**School of Occupational Therapy and Social Work**
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# A Randomised Controlled Trial of an Online Fatigue Self-management Group Intervention for Adults with Chronic Neurological Conditions

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**DECLARATION**

To the best of my knowledge and belief this thesis contains no material previously published by any other person except where due acknowledgement has been made. This thesis contains no material which has been accepted for the award of any other degree or diploma in any university.

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## ABSTRACT

**Background:** Fatigue is one of the most common symptoms of neurological conditions. Although the literature suggests different approaches to treatment of this pervasive symptom, there is not a single, agreed comprehensive and well-supported approach to manage fatigue. There is strong evidence (Mathiowetz, Finlayson, Matuska, Chen, & Luo, 2005; Mathiowetz, Matuska, Finlayson, Luo, & Chen, 2007) that the face-to-face fatigue self-management program designed by Packer et al (1995) is effective in improving fatigue in people with MS. However, in Australia and many other developed and developing countries this program is not available for those people who have difficulty accessing services due to geographical location, transportation problems, work commitments or who lack confidence to participate in face-to-face programs. Equity of access is an important issue not only for this particular program but also for any self-management program in Australia (and internationally) which has a large rural and remote population. Evidence highlights the need for self-management programs to be delivered in different formats to ensure equity of access. One of the suggested ways is delivering the programs online. There is sufficient evidence that people with a disability have access to the internet. Thus, this project was designed to refine and further develop a pre-designed online fatigue self-management (online FSM) program and to evaluate it in a sample of adults with chronic neurological condition through a randomised controlled trial (RCT). Further, the study intended to explore who and how people with fatigue improve in their health outcomes.

**Methodology and Results:** The aims of the project were fulfilled through four studies: 1) a pilot study; 2) a randomised controlled trial of the online FSM program; 3) a comparison with the face-to-face FSM program; and 4) exploration of predictors of improvement.

During the pilot study, three pilot tests were conducted for the purposes of formative evaluation and to make necessary changes to improve the program. During the third pilot test, the effectiveness of the online FSM was also tested using a pre-test post-test design on a sample of individuals with multiple sclerosis, Parkinson's disease or post-polio syndrome. The pilot study resulted in a standardised 7-week online FSM program mimicking its face-to-face version. Participants were offered fatigue self-

management skills through structured activities, sharing information and experiences, expressing their ideas or feelings and offering advice and support to one another. The participants in the third pilot study improved significantly on the Fatigue Impact Scale ($p<.05$) and showed a trend toward significance shown on the Personal Wellbeing Index ($p=.08$).

The RCT, the second study, included 95 participants who were randomised into one of three groups: an online FSM, an information-only FSM (info FSM) and a control group. The groups were compared at three time points (pre-test, post-test and at 3-months follow-up) on Fatigue Impact Scale, Activity Card Sort and Personal Wellbeing Index (FIS, ACS and PWI). Sores on Generalized Self-efficacy (GSE), Duke Social Support Index (SSI) and Depression, Anxiety and Stress Scale (DASS) were also used as covariates. The results showed that although both the online and information-only FSM groups improved over time on the FIS and ACS ($p < .05$), they were not significantly different from the control group or from each other at any time point. The low power in all analyses when comparing the groups revealed that a larger sample size is required to detect possible differences between the online FSM and control groups. Results of the secondary analysis on a combined group (online FSM group plus info FSM groups) showed that the online FSM and info FSM group complemented each other. The combined group showed significant differences when compared to the control group. This further suggests that the need for a larger sample size.

The literature suggests incorporating face-to-face interventions as one of the experimental conditions when testing the effectiveness of an online program. Therefore, in the third study, a face-to-face group was used as a non-randomized comparison group. As the online FSM program was designed to provide service for people who do not have access to the face-to-face program, randomisation of the participants to four groups (face-to-face FSM, online FSM, info FSM and control groups) was not feasible; restricting the inclusion criteria to participants who had access to both the face-to-face and online programs would have excluded the very people for whom the program was designed. Thus, this study compared a sample of 20 participants in a face-to-face FSM program with each of the three other groups (online FSM, info FSM and control groups) using a nonequivalent pre-test post-test

study. The findings showed that after controlling for the baseline data these participants had better scores on the FIS than the control group at post-test while these results were not seen in comparison to the online and info FSM groups. The results of this study on the face-to-face FSM program in comparison with online FSM program suggest that the online and info FSM program were successfully mimicking its face-to-face version. Further, the differences in some outcome measures and some clinical and demographic characteristics clearly demonstrated that the participants with access to the face-to-face program were significantly different than those in the RCT study. The participants who volunteered for participation in the online FSM program had lower activity levels and higher fatigue levels than the participants who had access to the face-to-face program. It appears that the two versions of the program provide access to significantly different participants.

The fourth study aimed to indicate predictors of improvement on the FIS, ACS and PWI. Regression analyses were performed to find whether baseline demographic, clinical characteristics and/or changes in clinical characteristics from pre-test to follow-up were predictors for positive health outcomes. In this study, 92 participants with complete data set (pre-test, post-test and follow-up) were included. In parallel to the results emerging in systematic reviews (Nolte, Elsworth, Sinclair, & Osborne, 2007; S. Taylor, 2005; Warsi, Wang, LaValley, Avorn, & Solomon, 2004), younger people with more severe baseline scores appear to be more likely to make clinically significant improvements in their health outcomes. Improvement in mood and self-efficacy of people with fatigue were found to be predictors of better results for fatigue. Another interesting finding of this study was that improvement in self-efficacy and stress helps people with neurological conditions to improve in their fatigue regardless of their activity level at baseline.

**Conclusion:** While fatigue is a common problem for people with fatigue secondary to neurological conditions, this online FSM program is the first of its kind to be implemented. The primary purpose of the fatigue self-management program is to help the participants improve their everyday performance and quality of life by incorporating ‘energy conservation techniques’ and self-management principles into their own life. Through the application of the fatigue self-management program,

occupational therapists and other health professionals expect that the participants will learn the self-management skills, make corresponding behaviour changes and experience a reduction in the effect of fatigue on their lives. New knowledge gained from this study can further support the idea of providing other self-management programs online. The results of this study also add to the growing body of evidence emerging regarding how information technology may assist with improving health outcomes related to chronic conditions. Further, some predictors of improvement in health outcomes in this group of people were determined. The findings provide some evidence of the potential benefits of online fatigue self-management program for people with chronic neurological conditions. Online interventions like the online FSM program represent an important strategy for bridging the gap in service for those who can not participate in face-to-face programs.

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| | |
|---|---|
| ABS | Australian Bureau of Statistics |
| ACS | Activity Card Sort |
| ANCOVA | Analyses of Covariates |
| ANOVA | Analysis of Variance |
| Aust. | Australian |
| BDI | Beck Depression Inventory |
| CAL | Current Activity Level |
| CI | Confidence Interval |
| CNS | Central Nervous System |
| COI | Combined Outcome Index |
| COPD | Chronic Obstructive Pulmonary Disease |
| CRDS | Centre for Research into Disability and Society |
| DASS | Depression, Anxiety and Stress Scales |
| EDSS | Expanded Disability Status Scale |
| FAI | Fatigue Assessment Instrument |
| FIS | Fatigue Impact Scale |
| FRS | Fatigue Rating Scale |
| FSM | Fatigue Self-management |
| FSS | Fatigue Severity Scale |
| GM | Grey Matter |

| | |
|---|---|
| GSE | Generalised Self-efficacy Scale |
| HADS | Hospital Anxiety and Depression Scale |
| HAP | Human Activity Profile |
| ICF | International Classification of Functioning, Disability and Health |
| Info FSM Program | Information-only Fatigue Self-management Program |
| ITT | Intent-to-treat |
| LOCF | Last Observation Carried Forward |
| MFMP | Multidisciplinary Fatigue Management Program |
| MPHS | Multi-Purpose Household Survey |
| MS | Multiple Sclerosis |
| Online FSM Program | Online Fatigue Self-management Program |
| PD | Parkinson's Disease |
| PPS | Post-polio Syndrome |
| PRECEDE | Predisposing, Reinforcing, and Enabling Constructs in Educational/Ecological Diagnosis and Evaluation |
| PWI | Personal Wellbeing Index |
| QoL | Quality of Life |
| RAL | Retained Activity Level |
| RCT | Randomised Controlled Trial |
| SD | Standard Deviation |
| SPSS | Statistical Package for the Social Sciences |

| | |
|---|---|
| SSI | Social Support Index |
| TICS | Telephone Interview Cognitive Status |
| UK | United Kingdom |
| US | United States |
| WA | Western Australia |
| WHO | World Health Organisation |
| df | Degree of Freedom |
| r | Pearson Product-moment Coefficient of Correlation |
| $\chi^2$ | Chi-square |
| $ | Australian Dollars |
| C$ | Canadian Dollars |

# CHAPTER 1

# INTRODUCTION

# 1 INTRODUCTION

## *1.1 STATEMENT OF THE PROBLEM AND SIGNIFICANCE OF STUDY*

Chronic disease contributes to over 70% of the disease burden in Australia. This is expected to increase to 80% by 2020 (2006). Chronic conditions are the main source of disability and the principal cause of health care expenditure in Australia (Aupperle, Beatty, Shelton Fde, & Gontkovsky, 2002). The Australian Better Health Initiative aims to reduce this cost to the individual, their family and the community by refocusing health systems to meet the needs of Australians with chronic conditions. The need for a change in the health care system seems to be more critical when the cost of chronic conditions is taken into consideration. The direct cost of the chronic conditions for the health care system (e.g. physician visits, hospitalisation) and the indirect cost (e.g. personal care, domestic care, unemployment) put burden on the society. For example, in 2005 total real financial costs of multiple sclerosis (MS) were estimated at $601m with the annual cost per person with MS estimated to be $37,333; $30 for every Australian.

Meeting health care needs of the growing population of people with chronic conditions is a problem faced by both developed and developing countries. However, traditional health care systems are primarily focused on prevention and control of acute illnesses leading to less emphasis, historically, on management of chronic disease, illness and/or disability. One strategy to bridge this gap between the persons' needs and the capacity of social and health services and to decrease the costs is the implementation of self-management programs for the individuals with chronic conditions and self-management support by health professionals (K. R. Lorig & Holman, 2003). Self-management programs provide people with chronic conditions with information, problem-solving skills and strategies to manage life with a chronic condition. This includes not only management of the symptoms but also the emotional consequences of living with a chronic condition and their day to day roles and responsibilities. There is also evidence that self-management programs are cost effective (Daniëlle, Manuela, Johannes, Emiel, & Johan, 2006; Gallefoss & Bakke,

1999; Groessl & Cronan, 2000; K. R. Lorig et al., 2002; Wheeler, Janz, & Dodge, 2003).

The Australian Government and the United Kingdom (UK) Department of Health both have a strong commitment to self-management of chronic conditions (Department of Health, 2002; South Australia Department of Human Services, 2004). Research suggests that an emphasis on chronic disease self-management can reduce general practitioner visits, hospitalisation rates and improve health outcomes (K. R. Lorig et al., 1999). Self-management programs have also been successful in reducing the morbidity of chronic conditions. Evidence in Australia highlights the need for self-management programs to reach the right people, particularly those who have difficulty accessing services due to geographical location, ethnicity, language barriers, limited literacy levels, or those who lack the confidence to be partners in their own care (South Australia Department of Human Services, 2004). Online interventions have been shown to be successful in transferring information to individuals with chronic conditions; therefore online self-management interventions may be a reasonable way to bridge the gap between needs of individuals with chronic conditions and traditional health services. However, the role of the internet in self-management of chronic conditions has received little attention in the literature.

Fatigue is one of the most common and debilitating symptoms experienced by people with chronic conditions. Fatigue secondary to chronic illness is a subjective experience associated with physiological and psychosocial manifestations. It is one of the most troublesome symptoms for people with neurological conditions, including multiple sclerosis, Parkinson's disease, and post-polio syndrome. Between 50 and 95% of these individuals report fatigue and mostly name it as their worst or one of their worst symptoms (Fisk, Pontefract, Ritvo, Archibald, & Murray, 1994; Kraft, Freal, & Coryell, 1986; Krupp, Alvarez, LaRocca, & Scheinberg, 1988). Fatigue has a known impact on quality of life and health status (Amato et al., 2001; Benedict et al., 2005; Benito-Leon, Morales, Rivera-Navarro, & Mitchell, 2003; Janardhan & Bakshi, 2002; Jonsson, Dock, & Ravnborg, 1996; Stuifbergen, 2006; Wollin et al., 2007). It results in major life changes. For example while 87% of Australians with MS are of working age (15-64 years), fatigue is reported as a central

cause of MS persons being unable to maintain full-time employment (Black , Grant , Lapsley , & Rawson, 1994; Jongbloed, 1998).

Therefore, the literature has called for rigorous research to treat fatigue. Management of fatigue includes pharmacological and non-pharmacological interventions. Pharmacological interventions have undergone randomised control studies (Canadian MS Research Group, 1987; Krupp et al., 1995; Weinshenker, Penman, Bass, Ebers, & Rice, 1992). Systematic reviews show that most pharmacological interventions result in severe side-effects and risk becoming refractory to treatment (Brañas, Jordan, Fry-Smith, Burls, & Hyde, 2000; Solari, Uitdehaag, Giuliani, Pucci, E. et al., 2008). The literature also suggests a range of non-pharmacological interventions to manage fatigue from cooling therapy to cognitive behavioural therapy, yoga, exercise and so on. One of the only standardised treatments well supported by the literature is *Managing fatigue: A six week course for energy conservation (T. L. Packer, Brink, & Sauriol, 1995).* This group 6-week program is the most well developed and commonly used fatigue self-management program internationally. The efficacy of the fatigue management program has been tested by several independent researchers (Mathiowetz et al., 2005; Mathiowetz, Matuska, & Murphy, 2001; Sauter, Zebenholzer, Hisakawa, Zeitlhofer, & Vass, 2008). Although the results have shown the efficacy of the fatigue self-management program, most Australians can not access it because the program is being offered in limited metropolitan areas. Those who live in rural and remote areas, or who have transportation difficulties, or are confined to the house due to disability or work full time are also denied access the face-to-face version of the program. Therefore, this research project examined the effectiveness of a newly developed online version of the program - a novel way to manage fatigue secondary to multiple sclerosis and other chronic conditions. If this program is effective, people with MS in Australia will have available an evidence-based intervention, accessible to people who face transportation barriers, the tyranny of distance or an inability to attend at set times.

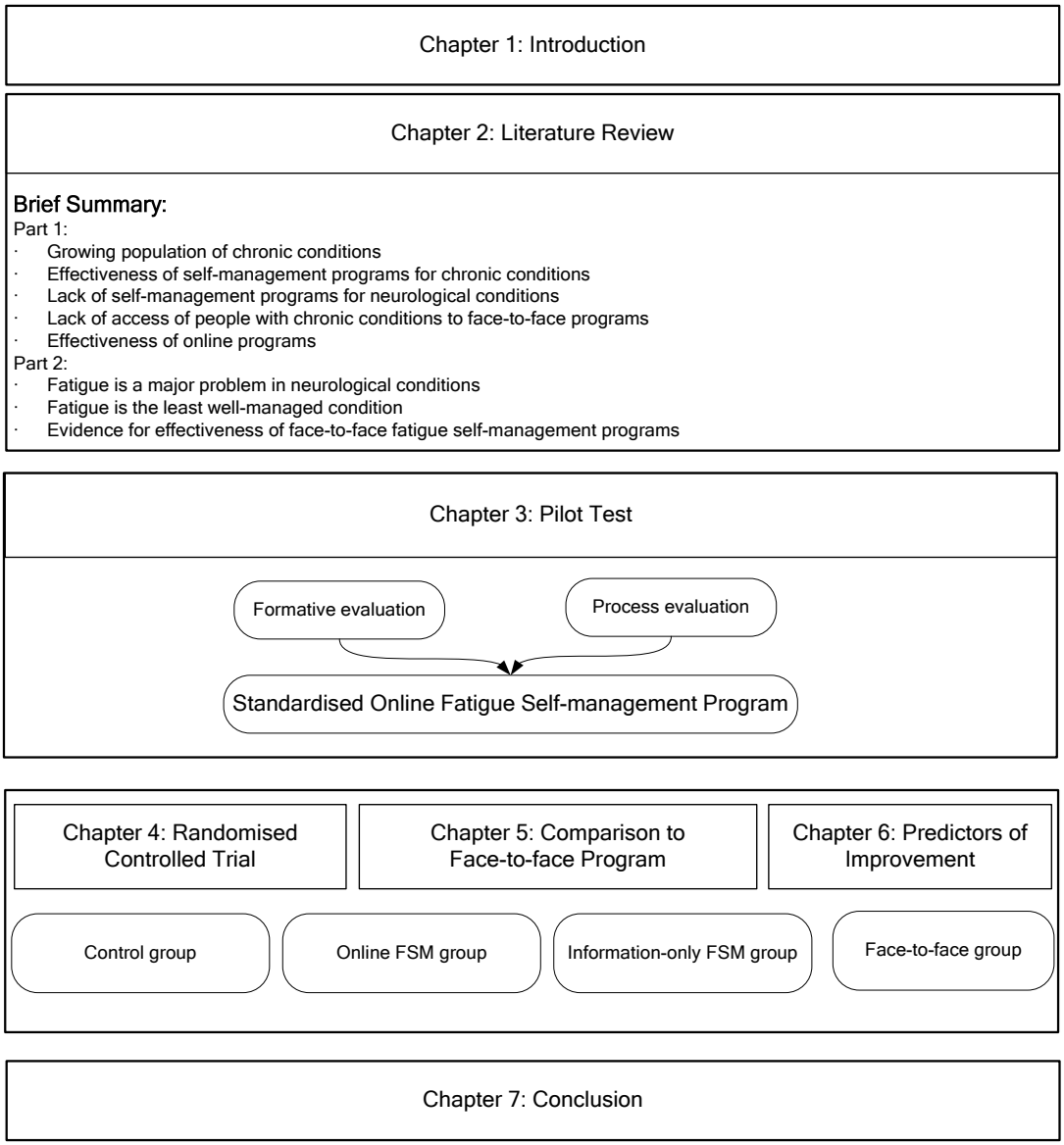
Hence, this study employed an RCT to evaluate the efficacy of an online self-management group intervention and compare it with an online information-only fatigue self-management group and a control group in a sample of adults with chronic neurological conditions. The literature suggests incorporating face-to-face

treatment interventions as one of the experimental conditions when testing the efficacy of an online program (Ritterband et al., 2003). Therefore, a face-to-face comparison was also included in this research. Although there are many systematic reviews on the efficacy of self-management programs, there is a scarcity of literature on who and how people improve in their health outcomes, and what should be done for people with different levels of activity to help them reduce their fatigue. Subsequently, this study also applied a secondary analysis approach to re-evaluate the data collected in the main part of study in order to facilitate a better understanding of the relationships between quality of life, fatigue and activity participation and social support, self-efficacy, mood, and their role in chronic disease management.

## *1.2 OVERVIEW OF THE THESIS*

This thesis is organised in seven chapters. The first two chapters are the introduction and literature review. The development process and formative evaluation of the online fatigue self-management program is presented in Chapter 3. This chapter also includes the results of a preliminary effectiveness evaluation in preparation for the RCT. In Chapter 4 the RCT is used to evaluate the efficacy of the online fatigue self-management program in comparison with information-only and control groups. Chapter 5 compares the participants in the face-to-face group with those of the online fatigue self-management, information-only fatigue self-management and control groups. In Chapter 6, predictors of improvement for the participants are explored. Chapters 2 to 6 also include discussions related to the study. An overview and conclusion of the results of the four studies is summarised in Chapter 7 (Figure 1).

Figure 1.1 Overview of the Study




## *1.3 OVERVIEW OF THE PROJECT*

### *1.3.1 STUDY 1: A PILOT TEST OF AN ONLINE FATIGUE SELF-MANAGEMENT PROGRAM*

The online fatigue self-management program was based on the face-to-face protocol developed by Packer et al. (1995). The prototype for the online FSM program was designed during the AussieNet Project funded by Lotterywest. While the researcher was involved in all stages of the AussieNet project, it was not part of this PhD study. Once the initial protocol was developed, formative evaluation was undertaken (Objective 1 of this PhD). The formative evaluation included three pilot tests. The

collected information during and after each pilot test was used to further improve the protocol.

The third pilot test of formative evaluation provided the opportunity to undertake a small, preliminary efficacy study (Objective 2) using a single group pre-test, post-test design. This resulted in a standardised program to be tested in the RCT study of this PhD project.

### *1.3.2 STUDY 2: A RANDOMISED CONTROLLED TRIAL OF AN ONLINE FATIGUE SELF-MANAGEMENT PROGRAM FOR ADULTS WITH CHRONIC NEUROLOGICAL CONDITIONS*

The main objectives of this study were to evaluate the efficacy of the online fatigue self-management program (Objective 3) and then to compare it with an information-only fatigue self-management group and a control group in a sample of adults with chronic neurological conditions (Objective 4). The primary outcomes were fatigue, quality of life and activity participation.

### *1.3.3 STUDY 3: COMPARISON OF THE FACE-TO-FACE FATIGUE SELF-MANAGEMENT PROGRAM WITH OTHER VERSIONS OF THE PROGRAM*

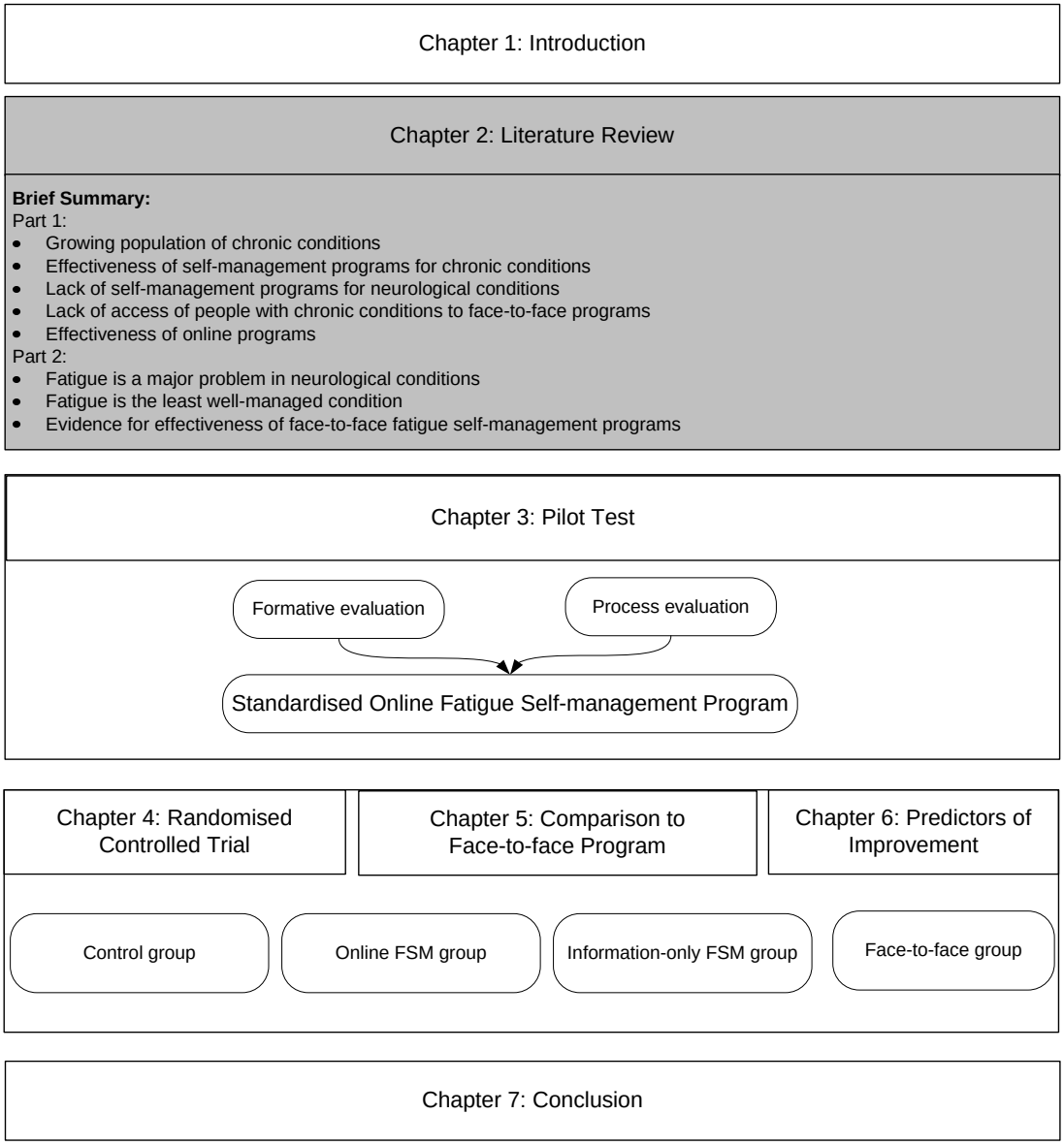
As the online FSM program was designed to provide service for the people who do not have access to the face-to-face program, randomisation of the participants to four groups (face-to-face FSM, online FSM, info FSM and control groups) was not feasible because restricting the inclusion criteria to participants who had access to both the face-to-face and online programs would have excluded the very people for whom the program was designed. Subsequently, a nonequivalent pre-test post-test control study of the face-to-face fatigue self-management program was designed to evaluate the efficacy of the face-to-face fatigue self-management program (Objective 5) and compare it with the online fatigue self-management, information-only fatigue self-management and control groups in a sample of adults with chronic neurological conditions (Objective 6).

### *1.3.4 STUDY 4: PREDICTORS OF IMPROVEMENT FOR ADULTS WITH FATIGUE SECONDARY TO CHRONIC NEUROLOGICAL CONDITIONS*

A secondary analysis was conducted on all complete data sets in order to re-evaluate all data collected from the fatigue self-management programs (RCT and face-to-face studies). Regression analysis, which is a powerful statistical approach for explaining and predicting quantifiable clinical outcomes (Portney & Watkins, 2008), was used to be able to predict outcomes and characteristics which are crucial to effective fatigue self-management programs. The aim of this study was to answer three clinical questions: What clinical and demographic characteristics predict the likelihood of improvement in people with fatigue? (Objective 7); What changes in clinical characteristics predict the likelihood of improvement people with fatigue? (Objective 8); and What are the predictors of improvement in fatigue for people with different baseline activity levels? (Objective 9). Data was collected at all time points in order to undertake the planned secondary analysis.

# CHAPTER 2

# LITERATURE REVIEW



# 2 LITERATURE REVIEW

## *2.1 INTRODUCTION*

This chapter provides background information needed to understand current literature on self-management programs and fatigue in neurological conditions. The literature on self-management is broad, ranging from self-management models to efficacy of self-management programs. Likewise, research reporting on different aspects of fatigue and its management is also extensive, including many characteristics of fatigue, its impact on the person's life and its management. Therefore, the literature outlined in this chapter is divided into two main parts: Part 1) chronic conditions, self-management and internet interventions, and Part 2) fatigue in neurological conditions. The first part includes prevalence and impact of chronic conditions, management of chronic conditions, definitions and models of self-management programs. This part also reviews the theoretical framework and important components of self-management programs, followed by an overview of who benefits most from self-management programs and how. Barriers to provide self-management programs are also reviewed. Then, online interventions, their advantages and disadvantages and effectiveness and access to the internet by people with chronic conditions are highlighted. The second part of this chapter reviews the definitions, prevalence, types, causes and correlates of fatigue. It also reviews how fatigue is related to depression and activity and how it impacts on psychological and physical aspects of life and then, how fatigue can be managed, again with emphasis on self-management.

## *2.2 PART 1: CHRONIC CONDITIONS, SELF-MANAGEMENT AND THE INTERNET INTERVENTIONS*

### *2.2.1 PREVALENCE AND IMPACT OF CHRONIC CONDITIONS*

Management of persons with chronic conditions is a long-standing challenge for health care organisations. A chronic health condition is "any condition that presents itself for longer than six months, involves slow changes and may be controlled but is often not curable" (The Royal Australian Colledge of General Practitioners, 2004, p.3). The World Health Organization (WHO) estimates that 41 million people will

die from chronic conditions in the year 2015, 20% of which will occur in high income countries, including Australia. Based on the results of a study in 2004-05, over three quarters of Australian people living in private dwellings had at least one chronic condition (WHO, 2005). The proportion of the population with at least one condition increased with age. Almost 100% of people aged 65 years and over were living with at least one chronic condition (Australian Bureau of Statistics, 2004-2005).

The impact of a chronic condition/s on the individual and community is immense. Although often not immediately life-threatening, chronic conditions place a substantial burden on the health, economic status, and quality of life of individuals, families and communities. In Australia, chronic conditions contribute to around 80% of the total burden of disease and health problems as measured by disability-adjusted life years (DALYs) (National Health Priority Action Council, 2006, p.3).

The financial costs for chronic conditions are also high. For example, in 2005 while only 14900 people across Australia were reported to have multiple sclerosis (prevalence of .08%) the total financial cost to the health care system was $601 million (Access Economics Pty Limited, 2005). The cost of arthritis is similarly very high. The reported cost for arthritis (16.5% of the population, which was equal to 3.1 million people in 2001) was $8.96 billion (Access Economics Pty Limited, 2001). The Australian Better Health Initiative (Department of Health, 2006) aims to reduce this cost to the individual, their family and the community by refocusing health systems to meet the needs of Australians with chronic conditions.

### *2.2.2 THE CURRENT CONTEXT FOR THE MANAGEMENT OF CHRONIC CONDITIONS*

The WHO recommends overcoming the high impact of chronic conditions by using accurate information, scientific knowledge and effective interventions (World Health Organization, 2005). Because of the nature of chronic conditions, management varies over time, with treatments adjusted according to changes in the person's symptoms and fluctuations as the condition progresses. A client-centred approach, with persons contributing to and driving the management process, gives the opportunity to the

individuals to live with their chronic condition with the least negative impact on their lives and consequently on their community.

One suggested strategy is the implementation of self-management programs for people with chronic conditions and self-management support by health professionals. Research shows that people with effective self-management skills make better use of health care professionals' time (Barlow, Turner, & Wright, 2000; K. R. Lorig et al., 1999). People live with their chronic condition on a daily basis over a long period of time therefore their ideas and behaviours are important. Changing attitude and behaviour can influence the way people manage their condition (The Royal Australian Colledge of General Practitioners, 2004). Consequently, persons with the chronic condition play an integral role in the management of the condition (Bodenheimer, Lorig, Holman, & Grumbach, 2002).

Given the current crisis in health care systems and the burden of chronic disease, the focus on self-management in health policy is not surprising. The WHO Global Strategy on Diet, Physical Activity and Health recommends "promoting incentive-based approaches to encourage prevention and control of chronic diseases" all over the world (World Health Organization, 2006, p. 53).

The current health system in Australia is based on acute care principles. There is a major difference between acute care and chronic disease management. With acute care, the treatment aims at returning the person to normal life while in chronic disease management, the person's life is irreversibly changed and neither the disease nor are its consequences static (Holman & Lorig, 2000). For chronic disease management, health care systems need to have the capability to respond to a unique person's choices and preferences, accommodate differences in a person's preferences, and also encourage shared decision making (Briere, 2001). Currently, the acute health care systems are known to be insufficient and ineffective in responding to the growing population of people with chronic conditions (Briere, 2001).

The importance of changing care for people with chronic conditions has also been reflected in different countries' health policies. In the US, the Chronic Care Model recognises self-management as one of the major components for treating chronic

conditions (Bodenheimer, Wagner, & Grumbach, 2002). Another example of a specific focus on self-management internationally is the Expert Patients Programme in the UK which aims to develope the confidence and motivation of the person to use their skills, information, and professional services to take effective control over living with a chronic condition (Kennedy, Gately, & Rogers, 2004).

In Australia, at the policy level, self-management is identified as one of the four key action areas along with prevention across the continuum, strengthening early detection and early treatment, and integration and continuity of prevention and care (National Health Priority Action Council, 2006). In 2006-2007, self-management programs were funded as a part of the Promoting good health, prevention and early intervention package by the Australian Government. The budget for this package is $250 million over 5 years.

### *2.2.3 DEFINITION OF SELF-MANAGEMENT*

Defining self-management requires an examination of the premises on which an acceptable definition is based. It is also necessary to understand the tasks and skills required for people to self-manage a chronic condition. Self-management programs are based on the premise that while the health professional is an expert on the disease/condition, persons with chronic conditions are the experts on living with the condition (Bodenheimer, Lorig et al., 2002). In most cases, health professionals cannot accurately set the goals themselves. Individuals with chronic conditions know their needs and can provide information and preferences that are complementary to the health professional knowledge. In general, the person with the chronic condition provides the individual information and the health professional the general information, and both are necessary for effective management (Holman & Lorig, 2000).

According to Corbin & Strauss (1988) there are three sets of tasks and skills required for self-management of chronic conditions. The first task is the medical management of the condition, such as taking medication, adhering to a diet, or taking a tablet. The second set of tasks is maintaining, changing and creating new meaningful behaviours or life roles. The third set of tasks is to deal with the emotional sequelae of having a chronic condition. As emotions such as anger, fear and frustration are commonly

experienced by people living with chronic conditions, learning to manage these emotions is part of the work required to manage the condition (K. R. Lorig & Holman, 2003). The skills needed for performing the tasks include problem solving, decision-making, finding and utilising resources, forming partnership with health professionals and taking action (Bodenheimer, Lorig et al., 2002).

Therefore, self-management is a dynamic multi-dimensional concept which is about personalised living, people choosing how to manage their condition(s), optimal living with the condition and its outcome is to promote health and well being (C. Foster, Brown, Killen, & Brearley, 2007). Self-management is related specifically to living with a long term condition: "The individual's ability to manage the symptoms, treatment, physical and psychosocial consequences and lifestyle changes inherent in living with a long term disorder" (Department of Health, 2005, p.6).

### *2.2.4 MODELS OF SELF-MANAGEMENT*

Recognition of the current burden of chronic conditions on the individual and the society has resulted in increasing interest and investment in examining self-management support models in order to meet the needs of people with chronic conditions. The literature identifies two major types of self-management support: the compliance based or medical model and the collaborative model, also known as empowerment (Bodenheimer, Lorig et al., 2002; Bodenheimer, Wagner et al., 2002; Jordan & Osborne, 2007; Koch, Jenkin, & Kralik, 2004). The former which appears to be more common in 'real life' clinical settings (Holmström & Rosenqvist, 2005) is a model where persons receive professional support and direction and follow the given instructions to self-manage aspects of their condition. A number of disadvantages are known for the 'compliance based' medical approach. This model represents a barrier to the uptake of self-management as the continued socialisation of people with chronic conditions into the medical approach encourages continued dependence on professionals (R. M. Anderson, Funnell, Barr, Dedrick, & Davis, 1991). In the compliance based approach, the main concept is adherence to the prescription of the health professionals, based on the professionals' identification of problems. In this model, it is thought that not only the persons bring little to the table besides their condition (Bodenheimer, Lorig et al., 2002) but also they may be blamed by the professionals for their shortcomings. This approach largely ignores the

'self' in self-management (Koch et al., 2004) and conflicts with the foundations of self-care and self-management for people living with chronic disease (Department of Health, 2005). Therefore, the compliance based model is no longer viable in light of current policy changes in Australia (National Health Priority Action Council, 2006).

The other type of self-management support relies on a collaborative relationship between health-care professionals and persons with chronic conditions. The collaborative model has been proposed as an approach which enables the link between persons' needs and health care systems (K. R. Lorig, 2003). This method of delivery of care represents a greater shift in control, from the health-care professional to the person (Department of Health, 2005). Programs based on this approach see the individuals as central in managing their condition, and the collaborative partnership between persons and providers is the means for achieving effective care (K. R. Lorig, Sobel, Ritter, Laurent, & Hobbs, 2001). In a collaborative model, persons accept responsibility to manage their own conditions and are encouraged to solve their own problems with information, but not prescriptions, from professionals (Bodenheimer, Lorig et al., 2002). In this model the persons seek, and are actively involved in a relationship with health professionals. This close relationship facilitates making choices by the persons in levels of support they receive. Although the level of support requested may vary subject to the illness trajectory and the individual's circumstances, Koch et al. (2004) suggest that self-management is related to decision making and personal accountability. In this approach, people with conditions have expertise of similar importance to the expertise of professionals. While professionals are experts about diseases, persons are experts about their own lives. Although the collaborative model of care is not the dominant approach in primary care practices, its effectiveness at managing chronic conditions is documented broadly in the literature.

### *2.2.5 SELF-MANAGEMENT PROGRAMS*

#### 2.2.5.1 THE ROLE OF SELF-EFFICACY IN SELF-MANAGEMENT PROGRAMS

As self-efficacy beliefs and expectations strongly influence individual's choices, decisions, behaviours, and persistence (Brekke, Hjortdahl, & Kvien, 2003), many argue that a good self-management program should rest on a theoretical basis of

changing self-efficacy (Burckhardt, 2005). Self-efficacy is defined as the confidence or belief that an individual has in their ability to execute a particular cognition or behaviour (Bandura, 1997a). Self-efficacy is a part of self-regulatory processes through which individuals shape environmental and interpersonal resources and behaviour toward a desired end (Bandura, 1997b). The concept of self-efficacy is the central tenet of Bandura's social learning theory (Bandura, 1997b). This theory emphasises the underpinning role of personal mastery in the psychological and behavioural processes leading to behavioural change (Maddux, 1995). Based on Bandura's theory, efficacy beliefs have a potent influence in self-knowledge and beliefs of self-determination and they direct human behaviour on a fundamental level (Bandura, 1997b). Bandura (1997b) argues that self-efficacy provides an explanation for one common mechanism through which people exercise influence over their own motivation and behaviour. Self-efficacy theory proposes that confidence in personal ability to carry out a behaviour (i.e. self-efficacy) influences the direction, intensity, and persistence of that behaviour (Bandura, 1997a).

Evidence for the importance of measuring self-efficacy in a self-management intervention can be extrapolated from the literature that shows a relationship between self-efficacy and quality of life (Han, Lee, Lee, & Park, 2003; Robinson-Smith, Johnston, & Allen, 2000). Moreover, Amir, Roziner, Knoll and Neufeld (1999) examined the influence of social support and mastery (measured by locus of control and self-efficacy) mediating between disease severity and quality of life (QoL) in a sample of 89 people with epilepsy. Ninety percent of the variance of the quality of life was explained by a combination of disease severity, self-efficacy in epilepsy, social support, and locus of control. Mastery was found to mediate the correlation between disease severity and quality of life, and social support was found to act as a mediator between disease severity and mastery. They concluded that self-efficacy and social support act as mediators between disease severity and quality of life in epilepsy. There is also evidence for association of multiple sclerosis (MS) quality of life and self-efficacy. A study indicated that base-line and change in self-efficacy for function and control (MS Self-efficacy scale) were predictors of changes in physical and psychological components of quality of life in the 29-item Multiple Sclerosis Impact Scale in people with MS (Motl & Snook, 2008). The authors have

emphasised that identifying educational and rehabilitation methods for increasing self-efficacy may maximise positive outcomes in treatment of MS symptoms.

There are a great number of studies with different settings/population showing improved self-efficacy as an outcome of self-management interventions. For example, an RCT with long-term follow-up showed significant improvements in self-efficacy and health management behaviours following participation in a tailored general chronic disease self-management program and these results were sustained for over 3 years (K. R. Lorig et al., 1999). This relationship is also seen in participants with different living situations. A study on an under-serviced, poor, rural population in US also showed improvement in self-efficacy and self-management behaviour in people with chronic disease (K. Farrell, Wicks, & Martin, 2004). Disease specific studies report improvement in self-efficacy, as well. An example is an RCT study by Girdler (2004) on efficacy of self-management intervention for adults with age-related vision loss. Participants showed significant improvement in generalised self-efficacy at post-test and follow-up (both $p < .0001$) compared to those who received usual care.

#### 2.2.5.2 IMPORTANT COMPONENTS OF SELF-MANAGEMENT PROGRAMS

While the reviews have reported the relative efficacy of self-management programs in chronic conditions, there are still unknowns when explaining the factors needed to be included in a program to be called a 'self-management program'. Some authors of systematic reviews criticised studies on self-management interventions for not fully describing the content of the interventions and providing little information about their intervention background and suggest that this problem could be overcome by publishing protocols to ensure consistency of content and allow accurate interpretation of the intervention and explaining how they are effective (S. A. Brown, 1999; Norris, Engelgau, & Narayan, 2001). Notable is the independent development of different interventions with little regard to building on previous research. An exception to this is the work within some research groups (for example see the work of Glasgow, 1995, Wing and Anhin, 1996, Wing and Epstein 1988) where more systematic development has occurred for interventions for self-management of diabetes. This led to the current position where aside from acknowledgement that

didactic interventions is insufficient there is little consensus over what components are most effective in self-management interventions.

However, some studies have highlighted some important components of the self-management program. Barlow and colleagues (2002) stated that for self-management to be effective, it needs to encompass the "ability to monitor one's condition and to affect the cognitive, behavioural and emotional responses necessary to maintain a satisfactory quality of life" (p. 190). This definition implies that a well-designed self-management intervention not only includes personal symptom management but also improves the daily occupations and the psychosocial life of the individual. The literature also suggests that effective interventions should be delivered in collaboration with individuals and their families and enable them to take an active role in their care, improve their knowledge and self-management skills (Holman & Lorig, 2000; Von Korff, Glasgow, & Sharpe, 2002). Further, a meta-analysis suggested that interventions that use face-to-face delivery, cognitive reframing or include exercise content are more likely to improve Glycaemic control (as a health outcome) than other approaches (Ellis et al., 2004).

The literature gives contradictory results on the effects of different components of self-management programs. While Norris (2002) suggest that interventions with greater contact time are associated with greater change in glycosylated haemoglobin (as a health outcome), Brown (1992) found that length of program was not associated with outcome.

In a meta-regression, Warsi et al. (2004) considered characteristics specific to the educational program: the duration of education, number of educational sessions or education contacts, background of facilitators (e.g. medicine, nursing, social work, health education), setting of the educational program (inpatient versus outpatient), educational format (group versus individual), method of the education (written, audiotape, telephone, or face-to-face) and use of a formal syllabus. They found that the only program characteristic associated with improved outcomes was face-to-face education. This suggests that for any controlled trial study on effectiveness of online self-management intervention, the results should be compared with face-to-face intervention. Chodosh et al. (2005) attempted to find components of self-

management programs which are most responsible for benefits. They hypothesised the following five elements to be essential for a successful self-management program: 1) Tailoring: providing a disease specific program 2) Having a group setting 3) Giving individual feedback 4) Having a psychological emphasis in the program 5) Providing the program by the participants' medical providers. However, despite their aim, they reported that the existing data does not provide enough information to determine which elements of the programs are most responsible for benefits. However, Mühlhauser and Berger (2002) argue that this attempt to dissect the programs into single components and to evaluate them separately is not suitable for self-management interventions which are complex interventions. "Complex interventions in health care comprise a number of separate elements which seem essential to the proper functioning of the intervention although the 'active ingredient' of the intervention that is effective is difficult to specify" (Medical Research Council, 2000 , p.1). Therefore, it is difficult to isolate the 'ingredients' to determine which of them is responsible for the outcome (Duncan, Paley, & Eva, 2007).

#### 2.2.5.3 EFFICACY OF SELF-MANAGEMENT PROGRAMS

Evidence based on RCTs shows self-management to be useful in maintaining and improving individuals' quality of life, health behaviours and health status, while lowering health care utilisation through improved self-management skills, self-efficacy, and better communication between individuals and health providers (For example Adams et al., 2003; Barlow et al., 2000; Bruce, Lorig, Laurent, & Ritter, 2005; Ghosh, 1998; K. R. Lorig, Ritter et al., 2001; K. R. Lorig et al., 1999). However, several systematic reviews of the literature have explored the efficacy of these programs more thoroughly, shedding new light on the weight of evidence.

Self-management interventions have been shown to have long-term effects on participants' quality of life (K. R. Lorig & Holman, 1989; K. R. Lorig, Ritter, Laurent, & Fries, 2004). A systematic review (Gibson et al., 2003) has assessed the effects of asthma self-management programs on adults' quality of life. They have included thirty six trials. Quality of life was assessed in ten studies, six of which provided mean total scores. Overall there was a significant improvement in total quality of life score for those participants receiving self-management intervention (standard mean difference 29, confidence interval .11 to .47). Recently Foster,

Taylor, Eldridge, Ramsay, & Griffiths (2007) reported a systematic review of lay-led self-management programs for people with chronic conditions. They included seventeen trials involving 7442 participants. The authors concluded that lay self-management education programs may lead to small short-term improvement in people's self-efficacy, self-rated health, cognitive symptom management and frequency of aerobic exercise. Although the review showed there is not sufficient evidence to suggest that such programs improve health quality of life, they have emphasised that the studies were heterogeneous in conditions, outcomes collected and effects. Steed, Cooke and Newman (2003) systematically reviewed studies on self-management and psychological intervention for people with diabetes and specifically focused on depression, anxiety, adjustment and quality of life as outcome measures for these studies. Reviewing 36 articles, they did not detect detrimental effects following any type of intervention. Depression was particularly improved following psychological interventions whilst quality of life improved more following self-management interventions. It is of note that beneficial effects of self-management interventions were less clear in the long term. The authors also reported that while most randomised controlled trials indicated no benefits for anxiety, pre-post trials reported improvements in this symptom.

It is also important to note that there is a growing evidence of significant association between social support and quality of life (S. Cohen, 1988). Change in social support is reported to be a significant predictor of changes in health-related quality of life in heart failure, rheumatic arthritis, spinal cord injury and other chronic conditions (Bennett et al., 2001; Hampton, 2001; Han et al., 2003; Minnock, Fitzgerald, & Bresnihan, 2003). A qualitative study in Australia showed social contact and comparison to be the strongest and most common perceived benefits of self-management for people with stroke (Catalano, Dickson, Kendall, Kuipers, & Posner, 2003).

Some systematic reviews have concentrated on medical outcomes of self-management programs. Warsi et al. (2004) report results of a systematic review evaluating the efficacy of interventions containing self-management education components that had a concurrent control group and evaluated clinical outcomes. They excluded the outcomes of knowledge, compliance, self-efficacy, satisfaction,

quality of life and/or depression. They also expelled studies involving physical or psychosocial therapies such as exercise and group therapy. They concluded that self-management education programs resulted in small to moderate effects for people with diabetes and asthma but not for arthritis. Another systematic review (Chodosh et al., 2005) also showed that pooled effects of the self-management programs were statistically significant but clinically small for pain and function outcomes for osteoarthritis. The systematic review was focused on chronic self-management programs for older adults with diabetes mellitus, hypertension and osteoarthritis. A random-effects meta-analysis was conducted and revealed a statistically and clinically significant pooled effect size of -.36 (95% CI, -.52 to .21) for hemoglobin $A_{1c}$, which is equivalent of the reduction in hemoglobin $A_{1c}$ level of about .81%. Decrease in systolic blood pressure by 5 mm Hg (effect size, -.39) and decreased diastolic blood pressure by 4.3 mm Hg (effect size -.51) was reported (Chodosh et al., 2005).

A systematic review on self-management studies on chronic obstructive pulmonary disease (COPD) by Monninkhof et al. (2003) found no improvements for hospital admissions, emergency room visits, days lost from work and lung function. They also pointed out that there are many limitations in published literature such as using inappropriate outcome measures and that the programs mostly focus on symptom management and not on improving self-management skills or behavioural change. Conversely, research reveals a positive effect of self-management programs on costs associated with COPD. In a study of the economic benefits of person with COPD in Canada, researchers estimated that providing chronic persons with education on self-management as well as ongoing supervision by a case manager would yield a savings of over C$2000 per persons per year (Bourbeau et al., 2006).

The literature on self-management has predominantly focused on chronic conditions like arthritis, diabetes, and respiratory disorders (Chodosh et al., 2005; Cicutto & Brooks, 2006; Kralik, Koch, Price, & Howard, 2004; Monninkhof et al., 2003; Norris et al., 2001; Norris, Nichols et al., 2002; Siebenhofer, Berghold, & Sawicki, 2004; Willems, 2006). Very few studies have been conducted on the efficacy of self-management for people with neurological conditions. For instance, only four out of

146 articles on self-management for chronic conditions which were reviewed by Barlow et al. (2002) specifically addressed neurological problems.

Although systematic reviews and meta-analyses provide the highest level of evidence for effectiveness of programs (Portney & Watkins, 2008), if the theory behind the programs and the difference between trials designed to determine efficacy and those focusing on implementation are not taken into consideration, the results would not allow for adequate appraisal (Mühlhauser & Berger, 2002). Self-management programs are considered complex intervention. When evaluating a complex intervention, the heterogeneity in their goals, methods and target populations should be accurately considered. Lenz, Steckelberg, Richter, & Mühlhauser (2007) conducted a methodological review on systematic reviews for complex interventions and used diabetes and hypertension self-management as examples. They included 14 reviews. Their review on comparable topics identified different publications of the same program which were classified differently within and between reviews. They concluded that methods of current systematic reviews are not fully equipped to appraise person education and self-management programs. Also they considered that since these programs are complex and heterogeneous, consideration of aggregated evidence in necessary.

#### 2.2.5.4 WHO BENEFITS MOST FROM SELF-MANAGEMENT PROGRAMS AND HOW

Although self-management programs are being used world-wide, there is little known about the characteristics of the participants who may benefit most from these programs. Structured reviews are limited partly by the difficulty in interpreting the included trials. In a paper reviewing asthma self-management, participants suitable for guided self-management are mentioned as the individuals with moderate or severe asthma, variable disease, history of emergency room visits owning to asthma, bad perception of the severity of the disease and good cooperation (Lahdensuo, 1999). However, the authors did not provide any proof for their opinion.

The literature suggests that a person's willingness to adopt the self-management approach is one example of a personal characteristic that determines effectiveness (Prochaska & DiClemente, 1992; Prochaska, DiClemente, & Norcross, 1992). That is, when people are not really convinced that self-management can be beneficial,

they may adhere to it as long as they are in the program, but they will be prone to relapse. This participant characteristic of willingness to adopt a certain new behaviour is conceptualised as 'readiness to change' (Dijkstra, Vlaeyen, Rijnen, & Nielson, 2001; McConnaughy, Eileen, Prochaska, & Velicer, 1983; Prochaska & Norcoss, 2001). Research shows significant difference in clinical improvement between participants in self-management program depending on their levels of readiness to change in pain and diabetes program (Peterson & Hughes, 2002). A motivational model for pain self-management goes one step further and suggests the perceived importance and self-efficacy influence an intermediary factor, readiness to change. They also called for further study to test whether readiness to change predicts engagement in self-management behaviours (Jensen, Nielson, & Kerns, 2003).

While several important variables like educational level, disease duration, disease severity, social supports, medication effects and the level of self-efficacy may contribute to the success of an educational program, Warsi et al (2004) reported that needed data was under reported in the literature. Nolte, Elsworth, Sinclair, and Osborne (2007) conducted large study on 1341 Australian individuals with a wide range of chronic conditions who attended self-management courses. They conducted a subgroup analysis to explore baseline differences by stratifying the sample by age, gender and level of education. The authors concluded that younger women were more likely to benefit from self-management interventions across most heiQ scales but they had lower baseline scores than older women (Richard H. Osborne, Elsworth, & Whitfield, 2007). There were no significant differences for people across educational levels.

Only a few studies have specifically explored what people do to help themselves, what enables them to do so, and how this can be supported. Foster et al. (2007) published a Cochrane Library systematic review and explored how people help themselves following a cancer diagnosis. They concluded that as self-management is poorly defined and lacks a theoretical framework, it is not yet possible to draw a conclusion on how self-management programs work.

#### 2.2.5.5 BARRIERS FOR SELF-MANAGEMENT PROGRAMS

Despite the importance and effectiveness of self-management programs for people with chronic conditions, these programs have been underused for several reasons. First, in some countries like the US, because there is no reimbursement, the programs are largely given outside the mainstream of the health care system (Kaplan & Davis, 1986). Second, a large number of people with chronic conditions cannot or will not attend group education programs for reasons including severity of disability, limited access to transportation or living in a rural or remote area (Jerant, Friederichs-Fitzwater, & Moore, 2005). Third, logistics problems such as scheduling could render it difficult to run the program (K. R. Lorig et al., 2004). Currently, most face-to-face courses are being run during the day. There is a view that this excludes people in the workforce who might benefit from the self-management programs. Consideration of running courses online or face-to-face programs at different times of the day to suit those in employment has been recommended (Kennedy et al., 2004).

The same barriers, more or less, exist in Australia. Recruitment of a sufficient number of participants able and interested to take part in the programs is known as one of the barriers integrating self-management programs into the Australian health care system (Jordan & Osborne, 2007). One of the major limitations of using community-based, face-to-face interventions is that participants must have their own transportation or the program providers must offer it. In Australia, being able to drive or to use public transportation is a major barrier to accessing community programs for many people with disabilities, including people with neurological conditions. For example, only 61% of people with MS live in major cities (Simmons, Hendrie, McDonald, Tribe, & Vowels, 2004). This means most people who need the programs can not attend. Workforce issues and referral issues are also barriers to self-management programs (Jordan & Osborne, 2007). Collectively, these findings highlight the importance of different formats of service delivery in overcoming barriers to accessing self-management support (Nour, Laforest, Ggnac, & Gauvin, 2005).

### *2.2.6 ONLINE INTERVENTIONS*

According to Jordan & Osborne (2007) delivery of programs at a local level is one of the factors essential for advancing chronic disease self-management programs in Australia. Internet self-management interventions may provide a new format of delivery for people who are traditionally marginalised as a result of geographical location, severity of disability or employment.

Optimism for the potential positive impact of online delivery is attributable to several advantages of the internet over other self-management intervention methods. These may act to reduce the barriers and increase access to self-management programs. Delivery of self-management programs using internet technology has the potential to reach a larger number of people with chronic conditions and reduce the burden of the condition on their life. The internet constitutes a widely available and affordable multimedia instructional medium that can help overcome some of the barriers to delivering effective self-management program (Devineni & Blanchard, 2005).

There are many other attractive features to online interventions. Madara (1997) argues that a community "is more easily found, chosen, or started online" (p.23). Online interventions require access to computer hardware and technical assistance but they are not limited by a local community's size, geography, or social services. Online interventions can deliver, customise and record all the program sessions and provide the person an opportunity to communicate with health professionals and with other people with chronic condition. The interactive nature of the internet, combined with the potential to store large volumes of information, provides a unique opportunity to offer high-quality interactive online interventions (Ritterband et al., 2003). The internet is available 24 hours per day, and can provide connection between clients and their health professionals. Web browser interfaces are easy to use, the person has only to click a mouse button to interact with the program and different programs utilise the same familiar looking screen layout. The information content of the Web page can be personalised for individual persons using data from their electronic record (Stoop, Rietb, & Berga, 2004). Displaying photographs and video clips in a Web browser does not need additional expensive hardware and quality person hand-outs containing text and graphics can be generated inexpensively. Conversely printed, education booklets are costly to produce and

update. Relaying information, enabling informed decision-making, promoting health behaviours, promoting peer information exchange, an emotional support, promoting self-care managing demand for health services and equity are assumed benefits of online interventions (E. Murray, Burns, Tai, Lai, & Nazareth, 2005; Ritterband et al., 2003; Stoop et al., 2004).

There are several disadvantages in using online interventions. Computers may never replace the human touch associated with traditional doctor-person communication but multimedia computer-based information resources can play an increasing part in the cost-effective delivery of health care resources. False or misleading information, privacy and malpractice are the potential negative consequences (Evers, Cummins, Prochaska, & Prochaska, 2005; E. Murray et al., 2005) and are also known as disadvantages for online interventions. Although the internet has the potential to affect health-related behaviours, it is important to note that internet users generally need to have familiarity with web navigation and the English language to successfully obtain useful information online. One can argue that this 'high-tech' approach is only suitable for well-educated individuals from affluent communities (Birru & Steinman, 2004). However, the literature suggests some fairly simple modifications when designing websites to overcome most navigation and language barriers for low-literate users (Zarcadoolas, Blanco, Boyer, & Pleasant, 2002). Online programs could be made available in public libraries, community centres, work places, hospital out-patient and family practice waiting areas.

Considering both the advantages and disadvantages of online interventions, there is a need to find out if online interventions can deliver self-management programs successfully.

#### 2.2.6.1 EFFICACY OF ONLINE INTERVENTIONS

The literature shows that potentially there are several benefits in using online interventions. However, to meet this potential, online interventions must demonstrate feasibility and efficacy through rigorous scientific testing. There is growing evidence for significant effectiveness of online education. Wantland, Portillo, Holzemer, Slaughter, & McGhee (2004) conducted a meta-analysis to compare online interventions and non-online interventions. They reviewed 22 studies with data from

11,754 participants in both online and non-online interventions. The results showed an improvement in outcomes for individuals using online interventions to achieve the specified knowledge and/or behaviour change for the studied outcome variables (Wantland et al., 2004). The outcomes included increased exercise time, increased knowledge of nutritional status, increased knowledge of asthma treatment, and increased participation in healthcare, slower health decline, improved body shape perception, and 18-month weight loss maintenance.

While the literature on effectiveness of online interventions for chronic condition non-specific programs is promising, there are also effectiveness studies on online interventions specifically designed for people with chronic conditions. A randomised controlled trial evaluating the effectiveness of a back pain e-mail discussion group on 580 people, showed improvement in health distress and health care utilisation in participants compared to controls after one year (K. R. Lorig et al., 2002). Another example of successful use of computers in intervention is a randomised controlled trial for testing a computerised system which provided for 204 HIV-positive individuals with information and decision support. The results showed that the system can improve a person's quality of life and promote more efficient use of health care (Gustafson et al., 1999). A study by McKay, King, Eakin, Seeley and Glasgow (2001) showed that an online intervention improved physical activity moderately and the authors concluded that "greater attention should be focused on methods to sustain involvement with internet intervention health promotion programs over time" (p.1333). Also, the effect of the internet on perceived social support has been reported in an experimental trial by Barrera et al. (2002). They stated that a 3-month internet-based support intervention could improve perception of social support in people with diabetes.

Murray, Burns, See Tai, Lai, & Nazareth (2005) further evaluated the effectiveness of online interventions for people with chronic conditions. Twenty four RCTs involving 3739 participants were included in this Cochrane Library systematic review. The definition of online interventions was operationalised in this article as "any package that required the user to interact directly with any form of computer, and contained health information plus at least one of peer support, decision support or behaviour change support and was not defined by the authors of the paper as a

decision aid or computerised cognitive behavioural therapy" (p.3). Online interventions were found to have largely positive effects, tending to improve user knowledge and perceived social support. The reviewers suggested that these positive effects of online interventions may extend to improved clinical outcomes. While the importance of the self-management approach for chronic conditions was pointed out in this article, having a self-management approach was not considered as one of the inclusion criteria for the type of interventions reviewed. Although tested online interventions were attended by people with a wide range of chronic conditions from headaches, posttraumatic stress and pathological grief, panic disorder, to diabetes management, AIDS, asthma and cancer, none of the studies reviewed were developed for managing symptoms in neurological conditions including fatigue.

Although both the effectiveness of online interventions and the problems in delivering the self-management programs are well recognised, there are few studies reporting self-management programs for adults delivered using the internet. Effectiveness of one internet-based self-management program for people with chronic conditions was tested in an RCT (K. R. Lorig, Ritter, Laurent, & Plant, 2006). The program consisted of password-protected, interactive web-based English-language instruction, web-based bulletin board discussion groups and a book, *Living a healthy Life with Chronic Conditions* (K. R. Lorig, Ritter et al., 2001). The book was to be referred to by the participants at various times in the program. The course was taught in an interactive manner designed to enhance self-efficacy. One other example of an online self-management program, a pilot study on the effectiveness of internet-based support for dyspnea self-management in people with chronic pulmonary disease, has been published. The results showed significant improvement in both self-efficacy and activities of daily living (both $p < .01$) (Nguyen, Carrieri-Kohlman, Rankin, Slaughter, & Stulbarg, 2005). Furthermore, a recent systematic review of internet-based self-management interventions for youth with health conditions showed that there is great promise on using the internet as a mode of delivery for self-management programs (Stinson, Wilson, Gill, Yamada, & Holt, 2008).

Kerr, Murray, Stevenson, Gore, and Nazareth (2006) conducted a qualitative study to determine the criteria used by people with chronic conditions and their caregivers for

assessing the quality of online interventions. They prepared criteria for the online interventions relating to information content, presentation, interactive components and trustworthiness. However, the online interventions which were assessed in this study were mostly person education web sites and not self-management interventions.

It appears that online self-management programs have potential as effective alternatives to face-to-face programs, thereby expanding the availability and diversity of communities from which individuals can choose. These practices also could help efforts to eliminate disparities in health that exist because of inequities in people's access to resources (Powell, Glover, Probst, & Laditka, 2005).

#### 2.2.6.2 ACCESS TO INTERNET BY PEOPLE WITH CHRONIC CONDITIONS

Recent research in the US shows that 51% of the adults with a disability or chronic condition use the Internet compared with 74% of those who report no disability or chronic conditions (Pew Internet & Americal Life Project, 2007). The study showed that once online, internet users with chronic conditions perform activities at the same rate as other users. Eighty-six percent of internet users with chronic conditions report that they search for health information online, compared with 79% of internet users who report no chronic conditions. Furthermore, the majority (75%) of individuals with chronic conditions or disability reported that their last health information search had an impact on their health care (Pew Internet & Americal Life Project, 2007).

While there is literature available on use of technology by people with physical disabilities, there is no evidence why they do not use it even if it is available to them. One reason may be their limitation in using the computer. An Australian study on people with physical disability (Pell, Gillies, & Carss, 1999) showed that only 13% of the participants were aware of the assistive hardware or software and the cost was the major reason given as to why these devices were not used.

The feasibility of conducting an online intervention in Australia has been examined. The Multi-Purpose Household Survey (MPHS) for 2006-07 showed that nearly three-quarters (73% or 6 million) of Australian households have access to a computer, and 5 million of these have Internet access. This is a five-fold increase in

the number of household Internet connections in ten years. The survey also found that the Internet is used daily by half (50%) of all Australians over the age of 15, and almost all (91%) use it at least weekly. In 2003 46% of farms used the Internet as part of their business operations, an increase of three percentage points from the previous year. These figures are even higher in urban areas (Australian Bureau of Statistics, 2005). A great number of people with disabilities take advantage of this tool, too. In 2003, just under half (48%) of people aged 15 years or over with a disability (excluding persons with a disfigurement or deformity without any limitations), reported having used a computer in the previous 12 months (Australian Bureau of Statistics, 2002-2003). For the same period, almost 2 in 5 (39%) had accessed the internet. Therefore, based on Australian information, there is strong evidence that many individuals with chronic conditions have the ability to access the Internet.

## 2.3 PART 2: FATIGUE IN NEUROLOGICAL CONDITIONS

### 2.3.1 FATIGUE DEFINITION, PREVALENCE AND PATTERNS

Fatigue is a common symptom experienced by virtually everyone during the course of their lives. Depending on the definition and the methods used to quantify fatigue, the prevalence of extreme fatigue may vary between 7% and 45% (Lewis & Wessely, 1992). It is possibly also the most common symptom to be found across all medical conditions (Abhijit. Chaudhuri & Behan, 2004). For ease of presentation, extreme fatigue is referred to as 'fatigue' in this thesis.

Fatigue secondary to chronic conditions is different from fatigue experienced by people without chronic conditions (Aaronson et al., 1999). Fatigue secondary to chronic conditions is associated with physiological and psychological manifestations which are not relieved by rest, sleep or positioning (Aaronson et al., 1999; Dittner, Wessely, & Brown, 2004; Swain, 2000) while an acute or 'normal' fatigue as a consequence of physical or mental efforts can be relieved by this way (Ream & Richardson, 1996). In chronic conditions fatigue is defined as "an overwhelming sustained sense of exhaustion and deceased capacity for physical and mental work at usual level" (North American Nursing Diagnosis Association, 2001, p.3).

Fatigue is a common symptom in most of chronic neurological conditions such as MS, Parkinson's disease (PD), post-polio syndrome (PPS), stroke and traumatic brain injury. Between 75 and 95% of individuals with MS report fatigue, with 50 to 60% naming it as their worst or one of their worst symptoms (Fisk et al., 1994; Kraft et al., 1986; Krupp et al., 1988). Fatigue also occurs in 59 – 89% of individuals with PPS, which is probably the major and most disabling symptom in this chronic condition (Berlly, Strauser, & Hall, 1991; T. L. Packer, Sauriol, & Brouwer, 1994; Schanke et al., 2002). Two national surveys in the US showed that 91% of polio survivors reported post-polio syndrome (PPS), a delayed syndrome characterised by excessive fatigue, with 41% reporting fatigue as significantly interfering with performing or completing tasks, and 25% reporting fatigue as interfering with their activities of daily living (Parsons 1989, as cited in Richard L. Bruno, Creange, & Frick, 1998). People with PD frequently report fatigue as well. A prevalence study by J. Friedman & Friedman (1993) using the modified version of the Fatigue Severity Scale (FSS) showed that 67% of 58 people with PD rated their fatigue as different to the fatigue experiences before the onset of the disease. The people with PD were more fatigued than age-matched controls. More than 50% of participants with PD claimed that fatigue constituted one of the three most disabling symptoms of the disease. The authors followed up 26 of the participants for nine years. The results showed that 50% of the participants still were affected by fatigue, explaining it as one of the most disabling symptoms of their condition (Friedman, 2001). In another prevalence study of 245 people with PD, only 43% of the participants were experiencing fatigue; however, the reliability and validity of the fatigue scale used for the study was not discussed (Karlsen, Larsen, Tandberg, & Jørgensen, 1999). These clearly show the high prevalence of fatigue in people with chronic conditions compared with the prevalence of 7% to 45% in the population assessed as being without chronic conditions (Lewis & Wessely, 1992). Fatigue is also reported by more than half of people with stroke (Ingles, Eskes, & Phillips, 1999; Leegaard, 1983) and is a common symptom of brain disease following the acute stages of brain injury (LaChapelle & Finlayson, 1998). Fatigue is the third most prevalent symptom of post concussion syndrome following headaches and dizziness (Middleboe, Andersen, Birket-Smith, & Friis, 1992).

Research on fatigue in PD and PPS is still new; it is about 15 years since the first studies on PD fatigue by van Hilton et al (1993) were published. The number of studies on PPS fatigue is also limited. In contrast, study on individuals with MS has been an area of interest by researchers and clinicians for many years. Research on fatigue in MS commenced about 25 years ago therefore there is extensive evidence around fatigue in MS.

The pattern of fatigue is very similar across diagnoses; it can be easily triggered and is not relieved by rest, sleep, or positioning (Dittner et al., 2004; Swain, 2000). It occurs daily, worsens as the day progresses, can last up to 24 hours per day and has a lengthy recovery time (Fisk et al., 1994; Karlsen et al., 1999; Krupp et al., 1988; Lou, Kearns, Oken, Sexton, & Nutt, 2001; Schanke et al., 2002). This pattern can be seen in most neurological conditions including MS, PD and PPS (Abe, Takanashi, & Yanagihara, 2000; Richard L. Bruno et al., 1998; Friedman & Friedman, 1993; T. L. Packer, Martins, Krefting, & Brouwer, 1991). The only distinctive feature of fatigue related to MS seems to be the heat sensitivity; ninety percent of people with MS report that their fatigue worsens in warmer environmental temperatures (Freal, Kraft, & Coryell, 1984; Kos, Kerckhofs, Nagels, D'Hooghe, & Ilsbroukx, 2008). Although evidence suggests that MS fatigue may pre-date the onset of other symptoms (Bakshi et al., 1999), qualitative studies of the experience of fatigue report a close relationship between fatigue and exacerbation of other symptoms(Stuifbergen & Rogers, 1997; Yorkston, Klasner, & Swanson, 2001) including physical, cognitive, and emotional symptoms.

### *2.3.2 TYPES OF FATIGUE*

The literature categorises fatigue in different ways. Fatigue, based on its origin, can be known as a primary symptom or as secondary to another symptom in a chronic condition. Fatigue may be the result from centrally mediated processes characterised by the disease, such as demyelination and axonal loss in the central nervous system or immune reactions or secondary to other variables. Both primary and secondary types of fatigue may occur simultaneously with each impacting on the other. Fatigue and depression also interact. Depression as a result of primary fatigue may cause decrease in activity level. This lower level of activity may in turn increase secondary fatigability as a result of deconditioning (Kos et al., 2008).

The clinical approach to fatigue is to categorise it into two types: central and peripheral. Peripheral fatigue is a sense of exhaustion caused by repeated use of muscles. It can be due to disorders in muscle and neuromuscular junction and is frequently observed in neurological diseases as myasthenia gravis or Guilain-Barre syndrome (Merkies, Schmitz, Samijn, van der Meche, & van Doorn, 1999) as well as immunological diseases such as rheumatoid arthritis (Swain, 2000). This objective reduction in motor power is measureable by testing the rate of decline in peak force generated during maximum voluntary muscle contraction. Peripheral fatigue is a distinctive topographic pattern of myopathic weakness. Central fatigue is characterised by a feeling of constant exhaustion. People with central fatigue have difficulty with initiating or maintaining any voluntary physical or even mental activity (A. Chaudhuri & Behan, 2000; Hoehn & Yahr, 1967). This subjective sense of fatigue is essentially perceived at the level of the central nervous system (CNS) (Abhijit. Chaudhuri & Behan, 2004). Both central and peripheral fatigue occur in PD, MS and PPS (R. L. Bruno, 1993; Friedman & Friedman, 1993; Karlsen et al., 1999; Krupp & Pollina, 1996).

Adding a time component to fatigue, it can be defined as acute fatigue or chronic fatigue. Acute fatigue is when fatigue exists for 6 weeks or less and chronic fatigue presents more than 50% of the time for more than 6 weeks (Bethoux, 2006).

Fatigue has different dimensions: physical and mental (psychological and cognitive). Physical fatigue may happen after minimal physical effort and worsens as the day progresses. Mental fatigue is frequently reported in people with MS in the cognitive domains of memory, learning, attention, and information processing (Krupp & Pollina, 1996). In comparison, no impairments in verbal memory or enhanced cortical function has been seen in people with PPS but they show important deficits in attention and information processing speed (R. L. Bruno, 1993). Word-finding difficulty and anomia are examples of task-specific mental fatigue seen in persons with PPS (R. L. Bruno, 2000). Physical and mental fatigue are known as two independent symptoms in PD, too (Lou et al., 2001). Physical effort is reported after physical exertion and mental fatigue is reported after mental effort. Apathy is a characteristic symptom of people with PD (Isella et al., 2002). Therefore, although

there are differences in fatigue dimensions between diagnoses, the overall pattern is similar in neurological conditions.

### *2.3.3 CAUSES OF FATIGUE*

Despite its prevalence and pervasive nature, the cause of fatigue is unclear. Fatigue includes a complex interaction between biological, psychological and behavioural processes (Swain, 2000). There are several hypotheses for the origin of fatigue in MS: 1) an increased number and volume of lesions in the white matter 2) diffused axonal damage 3) progression in brain atrophy (Kos et al., 2008).

The first two hypotheses have been rejected by research. Bakshi et al. assessed fatigue in 71 individuals with MS and categorised them into MS-fatigue and MS-non-fatigue groups. The results of the study did not show significant correlation between fatigue severity and regional or global MRI plaque load or atrophy assessed by conventional sequences. No significant differences were noted in any MRI measures between MS-fatigue and MS non-fatigue groups. (Bakshi et al., 1999; Codella et al., 2002). Another study investigated whether the extent of cerebral grey matter (GM) pathology was associated with the presence and severity of MS-fatigue. Fatigued and non-fatigued participants (14 participants in each group) did not differ in terms of grey matter pathology of the cerebral cortex of the frontal lobe and basal ganglia. The authors concluded that structural grey matter pathology is not a major contributing factor to the development of fatigue in persons with MS.

There is a hypothesis that the correlation of lesion load in brain and fatigue might be influenced by concomitant symptoms of MS like depression and physical disability. In a mixed method study (Colombo et al., 2000), fatigue was assessed by an interview and scored by the Fatigue Severity Scale (FSS). Two groups of MS participants, those with (n = 15) and those without (n = 15) fatigue, were matched for sex, age, disease duration, and scores on the Expanded Disability Status Scale score, Pyramidal Functional System score, and depression score. A significant association was found between the person scores on the FSS and the burden of MRI lesions ($r$ = .5; $p < .005$). Significantly higher parietal lobe ($p < .05$), internal capsule ($p < .05$), and periventricular trigone ($p < .05$) lesion loads were found in persons with fatigue compared with the group without fatigue. This study also supported the third theory

of a central nervous system origin of fatigue in people with MS (Colombo et al., 2000). The study showed that in non-disabled non-depressed persons with MS, pathophysiological process of demyelination and axonal loss caused higher fatigue levels (Colombo et al., 2000). A longitudinal study including 134 people with MS suggested that fatigue predicts brain atrophy as opposed to being a consequence of the demyelination process (Marrie, Fisher, Miller, Lee, & Rudick, 2005).

Several hypotheses have been proposed for cause of fatigue in PD: 1) altered activation of the hypothalamic-pituitary-adrenal system due to prolonged stress; 2) inflammatory processes; and 3) dysfunction in the basal ganglia and striato-thalamo-cortical loop caused by change in neurotransmitters (Fumihito YoshiiHirohide TakahashiRyuya KumazawaSatoko, 2006). Degeneration of the axon sprouts can explain the new muscle weakness and fatigue in polio survivors, but what causes the degeneration in the first place remains a mystery (Halstead, 1998). In PPS, it seems that poliovirus-induced damage to the brain activating system is responsible for decreasing cortical activation, impairing attention and generating the symptoms of post-polio fatigue (R. L. Bruno, 1995).

While both primary pathological mechanisms and secondary contributory factors on fatigue are extensively explored, research suggests that the etiology of fatigue is multi-factorial (Smith & Hale, 2007) and the nature of fatigue in MS, at least, appears to be more complex than other conditions (Smith & Hale, 2007).

### *2.3.4 IMPACT OF FATIGUE ON DAILY LIFE*

There is evidence for reduced activity participation level and negative emotional consequences as a result of secondary fatigue in chronic neurological conditions. The impact of fatigue was mostly studied in the 1980-1990s. Krupp et al. interviewed 32 people with MS and compared them with 33 healthy adults matched by age and sex. The MS participants suggested that MS fatigue was more severe and had more disabling impact on activities of daily living than fatigue experienced by the comparison group (Krupp et al., 1988). Their results were consistent with the results from Freal et al.'s (1984) study in which 309 individuals with MS were evaluated. Results of this study revealed that fatigue interfered with activities of daily living. Fatigue was worse for 83% after 'vigorous exercise' and for 64% after 'moderate

exercise' although 15% reported that moderate exercise helped to reduce fatigue. But a study shows that the fatigue perceived during a physical or cognitive activity does not correlate with an objective reduction of observed performance (Parmenter, Denney, & Lynch, 2003).

Packer, Sauriol and Brouwer (1994) used the FSS and the Human Activity Profile (HAP) to assess fatigue and activity level in people with and without chronic neurological conditions in comparison with a control group. Their study included 28 people with PPS, 13 people with chronic fatigue syndrome, 9 people with MS and 11 healthy participants. The participants with chronic conditions had significantly higher scores on the FSS and lower scores on the HAP compared to healthy participants. Their results support this hypothesis that higher fatigue may be correlated with decreased activity (or energy) levels. Packer, Foster and Bouwer (1997) continued their research evaluating activity patterns of people with and without chronic fatigue syndrome. The results showed significant difference between the percentage of time spent by the two groups with respect to the variable of rests, work and productivity (work and household). The study also found that the participants with chronic fatigue syndrome spent less time on productivity and greater time in rest than the controls.

Similar results are seen in studies on PD. People with PD who experience fatigue report that their fatigue prevents sustained physical activity (Hoff, Van Hilten, Middelkoop, & Roos, 1997). Fatigue was reported to be negatively correlated with self-report activities of daily living among people with PD with FSS more than 4 (Shulman, Taback, Bean, & Weiner, 2001). Gaber and Friedman (2003) found a significant inverse relationship between fatigue severity and leisure activity level, the frequency of vigorous physical activity and time spent performing daily tasks in people with PD. The results also showed that fatigue was correlated with more sedentary behaviour, lessened functional capacity for exercise and worse physical conditioning. In contrast, a study on individuals with PD showed that physical activity level of people with fatigue was not different from those without fatigue when it was measured objectively by waste-worn activity monitor (Hoff et al., 1997).

On the other hand, evidence supports the idea that a higher level of activity can decrease fatigue levels. One study reported that a 4-week aerobic exercise intervention resulted in improvement on quality of life and a tendency toward reduction in fatigue among people with MS (Mostert & Kesselring, 2002). Training consisted of 5×30 minute sessions per week of bicycle exercise with individualised intensity. Another example of negative correlation of fatigue and activity is a more recent study by Okan et al. (2004). Participants with MS and Expanded Disability Status Score less than or equal to 6.0 were randomly assigned to one of three groups lasting 6 months: weekly Iyengar yoga class along with home practice, weekly exercise class using a stationary bicycle along with home exercise, or a waiting-list control group. The participants in both active groups showed improvement on the Multi-Dimensional Fatigue Inventory, and the Short Form (SF)-36 health-related quality of life scores compared to the control group. This is while a cross-sectional study showed no relationship was between fatigue impact and spiroergometric parameters (Rasova, Brandejsky, Havrdova, Zalisova, & Rexova, 2005). However these studies only focused on structured activity rather than lifestyle activity.

Morris et al. (2002) tested the relationship of observed fatigue and motor performance. It was expected that higher fatigue scores in the afternoon would accompany reduced motor performance as the day progressed. In the study 14 individuals with MS and a similar number of matched controls were compared and no differences in gait pattern were found between morning and afternoon assessment, whereas fatigue scores increased in the afternoon. They concluded that the mechanisms for motor control and the subjective experience of fatigue were dissimilar (Morris et al., 2002).

In addition to physical and activity participation limitations as a result of fatigue, emotional consequences are also pointed out in the literature in the literature on fatigue. Flenser, Ek and Soderhamn (2003) provided a thorough description of persons' experience of fatigue in a qualitative study. A lowered sense of self-worth, feelings of shame, sorrow, and anger related to the perception of fatigue were the experiences that persons with MS described. The debilitating nature of MS fatigue has a known impact on quality of life and health status (Amato et al., 2001; Benedict

et al., 2005; Di Fabio, Choi, Soderberg, & Hansen, 1997; Lobentanz et al., 2004; Pittion-Vouyovitch et al., 2006; Stuifbergen & Rogers, 1997).

Fatigue not only limits performance in daily life and at home but also it has a negative impact on work (Vercoulen et al., 1996). Changes in employment are increasingly associated specifically with the symptom of fatigue (Black et al., 1994; National Health Priority Action Council, 2006). Fatigue is also reported as a central cause of MS persons being unable to maintain full-time employment (Jongbloed, 1998). Chaudhuri and Behan reported that people with fatigue may be inactive and overstressed by not achieving a return to the same job (Abhijit. Chaudhuri & Behan, 2004). Financial pressure is another outcome of living with extreme fatigue. A study of 113 adults with MS who lived in urban and rural regions of Australia showed that fatigue was the major health variable that predicted cost of MS and its economic pressure (McCabe, 2003).

### *2.3.5 FACTORS CORRELATED WITH FATIGUE*

Table 2.1 summarises studies regarding factors correlated with fatigue. Studies describing the relationship of fatigue with other variables are often limited by the use of cross-sectional correlation-based measures (either correlation coefficients or regression analyses), and therefore no conclusions can be drawn about the causality of the associations. Also the results are often contradictory. For example, while a study by K. M. Schreurs, D. T. de Ridder, & J. M. Bensing (2002) with 151 individuals with MS showed no association between fatigue and age, gender, disease duration, and clinical activity , other studies found increased fatigue scores in people with higher age, lower educational level, longer disease duration, and progressive MS (Colosimo et al., 1995; Flachenecker et al., 2002; Lerdal, Celius, & Moum, 2003). Studies on Parkinson's disease also do not support the correlation of fatigue with disease severity or duration (Friedman & Friedman, 1993, 2001).

Table 2.1 Factors Correlated with Fatigue

| *Fatigue correlate* | *Result* | *Population* | *Reference* |
|---|---|---|---|
| *Age* | *Age significantly correlated with fatigue (*r = *.20, p < .01).* | *MS* | *(Lerdal et al., 2003)* |
| | *Age significantly correlated with fatigue (*r = *.24, p < .05).* | *MS* | *(Schreurs et al., 2002)* |
| *Gender* | *Fatigue not significantly different between females and males (*p = *.06).* | *MS* | *(Lerdal et al., 2003)* |
| | *Fatigue not significantly different between females and males (*p = *.568).* | *PD* | *(Karlsen et al., 1999)* |
| *Depression* | *Depression significantly correlated with fatigue (*r = *.44*, p < *.01).* | *MS* | *(Kroencke, Lynch, & Denney, 2000)* |
| | *Depression significantly correlated with fatigue (*r = *.41*, p < *.01).* | *MS* | *(Flachenecker et al., 2002)* |
| | *Depression significantly correlated with fatigue (*r = *.45*, p < *.01).* | *MS* | *(Schreurs et al., 2002)* |
| | *Depression significantly correlated with fatigue (*r = *.58*, p < *.01).* | *MS* | *(Amato et al., 2001)* |
| | *General fatigue, physical and mental fatigue (beta = .34, .31 and .29 respectively). The relationships persist when the effects of gender and educational level controlled.* | *PD* | *(Havlikova et al., 2008)* |

Continued on next page

Table 2.1 continued

| Fatigue correlate | Result | Population | Reference |
|---|---|---|---|
| Type of MS | Primary and secondary progressive MS people had higher fatigue scores than relapsing-remitting patients (F = 3.4, df = 2, 204, p = .012) but after controlling for age, disability level and time since diagnosis there was no difference between the groups. | MS | (Kroencke et al., 2000) |
| | Positive relationship between fatigue and age ($p < .001$) among persons with primary progressive (when controlled for gender, level of education and time since disease onset). | MS | (Lerdal et al., 2003) |
| Education | Negative correlation between fatigue and education ($r = -.15$, $p < .01$). | MS | (Lerdal et al., 2003) |
| Disease duration | Positive correlation between fatigue and time since disease onset ($r = .11$, $p < .05$). | MS | (Lerdal et al., 2003) |
| | The participants with fatigue and without fatigue were not significantly different on time since diagnosis and time since onset of symptoms. | PD | (Herlofson & Larsen, 2002) |

Continued on next page

Table 2.1 continued

| *Fatigue correlate* | *Result* | *Population* | *Reference* |
|---|---|---|---|
| *Disability level* | *Fatigue significantly correlated with disability (r = .33, p<.0001).* | *MS* | *(Flachenecker et al., 2002; Kroencke et al., 2000)* |
| | *Physical fatigue was correlated with physical disability cross-sectionally and the physical fatigue was predictor of physical disabilities of a year later.* | *MS* | *(Schreurs et al., 2002)* |
| | *No correlation was found between the measures of fatigue and physical disability.* | *MS* | *(Penner et al., 2007)* |
| | *FSS and disability level were correlated (rho = .43, p= .003). But after controlling for depression, EDSS scores were not correlated with FSS scores (rho = .27, p= .09).* | *MS* | *(Bakshi et al., 2000)* |
| *Sleep quality* | *Fatigue significantly correlated with disturbed sleep and abnormal sleep cycle (*p = *.003).* | *MS* | *(Attarian, Brown, Duntley, Carter, & Cross, 2004)* |
| | *No correlation was found between fatigue and sleep disturbances.* | *MS* | *(Taphoorn, Van Someren, & Snoek, 1993)* |
| *Anxiety* | *33% of people with Parkinson's disease with FSS>4 reported anxiety.* | *PD* | *(Shulman et al., 2001)* |

Note. MS = Multiple Sclerosis; PD = Parkinson's Disease.

Another example of incongruency between results of different studies is the association between disability and fatigue. Post hoc analyses in some studies have revealed that disability status was mainly responsible for the differences in fatigue scores between types of MS (Kroencke et al., 2000; Pittion-Vouyovitch et al., 2006; Schreurs et al., 2002). However, other studies show no relation between disability status and fatigue (Bakshi et al., 2000; van der Werf et al., 1998). In a study of 71 people with relapsing remitting or secondary progressive MS, Bakshi et al (2000) examined the relationship between disability (using the EDSS), depression (Hamilton depression Inventory, Beck depression inventory) and fatigue (FSS). Although a weak correlation was found between the level of disability and level of fatigue, this relationship disappeared once depression was accounted for ($r = .27$; $p= .09$). In this study, level of disability was recorded using EDSS which assesses only physical impairments. In order to assess function, the level of activity and participation should also be evaluated (World Health Organization, 2001).

There is evidence that fatigue and depression are correlated. In research on people with PD (n=233) an association between fatigue and depression was demonstrated when disease severity, disease duration, levodopa dose, dementia and sleep medication were controlled in a multiple logistic regression analysis (odds ratio=1.2; B=.2, standard error=.04 and 95%confidence interval=1.1-1.3) (Karlsen et al., 1999). Bakshi et al (2003) also found a weak correlation between depression and fatigue which remained once disability was controlled. ($r = .37$; $p=.02$). A nine-year study (Friedman & Friedman, 2001) showed that fatigue was correlated with depression in people with PD.

The literature also shows the relationship between change of fatigue and change in depression. In a study on 504 people with MS, increasing depression scores (using Zung's Self-rating Depression Scale) were associated with increasing FSS scores ($F = 4.55$, $p < .0001$). In this study using regression analysis, EDSS, FSS and sleep quality were confirmed to be independent predictors of the mean depression score ($R^2= .466$; $p < .0001$) (Lobentanz et al., 2004).

Limited research has been conducted to date to understand fatigue levels in people with post-polio syndrome. Berlly, Strauser and Hall (1991) surveyed 86 people with

PPS and 20 healthy people by using the Fatigue Symptoms Questionnaire (developed by the authors) and the Beck Depression Inventory. The results showed that 64% of people with PPS had chronic fatigue and depression.

While research to date suggests a low to high association between fatigue and depression, some researchers suggest this correlation may be a result of an overlap between fatigue and depression. However, there is evidence that even after controlling for this overlap, fatigue and depression are significantly correlated. A study on 207 individuals with relapsing-remitting, primary progressive or secondary progressive MS, a weak correlation between depressive mood and fatigue was found ($r$ = .44; $p$ < .001). In this study, a modified version of Self-reporting Depression Scale was used. This scale had a high internal consistency (Chronboch's alpha score= .88) and excluded items related to fatigue (Kroencke et al., 2000). Kroencke et al. (2000) tested 207 individuals with clinically definite MS. The Fatigue Severity Scale and the Zung Self-rating Depression Scale were administered. Fatigue and depression were highly correlated ($r$ = .58), even when the depression measure was corrected for items overlapping with fatigue and other symptoms or consequences of MS ($r$ = .44). Fatigue and disability were also correlated ($r$ = .33). Multiple regression revealed that both depressed mood and disability were significant predictors of fatigue, together accounting for approximately 23% of the variance in persons' self-reported fatigue.

A cross-sectional descriptive study on 78 people with MS showed that only some dimensions of fatigue are correlated with mood (Ford, Trigwell, & Johnson, 1998). Using the Fatigue Rating Scale (FRS) and Hospital Anxiety and Depression Scale (HADS) fatigue and mood were tested. Fifty eight participants scored their fatigue as severe. Both the mental fatigue score and the total fatigue score were positively correlated with depression and anxiety while there was no significant correlation between the physical fatigue score and depression and anxiety on the HADS.

The relationship between fatigue and depression has also been explored by studies on effectiveness of depression treatments on fatigue levels. The treatment of depression is reported to be related to a reduction in the subjective severity of fatigue (Mohr, Hart, & Goldberg, 2003). Sixty persons with relapsing type of MS and moderate to

severe depression were randomly assigned to one of three treatments for depression: an individual cognitive behavioural therapy arm, support group arm, and an antidepressant medication (sertraline) arm. The primary outcome measures were the Fatigue Assessment Instrument (FAI), and the Beck Depression Inventory (BDI). The effect of treatment on fatigue did not differ across the modalities and could therefore not be explained by a treatment specific mechanism. The total FAI and the global fatigue severity subscale were significantly reduced ($p < .02$). Secondary analyses showed that a change in global fatigue severity (a subscale of FAI) was associated with a change in BDI ($p = .03$) but change in total FAI was only marginally related to a change in BDI ($p = .05$). These relationships were due entirely to change in mood ($p < .02$) and not to change in cognitive or vegetative symptoms ($p > .17$). The authors concluded that treatment for depression is associated with reductions in the severity of fatigue symptoms, and that this relationship is due primarily to treatment related changes in mood. The strong evidence for the relationship between fatigue and depression shows the importance of considering depression level and change in depression when testing a fatigue management program.

### *2.3.6 FATIGUE MANAGEMENT*

Management of fatigue includes pharmacotherapy and non-pharmacological interventions. Although effectiveness of different medications for managing fatigue have been reported (For example Cohen & Fisher, 1989; Kemp & Gora, 1993; T. J. Murray, 1985; Rosenberg & Appenzeller, 1988; Taus, Giuliani, Pucci, D'Amico, & Solari, 2003), systematic reviews do not confirm the results. A Cochrane Library systematic review showed that there is some support for using amantadine for fatigue in MS but the its efficacy in reducing fatigue in people with MS is poorly documented and there is insufficient evidence to make recommendations to guide prescription (Taus et al., 2003). Also, safety and efficacy of pemoline and potassium channel blockers is not established and primary studies have low quality (Brañas et al., 2000; Solari, Uitdehaag, Giuliani, Pucci, & Taus, 2008).

A systematic review of treatment of fatigue in multiple sclerosis reviewed studies both from a pharmacological view and from a psychosocial/psychological intervention perspective (Lee, Newell, Ziegler, & Topping, 2008). Ten

pharmacological studies were reviewed with moderate-to-high quality and showed statistically significant though modest impact on fatigue. The results for low–rated pharmacological studies were mixed with effectiveness of the interventions being absent to modest. Side-effects were noted as a problem in some pharmacological studies. The authors concluded that based on the studies reviewed there was no drug intervention that lead to reliable clinical decrease in fatigue in individuals with MS. In this study only 5 psychological/psychosocial studies (two studies on fatigue self-management, one study on cooling therapy, one study on pulsed electromagnetic therapy and one study on yoga and exercise) studies were found and reviewed. The quality of these studies was assessed as moderate or moderate to low. The major criticism of these studies was use of a waiting list as control which could enhance positive treatment expectations in the control group. Therefore, the authors of the systematic review concluded that regardless of the quality of the studies, effectiveness of both pharmacological and non-pharmacological interventions was modest at best and often absent. However, grouping the studies with very different treatment approaches to one category (psychological/psychosocial) limits the strength and generalisability.

Neill et al. (2006) reported the results of a systematic review on non-pharmacological interventions for fatigue in adults with MS, rheumatoid arthritis and systematic lupus erythemathous. The articles reviewed (n=36) were categorised into four groups: exercise, behavioural, nutritional and physiological. Ten different behavioural intervention types for fatigue were applied in 15 studies. Nine behavioural studies found statistically significant reduction in fatigue, but results were not always consistent across instruments used. The authors concluded low impact aerobic exercise may be effective in reducing fatigue in some adults with chronic auto-immune conditions. A range of behavioural interventions including energy conservation, cognitive behavioural therapy, health education and some rehabilitation programs may be helpful in reducing fatigue in this group of population. The authors also suggested that the electromagnetic field service deserve further research due to promising results. However, results of this study may not be attributable to people with other neurological conditions and the diversity of

interventions, designs and a broad range of instruments to measure fatigue limited comparison of the results.

There are some other well-designed studies on non-pharmacological interventions for fatigue which were not included in the systematic reviews. In an RCT on people with multiple sclerosis, 51 participants with MS were randomly allocated to a multidisciplinary fatigue management program (MFMP) or a placebo intervention program (Kos, Duportail, D'Hooghe, Nagels, & Kerckhofs, 2007). The participants in the placebo group received the MFMP after 6 months. The MFMP showed no efficacy in reducing the impact of fatigue compared to the placebo group.

A pre-post test study with people with mild to moderate MS evaluated the results of inpatient rehabilitation on symptomatic fatigue (Romberg, Ruutiainen, Puukka, & Poikkeus, 2007). The 3-week rehabilitation program included individual and group therapies. The participants were divided into fatigue (n=66) and non-fatigued (n=25) groups. The mean FSS scale score decreased by .34 points in the fatigue group while in the non-fatigue group it decreased by .23 points. The difference in change was significant between groups (p=.003) and a covariate analysis showed that this was strongly affected by a decrease in depression. However the long–term effect of the program was not evaluated.

Energy conservation techniques are one of the behavioural interventions which have been taught by occupational therapists for many years to help people manage their fatigue (Multiple Sclerosis Council for Clinical Practice Guidelines, 1998). Energy conservation education involves teaching people to identify and develop modification to their daily activities in order to reduce fatigue. People learn to evaluate their energy expenditure for daily activities, determine ways of modifying these activities, evaluate their rest-activity ratio, use ergonomic principles to use their bodies more efficiently to perform tasks, plan and balance their daily tasks to manage fatigue and examine their use of adaptive equipment and community resources for fatigue management (Trombly & Radomski, 2002). Although there are many descriptions of strategies for energy conservation (Multiple Sclerosis Council for Clinical Practice Guidelines, 1998; Ward & Winters, 2003), there is no evidence for effectiveness of techniques when they are taught in an individual basis. In

contrast, *Managing fatigue*: *A six week course for energy conservation* (T. L. Packer et al., 1995) is a published and standardised self-management group intervention for people with neurological conditions. This program is designed based on self-management principles to be delivered in a group setting. *Managing fatigue* consists of six 2-hour sessions of highly structured classes with 7-10 participants per group. The primary aim of this course is "reducing disability by increasing an ability to participate in those self-care, productive, and leisure activities that are self-identified as important, meaningful, or necessary" (T. L. Packer et al., 1995, p.2).

In examining the fatigue self-management program (T. L. Packer et al., 1995), Mathiowetz, Matuska and Murphy (2001) conducted a repeated measure design study (n=54) which showed significantly less fatigue impact , increased self-efficacy and improved Quality of Life in MS clients. Mathiowetz, Finlayson, Matuska, and Yun Chen (2005) also carried out a randomised controlled trial study (n = 169). The results of the study showed an increase in quality of life ($p < .05$) and self-efficacy ($p < .05$) as well as a decrease ($p < .05$) in physical and social subscales of Fatigue Impact Scale (FIS) for persons with MS. A further study, which evaluated the effects of the program on fatigue impact for persons with progressive MS (n = 35), whose symptoms caused moderate to severe cognitive impairment, showed significant decrease in FIS scores after intervention and remained steady 8 weeks after course completion (Vanage, Gilbertson, & Mathiowetz, 2003). Using wait list control groups is noted in a systematic review as the main critic for some of these studies (Lee et al., 2008) due to the possibility of enhanced positive treatment expectation events in controls. The results of Mathiowetz study (2005) were also confirmed by a pilot effectiveness study on group teleconference format of the fatigue self-management program (Finlayson & Holberg, 2007). Twenty nine participants with MS showed significant improvement in fatigue and quality of life after participation in the program. Qualitative data were collected following the study to explore the strengths and limitations of this method of delivering of the fatigue self-management program. Technical issues, lack of time for sharing and lack of time to practice strategies were mentioned as limitations. Feedback from both the people with MS and the facilitators of the program showed the format to be convenient and relaxed.

The authors raised questions about what therapists need to know to deliver telehealth interventions and the best strategies for preparing them for this delivery format.

Lamb, Finlayson, Mathiowetz, & Chen (2005) continued the study to determine whether there were any difference in the outcomes of individuals with multiple sclerosis who attended all six sessions of the *Managing Fatigue* program compared with people who missed a session and received a self-study module. The results showed that participants in both groups similarly benefited from the program. However, these participants attended 5 sessions of the course and could apply their gained self-management skills for the sixth sessions. A study on 32 Austrian people with MS also supported the results in the Mathiowetz et al studies added an examination of subjective sleep quality, demonstrating improvement post intervention that was still evident at 7-9 months follow-up (Sauter et al., 2008). Therefore, there is some evidence that the *Managing Fatigue* program is effective in improving fatigue, quality of life and self-efficacy in persons with fatigue secondary to chronic neurological conditions.

With one exception, there is no systematic review specifically reviewing studies on the effect of fatigue self-management programs. The one exception is a study by Foster et al. (2007) which reviewed effect of self-management programs by lay-leaders in which seven of the articles reviewed considered fatigue as one of the outcomes. The overall effect size for studies on 1836 participants in the interventions group and 1415 in the control group was 1.60 ($p$ = .1).

## *2.4 CONCLUSION*

While previous research has clearly documented the pervasive impact of chronic conditions on individuals and the community, meeting health care needs of the growing population of people with chronic conditions is a problem that most countries face. Traditional health care systems are primarily focused on prevention and control of acute illnesses leading to less emphasis, historically, on management of chronic disease, illness and/or disability. Further, evidence in Australia highlights the need for self-management programs to reach the right people, particularly those who have difficulty accessing services due to geographical location, transportation problems, work commitments or who lack the confidence to participate in face-to-

face programs. Based on the preceding review of the literature, research which addresses methods to overcome barriers for self-management programs is needed. Online interventions which are reported to be effective for different chronic conditions can be a practical solution for overcoming this barrier for accessing self-management programs. However, to date none have been reported in the literature.

One of the most common and troublesome symptoms for people with chronic conditions is fatigue which has substantial negative impact on people's lives. Although researchers have recently begun to investigate the different methods to manage fatigue for persons with chronic conditions, current evidence does not support effectiveness of most of them. Effectiveness of *Managing Fatigue* (T. L. Packer et al., 1995), a fatigue self-management program including skills to manage their activities, relationships and treatment based on their life style, is supported by the literature. This program is accessible in a face-to-face version and therefore only in metropolitan areas offering this service. Developing an online fatigue self-management program and then testing it through an RCT, a gold standard to test intervention protocols, may help bridge the gap in the literature.

# CHAPTER 3

# A PILOT TEST OF AN ONLINE FATIGUE SELF-MANAGEMENT PROGRAM

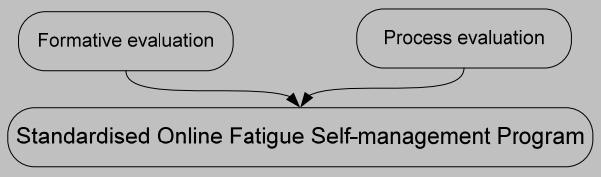
Chapter 1: Introduction

Chapter 2: Literature Review

**Brief Summary:**
Part 1:
- Growing population of chronic conditions
- Effectiveness of self-management programs for chronic conditions
- Lack of self-management programs for neurological conditions
- Lack of access of people with chronic conditions to face-to-face programs
- Effectiveness of online programs

Part 2:
- Fatigue is a major problem in neurological conditions
- Fatigue is the least well-managed condition
- Evidence for effectiveness of face-to-face fatigue self-management programs

Chapter 3: Pilot Test




Chapter 4: Randomised Controlled Trial

Chapter 5: Comparison to Face-to-face Program

Chapter 6: Predictors of Improvement

Control group

Online FSM group

Information-only FSM group

Face-to-face group

Chapter 7: Conclusion

# 3 PILOT TEST

## *3.1 INTRODUCTION*

Based on the British Medical Research Council (2000), a five-phase research process is required for development and evaluation of complex interventions. The pre-clinical phase (to explore relevant theory and literature) and the modeling phase (to outline the perceived active components of the program in greater detail) were completed prior to this PhD project as was the prototype of the online program designed based on *Managing Fatigue* (T. L. Packer et al., 1995). This pilot study focused on the third phase of evaluation of a complex intervention i.e. exploratory trial. The literature emphasises the need for pilot testing of online interventions once they are developed in order to determine issues of feasibility, usability and efficacy (Eng, 1999; Ritterband et al., 2003). In health research, pilot studies are also of particular importance in answering questions with regards to study populations and sample size (G. L. Anderson & Prentice, 1999). Pilot studies are critical in determining the overall feasibility of a study, serving to highlight issues relating to implementation, methodology, and operationalisation of research concepts (Altam, 1991; Portney, 2000). They enable the trialing of data collection measures, techniques and consent forms (Lancaster, Dodd, & Williamson, 2004). Therefore, this chapter aims to describe the final development and pilot testing of the online fatigue self-management program (Online FSM).

## *3.2 METHODS*

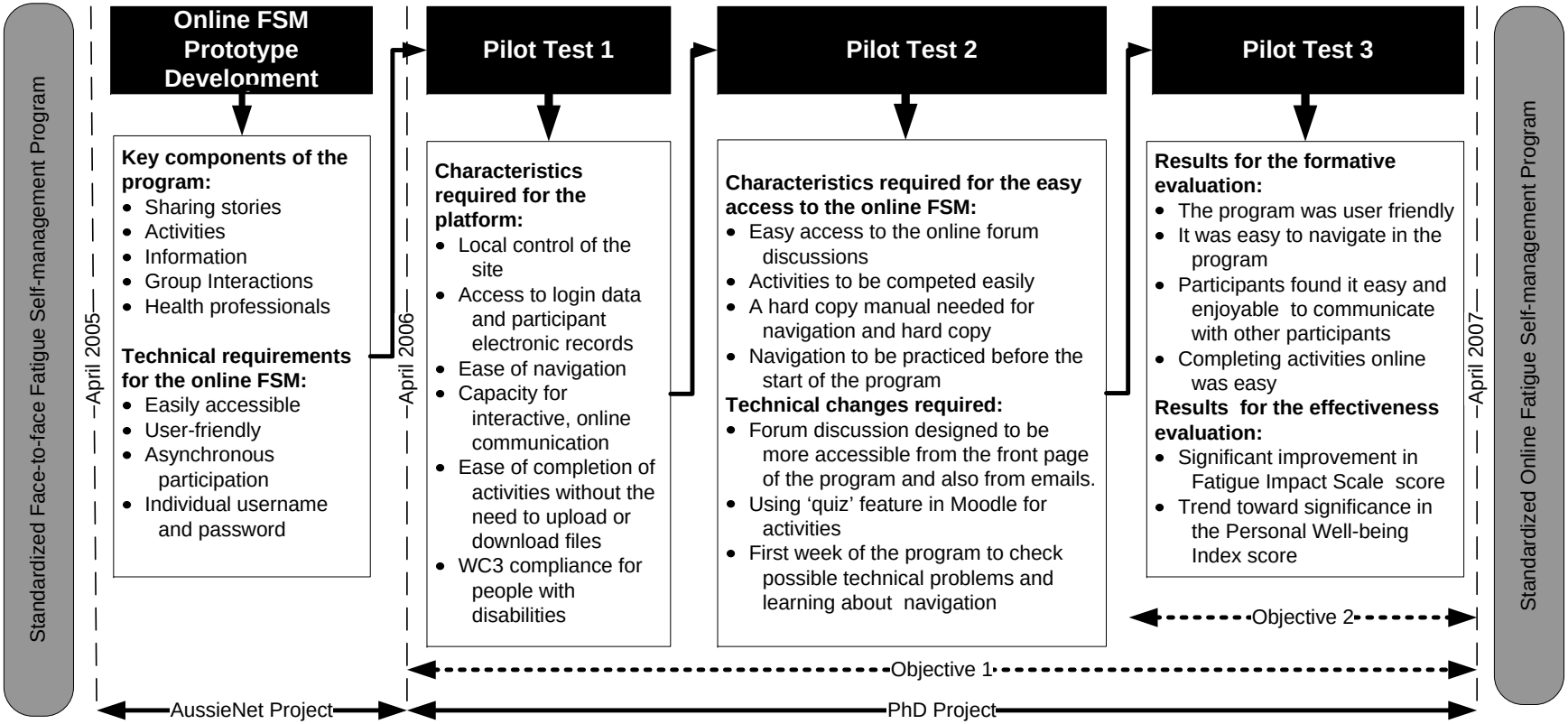
### *3.2.1 OBJECTIVES AND STUDY DESIGN*

The online FSM was based on the face-to-face protocol developed by Packer et al. (1995). As noted, the prototype for the online FSM program was designed via the 'AussieNet Project' funded by Lotterywest and was a separate project to this PhD study. The project began with deconstruction of the face-to-face program and reconstruction into an online prototype; the online FSM program. The PhD study commenced once the prototype design was complete and pilot testing included a formative evaluation (to test the usability of the program) (Objective 1) and a preliminary efficacy study (to test the efficacy of the program and the feasibility of the RCT following this study) (Objective 2). Formative evaluation involves a

comparison of program implementation with program plans, allowing for a reconsideration of program features. Feedback gathered via formative evaluation in one pilot test was used in subsequent stages to help improve the program (C. Mowbray, Holter, Teague, & Bybee, 2003). Also, suggestions from participants were solicited and aspects of the online FSM that needed improvement were identified. The formative evaluation included three pilot tests. During and after the pilot tests, feedback from users and facilitators was sought and electronic program records scrutinised. The collected information was used to further improve the protocol. Pilot Test 3 of the formative evaluation provided the opportunity to undertake a small, preliminary efficacy study (Objective 2) using a single group pre-test, post-test design. This resulted in a standardised program to be tested in the RCT phase of this PhD project.

For ease of understanding, the development stage, including initial prototype design, is briefly described in the present chapter. The relationship between each stage of development, a summary of findings at each stage and the relationship between the AussieNet project and this PhD project are depicted in the Figure 3.1.

Figure 3.1 The Development and Evaluation of the Online Fatigue Self-management Program (Online FSM)



### *3.2.2 PROTOTYPE DEVELOPMENT (AUSSIENET PROJECT)*

The literature suggests online programs should be founded on well-researched face-to-face programs (Medical Research Council, 2000). As described in the literature review, the face-to-face *Managing Fatigue* program (T. L. Packer et al., 1995) has demonstrated effectiveness (Mathiowetz et al., 2005; Mathiowetz et al., 2007). In order to transform the face-to-face program to an online format, information was gathered via a reference group consisting of participants from previous research projects testing face-to-face programs, the primary author of the program (T.L. Packer) and experienced facilitators of the face-to-face FSM. All participants in the focus groups had been participants in recent self-management research projects. The group deconstructed the face-to-face version identifying key components of the face-to-face program (Table 3.1 and Appendix A). The deconstructive process included an open discussion of aspects of the self-management program most valued by participants, those that most assisted with attitude and behaviour change and those that should be retained. Through prompting and use of open questions and frequent summaries, participants came to consensus on key components. This process was led by an educationalist independent of the program but familiar with self-management programs generally. Interestingly, past participants emphasised the self-management format of the program (use of problems solving, discussion etc) as being key to success, with the content seen more as a vehicle or structure for the process. This insight allowed development of a prototype and formed the basis for decision making in subsequent stages.

Table 3.1 Key Components of the Fatigue Self-management Program

| Components | Participants valued |
|---|---|
| Sharing stories | Personal narratives and story telling as a basis for validation, support and new learning. |
| Activities | Trial and error as a way of testing new strategies. |
| Information | The chance to use/learn problem solving; to personalise and choose strategies to make changes based on the information provided. |
| Group Interaction | The opportunity to ‘give’ as well as ‘receive’ in the group. |
| Health professional | Facilitation by a knowledgeable health professional. |

In addition to the key components required, focus group recommendations also included technical characteristics. It was determined that the online FSM should:

- be easily accessible and user-friendly for participants with limited computer knowledge and literacy (defined as the ability to use the internet for simple searches and send/receive emails);
- use asynchronous participation, such that participants could logon and remain online at their convenience;
- expect a weekly commitment of approximately 2-3 hours per week, similar to participation in the face-to-face version (both from the facilitator and the participants); and
- require individual usernames and passwords to enter the online program.

Following deconstruction and identification of key components, the online FSM was reconstructed ensuring key components were embedded in the prototype. The final step in producing the prototype was identification of an internet platform that met the technical considerations and had the potential to provide new information, enable communication between group members and allow completion of activities online. A potential platform was identified and the technical aspects of producing the prototype were undertaken, ready for pilot testing by participants.

### *3.2.3 PILOT STUDY*

#### 3.2.3.1 PARTICIPANTS

Each pilot test employed a sample of convenience. This recruitment method is acceptable when a pilot study is used for verifying procedures (Portney 2000). The online program was designed for a minimum of 8 and maximum of 12 people, hence the pilot study used a similar group size. In order to allow for attrition (estimated at 20%) 10-11 people were recruited for each of the pilot tests (goal of 8 per group after attrition).

Potential participants contacted the researcher in response to published information: fatigue self-management program flyers, notices in associations' newspapers and/or emails circulated by the Western Australian Multiple Sclerosis Society, Post Polio

Network of WA, Chronic Fatigue Syndrome Association and Parkinson's Disease Association. This method of recruitment was chosen to avoid a sense of coercion that may arise from patient/health professional relationships.

The criteria used to recruit participants were the same as those to be used later in the RCT part of this study. The selection criteria included confirmed diagnosis of multiple sclerosis, post-polio syndrome, Chronic Fatigue Syndrome or Parkinson's disease, 20 years of age or older, self-reported access to the internet three times per week for at least one hour, and a Fatigue Severity Scale score of 4 (the cut off score for extreme fatigue) or higher (Krupp, LaRocca, Muir-Nash, & Steinberg, 1989). Except for the diagnosis which was confirmed via a letter from participants' physicians, selection criteria were addressed through a screening telephone interview. Potential participants were excluded based on previous participation in the *Managing Fatigue* program (Face-to-face FSM) or poor cognitive ability. In Pilot Test 1, the Telephone Interview for Cognitive Status (Brandt & Folstein, 1987) was used as a screening test and a score below 20 was used to exclude interviewees from the study. In Pilot Tests 2 and 3, a score greater than 9 on the Memory Orientation Concentration Test (Katzman et al., 1983) was used as the cut off score for exclusion. Cognitive ability was considered as an exclusion criterion in order to consider safety of the participants. The reason for this change in explained in the results (section 3.3.3). People with moderate or severe cognitive impairment were not predicted to be able to use the internet efficiently and be able to benefit from the program.

#### 3.2.3.2 PROGRAM FIDELITY

Fidelity is defined as the extend to which delivery of an intervention adheres to the protocol or program model originally developed. It assures that the treatment being studied is delivered in a way that accurately reflects the underlying intervention principles (C. T. Mowbray, Holter, Gteague, & Bybee, 2003). Attention to fidelity advances the study aims (Horner, Rew, & Torres, 2006) and supports the researcher's conclusion about the association between the intervention and the study outcomes (Calsyn, 2000). In this study, to enhance the intervention fidelity, different methods (training the facilitators and monitoring the intervention) were employed to ensure that internal validity of the study was maintained (compared with the face-to-

face FSM) and external validity was enhanced (Horner et al., 2006). Moreover, preparing a manual for use in a clinical trial enhances fidelity (Burgio et al., 2001). In a treatment manual, the intervention being tested must be described as precisely as possible so that program facilitators can be trained and the programs delivered in a consistent and reproducible manner (Luborsky & DeRubeis, 1994). The manual provides a detailed plan documenting each step of the program and how to implement it. Therefore, during the process of pilot testing of the online FSM, a facilitator manual was developed consisting of instructions for both technological and therapeutic facilitation.

#### 3.2.3.3 DATA COLLECTION

*Formative Evaluation:* During the three pilot tests, data for the formative evaluation was collected in four ways: telephone interviews or focus groups (depending on whether the participants had access to transportation), login data and electronic records. Telephone interviews (at the completion of each pilot test and fortnightly during Pilot Test 3) and focus groups (at the completion of each pilot test) were conducted with participants using guided open-ended questions. This approach to the evaluation was used to obtain an in-depth understanding of the strengths and weaknesses of the intervention from the perspective of consumers (Dehar, Casswell, & Duignan, 1993). Feedback from facilitators was obtained through face-to-face interviews. Participants' and facilitators' directly relayed their experiences with and opinions of the program. The questions included exploration of technical problems in accessing different parts of the program, including use of interactive activities and participation in group discussions. The interviewer was familiar with the program but was not a member of the design team. Participants in Pilot Test 3 agreed to share their experiences and opinions about the online FSM directly with the researcher through fortnightly telephone interviews. These interviews gave the design team opportunity to make requested changes and seek feedback concurrently with running the pilot test. All information from the focus groups and interviews were tape-recorded and transcribed.

Login data provided quantitative information both on participants' interactions with each other and with the program. Participant usability of the program was examined by tabulating the number of 'hits' (different pages viewed) and 'posts' (contributions

through comments, submissions, activities completed) by each participant. Tracking participants' navigation in the online FSM demonstrated technical problems and navigation issues. Data from participants' activities online, the amount of time they spent to explore different parts of the program and login errors were recorded by the platform. Electronic records (group discussions and completed activities) were used to gather information on how the participants interacted with the program, other participants and the facilitators.

*Efficacy Evaluation:* During Pilot Test 3, pre-test (socio-demographic and outcome data) and post-test (outcome data) data were collected using paper-based measurements sent to participants' preferred address. Socio-demographic information included gender, age, education, marital status, living arrangement, socio-economic status and first language. The independent variable was the online FSM prototype described earlier.

The outcome variables were selected based on the literature, tools previously shown to be effective in evaluating the face-to-face program (Mathiowetz et al., 2005; Mathiowetz et al., 2001) and in preparation for the RCT part of the project. All measures were tested to examine response burden and time for completion in order to test the feasibility and practicality of data collection. Given variables were tested at pre-test by using paper-based versions of the measurements sent by post to participants' preferred addresses. This method of data collection was chosen because some of the participants in the face-to-face FSM part of this PhD study were not expected to have access to the internet to complete the questionnaires online. Whenever possible, Australian outcome measures or those with Australian norms were selected. The outcome measures used for this study are described below.

The Personal Wellbeing Index is a measure of subjective quality of life (Cummins, Eckersley, Pallant, van Vugt, & Misajon, 2003). It is a self-administered tool, of 7 items, each rated on a Likert scale of 11 points. It has strong validity ($r = .78$) and reliability (Cronbach alpha between .70 and .85) (Cummins et al., 2003). It was judged more suitable than the SF-36 as it was originally designed for Australian people and is shorter in length. Also, the SF-36 is reported to have floor and ceiling

effects for people with MS (Freeman, Hobart, Langdon, & Thompson, 2000; Hobart, Freeman, Lamping, Fitzpatrick, & Thompson, 2001).

The Fatigue Impact Scale (FIS) (Fisk et al., 1994) was used to measure the impact of fatigue on individuals' lives. The FIS is a valid and reliable measurement tool recommended for evaluating efficacy of fatigue management interventions such as energy conservation education for persons with MS (Mathiowetz, 2003). The FIS has three subscales: cognitive, physical and psychosocial. Subjects were asked to rate the extent that fatigue had caused problems for them in relation to 10 items of cognitive functioning, 10 items of physical functioning, and 20 items of psychosocial functioning using a five point scale (0 = no problem, 1 = small problem, 2 = moderate problem, 3 = big problem and 4 = extreme problem). The maximum FIS score is 160 with greater scores indicating higher impact of fatigue on the individual's life. It has strong psychometric properties: internal consistency (r = .93), a moderate correlation (r = .51) with the Sickness Impact Profile (construct validity) and is able to discriminate between people with MS and hypertension (discriminant validity) (Dittner et al., 2004).

The Australian version of the Activity Card Sort (ACS-Aus) (T. L. Packer, Boshoff, & Desleigh, 2007) was used to assess participants' current activity level by sorting 82 activities into 4 categories ('have not done in the last 5 years', 'gave up due to illness', 'beginning to do again' and 'do now'). The ACS-Aus, a well known occupational therapy assessment, has been used successfully in another RCT testing a self-management program for people with vision impairment (S. J. Girdler, 2006). It allows participants to describe the impact that an illness or disability has had on their activities. As the ACS-Aus is administered face-to-face, and data collection in this study was undertaken via post, a pen and paper version of the ACS-Aus was used. The questionnaire included a checklist of the activities but the pictures from the ACS-Aus were not included. Scoring was undertaken according to the manual. The ACS-Aus has demonstrated moderate concurrent validity (r = .434), moderate convergent construct validity (r = .354), and strong discriminative validity ($p$ = .000) (Doney & Packer, 2008). Three scores can be calculated; retained activity level, current activity level and previous activity level. In this study, retained activity level was used as one of the primary outcome measures.

The Depression Anxiety and Stress Scale (DASS) is a self-report measure with three subscales: depression, anxiety and stress. Each of the three DASS subscales contains 14 items divided into subscales of 2-5 items with similar content. Participants rate the extent to which they have experienced each symptom over the past week, on a four-point severity/frequency scale. Internal consistency (coefficient alpha) for each scale in a large clinical sample (n = 437) were: Depression .96; Anxiety .89; and Stress .93 (T. A. Brown, Chorpita, Korotitsch, & Barlow, 1997). Lovibond and Lovibond (1995) have demonstrated that the DASS Depression scale and the Beck Depression Inventory are strongly correlated (r = .81)(concurrent validity).

The 11-item Duke Social Support Index (SSI) was used which is a standard self-administered measure (Koenig et al., 1993). It consists of two subscales: the social interaction subscale with four items and the satisfaction subscale with seven items, which provide both a subjective evaluation of the adequacy of support received and a more objective evaluation of the type and number of social interactions (Goodger, Byles, Higganbotham, & Mishra, 1999). Goodger et al. (1999) evaluated the reliability and validity of the scale in a large sample of 565 Australian community dwelling people aged 70 years and over. They reported that the scale had good internal consistency (alpha = .77) and test-retest reliability (correlation of .70 to .81). Compared to the Multidimensional Scale of Perceived Social Scale which is designed for adolescents and young adults, the DSSI is a more suitable measure for participants who were 30 years old or over.

The Generalised Self-efficacy Scale (GSE) (Schwarzer, 1993) was used in this research as self-management programs are underpinned by Bandura's self-efficacy theory. The GSE is a uni-dimensional scale with a high level of internal consistency (alpha = .93) in the original German version. The English version of this scale has also been reported to have high internal consistency (alpha = .88) and test-retest reliability of .63 over a four month period (Barlow, Williams, & Wright, 1996).

Essential Computer Skills Test: Because there is no standardised measure for measuring computer competency at a very basic level, a researcher-constructed measurement tool was used to examine participants' ability to use computer. This

tool examined typing, clicking and scrolling skills. Five simple questions were asked. Time to complete the test was calculated in seconds (Appendix B).

#### 3.2.3.4 DATA ANALYSIS

*Formative Evaluation:* Audio taped focus groups and interviews were transcribed verbatim and views of participants and the facilitators were reviewed on an on-going basis. Suggestions for change were taken into consideration either between pilot tests, or in the case of Pilot Test 3, during the running of the seven week program. Numerical data from electronic records was entered into SPSS 15.0 for Windows and analysed using descriptive statistics to characterise the shape, central tendency, and variability within login data to describe how participants accessed and used the program. After each pilot test, Mann-Whitney U tests were used to evaluate the data from electronic records between pilot tests.

*Efficacy Evaluation:* Data from all outcome variables were entered into SPSS. Demographic characteristics were analysed using descriptive statistics. Because the sample was small and a sample of convenience, the Wilcoxon signed-ranks test, a nonparametric statistical procedure was used to test for changes over time on quality of life, fatigue and activity participation (Portney & Watkins, 2008).

### *3.2.4 ETHICS*

*Formative Evaluation*: Ethics approval for the pilot study was obtained from the Curtin University Human Research Ethics Committee (Approval number OT-2005-14). The focus group and telephone interviews were audio-taped. Information obtained as part of these discussions was treated as confidential and participants could not be identified after the group. At no time were people outside of the focus group able to identify individual responses. While other members of the group were reminded about confidentiality, the researcher was unable to guarantee total confidentiality among other members. Participants were aware of this prior to participation.

An individual username and password to enter the online program were provided to each participant, the facilitators and the administrator. Participants were informed that the Curtin University IT staff responsible for providing support for the program

had access to the program. The first name and a picture of participants were added to the program only if they gave verbal consent to the researcher during the telephone interview. Otherwise, a pseudonym and a symbol, chosen by the participants, were used in the online FSM (Appendix A). The participants were ensured that complete confidentiality was ensured in any publications or presentations that arise from the research and no personal details would be published.

*Efficacy Evaluation:* Ethics approval for the efficacy study was obtained from the same ethics committee as above (Approval number OT-2005-14). The researcher did not have a direct role in recruiting participants to the study. Participants interested in participating in the study contacted the researcher directly. Their participation was voluntary and they were free to withdraw at any time. Participants were asked to give verbal consent during the screening interview. Based on this consent, pre-test questionnaires were sent to them via post. Return of the questionnaires was taken as implied consent which was clearly stated in the covering letter sent with the questionnaires.

The screening interview addressing the selection criteria was conducted with each potential participant. At the beginning of this interview, an in-depth verbal explanation was given of the purpose of the study, the process of intervention and the use of the findings. It was emphasised that although a summary of the findings from the study may be published, the participants' personal results were confidential and would not be divulged. Participants' freedom to withdraw from the intervention at any time was highlighted. All participants were allocated an identification number. The 'key' to the identification code was stored in a locked filing cabinet separate from data set. All questionnaires were identified by number only.

## 3.3 RESULTS

### 3.3.1 FORMATIVE EVALUATION (OBJECTIVE 1)

Demographic characteristics of the participants in the three pilot tests are presented in Table 3.2. No participant was excluded based on the score on the Memory Orientation Concentration Test (Katzman et al., 1983). Participants came from a wide age range (from 26 to 77) and thus feedback allowed the program to be developed to suit participants with various backgrounds, life experiences and

computer skills. For ease of presentation, an overview of flow of the participants and results of each pilot test are presented first. This is followed by more detailed explanation of how each component of the program was further developed and refined using the information obtained in each pilot test.

Table 3.2 Demographic Characteristics of Participants in the Three Pilot Tests

| Participant characteristics | Pilot Test 1 | Pilot Test 2 | Pilot Test 3 |
|---|---|---|---|
| Gender | 5 Males | 2 Males | 2 Males |
| | 5 Females | 9 Females | 9 Females |
| Age | Range 38-75 | Range 26-77 | Range 27-66 |
| | Mean = 54.20± 11.71 | Mean = 50.27 ±16.16 | Mean = 47.38 ± 12.6 |
| Diagnosis | 1 person with PD | 1 person with PD | 2 persons with PD |
| | 9 persons with MS | 3 persons with PPS | 9 persons with MS |
| | | 5 Persons with MS | |
| | | 1 person with MS and PPS | |
| Total | 10 | 11 | 11 |

Note. PD = Parkinson's Disease; MS = Multiple Sclerosis,; PPS = Post Polio Syndrome.

Flow of participants in the three pilot tests is shown in Table 3.3. In Pilot Test 1, none of the participants were able to complete the program; technical problems encountered included difficulty uploading the content and accessing the program. The web-site was hosted off-shore, as was the technical support, making communication between researchers and internet administrators difficult. Loading content and changing settings were hampered by an eight hour time difference. Therefore, it was decided that the platform was not acceptable for the program. Although none of the participants in Pilot Test 1 completed the program, they agreed to give feedback to help improve the program. A focus group was conducted with 3 participants; telephone interviews were completed with 3 other participants and the two facilitators of the program. At the completion of Pilot Test 1 it was concluded that the chosen electronic platform was not compatible with Australian systems.

Table 3.3 Flow of Participants in the Pilot Tests and Reasons for Non-completion

| | Number of participants | | |
|---|---|---|---|
| | Pilot Test 1 | Pilot Test 2 | Pilot Test 3 |
| Recruited | 10 | 11 | 11 |
| Number withdrawn before start of program | 2 | 0 | 2 |
| Number not logged into the program | 1 | 5 | 1 |
| Not interested in completing the course for personal reasons | 1 | 0 | 1 |
| Not interested in completing the course as a consequence of technical problems | 6 | 4 | 0 |
| Active participation until end of the program | 0 | 2 | 7 |

In Pilot Test 2, only two of the participants completed the program. Five did not complete the program as a consequence of technical problems. As most of the participants in this pilot test were living in rural or remote areas, a focus group was not possible. Telephone interviews with 6 of participants who had logged into the program provided suggestions for improving the program and preparing it for the next pilot test. A list of technical problems was prepared based on the login data, electronic records, telephone interviews with the participants and a focus group with the facilitators. Login data and electronic records provided by the platform were also used to improve the program. These data guided the design team to track the participants' movements in the program and to find an explanation for each of the technological problems. Electronic records of the administrator (IT expert) and login data of the online FSM resulted in a more developed program to be evaluated in Pilot Test 3.

Eight participants started the program in Pilot Test 3. One of the participants in the Pilot Test 3 decided to withdraw from the program in the fourth week. She had recently been diagnosed with MS and stated that participating in the program was

upsetting her as she learned more about possible consequences of MS. The seven other participants remained active till the end of the program. Telephone interviews with the participants every fortnight during and at the end of the program provided the possibility to make immediate changes week to week.

As explained, none of the participants in the Pilot Test 1 were able to complete the program (Table 3.3). Based on the problems in administration and local access, criteria were established for selection of a new platform to house the online FSM: 1) local control of the site; 2) researcher and facilitator access to login data and participant electronic records; 3) ease of navigation by participants; 4) capacity for interactive, online communication and ease of completion of activities without the need to upload or download files; and finally, 5) likelihood of WC3 compliance for people with disabilities. With the added advantage of using open source coding, the platform called Moodle Version 1.7 (http://moodle.org; accessed 2006) originally developed in Australia, was judged to meet these criteria. This platform is free and uses open source coding. The content was uploaded to the new platform with in-built Moodle features used to create key components of the fatigue self-management program (online information, online activities, and communication facility for sharing stories).

Having local control of the online program facilitated the administration thereby smoothing progression of the designing process. The login data and electronic records were easily accessible both for the administrator and for the facilitators during Pilot Tests 2 and 3. Availability of the three other features (ease of communication, completing activities and navigation) and ease of facilitation were also tested and are explained thoroughly in separate sections below.

#### 3.3.1.1 ONLINE GROUP COMMUNICATION

The number of posts by participants is shown in Table 3.4. In Pilot Test 1, the interactive components of the platform proved to be complicated and restricted. Only 4 posts occurred in the program as a result of the complexity. Consultation with the IT staff revealed that changing the platform was the way to solve this major problem.

Communication was facilitated in Pilot Test 2 using 'forums' (an in-built feature of Moodle) as interactive features in the Moodle platform. Although the results of the interviews showed that participants were interested in group communication, the total number of posts by all of the participants remained limited to 42 posts over the seven week period (Mean = 7 per participant, Rang from 0 to 34 posts). Based on the interview data, it was clear that this low rate of posts was the result of difficulties in accessing the group communication facility.

In Pilot Test 3, the forums were designed to be easily accessible from the front page of the program, and all forum discussions were posted to all participants' email addresses. Participants could read and reply to the forums directly from their emails. Results of the interviews showed that the forums were very popular for the participants. The number of posts by participants in the program from Pilot Test 2 to Pilot Test 3 was compared. A Mann-Whitney U Test showed a trend toward significant improvement ($p$ = .081) from Pilot Test 2 (Median = .5, range = 0 to 34) to Pilot Test 3 (Median = 12.5 and range = 3 to 30) per participant.

Table 3.4 Number of Posts and Hits by the Participants in Pilot Testing of the Online Fatigue Self-management Program

| | Number of participants logged into the program | Number of 'Hits' | Number of 'Posts' by facilitators | Number of 'Posts' by participants | Number of activities completed online |
|---|---|---|---|---|---|
| Pilot Test 1 | 7 | Not recordable | 12 | Total = 4<br>Mean [a] = .57<br>Median = .0<br>Range = 0 - 3 | 0 |
| Pilot Test 2 | 6 | Total = 1006<br>Mean = 168<br>Median = 70<br>Range 18-573 | 55 | Total = 42<br>Mean = 7<br>Median = .5<br>Range = 0 - 34 | 0<br>(4 activities were completed offline and feedback was given to the group) |
| Pilot Test 3 | 8 | Total = 3560<br>Mean = 444.75<br>Median = 394.5<br>Range 144-875 | 85 | Total = 94<br>Mean = 12.62<br>Median = 12.5<br>Range = 3 - 30 | Total = 78<br>Mean = 9.75<br>Median = 11.00<br>Range = 2 - 13 |

[a] Mean scores are calculated per participant.

#### 3.3.1.2 COMPLETION OF ACTIVITIES

Completing the activities online was not possible in Pilot Test 1. Participants had to complete them offline and then upload the created file to the program. This process proved to be too complicated to be manageable by participants with limited computer knowledge. Feedback from the focus groups and the telephone interviews showed that none of the participants were able to follow the instructions for uploading the files.

In Pilot Test 2, activities were created as downloadable Microsoft Word documents in the online program. A hard copy was also sent in the 'The Guidebook and Activities' via mail. Participants were asked to complete the activities on the hard copy and give feedback to the group. Interviews with facilitators indicated that the feedback provided by participants was not sufficient to start any group discussion.

In Pilot Test 3, the format of activities was changed. They were presented online in the format of multiple choice questions, drop down menus and short answer questions in the form of a 'quiz', another in-built feature of Moodle. Completing these activities required only limited computer knowledge. The activities were easy to complete and the instructions were clearly understandable. To further assist, a hard copy of the activities was included in the 'The Guidebook and Activities' posted to participants at the start of the program. Most of the participants (7 out of 8) used the activities online and reported them to be helpful while one participant preferred to use the hard copy. The mean number of activities completed online by the eight participants was 9.75 out of 13. During the telephone interviews, participants reported the usefulness of having the hard copy of the activities available at the same time as completing them online. Facilitators reported that their feedback to the completed activities started new discussions in the group. During the fortnightly telephone interviews, the participants reported only one technical problem in the activities. The short answer questions allowed entry of only 14 characters; this was not suitable for some of the questions which required longer answers. This problem was overcome by using another feature of the Moodle platform called as 'journal' which let participants complete answers with the same facilities as a Microsoft Word document.

#### 3.3.1.3 NAVIGATION

In Pilot Test 1, four of seven participants who logged into the program needed considerable phone coaching to enter the site and 'get started'. Interview data determined that this occurred as a result of complexity of the website address and unavailability of any guidance for participants. Interviews with the participants also showed that all had difficulty with navigation in the program - particularly if they had limited computer skills. Consequently, none of the participants in Pilot Test 1 completed the program.

As noted, prior to Pilot Test 2, 'The Guide Book and Activities', which explicitly outlined the navigation methods, was posted to the participants. An orientation week was also added. During the orientation week the participants had the opportunity to become more familiar with the program and have any technical problems resolved by the facilitators. As a result, only two of the participants needed additional guidance to start the program. The total number of hits by the six active participants during the seven-week course was 1006 (range from 18 to 573, Mean = 168). Interview data revealed that navigation was easy for participants, particularly those with better computer skills. The orientation week gave participants time to become familiar with the program and to introduce themselves to each other. A drop in the number of participants logging in after the fourth day of the program showed that one week was too long for orientation.

The guidebook was reviewed and more details about navigation were added. Then it was sent to participants prior to commencement of Pilot Test 3. During the program, participants were contacted fortnightly by the researcher to check for problems and positive components of the program. Only minor navigation difficulties were reported. All of the problems were immediately overcome. During the last two weeks of the program no technical or navigation problems were reported by participants or facilitators. Over the seven-week period, the mean number of 'hits' per participant was 445 (range 144 – 878) with the 8 participants registering a combined total of 3560 'hits' (Table 3.4). Mann-Whitney U Test showed a significant increase in number of hits by participants in Pilot Test 3 compared to Pilot Test 2 ($p$ = .021). The online FSM designed with the Moodle platform was accessible and user-friendly for the participants.

#### 3.3.1.4 FACILITATION

Interviews with the facilitators after Pilot Test 1 revealed that it was difficult to facilitate discussions. As the interactive feature in the program was not working properly, facilitation was not possible and the twelve posts by the facilitators did not start any group discussions. Also, the platform did not provide facilitators with any data about how the participants were using the program.

In Pilot Test 2, the two facilitators entered 55 posts. However, as 4 out of 6 participants who logged into the program were not using the interactive features, these posts did not result in group communication.

Before Pilot Test 3, a one day training course was provided for the facilitators to assist them to use the technology supporting the program more efficiently. In Pilot Test 3, the two facilitators entered a total of 85 posts with the eight active participants in the program using the interactive features in the program. Interviews with the facilitators and participants showed positive outcomes. The facilitation of the program through group communication features and providing feedback for the completed activities improved group discussions. Facilitators' feedback and their daily records of their experience with the online FSM resulted in a manual for facilitators. This manual was prepared in two sections, i.e. technology and facilitation, to be used in the RCT.

#### 3.3.1.5 PROGRAM FIDELITY

While the program was being developed, the researcher was constantly going back to the *Managing Fatigue* manual (T. L. Packer et al., 1995), as the original resource, to see if the online program was following the same principles. The two facilitators of the online program, who were occupational therapists and experienced facilitators of the face-to-face FSM program, believed that the self-management goals in the face-to-face FSM program were met in the online program (internal validity). Also, as explained in the previous section a manual and training course was prepared for the facilitators. Fidelity of the online FSM program was monitored in Pilot Tests 3, when the online program could mimic the face-to-face FSM program. A checklist of weekly tasks was prepared for the facilitators to ensure they delivered the program in the same way as it was planned.

### *3.3.2 EFFICACY EVALUATION (OBJECTIVE 2)*

The nearly completed online FSM protocol used in Pilot Test 3 formed the independent variable for preliminary efficacy testing. From eleven participants who were recruited to participate in Pilot Test 3, only 6 consented and completed the pre-test questionnaire. One of the six participants withdrew in the third week of the program. This participant reported that becoming more familiar with possible consequences of MS was unwanted and withdrew.

The demographics and clinical characteristics of the five remaining participants are presented in Tables 3.5 and 3.6. In order to allow comparison of the results of this study with other published studies, both median and mean scores are presented as descriptive statistics. Pre-test data showed the participants' median self-efficacy score range to be 14 to 33. Participants mostly reported a very high level of social support (Median = 35). Missing data at the item level on the post-test measures was treated by carrying forward. Wilcoxon Signed Ranks test demonstrated a significant improvement on the Fatigue Impact Scale ($p$ = .042) and a trend toward significance on the Personal Well-being index ($p$ = .080). The results did not show a significant increase in participants' activity participation (Table 3.7).

Table 3.5 Demographics of Participants in Pilot Test 3 (Objective 2)

| Variable | Frequency | Variable | Frequency |
|---|---|---|---|
| Gender | | Living situation | |
| Men | 1 | Alone | 1 |
| Woman | 4 | With other adults | 3 |
| | | With other adults and children | 1 |
| Diagnosis | | Education | |
| Multiple Sclerosis | 4 | High school | 2 |
| Parkinson's Disease | 1 | Vocational qualification | 2 |
| | | Post-graduate qualification | 1 |
| Language | | Income per week | |
| English | 5 | $600 - $999 | 3 |
| Other languages | 0 | $1000 - $1399 | 1 |
| | | $1400 - $1999 | 1 |

Table 3.6 Baseline Clinical Characteristics of Participants in Pilot Test 3

| Outcome Measure | Mean | Standard Deviation | Median | Range |
|---|---|---|---|---|
| Age (in years) | 45 | 12.41 | 46 | 27 - 62 |
| Fatigue Severity Scale (Screening) | 5.76 | .67 | 6.0 | 5.00 - 6.56 |
| Generalised Self-efficacy Scale | 26.2 | 7.79 | 30 | 14 - 33 |
| SSI: Overall | 32.6 | 8.90 | 35 | 19 - 43 |
| DASS: Depression Subscale | 14.6 | 7.38 | 14.6 | 7 - 28 |
| DASS: Anxiety Subscale | 11.6 | 6.64 | 10.5 | 2 - 23 |
| DASS: Stress Subscale | 17.9 | 7.33 | 17.5 | 7 - 33 |

Note. SSI = Social Support Index, DASS = Depression, Anxiety and Stress Scale.

Table 3.7 Results of Pre-test and Post-test Primary Outcome Measures

| Outcome Measure | Time point | Mean | SD | Median | Range |
|---|---|---|---|---|---|
| Fatigue Impact Scale | Pre-test | 66.20 | 36.83 | 56 | 32 - 128 |
| | Post-test | 55.40 | 38.21 | 43 | 25 - 121 |
| Activity Card Sort | Pre-test | .87 | .18 | .91 | .59 - 1.03 |
| | Post-test | .97 | .21 | 1.06 | .63 - 1.18 |
| Personal Wellbeing Index | Pre-test | 35 | 17.82 | 37 | 9 - 56 |
| | Post-test | 48 | 13.30 | 41 | 39 - 71 |

Note. SD = Standard Deviation.

### *3.3.3 PREPARATION FOR THE RCT*

During the process of the three pilot tests, different aspects of recruitment and data collection were tested. As the same process of recruitment was carried out during the pilot study, the results of recruitment were analysed based on the three pilot tests. Almost 47% of people (32 persons out of 69 persons) who contacted the researcher were interested and eligible to participate in the pilot study. Also, during Pilot Test 3, there was an attrition rate of 12% (one out of eight participants who logged into the program). Confirmation of diagnosis by the participants' physician as an inclusion criterion proved to be impractical. As the letter to the doctors were sent by the participants, the researcher could not follow-upon the letters and the average time for receiving the letters was 3.7 weeks (range 2.1 - 5.4 weeks). Therefore, for the RCT

part of the study, diagnosis reported by the participants was not considered in the inclusion criteria and confirmation letter from the doctors was sought later.

The calculated time to complete telephone interviews for screening participants was an average of 14 minutes (range 9-50 minutes) per person. This time included the time needed to explain the research and the process of the pilot test and its goals. The delivery time when mailing envelopes to WA and eastern parts of the country was calculated to be 5 days as an average. The Telephone Interview for Cognitive Status (TICS) proved to be unsuitable for the Australian culture. Three of the participants were offended by being asked about the Prime Minister of Australia and repeating 'Methodist Episcopal' (items 8 and 9 of the test). The feasibility of the computer test which had been designed by the researcher was tested and the necessary revisions were made. Some instructions and a 'practice' test were added to make it easier for the participants to enter the computer test and follow the instructions.

In preparing for the evaluation of the online FSM program through an RCT, a specific objective of the pilot study was to conduct a sample size calculation based on one of the primary outcome measures, the FIS which was the main target of the fatigue self-management program. Analysis of the FIS change scores between pre-test and post-test revealed that one score lay significantly outside an obvious cluster. In the sample size calculation this score was discarded as an outlier, giving a mean pre-test to post-test change score of 11.75 (SD = 13.57). Using these figures gave an effect size of .87 and determined that 18 participants would be required for each group at 80% power and 5% level of significance. This result was compared with the literature. A previous RCT study on the face-to-face version of the FSM program found significant difference between groups with an average effect size of .72 (Mathiowetz et al., 2005) which was considerably smaller than the effect size calculated according to the pilot study results. Therefore, in order to guarantee a large enough sample in the study (to prevent Type II error), the smaller effect size was used and the power was re-calculated. Based on the assumption that in the RCT there would be no difference in the change scores of the control group over the course of the study, a power calculation for analysis of variance determined that 25 participants would be required for each group at 80% power, effect size of .72 and 5% level of significance. The attrition rate reported by the literature ranged between

16% to 20% for self-management programs (Warsi et al., 2004) and 4% to 51% for online patient education programs (Nguyen, Carrieri-Kohlman, Rankin, Slaughter, & Stulbarg, 2004). In the present study, to estimate the number of participants needed for the study, a 20% attrition of participants over the 22 weeks of the study was considered. It was calculated that the subsequent RCT would therefore require an overall sample size of 95 before attrition.

## *3.4 DISCUSSION*

Developing online interventions is known as 'an arduous, sometimes tedious and always time-intensive process' (Ritterband et al., 2003, p.530). Although the online program was designed based on an evidence-based face-to-face program, the formative evaluation of the program, which was facilitated by constant feedback from the participants and the facilitators, took longer than what was expected. Testing as an important stage in the development of online interventions (Eng, 1999; Ritterband et al., 2003) took half of the 2-year process of development and required intensive teamwork to ensure that the online program could mimic its face-to-face version. When designing the program, several difficulties were encountered; finding characteristics of a suitable platform to carry the self-management group program, designing the site to carry several components of the program and then facilitating access to and navigation through the program required three pilot tests. As recommended by the literature (Ritterband et al., 2003), the process of this study also required having a health professional with IT knowledge and an IT expert with some knowledge about rehabilitation interventions in the design team. Continuous feedback from the participants in Pilot Test 3 provided the possibility of testing the effectiveness of small technical changes concurrently with running the course hence saving time. Although the literature acknowledges the necessity of online programs and studies reporting the results of studies of efficacy of online interventions receive a lot of attention, the process of development of the interventions is rarely addressed.

The format and structure of online interventions provided in the literature vary from online information or email coaching to highly structured programs. There are pros and cons for each format but the literature emphasises use of a standardised face-to-face program as basis for the online interventions (Ritterband et al., 2003). Using the

internet components like interactivity or graphics to help the group dynamics is also recommended (Ritterband et al., 2003). This online FSM program delivered information online on a weekly basis with graphics added for ease of understanding. The activities provided opportunities to practice the introduced skills in real life. The group discussions were the most highly valued aspect of the program with participants sharing their experiences, and successes and failures with the newly learnt strategies with each other. While the program was being developed, the researcher was constantly referring back to the *Managing Fatigue* manual (T. L. Packer et al., 1995), as the original resource, to see if the online program was following the same principles. The two facilitators of the online program, who were occupational therapists and experienced facilitators of the face-to-face FSM, believed that the self-management goals in the face-to-face FSM were met in the online program (internal validity). Fidelity of the online FSM was monitored in Pilot Test 3. A checklist of weekly tasks was prepared for the facilitators to ensure they delivered the program in the same way as it was planned. There is a need for further documentation of formative evaluation and technical view of designing online programs to facilitate future development studies.

One of the limitations of this study was use of a checklist of the activities of the ACA- Aus tool instead of using the complete test with its pictures. The small sample size did not make it possible to undertake a reliability test between the two versions of the test.

Despite the small sample size, this study showed the efficacy of this online fatigue self-management program in improving fatigue and quality of life. These results are in parallel with that of other studies testing the efficacy of the face-to-face version of the fatigue self-management program for people with MS (Mathiowetz et al., 2005; Mathiowetz et al., 2001; Sauter et al., 2008). Although the literature shows that the positive effect of the face-to-face FSM were maintained one year after the course (Mathiowetz et al., 2007), future studies are needed to explore whether the online version has the same results. Future studies should also address effect decay and the need for 'booster' session for the online version of the program.

Self-management programs are considered complex interventions. Lenz, Steckelberg, Richter, & Mühlhauser (2007) concluded in a systematic review that when evaluating a complex intervention, the heterogeneity in their goals, methods and target populations should be accurately considered. Therefore, the development of this online FSM was based on the framework suggested for development and evaluation of complex interventions which includes one pre-clinical stage and four phases (Medical Research Council, 2000). The pre-clinical stage was completed before this study, when the theory for the face-to-face fatigue self-management program was determined. This study presents the results of the modeling and exploratory trial phases (Phases I & II) of the development. An RCT is required to evaluate the efficacy of this complex intervention (Phase III) in comparison with a control group.

## *3.5 CONCLUSION*

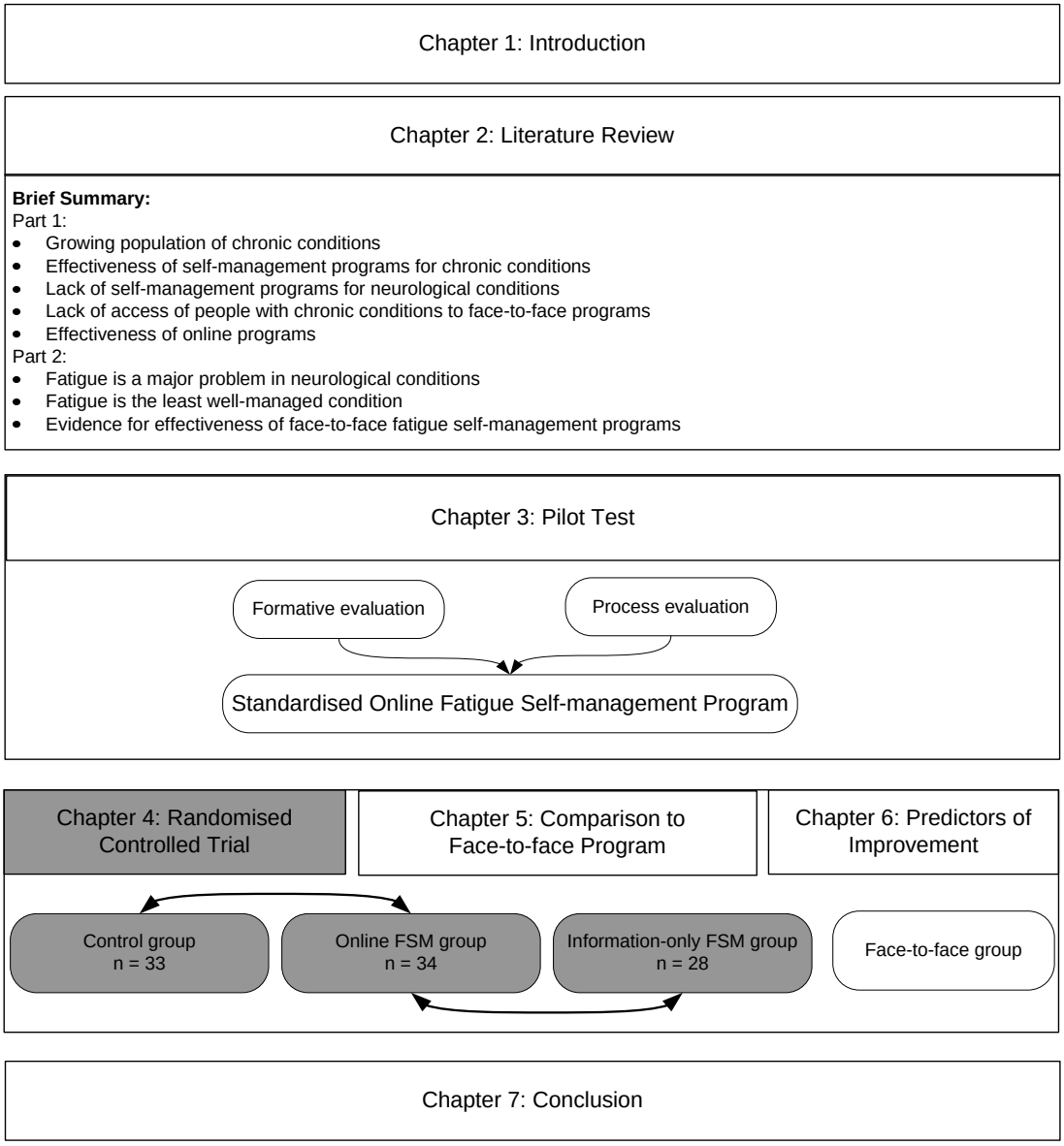
While fatigue is a common problem for people with fatigue secondary to neurological conditions, to our knowledge, this online FSM is the first of its kind to be implemented. The primary purpose of the fatigue self-management program is to help the participants improve their everyday performance and quality of life by incorporating 'energy conservation techniques' and self-management principles into their own life. Through the application of a fatigue self-management program, occupational therapists and other health professionals expect that the participants will learn the self-management skills, make corresponding behaviour changes and experience a reduction in the effect of fatigue on their lives.

The online FSM is now a standardised program with manuals for the participants and the facilitators mimicking its face-to-face version. The participants in the final pilot study reported that the program was easy to follow, completing the activities online was straightforward and interesting and that the most popular part of the program was the group discussions. The results show that the online fatigue self-management program is a viable complex intervention for people with neurological conditions. The participants in Pilot Test 3 improved significantly on the Fatigue Impact Scale and a trend toward significance was shown on the Personal Wellbeing Index. All outcomes showed a large effect size, however, the small sample size and non-

parametric statistics may have contributed. Further study with a larger sample size and more robust design is now required to compare the efficacy of this online program with its face-to-face version and a control group. Therefore, the exploratory phase of testing this complex intervention (Medical Research Council, 2000) was successfully completed. Different variations of the intervention components were tested and the feasibility of the study was evaluated.

# CHAPTER 4

# A RANDOMISED CONTROLLED TRIAL OF THE ONLINE FATIGUE SELF-MANAGEMENT PROGRAM



# 4 RANDOMISED CONTROLLED TRIAL

## *4.1 INTRODUCTION*

The previous chapter described the design, process and pilot testing of the online FSM program which is considered as Phase 2 (exploratory trial) of development and evaluation of a complex intervention (Medical Research Council, 2000). This chapter presents the methodology, results and discussion of the randomised controlled trial (RCT) study to evaluate the efficacy of the online FSM program in comparison with an online information-only FSM program (info FSM) and a no-intervention control group in a sample of adults with chronic neurological conditions. An RCT is the main and central step (Phase 3) in evaluating complex interventions (Medical Research Council, 2000). RCT methodology is known as the most rigorous way of determining whether a cause-effect relation exists between treatment and outcome and for assessing the efficacy of a treatment (Portney & Watkins, 2008). Further, the literature emphasises the importance of RCTs for testing the efficacy of complex and online interventions (Medical Research Council, 2000; Ritterband et al., 2003).

Despite the plethora of RCTs and systematic reviews examining self-management programs, (Barlow et al., 2002; G. Foster et al., 2007; Gibson et al., 2003; Monninkhof et al., 2003; Nolte et al., 2007; Steed et al., 2003; Warsi, LaValley, Wang, Avorn, & Solomon, 2003) and online programs (Gustafson et al., 1999; McKay et al., 2001; E. Murray et al., 2005; Wantland et al., 2004), there is a paucity of literature that focuses on efficacy of online self-management programs. The only available studies on online self-management programs (K. R. Lorig et al., 2006; Nguyen et al., 2005; Nguyen et al., 2008) were neither designed for people with neurological conditions nor were they focused on fatigue.

## *4.2 METHODS*

### *4.2.1 STUDY DESIGN*

A three-arm randomised clinical trial was used to evaluate the online FSM program in comparison with the info FSM and a control (no intervention) group. This RCT was registered through the Australian Clinical Trials Registry (Trial registration

number - ACTRN012607000268448). Randomisation to a face-to-face arm was not possible as the people for whom the online program was intended were exactly those people who could not attend traditional six week face-to-face programs due to distance, travel related fatigue, transportation difficulties etc. However, another study was included in this project to compare the efficacy of the face-to-face FSM group with that of the online FSM, info FSM and control groups (see Chapter 5).

The recruitment method and inclusion-exclusion criteria are the same (with two exceptions) as the pilot study and explained in the previous chapter. The first exception was that the participants who had access to the face-to-face FSM program (located in metropolitan area of Perth, Western Australia) were excluded from this part of the study and included in the study on face-to-face FSM program (Chapter 5). The second exception was that confirmation of diagnosis by the participants' physician was not considered in the inclusion criteria for the RCT. This decision was made based on the results of the pilot study (see section 3.3.3).

### *4.2.2 OBJECTIVES*

The main objectives of this study were to evaluate the efficacy of an online FSM program and then to compare it with the info FSM and a control group in a sample of adults with chronic neurological conditions. The primary outcomes were fatigue, quality of life and activity participation. To meet these objectives, three null hypotheses were considered:

1) There is no difference between the online FSM program and the info FSM program on primary and secondary outcome measures at post-test and follow-up among a sample of adults with chronic neurological conditions;

2) There is no difference between the online FSM program and the control group on primary and secondary outcome measures at post-test and follow-up among a sample of adults with chronic neurological conditions; and

3) There is no difference in fatigue, activity participation and quality of life from pre-test to post-test and follow-up for the online FSM group or either of the control groups.

### *4.2.3 PROCEDURE*

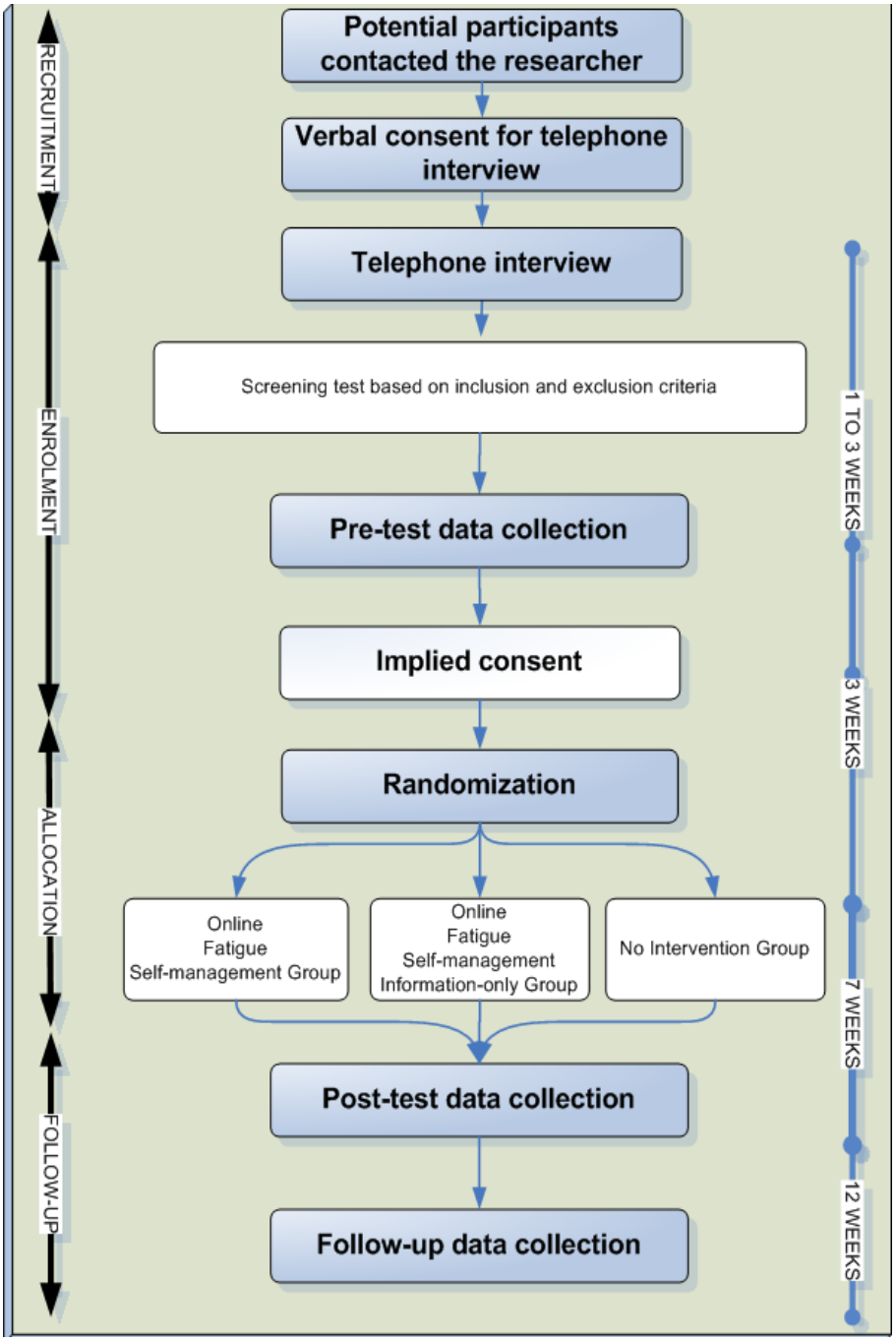
An overview of the RCT process is presented in Figure 4.1. Potential participants contacted the researcher. Subsequently, a mutually convenient appointment was arranged to discuss the study further via a telephone interview. The process of randomisation was clearly explained to the participants following which the participants were matched against the inclusion-exclusion criteria. Because confirmation of the participants' diagnosis was subsequently sought from participants' physicians, all the participants who self-reported their diagnosis as MS, PD, PPS or chronic fatigue syndrome were included in the randomisation and allocated to group. Also, as the online FSM program was designed to provide service for the people who do not have access to the face-to-face program, randomisation of the participants to four groups (face-to-face FSM, online FSM, info FSM and control groups) was not feasible because restricting the inclusion criteria to participants who had access to both the face-to-face and online programs would have excluded the very people for whom the program was designed. Therefore, the participants with access to the face-to-face program were excluded from the RCT study. Data from this group of participants was used in another part of the project (Chapter 5).

For those who met the criteria, envelopes including questionnaires and information sheets were sent via post. As indicated in the information sheets, return of the questionnaires was taken as implied consent. The process of data collection and randomisation were explained in the information sheet for the participants (Appendix C). In order to decrease attrition, participants were informed that they may be contacted by the researcher to be reminded to return the completed questionnaires. Questionnaires were sent to the participants three weeks before the start of the program (Pre-test), one week after the end of the program (Post-test) and also 3 months later (Follow-up).

Randomisation, which is known as a crucial aspect of clinical trial design, was used to eliminate selection bias in the assignment of interventions. It occurred after collection of baseline data. Permuted block design was used to generate the allocation sequence. Participants of every block of 30 were randomised with 1:1:1 ratio into the three groups; online FSM, info FSM or control group. This design was used to ensure that the comparison groups were approximately the same size (Altman

et al., 2001) (Also see section 4.2.3.1). Random numbers were generated by a computerised program downloaded from http://mahmoodsaghaei.tripod.com/softwares/randalloc.html. The computerised random number generation guaranteed adequate generation of an unpredictable allocation sequence (Schulz, Chalmers, Hayes, & Altman, 1995). The three groups of participants received interventions in parallel during each time block of the study. Subsequently the post-test data and three months follow up data were collected.

Figure 4.1 Stages and Procedures of the RCT



#### 4.2.3.1 ALLOCATION CONCEALMENT

Allocation concealment is a critical process during an RCT that prevents foreknowledge of treatment assignment and thus shields those who enroll participants from being influenced by this knowledge (Altman et al., 2001). Allocation concealment which seeks to prevent selection bias, protects the assignment sequence before and until allocation (Wood et al., 2008). In this research, participants were enrolled once pre-test questionnaires were returned (implied consent) and then allocated to a group by computerised central randomisation. This method of randomisation was used to decrease the likelihood of bias in group assignment (Altman et al., 2001). The sequence was unknown and unpredictable by the researcher, participants and the facilitators. Therefore, they did not know in advance to which treatment the next person would be allocated (allocation concealment).

#### 4.2.3.2 BLINDING

Although blinding is important to prevent bias (e.g. performance bias and detection bias) at several stages of a controlled trial (Altman et al., 2001) the feasibility of it depends on the nature of the experimental intervention and the response variables (Portney & Watkins, 2008). Performance bias is 'systematic differences in the care provided in the comparison groups other than the intervention under investigation' (Altman et al., 2001, p.688). One of the techniques to prevent this type of bias is blinding of either participants or therapists. Blinding was not possible in this study as both the participants and the therapists were actively engaged with each other - which is the nature of the self-management interventions. Detection bias (also known as assessment bias), which happens when knowledge of a participant's assignment influences the process of outcome assessment, was not possible. All the measurement tools used in this research were self-administered therefore blinding the assessors in order to preclude detection bias was not possible (Noseworthy et al., 2001).

#### 4.2.3.3 STRATEGIES TO PREVENT BIAS

Despite the limitation of this study in blinding the researcher, facilitators and participants to the group assignment, attempts to reduce bias were implemented. In order to isolate recruitment, data collection, facilitation and data entry, different

personnel were involved at each level (Portney & Watkins, 2008). Table 4.1 shows strategies used to prevent bias of the research team and participants. The strategies to prevent bias were as followings:

- A research assistant who was blind to the study objectives entered all the data into the data base. She was also blind to the allocation coding used within the ID codes in order to minimise data entry bias;
- The researcher conducted all the telephone interviews and organised posting of the questionnaires for the pre-test, post-test and follow-up data collection. However, both the researcher and the facilitators were blind to returned questionnaires and all data were received and entered into the data base by the research assistant;
- The researcher did not participate in any of the intervention programs and had no conversation with the facilitators or the participants about the progress of the groups or the efficacy of the program;
- Facilitators were, as far as possible, blind to the study objectives. Different facilitators delivered the online FSM and the info FSM programs, thus being unable to bias treatment of one group over another;
- Communication with participants other than related to actual intervention was undertaken by the researcher;
- Facilitators, who ran either of the interventions, had no contact with participants and the facilitators of the other intervention group and had no contact with control participants; and
- In order to prevent performance bias and detection bias, participants in the two online groups were blind to the components of the actual online intervention. Therefore, they did not know if they were allocated to the online FSM program or info FSM.

Table 4.1 Blinding of Participants, Facilitators, Research Assistant and the Researcher

| Research activity | Researcher | Research assistant | Facilitator | Participants |
|---|---|---|---|---|
| Data collection | - | √ | √ | - |
| Data entry | √ | | √ | √ |
| Treatment allocation | - | √ | - | √ (online and info FSM) |
| Data monitoring | √ | - | √ | - |
| Group facilitation | √ | √ | - | - |

Note. √ = Blind to research activities, FSM = Fatigue Self-management.

### *4.2.4 VARIABLES*

#### 4.2.4.1 INDEPENDENT VARIABLES

The independent variable had three levels summarised below and in Table 4.1. No changes were made to the usual care that the participants were receiving from the community, associations or private sector. Participants were asked to continue use of medication as usual, but to report any changes during the data collection period. Participants in all groups were tested before and after the program and also three months later.

**ONLINE FATIGUE SELF-MANAGEMENT GROUP (ONLINE FSM)**

The online version of the fatigue self-management program was an internet based program, developed from the face-to-face version using a deconstruction-reconstruction process. Key features of the face-to-face program were captured and transferred to the alternative medium creating a 7-week intervention (Ghahari, Packer, & Passmore, in press). The process of designing the program is explained thoroughly in Chapter 3. The online version mimicked the face-to-face version and included written content, online discussion and homework assignments. The program included six topics: the importance of rest, communication, body mechanics, re-arranging activity stations, setting priorities and standards and balancing schedule. The weekly information was based on self-management principles and blogs from previous participants in face-to-face FSM programs (expert panel) were also included in the content to facilitate transferring the message to the participants (vicarious learning and social persuasion). Participants shared information and

experiences, expressed their ideas or feelings and offered advice and support to one another. They were provided with a 'Guidebook and Activities' to help them navigate around the program. A hard copy of all the activities was included in this guidebook as participants in the pilot tests found it useful to prepare a draft prior to working online. Further details of the features of the program are described in Appendix A.

Facilitators of the online program were experienced occupational therapists with extensive group therapy background and also good knowledge of theory and facilitation of self-management programs. They received 2 days of training in use of the technology of the online FSM program. The manual of the original face-to-face program was used as a guide for intervention delivery. In addition, a second manual was provided for the online program. The manual included details about facilitation online for implementation. The facilitators actively guided the online group communication and commented on how the participants were completing activities in the program.

The online program was supported technologically by the Information Technology (IT) staff in Curtin University, Centre for Research into Disability and Society (CRDS). Facilitators were responsible for solving minor technological problems for the participants, while platform related problems required problem-solving by the IT administrators.

Table 4.2 Overview of Intervention Components by Group

| Components of the program | Online FSM group | Information only FSM group | Control group |
|---|---|---|---|
| Weekly self-management-based information | √ | √ | |
| Expert panel's blogs | √ | √ | |
| Facilitator | √ - active | √ - passive | |
| Group communication | √ | | |
| Activities | √ | | |
| Access to other participants | √ | | |

Note. √ = Components received by participants; FSM = Fatigue Self-management.

**INFORMATION-ONLY FATIGUE SELF-MANAGEMENT GROUP (INFO FSM)**

To evaluate the effectiveness of the interactive features of the self-management program through activities and the communication of participants with one another and the facilitators, a second group of participants received only weekly information for 7 weeks delivered through the internet. This group was designed as a placebo group to rule out the effect of attention. The content was identical to the written material used in the online FSM program (including weekly self-management based information and the expert panel's blogs), but participants had no access to activities, the interactive components of the program and to each other. The group facilitator undertook a passive role in the group; she interacted individually with participants simply checking for any technology problems and sending standardised weekly reminders to the participants. Like the online FSM program, this program was supported by the IT staff of the Centre for Research into Disability and Society.

**CONTROL GROUP (NO INTERVENTION)**

Participants in this group continued their normal life without intervention. As per all groups, they received their routine care which ranged from nothing to specialist care and/or community care.

#### 4.2.4.2 DEPENDENT VARIABLES

All primary and secondary measures described in the pilot study (Chapter 3) were used in the RCT study. Except for the Essential Computer Skills Test (which was tested via the internet for the two online groups) all variables were measured via the post using paper-based versions of the measures. This method of data collection was chosen because the participants in the other part of the study (the face-to-face fatigue self-management program - see Chapter 5) did not have access to the internet to complete the questionnaires online.

The primary outcomes in this RCT were quality of life, fatigue and activity participation, all of which were collected at pre-test, post-test and follow-up. Sociodemographic information (Appendix D) which was used as covariates was collected at pre-test. The other covariates for the RCT included depression, anxiety, stress, social support, self-efficacy and essential computer skills; all were collected at pre-test, post-test and follow-up in order to allow subsequent secondary analysis (to

collect data for another part of this PhD project) (see Chapter 6). Table 4.3 provides a summary of the outcome measures. Psychometric properties of the outcome measures were explained in section 3.2.3.3 in the Pilot Study Chapter.

Table 4.3 Summary of Outcome Measures

| Variable | Instrument | Acronym |
|---|---|---|
| Primary outcome measure (dependent variables) | | |
| Quality of Life | Personal Wellbeing Index (Cummins et al., 2003) | PWI |
| Activity Participation | Australian version of Activity Card Sort (T. L. Packer et al., 2007) | ACS |
| Fatigue | Fatigue Impact Scale (Fisk et al., 1994) | FIS |
| Secondary outcome measures (covariates) | | |
| Depression, Anxiety and Stress | Depression Anxiety and Stress Scale (S. H. Lovibond & P. F. Lovibond, 1995) | DASS |
| Social Support | Duke Social Support Index (Koenig et al., 1993) | SSI |
| Self-efficacy | Generalised Self-efficacy Scale (Schwarzer, 1993) | GSE |
| Essential Computer Skills | Self-constructed measurement (Appendix B) | - |

### *4.2.5 DATA MANAGEMENT AND ANALYSIS*

The primary analysis was intention-to-treat and all participants who underwent random allocation were analysed according to group assignment. This method was used to avoid bias associated with non-random loss of participants (Lachin, 2000) . All results were analysed using the software package SPSS 15.0 for Windows, 2007. Missing value analysis was conducted to test for patterns in missing data. Missing value analysis helps address several concerns caused by incomplete data. Checking for missing data is required for most statistical procedures as cases with missing values - which are systematically different from cases without missing values - can obscure the results. Also, missing data may reduce the precision of calculated statistics because there is less information than originally planned. Another concern is that the assumptions behind many statistical procedures are based on complete cases, and missing values can violate application of theories. The results of missing value analysis did not demonstrate any significant pattern of missing data.

Following the missing value analysis, missing data were imputed at two levels; item level when one or more questions/items of a scale was/were not answered; and scale level when none of the questions were answered in a questionnaire.

Missing data at pre-test at the item level were substituted with the mean of the group, while at post-test and follow-up, missing data was treated by carrying item scores forward from the previous time point Table 4.4. There was no pre-test missing data at the scale level as return of pre-test data was considered as consent for participation. Missing data at scale level at post-test and follow-up were analysed as intent-to-treat (ITT) by replacing missing values by carrying forward total scores from the previous data collection points. This method, known as last observation carried forward (LOCF), is suggested as the preferred method for continuous data (Portney & Watkins, 2008). The attrition rate was 9% (n = 9) at post-test and 21% (n = 20) at follow-up. For participants that dropped-out, scores from the previous time point were carried forward for all the outcome measures. As the number of non-compliers was small at post-test, no statistical test was used to evaluate the difference. The attrition rate at follow-up was not significantly different between the groups ($p > .05$).

Table 4.4 Imputation of Missing Data

| Missing data at | Pre-test | Post-test | Follow-up |
|---|---|---|---|
| Item level | Substituted with mean of the group | Pre-test score carried forward | Post-test score carried forward |
| Scale level | None | Pre-test score carried forward | Post-test score carried forward |

Preliminary checks were conducted to ensure that there was no violation of the assumptions of normality, linearity, homogeneity of variances and homogeneity of regression slopes. Kolmogorov-Smirnov test of normality revealed that except for the FIS score in the control group, all outcome measures showed a normal distribution. Therefore, they were analysed with parametric statistics. For non-normally distributed data (FIS scores), either logarithmic transformation was performed to

correct the skewness of the distribution or non parametric tests were used in the analyses.

One of the advantages of randomisation is that it allows for use of probability theory in the analyses to express the likelihood that any difference in outcome between intervention groups merely reflects chance (Greenland, 1990). Results of data analysis were considered statistically significant when $p < .05$. Initially, to ensure comparability of groups, the three groups were compared at baseline with respect to demographic and clinical characteristics, using analysis of variance (ANOVA) for continuous variables and chi-square test for nominal data.

Analysis of covariance (ANCOVA) was performed to examine the impact of the type of intervention on the primary outcome measures (FIS, PWI and ACS) at post-test and follow-up (Testing hypotheses 1 and 2). The independent variable was the type of intervention (online FSM program, info FSM program and no intervention). The dependent variables consisted of the scores on the FIS, PWI and ACS scale administered immediately after the completion of the intervention (post-test) and three months later (follow-up). In order to adjust for any group differences at baseline, participants' scores on the pre-intervention (pre-test) administration of the FIS, PWI or ACS and covariates (i.e. depression, anxiety, stress, social support and self-efficacy) were used as the covariates in these analyses.

To test the change in scores at pre-test, post-test and follow-up for the online FSM, info FSM or the control groups (Testing hypothesis 3), repeated-measures analyses of variance were performed with 1 within-subject factor, time (Three levels: pre-test, post-test and follow-up). If significant, pairwise comparison was performed with Bonferroni correction for multiple comparisons. For non-normally distributed data (FIS for control group), changes in fatigue over time was analysed by using Friedman ANOVA. To do non-parametric post-hoc procedures, the difference between the mean ranks of the different time points was calculated. Then, the difference was compared to a critical difference which was based on the z-score (corrected for the number of the comparisons being done), total sample size (n = 95) and the number of conditions (k = 3).

The inequality used for comparison of pre-test and follow-up is presented in Equation 4.1 is an example:

Equation 4.1: $$|R_{Follow-up} - R_{Pre-test}| \geq z_{\alpha/(k(k-1)}\sqrt{\frac{k(k+1)}{6N}}$$

Other comparisons (pre-test versus post-test and post-test versus follow-up) used analogous calculations. If the difference between the mean ranks was bigger than the critical difference, then that difference was considered as significant.

The effect size was also calculated for all analyses. 'Eta squared' is one form of effect size statistics widely used in the literature. A number of criticism have been leveled at eta squared (Pierce, 2004). For example, some authors believe that it is biased (Field, 2005). In the present study, 'partial eta squared' was used which overcomes a number of concerns raised (Pallant, 2005). This is the statistics calculated by SPSS although it is not labeled as such in the output (Pallant, 2005). To interpret the strength of partial eta squared the following guidelines were used (J. Cohen, 1988): .01 = small effect; .06 = moderate effect ; and .14 = large effect.

Secondary analyses included two sets of tests using ANCOVA and repeated measures ANOVA; firstly, comparison of a combined group (online FSM group plus info FSM group) with the control group and secondly, sensitivity tests using the data for the participants in the three groups who had complete data sets at pre-test, post-test and follow-up and who had completed more than 5 sessions of the FSM program.

### *4.2.6 ETHICS*

Ethics approval for the study was obtained from the Curtin University Human Research Ethics Committee (Approval number OT-2005-14) (see section 3.2.4). The process of randomisation was clearly explained in the telephone interview and also in the information sheet provided to the participants. The participants' questions about the randomisation process were answered precisely. The participants who were allocated to the control groups were promised the opportunity to participate in an online FSM program after the end of the study.

## *4.3 RESULTS*

### *4.3.1 FLOW OF PARTICIPANTS*

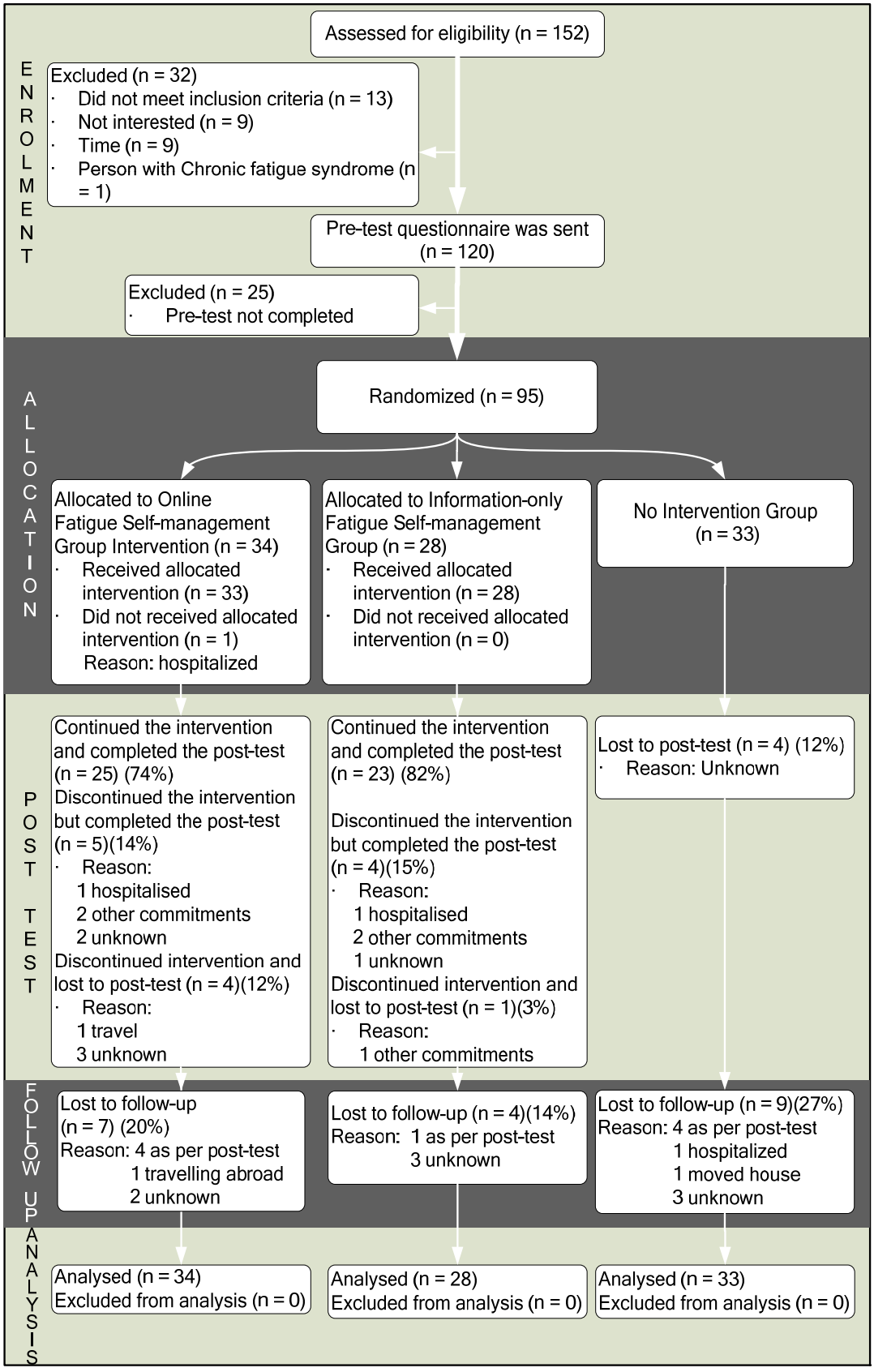
Based on the sample size calculation presented in section 3.3.3 of the pilot study, 95 participants were required for the RCT study before attrition to detect differences the groups in primary outcome measures between groups at post-test and follow-up. Figure 4.2 depicts the flow of participants through the study. One hundred and fifty two potential participants contacted the researcher. Thirty two potential participants (21%) were not included in the study; fourteen were not eligible because they had an FSS score lower than 4 or a diagnosis other than MS, PD, PPS or chronic fatigue syndrome; nine were not interested in the program and nine other people declined on the basis of time commitment or a clash of schedules. No participant was excluded based on the score on the Memory Orientation Concentration Test (Katzman et al., 1983). Thus, the pre-test questionnaires were sent to 120 potential participants. As return of this questionnaire was considered as implied consent, the twenty five individuals who did not return the completed questionnaire were excluded from the study, thus a total of 96 participants were allocated to groups. The study was conducted in four time blocks between May 2007 and March 2008. The final number of participants in the blocks ranged between 19 and 29 (Mean = 23.75). Participants in each block were randomised into three groups: online FSM, info FSM and control.

Ninety six participants were eligible for the study. The diagnosis confirmation letters from doctors were received for 77 persons (81% of the 96 participants). Self-report of chronic disease diagnosis is shown to agree with the medical record diagnosis from 73% to 83% of the time (Martin, Leff, Calonge, Garrett, & Nelson, 2000). In this study, in 100% of cases the diagnosis by the doctors matched with the participants' self-report. As confirmed diagnosis was not required for inclusion, participants whose diagnosis confirmation letters were not returned, were not excluded from the study.

Based on the inclusion criteria people with MS, PD, PPS and chronic fatigue syndrome were eligible. However, as only one participant (in the online FSM group) had chronic fatigue syndrome, these data were not included in any of the analyses and, for ease of presentation, have been excluded in all reporting of participants'

numbers, data, etc. Therefore, only the flow and the results for data collected for the ninety five participants are reported. The eligible participants were randomly allocated to the three groups; as a result 34 were allocated to the online FSM group, 28 to the info FSM and 33 to the control.

Figure 4.2 Flow of Participants through Each Stage of the RCT



For the total sample, attrition was 9% (n = 9) at post-test (uncompleted post-test questionnaire) and 21% (n = 20) at follow-up. Eleven percent of the participants in the online FSM group, 4% of the info FSM group and 12% of the control group neither continued with the program nor completed the post-test questionnaire. Because of the small attrition at post-test, using a statistical test to show the difference between the number of drop outs between the groups was not possible. The attrition rate at follow-up was not significantly different between the online FSM group (20%), info group (14%) and control group (27%), $\chi^2(1) = .434$, $p = .510$.

An independent t-test was conducted to test the difference between the participants who returned the post-test questionnaires and the ones who did not return them. Comparison of baseline data revealed that the participants who did not return the post-test data were significantly more stressed [t (1,93) = 7.099, $p = .009$] and more anxious [$t$ (1,93) = 4.428, $p = .38$] on the DASS scale compared to the others. Likewise participants who returned the post-test questionnaire but did not complete the follow-up questionnaire obtained significantly higher scores for depression [$t$ (2.124, 84), $p = .037$] and anxiety [$t$ (2.553, 84), $p = .12$] when compared with the participants who returned the follow-up data.

The attendance rates are reported in Table 4.5. One participant in the online FSM program did not log into the program, however, all 28 participants in the info FSM commenced the program. Almost 79% of the participants in the online FSM program and about 82% of participants in the info FSM 'logged on' during the orientation week and during at least 3 additional weeks of the interventions. More than 64% of the participants in the online FSM and 75% of the participants in the info FSM program participated in at least 5 weeks of the programs. An independent-samples t-test was conducted to compare the participation rate (i.e. the number of weeks that the participants in the experimental groups were actively involved in the program) between the online FSM and info FSM groups. There was no significant difference in the participation rate for the online-FSM group (Mean = 5.53, SD = 2.27) and that of the info FSM [Mean = 5.89, SD = 2.02; $t$ (60) = -.658, $p = .513$]. As the results were not significant, there was no risk of Type I error. Further, the number of forum posts by the participants in the online FSM group was calculated as an indicator of

participation rate. The number of forum posts ranged between 0 and 49 per person over the 7 week program (Mean = 9.32, SD = 11.90).

Table 4.5 Completion Rates in the Fatigue Self-management Programs

| Participation | Online FSM group | | Info FSM group | |
|---|---|---|---|---|
| | Participation per week | Cumulative Percent | Participation per week | Cumulative Percent |
| 6 Weeks | 22 | 64.7 | 20 | 71.4 |
| 5 Weeks | 24 | 64.7 | 21 | 75 |
| 4 Weeks | 24 | 73.5 | 23 | 82.1 |
| 3 Weeks | 27 | 79.4 | 23 | 82.1 |
| 2 Weeks | 29 | 85.3 | 23 | 82.1 |
| 1 Week | 30 | 88.2 | 27 | 96.4 |
| Orientation Week | 33 | 97 | 28 | 100 |
| Did not participate | 1 | 100 | 0 | 100 |

Note. FSM = Fatigue Self-management.

### *4.3.2 SOCIODEMOGRAPHIC AND CLINICAL CHARACTERISTICS*

**Error! Reference source not found.** gives a summary of the sociodemographic and clinical characteristics of participants in the online FSM, info FSM and control groups and the overall sample at pre-test. Randomisation resulted in equal groups with regards to these characteristics except for the education level which was significantly different between the three groups. While the number of the participants in the online FSM and control groups who had tertiary qualifications was equal, a smaller number of participants in the online FSM group had only high school or a lower level of education and a higher number of them had vocational qualifications. The majority of participants (77%) were female. This was expected as the majority of the participants were people with MS and 74% of all Australians with MS are female (Access Economics Pty Limited, 2005). Although the selection criteria included adults aged 20 and over, the mean age of participants was 50.25 ± 12.03

(range 23-90 years). This was also anticipated as about 78% of the participants had MS. Over half of the Australians with MS are aged 40-59 (Access Economics Pty Limited, 2005). Onset of Parkinson's disease also occurs in middle age or later and post-polio syndrome begins 25-30 years after an acute attack of paralytic poliomyelitis (Umphred, 2007).

While only 78.5% of the population in the 2006 census spoke English at home (Australian Bureau of Statistics, 2005), English was the first language for the entire group in this study. This shows that potential participants who speak languages other than English at home were underrepresented. According to their postal codes, sixty percent of the participants in the study lived in metropolitan areas of Australia and 40 percent in rural areas. This is almost almost the same as the population distribution which in 2006 showed that 68% of Australians lived in major cities and the remainder (32%) in regional and remote areas (Australian Bureau of Statistics, 2008).

About 80% of the participants in this study had a vocational qualification or higher education compared with about half the population in Australia aged 15 years and over (Australian Bureau of Statistics, 2006a). Participants with school level education or lower may have been underrepresented.

Only 18% of the participants were living alone. While four in five Australians without disability and over half of people with disability participate in the labour force in Australia (Australian Bureau of Statistics, 2006a), almost two third of the participants (65.3%) in this study were unemployed. The employed participants were only working an average of 14 hours per week. The gross household income for almost half of the participants was between AUS$600 and $1999 per week which is above the median gross household income in Australia (Australian Bureau of Statistics, 2006b). More than two thirds of the participants made the first contact with the researcher via the internet.

Table 4.6 Demographic Characteristics of the Participants in the RCT Study

| Sociodemographic characteristics | All Participants (n = 95) | Online FSM group (n = 34) | Info FSM group (n = 28) | Control group (n = 33) | Test | *p* - value |
|---|---|---|---|---|---|---|
| Gender | | | | | | |
| Male (%) | 18 (18.9) | 3 (8.8) | 6 (21.4) | 9 (27.3) | $\chi^2$ | .055 |
| Female (%) | 77 (81.1) | 31 (91.2) | 22 (78.6) | 24 (72.7) | | |
| Age, years | | | | | | |
| Mean (SD) | 50.25 (12.3) | 51.00 (13.6) | 47.86 (12.0) | 51.52 (11.0) | ANOVA | .47 |
| Range | 23 - 90 | 23 - 74 | 28 - 81 | 31 - 90 | | |
| State | | | | | | |
| Western Australia (%) | 25 (26.4) | 11 (32.4) | 6 (21.4) | 8 (24.2) | $\chi^2$ | . 856 |
| Queensland (%) | 34 (35.8) | 9 (26.4) | 12 (42.8) | 13 (39.4) | | |
| New South Wales (%) | 18 (18.9) | 7 (20.6) | 5 (17.9) | 6 (18.2) | | |
| South Australia & Victoria, Tasmania (%) | 18 (18.9) | 7(20.6) | 5 (17.9) | 6 (18.2) | | |
| Living Area | | | | | | |
| Metropolitan (%) | 57 (60) | 21 (61.8) | 16 (57.1) | 20 (60.6) | $\chi^2$ | .921 |
| Country (%) | 38 (40) | 13 (38.2) | 12 (42.9) | 13 (39.4) | | |
| Highest Education Level | | | | | | |
| Secondary school or less (%) | 29 (30.5) | 7 (20.6) | 9 (32.1) | 13 (39.4) | $\chi^2$ | .037* |
| Tertiary qualification (%) | 40 (42.1) | 13 (38.2) | 14 (50.0) | 13 (39.4) | | |
| Vocational qualification (%) | 26 (27.4) | 14 (41.2) | 5 (17.9) | 7 (21.2) | | |

Continued on next page

Table 4.6 continued

| Sociodemographic characteristics | All Participants (n = 95) | Online FSM group (n = 34) | Info FSM group (n = 28) | Control group (n = 33) | Test | *p* - value |
|---|---|---|---|---|---|---|
| Living Situation | | | | | | |
| Live alone (%) | 18 (18.9) | 7 (20.6) | 4 (14.3) | 7 (21.2) | $\chi^2$ | .953 |
| Live with others (%) | 77 (81.1) | 27 (79.4) | 24 (85.7) | 26 (78.8) | | |
| Employment | | | | | | |
| Employed (%) | 33 (34.7) | 10 (29.4) | 13 (46.4) | 10 (30.30) | $\chi^2$ | .929 |
| Unemployed (%) | 62 (65.3) | 24 (70.6) | 15 (53.6) | 23 (69.7) | | |
| Working Hours/week | | | | | | |
| Mean (SD) | 8.06 (14.63) | 6.00 (10.94) | 9.75 (14.67) | 8.76 (17.79) | ANOVA | .576 |
| Range | 0 - 74 | 0 - 40 | 0 - 50 | 0 - 74 | | |
| Gross Income/week | n = 81 | n = 32 | n = 18 | n = 31 | | |
| Less than $599 (%) | 34 (37.4) | 12 (37.5) | 9 (32.1) | 13 (41.9) | $\chi^2$ | .811 |
| Between $600 and $1999 (%) | 46 (50.5) | 17 (53.1) | 14 (50.0) | 15 (48.4) | | |
| More than $2000 (%) | 11 (12.1) | 3 (9.4) | 5 (17.9) | 3 (9.7) | | |
| Contact | | | | | | |
| Telephone contact (%) | 18 (18.9) | 8 (23.5) | 7 (25) | 3 (9.1) | $\chi^2$ | .136 |
| Email (%) | 77 (81.1) | 26 (76.5) | 21 (75) | 30 (90.9) | | |

Note. FSM = Fatigue Self-management

* $p < .05$.

Table 4.7 gives a summary of the clinical characteristics of participants in the online FSM, info FSM and control groups and the overall sample at pre-test. Randomisation resulted in equal groups with regards to these characteristics. More than two third of the participants were diagnosed with MS. This was the result of the fact that the MS Societies in different states of Australia showed interest in the program and published flyers for this project in their magazines or sent it to their members through email. Participants with PD and PPS were only recruited in Western Australia. Most participants with MS (66.1%) had relapsing-remitting MS which is the most common type of MS on initial diagnosis (Umphred, 2007). Time since diagnosis showed a wide range of 1-71 years (Mean = 11.44 ± 13.37). The participants in the three groups were not significantly different on any clinical characteristics. Compared to the Australian norms for the DASS, the participants' depression, anxiety and stress level were within the normal range for stress and the mild range for anxiety and depression (P. F. Lovibond & S. H. Lovibond, 1995). Participants' self-efficacy ranged between 12-40 with a mean of 29. The range of scores for social support was from 16 to 40 as measured by the Duke Social Support Index. This was comparable with the range of 12 to 33 reported for community dwelling older adults with good or better self-rated health (Goodger et al., 1999) and a Western Australian older adult sample with visual impairment (Mean = 26.8, SD = 3.3) (S. J. Girdler, 2006). However, a sample of Western Australian women with fatigue secondary to chronic conditions (mean age = 44.2, SD = 10.50) had a higher level of social support (Mean = 34.36, SD = 5.27) (Khemthong, 2006). Based on t-test results, there was no difference between the participants in the Online-FSM and info FSM groups in their computer skills ($p > .05$).

The participants were asked if they have changed their medication during the previous 3 months both at post-test and at follow-up. There was no significant difference between the three groups in change of their medication ($p > .05$ both at post-test and follow-up).

Table 4.7 Clinical Characteristics of the Participants

| Clinical Characteristics | All participants | Online FSM group | Info FSM group | Control group | Test | *p* - value |
|---|---|---|---|---|---|---|
| Diagnosis | | | | | | |
| Parkinson's Disease or Post-polio syndrome [a] (%) | 21 (22.1) | 9 (26.5) | 5 (17.9) | 7 (21.2) | $\chi^2$ | .602 |
| Multiple Sclerosis (%) | 74 (77.9) | 25 (73.5) | 23 (82.1) | 26 (78.8) | | |
| Time since Diagnosis (in years) | n = 73 | n = 24 | n = 23 | n = 26 | | |
| Mean (SD) | 11.44 (13.37) | 13.54 (17.74) | 11.48 (11.16) | 9.46 (10.33) | ANOVA | .963 |
| Range | 1 - 71 | 1 - 71 | 1 - 52 | 1 - 52 | | |
| Type of MS | | | | | | |
| Relapsing –remitting (%) | 39 (66.1) | 13 (65.0) | 14 (77.8) | 12 (57.1) | $\chi^2$ | .587 |
| Other types (%) | 20 (33.9) | 7 (35.0) | 4 (22.2) | 9 (42.9) | | |
| Medication use | | | | | | |
| Yes (%) | 85 | 31 | 24 | 30 | $\chi^2$ | .967 |
| No (%) | 10 | 3 | 4 | 3 | | |
| Essential Computer Skills Test (in seconds) | n = 47 | n = 23 | n = 24 | | | |
| Mean (SD) | 105.79 (105.91) | 91.70 (51.09) | 119.2 (139.82) | - | t-test | .378 |
| Range | 34 - 620 | 35 - 232 | 34 - 620 | - | | |
| General Perceived Self-efficacy Scale | | | | | | |
| Mean (SD) | 29.02 (4.76) | 29.44 (5.14) | 28.71 (3.81) | 28.85 (5.18) | ANOVA | .812 |
| Range | 12 - 40 | 18 - 40 | 19 - 36 | 12 - 38 | | |

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Table 4.7 continued

| Clinical characteristics | All Participants | Online FSM group | Info FSM group | Control group | Test | *p* - value |
|---|---|---|---|---|---|---|
| DASS: Depression Subscale | | | | | | |
| Mean (SD) | 10.68 (9.60) | 11.00 (9.99) | 10.81 (10.24) | 10.79 (8.89) | ANOVA | .944 |
| Range | 0 - 39 | 0 - 37 | 0 - 39 | 0 - 39 | | |
| DASS: Anxiety Subscale | | | | | | |
| Mean (SD) | 7.95 (7.02) | 8.97 (6.69) | 7.79 (7.68) | 7.03 (6.87) | ANOVA | .528 |
| Range | 0 - 33 | 0 - 24 | 0 - 32 | 0 - 33 | | |
| DASS: Stress Subscale | | | | | | |
| Mean (SD) | 13.06 (9.42) | 13.71 (8.96) | 13.54 (10.54) | 12.00 (9.08) | ANOVA | .727 |
| Range | 0 - 42 | 0 - 37 | 0 - 42 | 0 - 34 | | |
| SSI: Overall | | | | | | |
| Mean (SD) | 30.41 (4.65) | 29.97 (4.05) | 29.75 (4.76) | 31.42 (5.09) | ANOVA | .299 |
| Range | 16 - 40 | 22 - 37 | 16 - 36 | 19 - 40 | | |
| SSI: Social Interaction Subscale | | | | | | |
| Mean (SD) | 8.41 (1.75) | 8.21 (1.77) | 8.00 (1.72) | 8.97 (1.65) | ANOVA | .066 |
| Range | 4 - 12 | 4 - 12 | 4 - 11 | 4 - 11 | | |
| SSI: Satisfaction Subscale | | | | | | |
| Mean (SD) | 25.46 (4.33) | 25.15 (3.90) | 25.81 (4.60) | 26.03 (4.58) | ANOVA | .652 |
| Range | 13 - 34 | 16 - 32 | 13 - 31 | 16 - 34 | | |

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Table 4.7 continued

| Clinical characteristics | All Participants | Online FSM group | Info FSM group | Control group | Test | *p* - value |
|---|---|---|---|---|---|---|
| FIS: Overall score | | | | | | |
| Mean (SD) | 80.53 (31.60) | 79.94 (30.48) | 86.14 (32.57) | 76.36 (32.165) | ANOVA | .485 |
| Range | 11 - 159 | 11 - 135 | 30 - 147 | 28 - 159 | | |
| FIS: Physical Subscale | | | | | | |
| Mean (SD) | 24.40 (7.63) | 24.97 (8.02) | 25.04 (7.16) | 23.27 (7.72) | ANOVA | .581 |
| Range | 8 - 40 | 8 - 39 | 10 - 40 | 10 - 40 | | |
| FIS: Cognitive Subscale | | | | | | |
| Mean (SD) | 18.96 (9.28) | 19.18 (8.52) | 20.43 (9.54) | 17.48 (9.87) | ANOVA | .465 |
| Range | 1 - 40 | 10 - 40 | 6 - 38 | 2 - 40 | | |
| FIS: Psychological Subscale | | | | | | |
| Mean (SD) | 37.61 (16.95) | 36.29 (16.25) | 41.21 (17.51) | 35.91 (17.23) | ANOVA | .410 |
| Range | 3 - 79 | 10 - 40 | 10 - 74 | 10 - 79 | | |
| Activity Card Sort | | | | | | |
| Mean (SD) | .89 (.19) | .87 (.15) | .88 (.22) | .93 (.19) | ANOVA | .351 |
| Range | .28 - 1.48 | .47 - 1.04 | .28 - 1.20 | .30 - 1.48 | | |
| Personal Wellbeing Index | | | | | | |
| Mean (SD) | 58.48 (19.90) | 57.18 (21.56) | 59.74 (19.12) | 58.74 (19.30) | ANOVA | .879 |
| Range | 7 - 94 | 7 - 94 | 11 - 84 | 10 - 91 | | |

Note: FSM = Fatigue Self-management; DASS = Depression, Anxiety and Stress Scale; SSI = Duke Social Support Scale; FIS = Fatigue Impact Scale; Unless otherwise mentioned, n = 95 for all participants, n = 34 for the online FSM group, n = 28 for the info FSM group, and n = 33 the control group:* $p < .05$; [a] Groups combined because of small sample size.

### *4.3.3 PRIMARY ANALYSES*

This section provides results for the analyses conducted to test the three hypotheses of the study. For ease of understanding, the results are presented in two sections; results for primary outcome measures (FIS, ACS and PWI) and results for secondary outcome measures.

#### 4.3.3.1 RESULTS FOR PRIMARY OUTCOME MEASURES

Line graphs are provided for the primary outcome measures in the online FSM, info FSM and control groups in Figures 4.3 to 4.5 in order to help visualise the results. The marginal means are calculated based on the pre-test scores to simplify visual comparisons. It is of note that the patterns observed in the online FSM and info FSM are similar while those of the control group show consistently different patterns.

Figure 4.3 Estimated Marginal Means of Fatigue Impact Scale
(lower scores = less fatigue)

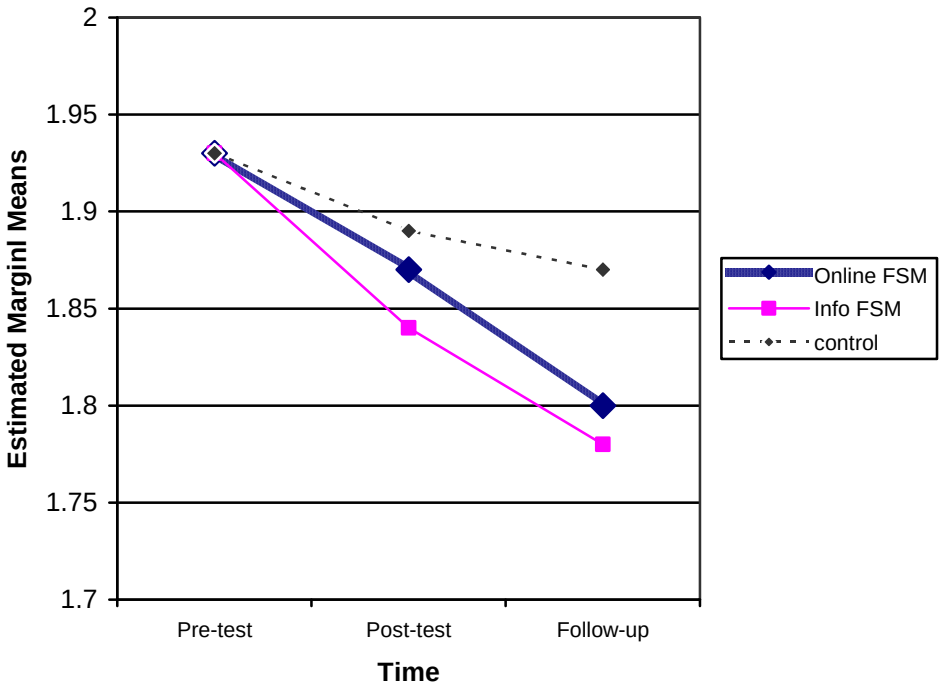


Figure 4.4 Estimated Marginal Means of Activity Card Sort
(higher scores = higher percentage retained activity)

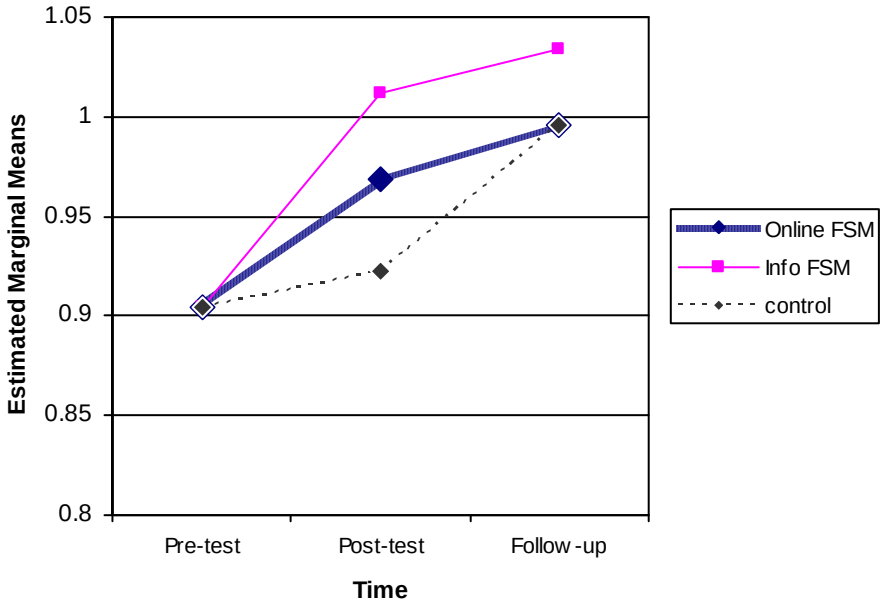
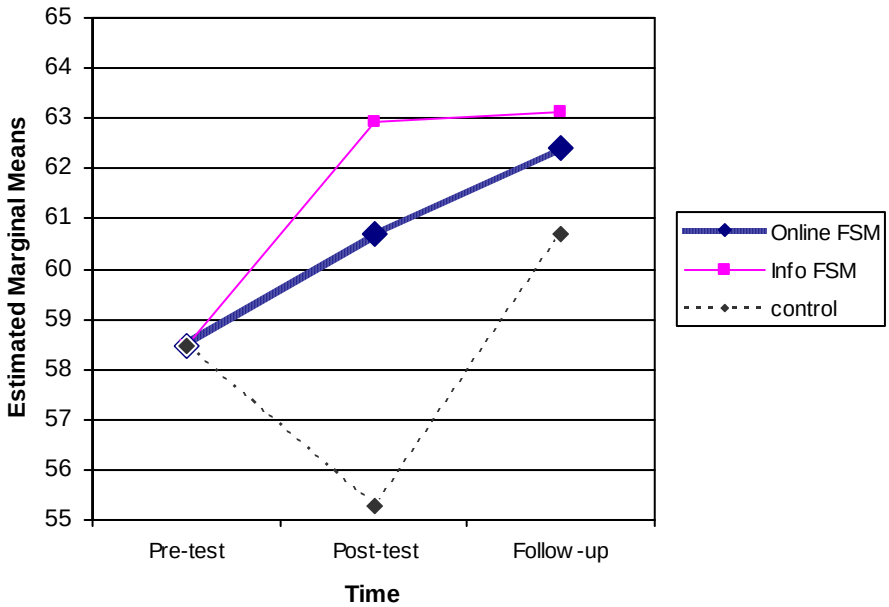



Figure 4.5 Estimated Marginal Means of Personal Wellbeing Index
(higher scores = better well being)



**TEST OF HYPOTHESES 1 & 2: COMPARISON OF ONLINE FSM GROUP WITH THE INFO FSM AND CONTROL GROUPS ON PRIMARY OUTCOME MEASURES.**

ANCOVA tests were used to test the effect of group allocation on the primary outcome measures at post-test and follow-up. The pre-test scores of the primary outcome measure as well as depression, anxiety, stress, social support and self-efficacy were controlled in these analyses. ANCOVA did not show any significant differences in the online FSM group relative to the info FSM and control groups for the FIS and ACS at post-test and follow-up (Tables 4.8 and 4.9). The observed power for these tests was low (between .11 and .64). Testing the effect of group allocation on PWI showed that while the groups were significantly different ($p$ = .034) on PWI scores at post-test, this difference was not seen at follow up ($p$ > .05). The effect size for the difference of the PWI scores at post-test was moderate to large. Post hoc tests showed that the info FSM group had a significantly higher level of PWI compared with the control group ($p$ = .036) at post-test. Mean scores on the FIS, PWI and ACS at baseline and post-test and also at follow-up are presented in Appendix E.

Table 4.8 Comparison of Groups on Primary Outcomes at Post-test

| Outcome Measure | ANCOVA Results [a] | | | | Post-hoc test | | | |
|---|---|---|---|---|---|---|---|---|
| | F [b] | Effect size | Observed power | *p*-value | Comparisons | 95% Confidence Interval for Difference | | *p*-value [c] |
| | | | | | | Lower bound | Upper bound | |
| FIS: Overall | 2.209 | .049 | .440 | .116 | Online FSM ~ Info FSM | -4.702 | 20.136 | .350 |
| | | | | | Online FSM ~ Control | -14.939 | 9.127 | .914 |
| | | | | | Info FSM ~ Control | -23.275 | 2.029 | .126 |
| FIS: Physical Subscale | 2.184 | .048 | .435 | .119 | Online FSM ~ Info FSM | -.776 | 6.271 | .172 |
| | | | | | Online FSM ~ Control | -3.292 | 3.610 | .999 |
| | | | | | Info FSM ~ Control | -6.194 | 1.017 | .231 |
| FIS: Cognitive Subscale | 2.001 | .044 | .403 | .141 | Online FSM ~ Info FSM | -1.939 | 5.109 | .621 |
| | | | | | Online FSM ~ Control | -4.811 | 2.064 | .704 |
| | | | | | Info FSM ~ Control | -6.561 | .643 | .139 |
| FIS: Psychosocial Subscale | 1.990 | .044 | .401 | .143 | Online FSM ~ Info FSM | -2.698 | 1.038 | .416 |
| | | | | | Online FSM ~ Control | -7.608 | 4.632 | .912 |
| | | | | | Info FSM ~ Control | -11.590 | 1.274 | .154 |

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Table 4.8 continued

| Outcome Measure | ANCOVA Results [a] | | | | Post-hoc test | | | |
|---|---|---|---|---|---|---|---|---|
| | F [b] | Effect size | Observed power | *p*-value | Comparisons | 95% Confidence Interval for Difference | | *p*-value [c] |
| | | | | | | Lower bound | Upper bound | |
| Activity Card Sort | 2.292 | .051 | .454 | .107 | Online FSM ~ Info FSM | -.142 | .064 | 1.000 |
| | | | | | Online FSM ~ Control | -.049 | .155 | .613 |
| | | | | | Info FSM ~ Control | -.014 | .198 | .108 |
| Personal Wellbeing Index | 3.519* | .076 | .642 | .034 | Online FSM ~ Info FSM | -9.506 | 4.858 | 1.000 |
| | | | | | Online FSM ~ Control | -1.648 | 12.361 | .196 |
| | | | | | Info FSM ~ Control | .366 | 14.994 | .036* |

Note: FIS = Fatigue Impact Scale, n = 34 for online FSM group; n = 28 for the info FSM group and n = 33 for control group.

[a] Covariates = Pre-test score for the Fatigue Impact Scale, Activity Card Sort Personal Wellbeing Index, Depression, Anxiety and Stress Scale, Social Support Index and Self-efficacy scores; [b] df = 2, 98; [c] Bonferroni used for adjustment for multiple comparisons; * $p < .05$.

Table 4.9 Comparison of Groups on Primary Outcomes at Follow-up

| Outcome Measure | ANCOVA Results [a] | | | | Post hoc test | | | |
|---|---|---|---|---|---|---|---|---|
| | F [b] | Effect size | Observed power | *p*-value | Comparisons | 95% Confidence Interval for Difference | | *p*-value [c] |
| | | | | | | Lower bound | Upper bound | |
| FIS: Overall [d] | 2.09 | .046 | .418 | .131 | Online FSM ~ Info FSM | -.86 | .138 | 1.00 |
| | | | | | Online FSM ~ Control | -.174 | .43 | .438 |
| | | | | | Info FSM ~ Control | -.205 | .022 | .160 |
| FIS: Physical Subscale | 3.473* | .075 | .636 | .035 | Online FSM ~ Info FSM | -1.561 | 6.476 | .364 |
| | | | | | Online FSM ~ Control | -5.926 | 1.946 | .528 |
| | | | | | Info FSM ~ Control | -8.559 | -.335 | .030* |
| FIS: Cognitive Subscale | 1.943 | .043 | .393 | .149 | Online FSM ~ Info FSM | -3.589 | 4.728 | .982 |
| | | | | | Online FSM ~ Control | -6.664 | 1.449 | .321 |
| | | | | | Info FSM ~ Control | -7.428 | 1.074 | .201 |
| FIS: Psychosocial Subscale | 3.098 | .067 | .583 | .050 | Online FSM ~ Info FSM | -5.095 | 10.615 | .778 |
| | | | | | Online FSM ~ Control | -12.697 | 2.400 | .272 |
| | | | | | Info FSM ~ Control | -15.842 | .025 | .051 |

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Table 4.9 continued

| Outcome Measure | ANCOVA Results [a] | | | | Post hoc test | | | |
|---|---|---|---|---|---|---|---|---|
| | F [b] | Effect size | Observed power | *p*-value | Comparisons | 95% Confidence Interval for Difference | | *p*-value [c] |
| | | | | | | Lower bound | Upper bound | |
| Activity Card Sort | .599 | .014 | .147 | .552 | Online FSM ~ Info FSM | -.145 | .072 | .795 |
| | | | | | Online FSM ~ Control | -.096 | .118 | .993 |
| | | | | | Info FSM ~ Control | -.063 | .159 | .657 |
| Personal Wellbeing Index | .363 | .008 | .106 | .697 | Online FSM ~ Info FSM | -7.874 | 6.458 | .993 |
| | | | | | Online FSM ~ Control | -5.242 | 8.737 | .905 |
| | | | | | Info FSM ~ Control | -4.842 | 9.753 | .800 |

Note: FIS = Fatigue Impact Scale, n = 34 for online FSM group; n = 28 for the info FSM group and n = 33 for control group.

[a] Covariates = Pre-test score for the Fatigue Impact Scale, Activity Card Sort Personal Wellbeing Index, Depression, Anxiety and Stress Scale, Social Support Index and Self-efficacy scores; [b] df = 2, 98; [c] Bonferroni used for adjustment for multiple comparisons; * $p < .05$.

**TEST OF HYPOTHESIS 3: DIFFERENCE IN PRIMARY OUTCOME MEASURES AT PRE-TEST, POST-TEST AND FOLLOW-UP.**

One-way repeated measures ANOVA were used to examine changes in FIS, PWI and ACS for each group at the three assessment time points (i.e. pre-test, post-test, follow-up). Overall, both the online and info FSM groups but not the control group showed improvement on FIS and ACS scores over time. The improvement in fatigue levels in the online FSM group [F (2, 66) = 7.196, p = .001] and info FSM group [F (1.436, 38.774) = 19.48, $p$ = .000] over time were strongly significant. The effect sizes for these improvements were large (partial eta squared >.014). As the FIS data for the control group was skewed, Friedman test was used for this part of analysis. The results showed that the fatigue in the control group did not improve statistically significantly over time [$\chi^2(2) = 5.75$, $p$ = .062]. Paired t-tests were used to determine which of the time points differed significantly from one another for the FIS scores. This analysis revealed significant change between the pre-test and follow-up for the online FSM group ($p$ = .003) and info FSM group ($p$ < .001). Although the result for the Friedman test for the control group was not significant, the paired post-hoc tests were conducted to further explore the results. The critical difference was calculated equal to .59 based on Equation 4-1. Differences between mean ranks for the FIS scores for the control group are presented in Table 4.10. It appeared that FIS did not significantly change between any of the time points as the differences between mean ranks were smaller than the critical difference.

Table 4.10 Difference between Mean Ranks for Fatigue Impact Scale Data in the Control group

| | R Follow-up - R Pre-test | R Post-test - R Pre-test | R Follow-up - R Post-test |
|---|---|---|---|
| Difference | .50 | .41 | .09 |

The repeated measures ANOVA test replicated the same findings for the ACS. While the overall F for this analysis was significant for the online FSM group ($F$ (2,23) = 3.91, $p$ = .025) and the info FSM group ($F$ (2,26) = 8.63, $p$ = .001), it was not statistically significant for the control group ($F$ (1.404, 44.932) = 3.21, $p$ = .066). Paired t-tests revealed significant changes from pre-test to follow-up for the online

FSM group ($p$ = .034) and info FSM group ($p$ = .006) but not for the control group ($p$ = .184). Although the paired t-test showed improvement of the control group in their ACS from post-test to follow-up, this result is not considered noteworthy as the overall F test for this group was not significant. The effect size calculated in the analyses for testing improvement of participants in the online FSM and info FSM groups over time was moderate to large.

The results of the repeated measures ANOVA for PWI were different from that of the FIS and ACS score. Overall, the info FSM and control groups improved in PWI scores but the online FSM group did not. The info FSM group improved over time in PWI ($F$ (2,54) = 4.11, $p < .05$). A paired t-test comparing the pre-test and follow-up mean PWI total scores revealed significant improvement for the info FSM group ($p$ = .012). The control group had lower PWI scores at post-test compared to pre-test and then improved from post-test to follow-up (Table 4.11, Figure 4.5). The results of the repeated measure ANOVA for the control group showed an overall improvement of PWI over time ($p$ = .043). However, after correcting for multiple comparisons, only a trend toward significant improvement from pre-test to follow-up was seen for the control group ($p$ = .057). The self-management program was not effective in increasing PWI in the online FSM group as revealed by the repeated measure ANOVA ($F$ (1.6, 53.56) = 1.15, $p > .05$). However, as the observed power for this test was extremely low (.22) this result must be viewed with caution.

Table 4.11 Change in Scores of Primary Outcome Measures at Pre-test, Post-test and Follow-up

| Outcome Measure | Group | Results of Repeated Measures ANOVA | | | | Post hoc test [c] | | |
|---|---|---|---|---|---|---|---|---|
| | | F ($df_{k-1}$, $df_{n-2}$) | Effect size | Observed power | *p*-value | Pre-test ~ Post-test | Pre-test ~Follow-up | Post-test ~ Follow-up |
| FIS: Overall | | | | | | | | |
| | Online FSM | 7.20 (2,66)* | .20 | .96 | .001 | .206 | .003 | .042 |
| | Info FSM | 19.48 (1.44, 38.77)* [a] | .39 | 1.00 | .000 | .000 | .000 | .306 |
| | Control | 5.57(2) [b] | - [b] | - [b] | .062 | NS | NS | NS |
| FIS: Physical Subscale | | | | | | | | |
| | Online FSM | 8.39 (2,66)* | .20 | .96 | .001 | .284 | .002 | .039 |
| | Info FSM | 19.55 (41.48,39.81)* [a] | .42 | 1.0 | .000 | .000 | .000 | .075 |
| | Control | 7.88 (2,64)* | .20 | .94 | .001 | .025 | .003 | 1.000 |
| FIS: Cognitive Subscale | | | | | | | | |
| | Online FSM | 4.97 (2,66)* | .13 | .79 | .010 | .474 | .023 | .151 |
| | Info FSM | 8.77 (1.62, 43.71)* [a] | .25 | .96 | .001 | .002 | .009 | 1.000 |
| | Control | 1.26 (2,64) | .04 | .26 | .292 | 1.00 | .432 | .951 |
| FIS: Psychological Subscale | | | | | | | | |
| | Online FSM | 8.31 (2,66)* | .20 | .96 | .001 | .151 | .003 | .053 |
| | Info FSM | 16.82 (1.51,40.70)* [a] | .38 | 1.0 | .000 | .000 | .000 | .550 |
| | Control | 3.15 (1.64, 52.62) [a] | .09 | .59 | .060 | .980 | .210 | 1.000 |

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Table 4.11 Continued

| Outcome Measure | Group | Results of Repeated Measures ANOVA | | | | Post hoc test [c] | | |
|---|---|---|---|---|---|---|---|---|
| | | F ($df_{k-1}$, $df_{n-2}$) | Effect size | Observed power | *p*-value | Pre-test ~ Post-test | Pre-test ~Follow-up | Post-test ~ Follow-up |
| Activity Card Sort | | | | | | | | |
| | Online FSM | 3.91 (2,23)* | .11 | .69 | .025 | .053 | .034 | 1.000 |
| | Info FSM | 8.63 (2,26)* | .24 | .96 | .001 | .012 | .006 | 1.000 |
| | Control | 3.21(1.40, 44.93) [a] | .09 | .59 | .066 | 1.000 | .184 | .003 |
| Personal Wellbeing Index | | | | | | | | |
| | Online FSM | 1.15 (1.6, 53.56) [a] | .03 | .22 | .316 | 1.000 | .571 | 1.000 |
| | Info FSM | 4.11 (2,54)* | .13 | .70 | .022 | .062 | .012 | 1.000 |
| | Control | 3.31 (2,64)* | .09 | .61 | .043 | .714 | .467 | .057 |

Note. FIS = Fatigue Impact Scale; NS = not significant based on Friedman ANOVA therefore no p-value is available.

[a] Greenhouse-Geisser Correction as the assumption of sphericity is violated; [b] Friedman ANOVA was conducted, therefore observed power and effect size was not calculated; [c] Bonferroni used for adjustment for multiple comparisons; * $p < .05$.

#### 4.3.3.2 RESULTS FOR SECONDARY OUTCOME MEASURES

**TEST OF HYPOTHESES 1 &2: COMPARISON OF ONLINE FSM, INFO FSM AND CONTROL GROUPS ON SECONDARY OUTCOME MEASURES**

The mean scores of the online FSM, the info FSM and control group on the secondary outcome measures were compared at post-test and follow-up after controlling for the covariates (Pre-test data for depression, anxiety, stress, self-efficacy and social support). The three groups were not significantly different in depression, anxiety, stress or social support but they were significantly different [$F$ (2, 86) = 3.797, $p < .05$] in their level of self-efficacy (Tables 4.12 and 4.13). The effect size for the difference between the self-efficacy scores was moderate to large (partial eta squared = .080). Paired t-test confirmed that both the online FSM group and the info group had higher levels of self-efficacy compared to the control group at post-test although after using Bonferroni for correction of multiple comparisons it showed the results to be marginal ($p$ = .057 for the online FSM group and $p$ = .058 for the info FSM group). The online FSM and the info FSM groups were not significantly different from each other in their self-efficacy scores.

The above results for self-efficacy were not returned at follow-up. The three groups were not different in self-efficacy, depression, anxiety and social support (overall score) levels at follow-up ($p > .05$). There were, however, significant difference between the groups in stress [$F$ (2,86) = 3.737, $p$ = .028] and satisfaction subscale of SSI [($F$ (2,86) = .030)]. Stress level was different among the three groups with a moderate to large effect size (partial eta squared = .079). Based on the paired t-test, the online FSM group had a lower level of stress than the control group three months after the intervention ($p$ = .037). The other comparisons (online FSM group versus info FSM group and info FSM group versus control group) did not show the groups significantly different. The groups were significantly different in satisfaction at follow-up, $F$ (2, 86) = 3.641, $p < .05$). The pairwise comparison showed that this difference was between the info FSM and the control group ($p$ = .045). The info FSM group had significantly higher level of satisfaction at follow-up than the control group. The effect size for this comparison was moderate to large. The power observed for all the analyses in this section (both post-test and follow-up) was low, ranging between .104 and .677.

**TEST OF HYPOTHESIS 3: DIFFERENCE IN SECONDARY OUTCOME MEASURES AT PRE-TEST, POST-TEST AND FOLLOW-UP**

The effect of time on the secondary outcome measures in each of the groups was tested using repeated measure ANOVA (Table 4.14). There was a marginally significant improvement in overall SSI score [$F$ (2,66) = 3.025, $p$ = .055] and satisfaction subscale of SSI score [$F$ (2,66) = 3.139, $p$ = .050] only for the online FSM group. These changes were significant from post-test to follow-up, however, the results should be viewed with caution as the main ANOVA results were not significant. The SSI scores did not change significantly in any other group. Only the participants in the info FSM program improved in their self-efficacy over time, $F$ (2, 54) = 3.886, $p$ = .027. The paired t-test with Bonferroni correction for multiple comparisons revealed a trend toward significant increase of self-efficacy scores for the info FSM group from pre-test to follow-up. None of the groups showed significant improvement in their scores for depression and anxiety or stress. The control group did not show significant change in any of the secondary outcome measures. However, the power for all tests was extremely low ranging between .03 and .678.

Table 4.12 Comparison of Groups on Secondary Outcomes at Post-test

| Outcome Measure | ANCOVA Results [a] | | | | Post-hoc test | | | |
|---|---|---|---|---|---|---|---|---|
| | F [b] | Effect size | Observed power | *p*-value | Comparisons | 95% Confidence Interval for Difference | | *p*-value [c] |
| | | | | | | Lower bound | Upper bound | |
| Generalised Self-efficacy Scale | 3.797* | .080 | .677 | .026 | Online FSM ~ Info FSM | -2.115 | 1.959 | 1.000 |
| | | | | | Online FSM ~ Control | -.043 | 3.939 | .057 |
| | | | | | Info FSM ~ Control | -.050 | 4.102 | .058 |
| DASS: Depression Subscale | .691 | .016 | .163 | .504 | Online FSM ~ Info FSM | -2.903 | 4.963 | 1.000 |
| | | | | | Online FSM ~ Control | -4.744 | 2.945 | 1.000 |
| | | | | | Info FSM ~ Control | -5.937 | 2.078 | .729 |
| DASS: Anxiety Subscale | .053 | .001 | .058 | .948 | Online FSM ~ Info FSM | -2.933 | 2.375 | 1.000 |
| | | | | | Online FSM ~ Control | -2.909 | 2.278 | 1.000 |
| | | | | | Info FSM ~ Control | -2.741 | 2.668 | 1.000 |
| DASS: Stress Subscale | .836 | .019 | .189 | .437 | Online FSM ~ Info FSM | -4.552 | 3.045 | 1.000 |
| | | | | | Online FSM ~ Control | -5.668 | -1.756 | .605 |
| | | | | | Info FSM ~ Control | -3.045 | 4.552 | 1.000 |

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Table 4.12 continued

| Outcome Measure | ANCOVA Results [a] | | | | Post-hoc test | | | |
|---|---|---|---|---|---|---|---|---|
| | F [b] | Effect size | Observed power | *p*-value | Comparisons | 95% Confidence Interval for Difference | | *p*-value [c] |
| | | | | | | Lower bound | Upper bound | |
| SSI: Overall | .470 | .011 | .125 | .627 | Online FSM ~ Info FSM | -2.912 | 1.380 | 1.000 |
| | | | | | Online FSM ~ Control | -2.771 | 1.424 | 1.000 |
| | | | | | Info FSM ~ Control | -2.094 | 2.279 | 1.000 |
| SSI: Social Interaction Subscale | 1.336 | .030 | .281 | .268 | Online FSM ~ Info FSM | -.820 | .781 | 1.000 |
| | | | | | Online FSM ~ Control | -1.257 | .309 | .429 |
| | | | | | Info FSM ~ Control | -1.278 | .369 | .543 |
| SSI: Satisfaction Subscale | .471 | .011 | .125 | .626 | Online FSM ~ Info FSM | -2.426 | 1.046 | 1.000 |
| | | | | | Online FSM ~ Control | -1.989 | 1.383 | 1.000 |
| | | | | | Info FSM ~ Control | -1.365 | 2.139 | 1.000 |

Note: FSM = Fatigue Self-management Program; SSI = Social Support Index; DASS = Depression, Anxiety and Stress Scale; n = 34 for online FSM group; n = 28 for the info FSM group and n = 33 for control group.

[a] Covariates = Pre-test Depression, Anxiety and Stress Scale, Social Support Index and Self-efficacy scores; [b] df = 2, 98; [c] Bonferroni used for adjustment for multiple comparisons; * $p < .05$.

Table 4.13 Comparison of Groups on Secondary Outcomes at Follow-up

| Measure | ANCOVA Results [a] | | | | Post-hoc test | | | |
|---|---|---|---|---|---|---|---|---|
| | F [b] | Effect size | Observed power | *p*-value | Comparisons | 95% Confidence Interval for Difference | | *p*-value [c] |
| | | | | | | Lower bound | Upper bound | |
| Generalised Self-efficacy Scale | 1.096 | .025 | .237 | .339 | Online FSM ~ Info FSM | -2.395 | 2.222 | 1.000 |
| | | | | | Online FSM ~ Control | -1.090 | 3.423 | .631 |
| | | | | | Info FSM ~ Control | -1.099 | 3.605 | .591 |
| DASS: Depression Subscale | 2.181 | .048 | .435 | .119 | Online FSM ~ Info FSM | -5.166 | 4.121 | 1.000 |
| | | | | | Online FSM ~ Control | -8.177 | .900 | .161 |
| | | | | | Info FSM ~ Control | -7.847 | 1.615 | .335 |
| DASS: Anxiety Subscale | .349 | .008 | .104 | .706 | Online FSM ~ Info FSM | -2.740 | 3.966 | 1.000 |
| | | | | | Online FSM ~ Control | -3.834 | 2.720 | 1.000 |
| | | | | | Info FSM ~ Control | -4.857 | 2.247 | 1.000 |
| DASS: Stress Subscale | 3.737* | .079 | .670 | .028 | Online FSM ~ Info FSM | -4.880 | 3.677 | 1.000 |
| | | | | | Online FSM ~ Control | -8.560 | -.197 | .037* |
| | | | | | Info FSM ~ Control | -8.136 | .583 | .112 |

Continued on next page

Table 4.13 Continued

| Measure | ANCOVA Results [a] | | | | Post-hoc test | | | |
|---|---|---|---|---|---|---|---|---|
| | F [b] | Effect size | Observed power | *p*-value | Comparisons | 95% Confidence Interval for Difference | | *p*-value [c] |
| | | | | | | Lower bound | Upper bound | |
| SSI: Overall | 2.406 | .052 | .474 | .096 | Online FSM ~ Info FSM | -2.707 | 1.487 | 1.000 |
| | | | | | Online FSM ~ Control | -.790 | 3.309 | .412 |
| | | | | | Info FSM ~ Control | -.267 | 4.006 | .107 |
| SSI: Social Interaction Subscale | .442 | .010 | .120 | .644 | Online FSM ~ Info FSM | -1.121 | .526 | 1.000 |
| | | | | | Online FSM ~ Control | -1.035 | .577 | 1.000 |
| | | | | | Info FSM ~ Control | -.778 | .916 | 1.000 |
| SSI: Satisfaction Subscale | 3.641* | .077 | .658 | .030 | Online FSM ~ Info FSM | -1.897 | 1.343 | 1.000 |
| | | | | | Online FSM ~ Control | -.190 | 2.957 | .104 |
| | | | | | Info FSM ~ Control | .025 | 3.295 | .045* |

Note: FSM = Fatigue Self-management Program; SSI = Social Support Index; n = 34 for online FSM group; n = 28 for the info FSM group and n = 33 for control group.

[a] Covariates = Pre-test Depression, Anxiety and Stress Scale, Social Support Index and Self-efficacy scores; [b] df = 2, 98; [c] Bonferroni used for adjustment for multiple comparisons; * $p < .05$.

Table 4.14 Change in Scores of Secondary Outcome Measures at Pre-test, Post-test and Follow-up

| Outcome Measure | Group | Results of Repeated Measures ANOVA [a] | | | | Post-hoc test [b] | | |
|---|---|---|---|---|---|---|---|---|
| | | F (df k-1, df n-2) | Effect size | Observed power | *p*-value | Pre-test ~ Post-test | Pre-test ~Follow-up | Post-test ~ Follow-up |
| Generalised Self-efficacy Scale | | | | | | | | |
| | Online FSM | 1,613 (2,66) | .047 | .0329 | .207 | .383 | .452 | 1.00 |
| | Info FSM | 3.886 (2,54)* | .126 | .678 | .027 | .070 | .056 | 1.00 |
| | Control | .594 (2,64) | .018 | .145 | .555 | 1.00 | 1.00 | .817 |
| SSI: Overall | | | | | | | | |
| | Online FSM | 3.025 (2,66) | .084 | .567 | .055 | .312 | 1.00 | .037 |
| | Info FSM | 2.180 (2,54) | .075 | .427 | .123 | 1.00 | .210 | .245 |
| | Control | 1.92 (1.69,53.90) | .056 | .349 | .163 | 1.00 | .337 | .494 |
| SSI: Satisfaction Subscale | | | | | | | | |
| | Online FSM | 3.139 (2,66) | .087 | .584 | .050 | .378 | 1.00 | .038 |
| | Info FSM | 1.456 (2,54) | .051 | .298 | .242 | 1.00 | .315 | .547 |
| | Control | 2.901 (2,64) | .083 | .548 | .062 | .843 | .115 | .469 |
| SSI: Social Interaction Subscale | | | | | | | | |
| | Online FSM | 1.020 (2,66) | .030 | .221 | .336 | .700 | 1.00 | .678 |
| | Info FSM | 1.688 (2,54) | .059 | .340 | .194 | 1.00 | .668 | .270 |
| | Control | .010 (1.551,49.623) | .000 | .051 | .990 | 1.00 | 1.00 | 1.00 |

Continued on next page

Table 4.14 continued

| Outcome Measure | Group | Results of Repeated Measures ANOVA [a] | | | | Post-hoc test [b] | | |
|---|---|---|---|---|---|---|---|---|
| | | F (df k-1, df n-2) | Effect size | Observed power | *p*-value | Pre-test ~ Post-test | Pre-test ~Follow-up | Post-test ~ Follow-up |
| DASS: Depression Subscale | | | | | | | | |
| | Online FSM | .6219 (2,66) | .018 | .150 | .54 | 1.00 | .931 | 1.00 |
| | Info FSM | .834 (2,54) | .030 | .186 | .44 | .626 | 1.00 | 1.00 |
| | Control | .827 (1.64,52.47) | .025 | .171 | .422 | 1.00 | 1.00 | .749 |
| DASS: Anxiety Subscale | | | | | | | | |
| | Online FSM | .248 (1.693,55.584) | .041 | .271 | .248 | .204 | 1.00 | .781 |
| | Info FSM | .285 (1.519,41.008) | .010 | .088 | .753 | 1.00 | 1.00 | 1.00 |
| | Control | .264 (1.64,52.61) | .008 | .086 | .726 | 1.00 | 1.00 | 1.00 |
| DASS: Stress Subscale | | | | | | | | |
| | Online FSM | 1.205 (2,66) | .060 | .382 | .130 | .654 | .264 | 1.00 |
| | Info FSM | 2.004 (1.833,49.495) | .069 | .396 | .145 | .973 | .077 | 1.00 |
| | Control | 1.205 (2,64) | .036 | .254 | .306 | 1.00 | .562 | .917 |

Note: FSM = Fatigue Self-management Program; SSI = Social Support Index; n = 34 for online FSM group; n = 28 for the info FSM group and n = 33 for control group.

[a] Covariates = Pre-test Depression, Anxiety and Stress Scale, Social Support Index and Self-efficacy scores; [b] Bonferroni used for adjustment for multiple comparisons;

* $p < .05$.

### *4.3.4 SECONDARY ANALYSES*

#### 4.3.4.1 COMBINATION OF THE ONLINE AND INFO FSM GROUPS

Based on the results in the primary analyses, there were more similarities than differences in improvement patterns between the online FSM and info FSM groups. Therefore, the two groups were combined and the statistical analyses were again conducted. The combined group consisted of 62 participants who were compared with the control group on the primary and secondary outcome measures at post-test and follow-up (using ANCOVA tests). Also the changes in their scores over time were tested using repeated measures ANOVA. A summary of results are presented in Tables 4.15 and 4.16. Results of the sensitivity test are also presented but will be further reported in section 4.3.4.2.

Table 4.15 Summary of Results for Comparison of Groups Using ANCOVA Test

| Outcome Measure` | Intent-to-treat (Main study) | | Combined group | | Sensitivity test | |
|---|---|---|---|---|---|---|
| | Post-test | Follow-up | Post-test | Follow-up | Post-test | Follow-up |
| Primary Outcome Measures | | | | | | |
| FIS: Overall | | | | ~√ | | |
| FIS: Physical Subscale | | √ | | √ | | ~√ |
| FIS: Cognitive Subscale | | | | ~√ | | |
| FIS: Psychosocial Subscale | | | | √ | | |
| Activity Card Sort | | | ~√ | | | |
| Personal Wellbeing Index | √ | | √ | | √ | |
| Secondary Outcome Measures | | | | | | |
| Generalised Self-efficacy Scale | √ | | √ | | √ | |
| SSI: Overall | | | | √ | | |
| SSI: Social Interaction Subscale | | | | | | |
| SSI: Satisfaction Subscale | | √ | | √ | | ~√ |
| DASS: Depression Subscale | | | | √ | | |
| DASS: Anxiety Subscale | | | | | | |
| DASS: Stress Subscale | | √ | | √ | | |

Note. √ = Groups were significantly different; ~√ = A trend towards significant difference between the groups; FIS = Fatigue Impact Scale; SSI = Social Support Index; DASS = Depression, Anxiety and Stress Scale.

Table 4.16 Summary of Results for Change of Scores Over Time Using Repeated Measures ANOVA

| Outcome Measure | Intent-to-treat study (Main study) | | | Study of combined group | | Sensitivity study | | |
|---|---|---|---|---|---|---|---|---|
| | Online FSM group | Info FSM group | Control group | Online combined group | Control group | Online FSM group | Info FSM group | Control group |
| Primary Outcome Measures | | | | | | | | |
| FIS: Overall | √ | √ | ~√ | √ | ~√ | √ | √ | |
| FIS: Physical Subscale | √ | √ | √ | √ | √ | √ | √ | √ |
| FIS: Cognitive Subscale | √ | √ | | √ | | √ | √ | |
| FIS: Psychosocial Subscale | √ | √ | ~√ | √ | ~√ | √ | √ | |
| Activity Card Sort | √ | √ | ~√ | √ | ~√ | √ | √ | √ |
| Personal Wellbeing Index | | √ | √ | √ | √ | | | √ |
| Secondary Outcome Measures | | | | | | | | |
| Generalised Self-efficacy Scale | | √ | | √ | | ~√ | √ | |
| SSI: Overall | ~√ | | | √ | | | | |
| SSI: Social Interaction Subscale | | | | | | | | |
| SSI: Satisfaction Subscale | ~√ | | | √ | | | | ~√ |
| DASS: Depression Subscale | | | | | | | | |
| DASS: Anxiety Subscale | | | | | | | | |
| DASS: Stress Subscale | | | | √ | | | | √ |

Note. √ = Groups were significantly different; ~√ = A trend towards significant difference between the groups; FIS = Fatigue Impact Scale; SSI = Social Support Index; DASS = Depression, Anxiety and Stress Scale.

Results of ANCOVA test comparing the combined group and control group showed some differences from the primary analyses (Table 4.15). At post-test, similar to the primary analyses, the combined and control groups were significantly different in PWI and self-efficacy. There was a trend toward significance for better results on the ACS for the combined group in comparison with the control group. These results were not seen for the ACS scores in the primary analyses. At follow-up, the participants in the combined group were significantly better on the physical and psychosocial subscales of FIS, overall social support score and satisfaction, depression and stress, than the control group. In the primary analysis only physical subscale of FIS, Satisfaction subscale of SSI and stress were significantly different between groups. Furthermore, the secondary analysis on the comparing the combined and control group revealed that there were trends toward significant differences between the two groups in their overall FIS scores and psychological subscale of FIS.

The results for the repeated measures ANOVA produced considerably different results in comparison with the results for primary analyses (Table 4.16). All the improvements seen in the online and info FSM groups on the primary outcome measures were also shown in the analysis on the combined group. Similar to the online and info FSM groups, the combined group improved on the FIS and all of its subscales, the PWI and the ACS. In addition, the combined group showed improvements in self-efficacy and on the satisfaction subscale and overall score of SSI. There were two other differences between the results of the analyses on the combined group and that of the primary analyses. The data on the DASS stress subscale for the combined group showed significant improvement of the participants over time, while the results for repeated measures ANOVA on stress subscale was not significant for any of the three groups in the primary analyses. The other difference between the results was seen on the social interaction subscale of SSI. While there was a trend toward significant difference for improvement in the online FSM group on satisfaction in the primary analyses, the combined group did not show this change over time.

F-ratios, effect size, observed power, p-value and the results for post-hoc tests for the ANCOVA tests and repeated measures ANOVA for the combined group are

presented in Appendix F. The analyses for the combined group compared to the control group had a greater power in comparison with the observed power for the primary analyses.

#### 4.3.4.2 SENSITIVITY TESTS

Sensitivity tests were performed using the data for the participants in the three groups (online, info FSM and control groups) who had complete data sets at pre-test, post-test and follow-up data and completed more than 5 sessions of the FSM program (both for the online and the info FSM groups). There was not a considerable difference between the intent-to-treat and sensitivity tests results (Tables 4.15 and 4.16).

The same results for the ANCOVA tests (comparison of the three groups in primary and secondary outcome measures at post-test and follow-up) were produced as in the intent-to-treat analysis. On the secondary outcomes, the only exceptions were between the groups on satisfaction subscale of the SSI at follow-up and self-efficacy at post-test. In contrast to the results of intent-to-treat, the results for the sensitivity test showed no difference between the groups in satisfaction subscale of the SSI. The p-value dropped from .030 in the intent-to-treat test to .053 in the sensitivity test which showed only a trend toward significant difference between the info FSM group and the control group at follow-up (Appendix G). The other difference between intent-to-treat analysis and the sensitivity test was seen between the groups on self-efficacy scores at post-test. There was only a trend toward significance for difference between the online FSM and info FSM, and the control group in the intent-to-treat test. But this difference was highly significant in the sensitivity test [$F$ (2, 86) = 7.69, $p$ =.001]. Both the online FSM group ($p$ = .004) and the info FSM group ($p$ = .005) had significantly higher self-efficacy scores than the control group at post-test. The effect size of the test was large (partial eta squared = .215). Similar to the primary analyses, the self-efficacy scores were not significantly different between groups at follow-up in sensitivity analysis.

There were almost no differences between the results of the primary analyses and the sensitivity test when comparing the pre-test, post-test and follow-up in each group. The only exception was improvement of the control group over time in their ACS

score which showed only a trend toward significance in the primary analysis but a statistically significant improvement was seen for the control group on the ACS in the sensitivity test. F ratio, effect size, observed power, p-value and the results for post-hoc tests for the ANCOVA tests and repeated measures ANOVA for the combined group are presented in Appendix F.

#### 4.3.4.3 ANALYSIS ON PEOPLE WITH MS

Analyses were performed using the data for the participants with MS only in the three groups (online, info FSM and control groups). Other than a slight trend toward significant difference between groups (using ANCOVA tests) in the depression scale, no differences between the results for people with MS and the results of the main analyses (MS, PD and PPD) were seen (Table 4.17).

Results of the main study and the study on people with MS when using repeated measures ANOVA showed only slight differences for the online and info FSM groups while the control group had very different results (Table 4.18). For the online FSM most of the results for the people with MS were the same as results of the main study. However, statistically significant improvement was seen in the people with MS on their anxiety and stress. This result was not seen in the main study. The other difference was significant improvement on the ACS in the main study while this result dropped to a trend towards significance in the analysis for the people with MS. The results of the two studies produced almost the same results for the info FSM group. The only difference was that the participants with MS showed only a trend toward significant improvement on the PWI while this improvement was significant when data for all participants were entered to the analysis.

The results for the two control groups (MS only and total group) had considerable differences. A trend toward significant improvement on the overall FIS and psychological subscale of the FIS was seen in the main study while this result changed to significant improvement on the overall FIS and no significant improvement on the psychological subscale of the FIS in the MS only control group. The control group of participants with MS improved over time on the SSI and

satisfaction subscale of SSI while these results were not seen in the control group in the main study.

Table 4.17 Summary of Results for Comparison of Groups Using ANCOVA Test (Only Participants with MS)

| Outcome Measure | All participants (Main study) | | Study on people with multiple sclerosis (Secondary analysis) | |
|---|---|---|---|---|
| | Post-test | Follow-up | Post-test | Follow-up |
| Primary Outcome Measures | | | | |
| FIS: Overall | | | | |
| FIS: Physical Subscale | | √ | | √ |
| FIS: Cognitive Subscale | | | | |
| FIS: Psychosocial Subscale | | | | |
| Activity Card Sort | | | | |
| Personal Wellbeing Index | √ | | √ | |
| Secondary Outcome Measures | | | | |
| Generalised Self-efficacy Scale | √ | | √ | |
| SSI: Overall | | | | |
| SSI: Social Interaction Subscale | | | | |
| SSI: Satisfaction Subscale | | √ | | √ |
| DASS: Depression Subscale | | | | ~√ |
| DASS: Anxiety Subscale | | | | |
| DASS: Stress Subscale | | √ | | √ |

Note. √ = The groups were significantly different; ~√ = A trend towards significant difference between the groups; FIS = Fatigue Impact Scale; SSI = Social Support Index; DASS = Depression, Anxiety and Stress Scale.

Table 4.18 Summary of Results for Change of Scores Over Time Using Repeated Measures ANOVA (Only Participants with MS)

| Outcome Measure | All participants (Main study) | | | Study on people with multiple sclerosis (Secondary analysis) | | |
|---|---|---|---|---|---|---|
| | Online FSM group | Info FSM group | Control group | Online FSM group | Info FSM group | Control group |
| Primary Outcome Measures | | | | | | |
| FIS: Overall | √ | √ | ~√ | √ | √ | √ |
| FIS: Physical Subscale | √ | √ | √ | √ | √ | √ |
| FIS: Cognitive Subscale | √ | √ | | √ | √ | |
| FIS: Psychosocial Subscale | √ | √ | ~√ | √ | √ | |
| Activity Card Sort | √ | √ | ~√ | ~√ | √ | ~√ |
| Personal Wellbeing Index | | √ | √ | | ~√ | √ |
| Secondary Outcome Measures | | | | | | |
| Generalised Self-efficacy Scale | | √ | | | √ | |
| SSI: Overall | ~√ | | | ~√ | | √ |
| SSI: Social Interaction Subscale | | | | | | |
| SSI: Satisfaction Subscale | ~√ | | | ~√ | | √ |
| DASS: Depression Subscale | | | | | | |
| DASS: Anxiety Subscale | | | | √ | | |
| DASS: Stress Subscale | | | | √ | | |

Note. √ = The groups were significantly different; ~√ = A trend towards significant difference between the groups; FIS = Fatigue Impact Scale; SSI = Social Support Index; DASS = Depression, Anxiety and Stress Scale.

## *4.4 DISCUSSION*

The aim of this study was to evaluate the efficacy of an online fatigue self-management program for people with chronic neurological conditions. Although the participants in both the online FSM and info FSM groups improved over time on the FIS and ACS, they were not significantly different from the control group or from each other. Therefore, the first null hypothesis (no difference between the online FSM group and the info FSM group) and second null hypothesis of the study (no difference between the online FSM group and the control group) could not be rejected. The thirds null hypothesis (no improvement in the online FSM group) was

rejected. The participants in the online and info FSM groups improved on the FIS and ACS. These may attributable to several reasons. Firstly, the info FSM group acted more similar to an experimental group than an 'attention' group. Secondly, the participants in the control group showed a trend towards significant improvement on the FIS and ACS. Thirdly, there is a possibility of Type II error in this study as the power of the ANCOVA analyses to test the hypotheses of difference between the online FSM group and the two control groups was low. Each of these three theories for non significant results of the differences between the online FSM group and the control groups are further discussed below. It is important to note that as a comprehensive discussion and comparison of the online FSM program with the face-to-face FSM program is presented in the next chapter, discussion in this chapter is focused on comparison of the online FSM program with the two control groups and the literature on online interventions.

Non significant differences between the online FSM group and the info FSM group were surprising as, when designing the present study, the info FSM group was planned as a control group to counter the possibility that effects may occur due to attention. However, the info FSM group seemed to offer more than attention to the participants. The info FSM program included 'self-management type' information such as the blogs from the expert panel (Appendix A) which showed others with chronic conditions successfully using the self-management skills introduced and practiced in the program. The information and the expert panel blogs provided for the participants in the info FSM group were identical to that presented to the online FSM group. Participants in the info FSM program received the information individually and without a facilitator and did not meet each other in the 'group'. Therefore, contrary to the online FSM group, the participants in the info FSM program did not have access to group communication component of the program. Given that the literature emphasises (Nguyen et al., 2004) that 'pure' information is not sufficient for behaviour change, it appears likely that the info FSM program offered more than simply 'attention' to the participants, in effect an 'individual self-management information' program.

Interestingly, while the online FSM and info FSM group were not significantly different from each other in any of the outcome measures at any of the time points,

there were similarities and differences in areas/patterns of improvement between the online and info FSM groups. Although both the online and info FSM groups improved on the FIS, their pattern of improvement over time was different. The info FSM group improved during the program (between pre-test and post-test) and not after completion of the program (between post-test and follow-up) and the opposite pattern was seen for the online FSM group (no improvement between pre-test and post-test and improvement between post-test and follow-up). This is consistent with the results of a systematic review on online interventions (Nguyen et al., 2004). The author found that information control groups which offered access to study websites with minimal or no feedback from the facilitators appeared to also show some benefit. A longer follow-up study was needed for the present study to test whether the benefits of online FSM and info FSM continue over time.

Another similarity between the online and info FSM groups was seen in the self-efficacy results. The ANCOVA tests showed that the three groups were significantly different in self-efficacy levels at post-test. Although after adjusting for multiple comparison there was only a trend toward significantly higher self-efficacy scores for the online and info FSM groups when compared to the control group, the less conservative sensitivity analysis (Appendix G), where the participants with complete data sets were analysed, reached statistical significance in this measure ($p < .05$). This finding parallels that of previous research (S. Girdler, 2004; K. R. Lorig et al., 1999; Mathiowetz et al., 2005) which has suggested that one of the positive outcomes of self-management interventions for adults with chronic conditions is an increase in self-efficacy. However, the difference on the self-efficacy at post-test was not apparent at 12-week follow-up. This is inconsistent with other studies which have found improvement in self-efficacy after online programs for chronic conditions (K. R. Lorig, Ritter et al., 2001; K. R. Lorig et al., 2004). This may be the result of using a general self-efficacy scale in the present study while other studies used either disease specific scales (K. R. Lorig, Ritter et al., 2001; K. R. Lorig et al., 2004) or a self-efficacy scale designed specifically to cover the intervention topics (Mathiowetz et al., 2005) . Because this study included participants with different neurological conditions, applying a disease specific measurement tool was not possible. A disease

specific self-efficacy scale may be more sensitive to change and difference between the groups.

The online and info FSM groups had other different areas of improvement over time. The participants in the info FSM group improved in their PWI over time while this improvement was not seen in the online FSM group. However, the improvement in the social support in the online FSM group was not seen in the info FSM group. The non significant improvement of PWI in the online FSM group is inconsistent with the results of the Mathiowetz, Finlayson, Matuska, Chen, & Luo's study (Mathiowetz et al., 2005). Both the present study and the study by Mathiowetz and colleagues were based on the same fatigue self-management program, and were specifically run by occupational therapists. Response shift may be an explanation for this result which has also been found in some people who take part in self-management programs (R. H. Osborne, Hawkins, & Sprangers, 2006). Response shift has been defined as a change in the meaning of one's self-evaluation of a target construct like quality of life as a result of (a) recalibration (change in a person's internal standards of measurement) (b) re-prioritisation (change in a person's values) or (c) re-conceptualisation (a change in the way a person defines a target construct; e.g. quality of life). The group-based intervention may stimulate social comparisons, improve knowledge of issues around self-care and understanding of symptoms. The response shift was more possible to happen in the online FSM group than the other two groups (info FSM and control group) as only the participants in this group had access to group communication. The second explanation for lack of improvement on the PWI scores for the participants in the online FSM groups may be performance bias (causing Type II error). As explained previously, the participants were not blinded to their allocation therefore the participants in the control group may have tried new strategies to help them with their fatigue.

The similarities and differences between the online and info FSM groups show the importance of determining which components of a self-management program are responsible for what outcomes. Authors of several systematic reviews have called for further research in this area (Nolte et al., 2007; S. Taylor, 2005; Warsi et al., 2004). Nguyen (2004) who reported on a systematic review on online patient education interventions also put emphasis on the importance of determining which participants

will most benefit from structured interventions that involve extensive professional guidance versus those programs with minimal contact between the participants and the facilitator as there is much available online information. The 'group communication' component of the FSM program is a good example. The group communication proved to be a popular component of the online FSM program. There was a high level of contribution by the participants (mean of 9.23 forum posts per person over the 7 week program) in comparison with other studies (K. R. Lorig et al., 2002) (mean of 8.0 posts per person during 1 year of the study with email discussion group). This shows the enthusiasm of participants for the interactive component of the program. This is also consistent with the results of the deconstruction-reconstruction stage of designing the online program (Ghahari et al., in press) which emphasised the interactive component as the most important part of this self-management program (Ghahari et al., in press). On the other hand, anecdotal feedback from the participants in the online group suggested that although participating in the group discussions and contributions was enjoyable, it was time consuming and required a great deal of energy which may have resulted in the lack of change from pre-test to post-test for this group of participants. This may explain why the participants in the online FSM group did not start improving in their fatigue and activity participants until after the end of the program while the info FSM group improvement was seen during the program but not after it. This result supports the literature which suggests that people are more likely to feel empowered by being able to digest the information at their own pace and to better use it to enhance treatment efficacy (Ritterband et al., 2003).

Improvement of the control group may be another reason for not finding significant difference between the three groups on the outcome measures. In this study, participants in the online FSM and the info FSM programs showed significant improvement over time (using repeated measures ANOVA analyses) in their overall FIS score and ACS levels. Therefore, null hypothesis number 3 of the study was rejected. But although the improvement in the control group in fatigue was not statistically significant, there was a slight trend towards significance. This may explain why there was no significant difference between groups (using ANCOVA analyses) in the overall FIS scores and the ACS at post-test and follow-up between

the groups i.e. the null hypotheses 1 and 2 were not rejected. In fact, the info FSM group had a sharp decrease in the physical and psychological fatigue from pre-test to post-test and then from the post-test to follow-up. As a result, the results of post-hoc tests showed significant difference between the info FSM and control groups on the physical subscale of the FIS and a marginally significant difference for the psychological subscales of the FIS at follow-up. The effect sizes for these differences were medium to large (.06 < partial eta squared < .14). These differences for the FIS subscales were not significant between the online FSM group and the other two groups. The change in scores in the control group may be a result of performance bias (causing Type II error) as the participants were not blind to their allocation. Alternatively, their failure in accessing the fatigue self-management program may have been a motivation to seek additional therapeutic interventions.

In general participants in this study did not show any improvement in depression, anxiety or stress. It is possible that people had already maximised their potential for adaptation to extreme fatigue at least in terms of mood, since analyses at baseline showed that DASS scores for participants in the present study were within the normal stress levels with only mild anxiety and depression levels compared to the Australian population. However, this may be attributable to the persons' diagnoses as the results of the secondary analysis showed that people with MS improved significantly in their anxiety and stress. The other possible reason for lack of significant improvement in the DASS scores for all participants may be attrition. The participants who dropped out had significantly worse anxiety and stress levels than the participants who completed the three data sets. It is possible that the most anxious participants withdrew. However, the three groups had different stress levels at follow-up with the online FSM group having a significantly lower level than the control group. The online FSM and the info FSM groups were not statistically different from each other at follow-up. The improvement on the stress subscale of DASS for the online FSM group may be attributable to the group communication component of this program. This result is consisted with the literature suggesting improvement in social support as a benefit of group self-management programs (Gallant, 2003). However, the groups may have behaved differently on the variables which were not measured in this study. For example, the control participants may

have accessed health-related websites at the same rate as the intervention participants. We do not know whether participants continued their routine care in the same manner as before they were randomised or if they sought other interventions for their fatigue. It is possible that people who volunteered for the program, also actively sought other information/programs to help them deal with their fatigue. It is also important to highlight that the online and info FSM programs were provided in addition to routine care. Although the medication used by the participants was monitored, it was not possible to control the type of other services they were receiving during the study.

Another possible explanation for the non significant difference between groups may be the low power of the analyses. The observed power for all ANCOVA tests (to test hypotheses 1 and 2) on all primary outcome measures at post-test and follow-up were low, ranging from 11% to 64% with most scores falling below 46%. Compared to a desired level of 80%, this is still low. The standard deviation for most of the scores was large. For example, the mean scores for overall FIS for whole the sample in the RCT study was 80.53±31.60 (observed power of 42%). This extremely low power and also visual analyses of the results (Figure 4.3 to 4.5) suggests that a larger sample size was needed to detect the difference between groups on the primary outcome measures at post-test and follow-up. The results for comparison of the combined group (online and info FSM groups) with the control group strongly confirms this theory. In comparison with the control group, the participants in the combined group showed significant improvement on the physical and psychological subscales of FIS at follow-up. Trend towards significance was also seen in the participants on the overall FIS and the cognitive subscale of FIS at follow-up. In addition, the combined group had a significantly higher PWI score and trend towards significant improvement on the ACS at post-test in comparison with the control group. The results for the repeated measure ANOVA for the combined group also confirmed the above findings. Similar tests for the secondary outcome measures also show similar results for the efficacy of the program for the combined group. The combined group was significantly better than the control group in self-efficacy (at post-test) and overall SSI, satisfaction subscale of SSI, depression and stress (at follow-up). Therefore, it seems that because of the small sample size (Portney &

Watkins, 2008) the analyses of sample data were unable to statistically document the difference between the three groups (online FSM, info FSM and control groups) (Type II error).

Several issues must be considered when interpreting the findings. These have been enumerated below.

(1) Some caution must be exercised in generalising these findings to the overall population of adults with chronic neurological conditions. This study was limited to people who had MS, PD or PPS, who had at most mild cognitive problems, and were older than 20 years of age. It is unknown if these findings would apply to all people with neurological conditions. Further, online interventions are limited to those people who are computer literate and who have access to the internet. This group of adults may have had particular characteristics which influenced the outcomes of the study such as access to other information online. Further, although clinically the online FSM program would be intended for such a group, participants recruited to the present study had higher levels of education compared to their peers in the same age range in the general population and are more likely to seek information as a strategy to manage their conditions. People with higher education are also more likely to need and/or have access to information technology. The use of computer also allows for participation by people who cannot or will not attend a face-to-face fatigue self-management program because of barriers like transportation, job commitments or geography. Given the nature of neurological conditions, some participants missed sessions of this randomised control trial because of exacerbations, hospitalisation, or other challenges. Seven people in the online FSM arm and 4 persons in the Info FSM arm were lost to follow-up. The elimination of these participants from a single outcome analyses (sensitivity analysis) would have threatened the internal validity of the study and possibly led to some misleading interpretations (Altman et al., 2001; Portney & Watkins, 2008). As such, the conservative intention-to-treat approach to analysis was adopted, with participant outcomes being analysed in line with study assignment, rather than according to the intervention actually received (Portney & Watkins, 2008). The self-selection of the participants may also raise the issue of how generalisable the findings are. However, self-selection takes place in all efficacy studies with respect to ethical right of the participants. Further, self-selection to

participate is likely to involve those with sufficient time, interest and motivation which is in line with the client-centred and readiness to change approaches (Dijkstra et al., 2001; Law, 1998; Prochaska & Norcoss, 2001).

(2) Although the external validity of the study may have been affected by the method of recruitment (self-selection through advertisement), the randomisation ensured the internal validity of the trial (Altman & Bland, 1999). In addition, because recruitment to the study was through self-selection, it was not possible to describe reasons for refusal or calculate participation rates; selection bias may have occurred. Based on the literature at least half of individuals with MS, PPS and PD suffer from extreme fatigue (Berlly et al., 1991; Fisk et al., 1994; Friedman & Friedman, 1993). The flyers for this program were not received by all those with extreme fatigue as the flyers were circulated by the related associations and not all the people with these diagnoses are members of the associations. Also, statistics shows that only half of people with disabilities have access to the internet (Australian Bureau of Statistics, 2002-2003). Therefore, this program did not reach all the people who could potentially benefit.

(3) A systemic bias in the evaluation may have occurred as the result of the desire to appease or reward the group facilitator. This effect may be linked to social desirability. Through the group process and sharing of personal information, strong positive relationships between participants and facilitators may develop during the course. Furthermore, participants may be conscious that they are evaluating the course and participation may have required considerable personal effort. The combined effects of these experiences may have led to an 'artificially' higher score on items resulting in an overestimate of the outcomes for individuals. This bias is difficult to control and has been found to be more common in women and older people (Visser, Breemhaar, & Kleijnen, 1989).

(4) The participants in this study were not tested for their level of disability and exacerbation of their condition. While the majority of the participants were people with MS it is possible that a relapse in symptoms prevented people using the skills they had newly learnt during the program. The level of disability at baseline and/or a change in the level of disability during the study could have impacted on the

outcomes of the fatigue self-management program. Although randomisation should have accounted for differences, this could not be confirmed. Also, it is unknown if the participants with different diagnoses (MS, PD and PPS) benefited from the program differently; establishing the results based on statistical tests was not possible because of the small sample size for participants with PPS and PD (Table 4.7).

(5) An important point to take into consideration in RCT studies is missing data. Missing data at post-test and follow-up, which is a common observation in RCTs, may have resulted in systematic bias in this study. The attrition rate in this study (9% at post-test and 21% at follow-up) was in the same range as other studies on self-management programs in chronic disease. In one systematic review of 71 trials there was an average dropout rate of 17% across all diseases, ranging from 16% to 20% (Warsi et al., 2004). Also, the attrition rate in the present study was not high when compared with other studies on online patient education and support interventions which report the attrition anywhere from 4% to 51% (Nguyen et al., 2004). The Nguyen review showed that studies with online recruitment which did not have face-to-face contact appeared to have higher attrition rates. Unlike other studies on online interventions that report higher attrition in the participants in the experimental groups comparing to the control groups (Nguyen et al., 2004), there was no significant difference in attrition rate among the three groups in the present fatigue self-management study. However, some differences were found in clinical characteristics between those who did and did not provide complete data. The higher anxiety and stress level of the participants who did not return the post-test questionnaires compared to the other participants suggests that the participants' mood can affect their participation in the programs. The participants with better psychological outlook may have greater capacity to benefit from online self-management programs.

Despite these cautions, the present study has important strengths. The methodology addresses many of the limitations noted in previous research designs, in particular randomised allocation to the intervention groups. Pre-test analysis revealed that this randomisation resulted in comparable groups with regards to sociodemographic and clinical characteristic indicating that the study was internally valid (Altman & Bland, 1999).

Findings in this study highlighted the need for further studies in the area of self-management. The cost effectiveness of this method of delivery compared to the traditional face-to-face delivery could be a subject for more exploration. Although there are obvious financial and structural barriers to design and development of such programs, they may be cost effective as they reduce the cost of travel (for the participants and/or the facilitators) to zero. As currently the face-to-face programs are known as 'gold standards', more rigorous studies are required to compare the online fatigue self-management program with the face-to-face fatigue self-management program. Also, a study with a larger sample size is needed to explore the effect of the program on the fatigue, activity level and quality of life in comparison with a control group. An RCT with different facilitators is also needed to compare the effect of characteristics of the facilitators on the efficacy of the program.

## *4.5 CONCLUSION*

The primary purpose of a fatigue self-management program is to help the participants improve their everyday performance and quality of life by incorporating 'energy conservation techniques' and self-management skills into their lives. Through the application of a fatigue self-management program, occupational therapists and other health professionals expect that the participants will learn the self-management skills, make corresponding behaviour changes and experience a reduction in the effect of fatigue on their lives. This involves introduction, practice and personal selection of specific strategies for managing fatigue and making behavioural and environmental changes. Specific strategies included in the FSM program are balancing activity and rest, modifying life standards, adjusting priorities and changing body position for certain activities. While some people may need to decrease the number of the activities they do to control their fatigue, the ultimate goal for a fatigue self-management program is decreasing fatigue level at the same time as improving activity choice and level and consequently improving quality of life.

In compliance with the framework for development and evaluation of complex interventions, this component of the project was an RCT to test efficacy of the online fatigue self-management program (Phase 3) (Medical Research Council, 2000). To

our knowledge, this online FSM program is the first of its kind implemented for people with neurological conditions. Although the RCT did not show significant differences between the online FSM program and the control groups, the participants in the online and info FSM programs definitely improved over time. The low power in all analyses when comparing the groups revealed that a bigger sample size is required to detect possible differences between the online FSM and control groups. Results of the secondary analysis on the combined group showed that the online FSM and info FSM group complemented each other. The combined group showed significant differences when compared to the control group. This further suggests that the need for a larger sample size. It also suggests that the online program needs to be edited. While the improvement in social support shows that the interactive component and the activities of the online program are needed, it needs to be less time consuming for the participants. The facilitators can rely more on the group dynamics and the self-management focus inherent in the program. Online interventions like the online FSM program represent an important strategy for bridging the gap in the service for those who can not participate in face-to-face programs. New knowledge gained from this study can further support the idea of providing other self-management programs online. The results of this study also add to the growing body of the evidence emerging regarding how information technology may assist with improving health outcomes related to chronic conditions. The findings provide some evidence of the potential benefits of online fatigue self-management program for people with chronic neurological conditions.

# CHAPTER 5

# COMPARISON OF THE FACE-TO-FACE FATIGUE SELF-MANAGEMENT PROGRAM WITH OTHER VERSIONS OF THE PROGRAM

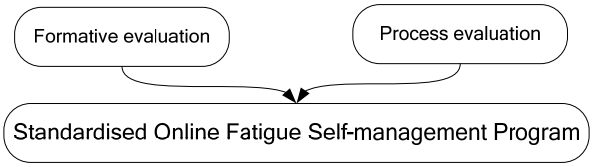
Chapter 1: Introduction

Chapter 2: Literature Review

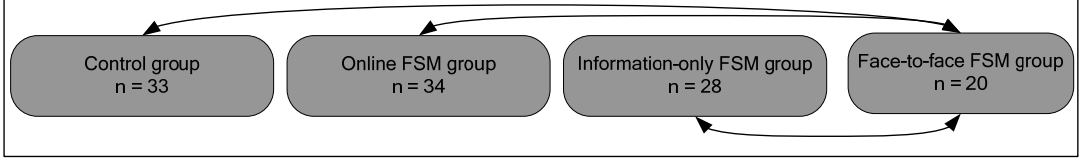
**Brief Summary:**
Part 1:
- Growing population of chronic conditions
- Effectiveness of self-management programs for chronic conditions
- Lack of self-management programs for neurological conditions
- Lack of access of people with chronic conditions to face-to-face programs
- Effectiveness of online programs

Part 2:
- Fatigue is a major problem in neurological conditions
- Fatigue is the least well-managed condition
- Evidence for effectiveness of face-to-face fatigue self-management programs

Chapter 3: Pilot Test




Chapter 4: Randomised Controlled Trial | Chapter 5: Comparison to Face-to-face Program | Chapter 6: Predictors of Improvement




Chapter 7: Conclusion

# 5 COMPARISON TO FACE-TO-FACE PROGRAM

## *5.1 INTRODUCTION*

The previous chapter presented the RCT study to evaluate the efficacy of the online FSM in comparison with the info FSM and control groups in a sample of adults with chronic neurological conditions. The literature suggests incorporating face-to-face treatment interventions as one of the experimental conditions when testing the efficacy of an online program (Ritterband et al., 2003). Therefore, a face-to-face group was also included in this study. As the online FSM program was designed to provide service for the people who do not have access to the face-to-face program, randomisation of the participants to four groups (face-to-face FSM, online FSM, info FSM and control groups) was not feasible because restricting the inclusion criteria to participants who had access to both the face-to-face and online programs would have excluded the very people for whom the program was designed. Subsequently, this part of the PhD project was designed to apply a nonequivalent pre-test post-test control study to compare participants in the face-to-face FSM group with participants in the online and control groups. Because the results of the study showed improvement in both the online FSM and the info FSM groups over time in primary and secondary outcomes, the info FSM group was also included in the nonequivalent pre-test post-test control study. As a result, this chapter presents the methodology, results and discussion of the nonequivalent pre-test post-test control study of the face-to-face fatigue self-management program. The participants' characteristics of the four groups are first compared at baseline. As per the RCT, the progress of the participants in the face-to-face group over time is explored and these results are compared with the online FSM, info FSM and control groups.

## *5.2 METHODS*

### *5.2.1 STUDY DESIGN AND PROCEDURE*

A nonequivalent pre-test post-test control group design was used to compare the efficacy of a face-to-face FSM group with the online FSM, info FSM and the control groups. The recruitment method, inclusion-exclusion criteria, blinding and procedures were identical to those explained in Chapter 4 (Efficacy of the Online

Fatigue Self-management Program). The only exception was that if the participants had access to the face-to-face program they were excluded from the RCT and allocated to the face-to-face group rather than being randomised to one of the other three groups (online FSM, info FSM or control group) (Figure 5.1).

### *5.2.2 OBJECTIVES*

The main objective of this study was to evaluate the efficacy of the face-to-face FSM program and compare it with an online FSM, info FSM and control groups in a sample of adults with chronic neurological conditions. To meet this objective, two null hypotheses were considered:

1) There is no difference between the face-to-face FSM program and each of the online FSM, info FSM and control groups on the on primary and secondary outcome measures at post-test and follow-up among a sample of adults with chronic neurological conditions; and

2) There is no improvement in fatigue, quality of life or activity participation at pre-test, post-test and follow-up for the face-to-face FSM group among a sample of adults with chronic neurological conditions.

### *5.2.3 VARIABLES*

#### 5.2.3.1 INDEPENDENT VARIABLES

The independent variable had four levels. The intervention groups, which are summarised in Table 5.1, included the online FSM, info FSM and control groups (explained in detail in Chapter 4) and a face-to-face FSM group. The face-to-face FSM was the 6-week intervention following the published protocol outlined in *Managing Fatigue* (T. L. Packer et al., 1995). The conceptual frameworks used in this protocol (self-efficacy theory, self-management approach and group model of service delivery) are explained thoroughly in Appendix A. Each session of this program was highly structured and included an education session, practice activities, discussions and homework assignment. All teaching content, worksheets, handouts and homework assignments were standardised and provided. Based on self-efficacy theory (Bandura, 1997b) each session incorporated strategies known to increase confidence in the ability to engage in specific behaviours.

The facilitators of the face-to-face group were occupational therapists at the MS Society of WA who completed a 2-day training course. They were trained using the material and content of the original intervention with step-by-step training in how to deliver the program. During the training, an explanation of fidelity and its importance were provided to the facilitators, and common challenges to fidelity, as well as strategies to enhance and monitor fidelity were discussed. Each face-to-face program was taught at a community setting easily accessible to group participants. Treatment delivery fidelity was measured with the use of weekly checklists completed by facilitators, documenting compliance with the protocol. Also the participants were asked to complete a checklist for testing the treatment enactment fidelity.

Table 5.1 Overview of Intervention Components by Group

| Components of the program | Face-to-face FSM group | Online FSM group | Info FSM group | Control group |
|---|---|---|---|---|
| Weekly self-management-based information | √ | √ | √ | |
| Expert panel's blogs | | √ | √ | |
| Facilitator | √ - active | √ - active | √ - passive | |
| Group communication | √ | √ | | |
| Activities | √ | √ | | |
| Access to other participants | √ | √ | | |

Note. √ = Components received by participants; FSM = Fatigue Self-management.

#### 5.2.3.2 DEPENDENT VARIABLES

All measures described in the pilot study (Chapter 3) and the RCT (Chapter 4) were used in this study. All variables were tested via the post by using paper-based versions of the measures. Data collection procedure was identical to the procedure for the pilot and the RCT studies (sections 3.2.3.3 and 4.2.3).

### *5.2.4 DATA ANALYSIS*

The primary analysis was intention-to-treat and the missing data were treated as explained in the RCT study. All results were analysed using the software package

SPSS 15.0 for Windows, 2007. Data analysis was performed using the same statistical tests as the ones used for the RCT study. Hence only a summary of data analysis is provided here. Missing value analysis was conducted to test for patterns in missing data. Preliminary checks were conducted to ensure that there was no violation of the assumptions of normality, linearity, homogeneity of variances, homogeneity of regression slopes, and reliable measurement of the outcome measures and covariates. T-test and chi-square test were used to compare the groups at baseline on their sociodemographic and clinical characteristics.

ANCOVA was performed to examine the impact of the type of intervention on the primary outcome measures (FIS, PWI and ACS) and secondary outcome measures (GSE, SSI, and DASS) at post-test and follow-up (Testing hypotheses 1 and 2). If significant, pairwise comparison was performed with Bonferroni correction for multiple comparisons. All analyses was adjusted for multiple comparisons of the four groups, hence $p < (.05/3) = .017$ (Bonferroni adjustment) was considered as significant. To test the change in scores from pre-test to post-test and follow-up for face-to-face FSM group (Testing hypothesis 2), repeated measures ANOVA were performed with time (pre-test, post-test and follow-up) as the within-subject factor. Results of repeated measures ANOVA were considered statistically significant when $p < .05$.

### *5.2.5 ETHICS*

Ethics approval for the study was obtained from the Curtin University Human Research Ethics Committee (Approval number OT-2005-14). See details in sections 3.2.4 and 4.2.6.

## *5.3 RESULTS*

### *5.3.1 PARTICIPANT FLOW*

Figure 5.1 depicts the flow of participants through the study. The study was conducted between April 2007 and August 2008. Description of the flow of the participants for the online FSM, info FSM and control groups is thoroughly explained in Chapter 4. Hence in the present chapter only the flow of the participants in the face-to-face group is presented.

Twenty nine participants were eligible for the study. Six people declined on the basis of time commitment or a clash of schedules. Three participants did not return the completed time 1 questionnaire therefore they were not included in the analyses as the return of the first questionnaire was considered as consent. The twenty participants, who completed the first questionnaire and gave consent, participated in the groups. The number of participants in each face-to-face group ranged between 3 and 8 (Mean = 5 ± 2.6). The diagnosis confirmation letters from the doctors were received for 16 persons (80% of the 20 participants) and in 100% of cases the diagnosis by the doctors matched with the participants' self-reported diagnosis.

Attendance rates are reported in Table 5.2 which includes the data for the online FSM, info FSM and face-to-face groups for comparison. One participant in the face-to-face FSM did not attend any sessions in the program. Almost 90% of the participants in the face-to-face FSM attended at least 4 weeks of the intervention but 55% missed at least one session of the program. An independent-samples t-test was conducted to compare the participation rate (i.e. the number of weeks that the participants in the experimental groups were actively involved in the program) between the online FSM, info FSM and face-to-face FSM groups. There was no significant difference in the participation rate for the face-to-face FSM group (Mean = 4.95, SD = 1.64) and that of the online FSM (Mean = 5.53, SD = 2.27; $t$ (2) = -.996, $p$ = .324) and the info FSM group (Mean = 5.89, SD = 2.02; $t$ (46) = -1.718, $p$ = .093).

Figure 5.1 Flow of Participants

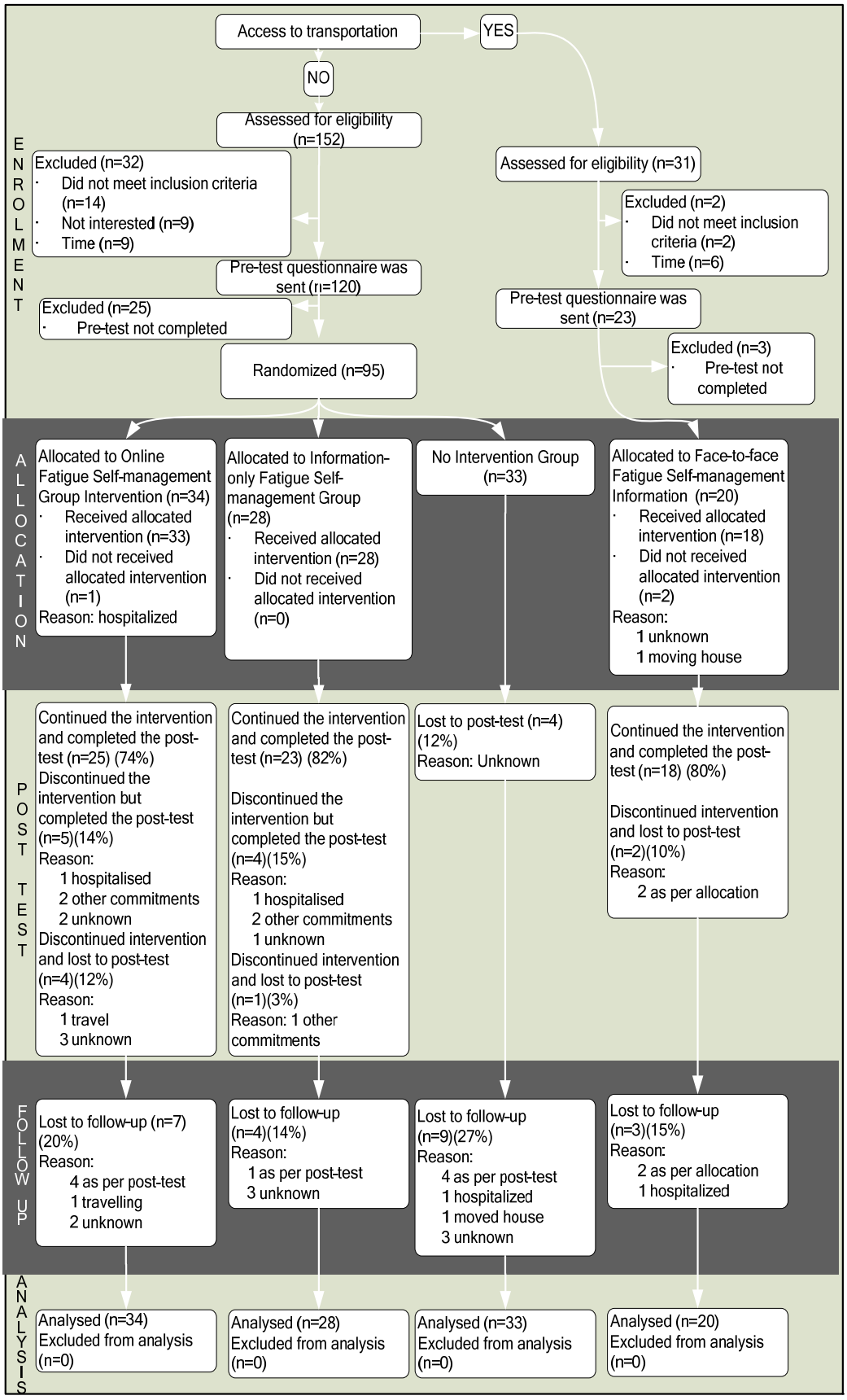


Table 5.2 Participation Rates in the Fatigue Self-management Groups

| Participation | Online FSM group | | Info FSM group | | Face-to-face FSM group | |
|---|---|---|---|---|---|---|
| | Participation per week | Cumulative Percent | Participation per week | Cumulative Percent | Participation per week | Cumulative Percent |
| 6 Weeks | 22 | 64.7 | 20 | 71.4 | 9 | 45 |
| 5 Weeks | 24 | 64.7 | 21 | 75 | 17 | 85 |
| 4 Weeks | 24 | 73.5 | 23 | 82.1 | 18 | 90 |
| 3 Weeks | 27 | 79.4 | 23 | 82.1 | 18 | 90 |
| 2 Weeks | 29 | 85.3 | 23 | 82.1 | 18 | 90 |
| 1 Week | 30 | 88.2 | 27 | 96.4 | 19 | 95 |
| Orientation Week | 33 | 97 | 28 | 100 | - | 100 |
| Did not participate | 1 | - | 0 | - | 1 | - |

Note. FSM = Fatigue Self-management.

### *5.3.2 SOCIODEMOGRAPHIC AND CLINICAL CHARACTERISTICS*

Table 5.3 gives a summary of the sociodemographic and clinical characteristics of participants in the four groups at pre-test. As expected by the sampling strategy, the groups differed by geographic area, both in terms of the state and country versus metropolitan area. The participants in the face-to-face group were all from one metropolitan area i.e. Perth, Western Australia. Unexpected difference also existed between groups. The participants in the face-to-face group had higher gross income than the other groups although this difference did not reach statistical significance. While the groups were not significantly different in time since diagnosis, the face-to-face group had a range of 1-17 years compared to 1-71 years for the online FSM group and 1-52 for the info FSM and the control group.

The scores on the FIS and FSS reflect the different constructs that the two measurement tools measure (Dittner et al., 2004). Although a score of 4 or higher on

the FSS was considered as an inclusion criterion, at least one of the participants in the face-to-face group had a score of zero on the FIS.

The face-to-face FSM group was not significantly different from the other groups in their mood (depression, anxiety and stress) and social support at baseline. But their self-efficacy level was higher than the info FSM group ($p < .017$), with the face-to-face group demonstrating higher self-efficacy. The ACS scores were considerably higher for the face-to-face FSM participants when compared to participants in the online FSM group ($p = .007$). This difference was not significant when the face-to-face group was compared with other groups ($.017 < p < .05$).

Table 5.3 Demographics of the Participants

| Sociodemographic characteristics | Face-to-face FSM group | Online FSM group | Significance of difference with the face-to-face FSM group | Info FSM group | Significance of difference with the face-to-face FSM group | Control group | Significance of difference with the face-to-face FSM group |
|---|---|---|---|---|---|---|---|
| Gender | | | | | | | |
| Male | 5 (25) | 3 (8.8) | .113 | 6 (21.4) | .519 | 9 (27.3) | 1.00 |
| Female | 15 (75) | 31 (91.2) | | 22 (78.6) | | 24 (72.7) | |
| Age, years | | | | | | | |
| Mean (SD) | 52.05 (11.76) | 51.00 (13.6) | .388 | 47.86 (12.0) | .236 | 51.52 (11.06) | .868 |
| Range | 27-74 | 23-74 | | 28-81 | | 31-90 | |
| State | | | | | | | |
| Western Australia | 20 (100) | 11 (32.4) | .000* | 6 (21.4) | .000* | 8 (24.2) | .000* |
| Queensland | 0 (0) | 9 (26.4) | | 12 (42.8) | | 13 (39.4) | |
| New South Wales | 0 (0) | 7 (20.6) | | 5 (17.9) | | 6 (18.2) | |
| South Australia, Victoria, and Tasmania | 0 (0) | 7(20.6) | | 5 (17.9) | | 6 (18.2) | |

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Table 5.3 continued

| Sociodemographic characteristics | Face-to-face FSM group | Online FSM group | Significance of difference with the face-to-face FSM group | Info FSM group | Significance of difference with the face-to-face FSM group | Control group | Significance of difference with the face-to-face FSM group |
|---|---|---|---|---|---|---|---|
| Living Area | | | | | | | |
| Metropolitan | 20 (100) | 21 (61.8) | .001* | 16 (57.1) | .000* | 20 (60.6) | .001* |
| Country | 0 (0) | 13 (38.2) | | 12 (42.9) | | 13 (39.4) | |
| Highest Education Level | n = 18 | n = 22 | | n = 19 | | n = 29 | |
| Secondary School or Less | 10 (55.6) | 7 (20.6) | .001* | 9 (32.1) | .042* | 13 (39.4) | .068 |
| Tertiary Qualification | 7 (38.9) | 13 (38.2) | | 14 (50.0) | | 13 (39.4) | |
| Vocational Qualification | 1 (5.6) | 14 (41.2) | | 5 (17.9) | | 7 (21.2) | |

Continued on next page

Table 5.3 continued

| Sociodemographic characteristics | Face-to-face FSM group | Online FSM group | Significance of difference with the face-to-face FSM group | Info FSM group | Significance of difference with the face-to-face FSM group | Control group | Significance of difference with the face-to-face FSM group |
|---|---|---|---|---|---|---|---|
| Living Situation | | | | | | | |
| Live alone | 3 (15) | 21 (61.8) | .728 | 4 (14.3) | .628 | 7 (21.2) | .725 |
| Live with others | 17 (85) | 13 (38.2) | | 24 (85.7) | | 26 (78.8) | |
| Employment | | | | | | | |
| Employed | 7 (35.0) | 10 (29.4) | .447 | 13 (46.4) | .311 | 10 (30.30) | .476 |
| Unemployed | 13 (65.0) | 24 (70.6) | | 15 (53.6) | | 23 (69.7) | |
| Working Hours/Week | | | | | | | |
| Mean (SD) | 6.75 (11.77) | 6.00 (10.94) | .670 | 9.75 (14.67) | .453 | 8.76 (17.79) | .656 |
| Range | 0-40 | 0-40 | | 0-50 | | 0-74 | |
| Gross Income/week | n = 18 | n = 32 | | n = 18 | | n = 31 | |
| Less than $599 | 3 (15) | 12 (37.5) | .0395 | 9 (32.1) | .334 | 13 (41.9) | .056 |
| Between $600 and $1999 | 11 (55) | 17 (53.1) | | 14 (50.0) | | 15 (48.4) | |
| More than $2000 | 4 (20) | 3 (9.4) | | 5 (17.9) | | 3 (9.7) | |

Note. FSM = Fatigue Self-management;; Unless otherwise mentioned n=20 for face-to-face FSM group, n=34 for online FSM group, n=28 for info FSM group and n=33 for control group; * $p < .017$.

Table 5.4 Clinical Characteristics of the Participants

| Clinical Characteristics | Face-to-face FSM group | Online FSM group | Significance of difference with the face-to-face FSM group | Info FSM group | Significance of difference with the face-to-face FSM group | Control group | Significance of difference with the face-to-face FSM group |
|---|---|---|---|---|---|---|---|
| Diagnosis | | | | | | | |
| Parkinson's Disease or Post-polio syndrome | 7 (35.0) | 9 (26.5) | .549 | 5 (17.9) | .198 | 7 (21.2) | .341 |
| Multiple Sclerosis | 13 (65.0) | 25 (73.5) | | 23 (82.1) | | 26 (78.8) | |
| Time since Diagnosis (in years) | n = 14 | n = 24 | | n = 23 | | n = 26 | |
| Mean (SD) | 6.48 (5.88) | 13.54 (17.74) | .155 | 11.48 (11.16) | .127 | 9.46 (10.33) | .314 |
| Range | 1-17 | 1-71 | | 1-52 | | 1-52 | |
| Type of MS | | | | | | | |
| Relapsing–remitting | 6 (60%) | 13 (65.0) | .548 | 14 (77.8) | .284 | 12 (57.1) | 1.00 |
| Other types (%) | 4 (40%) | 7 (35.0) | | 4. (22.2) | | 9 (42.9) | |
| Contact | | | | | | | |
| Telephone | 18 (90%) | 8 (23.5) | .000* | 7 (25) | .000* | 3 (9.1) | .000* |
| Email | 2 (10%) | 26 (76.5) | | 21 (75) | | 30 (90.9) | |

Continued on next page

Table 5.4 continued

| Clinical Characteristics | Face-to-face FSM group | Online FSM group | Significance of difference with the face-to-face FSM group | Info FSM group | Significance of difference with the face-to-face FSM group | Control group | Significance of difference with the face-to-face FSM group |
|---|---|---|---|---|---|---|---|
| General Perceived Self-efficacy | | | | | | | |
| Mean (SD) | 31.60 (4.10) | 29.44 (5.14) | .058 | 28.71 (3.81) | .016* | 28.85 (5.18) | .049 |
| Range | 25-40 | 18-40 | | 19-36 | | 12-38 | |
| DASS: Depression Subscale | | | | | | | |
| Mean (SD) | 9.25 (10.05) | 11.00 (9.99) | .269 | 10.81 (10.24) | .756 | 10.79 (8.89) | .564 |
| Range | 0-33 | 0-37 | | .39 | | 0-39 | |
| DASS: Anxiety Subscale | | | | | | | |
| Mean (SD) | 7.40 (7.70) | 8.97 (6.69) | .217 | 7.79 (7.68) | .865 | 7.03 (6.87) | .857 |
| Range | 0-34 | 0-24 | | 0-32 | | | |
| DASS: Stress Subscale | | | | | | | |
| Mean (SD) | 10.95 (8.36) | 13.71 (8.96) | .135 | 13.54 (10.54) | .367 | 12.00 (9.08) | .676 |
| Range | 0-34 | 0-37 | | 0-42 | | 0-34 | |

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Table 5.4 continued

| Clinical Characteristics | Face-to-face FSM group | Online FSM group | Significance of difference with the face-to-face FSM group | Info FSM group | Significance of difference with the face-to-face FSM group | Control group | Significance of difference with the face-to-face FSM group |
|---|---|---|---|---|---|---|---|
| SSI: Overall score | | | | | | | |
| Mean (SD) | 34.70 (4.08) | 29.97 (4.05) | .149 | 29.75 (4.76) | .296 | 31.42 (5.09) | .840 |
| Range | 24-41 | 22-37 | | 16-36 | | 19-40 | |
| SSI: Social Interaction Subscale | | | | | | | |
| Mean (SD) | 8.15 (1.79) | 8.21 (1.77) | .456 | 8.00 (1.72) | .771 | 8.97 (1.65) | .095 |
| Range | 3-10 | 4-12 | | 4-11 | | 4-11 | |
| SSI: Satisfaction Subtest | | | | | | | |
| Mean (SD) | 26.55 (4.19) | 25.15 (3.90) | .110 | 25.81(4.60) | .291 | 26.03 (4.58) | .681 |
| Range | 17-34 | 16-32 | | 13-31 | | 16-34 | |

Continued on next page

Table 5.4 continued

| Clinical Characteristics | Face-to-face FSM group | Online FSM group | Significance of difference with the face-to-face FSM group | Info FSM group | Significance of difference with the face-to-face FSM group | Control group | Significance of difference with the face-to-face FSM group |
|---|---|---|---|---|---|---|---|
| FIS: Overall | | | | | | | |
| Mean (SD) | 64.80 (31.68) | 79.94 (30.48) | .044 | 86.14 (32.57) | .014* | 76.36 (32.165) | .208 |
| Range | 0-107 | 11-135 | | 30-147 | | 28-159 | |
| FIS: Physical Subscale | | | | | | | |
| Mean (SD) | 20.40 (8.92) | 24.97 (8.02) | .029 | 25.04 (7.16) | .026 | 23.27 (7.719) | .221 |
| Range | 0-31 | 8-39 | | 10-40 | | 10-40 | |
| FIS: Cognitive Subscale | | | | | | | |
| Mean (SD) | 14.30 (7.81) | 19.18 (8.52) | .021 | 20.43 (9.54) | .011* | 17.48 (9.871) | .225 |
| Range | 0-27 | 10-40 | | 6-38 | | 2-40 | |
| FIS: Psychological Subscale | | | | | | | |
| Mean (SD) | 30.35 (16.61) | 36.29 (16.25) | .102 | 41.21 (17.51) | .018 | 35.91 (17.23) | .254 |
| Range | 0-54 | 10-40 | | 10-74 | | 10-79 | |

Continued on next page

Table 5.4 continued

| Clinical Characteristics | Face-to-face FSM group | Online FSM group | Significance of difference with the face-to-face FSM group | Info FSM group | Significance of difference with the face-to-face FSM group | Control group | Significance of difference with the face-to-face FSM group |
|---|---|---|---|---|---|---|---|
| Activity Card Sort | | | | | | | |
| Mean (SD) | 1.02 (.30) | .87 (.15) | .007* | .88 (.22) | .035 | .93 (.19) | .09 |
| Range | .80-1.93 | .47-1.04 | | .28-1.20 | | .30-1.48 | |
| Personal Wellbeing Index | | | | | | | |
| Mean (SD) | 66.00 (19.03) | 57.18 (21.56) | .68 | 59.74 (19.12) | .14 | 58.74 (19.30) | .09 |
| Range | 16-100 | 7-94 | | 11-84 | | 10-91 | |

Note. FSM = Fatigue Self-management;; Unless otherwise mentioned n=20 for face-to-face FSM group, n=34 for online FSM group, n=28 for info FSM group and n=33 for control group; * $p < .017$.

### *5.3.3 TEST OF HYPOTHESIS 1: COMPARISON OF THE FACE-TO-FACE FSM GROUP TO EACH OF THE ONLINE FSM, INFO FSM AND CONTROL GROUPS ON THE PRIMARY AND SECONDARY OUTCOME*

Results of ANCOVA tests (after controlling for time 1 scores of the primary outcome measure and all the covariates) showed that while the face-to-face, online and info FSM groups were not different at any time point on any outcome measures, there were significant differences between the face-to-face FSM and the control group. After controlling for pre-test scores, the face-to-face FSM group had significantly better scores than the control group at post-test on the overall FIS and also the cognitive and psychosocial subscales ($p < .017$). The effect size for the three tests was large (eta square > .14). The face-to-face and control groups were not different on the physical subscale of the FIS. However, the observed power for the test was only 31%. The two groups were not different on any outcome at follow-up (Tables 5.5 and 5.6). The groups were not significantly different on the ACS and PWI at post-test or follow-up. Further, as the results in Tables 5.7 and 5.8 show, the face-to-face group was not significantly different from other groups in any of the secondary outcome measures (self-efficacy, social support, depression, anxiety and stress) at post test and follow-up.

### *5.3.4 TEST OF HYPOTHESIS 2: DIFFERENCE ON PRIMARY AND SECONDARY OUTCOME MEASURES AT PRE-TEST, POST-TEST AND FOLLOW-UP IN THE FACE-TO-FACE GROUP*

One-way repeated measures ANOVA was used to examine changes in the primary and secondary outcome measures for the participants in the face-to-face FSM group at the three assessment time points (pre-test, post-test and follow-up). The results of the tests are presented in Tables 5.9 and 5.10. The participants showed significant improvement in overall FIS scores and all subscales (physical, cognitive and psychological). Scores on the ACS and PWI nor any secondary outcome measures showed statistically significant changes over time.

Table 5.5 Comparison of Face-face FSM to each of Online FSM, Info FSM and Control Groups on Primary Outcomes at Post-test

| Outcome Measure | Comparison group | F [a] | 95% confidence interval for difference | | ANCOVA Results [b] | | |
|---|---|---|---|---|---|---|---|
| | | | Lower bound | Upper bound | Effect size | Observed power | p-value |
| FIS: Overall | Online FSM | 3.109 | -22.212 | 1.469 | .063 | .408 | .085 |
| | Info FSM | .307 | -15.498 | 8.826 | .008 | .084 | .582 |
| | Control | 8.015* | -24.651 | -4.156 | .151 | .791 | .007 |
| FIS: Physical Subscale | Online FSM | 1.727 | -5.856 | 1.230 | .036 | .251 | .195 |
| | Info FSM | .516 | -2.715 | 4.035 | .004 | .067 | .695 |
| | Control | 2.196 | -5.167 | .787 | .047 | .305 | .145 |
| FIS: Cognitive Subscale | Online FSM | 2.671 | -6.222 | .646 | .055 | .361 | .109 |
| | Info FSM | .46 | -4.490 | 2.234 | .011 | .102 | .502 |
| | Control | 12.180* | -7.5559 | -2.027 | .213 | .927 | .001 |
| FIS: Psychosocial Subscale | Online FSM | 2.515 | -10.139 | 1.203 | .952 | .342 | .121 |
| | Info FSM | .614 | -8.030 | 4.806 | .006 | .079 | .614 |
| | Control | 6.797* | -12.330 | -1.582 | .141 | .723 | .012 |

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Table 5.5 continued

| Outcome Measure | Comparison group | F [a] | 95% confidence interval for difference | | ANCOVA Results [b] | | |
|---|---|---|---|---|---|---|---|
| | | | Lower bound | Upper bound | Effect size | Observed power | p-value |
| Activity Card Sort | Online FSM | .834 | -.042 | .112 | .018 | .145 | .366 |
| | Info FSM | .011 | -.111 | .100 | .000 | .051 | .919 |
| | Control | 1.583 | -.044 | .189 | .034 | .234 | .215 |
| Personal Wellbeing Index | Online FSM | .001 | -7.548 | 7.342 | .000 | .050 | .978 |
| | Info FSM | 4.228 | -10.688 | -.092 | .096 | .519 | .046 |
| | Control | .405 | -4.424 | 8.512 | .009 | .096 | .528 |

Note. FSM = Fatigue Self-management Program; FIS = Fatigue Impact Scale.

[a] df = 1; [b] Bonferroni used for adjustment for multiple comparisons; * $p < .017$.

Table 5.6 Comparison of Face-face FSM to each of Online FSM, Info FSM and Control Groups on Primary Outcomes at Follow-up

| Outcome Measure | Comparison group | F [a] | 95% confidence interval for difference | | ANCOVA Results [b] | | |
|---|---|---|---|---|---|---|---|
| | | | Lower bound | Upper bound | Effect size | Observed power | *p*-value |
| FIS: Overall | Online FSM | .834 | -.042 | .112 | .018 | .145 | .366 |
| | Info FSM | .154 | -12.494 | 18.510 | .008 | .084 | .582 |
| | Control | 2.658 | -.164 | .017 | .056 | .358 | .110 |
| FIS: Physical Subscale | Online FSM | .215 | -4.784 | 2.992 | .005 | .074 | .645 |
| | Info FSM | .780 | -2.493 | 6.362 | .019 | .319 | .382 |
| | Control | 1.578 | -5.479 | 1.270 | .034 | .233 | .215 |
| FIS: Cognitive Subscale | Online FSM | .161 | -4.957 | 2.176 | .013 | .120 | .437 |
| | Info FSM | .254 | -5.629 | 3.383 | .006 | .678 | .617 |
| | Control | 4.546 | -6.601 | -.188 | .092 | .550 | .038 |
| FIS: Psychosocial Subscale | Online FSM | .005 | -6.177 | 5.739 | .000 | .051 | .941 |
| | Info FSM | .518 | -4.929 | 10.379 | .013 | .108 | .476 |
| | Control | 2.203 | -12.048 | 1.825 | .047 | .306 | .145 |

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Table 5.6 continued

| Outcome Measure | Comparison group | F [a] | 95% confidence interval for difference | | ANCOVA Results [b] | | |
|---|---|---|---|---|---|---|---|
| | | | Lower bound | Upper bound | Effect size | Observed power | *p*-value |
| Activity Card Sort | Online FSM | .005 | -.113 | .122 | .000 | .051 | .941 |
| | Info FSM | .360 | -.103 | .191 | .009 | .090 | .552 |
| | Control | .500 | -.094 | .196 | .011 | .106 | .483 |
| Personal Wellbeing Index | Online FSM | .820 | -11.243 | 4.265 | .018 | .144 | .370 |
| | Info FSM | 5.251 | -10.448 | -.655 | .116 | .609 | .027 |
| | Control | 1.845 | -10.561 | 2.054 | .039 | .265 | .181 |

Note. FSM = Fatigue Self-management Program; FIS = Fatigue Impact Scale.

[a] df = 1; [b] Bonferroni used for adjustment for multiple comparisons; * p < .017.

Table 5.7 Comparison of Face-face FSM to each of Online FSM, Info FSM and Control Groups on Secondary Outcomes at Post-test

| Outcome Measure | Comparison group | F [a] | 95% confidence interval for difference | | ANCOVA Results [b] | | |
|---|---|---|---|---|---|---|---|
| | | | Lower bound | Upper bound | Effect size | Observed power | *p*-value |
| Generalised Self-efficacy Scale | Online FSM | 1.830 | -3.000 | .588 | .037 | .263 | .183 |
| | Info FSM | 3.790 | -3.409 | .062 | .085 | .477 | .058 |
| | Control | .589 | -1.33 | 2.96 | .013 | .117 | .4447 |
| SSI: Overall | Online FSM | 2.805 | -3.785 | .346 | .056 | .375 | .101 |
| | Info FSM | .175 | -1.603 | 2.440 | .004 | .069 | .678 |
| | Control | .000 | -1.61 | 1.62 | .000 | .05 | .993 |
| SSI: Social Interaction Subscale | Online FSM | 1.345 | -.302 | 1.123 | .028 | .206 | .252 |
| | Info FSM | .528 | -.540 | 1.146 | .013 | .109 | .472 |
| | Control | 1.46 | -1.27 | .32 | .031 | .22 | .234 |
| SSI: Satisfaction Subscale | Online FSM | 2.190 | -.456 | 2.994 | .045 | .305 | .146 |
| | Info FSM | .032 | -1.547 | 1.850 | .001 | .054 | .858 |
| | Control | .068 | -1.12 | 1.46 | .001 | .057 | .796 |

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Table 5.7 continued

| Outcome Measure | Comparison group | F [a] | 95% confidence interval for difference | | ANCOVA Results [b] | | |
|---|---|---|---|---|---|---|---|
| | | | Lower bound | Upper bound | Effect size | Observed power | *p*-value |
| DASS: Depression Subscale | Online FSM | .1018 | -3.464 | 3.957 | .000 | .052 | .894 |
| | Info FSM | 1.773 | -1.373 | 6.685 | .041 | .255 | .190 |
| | Control | .029 | -2.87 | 3.40 | .001 | .054 | .867 |
| DASS: Anxiety Subscale | Online FSM | .001 | -1.119 | 1.868 | .000 | .050 | .982 |
| | Info FSM | .035 | -2.562 | 3.088 | .001 | .054 | .852 |
| | Control | .923 | -2.66 | .940 | .020 | .156 | .342 |
| DASS: Stress Subscale | Online FSM | 1.666 | -4.756 | 1.038 | .034 | .244 | .203 |
| | Info FSM | 1.795* | -5.717 | 1.157 | .042 | .258 | .188 |
| | Control | 6.472 | -6.78 | -.7 | .123 | .702 | .14 |

Note. FSM = Fatigue Self-management Program; SSI =Duke Social Support Index; DASS = Depression, Anxiety and Stress Scale.

[a] df = 1; [b] Bonferroni used for adjustment for multiple comparisons; * $p < .017$;

Table 5.8 Comparison of Face-face FSM to each of Online FSM, Info FSM and Control Groups on Secondary Outcomes at Follow-up

| Outcome Measure | Comparison group | F [a] | 95% confidence interval for difference | | ANCOVA Results [b] | | |
|---|---|---|---|---|---|---|---|
| | | | Lower bound | Upper bound | Effect size | Observed power | *p*-value |
| Generalised Self-efficacy Scale | Online FSM | .633 | -3.107 | 1.346 | .013 | .122 | .430 |
| | Info FSM | .961 | -2.845 | .986 | .023 | .160 | .333 |
| | Control | .239 | -1.80 | 2.96 | .005 | .077 | .627 |
| SSI: Overall | Online FSM | .189 | -2.329 | 1.501 | .004 | .071 | .66 |
| | Info FSM | 2.641 | -3.481 | .377 | .061 | .355 | .112 |
| | Control | .004 | -2.03 | 1.91 | .000 | .050 | .951 |
| SSI: Social Interaction Subscale | Online FSM | 1.228 | -.289 | .998 | .028 | .192 | .274 |
| | Info FSM | .496 | -1.129 | .545 | .012 | .016 | .485 |
| | Control | .001 | -.899 | .871 | .000 | .050 | .974 |
| SSI: Satisfaction Subscale | Online FSM | .940 | -2.290 | .800 | .020 | .158 | .337 |
| | Info FSM | 2.813 | -2.812 | .260 | .064 | .374 | .101 |
| | Control | .002 | -1.51 | 1.45 | .000 | .050 | .962 |

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Table 5.8 continued

| Outcome Measure | Comparison group | F [a] | 95% confidence interval for difference | | ANCOVA Results [b] | | |
|---|---|---|---|---|---|---|---|
| | | | Lower bound | Upper bound | Effect size | Observed power | *p*-value |
| DASS: Depression Subscale | Online FSM | .558 | -2.542 | 5.544 | .012 | .113 | .459 |
| | Info FSM | .742 | -2.671 | 6.644 | .018 | .138 | .394 |
| | Control | .172 | -5.72 | 3.76 | .004 | .069 | .680 |
| DASS: Anxiety Subscale | Online FSM | .000 | -2.908 | 2.903 | .000 | .050 | .999 |
| | Info FSM | .453 | -2.236 | 4.474 | .11 | .101 | .504 |
| | Control | .204 | -4.27 | 2.71 | .004 | .073 | .654 |
| DASS: Stress Subscale | Online FSM | .119 | -2.814 | 3.976 | .003 | .063 | .732 |
| | Info FSM | .586 | -2.029 | 4.506 | .014 | .116 | .448 |
| | Control | 1.79 | -7.65 | 1.54 | .037 | .258 | .184 |

Note. FSM = Fatigue Self-management Program; SSI= Duke Social Support Index; DASS= Depression, Anxiety and Stress Scale.

[a] df = 1; [b] Bonferroni used for adjustment for multiple comparisons; * $p < .017$.

Table 5.9 Change in Scores of Primary Outcome Measures at Pre-test, Post-test and Follow-up in Face-to-face Group

| Outcome Measure | Results of Repeated Measures ANOVA | | | | Post-hoc test p-value [a] | | |
|---|---|---|---|---|---|---|---|
| | F (df k-1, df n-2) | Effect size | Observed power | p-value | Pre-test ~ Post-test | Pre-test ~Follow-up | Post-test ~ Follow-up |
| FIS: Overall score | 8.82 (2,38)* | .392 | .960 | .001 | .010 | .014 | 1.00 |
| FIS: Physical Subscale | 7.67(1.54,29.34)* | .288 | .931 | .004 | .040 | .061 | .655 |
| FIS: Cognitive Subscale | 5.85(2,38)* | .235 | .846 | .006 | .016 | .051 | 1.00 |
| FIS: Psychological Subscale | 8.54(2,38)* | .310 | .954 | .012 | .012 | .019 | 1.00 |
| Activity Card Sort | 2.49(1.27, 24.20) | .116 | .470 | .121 | .108 | .257 | 1.00 |
| Personal Wellbeing Index | 788(2,38) | .598 | .040 | .174 | 1.00 | .813 | 1.00 |

Note. FIS = Fatigue Impact Scale.

[a] Bonferroni used for adjustment for multiple comparisons; * $p < .05$.

Table 5.10 Change in Scores of Secondary Outcome Measures at Pre-test, Post-test and Follow-up in Face-to-face Group

| Outcome Measure | Results of Repeated Measures ANOVA | | | | Post-hoc test *p*-value [a] | | |
|---|---|---|---|---|---|---|---|
| | F ($df_{k-1}$, $df_{n-2}$) | Effect size | Observed power | *p*-value | Pre-test ~ Post-test | Pre-test ~Follow-up | Post-test ~ Follow-up |
| Generalised Self-efficacy Scale | .738 (2,38) | .037 | .166 | .485 | .683 | 1.00 | 1.00 |
| SSI: Overall | .986(2,38) | .049 | .209 | .383 | 1.00 | 1.00 | .453 |
| SSI : Social Interaction Subscale | .385 (2,38) | .020 | .107 | .683 | 1.00 | 1.00 | 1.00 |
| SSI: Satisfaction Subscale | 1.397 (1.99,37.87) | .068 | .281 | .260 | 1.00 | .678 | .414 |
| DASS: Depression Subscale | .056 (2,38) | .003 | .058 | .945 | 1.00 | 1.00 | 1.00 |
| DASS: Anxiety Subscale | .587 (1.33,25.09) | .030 | .122 | .497 | .208 | 1.00 | 1.00 |
| DASS: Stress Subscale | 2.046 (1.409,26.77) | .097 | .326 | .159 | .022 | 1.00 | .649 |

Note. SSI = Duke Social Support Index; DASS = Depression, Anxiety and Stress Scale.

[a] Bonferroni used for adjustment for multiple comparisons; * $p < .05$.

## *5.4 DISCUSSION*

The aim of this study was to evaluate the efficacy of the face-to-face FSM program in comparison with the three groups tested in the RCT part of this project (online FSM, info FSM and control groups). This study showed that, similar to other studies (Mathiowetz et al., 2001; Vanage et al., 2003) and similar to the results for the online and info FSM groups, persons with chronic neurological conditions who participated in the 6-week face-to-face FSM program significantly improved in all FIS scores (physical, cognitive and psychological) over time. They were also significantly different from the control group at post-test on the cognitive subscale, psychological subscale and overall FIS scores.

While the result for the overall FIS score and psychosocial subscale of FIS for the face-to-face FSM group is parallel to that of other studies on the same program (Mathiowetz et al., 2005; Mathiowetz et al., 2001; Vanage et al., 2003), the results for other FIS subscales were different between the studies. In the present study, the scores for cognitive FIS subscales were significantly lower than the control group while the scores for the physical subscale were not different. This is inconsistent with other studies that have found lower scores for the physical subscales after participating in the face-to-face FSM program but not for the cognitive subscale. This difference in results between studies may be because the participants in the present study had three different diagnoses (MS, PD and PPS) while the sample for the other three studies included only people with MS (Mathiowetz et al., 2005; Mathiowetz et al., 2001; Vanage et al., 2003). Further studies are needed to explain why the two versions of the program have different effects on the various aspects of fatigue.

Unlike participants in the online and info FSM groups who showed improvement in quality of life, activity participation, self-efficacy and social support, the participants in the face-to-face group in this study did not improve over time in any of these outcome measures other than the FIS. This result is also inconsistent with the findings in other studies which report increases in self-efficacy and quality of life scores after participating in the face-to-face fatigue self-management program (Finlayson, 2005; Mathiowetz et al., 2005) or other self-management programs (For

example S. J. Girdler, 2006; K. R. Lorig, 2001). This may be the result of using a general self-efficacy scale in the present study while the other studies used disease specific scales. This may be as a result of the fact that the participants in the face-to-face group were different from the participants in the RCT part of the study with respect to some demographic and clinical characteristics at base-line. The participants in the face-to-face group had higher levels of income and lower levels of education in comparison to the other groups. While the participants in the RCT part of the study had ACS score ranging from .87 to .93 at baseline (which suggests that they had lost some of their activities because of fatigue (Appendix E), the participants in the face-to-face FSM group had a mean score of 1.02 before starting the program (no change in their activity level because of fatigue). The high baseline scores indicated that, on average, the participants in the face-to face group had not experienced any loss in their activity. Hence, it is not surprising that scores did not improve post-intervention. Also, this group of participants had higher mean self-efficacy scores at pre-test when compared with the other groups. This difference reached statistical significance when compared with the info FSM group. Therefore, the likelihood of improvement in self-efficacy for participants in the face-to-face group was low. Further, the potential to improve for this group of participants on any of the subscales of DASS (depression, anxiety and stress) was also low as their DASS scores at baseline were within the normal range or marginal for mild difficulties (S. H. Lovibond & P. F. Lovibond, 1995). Although the scores for PWI in the face-to-face group were not significantly different from the other groups, the mean for the group (Mean = 66.00, SD = 19.03) was nearer the normal range in Australia (Mean = 74.92, SD = 12.36) (International Wellbeing Group, 2006); therefore the likelihood of improvement in PWI was lower for the participants in the face-to-face group. All these differences suggest that the participants who had access to the face-to-face program were different from the participants who only had access to the internet to participate in the program. This suggests that these two versions of the program can provide service for two different groups of people with fatigue.

The small sample size is an important limitation of this study which should be taken into consideration when generalising the results. The program was delivered in only two suburbs in the metropolitan area of Perth, Western Australia (WA). Therefore, a

limited number of Australians could access this version of the program during the study. Also, the MS Society WA Inc. had been providing this service for people with MS for three years before the start of this project. Consequently, a large number of the members of the MS Society had previously participated in the program and therefore were not eligible for this study. Another limitation of this research, which may have affected external validity of the results, was the quasi- experimental design of the study. Randomisation of the participants to the four groups was not feasible as the face-to-face program was only being delivered in WA during the data collection period of this project and the people for whom the online program was designed (e.g. people in rural or remote areas or people who were employed) had no access to the face-to-face program. Therefore, a non-equivalent pre-test post-test design was chosen for this part of the study and the sample recruitment happened in parallel with the RCT part of the program.

The results of this study suggest the need for further exploration of the efficacy of the fatigue self-management program in online and face-to-face versions with a larger sample size and also using an RCT design by providing the face-to-face version of the program in several metropolitan and country areas in Australia. It also suggests the need to examine equality of access to services. Those in the RCT and without access to effective interventions appear to have greater fatigue and poorer overall health.

## *5.5 CONCLUSION*

The results of this study on the face-to-face FSM program in comparison with online FSM program suggest that the online and info FSM program was successfully mimicking its face-to-face version. Further, the differences in some outcome measures, and some clinical and demographic characteristics show that the potential participants that these two versions of the program can target, are different. The participants who volunteered for participation in the online FSM program had lower activity levels and higher fatigue levels than the participants who have access to the face-to-face program. This suggests that the online program reaches people with poorer baseline scores. Therefore, providing the two versions of the program for the community may bridge one of the service gaps identified by the literature. Future

research is needed to determine whether similar results can be achieved if the face-to-face program was provided widely in Australia and a randomised controlled trial could be conducted.

# CHAPTER 6

# PREDICTORS OF IMPROVEMENT FOR ADULTS WITH FATIGUE SECONDARY TO CHRONIC NEUROLOGICAL CONDITIONS

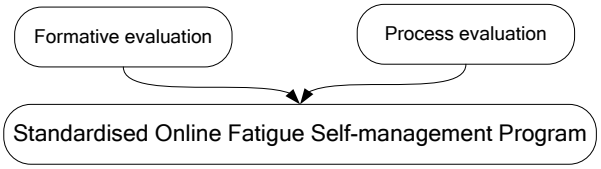
Chapter 1: Introduction

Chapter 2: Literature Review

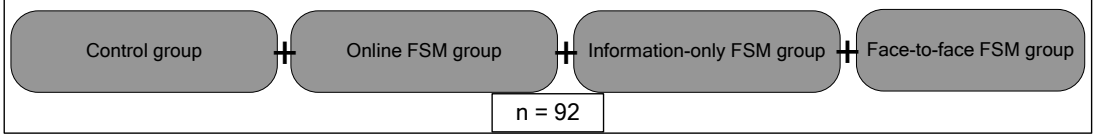
Brief Summary:
Part 1:
- Growing population of chronic conditions
- Effectiveness of self-management programs for chronic conditions
- Lack of self-management programs for neurological conditions
- Lack of access of people with chronic conditions to face-to-face programs
- Effectiveness of online programs

Part 2:
- Fatigue is a major problem in neurological conditions
- Fatigue is the least well-managed condition
- Evidence for effectiveness of face-to-face fatigue self-management programs

Chapter 3: Pilot Test




Chapter 4: Randomised Controlled Trial | Chapter 5: Comparison to Face-to-face Program | Chapter 6: Predictors of Improvement




Chapter 7: Conclusion

# 6 PREDICTORS OF IMPROVEMENT

## *6.1 INTRODUCTION*

The previous two chapters described the evaluation of the online and face-to-face versions of the FSM program. However, recent systematic reviews have emphasised the scarcity of literature studying which components of self-management interventions are essential to help people to improve in their quality of life and/or other intervention-specific outcomes (Lenz et al., 2007; S. Taylor, 2005; Warsi et al., 2004). This study tried to answer three of these clinical questions. The first question was 'who benefits most from self-management programs?'. For clinicians, it is important to know which group of people with what kind of clinical characteristics (such as level of self-efficacy, depression, anxiety and/or stress) should be selected for self-management programs. Some literature reviews report that there is evidence for more improvement in younger female participants (Nolte et al., 2007) and individuals with more severe symptoms (Guevara, 2003; R. Taylor, Lovibond, Nicholas, Cayley, & Wilson, 2005) as a result of self-management programs. However, they call for further study to determine which demographic or baseline clinical characteristics predict better outcomes. The second clinical question examined was related to the underlying mechanisms for self-management programs. This knowledge is required to decide how to design programs and to train the facilitators of the self-management programs and how to increase the likelihood of improvement of the participants. For example, while the literature shows strong relationships between fatigue and mood (specifically depression), it is unknown whether mood changes as a result of participation in a fatigue self-management program. Alternatively, it may be necessary to treat depression prior to enrolment. The third question to answer was whether activity level at baseline is a predictor for improvement in fatigue after participating in fatigue self-management programs. The evidence related to activity is contradictory. Some studies have found fatigue and activity level are negatively correlated and some have not found any significant relationship between them. As the emphasis of the fatigue self-management program (T. L. Packer et al., 1995) is how to balance activity and fatigue, it is important to

know how more active and less active people respond to the program and what helps them to improve their fatigue.

Therefore, in this part of the project a secondary analysis approach was employed to re-evaluate the data collected to answer these three questions, not yet answered in the literature. As Portney (2008) mentions "the major advantages of this approach are the minimal expense involved, the ability to study large samples, and the elimination of the most time-consuming part of the research process-data gathering" (p.353). This chapter presents the methodology, results and discussion of the secondary analysis of data collected from participants in all four study arms (face-to-face FSM, online FSM, info FSM and control). Only participants with complete data sets (pre-test, post-test and follow-up) were analysed.

## 6.2 METHODS

### 6.2.1 OBJECTIVES

The aim of this study was to answer the following clinical questions:

- What clinical and demographic characteristics predict the likelihood of improvement in FIS, PWI and ACS for people with fatigue?
- By what mechanisms do people improve? (i.e. Changes in which variables are predictors of positive health outcome?)
- What are the predictors of improvement in fatigue for people with different baseline activity levels?

### 6.2.2 STUDY DESIGN AND SAMPLE

A secondary analysis was conducted on all complete data sets in order to evaluate all data collected from the fatigue self-management programs (RCT and face-to-face studies). This included participants in the online, info and face-to-face FSM groups. The control group was also included as the participants in this group showed significant (or trends toward significant) improvements in some outcome measure in the RCT. All outcome measures (primary and secondary) were collected at pre-test, post-test and follow-up in the RCT study and face-to-face study in order to be used in this part of the research. Regression analysis which is a powerful statistical approach

for explaining and predicting quantifiable clinical outcomes (Portney & Watkins, 2008), was used to be able to predict outcomes and characteristics which are crucial to effective fatigue self-management programs.

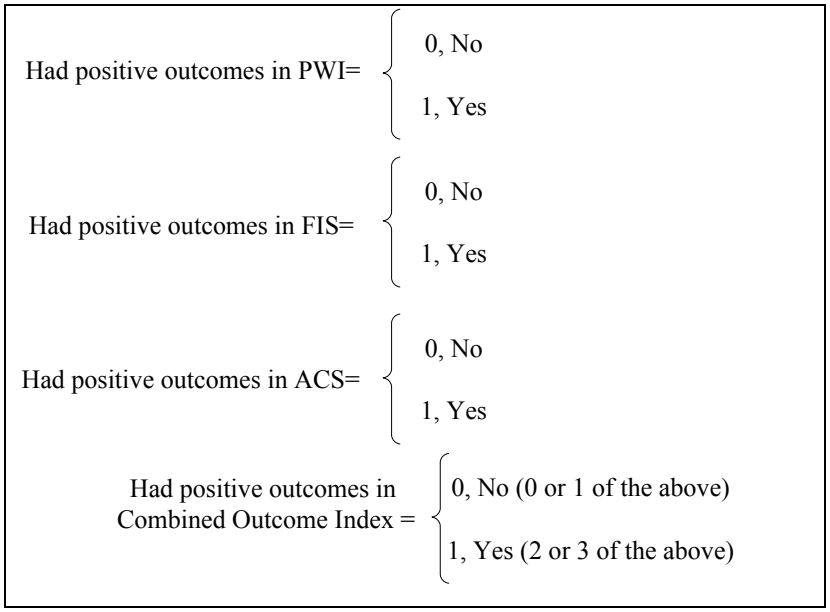
### *6.2.3 VARIABLES*

In order to address objectives 1 and 2 of the secondary analyses, three dependant binary variables were defined to categorise individuals into those who improved in the outcome of PWI, FIS, ACS and those who did not (Figure 6.1). The definitions used were based on the minimal clinically important difference (MCID). MCID is defined as 'the smallest difference in score in the domain of interest that can be defined which patients perceive as beneficial and which would mandate, in the absence of troublesome side-effects and excessive cost, a change in the patient's management' (Jaeschke, Singer, & Guyatt, 1989p. 408). It can be used as a cut-off score when there is not enough evidence to make decisions on clinically important changes in scores (Make, 2007). The literature reports that 7-20 point change in the modified version of the FIS (Gillson, Richard, Smith, & Wright, 2002; Kos et al., 2007; Kos et al., 2003; Oken et al., 2004; Rammohan et al., 2002) is clinically significant; however, there is no evidence available for the original FIS which was used in this study. Similarly, there is no evidence available to indicate clinically significant change for the ACS or PWI. Hence an MCID was required. A variety of approaches has been proposed for estimating the MCID (Sloan, 2005): the distribution (statistical) approach, the anchor (external measure) approach and the opinion approach. In this study, MCID was decided based on a statistical approach. Half the standard deviation of scores at baseline, which is the most common statistical method for deciding on MCID (Norman, Sloan, & Wyrwich, 2003) was used as the cut-off score for categorising the participants after considering its clinical usefulness. The participants were categorised into improved and not improved groups. The unimproved group was coded as 'zero' and the improved group was coded as 'one'.

One additional binary categorical variable 'Combined Outcome Index (COI)' was also defined. The scores on the three variables 'clinically improved in PWI', 'clinically improved in FIS' and 'clinically improved in ACS' were summed. The COI was coded based on 'Zero' as participants who improved in one or none of the

outcomes (PWI, FIS and ACS) and 'one' for the participants with improvement in 2 or all three measures (Figure 6.1).

Figure 6.1 Coding of Variables for Logistic Regression




These categorical variables were used instead of the continuous variables of PWI, FIS and ACS as the goal of this study was to find predictors of the clinically significant improvement in the outcomes rather than predictors for change. The independent variables were demographic variables, clinical characteristics of the participants at baseline and the change in the clinical characteristics from pre-test to follow-up (22 weeks difference).

As objective 3 was focused on improvement in fatigue and activity level of the participants, the dependent variables used in this part of the study were the binary categorical variable of clinical improvement in FIS (which was calculated for objectives 1 and 2), and a second variable named as 'activity level'. A binary categorical variable with two levels (less active group and more active group) was created for this dependent variable. The mean current activity level calculated via the ACS (refer to section 3-5) was used as the cut-off score for defining the binary activity level variable. Independent variables were the same as those used for objectives 1 and 2.

### *6.2.4 DATA ANALYSIS*

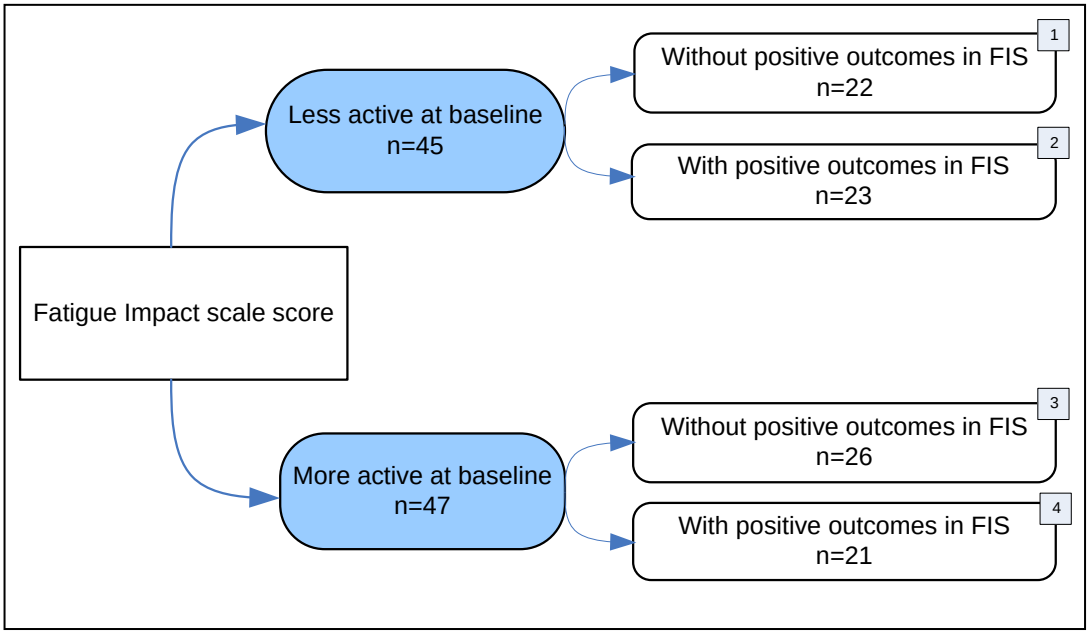
**OBJECTIVES 1 AND 2**

The participants in each group (with or without positive outcomes in FIS, PWI, ACS and COI) were compared on baseline demographic and clinical characteristics as well as their change in outcome measures from pre-test to follow-up. Differences between groups were examined using chi-square for categorical variables and independent t-tests for continuous variables. The variables which showed significant differences between groups were then entered into a logistic regression model to assess how well the set of predictor variables explained the dependent categorical variable (improved or not improved in FIS, PWI, ACS and COI). While the chi-square and t-tests can assess any association between two variables (one of which is the binary outcome variable), logistic regression may be used as a multivariate method to assess which of a set of associated variables independently predict the binary outcome variable (after adjustment for other variables in the regression model). Based on the literature, logistic regression is useful for situations in which the researcher needs to predict the presence or absence of a characteristic or outcome based on values of a set of predictor variables (Field, 2005). Similarly to multiple linear regression, a logistic regression model may be developed in a stepwise manner, either adding on deleting variables one at a time. Stepwise regression is a useful tool in the exploratory phase of research (Menard 1995). Exploratory testing makes no a-priori assumptions regarding the relationships between the variables, thus the goal is to discover relationships. Backward stepwise regression appears to be the preferred method of exploratory analyses, where the analysis begins with a full or saturated model and variables are eliminated from the model in an iterative process (Portney & Watkins, 2008). The fit of the model is tested after the elimination of each variable to ensure that the model still adequately fits the data. When no more variables can be eliminated from the model (based on the significance if variables remaining in the model), the analysis has been completed. In backward elimination (Likelihood Ratio) removal testing is based on the likelihood-ratio statistic based on the maximum partial likelihood estimates. For ease of presentation, logistic regression with backward stepwise selection elimination (Likelihood ratio) is referred to as 'logistic regression' in this thesis.

**OBJECTIVE 3**

The aim of Objective 3 was to examine if the baseline activity level (less active/ more active) may have a bearing on FIS outcome. This could be analysed using the logistic regression model as described. However, the model may need to include interaction terms between activity level and each other independent variable in case the relationship between each independent variable and FIS outcome differed for each activity level. It was decided that a simpler approach was to divide the participants into activity level groups first, and then develop a logistic regression model for each of these two groups. This would allow a (possibly) different set of variables to be associated with FIS outcome for each baseline activity level group. Therefore, the participants were categorised into four groups according to activity level (less active/more active) at baseline and FIS outcome (improved/not improved) and (Figure 6.2). Independent t-test and chi-square tests and then logistic regression were used in the same way as objectives 1 and 2. Chi-square and independent t-tests were used to find the differences between the groups and the logistic regression was applied to find the predictors for membership to the groups.

Figure 6.2 Groups Based on Improvement in Fatigue and Activity Level



## *6.3 RESULTS*

### *6.3.1 SAMPLE*

The sample included 92 participants (80% of the participants in the whole study) who had completed all measures at pre-test, post-test and follow-up. The participants were categorised using half the standard deviation for each outcome measure score at baseline (minimal clinical important change). The means and standard deviation, minimally important change and the resulting number of participants in each group is presented in Table 6.1. MCID for the FIS and ACS (15.95 and .11) were near or equal to the mean change scores (-17.6 and .11 respectively) but the MCID for PWI was 9.33 which was considerably higher than the mean change score of 2.8 for this outcome measure.

Table 6.1 Minimally Important Change, Mean and Standard Deviation for Baseline and Change Scores of Outcome Measures

| Outcome Measure | MCID | Mean (SD) | | Number of participants | |
|---|---|---|---|---|---|
| | | Baseline score | Change score | With positive outcome group | Without positive outcome group |
| Fatigue Impact Scale | 15.95 | 74.38 (31.89) | -17.62 (26.03) | 36 | 43 |
| Activity Card Sort | .11 | .93 (.22) | .11 (.23) | 50 | 29 |
| Personal Wellbeing Index | 9.33 | 62.66 (18.65) | 2.87 (11.57) | 26 | 66 |

MCID = Minimal Clinically Important Difference

### *6.3.2 RESULTS FOR OBJECTIVE 1: BASELINE CHARACTERISTICS THAT PREDICT POSITIVE OUTCOME*

A summary of results for chi-square and independent-sample t-tests exploring the relationship between demographic and baseline clinical characteristics and the positive outcomes in PWI, FIS and ACS are presented in Table 6.2 (For more

detailed results refer to Appendix H). None of the demographic characteristics were significantly different between the groups of participants with and without positive outcomes in PWI, FIS, ACS and COI with the exception of age which was significantly lower in the people with positive outcomes in PWI in comparison with people without positive outcomes in this outcome measure. This age difference was not seen for the participants with positive outcomes in the FIS, ACS or COI compared to those in the other group.

Table 6.2 Comparison of Participants 'With Positive Outcomes' and Those 'Without Positive Outcomes' Relative to Baseline Demographic and Clinical Characteristics

| | Independent variable | Difference between groups with/without positive outcome | | | |
|---|---|---|---|---|---|
| | | PWI | FIS | ACS | COI |
| Demographic variables | Group allocation (Face-to-face FSM/ Online FSM/ Info FSM/ Control) | × | × | × | × |
| | Diagnosis (MS/ PPS/ PD) | × | × | × | × |
| | Education (High school/ Tertiary education/ Vocational training) | × | × | × | × |
| | Gender (Male/ Female) | × | × | × | × |
| | Income (Less than $599/ Between $600 and $1999/ More than $2000) | × | × | × | × |
| | Job (Employed/ Unemployed) | × | × | × | × |
| | Age (year) | √ | × | × | × |
| Baseline Clinical variables | FIS: Overall | × | - | √ | √ |
| | FIS: Physical Subscale | × | - | √ | √ |
| | FIS: Cognitive Subscale | × | - | √ | √ |
| | FIS: Psychosocial Subscale | × | - | √ | √ |
| | Activity Card Sort | × | √ | - | × |
| | Personal Wellbeing Index | - | × | √ | √ |
| | Generalised Self-efficacy Scale | × | × | √ | √ |
| | SSI : Overall | × | × | × | √ |
| | SSI: Social Interaction Subscale | × | × | × | × |
| | SSI: Satisfaction Subscale | × | × | √ | × |
| | DASS: Depression Subscale | × | √ | √ | √ |
| | DASS: Anxiety Subscale | × | × | √ | √ |
| | DASS: Stress Subscale | × | √ | √ | √ |

Note. FIS = Fatigue Impact Scale; ACS = Activity Card Sort; PWI = Personal Wellbeing Index; COI = Combined outcome Index; SSI = Social Support Index; PPS = Post-polio Syndrome; PD = Parkinson's Disease; DASS = Depression Anxiety and Stress Scale; × = no difference between groups; √ = significant difference between groups at $p < .05$; -= Not included in the analysis.

Baseline clinical characteristics were similarly compared for the people with and without positive outcomes in PWI. Based on the results of independent t-tests, no significant difference was seen in clinical characteristics of the people who had positive outcomes and those who did not have positive outcome in PWI. This was

not the case on the FIS and ACS. The participants with positive outcomes on the FIS had significantly lower baseline ACS scores and higher depression and stress scores than the participants without positive outcomes on the FIS. People with positive outcome on the ACS showed lower baseline PWI, self-efficacy and subjective social support in SSI and higher scores on the FIS (overall score and all three subscales) and depression, anxiety and stress in comparison with people without positive outcome. This indicates that the people with positive outcome in either FIS or ACS, tended to be significantly worse at baseline than those who did not have positive outcome.

As only age was significantly different between the groups, no further analysis was performed for the demographic characteristics. Also, there was no significant relationship between having a positive outcome in the PWI and clinical characteristic of the participants at baseline. Therefore, logistic regression was only used to explore predictors for the positive outcome in FIS, ACS and COI (Table 6.3).

Table 6.3 Baseline Characteristics that Predict Improvements in Outcomes

| Outcome variable | R square | | Significant covariate/s | B | Exp (B) Odds ratio | 95% Confidence interval | | *p*-value |
|---|---|---|---|---|---|---|---|---|
| | Cox and Snell | Nagelkerke | | | | Lower bound | Upper bound | |
| FIS | .076 | .102 | ACS | -3.180 | .042 | .003 | .614 | .021 |
| ACS | .110 | .150 | FIS psychological subscale | .045 | 1.047 | 1.016 | 1.077 | .002 |
| COI | .154 | .212 | FIS physical subscale | .082 | 1.085 | 1.008 | 1.168 | .030 |

Note. ACS = Activity Card Sort; FIS = Fatigue Impact Scale; ACS = Activity Card Sort; COI = Combined Outcome Index.

Based on the results of chi-square and t-tests the participants who had a positive outcome on the FIS had significantly lower baseline scores on the ACS and better scores on depression and stress. Therefore, these baseline scores were entered into logistic regression model as independent variables to find which baseline scores predicted positive outcome on the FIS after adjustment for the other variables. The only significant independent predictor for positive outcome in FIS was baseline ACS score The results showed that a higher level of retained activity at baseline is a predictor of lower possibility of having a positive outcome in fatigue ($p$ = .02) but this set of variables only accommodated for between 8 and 10 percent of the variability. This result reveals that there are other important predictors for positive outcome in FIS.

A logistic regression model was also used to predict positive outcome in activity level. The independent variables to be entered to the logistic regression model were baseline PWI, self-efficacy, subjective social support, the three FIS subscales, and depression, anxiety and stress which were significantly different between the groups with and without positive outcome (Table 6.3). The only significant predictor of positive outcome on the ACS was the psychological subscale of FIS ($p$ = .002) but again the model accommodated for only between 11.0 and 15.0 percent of the variability. The results showed that selecting participants with a higher level of psychological fatigue at baseline increases the likelihood of having a positive outcome in ACS in a self-management program (OR = 1.047, CI = 1.016 and 1.077).

The same analysis was conducted to find predictors of positive outcome on the COI. Baseline scores for PWI, self-efficacy, the overall SSI score, all three subscales of the FIS and all three subscales of the DASS were significantly different between the participants in the positive outcome in COI group and the other participants. Therefore, these variables were entered into the model as independent variables. The results showed that a higher level of physical FIS at baseline increased the likelihood of positive outcome in two or more outcomes $p$ = .030 (OR = 1.085, CI = 1.008 and 1.168). This means that people with higher physical FIS are better candidates for fatigue self-management programs.

### *6.3.3 RESULTS FOR OBJECTIVE 2: CHANGE IN CLINICAL CHARACTERISTICS THAT PREDICT POSITIVE OUTCOMES*

Another set of analyses was performed to explore what changes in clinical characteristics predicts better outcomes following a fatigue self-management program. Tables 6.4 and 6.5 show results of group comparisons and logistic regressions. A greater positive change in self-efficacy, social interaction, SSI overall score and CAL, and a greater decrease in depression, stress, overall FIS, cognitive and psychosocial subscales of SSI were seen for the participants who had positive outcome in PWI in comparison with the participants without positive outcome on the PWI. Therefore, change scores of self-efficacy, social interaction, fatigue impact subscales, depression and stress were entered to the logistic regression model to find the best predictors of positive outcome in PWI. Improvement in depression ($p$ = .022) and social interaction ($p$ < .000) were the only two significant predictors of positive outcomes on the PWI, explaining between 25.2 and 36.2 percent of the variability. A decrease in depression and an increase in social interaction enhanced the likelihood of improvement in PWI scores. For every one unit increase in depression, the odds ratio of improvement (versus not improvement in PWI) decreased by 10% (OR = .90, CI = .81 to .98) while for every one unit increase on social interaction scores the odds ratio increased by 53% (OR = 1.53, CI = 1.21 to 1.92).

Table 6.4 Comparison of Change Score for Participants 'With Positive outcomes' and Those 'Without Positive Outcomes' on the Predictor Variables (t-test and chi-square)

| Change in independent variable from baseline to follow-up | Difference between groups with/without positive outcome | | | |
|---|---|---|---|---|
| | PWI | FIS | ACS | COI |
| FIS: Overall | √ | - | √ | - |
| FIS: Physical Subscale | × | - | √ | - |
| FIS: Cognitive Subscale | √ | - | √ | - |
| FIS: Psychosocial Subscale | √ | - | √ | - |
| Activity Card Sort | × | √ | - | - |
| Personal Wellbeing Index | - | √ | √ | - |
| Generalised Self-efficacy Scale | √ | √ | √ | √ |
| SSI: Overall | √ | √ | × | × |
| SSI: Social Interaction Subscale | √ | √ | × | √ |
| SSI: Satisfaction Subscale | × | × | × | × |
| DASS: Depression Subscale | √ | √ | × | √ |
| DASS: Anxiety Subscale | × | √ | × | √ |
| DASS: Stress Subscale | √ | √ | × | √ |

Note. FIS = Fatigue Impact Scale; ACS = Activity Card Sort; PWI = Personal Wellbeing Index; COI = Combined outcome Index; SSI = Social Support Index; DASS = Depression Anxiety and Stress Scale; × = no difference between groups; √ = significant difference between groups; - = not included in the analysis.

The next part of analysis was focused on finding the answer to the question of what changes in clinical characteristics predict positive outcomes on the FIS. The results showed that improvements in self-efficacy and anxiety were predictors of positive outcome in FIS. Independent t-test was used to compare the participants who improved on the FIS with those who did not improve. The results revealed that the participants who had positive outcomes on the FIS from pre-test to follow-up had significantly different change scores on self-efficacy, SSI overall score, the social interaction subscale of SSI, level of activity, PWI, and all subscales of the DASS (depression, anxiety and stress). These variables were entered to a logistic regression model. Improvement in self-efficacy ($p$ = .012) and reduction in anxiety ($p$ = .025) were the only two significant predictors of improvement in FIS. For every one unit increase in self-efficacy, the odds ratio of positive outcomes in FIS increased by 24% (OR = 1.24, CI = 1.048 to 1.467). Further, for every one unit increase in anxiety score the odds ratio of positive outcomes in FIS decreased by 13% (OR = .872, CI =

.773 to .983). These two variables explained between 30 to 40 percent of the variability. The other variables (SSI overall score, social interaction subscale of SSI, ACS, PWI, and depression and stress subscales of DASS) were not independently significant predictors in the model. Therefore, based on these results, improvement in self-efficacy and anxiety are strong predictors of a successful fatigue self-management program.

Table 6.5 Predictors for Improvement in Outcome Measures (Changes in Clinical Characteristics)

| Outcome variable | R square | | Significant covariate/s | B | Exp (B) Odds ratio | 95% Confidence Interval | | *p*-value |
|---|---|---|---|---|---|---|---|---|
| | Cox and Snell | Nagelkerke | | | | Lower bound | Upper bound | |
| PWI | .252 | .362 | Change in Depression | -.111 | .895 | .814 | .984 | .022 |
| | | | Change in SSI: Social Interaction subscale | .423 | 1.526 | 1.213 | 1.920 | .000 |
| FIS | .300 | .400 | Change in GSE | .215 | 1.240 | 1.048 | 1.476 | .012 |
| | | | Change in Anxiety | -.137 | .872 | .773 | .983 | .025 |
| ACS | .094 | .127 | Change in FIS psych | -.053 | .949 | .914 | .985 | .006 |
| COI | .311 | .429 | Change in GSE | .282 | 1.326 | 1.106 | 1.591 | .002 |
| | | | Change in FIS cog | -1.624 | .871 | .796 | .953 | .003 |

Note. FIS = Fatigue Impact Scale; ACS = Activity Card Sort; PWI = Personal Wellbeing Index; COI = Combined outcome Index; SSI = Social Support Index; DASS = Depression Anxiety and Stress Scale.

The same tests were performed in order to find predictors of positive outcomes on the ACS. Results of the independent t-test were significant for change in self-efficacy, the overall FIS score and all subscales of FIS. Logistic regression showed that the only significant predictor for improvement in ACS was psychological fatigue ($p$ = .006) but it explained only 9 to 13% of the variability. For every one unit increase in psychological fatigue, the odds ratio of improvement in ACS decreased by 5% (OR = .949, CI = .914 to .985). The results showed that variables other than those under exploration in this study need to be considered to understand a positive outcome in ACS

The participants who had positive outcome on the COI had a higher positive change in self-efficacy, social interaction subscale for SSI than the participants without positive outcomes. Also, their scores decreased significantly in all the three subscales of the FIS and the three subscales of the DASS in comparison with the group without positive outcome in COI. After entering the significant variables into a logistic regression model, change in *GSE* and change in the cognitive subscale of FIS were significantly correlated with improvement in 2 or more outcomes ($p$ = .002 and $p$ = .003 respectively). The $R^2$ for this model was large (between .311 and .429). For every one unit increase for *GSE* the likelihood to improve in 2 or more outcomes was increased 33%. Also, for one unit increase in depression level, the odds ratio of improvement was 13% lower. Therefore, change in self-efficacy is not only a predictor for positive outcome in FIS but also it is a strong predictor of positive outcome in COI, i.e. 2 or more outcomes (FIS, ACS and PWI).

### *6.3.4 RESULTS FOR OBJECTIVE 3: RELATIONSHIP BETWEEN IMPROVEMENT IN FATIGUE AND ACTIVITY LEVEL*

The third objective of this study was to find the predictors of improvement in fatigue for people with different baseline activity level. Results of chi-square tests showed that there was no relationship between activity level at baseline and positive outcome in FIS ($p$ = .677) and the participants were almost equally distributed between the four groups. For ease of presentation the four groups were numbered from 1 to 4 (Figure 6.2).

To explore the difference in demographic and clinical characteristics of the less active participants with positive outcome in their FIS (group 1) with the ones without a positive outcome in FIS (group 2), independent t-test and chi-square tests were performed. The only significant result was their baseline self-efficacy scores which were significantly lower for group 2 who did have a positive outcome (Table 6.6 and Appendix H).

The independent t-test examining change of scores in clinical characteristics from pre-test to follow-up, are presented in Table 6.7. The participants who were not active at baseline but had positive outcomes (group 2) on their FIS scores were significantly different in their change scores in self-efficacy, overall SSI, social interaction subscale of SSI, anxiety and stress as compared to the participants in group 1 who did not have a positive outcome.

The variables with significant difference were entered to a logistic regression model to explore predictors for the improvement in FIS for less active people. Change in self-efficacy and stress were shown to be the significant predictors of positive outcome in FIS in less active people ($p$ = .009 and $p$ = .038 respectively). The model explained between 32.7 and 43.7 percent of the variability (Table 6.8).

The same analyses were used to find the predictors of positive outcome in FIS for people who were more active at baseline. Independent t-tests were used to compare the demographic and clinical characteristics of the two groups (group 3 and group 4) and found that participants who had positive outcomes on their FIS had marginally significantly ($p$ = .049) higher scores in depression (Mean = 8.33, SD = 6.83) at baseline than the group who did not have a positive outcome (Mean = 4.73, SD = 5.4). When the mean change scores were tested, there was a significant difference between the groups in self-efficacy, depression and stress. The variables were entered into the regression model. Change in self-efficacy ($p$ = .021) and change in stress level were again the significant predictors for improvement in FIS. For every one unit increase in self-efficacy, the odds ratio of improvement in FIS increased by 37% (OR = 1.369, CI = 1.049 to 1.786). Further, for every one unit increase in stress level the odds ratio of improvement in FIS decreased by 25% (OR = .746, CI = .558 to .997). These two variables explained between 22 to 30 percent of the variability.

Therefore, regardless of the level of activity at baseline, an increase in self-efficacy and a reduction of stress are the predictors of improvement in FIS in people with fatigue.

Table 6.6 Summary of Results for Demographic and Baseline Clinical Characteristics of the Participants who Improved in FIS with Those Who did not Improve in FIS

| | Out come Measure | Activity Level | |
|---|---|---|---|
| | | Less active | More active |
| | | Comparison of groups with/without positive outcome in FIS | Comparison of groups with/without positive outcome in FIS |
| Demographic variables | Group allocation (Face-to-face FSM/ Online FSM/ Info FSM/ Control) | × | × |
| | Diagnosis (MS/ PPS/ PD) | × | × |
| | Education (High school/ Tertiary education/ Vocational training) | × | × |
| | Gender (Male/ Female) | × | × |
| | Income (Less than $599/ Between $600 and $1999/ More than $2000) | × | × |
| | Job (Employed/ Unemployed) | × | × |
| | Age (year) | × | × |
| Clinical Characteristics | Activity Card Sort | × | × |
| | Personal Wellbeing Index | × | × |
| | Generalised Self-efficacy Scale | √ | × |
| | SSI: Overall | × | × |
| | SSI: Social Interaction Subscale | × | × |
| | SSI: Subjective Support Subscale | × | × |
| | DASS: Depression Subscale | × | √ |
| | DASS: Anxiety Subscale | × | × |
| | DASS: Stress Subscale | × | × |

Note. FIS = Fatigue Impact Scale; MS =Multiple Sclerosis; PPS = Post-polio Syndrome; PD = Parkinson's Disease; SSI = Social Support Index; DASS = Depression Anxiety and Stress Scale; × = no difference between groups; √ = significant difference between groups.

Table 6.7 Comparison of Participants 'With Positive Outcomes' and Those 'Without Positive Outcomes' in FIS on Each Outcome Measure Based on Change Scores

| Change in Measure | Activity Level | |
|---|---|---|
| | Less active group | More active group |
| | Comparison of groups with/without positive outcome in FIS | Comparison of groups with/without positive outcome in FIS |
| Activity Card Sort | × | × |
| Personal Well Being Index | × | × |
| Generalised Self-efficacy Scale | √ | √ |
| SSI : Overall | √ | × |
| SSI: Social Interaction Subscale | √ | × |
| SSI: Subjective Support Subscale | × | × |
| DASS: Depression Subscale | × | √ |
| DASS: Anxiety Subscale | √ | × |
| DASS: Stress Subscale | √ | √ |

Note. FIS = Fatigue Impact Scale; SSI = Social Support Index; DASS = Depression Anxiety and Stress Scale; × = no difference between groups; √ = significant difference between groups.

Table 6.8 Predictors of Improvement in Fatigue

| Group | R square | | Significant Covariate | B | Exp (B) | 95% Confidence Interval | | *p*-value |
|---|---|---|---|---|---|---|---|---|
| | Cox and Snell | Nagelkerke | | | | Lower bound | Upper bound | |
| Less active | .327 | .437 | Change in *GSE* | .306 | 1.358 | 1.080 | 1.706 | .009 |
| | | | Change in Stress | -.114 | .892 | .801 | .994 | .038 |
| More active | .221 | .296 | Change in *GSE* | .314 | 1.369 | 1.049 | 1.786 | .021 |
| | | | Change in Stress | -.294 | .746 | .558 | .997 | .048 |

## *6.4 DISCUSSION*

In order to understand how self-management programs work, it is important to ask what influences which outcome measures and for whom. However, 35 systematic reviews available testing the efficacy of self-management programs for adults have shed only limited light on the predictors of improvement after participation in these programs (T. L. Packer, 2008). This shortage of evidence exits for both general and disease specific self-management programs including the fatigue self-management program. The authors of the systematic reviews pinpoint that subgroup analyses are under reported, hampering attempts at aggregating data or conduction meta-analysis. Therefore, the aims for this secondary analysis study were to find the answers to three questions: What clinical and demographic characteristics predict the likelihood of improvement in FIS, PWI and ACS for people with fatigue? What changes in clinical characteristics predict the likelihood of improvement in FIS, PWI and ACS for people with fatigue? What are the predictors of improvement in fatigue for people with different baseline activity levels?

Based on the results of this study, it appears that there is no need for the clinicians to select the participants for self-management programs based on any demographic characteristic except age. The participants with lower age were more possible to improve in PWI. Also, the more the person's activity participation is restricted compared to the previous five years (as measured by the retained activity score on the ACS), and the worse their fatigue at baseline, the higher the possibility that they will improve. These results are consistent with those emerging in some systematic reviews that suggest no demographic characteristic other than age contributes to better outcomes after participation in self-management programs (Nolte et al., 2007) and that people with more severe baseline scores benefit more than the others (Guevara, 2003; Nolte et al., 2007; S. Taylor, 2005).

From a clinical point of view, it is important to know how/why people improve in their fatigue. For the participants with fatigue in the present study, improvement in FIS was related to changes in all other variables (ACS, PWI, GSE, all three DASS subscale, and social interaction) except for subjective social support. However, when using these results, it should be considered that there were some overlaps between

the FIS and ACS items. The significant predictors for a better outcome in fatigue were changes in self-efficacy and anxiety. Anxiety is reported to be significantly correlated with fatigue (Shulman et al., 2001). However, the relationship between changes in fatigue and anxiety has not been reported in the literature. The finding that improvement in self-efficacy predicts better fatigue outcomes is consistent with previous research by Mathiowetz et al.(Mathiowetz et al., 2005). In their study, Mathiowetz et al. demonstrated an improvement in both fatigue and self-efficacy following participation in the fatigue self-management program but they did not report on the correlation of the changes.

An outcome that may be theoretically expected following the fatigue self-management program is improvement in activity participation. However, the literature does not show a clear relationship between fatigue and activity participation. Some authors have found negative correlations (Freal et al., 1984; T. L. Packer et al., 1994) while no significant relationship has been reported by others (Parmenter et al., 2003). A newly developed framework for self-management by Packer (2008) proposes that participation, as defined by the WHO, should be the outcome of interest in self-management interventions. The p*ART*icipation framework is underpinned by the *ART* of managing *A*ctivities, *R*elationships, and *T*reatment. In this framework, self-management is the clients' ability to manage their activities, roles and treatment to enable them to engage in the activities they need to and want to do. The RCT part of the present study supports this framework; participants in both online and info FSM groups improved over time in their activity level. However, the results of the study on predictors of improvement did not yield clear insight into how to help people with fatigue improve their level of activity. Although the results showed psychological fatigue of the participants as one of the significant predictors of improvement in activity level, it seems that there are other important contributing factors for improvement in activity as the change in psychological fatigue explained only about 10% of the logistic regression model. It is possible that the changes required for improving activity participation are quite complex and further exploration is therefore required. For example, disease specific scales may detect changes and correlations better ad the influence of other variables needs to be examined.

The mechanisms for improvement in quality of life, as an outcome of interest in most studies on self-management programs, are not identified yet. Diminished depression and increased social interactions were predictors of improvement in PWI for the participants in the present study. This result supports the studies on Australian populations which show that depression is the strongest correlate with PWI scores (Davern, Cummins, & Stokes, 2007). The result is also in parallel with the definition of self-management by Barlow et al who emphasise that a self-management program should include 'the ability to monitor ones condition and to affect the cognitive, behavioural and emotional responses necessary to maintain a satisfactory quality of life' (Barlow et al., 2002). Therefore, fatigue self-management programs, and perhaps other self-management programs as well, with an emphasis on social support and improving mood appear more likely to succeed in assisting people to improve their quality of life. This is also consistent with the results of studies on people with cancer which have did not find any factors associated with the changes following fatigue management (Barsevick et al., 2004; Yates et al., 2005). However, both of these studies used raw change scores rather than clinically meaningful change. Although there are studies on fatigue secondary to many acute/chronic conditions, no studies were found, that looked at predictors of improvement for people with neurological conditions.

It may be unrealistic to expect a clinically significant change in all outcomes of interest following one program, but to be cost effective, clinicians may target more than one outcome in a particular program. In this study, significant improvement in the FIS, PWI and/ or ACS were sought. The results showed that improvement in self-efficacy and cognitive fatigue are the predictors for better outcomes in at least two outcome measures (PWI, ACS or FIS). This emphasises the importance of self-efficacy suggested by the self-management literature (Burckhardt, 2005; Newman, Mulligan, & Steed, 2001). Based on the self-efficacy theory, self-efficacy beliefs provide the foundation for human motivation, well-being, and personal accomplishment. This is because unless people believe that their actions can produce the outcomes they desire, they have little incentive to act or to persevere in the face of difficulties. How people behave can often be better predicted by the beliefs they hold about their capabilities than by what they are actually capable of accomplishing

(Bandura, 1997b). The result that improvement in cognitive fatigue is congruent with other literature on effectiveness of self-management programs (Kathleen Farrell, 2002; S. J. Girdler, 2006; K. R. Lorig et al., 1999). While cognitive fatigue is shown to be the hardest component of fatigue to improve (Mathiowetz et al., 2005; Schwid et al., 2003), fatigue self-management programs need to have a strong focus on cognitive fatigue to help people improve in different aspects of their lives.

There is a clinical myth that less active people and more active people have different needs in regards to their fatigue. This study did not support this belief. Surprisingly, regardless of activity level of the participants at baseline, improvement in self-efficacy and stress were still the predictors of better fatigue outcomes. Change in some other aspects of the persons' life like changing the level of activity participation or social support were not shown to be important factors in increasing the possibility of reduced fatigue. This suggests that 'self-management' of fatigue is more internal than external to the person.

As discussed in the previous chapter, one of the difficulties in explaining how self-management programs work is that their 'active ingredients' are not known yet. One of the difficulties for the researchers is the complex nature of self-management programs (Duncan et al., 2007). Further studies similar to the present study are required to provide more information on how and for whom the self-management programs work.

## *6.5 CONCLUSION*

The need to understand precisely what is occurring in an intervention to achieve an observed change is an important area of inquiry that has profound implications for education, research and practice. The aims of this study were to answer three important clinical questions: who and how people improve in their fatigue, activity and quality of life, and what should be done for people with different levels of activity to help them improve in their fatigue. Younger people and people with severe symptoms appear to be candidates who benefit most from for self-management programs. Self-efficacy should be considered one of the most important aspects of a self-management program when designing and providing the service.

Also, the facilitators of the programs should pay special attention to improving the participants' mood in order to guarantee better results. The other clinical outcome of this study is that improvement in self-efficacy and stress helps both people with low levels and high levels of activity to reduce their fatigue. Therefore, these two groups of participants can both benefit from the same kind of fatigue self-management program.

# CHAPTER 7

# CONCLUSION

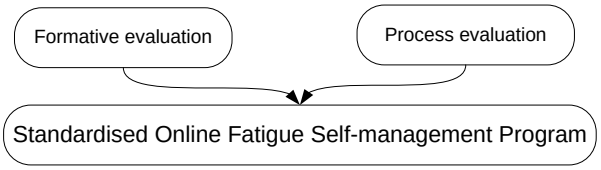
Chapter 1: Introduction

Chapter 2: Literature Review

**Brief Summary:**
Part 1:
- Growing population of chronic conditions
- Effectiveness of self-management programs for chronic conditions
- Lack of self-management programs for neurological conditions
- Lack of access of people with chronic conditions to face-to-face programs
- Effectiveness of online programs

Part 2:
- Fatigue is a major problem in neurological conditions
- Fatigue is the least well-managed condition
- Evidence for effectiveness of face-to-face fatigue self-management programs

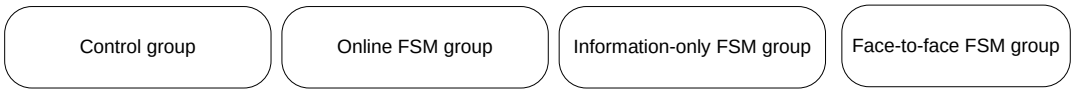
Chapter 3: Pilot Test




Chapter 4: Randomised Controlled Trial

Chapter 5: Comparison to Face-to-face Program

Chapter 6: Predictors of Improvement




Chapter 7: Conclusion

# 7 CONCLUSION

## *7.1 OVERVIEW*

The present thesis was organised to report the methodology, results, discussion and conclusion of each study in a separate chapter. Hereby, an overview of the study is presented to summarise the project followed by implications of the results for practice and policy, and recommendations for future research.

Fatigue is one of the most common symptoms experienced by people with neurological conditions. Although the literature suggests different approaches to treatment of this pervasive symptom, there is not a comprehensive well-supported guideline to manage fatigue. There is strong evidence that the face-to-face fatigue self-management program designed by Packer et al (1995) is effective in improving fatigue in people with MS. However, in Australia and many other developed and developing countries this program is not available to people who have difficulty accessing services due to geographical location, transportation problems, work commitments or who lack confidence to participate in face-to-face programs. This is the issue not only for this particular program but also for any self-management program in Australia. Evidence highlights the need for self-management programs to be delivered in different formats to ensure equity of access. One of the suggested ways is delivering the programs online. There is sufficient evidence that people with disability have access to the internet. Thus, providing and evaluating an online fatigue self-management program seemed to be both necessary and feasible.

This project was designed firstly to refine and further develop a pre-designed online fatigue self-management program and secondly to evaluate it in a sample of adults with chronic neurological condition through a randomised controlled trial. Further, the study intended to explore who and how people with fatigue improve in their health outcomes.

The aims of the project were met through four studies (a pilot study, an RCT, a study on face-to-face fatigue self-management group and a study on predictors of improvement). The pilot study included a formative evaluation (to further develop and standardise the online fatigue self-management prototype) and a preliminary

efficacy evaluation (in preparation for the subsequent RCT study). The pilot study which included three pilot tests took 12 months. The process of refining the online program was labour intensive and required a design team with different expertise. The information and feedback collected from the participants, facilitators and the electronic data were used to further develop the program after each pilot test. The final product of this part of the study was a standardised online fatigue self-management program which was user friendly for the population with basic computer skills. The fidelity of the program was also tested in different ways during the program to ensure that it was mimicking the face-to-face program and following self-management principles. Further, the information gathered during the final pilot test showed that, after minor refinements, the data collection and participant recruitment process planned for the RCT were feasible. A sample size calculation was also conducted based on the data obtained from the preliminary efficacy study.

The pilot study was followed with an RCT study that included 95 participants who were randomised to one of these three groups: online FSM, info FSM and control. The groups were compared in three time points (pre-test, post-test and follow-up) on primary outcome measures (FIS, ACS and PWI) and secondary outcome measures (self-efficacy, SSI and DASS). The results showed that although both the online and info FSM groups improved over time on the FIS and ACS, they were not significantly different from the control group or from each other. This may be attributable to the low observed power for the analyses and a larger sample size may detect significant differences. The findings of this study also showed that the online and info FSM groups acted similarly. Therefore, the two groups were combined to make a larger sample. In comparison with the control group, the participants in the combined group showed significant improvement on the physical and psychological subscales of FIS. Trend towards significance was also seen in the participants on the overall FIS, the cognitive subscale of FIS and the ACS. In addition, the combined group had a significantly higher PWI score at post-test than the control group. The results for the repeated measure ANOVA for the combined group also confirmed the above findings. Therefore, it is possible that a Type II error hindered the project with no significant differences between the online FSM and control group detected. Also, the findings suggested that the info FSM program was more than an attention group.

Further comparison of the online FSM group and the info FSM group revealed interesting differences between the areas/patterns of improvements in each group. While the interactive component of the online program seemed to be attractive for the participants in this group, it seems that the 'silence' in the info FSM group gave them time to start practicing their newly learnt skills sooner than the online FSM group. It may be the reason why the participants in the online FSM group started improving after the program while those in the info FSM group improved during but not after completion of the program. There were other similarities and differences between the two groups. The participants in both groups improved in their self-efficacy. This is consistent with the self-management principles which are based on the self-efficacy theory. But the stress level for the online FSM group was lower than the control group. This finding was not seen for the info FSM group. The difference between the groups on stress may be attributable to the group function of the online FSM group. Thus, although the results of the RCT did not show the efficacy of the program in comparison with no intervention, the findings are promising as the participants in this program improved over time in different aspect of their health. A larger study with a longer follow-up is required to further explore the efficacy of the online fatigue self-management program.

The literature recommends incorporating a well-supported face-to-face group as one of the experimental conditions when evaluating effectiveness on an online program. Thus, the third study was designed to compare a group of participants in the face-to-face FSM program with each of the three other groups (online FSM, info FSM and control groups) using a nonequivalent pre-test post-test study. The twenty participants in the face-to-face FSM group had better health status at baseline compared to the other groups. The findings showed that after controlling for the baseline data these participants had better scores on the FIS than the control group at post-test while these results were not seen in comparison to the online and info FSM groups. Therefore, further study is needed to explore the efficacy of the online FSM for people with fatigue secondary to chronic condition. The study also provided some evidence that the people with limited access to the face-to-face services have poorer baseline scores which may be a reflection of service availability for rural areas.

The fourth study was designed to explore who and how people improve in their health outcomes and how people with different activity level improve in their fatigue. Regression analyses were performed to find whether baseline demographic, clinical characteristics and/or change in clinical characteristics from pre-test to follow-up were predictors for positive health outcomes. In this study, 92 participants with complete data set (pre-test, post-test and follow-up) were included. In parallel to the results emerging in systematic reviews, younger people with more severe baseline scores appear to be more likely to significantly improve in their health outcomes. Improvement in mood and self-efficacy of people with fatigue were found to be predictors of better results for fatigue. Another interesting finding of this study was that improvement in self-efficacy and stress helps people with neurological conditions to improve in their fatigue regardless of their activity level at baseline.

## *7.2 IMPLICATIONS FOR POLICY AND PRACTICE*

The results of this study demonstrated that the online fatigue self-management program can significantly improve fatigue and activity participation for adults with chronic neurological conditions over time. This conclusion was reached using a rigorous methodology and a conservative approach to data analysis. To our knowledge, this is the first online self-management program to address fatigue for people with chronic conditions. The ability to improve health outcomes of vulnerable or at risk populations who traditionally are excluded from such programs has broad implications for health policy and funding. Providing this effective program online and integrating it to the health care system ensures equitable access to self-management programs by Australians in rural and remote areas, those who cannot travel to face-to-face programs and those who are isolated at home due to chronic conditions.

As evidenced in this research, online programs can significantly improve health outcomes for adults with chronic neurological conditions. This result is promising for those clinicians and researchers who wish to provide service for people with chronic conditions who have no access to the face-to-face services for any reason. Given that the results of repeated measure ANOVA showed that the online program is effective, it can be replicated for other conditions, symptoms or disease groups. However, the

results are more generalisable to people with one of the three diagnoses in this study (MS, PPS and PD) but it could be speculated that is would be beneficial to people with other neurological conditions.

An understanding of predictors of improvement in health outcomes may guide clinicians how to choose participants for the self-management programs. Clinicians are always worried about who to refer to their programs. The findings of the study showed that recruiting younger participants with more severe baseline scores increases the likelihood of improvement for the participants in self-management programs. Further, the facilitators of self-management programs need to be equipped with the knowledge and skills to improve self-efficacy and stress in the participants regardless of their activity level.

## *7.3 SUGGESTIONS FOR FURTHER RESEARCH*

Although the present study demonstrated that people with chronic neurological conditions benefit from participating in an online fatigue self-management program, it seems that possible differences between the experimental and control group was not detected as a result of low power due to small sample size. Therefore, another clinical trial with a larger sample size is required to confirm or refute the efficacy of the online FSM program in comparison with a control group. Also, adding a third arm to the study for the face-to-face group would allow for a comparison of the efficacy of different formats of the program using a more rigorous methodology. Future research should also examine if the changes fade/continue in long-term and the need for 'booster' sessions in sustaining the effects of program over time. Further study is required to develop and evaluate other online programs for other common symptoms in chronic neurological conditions like depression and cognitive problems. Using disease specific measurement tools may also result in different findings. A clinical trial may also provide the FSM program in different populations with fatigue (e.g. chronic fatigue syndrome, head injury, spinal cord injury, cancer). In addition, there is limited understanding of the role of some important variables like disability level, comorbidities, and/or exacerbation of symptoms on the effect of the FSM program.

With the growing population of people with chronic conditions it is necessary to find different options for treatment (Bodenheimer, Lorig et al., 2002; Jordan & Osborne, 2007). By examining the differential impact of different formats of self-management programs like online, telephone coaching, peer support, teleconference and video-taped programs, innovative programs may result. This is particularly important as Australians with chronic conditions have different levels of access to the health care service which is mostly provided in the metropolitan areas.

Although previous studies have found self-management programs to be cost effective for different diagnoses (Daniëlle et al., 2006; Gallefoss & Bakke, 1999; Groessl & Cronan, 2000; K. R. Lorig et al., 2002; Wheeler et al., 2003), the economic effects of the fatigue self-management program both from the view of DALY; and the cost to the health care system is, as yet, unknown. Objectifying the impact of self-management interventions like the FSM program on avoiding or delaying unemployment (which is strongly correlated with fatigue) would have important economic and social implications.

Research is required to explore if the program should be modified to meet the need for Australian people from different cultures (like indigenes population) and with first languages other than English. There is a possibility that the therapist's skills and competency may contribute to the results of the program. Research on this issue would clarify if the therapists need to be trained or have special expertise to promote better outcomes from self-management programs.

## *7.4 CONCLUSION*

While fatigue is a common problem for people with fatigue secondary to neurological conditions, this online FSM program is the first of its kind to be implemented. The primary purpose of the fatigue self-management program is to help the participants improve their everyday performance and quality of life by incorporating 'energy conservation techniques' and self-management principles into their own life. Through the application of the fatigue self-management program, occupational therapists and other health professionals expect that the participants will learn the self-management skills, make corresponding behaviour changes and experience a reduction in the effect of fatigue on their lives. New knowledge gained

from this study can further support the idea of providing other self-management programs online. The results of this study also add to the growing body of evidence emerging regarding how information technology may assist with improving health outcomes related to chronic conditions. Further, some predictors of improvement in health outcomes in this group of people were determined. The findings provide some evidence of the potential benefits of online fatigue self-management program for people with chronic neurological conditions. Online interventions like the online FSM program represent an important strategy for bridging the gap in service for those who can not participate in face-to-face programs.

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# APPENDIX A

# FATIGUE SELF-MANAGEMENT PROGRAM

# FATIGUE SELF-MANAGEMENT PROGRAM

## *A.1 AIM*

Packer et al. (1995) developed the six-week, community based Face-to-face Fatigue Self-management Program (face-to-face FSM program) for adults experiencing fatigue secondary to chronic conditions. The authors mention the following as the aim of the program: 'It does not aim to correct the underlying mechanisms that cause fatigue, nor does it accept that the solution is to decrease activity levels or reduce the breadth and extent of activities. Rather it promotes a positive attitude aimed at active decision-making and optimum use of available energy to fit the unique needs of each individual (p.2)'.

## *A.2 CONCEPTUAL FRAMEWORK*

The face-to-face FSM program was written using three theoretical models. The PRECEDE model (Green et al. 1979), which is an educational development model, was employed to determine content. An understanding of psychoeducational groups was used to guide the order of material presented and the structure of individual sessions, and to maximize participation of all group members. The program was also based on the definition of "Handicap" by WHO (1980), defined at the time as "the inability to participate in normal roles" (WHO 1980). The term 'handicap' was usually attributed to a problem at the level of society. Therefore the program was primarily aimed at reducing disability by increasing an individual's ability to participate in those self-care, productive, and leisure activities that are self-identified as important, meaningful, or necessary.

## *A.3 STRUCTURE OF THE FACE-TO-FACE FSM PROGEAM*

The face-to-face FSM program is a community program which is conducted in six sessions. Each session begins with a warm-up exercise and a review of homework. This is followed by presentation and discussion f new material and introduction of homework activities. A brief review concludes each session. The topics of the six sessions of the program are:

| | |
|---|---|
| Session 1 | The Importance of Rest |
| Session 2 | Communication and Body Mechanics |
| Session 3 | Activity Stations |
| Session 4 | Priorities and Standards |
| Session 5 | Balancing Your Schedule |
| Session 6 | Course Review and Future Plans |

All the necessary elements for a professional and effective intervention are included in the manual of the face-to-face FSM program. The highly structured manual of the face-to-face FSM program contains 10 sections as below:

- Introduction. Explains the purpose and rationale behind the program, the organization of the manual and instructions for its use.
- Planning and Preparation. Instructions to initiate and run the program.
- Pre-group Session. Information for the individualized pre-group screening session including assessments, interview questions, and selection criteria.
- Sessions 1-6. These sessions are all structured in the same way, with the convenience of the therapist in mind. Included in each session are the following:
- Purpose of the session
- List of all required overheads, handouts, and supplies
- Outline of the session
- Teaching notes for therapist
- Master copies of all overheads
- Master copies of all handouts
- Therapist worksheets
- Bibliography. Additional reading for interested therapists.

Two facilitators run the program. The facilitators can be occupational therapists or any other health professional who is equipped with the necessary group skills. Facilitators have the freedom to adjust the material in the interest of time and to meet the specific needs of group members; however, the authors emphasise that keeping the established format is necessary.

The sequence of teaching, activity, and homework assignments allows for carryover into the home setting, making the information more relevant to each group member's particular situation. Table A11 shows the phases of psychoeducational group in the face-to-face FSM program.

Table A1: Phases of Psychoeducational Group in the face-to-face FSM Program

| Activity | Stage of Psychoeducational Development | Facilitator Tasks |
|---|---|---|
| Warm-up activity | Orientation | Creating a safe working atmosphere.<br><br>Establishing focus of session |
| Outline of session | | |
| Homework review | Dissatisfaction/Resolution | Reviewing negative and positive aspects of each members experience |
| Teaching session, practice activity, and homework assignment | Working/Production | Presenting new information through didactic lecture, discussions, and activities.<br><br>Encouraging insight and feedback through discussion |
| Conclusion | Termination/Graduation | Reviewing new content.<br><br>Clarifying homework.<br><br>Emphasizing application of material to own life situation through homework. |

## *A.4 DECONSTRUCTION AND RECONSTRUCTION*

The goal in designing the Online Fatigue Self-management Program (online FSM) was to mimic the face-to-face FSM program and to follow the same aims (Refer to section A.1). Therefore, the fundamental principles and requirements of the self-management program were analysed through a deconstruction process. Participants in previous Face-to-face programs were invited to attend a focus group. They confirmed that sharing stories with other members of the group was the strongest and the most important part of this program (Figure A1). This is congruent with self-efficacy theory that highlights the potency of vicarious learning (Bandura, 1997).

Figure A1: Elements of the Face-to-face Fatigue Self-management Program

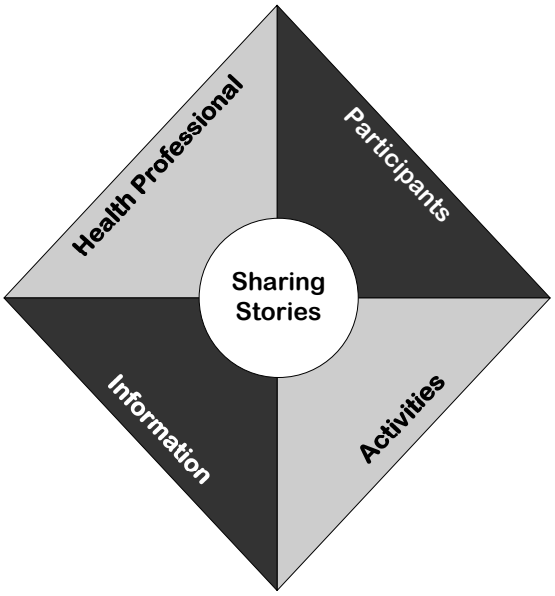
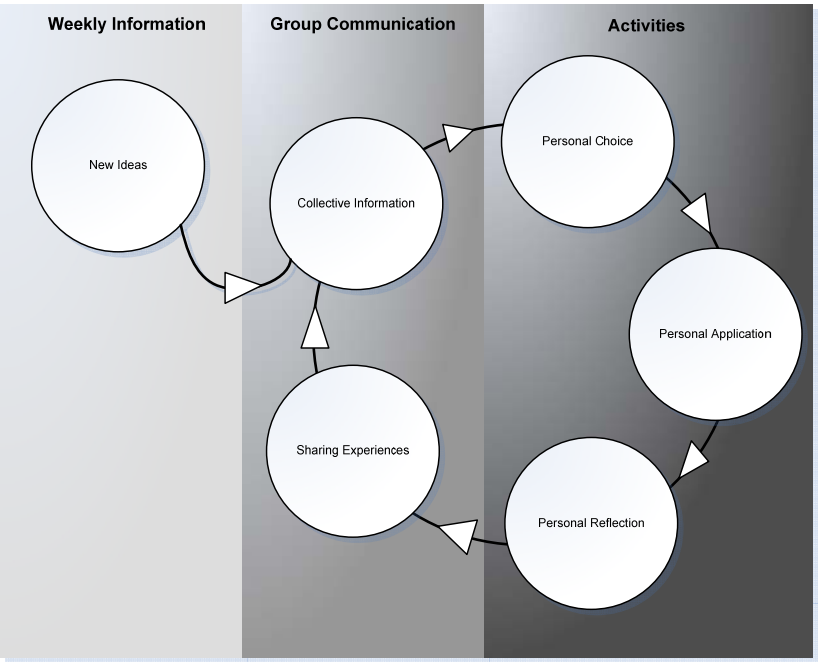



Figure A2 shows the main components of the fatigue self-management program as described by the group. The weekly information provide new ideas and strategies to the participants. Group communication around the application of the strategies highlights the importance of making changes and gives some ideas of how to customize them to each person's situation. Individuals practice using the new strategies in their lives while completing the activities. They learn the process of problem solving based on personal choice and a review of their life routines. The outcomes and consequences of the changes and new habits are reviewed in the group where the experiences are shared with other participants. The advantages and disadvantages of the new strategies for each person are discussed while other participants and the facilitators give feedback. This process in congruent with self-

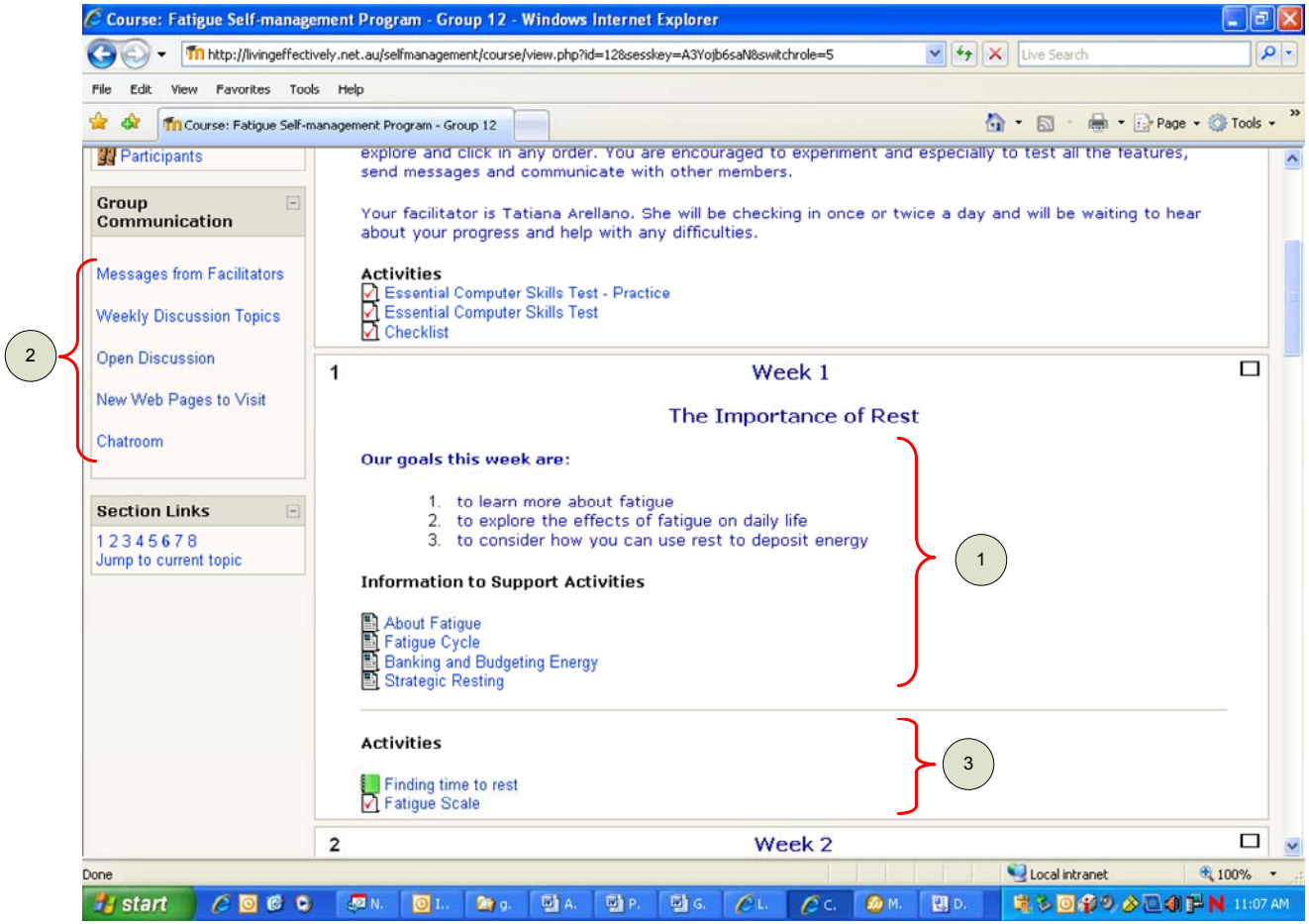
efficacy theory; it facilitates learning self-management skills through modeling, social persuasion and skills mastery.

Figure A2: The Three Important Components of the Fatigue Self-management Program




The online 7-week program was designed to follow the same principles and procedures as the face-to-face FSM program. Participants receive information weekly; they share their stories via group discussions and try the newly presented skills by completing the activities, posting feedbacks to gain comments from facilitators and other participants. Therefore, the three main components of the program include information, activities and group communication which were integrated into the online FSM program (Figure A3).

Figure A3: Three Components of the Online Fatigue Self-management Program




1= Links to Information ; 2= Group Communication ; 3= Activities

### A.4.1 INFORMATION

Information (Figures A3 and A4) is written in simple English based on the face-to-face FSM. It consists of the information text and expert panel comments and is posted to the website weekly. Expert panel consists of a group of participants in the previous face-to-face FSM. They talk about their experiences with fatigue and the impact of changes they have made in their life styles to manage fatigue. Their comments are added to the information text to facilitate the process of modeling for improving self-efficacy (Bandura, 1997).

Figure A4: Information Component of the Online Fatigue Self-management Program


1= Information Text ; 2= Expert Panel Blog

### A.4.2 GROUP COMMUNICATION

Group communication is facilitated using 'forums' (an in-built feature of Moodle). The forums are designed to be easily accessible from the front page of the program, and all forum discussions are posted to all participants' email addresses. Participants can read and reply to the forums directly from their emails. Group discussion is encouraged from the first week of the program when the participants start introducing themselves to each other and talk about their expectations from the

group. Questions about the weekly topics are discussed in 'Weekly discussions' (Figure A3). Participants are also encouraged to talk in 'Open Discussion' about the issues they face as a result of fatigue. They also add the address for useful email or webpage addresses which found or may find useful to 'New Web Pages to Visit'. 'Messages from Facilitator' is used for sending important general messages to all participants.

### A.4.3 ACTIVITIES

Activities, which are the same as those in the face-to-face FSM, are presented online in the format of multiple choice questions, drop down menus and journals. Completing these activities requires only limited computer knowledge. The activities are easy to complete and the instructions are clearly understandable. The activities are introduced weekly to participants according to the topic being discussed. The participants complete the activities online and seek and give feedback to the group. They share their experiences about the effects of changes on their fatigue based on the activities. The facilitators give individual and group feedback about the completed activities.

### A.4.4 ONLINE ACCESSIBILITY

Moodle, Version 1.7 (http://moodle.org; accessed 2006) is the platform used for carrying the online FSM program. The "Living effectively" website (http://livingeffectively.net.au/) was created in the central website of Curtin University and is administered by IT staff of the School of Occupational Therapy.

The first week of the program is designed to facilitate navigation and group formation online. It covers a basic overview of each of the components of the program. Participants are encouraged to introduce themselves to each other and talk about their expectations from the group. The information and activities in this week are designed to become familiar with the program and to learn about different components of the program. The following six weeks of the program include all the 3 components of information, group communication and activities. With the progress of the group toward the end, the amount of information decreases and the number of activities and discussion increases.

The online FSM is designed to be easily accessible and user-friendly for participants with limited computer knowledge. The minimum computer literacy necessary for the participants is the ability to use the Internet for simple searching and sending of email. Full participation in the program requires 2-3 hours weekly. As the program is open 24 hours and 7 days a week for the 7 weeks of the program, the participants can logon at their convenience. The number of participants in the program can vary between 4 and 12.

A "Guidebook and Activities" was prepared to further assist the participants to start the program. It is posted to participants prior to commencement of the program. It includes simple instructions and illustrations on how to enter the website, navigate through out the program and use different components of the program. Also, a hard copy of the activities is included in the guidebook to help the participants who prefer to prepare a draft before completing the activities online.

### A.4.5 FACILITATION

The facilitators of the program are health professionals specifically trained to deliver the face-to-face FSM. They receive a one-day training program to use technical aspects of the Moodle platform and also to learn online facilitation techniques. The login data and electronic records which are easily accessible for the facilitators provide the facility for them to observe the participants' behaviour online. The facilitators of the program are responsible for answering questions and helping participants to solve problems encountered in the program. If they are not able to overcome technical problems, the IT administration staff provide support (IT person in school of Occupational Therapy, Curtin University of Technology) to assist the participants. Group communication is always encouraged and guided by the facilitators of the online FSM. The facilitators also provide feedback for activities individually and for the group.

# APPENDIX B

# ESSENTIAL COMPUTER SKILLS TEST

## *ESSENTIAL COMPUTER SKILLS TEST*

The main purpose of this test was to test physical ability of navigating on the computer screen. The participants were asked to complete the test twice: once as a practice and once as a test. The time for completing the test was recorded electronically by the platform from the time they started the first question to the time they clicked on the 'submit all and finish' icon. The test (as per the whole online FSM program) is written with Verdana font size 10 to make it easier for the participants who may have visual impairments. Table B1 shows the questions of the test.

Table B1: Essential Computer Skills Test

Essential Computer Skills Test is to find out how fast you can complete computer tasks. The results of this simple, short test will be used for research purposes, so please try your best to answer the questions as fast as possible without making mistakes.

This is to test how fast you are in:
"scrolling";
"typing"; and
"clicking".

**Instructions**:

You can run this practice **only once**.
This is a timed test so please try your best to answer the questions as fast as possible.

This is to test how fast you are at "**clicking**".

Below are four pictures of appliances.


Using the mouse, take the pointer and click on the number that represents vacuum cleaner:
Choose one answer.

- a. Picture 1
- b. Picture 2
- c. Picture 3
- d. Picture 4

Continued on next page

Table B1 continued

This is to test how fast and accurate you are at "**typing**".
Please read the following sentence and type it in the box:
**I like to go to the beach.**
Answer:

This is to test how fast you are at **"scrolling**".
To begin, click on the word "start", using your mouse, scroll down the page until you see the word "stop" and click on it.
Choose one answer.

- a. Start
- b. Stop

ɵ
ɵ
ɵ
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ɵ
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ɵ
ɵ
ɵ (Note. The length of this part was about half a page on the screen).

Click on "stop"
Choose one answer.

- a. Start
- b. Stop

Continued on next page

Table B1 continued

This is to test how fast you are at **“clicking”**.
Using the mouse, take the pointer and choose “Apple” in the box below, then click on the "submit all and finish" then go back to the front page of program and complete the computer test.
Choose one answer.

- a. Orange
- b. Apple
- c. Banana
- d. Cherry

Save without submitting | Submit page | Submit all and finish

# APPENDIX C

# PARTICIPANT INFORMATION SHEET AND CONSENT FORM (PILOT TEST)

Figure C1: Advertisement


Continued on next page

Figure C1 continued

# Fatigue Self-management Program FAQ

**Facts about fatigue**

The symptom of fatigue is common in neurological conditions. It is a troublesome symptom that is frequently misunderstood by family and friends because it is not obvious. For some people it limits social ad work activities and can impact on lifestyles on a daily basis.

**What can be done?**

Changing life style and behavior is one way to help. We call this fatigue self-management. Some face-to-face programs already exist.

**Tell me more about the research study**

This is a research study, which means that it is being run for a limited time to test effectiveness of a new online fatigue self-management program.

If you have access to transportation you can participate in the face-to-face version of the program and if not, you will be randomized to one of the following groups:

- Online fatigue-management Group
- Online Support Group
- Control Group

**Do I need to be a computer expert to join the online program?**

Not at all! You will need only very basic computer skills, such as using a mouse and typing small amounts of text. You must have regular access to the Internet - this could be at home, a local community centre or library.

**How much does it cost me?**

Self-management program is ***free*** except for your telephone costs and any charges from any Internet service provider that you use to access the Internet.

**What should I do?**

Contact Setareh Ghahari Tel. (08) 9266 1790.
E-mail: **ghahari.setareh@postgrad.curtin.edu.au**.

Figure C2: Consent Form (Pilot Test)


I consent to participate in this research project. The nature of the research has been explained to me to my satisfaction and all of my questions answered. I understand that I am free to withdraw from the study at any time without any consequences.

I understand that the discussion session/telephone interview will be tape-recorded but information obtained as part of the discussions will be treated as confidential. I understand that I will be asked to complete a questionnaire and to return the completed questionnaires to the researcher within one week. If required, I may be contacted with in a two week period to confirm return of the completed questionnaire booklet. I further understand that there are no known risks to participating in this study.

I know that results of this study may be published but if so my identity will be protected and my personal results will not be disclosed.

Name: _____ Date: _____

Signature: _____

Principal Investigator: Setareh Ghahari, PhD Student, School of Occupational Therapy, Tel: (08) 9266 1790.

Supervisor: Professor Tanya Packer, School of Occupational Therapy,

Tel: (08) 9266 3621.

Figure C3: Consent Form (Diagnosis Confirmation)

Curtin University of Technology

Dear Dr._____

I, _____, am participating in a research study to examine the effectiveness of online self- management program for adults with chronic neurological conditions.

Self-management involves (the person with the chronic disease) engaging in activities that protect and promote health, monitoring and managing the symptoms and signs of illness, managing the impact on illness on functioning, emotions and interpersonal relationships and adhering to treatment regimes (Centre for the Advancement of Health, 1996).

The aims of the study are to:

1) To trial and standardize two online self-management group interventions for adults with chronic conditions.

2) To evaluate the effectiveness of online self-management group interventions.

3) To examine possible interactions among self-efficacy, social support and depression and how they influence change in quality of life and activity participation as a result of the intervention.

Setareh Ghahari (PhD Student), Professor Packer and I would like your help to ensure that we have the most accurate medical information about me.

Participant's Signature: _____

P.S. You are welcome to contact the principal investigator of the research project, Ms. Setareh Ghahari on 9266 1790 or
Email: Ghahari.setareh@postgrad.curtin.edu.au.

Her supervisor Professor Tanya Packer can be contacted on (08) 9266 3621.

This study has been approved by the Curtin University Human Research Ethics Committee. If needed, verification can be obtained either by writing to the Curtin University Human Research Ethics Committee, C/- Office of Research and Development, Curtin University of Technology, GPO Box U1987, Perth 6845 or by telephoning 9266 2784.

Figure C4: Diagnosis Confirmation Information


Participant's ID: ☐

Which one of the following medical conditions am I diagnosed with?

☐1 Post-polio Syndrome

☐2 Chronic Fatigue Syndrome

☐3 Parkinson's Disease

☐4 Multiple Sclerosis

Please specify the type

☐1 Relapsing/Remitting

☐2 Primary Progressive

☐3 Secondary Progressive

☐4 Progressive/Relapsing

☐5 Unknown

☐5 None of above

In what month and year was the diagnosis made?

Month_____ Year_____

Are you aware of any other factor/s that may interfere with participating in daily activities?

☐1 Yes ☐2 No

If yes, please describe:

Thank you for taking the time to complete this form.

Figure C5: Participant Information Sheet

**What is the research about?**

We are conducting a research to evaluate fatigue self-management group program for adults with chronic neurological conditions to evaluate its effectiveness for increasing individuals' quality of life and activity participation.

**What will I be asked to do?**

You will be asked to participate in

- ✓ a face-to-face program

or will be assigned randomly to

- ✓ an online self-management program
- ✓ an online support group or
- ✓ another group which will receive the program at a later stage.

The group consists of about 10 people and will take about 2-3 hours per week for a length of 6-7 weeks. You may also be asked to have a telephone interview to discuss the effect of the program on your life. In addition, facilitators of programs may need to make contact with you to follow up possible problems. You are not obliged to participate in the study and you may withdraw your participation from the study at any time.

**What information will I be asked to provide?**

You have received this envelope as a result of agreeing to participate in the program. You will receive a questionnaire to complete before and after the intervention and three months later. The questionnaires include questions about you (gender, age, education, marital status, language, living arrangement and socio-economic status), quality of life, activity participation, depression, social support, fatigue impact and self-efficacy. This will take approximately 45 minutes.

Completing the questionnaires and sending them back to researcher means that you have given your permission for your data to be used in the research

The researcher may call you to remind you.

Also, there is a letter to forward to your physician confirming your diagnosis.

Please complete and sign the letter and send it to your doctor (your GP or specialist) in the stamped envelope which is provided

Continued on next page

Figure C5 continued

In addition, your first name, the city where you live and your picture or the symbol that you have chosen previously in telephone interview will be visible to other participants. The online program is designed in a way that will send all the posts to your email automatically.

**What will happen to the private information and information from the groups?**

Complete confidentiality will be ensured in any publications or presentations that arise from this research and no personal details will be published. No names will be included on the questionnaires that you will be asked to complete. Instead you will be given a unique identity number and only the researchers will have access to the code. Your statements in the online program which will be analysed as data will be treated as confidential and your name will not be published in any way. All information will be kept in a secure cabinet.

**Who do I contact if I have any question or want further information?**

You are welcome to contact the principal investigator of this research project,

Ms. Setareh Ghahari on (08) 9266 1790 or email: Ghahari.setareh@postgrad.curtin.edu.au.

Her supervisor Professor Tanya Packer can be contacted on (08) 9266 3621.

This study has been approved by the Curtin University Human Research Ethics Committee. If needed, verification can be obtained either by writing to the Curtin University Human Research Ethics Committee, C/- Office of Research and Development, Curtin University of Technology, GPO Box U1987, Perth 6845 or by telephoning (08) 9266 2784.

# APPENDIX D

# SOCIODEMOGRAPHIC QUESTIONNAIRE

Figure D1: Sociodemographic Booklet

Curtin University of Technology

Participant ID number:

Questionnaire Booklet (1)

Evaluation of an
Online Fatigue Self-management Group Intervention for
Adults with Chronic Neurological Conditions

Thank you for taking the time to participate in this survey.

The purpose of this study is to test an online fatigue self-management group intervention for adults with chronic neurological conditions.

You will be asked questions about your quality of life, activity participation, depression, social support, fatigue and self-efficacy. This will take approximately 45 minutes.

The questionnaire will be treated with the strictest confidence.

Once you finish with the questionnaire, please place your completed questionnaire in the stamped envelope provided and post it back to the Principal Investigator within 7 days after receiving it.

Completing this questionnaire and sending it back to researcher means that you have given your permission for your data to be used in the research

Continued on next page

Figure D1 continued

Below are some questions regarding your personal background. Please put a cross (X) in the box which best describes you.

Gender

| | | |
|---|---|---|
| Male | (1) | ☐ |
| Female | (2) | ☐ |

How old are you?

| | | |
|---|---|---|
| 20-29 | (1) | ☐ |
| 30-39 | (2) | ☐ |
| 40-49 | (3) | ☐ |
| 50-59 | (4) | ☐ |
| 60-69 | (5) | ☐ |
| 70-79 | (6) | ☐ |
| 80 and Above | (7) | ☐ |

What is the language spoken most commonly in your home?

| | | |
|---|---|---|
| English | (1) | ☐ |
| Italian | (2) | ☐ |
| Greek | (3) | ☐ |
| Chinese | (4) | ☐ |
| Arabic | (5) | ☐ |
| Vietnamese | (6) | ☐ |
| Other | (7) | ☐ |
| (Please specify) | _____ | |

4. What is your highest education level?

Highest year completed at school _____
(Please specify)

| | | |
|---|---|---|
| University undergraduate degree | (1) | ☐ |
| Post-graduate degree | (2) | ☐ |
| TAFE | (3) | ☐ |
| Apprenticeship | (4) | ☐ |
| Other | (5) | ☐ |
| (Please specify) | _____ | |

5. What is your current living situation?

| | | |
|---|---|---|
| Alone | (1) | ☐ |
| With others: | (2) | ☐ |

(Please specify)
Number of adults: ____
Number of children: ____

Figure D1 continued

6. Are you currently in paid employment?

Yes (1) ☐ How many hours a week do you work in paid employment?

_____ Hours per week

No (2) ☐

7. Which income range best represents the total weekly gross income of your household?

| | | |
|---|---|---|
| Nil income | (1) | ☐ |
| $1 - 299 per week ($1 - $15,548 per year) | (2) | ☐ |
| $300 – 599 per week ($15,600 – 31,148 per year) | (3) | ☐ |
| $600 – 999 per week ($31,200 – 51,948 per year) | (4) | ☐ |
| $1000 - 1,399 per week ($52,000 – 72,748 per year) | (5) | ☐ |
| $1,400 – 1,999 per week ($72,800 – 103,948 per year) | (6) | ☐ |
| $2000 – 2,499 per week ($104,000 – 129,948 per year) | (7) | ☐ |
| $2,500 or more per week ($130,000 or more per year) | (8) | ☐ |

# APPENDIX E

# MEANS AND STANDARD DEVIATION OF PRIMARY AND SECONDARY OUTCOME MEASURES

Table E: Mean and Standard Deviation of Primary Outcome Measures

| Outcome Measure | Group | Time | | |
|---|---|---|---|---|
| | | Pre-test Mean (SD) | Post-test Mean (SD) | Follow-up Mean (SD) |
| FIS: Overall [a] | Face-to-face FSM | 64.80 (31.67) | 50.45 (32.03) | 50.95 (32.01) |
| | Online FSM | 79.94 (30.48) | 72.41 (33.21) | 64.29 (34.25) |
| | Info FSM | 86.14 (32.57) | 66.82 (32.30) | 69.79 (32.35) |
| | Control | 76.36 (32.16) | 69.79 (32.35) | 67.64 (36.69) |
| FIS: Physical Subscale [a] | Face-to-face FSM | 20.40 (8.92) | 17.05 (9.17) | 16.01 (9.09) |
| | Online FSM | 24.97 (8.02) | 23.00 (9.45) | 20.35 (9.52) |
| | Info FSM | 25.04 (7.16) | 19.75 (8.09) | 17.71 (9.69) |
| | Control | 23.27 (7.72) | 20.85 (8.47) | 20.12 (8.59) |
| FIS: Cognitive Subscale [a] | Face-to-face FSM | 14.30 (7.81) | 10.95 (8.54) | 11.09 (7.78) |
| | Online FSM | 19.18 (8.52) | 17.41 (9.10) | 15.56 (9.02) |
| | Info FSM | 20.43 (9.54) | 16.25 (8.94) | 15.25 (9.68) |
| | Control | 17.48 (9.87) | 16.97 (8.83) | 16.03 (10.03) |

Continued on next page

Table E1 continued

| Outcome Measure | Group | Time | | |
|---|---|---|---|---|
| | | Pre-test Mean (SD) | Post-test Mean (SD) | Follow-up Mean (SD) |
| FIS: Psychological Subscale [a] | Face-to-face FSM | 30.35 (16.61) | 23.10 (16.03) | 24.05 (16.64) |
| | Online FSM | 36.29 (16.25) | 32.50 (16.49) | 29.03 (17.33) |
| | Info FSM | 41.21 (17.51) | 31.11 (17.47) | 28.93 (19.95) |
| | Control | 35.91 (17.23) | 32.06 (17.38) | 31.73 (19.39) |
| Activity Card Sort [b] | Face-to-face FSM | 1.02 (.30) | 1.10 (.40) | 1.17 (.62) |
| | Online FSM | .87 (.15) | .92 (.17) | .93 (.20) |
| | Info FSM | .88 (.04) | .98 (.051) | 1.00 (.05) |
| | Control | .93 (1.00) | .93 (.05) | 1.00 (.049) |
| Personal Wellbeing Index [b] | Face-to-face FSM | 66.00 (19.03) | 65.07 (18.88) | 63.50 (18.16) |
| | Online FSM | 57.18 (21.56) | 59.20 (18.91) | 60.92 (20.91) |
| | Info FSM | 59.74 (19.11) | 63.62 (18.00) | 64.13 (20.63) |
| | Control | 58.74 (19.30) | 56.25 (21.69) | 61.36 (20.07) |

Note. FIS= Fatigue Impact Scale; FSM = Fatigue Self-management program.

[a] Decreasing scores= Improvement; [b] Increasing scores= Improvement.

Table E2: Mean and Standard Deviation of Secondary Outcome Measures

| Outcome Measure | Group | Time | | |
|---|---|---|---|---|
| | | Pre-test Mean (SD) | Post-test Mean (SD) | Follow-up Mean (SD) |
| Generalised Self-efficacy Scale [b] | Face-to-face FSM | 31.60 (4.10) | 30.75 (4.59) | 31.15 (3.86) |
| | Online FSM | 29.44 (5.14) | 30.32 (4.98) | 30.44 (5.71) |
| | Info FSM | 28.71 (3.81) | 29.79 (4.60) | 30.04 (4.35) |
| | Control | 28.85 (5.18) | 28.39 (5.92) | 29.18 (5.45) |
| SSI: Overall [b] | Face-to-face FSM | 34.70 (4.08) | 35.15 (5.33) | 34.30 (4.43) |
| | Online FSM | 33.04 (4.78) | 32.29 (5.70) | 33.65 (5.90) |
| | Info FSM | 33.18 (5.42) | 33.00 (7.40) | 34.25 (6.76) |
| | Control | 35.00 (5.79) | 34.61 (6.28) | 34.00 (6.49) |
| SSI: Social Interaction Subscale [b] | Face-to-face FSM | 26.55 (4.19) | 26.75 (4.80) | 25.90 (4.20) |
| | Online FSM | 25.51 (3.90) | 24.32 (4.74) | 25.50 (4.79) |
| | Info FSM | 25.18 (4.60) | 25.11 (6.18) | 25.93 (5.42) |
| | Control | 26.03 (4.58) | 25.61 (5.33) | 25.03 (5.29) |
| SSI: Satisfaction Subscale [b] | Face-to-face FSM | 8.15 (1.79) | 8.40 (1.54) | 8.40 (2.19) |
| | Online FSM | 8.21 (1.77) | 7.97 (1.87) | 8.15 (1.89) |
| | Info FSM | 8.00 (1.72) | 7.89 (2.10) | 8.32 (2.00) |
| | Control | 8.97 (1.65) | 9.00 (1.50) | 8.97 (1.76) |

Continued on next page

Table E2 continued

| Outcome Measure | Group | Time | | |
|---|---|---|---|---|
| | | Pre-test | Post-test | Follow-up |
| | | Mean (SD) | Mean (SD) | Mean (SD) |
| DASS: Depression Subscale [a] | Face-to-face FSM | 9.25 (10.05) | 9.15 (11.60) | 9.65 (11.92) |
| | Online FSM | 11.00 (10.00) | 10.41 (10.20) | 9.65 (9.70) |
| | Info FSM | 10.18 (10.24) | 8.43 (10.33) | 9.14 (11.95) |
| | Control | 10.79 (8.89) | 10.42 (9.92) | 11.94 (11.43) |
| DASS: Anxiety Subscale [a] | Face-to-face FSM | 7.40 (7.70) | 6.35 (7.51) | 6.95 (8.41) |
| | Online FSM | 8.97 (6.69) | 7.71 (6.32) | 8.47 (7.59) |
| | Info FSM | 7.79 (7.69) | 7.21 (9.67) | 7.11 (9.72) |
| | Control | 7.03 (6.87) | 6.85 (5.89) | 7.48 (7.62) |
| DASS: Stress Subscale [a] | Face-to-face FSM | 10.95 (8.36) | 8.60 (8.76) | 10.10 (8.64) |
| | Online FSM | 13.71 (8.96) | 12.21 (7.75) | 11.35 (8.98) |
| | Info FSM | 13.54 (10.54) | 12.32 (11.32) | 11.36 (11.21) |
| | Control | 12.00 (9.08) | 12.52 (10.13) | 13.85 (10.84) |

Note. SSI = Social Support Index; DASS = Depression, Anxiety and Stress Scale; FSM = Fatigue Self-management program.

[a] Decreasing scores= Improvement; [b] Increasing scores= Improvement.

# APPENDIX F

# COMPARISON OF THE COMBINED GROUP WITH THE CONTROL GROUP AND IMPROVEMENT OF THE COMBINED GROUP OVER TIEM

Table F1: Comparison of Combined and Control Groups on Primary Outcomes at Post-test

| Outcome Measure | *F* [a] | 95% confidence interval for difference | | ANCOVA Results | | |
|---|---|---|---|---|---|---|
| | | Lower bound | Upper bound | Effect size | Observed power | *p*-value |
| FIS: Overall | 2.097 | -15.142 | 2.377 | .017 | .226 | .226 |
| FIS: Physical Subscale | .739 | -3.624 | 1.435 | .008 | .136 | .392 |
| FIS: Cognitive Subscale | 2.795 | -4.579 | .395 | .031 | .280 | .098 |
| FIS: Psychosocial Subscale | 1.989 | -7.579 | 1.268 | .022 | .286 | .162 |
| Activity Card Sort | 3.752 | -.002 | .145 | .041 | .482 | .056 |
| Personal Wellbeing Index | 6.442* | 1.392 | 11.445 | .069 | .709 | .013 |

Note. FIS= Fatigue Impact Scale.

[a] df =1; *p< .05.

Table F2: Comparison of Combined and Control Groups on Primary Outcomes at Follow-up

| Outcome Measure | *F* [a] | 95% confidence interval for difference | | ANCOVA Results | | |
|---|---|---|---|---|---|---|
| | | Lower bound | Upper bound | Effect size | Observed power | *p*-value |
| FIS: Overall | 3.873 | -.155 | .001 | .043 | .495 | .052 |
| FIS: Physical Subscale | 4.664* | -5.973 | -.248 | .051 | .570 | .034 |
| FIS: Cognitive Subscale | 3.814 | -5.782 | .051 | .042 | .489 | .054 |
| FIS: Psychosocial Subscale | 5.480* | -11.825 | -.966 | .059 | .639 | .022 |
| Activity Card Sort | .514 | -.049 | .105 | .006 | .109 | .475 |
| Personal Wellbeing Index | .674 | -2.941 | 7.083 | .008 | .128 | .414 |

Note. FIS= Fatigue Impact Scale.

[a] df = 1; * p< .05.

Table F3: Comparison of Combined and Control Groups on Secondary Outcomes at Post-test

| Outcome Measure | *F* [a] | 95% confidence interval for difference | | ANCOVA Results | | |
|---|---|---|---|---|---|---|
| | | Lower bound | Upper bound | Effect size | Observed power | *p*-value |
| Generalized Self-efficacy Scale | 7.672** | .560 | 3.407 | .080 | .782 | .007 |
| SSI: Overall | .181 | -1.828 | 1.183 | .002 | .071 | .671 |
| SSI: Social Interaction Subscale | 2.698 | -1.028 | .098 | .030 | .369 | .104 |
| SSI: Satisfaction Subscale | .001 | -1.190 | 1.223 | .000 | .050 | .978 |
| DASS: Depression Subscale | .098 | -4.126 | 1.383 | .011 | .165 | .325 |
| DASS: Anxiety Subscale | .040 | -2.042 | 1.667 | .000 | .055 | .841 |
| DASS: Stress Subscale | 1.451 | -4.268 | 1.407 | .016 | .222 | .232 |

Note. SSI = Duke Social Support Index; DASS = Depression, Anxiety and Stress Scale.

[a] df =1; * p < .05, ** p < .01.

Table F4: Comparison of Combined and Control Groups on Secondary Outcomes at Follow-up

| Outcome Measure | *F* [a] | 95% confidence interval for difference | | ANCOVA Results | | |
|---|---|---|---|---|---|---|
| | | Lower bound | Upper bound | Effect size | Observed power | *p*-value |
| Generalized Self-efficacy Scale | 2.209 | -.407 | 2.819 | .024 | .312 | .141 |
| SSI: Overall | 4.332* | .070 | 3.008 | .047 | .539 | .040 |
| SSI: Social Interaction Subscale | .105 | -.677 | .487 | .001 | .062 | .747 |
| SSI: Satisfaction Subscale | 7.175** | .390 | 2.632 | .075 | .755 | .009 |
| DASS: Depression Subscale | 4.331** | -6.664 | -.153 | .047 | .539 | .004 |
| DASS: Anxiety Subscale | .504 | -3.184 | 1.507 | .006 | .504 | .479 |
| DASS: Stress Subscale | 7.430** | -7.094 | -1.112 | .078 | .769 | .008 |

Note. SSI = Duke Social Support Index; DASS = Depression, Anxiety and Stress Scale.

[a] df =1; * p< .05; ** p < 0.01.

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Table F5: Change in Scores of Primary Outcome Measures at Pre-test, Post-test and Follow-up in the Combined Group

| Outcome Measure | Results of Repeated Measures ANOVA | | | | Post-hoc test *p*-value | | |
|---|---|---|---|---|---|---|---|
| | *F* ($df_{k-1}$, $df_{n-2}$) | Effect size | Observed power | *p*-value | Pre-test~ Post-test | Pre-test~ Follow-up | Post-test~ Follow-up |
| FIS : overall score | 23.257 (1.626,99.165)*** | .276 | 1.000 | .000 | .000*** | .000*** | .009** |
| FIS: Physical Subscale [a] | 24.749 (1.728,105.400) *** | .289 | 1.000 | .000 | .000*** | .000*** | .002** |
| FIS: Cognitive Subscale [a] | 12.940 (1.759,107.929)*** | .175 | .000 | .000 | .004** | .000*** | .143 |
| FIS: Psychological Subscale [a] | 23.254 (1.601,97.635)*** | .276 | 1.000 | .000 | .000*** | .000*** | .023* |
| Activity Card Sort | 12.02 (2,122)*** | .165 | .993 | .000 | .001** | .000*** | 1.00 |
| Personal Wellbeing Index | 3.614 (2, 122)* | .056 | .659 | .030 | .259 | .052 | 1.00 |

Note. FIS= Fatigue Impact Scale.

[a] Greenhouse-Geisser Correction as the assumption of sphericity is violated.

*p < .05; **p< 0.01; *** p < 0.001.

Table F6: Change in Scores of Secondary Outcome Measures at Pre-test, Post-test and Follow-up in the Combined Group

| Outcome Measure | Results of Repeated Measures ANOVA | | | | Post-hoc test *p*-value a | | |
|---|---|---|---|---|---|---|---|
| | *F* ($df_{k-1}$, $df_{n-2}$) | Effect size | Observed power | *p*-value | Pre-test~ Post-test | Pre-test~ Follow-up | Post-test~ Follow-up |
| Generalized Self-efficacy Scale | 4.72 (2,122)* | .072 | .781 | .011 | .031* | .003** | 1.00 |
| SSI: Overall | 4.61 (2,122)* | .070 | .771 | .012 | .473 | .363 | .008** |
| SSI : Social Interaction Subscale | 2.059(2,122) | .033 | .417 | .132 | .691 | 1.000 | .106 |
| SSI: Satisfaction Subscale | 4.071(2.122)* | .063 | .714 | .019 | .615 | .325 | .020* |
| DASS: Depression Subscale | 1.11 (2,122) | .018 | .241 | .333 | .652 | .626 | 1.000 |
| DASS: Anxiety Subscale | 1.289 (2,122) | .021 | .275 | .280 | .406 | 1.000 | 1.00 |
| DASS: Stress Subscale | 4.11 (2,122)* | .063 | .719 | .019 | .331 | .026* | .612 |

Note. SSI = Social Support Index; DASS = Depression, Anxiety and Stress Scale.

*p < .05.

# APPENDIX G

# RANDOMISED CONRTOLLED TRIAL (SENSITIVITY TEST)

Table G1: Comparison of Online FSM, Info FSM and Control Groups on Primary Outcomes at Post-test (Sensitivity Test)

| Outcome Measure | ANCOVA Results | | | | Post-hoc Test | | | |
|---|---|---|---|---|---|---|---|---|
| | $F$ [a] | Effect size | Observed power | $p$-value | Comparisons | Confidence interval | | $p$-value |
| FIS: Overall | 1.494 | .052 | .305 | .233 | Online FSM ~ Info FSM | -11.375 | 20.932 | .851 |
| | | | | | Online FSM ~ Control | -21.709 | 9.209 | .691 |
| | | | | | Info FSM ~ Control | -26.869 | 4.812 | .252 |
| FIS: Physical Subscale | .629 | .022 | .150 | .537 | Online FSM ~ Info FSM | -3.287 | 6.010 | .854 |
| | | | | | Online FSM ~ Control | -5.212 | 3.819 | .974 |
| | | | | | Info FSM ~ Control | -6.629 | 2.514 | .615 |
| FIS: Cognitive Subscale | 2.346 | .079 | .455 | .105 | Online FSM ~ Info FSM | -3.675 | 4.869 | .981 |
| | | | | | Online FSM ~ Control | -6.934 | 1.292 | .263 |
| | | | | | Info FSM ~ Control | -7.637 | .801 | .145 |
| FIS: Psychosocial Subscale | 1.609 | .055 | .326 | .209 | Online FSM ~ Info FSM | -4.889 | 11.910 | .668 |
| | | | | | Online FSM ~ Control | -10.394 | 5.545 | .840 |
| | | | | | Info FSM ~ Control | -14.092 | 2.221 | .218 |

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Table G1 continued

| Outcome Measure | ANCOVA Results | | | | Post-hoc Test | | | |
|---|---|---|---|---|---|---|---|---|
| | *F* [a] | Effect size | Observed power | *p*-value | Comparisons | Confidence interval | | *p*-value |
| Activity Card Sort | 1.250 | .043 | .261 | .294 | Online FSM ~ Info FSM | -.187 | .112 | 1.000 |
| | | | | | Online FSM ~ Control | -.093 | .204 | 1.000 |
| | | | | | Info FSM ~ Control | -.053 | .238 | .366 |
| Personal Wellbeing Index | 4.395* | .138 | .735 | .017 | Online FSM ~ Info FSM | -11.500 | 6.654 | 1.000 |
| | | | | | Online FSM ~ Control | -1.155 | 16.224 | .110 |
| | | | | | Info FSM ~ Control | 1.191 | 18.725 | .021* |

Note. FSM = Fatigue Self-management program; FIS= Fatigue Impact Scale.

[a] df =1; *p < .05.

Table G2: Comparison of Online FSM, Info FSM and Control Groups on Primary Outcomes at Follow-up (Sensitivity Test)

| | | ANCOVA Results | | | Post-hoc Test | | | |
|---|---|---|---|---|---|---|---|---|
| Outcome Measure | $F$ [a] | Effect size | Observed power | $p$-value | Comparisons | Confidence interval | | $p$-value |
| FIS: Overall | 1.411 | .049 | .290 | .252 | Online FSM ~ Info FSM | -.105 | .166 | 1.000 |
| | | | | | Online FSM ~ Control | -.187 | .073 | .846 |
| | | | | | Info FSM ~ Control | -.220 | .044 | .321 |
| FIS: Physical Subscale | 2.970 | .097 | .555 | .060 | Online FSM ~ Info FSM | -2.502 | 6.951 | .581 |
| | | | | | Online FSM ~ Control | -6.962 | 2.221 | .505 |
| | | | | | Info FSM ~ Control | -9.243 | .054 | .054 |
| FIS: Cognitive Subscale | 1.959 | .066 | .389 | .151 | Online FSM ~ Info FSM | -5.587 | 4.969 | .999 |
| | | | | | Online FSM ~ Control | -8.769 | 1.393 | .220 |
| | | | | | Info FSM ~ Control | -8.591 | 1.833 | .309 |
| FIS: Psychosocial Subscale | 2.386 | .080 | .462 | .101 | Online FSM ~ Info FSM | -7.599 | 12.833 | .897 |
| | | | | | Online FSM ~ Control | -15.549 | 3.836 | .369 |
| | | | | | Info FSM ~ Control | -18.394 | 1.448 | .115 |

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Table G2 continued

| Outcome Measure | ANCOVA Results | | | | Post-hoc Test | | | |
|---|---|---|---|---|---|---|---|---|
| | *F* [a] | Effect size | Observed power | *p*-value | Comparisons | Confidence interval | | *p*-value |
| Activity Card Sort | .516 | .024 | .157 | .516 | Online FSM ~ Info FSM | -.194 | .070 | .584 |
| | | | | | Online FSM ~ Control | -.158 | .103 | .937 |
| | | | | | Info FSM ~ Control | -.094 | .162 | .887 |
| Personal Wellbeing Index | .305 | .011 | .096 | .738 | Online FSM ~ Info FSM | -7.097 | 10.073 | .964 |
| | | | | | Online FSM ~ Control | -5.614 | 10.823 | .823 |
| | | | | | Info FSM ~ Control | -7.175 | 9.409 | .983 |

Note. FSM = Fatigue Self-management program; FIS= Fatigue Impact Scale.

[a] df =1; *p < .05.

Table G3: Comparison of Online FSM, Info FSM and Control Groups on Primary Outcomes at Post-test (Sensitivity Test)

| Outcome Measure | ANCOVA Results | | | | Post-hoc Test | | | |
|---|---|---|---|---|---|---|---|---|
| | $F$ [a] | Effect size | Observed power | *p*-value | Comparisons | Confidence interval | | *p*-value |
| Generalised Self-efficacy Scale | 7.689* | .215 | .938 | .001 | Online FSM ~ Info FSM | -2.638 | 2.712 | 1.000 |
| | | | | | Online FSM ~ Control | .972 | 6.158 | .004 |
| | | | | | Info FSM ~ Control | .916 | 6.140 | .005 |
| DASS: Depression Subscale | .203 | .007 | .080 | .817 | Online FSM ~ Info FSM | -4.578 | 5.897 | 1.000 |
| | | | | | Online FSM ~ Control | -5.737 | 4.416 | 1.000 |
| | | | | | Info FSM ~ Control | -6.434 | 3.794 | 1.000 |
| DASS: Anxiety Subscale | .166 | .006 | .074 | .848 | Online FSM ~ Info FSM | -3.881 | 2.413 | 1.000 |
| | | | | | Online FSM ~ Control | -3.443 | 2.658 | 1.000 |
| | | | | | Info FSM ~ Control | -2.732 | 3.414 | 1.000 |
| DASS: Stress Subscale | .066 | .002 | .059 | .936 | Online FSM ~ Info FSM | -5.646 | 4.306 | 1.000 |
| | | | | | Online FSM ~ Control | -5.398 | 4.247 | 1.000 |
| | | | | | Info FSM ~ Control | -4.764 | 4.953 | 1.000 |

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Table G3 continued

| Outcome Measure | $F$ [a] | ANCOVA Results | | | Post-hoc Test | | | |
|---|---|---|---|---|---|---|---|---|
| | | Effect size | Observed power | *p*-value | Comparisons | Confidence interval | | *p*-value |
| SSI: Overall | .459 | .016 | .121 | .634 | Online FSM ~ Info FSM | -3.923 | 1.870 | 1.000 |
| | | | | | Online FSM ~ Control | -3.696 | 1.918 | 1.000 |
| | | | | | Info FSM ~ Control | -2.690 | 2.966 | 1.000 |
| SSI: Social Interaction | 1.248 | .043 | .261 | .295 | Online FSM ~ Info FSM | -.799 | 1.261 | 1.000 |
| | | | | | Online FSM ~ Control | -1.402 | .587 | .947 |
| | | | | | Info FSM ~ Control | -1.657 | .379 | .381 |
| SSI: Satisfaction Subscale | .649 | .023 | .154 | .526 | Online FSM ~ Info FSM | -3.487 | 1.287 | .781 |
| | | | | | Online FSM ~ Control | -2.926 | 1.700 | 1.000 |
| | | | | | Info FSM ~ Control | -1.821 | 2.794 | 1.000 |

Note. FSM = Fatigue Self-management program; FIS= Fatigue Impact Scale.

[a] df =1; *p < .05.

Table G4: Comparison of Online FSM, Info FSM and Control Groups on Primary Outcomes at Follow-up (Sensitivity Test)

| Outcome Measure | F [a] | ANCOVA Results | | | Post-hoc Test | | | |
|---|---|---|---|---|---|---|---|---|
| | | Effect size | Observed power | *p*-value | Comparisons | Confidence interval | | *p*-value |
| Generalised Self-efficacy Scale | 2.038 | .068 | .403 | .140 | Online FSM ~ Info FSM | -3.767 | 2.607 | 1.000 |
| | | | | | Online FSM ~ Control | -1.254 | 4.924 | .445 |
| | | | | | Info FSM ~ Control | -.697 | 5.527 | .182 |
| DASS: Depression Subscale | 1.323 | .045 | .274 | .275 | Online FSM ~ Info FSM | -8.028 | 4.969 | 1.000 |
| | | | | | Online FSM ~ Control | -10.391 | 2.206 | .343 |
| | | | | | Info FSM ~ Control | -8.908 | 3.782 | .969 |
| DASS: Anxiety Subscale | .323 | .011 | .099 | .725 | Online FSM ~ Info FSM | -3.619 | 5.412 | 1.000 |
| | | | | | Online FSM ~ Control | -4.907 | 3.846 | 1.000 |
| | | | | | Info FSM ~ Control | -5.836 | 2.982 | 1.000 |
| DASS: Stress Subscale | 2.180 | .072 | .427 | .123 | Online FSM ~ Info FSM | -6.762 | 4.779 | 1.000 |
| | | | | | Online FSM ~ Control | -10.071 | 1.116 | .159 |
| | | | | | Info FSM ~ Control | -9.121 | 2.148 | .397 |

Continued on next page

Table G4 continued

| Outcome Measure | F [a] | ANCOVA Results | | | Post-hoc Test | | | |
|---|---|---|---|---|---|---|---|---|
| | | Effect size | Observed power | *p*-value | Comparisons | Confidence interval | | *p*-value |
| SSI: Overall | 2.091 | .070 | .412 | .133 | Online FSM ~ Info FSM | -3.712 | 1.628 | 1.000 |
| | | | | | Online FSM ~ Control | -1.473 | 3.702 | .877 |
| | | | | | Info FSM ~ Control | -.450 | 4.763 | .138 |
| SSI: Social Interaction | .489 | .017 | .126 | .616 | Online FSM ~ Info FSM | -1.487 | .732 | 1.000 |
| | | | | | Online FSM ~ Control | -1.449 | .694 | 1.000 |
| | | | | | Info FSM ~ Control | -1.097 | 1.097 | 1.000 |
| SSI: Satisfaction Subscale | 3.095 | .100 | .574 | .053 | Online FSM ~ Info FSM | -2.613 | 1.510 | 1.000 |
| | | | | | Online FSM ~ Control | -.614 | 3.381 | .279 |
| | | | | | Info FSM ~ Control | -.058 | 3.928 | .060 |

Note. FSM = Fatigue Self-management program; SSI = Social Support Index; DASS = Depression, Anxiety and Stress Scale.

[a] df =1; *p < .05.

Table G5: Testing Effect of Time on the Primary Outcome Measures in the Participants (Sensitivity Test)

| Outcome Measure | Group | Results of Repeated Measures ANOVA | | | | Post-hoc test [a] | | |
|---|---|---|---|---|---|---|---|---|
| | | F ($df_{k-1}$, $df_{n-2}$) | Effect size | Observed power | *p* -value | Pre-test~ Post-test | Pre-test~ Follow-up | Post-test~ Follow-up |
| FIS: Overall | | | | | | | | |
| | Online FSM | 7.899 (2, 38) | .294 | .938 | .001 | .272 | .002 | .074 |
| | Info FSM | 12.331 (2,38) | .394 | .993 | .000 | .003 | .004 | .584 |
| | Control | 1.146 (2,46) | .047 | .240 | .327 | 1.00 | .611 | 1.00 |
| FIS: Physical Subscale | | | | | | | | |
| | Online FSM | 7.803(2,38)** | .291 | .935 | .001 | .313 | .001 | .155 |
| | Info FSM | 13.782(1.500,28.504)*** | .420 | .997 | .000 | .005 | .002 | .077 |
| | Control | 3.595(2,46)* | .135 | .637 | .035 | .294 | .044 | 1.000 |
| FIS: Cognitive Subscale | | | | | | | | |
| | Online FSM | 7.095(2,38)** | .272 | .910 | .002 | .202 | .007 | .162 |
| | Info FSM | 7.266(2,38)** | .277 | .919 | .002 | .003 | .028 | 1.000 |
| | Control | .704(2,46) | .031 | .121 | .489 | .833 | 1.000 | .960 |
| FIS: Psychological Subscale | | | | | | | | |
| | Online FSM | 520.831(1.507,28.624)** | .255 | .883 | .008 | .383 | .007 | .081 |
| | Info FSM | 1273.726(1.520,28.850)** | .382 | .991 | .001 | .003 | .005 | 1.000 |
| | Control | 45.597(2,46) | .031 | .142 | .489 | .833 | 1.000 | 1.000 |

Continued on next page

Table G5 continued

| Outcome Measure | Group | Results of Repeated Measures ANOVA | | | | Post-hoc test | | |
|---|---|---|---|---|---|---|---|---|
| | | F ($df_{k-1}$, $df_{n-2}$) | Effect size | Observed power | p -value | Pre-test~ Post-test | Pre-test~ Follow-up | Post-test~ Follow-up |
| Activity Participation | | | | | | | | |
| | Online FSM [a] | 3.852(1.507,28.662)* | .169 | .913 | .044 | .094 | .007 | 1.000 |
| | Info FSM | 7.28(2,38)** | .277 | .792 | .002 | .048 | .009 | 1.000 |
| | Control [a] | 4.565(1.386,31.875)* | .166 | .748 | .029 | 1.000 | .053 | .002 |
| Personal Wellbeing Index | | | | | | | | |
| | Online FSM | 2.360(2,38) | .110 | .347 | .108 | .586 | .175 | 1.000 |
| | Info FSM [a] | 1.885(1.405,26.602) | .090 | .707 | .179 | .176 | .189 | 1.000 |
| | Control | 3.820(2,46)* | .142 | .666 | .029 | .320 | .822 | .053 |

Note. FSM = Fatigue Self-management program.

[a] Greenhouse-Geisser Correction as the assumption of sphericity is violated; *p < .05; **p< .01.

Table G6: Testing Effect of Time on the Secondary Outcome Measures Scores on the Participants (Sensitivity Test)

| Outcome Measure | Group | Results of Repeated Measures ANOVA | | | | Post-hoc test [a] | | |
|---|---|---|---|---|---|---|---|---|
| | | F ($df_{k-1}$, $df_{n-2}$) | Effect size | Observed power | *p* - value | Pre-test~ Post-test | Pre-test~ Follow-up | Post-test~ Follow-up |
| Generalised Self-efficacy Scale | | | | | | | | |
| | Online FSM | 2.821(2,38) | .129 | .521 | .072 | .038 | .665 | 1.000 |
| | Info FSM | 4.421(2,38)* | .189 | .727 | .019 | .023 | .059 | 1.000 |
| | Control | .950(2,46) | .040 | .205 | .394 | .606 | 1.000 | .825 |
| SSI: Overall | | | | | | | | |
| | Online FSM | 1.547(2,38) | .075 | .308 | .226 | .734 | 1.000 | .310 |
| | Info FSM | 2.133(2,38) | .101 | .410 | .132 | 1.000 | .092 | .425 |
| | Control | 1.345(2,46) | .055 | .276 | .271 | 1.000 | .634 | .498 |
| SSI: Social Interaction Subscale | | | | | | | | |
| | Online FSM | 1.187(2,30) | .073 | .240 | .319 | 1.000 | .572 | .698 |
| | Info FSM | 1.970(2,38) | .094 | .382 | .154 | .635 | 1.000 | .207 |
| | Control | 1.389(2,38) | .068 | .280 | .264 | 1.000 | .137 | .796 |
| SSI: Satisfaction Subscale | | | | | | | | |
| | Online FSM | .331(2,30) | .022 | .098 | .721 | 1.000 | 1.000 | 1.000 |
| | Info FSM | .142(2,38) | .007 | .070 | .868 | 1.000 | 1.000 | 1.000 |
| | Control | 1.559(2,38) | .076 | .310 | .223 | 1.000 | .528 | .461 |

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Table G6: continued

| Outcome Measure | Group | Results of Repeated Measures ANOVA | | | | Post-hoc test [a] | | |
|---|---|---|---|---|---|---|---|---|
| | | F ($df_{k-1}$, $df_{n-2}$) | Effect size | Observed power | *p* - value | Pre-test~ Post-test | Pre-test~ Follow-up | Post-test~ Follow-up |
| DASS: Depression Subscale | | | | | | | | |
| | Online FSM | .984(2,38) | .049 | .208 | .383 | 1.000 | .614 | 1.000 |
| | Info FSM | .355(2,38) | .018 | .103 | .703 | 1.000 | 1.000 | 1.000 |
| | Control [a] | 1.256(1.495,34.391) | .052 | .225 | .288 | 1.000 | .684 | 1.000 |
| DASS: Anxiety Subscale | | | | | | | | |
| | Online FSM | .666(2,38) | .034 | .154 | .520 | .607 | 1.000 | 1.000 |
| | Info FSM | .614(2,38) | .031 | .145 | .546 | 1.000 | .721 | 1.000 |
| | Control [a] | .277(1.580,36.343) | .012 | .087 | .707 | 1.000 | 1.000 | 1.000 |
| DASS: Stress Subscale | | | | | | | | |
| | Online FSM | 1.307(2,38) | .664 | .265 | .282 | 1.000 | .514 | .806 |
| | Info FSM | .964(2,38) | .048 | .205 | .390 | 1.000 | .336 | 1.000 |
| | Control [a] | 1.228(1.608,36.990) | .051 | .229 | .297 | 1.000 | .567 | .926 |

Note. FSM = Fatigue Self-management program.

[a] Greenhouse-Geisser Correction as the assumption of sphericity is violated; *p < .05.

# APPENDIX H

# PREDICTORS OF IMPROVEMENT

Table H1: Comparison of Participants with and without Positive Outcomes in the Personal Wellbeing Index (Continuous Variables)

| Numeric Variables | | Group Mean (SD) | | *t* | *p*-value |
|---|---|---|---|---|---|
| | | Improved in PWI | Improved in PWI | | |
| Demographic | Age | 52.76 (10.58) | 47.73 (11.66) | 1.99* | .049 |
| | Time Since Diagnosis (year) | 10.92 (11.67) | 6.41 (4.54) | 1.55 | .127 |
| | Fatigue Impact Scale | 5.54 (.80) | 5.70 (.94) | -.83 | .409 |
| Clinical Characteristics | FIS: Overall | 72.56 (33.21) | 79.00 (28.35) | -.87 | .386 |
| | FIS: Physical Subscale | 22.11 (8.14) | 24.23 (7.40) | -1.16 | .251 |
| | FIS: Cognitive Subscale | 17.06 (9.25) | 19.04 (8.76) | -.94 | .351 |
| | FIS: Psychosocial Subscale | 33.71 (17.26) | 36.08 (19.94) | -.61 | .541 |
| | Activity Card Sort | .95 (.24) | .8861 (.16) | 1.22 | .225 |
| | Generalized Self-efficacy Scale | 29.80 (4.34) | 29.04 (4.05) | .78 | .440 |
| | SSI: Overall | 34.74 (4.54) | 33.08 (5.23) | 1.52 | .133 |
| | SSI: Social Interaction Subscale | 8.38 (1.804) | 8.35 (1.77) | .08 | .938 |
| | SSI: Satisfaction Subscale | 26.36 (3.79) | 24.73 (4.27) | 1.79 | .076 |
| | DASS: Depression Subscale | 8.62 (7.80) | 10.96 (10.88) | -1.15 | .252 |
| | DASS: Anxiety Subscale | 6.83 (7.15) | 7.15 (5.87) | -.20 | .840 |
| | DASS: Stress Subscale | 10.83 (7.68) | 12.81 (9.41) | -1.04 | .301 |

Continued on next page

Table H1 continued

| Numeric Variables | | Group Mean (SD) | | *t* | *p*-value |
|---|---|---|---|---|---|
| | | Improved in PWI | Improved in PWI | | |
| Change in Clinical Characteristics | FIS: Overall | -13.48 (21.23) | -28.12 (33.68) | 2.50* | .014 |
| | FIS: Physical Subscale | -4.53 (5.98) | -7.58 (8.98) | 1.90 | .061 |
| | FIS: Cognitive Subscale | -2.79 (6.12) | -7.00 (9.08) | 2.57* | .012 |
| | FIS: Psychosocial Subscale | -6.17 (10.97) | -13.39 (17.26) | 2.39* | .019 |
| | Activity Card Sort | .10 (.25) | .17 (.17) | -1.26 | .212 |
| | Generalized Self-efficacy Scale | -.09 (3.65) | 2.39 (4.22) | -2.81** | .006 |
| | SSI: Overall | -.65 (3.01) | 2.50 (2.98) | -4.53*** | .000 |
| | SSI: Social Interaction Subscale | -.71 (2.35) | 1.92 (2.54) | -4.73*** | .000 |
| | SSI: Satisfaction Subscale | .06 (1.322) | .58 (1.42) | -1.65 | .102 |
| | DASS: Depression Subscale | 1.50 (8.11) | -4.23 (7.46) | 3.12** | .002 |
| | DASS: Anxiety Subscale | -.08 (5.88) | -.96 (4.98) | .68 | .500 |
| | DASS: Stress Subscale | .39 (7.47) | -3.77 (6.72) | 2.47* | .015 |

*p < .05; **p< .01; *** p < .001.

Table H2: Comparison of Participants with and without Positive Outcomes in the Fatigue Impact Scale (Continuous Variables)

| Numeric Variables | | Group Mean (SD) | | *t* | *p*-value |
|---|---|---|---|---|---|
| | | Not improved in FIS | Improved in FIS | | |
| Demographic | Age | 53.19 (10.49) | 49.32 (11.44) | 1.69 | .094 |
| | Time Since Diagnosis (year) | 10.59 (11.55) | 8.94 (9.39) | .65 | .521 |
| | Fatigue Impact Scale | 5.52 (.78) | 5.654 (.91) | -.76 | .452 |
| Clinical Characteristics | Activity Card Sort | .985 (.20) | .871 (.23) | 2.59* | .011 |
| | Personal Wellbeing Index | 66.07 (16.77 | 58.93 (20.04) | 1.86 | .066 |
| | Generalized Self-efficacy Scale | 30.15 (4.13) | 28.98 (4.35) | 1.32 | .189 |
| | SSI: Overall | 35.08 (4.78) | 33.39 (4.66) | 1.72 | .089 |
| | SSI: Social Interaction Subscale | 8.54 (1.83) | 8.18 (1.73) | .97 | .336 |
| | SSI: Satisfaction Subscale | 26.54 (4.05) | 25.20 (3.82) | 1.63 | .108 |
| | DASS: Depression Subscale | 7.56 (7.59) | 11.16 (9.66) | -1.99* | .049 |
| | DASS: Anxiety Subscale | 5.90 (5.18) | 8.05 (8.09) | -1.53 | .129 |
| | DASS: Stress Subscale | 9.71 (7.10) | 13.23 (8.98) | -2.09* | .039 |

Continued on next page

Table H2 continued

| Numeric Variables | | Group Mean (SD) | | *t* | *p*-value |
|---|---|---|---|---|---|
| | | Not improved in FIS | Improved in FIS | | |
| Change in Clinical Characteristics | Activity Card Sort | .05 (.16) | .19 (.28) | -2.89* | .005 |
| | Personal Wellbeing Index | -.63 (9.83) | 6.69 (12.21) | -3.18** | .002 |
| | Generalized Self-efficacy Scale | -.98 (3.87) | 2.34 (3.28) | -4.41*** | .000 |
| | SSI: Overall | -.54 (3.14) | 1.09 (3.31) | -2.43* | .017 |
| | SSI: Social Interaction Subscale | -.77 (2.42) | .91 (2.69) | -3.15* | .002 |
| | SSI: Satisfaction Subscale | .23 (1.40) | .18 (1.33) | .17 | .869 |
| | DASS: Depression Subscale | 1.96 (6.96) | -2.39 (9.11) | 2.58* | .011 |
| | DASS: Anxiety Subscale | 1.31 (6.22) | -2.12 (4.30) | 3.05** | .003 |
| | DASS: Stress Subscale | 1.71 (7.62) | 3.50 (6.35) | 3.55** | .001 |

*p < .05; **p< .01; *** p < .001.

Table H3: Comparison of Participants with and without Positive Outcomes in the Activity Card Sort (Continuous Variables)

| Numeric Variables | | Group Mean (SD) | | *t* | *p*-value |
|---|---|---|---|---|---|
| | | Not improved in ACS | Improved in ACS | | |
| Demographic | Age | 52.00 (10.64) | 50.31 (11.78) | .18 | .477 |
| | Time Since Diagnosis (year) | 10.67 (12.79) | 8.46 (5.45) | .85 | .400 |
| | Fatigue Impact Scale | 5.57 (.90) | 5.61 (.76) | -.19 | .853 |
| Clinical Characteristics | FIS: Overall | 65.82 (31.09) | 87.69 (28.75) | -3.39** | .001 |
| | FIS: physical Subscale | 20.84 (7.92) | 25.61 (7.19) | -2.92** | .004 |
| | FIS: Cognitive Subscale | 15.45 (9.00) | 21.00 (8.31) | -2.97** | .004 |
| | FIS: Psychosocial Subscale | 29.95 (16.15) | 41.28 (15.01) | -3.38** | .001 |
| | Personal Wellbeing Index | 66.43 (17.35) | 56.79 (19.32) | 2.49* | .015 |
| | Generalized Self-efficacy Scale | 30.55 (4.24) | 28.08 (3.86) | 2.82** | .006 |
| | SSI: Overall | 34.82 (5.15) | 33.42 (4.04) | 1.38 | .170 |
| | SSI: Social Interaction Subscale | 8.18 (2.00) | 8.67 (1.35) | -1.29 | .202 |
| | SSI: Satisfaction Subscale | 26.64 (4.15) | 24.75 (3.43) | 2.28* | .025 |
| | DASS: Depression Subscale | 7.50 (7.08) | 12.06 (10.43) | -2.50* | .014 |
| | DASS: Anxiety Subscale | 5.79 (5.58) | 8.69 (8.08) | -2.04* | .044 |
| | DASS: Stress Subscale | 9.63 (6.76) | 14.14 (9.51) | -2.66** | .009 |

Continued on next page

Table H3 continued

| Numeric Variables | | Group Mean (SD) | | *t* | *p*-value |
|---|---|---|---|---|---|
| | | Not improved in ACS | Improved in ACS | | |
| Change in Clinical Characteristics | FIS: Overall | -11.66 (21.05) | 26.89 (30.33) | 2.84** | .006 |
| | FIS: Physical Subscale | -4.23 (5.83) | -7.19 (8.37) | 2.00* | .049 |
| | FIS: Cognitive Subscale | -2.55 (6.43) | -6.20 (8.03) | 2.40* | .018 |
| | FIS: Psychosocial Subscale | -4.93 (10.79) | -13.31 (15.40) | 3.07** | .003 |
| | Personal Wellbeing Index | .56 (11.17) | 6.47 (11.41) | -2.46* | .016 |
| | Generalized Self-efficacy Scale | -.23 (3.42) | 1.92 (4.40) | 2.63* | .010 |
| | SSI: Overall | .05 (3.30) | .53 (3.35) | -.67 | .505 |
| | SSI: Social Interaction Subscale | -.16 (2.59) | .33 (2.81) | -.86 | .390 |
| | SSI: Satisfaction Subscale | .21 (1.45) | .19 (1.24) | .07 | .946 |
| | DASS: Depression Subscale | 1.00 (7.33) | -1.86 (9.48) | 1.63 | .107 |
| | DASS: Anxiety Subscale | -.04 (5.13) | -.78 (6.37) | .62 | .540 |
| | DASS: Stress Subscale | .23 (7.13) | -2.36 (7.82) | 1.64 | .105 |

Note. ACS = Activity Card Sort; FIS= Fatigue Impact Scale; SSI = Social Support Index; DASS = Depression, Anxiety and Stress Scale.

*p < .05; **p< .01; *** p < .001.

Table H4: Comparison of Participants With and Without Positive Outcomes in the Combined Outcome Index (Continuous Variables)

| Variables | | Group Mean (SD) | | *t* | *p*-value |
|---|---|---|---|---|---|
| | | Not improved in COI | Improved in COI | | |
| Demographic | Age | 52.45 (10.82) | 49.25 (11.41) | 1.33 | .188 |
| | Time Since Diagnosis (year) | 10.76 (12.26) | 7.89 (5.46) | 1.07 | .289 |
| | Fatigue Impact Scale | 5.52 (.83) | 5.700 (.87) | -.94 | .349 |
| Clinical Characteristics | Generalized Self-efficacy Scale | 30.53 (4.07) | 27.81 (4.08) | 3.056** | .003 |
| | SSI: Overall | 35.17 (4.91) | 32.59 (4.07) | 2.53* | .013 |
| | SSI: Social Interaction Subscale | 8.42 (1.92) | 8.28 (1.53) | .35 | .731 |
| | SSI: Satisfaction Subscale | 26.75 (3.99) | 24.31 (3.50) | 2.91** | .005 |
| | DASS: Depression Subscale | 7.55 (7.19) | 12.53 (10.55) | -2.68** | .009 |
| | DASS: Anxiety Subscale | 5.87 (5.51) | 8.91 (8.42) | -2.09* | .040 |
| | DASS: Stress Subscale | 10.07 (6.97) | 13.88 (9.76) | -2.16* | .033 |

Continued on next page

Table H4 continued

| Variables | | Group Mean (SD) | | *t* | *p*-value |
|---|---|---|---|---|---|
| | | Not improved in COI | Improved in COI | | |
| Change in clinical characteristics | Generalized Self-efficacy Scale | -.73 (3.60) | 3.13 (3.34) | -5.02*** | .000 |
| | SSI: Overall | -.22 (3.20) | 1.09 (3.39) | -1.83 | .070 |
| | SSI: Social Interaction Subscale | -.52 (2.45) | 1.06 (2.81) | -2.80** | .006 |
| | SSI: Satisfaction Subscale | .30 (1.43) | .03 (1.23) | .90 | .371 |
| | DASS: Depression Subscale | 1.43 (6.91) | -3.03 (9.90) | 2.53* | .013 |
| | DASS: Anxiety Subscale | .55 (5.39) | -1.97 (5.79) | 2.08* | .040 |
| | DASS: Stress Subscale | .70 (7.12) | -3.56 (7.43) | 2.69** | .008 |

Note. COI = Combined Outcome Index; FIS= Fatigue Impact Scale; SSI = Social Support Index; DASS = Depression, Anxiety and Stress Scale.

*p < .05; **p< .01; *** p < .001.

Table H5: Comparison of Participants With and Without Positive Outcomes on the Personal Wellbeing Index and Fatigue Impact Scale (Categorical Variables)

| Variables | Personal Wellbeing Index | | | Fatigue Impact Scale | | |
|---|---|---|---|---|---|---|
| | Not Improved Group | Improved Group | *p*-value | Not Improved Group | Improved Group | *p*-value |
| Gender | | | | | | |
| Male | 13 (19.7) | 4 (15.4) | .770 | 8 (16.7) | 9 (20.5) | .789 |
| Female | 53 (80.3) | 22 (84.6) | | 40 (83.3) | 35 (79.5) | |
| Gross Income/week | | | | | | |
| Less than $599 | 22 (34.9) | 6 (25.0) | .369 | 15 (32.6) | 13 (31.7) | .969 |
| Between $600 and $1999 | 31 (49.2) | 13 (54.2) | | 23 (50.0) | 21 (51.2) | |
| More than $2000 | 10 (15.9) | 5 (20.8) | | 8 (17.4) | 7 (17.1) | |
| Highest Education Level | | | | | | |
| Secondary school or less | 12 (21.4) | 5 (23.8) | .361 | 11 (25.6) | 6 (17.6) | .583 |
| Tertiary qualification | 33 (58.9) | 8 (38.1) | | 21 (48.8) | 20 (58.8) | |
| Vocational qualification | 11 (19.6) | 8 (38.1) | | 11 (25.6) | 8 (23.5) | |

Continued on next page

Table H5 continued

| Variables | Personal Wellbeing Index | | | Fatigue Impact Scale | | |
|---|---|---|---|---|---|---|
| | Not Improved Group | Improved Group | *p*-value | Not Improved Group | Improved Group | *p*-value |
| Type of Intervention | | | | | | |
| Face-to-face FSM | 15 (22.7) | 2 (7.7) | .921 | 10 (20.8) | 7 (15.9) | .653 |
| Online FSM | 14 (21.2) | 13 (50.0) | | 13 (27.1) | 14 (31.8) | |
| Info FSM | 20 (30.3) | 4 (15.4) | | 9 (18.8) | 15 (34.1) | |
| Control | 17 (25.8) | 7 (26.9) | | 16 (33.3) | 8 (18.2) | |
| Diagnosis | | | | | | |
| Multiple Sclerosis | 42 (77.8) | 13 (68.4) | .537 | 29 (76.3) | 26 (74.3) | 1.000 |
| Post-polio Syndrome or Parkinson Disease | 12 (22.2) | 6 (31.6) | | 9 (23.7) | 9 (25.7) | |
| Employment | | | | | | |
| Employed | 21 (31.8) | 7 (73.1) | .802 | 15 (31.3) | 13 (29.5) | .860 |
| Unemployed | 45 (68.2) | 19 (73.1) | | 33 (68.8) | 31 (70.5) | |

Note. FSM = Fatigue Self-management program.

Table H6: Comparison of Participants With and Without Positive Outcomes on the Activity Card Sort and Combined Outcome Index (Categorical Variables)

| Variables | Activity Card Sort | | | Combined Outcome Index | | |
|---|---|---|---|---|---|---|
| | Not Improved Group | Improved Group | *p*-value | Not Improved Group | Improved Group | *p*-value |
| Gender | | | | | | |
| Male | 9 (16.1) | 8 (22.2) | .583 | 11 (18.3) | 6 (18.8) | 1.000 |
| Female | 47 (83.9) | 28 (77.8) | | 49 (81.7) | 26 (81.3) | |
| Gross Income/week | | | | | | |
| Less than $599 | 16 (30.2) | 12 (35.3) | .353 | 19 (32.8) | 9 (31.0) | .583 |
| Between $600 and $1999 | 26 (49.1) | 18 (52.9) | | 27 (46.6) | 17 (58.6) | |
| More than $2000 | 11 (20.8) | 4 (11.8) | | 12 (20.7) | 3 (10.3) | |
| Highest Education Level | | | | | | |
| Secondary school or less | 7 (14.0) | 10 (37.0) | .348 | 10 (18.2) | 7 (31.8) | .875 |
| Tertiary qualification | 32 (64.0) | 9 (33.3) | | 34 (61.8) | 7 (31.8) | |
| Vocational qualification | 11 (22.0) | 8 (29.6) | | 11 (20.0) | 8 (36.4) | |

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Table H6 continued

| Variables | Activity Card Sort | | | Combined Outcome Index | | |
|---|---|---|---|---|---|---|
| | Not Improved Group | Improved Group | *p*-value | Not Improved Group | Improved Group | *p*-value |
| Type of Intervention | | | | | | |
| Face-to-face FSM | 9 (16.1) | 8 (22.2) | .615 | 12 (20.0) | 5 (15.6) | .979 |
| Online FSM | 18 (32.1) | 9 (25.0) | | 16 (26.7) | 11 (34.4) | |
| Info FSM | 13 (23.2) | 11 (30.6) | | 16 (26.7) | 8 (25.0) | |
| Control | 16 (28.6) | 8 (22.2) | | 16 (26.7) | 8 (25.0) | |
| Diagnosis | | | | | | |
| Multiple Sclerosis | 32 (72.7) | 23 (79.3) | .589 | 38 (79.2) | 17 (68.0) | .392 |
| Post-polio Syndrome or Parkinson Disease | 12 (27.3) | 18 (24.7) | | 10 (20.8) | 8 (32.0) | |
| Employment | | | | | | |
| Employed | 20 (35.7) | 8 (22.2) | .246 | 20 (33.3) | 8 (25.0) | .481 |
| Unemployed | 36 (64.3) | 28 (77.8) | | 40 (66.7) | 24 (75.0) | |

Note. FSM = Fatigue Self-management program.

Table H7: Comparison of Less Active Participants With and Without Positive Outcomes on the Fatigue Impact Scale (Numerical Variables)

| Variables | | Group Mean (SD) | | *t* | *p*-value |
|---|---|---|---|---|---|
| | | Not improved in FIS | Improved in FIS | | |
| Demographic | Age | 54.45 (8.43) | 49.74 (14.03) | 1.36 | .18 |
| | Time Since Diagnosis (year) | 9.53 (7.42) | 10.71 (12.30) | -.34 | .74 |
| | Fatigue Impact Scale | 5.68 (.74) | 5.78 (.90) | -.41 | .68 |
| Clinical Characteristics | Generalized Self-efficacy Scale | 29.18 (3.92) | 26.83 (3.86) | 2.03 | .048* |
| | SSI: Overall | 32.86 (3.69) | 31.30 (3.96) | 1.36 | .180 |
| | SSI: Social Interaction Subscale | 8.36 (1.62) | 7.57 (1.50) | 1.72 | .093 |
| | SSI: Satisfaction Subscale | 24.50 (3.11) | 23.74 (3.58) | .76 | .452 |
| | DASS: Depression Subscale | 10.91 (8.52) | 13.74 (11.20) | -.95 | .347 |
| | DASS: Anxiety Subscale | 8.32 (5.66) | 11.04 (9.27) | -1.18 | .243 |
| | DASS: Stress Subscale | 12.82 (7.55) | 16.48 (10.45) | -1.34 | .187 |
| Change in clinical Characteristics | Generalized Self-efficacy Scale | -.95 (3.99) | 3.17 (3.73) | -3.59 | .001** |
| | SSI: Overall | -1.64 (2.89) | 1.22 (3.30) | -3.08 | .004** |
| | SSI: Social Interaction Subscale | -1.46 (2.40) | .96 (2.72) | -1.18 | .243 |
| | SSI: Satisfaction Subscale | -.19 (1.18) | .26 (1.32) | -3.14 | .003** |
| | DASS: Depression Subscale | 2.91 (8.01) | -1.87 (10.95) | 1.67 | .103 |
| | DASS: Anxiety Subscale | 2.50 (7.74) | -2.17 (5.07) | 2.41 | .020* |
| | DASS: Stress Subscale | 1.91 (8.29) | -4.49 (7.11) | 2.74 | .009** |

Note. FIS= Fatigue Impact Scale; SSI = Social Support Index; DASS = Depression, Anxiety and Stress Scale.

*p < .05; **p< .01; *** p < .001.

Table H8: Comparison of Less Active Participants With and Without Positive Outcomes on the Fatigue Impact Scale (Numerical Variables)

| Variables | | Group Mean (SD) | | *t* | *p*-value |
|---|---|---|---|---|---|
| | | Not improved in FIS | Improved in FIS | | |
| Demographic | Age | 52.12 (12.02) | 48.86 (8.05) | 1.06 | .293 |
| | Time Since Diagnosis (year) | 11.60 (14.58) | 7.27 (5.33) | 1.15 | .258 |
| | Fatigue Impact Scale | 5.39 (.81) | 5.52 (.92) | -.51 | .610 |
| Clinical Characteristics | Generalized Self-efficacy Scale | 30.96 (4.19) | 31.33 (3.62) | -.32 | .750 |
| | SSI: Overall | 36.96 (4.85) | 35.67 (4.36) | .95 | .346 |
| | SSI: Social Interaction Subscale | 8.69 (2.02) | 8.86 (1.74) | -.30 | .769 |
| | SSI: Satisfaction Subscale | 28.27 (4.00) | 26.81 (3.47) | 1.32 | .194 |
| | DASS: Depression Subscale | 4.73 (5.40) | 8.33 (6.83) | -2.02 | .049 |
| | DASS: Anxiety Subscale | 4.56 (4.86) | 4.76 (4.95) | -.72 | .474 |
| | DASS: Stress Subscale | 7.08 (5.59) | 9.67 (5.27) | -1.6 | .112 |
| Change in clinical Characteristics | Generalized Self-efficacy Scale | -1.00 (3.85) | 1.43 (22.50) | -2.50 | .016* |
| | SSI: Overall | .38 (3.10) | .65 (3.40) | -.60 | .553 |
| | SSI: Social Interaction Subscale | -1.95 (2.32) | .86 (2.73) | -1.43 | .160 |
| | SSI: Satisfaction Subscale | .58 (1.50) | .10 (1.37) | 1.14 | .262 |
| | DASS: Depression Subscale | 1.15 (5.97) | -2.95 (6.78) | 2.21 | .032* |
| | DASS: Anxiety Subscale | .31 (4.48) | -2.05 (3.40) | 1.99 | .053 |
| | DASS: Stress Subscale | 1.54 (7.16) | -2.52 (5.38) | 2.15 | .037* |

Note. FIS= Fatigue Impact Scale; SSI = Social Support Index; DASS = Depression, Anxiety and Stress Scale.

*p < .05; **p< .01; *** p < .001.

Table H9: Comparison of Participants With and Without Positive Outcomes on the Fatigue Impact Scale (Categorical Variables)

| Variable | Less active group | | | More active group | | |
|---|---|---|---|---|---|---|
| | Not Improved | Improved | *p*-value | Not Improved | Improved | *p*-value |
| Gender | | | | | | |
| Male | 4 (18.32) | 4 (17.4) | 1.00 | 4 (15.4) | 5 (23.8) | .486 |
| Female | 18 (81.6) | 19 (82.6) | | 22 (84.6) | 16 (76.2) | |
| Gross Income/week | | | | | | |
| Less than $599 | 9 (40.9) | 7 (35.0) | .728 | 6 (25) | 6 (28.6) | .964 |
| Between $600 and $1999 | 11 (50.0) | 11 (55.0) | | 12 (50) | 10 (47.6) | |
| More than $2000 | 2 (9.1) | 2 (10.0) | | 6 (25) | 5 (23.8) | |
| Highest Education Level | | | | | | |
| Secondary school or less | 7 (35.0) | 3 (30.0) | .501 | 4 (17.4) | 3 (17.6) | .750 |
| Tertiary qualification | 6 (30.0) | 8 (47.1) | | 15 (65.2) | 12 (70.6) | |
| Vocational qualification | 7 (35.0) | 6 (35.3) | | 4 (17.4) | 2 (11.8) | |
| Type of Intervention | | | | | | |
| Face-to-face FSM | 5 (22.7) | 3 (13.0) | .823 | 5 (19.2) | 4 (19.0) | .711 |
| Online FSM | 5 (22.7) | 9 (39.1) | | 8 (30.8) | 5 (23.8) | |
| Info FSM | 6 (27.3) | 7 (30.4) | | 3 (11.5) | 8 (38.1) | |
| Control | 6 (27.3) | 4 (17.4) | | (38.5) | 4 (19.0) | |
| Diagnosis | | | | | | |
| Multiple Sclerosis | 16 (72.7) | 17 (73.9) | 1.00 | 20 (76.9) | 17 (81.0) | 1.00 |
| Post-polio Syndrome or Parkinson Disease | 6 (27.3) | 6 (26.1) | | 6 (23.1) | 4 (19.0) | |
| Employment | | | | | | |
| Employed | 5 (22.7) | 3 (13.0) | .459 | 10 (38.5) | 10 (47.6) | .566 |
| Unemployed | 17 (77.3) | 20 (87.0) | | 16 (61.5) | 11 (52.4) | |

Note. FSM = Fatigue Self-management program.

*p < .05; **p< .01; *** p < .001.

# APPENDIX I

# LIST OF PUBLICATIONS

**Paper Presentations:**

Ghahari, S. (2007). Development and Standardization of an Online Fatigue Self-management Group Intervention. In *Mark Liveris Health Sciences Research Student Seminar*. Perth, Western Australia.

Ghahari, S. (2007). Update on Fatigue Management Research. In *MS Awareness Week health Professional Seminar*. Perth , Western Australia.

Ghahari, S., & Packer, T. (2007). Therapy Online: Fatigue Self-management Program for People with Neurological Conditions. In *Talk it up symposium*. Bunbury, Western Australia.

Ghahari, S., & Packer, T. (2008). Online Fatigue Self-management: A Randomised Controlled Trial. In *International Congress on Chronic Disease Self-management.* Melbourne, Australia.

Ghahari, S., & Packer, T. L. (2008). A Randomized Controlled Trial of an Online Fatigue Self-management Program for People with Neurological Conditions. In *State Occupational Therapy Conference* Perth, Western Australia.

Ghahari, S., & Wallace, S. (2008). Fatigue self-management: Face-to-face and online Programs in clinical practice. In *2nd Pan Asian MS Nurses Forum* Perth.

**Poster Presentation:**

Ghahari, S., & Packer, T. (2007). Development and Standardization of an Online Fatigue Self-management Group Intervention. In *4th Asia Pacific Occupational Therapy Congress* Hong Kong.

**Journal Article:**

Ghahari, S., Packer, T., & Passmore, A. (in press). Development, standardisation and pilot testing of an online fatigue self-management program. *Disability and Rehabilitation,* 00(0), 1-11.