptoms
- 3 = a great deal of symptoms

The SS scale score is the sum of the severity of the 3 symptoms (fatigue, waking un-refreshed, cognitive symptoms) plus the extent (severity) of somatic symptoms in general. The final score is between 0 and 12.

*Somatic symptoms that might be considered: muscle pain, irritable bowel syndrome, fatigue/tiredness, thinking or remembering problem, muscle weakness, headache, pain/cramps in the abdomen, numbness/tingling, dizziness, insomnia, depression, constipation, pain in the upper abdomen, nausea, nervousness, chest pain, blurred vision, fever, diarrhoea, dry mouth, itching, wheezing, Raynaud's phenomenon, hives/welts, ringing in ears, vomiting, heartburn, oral ulcers, loss of/change in taste, seizures, dry eyes, shortness of breath, loss of appetite, rash, sun sensitivity, hearing difficulties, easy bruising, hair loss, frequent urination, painful urination, and bladder spasms.

Figure 1.1: Fibromyalgia Diagnostic Criteria (Wolfe et al., 2010)

In the past, clinical diagnosis of fibromyalgia syndrome has relied heavily upon tender point counts, a convenient evaluation of pain sensitivity that has come under

scrutiny in terms of reliability and validity. The revised 2010 ACR diagnostic criteria have eliminated the use of this practice. This revised criteria (see Figure 1.1), set has been approved by the American College of Rheumatology (ACR) Board of Directors as Provisional which signifies that the criteria set has been quantitatively validated using patient data, but it has not undergone validation based on an external data set. Therefore, additional effort and research must be employed in a bid to ascertain the reliability of the criteria.

1.3 Psychological Aspects of Living with Fibromyalgia

The psychological impact fibromyalgia presents to those diagnosed with the condition is a significant barrier to successful living. There is often a sharp contrast between the symptoms reported by fibromyalgia patients and what present as routine musculoskeletal and neurological examinations along with normal laboratory and radiographic tests. Despite receiving normal results in physical examinations and testing, fibromyalgia patients are typically afflicted with substantial disability and emotional distress (Marcus & Doedhar, 2011). Owing to the complex aetiology of fibromyalgia and the presence of not just physical but also emotional symptoms, the assumption that there exists a psychological impact is a justifiable one. This chapter will examine the psychological aspects of living with fibromyalgia with particular consideration being given to psychological well-being, mood disorders and impaired cognitive function.

1.3.1 Psychological Well-being

An important starting point to the discussion pertaining to the psychological aspects of fibromyalgia is the overall psychological well-being of individuals with a diagnosis of the condition. Psychological well-being encompasses autonomy, environmental mastery, personal growth, purpose in life, positive relations with others, and self-acceptance (Ryff, 1989). The diagnosis of fibromyalgia is often challenging and there is a distinct lack of outward visible signs, therefore individuals living with a diagnosis of the condition may well find themselves tiring of trying to find help and/or often repeatedly explaining their situation to people who they feel are dismissing and stigmatizing them. Resulting from this, patients may feel not just unsupported but also that their illness experience is not being validated by family and friends or by the healthcare professionals involved in the provision of care, thus having a detrimental effect on their relationships and impacting directly on their psychological wellbeing, a finding that is in line with the conclusions contained in Chapter 2: *The Subjective Experience of Male and Female Fibromyalgia Patients in an Irish Population: A Qualitative Study*. Similar to these findings, in research conducted by Schaefer (2005) examining the lived experience of fibromyalgia patients ($N = 10$), it was reported that these patients often wish to have some degree of secrecy with their illness allowing them to create some sense of safety where they do not always feel judged, but noted that when they are labelled and stigmatized it angers them and they find they regularly must become self-advocates constantly trying to legitimize and validate their illness to others.

A lack of validation has the potential to impact negatively on the patients coping mechanisms. Johnson, Zautra and Davis (2006) found that in a sample of 51 women aged between 35 and 69 years, illness uncertainty played a role in increased difficulty in coping when increased fibromyalgia pain was present. A lack of validation also has the potential to impact directly on the patient's acceptance of the diagnosed condition; a valuable construct in current theories that demonstrates how a patient might react and subsequently adapt to chronic pain. Viane et al. (2003) have shown that psychological well-being can be predicted by the levels of acceptance of pain beyond the effects of pain catastrophizing and pain severity. In the presence of stigmatization and judgemental attitudes towards the diagnosis of fibromyalgia or presence of associated symptoms from health care providers or important others in the patient's life, fibromyalgia patients may themselves be less accepting of their diagnosis which can ultimately compromise their coping, adjustment and overall psychological wellbeing.

1.3.2 Mood Disorders

1.3.2.1 Depression

Fibromyalgia is associated with a combination of psychological and physical distress (Callahan & Blalock, 1997; Verbunt, Pernot & Smeets, 2008). Even though depression and fibromyalgia share similar characteristics like pain, low mood, headaches, reduced concentration, and insomnia, fibromyalgia patients typically reject any implication that their illness is primarily a psychological disorder. Instead, they see any psychological distress they suffer as secondary to, or a result of their intrusive physical symptoms (Schoofs, Bambini, Ronning, Bielak & Woehl, 2004).

Studies on depression rates in fibromyalgia patients show large a variation from 20% (Kirmayer, Robbins & Kapusta, 1988) to 65% (Alfici, Sigal, & Landau, 1989) or 71% (Hudson, Hudson, Pliner, Goldenberg & Pope Jr, 1985). There are a number of possible reasons for the wide variance in the reported prevalence rates, they may be explained by different definitions of depression being used, a difference in methods for assessing depression, sampling bias - for example, participants who are in receipt of psychiatric care; reliance on patients who actively seek out treatment to establish prevalence (those who seek treatment are likely to be the most distressed); or a combination of these factors (Thieme et al., 2004). If we were however to take the mean of the reported rates evidenced in the research, it may be possible to surmise that as many of 45% of patients with fibromyalgia will have co-morbid features of depression.

Fatigue, sleep disturbance and non-restorative sleep are key features of fibromyalgia (Wallace, 1997). Sleep disturbances are also typical features of depression (Franzen & Buysse, 2008), with as many as 90% of patients with depression making sleep quality complaints (Tsuno, Besset, & Ritchie, 2005). Russell (2001) indicated that depression may be the cause of fibromyalgia symptoms like fatigue and poor sleep. Further research has revealed that co morbid depression in fibromyalgia patients can further contribute to fatigue and sleep disturbance, which in turn may result in reports of a more severe impairment in their health status (Bergman, 2005; Niccassio, Moxham, Schuman & Gevirtz, 2002). These conclusions however may not be robust as one must remain cognisant of the fact that not all patients with a diagnosis of fibromyalgia meet the diagnostic criteria for depression

and so such conclusions should be interpreted with caution. Hence, while it is clear that there exists a link between fibromyalgia and depression, and that depression is associated with fatigue and with the ability to cope with the condition, the area would benefit from further research that should seek to establish whether the features of depression are an antecedent or consequence of fibromyalgia.

Cronan and Bigatti (2003) reported poorer psychological well-being including depression and helplessness, in fibromyalgia patients ($N=572$) than in an osteoarthritis comparison group. Verbunt et al. (2008) found that perceived disability and quality of life in fibromyalgia patients was influenced by the state of their mental health and that their psychological distress was higher compared to persons with complex regional pain syndrome or chronic low back pain. Also of significance is the finding that patients with a combination of depressive symptoms and body pain experience considerably more complaints of pain than those with pain alone (Greenberg et al., 2003); a clear indicator of the cyclical, interchangeable nature of pain and mood.

When compared to other patient groups, fibromyalgia patients are more likely to have complications associated with psychological functioning including depression hence, one of the aspects of living with the condition is the propensity to experience symptoms of depression.

1.3.2.2 Anxiety

There is a strong association between fibromyalgia and anxiety. In a study of 115 fibromyalgia patients an overall 32.3% of the patients revealed an anxiety disorder. These results are more than three times higher than the prevalence of these

psychiatric disorders in the general population in which 9% were found to have an anxiety disorder (Theime et al., 2004). This study also found that fibromyalgia patients with an anxiety disorder reported the greatest number of physical symptoms associated with fibromyalgia and the highest pain intensity and interference. In addition, this group had a high level of attentive behaviours from significant others as well as more avoidance behaviours.

Several studies have proposed that anxiety is most likely a reaction to the pain and disability associated with fibromyalgia in this group of patients (Dunne & Dunne, 1995; Goldenberg, 1989). Kurtze and Svebak (2001) examined the relationship between anxiety and depression and fatigue in patients with fibromyalgia and concluded that fatigue was significantly associated with depression and pain was associated with anxiety. The relationship between fibromyalgia and anxiety requires further study as research to date has failed to provide clarity in terms of the mechanisms underlying the association.

1.4 Pain related Fear Avoidance

Theories relating to the meaning of symptoms, the impact of pain on the patient's life, the patient's ability to control their pain and their worries about the future are just some patient beliefs that have been shown to play a major role in chronic pain (Turk & Okifuji, 2002). The suggestion therefore, that pain related behaviours and/or fears may serve a function in the maintenance or initiation of disability in chronic pain is not a new one. There is growing evidence for the notion that in chronic pain patients, pain-related fear (fear of pain, physical activity, re-injury or injury) may be more disabling than pain itself.

Pain-related fear has become the focus of research since there is increasing evidence for the notion that in some chronic pain patients the fear of expected evil is worse than the evil itself (Arntz, Van Eck & Heijmans 1990). Vlaeyen, Kole-Snijders, Rotteveel, Ruesink and Heuts (1995) found that fear of movement or (re)injury was a better predictor for self-reported disability than biomedical signs or symptoms and pain severity. Using the Fear-Avoidance Beliefs Questionnaire (FABQ), which measures patients beliefs about how physical activity and work has the potential to affect the patient's experience of pain, Waddell, Newton, Henderson, Somerville and Main (1993) found that fear-avoidance beliefs about work are strongly related with disability of daily living and absenteeism, and more so than pain variables such as pain severity, anatomical pattern of pain. These studies demonstrate the relevance of fear in the experience of some chronic pain patients.

Fear promotes escape from the object of threat and instigates avoidance behaviour and an immediate consequence of avoidance is that daily activities, which may once have been valued activities for the patient, expected to produce pain are no longer engaged in, thus leading to increased disability (Crombez, Eccleston, Baeyens & Eelen, 1998). Just like other forms of fear and anxiety (Eysenck, 1992; Williams, Mathews & MacLeod, 1996), pain-related fear has been shown to interfere with cognitive functioning hence; fearful patients will pay more attention to possible signals of threat and will be less able to selectively disregard pain-related information (Asmundson, Kuperos & Norton 1997; Crombez, Vlaeyen, Heuts & Lysens, 1999; Eccleston, Crombez, Aldrich & Stannard, 1997). As a consequence, other cognitive activities cannot be efficiently processed and the voluntary utilization of coping

strategies might be hindered (Crombez et al., 1999; McCracken, Gross, Sorg & Edmands, 1993). Longstanding pain avoidance and physical inactivity has been shown to affect various physiological systems. Bortz (1984) reported on the effects of inactivity on the musculoskeletal system and found that prolonged bed rest resulted in a significant reduction of muscle strength, a substantial loss of bone calcium and a shortening of the muscle tendons. Therefore, avoidance and physical inactivity may further worsen the pain problem. When patients with pain symptoms are presented with a feared situation, such as walking up a flight of stairs, some experience a range of avoidance responses including effort to avoid or escape the possibility of a flare up of symptoms or increased pain (Crombez et al., 1999).

The notion that fear of pain and (re)injury may be more disabling than pain itself (Crombez et al., 1999) refutes the early notion that the lowered ability to accomplish tasks of daily living in chronic pain patients is merely the consequence of pain severity. The fear-avoidance model (Figure 1.2) proposes that if pain, including that caused by an injury, is interpreted as threatening (pain catastrophizing), pain-related fear develops. This leads to avoidance behaviours, and hyper vigilance to bodily sensations followed by abandonment of valued activities, disability and depression. Depression has the potential to maintain the pain experiences thereby fuelling the vicious circle of increasing both fear and avoidance. In non-catastrophizing patients, no pain-related fear and prompt engagement with daily activities is likely to occur, leading to fast recovery. Pain catastrophizing is predicted to be influenced by negative affectivity and threatening illness information.

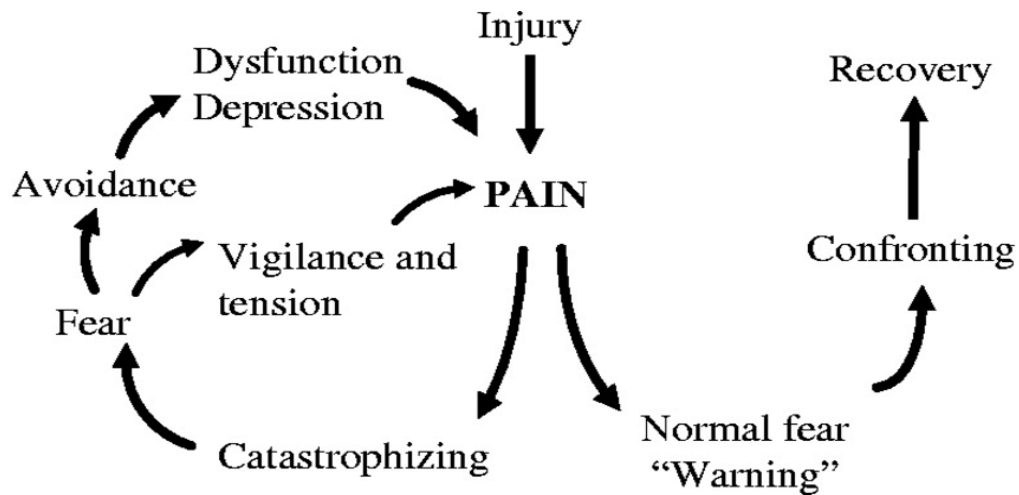


Figure 1.2: The fear-avoidance model of pain (adapted from Vlaeyen & Linton 2000)

1.5 Impaired Cognitive Function

Cognitive impairment is a common feature of the pain experience and this impairment is said to represent a considerable obstacle to rehabilitation and daily activities especially in chronic pain patients (Moriarty, McGuire & Finn, 2011). Over 50% of fibromyalgia patients report a decline in memory and mental confusion (Katz, Heard, Mills, & Leavitt, 2004) with cognitive problems such as concentration and forgetfulness reported as amongst the most severe symptoms by patients with the condition (Bennett, Jones, Turk, Russell & Matallana, 2007). Fibromyalgia patients frequently report a cognitive impairment sometimes referred to in the vernacular as ‘fibro fog’ (Starlanyl & Copeland, 2001). Fibro fog is defined by a co-occurring collection of mental clarity disturbances, short-term memory problems and dissociative symptoms and has been described by patients as being the single most debilitating symptom and as the symptom that is of most concern to them (Karper, 2007).

Fibromyalgia patients exhibit diminished cognitive performance in cognitive tasks which cause considerable disability (Park, Glass, Minear & Crofford, 2001), and there now exists a growing body of literature that indicates that this cohort of patients perform more poorly on a wide range of cognitive tasks than age matched controls (e.g. Grace, Nielson, Hopkins & Berg, 1999; Sletvold, Stiles & Landro, 1995). Glass and Park (2001) reported that fibromyalgia patients performed more poorly than controls on verbal fluency tests (the ability to access stored knowledge of words) and on tests of episodic and working memory (e.g. the ability to learn and later recall a list of words). More direct evidence comes from studies that link brain activity with cognitive function. Bangert et al. (2003) used fMRI to evaluate brain activity during a working memory task in 12 fibromyalgia patients and 9 education and age-matched control subjects. The results show that both fibromyalgia patients and healthy controls were capable of achieving similar performances on the assigned tasks. The imaging results, however, revealed that, in order to attain this similar level of performance, fibromyalgia patients needed to use far greater brain resources, with the fibromyalgia patients showing more extensive neural activation. These results support the hypothesis that fibromyalgia patients show an aging effect that is using increasing cognitive resources to maintain comparable levels of performance as their same-aged peers and support the findings of Park et al. (2001) who report that fibromyalgia patients perform similarly to people 20 years their senior. Such findings also corroborate with patients own reports of increased mental effort and difficulty in completing cognitive tasks even when performance levels do not differ from those of controls.

A definite cognitive dysfunction exists in individuals with a diagnosis of fibromyalgia with current findings demonstrating that fibromyalgia patients have cognitive function that is poorer than that in age-matched controls and similar to that of adults 20 years their senior with respect to working memory and long-term memory. An important difference between fibromyalgia patients and older control subjects, however, is an intact speed of processing. This suggests that the underlying cause of their memory dysfunction differs from that in older adults, since the cognitive decline in older adults is facilitated by deficits in the speed of processing. The intact speed of processing may therefore be viewed as a positive sign that cognitive, and in particular memory deficits in fibromyalgia can be remedied. Correlation analyses suggest that a poor memory function is related to pain, and although correlation does not imply causation, pain management and the taking into account of the individual's personal experience of pain and cognitive dysfunction may serve to enhance treatment options and outcomes for patients with this complex disorder. Some have also pointed to a correlation between depression and anxiety and cognitive dysfunction (Grace et al., 1999) while others dispute this finding (Park et al., 2001), however, regardless of whether a link exists between depression and anxiety and cognitive dysfunction, what remains clear is that there are objective, measurable cognitive impairments in fibromyalgia that impact on the patient's ability to cope with the disorder. Further research employing neuroimaging and the taking into account of the subjective experiences of the patient along with the possible co-existence of mental health issues would assist in the understanding of the mechanisms and underlying cognitive dysfunction present in fibromyalgia and the impact it has on the patient.

1.6 Treatment Options

There is no universally accepted treatment for fibromyalgia and current treatment options are non-curative. Typically, fibromyalgia patients depend on symptom management options. Developments in the overall understanding of the condition and the impact it has on patients' lives have led to an increase in treatment options, some of which have shown more efficacy than others in terms of positive outcomes for the patient. The present section will describe both non pharmacological and pharmacological treatment options that are available to these patients, reviewing the current literature and examining their effectiveness in terms of illness management.

1.6.1 Psychological Therapies

1.6.1.1 Cognitive Behavioural Therapy (CBT)

CBT is a widely used psychological treatment for a wide range of health problems including chronic pain. CBT is effective in enhancing patients' beliefs in their own abilities and developing ways to deal with health problems (Bernardy, Klose, Busch, Choy & Häuser, 2013). The principal goals of CBT to change negative thoughts and feelings that the individual may have of their mental and/or physical problems serve as a functional means of encouraging the chronic pain patient to alter his or her behaviour and thus develop further the skills required to successfully manage pain associated with their condition (Bernardy et al., 2013). Through active engagement with CBT, fibromyalgia patients have the potential to attain skills (for example, activity pacing or relaxation techniques) to assist them in the management of their pain or to

develop different attitudes towards pain (e.g., increase acceptance levels), or both (Bernardy et al., 2013). CBT as a treatment option for fibromyalgia has shown some success. Alda et al. (2011) demonstrated a significant decrease in pain catastrophizing and an increase in global functioning, pain acceptance and quality of life in a randomized controlled trial with 113 patients comparing CBT against treatment as usual. However, there was no significant effect on the patients' reported experiences of pain, which supports current opinion (e.g., Lumley, 2011), indicating that CBT, as a single treatment, does not offer a universal management method for fibromyalgia patients. Similarly, in a study where CBT was used to treat patients with juvenile fibromyalgia, results indicated that CBT as a single treatment modality, did not offer any distinct advantage over well-planned group programmes of exercise or education, or both (Bennett & Nelson, 2006). In the most compelling study to date, Thieme et al. (2006), randomly assigned 125 patients with fibromyalgia to either CBT ($N = 42$), operant behaviour therapy (OBT; $N = 43$) or an attention control group ($N = 40$). CBT addressed modifying maladaptive thoughts, decreasing psychological stress, problem solving, relaxation and pain coping strategies while OBT consisted of behavioural interventions to reduce pain behaviours. Results showed that when compared to the attention control; both CBT and OBT resulted in greater improvement in pain, improved physical functioning and decreased emotional distress for up to one year post treatment. Patients in both treatment groups also reported fewer visits to their physician when compared to those in the control group. The reported effect sizes were large for both the CBT and the OBT groups but for the most part the differences between the two were not significant. However, it was observed that patients in the CBT group demonstrated sustained decreases in catastrophizing and increases in

coping which have the potential to contribute to consistent improvements in emotional distress.

Effective CBT interventions for fibromyalgia should endeavour to target the modification of maladaptive thoughts and expectations, thus improving perceived stress, mood, problem solving and pain coping., while including behavioural interventions that seek to specifically address symptoms associated with the condition (e.g. activity pacing, sleep hygiene, relaxation training). In relation to fibromyalgia, the primary goal of CBT according to Hassett and Gevirtz (2010), is to increase self-management which includes moving patients toward more adaptive beliefs regarding their ability to control and cope with pain and other symptoms as well as taking action to decrease stress and symptoms resulting in increased functioning. The evidence for combining CBT with pharmacological treatment for fibromyalgia remains modest; therefore more randomized controlled trials are required. Furthermore, only subgroups of patients are likely to respond to CBT such as those with greater emotional support needs and fewer coping skills or those who have belief in CBT and its effectiveness as a treatment option. Future studies should cautiously explore individual factors associated with positive response to CBT, as well as the elements of CBT that are most highly associated with a positive response to treatment.

1.6.1.2 Acceptance Commitment Therapy (ACT)

ACT has been evaluated for both adult and paediatric chronic pain (McCracken et al., 2005) and was recently listed by the American Psychological Association, Division 12, as an empirically supported treatment for 'Chronic or Persistent Pain in General' (Division 12, A.P.A., 2010). ACT is therefore a commonly used treatment in

the management of chronic pain (Veehof, Oskam, Schreurs & Bohlmeijer, 2011), and has evidence of effectiveness with this population. However, only in recent times has research examined its possible impact on the symptoms of fibromyalgia (e.g., Wicksell et al., 2013). ACT uses acceptance techniques to facilitate a divide between one's thoughts, feelings and pain and the 'self'. It encourages patients to base their actions on personal values even though they may be experiencing elevated levels of pain and/or distress, i.e., it promotes psychological flexibility (Wicksell et al., 2013).

As a treatment option for chronic pain, ACT has shown significant success.

In a study comparing ACT with CBT, patients reporting chronic pain for at least 6 months ($N = 114$) were randomly assigned to 8 weekly group sessions of acceptance and commitment therapy (ACT) or cognitive-behavioural therapy (CBT) and were assessed after treatment and at 6-month follow-up. All participants continued with treatment as usual for pain and mood over the course of the intervention. ACT participants improved on pain interference, depression, and pain-related anxiety. ACT participants who completed treatment reported significantly higher levels of satisfaction than did CBT participants. These findings suggest that ACT is an effective and acceptable adjunct intervention for patients with chronic pain (Wetherell et al., 2011).

Results from the preliminary studies employing ACT as an intervention with fibromyalgia patients demonstrate its utility in the management of the condition. In the first study to examine efficacy of ACT for fibromyalgia, Wicksell et al. (2013), found significant differences in pain-related functioning, the impact of the illness on the life of the patient, self-efficacy, mental health-related quality of life, anxiety, depression

and psychological rigidity. Forty participants were randomly assigned to an intervention group or a waitlist control group. Assessments were made pre- and post-treatment and at a 3 months follow-up. The ACT intervention consisted of 12 weekly group sessions. Changes in psychological rigidity over the course of the ACT programme were found to mediate pre- to follow-up improvements in outcome variables. Such research shows promise for fibromyalgia patients. They correspond with previous studies on ACT for chronic pain thus suggesting the utility of ACT for fibromyalgia as well as the role of psychological rigidity as a mediator of improvement. Future studies should endeavour to validate further the potential impact of acceptance based interventions on the symptoms reported by patients living with fibromyalgia.

1.6.1.3 Mindfulness Based Therapies (MBT)

Research into and the clinical use of mindfulness as a therapeutic intervention have increased in recent years and the results have been promising in a wide range of chronic illness populations. One area in which such interventions have been trialled is fibromyalgia. Mind-body therapies (MBT) are an example of psychological treatments that have been shown to be clinically effective in numerous health-care settings, and often show comparable outcomes to pharmacological interventions (Pelletier, 2002). Mindfulness Based Stress Reduction (MBSR) as a therapy aims to promote the development of non-judgemental awareness of moment to moment experience within a framework of openness, kindness, acceptance and tolerance of emotional, mental and sensory phenomena (Schmidt et al., 2011). Many of the studies examining the effectiveness of MBTs have limitations such as small sample sizes (e.g. Plews-

Ogan, Owens, Goodman, Wolfe & Schorling, 2005) or the failure to use a control or comparison group (e.g. Kaplan, Goldenberg & Galvin-Nadeau, 1993). As a result, improved study design is necessary and their findings must be interpreted cautiously. Despite these limitations, there are many important findings and a growing body of evidence indicates MBSR can improve health related quality of life and coping in many chronic conditions including chronic pain (e.g. Grossman et al., 2004; Kabat-Zinn, Lipworth & Burney., 1985). Kaplan et al. (1993), in an MBSR intervention found that all 59 of the participants who completed the 10 week MBSR intervention showed a significant improvement in mean pre-post scores showing a positive change on the instruments used [Fibromyalgia Impact Questionnaire (FIQ), Fibromyalgia Attitude Index (FAI), Medical Symptom Checklist (MSCL), Visual Analogue Scale (VAS) and the Coping Strategies Questionnaire (CSQ)]. However, while this study assessing the efficacy of MBSR programmes for the treatment of fibromyalgia showed significant changes in participants, it was an uncontrolled trial with no control group for comparison.

MBT interventions refer to therapies that emphasise the fundamental connections between physical health, cognitions and emotions (Henke & Chur-Hansen, 2014). Studies have indicated moderate to strong efficacy for MBT for a range of chronic pain illnesses, including fibromyalgia in improvements in mental health ratings (Plews-Ogan et al., 2005), and sleep (Winbush, Gross & Kreitzer, 2007). It has been suggested that such treatments could produce stable and permanent changes that facilitate significant improvements in patients' symptoms (Cuadrose & Vargas, 2009). Mindfulness meditation is one such intervention that has been theoretically

and empirically associated with psychological well-being, and recently has gained momentum as an accepted form of 'third wave' psychotherapy (Chiesa & Seretti, 2011).

Higher degrees of mindfulness in patients with chronic pain are related to lower self-reported pain, reduced emotional distress, decreased disability, and less use of pain medication (McCracken, Gauntlett-Gilbert & Vowles, 2007). It has been demonstrated that mindfulness interventions produce positive results in relation to symptoms associated with fibromyalgia (Young, 2007). Sleep, for example, has been shown to be important in the management of fibromyalgia symptoms (Miró, Sanchez, Prados & Medina, 2011) and in a systematic review of the effect of mindfulness-based interventions on sleep disturbance, Winbush et al. (2007) established that such interventions served to improve sleep and decrease sleep-interfering cognitive processes such as rumination. However, the small number of studies ($N = 7$), the lack of standardized measures and the uncontrolled nature of those included in this analysis highlights the need for more research using standardised scales and methods. As a direct result of the weak methodologies characterising some research, including uncontrolled variables, small sample sizes and a lack of standardized measures, some researchers remain sceptical of the efficacy of mindfulness as an intervention for fibromyalgia (Ebell, 2001; Langhorst et al., 2012). Therefore, although some evidence suggests that mindfulness training may be a favourable treatment option for fibromyalgia patients and that it can have some positive psychological and physiological effects, reliable conclusions cannot be reached at this time and further investigation is warranted.

1.6.1.4 *Guided Imagery*

Guided imagery involving engaging all senses in experiencing pleasant circumstances or places has demonstrated some efficacy in patients with fibromyalgia. Guided imagery aims to increase muscle relaxation and has the potential to serve as a powerful distraction from pain (Hassett & Gevirtz, 2009). In a randomized study comparing a 6-week guided imagery intervention to treatment as usual, fibromyalgia patients ($N = 48$) receiving guided imagery reported a greater sense of self-efficacy for managing their pain although actual pain levels did not change. The intervention group also demonstrated improved functional status (Menzies, Taylor & Bourguignon, 2006). In a randomized controlled trial of women with fibromyalgia, Fors et al. (2002) found that those in a 'pleasant' guided imagery group ($N = 17$) who received guided instruction in pleasant imagery in order to distract from the pain experience, reported significantly less pain compared to the control group ($N = 17$). No significant reduction in pain was observed in the 'attention' imagery group ($N = 21$) who received relaxation training and attention imagery based upon the active workings of the internal pain control systems. This would suggest that diversionary activities as opposed to those that involve focussing on the pain experience have a potential benefit for fibromyalgia patients. In line with the hypothesis that diversionary activities are beneficial to this group of patients, Menzies and Kim (2008) reported positive findings for the use of guided imagery specifically for individuals with a diagnosis of fibromyalgia, with significant improvements in functioning, symptoms and self-efficacy for managing pain. Finally, in a study of female juvenile fibromyalgia patients ($N = 7$), a combination of PMR and guided

imagery was found to improve sleep and reduce pain in the majority of participants (Walco & Ilowite, 1992) demonstrating the potential advantage of using these interventions in conjunction with one another.

1.6.1.5 Psychoeducational Treatment

A psychoeducational treatment component is useful if not necessary when treating fibromyalgia (Carville et al., 2008). Typically such educational programmes increase the patients understanding of the complex nature of the interactions between behaviours such as sleep and/or activity levels, neurobiological processes, and the many symptoms associated with fibromyalgia (Luciano et al., 2011). Psychoeducational programmes have varied applications, but usually endeavour to dispel the stigma often attached to fibromyalgia (Hassett & Gevirtz, 2009). Goldenberg (2008) set out recommendations regarding psychoeducation. He suggested that: “When educating patients, a core set of information should be provided that includes a detailed discussion of potential pathophysiological mechanisms in the context of the bio psychological model. The clinician must dispel the notion that the absence of organic disease means that the symptoms are psychogenic” (p. 31).

Psychoeducation is a crucial element of illness management. LeFort, Donald, Rowat and Jeans (1997) conducted a randomized controlled trial that sought to examine the effect of a low-cost, community-based, group psychoeducation program entitled the Chronic Pain Self-Management Program (CPSMP) on an array of chronic pain conditions. Individuals ($n=110$) with a variety of chronic pain diagnoses were enrolled in the study and were randomly assigned to one of two conditions: a 12 hour

(CPSMP) intervention group, or the 3-month wait-list control group. Self-report measures of pain-related and other quality of life variables were collected pre-treatment and 3 months post intervention. Results indicated that the treatment group made significant short-term improvements in pain, dependency, vitality, aspects of role functioning, life satisfaction and in self-efficacy and resourcefulness as compared to the wait-list control group, promising results in the context of psychology and its role in the management of chronic pain.

Some health care practitioners have expressed concern that a diagnosis of fibromyalgia might serve to impact negatively on the state of the patient and may even intensify symptoms (Hassett & Gevirtz, 2009). However, research on this matter found that such a diagnosis had no adverse effect on the patient, and may have actually improved function (White et al., 2002). Therefore, while education seems warranted, limited data support this opinion. Only two well controlled trials have been reported. Burckhardt, Mannerkorpi, Hedenberg and Bjelle (1994) randomly assigned fibromyalgia patients to an education only condition ($N = 33$), an education plus physical training condition ($N = 33$), or a delayed treatment waitlist control ($N = 33$). Both active treatment groups improved on subjective ratings of self-efficacy and reports of physical activity compared to controls. Rooks et al. (2007) completed a randomized controlled trial with fibromyalgia patients who were assigned to one of four groups: (1) an aerobic and flexibility exercise group ($N = 35$); (2) a strength training, aerobic, and flexibility exercise group ($N = 35$); (3) the Fibromyalgia Self-Help Course ($N = 27$); or (4) a combination of group 2 (a strength training, aerobic, and flexibility exercise) and group 3 (the fibromyalgia self- help course) ($N = 38$). The

primary outcome assessed using the Short-Form Health Survey was a change in patients' self-rated physical function from baseline to completion of the intervention. Secondary outcomes included an increase in self-efficacy scores for group 1 and group 4. The combination group (group 4) showed the greatest improvement in self-efficacy scores. The fibromyalgia self-help course group did improve on self-efficacy scores, but significantly less than the groups that included physical training, thus, while more research is clearly needed, it would appear that psychoeducation will be most effective as part of a multidisciplinary intervention.

The gate control theory of pain explains why certain factors such as anxiety and depression worsen the experience of pain, while other factors like active coping, social support and positive affect moderate the experience of pain, it therefore serves to integrate psychology into the traditional biomedical model and describes a role for psychological causes and interventions for pain management. As a model of pain, it has afforded practitioners and researchers the opportunity to examine the complex relationship between psychology and pain and the place psychologically based treatment options holds in the management of many complex conditions. Psychological interventions are known to be effective in treating pain disorders (e.g. Eccleston, Williams & Morley, 2009) and therefore, could be a promising treatment option for patients with a diagnosis of fibromyalgia.

1.6.2 Pharmacological Interventions

Drug therapy is not mandatory for the management of fibromyalgia and in the absence of a single gold-standard medication, fibromyalgia patients are treated with a selection of drugs from different categories, often with limited evidence. Many of the

pain killing drugs that are prescribed to patients with fibromyalgia have limited clinical efficacy, are highly addictive and fail to impact positively upon the cognitive symptoms associated with the condition (Albrecht et al., 2015); therefore, only a minority of patients report a substantial benefit. As a result of this, non-adherence rates as high as 47% have been reported in the literature (e.g., Sewitch et al., 2004). According to Sewitch et al. (2004), women with fibromyalgia were less likely to take prescribed medications when they disagreed with their physician and when they were dissatisfied with the visit. Improving patient–physician communication may therefore serve to improve adherence. Many of the existing drug treatments for fibromyalgia have undergone limited research (Staud, 2010) and those that have been the subject of research have demonstrated a lack of efficacy in the treatment of symptoms. Several different classes of medication used to treat fibromyalgia pain have not demonstrated superior efficacy compared with placebo, including ibuprofen (Yunus et al., 1989) and benzodiazepines (Russell, Fletcher, Michalek, McBroom & Hester, 1991). Russell et al. (1991) confirmed the taking of benzodiazepines for fibromyalgia pain was no more superior to a placebo. Despite this, medications, though unsatisfactory as a primary illness management method, will likely continue to be a component of treatment strategy for many fibromyalgia patients (Häuser, Walitt, Fitzcharles & Sommer, 2014).

Evidence from drug trials suggest that in general about half of patients treated with prescribed medications report experiencing a 30% reduction in pain symptoms which indicates that many patients with fibromyalgia will require additional therapies thus strengthening the case for a multidisciplinary treatment approach (Staud, 2010).

From the current evidence, pharmacological treatment combined with non-pharmacological forms of treatment, including exercise, psychological therapies and self-management strategies, may be necessary in the promotion of best treatment outcomes for this cohort of patients (Dussias, Kalali & Staud, 2010). While pharmacological therapies can be helpful in alleviating some symptoms associated with fibromyalgia, patients must be engaged as active participants in the treatment process. Patients rarely achieve meaningful improvements without also adopting self-management skills such as being educated about the nature of the condition, stress management and exercise (Clauw, 2014).

1.6.3 Physical Treatments

1.6.3.1 Physiotherapy

Fibromyalgia is characterized by chronic widespread pain and is frequently associated with reduced physical function. As a treatment option, physiotherapy is a common recommendation in management of this condition (Mengshoel, 1999); however it is often a challenge for individuals with fibromyalgia to engage in exercise due to the nature of the condition and its many complex physical symptoms.

Evidence suggests that exercise produces benefits for fibromyalgia patients. Short-term aerobic training has been shown to generate important benefits for fibromyalgia patients in physical function, global wellbeing, and possibly pain experience and sensitivity at tender points (Busch, Schachter, Overend, Peloso & Barbe, 2008). Altan, Bingöl, Aykaç, Koç and Yurtkuran (2004), in a study investigating the effects of pool based exercises on fibromyalgia, found significant improvements in

pain, fatigue, sleep, morning stiffness and impact of illness across two groups; pool based exercise group ($N = 23$) and a balneotherapy group ($N = 22$). Gowans et al. (2001), investigated the effect of exercise on mood and physical function in fibromyalgia patients ($N = 50$) and found significant improvements in measures of depression (Becks Depression Inventory, BDI; Beck, Ward & Mendelson 1961), impact of illness (Fibromyalgia Impact Questionnaire, FIQ; Burckhardt, Clark & Bennett, 1991) and self-efficacy (SES; Self-Efficacy Scale; Sherer et al., 1982) for the exercise group ($N = 27$).

Resistance and flexibility training remain under evaluated as exercise treatments for fibromyalgia patients. However, additional support for the benefits of resistance training in fibromyalgia can be found in a recent systematic review (Bidonde, Busch, Bath & Milosavljevic, 2014). On the basis of 60 RCTs and a total of 3,816 participants, the authors concluded that resistance training improves pain, tenderness, multidimensional function, and muscle strength in women with fibromyalgia. However, the level of evidence remains low due to the small number of resistance training trials to date. Furthermore, men's response to resistance training has yet to be studied (Jones, 2015).

There is good evidence for the individualization of plans when recommending physiotherapy as a part of treatment to fibromyalgia patients, with the philosophy of "starting low and going slow" gaining popularity (Jones, 2015). Larsson et al. (2015) report the results of a randomized controlled trial in which they compared group-based progressive resistance training versus relaxation training in 130 women with fibromyalgia. The study was based on a person-centred model of exercise that

involved the patient taking an active role in planning the treatment. Small groups of five to seven women exercised together under the supervision of a physiotherapist, twice weekly for 15 weeks. Compared with the relaxation training group, the resistance training group demonstrated significant improvements in physical function (knee and elbow extension), 6-minute walk, and health status as measured by the Fibromyalgia Impact Questionnaire (FIQ; Burckhardt et al., 1991). At 13–18 months post intervention, differences were no longer found between the groups on any measure, underscoring the difficulty in adopting exercise outside of a formal programme. There is also evidence for the benefits of resistance training in terms of body composition, muscle strength, age-related muscle loss, that are associated with all-cause mortality (e.g. Fitzgerald et al., 2015; Katzmarzyk, Janssen & Ardern, 2003).

Physiotherapy is often prescribed for patients with fibromyalgia. This cohort of patients frequently report difficulty in performing daily activities in the home, their place of work as well as during their leisure time (Mengshoel, 1999); the condition therefore has the potential to have a direct impact on the valued activities of the individual. Physiotherapy was described in 2007 by the World Confederation for Physical Therapy (WCPT) as a therapy that “provides services to individuals and populations to develop maintain and restore maximum movement and functional ability throughout the lifespan. This includes providing services in circumstances where movement and function are threatened by ageing, injury, disease or environmental factors. Functional movement is central to what it means to be healthy” (WCPT, 2007). Physiotherapists focus directly on the problems people have in performing physical activities through the active promotion of appropriate physical

activity and the provision of encouragement to the patient to stay as physically active as they possibly can, the potential for maximising function exists. The theoretical rationale behind this is that when the patient becomes stronger they may observe improvements in their physical functioning in daily life.

Exercise programmes have a positive impact on health status in several patient groups, for example, in patients with depression (Martinsen, 1990), with rheumatoid arthritis (RA) and osteoarthritis (Semble, Loeser & Wise, 1990), with brain injuries (Jankowski et al., 1990), and with low back pain (McQuade, Turner & Buchner, 1988). Conditioning exercise is commonly recommended to reduce depression (Martinsen, 1990), as well as to improve physical capacity. Therefore, exercise has an important impact upon both physical and psychological issues; issues which are frequently observed in fibromyalgia patients. Improvement in such areas may subsequently serve to decrease feelings of helplessness and increase the feeling of being able to cope, thus facilitating future healthy behaviour (Mengshoel, 1999). Despite a number of studies investigating the effect of combination management strategies that include exercise on the symptoms of fibromyalgia (e.g., Rooks et al., 2007; Cedraschi et al., 2004), this area has received inadequate study. In order to clarify the effects of physical treatments on fibromyalgia and thus offer individuals with the condition and clinicians definitive guidance about implementing exercise as a means to manage the disorder, further research should endeavour to focus on high quality studies comparing one type of exercise to untreated controls, use American College of Sports Medicine (ACSM, 2006) and Centre for Disease Control and Prevention (CDC, 2005) exercise and physical activity guidelines when devising exercise plans for patients,

assess adherence during the intervention and during long-term follow up and use of standard outcome measures (Busch et al., 2008). In addition, given the potential challenges that patients may experience in the transference of skills obtained during research trials into their lives on a long-term basis without the on-going support of a therapist requires, future enquiry on supporting long-term maintenance is required.

Fibromyalgia is a condition expressed by chronic widespread body pain which leads to reduced physical function and frequent use of health care services. Exercise training is commonly recommended by health care professionals as a treatment option. Symptoms of the condition may deter people from exercising but studies show that the majority of patients are capable of exercise and that exercise has a positive impact on the complex symptoms associated with the condition. In a recent review of 34 studies comprising of 47 interventions and 1264 participants, Busch et al, (2007) provided moderate quality evidence that aerobic exercise training at recommended intensity levels has positive effects on global well-being, physical function, pain and tender points. This Cochrane review concluded that there is 'gold' level evidence that supervised aerobic exercise training has beneficial effects on physical capacity and fibromyalgia symptoms. It also provided evidence that strength training has the potential to promote health benefits on some fibromyalgia symptoms. Similarly Richards and Scott (2002) recently demonstrated significant improvements in tender point count and self-rated global improvement (ranging from very much worse to very much better) in 132 patients with fibromyalgia who undertook a 12-week graded aerobic exercise programme compared to a control group (relaxation and flexibility exercises). These changes persisted at one-year follow up. Further studies on muscle

strengthening and flexibility are required as is research on the long-term benefit of exercise for this cohort of patients.

Physiotherapy cannot eliminate pain in fibromyalgia as it can often do with acute pain (Mengshoel, 1999). Instead, it should focus on the functional everyday limitations faced by this patient group and assist the patient to remain physically active through appropriately designed exercise programmes and improve their ability to engage with everyday meaningful tasks.

1.6.4 Complementary and Alternative Medicine (CAM) Treatments.

Deciding exactly what treatments fit into this category is a challenging endeavour; however, a number of treatments have been investigated in terms of their utility in the treatment of fibromyalgia (Hassett & Gevirtz, 2009). As is the case for many disorders, very little scientific evidence exists for the efficacy of complementary or alternative approaches, yet fibromyalgia patients often seek out such interventions in an attempt to manage the often complex and debilitating symptoms associated with their diagnosis (Pioro-Boisset, 1996). Psychological distress and dysfunction of the stress response systems have been identified in this patient group (Dadabhoy, Crofford, Spaeth, Russel2l & Clauw, 2008); therefore, stress management has been incorporated into many interventions for this cohort of patients.

1.6.4.1 Relaxation Techniques

There is a significant overlap between CBT and behavioural interventions for relaxation. Most CBT interventions include one or more forms of behavioural relaxation; some of these techniques (e.g., mindfulness) have evidence for efficacy in

the absence of the cognitive therapy component (Hassett & Gevirtz, 2009). Relaxation techniques that are shown to be helpful for fibromyalgia symptoms include, but are not exclusive to, mindfulness, progressive muscle relaxation, autogenic training, guided imagery and acupuncture, each of which will be presented separately in the current chapter. Because psychological distress and dysfunction of the stress response systems have been observed in fibromyalgia patients, stress management has been a target of treatment and the utilization of relaxation techniques has the potential to serve a stress reduction function (Dadabhoy et al., 2008).

1.6.4.2 PMR-Progressive Muscle Relaxation

Progressive muscle relaxation (PRM) is a behavioural intervention that has been utilized in the treatment of chronic pain (Hosaka, Yamamoto, Ikeda, Taniyama & Yanagisawa, 1995; Van Tulder, Koes & Malmivaara, 2006). Even though no randomized controlled trials have evaluated PRM in isolation, this relaxation technique is commonly a part of CBT for fibromyalgia (Williams et al., 2002; Allen et al., 2006).

Muscle tension and anxiety levels are thought to be intricately linked. The goal of progressive muscle relaxation is to decrease muscle tension thus decreasing the patient's anxiety levels. PRM involves the systematic tightening and relaxing of various muscle groups (Jacobson, 1938). Since many patients persistently tense their muscles unknowingly which can contribute to their pain, PMR has an added benefit of informing the fibromyalgia patient of the difference between muscles that are relaxed and those that are tensed. Some evidence for including PMR comes from a study by Allen et al (2006) who reported that a CBT programme that included PMR as central

aspects of treatment resulted in decreased symptom severity when compared to altered medical care. However it is not possible to attribute the effects to the PMR specifically.

1.6.4.3 Autogenic Training

Autogenic training has been examined as a behavioural intervention for chronic pain (Hosaka et al., 1995; Van Tulder et al., 2006). In contrast to PRM, autogenic training involves the patient repeating phrases such as, “My arms are heavy and warm” while visualizing warmth and heaviness in their arms. The exercise calls to consciousness images associated with a relaxed state while moving the focus from one body area to the next. Two trials of employing autogenic training only for fibromyalgia, failed to find superiority for it compared to other treatment conditions (Keel et al., 1998; Rucco, Feruglio, Genco & Mosanghini, 1995). Luciano et al. (2011) conducted an RCT using an intervention where participants were assigned to an intervention comprising of 5 sessions of education and 4 sessions of autogenic training ($N = 108$) or to a usual care group ($N = 108$). The intervention group showed a greater improvement than the usual care group in pain, physical impairment, days not feeling well, morning fatigue, general fatigue, stiffness, depression, and anxiety as measured on the FIQ. The results of this study reveal that a 2-month psychoeducational and relaxation intervention improves the self-reported functional status of fibromyalgia patients to a greater extent than usual care. However, the results should be interpreted with caution as no follow up assessments were reported; therefore, one cannot conclude that the intervention caused a long-term improvement in patients’ functional status. While there remains a distinct lack of scientific evidence for this

intervention, it is generally accepted that frequent use of relaxation methods such as autogenic training may be effective for symptom management in fibromyalgia however further research is required.

1.6.4.4 Acupuncture

Acupuncture is one of the most frequently used of the complementary and alternative treatments in the management of fibromyalgia (Langhorst, Klose, Musial, Irnich & Häuser, 2010). An estimated 15-20% of patients seek acupuncture treatment (Bennett et al., 2007; Bombardier & Buchwald, 1996). Following a review of the literature, Mayhew and Ernst (2007) reported that acupuncture as a treatment option for fibromyalgia was not supported by rigorous clinical trials and therefore could not be recommended for the management of the condition. More recently, Langhorst et al. (2010) concluded, on the basis of a systematic review with meta-analysis of controlled clinical trials ($N = 7$), found evidence for the reduction of pain at post-treatment however, it was also established that the positive effects could not be maintained at follow-up. There was no evidence for a positive effect on other main symptoms of fibromyalgia such as fatigue, sleep disturbance or improvement in physical functioning. The authors reported acupuncture was not associated with serious harmful events and the attributed low drop-out rates to a good acceptance of this treatment by the patients.

1.7 Multidisciplinary Treatments

Patients report fibromyalgia as being both emotionally and psychologically distressing, and often report a perceived lack of support from health care

professionals (Daraz, 2012). As most pharmacological treatments aim to manage discrete symptoms, rather than the condition and its effects as a whole, the conventional medical model does not lead to a cure (Lawson, 2008; Traska, Rutledge, Moultapa, Weiss & Aquino, 2012). Goals of treatment are normally to increase functioning, control pain, facilitate adjustment and improve the wellbeing of patients (Peterson, 2007). Positive treatment outcomes from a singular intervention have yet to be identified thus, multi-disciplinary approaches that employ both pharmacological and non-pharmacological interventions are recommended as best practice in the treatment of fibromyalgia (Peterson, 2007).

No single intervention method included in the present analysis of treatment options for fibromyalgia patients is ideal, with each one having its own set of strengths and limitations. While studies have reported efficacy in some areas such as psychoeducation (e.g. Burckhardt et al., 1994), ACT (e.g., Wicksell et al., 2013) and exercise (e.g., Busch et al., 2008), not all treatment options tried by fibromyalgia patients have success in terms of symptom management. Acupuncture is one of the most frequently used alternative treatment by patients, yet to date there exists no data to suggest it is in fact beneficial in the treatment of the condition. This highlights the need for an intervention that is specific to the complex needs of this cohort of patients.

1.8 Areas for future research

Components for an intervention for the management of fibromyalgia should be selected based on existing empirical evidence from the literature pertaining to management of the complex symptomology of the condition that have been well-

validated. Any future intervention should be influenced by models of behaviour previously developed in other areas. For example, social cognition theory posits that self-efficacy beliefs operate in conjunction with discernible goals, outcome expectations, and perceived environmental obstacles and facilitators in the regulation of human action, motivation and well-being (Bandura, 1998). Applying a model of behaviour based on social cognition theory which has strong empirical support across multiple settings to the context of symptom management in fibromyalgia should be afforded reasonable consideration. Research has also demonstrated that higher self-efficacy scores are associated with positive patient outcomes. In a study of chronic pain in older adults ($N = 140$), Turner, Ersek and Kemp (2005) concluded that self-efficacy is an important feature of successful pain management. According to this study, higher levels of self-efficacy were associated with less disability and depression and with the increased use of pain coping strategies that are related to better adjustment. Similar results have been found in fibromyalgia patients. Buckelew, Murray, Hewett, Johnson and Huyser (1996) conducted a study that examined the effects of self-efficacy on self-reported pain and physical activities among fibromyalgia patients ($N = 79$). Findings from this study suggested that higher self-efficacy was associated with less impairment and pain on the Arthritis Impact Measurement Scale (AIMS, Meenan, Gertman & Mason, 1980) after controlling for demographics and disease severity. Buckelew et al. (1996) assessed pre and post treatment self-efficacy, disease severity, tender point index, pain and activity in 109 fibromyalgia patients who completed a 6 week intervention. Improvements in self-efficacy were associated with better outcomes on all measures.

Strong self-efficacy beliefs appear to have direct and indirect effects on an individual's pain management behaviour in a number of important ways; for example, self-efficacious pain sufferers are less likely to be anxious (Skevington, 1996). Similarly, chronic pain patients who expect to be self-efficacious possess a greater tolerance of pain, reduced need for pain medication, and increased levels of exercise (Turk, Meichenbaum & Genest 1983). Behaviour change is an important concept in relation to health promotion and ultimately disease prevention. Self-efficacy has been identified as an important determinant of health behaviour, health behaviour change and future health behaviour (Holloway & Watson, 2002). In order to effectively facilitate behaviour change, it is vital that interventions are research based, and emphasize the utility of theory in practice. The effective practice of self-management of a chronic illness requires a full understanding of the processes of patient behaviour. This research presents the role of a WRAP® informed wellness intervention in influencing health-related behaviour change. As a result of the important role self-efficacy holds in the enhancement of health promoting behaviours and behaviour change, the potential impact of the Wellness in Fibromyalgia intervention on self-efficacy will be examined extensively. Overall, the highly self-efficacious are more inclined to attempt and to persist at efforts to control pain by non-medical means. Self-efficacy therefore holds an important role in adjusting to, understanding and coping with pain and consequently future research should also endeavour to employ self-efficacy enhancing interventions in this group of patients who present with this distressing condition.

1.9 Conclusion

Fibromyalgia is a chronic pain condition that is not fully understood and is often misdiagnosed (Wierwille, 2012). While it is the body wide pain of fibromyalgia that usually lead patients to seek help, the symptoms are complex and include a combination of physical and emotional indicators including not only chronic pain, but also sleep disturbances, fatigue, somatic symptoms, cognitive difficulties, morning stiffness, IBS and psychological distress (Martinez, Sanchez, Miro, Medina & Lami 2011; Tausk, Elenkov & Moynihan, 2008). The combination of symptoms, the complexity surrounding its diagnosis and its many treatment options suggest a biopsychosocial approach ought to be adopted in the management of this multifaceted condition.

The traditional approach to human ill health embraced a dualistic viewpoint that conceptualized the mind and body as functioning separately and independently. The inadequacy of the dualistic model contributed to a growing recognition that psychosocial factors, such as emotional stress, could impact the reporting of symptoms, medical disorders, and compliance with and response to treatment. In a theoretical sense, the workings of the mind can affect the body, and the workings of the body can affect the mind. This suggests both a direct interaction between mind and body as well as indirect effects through intermediate factors. The biopsychosocial model presumes that it is important to acknowledge all three (biological, psychological and social factors) together, as a growing body of empirical literature suggests that patient perceptions of health and threat of disease as well as barriers in

a patient's social or cultural environment appear to influence the likelihood that a patient will engage in health-promoting or treatment behaviours.

During the past decade, there has been a significant growth in research on chronic pain, with significant advances in understanding its aetiology, assessment, and treatment and this research has important healthcare implications. The biopsychosocial approach is now widely accepted as the most heuristic perspective to the understanding and treatment of chronic pain disorders such as fibromyalgia (Gatchel, 2004). This model perceives chronic illnesses such as fibromyalgia as the result of the dynamic interaction between physiologic, psychological, and social factors, which perpetuates and may even worsen the clinical presentations. Each individual experiences pain uniquely, and a range of psychological and socioeconomic factors can interact with physical pathology to modulate a patient's report of symptoms and subsequent disability. It therefore is crucial to view the condition and its treatment through a biopsychosocial lens in a bid to ensure best practice in the treatment of the condition. Many of the individual dimensions of life with fibromyalgia, the treatment of the condition and its aetiology as well as psychological aspects of the condition that present as a barrier to successful living and social factors such as relationships and employment are depicted within the current chapter.

Whilst it is clear that many interventions can have positive psychological and physiological effects, there exists no gold standard treatment for fibromyalgia. The biopsychosocial approach of combining the most effective aspects of the existing intervention methods into a singular management programme to treat the symptoms

of this complex and often debilitating condition and promote wellness through self-management may be a feasible option at present for fibromyalgia patients.

Illness self-management programmes for people with chronic medical conditions are an important part of patient-centred care as articulated by the Institute of Medicine (2001). These programmes produce positive changes in health outcomes, attitudes, and behaviours through the acquisition of new skills and information to better manage challenging symptoms, enhance quality of life and maintain higher levels of health and functioning. Such programmes are a crucial aspect of patient care and demonstrate satisfactory efficacy rates across a wide spectrum of health care management from cardiac care (Janssen, De Gucht, Van Exel & Maes, 2014; McAlister, Lawson, Teo & Armstrong, 2001) to mental health care (Cook et al., 2011). We must therefore aim to engage patients with chronic pain conditions who will stand to gain from evidence-based management and treatment options. Successful pain management initiatives will serve to improve patients' health status and reduce dependency on an already struggling health system. Given the increasing incidence of fibromyalgia, the search for more effective strategies to promote self-management is essential.

2 Chapter 2: The Subjective Experience of Male and Female Fibromyalgia Patients in an Irish Population: A Qualitative Study

2.1 Introduction

Treatment of fibromyalgia is complex and multifaceted and so should be multidisciplinary in approach. With reference to psychological interventions, evidence of the effectiveness of some therapies exists (Refer to Section 1.6.1, Chapter 1); however, few studies take into account the patient's perspective of treatment interventions and what they experience as helpful or unhelpful in this regard. The contribution that patients with a lived experience of a condition can make to the development of treatments is increasingly becoming acknowledged as a positive step towards appropriate service provision and has been identified as a necessary and helpful component to the effective implementation of treatments in health care as evidenced by the Department of Health in the UK (2001; 2006). Stuifbergen, Harrison, Becker and Carter (2004), in a pilot study of an intervention for women with a diagnosis of fibromyalgia, sought input from a focus group of expert consultants and eight women with fibromyalgia. The specified purpose of the focus group was to obtain information about promoting health within the context of fibromyalgia and the information they provided was subsequently used to adapt and refine the content of an intervention originally developed for patients with Multiple Sclerosis (MS). Developing an intervention that is applicable to the needs identified by patients has benefits in terms of its potential to facilitate successful outcomes, increase overall interest and reduce dropout rates. In the context of the current research, patients' voices, views and experiences were central to the development of an intervention.

A diagnosis of fibromyalgia represents considerable psychological and physical impairment to the individual and can have associations with psychiatric and medical co-morbidities. The cost to the patient can be social, personal, economic, psychological or a combination of all four. Evidence suggests that chronic conditions such as fibromyalgia also represent a considerable economic burden to society (Spaet, 2009) as they are associated with the utilization of healthcare and non - healthcare resources and can have a detrimental impact on family, quality of life and social relationships (Preece & Sandberg, 2005). Chronic pain is thought to affect up to 35% of the population and the estimated prevalence rates for fibromyalgia is 0.5% - 5% of the general population, yet in Ireland, there exist few services charged with the provision of care for this cohort of patients. Fibrolreland, Chronic Pain Ireland and Arthritis Ireland are voluntary agencies whose remit includes providing support and information to fibromyalgia patients. Each of these services provides a combination of telephone and online support. Fibrolreland provides a combination of telephone, online and face to face group support in the form of monthly support meetings which run nationally. These agencies strive to support the patient along with providing practical advice pertaining to social welfare entitlements, health services and available treatment options. The practicalities of disease management such as making changes to the physical work or home environment, self-management techniques and medical information relevant to the condition are also dealt with by these agencies.

Qualitative methods are a valuable means of uncovering that which researchers may be otherwise unaware of, yet studies dealing with the psychological aspects of this condition have been mostly quantitative (e.g., Boissevain 1996; Clark,

Campbell, Forehand, Tindall & Bennett, 1985; Scudds, Rollman, Harth & McCain, 1987). In a qualitative approach, the patient is afforded the opportunity to describe their perceptions of the reality in their own words, to tell it how it is (Hallberg & Carlson, 2000). Few qualitative studies have been conducted in this area, and yet findings reveal that patients' responses to fibromyalgia are frequently highly emotional and debilitating (Henriksson, 1995). Patient's reported experiences of living with fibromyalgia give an invaluable insight into the experience of having to live with a chronic illness and how they manage the situation. In a qualitative study examining the experience of fibromyalgia, Raymond and Brown (2000), reported accounts from seven women with fibromyalgia that served to highlight the complex experiences of living with the condition. Analysis depicted patient's journeys along a continuum from experiencing symptoms such as pain, to attaining a diagnosis which entailed social isolation and frustration, to coping with the illness which was said to bring both a sense of relief and anxiety about the future. Qualitative research has shown fibromyalgia to be a challenging condition to live with. Having fibromyalgia means that pain is almost continuously present and affects every aspect of life. Results show patients to be pre-occupied with their pain and life seems to be guided by the pain and various strategies used by patients to manage their situation (Hallberg & Carlsson, 2000). These findings are in line with Henriksson (1995), who found that the influence of pain on daily activities was considerable.

2.1.1 Gender Differences and Pain

Pain is a complex multi-dimensional experience that is influenced by a variety of psychosocial and biological variables. Sex differences in the experience of both

clinical and experimentally induced pain have been widely reported (e.g., Katz, Mamyrova, Guzhva & Furmark, 2010; Paller, Campbell, Edwards & Dobs, 2009). As summarized in several reviews (Berkley, 1997; LeResche, 1999; Unruh, 1996), women are over represented in several chronic pain conditions. For example, fibromyalgia, IBS, migraine and tension type headaches are all more prevalent in women, with female to male ratios ranging from 2:1 to 9:1 (Fillingim, 2000). Furthermore, both survey and epidemiologic research has demonstrated higher frequencies of pain-related symptoms among females than males in the general population (Andersson, Ejlertsson, Leden & Rosenberg, 1993; Forgays, Rzewnicki, Ober & Forgays, 1993; Sternbach, 1986). Owing to the fact that these data are based on population derived samples, the sex differences cannot be attributed to the greater tendency among females to seek out treatment (Kandrack, Grant & Segall, 1991), consequently females appear to be at increased risk for experiencing pain related symptoms.

Studies in clinical settings suggest that women differ from men in their adjustment to pain. Haley, Turner and Romano (1985) reported that depressive symptoms were associated with pain severity among female pain patients, whereas depression was related to activity impairment in male pain patients. A self-reported history of trauma has been reported as being associated with poorer affective adjustment amongst males with chronic musculoskeletal pain, but trauma history was not related to adjustment among female patients (Spertus et al., 1999). Fillingim (2000) reported women's adjustment to pain was accounted for by cognitive variables, such as the meaning they attributed to their pain, whereas for male pain patients, social support was the strongest predictor for adjustment; and psychosocial

adjustment was related to health expenditures for women but not for men. Furthermore, studies have shown that women, as compared to men, respond more aggressively to pain through health-related activities e.g., taking medications or consulting a healthcare provider (O'Leary & Helgeson, 1997).

Gender differences also exist in the reporting of pain (Kroenke, & Spitzer, 1998). Culture and socialization may account for such differences between men and women. Women have been found to adopt a more relational, community based perception of the world that inspires them to form more social support networks and to express their emotions more than men (Davidson & Freudenberg, 1996). Because of such different socialization experiences, women's and men's styles of communication differ (Tannen, 1990) which most likely influences how they report their pain to health-care providers and to each other. Differences have also been reported in relation to diagnosing fibromyalgia. In a study which surveyed 61 practising rheumatologists, participants were asked to read a brief case description of a patient with fibromyalgia and select the criteria most important to them for confirming the diagnosis. As rheumatologists were more likely to require a physical finding to support a diagnostic conclusion in male participants, gender bias was reported with regard to disease classification (Katz et al., 2010).

2.1.2 The Current Study

The aim of qualitative research is to understand and represent the actions and experiences of people as they engage in and continue through life's situations (Elliott, Fisher & Rennie, 1999). Focus groups are particularly suitable to render in depth information about a concept or an issue, and acquire knowledge about people's

subjective experiences (Krueger & Casey, 2009). The benefit of this method is that it serves to create an open environment for group dynamics empowering participants to willingly express themselves in an open, honest and flexible discussion using their own words and meanings to highlight their own concerns, thoughts and reflections in relation to the subject of interest (Halkier, 2002). As a method of data collection it lends itself well to the examination of the subjective experience of living with a chronic condition and thus was the chosen approach in the present research. The opinions, experiences and voiced needs of the patient group will serve to inform the content of the proposed self-management intervention.

The needs of the patient were central in the decision making process in terms of the development of an appropriate intervention for individuals living with fibromyalgia. In order to capture the patients' perceptions of their illness, the helpful and unhelpful aspects of treatment and supports and the impact of their illness a qualitative approach was deemed most suitable. Thus, patients were brought together in focus groups to discuss the subjective experience of fibromyalgia. A method informed by the descriptive and interpretive qualitative framework outlined by Elliott and Timulak (2005) was subsequently adopted when identifying the domains and categories that emphasised the needs of this patient group and the type of intervention that would best meet those needs.

A key requirement of qualitative enquiry is that the method of analysis chosen must be appropriate to the data gathered and the research questions posed. Qualitative research methods are known by many 'brand names' in which various common elements are matched and combined according to each individual

researchers preferences (Miles & Gilbert, 2005). Current variations which have gained popularity include empirical phenomenology (Giorgi, 1975; Wertz, 1983), hermeneutic-interpretive research (Packer & Addison, 1989), interpretative phenomenological analysis (Smith, Jarman & Osborn, 1999), consensual qualitative research (Hill, Thompson & Williams, 1997) and grounded theory (Henwood & Pidgeon, 1992; Strauss & Corbin, 1998). In line with the opinion postulated by Barker, Pistrang and Elliott (2002), the emphasis on brand names has the potential to be somewhat confusing thus in the qualitative analysis contained within the current thesis, a generic approach; the descriptive interpretative approach (Elliott & Timulak, 2005), that serves to emphasise common methodological practices rather than relatively minor differences is adopted.

2.2 Method

2.2.1 Participants

Sixteen individuals living with a diagnosis of Fibromyalgia participated in the current research, with each attending one of two same sex focus group meetings. Five of the participants were male and eleven were female; all were Caucasian, Irish nationals. Their ages ranged from 29-69 years with a mean age of 49 years. All participated voluntarily in the research and met the following criteria

2.2.1.1 Eligibility Criteria

Adults over 18 years of with a diagnosis of fibromyalgia obtained from a registered medical practitioner (GP, Rheumatologist or consultant) were considered eligible for this study. No minimum time since diagnosis was set. Participants were

required to speak fluent English and be willing to engage in a 2 hour discussion on the impact of fibromyalgia on their lives. Those adults who fulfilled the inclusion criteria but were not willing to have their interaction with the group audio recorded, had communication difficulties, or those who had mental health problems, which may exacerbate any feelings of distress or anxiety that may arise during the focus group discussion, were also excluded based on verbal admissions made by the participants. The eligibility criteria were established through verbal discussion with each of the participants individually at the point of expression of interest and again at the demographic data collection stage.

2.2.2 Focus Groups

Focus groups are considered particularly suitable to render in depth information about a concept or an issue, and learn about people's subjective experiences (Krueger & Casey, 2009). It is a method that lends itself well to the examination of the subjective experience of living with a chronic condition. The benefit of this method is that it creates an open forum for group dynamics enabling participants to voluntarily express themselves in an open, honest and flexible discussion using their own words and meanings to highlight their own concerns, thoughts and reflections (Halkier, 2002).

2.2.3 Procedure

Following receipt of ethical approval (See Appendix 1), an advertisement seeking patients with a diagnosis of fibromyalgia to take part in a focus group session was placed on the website and Facebook pages of Fibro Ireland requesting interested

individuals to contact the researcher. The initial focus group was held in Clongriffin Community Centre, Dublin and 11 females attended this session. A subsequent advertisement was placed on the same forums requesting male volunteers for a focus group discussion on fibromyalgia. Five males took part in the second focus group which took place in the School of Psychology in Trinity College Dublin. Participants were provided with an information sheet (See Appendix 2) prior to commencing and all give written consent (See Appendix 3).

For the purpose of this chapters focus on the subjective experience of living with fibromyalgia. Differences in question structure can influence how questions are asked and interpreted, and therefore, what data are collected (Fisher, Rizzo, Caird & Lee, 2011). Non-directive questions alone may elicit vague answers that lack the detail necessary to conduct compelling research therefore in this instance the following combination of eight guiding, open-ended and more specific directive questions concerning living with fibromyalgia and perceived support were deemed to be relevant. They were generated with the specific intention of enhancing overall knowledge of fibromyalgia; the patients experience in terms of perceived support, frustrations faced by the patient and their perceived management of the condition by relevant medical professionals. Each of the two groups were presented with the same set of questions:

1. What was your experience with getting your diagnosis of fibromyalgia?
2. What is the most frustrating thing about having a diagnosis of Fibromyalgia?

3. Do you feel that the support you currently receive from your family has changed since your diagnosis?
4. Do you feel that the support you currently receive from your friends has changed since your diagnosis?
5. Are you satisfied with your doctors' management of your condition?
6. Describe to me the support that you have felt from those in the healthcare system since you were diagnosed with fibromyalgia.
7. How could the healthcare system be of better support to you?
8. How do you think the media and society in general perceive Fibromyalgia?

The focus group meetings were digitally recorded (audio only) and upon completion, participants were presented with a debriefing sheet which thanked them for their participation and offered contact numbers if they felt they had been adversely affected by the experience and required further assistance (See Appendix 4). The first author transcribed the interviews using pseudonyms to protect the identities of participants. Focus Group transcripts are presented in Appendix 7.

2.2.4 Data Analysis

Data analysis was carried out using a descriptive and interpretive qualitative research method described by Elliott and Timulak (2005). This approach was employed as it is systematic yet flexible and lends itself to checking and auditing through 'careful archiving' during all stages of the analytic process. The data were first transcribed verbatim. Transcripts for both focus group meetings were subsequently

read in their entirety in order for the first author to become familiar with the data. At this juncture redundancies, repetitions and unimportant digressions were removed from the data and each of the transcripts was independently audited.

The following steps were observed in the analysis phase of the descriptive-interpretive approach (Elliott & Timulak, 2005): (a) meaning units were delineated (the meaning units are the parts of the data that even if standing out of context would communicate sufficient meaningful information to the reader. These units were logged and categorised throughout the analysis); (b) domains were developed and data are assigned to each of the appropriate domains (domains are broad headings that form an organizing framework for the data and emerged from the research questions the participants were presented with); (c) the creation of categories is an interpretive process and in this instance, the categories were generated from the meaning in the meaning units; (d) the main findings are abstracted (frequently in the form of narratives or figures). The analysis also uses several safeguards that ensure its validity (e.g., triangulation and independent auditing). Categories were audited independently and were cross checked and similar categories were combined. Two main categories emerged in the present analysis (see Table 2.1). Pseudonyms are used when reporting quotes. In the interest of reliability, an independent researcher was involved in the analysis phase.

2.2.4.1 *Reflective Practice of the Researcher*

Reflexive Practice of the Researcher

This section will be written in the first person to describe my reflexive practice throughout this research. I tried to be mindful of how my own subjectivity was influencing the research process by keeping reflective notes throughout both the data collection and analysis phases, and through regular debriefing with my both my supervisor and my peers. I also engaged in actively checking the presence of any pre-existing assumptions I may have had in relation to fibromyalgia and those individuals diagnosed with it; assumptions that had derived through my own personal experience of having two family members with fibromyalgia and from my knowledge of the condition attained through my immersion in the fibromyalgia literature that might have been conflicting with the actual experiences of the interviewees.

2.3 Results

The main themes to emerge from the data related to treatment- (both helpful and least helpful aspects of treatment), the experience of living with fibromyalgia (see Table 2.1)

Treatment

Relief at diagnosis, relational support from GP, and medication were perceived as helpful; however the lack of a GP's knowledge and support, and the absence of integrated holistic approaches were sources of frustration.

The initial feeling of relief having attained a diagnosis was universal, and participants viewed the labelling of their symptoms as helpful:

When I got the diagnosis it was just a relief, it certainly put a name to the pain-absolute relief (Catherine).

However, as the reality of the diagnosis and the lack of information and support pertaining to it became more apparent, the nature of the relief was short lived:

Once the diagnosis was made I found it was a great comfort or support to know what the name was. That lasted for the day I was told and the day after and then as I began to learn what was involved that relief of having a name faded away (Adrian).

Table 2.1 : Domains, Categories and Meaning Units

Domain	Categories	Meaning Units
1. Participant view of treatment	a) Most helpful aspects of treatment	Diagnosis Relational support from GP Medications Obtaining a label Treatment plan put in place
	b) Least helpful aspects of treatment	Lack of knowledge by GP Perceived lack of empathy Failure to provide information Lack of relational support Not feeling understood
2. Life with fibromyalgia	a) The patient experience	Employment Daily functioning Impact on relationships Stigmatisation Adaptive behaviours
	b) Support from others	Perceived support from family Perceived support from friends Perceived support from others Support from professionals

Participants acknowledged receiving relational support from their GP and deemed such support to be helpful in relation to their treatment; males, however tended to report a higher perceived relational support from the GP than their female counterparts:

I always said how lucky I am with my GP. He would be the main source of treatment and his interest in fibromyalgia is huge.... He has taken time to get to know me.... I could be sitting in the waiting room and he'll call me and by the way I move, immediately he'll know.... He gives me his time no problem and he's interested and he'll listen (Adrian).

A perceived lack of relational support was more commonly reported by females:

When I was diagnosed I just assumed well I have a name for it now so I'll wait to see my doctor and surely he can do something for me.... But my own doctor didn't really give me much support. He used to say, you'll be grand just take these. You weren't given much information or support. I felt kind of alienated as if it was all in my head (Maria).

Female participants were also more likely to see the GP as not being an expert in fibromyalgia or as being knowledgeable in terms of its features, the challenges faced by the patient or the treatment of the complex myriad of symptoms. The GP was frequently viewed as not providing encouragement, guidance or validation, which consequently saw the patient experience a decrease in self-confidence, a decline in confidence in their GP and also in the treatment options presented to them:

Nobody explained to me properly what it was. I actually felt worse because the doctor said to me if you're feeling suicidal go and talk to somebody and I couldn't understand why he was saying this because he didn't explain the illness.... I really didn't know what to do...So I didn't find any answers (Patricia).

Participants saw the prescribing of medications as a helpful aspect of treatment by their GP as it was seen as a means to manage the symptoms of fibromyalgia and improve the overall quality of life:

When you have been living a long time with it you often choose a GP that will give you what you want and not a lecture again so someone that will say 'fine, I will give you anti-anxiety medications'. That works well for me; my symptoms aren't as bad since I've been on them. When I look at it now, since I started taking anti-anxiety medication I function 100% better than I did (Margaret).

With regard to shortcomings in treatment, in acknowledging that there was both a physical and emotional aspect to the diagnosis, patients highlighted the need for a multi-disciplinary approach to treatment so as a focus could be placed upon the underlying features and causes of fibromyalgia:

You see a lot of people with fibromyalgia get a diagnosis of anxiety and depression.... it's actually a reactive depression. When nothing in your body works you get frustrated (Catherine)

when dealing with the physical, mentally it's going to have a knock on effect (Patricia).

In relation to treatment options that are available to individuals with a diagnosis of fibromyalgia, a shared theme emerging from both groups was a recommendation indicating the need for a structured treatment or intervention:

What I think is missing is something like the cardiac rehabilitation programme for people with cardiac problems whereby there is a six week course where at least you're made aware this is a very individual thing, multi-faceted and I think something like that is useful because it takes a long time. You're left to walk out of the rheumatologists – delighted you have a label but you've nowhere to go after that;

The treatment options made available to fibromyalgia patients were discussed to a great degree by both groups. For the most part, each of the groups voiced a frustration at the lack of treatment options in relation to the management of their symptoms:

My doctor said to me recently that fibromyalgia is a very painful condition and I appreciated that. I know there's nothing he can do about it at this point in time because they don't know what to do about it, they don't have a clue (Fiona)

At the end of the day they have said there's not a huge amount they can do, a lot of it is up to yourself... (Philip)

.... I had read up on it so I knew what she (GP) was talking about but all she did was give me a prescription.... That was 10 years ago and nothing else since (Margaret)

it's approaching nearly 2 years and I still don't feel like I'm managing it (Fiona).

2.3.1 Experience of Fibromyalgia

Fibromyalgia impacted on employment, daily functioning, and relationships; in addition participants noted how the condition influenced their coping strategies (see Table 2.1). The impact of fibromyalgia on the individual's work life was related to the gender of the participant. Symptoms more frequently affected the work life of female participants than they did that of their male counterparts:

When I got the diagnosis I had to take time off work because I wasn't physically able to work (Patricia)

I don't think I've missed a day's work because of it and as I say I drag myself in, I'm not a brave fellow and I'm not a great man but as I always say to myself, I'm not giving into this (Thomas).

Living with the symptoms of fibromyalgia, which were frequently perceived as challenging, diverse, uncomfortable and unpredictable, was a common feature of the narratives of all participants:

It's the unpredictability of this. There are so many symptoms. It's not known what tomorrow will bring and no matter how good or bad you are today you have no idea about tomorrow. You can't plan.... It's something that you have to wake up in the morning and hope for the best. The unpredictability of it gets me because you become unreliable (Adrian).

The invisibility of outward signs of illness was a common thread throughout both focus group discussions:

It's unique in that everyone will tell you that you don't look sick.... now for me to try to explain that to anyone, well I just can't because they just wouldn't get it... that bothers me that no matter how hard I try to explain it, it just doesn't seem to get through" (Patricia)

well I did explain it, and said it was like arthritis but I actually looked the picture of health so that's the problem (Ann)

...you don't have a bandage or a cast so you don't deserve acknowledgement. It's not visible, it's not a visual kind of thing (Jenny)

You push yourself to do things that you shouldn't just to do it and because it's invisible it's harder still (Adrian).

Fibromyalgia impacted negatively on relationships, with participants acknowledging perceived changes to significant relationships post diagnosis:

It can affect you if you're in a relationship. I was engaged and ok, we did have the initial relief when I got the diagnosis.... I had to get physiotherapy twice a week just to get up and about and that just put a huge strain on our relationship and then when we realised that this wasn't a short-term thing well then things really changed. I think he was ok when he thought oh she'll be ok in 6 months but when he realised this was a deal for life he actually behaved so badly he left me with no option but to end the relationship (Patricia)

The notion of a stigma being attached to the diagnosis was discussed freely in relation to the impact on relationships in the context of personal relationships, vocational relationships and relationships with health professionals:

It's up to us to publicise it and to take the stigma out of it...

We are stigmatised... (Ruth)

I changed my pharmacist because I was quite friendly with her...

I was embarrassed (Kate)

I've stopped telling people because I was being discriminated against in jobs. I've worked in my job for 5 years and I've only told my current manager so nobody knows I have it. I was pushed out of my last job because I was made feel like I couldn't do the job anymore.... so when I moved job I made the decision not to tell anyone.... so I don't tell people I think you can get discriminated against. People judge you (Margaret).

Interestingly, stigma was also discussed in light of the differences between being a female with a diagnosis and a male having a diagnosis of fibromyalgia:

My perception is if I were female it would be more okay to talk about things, it's just more acceptable. Society probably sees women as being weaker which I wouldn't agree with at all but it is more acceptable for women to appear weak (Frank).

Distraction as a means of coping, accepting personal responsibility for one's own wellness, engaging in active engaged coping, working towards regaining control

post diagnosis and self-monitoring were reported as being helpful. Living with fibromyalgia saw patients employ adaptive behaviours that served to demonstrate a positive behaviour change:

I bought books, I had books given to me, I went to libraries, I looked it up on the internet. I researched as much as I could to know what was happening to me (Adrian)

I'm just trying to make myself well by changing my attitude. I'm trying not to be as negative. I took up roller skating. It was one thing I said right I'm going to start roller skating and I've done it now about 5 times and when my pains are really bad I just get up, get my skates and go to the park and I just feel freedom and feel that this fibromyalgia is not going to stop me living my life now where it has done in the past... I think you really have to make changes yourself. I don't rely on doctors.... (Maria)

I have to say I've swapped one pain for another. For me when I'm inactive the burning pain and the shooting pain and the numbness are at the worst so I go out and I push myself physically and I get the normal pain you get. Do you remember when you were active before fibromyalgia and you walked and then when you woke up the next day you were in agony? That's a soft pain, it's a real pain. I can take a pain killer for it and the pain killer works, so I swap pains. I force a swap in pain and that helps me (Margaret).

In terms of engaging in maladaptive behaviours such as passive, negative and emotional coping strategies, a gender difference was noted with females more likely to engage in such strategies:

There's nothing that can be done about it... You do physio, you do this you do that but generally there is not a lot you can do (Jenny)

... It's up to you to try and find them (courses), no one tells you about them... (Patricia)

I wouldn't be able to hold down a job (Catherine)

When you have been living a long time with it you often choose a GP that will give you what you want and not a lecture (Margaret)

2.3.2 Perceived support

Support for participants came from family, friends, others (e.g. peers, specialist support organisations) and healthcare professionals (see Table 2.1). Families are the source of much support and assistance to patients with males and females reporting similar levels of support from family members:

My wife is a great support actually.... I know my limitations and she does too and she accepts that. She's great (Thomas)

My husband and children live with me. They know exactly what it is like for me and how I have to pace myself. The things I would have been able to do a year and a half ago I now have to really pace myself doing. My husband and kids are great. They are really very good (Rosemary)

My Mum gives me very practical support that I really need (Patricia)

The perceived support from friends varied within both groups. Some participants found the understanding provided by their friends surpassed that shown by family members:

I found I got more support from my friends actually. My sister, when I first told her the pain was all down to a condition called fibromyalgia she didn't believe me. She was very dismissive and she still is.... my brothers and sisters wouldn't be good supports (Maria)

My friends know I have this and how it affects me so if I'm with them and I happen to be a bit tired they understand. It's not a problem (Thomas).

Others reported that often friends failed to understand the condition and its perceived inherent limitations:

I've had a mixed experience with friends. Some people get it and some people don't. I met with friends.... they're all at the stage where they're all starting to have families and they all know that I have this, they all know that I have it really bad and then they just kept saying it'll be your turn soon to have kids. Now fortunately enough I don't want to have kids so that's not the problem. The bit that bothered me was they were not getting that if I did, not only would the pregnancy be difficult but God knows what I'd be like during and after the pregnancy; so no understanding at all (Patricia).

Peer support, support from specialist organisations and need for appropriate rehabilitative support formed the 'support from others' category. Overall, participants saw support from peers and specialist organisations as significant in terms of its usefulness:

I went off and got the numbers for Arthritis Ireland and it was the best thing I could have done.... (Adrian)

If you have one person who is going to listen and understand and accept that you actually are ill, they don't even have to understand. I think that not everybody would have that one person and I think that's why this (group) is very important. To actually be able to come in and say just how bad it is (Catherine)

Perceived support from healthcare professionals received mixed opinions both across and within the groups; however male participants tended to report feeling more supported by healthcare professionals than did their female counterparts:

If there's anything bad when I go to him (GP) he'll refer me on.... I'm happy with him, he's my main port of call (Adrian)

My doctor just said you have this. I asked what it is and he didn't know. He said you go and find out about it (Margaret)

2.4 Discussion

Individuals with a diagnosis of fibromyalgia offer a unique opportunity to investigate the influence of individual illness representations on coping and adaptation. A diagnosis of fibromyalgia requires the patient to make adjustments to many aspects of their lives. The subjective experiences of the illness have a significant impact on how the patient views the illness and are likely to play a role in the way they cope and adapt to the condition. In the context of the current research, two categories emerged: *most helpful aspects of treatment* and *least helpful aspects of*

treatment. Interesting gender differences presented themselves within each of the main categories. Of significance are the gender differences that emerged in relation to perceived relational support from the GP, perceived shortcomings in important general characteristics of a GP, perceived shortcomings in important general characteristics of treatment and perceived support from healthcare professionals.

The *most helpful aspects of treatment* category contained six meaning units: diagnosis, perceived relational support from GP, the prescribing of medications, obtaining a label, validation of illness and development of treatment plan. Gender differences were observed in relation to time taken to diagnose, with males reporting shorter wait time than females. Furthermore, males perceived higher levels of validation from their GP and onward referral to appropriate specialists, with females reporting a lack of onward referral options and those that were proposed were frequently perceived as being inappropriate to their health needs.

The literature suggests that not only do men and women communicate differently to health care providers when reporting presence of pain, but that healthcare providers may respond differently to them (Hoffman & Tarzian, 2001). Research has indicated that women are more likely to be given sedatives for their pain and men to be given pain medication (Calderone, 1990). Furthermore, a growing body of literature indicates women are more likely than men to be undertreated or inappropriately diagnosed for their pain. Suggestions as to why this difference exists includes a myriad of theories including, women are more inclined to openly discuss health concerns and are more frequent healthcare consumers than are men, women provide less accurate reports of pain experience, men are more stoic, subsequently

when they do report pain it is viewed as 'real' pain, and women have better coping skills and are more able to tolerate pain than men (Hoffman & Tarzian, 2001). A prospective study of patients presenting with chest pain found that men were more likely than women to be admitted to the hospital. Of those hospitalized, women were just as likely to receive a stress test as men, but of those not hospitalized; women were less likely to have received a stress test at a one month follow-up appointment (Elderkin-Thompson & Waitzkin, 1999). The authors attributed the differences in treatment to the "Yentl Syndrome," i.e., women are more likely to be treated less aggressively in their early encounters with the health-care system until they prove that they are equally as unwell as male patients. Once they are perceived to be as unwell as their male counterparts, they are likely to be treated similarly (Johnson et al., 1996). It appears therefore that gender affects, not only pain perception, pain coping, and pain reporting but also the manner in which their reporting may be received by health care professionals.

Women with medically unexplained disorders have described medical encounters as being negative experiences. Accounts of being met with scepticism and lack of understanding, feeling ignored and rejected, being belittled, blamed for their condition and assigned psychological explanation models are common (Werner & Malterud, 2003). The findings of the present study are consistent with those reported by Elderkin-Thompson and Waitzkin (1999), who reported that physicians were found to consistently view female, but not male, patients' reported symptoms as originating from emotional factors, even in the presence of positive clinical test evidence. In support of these findings, Crook and Tunks (1990) found that female patients

presenting for treatment of chronic pain were significantly more likely than male patients to be prescribed psychotropic drugs from their General Practitioner.

Obtaining a label for one's condition was frequently seen as a source of great relief across both groups as patients reported that they had a sense that they could manage the symptoms once they knew what it was they were dealing with. As it frequently took a prolonged period of time filled with multiple medical examinations by multiple healthcare professionals, by the time a diagnosis was given, the patient was relieved to finally have a name to put to the symptoms. However, the initial sense of relief was short-lived as patients reported a lack of knowledge, support and treatment options pertaining to the condition, which again saw them in a position whereby there was a return to feelings of frustration at having to struggle to manage the complex symptomology associated with fibromyalgia.

The *least helpful aspects of treatment* category contained five meaning units: lack of knowledge of GP, perceived lack of empathy, failure to provide information pertaining to the illness and not feeling understood. These meaning units highlight a significant lack of relational support from GP, a perceived shortcoming in important general characteristics of a GP and perceived shortcomings in important general characteristics of treatment. Men's perceived level of support from healthcare professionals was higher than their female counterparts who indicated a substantially lower perceived level of support.

Social support refers to the experience of being valued, respected, cared about, and loved by others who are present in one's life (Gurung, 2006). It may come from different sources such as family, friends, community, healthcare professionals or

any social groups to which an individual is associated with. It has the potential to promote a reduction in the amount of stress experienced as well as to encourage active coping mechanisms that serve well in dealing with stressful situations. Numerous studies indicate that a lack of supportive interactions can see an increase in symptoms and psychological disorders such as stress, depression and other psychiatric disorders, while supportive relationships with significant others serve to promote positive physical and mental health, e.g., Nahid and Sarkis (1994). The importance of social support cannot be underestimated in the context of maintaining health within illness: in the absence of perceived support from healthcare professionals and relevant others, maintaining wellness may present a certain challenge for fibromyalgia patients. In the context of the current research, a significant gender difference was observed with female patients reporting a perceived lack of relational support from their GP, in particular a lack of validation in terms of their diagnosis along with a lack of guidance from their GP. A lack of validation and guidance has the potential to impact directly on acceptance; a valuable construct in current theories of motivation (Viane, Crombez, Eccleston Devulder & De Corte, 2004) that demonstrates how a patient might react and subsequently adapt to chronic pain. In recent times, there has been a shift from the control of pain to the acceptance of pain and several studies have demonstrated the importance of acceptance in adapting to chronic pain, e.g., McCracken, Spertus, Janeck, Sinclair and Wetzel (1999) and McCracken and Eccleston (2003) reported that acceptance was superior in explaining adjustment to chronic pain when compared with other coping variables, while Viane et al. (2003) have shown that mental well-being can be predicted by the levels of acceptance of pain beyond the effects of pain catastrophizing and pain severity. In the absence of relational

support from the person (i.e., GP) who is typically their first port of call and their principal provider of healthcare, females therefore may be less accepting of their diagnosis of fibromyalgia than their male counterparts, which may compromise their coping and adjustment.

Studies have highlighted important gender differences in various clinical characteristics of fibromyalgia (e.g., Yunus, Inanici, Aldag & Mangold, 2000; Wolfe, Ross, Anderson & Russell, 1995), yet little reference has been made to the patient's perceived treatment of the condition. Previous research has demonstrated that pain severity and physical functioning were not significantly different between male and female patients, nor were psychological factors such as stress, anxiety and depression. Women however, have been shown to experience significantly more all over body pain, fatigue, and total number of symptoms. Women also present with significantly more tender points than do their male counterparts. Gender differences have also been observed in other related syndromes, e.g., chronic fatigue syndrome (Faro et al., 2016) and irritable bowel syndrome (Chung & Heitkemper, 2002). The mechanisms of gender differences in these illnesses are not fully understood, but are likely to involve an intricate interaction between biology, psychology, and social factors.

An inherent belief in others' voices and their right to participation and contribution to science and knowledge, together with the role of human experience as a source of knowledge and learning were paramount to this study. The opportunity to speak openly and honestly about one's life experience must never be seen as optional, a privilege or something that must be earned in some way. Instead, it is essential that it is viewed as a human right. The impact of self was an ever present in

my conscious awareness as I undertook this piece of research. As a woman, the propensity to feel that the female voice at times must assert itself required some reflection on my behalf and throughout the process I endeavoured to separate the feelings, concerns and opinions shared from the gender of the participant in question. Upon reading the transcripts I was required to acknowledge the sense of sympathy that I was experiencing for each of the respondents because of the struggles they so eloquently described. This was something I needed to be aware of to prevent my feelings from having an impact on the manner in which I interpreted and took meaning from the transcripts and the themes used to encapsulate them. The powerlessness and desperation of the participant was acknowledged and reflected upon so I was in a position to remain impartial throughout the analysis. This reflection process adopted meant each of these issues were recognised thus ensuring I mitigated any possible influence that may have impacted upon the analysis of the data.

2.4.1 Limitations

There are a number of limitations that should be considered. Although the findings of the current research provide some direction for further research and practice, the sample size was small. In addition, the findings reported in this study may be limited due to the sampling method which employed. All focus group participants accessed the Fibrolreland website; a website developed and updated by fibromyalgia patients to provide information and support to others with a similar diagnosis, therefore the participants in the present study may have been more

proactive in seeking support compared to people with fibromyalgia who do not access such domains.

Volunteers for the study came from a small population of patients, therefore, in a bid to preserve anonymity; limited personal information was collected. This protection decision was a further limitation. It would have been advantageous to have ascertained a time since diagnosis for each of the participants. This would have allowed the researcher to examine differences in attitudes and management strategies of those who have been living with the condition for some time in comparison to newly diagnosed patients.

2.4.2 Future Study

The study was designed to conduct an initial exploration of the illness experience of both males and females with a diagnosis of fibromyalgia and to help develop an intervention that could have the potential to promote management of this complex syndrome. This will require further study. Potential effects of gender will also require future study given that women with fibromyalgia outnumber men by a ratio of 9:1. Future studies should endeavour to recruit a larger sample.

2.4.3 Conclusion

Fibromyalgia is a chronic condition that pervades all aspects of the patient's life and remains little understood. Findings from the present research suggest that there are specific areas of need that could be addressed through an appropriate intervention. While gender differences have emerged across the themes identified in this study, a shared feature that is non-gender specific is that fibromyalgia has a

substantial negative impact on the patient's health, well-being and overall quality of life. The findings of the current research therefore suggest that patients, both male and female, living with fibromyalgia may benefit from general healthcare support in relation to the validation of their illness experience and from psychological support that may serve to promote knowledge, acceptance, facilitate active coping strategies and reinforce their adaptive, health promoting behaviours. Future research should strive to establish the effectiveness of interventions designed to promote self-management of this complex disorder.

3 Chapter 3: Maintaining Wellness in Fibromyalgia Intervention

3.1 Introduction

There is increasing recognition that healthcare must incorporate health-promoting strategies that prevent illness and functional decline (Kaplan, 2000) and wellness interventions have gained support for promoting health in persons with chronic disabling conditions (Stuifbergen et al., 2003). Healthcare involves improving functioning, preventing disability, helping patients cope with symptoms of their condition and addressing mental health concerns as opposed to the mere detection and treatment of disease (Kaplan, 2000). Fibromyalgia is a complex condition. As illustrated in Chapter 2, for people living with fibromyalgia the experience of being diagnosed is often dominated by a battle for a diagnosis, the invisible and contestable nature of the condition leads to social isolation and frustration and the challenging symptoms and perceived loss of control permeates every aspect of their lives. Although there is no specific treatment, various management programmes have been proposed to deal with the different aspects of this condition, particularly functional impairments (Sandstrom & Keefe, 1998), psychological distress (Richards & Cleare, 2000), poor quality of life (Alarcon & Bradley, 1998), decreases in muscle strength (Mengshoel, Førre & Komnaes, 1990) and endurance and low levels of physical fitness (Bennett et al., 1989).

Wellness involves every aspect of living and includes an interaction between health, behaviours, attitudes, environment, relationships and spirituality. When an individual feels well, they are capable of accomplishing the tasks associated with everyday life and achieve their desired life goals (Moller & Rice, 2006). Wellness

interventions are focused programmes designed to increase self-management skills, resulting in improved physical and psychological health (Watt et al., 1998). Despite the need for wellness interventions, few have been tailored to the needs of fibromyalgia patients. The Wellness in Fibromyalgia Intervention in the present study takes a holistic approach to promoting health within illness. It emphasizes empowering patients by providing access to resources and knowledge used in selecting behaviours to decrease impact of illness, increase self-efficacy and enhance and sustain their health and overall quality of life.

3.1.1 Recovery

The “recovery model” was originally developed in the context of enhancing the present treatment model being offered to mental health service users. The recovery model within mental health services sought to give emphasis to the possibility of recovery from mental ill health and the promotion of both enhanced self-management for mental health service users and the development of services which would facilitate the individual’s personal journey towards recovery. According to the Mental Health Commission (2005) the recovery model does not seek to deny the neurobiological aspects of mental illnesses but instead actively promotes balance in terms of seeking a greater recognition that the experience of mental illness is intimately intertwined with the individual’s sense of personhood and their experience in their world. Clinical symptomatology is part of the person’s intimate experience of living with a mental health diagnosis and how the person views their own experience of illness is likely to have a measurable effect on their progress towards recovery. The person’s fears and hopes, their attitudes, their social situation and the behaviours the

engage in in respect of their own recovery are fundamental to any comprehensive treatment model.

Interest in the recovery model for mental health services, has grown considerably during the last 25-30 years. Roberts and Wolfson (2004) postulated that the recovery model is to some extent a rediscovery of psychiatric care and practices initiated almost two centuries ago by Tukes in York where therapeutic practice was based on kindness, compassion, respect and hope of recovery. Strong interest in incorporating the recovery philosophy into mental health care and in developing recovery orientated services is particularly evident in the United States, New Zealand and somewhat more recently in England. In the U.S. the recovery model is attracting the attention not only of mental health service users and service providers but is also engaging the interest of those who pay for services, to whom the prospect of enhanced results for their investment is obviously attractive (Ralph, 1999). At its simplest, recovery can be defined as a subjective experience of regaining control over one's life (Allott, Loganathan & Fulford, 2002)

The commencement of the de-institutionalisation of the large psychiatric hospitals in the 1960's saw a radical change in the provision of mental health services and the dawning of a new era for patients in Ireland. While many may have seen it as unachievable or indeed inappropriate in terms of meeting patient needs, the change is underway and represents a drastic shift in how mental health services are currently being provided. The foresight and commitment of those involved in Irish mental health care provision demonstrated that this kind of radical change was in fact possible, that it *could* and subsequently *would* happen. The movement towards a

recovery based model of service provision also represents an equally radical change in direction. Progress in the process of deinstitutionalisation and the on-going development of community based service models has served to provide a foundation upon which a recovery-based model of service can continue to be promoted and developed in the on-going attempt to promote wellness and recovery in those facing adversity in terms of their health.

Positive changes and recovery following adversity are not new concepts in the realms of psychology and have been reported empirically in cases of chronic pain, substance addiction, and in individuals with mental ill health. Positive changes share the common factor of struggling with adversity; and are therefore referred to collectively as adversarial growth. It is through the process of struggling with adversity that changes may arise that ultimately serve to drive the individual to a higher level of functioning than that which existed prior to the traumatic event (Linley & Joseph, 2004). Studies of adversarial growth and recovery are important areas of research for several reasons. Focusing only on the negative outcome of trauma and adversity can lead to a biased understanding of posttraumatic reactions. Any understanding of reactions to adversity and trauma, be it physical, psychological or a combination of both, must take account of the potential for positive as well as negative changes if it is to be considered complete.

From an applied perspective, clinicians ought to be aware of the potential for positive change in patients following adversity and trauma. Positive changes may be used as foundations for further therapeutic work, providing hope that the impact of the trauma encountered can be overcome (Calhoun & Tedeschi, 1999; Linley &

Joseph, 2002). It is therefore important to be aware of the potential for growth, but not to suggest that growth is to be expected or that the person has failed for not making more of their experience. Psychologists are beginning to unravel the ways in which growth may be facilitated and should be aware of the potential for positive change in individuals following adversity. But, importantly, the need to be careful not to inadvertently imply that there is anything fundamentally positive in trauma must be recognised. In discussing the clinical implications, Tedeschi and Calhoun (2004) make it clear that personal growth after trauma should be viewed as originating not from the event itself, but from within the person themselves through the process of their struggle with the event and its impact on their lives (Joseph, 2009). A clear link exists between recovery and adversarial growth, both are supported by the notion that despite traumatic life events that have the potential to impact negatively on one's health and wellbeing, there must always be the hope that health and illness; and life and ill-health can co-exist.

The present study aimed to examine the applicability of a recovery approach to the management of chronic pain and more specifically, fibromyalgia through the provision of information on recovery. The aim extended to lend encouragement and support to the possibility of pain management services in Ireland implementing a recovery based model to patients within their service. If recovery is achievable for those with mental health conditions, surely it too is within reach of those with chronic pain conditions. Recovery as defined by Allott et al. (2002) as a subjective experience of regaining control over one's life should be open to all health service consumers.

3.1.2 Wellness Recovery Action Plan (WRAP®)

Wellness Recovery Action Planning (WRAP®) was originally developed for patients with mental health diagnoses. WRAP® is an education programme designed by Mary Ellen Copeland (1997) and further developed by individuals who have experience of health difficulties and who have a history of struggling to incorporate wellness strategies into their lives. It is a self-management programme in which participants identify *early warning signs* and *triggers* for distress, in addition to identifying internal and external resources to support their wellness and recovery. Participants use this knowledge to create their own, individualised plans for successful living. It is now used extensively by individuals and by health care and mental health systems all over the world to address health issues (e.g., Cook et al., 2009; Cook et al., 2010; Higgins et al., 2012). The WRAP® programme has at its core goal setting and planning (Copeland, 1997). Through goal setting, participants devise their own personal wellness plan. There are 5 key concepts in WRAP®: hope, personal responsibility, support, education and self-advocacy. In 2010, WRAP® was recognized by the United States Substance Abuse and Mental Health Services Administration (SAMHSA) as an evidence - based practice and listed in the National Registry of Evidence-Based Programmes and Practices (NREPP).

Few studies have examined the effectiveness of WRAP® however those that have, have revealed promising results. Cook et al. (2009), in a study of 80 individuals with serious mental illness, reported significant improvement in recovery, self-reported symptoms, self-advocacy, hopefulness and physical health; a decrease in empowerment was reported. However, the study had a small sample and didn't use a

control group for comparison obtaining results from the experimental group only therefore limiting the power of the study in terms of definitively proving that changes observed were as a result of WRAP®. Cook et al. (2010) demonstrated significantly positive behavioural health outcomes for individuals ($N = 381$) with severe and persistent mental health challenges who participated in peer-led WRAP® groups. However, while the sample size was more substantial than that in the previous study, once more, no control group was utilized and therefore, changes observed among participants cannot be definitively attributed to the programme.

In a study examining the effects of WRAP® participation on psychiatric symptoms, hope, and recovery outcomes for people with severe and persistent mental illness, a quasi-experimental study, with an experimental group ($N = 58$) and a comparison group ($n = 56$) revealed statistically significant group intervention effects for symptoms and hope, but not for recovery. The study results offer promising evidence that WRAP® participation has a positive effect on psychiatric symptoms and feelings of hopefulness (Fukui et al., 2011). Higgins et al. (2012) completed an evaluation of mental health recovery and Wellness Recovery Action Planning education in Ireland. In what was the first mixed methods pre-post evaluation of WRAP®, this study's quantitative findings suggested a positive effect on sense of self belief and capacity for wellness and recovery, and were therefore perceived as an empowering experience among participants. Quantitative results indicated that the programme has a positive impact on participants' knowledge attitudes and beliefs about recovery with increases observed on measures of knowledge of recovery, recovery attitudes, WRAP® beliefs, confidence in ability to apply recovery and WRAP®

skills and teaching and facilitation skills. While the results of this novel evaluation are positive, they need to be interpreted in light of the fact that the study did not employ a control group for comparison.

These results, though limited, are promising and suggest that further research on WRAP® as a self-management intervention is warranted. Research employing larger numbers of participants and control groups for comparisons will serve to enhance knowledge and empirical support for this intervention. No research to date has been conducted to establish the applicability of a WRAP® programme to the management of conditions outside of the realm of mental health, an endeavour that has the potential to broaden the use of this staged process of active management that is rooted in the values of recovery.

3.2 Goal Setting Theory

Given the nature of the intervention in the present study, an overview of goal setting theory and its impact on human behaviour and motivation seems timely. The WRAP® programme has at its core goal setting and planning (Copeland, 1997). It is a self-designed plan for staying well and for helping participants to increase personal responsibility and improve overall quality of life. Through goal setting, participants devise their personal wellness plan centred on one of the main aspects of WRAP® - the daily maintenance plan. Goal setting Theory was formulated largely on the basis of empirical research conducted over almost four decades by Edwin Locke and Gary Latham (e.g. Locke, 1966; Locke, 1968; Latham, Erez & Locke, 1988; Locke & Latham, 1990; model illustrated in Figure 3.1 below). Much of the theory is based on Ryan's (1970) premise that conscious goal setting directly effects action and that human

motivation should be examined beginning with establishing the individual's immediate intentions and subsequently building from there to explain the sources of the intention. A goal is the aim or object of an action, for example to attain a specific standard of proficiency within a specified time limit (Locke & Latham, 2002)

Goals affect performance through four different mechanisms. Firstly, goals serve a directive function, that is, they direct attention away from goal irrelevant activities and effort towards goal relevant activities. This effect is said to occur both cognitively and behaviourally (Locke & Latham, 2002). Rothkopf and Billington (1979) found that students with specific learning goals paid attention to and learned goal relevant passages of text better than goal irrelevant passages. Secondly, goals have an energizing function and high goals lead to greater effort than low goals. This has been successfully demonstrated with tasks that directly entail physical effort such as the ergometer (Bandura & Cervone, 1983); that entails repeated performance of simple cognitive task; include physiological indicators of effort (Sales, 1970); and include measurements of subjective effort (Bryan & Locke, 1967). Thirdly, goals affect persistence, that is, when participants are allowed to control the amount of time they spend on a task, difficult goals prolong effort (LaPorte & Nath, 1976). And finally, goals affect action indirectly by leading to the discovery, arousal, and/or use of task relevant knowledge and strategies (Wood & Locke, 1990).

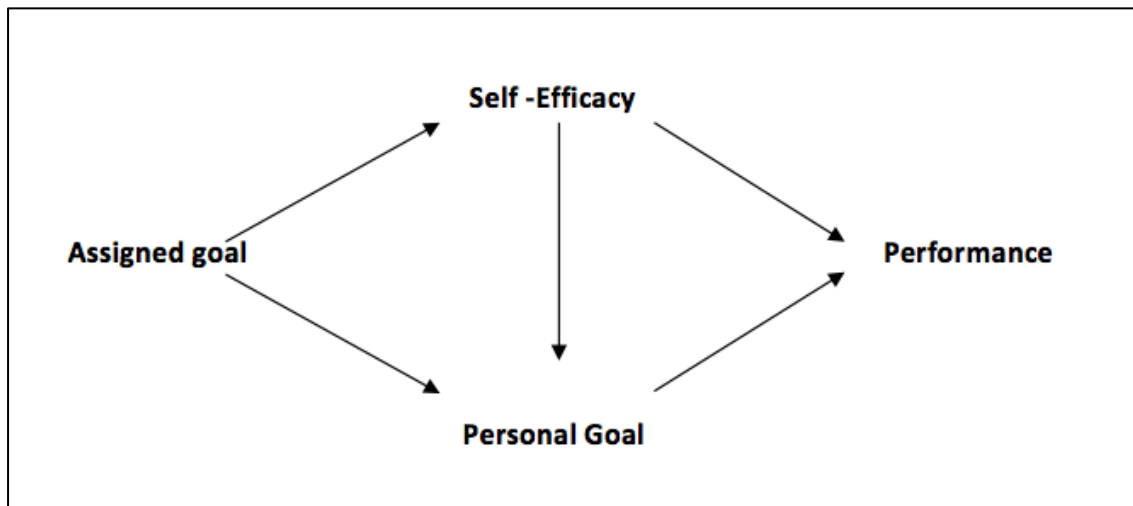


Figure 3.1: Relationship Among Assigned Goals, Self-Set Goals, Self-Efficacy and Performance. (Source Adapted From Locke and Latham, 1990, p. 72)

According to Locke and Latham (2002), goals also affect performance through a variety of moderators including the difficulty of the goal itself, the more specific or explicit the goal, the personal commitment to the goal, the provision of feedback showing the progress in relation to the goal and the influence that self-efficacy has on goal performance. Stenström (1994) evaluated the effects of a 12-week home exercise and cognitive treatment program in patients ($N = 42$) with rheumatoid arthritis. The patients were randomized to either a 'goal-setting' group, in which individual goals for the exercise were set and exercise encouraged despite pain, or to a 'pain attention' group, where patients were advised to decrease exercise in the presence of pain. All patients used the same program which was aimed at improved muscle function, range of motion and aerobic capacity. After the 12 week intervention period, improvements regarding pain were larger in the goal-setting subgroup. Therefore, in the context of managing chronic pain, goal setting theory provides a valued perspective. It suggests

an impact on self-efficacy and motivation thus linking goal setting with motivational change in illness behaviours, activity pacing and pain coping and adjustment

3.3 Study Aim and Hypotheses

The aim of the present study was to establish the impact of a Wellness Recovery Action Planning (WRAP®) informed intervention on the self-management of fibromyalgia.

The following hypotheses were tested:

3.3.1 Longitudinal Study

H1: An increase will be observed between Time 1 and Time 2 for the intervention group on measures of self-efficacy.

H2: An increase will be observed between Time 1 and Time 2 for the intervention group in pain acceptance scores.

H3: An increase will be observed between Time 1 and Time 2 on activities engagement scores for the intervention group

H4: An increase will be observed between Time 1 and Time 2 on pain willingness scores for the intervention group.

H5: A decrease will be observed between Time 1 and Time 2 on impact of illness scores for the intervention group.

H6: A decrease will be observed between Time 1 and Time 2 on impairment scores for the intervention group.

H7: An increase will be observed between Time 1 and Time 2 on physical functioning scores for the intervention group.

H8: A decrease in total number of days missed from work will be observed between Time 1 and Time 2 in the intervention group.

H9: An increase in total number of feel good days will be observed between Time 1 and Time 2 for the intervention group.

H10: An increase will be observed between Time 1 and Time 2 in internal control scores for the intervention group.

H11: A decrease in matter of chance scores will be observed between Time 1 and Time 2 in the intervention group.

H12: A decrease will be observed between Time 1 and Time 2 in powerful others having control scores for the intervention group.

H13: A decrease in doctors having control scores will be observed between Time 1 and Time 2 in the intervention group.

H14: A decrease in other people having control scores will be observed between Time 1 and Time 2 in the intervention group.

3.3.2 Comparison Study

H15: The intervention group will show more significant gains between Time 1 and Time 2 than the comparison group on measures of self-efficacy.

H16: The intervention group will show more significant gains between Time 1 and Time 2 than the comparison group on measures of pain acceptance.

H17: The intervention group will show more significant gains between Time 1 and Time 2 than the comparison group on measures of activities-engagement

H18: The intervention group will show more significant gains between Time 1 and Time 2 than the comparison group on measures of pain willingness.

H19: The intervention group will show more significant declines between Time 1 and Time 2 than the comparison group on measures of impact of illness.

H20: The intervention group will show more significant declines between Time 1 and Time 2 than the comparison group on measures of impairment.

H21: The intervention group will show more significant gains between Time 1 and Time 2 than the comparison group on measures of physical functioning.

H22: The intervention group will show more significant declines between Time 1 and Time 2 than the comparison group on total number of days missed from work.

H23: The intervention group will show more significant gains between Time 1 and Time 2 than the comparison group on total number of feel good days.

H24: The intervention group will show more significant gains between Time 1 and Time 2 than the comparison group on measures of internal control

H25: The intervention group will show more significant declines between Time 1 and Time 2 than the comparison group on measures of matter of chance.

H26: The intervention group will show more significant declines between Time 1 and Time 2 than the comparison group on measures of powerful others having control.

H27: The intervention group will show more significant declines between Time 1 and Time 2 than the comparison group on measures of doctors having control.

H28: The intervention group will show more significant declines between Time 1 and Time 2 than the comparison group on measures of other people having control.

3.4 Methods

3.4.1 Design

The present study utilized a pre-post longitudinal evaluation of a Wellness in Fibromyalgia Intervention. In addition, the study provides a comparison study between two groups: a Wellness in Fibromyalgia intervention group and a comparison group. Post-intervention interviews were completed with a sample of participants 12 months after completing the intervention.

3.4.2 Participants & Procedure

Participants were volunteers with a confirmed diagnosis of fibromyalgia and were recruited between January 2014 and January 2015 through information sessions

presented at fibromyalgia support group meetings in Dublin and Carlow, notices on Fibro Ireland's website and Facebook page, notices on Chronic Pain Ireland's website and fliers in GP surgeries. Potential participants contacted the researcher to indicate their interest in the study and their details were added to a participant database. The nature of the study was explained to those who made contact by the researcher and their eligibility was determined.

All interventions were offered at 3 locations: 2 community centres (Clongriffin, Dublin 13 and Askea, Co. Carlow) and the School of Psychology Trinity College Dublin. Those patients that could attend the intervention in any one of the chosen locations were allocated to the intervention group ($N = 78$) and the remaining participants who, due to their location or work or family commitments could not attend were offered a place on the comparison group ($N = 50$). All participants ($N = 128$) continued with treatment as usual while participating in the current research, regardless of whether they formed part of the intervention group and were participating actively in the seven week wellness in fibromyalgia programme or were part of the comparison group who completed questionnaires from home at three time points. The intervention was carried out between April 2014 and April 2015. The sessions were delivered by three facilitators and the intervention was delivered to five groups in total. Facilitator 1 delivered three programmes, Facilitator 2, one programme and Facilitator 3, one programme. Those who were interested and who met the eligibility criteria were given an information letter to read (See Appendix 2). Once this was read, those willing to participate were asked to sign a consent form (See Appendix 3) and were assigned a participant number. Participants were provided with an information

sheet containing contact numbers for support services before participation in case of distress (See Appendix 2). All participants continued with their present level of medical care for the duration of the study. Self-report data were collected from participants at Time 0: baseline (7 weeks prior to commencing the intervention), participants completed the questionnaires at home and returned them by post; Time 1: week 1 of the intervention, Time 2: week 7 of the intervention and Time 3: 6 months post-intervention, completed at home and returned by post (See Appendix 5 for the full battery of questionnaires). A debriefing sheet was provided (See Appendix 4). The comparison group completed their questionnaires at home and returned them by post Time 1, Time 2 (7 weeks later) and Time 3 (6 months later).

Follow-up Interviews

Those who participated in Groups 1, 2 and 3 ($N = 42$) were contacted 12 months post intervention (between June 2015 and December 2015) and invited to take part in a follow up interview. Ten individuals agreed to participate. Chapter 4 presents details pertaining to this qualitative study.

3.4.2.1 Eligibility Criteria

Participants over 18 years of with a diagnosis of fibromyalgia obtained from a registered medical practitioner (GP, Rheumatologist or consultant) and able to give informed consent were considered eligible for this study. No minimum time since diagnosis was set. The eligibility criteria were established through verbal discussion with each of the participants individually at the point of expression of interest and again at the Time 1 data collection stage. Severe psychiatric symptoms or behaviours

that may significantly interfere with the intervention, such as psychotic symptoms, high risk of suicide or severe depressive episodes, as assessed through responses provided on the measures utilised, resulted in exclusion from the study. One individual was excluded from the study on these grounds. The study received ethical approval from both the University and Fibro Ireland's ethics committees (See Appendix 1 for ethical approval documentation).

3.4.3 Power Analysis

Based on data from a trial conducted in Geneva on electroacupuncture and fibromyalgia (Deluze, Bosia, Zirbs, Chantraine & Vischer, 1992), and attrition rates in similar studies (e.g., Cedraschi et al., 2004), it was determined using G*Power analysis (Faul, Erdfelder, Lang & Buchner, 2007) that for a repeated measures ANOVA with a within-between interaction, a statistical power of .80 to detect a small to medium effect size ($f = 0.17$), as being significant at the .05 level, a sample of 140 should be recruited.

3.4.4 Intervention

The intervention consisted of 7 weekly group sessions (2 hours each). Information was provided through didactic teaching with facilitated group discussions and supplementary readings. Attendance at ≥ 5 sessions was considered full compliance. If a participant was absent for a session they had the opportunity to attend a 30 minute 1:1 with the facilitator the following week and was guided through the session they had missed. The intervention was delivered in small groups (from 12 to 18 participants) during the afternoon or early evening to 5 cohorts over the 25

month period. The facilitator role was rotated with 2 other individuals who themselves had experience in the area of group facilitation and of fibromyalgia. To ensure treatment fidelity, the lead researcher (Facilitator 1) provided 1:1 training in the delivery of the programme to each of the two additional facilitators. They were provided with a facilitator's manual containing all relevant documentation pertaining to the study (information sheets, consent forms, batteries of questionnaires and debriefing sheets). They were also provided with a copy of the Programme workbook (See Appendix 8), the accompanying PowerPoint presentation and weekly lesson plans (See Appendix 9). In line with The Copeland Centre guidelines, each of the facilitators themselves completed the seven week programme and each had devised their own WRAP® plan. Each facilitator was provided with a copy of the WRAP® Facilitators Values and Ethics document prior to delivery of the programme (See Appendix 10). The lead researcher attended the first and final week to assist with data collection and was available to each of the facilitators during the course of the intervention. The lead researcher also attended a minimum of two additional sessions to ensure consistency in the delivery of the programme.

The Wellness in Fibromyalgia Intervention was adapted from the Wellness Recovery Action Planning (WRAP®) Programme (Copeland, 1997), and designed to engage individuals with fibromyalgia in assessing their present health behaviours, setting meaningful goals for change and addressing the barriers, skills and resources necessary to change those behaviours.

To achieve the programme goals, the Wellness in Fibromyalgia Intervention was designed to: (1) provide accurate information that was specific to fibromyalgia;

(2) educate participants on the key concepts of WRAP®; (3) introduce participants to the notion of wellness toolbox, daily maintenance plans, early warning signs, triggers and crisis planning; (4) educate participants about goal setting theory (Locke & Latham, 1990) and SMART goals (Doran, 1981); (5) engage participants in individualized goal setting and monitoring and (6) enhance participant's self-efficacy for health behaviours. Participants received a workbook containing an outline of each weekly session, self-assessments of health behaviours, group and individual activities, goal setting activities and designated notes pages for the recording of their own personal notes (See Appendix 8 for full copy of programme workbook). Materials contained within the workbook promoted basic self-management techniques to manage symptoms and accomplish daily activities and incorporate wellness activities into daily life of participants

Table 3.1: Components of the Wellness in Fibromyalgia WRAP® Programme

Session	Content
Week 1: Introduction to WRAP®	Overview of WRAP® Introduction to key concepts (Hope, Personal Responsibility, Self-Advocacy, Education and Support) Reflection: How to promote personal wellness
Week 2: Developing a Wellness Toolbox	Introduction to Wellness Tools Identify potential Wellness Tools Develop a Wellness Toolbox
Week 3: Developing a Daily Maintenance List	Introduction to Daily Maintenance Reflection: What you are like when you are well Introduction to health within illness Develop a Daily Maintenance List
Week 4: Triggers	Develop an understanding of Triggers Identify personal Triggers Introduction to mindfulness Devise a Trigger Action Plan
Week 5: Early Warning Signs	Develop an understanding of Early Warning Signs Identify personal Early Warning Signs Devise an Early Warning Sign action plan Reflection: When things are breaking down
Week 6: Crisis Planning	Define the meaning of 'crisis' Importance of Crisis Planning Explore value of trust and boundaries in relationships Devise a crisis plan
Week 7: Revision	Review each module of the WRAP® Programme

3.4.4.1 Adapting the Wellness Recovery Action Planning Programme to Fibromyalgia Patients

During the adaptation of the WRAP® programme and subsequent development of the Wellness in Fibromyalgia Programme, the literature surrounding the needs of this patient group was reviewed and the intervention altered to meet their identified unique needs. An educational section containing key information

pertaining specifically to fibromyalgia was added to Module 1. This section contained specifics in terms of diagnosis, incidence rates, symptoms, proposed causes of the illness and The Fibromyalgia Cycle. Module 5 contained a section dedicated to 'Resources' specific to fibromyalgia including useful websites and essential reading. The content of the intervention was reviewed by the administrator of Fibro Ireland (a support network for individuals with fibromyalgia), who herself has a diagnosis of fibromyalgia; it was revised based upon her recommendations, for example, the font type and size was altered and additional pages added to the end of each workbook chapter for participants to record their notes and ideas throughout the intervention.

3.4.5 Measures

3.4.5.1 Demographic Characteristics

The demographic characteristics assessed were gender, age, education level, occupation current health status and treatments currently being received.

3.4.5.2 Acceptance

The *Chronic Pain Acceptance Questionnaire* (CPAQ; McCracken, Carson, Eccleston & Keefe, 2004) is a 20 item measure of acceptance in patients with chronic pain. It has 2 subscales derived from factor analysis, Activities Engagement (comprising of 11 items) and Pain Willingness (comprising of 9 items) which assess patients' participation in activities regardless of pain and relative absence of attempts to avoid or control pain (McCracken & Eccleston, 2005). The CPAQ has been shown to have a good test - retest reliability (intra class correlation coefficient .83) and internal consistency reliability (Cronbach's alpha .83) (Rodero et al., 2010) and demonstrate

significant correlations with measures of distress, avoidance and patient functioning in cross sectional analyses, supporting their validity as indices of acceptance of chronic pain (McCracken et al., 2004). In the current sample, Cronbach's alpha of .80 was reported for the overall scale; .87 for the Activities Engagement subscale, and .74 for the Pain Willingness subscale. Test-retest reliability analyses were performed. The test-retest reliability coefficient estimated from longitudinal data for 78 individuals on the CPAQ was .63.

3.4.5.3 *Impact of Fibromyalgia*

The *Fibromyalgia Impact Questionnaire* (FIQ) was developed to assess current health status and includes 10 items measuring various aspects such as physical function, psychological distress, pain, sleep, stiffness and wellbeing (Burckhardt et al., 1991). It is a self-administered questionnaire designed to assess the components of health status that are believed to be most affected by fibromyalgia. The FIQ contains 4 subscales. The Impairment subscale contains 11 items, the Feel Good subscale contains 1 item, the Miss Work subscale contains 1 item and the Physical Functioning subscale contains 7 items. It is a reliable and valid instrument for the measurement of both functional disability and health status in fibromyalgia patients. The FIQ has been found to have a reliability ($r = .96$ for physical functioning and .80 to .96 for all other items of the scale) and internal consistency (alpha 0.93) (Buskila & Neumann, 1996). In the current sample, Cronbach's alpha of .76 was reported for overall scale, .88 for the Physical Functioning subscale, .73 for the Impairment subscale. Test-retest reliability analyses were performed. The test-retest reliability coefficient estimated from longitudinal data for 78 individuals on the FIQ was .67.

3.4.5.4 *Perceived Control of Pain*

The *Pain Locus of Control Questionnaire* (PLCQ) Scale (Toomey, Mann, Abashian & Thompson-Pope, 1991) measures whether patients perceive that their control exists internally or whether control lies externally (health care professionals, medication). The scale's structure and the reliability of its data compare favourably with those of similar scales. It is a 18-item instrument using a 6-point Likert design, with 6 items representing each of the three subscales: internality, powerful others, and chance. The score on each subscale is the sum of all subscale items endorsed, and scores on each subscale can range from 6-36 with higher scores indicating better pain control or pain responsibility. Penzien et al. (1989; as cited in Seville & Robinson, 2000) demonstrated that the split-half reliability of the PLCQ is .89. Gibson and Helme (2000) found that internal consistency reliability of the three subscales is good to excellent, with Cronbach alpha coefficients of .87 for Powerful others, .81 for Matter of Chance, and .75 for Internality. The alpha coefficients failed to improve with the deletion of any single item, indicating that all items on each scale contribute to the reliability of the total scale score (Gibson & Helme, 2000). In the current sample, Cronbach's alpha of .54 was reported for overall scale, .64 for Powerful others subscale, .77 for Matter of Chance subscale, and .79 for Internality subscale. As there is no overall score on the PLCQ; test-retest reliability analyses were performed on the 3 subscales. The test-retest reliability coefficient estimated from longitudinal data for 78 individuals on the Powerful Others subscale was .63, .54 on the Matter of Chance subscale was and .67 on the Internal Control subscale.

3.4.5.5 *Self-Efficacy*

The *General Self-Efficacy Scale* (GSES) is a measure of perceived coping competence, or overall confidence in one's ability to cope across a range of demanding situations (Barlow, Williams & Wright, 1996). Items are designed to assess the individual's belief in their ability to respond to new or difficult situations. Studies have shown that the GSE has high reliability, stability, and construct validity (Leganger, Kraft & Roysamb, 2000; Schwarzer, Mueller & Greenglass, 1999). Cronbach alpha ranges from .75 to .94 across a number of different language versions (Luszczynska, Scholz & Schwarzer, 2005; Rimm & Jerusalem 1999). Relations between the GSES and other social cognitive variables (intention, implementation of intentions, outcome expectations, and self-regulation) are high and confirm the validity of the scale (Luszczynska et al., 2005). In the present sample, Cronbach's alpha .87 was reported for scale. Test-retest reliability analyses were performed. The test-retest reliability coefficient estimated from longitudinal data for 78 individuals was .72.

3.4.6 *Data analyses*

The analyses of effects of intervention on outcome measures and the discussion were based on an 'Intention-to-Treat' analysis, which was the primary method of analysis. To be included in the final study sample for the analysis examining the effect of the intervention, participants in the intervention group ($N = 78$) had to complete at least one of the 4 batteries of questionnaire; Time 0 (Baseline), Time 1 (Week 1 of intervention), Time 2 (Week 7 of intervention) or Time 3 (6 month follow-up).

Participants in the comparison group ($N = 50$) had to complete the battery of questionnaires at three equivalent time points, i.e. Time 1, Time 2 (7 weeks later) and Time 3 (6 months later). To be included in the final sample for analysis, participants from this group must also have completed at least one of the three batteries of questionnaires. Missing values were replaced with the last observation carried forward if the participant did not complete later surveys. Thus, as seen in Figure 3.2, data from 78 intervention participants were included; as seen in Figure 3.3, data from 50 comparison participants were included.

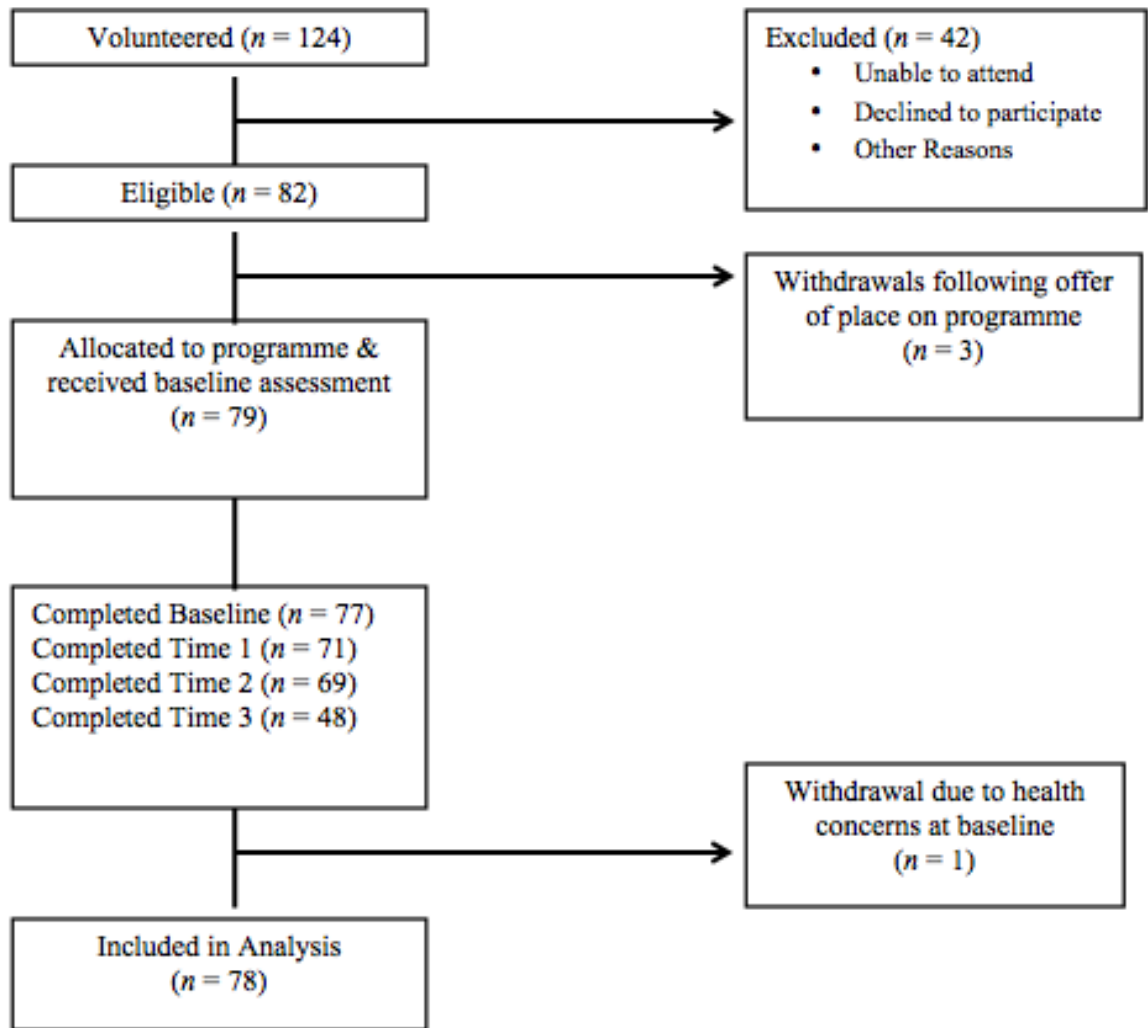


Figure 3.2: Participant Enrolment, Allocation, Follow up and Analysis - Intervention Group

One way repeated measures ANOVAs were employed to examine change over time in the intervention group. Where Mauchly's test of sphericity was not passed, Greenhouse Geisser correction was applied. The p -value was set at the .05 level. Where significant results were obtained, *post hoc* analyses using paired t-tests were applied and an alpha level adjusted for multiple comparisons, using a Bonferroni method were applied. The alpha level was adjusted to .017 ($.05/3 = .017$).

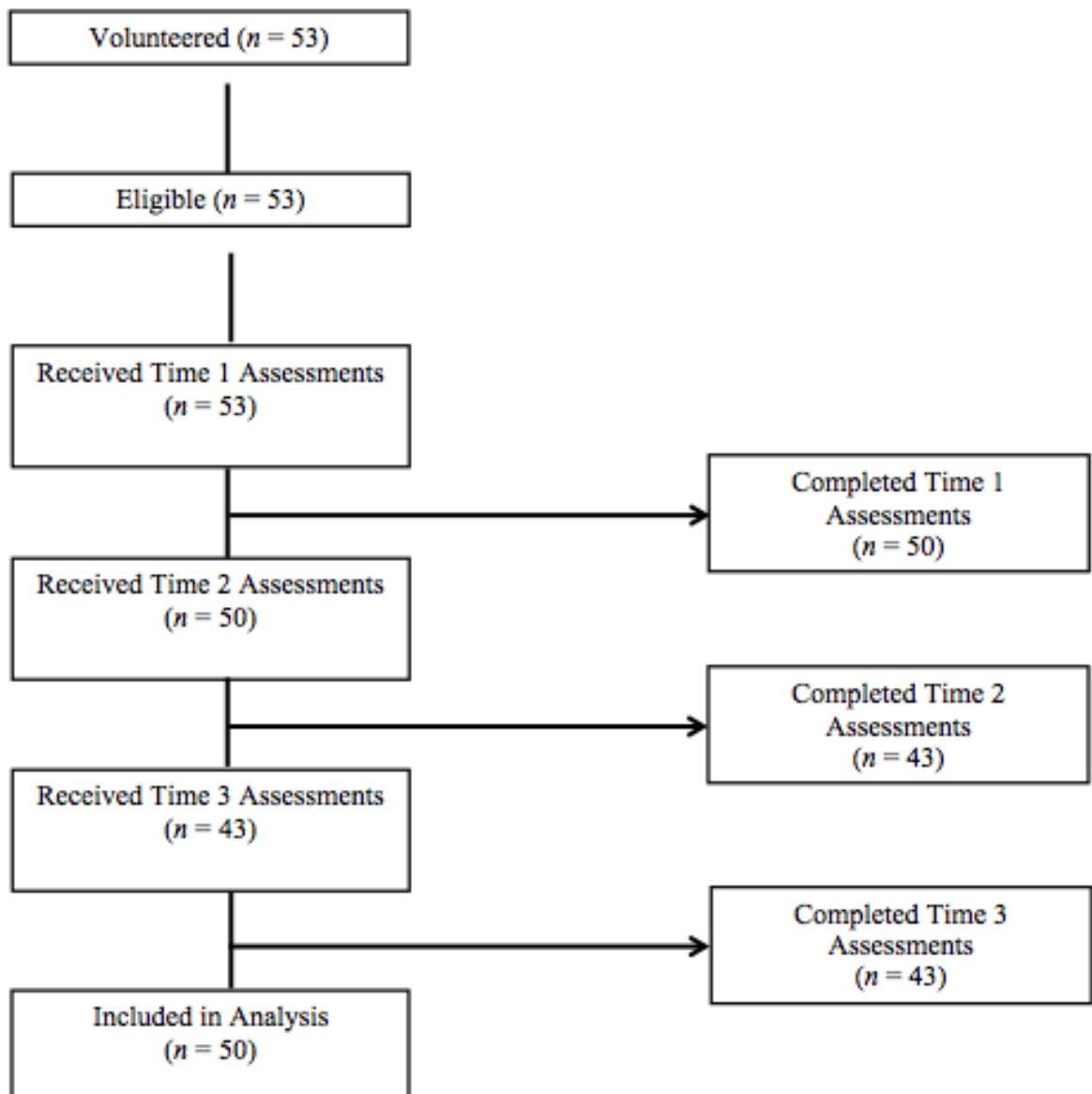


Figure 3.3: Participant Enrolment, Allocation, Follow up and Analysis - Comparison Group

Mixed factorial ANOVAs with repeated measure 'Time' (Time 1, Time 2 and Time 3) and between groups factor 'Group' (Intervention or Comparison) were applied in the current data. Where Mauchly's test of sphericity was not passed, Greenhouse Geisser correction was applied. The p -value was set at the .05 level.

Where main effects of time were observed, *post hoc* analyses using paired t-tests and an alpha level adjusted for multiple comparisons, using a Bonferroni method were applied. The alpha level was adjusted to .017 ($.05/3 = .017$).

Where significant interactions between time and group were observed, the source of these interactions was interrogated using three independent samples t-tests for group at each level of time. Further to this, the effect for time was investigated with repeated measures ANOVAs for the intervention and comparison groups separately. These five follow-up analyses were conducted using a reduced alpha threshold of .01 to control for the effects of multiple comparisons (Bonferroni correction, $p=.05/5 = .01$). Where a significant result of Time was obtained at this juncture, a further three paired samples t-tests were employed to comprehend the exact location of significance. These three follow up analyses were conducted using a reduced alpha threshold of .003 to control for the effects of multiple comparisons (Bonferroni correction, $p=.01/3 = .003$).

Owing to the novelty of the intervention a secondary 'As Treated Analysis' was conducted to establish if any substantive differences would be observed. To be included in the final study sample for the As Treated Analysis, participants in the intervention group were required to complete all questionnaires at all 4 time points; Time 0 (Baseline), Time 1 (Week 1 of intervention), Time 2 (Week 7 of intervention) and Time 3 (6 month follow-up). Participants in the comparison group were required to complete the battery of questionnaires at three equivalent time points, i.e. Time 1, Time 2 (7 weeks later) and Time 3 (6 months later). If Time one questionnaires were not returned, no further questionnaires were sent. Thus, as seen in Figure 7.1

(Appendix 6), data from 48 intervention participants were included; as seen in Figure 7.2 (Appendix 6), data from 43 comparison participants were included. As-Treated results in their entirety can be seen in Appendix 6.

3.5 Results

3.5.1 Participants

A total of 128 individuals were eligible for inclusion in the analysis. Based on chi-square analyses, the participants in both groups were not significantly different on any of the clinical demographic characteristics (see Table 3.2). The majority of participants in both groups were female: the intervention group ($N = 78$) comprised of 73 female and 5 male participants and the comparison group ($N = 50$) comprised of 47 female and 3 male participants.

The mean age of the participants in the intervention group was 48.41 ($SD=12.72$) years, while the comparison group had a mean age of 44.10 ($SD=12.10$) years. The age range of fibromyalgia patients in the intervention group was 19 to 73 years; that of fibromyalgia patients in the comparison group was 18 to 69 years. The education profiles of both groups were similar.

Approximately two thirds of the participants across both groups presented completed higher level education: 55% of the intervention group and 64% of the comparison group had completed a third level or post graduate course of study. Both groups were similar in the types of treatment they are currently receiving. Of interest is the high number of participants in receipt of both physical and mental health treatment: 26

(33%) of the intervention group and 14 (28%) of the comparison group fell into this category.

Table 3.2: Participant demographics

Demographic	Comparison Group N=50 N (%)	Intervention Group N=78 N (%)
Gender		
Male	3 (6%)	5(6%)
Female	47 (94%)	73(94%)
Education level		
Primary	2(4%)	3(4%)
Secondary	16(32%)	32(41%)
Third	19(38%)	34(44%)
Post graduate	13(26%)	9(11%)
Occupation		
Student	6 (12%)	3(4%)
Full time Employment	12 (24%)	10(13%)
Part time Employment	8(16%)	5(6%)
Unemployed	4 (8%)	12(15%)
Sick Leave	8 (16%)	19(25%)
Retired	6 (12%)	17(22%)
Other	6 (12%)	12(15%)
Current Treatment		
Mental Health Issue	0 (0%)	3(4%)
General Health Issue	23 (46%)	39(50%)
Both Mental and General Health Issue	14 (28%)	26(33%)
Not Receiving Treatment	13 (26%)	10(13%)

3.5.1.1 Group Characteristics

Mean baseline scores of participants in both groups in the present study were compared to the potential scale scores. The GSES scores range between 10 and 40,

with higher scores indicative of higher levels self-efficacy. In the present study, participants in the intervention group ($N= 78$) had a mean baseline score of 28.69 and a similar score was achieved by the comparison group ($N= 50$) who recorded a mean baseline score of 28.72 implying the participants who engaged in the study had a moderate level of self-efficacy at starting point.

A mean baseline score of 50.47 was obtained by the intervention group and 55.06 by the comparison group on the CPAQ, a scale with a potential range of 0- 120 where higher scores donate higher levels of acceptance. Such scores suggest an intermediate level of pain acceptance amongst the current patient group. The low mean baseline scores of 16.45 for the intervention group and 18.58 for the comparison group obtained on the CPAQ subscale of pain willingness where there was potential for a score of 54 are notable as they indicate the cohort in the present study showed extremely low levels of willingness to experience pain thus suggesting the potential for psychological inflexibility and fear of movement or re-injury. Slightly higher mean baseline scores of 34.03 for the intervention group and 36.48 for the comparison group out of a potential score of 66 on the activities engagement were obtained.

The average fibromyalgia patient scores 50 on the FIQ with severely afflicted patients scoring 70 plus (Bennett, 2005b). In the current study, participants in the intervention group recorded a mean baseline score of 70.20 and those in the comparison group recorded a score of 66.40 signifying severe levels of impairment across both groups.

In terms of control, internal control refers to patient beliefs in relation to the taking responsibility for their pain and their beliefs about how they themselves can affect their own pain levels. The intervention group recorded a mean baseline score of 22.03 while the comparison group obtained a mean baseline score of 22.14 out of a potential score of 36, an indicator of moderate levels of internal control at the start of the study.

3.5.1.2 Comparison of Completers and Non-completers

Completers are defined as those participants who provided complete data across all time-points. In the present study the completion rate was 72%, that is, 92 of the 128 participants provided all questionnaires at all time-points.

Chi squares also revealed no significant differences between completers and non-completers in terms of their clinical characteristics- age, education level, current type of treatment being received and occupation, or psychological variables- pain acceptance, fibromyalgia impact, locus of control and self-efficacy.

3.5.2 Longitudinal Study Data Analyses

Comparisons of Time 0 to Time 3 were completed on all measures in terms of the total scores and the subscale scores (see Table 3.3).

3.5.2.1 General Self-Efficacy

3.5.2.1.1 Total Self-Efficacy Scores

The results show that self-efficacy scores differ significantly across time points: $F(2.00, 154.39) = 23.80, p < .001, \eta^2 = .23$. Paired samples t-tests indicated a significant

increase from Time 1 ($M = 28.62$) to Time 2 ($M = 30.91$), $t(77) = -5.83$, $p < .02$, two-tailed, which were the immediate pre-intervention to immediate post intervention scores. No significant differences were observed between Time 0 and Time 1, or Time 2 and Time 3. Figure 3.4 indicates a pattern of stable self-efficacy levels between T0 and T1, with an increase over the course of the intervention (T1 to T2), followed by a maintenance of the increased self-efficacy from T2 to T3. As hypothesised (H1), an increase in self-efficacy scores was observed for the intervention group; therefore the hypothesis can be supported.

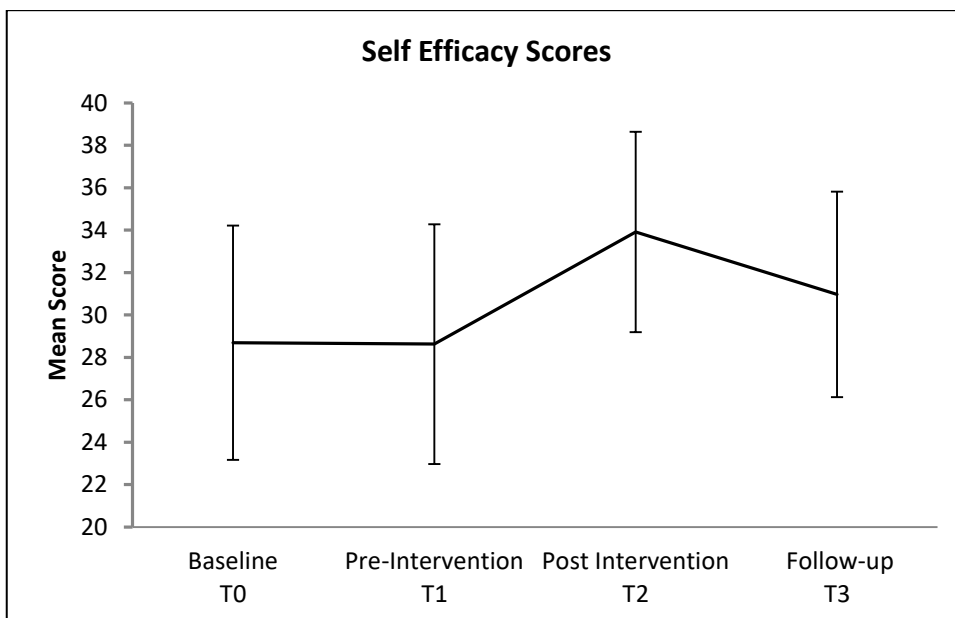


Figure 3.4: Mean Self-efficacy Scores for Intervention Group at Time 0, Time 1, Time 2 and Time 3. Error bars represent standard deviations.

3.5.2.2 Chronic Pain Acceptance

3.5.2.2.1 Total Pain Acceptance Scores

The results show that chronic pain acceptance scores differ significantly across the time points $F(1.67, 129.03) = 17.38$, $p < .001$, $\eta^2 = .18$. Paired samples t-tests

indicated a significant increase in pain acceptance scores from pre-intervention ($M = 52.38$) to immediate post-intervention ($M = 57.36$), $t(77) = -4.01$, $p < .02$, two-tailed. A significant increase was also observed between baseline ($M = 50.43$) and end of 6 month follow-up ($M = 57.63$), $t(77) = -4.63$, $p < .02$, two-tailed. No significant differences were observed between Time 0 and Time 1, or Time 2 and Time 3.

Figure 3.5 indicates a steady increase in acceptance scores from baseline (T0) to post intervention follow-up (T3). A stable pattern of chronic pain acceptance levels exists between T0 and T1, with an increase over the course of the intervention (T1 to T2), this is followed by maintenance of the increased chronic pain acceptance from T2 to T3. As hypothesized (H2), an increase was identified for the intervention group in terms of reported pain acceptance scores; hence, the hypothesis can be accepted.

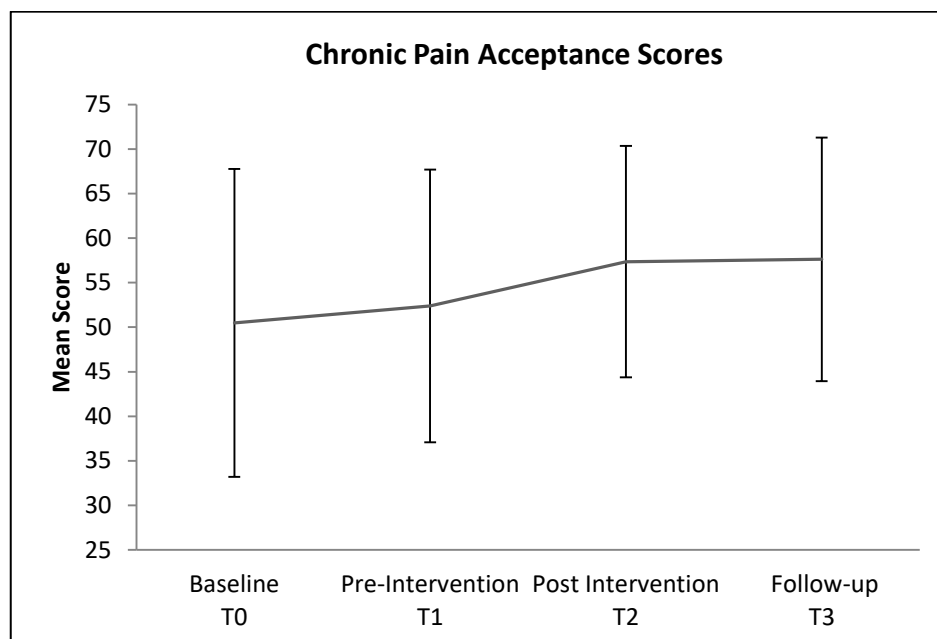


Figure 3.5: Mean Chronic Pain Acceptance Scores for Intervention Group Time 0, Time 1, Time 2 and Time 3. Error bars represent standard deviations.

Table 3.3: Descriptive Statistics for Intervention (N = 78) and Comparison Groups (N = 50) across time points

Measure	T0 <i>M(SD)</i>	T1 <i>M(SD)</i>	T2 <i>M(SD)</i>	T3 <i>M(SD)</i>
GSES (Total Score)				
Intervention	28.69 (5.52)	28.62 (5.66)	30.91 (4.73)	30.97 (4.85)
Comparison		28.72 (5.20)	29.26 (5.22)	29.58 (4.33)
CPAQ (Total Score)				
Intervention	50.47 (17.28)	52.38 (15.30)	57.36 (13.00)	57.63 (13.67)
Comparison		55.06 (15.82)	55.96 (16.14)	58.78 (15.20)
<i>Activities engagement</i>				
Intervention	34.03 (12.36)	34.96 (11.88)	40.01 (10.98)	40.27 (11.28)
Comparison		36.48 (12.40)	36.44 (12.15)	38.12 (11.29)
<i>Pain Willingness</i>				
Intervention	16.45 (8.60)	17.42 (7.39)	17.35 (6.57)	17.36 (7.04)
Comparison		18.58 (7.92)	19.52 (7.40)	20.66 (6.89)
FIQ				
<i>Total FIQ Score</i>				
Intervention	70.20 (16.74)	70.00 (16.27)	63.21 (17.72)	62.72 (19.67)
Comparison		66.40 (18.19)	64.79 (19.85)	64.16 (19.74)
<i>Physical Functioning</i>				
Intervention	15.64 (7.66)	16.57 (7.05)	15.07 (6.90)	15.02 (7.70)
Comparison		15.08 (7.85)	14.70 (7.87)	15.16 (7.96)
<i>Feel Good Days</i>				
Intervention	4.62 (1.82)	4.70 (1.70)	3.82 (1.75)	3.93 (1.85)
Comparison		4.46 (1.87)	3.92 (1.89)	4.08 (1.91)
<i>Missed Work Days</i>				
Intervention	2.96 (2.40)	2.66 (2.32)	2.37 (2.22)	2.16 (2.09)
Comparison		2.38 (2.33)	2.60 (2.24)	2.16 (2.28)
<i>Impairment Score</i>				
Intervention	46.49 (9.28)	46.05 (10.05)	41.93 (11.32)	41.66 (12.04)
Comparison		44.48 (9.75)	43.57 (11.29)	43.20 (10.62)
PLCQ				
<i>Internal Control</i>				
Intervention	22.03 (6.52)	21.76 (7.17)	24.37 (6.19)	23.37 (6.55)
Comparison		22.14 (6.57)	22.38 (6.09)	21.28 (6.43)
<i>Matter of Chance</i>				
Intervention	14.13 (5.77)	14.12 (6.17)	13.69 (5.67)	13.88 (5.76)
Comparison		14.46 (5.61)	15.06 (6.45)	15.44 (6.06)
<i>Powerful Others</i>				
Intervention	15.78 (5.24)	16.77 (5.47)	16.54 (5.11)	16.14 (5.39)
Comparison		16.44 (5.32)	16.18 (5.31)	16.12 (5.52)
<i>Doctor's Control</i>				
Intervention	7.74 (3.09)	8.06 (3.11)	7.90 (3.28)	7.82 (3.41)
Comparison		8.32 (3.18)	8.34 (3.52)	8.26 (3.30)
<i>Other People</i>				
Intervention	8.04 (3.36)	8.71 (3.66)	8.64 (3.05)	8.32 (3.22)
Comparison		8.12 (3.24)	7.84 (3.15)	7.86 (3.15)

Table Notes: *M* = Mean, *SD* = Standard Deviation, *N* = Number of Participants, *GSES* = General Self-Efficacy Scale, *CPAQ* = Chronic Pain Acceptance Questionnaire, *FIQ* = Fibromyalgia Impact Questionnaire, *PLCQ* = Pain Locus of Control Questionnaire

3.5.2.2.2 Total Activities Engagement Scores

The results show that total activities engagement scores differ significantly across time points, $F(1.95, 150.64) = 22.76, p < .001, \eta^2 = .22$. Paired samples t-tests indicated a significant increase in activities engagement scores between week 1 of intervention ($M = 34.96$) and week 7 of intervention ($M = 40.01$), $t(77) = -4.66, p < .02$, two-tailed and between baseline ($M = 34.03$) and post intervention follow-up ($M = 40.27$), $t(77) = -5.63, p < .02$. No significant differences were observed between Time 0 and Time 1, or Time 2 and Time 3. Figure 3.6 illustrates a gradual increase in activities engagement scores from baseline to post-intervention follow-up. A pattern of stable activities engagement scores between T0 and T1 emerges, with an increase over the course of the intervention (T1 to T2), followed by a maintenance of the increased activities engagement scores from T2 to T3. As hypothesized, (H3) an increase on activities engagement scores was observed for the intervention group.

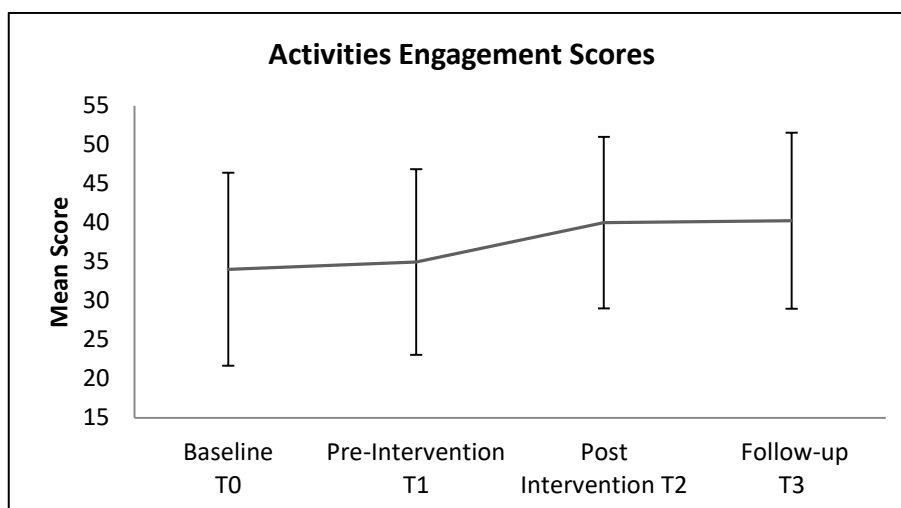


Figure 3.6: Mean Total Activities Engagement Scores for Intervention Group Time 0, Time 1, Time 2 and Time 3. Error bars represent standard deviations.

3.5.2.2.3 Total Pain Willingness Scores

The results show that total pain willingness scores do not significantly differ across the 4 time points $F(2.08,160.52) = 1.21, p > .05, \eta^2 = .01$. It was hypothesized; (H4) that a post-intervention increase on pain willingness scores for the intervention group would occur. However, no significant increase was recorded and hence, the hypothesis is rejected.

3.5.2.3 Fibromyalgia Impact

3.5.2.3.1 Impact of illness

The results show that fibromyalgia impact scores differ significantly across time points, $F(2.34, 180.45)=14.31, p < .001, \eta^2=.15$. Paired samples t-tests indicated a significant decrease in fibromyalgia impact scores between pre-intervention ($M = 70.00$) and immediate post-intervention scores ($M = 63.21$), $t(77) = 4.31, p < .02$, two-tailed. No significant differences were observed between Time 0 and Time 1, or Time 2 and Time 3.

Figure 3.7 illustrates a pattern of stable impact of illness scores between T0 and T1, with a decrease over the course of the intervention (T1 to T2), followed by a preservation of the reduced fibromyalgia impact scores from T2 to T3. As hypothesized; (H5), a decrease in impact of illness scores was observed; therefore, the hypothesis can be accepted.

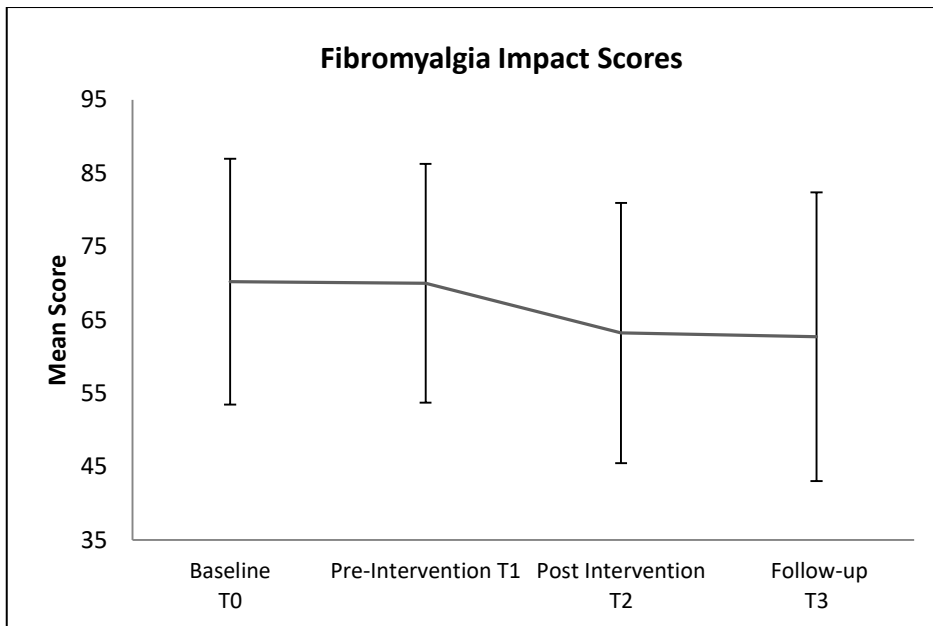


Figure 3.7: Mean Fibromyalgia Impact Scores for Intervention Group Time 0, Time 1, Time 2 and Time 3. Error bars represent standard deviations.

3.5.2.3.2 Impairment Scores

The results show that impairment scores differ significantly across the time points $F(2.41,186.20) = 12.52, p<.001, \eta^2=.14$. Paired samples t-tests indicated a significant decrease in fibromyalgia impairment scores between week 1 ($M = 46.05$) and week 7 of the wellness intervention ($M = 41.93$), $t(77) = 3.89, p<.02$, two-tailed. No significant differences were observed between Time 0 and Time 1, or Time 2 and Time 3. As hypothesized; (H6), Figure 3.8 indicates a pattern of stable impairment levels between T0 and T1, with a decline observed over the course of the intervention (T1 to T2), and followed by preservation of that decrease in impairment from T2 to T3. The hypothesis (H6) is therefore supported.

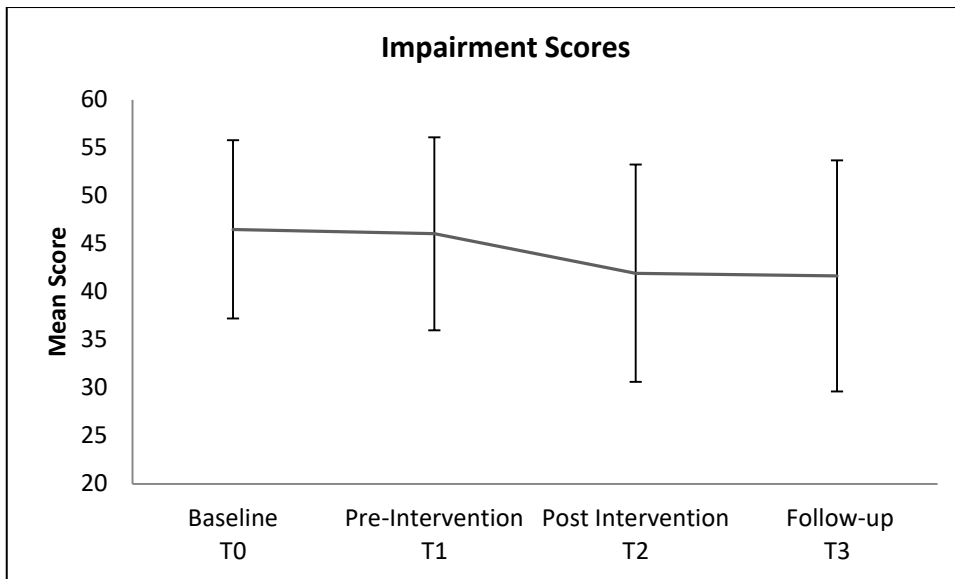


Figure 3.8: Mean Impairment Scores for Intervention Group Time 0, Time 1, Time 2 and Time 3. Error bars represent standard deviations.

3.5.2.3.3 Physical Functioning

The results show that there was a significant difference in total physical functioning scores across time points $F(2.14, 165.42) = 3.13$, $p < .05$, $\eta^2 = .03$. Paired samples t-tests indicated a significant decrease in physical functioning scores between scores obtained pre-intervention ($M = 16.57$) and those obtained immediately post-intervention ($M = 15.07$), $t(77) = 2.90$, $p < .02$, two-tailed. No significant differences were observed between Time 0 and Time 1, or Time 2 and Time 3. Figure 3.9 indicates a pattern of steady physical functioning levels between T0 and T1, with a decrease observed over the course of the 7 week intervention (T1 to T2), and followed by a return to just below baseline levels by the end of the 6 month follow-up. The hypothesis (H7), that an increase on physical functioning scores would be observed for the intervention group can therefore be accepted.

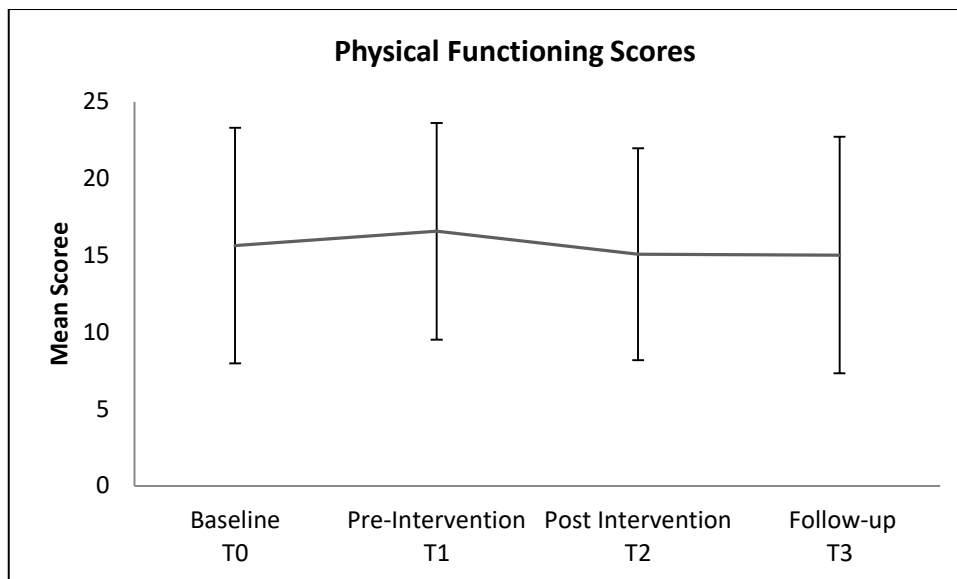


Figure 3.9: Mean Physical Functioning Scores for Intervention Group Time 0, Time 1, Time 2 and Time 3. Error bars represent standard deviations.

3.5.2.3.4 Total Days Missed from Work

The results show that total days missed from work differ significantly across time points, $F(2.47, 190.19) = 3.59, p < .05, \eta^2 = .04$. Paired samples t-tests indicated a significant decrease in total days missed from work between week 1 of intervention ($M = 2.66$) and week 7 of intervention ($M = 2.37$), $t(77) = 2.86, p < .02$, two-tailed and between baseline ($M = 2.96$) and post-intervention follow-up scores ($M = 2.16$), $t(77) = 2.86, p < .02$, two-tailed. No significant differences were observed between Time 0 and Time 1, or Time 2 and Time 3. Figure 3.10 illustrates a measured decrease in number of days missed from work from baseline to 6 month-follow-up. It was hypothesized (H8), that the intervention group would record a decrease in days missed from work post intervention. This hypothesis can be accepted.

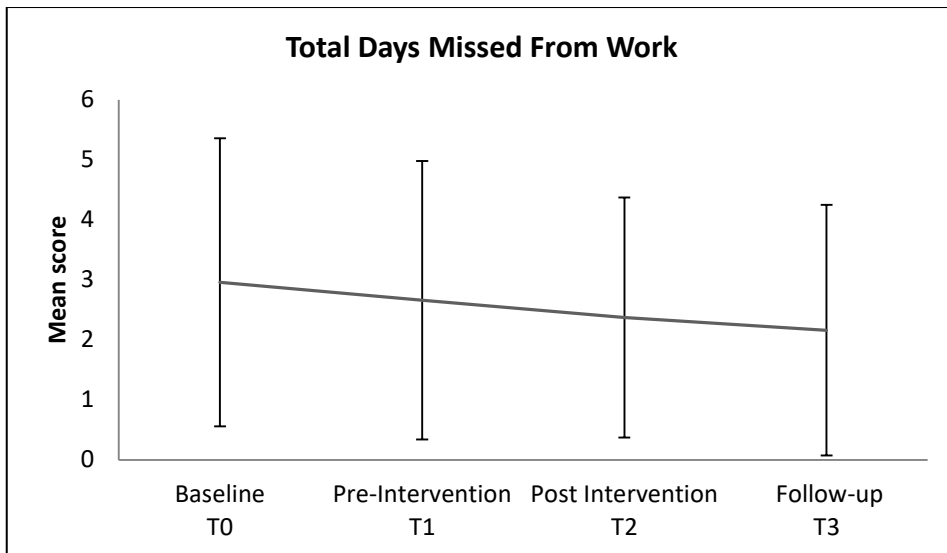


Figure 3.10: Mean Number of Days Missed from Work for Intervention Group Time 0, Time 1, Time 2 and Time 3. Error bars represent standard deviations.

3.5.2.3.5 Total Number of Feel Good Days

The results show that total number feel good days differ significantly across time points, $F(2.65, 204.07) = 18.57, p < .001, \eta^2 = .12$. Paired samples t-tests indicated a significant decrease in feel good days between week 1 ($M = 4.70$) and week 7 of the wellness intervention ($M = 3.82$), $t(77) = 4.60, p < .02$, two-tailed. No significant differences were observed between Time 0 and Time 1, or Time 2 and Time 3. Figure 3.11 indicates a constant pattern of feel good days between baseline and the beginning of the intervention (T0-T1) followed by a decrease in feel good days from week 1 to week 7 of the intervention (T1-T2). This decrease was sustained over the 6 months to follow-up (T2-T3). It was hypothesized (H9), that the total number of feel good days reported by the intervention group would increase over the duration of the intervention, as this was not the case in the present sample, the hypothesis is rejected.

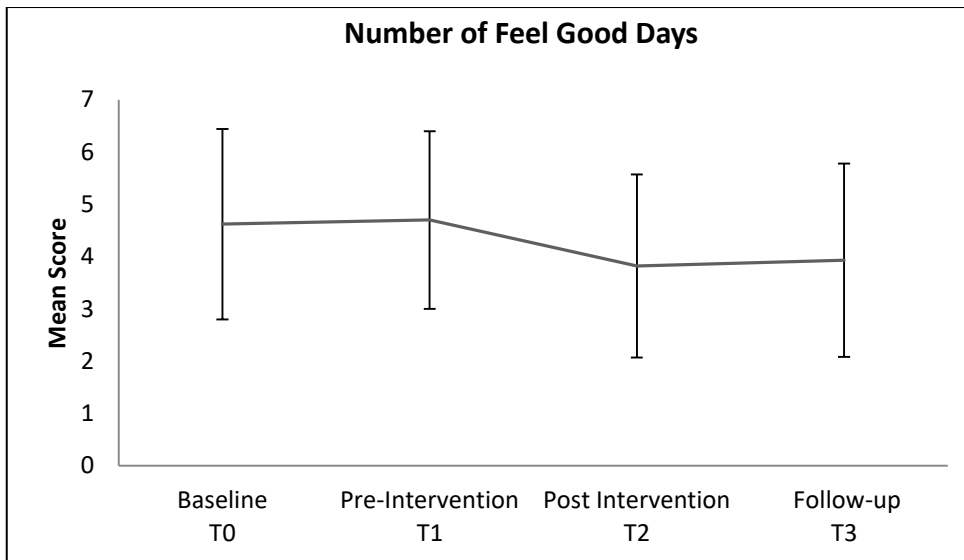


Figure 3.11: Mean Number of Feel Good Days for Intervention Group Time 0, Time 1, Time 2 and Time 3. Error bars represent standard deviations.

3.5.2.4 Pain Locus of Control

3.5.2.4.1 Internal Control

The results show that total internal control scores differ significantly across time points, $F(2.47, 190.33) = 8.93, p < .001, \eta^2 = .10$. Paired samples t-tests indicated a significant increase in total internal control scores between pre-intervention ($M = 21.76$) and post-intervention scores ($M = 24.37$), $t(77) = -4.32, p < .02$. There were no significant differences between Time 0 and Time 1, or Time 2 and Time 3. Figure 3.12 shows a steady pattern of internal control scores between baseline and the beginning of the intervention (T0-T1) followed by an increase in internal control scores from week 1 to week 7 of the intervention (T1-T2) and a retainment of that increase over the 6 months to follow-up (T2-T3). As hypothesized (H10), an increase occurred in internal control scores for the intervention group during the course of the wellness intervention.

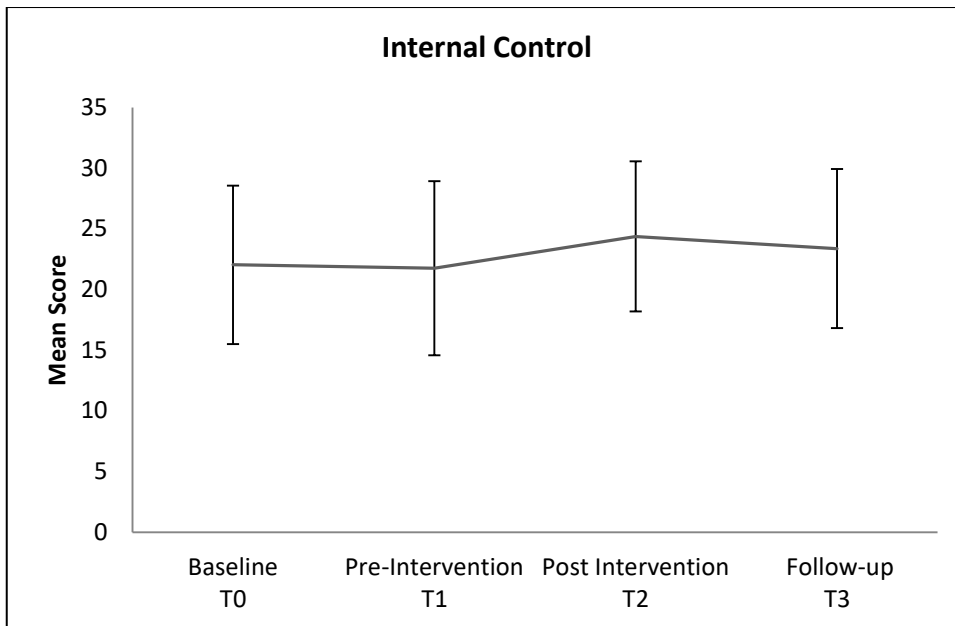


Figure 3.12: Mean Internal Control Scores for Intervention Group Time 0, Time 1, Time 2 and Time 3. Error bars represent standard deviations.

3.5.2.4.2 Matter of Chance

The results show that there was no significant differences in total matter of chance scores across the 4 time points, $F(2.59, 199.39) = 0.31$, $p > .05$, $\eta^2 < .01$; therefore, the hypothesis (H11) that posited a decrease in matter of chance scores for the intervention group is rejected.

3.5.2.4.3 Powerful Others Having Control

The results show no significant differences in powerful others having control across the 4 time points $F(2.68, 207.01) = 1.55$, $p > .05$, $\eta^2 = .02$. The hypothesis (H12) stating a decrease in scores would be observed in powerful others having control for the intervention group is therefore rejected.

3.5.2.4.4 Doctors Having Control

The results show that there were no significant differences in total doctors having control scores across the 4 time points, $F(3,231) = 0.41$, $p > .05$, $\eta^2 < .01$; therefore the hypothesis (H13) postulating a decrease in doctors having control scores the intervention group must be rejected.

3.5.2.4.5 Other People Having Control

The results show no significant differences in other people having control across the 4 time points, $F(2.62, 202.41) = 1.77$, $p > .05$, $\eta^2 = .02$. A decrease in other people having control scores for the intervention group was hypothesized (H14): the hypothesis was rejected.

3.5.2.5 *Summary of Findings*

Several significant findings emerged from the analyses of the longitudinal data. No significant changes were observed from baseline to week one of intervention across measures for the intervention group. Overall, the wellness intervention had a positive impact on measures of self-efficacy, pain acceptance, activities engagement, impact of illness and internal control. Increases were observed in self-efficacy, chronic pain acceptance, activities engagement and internal control, while decreases were observed across all subscales of FIQ - impact of illness, impairment and number of days missed form work. Physical functioning scores and total number of feel good days differed across time points with a significant decrease observed on each of these subscales over the course of the intervention.

3.5.3 Comparison Study Data Analyses

A comparison of Time 1 to Time 3 Scores was completed on all measure total scores and subscales. Means and Standard Deviations are presented in Table 3.3.

3.5.3.1 General Self-Efficacy

3.5.3.1.1 Total Self-Efficacy Scores

Results show that there was a significant main effect of time $F(1.73, 218.01)=17.74, p<.001, \eta^2=.12$, such that there an increase in self-efficacy scores occurred across time points. While no main effect for group was observed $F(1, 126)=1.34, p>.05, \eta^2=.01$, these findings should be interpreted in light of a significant interaction between time and group, $F(1.73, 218.01)=5.15, p<.05, \eta^2=.03$.

Three independent samples t-tests were conducted to investigate potential effect of group on time; however, no effect of group was observed at Time 1, $t(126)=0.105, p>.01$ two tailed, Time 2, $t(126)=-1.84, p>.01$ two tailed or Time 3, $t(126)=.101, p>.01$ two tailed.

Two repeated measures ANOVAs were conducted to investigate potential change across the 7 week intervention for each group separately. No significant differences emerged across time points for the comparison group. A significant effect was observed in the intervention group: $F(1.50,116.17)=26.66, p<.01, \eta^2=.25$. Three independent samples t-tests indicated a significant increase in self-efficacy scores from Time 1 ($M = 28.62$) to Time 2 ($M = 30.91$), $t(77) = -5.83, p<.003$, two-tailed, which were the immediate pre-intervention to immediate post intervention scores

and from Time 1 to Time 3 ($M = 30.97$), $t(77) = -5.40$, $p < .003$, two-tailed, which were week 1 of intervention to end of 6 month follow-up scores. No significant differences were observed between Time 2 and Time 3, which were week 7 of intervention to the end of the 6 month follow up. Figure 3.13 illustrates the interaction between time and group for self-efficacy. As hypothesized (H15), the intervention group show more significant gains than the comparison group on measures of self-efficacy.

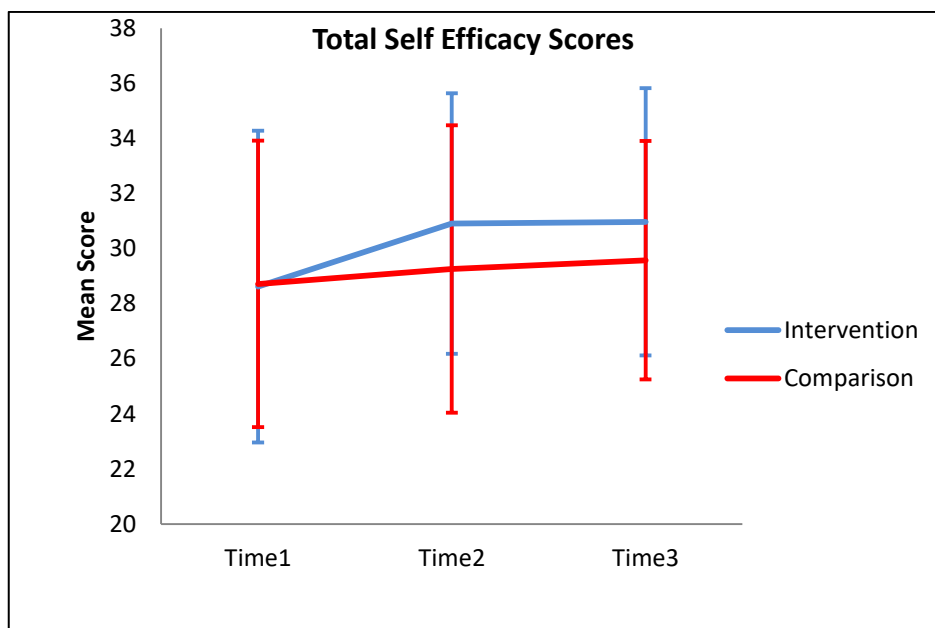


Figure 3.13: Illustration of the interaction between time and group for Total Self-Efficacy Scores. Error bars represent standard deviations

3.5.3.2 Chronic Pain Acceptance

3.5.3.2.1 Total Pain Acceptance Scores

Results show a significant main effect of time $F(1.79, 224.43) = 13.91$, $p < .001$, $\eta^2 = .10$, such that there was a significant increase in total chronic pain acceptance scores. No main effect for group was observed $F(1, 126) = 0.085$, $p > .05$ and there was no significant interaction between time and group, $F(1.79, 224.43) = 2.81$, $p > .05$.

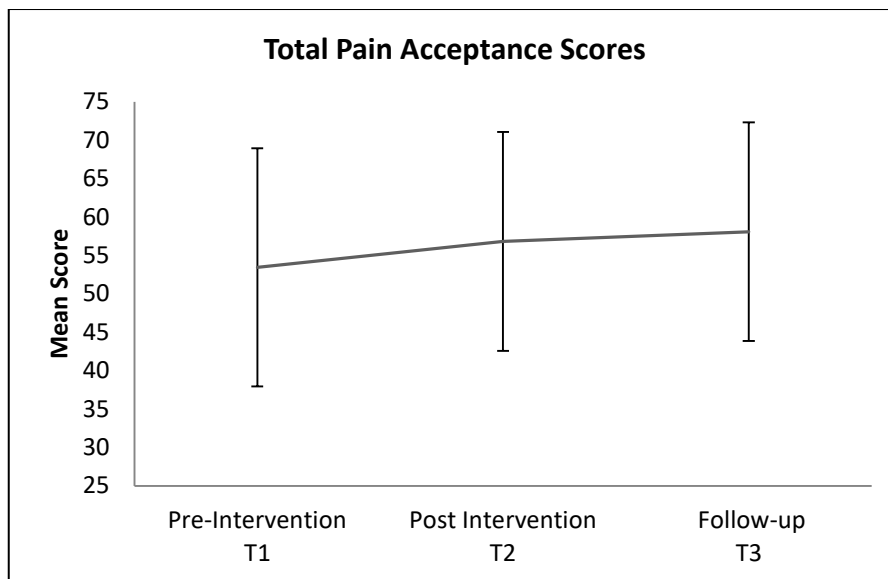


Figure 3.14: Mean Pain Acceptance Scores at Time 1, Time 2 and Time 3. Error bars represent standard deviations.

Paired samples t-tests identified that this effect was due to a significant increase in pain acceptance scores between Time 1 ($M = 53.43$) and Time 2 ($M = 56.81$), $t(127) = -3.68$, $p < .02$, two-tailed; between Time 1 and Time 3 ($M = 58.08$), $t(127) = -5.18$, $p < .02$, two-tailed, but no significant difference between Time 2 and Time 3. Figure 3.14 illustrates an increase in pain acceptance scores from Time 1 to Time 2 followed by maintenance of that increase over the 6 month follow up, Time 2 to Time 3. The hypothesis (H16) stated the intervention group would show more significant gains than the comparison group on measures of pain acceptance; the hypothesis is rejected.

3.5.3.2.2 Total Activities Engagement Scores

Results show a significant main effect of time $F(1.77, 221.64) = 12.26$, $p < .001$, $\eta^2 = .08$. There was a significant increase in total activities engagement scores across time points. While no main effect for group was observed $F(1, 126) = 0.54$, $p > .05$,

$\eta^2 < .01$, these findings should be interpreted in light of a significant interaction between time and group $F(1.77, 221.64) = 6.53, p < .005, \eta^2 = .05$.

Three independent samples t-tests were conducted to investigate potential effect of group on time; however, no effect of group was observed at Time 1, $t(126) = .305, p > .01$, Time 2, $t(126) = -1.78, p > .01$ or Time 3, $t(126) = -1.77, p > .01$.

Two repeated measures ANOVAs were conducted to investigate potential change across the 7 week intervention for each group separately. No significant differences emerged across time points for the comparison group. A significant effect for time was observed in the intervention group, $F(1.67, 128.71) = 20.41, p < .01, \eta^2 = .21$. Three independent samples t-tests indicated a significant increase in activities engagement from Time 1 ($M = 34.96$) to Time 2 ($M = 40.01$), $t(77) = -4.66, p < .003$, two-tailed, which were the week 1 to week 7 scores, and from Time 1 to Time 3 ($M = 40.27$), $t(77) = -5.44, p < .003$, two-tailed, which were week 1 of intervention to end of 6 month follow-up scores. No significant differences were observed between Time 2 and Time 3, which were week 7 of intervention to the end of the 6 month follow up. Figure 3.15 illustrates the interaction between time and group for activities engagement scores as measured on the Chronic Pain Acceptance Questionnaire. As hypothesized (H17), the intervention group exhibited more significant gains than the comparison group on measures of activities-engagement

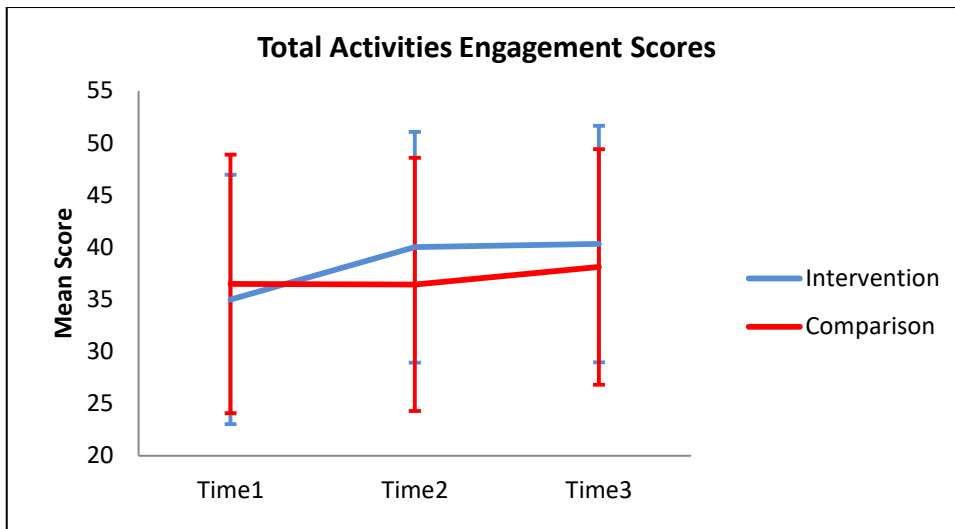


Figure 3.15: Illustration of the interaction between Time and Group for Activities Engagement Scores.

Error bars represent standard deviations

3.5.3.2.3 Total Pain Willingness Scores

Results show no significant main effect of time in total pain willingness scores, $F(1.78, 224.53) = 2.66, p > .02$. No main effect for group was observed, $F(1, 126) = 3.41, p > .05$, and there was no significant interaction between time and group, $F(1.78, 224.53) = 2.99, p > .05$. The hypothesis (H18) that the intervention group would display more significant gains than the comparison group on measures of pain willingness is rejected.

3.5.3.3 Fibromyalgia Impact

3.5.3.3.1 Impact of illness

Results show that there was a significant main effect of time: $F(2, 252) = 8.63, p < .001, \eta^2 = .06$. There was no main effect for group, $F(1, 126) = 0.004, p > .05$ and there was no significant interaction between time and group, $F(2, 252) = 2.77, p > .05$.

Paired samples t-tests identified that this effect was due to a significant decrease in impact of illness scores between Time 1 ($M = 68.59$) and Time 2 ($M = 63.82$), $t(127) = 3.84$, $p < .02$, two-tailed; between Time 1 and Time 3 ($M = 63.28$), $t(127) = 3.87$, $p < .02$, two-tailed, but no significant difference between Time 2 and Time 3. Figure 3.16 illustrates a decrease in impact of illness scores from Time 1 to Time 2 followed by preservation of that decrease from Time 2 to Time 3. The hypothesis (H19) that the intervention group would exhibit more significant declines than the comparison group on measures of impact of illness is rejected.

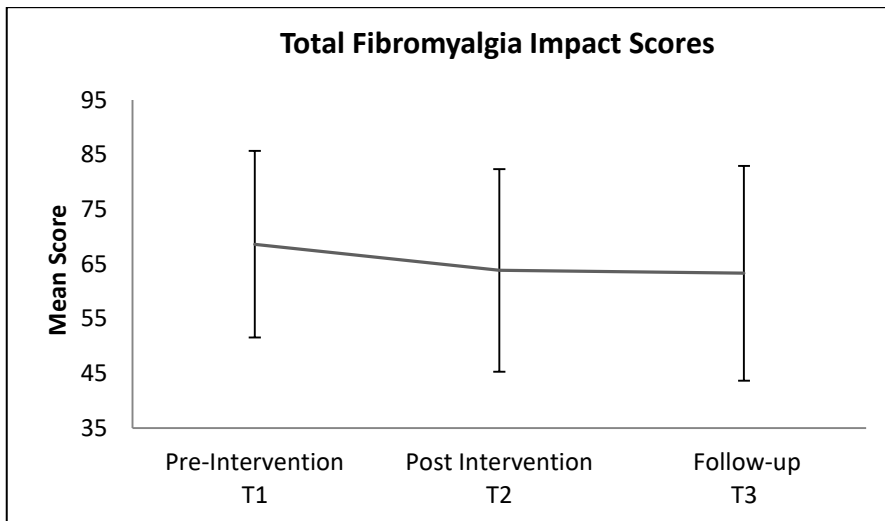


Figure 3.16: Mean Fibromyalgia Impact Scores at Time 1, Time 2 and Time 3. Error bars represent standard deviations.

3.5.3.3.2 Impairment Scores

Results show that there was a significant main effect of time, $F(1.89, 238.88) = 6.99$, $p < .005$, $\eta^2 = .05$. No main effect for group was observed, $F(1, 126) = 0.094$, $p > .05$ and there was no significant interaction between time and group, $F(1.89, 238.88) = 2.41$, $p > .05$.

Paired samples t-tests identified that this effect was due to a significant decrease in impairment scores between Time 1 ($M = 48.43$) and Time 2 ($M = 42.57$), $t(127) = 3.45$, $p < .02$, two-tailed; between Time 1 and Time 3 ($M = 42.26$), $t(127) = 3.56$, $p < .02$, two-tailed, but no significant difference between Time 2 and Time 3. Figure 3.17 illustrates a decrease in total impairment scores from Time 1 to Time 2 followed by maintenance of that decrease between Time 2 and Time 3, the hypothesis (H20) positing that the intervention group would show more significant declines than the comparison group on measures of impairment is therefore rejected.

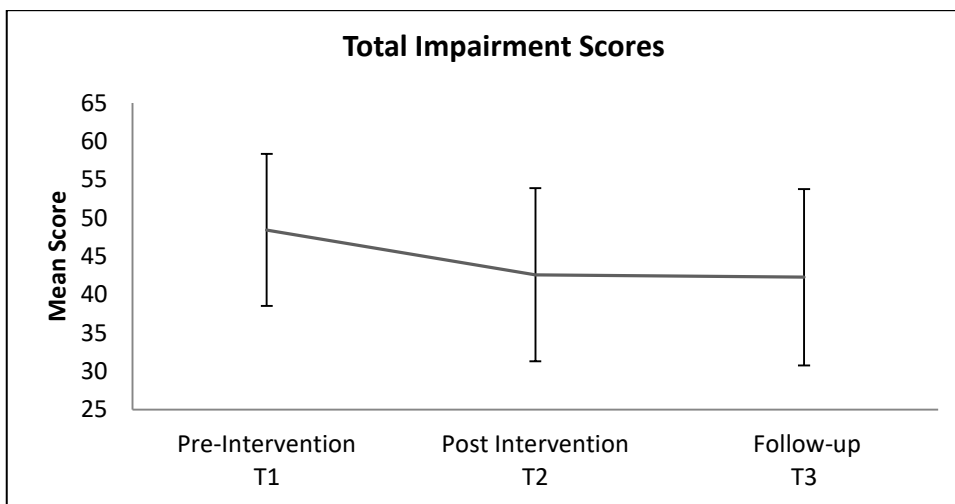


Figure 3.17: Mean Impairment Scores at Time 1, Time 2 and Time 3. Error bars represent standard deviations.

3.5.3.3.3 Physical Functioning

Results show no significant main effect of time in total physical functioning scores, $F(1.76, 221.91) = 2.29$, $p > .05$. No main effect for group was observed, $F(1, 126) = 0.22$, $p > .05$ and there was no significant interaction between time and group, $F(1.76, 221.91) = 1.63$, $p > .05$. The intervention group failed to show more significant

gains than the comparison group on measures of physical functioning thus, the hypothesis (H21) cannot be accepted.

3.5.3.3.4 Total Days Missed from Work

Results show no significant main effect of time in total days missed from work, $F(1.76, 222.28) = 2.17, p > .05$. No main effect for group was observed, $F(1, 26) = 0.01, p > .05$, and there was no significant interaction between time and group, $F(1.76, 222.28) = 0.92, p > .05$. Therefore, the hypothesis (H22), that the intervention group would demonstrate more significant declines than the comparison group on total number of days missed from work is rejected.

3.5.3.3.5 Total Feel Good Days

Results show that there was a significant main effect of time, $F(2, 252) = 12.28, p < .001, \eta^2 = .08$. No main effect for group was observed, $F(1, 126) = 0.1, p > .05$ and there was no significant interaction between time and group, $F(2, 252) = 0.98, p > .05$.

Paired samples t-tests identified that this effect was due to a significant decrease in feel good days between Time 1 ($M = 4.60$) and Time 2 ($M = 3.85$), $t(127) = 4.95, p < .02$, two-tailed; between Time 1 and Time 3 ($M = 3.99$), $t(127) = 3.89, p < .02$, two-tailed, but no significant difference between Time 2 and Time 3. Figure 3.18 illustrates a decrease in total number of feel good days from Time 1 to Time 2 followed by maintenance in such scores from Time 2 to Time 3. The hypothesis (H23), that the intervention group would show more significant gains than the comparison group on total number of feel good days is rejected.

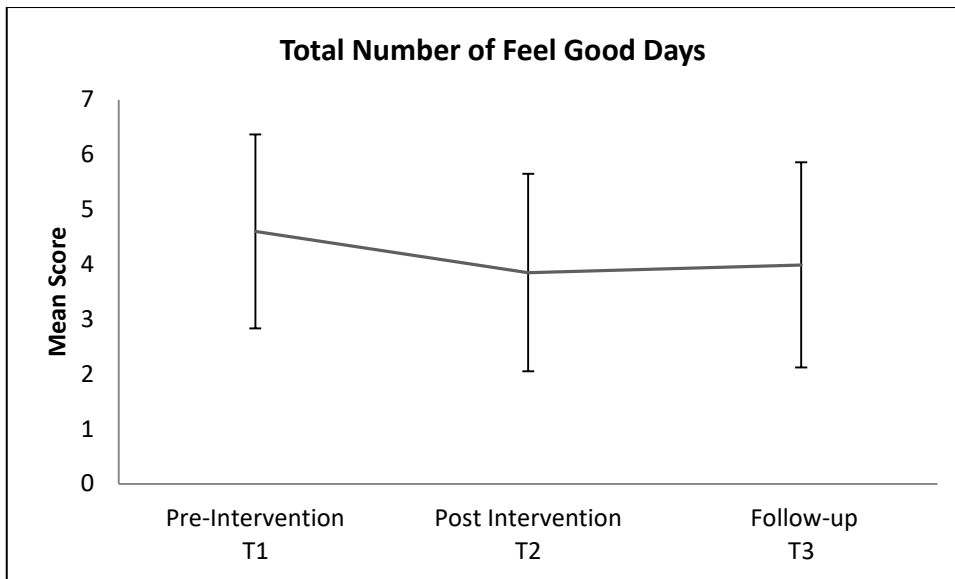


Figure 3.18: Total Number of Feel Good Days at Time 1, Time 2 and Time 3. Error bars represent standard deviations.

3.5.3.4 Pain Locus of Control

3.5.3.4.1 Internal Control

Results show that there was a significant main effect of time, $F(1.82, 230.43) = 5.19$, $p < .05$, $\eta^2 = .04$ such that there was a significant increase in internal control scores across time points. No main effect for group was observed, $F(1, 126) = 1.35$, $p > .05$. However, the results should be interpreted in light of a significant interaction between time and group, $F(1.82, 230.43) = 4.66$, $p < .05$, $\eta^2 = .03$.

Three independent samples t-tests were conducted to investigate potential effect of group on time, however, no effect of group was observed at Time 1, $t(126) = 0.305$, $p < .01$, Time 2, $t(126) = -1.78$, $p < .01$ or Time 3, $t(126) = 1.77$, $p < .01$.

Two repeated measures ANOVAs were conducted to investigate potential change across the 7 week intervention for each group separately. No significant

differences emerged across time points for the comparison group. A significant effect time was observed in the intervention group, $F(1.72,132.44)=10.17$, $p<.01$, $\eta^2=.11$. Three independent samples t-tests indicated a significant increase in internal control scores from Time 1 ($M = 21.76$) to Time 2 ($M = 24.37$), $t(77) = -4.32$, $p<.003$, two-tailed, which were the immediate pre-intervention to immediate post intervention scores.

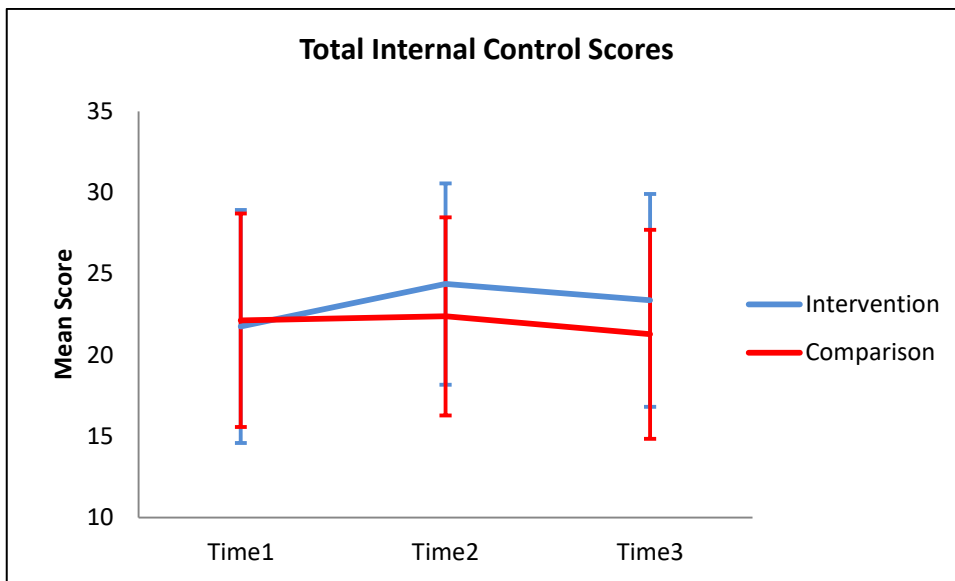


Figure 3.19: Illustration of the interaction between Time and Group for Total Internal Control Scores. Error bars represent standard deviations.

No significant differences were observed between other time points. Figure 3.19 illustrates the interaction between time and group for internal control scores. As hypothesized, (H24), the intervention group exhibited more significant gains than the comparison group on measures of internal control; therefore, the hypothesis is supported.

3.5.3.4.2 Matter of Chance

Results show no significant main effect of time in matter of chance scores, $F(1.82, 230.03) = 0.38, p > .05$. No main effect for group was observed, $F(1, 126) = 1.32, p > .05$ and there was no significant interaction between time and group, $F(1.82, 230.03) = 1.07, p > .05$. The hypothesis, (H25) that the intervention group will show more significant declines than the comparison group on measures of matter of chance is rejected.

3.5.3.4.3 Powerful Others Having Control

Results show no significant main effect of time in powerful others having control, $F(1.80, 227.39) = 0.83, p > .05$. No main effect for group was observed, $F(1, 126) = 0.074, p > .05$ and there was no significant interaction between time and group, $F(1.80, 227.39) = 0.128, p > .05$. The hypothesis, (H26), that the intervention group would display more significant declines than the comparison group on measures of powerful others having control is rejected.

3.5.3.4.4 Doctors Having Control

Results show no significant main effect of time doctors having control scores, $F(1.88, 237.95) = 0.253, p > .05$. A main effect for group was observed, $F(1, 126) = 0.485, p < .05$ and there was no significant interaction between time and group, $F(1.88, 237.95) = 0.126, p > .05$. The hypothesis (H27) that the intervention group would attain more significant declines than the comparison group on measures of doctors having control is rejected.

3.5.3.4.5 Other People Having Control

Results show no significant main effect of time in other people having control, $F(1.73, 218.74)=0.890, p>.05$. No main effect for group was observed, $F(1, 126)=.242, p>.05$ and there was no significant interaction between time and group, $F(1.73, 218.74)=0.254, p>.05$. The hypothesis, (H28) that the intervention group would show more significant declines than the comparison group on measures of other people having control is rejected.

3.5.3.5 Summary of Findings

Several significant findings emerged from the between group analyses. Overall, in comparison to the comparison group, the wellness intervention had significant effects on measures of self-efficacy, activities engagement and internal control. A significant main effect for time emerged for chronic pain acceptance, where an overall increase in scores was observed, and impact of illness scores, impairment scores and total number of feel good days, where an overall decrease in scores was observed. No significant changes occurred for physical functioning, days missed from work, pain willingness, matter of chance, powerful others having control, doctors having control or other people having control.

3.5.3.6 Summary of As Treated Analyses

In addition to a primary 'intention to treat' (ITT) method of analysis, a secondary analysis employing an 'as treated' (ATA) was undertaken. Results from the as treated analysis can be seen in their entirety in Appendix 6.

3.5.3.6.1 Longitudinal Study Data Analyses

Results from longitudinal data revealed increases in self-efficacy, chronic pain acceptance, activities engagement and internal control and decreases in impact of illness, impairment and feel good days. No significant findings emerged for pain willingness, physical functioning, number of days missed from work, matter of chance, powerful others having control, doctors having control and other people having control. Overall, the main difference between the results obtained through ATT analysis and those obtained through ITT analysis can be seen in the outcomes from the FIQ. ITT analysis showed significant differences on all subscales of the FIQ, while ATT failed to show significance on total number of days missed from work and physical functioning. Thus, it is suggested that ITT analyses provided the more meaningful results.

3.5.3.6.2 Comparison Study Data Analyses

Comparison of the intervention and comparison groups revealed an interaction effect only for self-efficacy scores. A main effect for time emerged for chronic pain acceptance, activities engagement, impact of illness, impairment, total number of feel good days and internal control. No significant changes occurred for pain willingness, physical functioning, number of days missed from work, matter of chance, powerful others having control, doctors having control or other people having control.

3.6 Discussion

As it is the first time WRAP® has been investigated as a management option for fibromyalgia, this study provided novel data pertaining to the utility of a WRAP® informed intervention in the self-management of the condition. Overall the intervention was associated with significant improvements on self-efficacy, chronic pain acceptance, internal control, and impact of illness and health behaviours. Although effects were small, three interaction effects emerged (self-efficacy, activities engagement, and internal control) and the intervention group had greater improvements than the comparison group on these three self-reported measures. In addition, all changes in scores that did occur over time were statistically significant and all, with the exception of Total number of feel good days and Physical Functioning scores were in the desired direction.

Enhanced levels of self-efficacy were observed in analysis of both the longitudinal analysis and the comparison analysis. As hypothesized (H1), an increase was observed for the intervention group on measures of self-efficacy. Similarly, as hypothesized (H15), the intervention group showed significant gains across time points while no significant differences were noted for comparison group on measures of self-efficacy. Wellness Recovery Action Planning (WRAP®) is a self-management programme in which participants identify internal and external resources to support their wellness and recovery. It aims to increase participants' sense of personal responsibility and empowerment. Previous evaluative studies employing WRAP® have measured attitudes, knowledge and beliefs in relation to recovery (Higgins et al., 2012), hope (Fukui et al., 2011), self-advocacy and social support (Cook et al., 2009),

and quality of life (Tierney et al., 2011). However, this is the first evaluation of WRAP® to include a measure of self-efficacy.

A recent meta-analysis (Häuser, Bernardy, Arnold, Offenbächer & Schiltenwolf 2009) provided strong evidence that multi-component treatment reduces fatigue, pain and depressive symptoms and improves self-efficacy for pain and physical fitness immediately post-treatment. Stuifbergen et al. (2009) in a randomized controlled trial of an 8 week wellness intervention for women with fibromyalgia ($N = 187$), found significant increases in self-efficacy, fibromyalgia impact, health behaviours and quality of life. Sahar et al. (2015), in a study with 117 participants examined the role of positive factors in adjustment to fibromyalgia highlighted self-efficacy and the positive impact it has on pain intensity in terms of psychological, functional, and total adjustment to fibromyalgia. Based on the promising results of such studies, this study tested the empirically based WRAP® programme to promote the health of women with fibromyalgia with a specific purpose of establishing whether the Wellness in Fibromyalgia Intervention would enhance participant's self-efficacy for health behaviours.

Self-efficacy is posited in social cognitive theory as fundamental to behaviour change. It is concerned with people's beliefs in their capabilities to carry out behaviour necessary to reach a desired goal and achieve an expected outcome (Bandura, 1997). According to social cognitive theory, the potential for a behaviour to occur increases as an individual's self-efficacy for the behaviour increases. In the context of illness management, chronic disease self-management is improved with self-efficacy (Farrell, Wicks & Martin, 2004). Patients in the intervention group in this

study showed significant improvements in self-efficacy scores over time, a promising finding given the existing evidence that self-efficacy is a mediating variable between self-reported pain and depression and functional limitation (Puente et al., 2015).

It was hypothesized (H2) that an increase would be observed for the intervention group in pain acceptance scores and that the intervention group would show more significant gains than the comparison group on measures of pain acceptance (H16). While an increase was observed overall, no main effect for time or group was observed, nor was there a significant interaction effect. When compared, however the intervention group alone did demonstrate a significant increase in pain acceptance scores. Acceptance of chronic pain involves the individual reducing unsuccessful attempts to control or avoid pain and focussing instead on the pursuit of personally relevant goals and participation in valued activities (McCracken et al., 2004). Research to date employing WRAP® has focused on mental health management and has not measured this construct. The current findings are therefore promising for the intervention's empirical status not just in the area of mental health but across the many chronic illnesses that have been shown to benefit from heightened levels of acceptance such as cancer (Thompson et al., 2009), chronic fatigue syndrome (Van Damme, Crombez, Van Houdenhove, Mariman & Michielsen, 2006) and chronic pain (McCracken & Eccleston, 2003). It is therefore suggested that promoting acceptance in patients with fibromyalgia may prove more beneficial than trying to control what are largely uncontrollable symptoms.

Pain willingness, the recognition that avoidance and control are often unworkable methods of adapting to chronic pain, forms a central part of acceptance

(McCracken et al., 2003). This subscale has higher correlations with overall psychological inflexibility and fear of movement, injury or re-injury than the activities engagement subscale (Fish, Hogan, Morrison, Stewart & McGuire, 2013) and has been proven to moderate and partially mediate the influence of pain intensity on physical quality of life (Elander, Robinson, Mitchell & Morris, 2009). In the current study, no significant difference was observed in pain willingness in either the longitudinal data or the comparison data and the follow-up interviews (refer to Chapter 4) revealed the intervention failed to impact upon pain levels, a finding that could be explained by the unchanged levels of pain willingness. Similar findings relating to unchanged pain levels in fibromyalgia were reported by Cedraschi et al. (2004) following an evaluation of the efficacy of a treatment programme based on self-management, exercise and education.

It was hypothesised (H10) that an increase would be observed in internal locus of control scores for the intervention group and that the intervention group would show more significant gains than the comparison group on measures of internal control (H24). Within group analyses demonstrated significant gains on internal locus of control for the intervention group. A comparison of the two groups saw an interaction effect emerge: the observed increases in internal control for the intervention group only.

Behavioural scientists (e.g., Arraras, Wright, Jusue, Tejedor & Calvo, 2002; Crisson & Keefe, 1988) have long been interested in how an individual's locus of control relates to coping and adjustment in chronic pain management. Locus of control for pain refers to patients' perceptions about their personal ability to control

pain. In studies of patients with chronic rheumatologic pain conditions, a stronger belief in internal locus of control for pain has been associated with lower levels of psychological and physical symptoms, and a better response to therapy (Crisson & Keefe, 1988; Gibson and Helme, 2000; Lipchik, Milles & Covington, 1993). In studies of fibromyalgia patients, internal locus of control has been associated with reduced symptom severity, better affect and less disability in upper and lower extremity function (Pastor et al., 1993) and generally improved levels of functional status (McCarbeg et al., 2002).

Research (e.g., Benson & Deeter, 1992) suggests that persons with an internal locus of control are better adjusted than persons with an external locus of control. Research (e.g., Crisson & Keefe, 1988) has also shown that patients who viewed outcomes as controlled by chance factors tend to rely on maladaptive pain coping strategies. In addition, patients who score highly on chance locus of control reported feeling helpless to deal effectively with their pain problems. Results relating to the locus of control construct in the present study show that the Wellness in Fibromyalgia Intervention confirmed the programmes efficacy in increasing internal locus of control, a promising result for patients diagnosed with this condition given its potential in promotion of adjustment to chronic illness.

It was hypothesised that a decrease across external locus of control subscales (matter of chance, powerful others, doctors having control or other people having control) would be observed however, no significant changes emerged, participants external control levels remained unchanged indicating a cohort of individuals who are more internally than externally orientated. This finding is a significant one as research

has shown that an individual with more internal beliefs is more likely to (a) be more attentive to those aspects of the environment which provide useful information for their future behaviour; (b) take steps to improve their environmental condition; (c) place greater value on skill or achievement and be generally more concerned with their ability, giving due attention not just to their abilities but also their limitations; and (d) be resistive to subtle attempts to influence them (Rotter & Hochreich, 1975).

It was hypothesized (H3) that an increase on activities engagement scores would be observed for the intervention group ,and that the intervention group would show more significant gains than the comparison group on measures of activities-engagement (H17). In each of these instances, significant increases in activities engagement were observed. Post-hoc analyses highlighted that those who took part in the intervention increased their engagement in valued activities. Recovery is based on the assumption that one can establish and lead a meaningful and successful life whether or not there are on-going or recurring symptoms. Cook et al (2012), in a study examining the impact a WRAP® programme on a cohort of mental health service users found that engagement in the WRAP® programme as opposed to usual treatment only led to an increase on quality of life measures. The ability to re-engage with what are deemed to be valued activities can have a positive impact on the quality of life of the individual thus it seems reasonable to infer that where an increase in activities engagement is observed, overall improvements in quality of life will ensue. Results from this study support previous findings pertaining to activities engagement. Activities engagement has been shown to correlate with an increased level of self-

efficacy and general acceptance (Fish et al., 2013), variables where significant increases were observed in the present study.

The FIQ is an assessment instrument developed to measure fibromyalgia patient status, progress and outcomes and was designed to specifically measure the components of health status that are believed to be most affected by the condition (Burckhardt et al., 1991). An overall significant decrease across the time points was observed in impact of illness; impairment and total number of feel good days. The longitudinal analyses showed a decrease on all subscales of the measure; hence while impairment, impact of illness and number of days missed from work decreased in the intervention group, so too did physical functioning and number of feel good days. In terms of the recorded decrease in number of feel good days, a number of factors may have contributed to the reported decrease. It could be proposed that the effort taken to attend and actively participate in the intervention over the period of seven weeks compromised the participants wellness, in other words, the decrease may be accounted for in terms of the increase in demands on the participants both physically and otherwise across the duration of the intervention. While this possibility was given due consideration, it must be reiterated that impact of illness, number of days missed from work and overall impairment showed significant increases therefore, it is proposed that, it is more likely that the participants reached a more realistic appraisal of their illness and understanding of their limitations and this contributed to the decrease reported by the intervention group. This unanticipated finding is similar to that of Cook et al. (2009) who reported an unexpected finding of a decrease in empowerment scores post WRAP[®] intervention in a group of 108 individuals with

serious mental illness. In this case, it was proposed that WRAP® promoted more realistic appraisals of the low levels of control people with mental illness have over their lives, resulting in lower self-perceived empowerment even in the presence of enhanced hopefulness, recovery and self-advocacy.

The Wellness in Fibromyalgia Intervention advocates the use of activity pacing through the goal setting process and the development and implementation of a daily maintenance list. The decrease in physical functioning may be a result of the intervention group having a more realistic approach to physical activities, a skill attained through the content of the programme that serves to promote the notion of the planning and pacing of upcoming activities and events. In other words, those who took part in the intervention may have made a conscious decision to cut back on their usual level of activities or employ activity pacing as a means to facilitate their attendance on the course and to manage their condition, a strategy that a number of the participants spoke about in the follow-up interviews completed with the intervention group (refer to Chapter 4). This finding corresponds with that of Nielson, Jensen and Hill (2001), who proposed that the extent to which fibromyalgia patients pace their activities is related to their overall level of physical impairment. The fact that positive gains were observed in the group on impact of illness and overall impairment would support further the proposition that participants were employing activity pacing as a means of illness management.

3.6.1 Clinical implications

The study empirically confirmed that a WRAP® informed intervention enhanced the overall wellbeing (i.e. activities engagement, illness impairment, impact

of illness and number of days missed from work), and self-management skills (i.e. self-efficacy, acceptance and internal control) in this patient group. WRAP® was originally designed to manage mental health but this study suggests that it has the potential to be a feasible management tool for fibromyalgia patients. Furthermore, given the programme promotes successful management of fibromyalgia, this research presents a possibility that the WRAP® programme could be adapted for other chronic illnesses.

WRAP® has demonstrated efficacy in the self-management of many chronic mental health conditions and the adapted Wellness in Fibromyalgia Intervention has shown great promise for patients living with a diagnosis of fibromyalgia. Given the universal need for strategies to help patients with chronic disabling conditions to promote self-management, and the easily adaptable framework provided with the Wellness in Fibromyalgia intervention, it is suggested that future research should seek to establish if adapting the programme to suit the informational needs of alternative patient groups would have clinical implications on the self-management of other chronic illnesses. This could be done for patients with rheumatoid arthritis, polymyalgia rheumatica, chronic fatigue syndrome or lupus; just some chronic conditions that share similar features with fibromyalgia.

3.6.2 Limitations

Findings from the wellness intervention that was specifically adapted for individuals with fibromyalgia should be interpreted with caution because of the convenience sample and the potential for selection bias. Although participants were recruited using online advertising and flyers, it seems likely that individuals responding to the recruitment call for a wellness study may have been more

interested in health behaviours and self-management than other fibromyalgia patients, and therefore more likely to initiate positive change, a bias similarly encountered by Higgins et al. (2012).

Given the comorbidity between fibromyalgia and anxiety and depression, it would have been of value to include a measure for one or both in the battery of questionnaires. A quality of life measure would also have been advantageous in allowing the researcher establish if the intervention impacted on overall quality of life of the patient, a construct that is negatively affected by fibromyalgia. Furthermore, a satisfaction survey was not included in the current research. The opportunity to gather rich data relating to the programme - duration, intensity, content, and effectiveness of the facilitator was lost and such feedback would have provided the impetus and evidence for potential adjustments to the programme in the future. A further limitation of the present study is generalizability, the programme recruited participants only from the Midlands and Dublin rather than a nationally representative population. Additionally, the overall number of participants who completed the follow-up questionnaires at the 6 month follow-up was smaller than expected.

A key limitation was the study did not employ multi-level modelling to take account of the fact there were three facilitators. Therefore it cannot be ruled out that the approach, knowledge and style of delivery adopted by each of the facilitators may have potentially impacted upon the results obtained.

3.6.3 Future Research

Despite the limitations of the current research, this is the first study to test the effectiveness of a WRAP® informed intervention on the self-management of fibromyalgia. According to Mullen and colleagues (Mullen, Green & Persinger, 1985; Mullen, Mains & Velez, 1992), the quality of an intervention is a key determinant of the effectiveness of patient education programmes. Based on two meta-analyses, these authors defined five fundamental principles central to ensuring a quality intervention: (1) *relevance*: tailoring the programme to circumstances, knowledge and beliefs of the participants; (2) *individualization*: allowing participants to have their own individual queries answered or pacing their instructions to meet their individual needs; (3) *feedback*: providing feedback to participants on their level of achievement; (4) *reinforcement*: rewarding the behaviour in ways other than feedback (e.g. social support); and (5) *facilitation*: providing a way for the participant to reduce barriers and/or take action. Each of these principles was evident in the Wellness in Fibromyalgia intervention. To enhance relevance, the wellness intervention format and content were adapted to meet the needs of the patient group. These adaptations were based on the information that emerged through the focus group meetings (refer to Chapter 2), a review of the literature surrounding the needs of this patient group together with recommendations from the administrator of Fibro Ireland (a support network for individuals with fibromyalgia), who herself has a diagnosis of fibromyalgia. Intervention strategies including provision of personal workbook for each participant, self-directed reflective exercises focusing on health behaviours, personalized goal setting and opportunity for 1:1 discussions with the facilitator

operationalized the important aspects of both individualization and feedback. The development of group support and skill acquisition in relation to such support served to reinforce and facilitate behaviour change.

This is the first study to employ WRAP to build self-efficacy for health behaviours with individuals with fibromyalgia. With this innovative approach to improve functioning, participants had the opportunity in the group setting to develop the knowledge and skills necessary to enact strategies that could support their cognitive and physical functioning. Cedraschi et al. (2004) found improvements in quality of life and control of symptoms in 164 participants in a study evaluating the efficacy of a 6 week treatment programme based on self-management. Stufbergen et al. (2004), in a wellness intervention developed initially for MS patients but adapted for use with fibromyalgia patients, showed a trend toward improved levels of health promotion with participants showing improvement in their self-reported health promoting behaviours. In line with results from such research on self-management programmes this study provides further evidence that reduction in suffering and improved sense of well-being is possible even for people who have experienced pain for many years. Future research should explore whether making further adaptations might generate more powerful positive effects on how the Wellness in Fibromyalgia Intervention might further enhance health-promoting behaviours and related outcomes in fibromyalgia and other chronic disabling conditions.

Activity pacing has been suggested as a behavioural strategy that may protect patients with fibromyalgia against activity dysregulation and disability (Birkholtz, Aylwin & Harman, 2004a). A random sample of patients with fibromyalgia ($N = 409$)

completed the Pain Catastrophizing Scale (PCS), the Physical Index of the Fibromyalgia Impact Questionnaire (FIQ-PH) and the Pain Disability Index (PDI). Results demonstrated that guarding and asking for assistance, but not pacing, were associated with disability. These findings are in line with fear-avoidance models and suggest that active avoidance behaviours are detrimental in fibromyalgia (Karsdrop & Vlaeyen, 2009). It is therefore suggested that pacing has the potential to assume a substantial role in illness management after fibromyalgia patients are taught this skill, a hypothesis that requires further research.

3.6.4 Conclusion

This study provided novel quantitative evidence for the use of a WRAP® informed intervention as a successful approach for the self-management of fibromyalgia. The study provides quantitative evidence linking the use of WRAP® to fibromyalgia and that many promising findings relating to an improvement of health promoting behaviours emerged. The Wellness in Fibromyalgia Intervention started a process of change. The participants learned new strategies for understanding and handling their pain and other symptoms. This initial phase of programme delivery provided some evidence that this intervention can provide fibromyalgia patients with the information that they need to develop skills and may have the potential to influence health promoting behaviours and attitudes that may serve to enhance their overall functioning and quality of life. Overall, the results indicate that WRAP® initially developed for those with mental health conditions may also be used for individuals with fibromyalgia.

The next chapter describes a qualitative examination of the impact of the intervention on fibromyalgia patients in Ireland. The impetus for the use of qualitative methods was to attempt to uncover subjective outcomes of the intervention and the influence it had on the health behaviours of those who completed it that were not captured in the quantitative study described here. The study sought to ascertain whether the participants had continued to utilise the WRAP® plan developed across the seven week intervention. The interviews examined how meaningful the intervention had been in terms of managing the complex nature of their condition.

4 Chapter 4: Overall Impact of the Wellness in Fibromyalgia Programme and Suggestions for Change

“The pain is the same but I’m not” (Theresa, programme participant)

4.1 Introduction

Poorly managed chronic pain generates feelings of distress, hopelessness and despair and can inflict disruption and change upon the individual and their personal, social and vocational functioning (LeFort, Gray-McDonald, Rowat & Jeans, 1998). Treatment and rehabilitation of fibromyalgia is challenging, partly due to an incomplete understanding of the biological origins of the condition, combined with the chronic pain and other invisible symptoms that are typically observed in fibromyalgia patients. Recent evidence suggests that several health promoting behaviours, such as stress management (Kaplan, Goldenberg & Galvin-Nadeau, 1993), and goal setting (Arnold, Clauw, Dunegan & Turk, 2012) may have positive effects on functioning, symptoms, coping and overall wellbeing and quality of life in this patient group.

Modern healthcare involves more than just the detection and treatment of disease, it involves improving functioning, preventing or reducing disability, relieving pain, addressing mental health concerns of the patient and helping the individual to cope with the frequently complex set of symptoms associated with chronic pain, all the while approaching the management in a respectful and empathic manner (Kaplan, 2000). Wellness interventions are focused programmes specifically designed to increase self-care activities resulting in improved physical, psychological and/or

spiritual health (Watt, Verma & Flynn, 1988). Wellness intervention studies have been effective in various samples of individuals with mental health conditions (e.g. Cook et al., 2011), however, despite the need for wellness interventions in other areas of healthcare, few have been tailored to the needs of patients living with chronic pain conditions. Consequently, patients with conditions such as fibromyalgia rarely have the opportunity to participate in such interventions that have the potential to enhance self-management strategies that would promote their health and quality of life.

In the current climate of evidence-based practice, studies evaluating intervention programmes for fibromyalgia patients have so far mainly used quantitative methods. Properly used, a qualitative method is often more appropriate for capturing significant aspects of the individual experience. Qualitative research methods provide the researcher with the capacity to explore the complexity of human behaviour and generate deeper understanding of illness behaviours and therapeutic interactions (Johnson & Waterfield, 2004). Previous research has reported that patients describe wellness and recovery interventions as being positive experiences. In a study evaluating mental health recovery and Wellness Recovery Action Planning in Ireland (Higgins et al., 2012) employed a mixed method approach. Quantitative results showed an increase in participant's knowledge of and attitudes towards recovery and Wellness Recovery Action Planning and qualitative results obtained from post intervention focus groups served to enhance the quantitative findings and provided the views of the participants in relation to their experience of the programme and its impact on their lives. The intervention reportedly served to

invigorate, empower and inspire people and many reported that the completion of the programme was deemed a life changing experience (Higgins et al., 2012). Cook et al. (2010) sought written feedback from participants following participation in a WRAP® intervention for patients with mental illness. Themes relating to participants view of wellness, increased ability to identify and manage stressors and application of WRAP® strategies and skills in everyday life emerged along with a high level of self-reports of programme satisfaction. Such studies enhance knowledge and of and confidence in wellness and recovery interventions.

This chapter explores the subjective experiences of a sample of participants twelve months after receiving a seven week Wellness in Fibromyalgia Intervention. It examines some of the most frequently cited categories and meaning units as well as responses to questions seeking suggestions for changes that could be made to the programme which were aimed at evaluating the calibre of the programme and its relevance to the fibromyalgia patient. Presented within are the qualitative findings from follow-up interviews twelve months post-intervention which have been employed as a means of evaluation.

A key requirement of qualitative enquiry is that the method of analysis chosen must be appropriate to the data gathered and the research questions posed. Qualitative research methods are known by many 'brand names' in which various common elements are matched and combined according to each individual researchers preferences (Miles & Gilbert, 2005). Current variations which have gained popularity include empirical phenomenology (Giorgi, 1975; Wertz, 1983), hermeneutic-interpretive research (Packer & Addison, 1989), interpretative

phenomenological analysis (Smith, Jarman & Osborn, 1999), consensual qualitative research (Hill, Thompson & Williams, 1997) and grounded theory (Henwood & Pidgeon, 1992; Strauss & Corbin, 1998). In line with the opinion postulated by Barker, Pistrang and Elliott (2002), the emphasis on brand names has the potential to be somewhat confusing thus in the qualitative analysis contained within the current thesis, a generic approach; the descriptive interpretative approach (Elliott & Timulak, 2005), that serves to emphasise common methodological practices rather than relatively minor differences is adopted.

The notion of wellness tools, the extent to which patients are utilizing the WRAP® plan developed while participating in the intervention, what wellness means to them, some suggestions for change that they may have in relation to the programme and participant testimonials will be discussed. Self-efficacy, acceptance and goal setting in the context of self-management of fibromyalgia emerge in the narratives of the participants and are also discussed.

4.2 Methods

4.2.1 Participants & Procedure

Patients who completed a Wellness in Fibromyalgia Intervention ($N = 42$) were invited to take part in a follow up interview. Ten individuals agreed to participate. All participants were female. Participants had the option to attend in person or have a telephone interview. Eight participants opted to attend the interview which took place in the School of Psychology, Trinity College Dublin. Two participants opted for phone interviews. Participants were provided with an information sheet prior to

commencing (See Appendix 2) and all give written consent (See Appendix 3). The interviews were digitally recorded (audio only) and upon completion, participants were presented with a debriefing sheet which thanked them for their participation and offered contact numbers if they felt they had been adversely affected by the experience and required further assistance (See Appendix 4). The first author transcribed the interviews using pseudonyms to protect the identities of participants. Interview transcripts are presented in Appendix 11.

The following combination of guiding, open ended questions and more specific closed questions concerning the Wellness in Fibromyalgia Intervention were put to each of the ten participants

1. Can you tell me how you have been since completing the Wellness in Fibromyalgia Course?
2. Can you describe how you have been in general since completing the course?
3. Have you noticed any health changes since completing the course?
4. What impact, if any, has the course had on your fibromyalgia symptoms?
 - Can you give me an example?
5. What impact, If any, has the course had on how you manage your fibromyalgia symptoms?
 - Can you give me an example?
6. What impact, if any, has the course had on your wellness?

- Can you give me an example?
- 7. What do you think of the notion of wellness tools?
- 8. To what extent are you employing the WRAP® plan in your life since completing the Wellness in Fibromyalgia course?
- 9. Tell me about how you are today compared to 1 year ago.
 - a. What is the same?
 - b. What is different?
- 10. What does wellness mean to you?
- 11. What would you change about the Wellness in Fibromyalgia course?

4.2.1.1 Eligibility Criteria

Participants over 18 years of with a diagnosis of fibromyalgia obtained from a registered medical practitioner (GP, Rheumatologist or consultant) and able to give informed consent were considered eligible for this study. No minimum time since diagnosis was set. The eligibility criteria were established through verbal discussion with each of the participants individually at the point of expression of interest and again at the demographic data collection stage. It must have been twelve months since participants completed the Wellness in Fibromyalgia Intervention.

4.2.2 Data Analyses

Data analysis of the post intervention interviews was carried out using a descriptive and interpretive qualitative research method described by Elliott and Timulak (2005). The data were first transcribed verbatim. Transcripts for interviews were subsequently read in their entirety in order for the first author to become familiar with the data. At this juncture redundancies, repetitions and unimportant digressions were removed from the data.

The following steps were observed in the analysis phase of the descriptive-interpretive approach (Elliott & Timulak, 2005): (a) meaning units were delineated (the meaning units are the parts of the data that even if standing out of context would communicate sufficient meaningful information to the reader. These units were logged and categorised throughout the analysis); (b) domains were developed and data are assigned to each of the appropriate domains (domains are broad headings that form an organizing framework for the data and emerged from the research questions the participants were presented with); (c) the creation of categories is an interpretive process and in this instance, the categories were generated from the meaning in the meaning units; (d) the main findings are abstracted (frequently in the form of narratives or figures). The analysis also uses several safeguards that ensure its validity (e.g., triangulation and independent auditing). Categories were audited independently and were cross checked and similar categories were combined. Two main categories emerged in the present analysis (see Table 4.1). Pseudonyms are used when reporting quotes. In the interest of reliability, an independent researcher was involved in the analysis phase.

4.3 Results

The main categories to emerge from the data were: Illness Adjustment (most significant illness adjustments and least significant illness adjustments), Wellness (maintaining wellness through WRAP® and meaning of wellness), and Programme Review (suggestions for change and testimonials).

Table 4.1 : Domains, Categories and Meaning Units

Domain	Categories	Meaning Units
1. Impact of intervention	a) Most significant illness adjustment	Self-management Pacing Goal setting Activities engagement Acceptance
	b) Least significant illness adjustment	Impact on illness Physical functioning
2. The WRAP® Programme	a) Maintaining wellness through WRAP®	Use of toolbox Advantages of toolbox Daily maintenance list
	b) Meaning of Wellness	Definition of wellness Maintaining wellness
	c) Programme Review	Suggestions for change Testimonials

4.3.1 Illness Adjustment

The *Most Significant Illness Adjustment* category contained the following meaning units, self-management, pacing, goal setting and planning, activities engagement and acceptance and an increased sense of personal responsibility.

Participants spoke unequivocally about the positive impact the intervention had on their ability to self-manage their illness. The comments provided an insight into a change in the manner in which the participants both viewed their illness and

also how they now actively participate in the management of the associated symptoms:

I'd be a lot more logical about it, a lot less emotional. Beforehand all of my decisions were impulsive and all emotional, like letting the pain take over, so my decisions are a lot more logical now (Michelle)

I use my tools now. I meet up with my friends and that's a great help to me to have someone to talk to (Sinead)

I mean I can't say that it (the course) has done anything for my symptoms but I'm able to manage them better so that improves my wellness (Suzanne).

Acceptance of pain and the potential disability associated with it has emerged as holding great potential in terms of understanding how some chronic pain patients can be enabled to live a positive life whereby meaningful goals can be set and achieved despite experiencing chronic pain. Throughout the follow-up interviews, participants frequently referred to acceptance and framed their experience of the construct in a considered and meaningful manner:

I know I can't change that I have fibromyalgia therefore I have to deal with learning to live with it... I haven't been able to change it but I've accepted that this is just one of those things and am getting on with it (Charlotte)

I don't notice any changes to my physical health but I do notice a change to the way I'm thinking about things. Acceptance and I notice that I accept the pain I have (Sinead)

Among the key concepts of WRAP® is personal responsibility. According to WRAP®, the patient should strive to become their own expert. This sometimes involves taking back control that may have been lost in the past. An encouraging outcome of the intervention is that for many of the participants, an increased sense of personal responsibility emerged during the interviews:

I kind of feel it's not a case of waiting for the doctors to come up with the right drug, there are actions and behaviours that if I do they can have a positive or negative impact on my fibromyalgia (Maura)

What is different is I'm more focused on getting better and I'm looking actively for things that weren't in my mind set to improve my health situation myself (Sharon)

I was more going, oh God I'm so overwhelmed and I'm in pain and almost expecting someone else to kind of sail in and save the day but I think I've realised that you have to be your own hero... (Michelle)

I know now that I can't changes the fact that I have fibromyalgia but I can live with it. So in other words, my condition hasn't changed but my reaction to it has (Charlotte)

A decreased impact of illness was evidenced in the themes that emerged in the post-intervention interviews. The impact fibromyalgia had on personal relationships was discussed at length by one participant who reflected on the attitude her family had towards her diagnosis of fibromyalgia and how that has subsequently changed:

...my sister used to say to me, you don't have to tell everyone you have fibromyalgia... there was hostility towards it because I wasn't getting better over a certain amount of time... so there was frustration on the part of my parents... I had an uncle who decided I was pretending... (Michelle)

As Michelle proceeded through the interview and began to discuss the impact of the intervention it became clear that there had been a positive change in the relationships in her life post intervention:

My personal relationships with friends and family would be a lot better because I'm no longer, I'm not a burden. They don't have to worry about me... there can be a more normal relationship, we're more equals now...

What has changed is that I take no nonsense from others the way I used to, not from my ex-husband or my daughter. Now, I get on well with my daughter and she's a great help to me (Sinead)

Its impact on levels of knowledge was a discussion point for many of the participants and the themes indicate that acquisition of new knowledge pertaining to their illness was an outcome of the intervention:

I'm able to pinpoint better the points of fibromyalgia (Aoife)

I'm able to distinguish between fibromyalgia and the rest and I wouldn't have been able to do that but now I can (Suzanne)

For some of the participants, the intervention inspired an attitudinal shift:

My mental attitude is different. I know I have been better and I will be better than this again (Theresa)

Definitely a whole attitude change, I'm no longer looking at fibromyalgia as a life sentence; I know it won't be this bad all of the time (Laura)

More positive, I'm more positive and less feeling that I didn't really have an illness that people weren't going to recognise and I feel more positive about that (Suzanne)

I think it's a change in attitude; you just go with the flow no matter how bad you are (Aoife)

I'm a little bit more compassionate and more kind to myself (Sharon)

I have a different attitude now. It's not like oh fibromyalgia, no cure, no cause. It's just deal with it on a daily basis and you'll be fine. Tomorrow is another day (Aoife)

A prevailing theme throughout all of the interviews concerned activities engagement and how, since the intervention, participants observed an increase in their enthusiasm to both seek out new activities and re-engage with previously valued activities, a finding that correlates with those (See Section 3.5.2.2.2) in the previous chapter:

I have since joined the active retirement; I do yoga once a week and I walk every day. I'm more open to things and I think that has helped me greatly, it has taken my mind in a lot of directions, it's brilliant (Breda)

I have started college since completing the WRAP course... Because of the course, I have started looking into other things, like I go to tai chi now... I've also started to go away with friends and I never did that before (Laura)

I'm horse-riding now and that's a form of exercise... I'm doing hydrotherapy now too. So I'm doing exercise of some sort three times a week now (Theresa)

I'm more open-minded to things now... I would have been very resistant to try new things before but not now. I suppose I'm embracing new things. I do sewing classes now and they're great (Charlotte)

The sharing of experiences and management techniques amongst the members of the intervention groups was deemed an important advantage of being part of the group:

I'd say my fibromyalgia is a lot more under control. I learned a lot of things about fibromyalgia that I didn't know by being with the group (Michelle)

I would say it has helped me see you can have a condition but still have a reasonable quality of life. It was helpful working in a group seeing other people with similar stuff and also maybe things that they were doing or not doing that was helpful (Maura)

Really the main things that I do use are the wellness tools that I wrote into my workbook. I got great ideas from the group (Sinead)

In one particular instance, being part of the group served to validate the participant's illness experience and diagnosis of the condition and was seen to impact on acceptance of the diagnosis:

It (the course) just made me more confident because I've had it for a long, long time and when I first got it over 20 years ago nobody had ever heard of it so it was great to see all the other people on the course that have it, all the different symptoms (Suzanne)

For another participant, a very practical piece of advice obtained from a group member has had a hugely beneficial impact on her symptoms:

I learned from someone on the course not to look at the clock when I'm lying awake in bed at night, now I never look at it and so I don't stress about how little sleeping time I have left and I feel so much the better of that (Charlotte)

Unsurprisingly, given that planning and goal setting underpins WRAP®, the concept of pacing through the practice of goal setting formed a considerable part of the discussion with those who took part in the follow-up interviews with participants acknowledging the value of employing such a strategy:

I'm not one for lying down but now I will just lie on the bed for 10 minutes or sometimes I'll stop myself after a half an hour of housework and say I'm going to suffer afterwards if I don't (Suzanne)

I'm looking after myself better. If I have a spare moment and have nothing on I'll take a break instead of finding something else to do. I might take a nap or go for a walk or a coffee... I pace myself in the time leading up to taking on something (Laura)

I go along to a couch to 5k three times per week and do as much of the 5k as I can. If I have other things on now during the day I will barter with that so I'd miss the

couch to 5k for one day and do those other things... I always plan ahead now... I can prioritise (Theresa)

Overall, within the *most significant illness adjustment* category, the analyses attested that participants held the wellness in fibromyalgia programme in very high esteem and alluded to its many benefits throughout their interviews. Many commonalities existed in where the intervention had its most significant impact; however, the components that commanded most discourse were acceptance and the attitudinal change that served to reduce the impact that the diagnosis of fibromyalgia was having on the overall quality of life of the individual

The *Least significant Illness Adjustment* domain contained two prominent meaning units, impact on illness and physical functioning.

While the Wellness in Fibromyalgia Programme was viewed in very favourable terms by participants and promoted significant changes in the promotion of health behaviours and illness adjustment, participants in the current study reported that its impact on the actual physical symptoms associated with fibromyalgia were limited. A number of the participants spoke candidly about this:

My symptoms - tiredness, fatigue and pain didn't improve really... pain wise, the pain is still there... and the brain fog, definitely the same (Sharon)

However, this participant did recognise that while no change had occurred in the many physical symptoms she experiences, there had been other changes and these she acknowledged were greatly beneficial to her:

...but what has improved is just my whole outlook, as in, being aware that I can be a little bit more proactive and that if you have a certain mind set you can manage the symptoms of fibromyalgia... I just deal with it in a different way

I don't notice any changes to my physical health... It had no impact on my symptoms and my pain. I'm still in pain (Sinead)

In a similar way to the previous participant, Sinead, while conceding that there has been no change to her physical wellbeing in terms of her physical health or pain levels, did acknowledge a change in her mental wellbeing:

...but I do notice a change to the way I'm thinking about things. Acceptance. And I notice that I accept the pain I have...

Other interviewees, while acknowledging a shift in the manner in which they were able to manage the symptoms, expressed the viewpoint that an impact on physical symptoms was not something that they had noticed as an outcome of completing the Wellness in Fibromyalgia Intervention:

I mean I can't say that it has done anything for my symptoms but I'm able to manage them better (Suzanne)

My pain is worse but I'm dealing with it better. I have more pain at the moment than I have had in a long time but I'm dealing with it better. My mental attitude is different (Theresa)

Overall, within the least significant illness adjustment category, the analyses demonstrated that participant's experience of pain and other physical symptoms

remained unchanged. However, it must be noted that whilst symptom levels were reportedly unchanged, compelling progressive changes that encompassed all aspects of the participant's lives were disclosed during the course of the interviews.

4.3.2 Wellness

The WRAP® programme domain contained three categories, *Maintaining wellness through WRAP®, meaning of wellness and programme review*

The promotion and maintenance of wellness is at the core of the WRAP® programme. Findings from the post-intervention interviews suggest that participant's understanding of the concept of wellness was enhanced through participation in the programme with the word itself appearing in the vernacular of many of the interviewees. The wellness toolbox is a list of wellness tools, strategies and skills that the patient can use to keep themselves well as well as those things that they may need on occasion to help themselves feel better when they're not doing so well. They include things that may have worked well in the past as well as things that they may have heard about and wish to try or things that may have been recommended to them by peers or healthcare providers. Participant's opinions of the wellness toolbox were very positive:

It's a very good idea because it's kind of a physical representation of things that you can have that will help you (Michelle)

What I appreciated most was the wellness toolbox. It worked well (Sharon)

It's like an invisible box you can bring around with you and you can take the tools out on the bus or on the train or anywhere... nobody needs to know that you're carrying the toolbox with you only yourself. I have loads of things in it (Breda)

The use of the wellness tools and the advantages of employing them as a means of illness management emerged as being a meaningful theme in the analysis:

Before I knew about the wellness tools I would kind of think, oh what can I do to help. You don't have a physical image of the things that can help whereas with the wellness tools you can think, ok, if this happens I know I have this... You can be less panicked and less overwhelmed by a situation because there is a solution to the problem (Michelle)

Oh I think the wellness tools are a great idea and have taken them on board big time. When I'm struggling and things are bad I dip into my mental toolbox

I think the wellness tools are wonderful. I tell people about them all the time. My tools help me to forget about issues... I did know about wellness tools before the course but wouldn't have called them that and wouldn't have been thinking to use them. The course reinforced the idea for me (Charlotte)

The daily maintenance list forms an integral part of the WRAP® plan. There are certain things that need to be done every day in order to maintain wellness and the notion that writing them down to remind the individual daily to do these things is endorsed in WRAP®. A daily maintenance plan helps participants to recognise those things that need to be carried out on a daily basis to remain well. The worth and the

advantages of the daily maintenance plan were acknowledged by the participants in the current study:

Well I notice if I stick to my daily maintenance list I have a better chance of avoiding flares and if I'm having a particularly bad flare, if I go back to my daily maintenance list, yeah maybe some things on that have slipped... so if I am having a flare up I'm not as frustrated and if I follow my daily maintenance list, I feel like I have a bit more control over it (Maura)

I found the daily maintenance list really good. I plan my day better because of it. I have started a college course since the WRAP course. Now I drop my daughter to school earlier leaving me an extra 30 minutes and then with this time, I take out my college books and do a bit before I have to go to work (Laura)

The Wellness in Fibromyalgia Intervention was adapted from the Wellness Recovery Action Planning (WRAP®) Programme (Copeland, 1997), and was specifically designed to engage individuals with a diagnosis of fibromyalgia in evaluating their current health behaviours, setting meaningful goals for change and addressing any barriers, skills or resources that are necessary to change those behaviours. Goal setting formed a substantial part of the wellness programme and the feedback from participants indicate its virtue in relation to the promotion of health promoting behaviours and self-management techniques:

I evaluate what's wrong and then I choose the proper tool I can use to fix it. I evaluate the day and set realistic goals for myself. If I think yes I can do that I go ahead

with it if not I re-evaluate. I plan a week ahead and if things have to change they go into the following week (Theresa)

I always plan ahead now. One week I didn't plan and had things on 5 days so I ended up in bed for 2 weeks after that (Laura)

I manage things better. I have a plan every day and if I don't plan things just don't work. I plan realistically and I didn't do this before and I expect less of myself. So I won't be upset if I don't get the whole house cleaned in 1 day, instead I'll do 2 rooms at a time (Charlotte)

Each participant on the wellness in fibromyalgia programme received their own workbook (see Appendix 8) on week 1 of the intervention. This workbook contained all of the 6 course modules and associated exercises along with additional notes pages for the recording of personal notes or ideas. The workbook belonged to the recipient, was kept in their possession at all times and was brought to each of the weekly sessions. During the course of the post-intervention interviews, many of the participants referred to the workbook and its usefulness as it became a means of recording information throughout the intervention and a source of reference once the programme had been completed:

It was good the way you had the workbook to write things out and the way it explained things... it was really good because you can go home with that, especially with the fibrofog, you can remember what each week was about... you write things down and you can remember them and it's good to keep afterwards because it's almost like a little diary (Michelle)

When I'm feeling bad I go back to the notes in the book... A couple of weeks ago I was really bad but I was trying to get my blood pressure down so I was walking up and down hills flying it and then I crashed and I looked up my WRAP book and saw that was it (Suzanne)

Really the main thing I do use is the book, the wellness tools that I have written in there (Sinead)

The *Meaning of wellness* category contained the following meaning units: Definitions of wellness and Maintaining wellness. Participants were requested to reflect on what wellness meant to them. For the majority, it was about normality, fulfilling basic needs and having a reasonable quality of life:

Wellness is having a quality of life and being able to get through the tasks that you want to get through with not too much difficulty (Maura)

Wellness to me is peace of mind, peace of health. Feeling healthy in yourself, physically healthy, having good stability around you in your whole life... being happy and content and safe (Sharon)

Wellness to me is to get up in the morning and be able to do my stuff and get out for a walk everyday (Suzanne)

Wellness was maintained by promoting concentration. Encouraging the participants to concentrate on the illness and adjusting the way they thought about it taking stock of it and their lives,

...it impacted on my wellness because it made me concentrate on my life and also made me concentrate more analytically on the illness instead of kind of wallowing in it- made me look at it from an outside perspective and look at the factors of what I need to do in order to cope and manage with it which I wasn't doing at all (Michelle)

Wellness is also maintained through the identification of wellness tools and the use of such tools as a management technique

I don't feel guilty about going to have a massage and feel that that's a luxury, I just feel that that's to help with my condition. I know it's alright (Suzanne)

Overall, the Maintaining wellness through WRAP® category indicates that participant's understanding of the concept of wellness was enhanced through participation in the programme. The responses given by the participants suggest that they have embraced the concept of wellness through their regular use of their WRAP® plans which they developed over the course of the seven week intervention, a finding similar to that of Cook et al. (2010) who identified the application of specific WRAP® strategies and skills in everyday life.

4.3.2 Programme Review

In an endeavour to ascertain whether the programme could be adjusted in any way to improve upon the experience of those participating in it each of the ten individuals were asked what they would change about the course

An over-riding response in relation to suggestions for change was concerned with the possibility of having a follow-up for those who had completed the WRAP® programme,

Maybe a follow-up because what I notice with myself and with the fibro group in general is that people are great at starting things and then when they're finished they say that was great and they put it away in a drawer and never use it so some way of how to get people to maintain it-whether it's an email or an online thing that they could check on even once a month (Maura)

I think it would be great if there was a follow-up so we could meet again and go over our plans again because sometimes it's hard to keep going with something and especially if you have pain (Sinead)

Maybe we should have a refresher once a year... to bring it back to focus again, like a follow-up every year (Breda)

The only thing I would change is to offer it more than once... I'd love to do it again, like a check in or a refresher (Laura)

Other participants suggested additions they would like to see being made to the course

It'd be nice to have an exercise piece built into it, so combine it with an exercise programme (Laura)

Maybe more discussions because I think a lot of people would benefit from it because they have no one to talk to about it (Michelle)

To me I would look at maybe splitting it up. Seven weeks in a row was intense so maybe three weeks then a break and then the remainder. Break it up and have time in between to let it sink in (Laura)

While some of the participants used the opportunity to express their satisfaction by stating there were no changes they could see as having a value adding effect on the course,

Nothing springs to mind...It was a very well thought out programme (Sharon)

I can't think of anything off hand (Aoife)

I wouldn't make any changes, it was wonderful (Charlotte)

Throughout the analysis phase of this evaluation of a Wellness in Fibromyalgia intervention, it became apparent that the participants had very strong views on the programme and its impact on the management of symptoms and overall quality of life. It also became clear the value these participants placed upon the WRAP® as a self-management tool. In light of the powerfulness of such expressions, it was decided to include them as testimonials

I feel the world has opened up to me, like I feel like I have possibilities whereas beforehand I didn't feel like I had possibilities because I was almost clouded by my fibromyalgia. I couldn't participate in my normal life anymore so I felt like I was going backwards... You cut yourself off from your everyday goals and ambitions. Now I feel totally different, I'm even thinking of going to college next year and I would never have thought that that would be possible (Michelle)

I'd say I'm under more stress at the moment and my health is slightly worse but it would have been a whole lot worse if I hadn't done the WRAP course (Maura)

The WRAP® course has shown me that I have choices (Aoife)

It gave me the courage and confidence to explore more alternative things that I might never have tried (Breda)

The pain is the same but I'm not (Theresa)

Whatever happened, whether it was mind over matter or what, my energy levels are back up to their usual level (Breda)

The WRAP® plan has shown me that I have choices. I can accept or not accept. I can be upset and it's ok to be upset... doing WRAP® instilled in my head that acceptance and working with the programme works for me (Aoife)

It's something I wouldn't like to be without ever again (Breda)

My mental attitude is different. I know I have been better and I will be better than this again (Theresa)

One of the best bits of the course was getting out and having something every week to get up and go to (Laura).

4.4 Discussion

This study presents the first one year post intervention follow up evaluation of a WRAP® informed programme with a group of fibromyalgia patients. The interviews gave the impression of ten very determined and aware women with a striking ability

to reflect on, formulate and report their illness and self-management experiences. The categories that emerged from the data (Most Significant Illness Adjustment, Least Significant Illness Adjustment, Maintaining Wellness through WRAP®, Meaning of Wellness and Programme Review) served to demonstrate a substantial positive regard towards the programme with patients reporting significant changes in their self-management, acceptance, levels of personal responsibility, personal relationships, goal setting and planning, pacing and important insight into their views of the WRAP® programme and the usefulness of its main components - the wellness toolbox, wellness tools and daily maintenance list.

It may be useful to frame the treatment of chronic pain practically, as a problem of acceptance and change. Somewhat paradoxically, there may be occasions when helpful change in the quality of a patient's life can only occur when some aspects of the problem are accepted as they are. Change efforts may then be directed away from encounters that keep the person stuck, such as with unwanted thoughts, feelings, or sensations, toward circumstances that yield overall better results, such as a course of action that is personally meaningful and satisfying. Acceptance of pain and associated disability has emerged as potentially useful in understanding how some pain patients can be helped to live a positive life despite experiencing chronic pain (McCracken, Vowles & Eccleston, 2004).

Acceptance is a complex construct that is understood in many different ways. Risdon, Eccleston, Crombez and McCracken (2003) identified common features in accounts of chronic pain: recognition that the cure of pain is unlikely, the need for a shift in focus from pain to non-pain aspects of life, and a rejection that acceptance of

pain is an indicator of personal failure. Several studies have shown the importance of acceptance in adapting to a life with chronic pain. McCracken et al. (1999) reported that acceptance of pain predicted whether a patient could be classified as either someone who coped in an adaptive manner or someone who coped in a more dysfunctional way. Acceptance of pain and associated disability is potentially useful in understanding how some chronic pain patients can be helped to adjust to a life with pain and lead a positive life with meaningful goals and activities despite pain (Evers et al., 2001). McCracken & Eccleston (2005) examined acceptance of pain and patient functioning in a prospective study of 118 adults attending a pain clinic. Findings showed that those pain patients who reported higher levels of acceptance reported less medication consumption, better social, emotional and physical functioning, and better work status. These results suggest that willingness to experience pain, and willingness to engage in activity despite pain, can lead to healthy functioning and adjustment for chronic pain patients. Viane et al. (2003) have shown that acceptance of pain predicted mental well-being and McCracken and Eccleston (2003) found that acceptance was superior in accounting for the adjustment to chronic pain when compared with other coping variables.

Research employing acceptance based therapies has demonstrated the effectiveness of such interventions in the management of fibromyalgia. Acceptance and commitment therapy (ACT) has produced significant differences in pain-related functioning, fibromyalgia impact, mental health-related quality of life, self-efficacy, depression, anxiety and psychological inflexibility (Wicksell et al., 2012). ACT has also been shown to produce a greater increase in global functional status than

recommended medications and no treatment. Additional significant improvements have been reported in pain acceptance, pain catastrophizing, subjective pain, quality of life, anxiety and depression (Luciano et al., 2014). By all accounts, acceptance formed a considerable part of the narratives of the patients in the present study and their descriptions of a new found acceptance and its impact upon how they view their illness would indicate that the wellness in fibromyalgia intervention increased their levels of acceptance subsequently creating a more accepting view of their health status, as is evidenced by Charlotte, who when speaking of her diagnosis made reference to her acceptance of and subsequent adjustment to the condition: *I know I can't change that I have fibromyalgia therefore I have to deal with learning to live with it... I haven't been able to change it but I've accepted that this is just one of those things and am getting on with it.* The result therefore, that indicates a significant impact on acceptance holds much promise in the context of adjustment and disease management in fibromyalgia.

One of the key concepts of WRAP® is personal responsibility. In accordance with WRAP®, the patient is their own expert who should strive to determine exactly what it is that they require in their bid to achieve and maintain wellness. WRAP® proposes that those who take personal responsibility achieve the highest levels of wellness, happiness and life satisfaction (Copeland, 2004). The current cohort of patients repeatedly referred to personal responsibility in their interviews and appeared to be empowered by this new sense of charge they had over their illness as evidenced by Maura, *'I kind of feel it's not a case of waiting for the doctors to come up with the right drug, there are actions and behaviours that if I do they can have a*

positive or negative impact on my fibromyalgia'. The taking back of personal responsibility requires empowerment, confidence and self-belief all of which are dynamic features of the construct of self-efficacy-the extent or strength of one's belief in one's own ability to complete tasks and reach goals (Ormrod, 2006). Self-efficacy affects every aspect of human endeavor. By shaping the beliefs a person holds in relation to their individual power and ability to affect situations, both the power that person actually has to face challenges competently and the choices that person is most likely to make is impacted upon. These effects are particularly observable and convincing, with regard to behaviours affecting health (Luszczynska & Schwarzer, 2005). Stuifbergen et al. (2010) in an RCT of a wellness intervention for 187 women with fibromyalgia reported that participants improved significantly over time on measures of self-efficacy after an eight week intervention. Results from the current WRAP® programme have also shown promising effects in terms of self-efficacy in both the longitudinal data where an overall increase was observed across time; and in the data comparing the intervention group with the comparison group where the intervention group showed more significant gains than the comparison group on measures of self-efficacy. These initial findings are supported by the accounts given by the patients in their follow up interviews.

Based on previous research, it is not surprising that self-efficacy is an important factor in the understanding of adjustment to and management of fibromyalgia. In a study examining adjustment to the condition highlighted that self-efficacy had a considerable impact on the illness experience of the fibromyalgia patient, Sahar, Thomas and Clarke (2015) suggested that individuals who felt better

able to manage their pain, symptoms or functioning were also more likely to report lower functional impairment, pain intensity or fibromyalgia related psychological symptoms. Self-efficacy is therefore an attractive concept in the realms of pain management since it redirects focus and attention to the patient's strengths in adversity, rather than see them concentrate on insurmountable difficulties (Valente, Ribeiro & Jensen, 2009).

People with chronic pain frequently adopt activity patterns that can intensify their pain and undermine their quality of life. Activity pacing is considered an essential component of pain management and is employed in an attempt to counteract the over activity – under activity cycle (Birkholtz et al., 2004a). It is a strategy in which people learn to pre-plan rest breaks to avoid symptom exacerbations (Murphy et al., 2011). In order to attain activity goals, it is important to replace activity contingent on pain with activity contingent on quota, such as time or frequency. This is one aspect of activity pacing, which can help to break the detrimental over activity-under activity cycle (Birkholtz, Aylwin & Harman, 2004b). Research examining activity pacing is limited; however, there are a number of studies that have supported the effectiveness of pacing as an intervention (e.g. Murphy et al., 2011; van Koulil et al., 2010). In a study of patients with osteoarthritis and knee or hip replacements, symptoms such as pain and fatigue have the potential to interfere with mobility and physical activity. Whereas symptom management is a cornerstone of the treatment for such health challenges, limited evidence exists for behavioural interventions within the context of clinical care that address how such symptoms affect participation in valued daily activities. In a pilot study, Murphy et al. (2011) found that participants who

underwent a tailored activity pacing intervention had reduced fatigue interference with daily activities. Van Koulil et al. (2010) described a tailored cognitive-behavioural treatment programme for patients with fibromyalgia. Individuals presenting with persistent pain were given a form of CBT that involved learning pacing skills. This treatment resulted in much larger effect sizes than are typically noted in CBT programs for fibromyalgia. In the current qualitative follow-up study, many of the participants referred to pacing, for example, Suzanne stated: *I'm not one for lying down but now I will just lie on the bed for 10 minutes or sometimes I'll stop myself after a half an hour of housework and say I'm going to suffer afterwards if I don't.* This marks an obvious attempt to pace activities in an attempt to self-manage and prevent a flare up of symptoms. While pacing wasn't an explicit element of the Wellness in Fibromyalgia Intervention, goal setting forms an integral part of WRAP® and an explanation for the implementation of pacing may be directly related to this. In order to pace activities, it is important to have an understanding of reducing activities and associated tasks into specific, measurable, achievable, realistic and timed units. Module 3 of the Wellness in Fibromyalgia Intervention (see Appendix 8) afforded participants the opportunity to discuss and become familiar with the notion of goal setting, the use of SMART goals (Doran, 1981), and the impact goals have on one's levels of motivation and attention. It is therefore proposed that in the context of the present research, goal setting skills attained were utilized by participants like Suzanne to pace valued activities.

The main focus of WRAP® is to help participants learn strategies to manage symptoms using a variety of self-management techniques (Copeland, 1997; 2004). In

summary, this 12 month follow-up study captured symptom reduction that is typically difficult to observe in a shorter term study (Starnino et al., 2010). The narratives of the participants lend strong support to the effectiveness of the seven week Wellness in Fibromyalgia Intervention. The positive responses of participants to this intervention are similar to those reported in previous qualitative research studies employing WRAP® (e.g. Cook et al., 2010; Higgins et al., 2012).

4.4.1 Limitations

While considering the improved outcomes observed in this study, several limitations must be acknowledged. Firstly, the study comprised a small sample from the original intervention group with 12% of those who completed the intervention taking part in the qualitative follow-up study. Secondly, the study comprised of a sample of females. The ability to generalize outside this population is therefore limited. Future studies using a larger sample with a mix of males and females could address these limitations.

4.4.2 Conclusions

This study provides a novel insight into the experience of receiving a WRAP® intervention for the self-management of fibromyalgia. The main categories to emerge from the data, Illness Adjustment (most significant illness adjustments and least significant illness adjustments), Wellness (maintaining wellness through WRAP® and meaning of wellness), and Programme Review (suggestions for change and testimonials), detailed the complexity of fibromyalgia, the impact the Wellness in

Fibromyalgia Intervention had on the condition and the participants subjective opinions of WRAP®.

This research is the first to detail the utility of a WRAP® intervention by fibromyalgia patients, and the qualitative study presented in this chapter details the manner in which a WRAP® programme can impact upon self-management of this chronic pain condition. The categories that emerged serve to highlight the areas upon which the intervention impacted as well as those where no impact was noted and the positive regard of the participants towards WRAP® as a concept and the Wellness in Fibromyalgia Intervention as a whole. Overall, participants were enthusiastic about the intervention and reported positive personal changes.

5 Chapter 5: General Discussion

This thesis has emphasized that while there exists a plethora of treatment options, both pharmacological and non-pharmacological, for the management of fibromyalgia; patients with the condition suffer considerably with complex symptoms. Interest in fibromyalgia as a research topic has gained momentum in the past decade; yet in many ways it remains little understood. The cause of the condition remains unknown; there are no preventive measures and treatment is often ineffective. Full recovery is unusual and fibromyalgia is inclined to follow a non-remitting course, often resulting in substantial disability.

Since the prevalence of fibromyalgia is much lower in males than females, the literature about the condition has developed focusing mainly on women. Before determining whether sex is an influential variable in the diagnosis and treatment of fibromyalgia, it is essential to identify the characteristics of fibromyalgia in women and men and the impact of its diagnosis irrespective of gender. No studies have employed WRAP® as a management option in fibromyalgia and any wellness interventions conducted to date have analysed their impact on women with fibromyalgia excluding completely the male patient. The main aim of the present research was to determine the subjective experience of both men and women living with fibromyalgia and to establish whether WRAP® is an acceptable intervention for fibromyalgia.

Psychological research is warranted in order to advance our current knowledge of fibromyalgia, and consequently to improve the lives of those living with the condition by reducing the distress associated with the many complex, and at times,

life altering symptoms. This holds true for all people living with fibromyalgia, and is not gender specific. In the remainder of this chapter, the research conducted during the present research will be summarised, the implications will be discussed along with possibilities for future research, and the limitations of the research will also be pointed out.

5.1 Summary of the Research

Chapter 2 examined the subjective experience of living with fibromyalgia. In order to appreciate the patients' perceptions of support, their illness and its treatment a qualitative approach was undertaken. Qualitative data were obtained through two focus groups, and analysed using a descriptive and interpretive framework (Elliot & Timulak, 2005). Findings revealed that fibromyalgia has a substantial negative impact on the patient's lives regardless of gender, and patients living with fibromyalgia may benefit from general healthcare support in relation to the validation of their illness experience and from psychological support that may serve to promote knowledge, acceptance, facilitate active coping strategies and reinforce their adaptive, health promoting behaviours. Two dominant themes emerged: *most helpful aspects of treatment* and *least helpful aspects of treatment* and interesting gender differences presented within each of the main themes. Of significance were the gender differences that emerged in relation to perceived relational support from the GP, perceived shortcomings in important general characteristics of a GP, perceived shortcomings in important general characteristics of treatment and perceived support from healthcare professionals. The establishment of effective interventions designed

to promote self-management of this complex disorder was pointed out as a key focus for future research.

Chapter 3 investigated the impact of a WRAP® informed wellness intervention on the self-management of fibromyalgia. The study utilized a pre-post longitudinal evaluation of a seven week Wellness in Fibromyalgia Intervention. In addition, the study provided a comparison study between two groups: a Wellness in Fibromyalgia Intervention group ($N = 78$) and a comparison group ($N = 50$). Analysis of the longitudinal data demonstrated that overall, the Wellness in Fibromyalgia Intervention had a positive impact on measures of self-efficacy, pain acceptance, activities engagement, impact of illness and internal control. Physical functioning scores and total number of feel good days differed across time points with a significant decrease observed on each of these subscales over the course of the intervention. In the comparison study, the Wellness in Fibromyalgia Intervention had significant effects on measures of self-efficacy, activities engagement and internal control compared to the comparison group. No significant changes occurred for physical functioning, days missed from work, pain willingness, matter of chance, powerful others having control, doctors having control or other people having control. The results supported previous research that suggested the efficacy of self-management programmes as a treatment option for fibromyalgia (e.g. Stuifbergen et al., 2010).

Chapter 4 examined post-intervention interviews that were completed with a sample of participants ($N = 10$), 12 months after the completion of the Wellness in Fibromyalgia Intervention. This chapter described how the interviews were analysed

using a descriptive and interpretive approach in an attempt to understand the views of those participants in terms of their experience of receiving a WRAP® informed intervention for the management of fibromyalgia. The analysis proposed five categories – Most Significant Illness Adjustment, Least Significant Illness Adjustment, Maintaining Wellness through WRAP®, Meaning of Wellness and Programme Review. Overall the intervention appeared to empower the participants to make positive changes in their lives and for many, was considered a life changing experience. Participants reported being very enthusiastic about WRAP® and the gains they had accomplished through participation. Findings supported WRAP® in the promotion of empowerment and personal change, similar to those of Higgins et al., 2012.

5.2 Implications of Research

The results of this research have implied that an intervention informed by WRAP®, a model developed for the management of mental health conditions, is transferrable, and holds substantial credence in its potential to impact positively on the management of fibromyalgia. In Chapter 3, several significant changes were observed in the longitudinal data. The Wellness in Fibromyalgia Intervention had a positive impact on a number of constructs and the qualitative analysis of the post-intervention interviews served to enhance the quantitative findings along with providing an insight into the overall satisfaction and impact the programme had on the lives of the participants.

The study in Chapter 2 set out to establish the subjective experience and support needs of patients with fibromyalgia and highlighted an absolute lack of support for fibromyalgia patients in relation to their diagnosis and the management of

the condition. The qualitative results obtained in this chapter served to justify the development and subsequent delivery of an intervention aimed specifically at promoting self-management through education - in relation to fibromyalgia, WRAP® (Copeland, 1997) and goal setting theory (Locke & Latham, 1990), and to engage participants in individualized goal setting and monitoring and enhance participant's self-efficacy for health promoting behaviours. The research sought to explore the impact of a WRAP® intervention on the self-management of fibromyalgia and while the quantitative findings presented in Chapter 3 were mixed, overall, taken together with the results from the qualitative study presented in Chapter 4, results show great promise for patients with this condition.

Prompted by previous research findings (e.g. Sahar, Thomas & Clarke, 2015) that determine self-efficacy to be a fundamental factor in the understanding of adjustment to and management of fibromyalgia, one of the primary aims of the Wellness in Fibromyalgia Intervention was to enhance participant's self-efficacy for health behaviours. The evidence for this was evaluated in Chapter 3 and findings supported the interventions capacity to promote a significant increase in self-efficacy in both the longitudinal and comparison studies. To date, no other study evaluating WRAP® has examined self-efficacy as an outcome of the intervention.

Chapter 1 described the wide array of treatment options available to fibromyalgia patients and highlighted that in recent years there has been a growing interest in acceptance interventions, which focus on the willingness to experience thoughts, feelings and physiological sensations without having to control them or allow them to determine one's actions (Bond & Bruce, 2003). In Chapter 3, it was

hypothesized that an increase in pain acceptance would be observed post intervention. The longitudinal study data and the comparison study data presented indicated a significant increase in pain acceptance scores from week 1 to week 7 of the Wellness in Fibromyalgia Intervention. Moreover, observed increases were maintained over the 6 month follow up in each of the studies. Qualitative findings from post intervention interviews presented in Chapter 4 verified the findings presented in Chapter 3. Participants frequently made reference to a new found sense of acceptance and the positive impact this was having on their overall quality of life. Research to date employing WRAP® has focused solely on mental health management and has not measured this construct. The current findings are therefore promising for the intervention's empirical status not just in the area of mental health where higher acceptance predicts positive outcomes (Bond & Bruce, 2003), but across the many chronic illnesses that have been shown to benefit from heightened levels of acceptance such as cancer (Stanton, Danoff-burg & Higgins, 2002), multiple sclerosis (Pakenham & Fleming, 2011) and chronic pain (Viane et al., 2003). It is therefore suggested that intervention strategies promoting acceptance in patients with fibromyalgia may prove more beneficial to this group than trying to control what are largely uncontrollable symptoms. It is also suggested that WRAP® may have the potential to be modified and applied to other chronic illness patient groups.

While in her description of the WRAP® programme its founder Mary Ellen Copeland states it can be applied to the management of many illnesses (Copeland, 1997), a limited amount of research has been carried out and of the studies that have been conducted to examine its utility, all have studied the management of serious

mental health conditions (e.g. Cook et al., 2009; Cook et al., 2010, Fukui et al., 2011; Higgins et al., 2012; and Scott & Wilson, 2011). As presented in Chapter 1, fibromyalgia is associated with a number of adverse psychological states with research indicating a high co-morbidity rate of psychological disorders in this cohort of patients. Findings presented in Chapter 3 indicate a co-morbidity rate for mental health issues of 28% for the comparison group and 33% for the intervention group in this study. Despite the existence of such rates of co-morbidity and theories suggesting a psychological cause of fibromyalgia, little evidence exists to support this stance. In a literature review of 83 studies relating to the pain-depression association, Fishbain et al. (1997) indicated a relationship does exist between chronic pain and depression, but proposes greater support for the consequence hypothesis than the antecedent hypothesis. This suggests that depression therefore a consequence of the presence of pain, a suggestion that is in line with opinions voiced by participants in the focus group study presented in Chapter 2. Consideration must be given to the fact that there is a possibility that the elevated incidence rates of mental health issues in this cohort may go some way towards explaining the success of the WRAP® intervention with a group of fibromyalgia patients and should not be discounted when considering the success of the intervention.

WRAP®, as described in Chapter 3, is a relatively new approach to illness management that is currently working towards expanding its evidence base. Support is one of the core concepts underpinning WRAP®. It is therefore unsurprising that it emerges as a common theme in existing WRAP® research (e.g. Cook et al., 2009). The findings contained in Chapter 2 of this study revealed that fibromyalgia patients had a

mixed experience of perceived support from family and some perceived friends as being a greater source of support. According to a study by Jamison and Virts (1990) chronic pain patients who reported having non-supportive families tended to report more pain, showed more emotional distress and relied more on medication compared with pain patients coming from supportive families. These researchers propose that perceived support is an important factor in the treatment of chronic pain patients.

According to Fitzcharles, Ste-Marie and Pereira (2013), strategies aimed at improving coping skills and empowering an internal locus of control is expected to facilitate a return to work and valued activities for fibromyalgia patients. Findings documented in Chapter 3, indicate a significant increase in internal control in both the longitudinal study and the comparison study and a decrease in total number of days missed from work. It is proposed that these findings in the context of the present study are interrelated and supported by the claims made by Fitzcharles et al. (2013). Maintaining a life pattern as close to normal as is possible is desirable in chronic illness. Patients with fibromyalgia who are in the workforce generally self-report less severe symptoms and an overall better quality of life than those individuals who are not employed, and this improved health status is maintained over time (Reisine, Fifield, Walsh & Forrest, 2008). The findings presented in Chapter 3 showing a decrease in days missed from work even in the presence of a decrease in physical functioning scores and in number of feel good days (as acknowledged in Section 3.5, Chapter 3) are equally unanticipated and conflicting, as one would have expected an increase in days missed from work in the presence of a decrease in physical functioning and feel good days. The proposed explanation for these conflicting

findings is the decrease in number of feel good days may be attributed to a more realistic appraisal of what it means to feel good (as discussed at length in Section 3.6, Chapter 3) while the increase in internal control scores may be serving to promote a sense of improved management of one's illness and thus promotes an increase in personal control over recovery. Future research should endeavor to establish the possible link between these variables.

Many positive changes were observed over time in both the longitudinal study and the comparison study in this research. It is encouraging to observe such notable changes and in particular on those measures where gains were preserved over the six month follow up as they signify not just the possibility for change on important constructs critical for behaviour change in illness management, but also the ability of the Wellness in Fibromyalgia Intervention to instigate lasting change. However, positive changes were not observed on all measures. Unsurprisingly, results described in Chapter 3 in relation to physical functioning showed the intervention failed to show any positive influence and in fact signified a decrease in scores over time. The focus of the Wellness in Fibromyalgia Intervention was the promotion of health within illness. An emphasis was placed on empowering patients by providing access to resources and knowledge used in selecting behaviours to decrease impact of illness, increase self-efficacy and enhance and sustain their health and overall quality of life. The additional demands of attending an intervention across a seven week period that required travelling to the location where the intervention was located, and sitting in a classroom environment is suggested to have impacted negatively on these scores.

5.2.1 Theoretical Implications

Bandura's (1974) model of self-efficacy provides a framework for understanding some of the behaviours of the person living with pain. Bandura (1977) described self-efficacy as a set of beliefs held by an individual that they will be able to perform certain behaviours within a particular environment. Self-efficacy is therefore, a personal conviction that one can be successful in engaging in preferred behaviours in particular conditions. Perceived self-efficacy predicts functional disability regardless of duration of disease or pain intensity (Schiaffino & Revenson, 1992). An enhanced sense of self-efficacy fosters beneficial coping strategies, which in turn decrease impact of illness and functional disability. To date, little thought has been given to the notion that WRAP® has the potential to impact upon self-efficacy. Limited empirical research has been conducted in relation to evaluating its overall effectiveness as an intervention and no study has measured self-efficacy. Self-efficacy is a clear predictor of successful illness management and has been linked to pain coping (Turner et al., 2005), control (Litt, 1988), and acceptance (Nicholas & Asghari, 2006). A significant improvement in self-efficacy was observed in both the longitudinal study and for the intervention group in the comparison study in the present research. Such findings are encouraging and add to an increasing body of theoretical findings supporting the critical role of efficacy beliefs in the management of chronic pain (Spinhoven & Linsson, 1991).

Research reporting on this construct has indicated that when combined, self-efficacy and perceived control act as cognitive mediators of pain tolerance (Litt, 1988). Patient's perceptions of their personal control over recovery have been shown to be

predictive of their future progress and illness management (Johnston, Gilbert, Partridge & Collins, 1992). Their perceived control over their health and beliefs about their own ability to perform health promoting behaviours affect how the patient adjusts to their chronic illness (Willis et al., 1997). Along with self-efficacy, a significant increase in internal control was also observed in the current study. This finding suggests the intervention may serve to enhance illness adjustment in fibromyalgia patients.

Intervention programmes for pain do not always focus on the most relevant empirical factors in predicting positive adjustment to pain (Valente et al., 2009). Identifying sources of positive coping, such as self-efficacy may enable more successful adjustment among patients with chronic pain, including the enhancement of positive function and well-being (Sturgeon & Zautra, 2010). Results from the present study are closely associated with the view that self-efficacy based interventions promote a motivational context that makes it easier for people to adjust to their illness (Ryan, Lynch, Vansteenkiste, & Deci, 2011). Taken together, the elevated levels of self-efficacy observed in the participants who completed the Wellness in Fibromyalgia Intervention in Chapter 3 and the emergence of a more adjusted individual in the narratives of those represented in Chapter 4, this study's findings are in line with the findings of Ryan et al. (2011) who identified an association between self-efficacy and illness adjustment.

These initial findings concerning self-efficacy are supported by similar evaluations worldwide (e.g. Stuifbergen et al., 2010) and by the fact that self-efficacy consistently predicts behavioural outcomes more than any other motivation construct

(Graham & Weiner, 1996). The Wellness in Fibromyalgia Intervention highlights the fact that while psychoeducation formed a critical element of a self-management programme for fibromyalgia, it was not solely limited to the education of patients; it was based on enhancing the motivation and confidence of patients to use the knowledge and skills they have to take effective control over life with this complex condition. The current study's initial findings support the WRAP® programmes utility in the context of fibromyalgia and has far reaching possibilities in terms of its applicability to it and other chronic pain conditions.

In the last decade, acceptance has emerged as a valuable construct in psychological therapies. Recently, a shift has occurred with the focus currently on acceptance of pain rather than engaging in what can be unsuccessful attempts to try to overcome it and there is presently a growing body of evidence in the chronic pain literature for therapies such as ACT, which are based on the promotion of acceptance (Veehof et al., 2011). Chronic pain is not a disabling condition for all sufferers which signifies that there are certain responses made by the individual to their pain experience that have the potential to contribute to disability. Such responses include patterns of unsuccessful attempts to exert control over symptoms and frequently, in their attempt to control what are undesirable experiences, those suffering with chronic pain lose control over their lives and their valued activities (McCracken et al., 2004). Acceptance of pain promotes a change in behaviour patterns so the pain patient is less inclined to have the controlling of pain as their main focus and instead directs their attention toward features of healthy living such as engaging in valued activities (McCracken et al., 2004). The Wellness in Fibromyalgia Intervention sought

to increase acceptance levels in those who completed the programme and programme participants successfully gained on this measure in both the longitudinal study and the comparison study. These findings are in line with, and further enhance those presented in the pain literature that suggests acceptance holds a significant place in the management of chronic pain.

The WRAP® programme has at its core goal setting and planning (Copeland, 1997). Much of the theory is based on Ryan's (1970) notion that conscious goal setting directly effects action and that human motivation should be examined beginning with establishing the individual's immediate intentions and subsequently building from there to explain the sources of the intention. Goal setting Theory exists largely on the empirical research of Edwin Locke and Gary Latham (e.g. Locke, 1966; Locke, 1968; Latham et al., 1988; Locke & Latham, 1990). In terms of the self-management of pain, goal setting theory provides a respected perspective. As evidenced in Chapter 3, it proposes an impact on self-efficacy and motivation thus linking goal setting with motivational change in illness behaviours, pain self-management and activity pacing. The Wellness in Fibromyalgia Intervention actively promoted goal setting theory and the results that emerged highlight its effectiveness as an intervention for the self-management of fibromyalgia. The findings in the present research, add further acknowledgement to the value of the fundamentals set out by goal setting theory and justifies giving due consideration to the possibility of considering this theory for inclusion in future interventions for fibromyalgia.

Recovery has been claimed by individuals with disabilities and used to frame a vision of personal, social and political change (Resnick & Rosenheck, 2006). The joining

together of the study of self-efficacy and acceptance with the action orientated goals associated with WRAP® and the broader theories of goal setting and recovery hold important theoretical implications as it may demonstrate that these theories can productively reinforce one another, in part, because they pursue universal goals such as illness adjustment, that are meaningful to the individual living with a chronic pain condition.

Adaptation to chronic illness is a critical feature of living successfully despite one's diagnosis. According to Krupp (1976) adaptation to a chronic illness is making the best of a bad situation. Theories of adaptation emphasise that illness acceptance, perceptions of control over one's diagnosis and self-efficacy have the potential to impact on how the patient adapts to the limits set by a diagnosis of a chronic illness (Taylor, 1983). Patients who believe they can control their pain function better, have a better quality of life and engage in more meaningful activities than those who do not. Moreover, such beliefs may mediate some of the relationships between pain severity and adjustment (Jensen, Turner, Romano & Karoly, 1991).

There are a number of empirical studies that demonstrate a positive association between acceptance and successful adaptation to chronic pain. Schmitz, Saile and Nilges (1996) have revealed that pain patients who change unachievable goals or who substitute such goals for more achievable ones (accommodation) report less pain-related distress. Jacob, Kerns, Rosenberg and Haythornthwaite (1993) reported that people who accommodate pain, defined as the ability to live a fulfilling life despite the presence of chronic pain, presented with less obvious pain behaviours and lower levels of depression. McCracken (1998) found that patients with more

accepting responses to chronic pain exhibited better adjustment as measured by the self-report of depression, anxiety, and disability. And in a similar and more current study McCracken et al. (1999) found that accepting pain was the most dominant predictor of whether patients are categorized as functional or dysfunctional copers, independent of pain intensity or depression. Participants in the present study recorded significant improvements in acceptance—a promising implication for WRAP® as an intervention and for fibromyalgia patients in terms of their adaptation to illness.

Part of the experience of pain is perception based and influenced by behavioural, cognitive, learning and personality attributes. An individual's sense of perceived control has a major influence on pain. The construct of control is complex and multidimensional (Pallant, 2000). A lack of control has been associated with psychological disorders, including depression and anxiety, and with physical illness, including chronic pain (Roddenberry & Renk, 2010). Internal locus of control benefits adaptation to chronic illness. It has been proposed in the context of fibromyalgia that internal locus of control can provide a cognitive structure that connects actions with expectations of controllable outcomes (Velasco Furlong, Zautra, Penacoba Puente, López-López, & Barjola 2010). In the context of chronic pain, patients with high internal control mechanisms report more active coping techniques to reduce their pain and also present with less psychological distress (Shuster, McCormack, Pillai Riddell & Toplak, 2009). Overall, they function better than those with low internal control who report passive coping techniques (Turner & Clancey, 1986).

A better-functioning internal control mechanism is associated with a better adjustment to pain and other symptoms of chronic illness. Hence, the more the

individual feels in control of a situation, the easier it is to facilitate the adaptation process that is crucial in managing a chronic health condition. Being in control and being able to adapt to new situations, including chronic pain, is central to the establishment of self-management approaches that have been shown to be effective in chronic pain conditions (Torres et al., 2009). There are few studies that investigate control in fibromyalgia. Fibromyalgia patients report lower control over their pain when compared with those with rheumatoid arthritis or systemic lupus and treatment that used a self-management approach to increase internal control showed fibromyalgia patients to improve significantly (Burckhardt & Bjelle, 1996). It has also been shown that those with higher internal control reported more positive change following participation in different therapeutic interventions. A higher level of control in fibromyalgia is correlated with an increased physical activity level, improved quality of life, and less pain and fatigue (Malin & Littlejohn, 2012). Findings reported in the current research show that the Wellness in Fibromyalgia Intervention successfully impacted upon levels of internal control - a promising implication for the efficacy of the intervention in a chronic pain patient group and their potential to adapt to what is a disabling condition that pervades all aspects of their lives.

While adaptation was not measured in the current study, quantitative results obtained in terms of acceptance and control combined with the narratives of the participants in the post-intervention interviews that communicated a perceived increase in control over and acceptance of the condition, indicate that adaptation to fibromyalgia was indirectly affected by the Wellness in Fibromyalgia Intervention.

5.2.2 Clinical Implications

Fibromyalgia causes significant distress in patients and impacts on every facet of their lives. While these research findings point to the value of psychological interventions for fibromyalgia, and have important clinical implications not just for this patient group but for the wider group of patients living with chronic pain conditions, access to effective interventions is often limited, due to a scarcity of services (Ehde, Dillworth & Turner, 2014). In Ireland, there is a substantial shortage of pain management services (Fullen, Hurley, Power, Canavan & O’Keeffe, 2006), despite the fact that chronic pain affects up to one third of patients surveyed using General Practice lists (Raftery et al., 2011) and in economic terms costs 2.5% of GDP (Raftery et al., 2012). There is an absolute shortage of services for this cohort and psychological management programmes need to be considered and offered as a treatment option.

To date, recovery has exclusively been applied to the management of illness in the mental health domain. This study has succeeded in promoting the notion that recovery should be open to all, and that both theoretically and conceptually, it shows promise in the management of fibromyalgia and therefore, should be given due consideration in the treatment of this patient group and those with other chronic pain conditions that share similar symptoms. The WRAP® programme undertaken by fibromyalgia patients showed its efficacy on many of the measures reported in Chapter 3 and indicates clinically meaningful results for patients living with the condition. Improving the quality of healthcare interventions for patients with fibromyalgia requires that patients take some responsibility for their own personal

healthcare needs. The implementation of carefully designed self-efficacy enhancing programmes for this cohort may specifically enable individuals with fibromyalgia to successfully undertake interventions and self-care activities that are essential for promoting and maintaining both physical and mental well-being, including pain management, stress management and symptom control.

The research described in this thesis clearly points to the need for self-management interventions for individuals with a diagnosis of fibromyalgia. Interventions are necessary for several reasons, not only to reduce the distress associated with the diagnosis and complex nature of the often life altering symptoms associated with fibromyalgia, but also to inform patients about the role they can assume in managing the condition, to educate patients about fibromyalgia, to reduce the apprehension associated with the receipt of a diagnosis of the condition, and to reduce the distress associated with living with fibromyalgia. Unlike costly pharmacological interventions, there are also few risks associated with attempts to promote a patients self-confidence, acceptance and self-efficacy for health promoting behaviours. The Wellness in Fibromyalgia Intervention shows great promise for this patient group. With appropriate interventions, those diagnosed with fibromyalgia can be optimistic of continued good health and a respectable quality of life. Further research evaluating WRAP® with a diverse range of patient groups has the potential for important clinical implications for health consumers across all domains.

5.3 Limitations

There are a number of limitations that should be considered. Although the findings of the current research provide some direction for further research and

practice, the sample size was small. In addition, the findings reported in this study may be limited due to the sampling method which was employed. All of those who participated in the focus group discussions accessed the Fibrolreland website; a website developed and updated by fibromyalgia patients to provide information and support to others with a similar diagnosis, therefore the participants in the study presented in Chapter 2 may have been more proactive in seeking support compared to people with fibromyalgia who do not access such domains.

Similarly, findings from the Wellness in Fibromyalgia Intervention presented in Chapter 3 should be interpreted with caution because of the convenience sample and the potential for selection bias. Although participants were recruited using online advertising and flyers, it seems likely that individuals responding to the recruitment call for a wellness study may have been more interested in health behaviours and self-management than other fibromyalgia patients, and therefore more likely to initiate positive change.

Volunteers for the focus group study presented in Chapter 2 came from a small population of patients, therefore, in a bid to preserve anonymity; limited personal information was collected. This protection decision was a further limitation. It would have been beneficial to have ascertained a time since diagnosis for each of the participants. This would have allowed the researcher to examine differences in attitudes and management strategies of those who have been living with the condition for some time in comparison to newly diagnosed patients. It also would have been advantageous to have presented defining characteristics for each of the pseudo-named individuals who took part in the focus group discussions as this would

have provided the reader with an opportunity to create a personal profile, combining the demographics and the comments and feedback provided by each individual thus making the entire experience more meaningful to the reader.

A fundamental limitation of the study is that it is not a randomized controlled trial (RCT). The study employed an intervention group and a comparison group, however, participants were not randomly assigned to groups, instead those participants that could attend the intervention in any one of the chosen locations were allocated to the intervention group and the remaining participants who, due to their location or work or family commitments could not attend were offered a place on the comparison group.

An additional key limitation was the study did not employ multi-level modelling to take account of the fact there were three facilitators. Therefore it cannot be ruled out that the approach, knowledge and style of delivery adopted by each of the facilitators may have potentially impacted upon the results obtained. This is a consideration for future research.

While considering the improved outcomes observed in the follow up study, several limitations must be acknowledged. The study comprised a small sample from the original intervention group with just 12% ($N = 10$) of those who completed the intervention accepting the opportunity to attend for an interview as part of a follow-up study. Also, the study comprised of a sample of females. Furthermore, those who volunteered for the follow-up interviews may have agreed to be interviewed because they were actively engaged in the use of their WRAP® plans, thought highly of the intervention and welcomed the opportunity to speak about the topic in a confidential

interview setting. The ability to generalize outside this population is therefore limited. Those who were less comfortable with the prospect of discussing their experience of the intervention and those who avoided the opportunity to attend for interview for alternative reasons were therefore not represented in the research, and therefore the findings may not generalize to these individuals. Future studies using a larger sample with a mix of male and female participants could address these limitations.

While the intervention is based upon a recovery ethos, in the absence of an empirically validated measure of recovery, the decision was made to rely solely on qualitative data to establish if recovery was a feature of change resulting from the intervention. Preferably, both quantitative methods and qualitative methods would have been employed to inform the researcher of changes relating to recovery. Including measures of hope and optimism would also have enhanced the findings relating to the efficacy of WRAP®.

Given the comorbidity between fibromyalgia and anxiety and depression, it would have been of value to include a measure for one or both in the battery of questionnaires. A quality of life measure would also have been advantageous in allowing the researcher establish if the intervention impacted on overall quality of life of the patient, a construct that is negatively affected by fibromyalgia. Obtaining a measure of post-traumatic growth and coping would also have been beneficial to the research. Furthermore, a satisfaction survey was not included in the current research. The opportunity to gather rich data relating to the programme - duration, intensity, content, and effectiveness of the facilitator was lost and such feedback would have provided the impetus and evidence for potential adjustments to the programme in

the future. A further limitation of the present study is generalizability, the programme recruited participants only from the Midlands region and Dublin rather than a nationally representative population. Additionally, the overall number of participants who completed the follow-up questionnaires at the 6 month follow-up was smaller than expected.

Given the limited number of empirically based studies employing WRAP® and the fact that this is the first study to utilize WRAP® with a group of fibromyalgia patients, replication of the research is warranted.

5.4 Future Research

In line with previous research it is proposed within this study that perceived support is an important factor in the treatment of chronic pain patients. Further qualitative research detailing perceived supportive responses and how family might respond better may serve to inform therapeutic interventions for fibromyalgia patients. Furthermore, a quantitative study evaluating the effects of family education and support programmes could demonstrate effective practices for increasing family support for those with fibromyalgia.

It is also clear from the results concerning perceived support that these interventions need to target communities and health care providers. Attempting to address the problems emerging from the complexity of fibromyalgia by intervening exclusively with those living with the condition is a strategy that can only have very limited benefits. Even interventions that attempt to reduce the distress associated with the diagnosis of fibromyalgia should be aimed at a broader community-wide

level, as distress can only truly be reduced when those living with fibromyalgia know that their diagnosis will not lead to the possibility of a debate concerning whether its medically unexplained symptoms constitute a legitimate condition, their accounts of their illness experience being disbelieved or challenged and/or social marginalization. Research into the development of interventions should be informed and enhanced by further research into the impact a diagnosis of fibromyalgia has on the patient. While research of all types is equally valued, qualitative research employing both male and female participants, would be instrumental in examining the issues of fibromyalgia patients' subjectivity.

A further recommendation for future wellness programmes with this patient group is the possibility of offering an online intervention. This emerges from the observed decrease in self-reported physical functioning scores in participants who completed the intervention. However, while this would negate any difficulties in terms of over exertion it may serve to further isolate an already marginalized group. To counterbalance this, the opportunity for blended learning should be considered whereby patients could complete online elements of the intervention from their own home and attend group sessions for the remainder.

A decrease in self-reported number of feel good days was observed in the intervention group in the present research, a finding which was unanticipated. It is proposed that a follow-up study should aim to determine the meaning of a 'good day' for fibromyalgia patients. Participant's 'good day' definitions could be obtained across time points to establish changes over the course of an intervention and identify factors that may influence such a change.

Self-efficacy, acceptance and control emerged as leading constructs that were impacted upon in this patient group by the Wellness in Fibromyalgia Intervention. To date, no other study evaluating WRAP® has examined these constructs as outcomes of the intervention, however, the promising findings reported here showing the potential WRAP® has to promote self-efficacy, acceptance and internal control should be examined in future evaluation studies.

5.5 Conclusion

The aim of this research was to gain an understanding of the subjective experience of life with fibromyalgia from an Irish perspective and to produce and deliver an empirically supported intervention in this context. This aim was achieved through the application of a range of research methods, and the results generated represent a significant contribution to the psychological literature in the field of study associated with the self-management of chronic illness, and in particular fibromyalgia. A recovery-focused intervention was developed and delivered to a group of patients who are understudied and underserved. The research has emphasised the complexity of fibromyalgia and both the emotional and physical distress associated with it, and serves as a call for future research and interventions to improve the lives of both men and women living with the condition.

6 References

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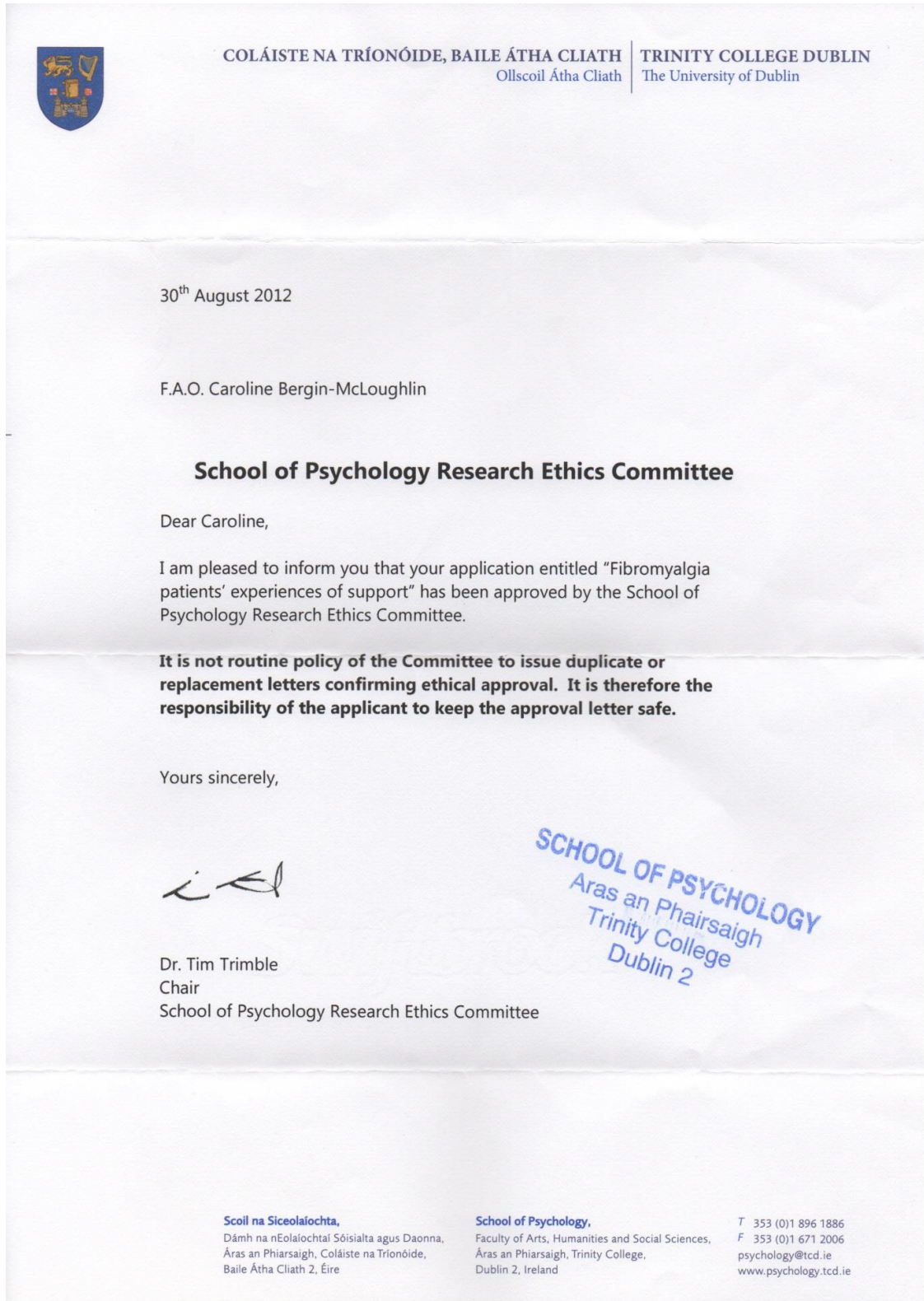
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7 Appendices

7.1 Appendix 1: Ethical Approval Letters



F.A.O. Caroline Bergin-McLoughlin

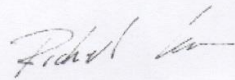
School of Psychology Research Ethics Committee

8 April 2014

Dear Caroline,

Following receipt of amendments, I am pleased to inform you that your application entitled "Promoting self-management in fibromyalgia" has been approved by the School of Psychology Research Ethics Committee.

Yours sincerely,



Richard Carson
Chair,
School of Psychology Research Ethics Committee

**SCHOOL OF PSYCHOLOGY
Arás an Phiarsaigh
Trinity College
Dublin 2**



F.A.O. Caroline Bergin-McLoughlin

School of Psychology Research Ethics Committee

10 July 2015

Dear Caroline,

Following receipt of amendments, I am pleased to inform you that your application entitled "Promoting self-management in fibromyalgia" has been approved by the School of Psychology Research Ethics Committee.

Yours sincerely,

Richard Carson
Chair,
School of Psychology Research Ethics Committee



24.08.12

To whom it may concern,

On behalf of Fibromyalgia Ireland I wish to take this opportunity to confirm that we have granted Caroline Bergin McLoughlin permission to access participants through our organisation.


We are happy to host the project entitled "Fibromyalgia patients experiences of support" and can confirm that there are appropriate numbers available to accommodate the needs of the research.

If you have any queries in relation to this matter, please do not hesitate to contact me.

Yours Sincerely,

Rachel Lynch

www.fibroireland.com

 facebook.com/NorthsideFibroDublin

0879976252 • info@fibroireland.com • 46 Beach Park, Portmarnock, Co. Dublin.





02.02.14

To whom it may concern,

On behalf of Fibromyalgia Ireland I wish to take this opportunity to confirm that we have granted Caroline Bergin McLoughlin permission to access participants through our organisation.


We are happy to host the Intervention Study entitled "Maintaining Wellness in Fibromyalgia" and can confirm that there are appropriate numbers available to accommodate the needs of the research.

If you have any queries in relation to this matter, please do not hesitate to contact me.

Yours Sincerely,

Rachel Lynch

www.fibroireland.com

 facebook.com/NorthsideFibroDublin

0879976252 • info@fibroireland.com • 46 Beach Park, Portmarnock, Co. Dublin.

7.2 Appendix 2: Information Letter For Chapters 2, 3 and 4

Perceived Support and Fibromyalgia

The focus of this research will be on people's levels of support from friends, family and health care professionals. We are interested in talking to people who have a diagnosis of Fibromyalgia about their experiences of support who would be willing to attend a focus group meeting. During this meeting, I will be asking some questions and individuals will have the opportunity to discuss openly and honestly their personal experiences of support. The discussion will be tape recorded and transcribed by myself at a later date.

Following the group discussion, participants will be asked to complete 3 short questionnaires. The entire session should take a maximum of an hour and a half, with breaks as required.

Our plan is to use the information from the focus group to help us develop an intervention to enhance support for people with Fibromyalgia. We are still in the early planning stages and our research will become more focused based on what we understand more about people's experiences of support from others. We hope that this study will ultimately contribute to better support systems for people with Fibromyalgia in future.

Research Team:

Caroline Bergin-McLoughlin, School of Psychology, Aras An Phiarsaigh, Trinity College, Dublin 2.

Tel: 087 9291261

E-mail: berginmc@tcd.ie

Dr. David Hevey, School of Psychology, Aras An Phiarsaigh, Trinity College, Dublin 2.

Tel: 01 896 2406

E-mail: heveydt@tcd.ie

Wellness in Fibromyalgia Intervention (WRAP)

The focus of this research will be on whether a Wellness Recovery Action Planning (WRAP) programme designed specifically for individuals with a diagnosis of Fibromyalgia has the potential to impact on the management of the symptoms associated with the disorder. The results of this intervention study will contribute to our understanding of fibromyalgia, and may advance management techniques for patients.

WRAP was first developed by Mary Ellen Copeland and is aimed at individuals who experience health and lifestyle challenges. In WRAP, participants identify early warning signs for the onset of symptoms and have the opportunity to create an individualized plan for successful living. The plan will include strategies for staying well and minimizing triggers to a flare up of symptoms/distress. Through WRAP, people are empowered to take control of their own wellness. The programme being offered in the context of the present study has been modified to suit the needs of patients with a diagnosis of Fibromyalgia.

The intervention consists of 7 sessions, each lasting 1 ½ hours which will run weekly. You will be provided with all relevant materials necessary for completion of the course including information and course workbook. You will be asked to complete a number of questionnaires both before and after the intervention. You will have access to all data collected and have the right to withdraw from the research at any given point.

Should you feel upset or distressed either during or after the intervention I would advise you contact your GP, a local healthcare professional or any member of the research team. The following support services are also available to you

AWARE: 1890 303 302 (Monday to Sunday 10am-10pm)

SAMARITANS: 1850 60 90 90 (Monday to Sunday, 24 hours per day)

If you have any further questions regarding this study, my details are given below.

Research Team:

Caroline Bergin-McLoughlin, Dr. David Hevey, School of Psychology, University of Dublin, Trinity College, Dublin2

Tel: 01 896 1886; E-mail: berginmc@tcd.ie

Maintaining Wellness in Fibromyalgia

The focus of this research will be on reported experience of the impact of a Wellness Intervention on Fibromyalgia symptoms. We are interested in talking to people who have completed the 7 week Wellness in Fibromyalgia Intervention Programme. During this meeting, I will be asking some questions and individuals will have the opportunity to discuss openly and honestly their personal experiences since completion of the intervention. The discussion will be tape recorded and transcribed by myself at a later date.

Our plan is to use the information from these interviews to help us establish if the Wellness Intervention has enhanced the lives of those people with Fibromyalgia. We hope that this study will ultimately contribute to better treatment options for people with Fibromyalgia in future.

Research Team:

Caroline Bergin-McLoughlin, Centre for Psychological Health, School of Psychology, Aras An Phiarsaigh, Trinity College, Dublin 2.

Tel: 087 9291261

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Dr. David Hevey, Centre for Psychological Health, School of Psychology, Aras An Phiarsaigh, Trinity College, Dublin 2.

Tel: 01 896 2406

E-mail: heveydt@tcd.ie

Comparison Group Information Sheet

The focus of this research is on whether a Wellness Recovery Action Planning (WRAP) programme designed specifically for individuals with a diagnosis of fibromyalgia and has the potential to impact on the management of the symptoms associated with the disorder. The results of this intervention study will contribute to our understanding of fibromyalgia and may advance management techniques for patients.

WRAP was first developed by Mary Ellen Copeland and is aimed at individuals who experience health and lifestyle challenges. In WRAP, participants identify early warning signs for the onset of symptoms and have the opportunity to create a plan for successful living. The plan includes strategies for staying well and minimizing triggers to a flare up of symptoms/distress. Through WRAP, people are empowered to take control of their own wellness.

In order to establish the effectiveness of WRAP on fibromyalgia management, two groups of patients are required; **an intervention group** who will complete the 7 week intervention and **a comparison group** who will continue with their treatment as usual. The intervention group will attend the 7 week Wellness Programme and will complete a number of questionnaires at different time points before, during and after the intervention programme. The comparison group will continue with their usual treatment and will be asked to complete a number of questionnaires at different time points so a comparison can be made between the groups. You will have access to all data and have the right to withdraw from the research at any given point.

Data will be stored on a password protected computer. Your data will be combined and analysed as a group. Each participant will be assigned a number therefore protecting your identity. Your name **will not** appear in any aspect of the research.

If you have further questions regarding the study, my details are provided below.

Research Team

Caroline Bergin-McLoughlin, Dr. David Hevey, Centre for Global Health, School of Psychology, University of Dublin, Trinity College, Dublin2.

Tel: 01 8961886

Mob: 087 9291261

Email: berginmc@tcd.ie

7.3 Appendix 3: Consent Forms For Chapters 2, 3 and 4

Consent Form: Perceived Support and Fibromyalgia

I hereby give consent to take part in a study on “support experienced by individuals with a diagnosis of Fibromyalgia” carried out by Caroline Bergin–McLoughlin from the School of Psychology, Trinity College Dublin.

I understand that participation in this study is entirely **voluntary** and that I can withdraw at any time, including withdrawal of my data after my participation. I understand that the data obtained from my participation are **confidential** and **anonymous** and will be used only for the purposes of research. Under the Freedom of Information Act, 1997 (amended 2003), I can request access to any data stored under my name.

I have already been informed of the nature of the study and a complete explanation of the underlying principle of it will be provided after participation. At that time, any further questions that I might have about the study will be answered fully by the researcher.

I understand that I will not be requested to participate in any study that is harmful to my health or personal circumstances and can confirm that I have read and understood the above information.

Name (Print) _____

Signed _____ Date _____

Researcher (Print) _____

Signed _____ Date _____

Research Team:

Dr. David Hevey, School of Psychology, University of Dublin, Trinity College, Dublin 2. **Tel:** 01 896 2406 , **E-mail:** heveydt@tcd.ie

Caroline Bergin-McLoughlin, School of Psychology, University of Dublin, Trinity College, Dublin 2. **Tel:** 087 9291261; **E-mail:** berginmc@tcd

Consent Form: Wellness in Fibromyalgia Intervention (WRAP)

I hereby give consent to take part in a 7 week WRAP Programme promoting understanding and self-management in Fibromyalgia carried out by Caroline Bergin-McLoughlin from the School of Psychology, Trinity College Dublin.

I understand that participation in this study is entirely **voluntary** and that I can withdraw at any time, including withdrawal of my data after my participation. I understand that the data obtained from my participation are **confidential** and **anonymous** and will be used only for the purposes of research. Under the Freedom of Information Act, 1997 (amended 2003), I can request access to any data stored under my name.

I have already been informed of the nature of the study and a complete explanation of the underlying principle of it will be provided after participation. At that time, any further questions that I might have about the study will be answered fully by the researcher.

I understand that I will not be requested to participate in any study that is harmful to my health or personal circumstances and can confirm that I have read and understood the above information.

Name (Print) _____
Signed _____ Date _____

Researcher (Print) _____
Signed _____ Date _____

Research Team:

Dr. David Hevey, School of Psychology, University of Dublin, Trinity College, Dublin 2. **Tel:** 01 896 2406 , **E-mail:** heveydt@tcd.ie

Caroline Bergin-McLoughlin, School of Psychology, University of Dublin, Trinity College, Dublin2. **Tel:** 087 9291261; **E-mail:** berginmc@tcd.ie

Consent Form : Maintaining Wellness in Fibromyalgia

I hereby give consent to take part in a follow up study examining the impact of a Wellness Intervention on Fibromyalgia carried out by Caroline Bergin-McLoughlin from the School of Psychology, Trinity College Dublin.

I understand that participation in this study is entirely **voluntary** and that I can withdraw at any time, including withdrawal of my data after my participation. I understand that the data obtained from my participation are **confidential** and **anonymous** and will be used only for the purposes of research. Under the Freedom of Information Act, 1997 (amended 2003), I can request access to any data stored under my name.

I have already been informed of the nature of the study and a complete explanation of the underlying principle of it will be provided after participation. At that time, any further questions that I might have about the study will be answered fully by the researcher.

I understand that I will not be requested to participate in any study that is harmful to my health or personal circumstances and can confirm that I have read and understood the above information.

Name (Print) _____

Signed _____ Date _____

Researcher (Print) _____

Signed _____ Date _____

Research Team:

Dr. David Hevey, School of Psychology, University of Dublin, Trinity College, Dublin 2. **Tel:** 01 896 2406 , **E-mail:** heveydt@tcd.ie

Caroline Bergin-McLoughlin, School of Psychology, University of Dublin, Trinity College, Dublin2. **Tel:** 087 9291261; **E-mail:** berginmc@tcd.ie

Consent Form: Comparison Group

I hereby give consent to take part in a study examining living with fibromyalgia and the management of the condition carried out by Caroline Bergin-McLoughlin from the School of Psychology, Trinity College Dublin.

I understand that participation in this study is entirely **voluntary** and that I can withdraw at any time, including withdrawal of my data after my participation. I understand that the data obtained from my participation are **confidential** and **anonymous** and will be used only for the purposes of research. Under the Freedom of Information Act, 1997 (amended 2003), I can request access to any data stored under my name.

I have already been informed of the nature of the study and a complete explanation of the underlying principle of it will be provided after participation. At that time, any further questions that I might have about the study will be answered fully by the researcher.

I understand that I will not be requested to participate in any study that is harmful to my health or personal circumstances and can confirm that I have read and understood the above information.

Name (Print) _____

Signed _____ Date _____

Researcher (Print) _____

Signed _____ Date _____

Research Team:

Dr. David Hevey, School of Psychology, University of Dublin, Trinity College, Dublin 2. **Tel:** 01 896 2406, **E-mail:** heveydt@tcd.ie

Caroline Bergin-McLoughlin, School of Psychology, University of Dublin, Trinity College, Dublin 2. **Tel:** 087 9291261; **E-mail:** berginmc@tcd.ie

7.4 Appendix 4: Debriefing Letter For Chapters 2, 3 and 4

Perceived Support and Fibromyalgia

Thank you for participating in this study, which investigates how people with a diagnosis of Fibromyalgia have experienced support following their diagnosis. The results of this study will contribute to our understanding of fibromyalgia, with a view to aiding in the development of management techniques for patients.

The reason for your participation in the study was as follows. Completing the questionnaires will help us to assess perceived levels of social support and also the level of support provided to you by health care professionals, family and friends. Telling us about your personal experience of getting your diagnosis, frustrations experienced and the support provided by significant individuals in your life will help us to assess the impact of support on your well-being and ability to manage the complex and often debilitating symptoms of Fibromyalgia.

If you have any further questions regarding this study, my details are given below.

Researchers:

Caroline Bergin-McLoughlin, School of Psychology, Aras An Phiarsaigh, Trinity College, Dublin 2.

Tel: 087 9291261

E-mail: berginmc@tcd.ie

Dr. David Hevey, School of Psychology, Aras An Phiarsaigh, Trinity College, Dublin 2.

Tel: 01 896 2406

E-mail: heveydt@tcd.ie

Wellness in Fibromyalgia Intervention (WRAP)

Thank you for participating in this study, which investigates whether a Wellness Recovery Action Planning (WRAP) programme designed specifically for individuals with a diagnosis of Fibromyalgia impacts on the management of the symptoms associated with the disorder. The results of this intervention study will contribute to our understanding of fibromyalgia, and may advance management techniques for patients.

The reason for your participation in the study was as follows. Completing the questionnaires pre and post intervention will help us to assess whether participation in the intervention made a significant difference to your quality of life. They will also show us the psychological constructs that you as an individual utilise in the management of the complex, and often debilitating symptoms associated with fibromyalgia and whether these changed in any way as a result of the intervention.

If you have any further questions regarding this study, my details are given below.

Research Team:

Caroline Bergin-McLoughlin, Dr. David Hevey

School of Psychology, University of Dublin, Trinity College, Dublin2

Tel: 01 896 1886; E-mail: berginmc@tcd.ie

Maintaining Wellness in Fibromyalgia

Thank you for participating in this study, which aims to investigate if those who have completed the 'Wellness in Fibromyalgia' programme have noticed any changes in the management of their symptoms. The results of this study will contribute to our understanding of fibromyalgia and our understanding of whether the intervention promotes change.

Telling us about your personal experience since completing the programme 12 months ago will enable us to assess the impact of this intervention on your well-being and ability to manage the complex and often debilitating symptoms of Fibromyalgia.

If you have any further questions regarding this study, my details are given below.

Researchers:

Caroline Bergin-McLoughlin, School of Psychology, Aras An Phiarsaigh, Trinity College, Dublin 2.

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Comparison Group

Thank you for participating in this study, which investigates whether a Wellness Recovery Action Planning (WRAP) programme designed specifically for individuals with a diagnosis of Fibromyalgia impacts on the management of symptoms associated with the disorder. The results of this controlled intervention study will contribute to our understanding of fibromyalgia, and may advance management techniques for patients.

The study involved 2 groups of patients, an Intervention group and a Comparison Group. The Intervention Group completed questionnaires at three time points in combination with the completion of a 6 week intervention. The Comparison Group (of which you were part of), completed the questionnaires at similar time points but did not take part in the intervention. The reason for your participation in the study was as follows. Completing the questionnaires at 3 separate time points will allow us compare your results against the Intervention Group thus enabling us to determine whether participation in the intervention made a significant difference to the quality of life of Fibromyalgia patients. The questionnaires will also show us the psychological constructs that are utilised in the management of the complex, and often debilitating symptoms associated with fibromyalgia and whether these changed in any way as a result of taking part in the intervention programme.

If you have any further questions regarding this study, my details are given below.

Research Team:

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7.5 Appendix 5: Questionnaires For Chapter 3

Demographic Data

Id. _____

(Please circle appropriate response)

1. Gender

- a. Male
- b. Female

2. Age _____

3. Marital Status

- a. Single
- b. Married/Cohabitation
- c. Divorced/Separated
- d. Widow (er)

4. Highest Education level

- a. Primary level
- b. Secondary level
- c. Higher (Third) level
- d. Postgraduate level

5. Occupation

- a. Student
- b. Full time worker
- c. Part time worker
- d. Unemployed
- e. Maternity leave
- f. Sick leave

- g. Retired
- h. Other

6. Are you currently receiving any treatment for (please tick where appropriate)

- a. a mental health problem
- b. a general health problem
- c. both mental health and general health problems
- d. not currently on any treatment

7. In the past month have you visited any of the following in relation to your fibromyalgia

(If you answer 'yes' to any of the following, please state the number of visits in the space provided)

- a. GP _____
- b. Medical Specialist/Consultant _____
- c. Physiotherapist _____
- d. Occupational Therapist _____
- e. Other (Please state) _____

CPAQ

Directions: Below you will find a list of statements. Please rate the truth of each statement as it applies to you. Use the following rating scale to make your choices. For instance, if you believe a statement is 'Always True,' you would write a 6 in the blank next to that statement.

0	1	2	3	4	5	6
Never True	Very rarely true	Seldom true	Sometimes true	Often true	Almost always true	Always true

1. ____ I am getting on with the business of living no matter what my level of pain is.
2. ____ My life is going well, even though I have chronic pain.
3. ____ It's OK to experience pain.
4. ____ I would gladly sacrifice important things in my life to control this pain better.
5. ____ It's not necessary for me to control my pain in order to handle my life well.
6. ____ Although things have changed, I am living a normal life despite my chronic pain.
7. ____ I need to concentrate on getting rid of my pain.
8. ____ There are many activities I do when I feel pain.
9. ____ I lead a full life even though I have chronic pain.
10. ____ Controlling pain is less important than any other goals in my life.
11. ____ My thoughts and feelings about pain must change before I can take important steps in my life.
12. ____ Despite the pain, I am now sticking to a certain course in my life.
13. ____ Keeping my pain level under control takes first priority whenever I'm doing something.
14. ____ Before I can make any serious plans, I have to get some control over my pain.
15. ____ When my pain increases, I can still take care of my responsibilities.
16. ____ I will have better control over my life if I can control my negative thoughts about pain.
17. ____ I avoid putting myself in situations where my pain might increase.
18. ____ My worries and fears about what pain will do to me are true.
19. ____ It's a relief to realize that I don't have to change my pain to get on with my life.
20. ____ I have to struggle to do things when I have pain.

FIBROMYALGIA IMPACT QUESTIONNAIRE (FIQ)

Name: _____

Date: / /

Directions: For questions 1 through 11, please circle the number that best describes how you did overall for the *past week*. If you don't normally do something that is asked, cross the question out.

	Always	Most	Occasionally	Never
Were you able to:				
<i>Do shopping?</i>	0	1	2	3
<i>Do laundry with a washer and dryer?</i>	0	1	2	3
<i>Prepare meals?</i>	0	1	2	3
<i>Wash dishes/cooking utensils by hand?.....</i>	0	1	2	3
<i>Vacuum a rug?.....</i>	0	1	2	3
<i>Make beds?</i>	0	1	2	3
<i>Walk several blocks?</i>	0	1	2	3
<i>Visit friends or relatives?</i>	0	1	2	3
<i>Do yard work?.....</i>	0	1	2	3
<i>Drive a car?</i>	0	1	2	3
<i>Climb stairs?</i>	0	1	2	3

12. *Of the 7 days in the past week, how many days did you feel good?*

0 1 2 3 4 5 6 7

13. *How many days last week did you miss work, including housework, because of fibromyalgia?*

0 1 2 3 4 5 6 7

(continued)

FIBROMYALGIA IMPACT QUESTIONNAIRE (FIQ) – page 2

Directions: For the remaining items, mark the point on the line that best indicates how you felt overall for the past week.

14. *When you worked, how much did pain or other symptoms of your fibromyalgia interfere with your ability to do your work, including housework?*

No problem with work • _____ • Great difficulty with work

15. *How bad has your pain been?*

No pain • _____ • Very severe pain

16. *How tired have you been?*

No tiredness • _____ • Very tired

17. *How have you felt when you get up in the morning?*

Awoke well rested • _____ • Awoke very tired

18. *How bad has your stiffness been?*

No stiffness • _____ • Very stiff

19. *How nervous or anxious have you felt?*

Not anxious • _____ • Very anxious

20. *How depressed or blue have you felt?*

Not depressed • _____ • Very depressed

PAIN LOCUS OF CONTROL QUESTIONNAIRE

Instructions: Each item below is a belief statement about your medical condition with which you may agree or disagree. Beside each statement is a scale which ranges from strongly disagree (1) to strongly agree (6). For each item we would like you to circle the number that represents the extent to which you agree or disagree with that statement. The more you agree with a statement, the higher will be the number you circle. The more you disagree with a statement, the lower will be the number you circle. Please make sure that you answer **EVERY ITEM** and that you circle **ONLY ONE** number per item. This is a measure of your personal beliefs; obviously, there are no right or wrong answers.

1=STRONGLY DISAGREE (SD) 2=MODERATELY DISAGREE (MD) 3=SLIGHTLY DISAGREE (D)	4=SLIGHTLY AGREE (A) 5=MODERATELY AGREE (MA) 6=STRONGLY AGREE (SA)
--	---

		SD	MD	D	A	MA	SA
1	If my Fibromyalgia worsens, it is my own behavior which determines how soon I will feel better again.	1	2	3	4	5	6
2	As to my Fibromyalgia, what will be will be.	1	2	3	4	5	6
3	If I see my doctor regularly, I am less likely to have problems with my Fibromyalgia.	1	2	3	4	5	6
4	Most things that affect my Fibromyalgia happen to me by chance.	1	2	3	4	5	6
5	Whenever my Fibromyalgia worsens, I should consult a medically trained professional.	1	2	3	4	5	6
6	I am directly responsible for my Fibromyalgia getting better or worse.	1	2	3	4	5	6
7	Other people play a big role in whether my Fibromyalgia improves, stays the same, or gets worse.	1	2	3	4	5	6
8	Whatever goes wrong with my Fibromyalgia is my own fault.	1	2	3	4	5	6
9	Luck plays a big part in determining how my Fibromyalgia improves.	1	2	3	4	5	6
10	In order for my Fibromyalgia to improve, it is up to other people to see that the right things happen.	1	2	3	4	5	6
11	Whatever improvement occurs with my Fibromyalgia is largely a matter of good fortune.	1	2	3	4	5	6
12	The main thing which affects my Fibromyalgia is what I myself do.	1	2	3	4	5	6
13	I deserve the credit when my Fibromyalgia improves and the blame when it gets worse.	1	2	3	4	5	6
14	Following doctor's orders to the letter is the best way to keep my Fibromyalgia from getting any worse.	1	2	3	4	5	6
15	If my Fibromyalgia worsens, it's a matter of fate.	1	2	3	4	5	6
16	If I am lucky, my Fibromyalgia will get better.	1	2	3	4	5	6
17	If my Fibromyalgia takes a turn for the worse, it is because I have not been taking proper care of myself.	1	2	3	4	5	6
18	The type of help I receive from other people determines how soon my Fibromyalgia improves.	1	2	3	4	5	6

General Self Efficacy Scale

1 = Not at all true 2 = Hardly true 3 = Moderately true 4 = Exactly true

1	I can always manage to solve difficult problems if I try hard enough.
2	If someone opposes me, I can find the means and ways to get what I want.
3	It is easy for me to stick to my aims and accomplish my goals.
4	I am confident that I could deal efficiently with unexpected events.
5	Thanks to my resourcefulness, I know how to handle unforeseen situations.
6	I can solve most problems if I invest the necessary effort.
7	I can remain calm when facing difficulties because I can rely on my coping abilities.
8	When I am confronted with a problem, I can usually find several solutions.
9	If I am in trouble, I can usually think of a solution.
10	I can usually handle whatever comes my way.

7.6 Appendix 6: As Treated Analysis Results

Participants

A total of 91 individuals were eligible for inclusion in the analysis (refer to Figure 7.1 and Figure 7.2). Based on Chi square analyses, the participants in both groups were not significantly different on any of the clinical demographic characteristics (see Table 7.1). The majority of participants in both groups were female: the intervention group ($N = 48$) comprised of 45 female and 3 male participants and the comparison group ($N = 43$) comprised of 41 female and 2 male participants. The mean age of the participants in the intervention group was 44.49 ($SD= 11.82$) years, while the comparison group had a mean age of 49.29 ($SD= 13.35$) years. The age range of fibromyalgia patients in the intervention group was 19 to 73 years; that of fibromyalgia patients in the comparison group was 18 to 69 years. The education profiles of both groups were similar. Approximately two thirds of participants across both groups presented completed higher level education; 65% of the comparison group and 60% of the intervention group had completed a third level or post graduate course of study. Both groups were similar in the types of treatment they are currently receiving. Of interest is the high number of participants in receipt of both physical and mental health treatment, 16 (33%) of the intervention group and 10 (23%) of the comparison group fell into this category. Demographic characteristics for the 91 participants are summarized in Table 7.1.

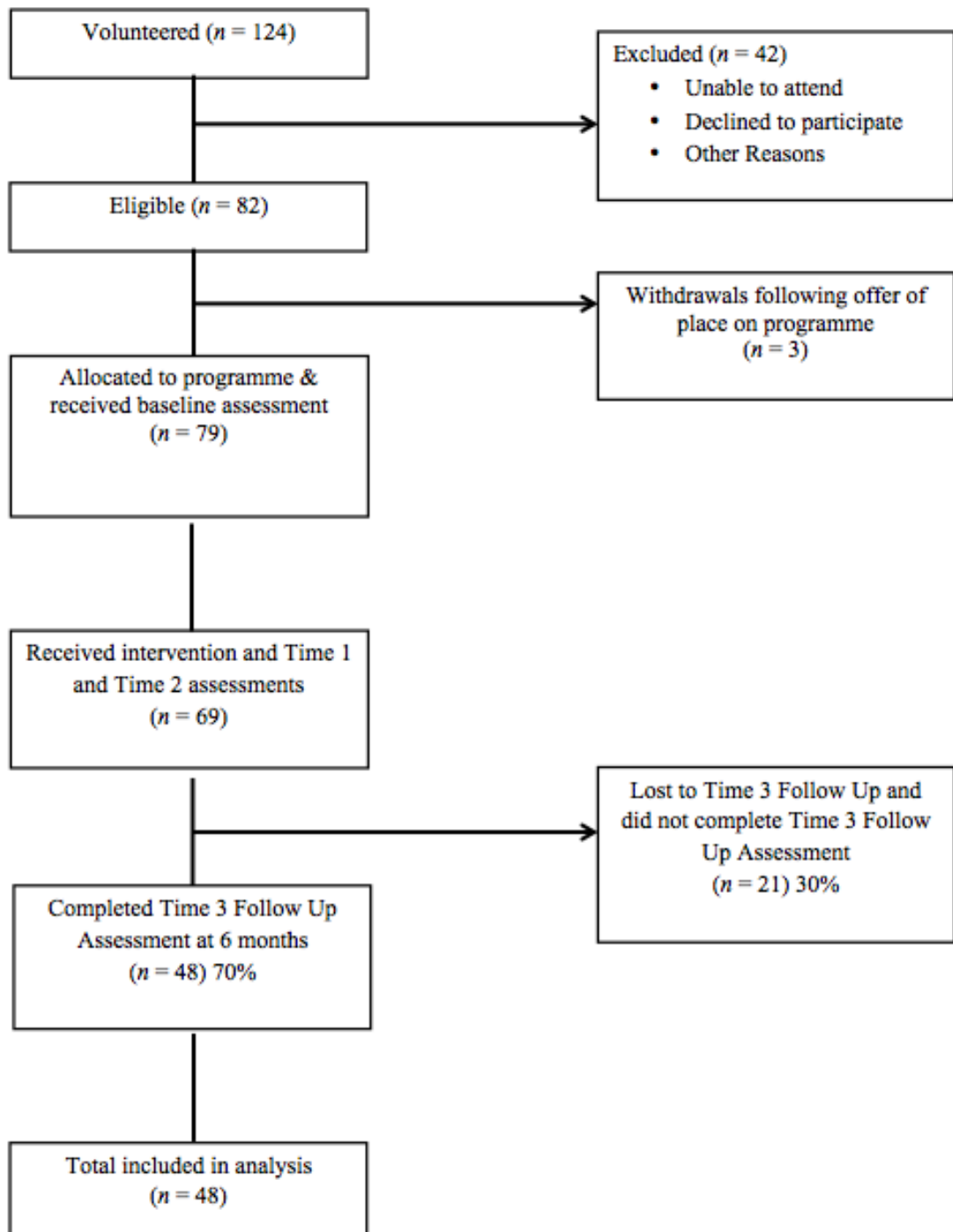


Figure 7.1: Participant Enrolment, Allocation, Follow up and Analysis - Intervention Group

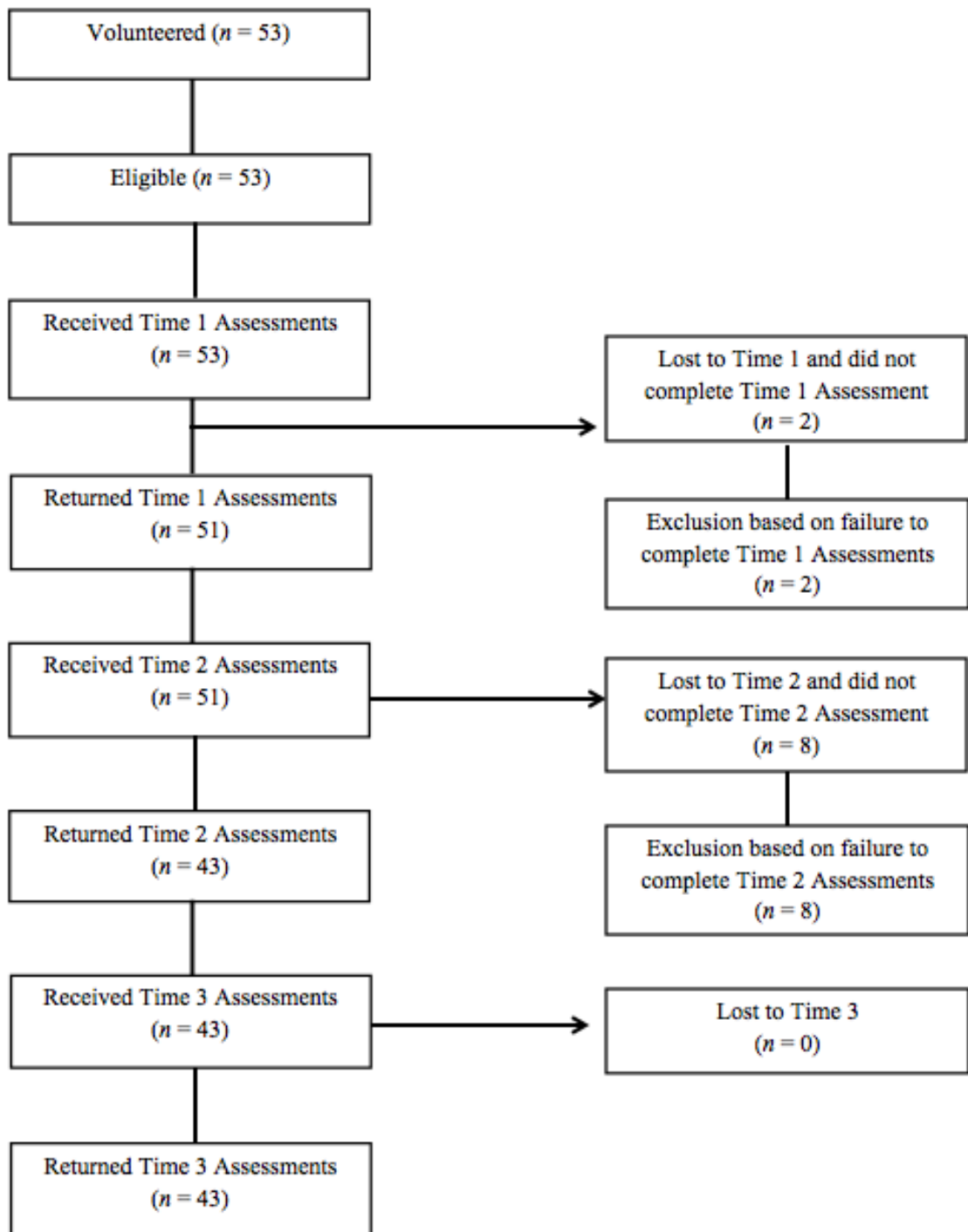


Figure 7.2: Participant Enrolment, Allocation, Follow up and Analysis - Comparison Group

Table 7.1: Participant demographics

Demographic	Comparison Group N=43 N (%)	Intervention Group N=48 N (%)
Gender		
Male	2 (5%)	3 (6%)
Female	41 (95%)	45 (94%)
Education level		
Primary	2(5%)	2(5%)
Secondary	13(30%)	17 (36%)
Third	17(40%)	26 (54%)
Post graduate	11 (25%)	3(6%)
Occupation		
Student	5 (12%)	2 (4%)
Full time Employment	10 (24%)	3 (6%)
Part time Employment	7 (16%)	4 (8%)
Unemployed	3 (6%)	11 (23%)
Sick Leave	6 (14%)	11 (23%)
Retired	6 (14%)	11 (23%)
Other	6 (14%)	6 (13%)
Current Treatment		
Mental Health Issue	0 (0%)	1 (2%)
General Health Issue	23 (54%)	24 (50%)
Both Mental and General Health Issue	10 (23%)	16 (33%)
Not Receiving Treatment	10 (23%)	7 (15%)

Longitudinal Study Data Analyses

Comparisons of Time 0 to Time 3 were completed on all measures in terms of the total scores and the subscale scores (see Table 7.2).

General Self-Efficacy

Total Self-Efficacy Scores

The results show that self-efficacy scores differ significantly across time points: $F(2.17, 102.07) = 11.69, p < .001, \eta^2 = .19$. Paired samples t-tests indicated a

significant increase from Time 1 ($M = 28.90$) to Time 2 ($M = 31.29$), $t(77) = -4.36$, $p < .02$, two-tailed, which were the immediate pre-intervention to immediate post intervention scores. No significant differences were observed between Time 0 and Time 1, or Time 2 and Time 3. Figure 7.3 indicates a pattern of stable self-efficacy levels between T0 and T1, with an increase over the course of the intervention (T1 to T2), followed by a maintenance of the increased self-efficacy from T2 to T3.

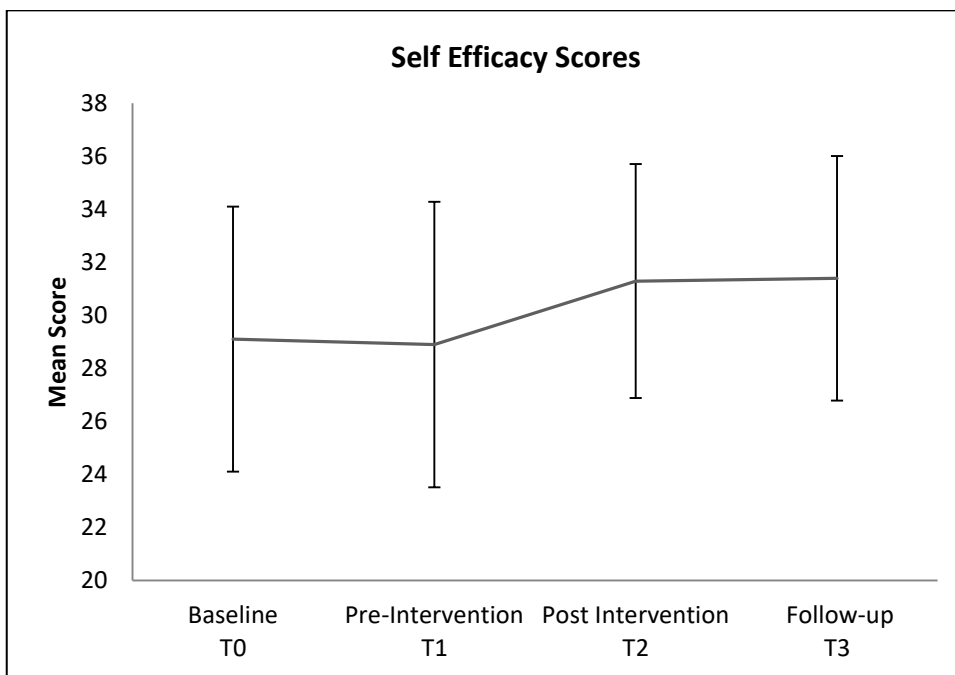


Figure 7.3: Mean Self-efficacy Scores for Intervention Group Time 0, Time 1, Time 2 and Time 3. Error bars represent standard deviations.

Chronic Pain Acceptance

Total Pain Acceptance Scores

The results show that chronic pain acceptance scores differ significantly across time points $F(1.78, 84.45) = 6.74$, $p < .005$, $\eta^2 = .12$. Paired samples t-tests indicated a significant increase from Time 1 ($M = 53.42$) to Time 2 ($M = 59.74$), $t(47) = -2.38$, $p < .02$, two-tailed, which were the immediate pre-intervention to

immediate post intervention scores. No significant differences were observed between Time 0 and Time 1, or Time 2 and Time 3. Figure 7.4 indicates a pattern of pain acceptance levels between T0 and T1, with an increase over the course of the intervention (T1 to T2), followed by a maintenance of the increased pain acceptance from T2 to T3.

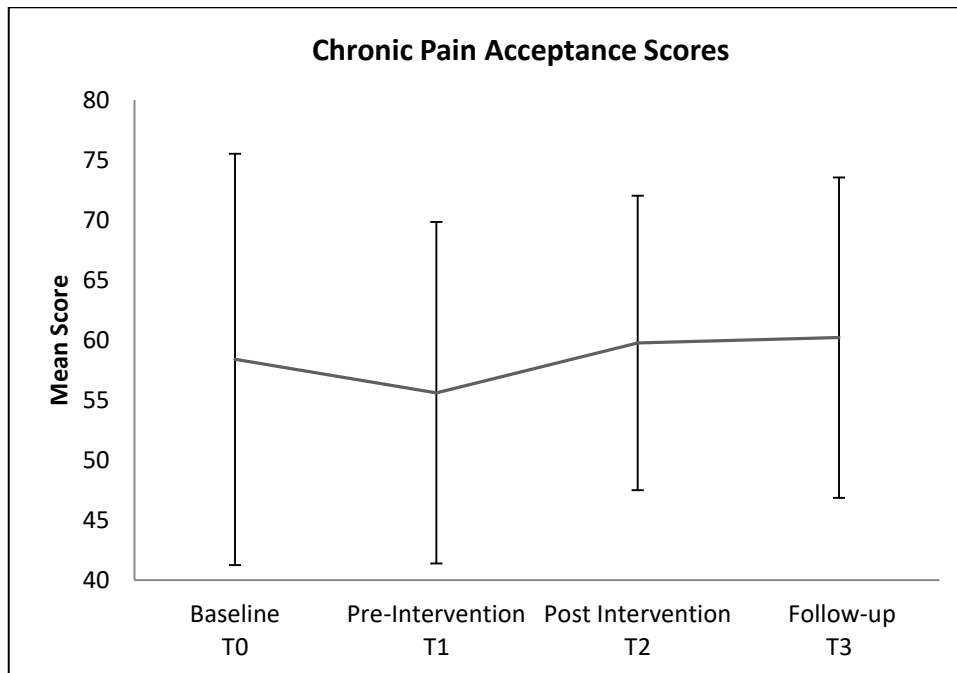


Figure 7.4: Mean Chronic Pain Acceptance Scores for Intervention Group Time 0, Time 1, Time 2 and Time 3. Error bars represent standard deviations.

Total Activities Engagement Scores

The results show that total activities engagement scores differ significantly across the time points $F(2.11, 96.68) = 7.71, p < .005, \eta^2 = .14$. Paired samples t-tests indicated a significant increase from Time 1 ($M = 36.40$) to Time 2 ($M = 40.43$), $t(47) = -2.58, p < .02$, two-tailed, which were the immediate pre-intervention to immediate post intervention scores. No significant differences were observed between Time 0 and Time 1 or Time 2 and Time 3. Figure 7.5 indicates a pattern

of stable activities engagement levels between T0 and T1, which are baseline to start of intervention scores, with an increase over the course of the intervention (T1 to T2), followed a maintenance in the increased activities engagement from T2 to T3 which are scores from week 7 of intervention across the 6 month follow-up.

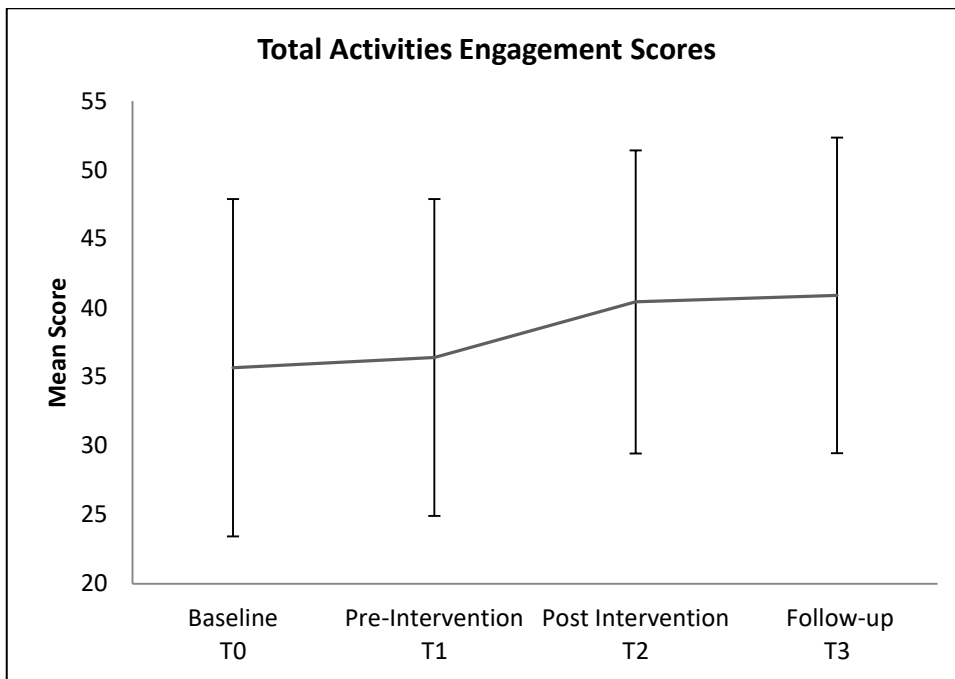


Figure 7.5: Mean Activities Engagement Scores for Intervention Group Time 0, Time 1, Time 2 and Time 3. Error bars represent standard deviations.

Total Pain Willingness Scores

The results show that total pain willingness scores do not significantly differ across the 4 time points $F(2.18,102.73) = 1.34, p>.05$.

Table 7.2: Descriptive statistics for Intervention (N = 48) and Comparison Groups (N = 43) across time points

Measure	T0 M(SD)	T1 M(SD)	T2 M(SD)	T3 M(SD)
<u>GSES (Total Score)</u>				
Intervention	29.10 (5.00)	28.90 (5.38)	31.29 (4.41)	31.40 (4.61)
Comparison		28.33 (5.19)	28.95 (5.26)	29.33 (4.24)
<u>CPAQ (Total Score)</u>				
Intervention	53.42 (16.96)	55.35 (14.17)	59.58 (12.19)	60.02 (13.26)
Comparison		54.56 (16.32)	55.60 (16.70)	58.88 (15.67)
<u>Activities engagement</u>				
Intervention	35.62 (12.36)	36.47 (11.54)	40.43 (10.98)	40.91 (11.44)
Comparison		36.70 (12.84)	36.65 (12.57)	38.60 (11.53)
<u>Pain Willingness</u>				
Intervention	17.75 (8.62)	18.96 (6.94)	19.17 (6.39)	19.19 (7.15)
Comparison		17.86 (8.02)	18.95 (7.51)	20.28 (7.02)
<u>FIQ</u>				
<u>Impact of Illness</u>				
Intervention	68.94 (16.94)	68.97 (15.86)	61.34 (18.53)	66.55 (21.43)
Comparison		67.03 (17.37)	65.16 (19.42)	64.43 (19.30)
<u>Physical Functioning</u>				
Intervention	14.77 (8.07)	15.77 (7.38)	14.33 (7.20)	14.25 (8.42)
Comparison		15.30 (7.73)	14.86 (7.76)	15.39 (7.85)
<u>Feel Good Days</u>				
Intervention	4.72 (1.89)	4.79 (1.68)	3.68 (1.74)	3.87 (1.90)
Comparison		4.51 (1.88)	3.88 (1.90)	4.07 (1.93)
<u>Missed Work Days</u>				
Intervention	2.87 (2.48)	2.52 (2.33)	2.22 (2.32)	1.89 (2.08)
Comparison		2.34 (2.32)	2.60 (2.22)	2.09 (2.25)
<u>Impairment Score</u>				
Intervention	45.43 (8.97)	45.89 (9.96)	41.09 (11.65)	40.65 (12.74)
Comparison		44.87 (9.34)	43.81 (11.22)	43.38 (10.43)
<u>PLCQ</u>				
<u>Internal Control</u>				
Intervention	21.38 (5.97)	21.58 (6.75)	23.90 (5.87)	22.27 (6.27)
Comparison		21.77 (6.57)	22.05 (6.01)	20.77 (6.32)
<u>Matter of Chance</u>				
Intervention	14.17 (5.71)	14.10 (5.89)	13.44 (5.76)	13.75 (5.92)
Comparison		14.63 (5.81)	15.33 (6.73)	15.77 (6.27)
<u>Powerful Others</u>				
Intervention	15.06 (4.76)	16.44 (5.05)	15.71 (4.43)	15.06 (4.81)
Comparison		16.81 (5.42)	16.51 (5.43)	16.44 (5.67)
<u>Doctor's Control</u>				
Intervention	7.29 (3.05)	7.60 (2.74)	7.13 (2.80)	7.00(3.02)
Comparison		8.56 (3.18)	8.58 (3.56)	8.49 (3.32)
<u>Other People</u>				
Intervention	7.77 (3.19)	8.83 (3.82)	8.58 (2.90)	8.06 (3.17)
Comparison		8.26 (3.31)	7.93 (3.21)	7.95 (3.22)

Table Notes: M = Mean, SD = Standard Deviation, N = Number of Participants, GSES = General Self-Efficacy Scale, CPAQ = Chronic Pain Acceptance Questionnaire, FIQ = Fibromyalgia Impact Questionnaire, PLCQ = Pain Locus of Control Questionnaire

Fibromyalgia Impact

Impact of illness

The results show that fibromyalgia impact scores differ significantly across the 4 time points $F(2.42, 114.43)=8.52, p<.001, \eta^2=.15$. Paired samples t-tests indicated a significant decrease from Time 1 ($M = 68.97$) to Time 2 ($M = 61.34$), $t(47) = 3.49, p<.02$, two-tailed, which were the immediate pre-intervention to immediate post intervention scores. No significant differences were observed between Time 0 and Time 1, or Time 2 and Time 3. Figure 7.6 indicates a pattern of stable impact of illness levels between T0 and T1 which were baseline to week 1 of intervention, with an increase over the course of the intervention (T1 to T2), followed by a maintenance of the decreased impact of illness from T2 to T3.

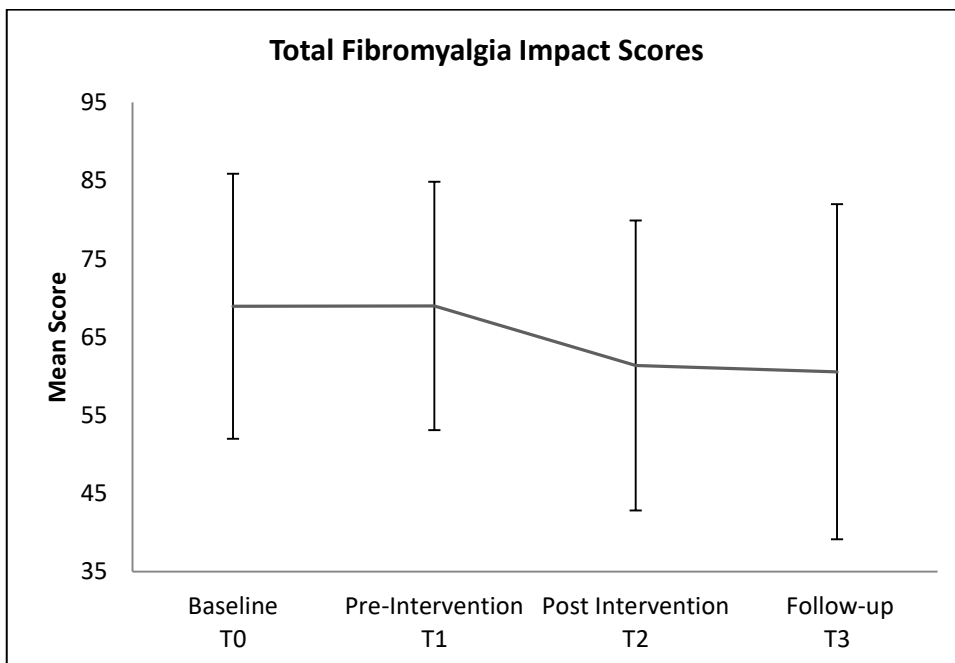


Figure 7.6: Mean Fibromyalgia Impact Scores for Intervention Group Time 0, Time 1 Time 2 and Time 3. Error bars represent standard deviations.

Impairment Scores

The results show that total impairment scores differ significantly across the 4 time points $F(2.36,111.02) = 6.97, p<.005, \eta^2=.12$. Paired samples t-tests indicated a significant increase from Time 1 ($M = 45.89$) to Time 2 ($M = 41.09$), $t(47) = 3.32, p<.02$, two-tailed, which were the immediate pre-intervention to immediate post intervention scores. No significant differences were observed between Time 0 and Time 1, or Time 2 and Time 3. Figure 7.7 indicates a pattern of stable impairment levels between T0 and T1, with a decrease occurring over the course of the intervention (T1 to T2), followed by a maintenance of the decrease impairment scores from T2 to T3.

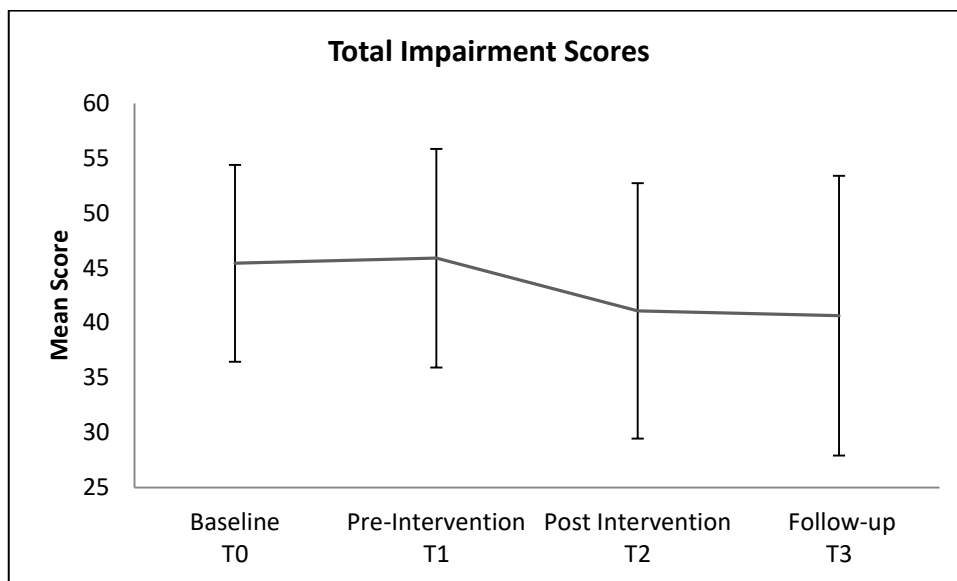


Figure 7.7: Mean Impairment Scores for Intervention Group Time 0, Time 1, Time 2 and Time 3. . Error bars represent standard deviations.

Total Feel Good Days

The results show that total feel good days differ significantly across the 4 time points $F(3,141) = 8.86, p<.000, \eta^2 = .15$. Paired samples t-tests indicated a

significant decrease from Time 1 ($M = 4.79$) to Time 2 ($M = 3.68$), $t(47) = 4.66$, $p < .02$, two-tailed, which were the immediate pre-intervention to immediate post intervention scores. No significant differences were observed between Time 0 and Time 1, or Time 2 and Time 3. Figure 7.8 indicates a stable pattern of number of feel good days between T0 and T1 which were baseline to week 1 of intervention, with a decrease over the course of the intervention (T1 to T2), followed by a maintenance of that decrease from T2 to T3.

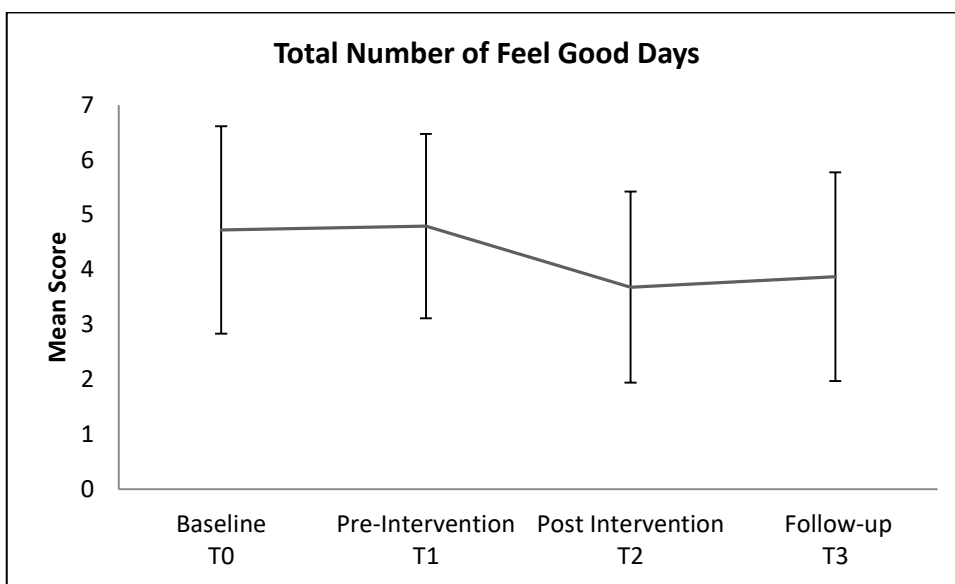


Figure 7.8: Mean Number of Feel Good Days for Intervention Group Time 0, Time 1, Time 2 and Time 3. Error bars represent standard deviations.

Physical Functioning

The results show that there were no significant differences in total physical functioning scores across the 4 time points $F(2.17, 102.12) = 1.46$, $p > .05$.

Total Days Missed from Work

The results show that there were no significant differences in total number of days missed from work across the 4 time points $F(3) = 2.51$, $p > .05$.

Pain Locus of Control

Internal Control

The results show that total internal control scores differ significantly across the 4 time points $F(3,141) = 3.91, p < .05, \eta^2 = .07$. Paired samples t-tests indicated a significant increase from Time 1 ($M = 21.58$) to Time 2 ($M = 23.90$), $t(47) = -2.82, p < .02$, two-tailed, which were the immediate pre-intervention to immediate post intervention scores. No significant differences were observed between Time 0 and Time 1 or Time 2 and Time 3. Figure 7.9 indicates a pattern of stable internal control levels between T0 and T1, which are baseline to start of intervention scores, with an increase over the course of the intervention (T1 to T2), followed a maintenance in internal control from T2 to T3 which are scores from week 7 of intervention across the 6 month follow-up.

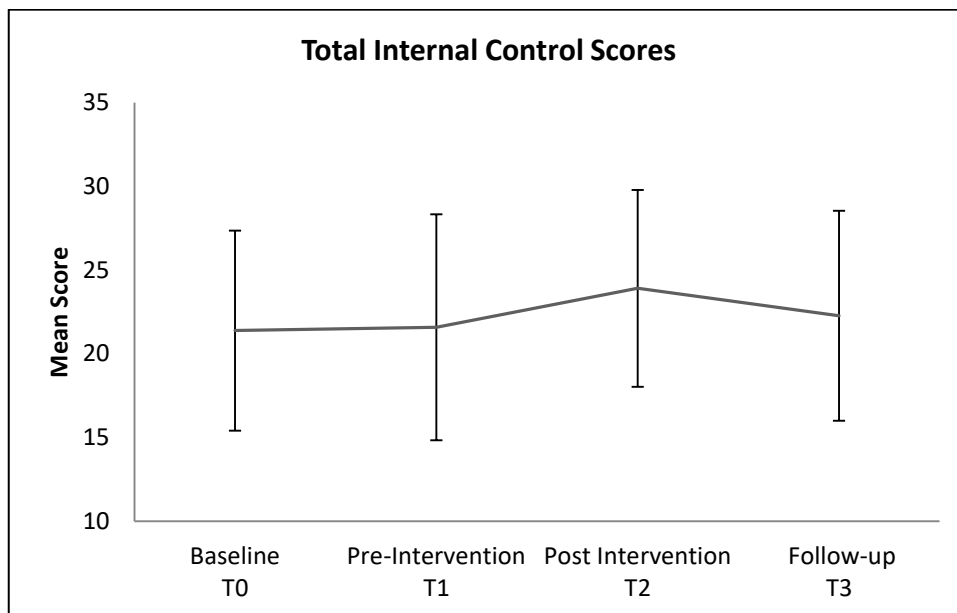


Figure 7.9: Mean Internal Control Scores for Intervention Group Time 0, Time 1, Time 2 and Time 3. Error bars represent standard deviations.

Matter of Chance

The results show that there was no significant differences in total matter of chance scores across the 4 time points $F(2.55, 120.07) = 2.55, p>.05$.

Powerful Others Having Control

The results show no significant differences in powerful others having control across the 4 time points $F(3) = 1.74, p>.05$.

Doctors Having Control

The results show that there were no significant differences in total doctor having control scores across the 4 time points $F(2.62, 586.90) = 2.62, p>.05$.

Other People Having Control

The results show no significant differences in other people having control across the 4 time points $F(3) = 2.10, p>.05$.

Summary of Findings

Several significant findings emerged in the longitudinal study. An increase was observed in self-efficacy, acceptance, activities engagement and internal control. Decreases were observed in impact of illness, impairment and total number of feel good days.

Comparison Study Analyses

A comparison of Time 1 to Time 3 Scores was completed on all measure total scores and subscales. Means and Standard Deviations are presented in Table 7.2.

General Self-Efficacy

Total Self-Efficacy Scores

A mixed factorial ANOVA of Time (T1, T2, T3) and Group (Intervention versus Control) found that there was a significant main effect of Time $F(1.82, 162.26) = 12.45, p < .001, \eta^2 = .12$ such that there was a significant increase in self-efficacy scores between across time points. No main effect for group was observed $F(1, 89) = 3.23, p = .08$, however, these findings should be interpreted in light of a significant interaction between time and group, $F(1.82, 162.26) = 3.13, p = .05, \eta^2 = .03$.

Three independent samples t-tests were conducted to investigate potential effect of group on time, however, in this instance, no effect of group was observed at Time 1, $t(89) = -.513, p < .609$, two tailed. Group also failed to reach significance at Time 2, $t(89) = -2.30, p = .024$, two tailed or Time 3, $t(89) = -2.22, p = .029$, two tailed, however, it must be noted that at Time 2 and Time 3, results were close to significance.

Two repeated measures ANOVAs were conducted to investigate potential change across the 7 week intervention for each group separately. No significant differences emerged across time points for the comparison group. A significant

effect Time was observed in the intervention group between. Three independent samples t-tests indicated a significant increase from Time 1 ($M = 28.90, SD=5.38$) to Time 2 ($M = 31.29, SD=4.41$), $t(47) = -4.36, p<.003$, two-tailed, which were the immediate pre-intervention to immediate post intervention scores and from Time 1 to Time 3 ($M = 31.49, SD=6.41$), $t(47) = -3.96, p<.003$, two-tailed, which were week 1 of intervention to end of 6 month follow-up scores. No significant differences were observed between Time 2 and Time 3, which were week 7 of intervention to the end of the 6 month follow up. Figure 7.10 illustrates the interaction between time and group for self-efficacy scores.

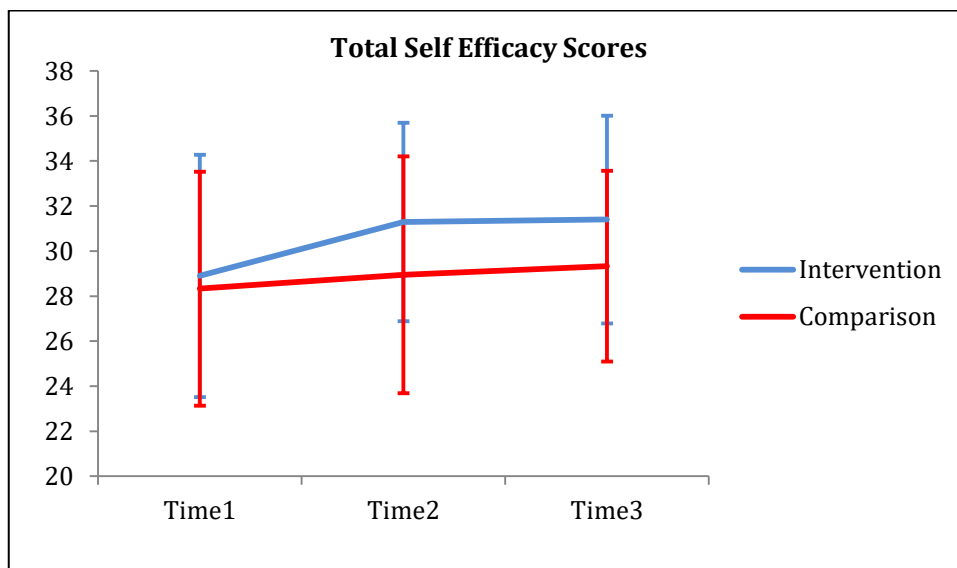


Figure 7.10: Illustration of the interaction between Time and Group for Self-Efficacy Scores. Error bars represent standard deviation.

Chronic Pain Acceptance

Total Pain Acceptance Scores

Results show a significant main effect of Time $F(2, 178) = 8.45, p<.001, \eta^2=.08$. There were no significant differences in scores from other time points. No

main effect for group was observed $F(1, 89)=0.49, p>.05$ and there was no significant interaction between time and group, $F(2, 178)=1.26, p>.05$.

Paired samples t-tests identified that this effect was due to a significant increase in pain acceptance scores between Time 1 ($M= 54.98$) and Time 2 ($M= 57.70$), $t(90)= -2.32, p<.02$, two-tailed; between Time 1 and Time 3 ($M= 59.48$), $t(90)= -3.91, p<.02$, two-tailed, but no significant difference between Time 2 and Time 3. Figure 7.11 illustrates an increase in pain acceptance scores from Time 1 to Time 2) followed by a maintenance of that increase over the 6 month follow up (T2-T3).

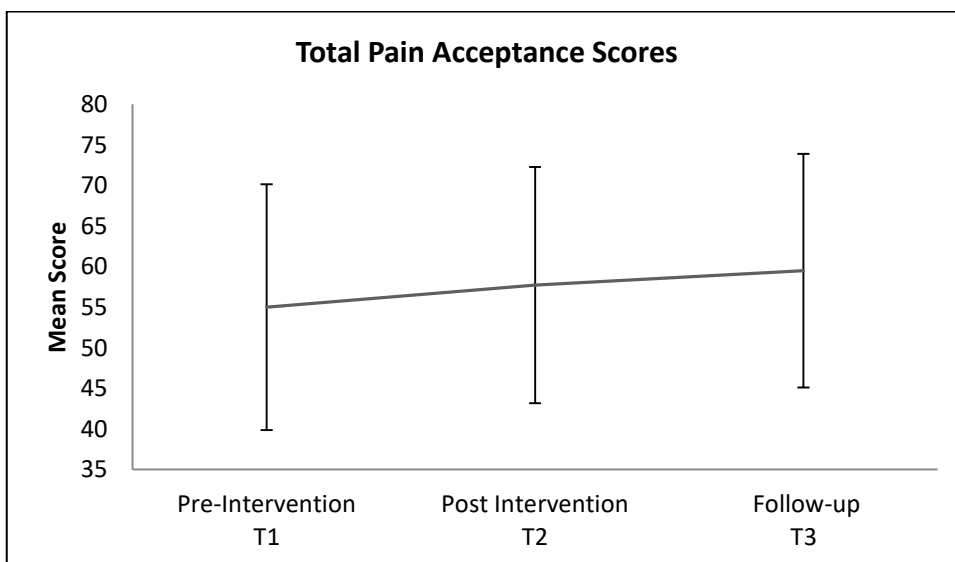


Figure 7.11: Mean Pain Acceptance Scores Time 1, Time 2 and Time 3. Error bars represent standard deviations.

Total Activities Engagement Scores

Results show a significant main effect of Time $F(1.87, 166.47)= 6.01, p<.005, \eta^2=.06$. No main effect for group was observed $F(1, 89)=0.73, p>.05$ and

there was no significant interaction between time and group, $F(1.87, 166.47)=2.46, p>.05$.

Paired samples t-tests identified that this effect was due to a significant increase in activities engagement scores between Time 1 ($M= 36.54$) and Time 3 ($M= 39.78$), $t(90)= -3.35, p<.02$, two-tailed. No significant differences were observed between Time 1 and Time 2 or Time 2 and Time 3. Figure 7.12 illustrates a gradual increase in total activities engagement scores from Time 1 to Time 3.

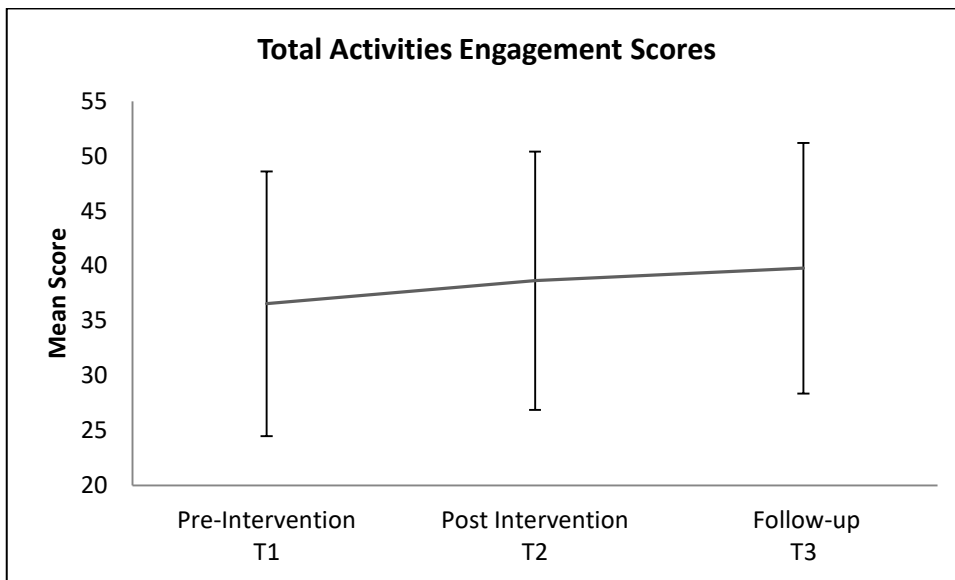


Figure 7.12: Mean Activities Engagement Scores Time 1, Time 2 and Time 3. Error bars represent standard deviations.

Total Pain Willingness Scores

Results show no significant main effect of Time in total pain willingness scores $F(1.84, 164.12)= 2.77, p>.05$. No main effect for group was observed $F(1, 89)=0.003, p>.05$ and there was no significant interaction between time and group, $F(1.84, 164.12)=0.19, p>.05$

Fibromyalgia Impact

Impact of illness

Results show that there was a significant main effect of Time $F(2, 178)=6.77, p<.005, \eta^2=.07$. No main effect for group was observed $F(1, 89)=0.31, p>.05$ and there was no significant interaction between time and group $F(2, 178)=2.12, p>.05$.

Paired samples t-tests identified that this effect was due to a significant decrease in impact of illness scores between Time 1 ($M= 68.06$) and Time 2 ($M= 63.14$), $t(90)= 3.07, p<.02$, two-tailed; between Time 1 and Time 3 ($M= 62.38$), $t(90)= 3.17, p<.02$, two-tailed, but no significant difference between Time 2 and Time 3. Figure 7.13 illustrates a decrease in impact of illness scores from Time 1 to Time 2 followed by maintenance of that decrease over the 6 month follow up (T2-T3).

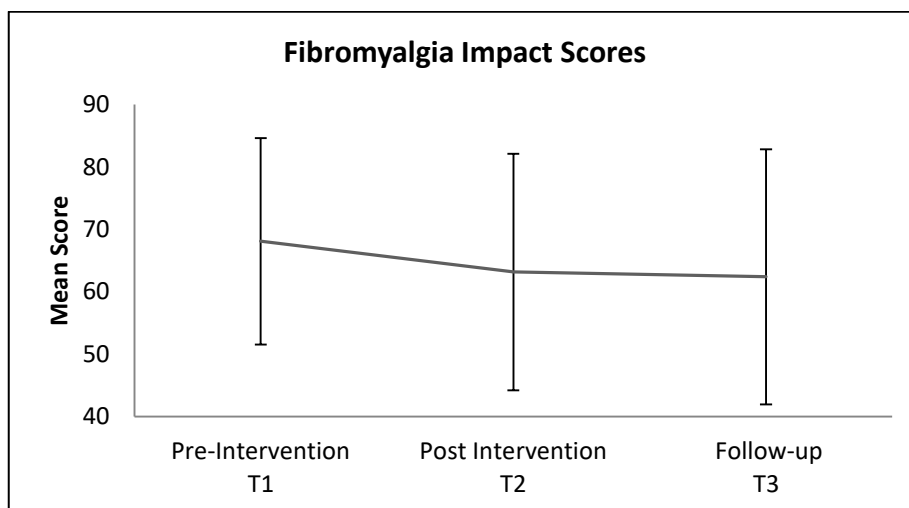


Figure 7.13: Mean Total Score on FIQ Time 1, Time 2 and Time 3. Error bars represent standard deviations.

Impairment Scores

Results show that there was a significant main effect of Time $F(2, 178)=5.87, p<.005$. No main effect for group was observed $F(1, 89)=.572, p>.05$ and there was no significant interaction between time and group $F(2, 178)=2.05, p>.05$.

Paired samples t-tests identified that this effect was due to a significant decrease in impairment scores between Time 1 ($M= 45.41$) and Time 2 ($M= 42.37$), $t(90)= 2.86, p<.02$, two-tailed; between Time 1 and Time 3 ($M= 41.94$), $t(90)= 3.01, p<.02$, two-tailed, but no significant difference between Time 2 and Time 3. Figure 7.14 illustrates a decrease in total impairment scores from Time 1 to Time 2 followed by maintenance of that decrease over the 6 month follow up (T2-T3).

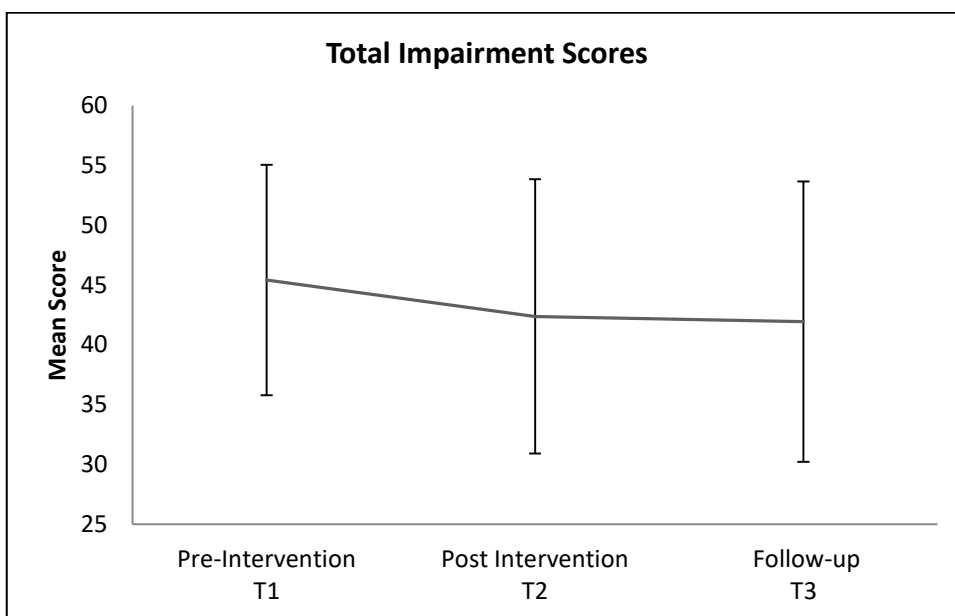


Figure 7.14: Mean FIQ Impairment Scores Time 1, Time 2 and Time 3. Error bars represent standard deviations.

Total Feel Good Days

Results show that there was a significant main effect of Time $F(2, 178)=11.45, p<.001, \eta^2=.11$. No main effect for group was observed $F(1, 89)=0.01, p>.05$ and there was no significant interaction between time and group, $F(2, 178)=1.03, p>.05$.

Paired samples t-tests identified that this effect was due to a significant decrease in feel good days between Time 1 ($M= 4.65$) and Time 2 ($M= 3.78$), $t(90)= 4.79, p<.02$, two-tailed; between Time 1 and Time 3 ($M= 3.96$), $t(90)= 3.52, p<.02$, two-tailed, but no significant difference between Time 2 and Time 3. Figure 7.15 illustrates a decrease in total number of feel good days from Time 1 to Time 2 followed by maintenance in such scores across the 6 month follow-up period.

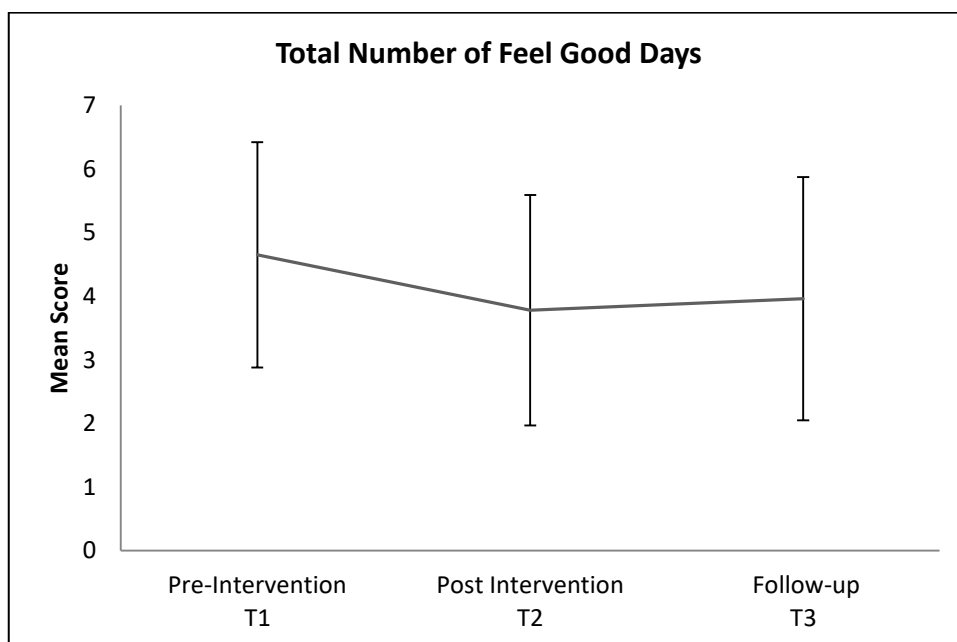


Figure 7.15: Mean Number of Feel Good Days- Time 1, Time 2 and Time 3. Error bars represent standard deviations.

Physical Functioning

Results show no significant main effect of Time in total physical functioning scores $F(1.78, 159.10) = 1.30, p > .05$. No main effect for group was observed $F(1, 89) = 0.08, p > .05$, and there was no significant interaction between time and group, $F(1.78, 159.10) = 0.90, p > .05$.

Total Days Missed from Work

Results show no significant main effect of Time in total days missed from work $F(1.85, 165.33) = 2.08, p > .05$. No main effect for group was observed $F(1, 89) = 0.12, p > .05$, and there was no significant interaction between time and group, $F(1.85, 165.33) = 0.66, p > .0$

Pain Locus of Control

Internal Control

Results show that there was a significant main effect of Time $F(2, 178) = 3.76, p < .05, \eta^2 = .04$. No main effect for group was observed $F(1, 89) = 0.86, p > .05$ and there was no significant interaction between time and group, $F(2, 178) = 1.75, p > .05$.

Paired samples t-tests identified that this effect was due to a significant increase in internal control scores from Time 1 ($M = 21.67$) and Time 2 ($M = 23.02$), $t(90) = -2.47, p < .02$, two-tailed; between Time 2 and Time 3 ($M = 21.56$), $t(90) = 2.68, p < .02$, two-tailed, but no significant difference between Time 1 and Time 3. Figure 7.16 illustrates an increase in total internal control scores from Time 1 to

Time 2 followed by a continuing increase in such scores across the 6 month follow-up period.

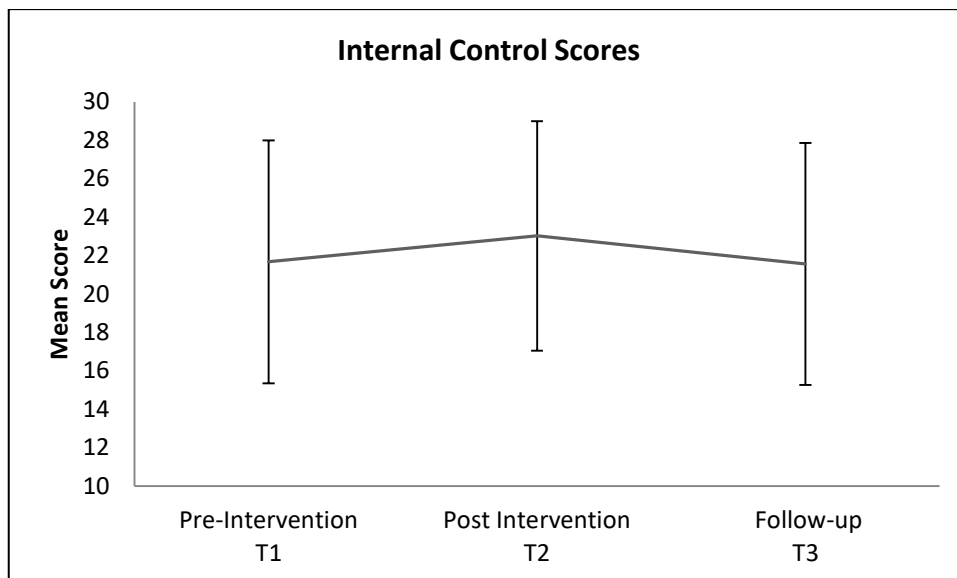


Figure 7.16: Mean Internal Control Scores Time 1, Time 2 and Time 3. Error bars represent standard deviations.

Matter of Chance

Results show no significant main effect of Time in matter of chance scores $F(1.87, 166.93) = 0.29, p > .05$. No main effect for group was observed $F(1, 89) = 1.85, p > .05$ and there was no significant interaction between time and group, $F(1.87, 166.93) = 16.25, p > .05$.

Powerful Others Having Control

Results show no significant main effect of Time in powerful others having control $F(1.86, 165.68) = 1.79, p > .05$. No main effect for group was observed $F(1, 89) = 0.83, p > .05$ and there was no significant interaction between time and group, $F(1.86, 165.68) = 0.59, p > .05$.

Doctors Having Control

Results show no significant main effect of Time doctors having control scores $F(2, 178) = 0.80, p > .05$. A main effect for group was observed in this instance $F(1, 89) = 5.16, p < .05$ and there was no significant interaction between time and group, $F(2, 178) = 0.61, p > .05$.

Other People Having Control

Results show no significant main effect of Time in other people having control $F(1.83, 163.16) = 1.50, p > .05$. No main effect for group was observed $F(1, 89) = 0.57, p > .05$, and there was no significant interaction between time and group, $F(1.83, 163.16) = 0.45, p > .05$.

Summary of Findings

Results from the as treated analysis yielded significance increases in self-efficacy, chronic pain acceptance, activities engagement and internal control and decreases in impact of illness, impairment and feel good days while no significant findings emerged for pain willingness, physical functioning, number of days missed from work, matter of chance, powerful others having control, doctors having control and other people having control in the within group analysis. A comparison of the groups revealed a single interaction effect; this was observed on the self-efficacy measure. Main effect for Time emerged for chronic pain acceptance, activities engagement, impact of illness, impairment, total number of feel good days and internal control indicating that while changes did occur, these changes were not group specific. No significant changes occurred for pain willingness, physical functioning, number of days missed from work, matter of

chance, powerful others having control, doctors having control or other people having control

7.7 Appendix 7: Focus Group Transcripts For Chapter 2

Date: 30.08.2012

Venue: Clongriffin, Dublin

N = 11

What was your experience with getting your diagnosis of Fibromyalgia?

Catherine: I would say relief, when I got the diagnosis it was just a relief. Cause and effect was an answer of sorts, limited but it certainly put a name to the pain – absolute relief.

Patricia: For me it was confusion. I was having ongoing chest problems so it was actually a lung specialist that diagnosed it and then I had to go through a rheumatologist to have it confirmed. Nobody explained to me properly what it was. I actually felt worse because the rheumatologist said if you're feeling suicidal go and talk to someone and I couldn't understand why he was saying that because he didn't explain the illness that well and it was only when it kept getting worse I read up on it. I really wasn't even given a plan so I didn't really know what to do, because he just handed me a prescription and said, here try these drugs but they probably won't work. So I didn't find any answers.

Fiona: Again, I would have felt relief initially just to have been able to put a name on it and thinking that now that I know what it is that's it sorted now but I was instead just left with one sheet to read about it and I think I was left floundering after that. What I think is missing is something like the cardiac rehabilitation programme for people with cardiac problems whereby there is a six week course where at least you're made aware this is a very individual thing, multi-faceted and I think something like that is useful because it takes a long time. You're left to walk out of the rheumatologists – delighted you have a label but you've no where to go after that.

Catherine: Pure misery. I think that for someone who has symptoms that are so widespread and that actually tethered into multiple sclerosis, you heard MS wasn't it and then relief that it had a name. All the symptoms that are there that are so radical, but it's not going to kill you. Now having said that, it wasn't explained to you that it might take your life, you know take your life by the ears but it wasn't multiple sclerosis so I think the relief is the initial thing because the symptoms are so broad they tether into other illnesses that are fatal.

Maria: When I was diagnosed I just assumed well I have a name now so I'll wait to see my doctor, shur they must be able to do something that will cure it, so I was handing it immediately to them but my own doctor really didn't give me much support he used to say you'll be grand just take these so you weren't given much information or support. I felt kind of alienated as if it was all in my head.

Kate: I felt the same. I must have spent nearly 30 years going for an x-ray for this part or that part. Different parts of my body were tired all of the time and then feeling like I was lazy, just being lazy because nothing was showing up and then I was told that I had Fibromyalgia and to look it up on the internet and that's and that's the sort of support I've had so far until I came here (to fibro Ireland support group meetings).

Margaret: My doctor just said you have this. I asked what is it and he didn't know. He said you go and find out about it and I'll make an appointment for you with a rheumatologist. The rheumatologist's appointment came about six months later. He did this thing of pushing me around and said you have Fibromyalgia and that it was it. I actually haven't gone back to the rheumatologist since; I thought I'll just figure it out myself. I was diagnosed over 10 years ago and I

actually diagnosed myself but now have a daughter with it who is going through a diagnosis of it now and the doctors are doing the same thing. It hasn't changed.

Jenny: No it hasn't changed since that. There's nothing that can be done about it just do a bit of exercise so it hasn't changed in about 10 years. You have good days and bad days. You do physio, you do this you do that but generally there is not a lot you can do.

Margaret: My daughter got an appointment for yesterday and she went off to that appointment and it was in the department of psychiatry and she's not stupid, she's nearly an adult and that was awful devastation that she was getting on an appointment for psychiatry. She's not a psychiatric patient. I tried to explain to her, as much as I could from work I had learned that it's an emotional effect on having Fibromyalgia and it's probably not a psychiatrist it's probably a psychologist and that that psychologist will at least eliminate if you have got any psychological problems. She has issues relating to her health, you know emotions. It took me a long time to convince her. She was devastated to think that the GP might have organised a psychiatric appointment for her without having discussed it. I think they're trying to get a few things out of the way before her next appointment. I go to all of the appointments with her to the rheumatologist but at the end of the day, god help her, she will just have to adjust to it. She'll have to cope with it. She'll have to accept it and that will be it. She may go through life with it. She could get addicted to pain killers so at the end of the day, her attitude will help her not any doctor. Maybe a psychologist in the right sense.

Patricia: You see a lot of people with Fibromyalgia get a diagnosis of anxiety or depression but for the majority of cases it's actually a reactive depression. When nothing in your body works you just get frustrated.

Catherine: I believe it's not depression that can come in on you. I think it's generally understanding your circumstances, that doesn't mean that's depression. I think you become conscious of your reality very clearly and your limitations and I don't connect that with depression myself. I connect that with realism but I do understand that many people do become depressed.

Patricia: About 8% of people with Fibromyalgia do have clinical depression as with any illness. Sure you can have cancer and have depression so there is a co-morbid factor but it's being presented that all fibromyalgia patients are psyche cases.

Catherine: I think exactly what you just said there about your daughter being referred. That's the medical practitioners that were sending her straight as a psyche case which is wrong. Just because she's dealing with the physical, mentally it's going to have a knock on effect.

Maria: You shouldn't have been referred without it having been discussed with you at all.

Margaret: I allow her to have a certain amount of time with her doctors, she's nearly 18 so for her own independence. She could have organised it there and Ciara didn't recognise what she was talking about, you know, the language. So it's a blur for me all those years ago and as I got over it but I feel so angry now that it's happening to her. It took me to go to an alternative doctor to even accept it.

Catherine: I think I was lucky to have found one (a doctor) because I only changed at Christmas and I think it's important to get a good doctor that is understanding of your circumstances and that doesn't blame every symptom on that – on the fibromyalgia, which was just detrimental to me before Christmas. I needed surgery and needed it quickly and the doctor just kept telling me that the facial pain that I had was fibromyalgia. And the lack of sleep, the pain ok, but these were new symptoms for me and I clearly knew it wasn't that but my doctor constantly kept saying you're stressed, you've a lot of stress in your life, I understand that and you'll have to come to terms with this and I said what do I do, shoot the children – get rid of them? They weren't any more stressful than anyone else's to be honest. They will put down any symptom to FMS and I think it's to the patient's detriment because I was in serious need of surgery and it took to move to another doctor for them to reassess me and have me sent to a specialist immediately so I think at your detriment listen to someone telling you that your symptoms are wrong. That's to your detriment in our situation because the goal posts keep moving the symptoms are radically changing all of the time

and that is the one big problem with our illness is that we are fobbed off, that it's all stress and it's a relentless condition. I have nerve damage from a car crash. The CNS and was assessed medically rather than clinically after that accident. I had a still birth after that, I was pregnant at the time, so the pain I was in was associated with a mental condition rather than actually realising I was in pain after the crash regardless and therein lies the problem, it's just being fobbed off.

Jenny: I suppose it's about being confident when you go to the GP. To be confident in yourself that you're not usually like this and so there must be something else wrong with me.

Margaret: When you have been living a long time with it you often choose a GP that will give you what you want and not a lecture again so someone that will say 'fine, I will give you anti-anxiety medications'. That works well for me; my symptoms aren't as bad since I've been on them. When I look at it now, since I started taking anti-anxiety medication I function 100% better than I did but a doctor won't normally prescribe that for years and years for different reasons and so a lot of the time, I just stick with my doctor because she doesn't give me a hard time.

Patricia: The average person takes 10 years to be diagnosed. For most it takes years.

Fiona: I didn't have that experience, I hit the wall in November, I got an appointment with a rheumatologist for December or January and got the diagnosis in February.

Ruth: I was diagnosed pretty quick. I went to my GP and he said I think you have fibromyalgia. I remember it was the weekend and he gave me an article on it, not it's symptoms-they weren't what I had so then he referred me onto a rheumatologist and he thought it might be my thyroid and did lots of tests so then they too said FMS. I had read up on it so knew what she was talking about but all she did was give me a prescription for amitriptyline and that was 10 years ago and nothing else.

Jenny: 6 weeks for me. I hit the wall in April and was diagnosed end of May but looking back, I'd have had symptoms for 10 years.

Ruth: Well I find when you mention fibromyalgia, see I attend the hospital regularly and they say well what's this, what's that and I say I have fibromyalgia and they say oh that's terrible isn't it and that's the end of it.

What is the most frustrating thing about having a diagnosis of Fibromyalgia?

Jenny: Other people saying you look fine – you don't have a bandage or a cast so you don't deserve acknowledgement. It's not visible, it's not a visual kind of thing.

Ruth: There's no point in saying it to anyone because they don't understand it, they just don't get it.

Maria: I find people who don't have fibromyalgia haven't a clue what we're on about and there's no point, you just end up frustrating yourself. You don't expect them to understand anyway so they just don't.

Catherine: I have it 23 years. The perception is that it's a psychological illness and so I just don't go there with other people, I don't let it be known. I don't want to think that anyone would have a perception of me.

Maria: That you're lazy?

Catherine: Yes, so I keep it very private. I have adjusted myself around what my boundaries are but I think that I'm smarter than that than to get into it with anyone and try to explain it because for those of us who have it it's bloody hard to understand never mind try to explain it.

Jenny: What do you say to people then when you have a flare up?

Catherine: I don't explain myself, I really don't. To my own kids I think it's an awful shame because it's been 23 years and I came through the school years with them being small and trying to drive them in the car to school every morning when I had a massive hangover – now I wasn't a drinker but these hangovers would last until after lunchtime and you just adjust your life because you have to be practical of who you are going to interact with. I have limitations on my interactions with people because it just is smarter than always having to ring someone and say – no, I can't do this, no I can't make that. It sounds like excuses. It impacts on your life. It's huge. I keep a short leash on a lot of things for myself to be practical. And that's not depressed.

Ruth: And you know when you say that you can't do this or you can't do that, people don't really understand, they think it's kind of just an excuse – you just can't be bothered, you know that sort of an attitude. And you know the way you want to be doing things but you're just so exhausted that you physically cannot do it. People just don't understand that.

Catherine: It doesn't matter how many plans you make or ideas you have, it just gets torn asunder. You can't do anything. I was going on holidays in June. You have to leave it to the day before to book anything to see how you're feeling. I lost the first week because I was in serious pain. That's where my limitations are. In a smart way those who know about it know about it. Those who don't aren't concerned. I don't stretch myself. I'm very helpful, I know I'm helpful – I don't lack that but I think it is to be smart. You're not always answerable to everybody that you meet – no I can't do that, sorry about that, no it's not a good day, not a good time, not a good night, not a good month so then you realise how bad it is.

Jenny: I think the name as well. I mean the name itself is quite a long one. I know it sounds really simple but with a name like that when you say it to someone they're like 'fibro what'? So if you said you have ME well then you have ME, whereas if you say you have fibromyalgia they just don't get it.

Fiona: My biggest frustration is the time it has taken me to either accept it or get to the best place to manage it. That's my biggest frustration that it's approaching nearly 2 years since I hit the wall and I still don't feel like I'm managing it – I'm getting there. I know now what I might have to do or how I might have to approach it but it has taken me that length of time and that's where I feel the gap is in that if you had some guidance or you had something to steer you. I have bought all the books, I have read all the articles and it's an expensive illness. I just think there would be a benefit to summarize all of the information and for someone to bring it together and that you could do something and then maybe a refresher because as you're living with this you're learning more about yourself. It's very individual as well.

Catherine: We only have anecdotal evidence on everything. We have no individual assessments collectively correlated and marked. We have nothing like that. It's a mish mash of what is on the internet. You spend a fortune. You take yourself to everyone. Everyone has a Jack that you must see because they're always meant to be great. Years of doing that waste your money, waste your time. You stress yourself. You still just look for small pieces of information. I think this group is a working paper. It is a transfer of information when we talk about things. We have nobody standing over us; we have no input that I know of. None of us that I know are feeding information to any working group. It's a ridiculous situation.

Margaret: I've stopped telling people because I was being discriminated against in jobs. I've worked in my job for 5 years and I've only told my current manager so nobody knew I had it. I was pushed out of my last job because I was made feel like I couldn't do the job anymore. There was a period where I hit the wall but I got over it, I had no choice I had to keep going there was just no other option. So when I moved job I made the decision not to tell anyone. I only told my manager a month ago and the only reason I told her was because she was leaving and I was getting her job. So I don't tell people I think you can get discriminated against. People judge you.

Catherine: I wouldn't be able to hold down a job.

Ruth: Yeah you're lucky that you can cope.

Margaret: Well I have no other option. I'll tell you how I do it. I get up in the morning and get my girl off to school. I clean my house, go to work and work all day. I go home at 5 o'clock and have a sleep. I do dinner and at night I knock myself out so I don't feel any pain and I sleep like a baby. I wake up everyday and I don't get a hangover from the drugs.

Ruth: Do you not wake up absolutely jaded?

Margaret: Of course I do. I feel like I've been hit by a brick but I have a child who wakes up like that everyday so I can't let her life fall apart. I have to get her into the bath everyday so she can go to school and finish her last year of school. The advice is you don't push yourself and that you always be careful but I found the opposite. The more I push myself the better I feel. The more distracted I am the better. I feel I have no other option.

Catherine: I have to say I agree with you. That's how I work. I'm in pain now tonight but I have had a full day, a very full day and I have achieved everything because that's my goal. My goal is not to think of the pain. I got into doing that quite a while ago so I achieve my goal. It's a decision to be made and if you don't use the muscles, you'll lose them, so definitely I agree with that.

Maria: I find that if I did give up work I'd just be moping at home feeling sorry for myself so I have to keep going. I go into work in pain and people go how can you be here but I just have to keep going, that's what I do. I work with people in wheelchairs and when I say I can't physically do something they turn around and say it's not that hard. It's not visible you see.

Patricia: I had a problem like that when I was really sick. I was out shopping with my mother and my Mum is in her late 60's and she was carrying all of the shopping and I could hear people going 'would you look at that young one not bothering to help her'. My mother was actually in better condition than I was at that time.

Catherine: I think the challenges are simply daily living.

Patricia: My physio spoke to a consultant at a pain conference and he actually advised her not to touch people with fibromyalgia with a barge pole that we're too difficult, that we're psyche cases and to steer clear. She's actually really good because she did all her training in America and they're miles ahead over there with fibromyalgia so luckily she didn't really listen to what he said and told me about it in a way that was giving out about him.

Anne: Oh in America everybody knows about it. It's like the common cold or the flu. Everybody hears about it through the media where medications are so openly advertised where as here it's 'fibro what'?

Margaret: We all have fibromyalgia for different reasons and we all feel it in different parts.

Anne: On television in America it's saying ask your doctor to prescribe this for fibromyalgia in the same way as we see ads saying use this for your hay fever, or this cough mixture for your cold. It's different.

Fiona: Here people don't know what fibromyalgia is but maybe I'm different. I wouldn't get overly involved in what other people are aware of because at the end of the day it's my illness and it's about what I can do about it and how either the medical profession or whoever else can assist and there's lots and lots of illnesses and there's lots of illnesses I don't understand.

Anne: It's unique in that everyone will tell you that you don't look sick. I can personally say that my social life has gone. And trying to explain to people is difficult. I was at a party Saturday night and the moment I opened the door and heard the music I wanted to turn and go home. It was an endurance test for me. Now for me to try to explain that to anyone, well I just can't because they just wouldn't get it. My sister is in her 70's, she's 10 years older than me and she doesn't get it and that bothers me that no matter how hard I try to explain it, it just doesn't seem to get through.

Maria: People say “oh just have a few drinks and you’ll be grand and just can’t understand that you don’t want to be there in the first place. Like my partner’s family are all into having parties at each other’s houses and I just do not want to be there. You’re just not in the humour of making small talk when you’re in pain. They just don’t understand that.

Patricia: It’s quite hard to follow a conversation. I’m not bad now with my fibromyalgia symptoms but when I was in the throws of it, it was really hard to follow a conversation. It takes a huge amount of energy so you tire quicker and then with the sensory overload as well it means that you’re hearing all of the conversations at the same level and then the noise, the music, they all sound louder. With the alcohol it’s really difficult in Ireland because people find it really difficult to be around someone who is not drinking and you become a party pooper. People don’t realise that you’ve had to drag yourself out. It’s very frustrating.

Do you feel that the support that you currently receive from your family has changed since your diagnosis?

Catherine: I think that I’m very lucky. It had gone on for so long and a serious deterioration of my life that my husband actually decided to go back to college and do anatomy and physiology because we were going to speak to people on a level that we would understand. In order to converse with these people we would need some background knowledge. I wasn’t in a position. The brain fog was very serious to remember what was said 5 minutes ago was impossible but my husband actually did do that. I have a great respect for doctors because we actually do need them but setting that aside, it was to be able to talk to anybody who was professing to have a helpful therapy. To be able to listen and know, even to have a background to understand it because we kept spending lots of money and this money was then spent on going to college to be smart. He understood hugely what was going on. That was a huge support and the knock on effect was to find solutions and Australia was where we found the solutions. The Bowen technique was best practice there with fibromyalgia patients so he went on to qualify in that. I was going to a Bowen therapist which was long term treatment and long term money so it just made common sense that he would treat me himself. It is one of those things that if you have one person who is going to listen and understand and actually accept that actually are ill, they may not even have to understand. I think that not everybody would even have that one person and I think that’s why this is very important – this group. To actually be able to come in and say just how bad it is.

At this point the original question was again put to the group.

Rosemary: Yes, to a certain extent. Not my own kids or my own husband, but my siblings. And then if you say something, say you sit down and say my back is sore, they say oh are you moaning again? Now I just don’t say anything. My husband and children live with me. They know exactly what it is like for me and how I have to pace myself. The things I would have been able to do a year and a half ago I now have to really pace myself doing. I still can do it though. Work isn’t an option for me. My girls need me so I can’t just disappear. If I was working I’d have to come home from work and go to bed and I can’t do that, they need me because my husband is a shift worker so it’s important to be there. My husband and kids are great, they are really very good.

Fiona: I would have found a change with my sister in law that I would have been close to. I don’t even get phone calls anymore. I don’t moan, and in terms of people coming to visit me I’m not horribly sick or anything and I’m not wanting to talk about it all of the time either. It’s quite hurtful really. Then I just went through a phase of saying just lift the phone and don’t lose the friendship because maybe she just can’t deal with it but I did that. I made the call and haven’t had any response so I presume most people will have that sort of an experience. The majority of certainly my own family, I would find that even if they don’t fully understand and read about it they know I’m genuine and that’s great.

Rosemary: Well I think if they spend time with you more they can see it, they understand more. That’s the difference. If you see somebody for 5 to 10 minutes they say you’re looking well, you look fine; but start living with you, see you more often then they’ll see the difference. She’s not

walking as well as she usually does, she's not as quick as she usually is or her face, she has a pained expression or she looks tired.

Ruth: The family members who are close to you, they know about it.

Catherine: That's all that matters really. I just think you need to pull away and forget all else. I don't need that stress.

Patricia: It can affect you if you're in a relationship. I was engaged and ok, we did have the initial relief when I got the diagnosis but then I had to take time off work because I wasn't physically able to work and I had to get physiotherapy twice a week just to get up and about never mind going to work and that just put a huge strain on our relationship and then when we realised that this wasn't a short term thing well then things really changed. I think he was ok when he thought oh she'll be ok in 6 months but when he realised this was a deal for life he actually behaved so badly he left me with no option but to end the relationship. He didn't have the courage to say I can't do this. If he has to say that it would have made things so much easier.

Margaret: I've been married for a long time and like that, at first there was some understanding after the diagnosis but then he got sick. He has a brain tumour and he's been sick ever since so my life goes last on the list with everybody. Because it's not a brain tumour I don't get a look in – ever. And unfortunately I can't walk away from my marriage as easily as he could break up with me but it can be very cruel when you're the last person and everyone else forgets that you have needs so I find it very difficult.

Do you feel the support you currently receive from your friends has changed since your diagnosis?

Maria: I found I got more support from my friends actually. My sister, when I first told her the pain was all down to a condition called fibromyalgia, for months didn't believe me. She was very dismissive and she still is. I did get a lot of support from my aunt and I still do, she was great. My brothers and sisters wouldn't be good supports. Then a year ago I remember I was walking up the steps and my brother saw me and said are you ok, what's wrong with you? He knows I have this but that's his response.

Ruth: You see if people know about it then they have to do something about it.

Anne: My sister said to me once, what exactly is fibromyalgia so I said I won't explain it to you, I'll print something off for you to read so I printed 2 pages off and it described it to a tee. It started off with 'imagine you have the worst case of flu that you could ever imagine'. So I gave the 2 pages to her and said now read that and you'll understand fibromyalgia and actually that's the last mention of it from her. She never has said, I've read that and I understand it or I didn't realise that. I just never heard any more.

Catherine: I don't think we should be too hard on other people. Their ability to deal with things is very individual in the same way as our illness is. I have great support completely from those who are close to me. I walked out on everything last year, I just upped and left, I was gone for a month and a half. Before that my doctor had said that I was stressed and I was the problem and I'll have to be honest with you, I was sick of myself. I couldn't imagine how my husband felt and how my kids felt. I was sick of me so for somebody else to walk away, well I get that. I actually wanted to walk away. I took myself to Galway for the 6 weeks and I literally buried myself. Initially, I slept and then I walked. I can understand why people can't understand it because who puts themselves in this situation? Who decides this life? This is not a desired life. This is an existence. This is killing time. For a great deal of us it can be just killing time so I'll admit I walked away last year and if someone else walks away from me I will totally get that. The last thing anyone else needs is somebody else's need; as needy as we can be. Now I try to keep myself not needy, don't get me wrong but I can understand someone else walking away because I did. I wanted to leave the face of my husband, the faces of my children because when I cringe or try to get up and end up walking around like an 80-year-old woman crossing the room it's demoralizing; even if there is understanding that is the reality. There's a reality, what are these people doing with me watching me suffer for all those

years? So for anybody else to take it on and see it and say no thanks I kinda get that. I say no thanks myself.

Margaret: For all of that it's still a fact of life this thing and it's there and it's not going away.

Catherine: But for others they can walk away and I actually think that's ok. I genuinely think that. I think it depends on the tolerance of some people; some can handle things that others just can't. I think as a rule we handle an awful lot of things. We are resilient people for some reason. It's not something lacking in us.

Margaret: There's a word popping up lately on the internet 'fibromyalgia remission'. I never thought you could go into remission from it. I never thought you have a day off never mind a week or a month. So people are having this break and I want to know how they do it. In my head you had a period of remission (directed at another group member).

Patricia: Well it's just I started monitoring it. I'm very careful with the food I eat, very careful with the company I keep.

Margaret: That's exactly how these people do it.

Patricia: I learned how to say 'no'.

Margaret: But they say that, that you should learn how to say no more often.

Catherine: I absolutely believe that you need the support from others. Absolutely, you'd be lost without it really.

Patricia: My Mum gives me very practical support that I really need. I was going to the chiropractor this week so for the first 2 sessions Mum dropped me until I was comfortable enough with the route and then I was fine. That was a huge relief because otherwise I'd have had to print off directions. Traffic makes me a little edgy because part of fibromyalgia is the CNS is affected so the senses are really heightened. Then also after the first session with the chiropractor, it was a bit rough so I actually wouldn't have been safely able to drive so if you're going for a treatment for the first time and you're not really sure what to expect, it can be a safety issue to have someone there with you. Also when I was really bad with my fibromyalgia I couldn't even follow a recipe but I knew I had to get into healthy eating so my Mum did all that until I was well enough to manage it myself. She wasn't doing it all for me, she was helping me and getting me to the position where I could do it myself and then she gradually backed away.

Do you feel the support you currently receive from your friends has changed since your diagnosis?

Maria: Yes. I isolated myself after a few months but that has changed over time. I keep in touch with them and am trying to get my life back. I definitely notice a change in myself and other people have said it to me too in the last month or so. I'm just trying to make myself well by changing my attitude. I'm trying not to be as negative. I took up roller skating. It was one thing I said right I'm going to start roller skating and I've done it now about 5 times and when my pains are really bad I just get up, get my skates and go to the park and I just feel freedom and feel that this fibromyalgia is not going to stop me living my life now where it has done in the past. I also gave up smoking in the last month. I think you really have to make changes yourself. I don't rely on doctors.

Fiona: You need a sense of achievement and no matter where you're getting that fulfilment or sense of achievement from it's good and I think that going back to something that you can do is good.

Catherine: You take the full potential of a day and you use it, you have to be wise with it. You have to say that was today, that was a day. Because many times I had no days, I had no nights. I didn't sleep, no sleep involved, insomnia is there but you have to say I've had a day and it's very important. You have to have a life.

Margaret: I have to say I've swapped one pain for another. For me when I'm inactive the burning pain and the shooting pain and the numbness are at the worst so I go out and I push myself physically and I get the normal pain you get. Do you remember when you were active before fibromyalgia and you walked and then when you woke up the next day you were in agony? That's a soft pain, it's a real pain. I can take a neurofen for it and the neurofen works, so I swap pains. I force a swap in pain and that helps me. As part of my job I'm with kids so I'm very active doing mountain climbs and all that kind of stuff.

Patricia: I've had a mixed experience with friends. Some people get it and some people don't. I met with friends, now I hadn't seen them for a while – they were from school and so we were catching up. They're all at the stage where they're all starting to have families and they all know that I have this, they all know that I have it really bad and then they just kept saying it'll be your turn soon to have kids. Now fortunately enough I don't want to have kids so that's not the problem. The bit that bothered me was they were not getting that if I did, not only would the pregnancy be difficult and God knows what I'd be like during and after the pregnancy but there is also the possibility that I would pass this onto the child and would I want to live with that? So no understanding at all.

Fiona: It's about meaning as well. 'I know someone who has had it and they're better now so you will too. You'll be alright'.

Ruth: And did they not take on board that you had fibromyalgia?

Patricia: Well I did explain it and said it was like arthritis but I actually looked the picture of health so that's the problem.

Jenny: I suppose it's new for me so I'm still trying to get my head around it. I haven't told any of my friends. That might change, I don't know.

Margaret: I told a few of my friends. One of my friends I have known for a long time and she always wondered what was up with me. She just couldn't understand what the hell I was on about so I said to her, you know when you had your appendix out and you survived it, everything is fine, you go back to the doctor and he tells you you're grand. Well some people go back and they've been left with scar tissue and that scar tissue can irritate you for the rest of your life. I actually believe my FM came from a serious trauma in my life so I believe that in my body I have scar tissue that has had an impact throughout my life. So for me, my explanation to people who really want to know is that this is the lasting effect of something that happened to me and they get that because most people can at least understand the emotional side to it and while some people survive that appendix operation without any future problems, some are left with scar tissue and that's the way I see it. It's a physical thing. But the emotions are there too so we can understand that.

Are you satisfied with your Doctor's management of your condition?

No (group response). On a show of hands, no=10; yes=1

Fiona: I am because they can't do any more. My doctor said to me recently that FM is a very painful condition and I appreciated that. I know there's nothing he can do about it at this point in time because they don't know what to do about it, they don't have a clue.

Ruth: They can understand you and listen to you and be understanding about it.

Catherine: Well they can make sure the diagnosis is right. That's the first thing they can do. They can be a doctor to you and not a mental assessor because I think they take on that role too quickly, certainly in the practice where I have gone to. You arrived here last week (directed at another group member), we never met each other before and you just said to me that you were seriously upset with your doctor. That's your story; I'll let you say the rest.

Kate: I was diagnosed 3 years ago by a locum in the surgery. She told me to go off and look it up on the internet which I did and I didn't find much. I was looking after my mother who was living with me, she had alzheimer's, and then my husband was killed so I didn't really have time to pursue it. I then had an operation on my foot and was sent to a physiotherapist and he said to me after noticing that everywhere he touched made me jump off the table, have you ever heard of FM and I said yes and he said well I think that's what you have so he gave me some exercises which were weight bearing and then he decided after a while that they weren't right for me. He wrote to my GP and I went back to her and she said oh yes I've been up all night reading your notes, maybe you do have fibromyalgia and you'll need to go to a psychiatrist and I'll give you amitriptyline/amitriptyline (arthritis medication). Her view on FM is if you don't get enough sleep you'll get FM. You should take amitriptyline/amitriptyline (arthritis medication) then you will sleep and all of your pains will be gone. That's what she told me. Then I met Maeve (another group member) and she said she had been to the same GP and had the same experience. I've been attending for 17 years and I've been treated for anxiety, pains, everything and I just felt it's too simplistic to think you get a good night's sleep and your aches and pains are going to go away. She took me off everything I had been taking. She blamed stress too.

Catherine: Trust me; I took the blame for years of it being my stress. I took the blame for that. I resent that claim.

Kate: She had me on lexapro, a really strong dose of lexapro for I don't know how many years, I can't remember, maybe 6 or 7 years.

Ruth: How did you feel on lexapro? Were you twice as tired?

Kate: Yes probably, but mostly I felt on lexapro that I was dealing too well with difficulties. Like when the Gardai came to my door to tell me about my husband there was no emotion and I wanted to feel again, I wanted to be human again and not this no up and no down; to be excited about things and to be upset about things. I wanted just to take life warts and all. I wasn't allowed to move for 12 weeks after my operation and I wanted to come off it and she said don't come off it in the winter you'll get twice as depressed. So I had my operation in March and it was coming into the summer so I started to come off it very slowly. I was hallucinating, I was nauseous. I was seeing snakes, people had tongues like snakes. I reduced it and I'd say I came off it over 6 weeks. I was absolutely horrific. I was freezing, I was shaking. The same GP treated us and treated us in the same way.

What support do you get from your GP?

Patricia: The GP in Portmarnock is very good – we all have the same GP (3 members). She's quite open indeed. Every 2 years I would ask for a thyroid test to be done and it would always come back on the normal level. There was an article that a doctor in America had written and I really wanted to push for it because I've always felt the thyroid was my problem and the GP kindly made a referral to an endocrinologist. The endocrinologist refused point blank to see me because he said the bloods were normal. It turns out that I have a serious thyroid problem. It took me 2 years to actually find a consultant that would do the tests.

Fiona: Just accepting that we have it is very important. I think that our GP accepts it as an illness and I think that's crucial.

Kate: She has sent me for lots more tests. She said to me that she didn't want me thinking that everything I have is down to my fibromyalgia.

Catherine: She saved me because I had a growth at the back of my face. I couldn't lie down, I couldn't stand up. I was vomiting and the day I made the move to her, it was amazing that she said no, if you don't think that's what it is, the fibromyalgia, we'll find out what it is and the growth was found and next thing I was in surgery, having radical surgery.

Kate: She's not taking any of my aches and pains as definitely fibromyalgia so she's looking at me surgically. She has accepted that I have FM but she's looking at everything else.

Patricia: You see there is a different quality to the pain. You know the difference between fibro pain and new stuff but the doctors don't seem to take it seriously. They attribute it all to FM. I have talked to numerous people where this has been a problem. One lady had appendicitis and her appendix burst but they said the pain was fibro pain. Another had a tumour on her kidney but they said the back pain was fibro pain.

Margaret: You can never neglect yourself because of that. I am a smoker so I get a lot of lung pain. I had pneumonia and I didn't even realise. I thought it was the fibromyalgia. I had gone to my doctor for 2 weeks crying with the pain. You neglect yourself because you go to your doctor and he says it'd fibromyalgia, give it 3 or 4 days of rest and it'll be fine.

How do you think the healthcare system could be of better support to you?

Catherine: I think a psychotherapist in surgeries is needed. It's not just needed its best practice. We can't go to work. We couldn't support ourselves, we have no income. If we were to split from our husbands God knows what would happen.

Patricia: I think Margaret made a very good point about a 6 week course. I know Arthritis Ireland do courses but it's up to you to try and find them, no one tells you about them.

Ruth: It's up to us to publicise and to take the stigma out of it. We are stigmatised.

Patricia: Doctor Woods calls it the F word!

Catherine: I think it would be best practice, it's sensible to have a situation where 16 to 18 trigger points are active at any given time. I'm crippled. I've decided if my upper body works I will use it, if my legs work I do the opposite. I will use what is working. I will take the pain and I won't concentrate on it but I will concentrate on my achievements and there are many. We have no choreography of medical care.

Patricia: Given a proper explanation of drugs because the rheumatologist shoved a prescription across the desk with 2 names of drugs on it but didn't actually explain what they were. I know one woman who was quite angry because she had been prescribed anti-depressants. She thought she was being dismissed as a psyche case. Now when I explained to her that an effect of an anti-depressant is that it affects the CNS and helps reduce the pain she was a little bit more comfortable with that and she said that if the doctor had explained it like that in the first place she would have left the office and tried them out.

Kate: Every letter that my doctor wrote to refer me onto a specialist said that I had depression. She never told me that I had depression. I didn't know I had it and I changed my pharmacist because I was quite friendly with her. That was 12 years ago and at the time I was embarrassed.

Ruth: When I was given anti depressants at the start I said I'm not depressed, I don't need them and the doctor said it was for my sleep but at the sane tine I wasn't happy with it.

Kate: They need to have a multi disciplinary team for us and they need to be all working in tandem.

Catherine: It's so expensive. We pay €139 a month on drugs. We're dependents, we can't take a job. We have no entitlements; we're not allowed a disability payment.

Patricia: Part of the problem is who do you go to? So many different problems so you go to different people but then there is no communication between them.

Catherine: I had to go to my GP every Friday for years, €55 every Friday just to assess my symptoms- moving and shaking and goal post moving and it's quite bizarre what they'll take off you.

Kate: My new GP, she said to me 'oh you poor thing'. I have never been spoken to like that with so much empathy and understanding. She put me on new meds. They didn't agree with me and my knees swelled up. I didn't want to go back to her and hand over another €55 but I was going down the country for a few days and had to get it sorted. When I got out to reception to pay she had phoned out to say not to charge me.

Catherine: Oh the old GP wouldn't have done that, she charged every time. It's an expensive illness.

Fiona: Because you have fibro fog you feel awful. I mean up to this I wouldn't have accepted that awful treatment but you no longer have the energy, you're no longer that person and then because you doubt yourself and you think maybe I am just lazy, I should just get on with it. I think that's very difficult when you don't have the wherewithal to say this isn't acceptable. I've been fortunate not to have had any of that carry on that you've had but it's just a vicious circle. Just tell me what it is and tell me what to expect.

Patricia: The other thing is that consultants don't share information, its €200 each time and so it ends up like a bottomless pit. They're not working together.

Catherine: I think it should be classed as a disability.

Margaret: Actually even to have a GP visit card would make a huge difference.

Patricia: When I went for a social welfare assessment the fibro fog was very bad so I had everything typed up and one of the doctor's questions was tell me who you've been to and I said well I've typed it up here and he said you cannot look at the list and you must tell me yourself. I explained to him that I had really bad fibro fog and that was why I had typed up the information. I also wanted my Mum in the room with me, not to answer any of the questions but just in case I didn't understand anything or if I missed anything so just for her to sit in the back but I was refused that too. I felt I was being treated as a criminal. I got it but I had to fight for it tooth and nail.

How do you think the media and society in general perceive fibromyalgia?

Patricia: I don't think the media are too bad. They're actually quite good.

Kate: I sometimes think ME is fine to have but FM isn't. Is it that they are better at putting it out there than we are or how did that happen?

Patricia: Depending on who you go to you will get a diagnosis of ME, FM or CFS and it can differ depending on what specialist you go to. The guy I go to doesn't differentiate between them at all.

Ruth: Most of the reports in the media have been positive, like the health supplement of the Irish Independent.

Fiona: In FAS they recognise fibromyalgia as a disability, it's on their list but it's very hard to get a disability payment.

Patricia: Society will have to be acknowledging and acknowledge FM as a condition.

NOTE: (1 member of the group didn't take part in the discussion)

Date: 26.01.2013

Venue: Trinity College, Dublin

N = 5

What was your experience with getting your diagnosis of Fibromyalgia?

Mark: Mine, to be quite honest was quite fast but in another way it may have been 3 to 4 years because I didn't go near a doctor until dire straits. I went to the chemist and bought boxes and boxes of neurofen and kept myself going with them. But when I did go the doctor the GP was very fast and even before I was diagnosed in St. Vincent's Hospital he said to me that he thought it may be a case of fibromyalgia so I thought that was very good. It was slightly over a year, maybe 14 months from first visit to diagnosis. That was because I was waiting to see a specialist in Vincent's – that was the longest part of it. My initial appointment date was a wait of over a year but I phoned them and the secretary brought it forward so I was waiting about 10 months.

Frank: My diagnosis was fairly quick aswell. It was triggered by work. I can't remember but I'd say over a year. It was a rheumatologist who checked it out and said its fibromyalgia. I have heard stories of people being dragged around and then just figuring out themselves that they have it but I seem to have been lucky. At least I have a name for it now. I had a sense of what I know I can deal with. If you go away you can go away and learn about it and figure out how you're going to deal with it.

Adrian: Similarly mine would have been triggered by an accident I had in work and I only figured that out after the event – after the diagnosis that's what started the process so that would have been about 18 months before I presented to the doctor with the symptoms that I was experiencing. Once I presented to my GP he carried out all of the tests. He did blood tests because he thought it was arthritis first so he checked for rheumatoid arthritis first and then he sent me to a rheumatologist who then diagnosed me. But both of them said to me once I was diagnosed that they knew the first time they saw me what it was but they had to go through the process of ruling out everything else. It was very much a diagnosis by exclusion so they both said that they could see by me and my history but they just had to follow the process. Again, once the diagnosis was made I found it was a great comfort or support to know what the name was but that lasted for about the day I was told and the day after and then as I began to learn what was involved that relief of having a name for it faded lucky for a while when I had to learn about the surrounding feelings and symptoms that go along with it.

Interviewer: And when you say you had to learn, how did that work?

Well the day the rheumatologist diagnosed me and put a name to it for me for the first time, she handed me a 2 page printout with 'what is fibromyalgia' on it and that was basically what I was left with to go off and after that it was up to me. I bought books, I had books given to me, I went to libraries, I looked up on the internet. I researched as much as I could to know what was going to happen to me in the future.

Philip: I'm the other end of the scale; it took me 21 years to get a diagnosis. I got sick originally back in 1990. Major fatigue, pain, I was out of work at the time for about 4 or 5 months and I was the healthiest person in Ireland because I was sent to so many specialists and they all said there is absolutely nothing wrong with you, everything is fine! Eventually my GP said this could be depression and he gave me an anti depressant and that actually helped, as a lot of people with FMS find so they said "ah you're depressed" so I went down the road of psychologists and psychiatrists and all the rest, and while that helped to a certain extent, and allowed me to function, I knew deep down it wasn't the answer and when I did group therapy, one thing that struck me was that everyone sitting around me had a major life event that they were trying to deal with and I didn't, apart from the fact that I was sick and so I just felt that that wasn't my problem (the depression). I went for years basically in pain. Previous to that I was very active. I was a runner and I kept getting injured and so I was diagnosed with a type of arthritis – ankylosis spondylitis so I mean I really

took responsibility for this myself. I went through years of being depressed and sick and not doing much and other times I would go and see other Doctors. The internet is great because it does allow you to read up and I read up a lot on symptoms and what I was experiencing. Then the consultant I was seeing in Beaumont retired and this young guy came in, he was an endocrinologist and I went to see him and he did all the tests again and said I can't see anything but what I want to do is take you into hospital for a few days and just run a few deeper tests and he ran a few deeper tests and he found that my cortisol level was extremely low. He said that was the only thing he could find and he put me on hydrocortisol which did help a bit. Prior to that, from reading up I went on a gluten free diet which again I found it did help and assist a bit. It's amazing, when you talk to other people we're all different, some things work for some people and not for others. The specialist I was seeing every couple of months for the low cortisol he said to me, this ankylosis spondylitis, I want to have it checked out – I hadn't seen anyone in years, and he said he had in the back of his mind FMS from listening to my symptoms. Now he said in FMS you find low levels of cortisol but my level was really really low, much lower than he would normally see. So he sent me to a rheumatologist, he examined me and said if you were diagnosed with ankylosis spondylitis which fuses your spine, back in the late 1980's I would have expected you to be pretty immobile and yet you're very good. So he sent me for scans and I went back to him after the scans and you have FMS, I'm fairly confident that's what your problem is. So that was September 2011. He put me on Lyrica and said work with your GP around increasing that and that was it. He said there is nothing else I can really do just try to get out and exercise and keep yourself relatively fit which is easier said than done. Some days it's ok, other days it's not. That's really it. It's been a long long journey. Getting a diagnosis – it's probably good to have a label on it. One of my biggest issues was people look at me, even my own family, and say you don't look very sick, you look fine, what's wrong with you? It's very hard to say I'm tired. You know my wife kinda throws her eyes up to heaven when she says how are you and I say I'm tired. Some days are worse than others. Some days I can play along with the kids and run around and other days I just shouldn't have gotten up out of bed.

Frank: You don't look your age – well I feel it!

Philip: Plus 20 or 30 years!

Thomas: I suppose I'm luckier than most of you in that I was diagnosed very quickly altogether. I used to play a bit of golf. I used to get terrible pains in my shoulders and I thought I was hurting myself playing golf. I'm a diabetic and that helped in a way because once you're in the system with diabetes anything that is wrong with you is investigated straight away. And so I went to my doctor and I remember the morning I went in I actually couldn't put my hands behind my back. He looked at me and asked me to try to lift my hands up. I could lift them but with a lot of effort and he looked at me and said I think you have fibromyalgia straight off. He did some blood tests, they came back a few days later and he said yes that's what it is. It was diagnosed that quickly. I couldn't believe it. When I read about it after I saw that there are people in the states that are saying that a lot of people that have been diagnosed with MS actually have fibromyalgia and that it had taken years to get a diagnosis. Maybe I just have a doctor who is spot on and knows what he's at. He was able to look at me and knew from the symptoms and the way I felt that I had it. I was diagnosed 3 years ago now.

Adrian: I'm just wondering is it becoming more diagnosed more, putting the name on it because I'll be 2 years diagnosed is there more awareness now and they can put a name on it quicker than maybe 10, 15, 20 years ago?

Frank: I'm diagnosed 15 years.

Thomas: I think a lot more research has gone into it in the meantime and in the last 5 years doctors are able to diagnose it more quickly and are prepared to put a name on it.

Frank: The younger doctors are more in tune maybe? Was yours a young doctor? (Directed at Thomas)

Thomas: He's not no, but he was telling me has seen a fair few cases of it.

Mark: I met a young doctor and she didn't know anything at all about it and the doctor who eventually diagnosed me was about to retire.

What is the most frustrating part of having a diagnosis of fibromyalgia?

Thomas: There are days I can get up and do anything and then there are days I can't get out of bed with the tiredness.

Adrian: The unpredictability. There are so many symptoms. We all have our own and the little basket of symptoms means it's not known what tomorrow will bring and no matter how good or bad you are today you have no idea about tomorrow. You can't plan. You can't say tomorrow I'll definitely do that. It's something that you have to wake up in the morning and hope for the best. The unpredictability of it gets me because you become unreliable then.

Philip: I find work is difficult. I do work and like that some days I'm fine and then other days I'm just so tired I could get in under the desk and just go asleep.

Frank: And there are some days that you just have to get through the day to hold onto your job.

Philip: You do. You have to hide almost and that's not good.

Frank: Some days you have to say 'today is going to be crap and I just need to survive'. The alternative is to go sick because I have this but then I'm going to get into the habit of going sick and end up twice as bad so I don't take sick leave for this. I would for a chest infection or something but not pain, I just drag myself in. It's like a slippery slope – if you start you won't stop.

Adrian: The other side of that is the job that I was doing, I was a barman for 10 years and it's unpredictable hours, its shifts, it's lifting, it's hauling and you're on your feet the whole time so that's actually not a job I could've hidden in. It was just unfortunate.

Frank: Yeah but I'm a nurse and I was doing 7 nights on the trot. In the last few years I'm a manager but before that I was giving away my nights and no one really understood why. They know why now, it was because the nights were absolutely killing me.

Philip: I can imagine shift work. I'm lucky I work in an office and I'm sitting down. I've always said if I had to have been in a physical job I probably wouldn't be able to work.

Adrian: I have the utmost respect, I met a nurse recently who has fibromyalgia and works and if I could I would but by the same token....

Frank: I'm at a managerial level so some is hands on, some is physical but it's also part admin which is probably a good match for me because it probably wouldn't be good for me to be sitting down all the time either and it's not Monday to Friday but its nearer to Monday to Friday than the nights and all that.

Adrian: So accommodations have been made or come about and that all helps.

Frank: I have a bit of room to tweek. I was doing 2 long days which is 2 12 to 13 hour shifts before the management position and now I'm doing one.

Thomas: Are there different degrees of it because I don't think I've missed a days work because of it and as I say I drag myself in, I'm not a brave fellow and I'm not a great man but I always say to myself 'I'm not giving into this'.

Philip: Well I don't think we give ourselves enough credit sometimes to be honest. I look back on it probably the fact that I functioned – I should be proud of that. We don't give ourselves enough credit.

Adrian: That's part of it, that not even thinking about ourselves.

Frank: That dawned on me too in the last year or two.

Adrian: It's like that's a similarity. We're all kind of the carers – we're all the givers and we don't even think of ourselves and I've noticed that pattern where people would be very much putting others first and then you realise very late that I need to look after myself and as I say when I fell asleep on the bar counter that was the last time I worked because like that, you keep going you try and try and try and for me it got to a point where my manager said for your own safety and for our safety you can't be here. Even driving home at night was an issue because you're so tired but yeah I do think we do all have that beating yourself up element in our lives.

Frank: I was doing nights and coming home, spending 6 or 7 hours in bed and maybe sleeping 3 or 4 whereas when I was 20 and in my mother's house, I slept through the noise there no problem and it's because of my health problem.

Interviewer: So the main frustrations are around the tiredness and the unpredictability?

Frank: The mismatch between the brain wanting to and the body saying no way or vice versa. Having all these ideas and not having the umph to get up or you put it all into work so when you get home it's hard.

Adrian: It's really about prioritising. You're trading one off the other saying if I get into work and do my work then that's all I can do that day and that's all I have. You feel good and you go like the clappers and that's not good. And then a week or so later you say 'what happened there'?

Frank: An Ikea shelving unit was enough to send me back to my specialist!!!

Philip: I think a diagnosis for me helped because I used to get so tired. It was picked up on in work, at meetings falling asleep, the head going and I would pass it off saying 'oh I had a late night' or 'the kids had me up'. Eventually now I have thought myself that when I'm tired I just go into a trance and keep the eyes open. But that tiredness, I didn't know where it came from but now I have a diagnosis I know where it's coming from. The fact that I don't sleep properly and even though I might have been in bed for 9 hours I may have only had 4 hours sleep and that's why I'm feeling so tired. I've learned as well to try and pace myself. It's difficult at times but knowing that there's only so much you can do in a day and if you do too much in 1 day you're going to pay for it over the next few days.

Do you feel the levels of support within your families has changed since your diagnosis?

Frank: I think she tries to be understanding and supportive but I think sometimes she does get frustrated.

Mark: Yes like that, my wife is very very supportive but then when I sit down on the chair and fall fast asleep and she's saying there you go again and I suppose you couldn't expect much different because she sees so much of it. I don't work, I'm retired. Now I walk my dog and that's all I do but like that you wake up in the morning and wonder will I take him or will he take me! Support from my wife is excellent but every now and then she gets frustrated – will you be able to do this tomorrow, I don't know, I might I might not.

Philip: I'd be the same. My wife is generally but yeah there are sometimes I'm at home in the evening and I'm just completely knackered and the kids are acting up and I just don't have the energy and I'm cranky and whatever else and then she's not so supportive. Sometimes you need a kick up the arse as well! We're doing home decorating at the moment and that can be a bit of a chore as well because I'm doing bits and some days I'm ok and I can get up and other days I come home and I can't and she says 'ok get home early and we're going to do this' and it's like yeah not a chance today, I'm just too knackered so it drags out a bit.

Mark: Last summer the hedge at the front of my house needed to be cut back, it had got too wide and too high and this one day I was feeling good. I thought right I'm going to divide this hedge. I'm going to cut it down and that took over a month!

Thomas: Well I try not to tackle anything; I get someone to do it.

Adrian: I don't do anything like that. I get the man who has done his training and that's the reason you go to them! I live on my own. It has pluses and minuses because there is nobody if I do lie on the couch – I don't have to explain myself to anybody but by the same token, if I'm feeling well enough to visit my family they only see that good day so I've had to explain that to them. Now they're very understanding and they have seen me when I've rocked up at my parent's door and said "I'm not going anywhere for a couple of weeks and I can't even make myself a cup of tea because I'm so done in" and they understand that that might happen but at the same time if I feel good enough to leave my house they see me on that good day, they don't see the 3 days that I prepared for that beforehand and the 3 days I might take to recover afterwards and that would be the same with my siblings as well. Living on my own gives me a lot more time to think about these things but it also give a little bit of freedom. With my nieces aged 4 and 2, trying to explain I can't lift you up, I've to come down to you on the floor or those kinds of things. I can only imagine the effects when it's your own family. I think FMS has brought us a lot closer because we've had to have discussions about how I'm actually feeling, whether it's tired or frustrated or whatever it is so you're actually opening up a little bit more to them so as a result I've found that they've opened up more to me so I think we've become a lot closer. The pleasantries of having a meal together is one thing but then you get into the depths of it and have a chat about what they can do to help or 'how are you feeling today' not just the Irish - how are you but it's how are you, how are you getting on, what can I do to help and I think that's brought us a lot closer.

Thomas: My wife is a great support actually but early on when I was I learned I'm not doing any more of these jobs if they need to be done I'll get someone in to do them because I just decided no I'm not able to do them and that's it, I accept that. I know my limitations and she does too and she accepts it, she's great. Luckily my 2 children are grown up and they have their own lives, they know I have this, they know what it is, it doesn't bother them and I don't bother them with it. An odd time if we're on holidays they'll see it and they're very supportive.

Adrian: I think in respect to what you said, sometimes you do need a kick up the arse, like my brother would say to me 'look, which do you want today, do you want me to put my arm around your shoulders or do you want me to tell you to get up and get out?'. Then there's days when both are necessary and some days you do need that little push and even if that little push is to get out of bed that's a successful day and I've been lucky that my family know and they can sense what I need at that time.

Frank: My kids are 14, 16 and 20 and they would have known through the years that I'd have had aches and pains – earlier I used to get them to walk on my back – it was good! But it's only the last 2 years that I've actually said I have fibromyalgia. I don't know why, that's just the way and it's the same in work. I'm only having a bit more treatment in the past couple of years so I've taken time off so I've had injections. I wasn't saying anything to the kids or work about it.

Do you feel that the support you currently receive from your friends has changed since your diagnosis?

Frank: I'm also a trained counsellor, I did a diploma in 2003 and upgraded it to a degree in 2010 and in that group where you talk about your feelings I was quicker to say it because I felt it would be more acceptable.

Thomas: I'd say all of my friends know about it but they wouldn't necessarily ask me about it unless I go into one of their houses and I'm really knackered and sometimes I might nod off to sleep and I can nod off in a few seconds. I remember one day my wife was sitting on the couch and she said to me 'what's on television' I took up the control and next thing she said 'why did you stop on that' and she looked at me and I was fast asleep – that quickly! That's the only time anyone would ever ask. They'd know it's there but wouldn't really know what it is.

Interviewer: And what do you think of that? Do you think that it's ok not to enquire? Are you happy with that?

Thomas: Yeah I think I am. It doesn't bother me too much. I'm not a brave man or anything like that but I have it in my mind all the time that I'm not going to let it win. Now there are days when it can win but as I've said I've never missed a day's work and I won't allow that to happen and there are days when I just had to drag myself out of bed and get showered and dressed and go into work but I do it and at the end of the day I'm at home I'm back home, I sit on the chair and I'm asleep in seconds I'm that exhausted.

Mark: I think that goes back to people not knowing what it is. You walk into a house and you've told them a month ago you have fibromyalgia and they say how are you? The next month you walk in and they don't even ask you anymore because they know nothing about it and there is no public awareness. That's what I find. My immediate family know about it and my extended family to a certain extent do know about it but like that, you meet them and they would never say to you 'how are you, how are you today'? And I think that's down to the fact that they know nothing about it, they don't know what the name even means.

Philip: It's hard to explain what it is

Frank: The name doesn't immediately explain what it is. With chronic fatigue you immediately get a sense of what the person is dealing with. With this it's 'fibro what'?

Interviewer: So the name itself seems to lend itself to confusion amongst people

Philip: You say it to people and they say what is it and you say its pain and fatigue and they say what causes it and nobody knows so it's hard to explain it.

Interviewer: What about friends, as a group would you think support levels have changed within your network of friends?

Thomas: I've told my friends I have this and how it affects me so if I'm with them and I happen to be a bit tired they understand. It's not a problem.

Frank: I wouldn't have said much about it. Well there's one friend I trained with as a counsellor and he knows, I would talk to him.

Mark: At times they might ask you how you are but it'd be like 'take a couple of aspirins and you'll be fine'.

Adrian: I found it has been a great separator in that I found that my real friends have come through. I'd never hidden it, if anyone asked I'd have told them what it is. I've noticed that my real friends, particularly now, will ring and say 'are you coming out on Saturday' and I'd say 'no I'm not feeling great', 'you coming out Sunday' - 'no'. That would go on week after week and you'd constantly be saying no and some of my friends have just stopped calling and they disappeared and so they are no longer in my group whereas there has been 3 or 4 core friends that come to the top. I could cancel 20 times in a row but they would still ring me and say can you come out today and then when I do go out with them it's not the main topic of conversation. They understand that I'm there as the mate in the group to have a laugh too. It has certainly shown me who are the people who really care, who wants to be in my life and who wants to support me. I think in many ways it has focussed me more on those relationships because you end up getting closer to them because they're the ones you're seeing more often and the one's you can talk to but yet they carry on as normal - they don't treat me as someone with FMS, just myself. That's taught me who cares and who doesn't.

Thomas: When I was first diagnosed I thought I was having a heart attack, I had pains in both arms, it was dreadful and I always associated that with something wrong with the heart. I remember I went to the doctor and he said there's nothing wrong with your heart, that's the fibromyalgia.

Adrian: I've had 2 instances of that where I'd to go to A&E because I had chest compression and left arm pain and felt like someone 20st was standing on me. The pain was that intense. The paramedics were looking at me going as far as we know it's your FMS but we'll have to have you checked out. As it turns out it was the FMS.

Are you happy with your Doctor's management of the condition?

Frank: There are 4 GPs in my practice; I would rate them 1 to 4 in terms of who I would want to go to. There is 1 I definitely wouldn't go to. The best is female, the next one male, and the next one female and next one male so it's not necessarily gender. The lady I go to I have come to through my son..... The man I wouldn't go to knew nothing about FMS. She's open to alternatives; she's not stuck in the traditional medical model. The one I wouldn't go to is very much 'I'm the Doctor and I'll tell you' and being a nurse I'm medically based myself and want someone who will listen to me and not swallow what I say but listen, and then make a decision so in that sense I find her good. If I want my FMS dealt with in any way I'll phone and get an appointment even for the following week so I can be sure I get her.

Adrian: I always said how lucky I am with my GP. He's signposted me to every 'ologist' you can think of over the last few years and I've had all the tests. There are good ones and there are bad ones. You clash with somebody or you get on with somebody, that happens along the way but my GP would be the main source of treatment and his interest in FMS is huge but he has taken time to get to know me as well. I could be sitting in the waiting room and he'll call me and by the way I move, if you're used to seeing people you can tell whether it's pain, fatigue, depression, whatever it is by the way I walk in and immediately he'll know and he'll take the time and he gives me his time no problem and he's interested and he'll listen because he'll take it in, like you said (directed at Frank), some people just don't listen to what you're saying to them.

Frank: Yeah, you are whatever because I say so and with being a nurse I've had battles with doctors over the years because I'm not going to sit there and take it.

Adrian: I've had great experiences with some and bad experiences with some. The worst one I had was a rheumatologist I went to see and my brother had played a cup final match the night before and I managed to stand for 20 minutes and then I had to ask one of the old dignitaries who was there to present the trophy could I have their seat and I sat for the rest of the game. I saw the rheumatologist the next day and I told him this and 2 minutes later he said all you have to do is go back playing football, you obviously miss it and if you got back into a team, not only would you get your fitness but you'd also get your social life back. I said to him, 2 minutes ago I told you I can't even stand watching a match. But that's only 1 out of all of the 'ologists' I have seen. As I said, they've all had a look, they've all had a camera crew do their business and 99 out of 100 times they've been fantastic and they've diagnosed something or they've given me information and it always comes back to my GP and if there's anything bad when I go to him then he'll refer me on but he's happy enough, and I'm happy with him, he's my main port of call.

Thomas: I nearly manage my own. I might go to my doctor once a year. I read as much as I can about it and the only thing that I'm on for it is Lyrica. Other than that I suppose I could go and talk to him any time but I don't bother. I just get on with it.

Philip: I'd be the same myself, I just manage it myself and the doctor is there if I need him but there's not a hell of a lot they can do other than prescribe painkillers or lyrica.

Adrian: I think then as well the reason that I go to the doctor once a month is, I know others would have other illnesses or diagnoses around FMS and at the moment there's a lot of medications so I have to keep on top of them so that's why I'm in constant contact. You're only on Lyrica (directed at Philip) whereas I'm on 12 or 13 tablets a day to treat different things so it's important to keep getting my bloods checked and for the doctor to keep on top of it all the medications and so that'd be the reason why I go back so often.

Frank: I would have been like Philip for years and then after meeting with the pain specialist I was started on Lyrica, about 15 months ago. I just had to do something.

Adrian: I think unless there is a reason we seem to be happy with GP care and then if there is something specific that crops up, we all know the pain/fatigue that we can put up with and then if there's something different...

Frank: 80% of the pain I get I accept it; it's the other 20% that just gets in on me. A lot of it, it's there, its part of life. It's just the 10-20% that is really tough.

So for the most part you're happy with your GPs management. If you move outside of that and think of the rest of the healthcare team that you may or may not be involved with. Would you be happy in general with the healthcare systems management of it?

Mark: No. I feel like I'm treated like it's all in the head that there's nothing wrong with you and eventually it was said you have fibromyalgia, go home and look after it. That was it. I was given no information on it. I had to find out everything myself.

Thomas: Well I've done the same, bar the GP. I get on really well with him and he told me what I had straight off but anything I've learned about it I've learned myself from the internet, I wasn't even given a leaflet.

Mark: My own GP, there are 2 doctors in the practice and on 1 occasion I was sent into the second doctor, not my own GP and he told me to lose weight and do more walking and that was his line. Yep, you'll be alright, lose weight and go and walk.

Frank: I'm coming around to the idea that exercise is a big part of it.

Thomas: But there's a train of thought too that when you have it bad the worst thing you can do is exercise because you get worse.

Frank: I was going to the gym. I didn't know if I was getting much fitter but I went away after Christmas with my wife for a couple of days and did some swimming and could see I had been getting fitter.

Thomas: We'd go to the gym but there are times when it's that bad I can't and won't do it. I just leave it. I've been told not to do it.

Adrian: You've so many other responsibilities as well, the responsibility of a job or so many other things. If I was a fulltime athlete I'd manage it a whole lot better because you could give all of your energy to your exercise and fitness but you just have so many other things to contend with and again the unpredictability of it that you just can't structure fitness or training regime.

Frank: In relation to healthcare professionals, I went to a pain specialist and on his letterhead it said 'other interests, holistic medicine'. He suggested things like mindfulness so he's quite open to whatever works do it. If it works for you do it, it's not just take the pills. The others like the holistic side and the alternative therapies. There is a lot out there and if you can get a GP or someone who is open to that and not a doctor who will say I'm the doctor and I'll tell you what to do you can go to them and say what do you think about this? I wouldn't have a healthcare team that I would use on a regular basis, just the GP and if anything gets worse I will be sent further afield because so far I'm still in the private side but at the same time I have asked for an appointment in the public system just because I will have this long term and I can't afford to be paying private all the time so I started off and had an 18 month wait for an appointment in the public system so I've gone through and paid as much as I can, and now I'm nearly there, my public system appointment is in June this year so I'm hoping that will open up more. In the private, I've noticed there's not as much sharing of information so if I've gone from the neurologist to the urologist, I've to again start with 'this is what I have, this is what I have had done' and I don't have a file that follows me, they have a file on me and that can be a bit frustrating in the private side of things because sometimes you'd like for you to have the information in the file and have a holistic, whole body treatment but unfortunately that's just not the case for me anyway.

Philip: Well mine wasn't too positive for 21 years but it's been pretty good now and I'm getting the best care I can get. At the end of the day they have said there's not a huge amount they can do, a lot of it is up to yourself.

Thomas: I'm a diabetic so I have a check up every 6 months and all the bloods are done. I don't think I've ever been as well looked after.

How could the healthcare system change so it could be better for you? How could it change that it'd be a better support to you?

Frank: Doctor's training. More education of doctors – not necessarily to be huge but enough that they would refer you to a rheumatologist who would know more about it.

Adrian: And I think maybe having a booklet or a leaflet. Something that you're not just given a name and told to go on about your business. And to be given, I know there's no national support group, but to be given the number for Arthritis Ireland who will look after people with FM or your local group so that you have a next step to take, whereas I just got a 2 page handout and everything I did then was my own investigating. Even if they don't know a hell of a lot about it but they had a booklet beside them. Like if you go in there will be a booklet on diabetes or any other thing but there just doesn't seem to be anything on FM. All it would take is for them just to hand you a booklet.

Thomas: It's not even that. I mean now a days they could just have a standard thing on the computer and just print the page and hand it to you. It's as simple as that.

Frank: It seems to be a hit and miss as to whether or not you even get diagnosed.

Thomas: I think I was the quickest and I think that was because when I went in the symptoms were extreme so he could see straight away. He had to put me on steroids for the pain – I was absolutely doubled up in pain.

Adrian: It can happen that it's better if the doctor already knows you but as it turned out I had moved house after having my accident at work and before my symptoms really go bad and originally I was going back to my old GP who I'd have had all the way along growing up but the very first time I decided that I needed to go to see someone when these symptoms got so bad I actually went to a new GP and my very first visit to him was me saying 'I'm really tired, I'm really sore' and my relationship with him is really solid. I have only actually dealt with him for FM so while he didn't really know my history before that he took the time to learn and recognised it very quickly so in that sense I was lucky with my GP.

Frank: It's to get on that list that if someone is coming into you and they've got ongoing chronic pain and they need to get on that list because there are things that need to be put in place.

Adrian: It's like the insurance thing, there's a list of 27 illnesses and it doesn't appear on it.

Frank: The sense I'm getting is that the ME, Chronic Fatigue and FMS are all in the one group of diseases so it's that group that needs to be looked at during GP or doctor training. Doctors sometimes just don't know about it.

How do you think the media and society perceive FMS?

Thomas: I don't think they know anything about it at all.

Philip: Anyone I have ever said it to have never heard of it.

Thomas: Same here. Anyone I told it was like 'you what'???

Mark: It's only in the last couple of years that you see any reference to it. Like yesterday I was in the holiday show and there was one place where they were doing massages and they actually had fibromyalgia written up on the wall. Two years ago you wouldn't have seen that.

Adrian: Initially when I started telling people I got the old "you're putting it on, you're lazy" and because of my age especially, I'm only in my mid twenties.

Frank: Whereas the latest thing on the web seems to be saying it's neurological.

Adrian: And I do think that while rheumatologists sometimes won't diagnose it, neurology is now where it is because it is the nervous system rather than the joints and I think the rheumatologists aren't going to give up the handy number where they're getting the referrals, they're not going to say 'we're not the best person to do this, don't them here'! I think we should probably be going to neurologists.

Frank: Neurologists probably would sign you towards pain management because they don't really care what the cause is it's about managing the pain.

Thomas: The best description I ever got for FM is it's the same as arthritis of the muscle. I find that a good way to describe it.... It's not well perceived in the public arena.... Twenty years ago nobody had heard of ME and now everybody knows about it and now it's the same with FM. We're at the stage where nobody knows about it but hopefully it'll take less time for people to get to know a little bit about it.

Adrian: Well I found it useful to write. I write a blog on what I'm going through, and that's been brilliant because people come back to me then and say 'I didn't know this was involved or I didn't realise that it had that level of effect'. So I found that to be a great way of breaking down the barriers particularly with my family, friends and extended family that they can actually read and see what my day to day life is like and then they understand it more and can talk about it in their circles. It's a slow process but anything that gets the name out there has got to be good. Particularly being men with FM and the 90:10 split. I think that there is a bit of 'will I say it, will I tell it'? And you have to put yourself over that hurdle and say 'ok, I will now'. I think we've all at some point said, do I really want to admit to this?

Frank: I've been in the Carlow support group and for my own reasons that I won't go into I won't be going back, but they have been trying to get it recognised as a long term illness.

Do you have any views on that – the male versus female experience of fibromyalgia?

Adrian: My big thing with it is it's very stereotypical – I should be the one working, I should be the one providing, I should be the one able to do all this and I'm not because I can't and I'm so hard on myself, I beat myself up and that makes me worse and that's the way I feel about it particularly being at the age that I am at.

Frank: My perception is if I were female it would be more ok to talk about things and it's just more acceptable. Society probably see women as being more weak which I wouldn't agree with at all but it is more acceptable for women to appear weak.

Adrian: As a man you're afraid to show weakness, you're afraid to show any of what I would describe as putting on a show. I think I mentioned it earlier, when I go down to visit family you're on stage for a few hours and then I know I did it for a few hours and then I can head back out.

Thomas: That's the macho thing coming into it and I think that's a load of shit, pardon my language. I look at it, I see 600 suicides, for every woman that dies by suicide there are 12 men and it's all because they won't talk and I think that's ridiculous I really do because there's help there. If you're sick you're sick, there's nothing you can do about it. If there's something with you there's something wrong with you – no matter what you try to do you'll only make a mess of it if you try to fight through it alone.

Frank: It's ok not to be ok.

Adrian: And that's something that has changed in me – certainly since the diagnosis and since I heard it's not life threatening. Its life changing and I've made a lot of changes, especially in talking about it. I've struggled big time for months trying to get to the stage where I can talk about it to other people and not bottle things up and I think it is something that particularly as a young man all of those things weigh heavily on me – that I can't provide, I can't do anything, what have I got to offer? I'm a single guy looking for a girlfriend, wife, kids down the line and I beat myself up because what have I got to offer? I can't work, I can't do this and as I said with a number of different tablets, some of them would be anti-depressants because it is something difficult but I have found talking helpful and it's bringing me around to that way of opening up. I'm comfortable here even though I've just met everyone. I can say whatever I want and may never meet ever again and that's fine but I'm beginning to be able to say things like this now to everybody and it's very hard to do.

Frank: I think a good expression is 'it's the creaking door that never closes'.

Philip: I find it difficult not being strong, I mean physically because your muscles go. I found that I've gone from being an athlete and very strong to being someone who has put on a lot of weight very quickly and lost muscle tone and it's very difficult and even doing things around the house or someone comes and you want to help them. I remember one time there was an electrician and he wanted me to lift out an oven with him and I nearly dropped it and he looked at me as much as to say what the hell is wrong with this guy?! I just wasn't physically strong enough to do it, I did it though and nearly killed myself in the process but I did it and it's difficult. Women probably don't have that aspect of it and you do beat yourself up about it.

Adrian: It's a pride thing isn't it?

Philip: It is yeah.

Adrian: You push yourself to do things that you shouldn't just to do it and like that because it's invisible it's harder still. I did a course and we stopped for a tea break. There were 20 of us on the course and the porter came over with an industrial kettle and there were only 3 lads and the rest were girls and he saw me 6 ft 2", a young fella and thought ah yeah he'll do and went to hand it to me. One of the course facilitators of the course knew that I had FM and immediately she stepped in because at that stage I was suffering with shaking and dropping things and I wouldn't have had the strength to hold it. So there's a lot of that. I trained, I played a lot of football at the top level and that vanity of the muscle tone, the weight, being fit and active, healthy – it's an awful lot to take on board and because we don't talk about it maybe it builds up a bit more.

Frank: Just when we're talking about support, I did athletics in my early teens and into my early 20's and always a sprinter, I never did have the stamina for cross country which would fit in with what I have now.

Philip: Shur I went from running 70 to 80 miles a week to not being able to walk up the stairs.

Frank: It's within you and without you, in that it's with you but it's society aswell.

Adrian: It's almost double guilt. We feel guilty that we can't do it but we also feel for the person who's standing watching us saying oh isn't that awful, they can't do it. So you're feeling bad because they're feeling bad for you..... I went off and got the phone number for arthritis Ireland and that's the best thing I have ever done because I'm now volunteering with them and I'm trying to get them to say 'arthritis Ireland and fibromyalgia' so it's just anything that can be done that could change things. A national support network would be great because I see what the support has done for me and I'd like to be able to pass that on.

Frank: I don't like the term 'fibro' – I'd say FM or fibromyalgia or FMS.

Adrian: I find the groups are great. The fact you never met doesn't matter because you say I've got FMS and everyone can say oh that's ok, I have that too, I know what it's like. It brings you to a new level very quickly.

Thomas: I couldn't believe once I was diagnosed the number of people who have it. I suppose I had never heard of it before I myself was diagnosed with it.

Maintaining Wellness in Fibromyalgia



Module 1

Introduction: The Key Concept of Wellness Recovery Action Planning - WRAP



Introduction to WRAP and the Key Concepts, Program Goals and Overview

Session Goals

1. Get acquainted with fellow participants and group facilitator
2. Learn programme goals
3. Become familiar with the Wellness Recovery Action Plan Model and the key concepts underpinning WRAP.

Programme Goals

Understand the potential for health within the context of fibromyalgia

Understand strategies to support and maximise a pro-active approach to managing health

Examine the key concepts of WRAP

- Hope
- Personal Responsibility
- Education
- Support
- Self-Advocacy

Develop a personalised WRAP plan

Ground Rules

We will begin and end classes at the same time, so punctuality is important and appreciated. There are no invalid questions. Use post it notes to help you remember topics for discussion. During the course of the classes, individuals may share strategies that have been helpful, however, remember to be respectful of others, share from your experience rather than advice giving, and to respect each other's right to confidentiality. Please make yourself comfortable and feel free to stretch during the class.

A Brief Review of Fibromyalgia



What is Fibromyalgia (FM)?

Fibromyalgia is a chronic illness common in the general population; which lacks a clear organic cause and is evidenced principally by a debilitating combination of widespread musculoskeletal pain, multiple tender points and chronic fatigue. Patients with this disease notice a clear deterioration in vocational, social and personal relationships and overall quality of life.

How is Fibromyalgia Diagnosed?

In 2010, The American College of Rheumatology updated their criteria to diagnose Fibromyalgia

- A history of widespread pain lasting more than 3 months, affecting all four quadrants of the body at 11 or more tender points.
- Fatigue
- Non-restorative sleep
- Cognitive difficulties (memory/concentration)
- No other health problems that would explain pain and other symptoms

Incidence Rates

In developed countries, between 1% and 3% of individuals receive a diagnosis of fibromyalgia and amongst those diagnosed, the female to male ratio is six to one.

Symptoms

Individuals with Fibromyalgia experience a wide variety of symptoms and at different levels of severity. However, many experience common symptoms such as disrupted sleeping patterns, cognitive dysfunction (memory impairment and fibro fog), pain, fatigue, anxiety and depression.

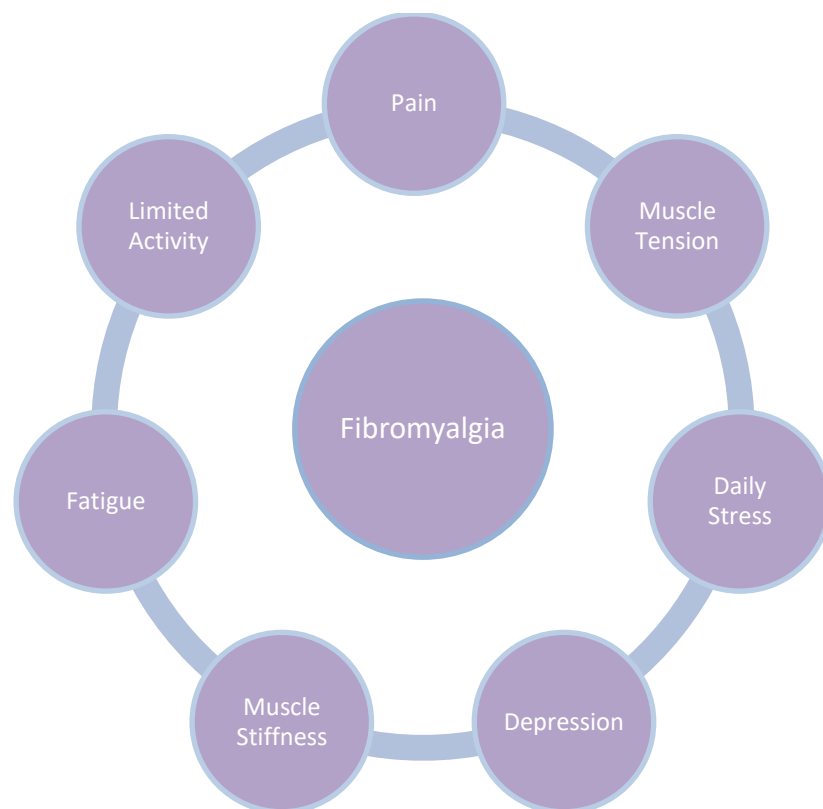
Symptom	Percentage of patients affected
Muscular Pain	100
Fatigue	96
Insomnia	86
Joint Pain	72
Headaches	60
Restless Legs	56
Parasthesias	52
Impaired Memory	46
Leg Cramps	42
Impaired Concentration	41
Nervousness	32
Major Depression	20

Wolfe, F., Smythe, H.A., &Yunus, M. (1990).Criteria for the classification of fibromyalgia.*Arthritis and Rheumatism*, 33,(2), 160-172.

What causes Fibromyalgia?

The exact cause of Fibromyalgia remains unknown. There are numerous theories relating to what triggers the disorder. Some professionals believe it is caused by a trauma or an injury, which may affect the central nervous system. Another theory presented is that abnormal levels of neurotransmitters may cause heightened sensations of pain; while others believe that it may be due to changes in muscle metabolism resulting in pain and fatigue. Given the higher proportion of women with Fibromyalgia, it has been proposed that the symptoms may be linked to sex hormones. Still others believe it is due to a genetic predisposition or due to changes in the immune system that result after a virus or other infectious agents have entered the body. More recently, researchers have found that sleep disruption for several consecutive nights in healthy women resulted in the Fibromyalgia symptoms of decreased pain thresholds, increased discomfort, fatigue, and inflammation of the skin.

The Fibromyalgia Cycle



WRAP Key Concepts



Hope

People who experience mental health difficulties get well, stay well and go on to meet their life dreams and goals

Personal Responsibility

It's up to you, with the assistance of others, to take action and do what needs to be done to keep yourself well

Education

Learning all you can about what you are experiencing so you can make good decisions about all aspects of your life

Support

While working toward your wellness is up to you, receiving support from others, and giving support to others will help you feel better and enhance the quality of your life.

Self-Advocacy

Effectively reaching out to others so that you can get what it is that you need, want and deserve to support your wellness

What can the key concepts mean for me?

There is so much to *hope* for! You can feel well for long periods of time

Become a strong *advocate* for yourself.

This means: "**Going for it**" with courage, persistence and determination.

Express yourself clearly and calmly until you get what you need for yourself.

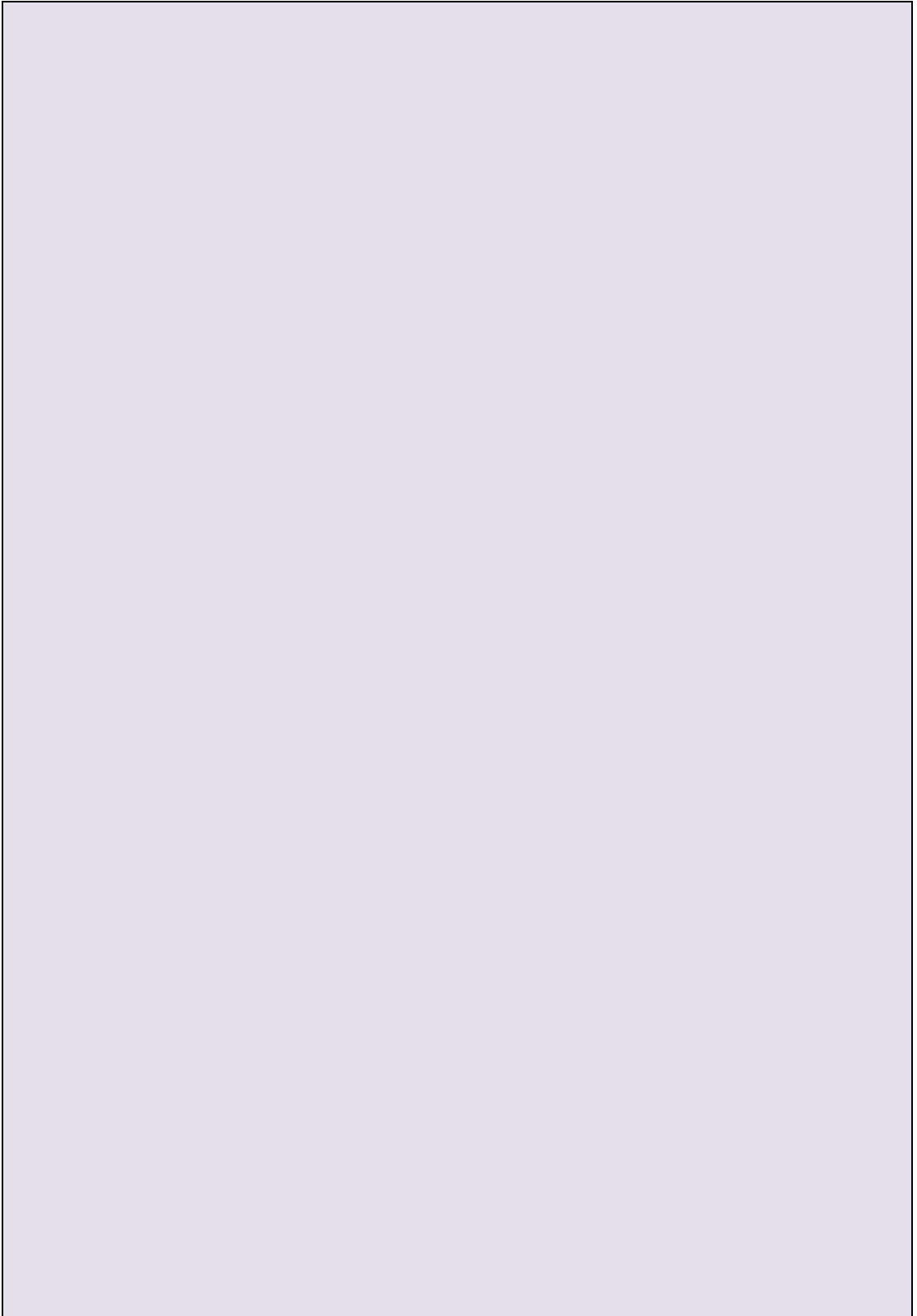
Educate yourself! Learn all you can about fibromyalgia so you can make good decisions about treatment, lifestyle, career, living space and leisure activities

You are an expert on yourself. It is up to you to take *personal responsibility* for your wellness

Develop and maintain a strong support system. *Support* from family, friends, and care providers is definitely helpful. Being

Set personal *goals* and work towards meeting them

Your Wellness Strategies





Pause

Before moving forward lets pause for a moment and reflect on ways you work towards your own wellness

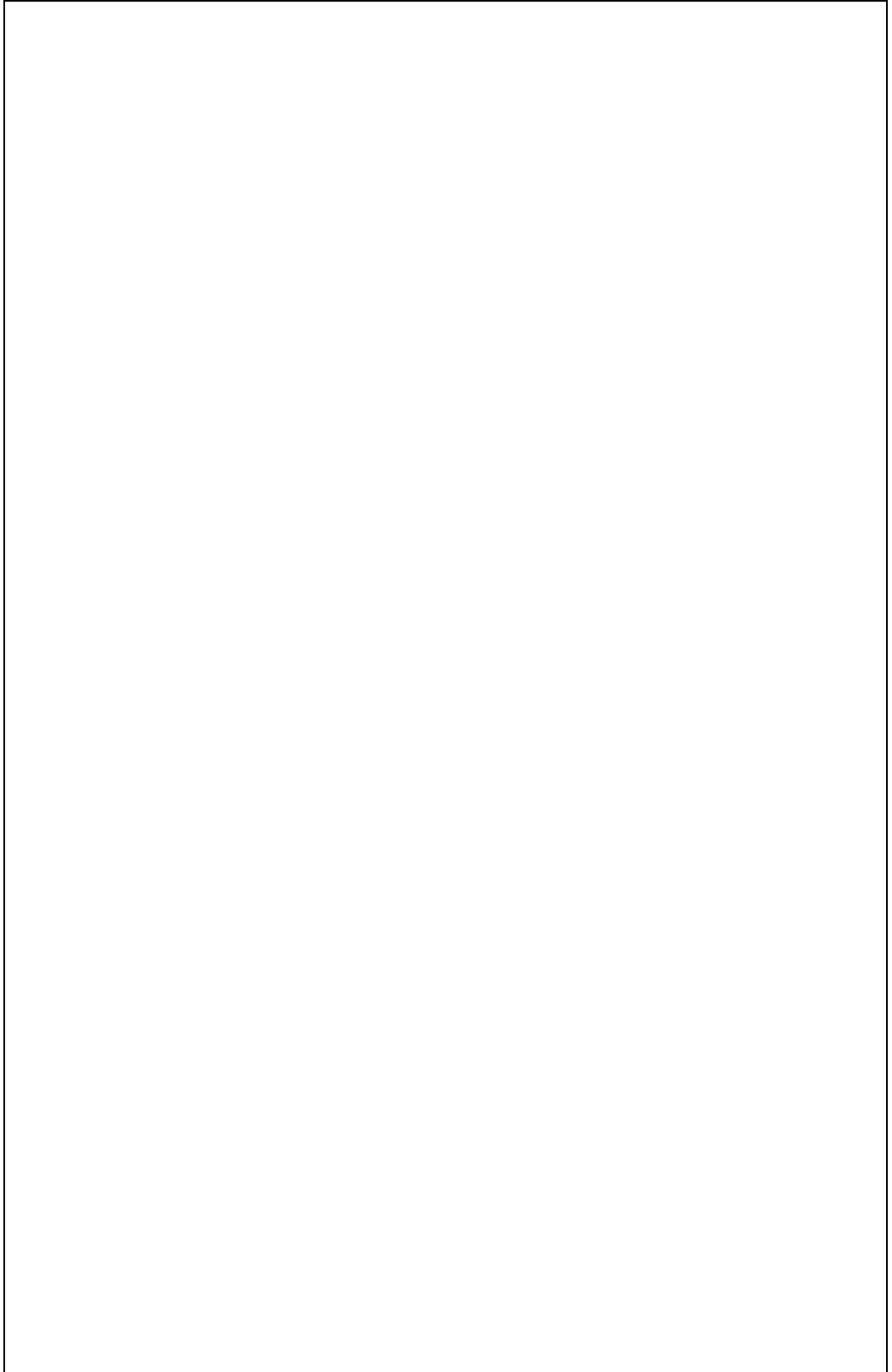
This activity has been designed to help you to think about the things that you already do to promote wellness in your life. It will also help you think about future goals in relation to the promotion of your wellness

Two activities that I am currently doing to manage my Fibromyalgia are:

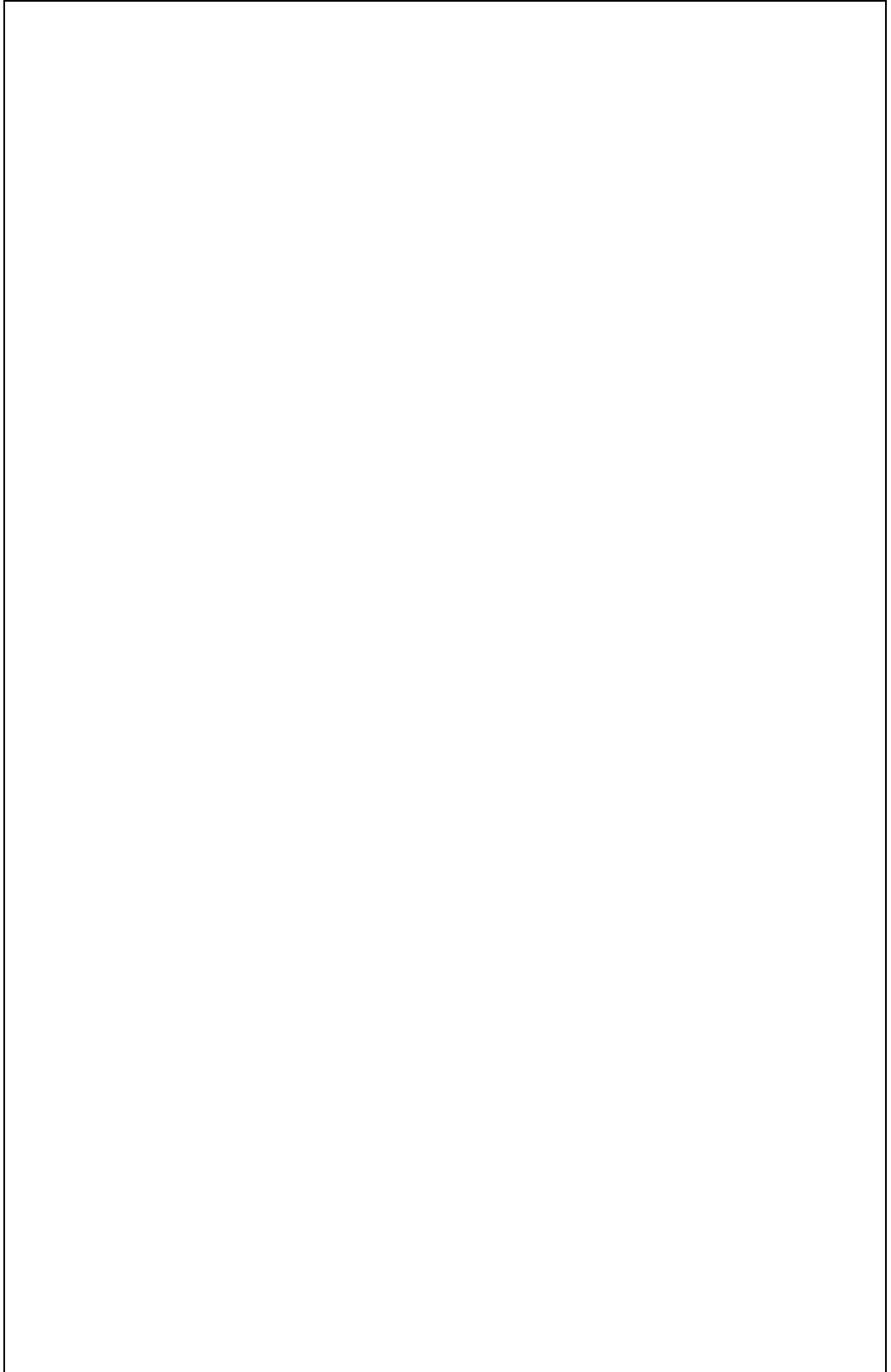
How do these activities help me feel well?

Here are two activities that I have thought would help me and that I might engage in

My Notes & Ideas

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My Notes & Ideas

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Module 2

Developing a Wellness Toolbox



Developing your Wellness Toolbox

Session Outline

Introduction to the notion of a *Wellness Toolbox*

Understand the importance of *Wellness Tools*

Group Activity: Self-Reflection on my Preferred Activities

Take time to explore what tools you may already be using

Develop a personalised Wellness Toolbox – a listing of tools that you will use to develop your WRAP Plan

Wellness Recovery Action Planning and Fibromyalgia

Fibromyalgia brings change to your life. It affects your ability to manage your life on a day to day basis. Fibromyalgia is a chronic condition that can affect every aspect of your life, possibly for the rest of your life so it is so important that you learn to develop strategies to deal with it. The good news is that many people have learnt to manage their condition so that they can continue to live their lives enjoyably

Managing the complex symptoms of this chronic illness can be a daunting task but there is light at the end of the tunnel. Developing a Wellness Recovery Action Plan (WRAP) for yourself and using this plan on a daily basis may help you manage your symptoms and also help you to feel as well as you possibly can.

WRAP is a monitoring and response system that was developed by patients themselves who have been dealing with a variety of chronic conditions for many years and who work hard to feel better and have a life with their condition. It is not a replacement for working with your healthcare team, instead, WRAP is a safe and wise addition to any chosen course of treatment (Starlanyl & Copeland, 2001).





Group Activity

Something to consider.....

1. What activities are most important for me to accomplish on a regular basis (List in order of importance)

- a) _____
- b) _____
- c) _____
- d) _____

2. Here are some things that I would like to be able to do but am unable to do so at the moment

- a) _____
- b) _____
- c) _____
- d) _____

3. Here is what prevents me from doing the things I have listed in Q. 2

- a) _____
- b) _____
- c) _____
- d) _____

4. What or who might help me accomplish the list I made at Q.2?

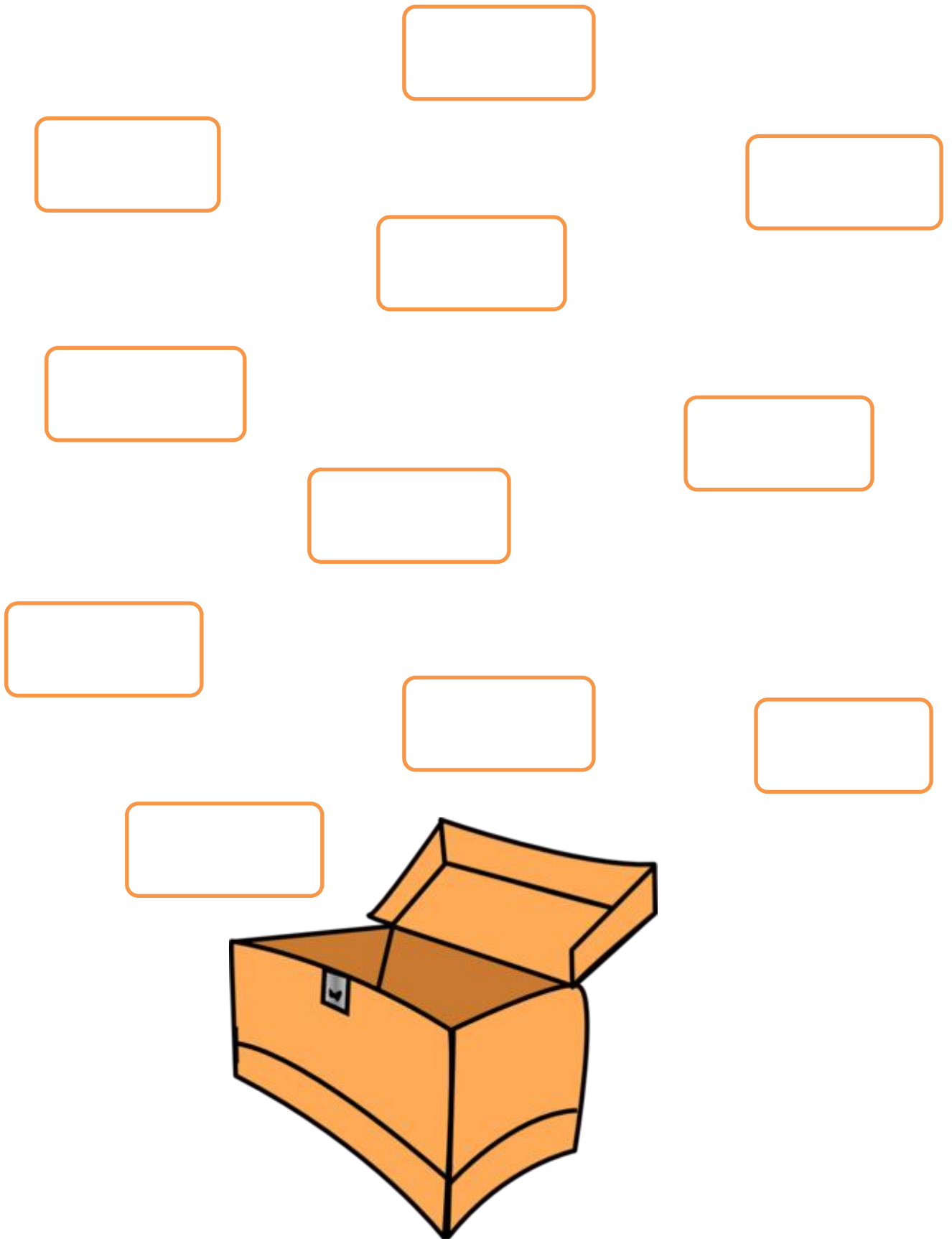
- a) _____
- b) _____
- c) _____
- d) _____

Wellness Toolbox

List any tools you have learned, in this session or from your own life experience, including things that you would like to try, even if you haven't already. Then keep adding new ones and/or eliminating ones that you decide aren't right for you.

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My Wellness Toolbox





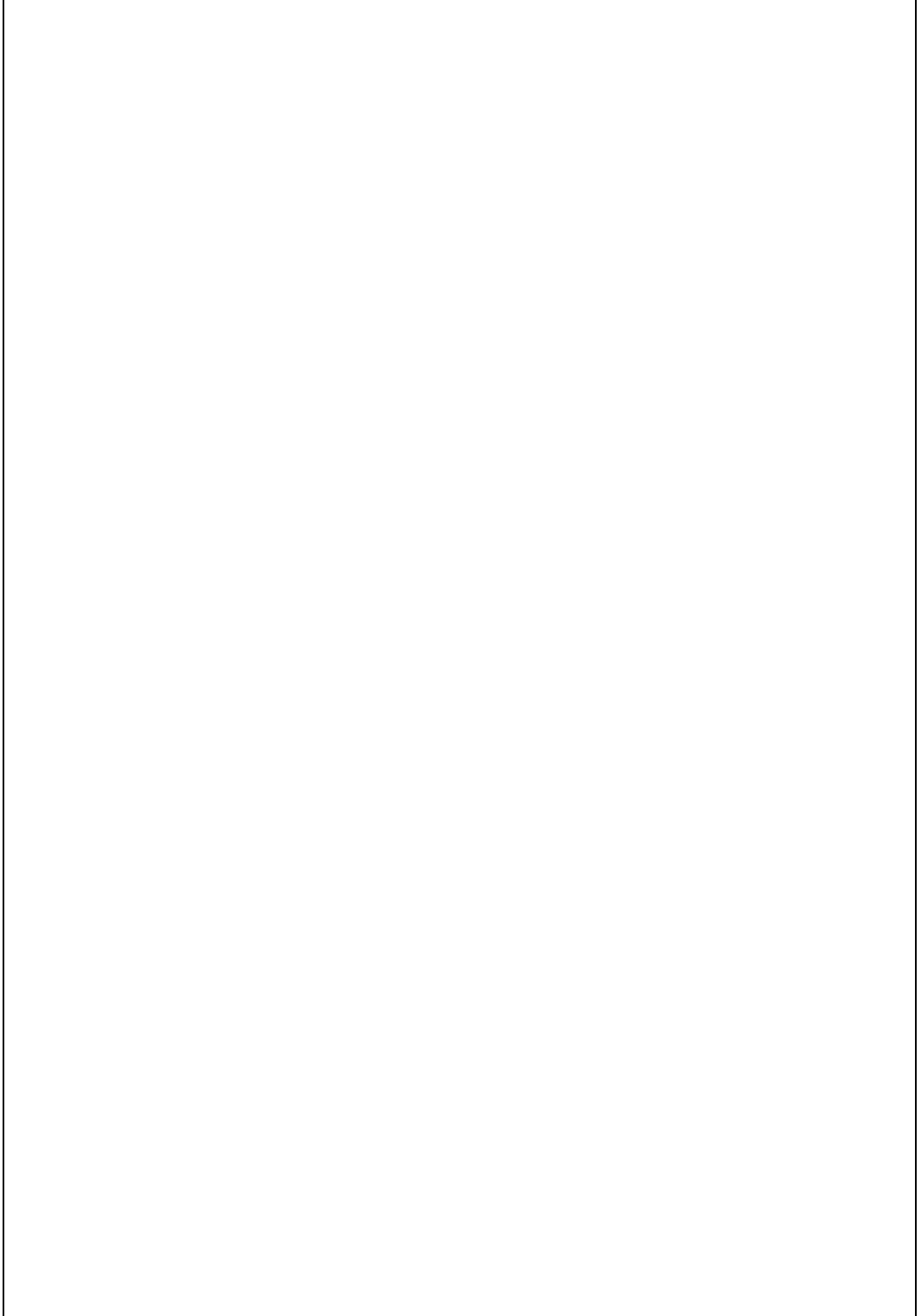
Self-Monitoring

Pay attention to your body. It is so important that you learn the signs that are unique to you because these signals serve as warning signs that a flare up of symptoms may be imminent.


Here are some important things to know about your body as you work on mastering the skill of self-monitoring

- ❖ What is the first sign that you notice when your fibromyalgia symptoms are worsening?
- ❖ What can help you in deciding if today is the day that you need to exert yourself less?
- ❖ What can help you in deciding if today is that day that you need to take the time to look at how you might modify your activities?
- ❖ How can you tell if you need a break?

My Notes & Ideas

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My Notes & Ideas

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Module 3

Developing a Daily Maintenance List



Developing a Daily Maintenance List

Session Outline

Introduction to the notion of a *Daily Maintenance Plan*

Understand the importance of a *Daily Maintenance List and preferred Activities*

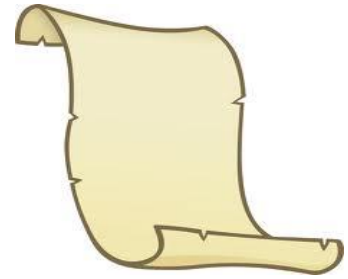
Health within illness

Group Activity: A glance to the future

Take time to explore what you are like when you are well

Develop a personalised Daily Maintenance List – a listing of everyday activities, duties or items that you will use on a daily basis to keep yourself feeling as well as possible

The Daily Maintenance Plan



You may have already discovered that there are certain things that you need to do every day to maintain your wellness and manage your fibromyalgia and the many symptoms that have to live with. Writing them down and reminding yourself daily to do these things is an important step towards wellness.

Taking the time to devise a daily maintenance plan will help you to recognise the things which you need to do to keep healthy, and then to plan your days accordingly. Also, when things have been going well for a while and suddenly you notice your health is starting to worsen, it is important to have this daily maintenance plan to remind you of what daily routine you have had that worked in helping you to feel as well as you can feel. For most people who use WRAP, when they are starting to feel unwell or their symptoms are becoming more and more noticeable, they can often trace it back to having not done something on the daily maintenance list.

To some, the daily maintenance list may seem senseless or overly simplistic and you may be tempted to glance over it and not give it due attention. However, most people find that it turns out to be the most important part of their whole plan.

(Copeland, 2002)

Goal Setting

Did you know..... Research suggests that goal setting serves to increase motivation (e.g. Locke, 1996).

Goals affect our performance in many ways:

- * They direct attention away from irrelevant activities and towards goal relevant activities.

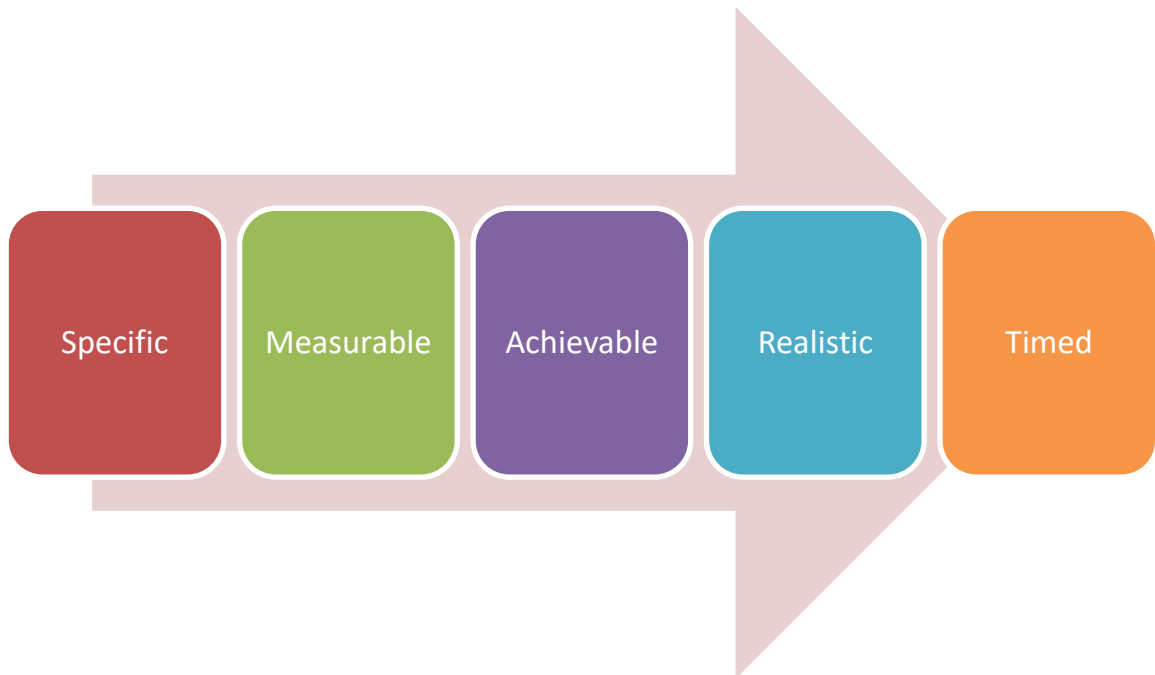
- *They have an energizing function and lead us to perform better in activities directly associated with areas of interest in our lives.

- *They also affect persistence, that is, we are more likely to persist with an activity or a task when we have set a conscious goal for ourselves.

- *And finally, goals affect our level of action, that is, when we set a goal for ourselves, we are more likely to take action in a bid to achieve the goal.

SMART GOALS

In order to give yourself the very best chance of achieving your goals try to make sure that they are **SMART** – **S**pecific, **M**easurable, **A**chievable, **R**ealistic and **T**imed.



Specific – Are your goals *specific*? Keep your goals specific rather than general. Choose a specific goal that describes how you want to be not how you do not want to be. For example, I want to be able to go back to work.

Measurable – Are your goals *measurable*? How will you know if you have achieved your goal or if you are making progress? Put a number on what you would like to achieve. For example, I would like to work 2 days per week.

Achievable – Are your goals *achievable* and within your control? For example to have a goal that “I want to sleep for 8 hours every night” if you have never been a good sleeper is unlikely to be achievable.

Realistic – Are your goals *realistic*? If your goals are not realistic at the start you are more likely to fail regardless of how hard you try. Break bigger goals into smaller ones. Remember your body is going through a lot and for some people it may not be possible to return to the way things were before their diagnosis fibromyalgia.

Timed – Set a realistic time frame to your goals. Breaking this into steps may be useful. For example where do you want to be in 2 months, 3 months, 4 months? Remember wellness and recovery take time. Be kind to yourself. It is always better to exceed your expectation rather than put undue pressure on yourself!

(Adapted from Collier & O’Dwyer, 2011)

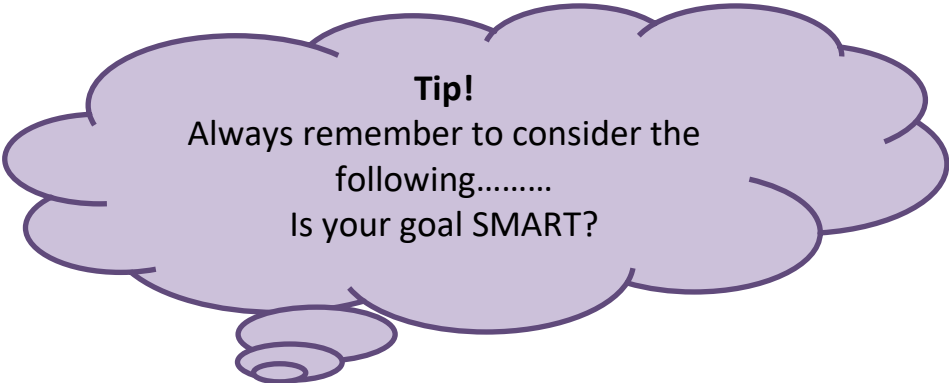
Activity: A glance to the future

In one sentence, what is your goal for when you have completed your WRAP workshops?

The benefits of achieving this goal will be

The challenges to achieving this goal are

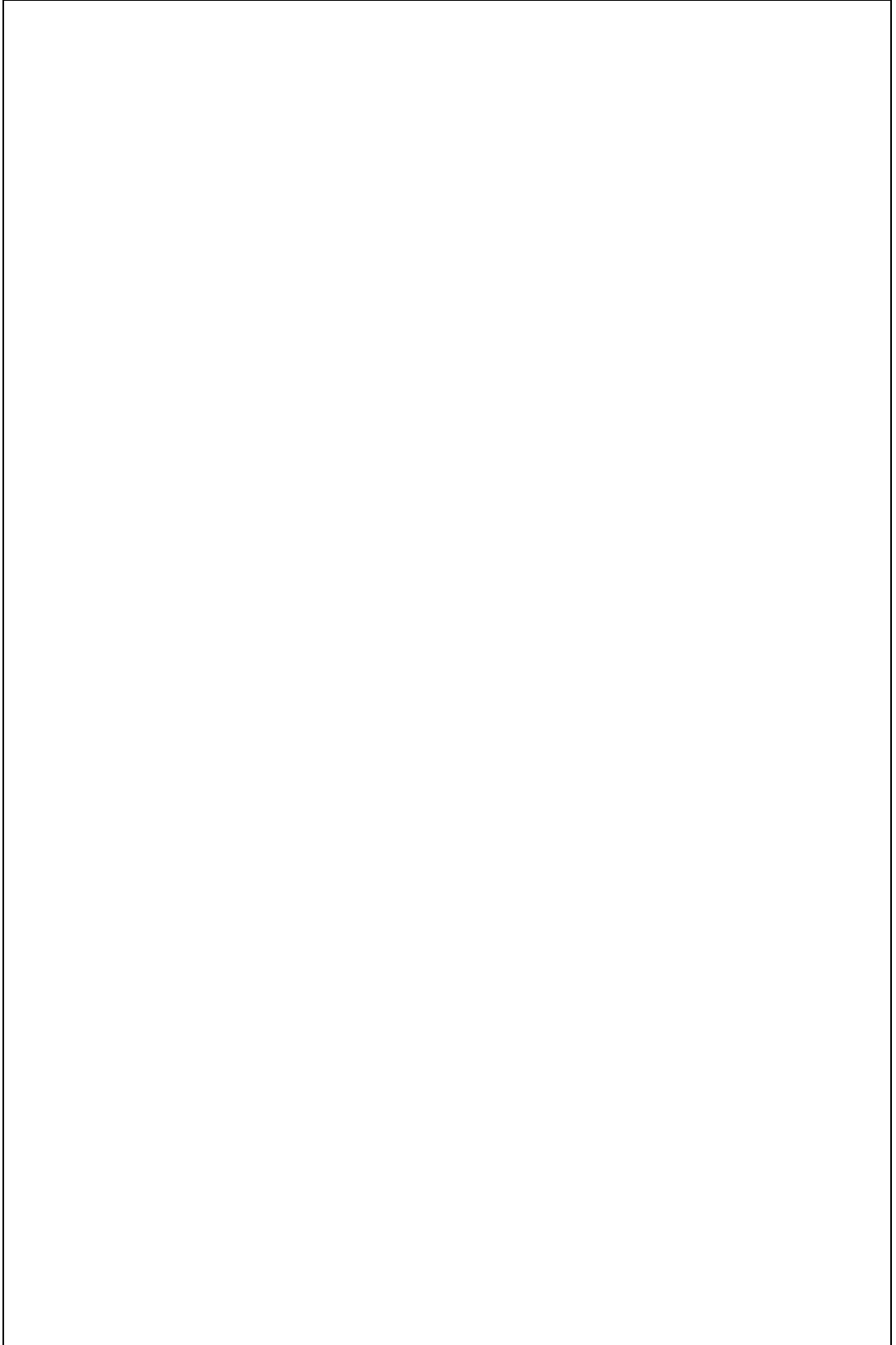
What are the things you could do to overcome the challenges?



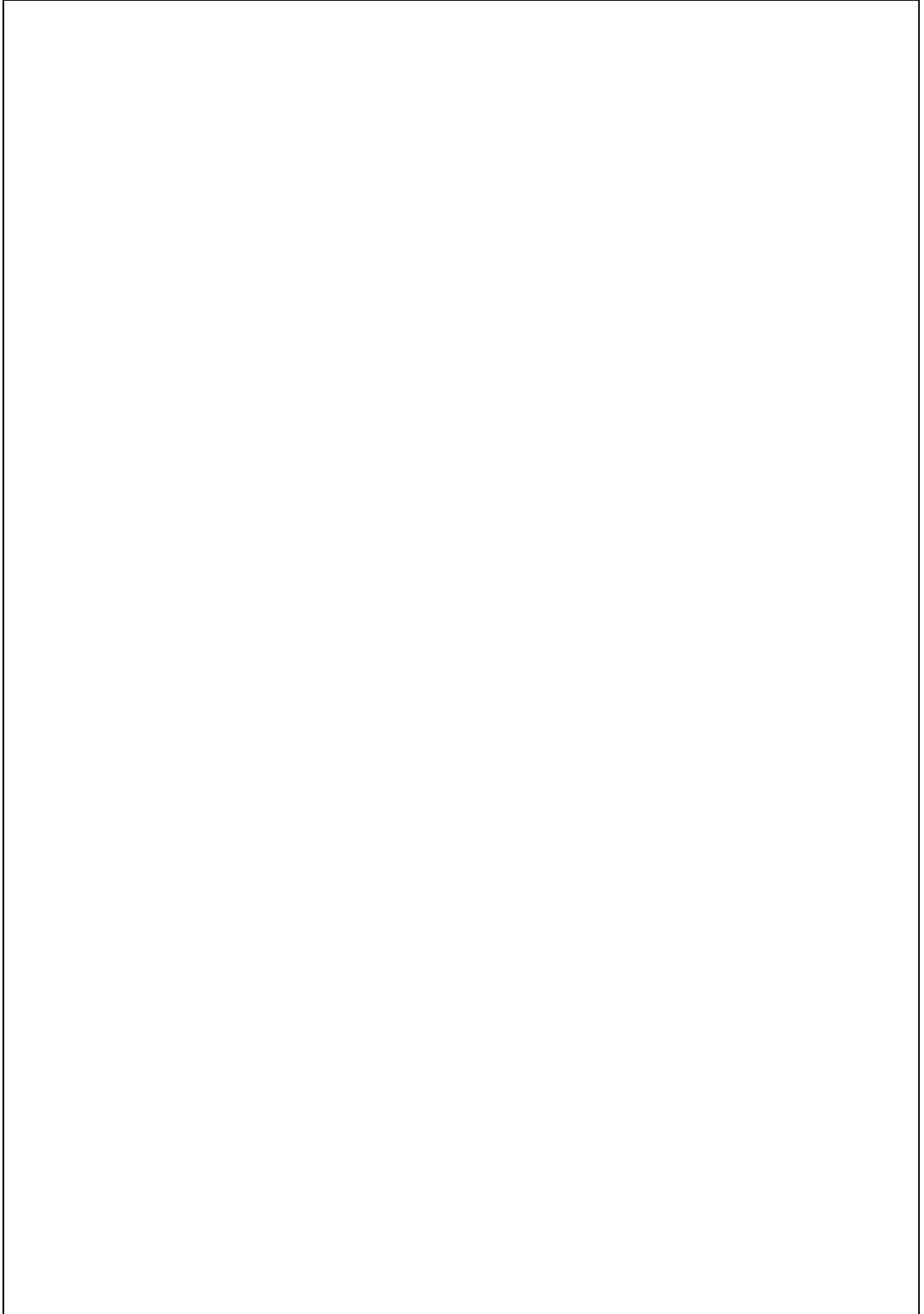
My Daily Maintenance List

These are the things I ***need to avoid*** every day to keep myself well.....

My Notes & Ideas

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Module 4

Triggers



Triggers

Session Outline

Develop an understanding of what Triggers are.

Identify personal Triggers

Group Activity: Mindfulness Exercise

Develop a Trigger Action Plan

Triggers

Triggers are external events or circumstances that, if they happen, may produce symptoms that are, or may become very uncomfortable. These symptoms have the potential to make you feel like you are becoming unwell.

Triggers are *normal* reactions to events in our lives but if we ignore them and fail to respond and deal with them in some way, they may actually cause a worsening in fibromyalgia symptoms.

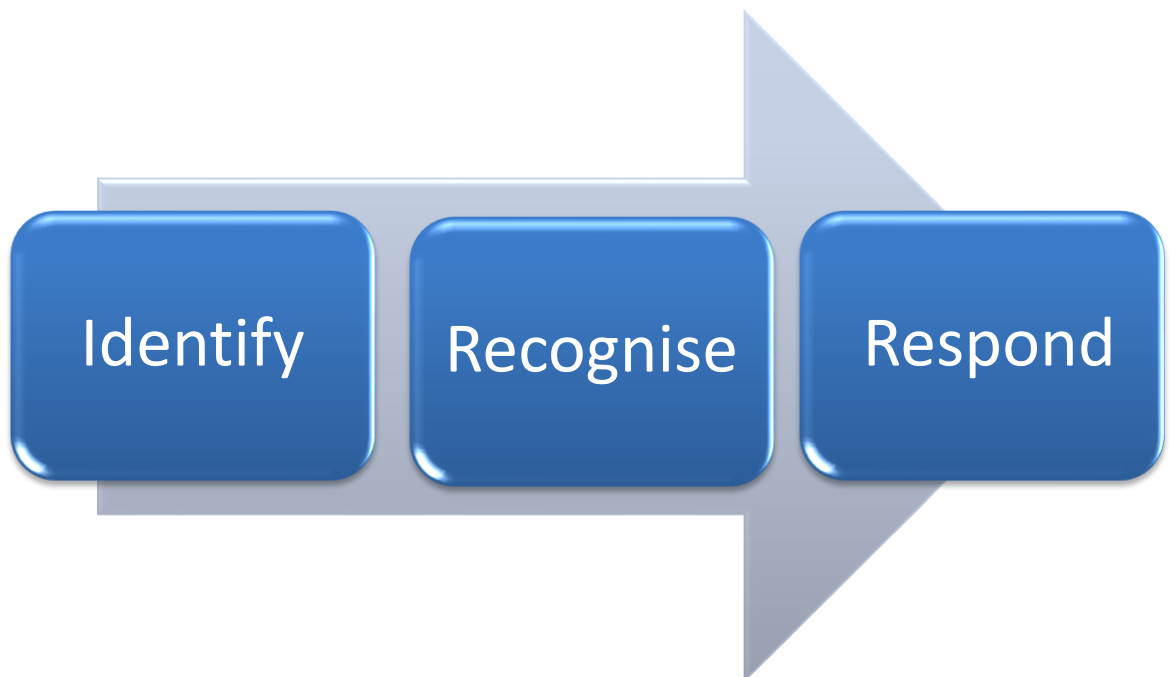
Having an awareness of your vulnerability to such events and developing a plan to deal with specific triggers when they present themselves will increase your ability to cope, and to avoid the development of an acute onset of more severe symptoms.

Triggers are those things that may cause an increase in symptom severity. They may have triggered or increased symptoms in the past.

Some examples include:

- an anniversary date of a loss or trauma
- being overly tired
- family friction
- a relationship ending
- excessive stress
- substance abuse
- physical illness
- being judged, criticized, teased or put down
- financial problems

Triggers



Mindfulness

Mindfulness is continuous undisturbed awareness of the present moment; being fully aware of the here and now. In mindfulness we pay attention to what is happening right in front of us. Being mindful is the opposite of being absent minded or on auto pilot. Mindfulness is taking control of your mind rather than allowing your mind to be in control of you.

Our mind is constantly busy with thoughts and feelings about our past, present or future – constant chat. We must learn how to hear this noise, how to become aware of it, and use the power of concentration to guide us into mindfulness. To be mindful we have to re-train our mind.

A human being has 70,000 thoughts per day. Researchers say that the conscious mind controls our brain only 5% of the day, whereas the subconscious mind has control of our thoughts 95% of the time. With 70,000 thoughts a day and 95% of our activity controlled by the subconscious mind, no wonder that it feels as though we are asleep most of the time. To awaken our mind, we need to train self - remembering and mindfulness. Since thoughts enter our minds from every direction, to quieten them and to stop their relentless flow through our minds, we need to find an object of concentration and focus on it with all our might.

Challenging your pre - existing beliefs and breaking the existing thought patterns is not something that comes naturally to you, and yet once you manage to do it, you create space for a new way of thinking, a new way that has the potential to be filled with acceptance, knowledge and self-belief.

Mindfulness and Fibromyalgia



Exercise: Mindful Focus on a Candle Light

During this exercise, I will give instructions to guide the focus of your attention. It is likely that while you are doing the exercise, your mind will wander off to other things. This is normal. When you notice this happening, just gently guide your mind back to the instructions. Don't worry if you have to bring your mind back many times, because when you are doing this you are being mindful.



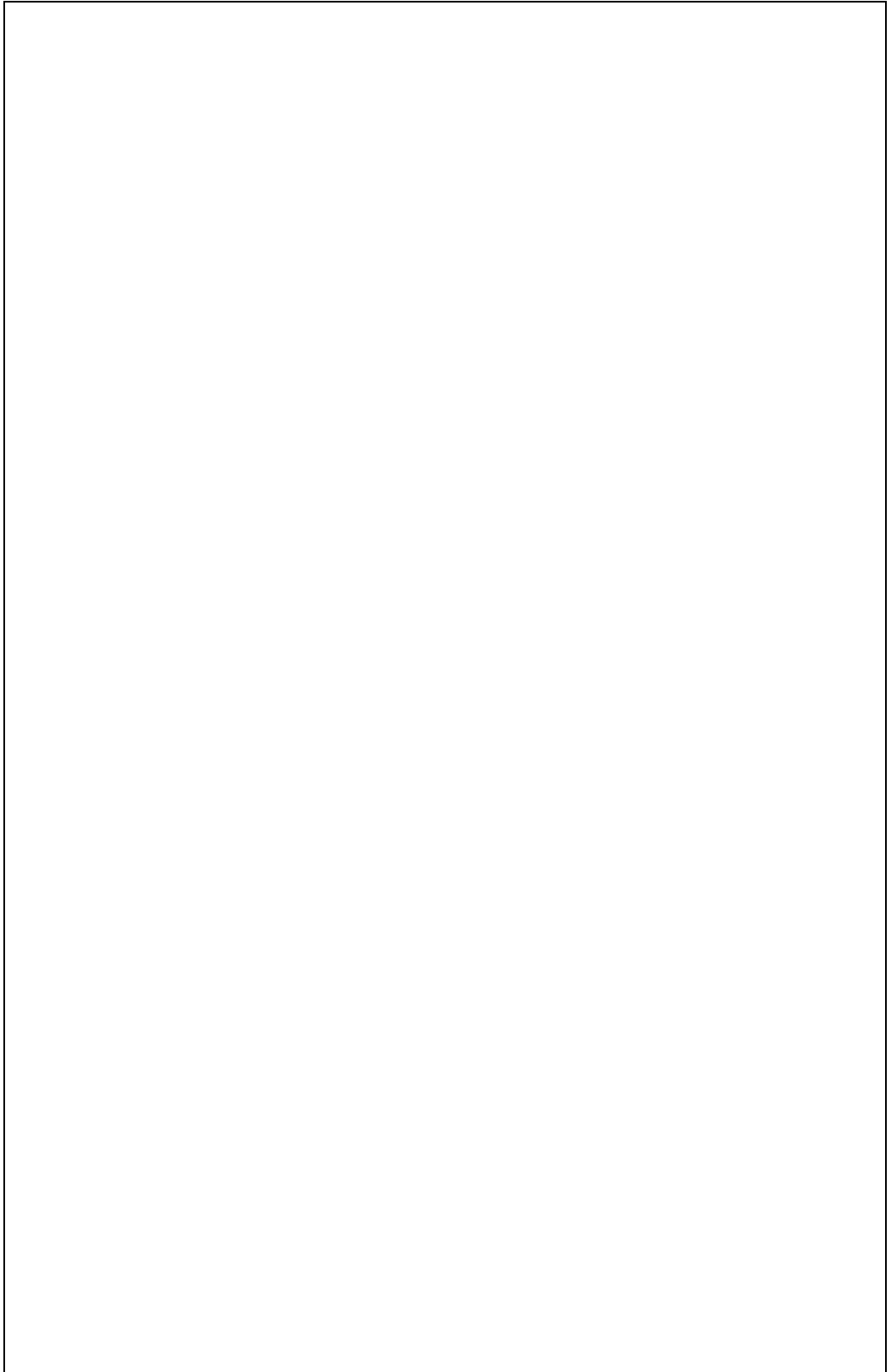
Self - Monitoring

Pay attention to your body. It is so important that you learn your triggers and the effects they have on you. These triggers are **the things that happen to you** that are likely to set off a chain reaction of uncomfortable or unhelpful behaviours, thoughts and/or physical feelings. These triggers are unique to you and they serve as warning signs that a flare up of symptoms may be imminent.

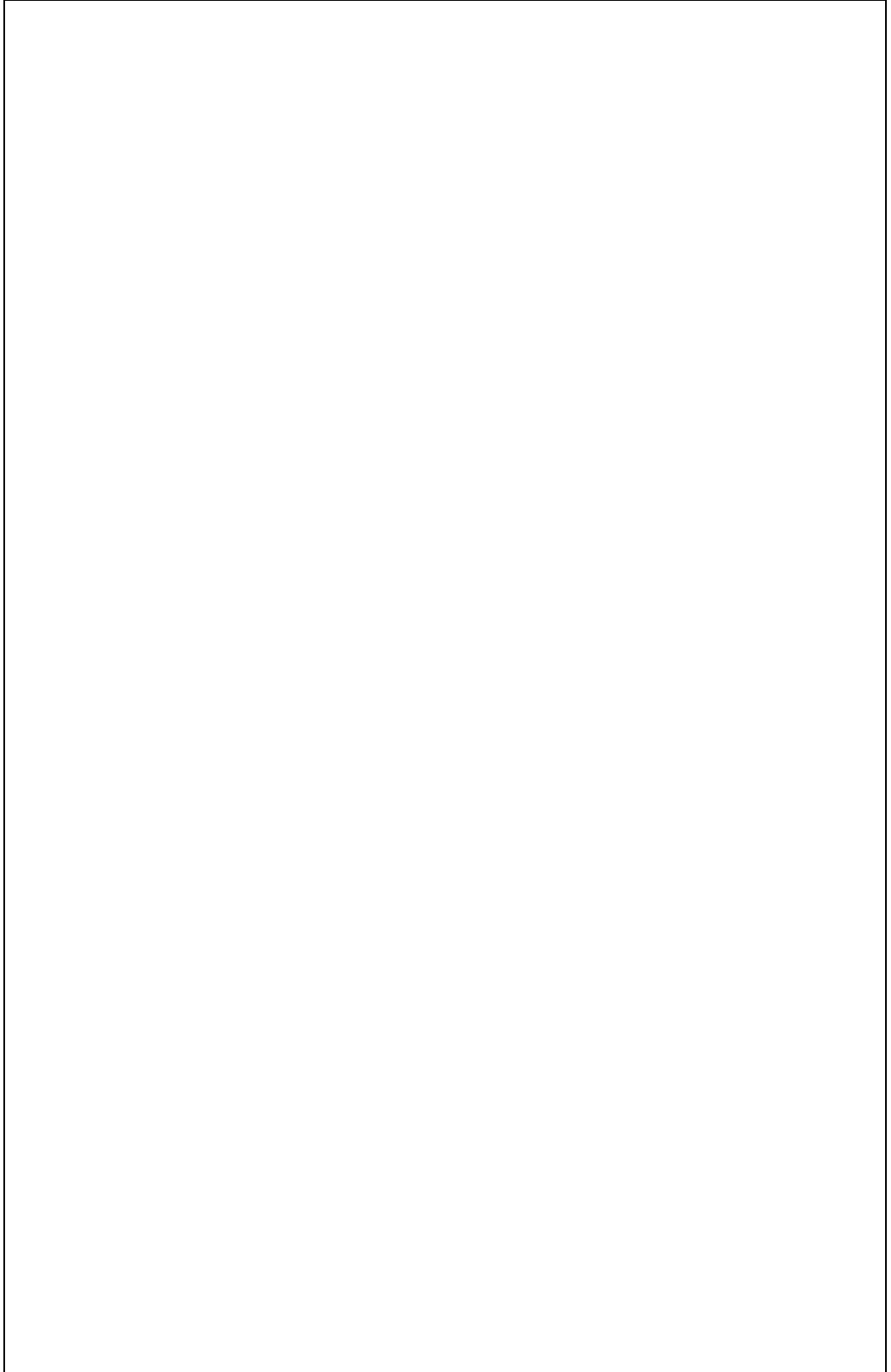
If you can get to know your triggers, you can put a plan in place that may keep your symptoms from worsening even if a triggering event occurs. Some ideas might be:

- Make sure I do everything on my Daily Maintenance List
- Do some deep breathing exercises
- Have some rest
- Call a friend
- Attend a support meeting
- Do a half hour relaxation exercise

My Notes & Ideas

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Module 5

Early Warning Signs



Early Warning Signs

Session Outline

Define Early Warning Signs

Identify our own Early Warning Signs

Develop an Early Warning Signs Action Plan

Group Exercise: Value of Support

When things are breaking down

Early Warning Signs

Early warning signs are internal and may be unrelated to reactions to stressful events or situations. Sometimes, in spite of our best efforts at reducing symptoms, we may begin to experience early warning signs, subtle, internal signs of change that indicate you may need to take some further action. Early warning signs are frequently the kind of signs that are overlooked.

Getting into the habit of taking time and reviewing early warning signs regularly will help you to become more aware of them, and encourage you to take action before they worsen.



Something to think about.....

Recognition

What changes for me? What are my early warning signs?

Action

What can I do about this? What action can I take when I notice the presence of my early warning signs?

Early Warning Signs

Here are some early warning signs that others have reported

Excessive
Sweating

Numbness and Tingling

Bruising

Fatigue

Dizziness

Shakiness

Nausea

Clumsiness

Very cold skin

Muscle Cramping

Aches & Pains

Increase in use of pain medication

Infections

Forgetfulness

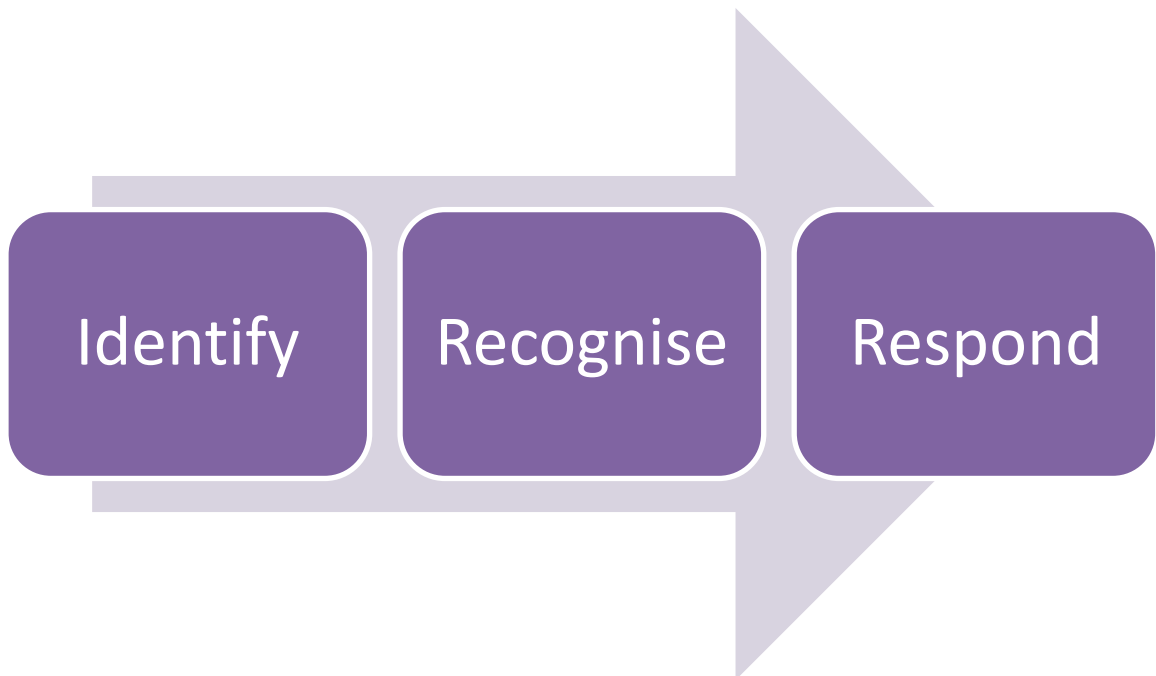
Morning Stiffness

Anxiety & Nervousness

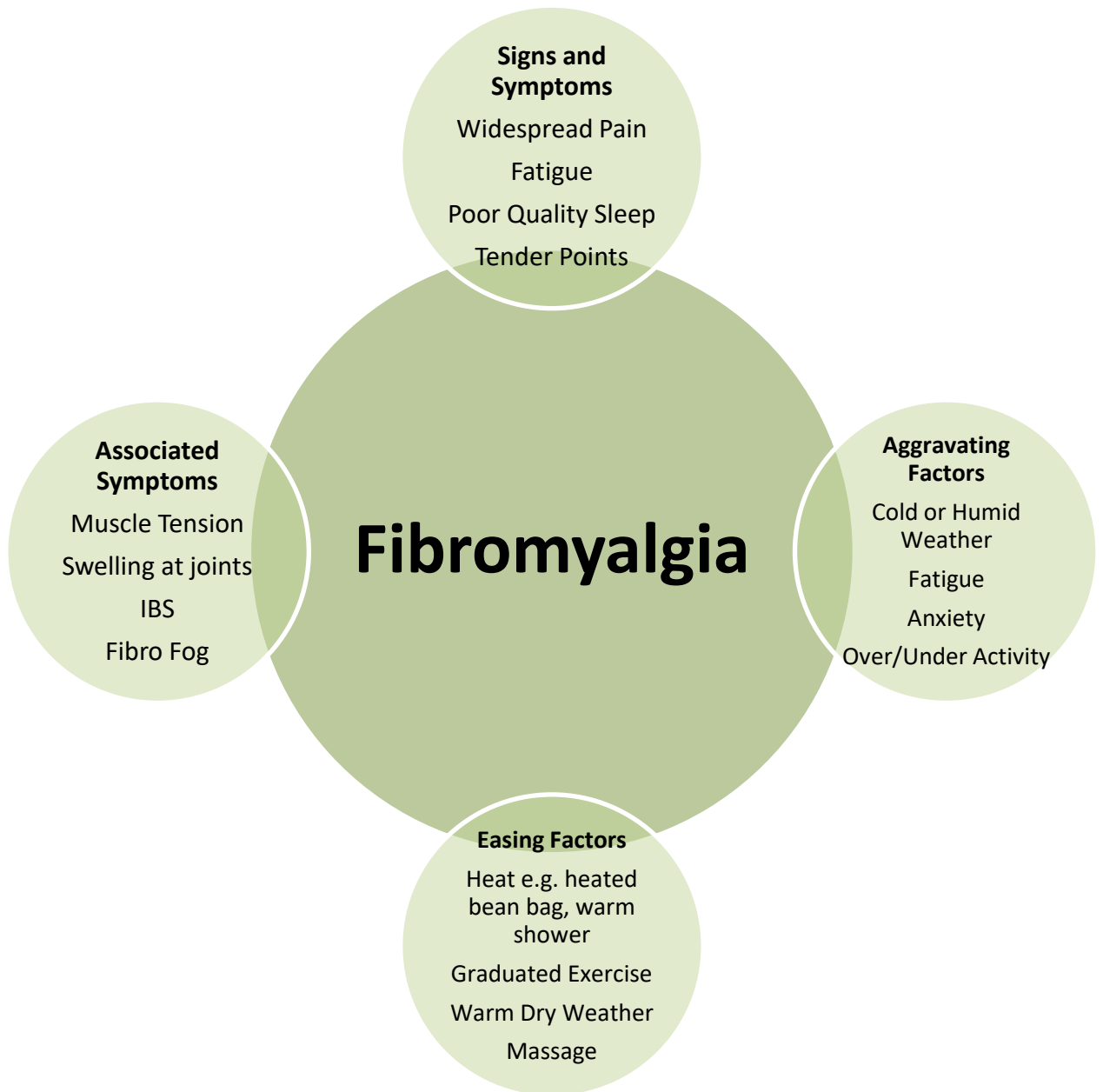
Taking Action

When you become familiar with and begin to notice your early warning signs, you will want to take action before they get worse.

Remember.....



The next few pages are for your responses to early warning signs. Using your Wellness Toolbox, take time to develop a plan that you can follow that will help reduce your early warning signs and keep yourself from entering a cycle of increased symptoms and ill health.



(Adapted From Living Day to Day with Fibromyalgia: A Practical Guide, Published by The Kerry Fibromyalgia Support Group)

Resources

USEFUL WEBSITES

www.fibroireland.com(Official Northside Dublin Support Group Website)

www.arthritisireland.ie

www.chronicpain.ie

www.ukfibromyalgia.com

UK Fibromyalgia group produce an excellent monthly magazine, 'The Family – Everything you need to know about Fibromyalgia'. This can be purchased directly from UK Fibromyalgia

www.myalgia.com (Oregon Fibromyalgia)

www.stiffuk.com

www.chronicpainireland.org (Irish Chronic Pain Association)

www.assistireland.ie (A practical website that is hosted by the Citizen Information Board which has a comprehensive list of assistive devices along with the contact details of Irish Suppliers)

www.citizeninformation.ie

www.hse.ie

www.enfa-europe.eu (European Network of Fibromyalgia Associations)

www.fibromyalgiasupport.ie (Official Kerry/Cork Support Group Website)

www.arthritis-foundation.com

Books

Fibromyalgia and Chronic Myofascial Pain – A Survival Manual. Devin J. Starlanyl,
Mary Ellen Copeland, Christopher R. Brown, New Harbinger

Creative Pain Management – the Fibromyalgia Guide Book. Dan Gibson, Xlibris
Corporation

Fibromyalgia and Muscle Pain – Your Self Treatment Guide. Leon Chaitow,
Thorsons & Harper Collins

The Fibromyalgia Healing Diet. Christine Craggs-Hinton, Sheldon Press

Living with Fibromyalgia. Christine Craggs-Hinton, Sheldon Press

Coping with Fibromyalgia. Christine Craggs-Hinton, Sheldon Press

Freedom from Fibromyalgia. Nancy Selfridge, Franklynn Peterson, Times Books

From Fatigued to Fantastic. Jacob teitelbaum, Avery Publishing

Making Sense of Fibromyalgia. Daniel J. Wallace, Janice Wallace, Oxford University
Press INC.

Fibromyalgia Fatigue and You. Dr. michael Kelly, Kelmed Publishing

Fibromyalgia. Dr. Don L. Goldenburg, Piakus

Dealing with Chronic Pain. Dr. Jack Barrett, On Stream Publishing

Inside Fibromyalgia. Dr. Mark Pellegrino, Anadem Publishing

The Fibromyalgia Survivor. Dr. Mark Pellegrino, Anadem Publishing

Fibromyalgia for Dummies. Roland Staud MD., Christine Adamec, Wiley Publishing

Self-help Exercise guide for Fibromyalgia. Dr. Alex Aallinson, ukwellness.com

**Supplements for Fibromyalgia – Natural Aids for Overcoming Fibromyalgia and
Other Related Disorders.** Joe M. Elrod Woodland Health

Fibromyalgia: Simple Relief Through Movement. Stacie Bigelow, Wiley Publishing

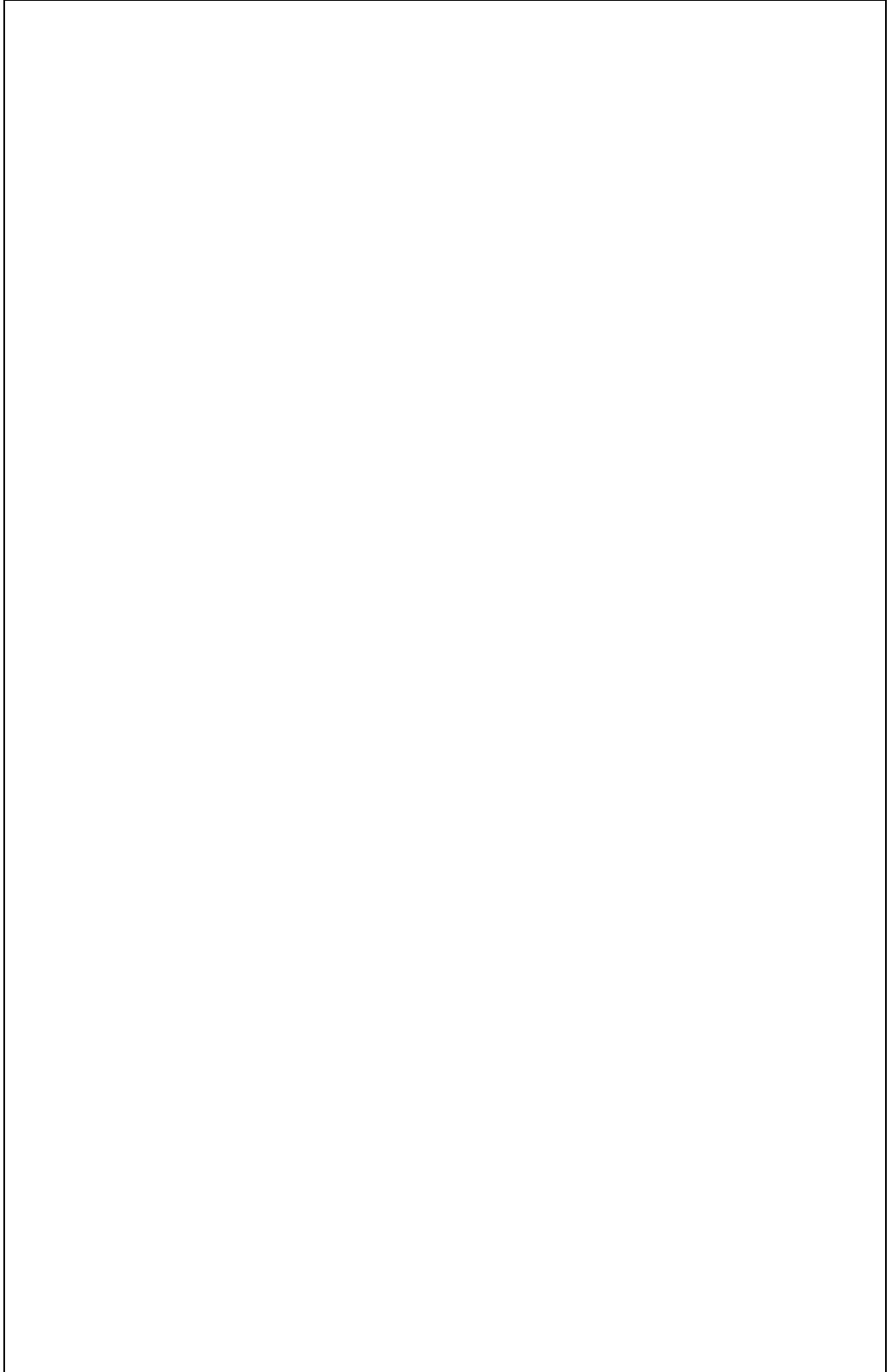
Fibromyalgia: An Essential Guide for Patients and Their Families. Daniel J. Wallace,
J.B. Wallace, OUP USA

You can Heal your Life. Louise L Hay

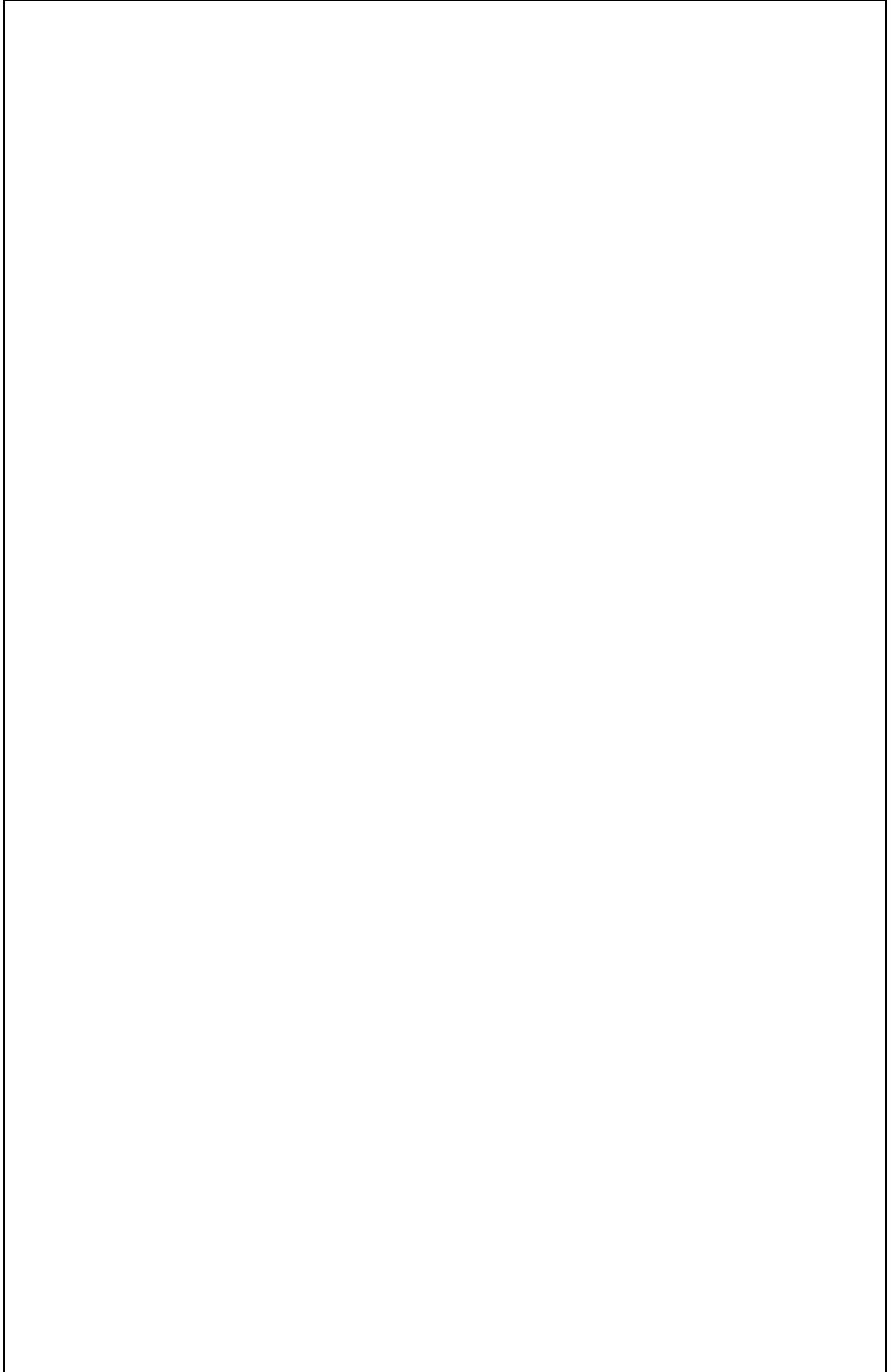
The Chronic Illness Experience. Cheri Register

Dealing with Chronic Pain. Dr. Jack Barrett, Marina Carey, & Dr. Gillian Moore Groake

My Notes & Ideas

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My Notes & Ideas

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Module 6

Crisis Planning



Crisis Planning

Session Outline

Define what 'crisis' means for you

Learn why crisis planning is important

Develop a comprehensive crisis plan

Group Exercise: Value of trust and boundaries in our relationships with those around us

What is a Crisis Plan?

Noticing and responding to your symptoms early reduces the chances that you will find yourself in a crisis. Having that said, owing to the unpredictable nature of Fibromyalgia, it is so important to confront the possibility of crisis because in spite of your best planning and assertive action on your own behalf, you may find yourself in a situation where others will need to step in and take over some of your responsibilities.

Some people like to devise a plan and have it in place that ensures that others can help them if they become unable to care for themselves or carry out their daily duties. Such a plan can keep you in control even at times when it may seem like everything is out of your control – when your symptoms are so severe and you have so much pain that you can't think well enough to make decisions and are too debilitated to take any form of action. If you have co-occurring illnesses, having a crisis plan can be especially valuable.

How will a crisis plan help me?

Writing a clear plan when you are feeling well, to instruct others about the support that you will require keeps you in control and allows you to have a sense of responsibility for your own health and wellbeing even during those times when your illness is making an impact on your daily living. It also ensures that your needs will be met and that you will recover as quickly as possible.

A crisis plan also helps others as it serves to relieve the worry and guilt felt by family members and other caregivers, who may wonder whether they are taking the right action.

Who needs a crisis plan?

A crisis plan is a very personal thing and only you can decide if it is something that you would need to have. It is however something that cannot be completed quickly as decisions take time, much thought and often some level of collaboration with health care professionals, family members and other supporters.

What should my crisis plan include?

The most helpful crisis plans include lists of the following kinds of information:

- How you feel when you are well (you can copy this from the first section of your workbook) so that you can provide health care providers who may not have known you previously with a clear idea of what you are like when you are well.
- Those symptoms that would indicate to others that you are in a crisis, things like severe pain, numbness, tingling, stiffness, acute abdominal pain, acute fatigue or cognitive difficulties.
- Who your supporters are, including family members, friends, and the health care professionals you are involved with, how they help you, and their phone numbers. Include as many family members and friends as possible, as they are usually more accessible at short notice than health care professionals. Depending on your own

personal situation, you may also wish to consider including a list of people you do not want involved in providing you with support or care.

- The names and contact details of your Doctor(s), pharmacy and Health Insurance Company
- Any allergies you may have and any other things or circumstances that need to be avoided
- Medications you are currently using and why you are using them; also make a list of medications you would prefer to use if additional medications are deemed necessary and make a separate list of medications that should be avoided. Base these lists on past experiences of what was useful and what was not so useful.
- Treatments that would be helpful to you and those that you would wish to avoid.
- Activities that your supporters could do for you that could be helpful. You might also list the things that they tend to do that you would not want done. Include a list of tasks that need to be done and who you would like to do them, practical tasks such as cleaning the house, doing your groceries, doing your laundry, paying the bills or feeding your pets.
- Indicators that you have recovered enough to start taking back some responsibility for your own care such as “when I’ve been able to reduce my pain medication” and “when I’m able to reengage with my physiotherapist”.

Before taking the next step

- time to reflect:

When was the last flare up of your Fibromyalgia symptoms?

What were the main things you couldn't manage at this time?

What would have been helpful for you?

Who could you have asked to help you with these things?

My Crisis Plan

Part 3: Supporters

List those people who you would want to take over some tasks for you when the symptoms you have listed occur. You may want to name certain people for certain tasks

Name	Connection/Role	Phone Number

There may also be people you *would not* want to be involved in assisting you with tasks during a spell of ill health. If there are, complete the following. This is optional.

Name	Reason for <i>not</i> wanting support

Part 4: Medications

List all of the Doctors and/or Health care professionals with whom you have contact

Doctor/Healthcare Professionals Name	Phone Number

Now take time to list all of the medication (if any) that you currently use and the reasons for taking them.

Medications	
Name	Purpose

You may have medications that would be acceptable and you may have medications that would be unacceptable should additional medications be necessary. List each, along with the reasons why.

Acceptable Medications	
Name	Reason

Unacceptable Medications	
Name	Reason

Part 5: Help from Others

These are the things that other people can do for me that would help to reduce my symptoms/triggers and make me more comfortable.

What I want done	Why I prefer this

These are other tasks that I need others to do for me.

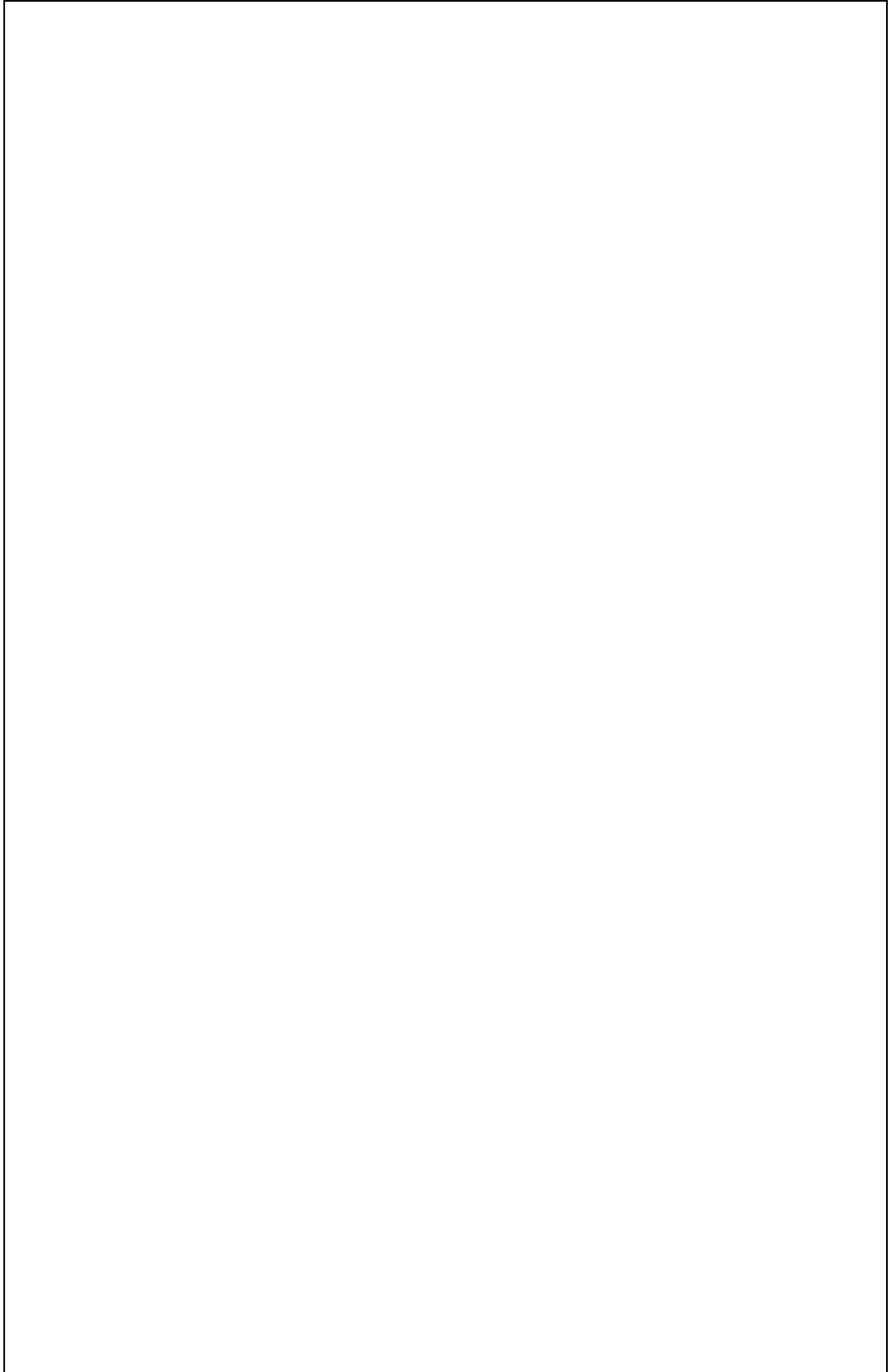
What I need done	Who I would like to do it

Part 6: Things that would not help

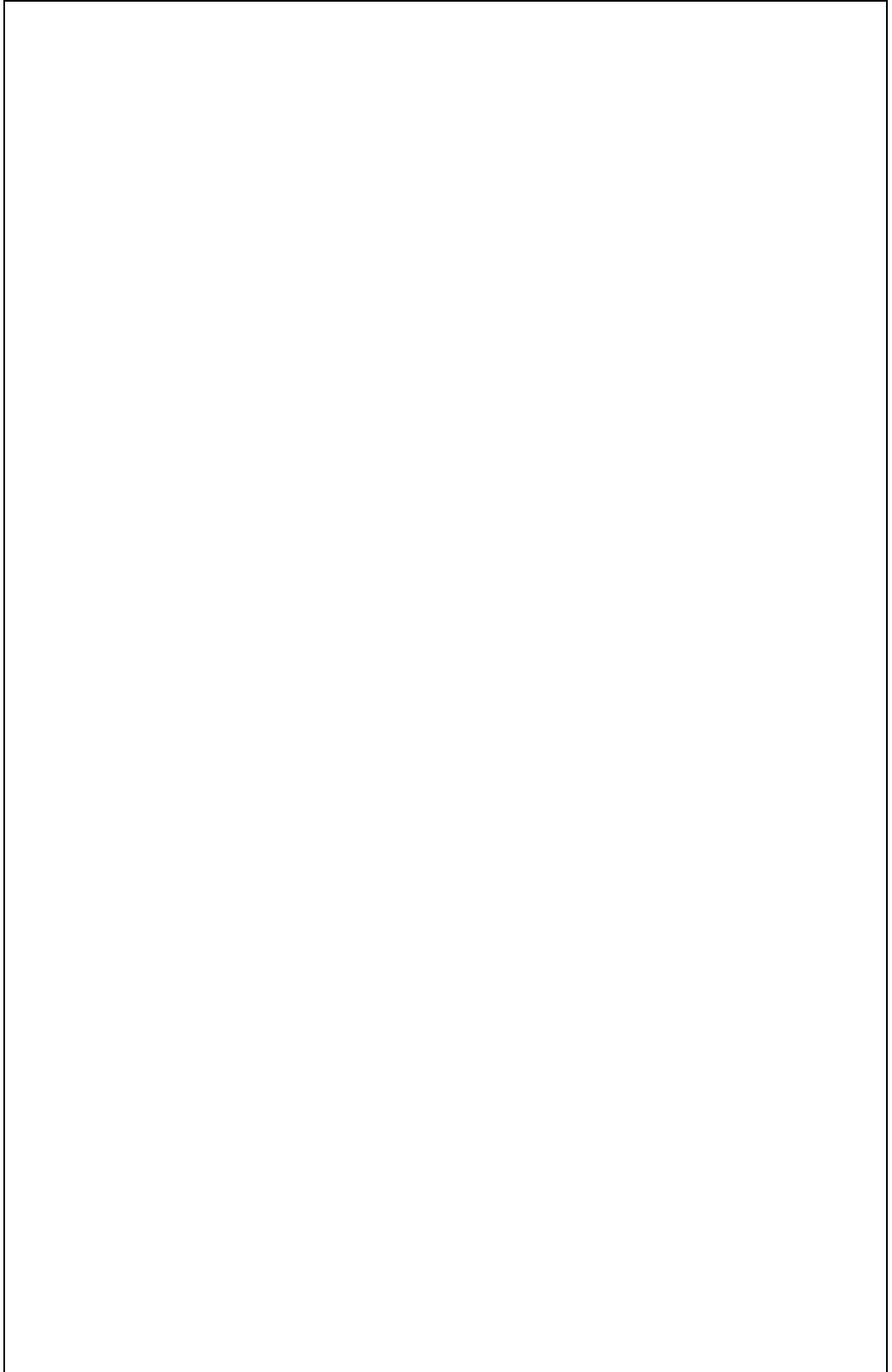
These are things that others might DO, OR have done in the past that would NOT help. They might even worsen my symptoms.

Things They Did	Why It Did Not Help

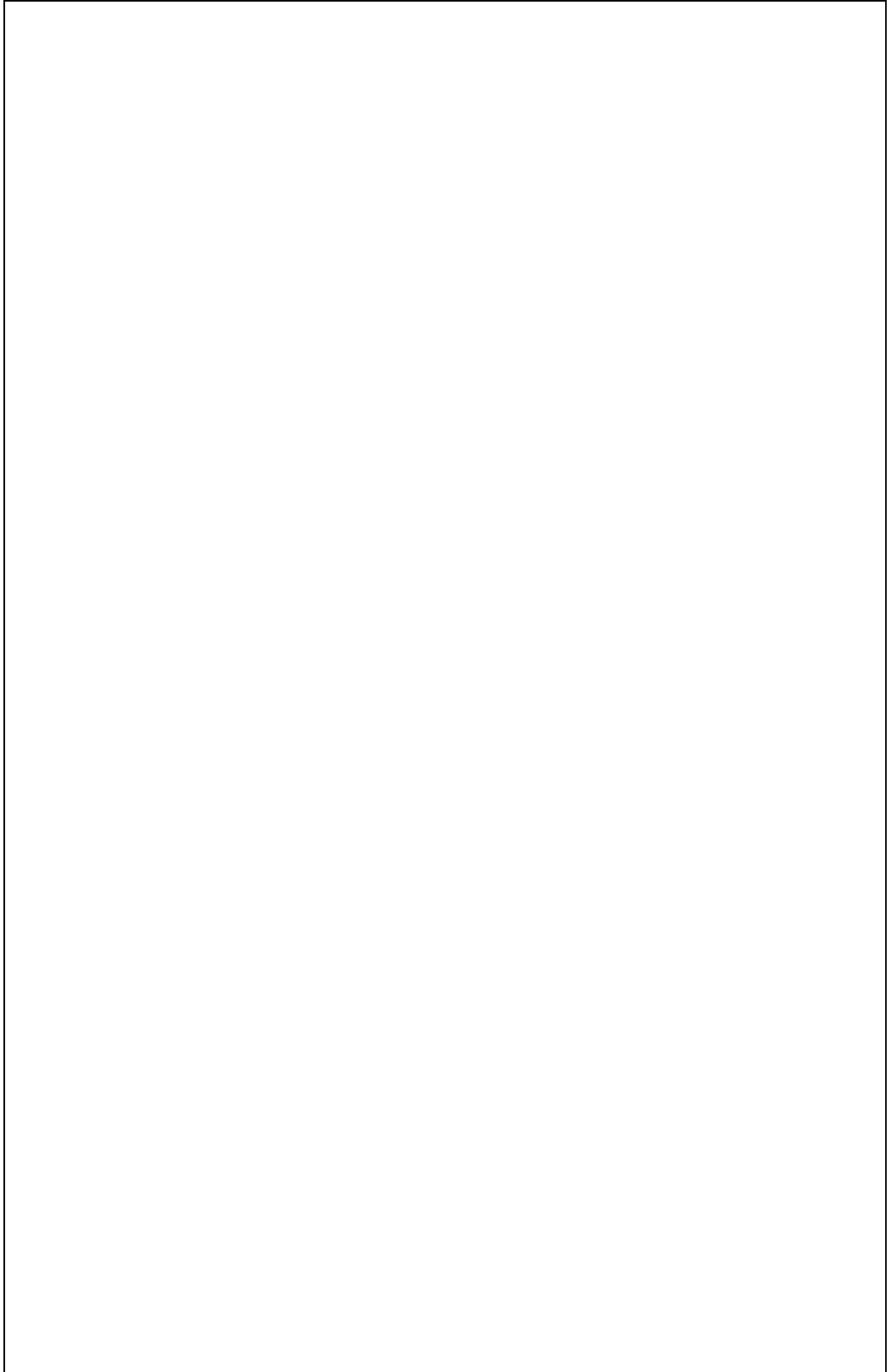
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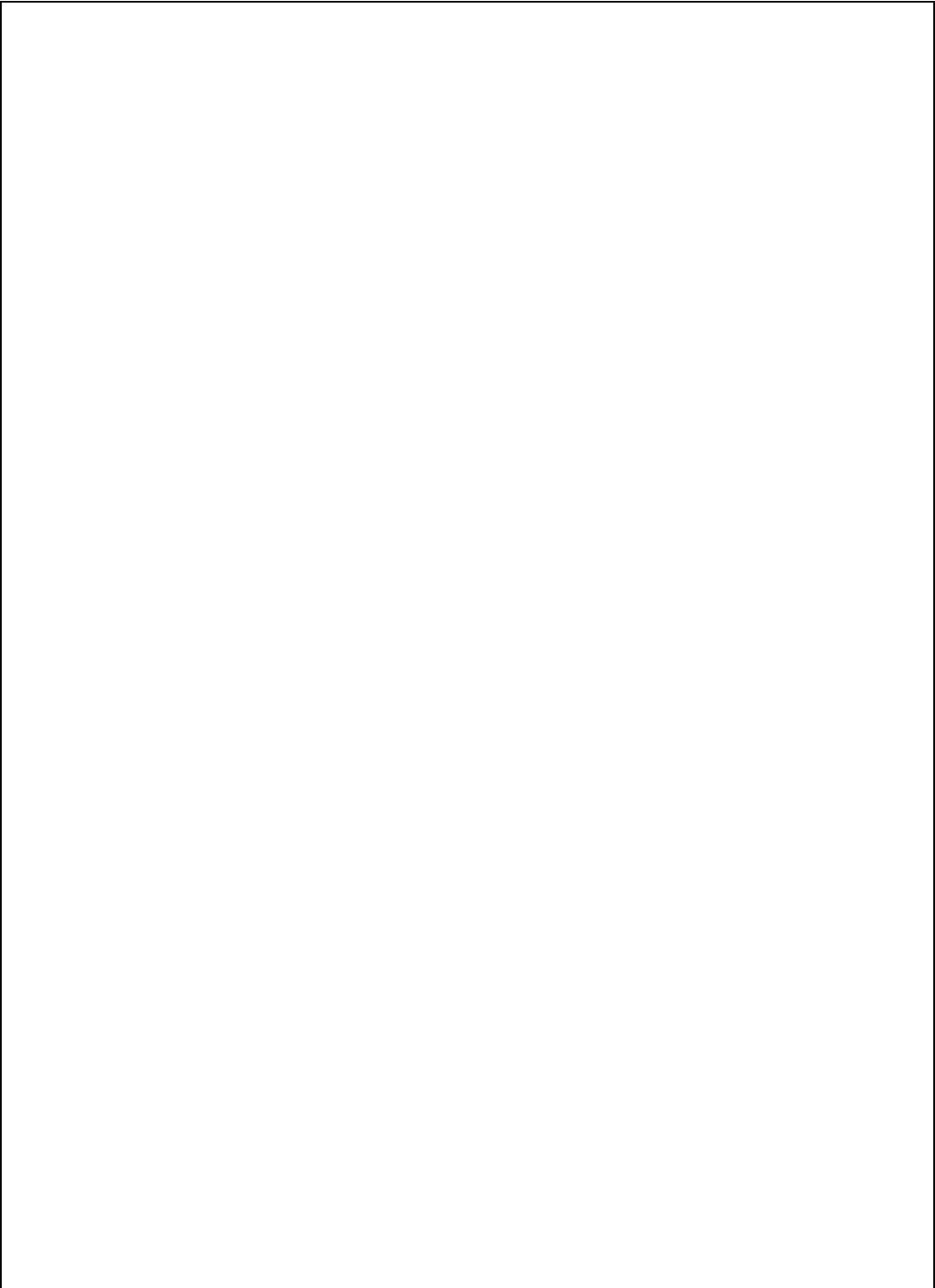
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7.9 Appendix 9: Lesson Plans

Week One: Introduction to WRAP

Time	Topic/Activity
2.30pm – 2.45pm	Complete T2 Measures Personal Introduction Description of WRAP
2.45pm – 3pm	Group Agreement – what it means and why we have one Draw up Group Agreement Flip Chart
3pm – 3.20pm	Key concepts of WRAP Slides 1-14 Workbook Module 1
3.20pm – 3.30pm	Break
3.30pm – 3.45pm	Key concepts of WRAP Slides 1-14 Workbook Module 1
3.45pm-4pm	Workbook Module 1 <ul style="list-style-type: none">• Your Wellness Strategies (Flip Chart)• Promoting Wellness Exercise

Week Two: Wellness Toolbox

Time	Topic/Activity
2.30pm – 2.45pm	Group Activity “Something to consider.....” WRAP Workbook
2.45pm – 3pm	Explanation of what a Wellness Toolbox is Slides 16 - 19
3pm – 3.20pm	Sample Wellness Tools Slides 19 - 21
3.20pm – 3.30pm	Break
3.30pm – 3.45pm	Group Discussion of wellness tools they already use or ones that they might like to try. Flip chart ideas
3.45pm-4pm	Slide 22 Enter Wellness Tools into Workbook <ul style="list-style-type: none">• Wellness Toolbox• My Wellness Toolbox

Week Three: Daily Maintenance List

Time	Topic/Activity
2.30pm – 2.40pm	Difference between Daily Maintenance and Wellness Toolbox
2.40pm – 3pm	SMART Goals Activity: A Glance to the future (WRAP Workbook)
3pm – 3.20pm	What I am like when I'm well Slides 25 – 27 Complete "This is what I'm like when I'm well" in WRAP Workbook
3.20pm – 3.30pm	Break
3.30pm – 4pm	Daily Maintenance List The things I need to do everyday to keep myself well Slides 28 & 29 The things in need to avoid everyday to keep myself well Slides 30 & 31 Finish up session on slide 32

Week Four: Triggers

Time	Topic/Activity
2.30pm – 3pm	An understanding of what Triggers are Slides 33 - 37 WRAP Workbook
3pm – 3.20pm	Group discussion of Triggers Flip chart feedback from group Record personal Triggers in WRAP Workbook
3.20pm – 3.30pm	Break
3.30pm – 3.50pm	Triggers Action Plan Slides 38 - 41 Complete Triggers Action Plan in WRAP workbook
3.50pm-4pm	Mindfulness exercise

Week Five: Early Warning Signs

Time	Topic/Activity
2.30pm – 3pm	An understanding of what Early Warning Signs are Slides 42 – 44 WRAP Workbook Reiterate difference between Early Warning Signs (Internal Responses) and Triggers (External Events)
3pm – 3.20pm	Group discussion of Early Warning Signs Flip chart feedback from group Record personal Early Warning Signs in WRAP Workbook
3.20pm – 3.30pm	Break
3.30pm – 4pm	Taking Action: Early Warning Signs Action Plan Slides 45 - 47 Complete Relieving my Early Warning Signs Action Plan in WRAP workbook

Week Six: Crisis Planning

Time	Topic/Activity
2.30pm – 3pm	An understanding of what a crisis is and how it differs for each of us Slides 48 - 50 WRAP Workbook Complete “Time to reflect” exercise in WRAP Workbook
3pm – 3.20pm	Overview of Crisis Plan Slides 51 & 52
3.20pm – 3.30pm	Break
3.30pm – 4pm	Group Discussion based on the sections of the Crisis Plan Crisis Plan to be completed at home by each individual

7.10 Appendix 10: Copeland Centre Values and Ethics



Values and Ethics of Wellness Recovery Action Plan®

WRAP® is underpinned by a core set of values and ethics which form an essential part of the delivery of all WRAP® programmes.

1. Each session supports the premise that there is hope, that people can get well, stay well for long periods of time, and do the things they want to do with their lives.
2. Self-determination, personal responsibility, empowerment, and self-advocacy are key aspects of this programme.
3. The programme supports workshop decision making and personal sharing.
4. Participants are treated as equals with dignity, compassion, mutual respect, and unconditional high regard.
5. There is unconditional acceptance of each person as they are, unique, special individuals, including acceptance of diversity with relation to culture, ethnicity, language, religion, race, gender, age, disability, sexual orientation, and 'readiness' issues.
6. This programme is based on the premise that there are "no limits" to recovery.
7. Participants are given the opportunity to explore choices and options, and are not expected to find simple, final answers.
8. All participation is voluntary.
9. It is understood that each person is the expert on her or himself.
10. The focus is on individual strengths and away from perceived deficits.
11. Clinical, medical and diagnostic language is avoided.
12. The focus is on peers working together and learning from each other to increase mutual understanding, knowledge and promote wellness.
13. The programme emphasises strategies that are simple and safe for anyone, and it stays away from strategies that may have harmful effects.
14. Difficult feelings and behaviours are seen as normal responses to traumatic circumstances and in the context of what is happening and not as symptoms or a diagnosis.
15. There is unconditional acceptance of all creative work and expressions that are created or brought to each session.

7.11 Appendix 11: Interview Transcripts For Chapter 4

Participant Id. 1

1. Can you tell me how you have been since completing the Wellness in Fibromyalgia Course?

Since I completed the WRAP course I would say that my life has been a totally 360 turnaround from where I started. I would have started very unwell and very, not able to plan and to kind of get in control of the illness really. Probably quite overwhelmed by it and the WRAP course really helped in helping me to organise myself and because I think when I was overwhelmed with the pain that was all I could think about, just the pain and how you're not getting maybe the help that you want from doctors or people around you and then I think you spend a lot of energy, wasted energy on that and I think the WRAP course helped me to basically say ok I have to put that aside. Yes I'm in pain, yes I'm not getting the help that I want but I need to plan for my life and I need to look at what I want to do and how I want to get better and I think especially the going to a group and seeing other people is very reassuring in a way because when you're going through the illness it can be quite isolating. No one else has it that you're aware of in your immediate circle of people that you socialise with people just kind of say things like oh how are you feeling but that would be it. They don't really want to know, they don't want to hear you talking about fibromyalgia their eyes kind of glaze over and they roll their eyes or whatever so going to the group is really good because you get to talk about it with people who not only want to hear what you have to say but benefit from hearing it and vice versa, you benefit from hearing their advice.

2. Can you describe how you have been in general since completing the course?

I'd say my fibromyalgia is a lot more under control. I learned a lot of things about fibromyalgia that I didn't know by going to the group. I also learned that one of the pain killers I was taking was detrimental and that I shouldn't have been taking it just from talking to other people and they were saying that they were on it and they did their own research and they were right because my hair was falling out with it and it wasn't good at all and as soon as I stopped taking it then my hair was fine and I noticed I had a lot more energy and I noticed that the pain killer wasn't really doing that much for my pain and I also joined the gym which I didn't think I would do because I would have thought I would be too fatigued and in too much pain but I've been doing that since April and I hope that in March to join a gym with a swimming pool. I'm a lot more proactive, that's what I would say, more proactive.

3. Have you noticed any health changes since completing the course?

Yeah. I've noticed I'm able to sleep better-my sleep was very disturbed. I wouldn't get a full night's sleep and my Mam she'd even say that she'd feel so bad for me that she'd get up in the middle of the night and she'd see that I was still there awake, you know, struggling to sleep and now she said that I get 6 or 8 hours sleep. I would notice, I got my bloods taken and I'm a lot healthier in my bloods. Beforehand my iron and vitamin D were very low because I didn't have the energy to get out as much as I wanted to so that's all perfect now and at a good level and also my cholesterol is at a perfect level. I never had any problems with my cholesterol but it was heading to a bad patch because I wasn't moving. My hair came back to normal, my skin came back to normal- my skin was very, very, very dry from the stress of having the illness because I had a very bad patch for 6 or 8 months I developed a condition called dermatitis and that's all gone now and that was directly related to the stress of having fibromyalgia

**4. What impact, if any, has the course had on your fibromyalgia symptoms?
Can you give me an example?**

My personal relationships with friends and family would be a lot better because I'm no longer, not a burden, but they don't have to worry about me or thing oh god what's C going to do so there can be a more normal relationship, we're more equals now, it's not like oh C is unwell and here isn't hostility towards that because I wasn't getting better over a certain length of time so there was that frustration on the part of my parents because they were frustrated and thinking there's nothing we can do and then it didn't help that I had an uncle who decided that I was pretending even though he knew nothing about fibromyalgia and he'd ask me to go get him a cup of tea and just because I could lift my arm up he'd be like that's proof even though he's an expert in nothing really (laughs).

5. What impact, if any, has the course had on how you manage your fibromyalgia symptoms?

Can you give me an example?

Yeah. I'd be a lot more logical about it, lot less emotional about it. That's what the WRAP course would have helped me a lot with because beforehand all my decisions were impulsive and all emotions, like letting the pain kind of take over, so my decisions are a lot more logical, you know just thinking about I need to do this and this and this but if I don't do this I can do it tomorrow so a lot more of taking time out if I need to. I'm really into reading so I take time out to read even if I'm in pain it could be a distraction or also to be aware of the levels of pain, so it's not as bad like I haven't had a flare up in a very long time. Just the other symptoms too, the fibro fog has really reduced a lot, that used to be very bad and quite embarrassing especially if you're out and about and you get the fibro fog but that's a lot better now and I think I'm even a more of like proactive member of society now, a lot more social, a lot more, I don't know, a lot more passion to do the things I want to do.

6. What impact, if any, has the course had on your wellness?

Can you give me an example?

Yes I would say it impacted on my wellness because it made me concentrate on my life and also made me concentrate more analytically on the illness instead of kind of wallowing in it made me look at it from an outside perspective and look at the factors of what I need to do in order to cope and manage with it which I wasn't doing at all. I was more going, oh god I'm overwhelmed and I'm in pain and almost expecting someone else to kind of sail in and save the day but I think I've realised that you have to be your own hero in those situations and that really only you know what well feels like and what not feeling well feels like so you kind of have to be mature about it and deal with it yourself.

7. What do you think of the notion of wellness tools?

I think it's a very good idea because it's kind of a physical representation of things that you can have that will help you because before I knew about the wellness tools and you kind of think oh what can I do to help you don't have a physical image of things that can help whereas with the wellness tools you can think ok if this happens I know I have this and writing it down reinforces it. You can be less panicked and less overwhelmed by a situation because there's a solution to the problem.

8. To what extent are you employing the WRAP plan in your life since completing the Wellness in Fibromyalgia course?

I do a check in every week and see how things are going I still have my WARP notebook so I look through that and look at maybe the goals I have or if I have achieved things or the wellness tools or things that I plan on doing like if I want to try reflexology or things like that or even to make time for myself or communicate with other people. I think beforehand I would have communicated with people in almost like a very feral way just like oh I'm in pain but now I realise that if you're in pain if you can deal with it yourself you don't need to tell other people because they can block you out because they don't have a solution for it so they just kind of put the shutters down and I've just realised that. I don't talk about fibromyalgia with any of my family or anything because they just glaze over with it, they don't understand it and they don't know what to do about it and even my Mam now, if I bring up fibromyalgia now she's like, I thought you were finished with that so I just don't bring it up at all. And I just deal with it myself and I think that's better because I think their input would be a bit, not negative but it wouldn't be helpful so I just don't waste my energy on it I've gotten over the fact that I can't educate them in any way (laughs) so I just leave it.

9. Tell me about how you are today compared to 1 year ago.

(a) What is the same?

There's not actually a lot, just where I live. That's just the same.

(b) What is different?

There's actually not much the same because I feel like I've changed and I feel like, this is probably a bit cheesy but I feel the world has opened up to me like I feel like I have possibilities whereas beforehand I didn't feel like I had possibilities because I was just very almost clouded by the fibromyalgia. I couldn't participate in my normal life anymore so I felt very almost as if I was going backwards so you're not living your life so you cut yourself off from your everyday life or goals or ambitions. Now I feel totally different. I'm even thinking of going to college next year and I would never have thought that would be possible because I would never have thought that I would be well enough and then I would have felt too fatigued or too much in pain to listen to the lectures or things like that and even when I joined the gym I didn't even tell them that I had fibromyalgia. You know, I'd forgotten because even beforehand at anything, you know even to go to the hairdressers to put my neck back I was like I have fibromyalgia, be careful with my neck and unfortunately not realising where the girl didn't have English so she was like sit down, you know, they had no idea what I was saying but even my sister used to say you don't have to tell everyone that you have fibromyalgia and I was like I wasn't telling people, it's just for certain things but now I realise a lot of people don't know what fibromyalgia is and there is literally no point telling people so you might as well just have your own wellness in those situations and just realise it might be like put your neck back for 5 minutes but just bear it or even put a towel around your neck or whatever you can do. I have realised that the world is not fibromyalgia access friendly, that they don't care, no one has been told about it and they just nod and smile and move on, they have no idea what you've said and I just don't bother anymore

10. What does wellness mean to you?

Wellness to me would mean kind of that you're fulfilling your basic needs, like when I was really unwell like you'd go a good week without washing your hair because you just wouldn't have the energy you know and that wouldn't make you feel great, you're putting yourself down almost and then wellness just being able to live your life, being able to have the breakfast, lunch and dinner and not to feel sick or not to, I found that when I was really unwell I was skipping meals, not on purpose, but just because you'd be in so much pain you'd forget to eat and I didn't realise I had an inflamed digestive system so I didn't realise that was affecting my appetite and then every time I ate I felt very nauseous and that sort of thing so wellness is just really being able to have a normal life and also socially being able to go to the cinema or go out and being able to participate in life and then also being able to have good healthy relationships with people, that's also wellness to me because I think that's really important and also being able to talk like when I was really unwell you're really not able to talk about anything else except for your fibromyalgia and you don't mean to but you're quite obsessed with it but now I think this my first time to talk about fibromyalgia in months because I only talk about it with myself (laughs), I don't talk about it with anyone else so that's a big thing of wellness, talk outside your issues in order to keep your connection with your friends and family because if you don't they will block you out, because you're like white noise, you're just the same thing over and over again.

11. What would you change about the Wellness in Fibromyalgia course?

No I think it's quite proficient as a WRAP course goes. It's good the way you have the notebook to write things out and also the discussions, the way the book is explained, no I think it's good. Maybe more discussion, I think the group therapy because I think a lot of people would benefit from it because they have no one to talk to about it. I remember one girl about my age said; oh my boyfriend thinks it's great because he said I don't moan any more. That's what they view us as. We're talking about something very serious but they don't hear us as someone who is in an overwhelming situation, they just hear us like a moaning white noise so I think group therapy would be really good because we're not heard and we need to be heard.

NOTE: Interviewer clarified that the participant, when referring to 'notebook' was making reference to the workbook that was provided.

That's really good because you can go home with that, especially with the fibrofog you can remember what each week was about and you can remember oh yeah, this, this and I'll try this and things or ideas that you had during the class, you write them down and you can remember then and it's good to keep because it's yours and it almost like a little diary

Participant Id. 2

1. Can you tell me how you have been since completing the Wellness in Fibromyalgia Course?

Well I've been under a lot more external stress since doing the course but I felt the course helped so I would say my health is probably worse due to external stressors but it would have been far worse if I hadn't done the course. I also had surgery at the start of the year so that kind of would have wiped me a bit, but again, I was able, because of the stuff I learned on the course like being gentle and patient with myself and I use the meditation exercises as well from the course.

2. Can you describe how you have been in general since completing the course?

I've been ok. As I said there's a lot of external stress but it could have been worse, I implemented the skills from the course.

3. Have you noticed any health changes since completing the course?

Well I notice that if I stick to my daily maintenance list I have a better chance of avoiding flares and if I'm having a particularly bad flare, if I go back to my daily maintenance list yeah maybe some things on that have slipped. It is useful because you can kind of see a pattern to things and things are doable and also I'm a bit of a devil for overdoing it so it reminds me that I need to take it easy (laughs)

4. What impact, if any, has the course had on your fibromyalgia symptoms?

Can you give me an example?

I think it has made them easier to manage so if I am having a flare up I'm not as frustrated and if I follow my daily maintenance list, if I watch the triggers I feel I have a bit more control over it, I kind of feel it's not a case of waiting for the doctors to come up with the right drug, there are actions and behaviours that if I if I do they can have a positive or negative impact on my fibromyalgia.

5. What impact, if any, has the course had on how you manage your fibromyalgia symptoms?

Can you give me an example?

Yes, I think I would have been a bit blaze with the things I need to do to keep myself well but I think actually having a physical list, again I keep coming back to the daily maintenance list, but it's just so helpful to see right I forgot to do that because again with the fibro, I think it's helpful having everything printed out and put into the different categories as well you know to see ok if I am having a really bad day, what is it I do again.

6. What impact, if any, has the course had on your wellness?

Can you give me an example?

I would say it has helped me see that you can have a condition but still have a reasonable quality of life. I think it was helpful working in a group seeing other people with similar stuff and also maybe things that they were doing or not doing was helpful.

7. What do you think of the notion of wellness tools?

I think they're very helpful because at least you feel you have something because fibromyalgia is so complex that you kind of feel like it's an unslayable dragon whereas having stuff, while it's not going to fix it, it can take the edge off of things.

8. To what extent are you employing the WRAP plan in your life since completing the Wellness in Fibromyalgia course?

Oh I'm doing it on a regular basis. Again, I say typically, the daily maintenance list, the triggers and the meditation piece too. Again it makes you realise the importance of meditation and mindfulness.

9. Tell me about how you are today compared to 1 year ago.

That's kind of a tricky one because my circumstances are different.

(a) What is the same?

(b) What is different?

I mentioned the external stressors with work so I'd say I'm under more stress and my health is slightly worse but it would have been a lot worse if I hadn't done the WRAP course so on a scale of 1 to 10 how do I feel overall, I'd say I feel 6 or 7. I might have been an 8 or 9 last year. There's massive external stuff going on so I think that's more of a contributing factor than anything else.

10. What does wellness mean to you?

For me wellness would have meant that you could do a marathon and be a size 8 (laughs), I think I would have had a completely unrealistic definition of wellness but to me now, wellness is having quality of life and being able to get through the tasks that you want to get through with not too much difficulty.

11. What would you change about the Wellness in Fibromyalgia course?

I think maybe shorten it, just with fibromyalgia it's hard to concentrate. You want to see how people change over time but again, less is more with fibro so if there's any way of condensing it down, simplifying things and then maybe follow up because what I notice with myself and with the fibro group in general is that people are great at starting things and then when they're finished they say that was great and they put it in the drawer and never use it so some way of how to get people maintaining it, whether it's an email or an online thing that they check in every month. Something that they keep that link that they keep it up because I think the majority of the people will fall by the wayside, Again I think it's that thing that it's not curing me so I'm going to move on and find something else but it is actually a very useful tool.

Participant Id. 3

1. Can you tell me how you have been since completing the Wellness in Fibromyalgia Course?

Ok, I have been up and down I would say. My fibromyalgia as such did not improve a lot however my whole outlook and my approach did and I guess that would have helped me to manage my life maybe a little bit better or in a more conscious way.

2. Can you describe how you have been in general since completing the course?

It's been quite a while! I think I did have me difficult times as such, my symptoms-tiredness, fatigue and pain didn't improve really but what has improved as I was saying is just my whole outlook, as in, being aware that I can be a little bit more proactive and that I can, and if you have the certain mind set you can manage the symptoms of fibromyalgia and I think I used that quite a bit and it helped, it helped. I've been able to make progress in a way in that I've been getting involved with 2 agencies, FibroIreland and Chronic Pain Ireland and that gave me a bit of a boost, the success that we have had so far. I can see that for myself.

3. Have you noticed any health changes since completing the course?

Not much. Maybe focus and concentration might be a little better. Pain wise, the pain is always there. Ok I had to change medication, I actually came off pain medication that probably did something as I feel my pain probably quite a bit stronger than I used to, they said I simply can't take it (the medication) anymore and there's nothing in the world which they can give me in exchange so I'm stuck for that and that can be tough.

4. What impact, if any, has the course had on your fibromyalgia symptoms?

Can you give me an example?

What I appreciated most was the development of the wellness toolbox. It worked quite well, such as having a certain amount of things that hopefully I should remember on the day that really should need them or just to maintain a certain amount of things like

maintaining good hydration, just to have it in the mind so its there. Getting better sleep, getting a better sleep routine and that's it.

5. What impact, if any, has the course had on how you manage your fibromyalgia symptoms?

Can you give me an example?

Ok. Goodness, yes maybe in that way that for example if I experience a lot of pain that I would focus on something else and I'm practicing mindfulness more, more than I did before. Sorry my hands are in bits today... I put the radio on, I listen to the radio when I was holding my steering wheel today, things like that. Not focusing on the pain because ultimately you don't feel it as much.

6. What impact, if any, has the course had on your wellness?

Can you give me an example?

Yes it did in that way that I'm looking after myself a little more in that I actually take myself more into consideration and attending the course, just doing this, the very fact that I had started it and did the course I saw I needed to start to look at myself more because I definitely, I want to get better. There is not much space in my life for this so I would really like to get through it. I'm looking after myself better, I'm a little more compassionate and more kind to myself, those things. Attending that course, the very fact that doing something for myself has helped.

7. What do you think of the notion of wellness tools?

It's brilliant. Very, very good because you can choose your own tools, it's a very individual thing, you can put whatever tool you think you want to use once you have found it you can put it in the so called toolbox and use it whenever you need it. I think it's useful, it's good. Keeps it very much present in the mind actually.

8. To what extent are you employing the WRAP plan in your life since completing the Wellness in Fibromyalgia course?

Kind of, it's hard. Some days I get small bits of some things but I use them for example the wellness toolbox, my sleep routine and being more compassionate, kinder and a bit more gentle with myself. Looking after my own needs a little bit more than I have before. I think that is what I took from it. It is a lot, the whole course comprised a lot of information, a lot of things to do and also when you are in the course you're quite conscious but when the course finishes it often is that you switch back to the way your life was before.

9. Tell me about how you are today compared to 1 year ago.

(a) What is the same?

The pain levels, definitely the same and brain fog as in today I'm not too good, it's a bit odd. That hasn't improved that much I just deal with it in a different way. I'm kind of more conscious that I have 2, 3 or 4 hours per day that I can use actively-physically, mentally and whatever or a combination of both and that I know the other time is not as good so I'm not getting angry about it or upset or frustrated or I wouldn't get angry anyway but that is just the way it is, I'm still on the way to trying to improve it.

(b) What is different?

What is different is I'm more focused on getting better and I'm looking actively for things that weren't in my mind set to improve my health situation that probably has to do with the course but also the fact that I'm slightly getting fed up with it (laughs). It's understandable because you go through phases but at a certain stage you just say ok this is it and at the moment I'm thinking ok this just has to go.

10. What does wellness mean to you?

Wellness to me is peace of mind, peace of health. Feeling healthy in yourself, physically healthy, having good stability around you in your whole life, your social life-just a good base. Being happy and content and safe.

11. What would you change about the Wellness in Fibromyalgia course?

Oh dear I should have looked into it (laughs). Nothing that springs to mind, nothing that even when I did look back, nothing sprang to mind. I think it is a very well thought out programme.

Note: Participant's native tongue is German

Participant Id 4.

1. Can you tell me how you have been since completing the Wellness in Fibromyalgia Course?

I haven't been well and I discovered through the course I'm able to pinpoint better the points of fibromyalgia I wasn't sure because I have arthritis, osteoporosis and a few other things. I never was able to distinguish between pains, which was which, but since the course, I can nearly always say which is which like I have arthritis in my hands and this and my toes are going that direction but fibromyalgia hits me here (points to upper chest) or up on the shoulders. I really didn't know the difference, I know I was diagnosed with it and I have it and when they touch certain points in my shoulders I would scream but I'm able to distinguish which. It's kind of like a strain pain and a lot of times you don't know until like while I was in hospital they'd hold your arm and that would hurt. I have swollen ankles and I was at the doctors yesterday and he was lifting my foot just to examine it and I could tell you the different points where it was fibromyalgia where it's a sudden sharp pain whereas the other is a dull continuous pain. Sometimes with the fibromyalgia you don't know that it's there at that point until somebody touches it but you know with the arthritis because you know it's the swelling or just the pain.

2. Can you describe how you have been in general since completing the course?

The lower back is kind of a new one. It's kind of, well I would have had back pain but I would have put it down to the arthritis. Now I know it's not, it's the fibromyalgia and I'm on Lyrica and I find that deals with the fibromyalgia rather than a pain killer for the arthritis. I take one of them in the morning and one in evening and at midday if I find I need it I can take another one, you know what I mean and it definitely does help. When you know what the pain is you've definitely more acceptance of it. Like I have pain up the back of my neck and I get headaches and they come into my eyes and I was at the Doctor yesterday and he said that's stress and I do have stress at home..... I'm in a stressful situation and he (the doctor) was able to answer all my questions because he knows the situation.

3. Have you noticed any health changes since completing the course?

Before Christmas I wasn't well but I put that down to the weather, I put it down to because I have asthma and I put it down to anything because there's nothing specifically wrong with me. From the 21st of January to now (August 7th) I've been on steroids and antibiotics-well I finished the steroids 2 weeks ago and I'm on the antibiotics until September and they review the situation then and they'll see, they were just trying to give me a break from infections and to just give my body time to recuperate. I've been in hospital twice and have had the flu. The meds are to manage not to get another chest infection. They can't guarantee anything because the only thing they will guarantee is that I will be back to them but they can't guarantee anything else. When I was in isolation they lost control of everything but they were so nice...

4. What impact, if any, has the course had on your fibromyalgia symptoms?

Can you give me an example?

I think the change would be mainly in my head, the mental attitude accepting that I am the way I am. Accepting that I am very unfit and that I need to get back swimming but I'm hesitant about it because what I would normally do is that I would join a club every year but I just know I won't be able to go in the winter, once I get a little sniff at all I just have to mind myself. I think it's acceptance of all that, it's not being angry because I can't do the things I want to do. I was at the horse show on Wednesday, I was never at it before but we got a lift over and we got a taxi home and I had the best day ever. Now I was so tired, the

tiredness I will never forget it but it was so worth it. I just came home I went to bed and that was it.... I just feel it was a great help. It kind of laid everything out on the table and this is what you have and this is what you're going to cope with, you're going to cope with it, it's not as if I'm going to say well I'll just stay in bed. I mean there would be 5 minutes in every week that I would think ah just stay in bed don't make the effort but it's all falling into place for me..... I just feel my attitude has changed, I just feel like oh yeah that's the pain in my back now, the only cure for that is take a tablet and go to bed not suffer on and go around saying oh my back, oh my back and then walk funny, walk with a twitch. Go to bed and get on with it.

5. What impact, if any, has the course had on how you manage your fibromyalgia symptoms?

Can you give me an example?

I suppose spending so much time in bed the only time I would feel the pain is when someone would touch so I've been on so much steroids and antibiotics that quells the pain as well and so I haven't really had a lot of pain like that. Now I've had a good few spasms of the lower back but that's when I do too much. It's like a plank embedded into your back, it's so heavy to carry around but you know it's going to go, a tablet and go to bed and it mightn't come tomorrow, it might come tomorrow but it mightn't. I have a different attitude now. It's not like oh fibromyalgia-no cure, no cause like, it's just to deal with it on a daily basis and you'll be fine, tomorrow is another day.

The course gave me an attitude that I have it, accept it, deal with it and most times that's what I do-I accept it and I deal with it. I think if you didn't accept it you're kind of fighting all of the time wanting to find a cure, you know I think acceptance is key, if you just accept it and then deal with it as best you can whatever way you can.

6. What impact, if any, has the course had on your wellness?

Can you give me an example?

On my mental wellness yes, no matter what happens, even if I don't come out of it and I die, that's a fact. I was very sick, lots of different things happened, I was hallucinating, I had a very high temperature, I still had a temperature in the ambulance..... I wasn't aware of how I was, it was a lost weekend. I think it's a change in attitude; you just go with the flow no matter how bad you are.....

7. What do you think of the notion of wellness tools?

I suppose I would have, my wellness tools would be my friends and sharing how I feel and hearing myself say it and knowing what the problem is really. I haven't looked back on my notes but I am on my way to recovery and I know that maybe next week I could be in hospital and that's fine, that's the diseases I have and there's no cure for any of them. The programme just set the lines for me, that there are choices and I can choose what I want to do and I know when I go back to my notes and I'm well enough and clearer in the head, I know at the moment it's the steroids that are keeping me going. It's just in the listening, you know listening to yourself when you're sharing something.... It's in talking that would be my too, at the moment. I haven't been well enough to think about using anything else

8. To what extent are you employing the WRAP plan in your life since completing the Wellness in Fibromyalgia course?

The WRAP plan has shown me that I have choices. I can accept or not accept, I can be upset and it's ok to be upset and cry and share whatever it is and that's my way out at the moment and like doing WRAP instilled that in my head that acceptance and working the programme whatever way you want to work it works for me. I will expand on it, I will...

9. Tell me about how you are today compared to 1 year ago.

(a) What is the same?

(b) What is different?

I didn't think that I could have a better attitude to my illness. I couldn't believe that you know you could be ok and smile and yet be in pain and feel ok in your head. My head is much clearer; I'm much less given to responding to people in a negative way. I don't bother, it doesn't do me any good so what's the point, only if it's very important then I

would but actually it's my silence that works for me now..... Even to see the good in people rather than knocking people and it wouldn't knocking people it'd be that in my head I'd be thinking I'd be feeling sore and you don't realise how sore I am so if you say something wrong I'm going to pounce at you and I have the excuse you see, I've allowed myself and it was a horrible way to be whereas now if I'm in pain I'd say it..... I'm more at peace with the world.....

10. What does wellness mean to you?

Peace of mind, serenity and trying not to let anyone take that serenity from me and when they do ring a friend and talk about it and your friend might say something like what were you thinking about at that stage or why did you get that or they might talk about what they did in a similar situation but they'd have a different analogy of the whole thing and between us we'd find out what we need. It's not what you say it's how you say it.

11. What would you change about the Wellness in Fibromyalgia course?

Probably if I had gone over the notes, I can't remember anything off hand.

Participant Id. 5

1. Can you tell me how you have been since completing the Wellness in Fibromyalgia Course?

It has been up and down. I've been in hospital 7 times since November due to complications with my lupus so I'm feeling absolutely exhausted at the moment. And to make matters worse I'm moving house at the moment and have my own house on the market so I'm under a lot of pressure and stress with all of that and I have no help because I'm recently divorced.

2. Can you describe how you have been in general since completing the course?

Well as I was saying, my health isn't good at the moment and I'm not sure if it's the lupus or the fibromyalgia but I think it's the lupus and I've been put on a new treatment for that so I'm praying to God that this works for me. I did try lots of things in the past for my lupus and got some relief but only for short bursts of time so this new treatment is nearly like chemotherapy they say and I hope it will work for me.

3. Have you noticed any health changes since completing the course?

I don't notice any changes to my physical health because of this lupus and the way it's been acting up lately but I do notice a change to the way I'm thinking about things. Acceptance and I notice that I accept the pain I have. I also don't take any nonsense from people the way I have always done in the past.....

4. What impact, if any, has the course had on your fibromyalgia symptoms?

Can you give me an example?

It had no impact on my symptoms and my pain. I'm still in pain

5. What impact, if any, has the course had on how you manage your fibromyalgia symptoms?

Can you give me an example?

I use my tools now. I meet up with my friends and that is a great help to me to have someone to talk to, especially with all that's happening with me at the moment with my divorce and with the house having to be sold now. I'm so stressed out about it but the auctioneer said I will get a lot of money for my house, it's very valuable with the nice big garden and the way I have it decorated. I had an offer today so I need to think about that. Another thing I do is my gardening. I love that and when I do it I don't feel the pain. I forget all about it. Isn't that very odd?

6. What impact, if any, has the course had on your wellness?

Can you give me an example?

I don't feel well at all. I'm in so much pain and I'm just so tired. The lupus means that my body is attacking itself

7. What do you think of the notion of wellness tools?

The wellness tools are a great idea. That's one of the things that I can say I took away from the course, the toolbox. I have loads of thing but the big thing I use is the gardening. As I was saying I love my garden and can forget all about my problems when I'm out there. I'm very house proud you know and people always comment on the way I keep my house and my garden.....I go to the gym now as well, oh and I love to get away for the night, have me time. Sometimes if I feel very low or if the fibro is flaring up then I get myself out of the house. I walk to the shop and I buy myself a treat, usually my favourite bar of chocolate and then I go home, make a cup of tea and sit and enjoy the treat. I love that; I'm a chocoholic (laughs).

8. To what extent are you employing the WRAP plan in your life since completing the Wellness in Fibromyalgia course?

To be honest I haven't really had the chance to use it as much as I would have liked to use it because I've been in hospital for so long. Really the main thing that I do use are the wellness tools that I written into my book. I got great ideas from the group too. The one about meeting up with friends was a great idea.

9. Tell me about how you are today compared to 1 year ago.

Oh now that's a very tough one, let me think.

(a) What is the same?

Well what is the same is that I'm still in pain.

(b) What is different?

What has change is that I take no nonsense from others the way I used to, not from my ex-husband or from my daughter. Well now to be fair I get on well with my daughter and she's a great help to me.

10. What does wellness mean to you?

Wellness means security and peace of mind to me. I know I will have security when I sell my house because I will have enough to pay off the mortgage and buy a nice little house and have no mortgage to worry about every month. That will be great and I'm so happy about that. I just need to sell it now (laughs).

11. What would you change about the Wellness in Fibromyalgia course?

I think it would be great if there was a follow up so we could all meet up again and go through our plans again because sometimes it's hard to keep going with something and especially if you have pain. It's hard for me because when this lupus calms down I'll still have the fibromyalgia to contend with but shur c'est la vie (laughs)

Participant Id. 6

1. Can you tell me how you have been since completing the Wellness in Fibromyalgia Course?

Well as I say it gave the tools, the tool kit as you explained and it was like opening a toolkit and going into it and picking out the pieces that first of all I felt would relate to me and from then it gave me better understanding and then it opened me up into doing other things and I have since joined the active retirement, I do yoga once a week and I walk every day-I always did that, and exercise but I'm more open and I'm into things and I think that's helped me greatly, it's taken my mind in a lot of directions, you know. Brilliant. So from that point of view I do feel that I'm a lot better than I was. This time last year I was very, what would I say-delicate, kind of very tender. I was like a flower that was on its last legs and you were trying to keep it going with a drop of water and that's the way I would describe myself and I must say I have come full circle since last year, I mean I've recommended the WRAP to a lot of people with other complaints that would be similar, you know, that are not going to go away, you know I just told them about it, I said it's well worth it.

2. Can you describe how you have been in general since completing the course?

I would say I'm more optimistic and more positive, yeah I'd say I'm a lot more positive. I've since now believe it or not made a big decision there last year, I live on my own you know since my son went off and moved out and got married and I have grandchildren and then last year they were talking about moving to a bigger place and all the rest of it and then we were having a discussion before Christmas and we were saying well maybe if we put the 2 houses on the market together after Christmas and we bought a big enough place and they would put on a complete separate apartment for me which is grand, it's like a gift out of the blue because I was always saying god getting old and being on your own and you know isolation because I'm a long time on my own now, since my Mom died but even before that I'm 26 years now separated, it's a long time to be on your own you know, but I was busy for most of my life with my Mom looking after her and then putting my son through college and getting him on the road to life which was my priority but I just felt this kind of was a good decision for us all. So that's what we've done. We've sold both of our houses and we've bought a lovely new, not a new, but a big house which we have a lot of work to do on it but it's going to be life changing, another episode. So I wouldn't have even thought of that last year because Caroline, I would have said oh I just wouldn't have the energy because last summer I found my energy was rock bottom, I couldn't bring it up but whatever happened, whether it was the mind over matter or what, my energy levels are back up to their usual. I do really feel that and no tablets, no drugs, nothing only vitamins-vitamin C sometimes I take a course of that, not in the summer time but in the winter I take 1000mg a day.

3. Have you noticed any health changes since completing the course?

Other health changes, well I feel a lot more well in myself, I would say I'm a bit back to my old self. You never go back 100% to what you were before, I mean I'm getting older and I realise that, when you're in your 70's you're not going to be like what you were in your 60's and it'll also be the same when I go into my 80's but I think that for 75 I'm pretty energetic and pretty fired up.

4. What impact, if any, has the course had on your fibromyalgia symptoms?

Can you give me an example?

Well I'll tell you what I did- I explored a lot of things which I probably wouldn't have. I think it opens a lot of doors to you because it tells you, do this, you know you were saying before, explore yourself, find yourself, what you feel like, what's good for you. If it's not good for you, you don't feel well doing it even if it's the best thing in the world it's not for you and I found I was very lucky to meet, it was a friend of mine recommended me to this girl, she was doing a course in acupuncture and she's working with a medical doctor and he wanted her to get people with specific complaints that he felt would show some improvement or not in their field and they were looking at people say with asthma, with other kind of altered things and fibromyalgia came up and my friend must have been saying to the lady that M has very bad fibromyalgia, I must tell her about you and she said, because she was asking would Emily go but Emily didn't really feel like she needed it for any reason but she said I have a friend with fibromyalgia and she said oh I would be interested in that I must mention it to the Doctor, now I can't remember his name but she mentioned it to him and he said a very good case because he said I'll tell you what, you'll either see nothing will happen at all or you'll see a big improvement and he told her that so he brought me in for a few sessions to take a case history of how long I had it, when was I diagnosed, my symptoms. He seemed to know an awful lot about it and the symptoms around it, he was able to tell me a lot of things, so then he spoke to Corinne and he told her what he felt was down in my body from the fibromyalgia so he said there was certain parts of my body that needed help because I suffered an awful lot, a lot of heat an uncomfortable feeling of heat and being hot like as if I was running a temperature. He said it was something to do with the liver and it made a lot of sense. Of the 2 I would prefer to be cold than to be hot, isn't it funny. So he worked with that, he told her what needles to use and for the first 3 weeks he showed her where to put them and I'll tell you what after 3 weeks I felt wonderful, the pain lifted. But now we're doing a maintenance, she comes every 6 weeks to my house, she just qualified this year, she was still studying so it was under him that she was doing this but now she sees me improve. The 1st time I went I was hardly able

to get up on the table so that's something I've tried. It (WRAP) gave me the courage or the confidence to explore more alternative things that I mightn't have ever tried. I mightn't have ever tried acupuncture, it wasn't something I ever thought would work but it definitely worked for me.

5. What impact, if any, has the course had on how you manage your fibromyalgia symptoms?

Can you give me an example?

They would be less; they would be a lot less. I would say the only thing is that I still get is the neck pain and going up into the head because mine is in my head and when I'm tired then I notice but it's my own, I know how to control it now and before I think I would keep going until alarm bells were going off where I don't now, I kind of say to myself, go to bed Mary you're tired and I leave a sink full of washing up to be done and I say I can do it tomorrow. Now before I mightn't have done that because I was always, what would you call it, judging yourself, that's the word I would use. I was in judgement of myself all of the time and if I didn't wash up that was a black mark, you should have washed up-a little bit hard on myself I would say more than anything else. Maybe it's part of the personality thing. This has changed because now I allow myself to make mistakes because I say I'm only human but before I didn't allow myself because I'd be saying what did I do that for, how did I let that happen and I'd be spending days trying to worry out what I had actually done, why I had done it instead of saying it's done and go on from that and move back in the direction I should have been going and leave it.

6. What impact, if any, has the course had on your wellness?

Can you give me an example?

In so far as feeling well yes. Well I found that using the tools that you gave us yes would have helped. I would say not straight away but a gradual, I would say it was very gradual and it was only there was one day I remember saying gosh I think I have a pain in my leg and it's suddenly about distracting a child, a small child. I actually think it's probably a good thing because it distracts us from ourselves. I was in my head, I was living in my head for a long time but maybe I think living on your own does that to you too and I began to dwell there. I don't do that anymore.

7. What do you think of the notion of wellness tools?

Oh I think it's great because it's an invisible box you can bring around with you and you can take them out on the bus or on the train or anywhere. I've often sat on the bus and I've done my breathing and I can close my eyes and do a bit of meditation. Now there's things like that nobody needs know that you're carrying this tool box with you only yourself. I have loads of thing in it.

8. To what extent are you employing the WRAP plan in your life since completing the Wellness in Fibromyalgia course?

Well now as I say, you wouldn't be using it on a daily basis and you know the better you are the less you use it because you kind of say ah I don't need it any more, throw away the crutch! But I do find in the summer months I don't as much because you kind of can let go of everything that you do on a regular basis but come the winter I would say I will get back into it and I do a certain amount of exercise I go walking every day and I still do that but I'm not doing the yoga for the summer, I'm not doing a lot of things so you kind of throw all those things to the wind for the summer but that's just taking your holidays kind of thing but I would use it yes, I would have it close by yes, it's something I wouldn't like to be without ever again.

9. Tell me about how you are today compared to 1 year ago.

(a) What is the same?

What would be the same, I'm just trying to think. I mean I haven't got rid of the fibromyalgia it's still there, I'm aware of that because there are niggles in the background but nothing compared to last year. With regards to what is the same, I would say that almost everything has moved on to a better place.

(b) What is different?

This time last year it was a big hard thing for me to get on a bus and come to town. I just felt very panicky, anxious, all that. All those kind of things came together and I would only go into town and I would come back out again. It was like as if all of my confidence had been taken that time, for a long time and now it doesn't worry me anymore and also driving long distances, I wouldn't have trusted myself to drive, now I would do that so that's the difference I would see from this time last year.

10. What does wellness mean to you?

Wellness, what does wellness mean to me. It means being able to do the things that I want to do and being able to enjoy doing them Caroline, that's really what I think when I think of wellness.

11. What would you change about the Wellness in Fibromyalgia course?

Well I thought it was very well covered in every aspect but I suppose there's always improvements but I can't think of anything off hand Caroline but I do think that maybe we should have a refresher once a year, so a one day seminar and to have an assessment of yourself, examine yourself and do this to bring it back to focus again, like a follow up every year. Like a drivers licence that you renew this every year and you go back into it. I'm going to suggest that to my support group when I go back in September that maybe we would do that on yearly basis, maybe we could have yourself out to give a talk or something to keep reiterating don't lose sight of what you've achieved, don't let it slip from your hands. I think it's a good thing to keep it up, like a small miniature version of it.

Participant Id. 7

1. Can you tell me how you have been since completing the Wellness in Fibromyalgia Course?

I can't say that I've had a great year but then I was pretty bad when I came and I have to say I really felt good after the 7 weeks in myself, you know maybe not pain wise but I felt good and I think that helped me. I was pretty ok, I went to visit a kinesiologist so that was working on allergies and stuff like that and I'm good. I probably wish I was better but I think as you get older and you're on other medications you're trying to figure out which is which but I know at this moment what is the fibromyalgia. I'm able to distinguish between fibromyalgia and the rest and I wouldn't always have been able to do that but I know now.

2. Can you describe how you have been in general since completing the course?

Probably more positive, more positive and less feeling that I didn't really have an illness that people weren't going to recognise and I felt a bit more positive about that.

3. Have you noticed any health changes since completing the course?

I don't know because the only thing that I could say is that when I was feeling bad I would go back to my WRAP notes, the book, and I realised the last couple of weeks when I was having a bad time and I went back to them and I realised I didn't heed the warning signs. So I think one of the main things that I got out of the course was the warning signs. I had increased energy, now in a sense I was feeling good but not realising that I shouldn't overdo it so that was the thing that I felt yeah that was good.

4. What impact, if any, has the course had on your fibromyalgia symptoms?

Can you give me an example?

I couldn't truthfully say. I couldn't really say because there's a lot of other stuff going on, I have osteoporosis so I'm kind of, if I'm on medication for that I'm actually blaming, you know there are 6 monthly injections that a lot of women are getting now, and I felt that when I got the injection and I've had 2, that my fibromyalgia symptoms were much worse, now I don't know whether that's it or not but I'm due to get another one in August and I'm going to ask for a break even for 3 months to see. I feel that when you have fibromyalgia you can't really take anything like an infusion like that, I think you're just not able to take it. It's probably not good that I got them injections since I did the course but it just happened that I got the 1st one just after I started the course.

5. What impact, if any, has the course had on how you manage your fibromyalgia symptoms?

Can you give me an example?

Yes, absolutely yes.

Well I'm not, I now rest myself and I'm not afraid to say I'm just not doing it. You do get the whole thing from people, it's the weather, do you not think it's the weather and now I'd say no I know it's not the weather, I know. It's just made me more confident because I've had it for a long, long time and when I 1st got it over 20 years ago nobody had ever heard of it so it was great to see all the other people on the course that have it, all the different symptoms.

6. What impact, if any, has the course had on your wellness?

Can you give me an example?

Yes, yeah. I kind of feel it has in the background. I mean I can't say that it has done anything for my symptoms but I'm able to manage them better. So that improves my wellness and also I have to say that the fact that you ran the course is huge, you had great empathy and I think that comes across. I went that to my doctor 2 weeks ago and she didn't just brush me off so it makes a huge difference and I got that from you, I kind of felt that you understood even though it's hard to understand if you haven't got it but this time the doctor, I've changed my doctor since and I mean my other doctor did understand about fibromyalgia but this doctor would talk about it and say don't wait until you're bad, take the pain killers-see I'm not inclined to take pain killers but I think maybe that's the way I feel well.

7. What do you think of the notion of wellness tools?

I think it's good but a lot of my wellness tools cost money but I would treat myself. Like reflexology. I don't feel guilty about going to have a massage and feel that that's a luxury, I just feel that that's to help with my condition. I know it's alright. I'm not one for lying down but now I will just lie on the bed for 10 minutes and sometimes I'll stop myself after a half hours housework and say I'm going to suffer afterwards.

8. To what extent are you employing the WRAP plan in your life since completing the Wellness in Fibromyalgia course?

I'm only dipping in and out to be honest because it might depend on your personality but I think deep within I keep thinking I'm going to be cured so when I'm feeling well I'm thinking that's it now. But when I was feeling bad this time I definitely went back to the WRAP.

9. Tell me about how you are today compared to 1 year ago.

(a) What is the same?

I don't really know, like I'm the same person. I can't really answer that Caroline

(b) What is different?

What's different is that mentally I'm different. Well I'm kind of more confident in how I am in saying what I have because if somebody close to you doesn't understand your condition that can bring you down a lot but now that doesn't bother me, actually doesn't bother me at all where that was a huge thing before, huge, that they didn't believe in it so mentally. I can't always say that physically I'm feeling better because you see I think I have arthritis too. So my take on it is if you have it, like I have it in the knees, other stuff starts to bother you then.

10. What does wellness mean to you?

Wellness to me is to get up in the morning and be able to do my stuff and get out for a walk every day. I really realise how bad you can really get. A couple of weeks ago I was really bad but I was trying to get my blood pressure down so I was walking up and down hills flying it and then I crashed and I looked up my WRAP book and saw that was it.

11. What would you change about the Wellness in Fibromyalgia course?

Maybe I was thinking that the group of people that were there, a few men and a lot of women and I don't know where they came from with their illness so a lot of them seem to have had an illness and got the fibromyalgia from that and I don't know did anybody start off like me that I just in my 40's was achy all over and doctor saying it's not arthritis so it's just interesting how many people, it's just there in their life seemingly without any cause or is it that mine without realising it was some stress in my life at some stage. I don't really know who in that group was like me. I would be interested in that. It's such a short time that people can't really talk about stuff like that. I would have liked an informal discussion on this. I'd love to have known this.

Participant Id. 8

1. Can you tell me how you have been since completing the Wellness in Fibromyalgia Course?

Well very mixed unfortunately. The winter has been very bad mostly because of all the rain we have had and I always find the wet weather particularly difficult to deal with. The fatigue is worse now and has gotten worse over the past year and a half. My pain is also worse but I have rheumatoid arthritis and that contributes to the pain. I know the pain is more from that than from the fibromyalgia. I find I have gone from a person who wouldn't stay in bed during the day if I was feeling unwell to someone who goes back to bed every day now for an hour. I find with the fibromyalgia it can be great for a while and then it flares up. It comes in cycles and unfortunately I'm in a bad cycle now (laughs). Really it varies from day to day. I use a pedometer and I can go from 1000 steps to 20,000 steps a day so I know I can do it. I was in Lanzarote and did 20,000 steps but I know the good weather was a great help with that. I'm still a member of the gym and go but then I might hit a wall and am right back to the beginning and sometimes right back to an even lower point, it's just really mixed.

2. Can you describe how you have been in general since completing the course?

I really got a lot from the course. I'm looking after myself better, especially my mind. I'm definitely better at looking after myself and better at stress management. For example, if I have a spare moment and have nothing on I'll take a break instead of finding something else to do. I might take a nap, go for a walk, go out for a nice coffee or spend some time browsing on facebook. I'm definitely doing this more now so in some ways I'm looking after myself better and so I feel better in general despite the fact that I have fibromyalgia and fatigue.

3. Have you noticed any health changes since completing the course?

Oh... To be honest I haven't really seen any real health changes. Well I have cut down on 1 medication and cut out 1 other medication completely. A year ago I would have taken months to pull myself out of a flare up but now it's different. I'm more motivated. I use a pedometer and I keep check on it and if I'm only 300 steps away from 10,000 I'll get up and walk around until I reach that goal, I try harder now to do that. My motivation has definitely increased.

4. What impact, if any, has the course had on your fibromyalgia symptoms?

Can you give me an example?

I don't know if it had any impact on the symptoms but I found the daily maintenance list really good. I plan my day better because of it. I have started a college course since the WRAP course. Now I drop my daughter to school earlier leaving me an extra 30 minutes and then with this time, I take out my college books and do a bit before I have to go to work.

5. What impact, if any, has the course had on how you manage your fibromyalgia symptoms?

Can you give me an example?

The course has helped me prioritise. I make sure that what needs to get done gets done. You know I have my own business and I work from home so now I do the important things

and then I start with my work. I have had an attitude change and this is helping me manage my symptoms a hell of a lot better than I had been doing. Because of WRAP I have started looking into other things, like I go to tai chi now.

6. What impact, if any, has the course had on your wellness?

Can you give me an example?

On my wellness? Well the course made me realise how important it is to mind yourself, like for example what I've been saying about changing my priorities. Now I keep an eye out on the internet for local deals on facials and massages and I buy them and use them at different intervals. This is a real treat. I also have started to get away with my friends and I never did this before. We book 3 months in advance and it's so nice to have something to look forward to. Definitely a whole attitude change.

7. What do you think of the notion of wellness tools?

Well I can get down when things aren't working out the way I had planned and knowing in advance the things I can do to help myself feel better is so great. I think they motivate you to do something too, even if it's only something small. One of my tools is doing reading for my college course. I am no longer looking at fibromyalgia as a life sentence; I know it won't be this bad all of the time. I have 2 sisters who have this and their attitudes are very different to mine-actually they would probably really benefit from that course, I'm only thinking of that now.

8. To what extent are you employing the WRAP plan in your life since completing the Wellness in Fibromyalgia course?

It wouldn't be like a plan that is set in stone. It's more like a check list. I can remember all of the things I have done in it. Generally I think it has become a part of how I do things. People tell me I seem great and I look well and that's always good to hear (laughs).

9. Tell me about how you are today compared to 1 year ago.

(a) What is the same?

Sleep, I'm not sleeping well and that hasn't changed.

(b) What is different?

Physically I'm not as well but that's a combination of things. I almost always use my walking stick now but that's really down to the rheumatoid arthritis. Mentally I've definitely changed. My overall wellbeing is better and how I feel about myself is different. I've learned to mind yourself and move on. I'm more inclined to do things now, like I visit my family whereas before I'd be saying oh I'm too tired I won't bother. Now I will do it. I pace myself in the time leading up to doing something. On the other hand, if I can't do it I will turn it down and I no longer feel bad about doing that. I have a much better attitude.

10. What does wellness mean to you?

For me, physically I was never really able to do a huge amount but wellness for me is mentally and emotionally rather than physically. With illness I think it's about looking at what it's doing for you rather than to you.

11. What would you change about the Wellness in Fibromyalgia course?

The only thing I would change is to offer it more than once. To me I would look at maybe splitting it up. 7 weeks in a row was intense so maybe 3 weeks, then a break and then the remainder. Break it up and have time in between to let it sink in. I'd love to do the whole thing again, like a check-in or a refresher. It'd be great if it was on-going so that people could go it regularly.-a service you could access if you were feeling unwell. It'd be nice to have an exercise piece built into it, so combine it with an exercise programme. One of the best bits of the course was getting out and having something every week to get up and go to. I enjoyed the social side of it and would always make a day of it and treat myself to a nice lunch and coffee on the day of the course.

Participant Id. 9

1. Can you tell me how you have been since completing the Wellness in Fibromyalgia Course?

Well for the 1st 3 months after completing the course everything was great, I was on track, I was reducing my medications, taking regular exercise and using my tools. Then my daughter had a very serious accident in Cork and sustained a serious head injury. We thought we were going to lose her for the 1st 2 weeks, it was so terrible. So basically I had to up and move to Cork and moved into her house for 7 months. She was in hospital for 4 months and for that 4 months I went into the hospital 3 times per day to help with her care because she didn't want anyone else doing it for her. That was very hard. Last May she started to get back on her feet and is in a new relationship now so the pressure is off me and I'm taking a step back. I'm almost medication free now. I take a half sleeping tablet every night and use paracetamol to manage the pain. I finally got to see a rheumatologist after a 23 month wait. I brought all my medical notes with me and he went through them all and basically said so you have fibromyalgia, what do you want me to do. Imagine how unhelpful that was and after waiting for so long for the appointment. I'm doing hydrotherapy now and that's great.

2. Can you describe how you have been in general since completing the course?

I've been very up and down. I've had bad times and good times. It's remembering to use the tools and take a step back to look at why things are going wrong and what I have done or could do differently. I've been trying to get regular exercise and have managed 2 park runs in the past year, so increasing the exercise. I go along to a couch to 5k on Monday, Wednesday and Friday, I do as much of the 5k as I can and then head on away home. If I have other things on now during the day I will barter with that so I'd miss the couch to 5k for one day and do the other things. Also, I'm horse riding now and its exercise so exercise of some sort 3 times per week. I always plan ahead now. One week I didn't plan and had things on 5 days so I ended up in bed for 2 weeks after that.

3. Have you noticed any health changes since completing the course?

It's hard to tell because I've been under so much stress with my daughter but yes I think in some respects I have. I mean with the brain fog, when that happens I just vegetate. I might go for a walk to get fresh air.

4. What impact, if any, has the course had on your fibromyalgia symptoms?

Can you give me an example?

I can now prioritise. My pain is worse but I'm dealing with it better. I have more pain at the moment that I've had in a long time but I'm dealing with it better. My mental attitude is different. I know I have been better and I will be better than this again.

5. What impact, if any, has the course had on how you manage your fibromyalgia symptoms?

Can you give me an example?

I manage things better. I have a plan every day and if I don't plan things just don't work. I plan realistically and I didn't do this before and I expect less of myself. So I won't be upset if I don't get the whole house cleaned in 1 day, instead I'll do 2 rooms at a time. I'm quicker to say no, I need help or I want something done. I chose my care givers too. I will not be spoken to like I'm a hypochondriac. My GP is semi-retired and there's a new locum in there, he's not very nice and doesn't understand so I wait now and only make appointments for when my GP is working. In the past I would have taken that bad attitude, now I won't. I take ownership of my fibromyalgia, it's not a dirty secret and I won't be put down. I'm more proactive now when trying to manage my symptoms.

6. What impact, if any, has the course had on your wellness?

Can you give me an example?

The course had a huge impact on how I live my life and I now have more of an input into how I live my life. It's just been so beneficial. I look at what's happening, I ask myself why is that happening and what can I do to change it. I can now say things don't matter and

stay less stressed. I can now put up a barrier and not take things on board. I wouldn't have been able to do thing like that in the past

7. What do you think of the notion of wellness tools?

Oh I think they're a great idea and have taken them on board big time. When I'm struggling and things are bad I dip into my mental toolbox. I might go get my eyebrows done; I might do some reflexology or go horse riding. I love the horse riding. I love the fresh air and it kills me you know but I put up with the pain because it makes me feel so good.

8. To what extent are you employing the WRAP plan in your life since completing the Wellness in Fibromyalgia course?

Most days I would say, it really did have a positive effect on me. I simply wouldn't have survived the stress of the 7 months in Cork without it. I did different things every day to keep me going and to normalize the situation like getting my hair done.

9. Tell me about how you are today compared to 1 year ago.

(a) What is the same?

The pain is the same but I'm not (laughs).

(b) What is different?

I'm taking the driving seat rather than the passenger seat in my condition. I go with the flow now. When I can concentrate I say to heck with it, I leave it and I do it when I can. My mental attitude is different. I now have my imaginary toolbox and if something goes wrong I use my tools to fix it. So if I'm having a bad day I think why is that happening, if I've done too much I'll take it easy for a while. If I'm tired I'll sleep. If I'm stressed I'll have a bath or if I'm in pain I'll take meds, use my back brace or my compression gloves. I evaluate what's wrong and then I choose the proper tool I can use to fix it. I evaluate the day and set realistic goals for myself. If I think yes I can do that I go ahead with it if not I re-evaluate. I plan a week ahead and if things have to change they go into the following week. My husband and I keep a calendar with my things, his things and the things we both do together written on it. If I think my calendar is starting to look full I'll stop taking on things. My pain is worse but it will get better again, I know it won't go away but it will get better.

10. What does wellness mean to you?

As well as I can be with fibromyalgia. Eating healthily and sleeping healthily is wellness to me. Being the best I can be using the knowledge I have to be the best that I can be.

11. What would you change about the Wellness in Fibromyalgia course?

I would have liked if it had been during the day because evening tend not to suit me. I loved the course, loved the content but evenings didn't suit; but I would rather have done it in the evening than not at all.

Participant Id. 10

1. Can you tell me how you have been since completing the Wellness in Fibromyalgia Course?

Well now I haven't been bad, I got a knee replacement 3 months ago and can see a massive difference in my pain. Everything I learned in the course I'm putting into place. I go to bed early now and at the same time every night and have been sleeping better, I have a better sleeping pattern so the tools I got at the course have been wonderful. I'm embracing the whole concept. Some things I already knew, it reaffirmed what I already knew but in a very focused way.

2. Can you describe how you have been in general since completing the course?

I've been good. My health is good. I know I can't change that I have fibromyalgia therefore I have to deal with learning to live with it.

3. Have you noticed any health changes since completing the course?

Health changes, let me see, Well I hadn't been taking my prescribed pain killers, I hated feeling like I needed them but now I am taking them and I'm in much less pain. I suppose I've given myself permission to take them.

4. What impact, if any, has the course had on your fibromyalgia symptoms?

Well many are still the same. I have always in the morning had to have my shower, dry myself and sit down and do my hair. By the time I have all of this done I've started sweating again. This was always a big annoyance for me. Now I haven't been able to change it but I've accepted that this is just one of those things and am getting on with it. It's the same when I drink a cup of tea, I sweat and I'm aware that this happens to me and I just accept it now.

Can you give me an example?

Well the sweating is definitely a good example. My temperature gauge is not the best (laughs) but this is a symptom and I have acceptance of it now and I got that from the course.

5. What impact, if any, has the course had on how you manage your fibromyalgia symptoms?

I suppose I focused on what was learned on the course. If someone said go to bed whatever time, don't drink tea after whatever time I'd have thought that was ridiculous. Now I have embraced the change. I did all the things that I have learned and I find I don't get as easily agitated anymore.

Can you give me an example?

I learned from someone on the course not to look at the clock when I'm lying awake in bed, now I never look at it and so I don't stress about how little sleeping time I have left and I feel so much the better for that.

6. What impact, if any, has the course had on your wellness?

I feel more confident. I know I can't change the fact that I have fibromyalgia but I can live with it. So in other words, my condition hasn't changed but my reaction to it has.

Can you give me an example?

I'm more open-minded to things now. I have more tools in my armoury. I would have been very resistant to try new things before but not now. I suppose I'm embracing new things. What I had been doing obviously wasn't working so now I try something different. The course reinforced what was right.

7. What do you think of the notion of wellness tools?

I think they're wonderful. I tell people about them all the time. My tools help me to forget about issues. They're not gone but I'm distracted so I'm not thinking about them. Distraction is brilliant. I do sewing classes now and they're a great distraction from the pain. I find that now I will ask for help and if someone offers then I'll accept. I never would have done this. Hell would have frozen over before I'd have done this (laughs). In the past I'd have been thinking I can do it, I don't need help. I'm not one bit ashamed of asking for help now. I got myself a cleaner. That was a wellness toll for me because I couldn't do all of the house work that needed to be done and then I was stressed about not being able to do it. I used to worry about what the neighbours would think about me having a cleaner, now I don't care. It's been one of the best things I ever did.

8. To what extent are you employing the WRAP plan in your life since completing the Wellness in Fibromyalgia course?

It's hard to say. I did know about wellness tools before the course but wouldn't have called them that and wouldn't have been thinking to use them. The course reinforced the idea for me. It's ok to ask for help for example.

9. Tell me about how you are today compared to 1 year ago.

(a) What is the same?

Very few things are the same, the fun side, the spiritual side and the real me are all still there. They were covered by my pain and depression but not anymore and I have remained the same.

(b) What is different?

Before I did the course, I did things on my own but now I'm giving things a go. Also what is very different is that up to this I had been attending weekly counselling. Now it's no big deal if I miss a session and it would have been in the past, I would have been freaking out. I almost have to think about things to take to the session now. I'm now coping with life better. I'm more confident, more expressive and more certain in feelings about things. Another difference is I'm allowing people to help, especially my husband. I've also learned to tune out and not listen and I avoid people who drain me. I think differently about people now. I now recognise these people and won't waste energy on them.

10. What does wellness mean to you?

Wellness I suppose means being content, happy and healthy. It means everything is well. Wellness is having friends at the end of the phone, having family over for dinner, having the children visit. Praying is wellness for me, I get great comfort from it.

11. What would you change about the Wellness in Fibromyalgia course?

I wouldn't make any changes. It was wonderful and it was great that it was delivered by someone who admitted to using the programme for working on your own life. That person's revelation was very powerful. It made me realise that there are stumbling blocks but you will get back on top. It would be nice to have a follow up to reinforce the main lessons of the programme and let you check in with whether you have stuck to the principles. Even just one session to reinforce what was learned and if you need to you can get back on track. Maybe you did the course but weren't in the right place but could be now. I find you could fall into old habits if you're not reminded.