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The Relationship between Frequency and Satisfaction of Leisure Participation and Health-Related Quality of Life in Women with Fatigue Secondary to Chronic Illness

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This thesis is presented for the Degree of
Doctor of Philosophy
of
Curtin University of Technology

December 2006

ABSTRACT

Fatigue secondary to chronic illness (FSCI) is a common experience in individuals with chronic conditions, with fatigue impacting on performance of daily activities and health-related quality of life (HRQoL). Due to the higher prevalence of FSCI in women, they may experience even greater disruption to roles and activity engagement. The literature consistently points to three main aspects when defining fatigue regardless of diagnoses; a physical aspect, a psychological aspect, and the impact on activity and participation. Research into the first two aspects has demonstrated relationships between fatigue, pain, depression, and social support. However, examination of the third aspect has been largely overlooked with respect its relationship to, and impact on, fatigue.

Leisure theorists have hypothesized that engagement in leisure activities makes a positive contribution to physical and mental health. Previous research has measured leisure activities based on frequency of, or satisfaction with, participation. While some research has shown that physical and social activities have positive health benefits, gaps still exist in understanding the relative contribution of different types of leisure participation to fatigue and HRQoL. For example, little research has examined the contributions of leisure participation and leisure satisfaction to HRQoL and fatigue in women with chronic conditions. One explanation for the lack of research may be the absence of measurement tools developed to classify and quantify participation in different types of leisure activities for women with FSCI. Without a measurement tool, the relative contribution of participation in different activities (by frequency and/or satisfaction) to fatigue and HRQoL cannot be examined.

This PhD research aimed to fill the current gaps in understanding different types of leisure participation in related to fatigue and HRQoL. It sought to address two component parts: development and testing of the Classification of Leisure Participation (CLP) Scale; and an examination of the contribution of leisure participation to fatigue and HRQoL in women with FSCI.

Part 1

To develop the preliminary CLP Scale, a process of item generation was undertaken by the researcher. Sixty-one leisure and social activity items were identified from previous studies. This was followed by item reduction and determination of domains. Using a telephone survey, female participants without chronic conditions (N = 102) in the age range of 25 to 64 years were recruited and asked to indicate whether each item represented mostly physical, social, educational/creative, or passive leisure. After data collection, the generated items were reduced based on 60% agreement among participants. Domains were determined using cluster analysis. The four clusters identified were physical (5 items), social (12 items), educational/creative (6 items), and passive (6 items). To verify these results as accurate for participants with chronic conditions, two small studies were conducted (validation study 1 and 2), post development of the scale.

Validation study 1 compared domains between women with and without chronic conditions. Female participants, ranging from 25 to 64 years of age, and diagnosed with either rheumatoid arthritis, multiple sclerosis, chronic fatigue syndrome, or post polio syndrome were recruited. Using the same methods for item reduction and determination of domains as used for cluster analysis, a dendrogram for participants with chronic conditions (N = 24) was undertaken. It consisted of physical (14 items), social (18 items), and passive (9 items). The dendrogram for participants without chronic conditions (N = 102) were used in order to establish a comparison. It became evident that activities were perceived differently by the two groups. Therefore, a CLP Scale specific to participants with chronic conditions was required.

Validation study 2 compared phone and postal administrations for participants with chronic conditions (N = 24). Kappa statistics indicated only poor to fair agreement between the two data collection approaches. This resulted in the researcher selecting only one method of administration (postal) for the main study. Due to the small initial sample size, a final development of the CLP Scale (item reduction, determination of domains and a scoring method) was undertaken with a larger sample population. Physical (16 items), social (14 items), and passive (8 items) domains were identified in participants with chronic conditions (N = 102) using a reply-paid postal survey.

Psychometric properties of the CLP Scale for women with chronic conditions were evaluated. Face validity was based on the literature, item generation from existing research, and participation of women with chronic conditions. Moderate internal consistency reliability (Cronbach's Alpha = 0.74) was found in the overall scale. Construct validity (hypothesis testing method) found correlations between physical/social leisure and some subscales of the Short Form-36® Health Survey (SF-36®) at $p < 0.05$. Study results indicate the CLP Scale provides a mechanism by which to further investigate the impact of leisure participation on physical and mental health in women with chronic illness.

Part 2

A cross-sectional design using a mailed survey was employed. Women with chronic conditions voluntarily completed a demographic questionnaire and seven known questionnaires: the Numeric Rating Scale (NRS), the Depression Anxiety and Stress Scale (DASS 21), the Duke Social Support Index (DSSI), the Fatigue Impact Scale (FIS), the Medical Outcome Study Short Form (SF-36®), the Leisure Satisfaction Survey (LSS), and the Classification of Leisure Participation (CLP) Scale. Pearson's correlations showed positive relationships between leisure variables and HRQoL, and negative relationships between leisure variables and fatigue. The higher the level of fatigue the poorer the HRQoL, the more pain and depression, less social support has reported. These findings were consistent with other published research conducted with people with chronic conditions.

To extend these correlations, stepwise multiple regression indicated that engagement in physical activities and leisure satisfaction made a significant contribution to the prediction of physical and mental HRQoL respectively. Physical and mental HRQoL were significant contributors to the prediction of perceived level of fatigue. Depression was found to be a unique contributor to respondents' level of physical and mental health in addition to the psychosocial impact of fatigue. Social support, on the other hand, was found to be a contributor only to the cognitive and psychosocial impacts of fatigue. In conclusion, strong results found that none of the leisure variables contributed to the prediction of fatigue but frequency of participation in physical leisure activities and leisure satisfaction was predictive of HRQoL in women with FSCI. Importantly, the study provides women with FSCI,

their families and service providers with information about the valued role of leisure participation with respect to living with chronic conditions. This is of particular significance because the type and range of leisure activities may be easier to change in the short to medium term than one's perception of levels of fatigue. Therefore, leisure participation provides a suitable medium for intervention.

ACKNOWLEDGEMENTS

I wish to thank the following people and organisations for their support throughout my studies, without their kind assistance I would not have been able to complete this PhD thesis. I would, therefore, like to thank:

- Professor Tanya Packer, my supervisor, for developing my academic and research skills, and for correcting all research documents in this study.
- Associate Professor Anne Passmore, my co-supervisor, for sharing knowledge and providing guidance throughout this study.
- The Government of Thailand for the financial assistance their scholarship provided me, and the Multiple Sclerosis Society, for the financial assistance they provided via their Multiple Sclerosis Society Nursing and Allied Health Research Student Scholarship.
- The generous assistance of David Packer, who worked enthusiastically with me to improve my writing and presentation skills, and assisted me to edit many of the drafts produced in the preparation of this thesis.
- Dr. Maureen Massam, for encouraging and developing my writing skills during the preparation of my research proposal.
- Satvinder S. Dhaliwal, who assisted me with matters surrounding the data analysis required for this study; his guidance helped me to choose suitable research methods and statistical analysis for this study.
- Diane Howell and Gavino Achenza, for a final proof-reading of this thesis.
- Patterson Market Research, who conducted the telephone interviews required to generate the data for this study.

- Curtin FM 100.1, The National Industry Association for Disability Services, and People with Disabilities (WA) Inc., who kindly advertised this study, assisting me to recruit the required number of research participants.

- The Australian Neuromuscular Research Institute Ltd., Multiple Sclerosis Society of WA (Inc), Arthritis Foundation of WA, The ME/Chronic Fatigue Syndrome Society of WA (Inc), Post Polio Network of WA (Inc), and Centre for Research into Disability and Society, all of whom assisted in the coordination and administration necessary to work with the recruits in this study.

- Many thanks to those kind women with and without chronic conditions, who generously agreed to participate in this study. Thank you for your patience and your willingness to share so freely your time and your thoughts.

- Lastly, I would like to thank my beloved parents, younger brother and best friends for their encouragement and support.

DECLARATION

This thesis contains no material which has been accepted for the award of any other degree or diploma in any university.

To the best of my knowledge and belief this thesis contains no material previously published by any other person except where due acknowledgment has been made.

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Date: 15 December 2006

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LIST OF OPERATIONAL DEFINITIONS

The following section outlines the operational context of terms used in this thesis.

Health-related quality of life: "an individual's own assessment of how health and health-related treatments affect his or her performance of customary or desired roles and activities."

(Dilorenzo, Halper, & Picone, 2003, p. 891)

Leisure: "free or un-obligated time during which one is not working or performing other life-sustaining functions."

(Leitner & Leither, 2004, p. 3)

Participation: "involvement in a life situation."

(World Health Organization, 2001, p. 14)

Fatigue Secondary to chronic illness: "the awareness of a decreased capacity for physical and/or mental activity due to an imbalance in the availability, utilization and/or restoration of resources needed to perform activity."

(Aaronson et al., 1999, p. 46)

LIST OF ABBREVIATIONS AND ACRONYMS

AAP	Adelaide Activity Profile
ABS	Australian Bureau of Statistics
ACS	Activity Card Sort
ADL	Activities of Daily Living
ANCOVA	Analyses of Covariance
ASMP	Arthritis Self-Management Program
BDI	Beck Depression Inventory
CATI	Computer Assisted Telephone Interviewing
CBT	Cognitive Behavioural Therapy
CDSMP	the generic Chronic Self-Management Program
CES-D	Center of Epidemiological Studies Depression Scale
CFS	Chronic Fatigue Syndrome
CIS	Checklist Individual Strength
CLP	Classification of Leisure Participation
CMDI	Chicago Multiscale Depression Inventory
DASS	Depression Anxiety and Stress Scale
DSSI	Duke Social Support Index
EAS	Education and Support
EDSS	Expanded Disability Status Scale
FIS	Fatigue Impact Scale
FRS	Fatigue Rating Scale
FSCI	Fatigue Secondary to Chronic Illness
FSS	Fatigue Severity Scale
HAD	Hospital Anxiety and Depression Scale
HAP	Human Activity Profile
HRQoL	Health-Related Quality of Life
ICF	International Classification of Functioning, Disability and Health
LAM	Leisure Attitude Measure
Late Life FDI	Late Life Function and Disability Instrument
LDB	Leisure Diagnostic Battery
LIM	Leisure Interest Measure
LMS	Leisure Motivation Scale

LQA	Leisure Questionnaire for Adolescents
LSM	Leisure Satisfaction Measure
LSS	Leisure Satisfaction Scale
NGO	Non-Government Organization
MAF	Multidimensional Assessment of Fatigue
MET	Metabolic Equivalents
MFI	Multidimensional Fatigue Inventory
MOS	Medical Outcome Study
MS	Multiple Sclerosis
MSQOL	Multiple Sclerosis Quality of Life Instrument
MSPSS	Multidimensional Scale of Perceived Social Support
NPHS	National Population Health Survey
NRS	Numeric Rating Scale
PAL-E	Paragraphs About Leisure Form E
PASS	Power Analysis and Sample Size
POMS	Profile of Mood States
PPS	Post-Polio Syndrome
QoL	Quality of Life
RA	Rheumatoid Arthritis
RAS	Recreative Activity Schedule
RCT	Randomised Controlled Trial
SD	Standard Deviation
SDSA	Stroke Drivers Screening Assessment
SDT	Self-Determination Theory
SEG	Supportive-Expressive Group Therapy
SEM	Structural Equation Modeling
SF-12®	Short Form-12® Health Survey
SF-36®	Short Form-36® Health Survey
SF-36® PCS	SF-36® Physical Component Summary
SF-36® MCS	SF-36® Mental Component Summary
SIP	Sickness Impact Profile
SMART	Self-Management Arthritis Relief Therapy
SMC	Standard Medical Care
SPSS	Statistical Package for the Social Sciences

SWLS	Satisfaction with Life Scale
TEA	Lottery Form Test of Everyday Attention
TIFS	Task Induced Fatigue Scale
VAS	Visual Analogue Scale
VO_2 max	Maximal aerobic capacity
WHO	World Health Organization

CHAPTER 1

INTRODUCTION

1.1 BACKGROUND TO THE PROBLEM

Chronic conditions have been defined as diseases which have the following characteristics: they are permanent, leave residual disability, are caused by nonreversible pathological alteration, require special training of the patient for rehabilitation, or may be expected to require a long period of supervision, observation, or care (World Health Organization, 2006). The World Health Organization (WHO) estimates that 41 million people will die from chronic conditions in the year 2015. Around 80% of deaths will occur in low and middle income countries, while 20% will occur in high income countries including Australia. The burden of chronic conditions creates economic problems to families, communities and societies. Thus, it is important to overcome the high impact of chronic conditions by using accurate information, scientific knowledge, and effective interventions (World Health Organization, 2005).

Fatigue is the most poorly managed symptom for people with many chronic conditions for which there are few pharmacological solutions. The prevalence of fatigue across chronic conditions or fatigue secondary to chronic illness (FSCI) has been shown to be higher in women than men (Sharpe & Wilks, 2002; Tiesinga et al., 1999). FSCI can have a negative impact on health-related quality of life (HRQoL) (Swain, 2000). New solutions are needed, and leisure engagement is one promising area worthy of closer scrutiny. Leisure activity has been extensively studied as a way to enhance physical and mental health in general populations, but little research has examined the impact of leisure activity on HRQoL and FSCI in women with FSCI. A greater appreciation of the relationship may assist in the development of more beneficial activity interventions for fatigue management in people with chronic conditions.

Most fatigue research has examined one specific diagnosis; less research across diagnoses. Based on the literature, the accepted definition of FSCI (Aaronson et al., 1999) is the individual perception of having inadequate physiological and psychological capacity to engage in activities. This definition reflects three aspects of FSCI including physiological, psychological, and activity and participation. The physiological and psychological aspects have already been studied. Pain, depression

and lack of social support have been found to be significant correlates of fatigue across many different chronic conditions (Huyser et al., 1998; Hwang, Chang, Rue, & Kasimis, 2003; Patti et al., 2002). The aspect of activity and participation may be an important factor in FSCI (Aaronson et al., 1999; Sharpe & Wilks, 2002; Tiesinga, Dassen, Halfens, & van den Heuvel, 1999), but its contribution needs to be further clarified.

To date, little research has simultaneously examined all three aspects present in the definition of FSCI, so findings remain incomplete. To facilitate the research of fatigue definition, activity and participation as defined by the International Classification of Functioning, Disability and Health or ICF (World Health Organization, 2001) are useful. Activity means the execution of a task or action by an individual, whereas participation means involvement in a life situation (World Health Organization, 2001). Activity and participation in the ICF are compatible with the four areas of an individual's life (rest, work, self-care, and leisure) based on occupational therapy theory (Law, 2002; Law, Steinwender, & Leclair, 1998). These four areas have been measured for frequency of participation in various populations with many measurement tools (Law, 2002).

However, very few measurement tools have been developed to measure one particular area of activity and participation, such as leisure. From the Australian Bureau of Statistics (ABS), the results of the second nationwide Time Use Survey (1998a) showed that 85% of Australian people spent free time on leisure activities. For people with FSCI, only one study (Packer, Foster, & Brouwer, 1997) found there was no significant difference of mean of % time spent in leisure activities between people with CFS (24.72 $\pm$ 0.65%) and without CFS (16.22 $\pm$ 7.54%). This large % of time suggests that leisure participation has the potential to impact on HRQoL. It is therefore necessary to have such a tool for people with FSCI to classify different types of leisure activities and measure individual frequency of participation.

A number of theorists (Coleman & Iso-Ahola, 1993; Mannell & Stynes, 1991; Passmore, 2003; Tinsley & Tinsley, 1986) have proposed hypotheses of good health by viewing leisure from psychological, physiological and social perspectives. The models are: the relationship between leisure and health (Coleman & Iso-Ahola,

1993); the psychological and social benefits of leisure (Mannell & Stynes, 1991); the impact of the occupation of leisure on mental health (Passmore, 2003); and the relationships between leisure, psychological need fulfilment, and psychological benefit (Tinsley & Tinsley, 1986). In particular, the work of Coleman and Iso-Ahola (1993) was recently tested and supported by Coleman (1993 and 1999), Iso-Ahola & Park (1996), and Zoerink (2001). The work of Coleman and Iso-Ahola (1993) revealed that people who experienced certain leisure activities were more likely to experience feelings of social support (companionship and friendship) and capacity for self-determination (perceived freedom and intrinsic motivation). They proposed that this buffered negative life events and maintained good physical and mental health. However, this hypothesis has not been tested. A possible explanation is that studying the phenomenon of leisure itself is challenging (Caldwell, 2005; Henderson & Bialeschki, 2005). It requires measuring not only types/characteristics of activities, but also frequency of leisure participation and some qualitative dimensions (e.g., freedom of choice, level of enjoyment/satisfaction).

Many studies (Beard & Ragheb, 1980; Caldwell, 2005; Christensen & Mackinnon, 1993; Iwasaki & Smale, 1998; Wikström & Jacobsson, 2005; Zimmer, Hickey, & Searle, 1995) have examined health benefits of engaging in different types of leisure activities (e.g., physical, social, educational/creative, and passive leisure). Physical leisure has been defined as activity which involves physical strength, fitness, flexibility and mobility; social leisure involves a sense of companionship and relationship with other people; and passive leisure involves a minimal degree of mental participation and provides relief from the stress and strain of life (Zimmer et al., 1995). Educational/creative leisure is defined as involvement in an interesting and well designed learning situation that provides intellectual and creative stimulation (Beard & Ragheb, 1980). These definitions and related measurements have been used to study various perspectives related to the health outcomes of general populations and those with chronic conditions. However, these studies have not explained the relative contribution of different types of leisure participation to the prediction of health and fatigue in people with chronic conditions. One reason for the existing gap may be the lack of a measurement tool that differentiates types of leisure activities, therefore making it difficult to examine the impact on health or fatigue.

1.2 OBJECTIVES OF THE STUDY

The relationship between fatigue and activity engagement is complex with activity leading to fatigue and fatigue curtailing activity. Leisure participation is believed to contribute to well-being and health status in women with chronic conditions or fatigue secondary to chronic illness (FSCI). The main purpose of this research was to investigate the contribution that leisure participation has on fatigue and health-related quality of life (HRQoL). Because pain, depression and social support are already known to be related to fatigue and HRQoL, they were included in the regression model. Univariate and multivariate analysis was used concurrently in a cross-sectional design to examine the unique or additional contribution of participation in different types of leisure activities to fatigue and HRQoL. Thus, the main research questions were:

1. Do frequency of leisure participation and leisure satisfaction correlate with HRQoL and fatigue?
2. Do frequency of leisure participation and leisure satisfaction contribute to the prediction of HRQoL?
3. Do frequency of leisure participation and leisure satisfaction contribute to the prediction of HRQoL?

Prior to the main study the following research objectives had to be addressed:

1. to determine the most common leisure activities of Australian adults;
2. to select the most representative items to form the preliminary Classification of Leisure Participation (CLP) Scale;
3. to assign items domains within the categories of "physical", "social", "educational/creative" and "passive" leisure in women without chronic conditions;
4. to compare leisure domains between women with and without chronic conditions;
5. to compare two formats of test administration; and
6. to determine face validity, construct validity, and internal consistency of the CLP Scale.

1.3 SIGNIFICANCE OF THE STUDY

In Australia 70% of the health care burden is due to chronic conditions (Australian Bureau of Statistics, 2001). This is expected to rise to 80% by 2015 (World Health Organization, 2006). Previous research has hypothesized the positive relationship between leisure and health (Coleman & Iso-Ahola, 1993; Mannell & Stynes, 1991; Passmore, 2003; Tinsley & Tinsley, 1986) and examination of this relationship in population with chronic conditions, such as women with FSCI, would be required. The knowledge gained in this research has important implications for occupational therapists, recreational therapists and other health professionals working with women with FSCI. The research provides women with FSCI, their families and service providers with information about the role of leisure participation in living with chronic conditions. The major outcomes provide a better understanding of the nature of leisure participation, fatigue related factors (pain, depression and social support), and the different contributions of leisure satisfaction, type of leisure activity and frequency of leisure participation to HRQoL and fatigue. This conceptual knowledge may further encourage health professionals to develop activity interventions in a wider population. The interventions may have the potential to reduce the impact of fatigue and its consequent effects on HRQoL. Importantly, this knowledge assists our understanding of how leisure contributes to health and its potential as a therapeutic approach in chronic conditions.

Very few measurement tools have been developed to measure all areas of leisure simultaneously. A secondary benefit is the newly developed CLP Scale which has application for a number of professionals in a number of settings. Health professionals, recreation providers, and community agencies will be able to monitor changes in leisure participation over time or in response to specific intervention strategies. By examining the differential impact of different types of leisure on health, innovative interventions may be further developed. This is particularly beneficial for people with FSCI who are less able to participate in leisure due to fatigue impact.

1.4 OVERVIEW OF THE STUDY

A major rationale for this study was to fill the gap of understanding regarding the impact of leisure participation on FSCI and/or HRQoL. The first two chapters are introduction and literature review for this study. The three chapters of the study that follow these are: Chapter 3 development of the preliminary CLP Scale in women without chronic conditions; Chapter 4 validation studies and final development of the CLP Scale in women with chronic conditions; and Chapter 5 psychometric evaluation of the CLP Scale. These describe the development of the CLP Scale. Chapter 6 examines the contribution of leisure participation to the prediction of fatigue and HRQoL (main study), as illustrated in Figure 1.1.

This study lacked a measurement tool that can differentiate the impact of different types of leisure activities on fatigue and HRQoL in women with chronic conditions or FSCI. Thus, the preliminary CLP Scale was developed using three processes: item generation, item reduction, and determination of domains. Women without chronic conditions were used as the population of choice due to their availability and the desire not to deplete the sample for the main study.

Next, there were two validation studies to verify the preliminary CLP Scale in women with chronic conditions. Leisure domains were compared between women with, and without, chronic conditions. Phone and postal administrations in women with chronic conditions were then compared. Final development of the CLP Scale was conducted in a larger study. Finally, the CLP Scale for women with FSCI was then evaluated for face validity, construct validity, and internal consistency reliability (Cronbach Alpha Score).

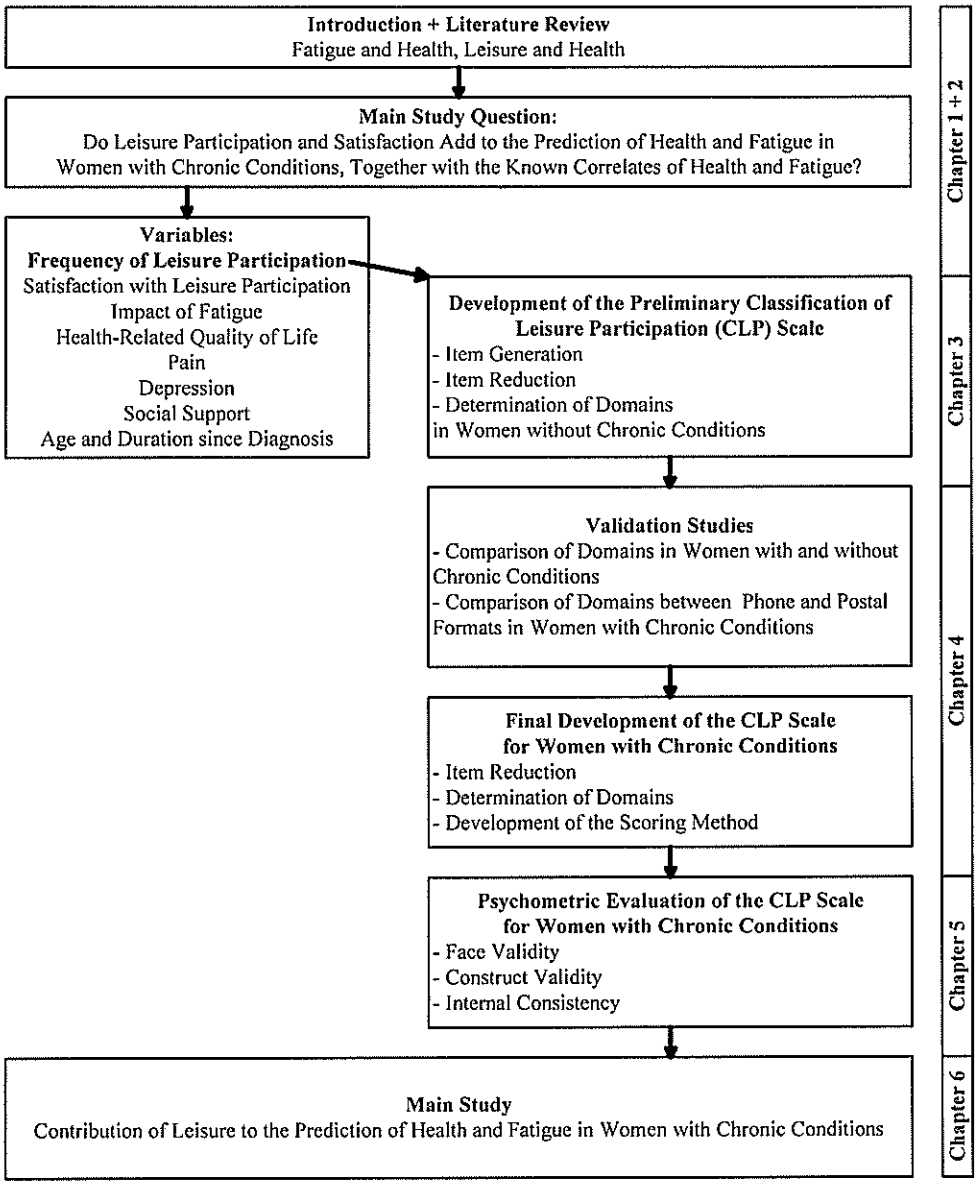

Figure 1.1. Flow-chart of the development of the CLP Scale.

Finally, the CLP Scale was used in the main study, together with other standardized questionnaires including the Numeric Rating Scale (NRS), the Depression Anxiety and Stress Scales (DASS 21), the Duke Social Support Index (DSSI), the Leisure Satisfaction Scale (LSS), the Fatigue Impact Scale (FIS), and the Medical Outcome Study Short Form-36 (SF-36®). To determine the relationships of all independent variables, Pearson's correlation was performed due to the normal distribution of all data. Stepwise multiple regression was also performed (Dawson & Trapp, 2001b) to

investigate the contribution of frequency and satisfaction of leisure participation, fatigue, pain, depression, and social support to the predictions of physical and mental domains of HRQoL. For the impact of fatigue model, frequency and satisfaction of leisure participation, physical and mental domains of HRQoL, pain, depression, and social support to the predictions of physical and mental domains of HRQoL were examined.

The specific objectives, methods, results and discussion are reported in each section independently.

1.5 GENERAL LIMITATIONS/DELIMITATIONS OF THE STUDY

All research has limitations. In this study limitations of the CLP Scale and the main study need to be acknowledged. Although the CLP has strong potential as a method of examining leisure participation in a variety of settings, relates to these varying the item selection was based specifically on the perceptions of women with chronic conditions. Caution should be exercised in use of the scale with people without chronic conditions or other chronic conditions that were not included in this research. It is possible that the procedure for item selection and the analysis of construct validity would need to be repeated in order to measure leisure participation in these other groups. Also, this study used only one sample of both women with and without chronic conditions; respondents in the sample for Study I were also involved in Study II. However, the findings were considered adequate to meet the research objectives and questions of this study.

In the main study, use of a convenience sample may have created selection bias. A true representative sample of women with FSCI around Australia would be required in order to reduce the selection bias. The sample size of people with FSCI ($N = 102$) was adequate but not large. All variables were normally distributed provided increased confidence in the use of quantitative statistics. In future studies to confirm the resulting models - a sample size of fifteen times the number of study variables, which were found significant predictors in this research is recommended. Causal relationships cannot be determined due to the cross sectional nature of the current

study. Findings of leisure intervention programs in addition to the existing effective interventions of fatigue management is further required.

CHAPTER 2

LITERATURE REVIEW

2.1 INTRODUCTION

This chapter provides background information needed to understand current literature on the relationships between fatigue, leisure and health. The health benefits of leisure participation for general populations and people with chronic conditions are outlined. The literature outlined in this chapter can be divided into two main parts: (1) fatigue and health and (2) leisure and health. The first part includes prevalence and impact of fatigue on health, definition of fatigue, measurement of fatigue, factors related to fatigue, "activity" in health research, and the impact of fatigue on activity and participation. The second part reviews how leisure is related to activity and participation, leisure across the lifespan, definition of leisure, theory of leisure and health, measurement of leisure, and leisure studies in people with, and without, chronic conditions.

2.2 FATIGUE AND HEALTH

2.2.1 Prevalence of Fatigue and Impact on Health

Among people with specific chronic conditions, fatigue is a common complaint (Evans & Wickstrom, 1999; Swain, 2000). It is perhaps the most common symptom to be found across all conditions (Chaudhuri & Behan, 2004). There are numerous chronic conditions in which fatigue is a significant symptom then include multiple sclerosis (MS) (Chaudhuri & Behan, 2004; Evans & Wickstrom, 1999; Swain, 2000), rheumatoid arthritis (RA) (Evans & Wickstrom, 1999; Pollard, Choy, Gonzalez, Khoshaba, & Scott, 2006; Swain, 2000), postpolio syndrome (PPS) (Chaudhuri & Behan, 2004), and chronic fatigue syndrome (CFS) (Asbring, 2000; Chaudhuri & Behan, 2004). Studies have indicated the prevalence of fatigue to be about 78% of people with MS (Schwid, Covington, Segal, & Goodman, 2002), 41% of people with RA (Wolfe, Hawley, & Wilson, 1996), 68% of people with PPS (Berlly, Strauser, & Hall, 1991), and 100% of people with CFS (Lloyd, Hickie, Boughton, Spencer, & Wakefield, 1990). This clearly shows the high prevalence of fatigue in people with chronic conditions compared with the prevalence (18.3%) in the population assessed as being without chronic conditions (Pawlikowska et al., 1994). For those with chronic conditions, a higher prevalence of fatigue has been shown in women than men (Australian Bureau of Statistics, 2001; Sharpe & Wilks, 2002; Tiesinga et al.,

1999). The prevalence of fatigue is not associated with age or occupation (Sharpe & Wilks, 2002).

Fatigue is rapidly becoming recognized as the least well-managed symptom in many chronic conditions (Sharpe & Wilks, 2002; Smith, Avis, & Assmann, 1999; Swain, 2000) and is associated with lost quality of life (QoL) (Sharpe & Wilks, 2002; Smith et al., 1999; Swain, 2000). However, fatigue is often ignored by clinicians because of its invisible nature (Swain, 2000). Its multi-factorial nature is poorly understood in the main (Sharpe & Wilks, 2002; Tiesinga et al., 1999) and causes significant problems (Evans & Wickstrom, 1999) related to physiological, psychological, and behavioural processes (Swain, 2000).

Severity and unpredictability of fatigue has a great impact on the lives of people with chronic conditions (Ream & Richardson, 1996; Swain, 2000) who may be forced to change their lifestyle (MacAllister & Krupp, 2005; Sharpe & Wilks, 2002). Kralik, Telford, Price, & Koch (2005) reported the findings of the fatigue experience through email group conversations with 30 women with chronic conditions (e.g., MS, RA, CFS). Significant themes about the fatigue experience arose from the data and were later confirmed by participants as part of the face validity process. Participants reported that they experienced extreme fluctuations of fatigue throughout each day and from day to day. Fatigue disrupted their lives and connections with family, friends, and the community. The participants also described how they monitored the impact of fatigue themselves; for instance, they saved energy so that they could maintain a role in the family as well as connections with others through social participation.

Research has focused less on the impact of fatigue in maintaining roles in the family or social participation, and more on impact on employment. Chaudhuri and Behan (2004), supported by Sharpe and Wilks (2002) reported that people with fatigue may be inactive and overstressed by not achieving a return to the same job (Chaudhuri & Behan, 2004; Sharpe & Wilks, 2002). Benedict et al (2005) measured health-related quality of life (HRQoL) via the MS Quality of Life-54 and vocational status (employed vs. unemployed) in 120 people with MS. Chi-square tests showed that people with poorer HRQoL were more likely to be unemployed (45% of participants,

$p < 0.001$). Importantly, Benedict et al (2005) concluded that employment status in this population was predicted by cognitive dysfunction using the Minimal Assessment of Cognitive Function in MS Battery (Benedict et al., 2002). A systematic review of the literature published between January 1, 1988 and November 15, 2001 (Ross et al., 2004) also reported the employment status in people with CFS. Of 3840 studies identified, 22 studies reported that people with CFS were more likely to be unemployed compared with those without CFS. Of those 22 studies, 8 studies reported that unemployed people with CFS had poorer physical health (Medical Outcome Study SF-36®), greater fatigue (Profile of Mood States or POMS for fatigue) and greater depression (the POMS for depression) than those without CFS.

2.2.2 Generic and Specific Definitions of Fatigue

It is difficult to define the fatigue phenomenon since it is a complex, dynamic process (Swain, 2000; Vercoulen et al., 1998). For example, fatigue secondary to chronic illness (FSCI) is different from fatigue experienced by people without chronic conditions (Aaronson et al., 1999). FSCI is a subjective experience associated with physiological and psychosocial manifestations which are not relieved by rest, sleep, or positioning (Aaron & Buckwald, 2003; Aaronson et al., 1999; Dittner et al., 2004; Swain, 2000). "Normal" or acute fatigue, in contrast, is a consequence of physical or mental exertion and is relieved by rest, sleep, or change of position (Crosby, 1991; Ream & Richardson, 1996).

A useful step in developing an understanding of fatigue in chronic conditions (FSCI) is to examine generic definitions for commonalities (Aaronson et al., 1999). Michielsen and colleagues (2004, p. 40) defined fatigue as "complex interactions between physical and mental elements in task and job demands and consequences of effort." Ream and Richardson (1996, p. 527) defined fatigue as "a subjective, unpleasant symptom which incorporates total body feelings ranging from tiredness to exhaustion creating an unrelenting overall condition which interferes with individuals' ability to function to their normal capacity." A third definition (Aaronson et al., 1999, p. 46) is "the awareness of a decreased capacity for physical and/or mental activity due to an imbalance in the availability, utilization and/or restoration of resources needed to perform activity." The common elements in these

three generic definitions are a physical aspect, a mental aspect, and an activity performance aspect.

Disease-specific definitions have also been developed that may aid in the understanding of the fatigue experience (Aaronson et al., 1999; Glacken, Coates, Kernohan, & Hegarty, 2003). In fact, much of the literature examines the phenomenon of fatigue in diagnosis specific terms. For example, MS fatigue has been defined as a subjective lack of energy in sustaining physical and mental activity (MacAllister & Krupp, 2005; Merkelbach, Sittinger, & Koenig, 2002; Stuifbergen & Rogers, 1997). RA fatigue has been defined as a feeling of extreme tiredness, muscle weakness, difficulties completing daily living activities, a lack of energy, and increased pain (Cook, 1999; Neuberger et al., 1997). People with CFS have chronic persistent fatigue exacerbated by minor exercise, causing significant disruption of usual daily activities that present for greater than six months (Lloyd et al., 1990, p. 522). Fatigue with PPS is described as increasing physical weakness, increasing loss of strength during exercise, and a heavy sensation of the muscle (Berlly et al., 1991, p. 116). This review of disease-specific definitions reinforces the three common themes arising from the more generic descriptions of FSCI: the physical aspects, the psychological aspects, and the impact on activity and participation (Aaronson et al., 1999; Dittner et al., 2004; A. Hartz, Bentler, & Watson, 2003; Swain, 2000). These elements, then, require further exploration.

2.2.3 Measurement of Fatigue in People with Chronic Conditions

The measurement of fatigue is difficult due to a lack of understanding of this complex phenomenon in people with chronic conditions (Yasuda, 2002). Aaronson, et al (1999) suggested using a combination of self-report and biological parameters (e.g., blood tests, electrolyte and metabolism status), but these measures have not been successful, because relationships between fatigue symptoms and the biological measures have proven difficult to establish (Aaronson et al., 1999; Swain, 2000).

Chipchase, Lincoln and Radford (2003) compared measures of fatigue in a cross-sectional study of 40 people with MS and 20 people without MS. The participants were asked to complete the subjective fatigue scales as follows: Task Induced Fatigue Scale (TIFS), Fatigue Assessment Instrument (FAI), Fatigue Impact Scale

(FIS), and Fatigue Severity Scale (FSS). Physical fatigue was objectively measured by finger tapping while mental fatigue was measured with the Dot Cancellation Test from the Stroke Drivers Screening Assessment (SDSA) and the Lottery Form Test of Everyday Attention (TEA). The researchers used a Mann-Whitney U-test to compare the performance of MS group and control participants. The results showed significant ($p < 0.001$) differences on TIFS (physical fatigue), FAI (fatigue severity), FSS, and FIS (cognitive, physical and social dimensions). The objective measures (finger tapping, SDSA and TEA) showed similar results in both groups except that the MS group had a significantly ($p < 0.001$) lower mean number of finger taps in both hands than the controls. In this study, using the subjective measures distinguished MS-related fatigue among the participants better than the objective measures.

Further research has also shown that subjective measures seem to be more sensitive than objective measures in detecting changes in the fatigue experience. Friedberg (2002), using a case study, measured physical activity 6 times over 12 months. Self-reported improvements in the mean values of walk-time and fatigue (via a daily diary) were not significantly associated with objectively measured locomotion (step count). An outcome of this and other research (Fu, LeMone, McDaniel, & Bausler, 2001) is that objective measurement of fatigue is considered inappropriate because of its nature and multidimensional impacts. The emphasis, then, on subjective measures reinforces the importance of self-report questionnaires as one important way to measure fatigue (Dittner et al., 2004; Shapiro & Moller, 2002). In support of this position, authors have argued that fatigue questionnaires should be reliable and applicable in assessing populations with chronic conditions or differentiating between people with and without diseases, and that scoring should be directly interpretable and easily understood (Flechtner & Bottomley, 2003; Swain, 2000). Others suggest that good self-report measures enable us to understand fatigue as a biobehavioral human experience of chronic illness (Aaronson et al., 1999; Crosby, 1991; Piper, 1997).

Different rating scales have been utilised, but no single subjective measure of fatigue captures the complexity of the phenomenon (Aaronson et al., 1999; Dittner et al., 2004). It is challenging to quantify fatigue (Shapiro & Moller, 2002). Dittner et al

(2004) suggested that there are three types of fatigue measures. These are the clinical symptom, the severity, and the functional impact of fatigue, which could be constructed into unidimensional or multidimensional scales. Unidimensional scales of fatigue are designed to derive a single score that captures heterogeneous symptoms and behaviours as a brief screening instrument (Chipchase, Lincoln, & Radford, 2003). Multidimensional scales, on the other hand, provide a detailed assessment of different dimensions of fatigue and can potentially identify the mechanisms underlying specific aspects of fatigue (Chipchase et al., 2003). When researchers are interested in understanding the impact of fatigue on different functions (e.g., cognitive, physical, and psychosocial), use of the multidimensional scales would be appropriated. To extend the advantage of using multidimensional scales, many aspects of fatigue could be identified as predictor variables fit in a process of multivariate analysis.

2.2.4 Factors Related to Fatigue

People with chronic conditions can be expected to experience a high degree of stress, pain, depression, or lack of social support (Swain, 2000). Current evidence (Chaudhuri & Behan, 2004) explains these variables in terms of physical and psychological stressors which increase the levels of fatigue. Research has extensively investigated the relationships between fatigue in specific diagnoses and variables, such as pain, depression, and lack of social support. The following sections highlight the literature on specific chronic conditions that are associated with a high incidence of fatigue (Chaudhuri & Behan, 2004; Swain, 2000).

2.2.4.1 Multiple Sclerosis (MS) Fatigue

MS fatigue has been associated with physical aspects such as pain, and psychological aspects such as depression. Pain was positively associated with daytime fatigue (MacAllister & Krupp, 2005; Miller & Dishon, 2005). Lack of social support negatively contributed to the prediction of MS fatigue (Schwartz & Frohner, 2005). The more severe the level of fatigue, the higher the level of depression was reported (Benito-Leon et al., 2003; Ford, Trigwell, & Johnson, 1998; MacAllister & Krupp, 2005; Schwartz, Coulthard-Morris, & Zeng, 1996). Ford, Trigwell, & Johnson (1998) used the Fatigue Rating Scale (FRS) and the Hospital Anxiety and Depression Scale (HAD) in 68 people with MS. Pearson's correlation indicated positive

associations between the total fatigue score and the depression score ($r = 0.42$, $p < 0.0001$). Schwartz et al (1996) used the Multidimensional Assessment of Fatigue (MAF) Scale, the Impact Measurement Scales (subscales of depression, anxiety and social activity limitation) in stepwise multiple regression with 139 people and found that depression contributed to the prediction of the severity of fatigue ($R^2 = 0.28$, $p < 0.01$). However, there is no explanation for the physiological and psychological basis of MS fatigue associated with pain, social support, or depression.

2.2.4.2 Rheumatoid Arthritis (RA) Fatigue

Research has also investigated fatigue in relation to pain, depression, and social support in people with RA. Crosby (1991) attempted to analyse the relationship between joint pain, grip strength, sleep quality and RA fatigue by comparing 12 people without RA and two RA groups (5 people with high levels and 10 people with low levels of joint pain). Joint pain was measured using the Modified McGill Pain Inventory. The researcher measured grip strength (via grip dynamometer), sleep quality (via electroencephalogram), and fatigue (via a 10 cm vertical visual analogue scale or VAS). Pearson product-moment correlations found that fatigue levels of people with high levels of joint pain were significantly positively correlated with joint pain ($r = 0.62$), fragmented sleep ($r = 0.42$), and right grip strength ($r = 0.52$). For those with low levels of joint pain, fatigue levels were significantly negatively correlated with joint pain ($r = -0.24$), fragmented sleep ($r = -0.38$), and right grip strength ($r = -0.01$). The explanation for the latter result lies in the fact that high levels of joint pain emerged as an indicator for disease activity of RA, which in turn may be related to the increased level of RA fatigue reported by study respondents.

Belza and colleagues (1993) recruited 225 participants for a study of RA fatigue. Fatigue was measured using the Multidimensional Assessment of Fatigue (MAF), which measures four dimensions: severity, distress, timing, and degree of interference in activities of daily living. A hierarchical multiple regression showed that fatigue was explained by being female (accounting for 13% of the variance), pain (19%), depression and social support (4%). The findings were more definitive than the Crosby (1991) study, and were similar to Huyser and colleagues (1998), who identified six predictors of RA fatigue ($N = 73$) including depression (11% of variance), pain (19%), gender (6%), social support (2.7%), disease activity (2%), and

symptom duration (3%). Also, Riemsma et al. (1998) confirmed that in RA fatigue 37% of the variance (N = 229) can be explained with the inclusion of pain, social support, and self-efficacy towards coping with RA. The previous four studies, using multiple regression, all found pain and social support to be predictors of the level of RA fatigue.

2.2.4.3 Post-Polio Syndrome (PPS) Fatigue

Limited research has been conducted to date to understand fatigue levels in people previously diagnosed as having polio. 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 (BDI). The study reported that PPS fatigue occurred daily and increased in severity over the day. Twenty-three percent of people with PPS also had a score greater than 14 on the BDI, indicating mild to moderate symptoms of depression, whereas none of the people without PPS had similar symptoms. They concluded that 64% of people with PPS had chronic fatigue and depression. Hansson & Ahlström's (1999) qualitative study of 24 people with PPS found that they experienced fatigue, pain, general weakness, and emotional stress. These were described by participants as progressive physical deterioration experienced in everyday life. Participants also reported that seeking social support from friends and neighbours was one positive means of coping with this chronic condition.

2.2.4.4 Chronic Fatigue Syndrome (CFS) Fatigue

A number of studies have investigated fatigue correlates in people with CFS. Ciccone, Benjamin and Natelson (2003) interviewed 163 women with CFS (via Diagnostic Interview Schedule) for evidence of unexplained illness. The participants were asked to complete questionnaires including the Short Form-36® Health Survey (SF-36®), the Mutidimensional Fatigue Inventory (MFI), and the Beck Depression Inventory (BDI). This study found that people with CFS met the diagnostic criteria for multiple unexplained symptoms, such as depression and pain. The more additional symptoms reported, the more severe the level of fatigue reported. Further evidence to this effect comes from a study by Morriss et al. (1999) who found that participants with CFS (N = 42), who reported high levels of fatigue and depression, were likely to also have impaired social function. Prins et al (2004) confirmed that

lack of social support was associated with severity of fatigue (via Checklist Individual Strength, CIS). They assessed social support in 270 people diagnosed with CFS, 151 employees on sick leave with fatigue, and 108 healthy controls. One year after treatment (guided support group and cognitive behaviour therapy), on measures of social support, the CFS and fatigued employee groups were worse than the control group. This study developed a link between social support and fatigue; however, the authors have commented that the relationship between fatigue, pain, depression and social support remains controversial in this population as well as others (Afari & Buchwald, 2003).

2.2.5 "Activity" in Health Research

Activity is defined as "the execution of a task or action by an individual" and participation as "involvement in a life situation" (World Health Organization, 2001, p. 14). The ICF further defines activity limitations as "difficulties an individual may have in executing activities" and participation restrictions as "problems an individual may experience in involvement in life situations" (World Health Organization, 2001, p. 14). 'Activity' is frequently used in health sciences research as a core variable (Vuillemin et al., 2005; Wendel-Vos, Schuit, Tijhuis, & Kromhout, 2004). Use of the term can be broadly grouped into three types of health-related activities. The first use (Rogers & Holm, 2003) is "activities of daily living; ADL." Health care providers often focus on self-maintenance or self-care activities in clients with acute or chronic conditions. Those activities are feeding, dressing, bathing, grooming and homemaking. The second use of the term (Proper et al., 2003) is "physical activities", used in the fields of exercise physiology and neuroscience. It is associated with studies of optimal intensity levels of activities, in the laboratory or the field, at the level of brain activities and physiological mechanisms. The final use of the term is "activity and participation" which is part of WHO's conceptualization of health and disabilities; the International Classification of Functioning, Disability and Health (ICF). Activity limitation and participation restriction can be the consequence of a health condition or a restrictive environment. ICF has highlighted the important relationship between activity, participation and health benefits in people with disabilities (Katz, Karpin, Lak, Furman, & Hartman-Maeir, 2003). According to the ICF Australian version (World Health Organization, 2001), a person's disability is conceived as a dynamic interaction between health conditions, environmental

barriers/facilitators, and personal factors (e.g., age, sex, and indigenous status) as illustrated in Figure 2.1.

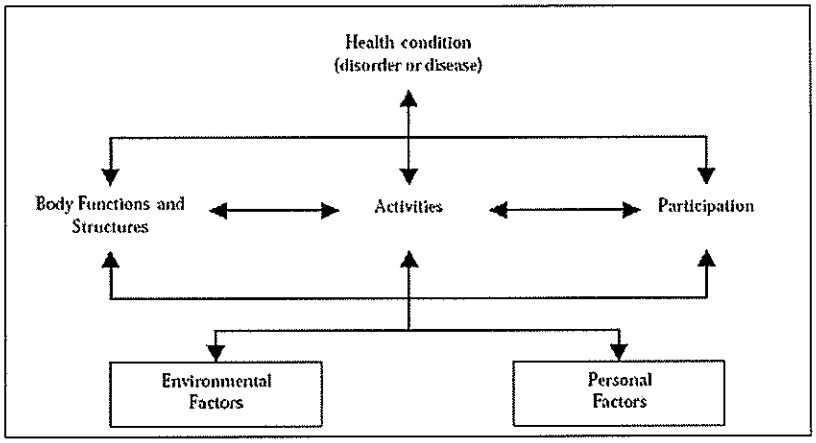

Figure 2.1. Interactions between the components of the ICF (World Health Organization, 2001, p. 18).

Haglung and Henriksson (2003) have argued that this classification provides an excellent communication tool between health professionals, assisting them to understand how people with health conditions perform activities and participate in everyday life within manageable limitations. Based on its international acceptance, this classification serves as an important tool in understanding activity and participation. Some researchers have attempted to employ the ICF for research in people with chronic conditions. Jette and Kooyoomjian (2003) developed the Late-Life Function and Disability Instrument (Late Life FDI), which consists of 48 items (5-point Likert scale) across life actions and activities, such as basic ADLs, changing body positions, and social activities. The researchers hypothesized that activity and participation were two distinct domains. However, the results of a factor analysis showed one unified activity and participation dimension ($p < 0.001$). All 48 items were combined into a single construct or meaning (61.1% of variance) of activity and participation. This research suggested that 'activity' and 'participation' should be measured together if the researchers aim to investigate the impact of health problems on daily activities. It can be concluded that leisure, as a construct, should not be separated into activity and participation domain.

Measuring 'activity limitation' and 'participation restriction' was found to be problematic by Adamson, Lawlor and Ebrahim (2004). They conducted a cross-sectional survey of 4,286 older women. Participants were asked about 'activity limitation' they had difficulty performing six locomotor activities. They were also asked to complete a questionnaire about their history of chronic diseases and pain during employment, household, and social activities. Multiple logistic regression showed locomotor activity limitation was significantly related to problems of chronic diseases and pain during social activity ($p < 0.05$). This result indicates that people with chronic diseases and pain have difficulty participating in social activities.

2.2.6 Impact of Fatigue on Activity and Participation

Researchers (Aaronson et al., 1999; Tiesinga et al., 1999) have noted that activity and participation may be an important factor in fatigue. The definition of fatigue usually includes decreased capacity for physical and mental activities (Sharpe & Wilks, 2002). To date, the impact of activity and participation on fatigue (and vice versa) has been studied by a few researchers but there has been no systematic examination of this aspect of the fatigue definition.

Packer, Sauriol and Brouwer (1994) studied the severity of fatigue using the Fatigue Severity Scale (FSS). They also assessed the activity level of study respondents utilising the Human Activity Profile (HAP). The rationale which underpinned this study was to explore fatigue related to concurrent demands rather than a specific activity. It was hypothesized that the level of fatigue and activity level would be different in people with FSCI and a control group. This study was conducted with people with FSCI: 28 people with PPS, 13 people with CFS, and 9 people with MS. The participants with FSCI had significantly higher scores on the FSS than the control group (11 healthy people). People with MS and CFS had significantly lower scores on the HAP than the control group. This result suggests higher fatigue may be related to decreased activity (or energy) level.

Packer, Foster and Brouwer (1997) continued researching activity patterns of people with, and without, CFS. The results showed significant differences between the percentage of time spent by the two groups with respect the variable of rest, work, and productivity (work and household). The study also found that people with CFS

spent less time in productivity and greater time in rest than the controls. This preliminary result attempted to explain the impact of fatigue on specific activities with people with CFS, but it is not possible to identify a direct relationship between activity (via time use) and fatigue.

Schreurs and colleagues (2002) assessed the relationships between subscales of Multidimensional Fatigue Inventory (MFI), depression, and physical disability. This was a modified cross-sectional study which interviewed 98 people with MS twice, at an interval of one year between interviews. Regression analysis with the first data collection showed that physical fatigue was associated with physical disabilities (R^2 = 0.45, $p < 0.01$), and mental fatigue was related to depression (R^2 = 0.35, $p < 0.01$). In the longitudinal data, analysed by means of structural equation modelling, depression was predictive of the subscales of physical fatigue and reduced activity a year later. However, this study did not adequately explain the relationship between fatigue and its aspect of activity and participation.

2.3 LEISURE AND HEALTH

2.3.1 Leisure: an important part of Activity and Participation

The ICF includes nine activity domains: learning and applying knowledge; general tasks and demands; communication; mobility; self-care; domestic life; interpersonal interactions and relationships; major life areas such as work or school; and community, social, and civic life (World Health Organization, 2001). These activity domains, although they may be labelled differently, have meaning, and are related to the four roles/areas of an individual's life (rest, work/productivity, self-care, and leisure/play), emphasised in occupational therapy theories (Baum & Edwards, 2001; Christiansen & Baum, 1997; Law, 2002; Law et al., 1998; Trombly, 1995). Those four areas have been examined using time use methodologies in various populations (Pentland & McColl, 1999), but have largely focused on individual activities, as opposed to assignment to type or classification of activity.

The Australian Bureau of Statistics (ABS), in reporting the results of a second nationwide Time Use Survey (1998a) showed that Australians spent most of their time (46.2% of each day) on necessary activities (e.g., sleeping and eating), 15.4%

on contracted activities (e.g., employment and education) and 16.3% on committed activities (e.g., childcare, household, shopping, and voluntary work). These activities together account for 77.9% of time each day, used in non-free time activities. Free time activities (e.g., social and leisure participation) accounted for 22.1% of time each day. People frequently perform not only one (main) activity but also other (secondary) activities at the same time (Australian Bureau of Statistics, 1998a; Stanley & Gregory, 1983). This situation demonstrates the complexity of activity and participation, which consists of individual characteristics, a specific environmental/societal context, and change over time (Ajzen, 1991; Gray, Kennedy, & Zemke, 1996; Mason & Redeker, 1993).

In the Australian Time Use Survey (1998a, 1998b) most of the free time (85.8%) was spent on leisure activities: 94.5% of the population participated in passive audio/visual media activities, 48% participated in reading, and 27.1% participated in active sports. This information suggests what Australian people do with their free time, but it does not address the qualitative dimension of leisure activities. Previous research (Parker, 1996; Stanley, 1995) failed to show a significant relationship between life satisfaction and time spent in leisure activities, because people have different ways to categorise leisure activities. Pentland, Harvey and Walker (1998) also studied time allocations of four activities (i.e., leisure, self-care, productivity and sleep) in 312 people with spinal cord injury. Multiple linear regressions showed no correlation between the time allocations and well-being.

2.3.2 Definitions of Leisure

Previous research has attempted to establish a definition of leisure (Sachs & Josman, 2003). In 1980, Gunter and Gunter defined leisure as "an individual-activity (or time) relationship which contains, to an unknown degree, either positive effect and involvement, or freedom from constraint, or both" (p. 368). Beard and Ragheb (1980) also defined leisure as "non-work activities in which the individual has a free choice as to whether or not to participate (p. 24)." These definitions are similar to Leitner and Leither (2004, p. 3) who stated that "leisure is defined as free or un-obligated time during which one is not working or performing other life-sustaining functions." Therefore, the common features of leisure are: free unobligated time, non-working activities, and activity choices.

A number of researchers (Driver, Tinsley, & Manfredo, 1991; Lynch & Veal, 1996; Roelofs, 1999) have identified different aspects of leisure experiences including type of activity, frequency of participation, and satisfaction with participation. These three aspects illustrate that the simple definition of leisure as 'free time' may not capture the full meaning (Mannell & Stynes, 1991). Leisure experience could be conceptualized in a dynamic social context/process; for instance, social roles have influenced individual interpretation of leisure experience (Kelly, 1982). Researchers have argued that all these aspects must be examined in order to understand the benefits of leisure activities to individuals and society (Mannell & Stynes, 1991; Passmore & French, 2001). It would be useful to examine the physical, psychological, and social benefits of leisure activities. There would seem to be some relationships among these benefits of leisure activities; however, the relationships and leisure participation in terms of optimal experience are unclear (Mannell & Kleiber, 1997) and described differently by individuals or specific populations (Ajzen, 1991).

2.3.3 Theoretical models of Leisure and Health

Theories of leisure participation are developing; however, consensus has not been reached. Thus, it is important to find an appropriate theory to understand leisure experiences (Henderson, Presley, & Bialeschki, 2004) and the health benefits of leisure participation across populations (Leitner & Leitner, 2004b). Previous leisure research has used one of two theoretical models, Tinsley & Tinsley's theory or Coleman & Iso-Ahola' theory, as a conceptual framework for understanding leisure and health.

The first model is Tinsley and Tinsley's leisure experience theory, established in 1986 (See Figure 2.2). This theoretical model suggests psychological needs can be met through leisure participation. Satisfaction of psychological needs then promotes life satisfaction and enhancement of physical and mental health, ultimately improving overall personal growth. The satisfaction of psychological needs via leisure participation seems to be a concept based on gaining psychological benefits from leisure.

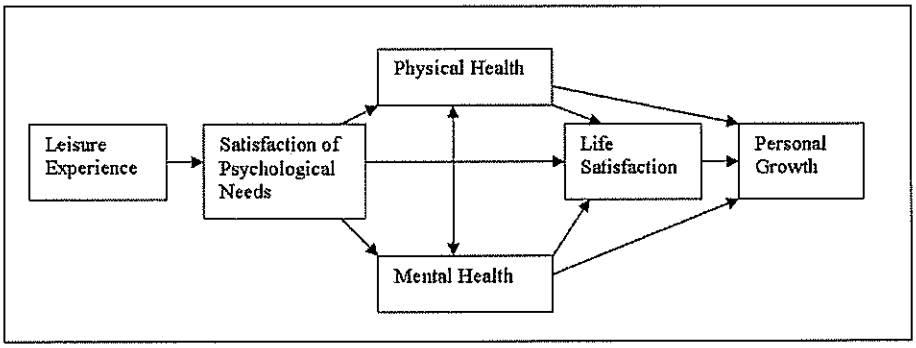

Figure 2.2. Causal effects of leisure experience (Tinsley and Tinsley, 1986, p. 20).

In Tinsley and Tinsley's model, leisure participation is believed to have beneficial consequences for physical and mental health in healthy populations across the lifespan. Coleman and Iso-Ahola (1993) referred to the Tinsley and Tinsley's model while incorporating self-determination theory. Self-determination has been defined as "the capacity to choose and to have those choices be the determinants of one's actions" (Deci and Ryan, 1985, p. 38). Self-determination theory (SDT) is a general theory of psychology focusing on the degree of motivation in regard with volitional performance of activity and participation (Ryan and Deci, 2000). This theory has been developed by Deci and Ryan (1985) and highlights self-regulation for understanding types of motivation, human behavior, and social environment in order to optimize individual learning, performance, and experience (Ryan and Deci, 2000). Motivation is an essential construct of psychosocial development (Ryan and Deci, 2000). People can be motivated when they have a repetoir of valued and enjoyed activities (Csikszentmihalyi & Rathunok, 1993). However, there are different types of motivation; internal performance refers to the performance of an activity with intrinsic motivation and behavioral regulation through interest, enjoyment, and satisfaction (Ryan and Deci, 2000). Whereas external performance refers to the performance of an activity in order to attain extrinsic motivation, including self-control, feelings of worth, and personal importance (Ryan and Deci, 2000).

Currently, the SDT research has explored the process that demonstrates the effective and healthy performance of individuals in various forms of activity and participation. Coleman and Iso-Ahola (1993) hypothesised that social support derived from leisure participation seemed to be one of the most effective ways of coping with life stress (See Figure 2.3). They suggested that people who participated in certain leisure

activities feel they have increased social support (companionship and friendship) and self-determination (perceived freedom and intrinsic motivation). The SDT has been also applied to different areas of research such as leisure and health. In leisure research, self-determination that has been developed through leisure participation might contribute to improved well-being (Coleman & Iso-Ahola, 1993; Coleman, 2004). Choices of leisure participation provide opportunities for self-determination (Ryan and Deci, 2000), and the self-determination disposition may be both a cause and effect of leisure (Coleman, 1997; Iso-Ahola, 1993; Mannell & Kleiber, 1997). Mannell and Kleiber, (1997) agreed with Ryan and Deci (2000) that self-determination can be considered as the level of integrated regulation in having activity choices and performing important activity. People may choose to perform leisure activities for internalised or external reasons (Coleman, 1999). In the strong sense of self-determination, people who have freely chosen their leisure choices are believed to value certain leisure activities that appear to be controlled (e.g. family leisure). This leisure self-determination is related to intrinsic leisure motivation (e.g. satisfaction, interest, enjoyment) and extrinsic leisure motivation (e.g. leisure participation, leisure achievement) (Coleman, 1999). Both types of leisure motivation has been seen by many leisure researchers as a characteristic of the leisure experience (Iso-Ahola, 1980; Mannell & Kleiber, 1997), but no known studies have found their internal causal relationships (Coleman, 1999).

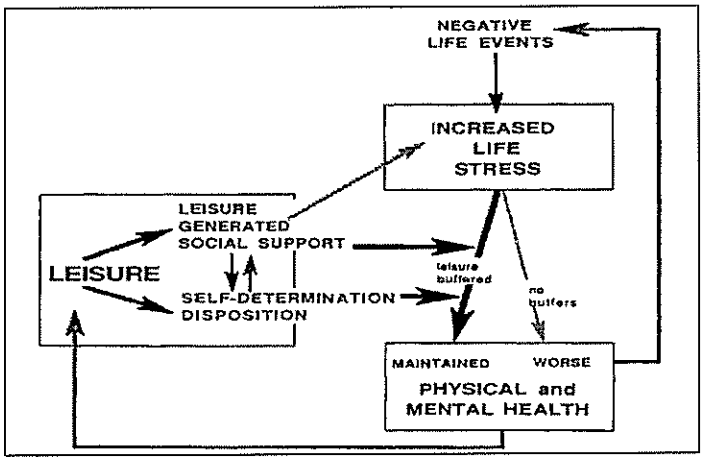

Figure 2.3. A theoretical model of the relationship between leisure and health (Coleman & Iso-Ahola, 1993, p. 115).

To support the theory Coleman (1993) studied the moderating effects of leisure participation on health. The researcher mailed questionnaires to 104 healthy people to test the hypothesis that leisure activity maintained good health by buffering against the harmful impact of a life stress, such as illness. There were four variables in this study: life stress, social support, perceived leisure freedom, and health status. Life stress was measured using the Social Readjustment Rating Scale. Social support was measured using the Social Support Appraisals Scale. Perceived leisure freedom was measured using a 5-point Likert scale with items selected from a number of leisure scales that included a sense of control and mastery. Health status was measured using the Seriousness Illness Rating Scale. Incremental regression analysis showed that life stress, social support, and perceived leisure freedom predicted 35% of the variability in health status. Perceived leisure freedom and life stress predicted 11% of the variability in health status. These results suggest perceived leisure freedom might directly predict health status when facing higher levels of life stress.

Iso-Ahola and Park (1996) studied leisure-generated social support and self-determination generated through participation in Tae Kwon Do. This study aimed to determine the buffering effects of Tae Kwon Do on physical and mental health, as per the Coleman & Iso-Ahola model. There were four variables in this study: physical health, mental health, life stress, and leisure participation. The researchers assessed two components of leisure participation: self-determination (Intrinsic Leisure Motivation Scale and the Perceived Leisure Freedom Index), and leisure-generated social support (Social Support Appraisals Scale and Leisure Companion Index). Self-determination included intrinsic leisure motivation and perceived leisure freedom. The leisure generated social support included an attitudinal variable (feeling of leisure friendship), and a behavioural variable (companionship in shared leisure participation). Hierarchical multiple regression showed that leisure companionship moderated life stress derived from depression, and leisure friendship moderated life stress derived from physical illness symptoms. This study supported the leisure theory that social support generated through leisure participation (Tae Kwon Do) buffered life stress and maintained physical and mental health.

Coleman (1999) has developed the Leisure Self-Determination Scale using Deci and Ryan's (1985) concept. This scale development aimed to investigate the buffering

effects of leisure self-determination on health due to life stress. Three hundred and fifty seven Australian university students (58% women and 42% men) were recruited to rate this scale. The students were newly enrolled in justice administration (40%), leisure studies (40%) and teacher education (17%) courses. Different aspects of leisure self-determination were captured in five subscales including autonomous tendencies or self (6 items), fulfillment of personal values or personal values (6 items), perceived expectations of others or internalized others (5 items), deferment to others ideas and requests or valued others (3 items), and observations of environmental dominance or external control (4 items). Examples of subscales were: "I try to spend my time the way I want to spend it" (self), "I do things in order to maintain my sense of self-esteem" (personal values), "I tend to do what I think other people would like me to do" (internalized others), "I like to go along with what other people are doing" (valued others), and "My situation restricts what I can do, I don't really have a choice" (external control). These items were rated on a 5-point Likert scale ranging from strongly disagree (1) to strongly agree (5). Adequate convergent validity of this scale was demonstrated as correlation with Intrinsic Leisure Motivation Scale (Weissinger, 1985) ($r = 0.57$, $p < 0.05$). Item-total correlations ranged from .27 to .61 with an average item-total correlation of .40, showing a unified construct (Coleman, 1999). Craike & Coleman (2005) used this scale to provide additional research on leisure determination and health. One-hundred and fifty two Australia older adults (57.1% females and 42.9% males) completed the Leisure Determination Scale, ratings of life stress (Rice, 1998), and the Centre for Epidemiological Studies Depression Scale or CES-D (Radloff, 1977). Incremental regression analyses showed that higher levels of leisure self-determination buffer the negative impact of life stress (e.g. someone close died, financial problem) on depression. This finding is consistent with Coleman and Iso-Ahola (1993) and Coleman (1999), who found that leisure provides coping with life stress through leisure self-determination. However, self-determination could involve the decision-making process about type and frequency of leisure participation, not only leisure behavior (Craike & Coleman, 2005; Mannell & Kleiber, 1997).

Zoerink (2001) also reviewed the earlier findings of Coleman & Iso-Ahola (1993). The outcome variable was health perceptions, which consisted of mental and physical health. This variable was measured using The Center of Epidemiological

Studies Depression Scale (CES-D) for mental health, and two health-related questions for physical health. For the independent variables the Leisure Satisfaction Scale-Short Form, developed by Beard & Ragheb (1980), was used to measure the degree to which participants gained 6 types of satisfaction from leisure participation, including psychological (enjoyment), educational (learning), social (relationship), relaxational (stress releasing), physiological (fitness), and aesthetic (pleasing) satisfaction. These types of satisfaction were derived from 24 items using a five-point Likert scale (from 5 = almost always true for me to 1 = almost never true for me). Linear regression analysis showed that leisure satisfaction positively contributed to the prediction of health perceptions into 48 older people with orthopaedic disabilities. This result supported the leisure theory that leisure satisfaction maintained physical and mental health when faced with a negative life event (orthopaedic disability). This literature suggests an extension of the impact of leisure participation on physical and mental health in populations with health problems.

In summary studies examining the theory of Coleman and Iso-Ahola (1993), leisure participation contributes positively to health (Iso-Ahola, 1980; Mannell & Kleiber, 1997) and the health benefits of leisure participation have been established through systematic research in particular for a contribution of physical activity to fitness (Coleman, 2004). Leisure participation may be an effective resource for resistance of stress, and the ways that people use their leisure time may be a critical determinant of their capacity to cope with stressful events (Caldwell, 2005; Craike & Coleman, 2005). Leisure participation could be a buffer for reducing the impact of stress on health, in part, leisure participation is believed to maintain good mental and physical health (no illness) (Coleman & Iso-Ahola, 1993). Certain types or experience of leisure participation are believed to help people cope with life stress in several ways; for instance, feeling good, improved fitness, increment of social support through social activities, stress management via outdoor active sport (Caltabiano, 1995; Coleman, 1997; Coleman, 2004; Driver, Brown & Petersen, 1991). Patterson and Coleman (1996) identified which types of leisure participation were used by people during stress. The results showed that leisure in which people were in control, exciting leisure, relaxation leisure, and physical leisure were selected when stressed. However, these types of leisure participation were not for all people. Different

groups of people may have performed different types of leisure participation. These were studies of healthy adults and did not include people with chronic conditions.

2.3.4 Measurements of Leisure Participation

To date, findings on the three aspects of leisure participation: type, frequency, and satisfaction seem somewhat inconsistent due to sophisticated measurement tools as well as some methodological limitations. Many self-report questionnaires have been developed to measure everyday activities, including leisure (Law, 2002). Examples of self-report questionnaires utilised in healthy populations are described in Table 2.1.

Table 2.1

Tools for measuring different aspects of leisure participation

Tool	Measurement of leisure participation	Study
Paragraphs About Leisure-Form E	Type	Tinsley et al. (1985)
Human Activity Profile	Frequency	Fix & Daughton (1988)
Adelaide Activity Profile	Frequency	Bond & Clark (1998)
Activity Cart Sort	Frequency	Baum & Edwards (2001)
Recreative Activity Schedule	Frequency	DeCarlo (1974)
Leisure Satisfaction Scale	Satisfaction	Beard & Ragheb (1980)
Leisure Diagnostic Battery (Leisure Attitude Measure, Leisure Interest Measure, Leisure Motivation Scale, and Leisure Satisfaction Measure)	Type and satisfaction	Ellis & Witt (1984)
Variety of leisure participation and Modified LSS	Frequency and satisfaction	Griffin & Mckenna (1998)
Leisure Questionnaire for Adolescents	Type, frequency, and satisfaction	Passmore and French (2001)

2.3.4.1 Type of Leisure Participation

In 1985, Tinsley and co-researchers developed the Paragraphs About Leisure-Form E (PAL-E) to report types of leisure based on its psychological benefits. Using Ward's hierarchical grouping procedure, 6 clusters were identified: companionship (playing cards, playing bingo, bowling, dancing); compensation (picnicking); temporary disengagement (watching sports-not on TV, watching TV); comfortable solitude (raising house plants, collecting photographs, collecting antiques, reading); expressive solitude (knitting and crocheting, woodworking, ceramics); and expressive service (volunteer service activities, volunteer professional activities, attending meetings of social groups, attending meetings of religious organizations). These labels differ from those used by others. Previous research has explained

psychological benefits of leisure participation as educational (e.g., intellectual or cognitive leisure) (Hilleras, Jorm, Herlitz, & Winblad, 1999), learning and creativity (Coleman, 1997; Ryan & Deci, 2000), and passive (relaxation) (Lynch & Veal, 1996; Parker, 1996) making comparison difficult. The complexity is increased by research that demonstrates that participants have different perceptions, or attach different meanings to psychological benefits of leisure participation (Parker, 1996; Roelofs, 1999; Shogan, 2002).

2.3.4.2 Frequency of Leisure Participation

As early as 1974, DeCarlo developed a Recreative Activity Schedule (RAS) to measure frequency of leisure participation (often, occasional, and never) within sensory-motor, cognitive, and affective domains. This study evaluated "successful aging" of 60 older twins including performance on the RAS (physical health, mental health, and intellectual performance). A correlation matrix showed that frequency of leisure participation in all domains was positively correlated with mental health, but only the cognitive domain was positively correlated with physical health ($p < 0.025$). These results suggest that frequency of leisure participation is related to physical and mental health, but this kind of measurement explains only one aspect of leisure participation. It is unable to measure type of leisure participation or satisfaction with leisure participation.

To date, three questionnaires have been developed to measure frequency of participation in everyday activities, including leisure activities, however, these questionnaires are not a direct measurement of leisure participation. Firstly, the Human Activity Profile (HAP) (Fix & Daughton, 1988) is a survey of 94 activities using metabolic equivalents (MET). The activities include self-care, transportation, home maintenance, entertainment, and physical exercise. For each activity, one selection is made from the three responses as follows: 1) still doing the activity, 2) have stopped doing the activity, and 3) never did the activity. Two scores are obtained from this information. The Maximum Activity Score (MAS) indicates the activity with the highest MET level that is performed. The Adjusted Activity Score (AAS) is calculated by subtracting the number of activities that have been stopped. The AAS indicates the average MET level in a typical day.

Secondly, the Adelaide Activity Profile (AAP) (Bond & Clark, 1998), a valid measure of lifestyle activities (frequency of participation), was developed in a study involving 1,799 older Australians. This tool measures 21 activities against four lifestyle activities: domestic chores, household maintenance, service to others, and social activities. Each activity is rated on a 4-point Likert scale to reflect frequency of participation. While the 21 activities reflect commonly undertaken activities, the scoring does not take into account those activities never done or of no interest to the respondent.

Thirdly, the Activity Card Sort (ACS) (Baum & Edwards, 2001) is a unique assessment of participation. Its four activity domains are instrumental, social-cultural, high-demand leisure (physical), and low-demand leisure (passive). Participants sort photograph cards of people performing activities (one at a time) into 1) never done, 2) not done as an older adult, 3) do now, 4) do less, and 5) given up. The numbers of current activities are divided by previous activities to provide a measure of retained activity level. This tool has been used with older adults (Everard, Lach, Fisher, & Baum, 2000; Packer et al., 2006; Sachs & Josman, 2003), and people with chronic conditions (Katz et al., 2003). The original ACS has now been adapted for use in other countries including Israel (Katz et al., 2003), Hong Kong (Chung, Chan & Packer, 2006), and Australia (Packer et al., 2006).

2.3.4.3 Satisfaction with Leisure Participation

Beard and Ragheb (1980) defined leisure satisfaction as "the positive perceptions or feelings which an individual forms, elicits, or gains as a result of engaging in leisure activities and choices (p. 22)." They established a way to study the meaning of leisure utilising a Leisure Satisfaction Scale (LSS). This scale addressed six types of satisfaction gained from engaging in common leisure activities: psychological, educational, social, relaxing, physiological, and aesthetic. Roelofs (1999, p. 33), in support of the measure stated, "the more satisfied subjects were with how they spent their leisure time, the more satisfied they were with their lives in general." The LSS has been widely used in leisure studies (Lloyd, King, Lampe, & McDougall, 2001; Trottier, Brown, Hobson, & Miller, 2002). Strong internal consistency score of 0.93 (from 347 students) and good content-related evidence of validity (from 160 experts) have been reported (Beard & Ragheb, 1980). The LSS shows good levels of

reliability in 37 adolescents (Trottier, Brown, Hobson, & Miller, 2002) and 100 people with psychiatric disabilities (Lloyd, King, Lampe, & McDougall, 2001). However, this scale does not measure other aspects of leisure participation, such as type or frequency of leisure participation.

2.3.4.4 Multidimensional Measurements of Leisure Participation

The Leisure Diagnostic Battery or LDB (Ellis & Witt, 1984) is a set of four separate assessments: Leisure Attitude Measure or LAM, Leisure Interest Measure or LIM, Leisure Motivation Scale or LMS, and Leisure Satisfaction Measure or LSM. The LDB is the first comprehensive battery to assess personal choices of leisure participation and perceived freedom in leisure (e.g., type and satisfaction). Witt (1990) reported that normative data of the LDB has been generated in various populations (e.g., severely physically disabled children and adults, psychiatric clients). Strong internal consistency for each assessment was found such as total score of the LAM (Cronbach's alpha = 0.94), total score of the LIM (Cronbach's alpha = 0.87), total score of the LMS (Cronbach's alpha = 0.90), and total score of the LSM (Cronbach's alpha = 0.93). However, validity data for the combination of all four tools as well as the relationship between the tools has not been well-reported (Law, Baum, & Dunn, 2005).

Griffin and McKenna (1998) attempted to measure two aspects of leisure: frequency and satisfaction. Amount and variety of leisure participation (Kelly, Steinkamp, & Kelly, 1987) were measured by rating the frequency of leisure participation in 27 activities (0 = never to 3 = frequent). Factor analysis reduced these activities into 8 categories, including organizations, cultural activity, travel, home-based, sport/exercise, family, outdoor, and social. Leisure satisfaction was assessed using the modified Leisure Satisfaction Scale (LSS) (Brown, Frankel, & Fennell, 1991), with 12 items on 5-point Likert scales (very satisfied to very dissatisfied). Life satisfaction was assessed using the Satisfaction with Life Scale (SWLS). Leisure satisfaction and life satisfaction were not influenced by any leisure variables. This study failed to find a relationship between valued leisure variables and life satisfaction. The researchers noted that choices of leisure in this study might provide different meanings of satisfaction for older adults. It may be necessary to consider

types of leisure participation for a specific population prior to measuring frequency and satisfaction of leisure participation.

It is, however, challenging to describe three aspects of leisure participation (activity type and satisfaction) (Harvey, 1993; Lynch & Veal, 1996; Roelofs, 1999). Passmore and French (2001) developed a Leisure Questionnaire for Adolescents (LQA) to assess the participation of adolescents in 21 items, classified into three domains: achievement (challenging activities), social (engaging in the company of other people), and time-out leisure (solitary and passive activities). Moderate internal consistency of the total score (Cronbach's alpha = 0.74) was found (N = 150 adolescents). For each type of leisure pursuit, three questions were asked: (1) how often the adolescents participated (daily, 2-3 times per week, every week, once a month, or every few months); (2) how enjoyable they found it (very enjoyable, enjoyable, somewhat enjoyable, or not enjoyable); and (3) whether their participation was freely chosen (yes or no). A sample of 850 adolescents was asked to complete the leisure questionnaire along with a mental health score survey called Youth Self-Report (Achenbach, 1991). Structural equation modelling (SEM) yielded positive associations between two types of leisure (achievement and social) and mental health (Passmore, 2003). This is an attempt to examine the effects of different types of leisure activities on health in adolescents; no study has specifically examined these effects in adults.

2.3.5 Leisure Studies Involving People without Chronic Conditions

Traditionally, research has focused on frequency of participation in physical leisure activities and its health benefits (Caldwell, 2005; Wankel & Berger, 1991). Physical leisure has been defined as activity and participation which involves physical strength, fitness, flexibility and mobility (Zimmer et al., 1995). Individuals share their beliefs, values, goals, actions, social support, and social skills with other people during physical activities (Paffenbarger, Hyde, & Dow, 1991). Exercise (physical domain) is the most researched leisure pursuit. Studies have focused on the ability of exercise to enhance physical health, such as cardiovascular fitness, and mental health, such as stress reduction (Wankel & Berger, 1991).

Relationships between health, stress and the level of physically active leisure were investigated in 17,626 Canadians via the 1994 National Population Health Survey (NPHS) (Iwasaki, Zuzanek, & Mannell, 2001). Health variables in this study consisted of physical health, mental health, and well-being. Their measurement tools were the Subjective Assessment of Physical Health and the Health Utility Index (Statistics Canada, 1995), the Mental Distress Scale and Depression Scale (Kessler & Mroczek, 1995), and a 5-point Likert scale for feeling of happiness (Iwasaki, Zuzanek, & Mannell, 2001). The Adjusted Specific Chronic Stress Index, the Adjusted Recent Life Event Index, and the Work Stress Index (Statistics Canada, 1995) assessed chronic stress, negative life events, and work stress, respectively. The level of physical leisure was measured using the Physically Active Leisure Index (Statistics Canada, 1995). The index score were calculated by weighting a 5-point Likert Scale of frequency of participation (1= very infrequent to 5 = very frequent) in 20 leisure activities during the past three months. Structural equation modelling (SEM) showed the positive effects of physically active leisure on health for people who experienced higher levels of stress.

Two types of leisure, other than physical leisure, have also received attention. Firstly, social leisure has been defined as participation in activities which involve a sense of companionship and relationship with other people (Zimmer et al., 1995). Leisure experience gained in social activities creates a social role of being a 'good person of the community' (Allen, 1991) and an enjoyment of social productivity (Glass, de Leon, Marottoli, & Berkman, 1999). Social engagement was measured in a 9-year prospective epidemiologic study of 2,812 older people (Mendes de Leon, Glass, & Berkman, 2003). Frequency of participation in 8 social activities was measured via interview, with ratings of 0 (never), 1 (sometimes), and 2 (often). Disability status was defined as the ability to perform gross mobility and basic physical functions of ADLs and measured using a new questionnaire derived from previous studies (e.g., Nagi, 1976; Rosow & Breslau, 1966). Generalized linear modelling (GLM) showed the protective effect of social participation in decreasing long-term disability.
Secondly, passive leisure which involves a minimal degree of mental participation and provides relief from the stress and strain of life (Zimmer et al., 1995) has been studied. This type of leisure activities has been less well researched. One cross-sectional study (Everard et al., 2000) was conducted with 244 older adults. The

Activity Card Sort (ACS) (Baum, 1995), the Social Support Inventory (SSI) (Everard et al., 2000), and the SF-12 Health Survey (Ware, Kosinski, & Keller, 1996) were used as the measures of engagement in activities, social support in life, and health, respectively. Hierarchical multiple regression indicated the maintenance of low-demand (passive) leisure activities contributed to the prediction of more positive mental health.

Interestingly, Iwasaki, Mannell, Smale, and Butcher (2005) found it important to study the health benefits of engaging in both physical and non-physical forms of leisure. A leisure participation inventory, based on Ragheb's (1980) study and Mannell & Kleiber's (1997) deliberations on leisure experience, was used to assess frequency and enjoyment of leisure participation across different activities. These activities were proposed into 7 groups of leisure: physically active, social, relaxing, outdoor recreation, cultural, hobbies, and travel. Hierarchical regression analysis highlighted the importance of non-physical forms of leisure (i.e., social and passive leisure) as ways of coping with stress (via measures of perceived coping effectiveness adapted from Beehr and McGrath's study, 1996) and enhancing health (via SF-36®) in police and emergency response services workers (N = 132). This study suggested a further investigation for the health benefits of participating in physical and non-physical leisure activities across people with other health problems, such as chronic conditions was warranted.

2.3.6 Leisure Studies Involving People with Chronic Conditions

Chronic conditions have an impact on the individual experience of leisure involvement (Caldwell, 2005; Paffenbarger et al., 1991). Research in people with chronic conditions has focused primarily on frequency of leisure participation in the physical domain alone, rather than the non-physical domains (Caldwell, 2005). That research has found that higher frequency of physically active leisure is associated with better health outcomes in people with MS (Eldar & Marincek, 2000; Motl et al., 2005; Romberg, Virtanen, Aunola, Karppi, & Ruutiainen, 2004); people with RA (Da Costa, Dritsa, Ring, & Fitzcharles, 2004; Da Costa, Lowensteyen, & Dritsa, 2003); people with CFS (Taylor & Kielhofner, 2003; Wallman, Morton, Goodman, & Grove, 2005); and people with PPS (Eldar & Marincek, 2000; Rekand et al., 2004).

Wikström & Jacobsson (2005) and Zimmer et al. (1995) are two of a limited number of studies which investigated the health benefits of engaging in both physical and non-physical domains of leisure activities, including social and passive leisure. Zimmer, Hickey and Searle (1995) firstly categorized leisure activities in people living with RA. This study chose ten common leisure activities and asked 225 people with RA to rate their frequency of participation, on a scale of 1 (less than once a month) to 5 (daily participation). These items were based on a number of previous surveys of older people and a consultation with a local arthritis agency (Zimmer, 2004). Well-being was measured using the Bradburn Balance Affect Scale, which involved two sets of five items (positive and negative feelings on a scale of 1 to 3). Using a principal component factor analysis, these activities were described as social (4 items, 23.7% of variance), physical (3 items, 16.7%), and solitary/passive (3 items, 13.3%) domain. The results of regression equations indicated that well-being was influenced by the social domain of leisure activities, severity of arthritis, social satisfaction, age and income (at 26% of the variance). People with RA may reduce frequency of participation in the physical leisure activities and maintain either social or passive leisure activities.

The explanations of Zimmer and his co-researchers (1995) run contrary to findings of a prospective study of 80 people with RA (Wikström & Jacobsson, 2005). This study used different measures, compared with Zimmer and his co-researchers' study, but not significant correlation between quality of life (via Health Assessment Questionnaire, HAQ) and participation in physical and non-physical leisure activities (via a structured interview and the Norlings Index) was found. Norling (1996) developed the Norlings Index using factor analysis in a leisure survey in a Swedish population ($N = 11, 272$). This index measures frequency of participation in 8 items of physical (active), 5 items of passive, and 5 domains (active and passive) of social leisure (Wikström, 2005). The participants were asked to name all leisure activities they currently participated in, and then the researchers counted numbers of participants who participated in the same domains. Multiple linear regressions found that increasing physical leisure or maintaining social leisure did not contribute to the prediction of quality of life or QoL.

However, previous research has mostly focused on the contribution of positive engagement in physical forms of leisure activities to health in FSCI. Voss et al. (2002) provided the first attempt to measure dysfunction in domains of QoL (the Sickness Impact Profile, SIP), the impact of fatigue on physical function (Fatigue Impact Scale, FIS), depression (Chicago Multiscale Depression Inventory, CMDI), and physical disability (Expanded Disability Status Scale, EDSS) in 76 people with MS. Using structural equation modelling, limitations in engaging in leisure activities via the SIP were related to three variables: the impact of fatigue on physical function ($r = 0.38, p < 0.01$), physical disability ($r = 0.43, p < 0.01$), and depression ($r = 0.28, p < 0.05$). These relationships raise a further hypothesis that leisure participation may reduce the impact of fatigue on physical functions, physical disability, and depression.

Pattie and co-researchers (2002) examined the impact of a rehabilitation program, including appropriate exercise, on HRQoL (Medical Outcome Study Short Form, SF-36®), depression (Beck Depression Inventory, BDI), fatigue (the FIS), and social function (Tempelaar Social Experience Check-list, SET) in 111 people with MS. The participants were randomly assigned to a treatment group ($N = 58$) or control group ($N = 53$). Improvements on all parameters were significant for the treatment group ($p < 0.001$). Exercise had a positive impact on coping with fatigue and depression, which is similar to a study by Petajan and others (1996). They conducted a 15-week aerobic training program for 54 people with MS. Compared with baseline, the exercise group significantly improved in physical fitness (maximal aerobic capacity, VO_2 max and isometric strength) and physical domains of quality of life (the SIP), and had reduced depression (Profile of Mood States, POMS) and fatigue (Fatigue Severity Scale, FSS). However, other research (MacAllister & Krupp, 2005; Mostert & Kesselring, 2002) has failed to show a positive impact of exercise due to a small sample size, low sensitivity of measurement tool, and the unpredictable nature of fatigue.

Previous research noted that fatigue may reduce individual satisfaction with leisure participation (Kielhofner, 2002; Taylor et al., 2003). People with greater impact of fatigue experience social isolation (Barnwell & Kavanagh, 1997; Yorkston, BC-NCD, Johnson, CRC, & Klasner, 2005) and less participation in social leisure

activities which may be associated with poor health (Flechtner & Bottomley, 2003; Lucia, Earnest, & Perez, 2003) and QoL (Kesselring & Beer, 2005). Participation in social leisure activities has been less well researched in people with chronic conditions. Barnwell and Kavanagh (1997) attempted to examine the predictive value of engagement in social activity in 71 people with MS. Self-efficacy and engagement in social activity were separately measured over two months. Stepwise regression indicated that past engagement in social activity was the strongest predictor of later engagement in social activity.

Apart from social and physical leisure, some individuals avoid physical leisure (Sutherland & Andersen, 2001) and take a rest (Lobentanz et al., 2004) in order to reduce the risk of increasing fatigue. However, there has been no clear explanation of the cause and effect of these activities on fatigue and health. The effect of a 10-week-autogenic training program, including relaxation as a leisure pursuit (passive domain), was studied in 11 people with MS (Sutherland, Andersen, & Morris, 2005). Four variables were measured in this study: HRQoL (Multiple Sclerosis Quality of Life Instrument, MSQOL), fatigue (the POMS), depression (Centre for Epidemiological Studies Depression Scale, CES-D), and social support (Multidimensional Scale of Perceived Social Support, MSPSS). Compared with the baseline, a medium to large effect on HRQoL, fatigue, depression, and social support were demonstrated. However, this study did not examine the effectiveness of leisure participation other than for the variable of relaxation.

Previous studies suggest that living with a chronic condition appears to alter perceptions of the demands and rewards of participating in both physical and non-physical forms of leisure activities (Khemthong, Packer, & Passmore, 2005). That stated, gaps still exist however with respect understanding the relative contribution of different types of leisure participation to physical and mental health. In part, this could well be because of a lack of appropriate measurement tools for such a line of inquiry.

2.3.7 Implications for the Management of FSCI

In early 1988, Corbin and Strauss did a qualitative study based on the perceptions of people about their chronic conditions. Three tasks for chronic illness management have been established (Corbin & Strauss cited in Lorig & Holman, 2003). The first task is medical management of the condition such as taking medication and receiving therapeutic activities to manage symptoms. The second task is emotional management such as coping with depression as a consequence of the condition. The third task is role management such as changing behaviours to perform new activities of daily living. To date, clinical research is beginning to examine effectiveness of programs for managing fatigue. Table 2.2 demonstrates three types of interventions noted in literature: cognitive behaviour therapy (CBT) self-management, and leisure. Both CBT and self-management have been shown to be effective in recent clinical trials. Based on the findings from the PhD research, the potential of leisure programs as an optional intervention for people with FSCI can be examined. Using the framework of Corbin and Strauss (1988), the focus and effectiveness of these three types of intervention have been examined in relationship to whether they are able to manage symptoms of FSCI, emotional consequences of FSCI, or the impact of FSCI on life activities.

Table 2.2

Management of chronic illness and types of interventions noted in literature

Chronic illness management	Types of interventions		
	CBT	Self-management	Leisure
1. Medical management	√	√	?
2. Emotional management	√	√	?
3. Role management	?	√	?

Note. √*= significant outcome, ? = No measure/evidence.*

CBT is based on the client's beliefs about the impact of fatigue and the way they manage behaviour in relation to fatigue (Swain, 2000). CBT has been used successfully to lessen symptoms and emotional consequences of fatigue in people with CFS (Mohr, Boudewyn, Goodkin, Bostrom, & Epstein, 2001; O'Dowd, Gladwell, Rogers, Hollinghurst, & Gregory, 2006). A comparative study of three 16-week interventions was conducted with people with MS (Mohr, Boudewyn, Goodkin, Bostrom, & Epstein, 2001). The interventions and participants per group

included supportive-expressive group therapy (SEG) (N = 22), antidepressant sertraline (N = 21), and CBT (N = 20). Significant reduction of depression was seen from pre- to post-treatment in both CBT and antidepressant sertraline, but not in SEG group. This result suggests CBT and medication increased coping with depression. A double-blind randomised controlled trial (RCT) was conducted to compare CBT with education and support (EAS) and with standard medical care (SMC) for people with CFS (O'Dowd, Gladwell, Rogers, Hollinghurst, & Gregory, 2006). The CBT intervention (N = 52) was the most effective in managing health outcomes (fatigue, mood, and physical fitness activities) compared with the other two (EAS, N = 50 and SMC, N = 51). Thus, CBT has addressed two tasks of chronic illness management: medical and emotional management.

Self-management programs are effective interventions for people with MS (Mathiowetz, Finlayson, Matuska, Chen, & Luo, 2005), RA (Lorig, Ritter, & Plant, 2005; Lorig, Ritter, Laurent, & Fries, 2004), and diverse chronic conditions (Lorig, Ritter, Stewart, Sobel, Brown, Bandura, et al., 2001). Mathiowetz and his colleague (2005) randomly assigned 169 people with MS to a six-week energy conservation course (N = 78) or a delayed control group (N = 91). Mixed effects analysis of variance models demonstrated the program had positive effects on fatigue, self-efficacy, and HRQoL. The effectiveness of Self-Management Arthritis Relief Therapy (SMART) was examined (Lorig, Ritter, Laurent, & Fries, 2004) using two studies: participants randomized to SMART (N = 468) or usual care (N = 413), and participants randomized to SMART (N = 166) or Arthritis Self-Management Program (ASMP) (N = 142). Analyses of covariance (ANCOVA) demonstrated that SMART at 1 year decreased disability, decreased pain, decreased depression, improved role function, and increased self-efficacy when compared with usual care or ASMP. Improvements from baseline were shown in all variables in both SMART and ASMP. Lorig and her colleague (2005) also conducted the ASMP for 239 clients and the generic Chronic Self-Management Program (CDSMP) for 116 clients. Both programs had positive effects on many health outcomes such as fatigue, self-efficacy, HRQoL, health behaviours (stress management and exercises). The CDSMP has also reduced health outcomes (e.g., fatigue, role activity limitation, distress), improved self-efficacy, and decreased health care utilization for people with heart disease, lung disease, stroke, or arthritis (N = 831) (Lorig, Ritter, Stewart, Sobel, Brown, Bandura,

et al., 2001). Thus, self-management enables symptom, emotional, and role management.

Leisure interventions have been tested as a method to improve HRQoL and leisure satisfaction in people with paraplegia (Daniel & Manigandan, 2005). Participants were stratified into a leisure group ($N = 15$) and a control group ($N = 10$). The leisure intervention included 1 hour-long session (3 times a week) for group discussion (including home assignments) on the benefits of leisure participation and how to overcome problems faced in leisure participation. After 15 days, this intervention showed positive effects on leisure satisfaction and HRQoL, using independent t – test analysis between the two groups. This result suggests that the leisure intervention changed the attitude of the participants toward leisure activities and resulted in health benefits. However, the effectiveness of leisure intervention on fatigue and its emotional consequences has not been studied.

2.4 SUMMARY

Theorists (Coleman & Iso-Ahola, 1993; Mannell & Stynes, 1991; Passmore, 2003; Tinsley & Tinsley, 1986) have proposed models of good health outcomes (physical and mental) by viewing leisure from a number of perspectives. In particular, Coleman and Iso-Ahola (1993) proposed and tested a model (Coleman, 1993; Iso-Ahola & Park, 1996). However, as detailed previously, conceptualizing leisure itself is challenging. It requires measuring not only frequency, but also characteristics of activities and some qualitative dimension (e.g.,, freedom of choice, level of enjoyment/satisfaction). Earlier studies (Beard & Ragheb, 1980; Christensen & Mackinnon, 1993; Zimmer et al., 1995) used various classifications/types of leisure activities based on frequency and/or satisfaction of participation, such as physical, social, educational/creative, and passive leisure. These classifications and measurements have been studied from various perspectives related to health outcomes in the general population and in people with chronic illness. Some studies have illustrated how fatigue mediates pain, depression, and social support, and that all of these, in turn, are related to HRQoL. However, little research has been able to measure all fatigue related factors, suggested by the definition, physiological (e.g.,

pain), psychological (depression and social support) and activity and participation. To date, no published studies for people with FSCI have focused on the contribution of positive or negative engagement in leisure (type, frequency, and satisfaction) to fatigue or HRQoL while considering known contributing factors of fatigue (i.e. pain, depression, and social support).

CHAPTER 3

DEVELOPMENT OF THE PRELIMINARY CLASSIFICATION OF LEISURE PARTICIPATION SCALE

3.1 INTRODUCTION

Research into the relationship between leisure and health has shown that leisure activities have a positive effect on health. Different types of leisure activities, such as participating in physical, social, educational/creative, and/or passive activities, have been addressed in general populations and, more particularly, people with a specific chronic condition. However, little research has focused on the contribution of those leisure activities to health and fatigue.

The overall purpose of this study was to examine the relationship between leisure, health and fatigue. However, there has been no reliable tool developed that could differentiate the impact of those leisure activities on health in women with FSCI or chronic conditions. This chapter reports on the development of the preliminary CLP Scale using a population of women without chronic conditions. The preliminary tool is then examined in two validation studies that led to the final development of the measurement tool (Chapter 4).

Specifically, the goals of this component of the overall study were to:

1. determine the most common leisure activities of Australian adults (item generation);
2. select the most representative items to form the preliminary CLP Scale (item reduction); and
3. assign items domains within the categories of "physical", "social", "educational/creative" and "passive" leisure (determination of domains) in 102 women without chronic conditions.

3.2 BRIEF LITERATURE REVIEW

The International Classification of Functioning, Disability and Health, ICF has defined activity and participation, and described different domains for active participation in people with disabilities (World Health Organization, 2001). Some examples of activity domains are mobility, self-care, domestic life, and major life areas (World Health Organization, 2001). These domains are compatible with the four roles/areas of an individual's life cited in occupational therapy literature: rest,

work, self-care, and leisure (Baum & Edwards, 2001; Law, 2002; Law, Steinwender, & Leclair, 1998; Trombly, 1995). Time use in these four areas has been measured (Pentland, Hervey, & Walker, 1998), however, studies have mostly focused on participation in discrete tasks as opposed to assignment to type or classification of activity.

A number of self-report questionnaires for assessing participation have been developed, mostly consisting of a list of activities. Examples of the questionnaires include the Sickness Human Profile (SIP) (Bergner et al., 1976); Human Activity Profile (HAP) (Fix & Daughton, 1988); the Adelaide Activity Profile (AAP) (Bond & Clark, 1998); and the Activity Card Sort (ACS) (Baum & Edwards, 2001). All these examples were developed based on participation of a healthy population, and many aim to measure frequency of participation in everyday activities (Law, 2002) without a focus specifically on leisure participation. These measurement tools assess all activity domains together (i.e., rest, work, self-care, and leisure); therefore, they cannot classify different types of leisure activities.

An adolescent leisure questionnaire, developed by Passmore and French (2001) for measuring adolescent leisure, was one of the first instruments to focus not only on time and participation but also accounted for the qualitative dimension of leisure. It has subsequently been found that the nature and types of leisure activity in which young people engage may play an important part in the relationship between leisure and health (Passmore, 2003). This measurement tool classified leisure participation of adolescents into achievement, social and time-out leisure.

For adults, quantification of different aspects of leisure has been limited. Most study-specific-questionnaires have been based on previous surveys of a national population. This method of item generation has face validity, but lacks rigor in assigning activities to different classifications. Item selection and assignment, based on statistical analysis, is required to construct an appropriate measure of leisure activities for particular populations, such as people with and without chronic conditions.

Previous research has attempted to examine the health benefits of physical (Motl, McAuley, & Snook, 2005; Sutherland & Andersen, 2001), social (Barnwell & Kavanagh, 1997; Zimmer et al., 1995), and passive (Sutherland et al., 2005) leisure but different forms of questionnaire and statistical analyses have been used. A greater understanding of the complexities is therefore needed to identify the relative contribution of leisure engagement to population health (Christensen & Mackinnon, 1993; Connolly & Law, 2001; Iwasaki & Mannell, 2000) and within populations with specific health conditions (Zimmer et al., 1995).

Despite the lack of measurement tools, evidence is emerging that highlights the importance of being able to classify and measure leisure. Leisure participation has been proposed as an individual pathway for transforming the negative experience of a chronic condition into positive well-being (Caldwell, 2005). For example, it has been shown that people who participate in leisure activities are more likely to experience feelings of social support and capacity for self-determination (Coleman & Iso-Ahola, 1993; Passmore, 2003). These experiences provide a buffer against negative life events while maintaining good physical and mental health (Coleman & Iso-Ahola, 1993). Different types/domains of leisure participation may unequally contribute to this transforming experience (Bull, Hoose, & Weed, 2003; Caldwell, 2005; Lynch & Veal, 1996; Parker, 1996; Roelofs, 1999).

As noted earlier, research in people with chronic conditions has primarily focused on the frequency of leisure participation in the physical domain in isolation, rather than with due consideration of the non-physical domains of leisure activities (Caldwell, 2005). Physically active leisure has been found to improve health outcomes in people with multiple sclerosis (MS) (Eldar & Marincek, 2000; Motl et al., 2005; Romberg, Virtanen, Aunola, Karppi, & Ruutiainen, 2004); rheumatoid arthritis (RA) (Da Costa et al., 2004; Da Costa et al., 2003); chronic fatigue syndrome (CFS) (Taylor & Kielhofner, 2003; Wallman, Morton, Goodman, & Grove, 2005); and post polio syndrome (PPS) (Eldar & Marincek, 2000; Rekand et al., 2004). A few studies have also investigated the health benefits of engaging in the non-physical domains of leisure activities (Karp et al., 2005; Wang et al., 2002; Wikström, 2005; Zimmer, 1995) including social, educational/creative, or passive activities. These recent studies highlight the importance of investigating health benefits of all types of

leisure, particularly for those people for whom physical activity is painful or difficult due to a chronic condition. To date, the degree to which different leisure activities contribute to physical and mental health has not been fully investigated in adults with chronic conditions.

The complexity of this investigation is highlighted by research that demonstrates that participants have different perceptions, or attach different meanings to physical and non-physical leisure activities (Parker, 1996; Roelofs, 1999; Shogan, 2002) and that living with a chronic condition appears to alter perceptions of the demands and rewards of participating in physical, social and passive leisure activity (Khemthong, Packer, de Jonge, & Boshoff, 2006). To date, the non-physical domains of leisure activity have been difficult to define (Bull et al., 2003; Lynch & Veal, 1996) and are less well examined (Lynch & Veal, 1996; Roelofs, 1999) in people with chronic conditions. Thus, gaps still exist in understanding the relative contribution of different types of leisure participation, particularly in specific population groups. Lack of appropriate measurement tools may be the critical factor in understanding these important relationships. To date, however, no measurement tool has been available except for use with adolescents (Passmore & French, 2001) that simultaneously and systematically quantifies and classifies engagement in different types of leisure. This chapter reports on the development of such a tool for use with women with chronic conditions.

3.3 ITEM GENERATION

Two sources of data were used in order to generate potential leisure items for the CLP Scale. The first source was data collected to develop the Activity Card Sort (ACS)-Australian version (Packer et al., 2006). The second source consisted of data published by the Australian Bureau of Statistics (ABS) (Australian Bureau of Statistics, 1998a, 1998b, 1999).

Development of the ACS-Australia included compilation of a comprehensive list of activities undertaken by older Australians. Sources included items from the original and Israeli ACS versions as well as time use data from 292 older Australians. After

accounting for duplicates 114 potential items were generated. The final list of the ACS-Australia included 82 items categorized into 46 leisure, 24 social/educational, and 12 household/work activities (Packer et al., 2006). From the ACS-Australian version, seventy items (46 leisure and 24 social/educational) were selected as potential items for the CLP Scale. These matched the definition of leisure used in this study (See List of operational definitions and abbreviation); activities done in free time or non-work time (Leitner & Leitner, 2004).

The second source was the 1997 National Time Use Survey (TUS) which measured how Australian people (N = 7,260 Australians over 15 years of age) allocate time into four time categories: necessary time, contracted time, committed time, and free time (Aas, 1982 cited in Australian Bureau of Statistics (ABS), 1998a, 1998b, 1999). This survey divided the time categories into nine activity categories: one category for necessary time (personal care activities); two categories for contracted time (employment and education activities); four categories for committed time (domestic, child care, purchasing, voluntary work and care activities); and two categories for free time (social and community interaction, and recreation and leisure). The activities included in free time were used as the second source of potential items for the preliminary CLP Scale.

Items in the category of free time, which was defined as "the amount of time left when the previous three types of time have been taken out of a person's day (Australian Bureau of Statistics, 1998a, p. 77)," were considered to be compatible with the definition of leisure in the this study. This ABS survey used self-completion diaries and trained interviewers to collect respondents' activities including nature/type, timing and duration of activities over two separate days. Activities were classified and coded in a database using a tailored microcomputer system (Australian Bureau of Statistics, 1998b). The 'free time' category consisted of 36 items (12 social and 24 leisure activities). These items were matched to the selected items from the first source (70 items). Interestingly, 100% of the ABS items were included in the ACS Australia demonstrating commonality between the two sources.

Because no additional items were added, the available data of the 70 social and leisure items (Packer et al., 2006) was reanalysed for the preliminary CLP Scale.

This secondary analysis was based on data collected from 57 older Australians who had been shown all 114 activity cards and asked, "How common do you think it is for Australian adults aged 65 and over to participate in each activity." Participants rated each of the activities using a 5-point rating scale (0 = no-one does this activity to 4 = most people do this activity). Mean scores for each item were calculated and activities ranked from most to least common. Only the data for the 70 leisure activities was examined for the preliminary CLP Scale. In order to select the most common items, items with a mean score of < 2.0 were eliminated leaving 61 out of the 70 items. These items remained for potential inclusion in the CLP Scale (See Table 3.1).

3.4 ITEM REDUCTION AND DETERMINATION OF DOMAINS

3.4.1 Purposes for this Step

The item reduction was used to reduce the number of potential items generated in the previous step by selecting those items most representative of four categories (physical, social, educational/creative, and passive leisure), based on the perspective of women without chronic conditions. Once the items were selected a final determination of domains was undertaken using cluster analysis.

3.4.2 Design

A cross-sectional survey was designed to gain perspective of women with reference to the characteristics of leisure activities. Because most leisure activities include components of four types (physical, social, educational/creative and passive) (See Chapter 2), selection and nomination to category was undertaken based on the beliefs of Australian adults and determined through use of a phone survey that evaluated all potential items from the item generation phase.

3.4.3 Rationale for Using a Telephone Survey

The rationale for use of a telephone survey was that it offers a schedule of questions in the same format (order, wording, and voice tone) and increases accuracy of data collection in time-use research (Stinson, 1999). Higher response rates (less missing data) are achieved (Duncan et al., 2005; Perkins & Sanson-Fisher, 1998). This mode

Table 3.1

Potential items for the preliminary CLP Scale

Going to place of worship
Volunteer work
Interest group/club
Community/civic activities
Going to children's or grandchildren's activities
Storytelling with children
Marriage/relationship
Entertaining at home or club
Travelling
Parties/picnics/BBQ
Family gatherings
Visiting with friends
Going out for a meal or drinks
Taking a day trip
Doing favours and helping out
Talking with family and neighbours
Gardening/growing flowers
Watching movies (theatre or home)
Watching television
Listening to music
Sitting and thinking/reminiscing
Cards
Computer (email, games)
Collecting
Crosswords and word games
Puzzles
Spectator sports
Recreational shopping
Sewing
Handcrafts
Reading magazines/books
Reading newspapers
Letter writing
Going to the library
Attending concerts
Going to the theatre
Bowling
Golfing
Walking
Exercising
Knitting/crocheting
Going to beach
Having morning or arvo cuppa
Listening to radio
Bingo
Lawn Bowls
Gambling
Going to art/craft classes/groups (folk art, sewing)
Preparing for outing/trip
Getting petrol
Taking care of a pet
Talking on the phone
Shopping in a store
Driving
Visiting friends who are ill
Resting
Beauty/Barber shop
Care-giving (grandchildren, family/friends who are ill/disabled)
Using public transport
Going to the post office
Health-related activities (health appointments, aqua-aerobic, walking)

is appropriate for short questionnaires that require less than 15 minutes of interviewing time per person (Burns, 2000) and ensures participants who may be inexperienced or poorly motivated (McHorney, Kosinski, & Ware, 1994; Perkins & Sanson-Fisher, 1998). Item reduction and determination of domains also required a large sample of women without chronic conditions who were easily recruited and surveyed via the phone administration. This was a way to preserve the sample of women with chronic conditions for the main study.

3.4.4 Participants

Women living in the State of Western Australia, able to complete questionnaires in English, between 25 and 64 years of age (inclusive) and with no history of chronic conditions were recruited. Women were recruited based on the known higher prevalence of fatigue compared to men (See Chapter 2). The sample size (at least 100 participants) was matched to the sample size for women with chronic conditions needed in the main study. The required number of participants was determined by two statistical calculations (See power calculation of sample size in Chapter 6).

3.4.5 Ethical Consideration

Ethics approval (OT-2005-03) was granted through the Human Research Ethics Committee of Curtin University of Technology. The purpose of the research focusing on item selection was explained to eligible participants. Willingness and verbal consent to participate were sought by asking the question (See Appendix 1) "Do you have a few minutes to help the PhD student with his research?" If they declined, the interview was terminated and there was no further contact. As data were collected only one time when they agreed to participate, no names were required and all data were anonymous.

3.4.6 Procedures

A telephone market research company was engaged to undertake the survey administration, data coding and summarization process. The rationale for using the company lay with the use of a Computer Assisted Telephone Interviewing (CATI) resource and the fact that a team of 6 female interviewers, who had been trained by Interviewers Quality Control Australia (IQCA), were available to facilitate process. Prior to commencing the interview process, each was fully briefed on the aims of the

research and approach to the questionnaire prior to commencing interviewing work. This briefing was conducted by the company's senior consultant and the researcher.

The CATI protocol included a two-stage random selection process: initial telephone sampling and a "birthday" method. Initial telephone sampling is from the "White Pages on disk" which includes the residential telephone numbers in the Western Australia White Pages (business numbers removed). This is done via electronic software that uses a standard random dialing procedure.

Up to three calls were made to an unanswered number (after a minimum of two hours had elapsed) to give heightened opportunity for more mobile (and smaller households) to be included in the survey. Answering machines were treated as a "non answer" and were called back over subsequent days, with a message to contact the interviewers being the last resort. Engaged numbers were called back on 15-minute intervals in an attempt to secure an interview. Once contact was made with a household, a random selection of respondent was made (generally based on the "birthday" method). If the nominated person was not available, up to two further calls were made in an effort to interview the randomly selected individual.

When the contact was made and the nominated person was available women without chronic conditions were interviewed via a telephone interview form (See Appendix 1), which included the data as follows:

Demographic data: Age, education, marital status, employment, and number of adults living at home were obtained.

Leisure activities: Participants were asked to assign each of the potential 61 items into one of four categories; "mostly physical, social, educational/creative, or passive leisure activities." The rationale for focusing on these 4 categories was that many studies (Beard & Ragheb, 1980; Christensen & Mackinnon, 1993; Wikström & Jacobsson, 2005; Zimmer, Hickey, & Searle, 1995) examined these categories in relation to the health outcomes in the general population and a chronic condition, and that it is unknown whether Australian women without chronic conditions identify leisure activities in the same way.

3.4.7 Data Analysis

All data were entered into and managed via the Statistical Package for the Social Sciences, SPSS software for Windows version 11.5 (© 2005 SPSS Inc., Chicago, Illinois). One step was used to select items and one step was used to assign them to domains. First, percentage agreement per item was calculated. All items that reached 60% or greater agreement for one category were selected. The 60% cut-off indicates that more than half the participants classified the item in the same way.

Secondly, these items were grouped into domains (determination of domains) using Hierarchical Cluster Analysis (Coakes & Steed, 2005; Dawson & Trapp, 2001c). This classification method identifies similarities between the items when forming the clusters (Dawson & Trapp, 2001c). Similarities are a set of conditions that serve as criteria for grouping the items. In hierarchical technique, the resultant classification increases homogeneous domains among different items (Dawson & Trapp, 2001c). The rationale for adding cluster analysis to the step of % agreement was to ensure whether the selected items had been statistically grouped in a form of dendrogram.

3.4.8. Results

3.4.8.1 Description of the Sample

Using the described random sampling procedure, 102 participants were engaged in telephone interviews. Of the 1, 214 calls made to a random selection of households, there were 489 disconnected households and 725 contacted households. Of the 725 contacted households, 358 households did not have any women aged 25 to 64 years living there. Of the 367 households with eligible women, 265 households refused; and 102 households agreed to participate in the survey (27.79% of 367 households).

The mean age of participants was 43.39 years (SD 10.45). No participants had self-reported medical conditions. Most of the participants were married (74.5%) and employed (66.7%). Approximately one third (32.4%) had obtained a university degree and more than half of the participants were living with one adult at home (64.7%), as illustrated in Table 3.2.

3.4.8.2 Leisure Activities and Domains

As shown in the Figure 3.1, the 60% agreement level was achieved on 29 leisure activities. The cluster analysis confirmed the four dominant types of leisure participation: physical, social, educational/creative, and passive leisure. Five items clustered around physical leisure – exercising, health- related activities, walking, golfing, and bowling. Educational/creative leisure consisted of 6 items, for example, crosswords and going to art classes. Six items clustered around passive leisure. Examples included listening to music and reading. Social leisure showed the highest number of items, such as family gatherings, visiting friends, and talking on the phone.

Dendrograms provide a visual display of similarity of items. Those items most similar (based on inter-correlation) are grouped together. The level of similarity is indicated by nested lines. In this study four clear groups emerged and were labelled physical, social, educational/creative, and passive leisure.

Table 3.2

Demographic of the participants without chronic conditions (N = 102)

Demographic	Raw number	Percent
	Marital status	
Married	76	74.5
Divorced	15	14.7
Never married	11	10.8
	Employment status	
Employed	68	66.7
Unemployed	6	5.9
Retired	8	7.8
Full-time homemaker	20	19.6
	Educational levels	
Primary school	2	2.0
Year 10 high school	23	22.5
Year 12 high school	21	20.6
Diploma	23	22.5
University degree	33	32.4
	Number of adults living with	
None	21	20.6
One person	66	64.7
Two people	8	7.8
Three people	6	5.9
Four people	1	1.0

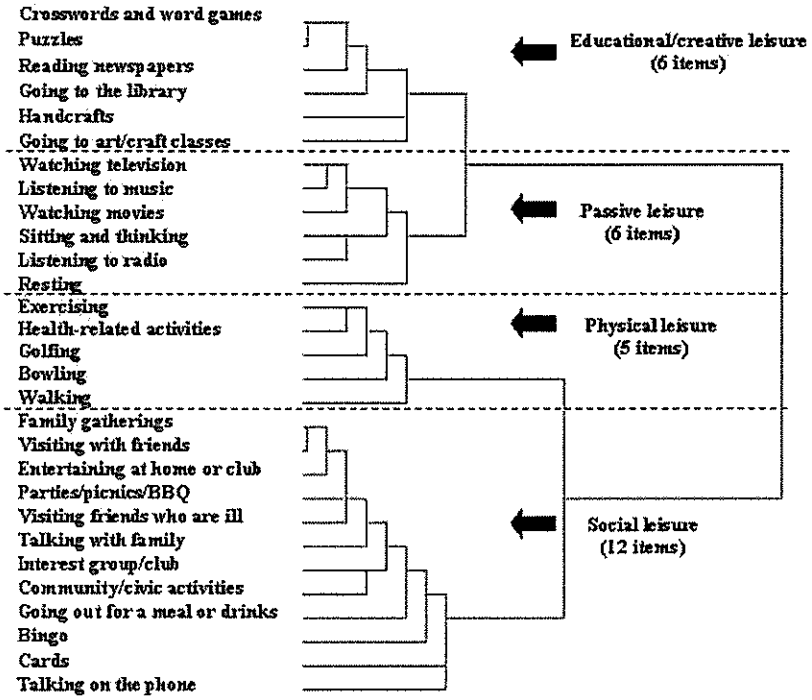

Figure 3.1. A dendrogram of leisure activities classified into 4 categories by 102 women without chronic conditions.

3.4.9. Discussion and Implications for the Main Study

This study determined 29 leisure activities for inclusion in the preliminary CLP Scale. These leisure activities were identified as item generation from the ABS checked with the ACS data. Hierarchical Cluster Analysis then classified the selected items into four categories: physical (5 items), social (12 items), educational/creative (6 items), and passive (6 items) leisure. These item domains provide a more focused agreement and classification for women without chronic conditions. The 60% cut-off was selected for two reasons. First, agreement at this level indicates that 60% of respondents were in agreement on a single category. Given the option of four categories, this indicates strong agreement across participants. Secondly, consistent with hierarchical cluster approaches, meaningful grouping of items into categories is required. Using items with this level of agreement provided a dendrogram with clear aggregation of items into groups, confirming this as a reasonable cut-off score. Thus, activities with the most consistency across participants were selected based on perceptions of women without chronic conditions, but actual allocation to category was performed statistically (see Khemthong, Packer, & Passmore, accepted).

Not all items in each category were consistent with Passmore and French's (2001) study that reported three categories of leisure participation classified by young adults, even though they were labelled differently. Those examples are: talking on the phone, visiting with friends and going out for a meal or drinks (social leisure); listening to music and watching television (passive leisure or time-out). Women without chronic conditions viewed more items in the social domain, indicating their unique characteristics might have been influenced by the benefits of social leisure. Previous research found that social leisure contributed to the prediction of mental health for 850 adolescents (Passmore, 2003) and for 132 police and emergency response services workers (Iwasaki, Mannell, Smale, & Butcher, 2005). Leisure activities for these healthy populations often takes place in social settings, and the social nature may play an important role of improving health (Iwasaki, Mannell, Smale, & Butcher, 2005). However, these studies did not examine health benefits of social leisure for women without chronic conditions, whom are known to have decreased social networks (Kesselring & Beer, 2005; Mullins et al., 2001).

As known, different populations may not participate in leisure activities in the same way due to their coping with negative life events and health status (Coleman, 1993; Iwasaki & Mannell, 2000). The main study of PhD research aimed to examine relationship between leisure and health in women with FSCI or chronic conditions. Thus, the resultant classification in this study was to preserve the sample of women with chronic conditions ($N = 102$) needed for the main study.

CHAPTER 4

TWO VALIDATION STUDIES

AND FINAL DEVELOPMENT OF THE CLP SCALE

4.1 VALIDATION STUDY 1: A COMPARISON OF DOMAINS IN WOMEN WITH AND WITHOUT CHRONIC CONDITIONS

4.1.1 Rationale and Purpose for Validation Study 1

In Chapter 3, women without chronic conditions classified leisure activities into four domains: physical, social, educational/creative, and passive leisure. Before progressing to the main study, confirmation that women with, and without, chronic conditions classify leisure activities in the same way was required. Thus, this validation study compared leisure domains categorized by women without chronic conditions to domains categorized by women with FSCI. Since this study was a preliminary comparison using the phone interviews, a small sample size was used for both groups.

4.1.2 Participants

Women with chronic conditions were recruited on a voluntary basis through advertisements (See Appendix 2), newsletters, and membership lists of related non-government organizations (NGOs) and associations. Women with chronic conditions were recruited for and participated in both validation study #1 and #2. Women without chronic conditions were recruited randomly from residential telephone numbers of Western Australian White Pages via electronic software as previously described. Different sampling techniques for the two groups were required due to the availability and accessibility of each group. The NGOs and associations have large memberships and are a convenient way to recruit women with chronic conditions whereas the residential telephone numbers were an effective strategy to contact women without chronic conditions.

The inclusion criteria of participants were the same as the previous chapter, except women with chronic conditions had the added criteria of diagnosis with at least one of four chronic conditions, MS, RA, CFS, and PPS, all of which have a high prevalence of fatigue. The exclusion criteria for women with chronic conditions were: experiencing an acute exacerbation (self-report); having additional medical conditions known to cause fatigue (such as anemia, severe respiratory deficit, and clinical depression, assessed via self-report check-list); being diagnosed or self-reporting symptoms of neuropsychological impairments (such as memory loss,

aphasia). Women were not selected on the basis of level or severity of fatigue in order to ensure the CLP and the final research was applicable across the entire range of fatigue.

4.1.3 Ethical Consideration

Data from women without chronic conditions was collected anonymously (See Section 3.4.5). Women with chronic conditions (RA, MS, and other chronic conditions) were recruited on a voluntary basis due to the constraints imposed by the Privacy Ordinance. Interested participants directly contacted the researcher or, where appropriate and with individual permission, staff from the related associations passed the contact details of the interested participants to the researcher. The researcher contacted the participants and explained the purpose of the research, which included both this and the Validation Study #2 (See Section 4.2). Once willingness to participate in the research was ascertained, they were engaged in telephone interviews and all data were de-identified. For Validation Study #2, a consent form and a questionnaire booklet were also mailed to them. The participants were asked to fill out and return the documents in a pre-paid envelope within one week. The signed consent forms were kept separately from the questionnaires. All questionnaires were thus received in a de-identified form.

4.1.4 Procedures

Demographic data: Age, education, marital status, employment, medical history and duration of diagnosis, and number of adults living at home were obtained (See Appendix 1).

Leisure activities: Participants were asked to assign each of the potential 61 items into one of four categories; "mostly physical, social, educational/creative, or passive leisure activities (See Appendix 1)."

4.1.5 Data Analysis

All data were entered into and managed via the SPSS software for Windows version 11.5 (© 2005 SPSS Inc., Chicago, Illinois). Women with (N = 24) and without chronic conditions (N = 102) were compared for differences on the demographic variables using independent t tests and Chi-square (χ^2) tests. Items which achieved

60% or greater agreement were selected and included in a cluster analysis (See Section 3.4.7). The resultant dendrogram (one per group) identified the most representative items for each domain. The dendrograms from both groups of the participants were then visually compared for number of domains and item per domain. This visual inspection determined if the item selection and determination of domains for the two groups were different.

4.1.6 Results

4.1.6.1 Description of the sample

Twenty-four women with chronic conditions and 102 women without chronic conditions participated in this study (total = 126). The mean (SD) age of women with and without chronic conditions was 44.21 (10.50) and 43.39 (10.45). No significant differences were found between the two groups on the demographic variables of age, education level, and marital status. Women with and without chronic conditions were married (74.1% and 74.5% respectively), employed (64.5% and 66.7%), university graduates (30.3% and 32.4%), and living with one adult (67.6% and 64.7%) (See Table 4.1).

Table 4.1

Comparisons of data between women with and without chronic conditions

Demographic and clinical characteristics	Women with chronic conditions	Women without chronic conditions	P-values of statistical test
Mean (SD) of Age	44.21 (10.50)	43.39 (10.45)	0.17
Percents of Medical Diagnoses			-
Multiple Sclerosis	41.7		
Rheumatoid Arthritis	20.8		
Chronic Fatigue Syndrome	25.0		
Post Polio Syndrome	8.3		
Chronic Fatigue Syndrome and Multiple Sclerosis	4.2		
No medical condition		100	
Percents of Marital Status			0.54
Married	74.1	74.5	
Divorced	15.4	14.7	
Never married	10.5	10.8	
Percents of Employment Status			0.31
Employed	64.5	66.7	
Unemployed	6.3	5.9	
Retired	8.4	7.8	
Full-time homemaker	20.8	19.6	
Percents of Educational Levels			0.61
Primary school	2.0	2.0	
Year 10 high school	25.6	22.5	
Year 12 high school	20.5	20.6	
Diploma	21.6	22.5	
University degree	30.3	32.4	
Percents of Adults Living with			0.64
None	20.8	20.6	
One person	67.6	64.7	
Two people	5.9	7.8	
Three people	4.2	5.9	
Four people	1.5	1.0	

4.1.6.2 Comparison of dendrograms

Different dendrograms emerged for the two groups. These dendrograms illustrates two separate figures of leisure classification for two different groups: women with and without chronic conditions. In each dendrogram, leisure items were grouped into three to four domains or categories due to the most significant aggregation and allocation of leisure items using cluster analysis. Women with chronic conditions agreed on 41 items in three domains (no educational/creative) whereas those without chronic conditions agreed on only 29 items divided into four domains, same as for N = 102 (Figure 3.1). Examples of common activities for both groups were exercising and walking (physical leisure), bingo and talking on the phone (social leisure), watching television and resting (passive leisure). Interestingly, women with chronic conditions experienced more leisure activities in a physical way than those without.

4.1.7 Discussion and Implications for the Main Study

This study demonstrated that women with, and without, chronic conditions appear to classify the same activities into different categories/domains. Women with chronic conditions identified only three types of leisure participation, with no educational/creative activities cluster. They also viewed many more activities in a physical way than women without chronic conditions. One possible explanation for this result is that living with different chronic conditions has influenced their perception of the leisure participation of the individuals (Caldwell, 2005); for instance, increasing their perceptions of health benefits in relation to physical forms of leisure activities (Khemthong, Packer, de Jonge, & Boshoff, 2006). Previous research also confirmed a positive relationship between frequency of participation in physical leisure and health outcomes in people with MS (Motl et al., 2005); people with RA (Da Costa, Dritsa, Ring, & Fitzcharles, 2004); people with CFS (Wallman, Morton, Goodman, & Grove, 2005); and people with PPS (Rekand et al., 2004). These studies were conducted with people with one particular chronic condition, so that a determination of that relationship for women with different chronic conditions was further needed in the main study.

This study distinguished two different dendrograms classified by women with, and without, chronic conditions. Thus, the main study could not use the preliminary CLP Scale developed based on the views of women without chronic conditions. Instead the CLP Scale needed to be based on the perceptions of women with chronic conditions. However, use of a telephone survey might be considered as an inappropriate form of administration when many standard scales including the CLP Scale were required for the main study. Use of a postal survey was considered as an alternative way for each participant because of the issue of having sufficient time to complete a long questionnaire. A determination of leisure classification between two formats of the preliminary CLP Scale (phone and postal) was determined as necessary in order to finally develop the CLP Scale, for women with chronic conditions.

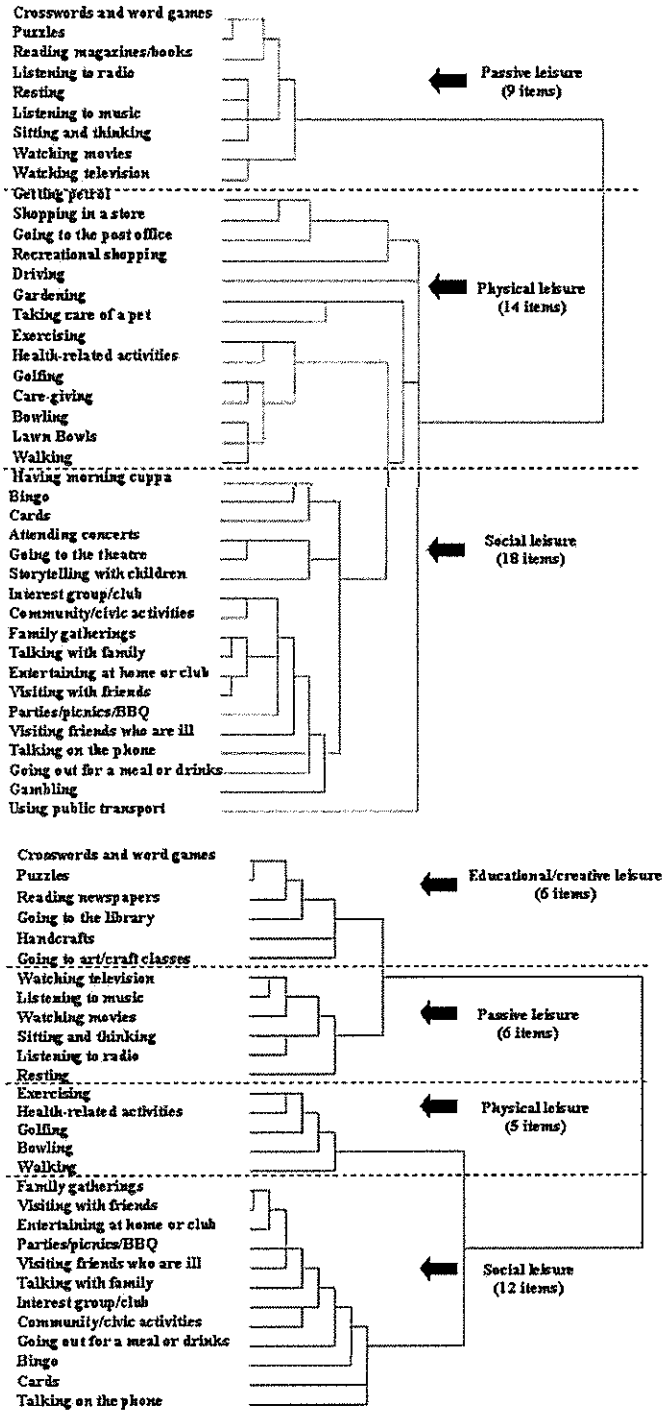

Figure 4.1. Comparison of dendrograms of leisure activities in women with (upper) and without (lower) chronic conditions.

4.2 VALIDATION STUDY 2: A COMPARISON OF PHONE AND POSTAL ADMINISTRATION IN WOMEN WITH CHRONIC CONDITIONS

4.2.1 Rationale and Purpose for Validation Study 2

To obtain a sample of women without FSCI, a random telephone survey method was used in order to gain a representative sample. This method was not feasible for women with FSCI who were accessed through data bases and sent postal questionnaires. Therefore, comparison between women with and without FSCI could only be made after testing the comparability of testing methods. Knowing the comparability of testing methods (example telephone and mail) is important to provide flexibility of data collection methodologies (Hepner, Brown, & Hays, 2005). When having the same content of the tool, different modes of questionnaire administration may influence the quality of the data (Bowling, 2005; Duncan et al., 2005; Perkins & Sanson-Fisher, 1998) such as survey response rates, the accuracy of responses, or questionnaire item response rates. Examination of the two methods of survey completion (postal and telephone) was needed in order to inform methodology for the main study.

4.2.2 Participants and Procedures

The same 24 participants with chronic conditions from Validation Study #1 participated in Validation Study #2. The same inclusion and exclusion criteria, recruitment strategy, and ethical consideration were thus used (See Sections 4.1.2 to 4.1.3). All 24 participants with chronic conditions voluntarily completed both phone and mail formats, which were conducted within a one month period of each other. This time frame was believed to be long enough to reduce the influence of memory but short enough to ensure no change in views. Participants were asked to classify 61 activities into one of four categories as described in Section 4.1.4 both by phone and via postal survey.

4.2.3 Data Analysis

Categorical data (item counts per category) from the two formats was compared using the Kappa Statistic (Ludbrook, 2002, 2004). All four categories (physical, social, educational/creative, and passive leisure) for each item were examined

between phone and postal formats. The Kappa Statistic (*K*) was calculated as a measurement of agreement (Coakes & Steed, 2005; Field, 2000; Portney & Watkins, 2000a). To interpret the strength of agreement (Landis & Koch, 1977), *K* less than 0 indicates poor agreement; *K* ranging from 0 to 0.20 indicates slight agreement; from 0.21 to 0.40 suggests a fair degree of agreement; 0.41 to 0.60 moderate agreement; 0.61 to 0.80 substantial agreement; and values of 0.81 to 1.00 are considered almost perfect.

4.2.4 Results

As the same sample was used for both Validation Study #1 and #2 the sample has already been described (See Section 4.1.6). Kappa Statistic (*K*) values across the 61 activity items ranged in strength from –0.01 to +0.61. As shown in Figure 4.2 and Table 4.2, more than half the items demonstrated fair or less that fair agreement. Only 7 activity items demonstrated moderate and substantial agreement.

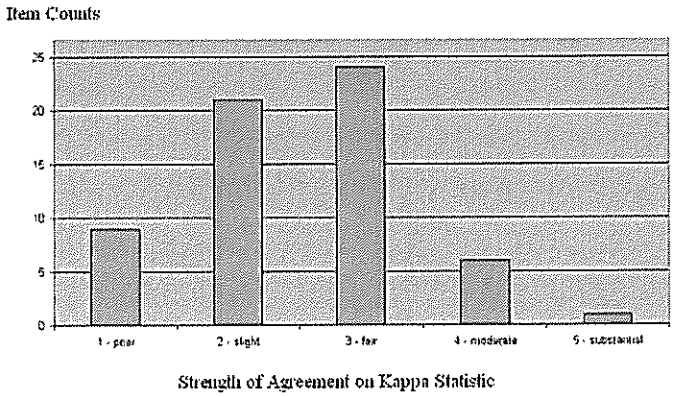

Figure 4.2. Strength of agreement on item counts between phone and postal surveys.

Table 4.2

Items and Kappa Statistic ranged in strength of agreement

Strength of Agreement	Item	Kappa Statistic
Poor	Parties/picnics/BBQ	-0.16
	Family gatherings	-0.08
	Going out for a meal or drinks	-0.04
	Talking with family and neighbours	-0.11
	Cards	-0.08
	Walking	-0.04
	Exercising	-0.02
	Taking care of a pet	-0.03
	Shopping in a store	-0.01
Slight	Interest group/club	0.07
	Community/civic activities	0.06
	Going to children's or grandchildren's activities	0.05
	Storytelling with children	0.15
	Marriage/relationship	0.15
	Visiting with friends	0
	Taking a day trip	0.07
	Gardening/growing flowers	0.19
	Watching movies (theatre or home)	0.10
	Watching television	0.04
	Listening to music	0.18
	Computer (email, games)	0.02
	Recreational shopping	0.15
	Handcrafts	0.08
	Letter writing	0.16
	Going to the library	0.09
	Going to the theatre	0.21
	Having morning or arvo cuppa	0.12
	Bingo	0.20
	Talking on the phone	0.19
	Resting	0
Fair	Going to place of worship	0.35
	Volunteer work	0.23
	Entertaining at home or club	0.34
	Travelling	0.24
	Doing favours and helping out	0.30
	Sitting and thinking/reminiscing	0.22
	Collecting	0.30
	Puzzles	0.37
	Spectator sports	0.33
	Sewing	0.29
	Reading newspapers	0.26
	Attending concerts	0.25
	Bowling	0.23
	Golfing	0.35
	Going to beach	0.32
	Lawn Bowls	0.32
	Gambling	0.28
	Going to art/craft classes/groups (folk art, sewing)	0.37
	Preparing for outing/trip	0.28
	Getting petrol	0.26
	Driving	0.31
	Beauty/Barber shop	0.37
	Going to the post office	0.36
	Health-related activities (health appointments, aqua-aerobics, walking)	0.36
Moderate	Crosswords and word games	0.42
	Reading magazines/books	0.46
	Knitting/crocheting	0.45
	Listening to radio	0.43
	Visiting friends who are ill	0.51
	Care-giving (grandchildren, family/friends who are ill/disabled)	0.46
Substantial	Using public transport	0.61

4.2.5 Discussion and Implications for the Main Study

Fair or less agreement was found between phone and postal version of the CLP Scale. Although this study was conducted with the same women with chronic conditions different formats of the CLP Scale influenced the questionnaire item response, which has been suggested in previous studies (Bowling, 2005; Duncan et al., 2005). However, Kappa Statistics knows only agreement for each item surveyed in between phone and postal formats. These statistics do not know in what way the participants differently completed the survey.

It is noteworthy to comment that a more important subsequent validation would have been to evaluate the content of the tool rather than mode of administration. The postal format of the CLP Scale may be provided to a large sample size of women without chronic conditions or other populations in the future. As mentioned, the main study collected the CLP Scale together with other standard questionnaires; each participant with chronic conditions might spend a long time to complete these questionnaires. The different results between telephone and postal formats of the CLP Scale also suggested that the researcher should select an effective administration for those long questionnaires, which was a mail survey. Therefore, a final development of the CLP Scale (postal format) - women with chronic conditions was further required.

4.3 FINAL DEVELOPMENT OF THE CLP SCALE

4.3.1 Rationale and Purpose of this Step

In Validation Study #1 women with chronic conditions viewed many more activities in a physical way than those without, and they did not classify any activities as educational/creative. In Validation Study #2 the level of agreement between phone and postal formats was insufficient to recommend a mixed method of data collection. Thus, it was concluded that separate CLP Scales were needed for women with, and without, chronic conditions. Due to the small sample size used for women with chronic conditions, a second study was undertaken to confirm the domains using a larger sample size. Furthermore, the lack of agreement suggested the need to survey a larger sample in order to gain consensus. For logistic and efficiency reasons, the final development of the CLP Scale for women with chronic conditions was

conducted concurrently with data of other standard questionnaires (via postal format) collected for the main study, and sample size was determined in consideration of the larger study (See Chapter 6). For the rest of the thesis, use of 'the CLP Scale' means the final version of the CLP Scale for women with chronic conditions.

4.3.2 Participants and Procedures

The same inclusion and exclusion criteria, recruitment strategy, and ethical consideration were thus used for women with chronic conditions (See Sections 4.1.2 to 4.1.3); 211 letters were sent to the interested participants. Each participant was asked to fill out a postal questionnaire including demographic data, clinical characteristics, and classification of leisure activities (See Section 4.1.4).

4.3.3 Data Analysis

All data were entered into and managed via the SPSS software for Windows version 11.5 (© 2005 SPSS Inc., Chicago, Illinois). Items which achieved agreement of 60% or greater in one of the four categories were selected and included in a cluster analysis (See Section 3.4.7). The agreement of 60% indicates that 60% or more nominated an item to the same category. In other words, less than half the participants classified the item in the different way.

4.3.4 Results

4.3.4.1 Description of the sample

Using convenience sampling, 126 participants were recruited (59.72% of response rate, from 211 letters sent out). The final sample was 102 participants; 14 participants who had a history of clinical depression and/or anaemia, known to cause fatigue (assessed via medical history) were excluded from the study as were 5 participants who withdrew at the stage of returning questionnaires and 5 participants with missing data. None of the final participants had been diagnosed with neuropsychological impairments.

Demographic and clinical characteristics of the study participants are presented in Table 4.3. The mean age of participants was 49.42 years (SD 11.52). Participants had been diagnosed with at least one of the chronic conditions (MS, CFS, RA, and PPS), on average, for 6.88 years prior to the study (SD 6.72). Participants were diagnosed

with one of four medical conditions: 58.8% MS, 17.6% CFS, 13.7% RA, 5.9% PPS, 2% MS and CFS, and 2% MS and RA. More than half of the participants were married, but less than half were employed. The highest education level obtained was a university degree (32.4% of participant). Nearly half of the participants were living with one other adult at home at the time of the study.

Table 4.3

Demographic and clinical characteristics of the participants with chronic conditions (N = 102)

Demographic and clinical characteristics	Raw number	Percent
	Medical conditions	
Rheumatoid Arthritis (RA)	14	13.7
Chronic Fatigue Syndrome (CFS)	18	17.6
Multiple Sclerosis (MS)	60	58.8
Post Polio Syndrome (PPS)	6	5.9
MS and CFS	2	2.0
MS and RA	2	2.0
	Marital status	
Married	66	64.7
Divorced	27	26.5
Never married	9	8.8
	Employment status	
Employed	39	38.2
Unemployed	16	15.7
Retired	24	23.5
Full-time homemaker	19	18.6
On leave for employment	4	3.9
	Educational levels	
Primary school	2	2.0
Year 10 high school	21	20.6
Year 12 high school	15	14.7
Diploma	31	30.4
University degree	33	32.4
	Number of adults living with	
None	31	30.4
One person	49	48.0
Two people	13	12.7
Three people	8	7.8
Four people	1	1.0

4.3.4.2 Item Reduction and Determination of Domains

As shown in Table 4.4, the first step, item reduction, yielded 38 items ranging from 61.8% to 94.1% agreement per item (Table 3.4). For instance, 61.8% of the participants agreed 'going to the library' was social leisure. The second step, using cluster analysis, classified leisure activities into physical, social, and passive categories. No items were classified as educational/creative through this step. The CLP Scale was thus reduced to 3 rather than the original 4 categories, which was the same as for the sample size of 24 in the previous study. In 102 women with chronic

conditions physical leisure showed the highest number of items (16 items), such as exercising, walking, health-related activities. Social leisure consisted of 14 items, for example, family gathering, talking on the phone. Eight items clustered around passive leisure. Examples are watching television, resting. These items were included in the CLP Scale for women with chronic conditions.

Table 4.4

Classification of leisure participation per cluster (60% agreement) in women with chronic conditions (N =102)

Leisure classification	**Item selection (in order of a dendrogram of cluster analysis)**	**Percentage of agreement (%)**
Physical leisure (16 items)	Bowling	74.5
	Golfing	84.3
	Walking	91.2
	Exercising	94.1
	Lawn Bowls	64.7
	Health-related activities (health appointment, aqua-aerobics, walking)	85.3
	Care-giving (grandchildren, family/friends who are ill/disabled)	71.6
	Preparing for outing/trip	67.6
	Shopping in a store	74.5
	Going to beach	70.6
	Gardening/growing flowers	68.6
	Getting petrol	80.4
	Going to the post office	75.5
	Using public transport	77.5
	Driving	68.6
	Taking care of a pet	65.7
Social leisure (14 items)	Family gatherings	88.2
	Visiting with friends	94.1
	Going out for a meal or drinks	91.2
	Parties/picnics/BBQ	83.3
	Entertaining at home or club	75.5
	Interest group/club	65.7
	Community/civic activities	65.7
	Visiting friends who are ill	71.6
	Talking with family and neighbours	80.4
	Bingo	71.6
	Going to the library	61.8
	Going to art/craft classes/groups (folk art, sewing)	60.8
	Talking on the phone	63.7
	Having morning or arvo cuppa	67.6
Passive leisure (8 items)	Crosswords or word games	65.7
	Puzzles	61.8
	Listening to music	77.5
	Listening to radio	72.5
	Watching television	72.5
	Sitting and thinking/reminiscing	84.3
	Resting	92.2
	Watching movies (theatre or home)	65.7

4.4 DEVELOPMENT OF THE SCORING METHOD

Identification of domains allowed leisure activities to be classified into three domains (physical, social, and passive). This classification was needed to examine whether different types of leisure activity have a differential affect on HRQoL and fatigue. Scoring of each domain was based on frequency of participation. For each item/activity, frequency of leisure participation was based on the average number of days per week in which an individual participates, using an eight-point scale (0 = no participation, 1 = one day per week to 7 = seven days per week). Domain scores were calculated using the following equation:

$$\text{Average frequency of leisure participation per domain} = \frac{\sum_{1}^{n} F}{n}$$

Where F = total frequency score in each domain; and
n = number of selected items in each domain
(16 physical; 14 social; and 8 passive domains)

A rationale for this scoring method was to extend the classified items and domains into a quantitative calculation for frequency of leisure participation. Using the quantitative data, the researcher was able to assess the psychometric properties of the CLP Scale, for women with chronic conditions. In the main study, calculation of physical, social and passive leisure could compare average frequency of participation regardless of the different numbers of activities per domain. This scoring method then allowed the researcher to further examine the relative contribution of leisure participation to the prediction of fatigue and HRQoL for women with chronic conditions.

4.5 DISCUSSION

This chapter described the development of a scale for measuring and classifying leisure participation (CLP) in women with chronic conditions. Two major findings of this chapter are discussed. Firstly, the difference in the CLP items as selected by

women with and without chronic conditions is examined. Secondly, the clinical application of the CLP Scale and its use in future studies is discussed.

4.5.1 Different Item Determination by Women With, and Without, Chronic Conditions

Reduction of leisure items and determination of domains led to large discrepancies determined by women with and without chronic conditions. Different domains were found in both groups, indicating that a separate CLP Scale should be developed for women with chronic conditions. These results demonstrated that participants have different perceptions of the characteristics of leisure activities (Parker, 1996; Shogan, 2002). Parker (1996) found that older adults enjoyed their lives when they spent more time in different domains of leisure activities, but women with chronic conditions would have life satisfaction through a specific domain of leisure activities. One possible explanation is that living with chronic conditions may increase constraints leading to restrictive participation in leisure activities. Parker (1996) identified constraints that may reduce or modify participation in leisure activities, such as constraints of space, time, and movement skills. Women with chronic conditions may have time commitments, lack of skills and interpersonal relationships when compared to women without chronic conditions. This chapter also highlighted a finding that women with chronic conditions viewed many more activities as physically demanding than those without. Therefore, living with a chronic condition appears to alter perceptions of the demands and rewards of participating in activities (Khemthong et al., 2006). This conclusion has important implications for future studies of interventions. It also provides useful information for the development of a scale for measuring the effectiveness of interventions that aim to improve quality of life through engagement in meaningful leisure activities

4.5.2 Clinical Application of the CLP Scale

The CLP Scale has been developed using a quantitative method to classify leisure activity by type and to quantify frequency of leisure participation in adults across multiple chronic conditions. Interestingly, The CLP Scale was validated for use in women with a range of chronic conditions, including MS, RA, CFS, and PPS. Having broader application, then, the CLP Scale provides a level of usefulness not achieved prior to this study, even though other studies (Da Costa et al., 2004; Motl et

al., 2005; Rekand et al., 2004; Wallman, Morton, Goodman, & Grove, 2005) have utilised scales that were able to describe leisure participation for people with one particular condition. Individuals have different expectations of particular leisure activities because of many factors: interest, age, gender, social class, culture, practical skills, and disability level (Bull, Hoose, & Weed, 2003; Lynch & Veal, 1996; Roelofs, 1999; Shogan, 2002). A limiting feature of the CLP Scale relates to these varying expectations. Because the item selection was based specifically on the perceptions of women with chronic conditions, caution should be exercised in use of the scale with males with chronic conditions, young or elderly people without chronic conditions, and/or people with specific/acute/pathological conditions (e.g., cancer, stroke). It is possible that the procedure for item determination and the analysis of construct validity would need to be repeated in order to measure leisure participation in these other groups. However, for women with chronic conditions, the CLP Scale, including the scoring system, is a useful tool for further investigation its psychometric properties in the next chapter.

CHAPTER 5

PSYCHOMETRIC EVALUATION OF THE CLP SCALE FOR WOMEN WITH CHRONIC CONDITIONS

5.1 INTRODUCTION

This chapter describes the evaluation of psychometric properties of the CLP Scale, for women with chronic conditions. Face validity based on the development of the CLP Scale is described. Construct validity was examined by calculating the correlations between frequency of leisure participation for each leisure domain and the domain scores of a standardized measurement of HRQoL (the SF-36®). Internal consistency for each leisure domain of the CLP Scale was examined.

5.2 BRIEF LITERATURE REVIEW

As early as 1986 Tinley and Tinley hypothesized that people with chronic conditions might engage in the particular types of leisure activities which they believed would lead to better health. Much of previous empirical research has measured how frequency of leisure participation has impacted on health, but very little research has measured how frequency of leisure participation in different types of activities (classified by participants) has impacted on health. Classification by type remains difficult to measure due to individualized perceptions (Lynch & Veal, 1996; Parker, 1996), leisure behaviour, and satisfaction with leisure participation (Connolly & Law, 2005).

In the leisure literature (Lynch & Veal, 1996; Roelofs, 1999), the leisure experience of individuals has been measured by scales or self-reports reflecting both quantitative (e.g., frequency) and qualitative (e.g., types, satisfaction) dimensions. Self-report questionnaires are efficient to administer in large groups to ascertain opinions or frequency of participation (Mason & Redeker, 1993). The instrument should be brief, easy to score, and an interpretable tool for use in clinical practice (Mannerkorpi & Hernelid, 2005). The instrument should also have good psychometric properties as well as quality of measurement (Portney & Watkins, 2000d).

A common way for ensuring the quality of measurement (reproducibility and accuracy) is reliability and validity testing (Dawson & Trapp, 2001a; Portney & Watkins, 2000d). Reliability is the extent to which a measurement yields consistent scores (Kurpius & Stafford, 2006a; Portney & Watkins, 2000e). There are several

types of reliability, but internal consistency, utilising Cronbach's Alpha, is the most common test. This statistical procedure is based on inter-item correlations; the greater the number of similar items, the greater the internal consistency.

Validity is the extent to which a measurement tool measures what it is supposed to measure (Portney & Watkins, 2000h). There are a number of ways to ensure that a measurement is valid. One is face validity, which has been described as an empirical analysis of how well the tool measures something or reflects the content domains (Kurpius & Stafford, 2006b). Construct validity is the most important type of validity. The "construct", or underlying theoretical basis of the tool underpins its characteristics. Construct validity indicates the degree to which items in the tool measure the theoretical trait or construct the tool is designed to measure (Kurpius & Stafford, 2006b). There are many procedures to test construct validity such as hypothesis testing, convergent and discriminative construct validity, and the known groups method (Portney & Watkins, 2000h). Hypothesis testing assesses specific hypotheses that support a theoretical basis behind the constructs of measurement tool. Convergent validity is shown when a measure provides similar results to other measures, whereas discriminative validity indicates that different results are expected from two measures when assessing different characteristics/constructs. The known groups method is used to demonstrate that a test discriminates between individuals who are known to have the trait and those who do not. For this study, face validity, construct validity, and internal consistency of the CLP Scale were evaluated.

5.3 EXAMINATION OF VALIDITY AND RELIABILITY

5.3.1 Face Validity of the CLP Scale

Face validity is validation based on existing literature or research (Portney & Watkins, 2000h). It indicates the items of the measurement tool are representative of the knowledge or the conceptual definition that is being measured (Portney & Watkins, 2000h). Because the items of the CLP Scale were generated based on existing research (Australian Bureau of Statistics, 1998a; Packer, Boshoff, DeJonge, Baum, & Doney, 2006) and the opinion of women with chronic conditions, it can be concluded that the scale is a reasonable measure of leisure participation, indicating strong face validity.

5.3.2 Participants for Construct Validity and Internal Consistency Testing

The same participants with chronic conditions ($N = 102$) who participated in the final development of the CLP Scale participated in this phase. They were asked to fill out the postal questionnaires including frequency of participation in physical, social, and passive leisure activities. The inclusion and exclusion criteria, recruitment strategy, and ethical consideration were addressed previously in Chapter 4.

5.3.3 Construct Validity of The CLP Scale

Construct validity demonstrates the ability of the tool to measure a theoretical concept (Portney & Watkins, 2000h). Because no gold standard exists, nor is there a tool that measures the same construct, hypothesis-testing procedure of construct validity was chosen (Portney & Watkins, 2000h). This procedure is not to compare this scale to another measure of leisure (gold standard), but aims to demonstrate whether the scale can predict a known relationship. Based on the literature, a relationship between leisure and health exists (Coleman & Iso-Ahola, 1993; Mannell & Stynes, 1991; Passmore, 2003; Tinsley & Tinsley, 1986). This relationship was addressed as the rationale for testing the construct validity of the CLP Scale. This study hypothesised that a positive relationship would be found between frequency of leisure participation (CLP Scale) and health-related quality of life or HRQoL (SF-36®) in women with chronic conditions at the level of both the domain and total scores. The SF-36® was chosen because of well-known and validated measurement tool for health status. A correlation analysis is an acceptable way to prove this hypothesis.

5.3.3.1 Measurement Tools

The Classification of Leisure Participation (CLP) Scale – women with chronic conditions was used. This scale was developed by the researcher to quantify frequency of participation in physical, social and passive leisure. The CLP scale consists of 16 physical items, 14 social items, and 8 passive items. The average frequency of leisure participation per domain and the overall total was calculated by using the scoring method of the CLP Scale as previously described (See Section 4.4 in Chapter 4).

The Medical Outcome Study Short Form (SF-36®) (Ware & Sherbourne, 1992a) was used to measure HRQoL. This study was granted a license agreement for the SF-

36® Australian version 1.0 (F1-021305-21457) (See Appendix 3). This measurement tool has high internal consistency (Cronbach's alpha ranged from 0.81 to 0.92) for use in Australia (Sanson-Fisher & Perkins, 1998), and Australian norms for women are available (Australian Bureau of Statistics, 1997). All health domains of the SF-36® were calculated as per the manual instructions (Ware & Kosinski, 2002). See more information in Chapter 6. Scores of all health domains were used in this study whereas only the PCS and MSC scores were used in the main study.

5.3.3.2 Statistical Analysis

One-sample *t* tests (Portney & Watkins, 2000g) were used first to compare scores of the SF-36® to the Australian norms (Australian Bureau of Statistics, 1997). Spearman rank correlation (Portney & Watkins, 2000b) was then calculated to examine the relationship between each domain of the CLP Scale and each health domain of the SF-36®. The rationale for using Spearman rank correlation was that four scales of the SF-36® (i.e., role-physical functioning, bodily pain, role-emotional functioning, and social functioning) were not normally distributed using the Kolmogorov-Smirnov with Lilliefors Significance Correction. Thus, the data did not meet the criteria for using parametric correlations. A p-level of 5% statistical significance was used. The strength of association using the Spearman rank correlation gives an indication of construct validity and can be interpreted as weak ($0 < r \leq 0.25$), moderate ($0.25 < r \leq 0.50$), strong ($0.50 < r \leq 0.75$), and very strong ($0.75 < r \leq 1$) (Dawson & Trapp, 2001a; Portney & Watkins, 2000b). While non-parametric analysis was used to test the relationship, both mean (SD) and median (range) were calculated and reported. This allows comparison to normative data.

5.3.3.3 Results

Median (range) scores for each domain of the CLP Scale were 1.50 (0.38-3.63) for physical leisure, 1.50 (0.36-2.86) for social leisure, 3.50 (0.13-5.75) for passive leisure, and 1.93 (0.92-3.58) for total leisure. Mean (SD) scores of the CLP Scale included 1.58 (0.68) for physical leisure, 1.48 (0.53) for social leisure, 3.54 (1.09) for passive leisure, and 1.96 (0.54) for total leisure. These scores can be interpreted as the average number of days per week in which participants engaged in each type of leisure activities. Median (range) scores of the health domains ranged from 25 (0-100) to 100 (0-100), whereas their mean (SD) scores ranged from 35.78 (39.10) to

66.86 (19.94). When compared to norms, participants had lower HRQoL scores than Australian women (t = -3.918 to –11.112, $p < 0.0001$) as illustrated in Table 5.1.

Table 5.1

Median (range) and mean (SD) for leisure and HRQoL variables in women with chronic conditions (N = 102)

Variables	Median (Range)	Mean (SD)	Mean (SD)- Australian Women Norms
Physical leisure	1.50 (0.38-3.63)	1.53 (0.68)	-
Social leisure	1.50 (0.36-2.86)	1.48 (0.53)	-
Passive leisure	3.50 (0.13-5.75)	3.54 (1.09)	-
Total leisure	1.93 (0.92-3.58)	1.96 (0.54)	-
Physical functioning	55 (0-100)	51.7 (29.0)	81.1 (24.3)
Role limits-physical	25 (0-100)	35.8 (39.1)	78.8 (36.0)
Bodily pain	62 (0-100)	58.7 (27.1)	75.7 (25.4)
General health	50 (0-100)	52.1 (23.7)	72.0 (20.3)
Vitality	40 (0-95)	40.8 (22.6)	62.5 (20.1)
Social functioning	62.50 (0-100)	63.7 (26.9)	84.1 (22.9)
Role limits-emotional	100 (0-100)	64.1 (41.3)	81.6 (33.6)
Mental health	68 (16-100)	66.9 (19.9)	74.6 (17.3)

Note. Mean (SD) of HRQoL has been reported to one decimal number for a comparison with the norms.

Table 5.2 shows results using the Spearman rank test. Moderate, but significant correlations were found between physical leisure (CLP) and the SF-36® domains of physical functioning, and general health. Physical leisure was weakly but significantly correlated with vitality and social functioning. Social leisure was weakly but significantly correlated with physical and social functioning. Negative but very weak correlations were found between passive leisure and all domains of the SF-36® (r = -0.01 to -0.11, p = 0.26 to 0.92). None of the correlations between passive leisure and HRQoL were statistically significant. When the three domains were considered together, the total leisure score was weakly but significantly correlated with physical functioning.

Table 5.2

Correlation between leisure participation and HRQoL in women with chronic conditions (N=102) using the Spearman rank test

HRQoL (SF-36®)	CLP Scale			
	Physical leisure	Social leisure	Passive leisure	Total
Physical functioning	0.43***	0.20*	-0.04	0.25*
Role limits-physical	0.18	0.14	-0.05	0.09
Bodily pain	0.01	0.01	-0.11	0.04
General health	0.27*	0.18	-0.07	0.15
Vitality	0.20*	0.19	-0.07	0.13
Social functioning	0.25*	0.22*	-0.05	0.17
Role limits-emotional	0.10	0.10	-0.01	0.09
Mental health	0.09	0.06	-0.06	0.04

Note. $*p < 0.05$, $**p < 0.01$, $***p < 0.001$.

5.3.3 Internal Consistency of the CLP Scale

Internal consistency of the items, a form of reliability, reflects the degree to which the tool/domain measures a single characteristic (Dawson & Trapp, 2001a). Cronbach's alpha (α) is the most commonly applied statistical index for internal consistency and is a reflection of the correlation among different items in the instrument (Portney & Watkins, 2000f).

5.3.3.1 Statistical Analysis

Frequency scores of leisure participation recorded by women with chronic conditions (N = 102) were used. This study examined Cronbach's Alpha for the three domain scores and the total score. Internal Consistency was calculated using Cronbach's Alpha, α (Portney & Watkins, 2000e). Correlations of α from 0.70 to 0.90 are considered to represent moderate to strong internal consistency (Portney & Watkins, 2000f); less than 0.70 are rated as low internal consistency (Streiner & Norman, 1989). When internal consistency is very low (near zero), the items measure different traits. On the other hand, the items are redundant when internal consistency is very high (near one) (Portney & Watkins, 2000f). Refinement of the CLP Scale, for the domain scores and the total score, was confirmed using item-total correlations and reliability if item deleted to assess the contribution of items to overall reliability (Portney & Watkins, 2000f).

5.3.3.2 Results

Based on Portney and Watkins (2000f)'s statistical criteria there was moderate internal consistency for the total CLP score ($\alpha = 0.74$) as shown in Table 5.3. This result suggests that there is homogeneity across all 38 items. No single item detracted from that reliability. Item-total correlation ranged from 0.11 to 0.41 with an average item-total correlation of 0.28. Over 50% of the item-total correlations were marginally above an item-total correlation of 0.30. Consequently, the total score of the CLP Scale (taken as a single characteristic) reflect a good measure of leisure participation.

Table 5.3

Internal consistency of the CLP Scale for total score (38 items)

Items of the CLP Scale for Total Score	Item Total Correlation	Reliability If Deleted	Cronbach's Alpha (α)
Bowling	0.19	0.742	0.74
Golfing	0.31	0.737	
Walking	0.35	0.729	
Exercising	0.31	0.732	
Lawn bowls	0.52	0.727	
Health-related activities	0.20	0.739	
Care-giving	0.30	0.733	
Preparing for an outing/trip	0.28	0.735	
Shopping in a store	0.41	0.728	
Going to the beach	0.24	0.738	
Gardening	0.41	0.727	
Getting petrol	0.33	0.734	
Going to the post office	0.36	0.734	
Using public transport	0.18	0.744	
Driving	0.32	0.731	
Taking care of a pet	0.17	0.744	
Family gathering	0.33	0.734	
Visiting with friends	0.25	0.737	
Going out for a meal	0.33	0.735	
Parties	0.31	0.737	
Entertaining at home	0.31	0.737	
Interest group/club	0.19	0.744	
Community/civic activities	0.11	0.741	
Visiting friends who are ill	0.22	0.738	
Talking with family	0.34	0.729	
Bingo	0.19	0.742	
Going to the library	0.19	0.742	
Going to art/craft classes/groups	0.18	0.744	
Talking on the phone	0.36	0.729	
Having morning cuppa	0.21	0.742	
Crosswords	0.19	0.739	
Puzzles	0.31	0.732	
Listening to music	0.36	0.728	
Listening to radio	0.28	0.734	
Watching television	0.21	0.737	
Sitting	0.33	0.731	
Resting	0.19	0.744	
Watching movies	0.31	0.733	

Table 5.4

Internal consistency of the CLP Scale for domains

Domain of the CLP Scale	Item Selection	Item Total Correlation	Reliability If Deleted	Cronbach's Alpha (α)
Physical leisure (16 items)	Bowling	0.01	0.609	0.61
	Golfing	0.02	0.607	
	Walking	0.48	0.532	
	Exercising	0.38	0.559	
	Lawn bowls	0.02	0.607	
	Health-related activities	0.30	0.576	
	Care-giving	0.21	0.593	
	Preparing for an outing/trip	0.13	0.602	
	Shopping in a store	0.39	0.566	
	Going to the beach	0.26	0.593	
	Gardening	0.33	0.570	
	Getting petrol	0.30	0.587	
	Going to the post office	0.37	0.580	
	Using public transport	0.03	0.614	
	Driving	0.29	0.578	
	Taking care of a pet	0.14	0.633	
Social leisure (14 items)	Family gathering	0.32	0.535	0.57
	Visiting with friends	0.40	0.525	
	Going out for a meal	0.35	0.536	
	Parties	0.26	0.554	
	Entertaining at home	0.47	0.505	
	Interest group/club	0.12	0.567	
	Community/civic activities	0.13	0.565	
	Visiting friends who are ill	0.23	0.553	
	Talking with family	0.31	0.534	
	Bingo	0.10	0.570	
	Going to the library	0.07	0.574	
	Going to art/craft classes/groups	0.08	0.573	
	Talking on the phone	0.26	0.544	
	Having morning cuppa	0.27	0.560	
Passive leisure (8 items)	Crosswords	0.19	0.528	0.54
	Puzzles	0.29	0.503	
	Listening to music	0.37	0.465	
	Listening to radio	0.27	0.502	
	Watching television	0.31	0.493	
	Sitting	0.40	0.449	
	Resting	0.18	0.530	
	Watching movies	0.20	0.526	

However, the CLP Scale demonstrated low internal consistency in the physical domain ($\alpha = 0.61$), social domain ($\alpha = 0.57$), and passive domain ($\alpha = 0.54$) as shown in Table 5.4. The results indicate that the items of the CLP Scale could be divided into three separate domains, and each domain consists of homogeneous items. For instance, all 14 items measure social leisure. Single item was not detracted from the reliability if deleted. Item-total correlation per domain ranged from 0.01 to 0.48 (physical leisure), 0.08 to 0.47 (social leisure), and 0.18 to 0.40 (passive leisure). This result suggests mild to moderate correlation among items for each domain.

5.4. DISCUSSION

The three aims of this chapter were to: (1) examine face validity of the CLP Scale, (2) examine construct validity of the CLP Scale, and (3) examine internal consistency of the CLP Scale.

The CLP Scale – women with chronic conditions has sound face validity for participation in physical, social, and passive leisure activities. The development of the CLP Scale used systematic inclusion of leisure activities from existing research and a statistical approach to item reduction and determination of domains for women with chronic conditions. This sound development contributes to good face validity, with a scale that consists of representative items of leisure activities for women with chronic conditions. Representation was assured through the item selection process in which % of agreement was used to eliminate items of ambiguity. This scale is thus an acceptable tool for measuring frequency of participation in different domains of leisure. However, agreement of classification of leisure activities into three domains was assessed as representative items for women with FSCI, not for Australian population. Representativeness of leisure activities and domains is further assessed for a wider population with and without FSCI.

The examination of construct validity demonstrated correlations between some domains of the SF-36® and the physical and social domains of the CLP Scale. The physical domain of the CLP Scale showed moderately positive correlations ($0.25 < r \leq 0.50$) with physical functioning and general health. These correlations are consistent with the theoretical model of Coleman and Iso-Ahola (1993) who hypothesized that leisure participation can enhance health in healthy populations. As demonstrated earlier in this thesis, women with and without chronic conditions view activities differently. Hence, the basis for classification of activities by the women may reflect a somewhat different view of leisure. It is possible that physical and non-physical leisure activities may have different degrees of relationship with HRQoL in women with chronic conditions (Bull et al., 2003; Caldwell, 2005). Given the heavy emphasis on physical activities of women with chronic conditions it is not surprising that the strongest correlations were found between the physical domain of SF-36® and the physical domain of CLP Scale.

In the final examination, moderate internal consistency of the total scores of the CLP Scale was found. This result reflects a measurement of the same attribute; that is, all items are homogeneous for measuring leisure participation. With respect to the three domains (physical, social and passive leisure) – internal consistency scores ranged from 0.54 to 0.61. These fall just below the level of strong internal consistency. One possible explanation is that internal consistency for each domain might have been affected by the number of items in the CLP Scale (Portney & Watkins, 2000f). The fewer the items in a domain the less internal consistency score for that domain is expected. For example, the physical domain consists of 16 items with internal consistency of 0.61 whereas the passive domain consists of 8 items with internal consistency of 0.54. In summary, the CLP Scale for women with chronic conditions has resulted in scales with strong face validity, mild to moderate construct validity, and strong overall internal consistency.

CHAPTER 6

CONTRIBUTION OF LEISURE TO

THE PREDICTION OF FATIGUE AND HEALTH

6.1 INTRODUCTION

The previous two chapters described the development of the CLP Scale for women with chronic conditions. This chapter reports on use of the CLP to examine how leisure participation is related to health and fatigue. This chapter begins with a brief literature review, followed by the purpose of the study, research questions, research design, methodology, and ethical considerations. Measurement tools, data collection procedures, and data analysis are outlined. Results and discussion of the study conclude the chapter.

6.2 BRIEF LITERATURE REVIEW

Fatigue is rapidly being recognized as the least well managed symptom in many chronic illnesses, leading to loss of health-related quality of life (HRQoL) (Swain, 2000). Fatigue has a great impact on the lives of people with chronic illness not only at the human level but also at the community level (Dittner et al., 2004; Schreurs, de Ridder, & Bensing, 2002); for instance, people with fatigue are more likely to be unemployed and socially isolated. Although fatigue has been shown to be a major indicator of HRQoL (Merkelbach et al., 2002; Swain, 2000), the multi factorial nature of fatigue and its impact on HRQoL is poorly understood across chronic illnesses (Flechtner & Bottomley, 2003; Sharpe & Wilks, 2002; Tiesinga et al., 1999).

Fatigue secondary to chronic illness (FSCI) is a subjective experience involving physiological and psychosocial impacts on activity performance (Aaron & Buckwald, 2003; Aaronson et al., 1999; Dittner et al., 2004; Swain, 2000). Some attention has been given to identifying the contributing factors of FSCI using a universal or generic definition; which is "the awareness of a decreased capacity for physical and/or mental activity due to an imbalance in the availability, utilization and/or restoration of resources needed to perform activity (Aaronson et al., 1999, p. 46)." Much of the literature (Glacken et al., 2003; McCann & Boore, 2000; Merkelbach et al., 2002; Neuberger et al., 1997; Stephen, 2000) examines the phenomenon of FSCI as diagnosis specific, but its definition across specific diseases shares three common aspects, also present in the generic definition (Aaronson et al.,

1999; Dittner et al., 2004; Hartz et al., 2003): a physical aspect, a psychological aspect, and an aspect of activity and participation. Understanding of these aspects across all diagnoses is still required in order to fully understand FSCI.

Many studies have focused extensively on the physical and psychological aspects of fatigue in a single, specific condition. For example, increased levels of fatigue have been shown to be related to higher levels of pain (Crosby, 1991; Huyser et al., 1998; Pollard et al., 2006; Riemsma et al., 1998), greater depression (Huyser et al., 1998; Pollard et al., 2006; Wolfe et al., 1996), and lower levels of social support (Huyser et al., 1998; Prins et al., 2004; Riemsma et al., 1998) in people with RA. Merkelbach, Sittinger and Koenig (2002) also showed that fatigue in people with MS was significantly related to depression ($r = 0.51$, $p < 0.001$), physical health ($r = -0.51$, $p < 0.001$), and mental health ($r = -0.39$, $p < 0.001$). However, the heterogeneity of measurement tools used in previous research creates difficulties with comparisons. Further confirmation of these relationships has been recommended across diagnoses (Huyser et al., 1998; Hwang et al., 2003).

Previous studies (Aaronson et al., 1999; Eriksen & Bruusgaard, 2005; Franssen, Bultmann, Kant, & van Amelsvoort, 2003; Schreurs et al., 2002; Theander & Unosson, 2004; Tiesinga et al., 1999; Wikström & Jacobsson, 2005) have noted that activity and participation may be an important factor in fatigue. Furthermore, the definition of fatigue usually includes decreased capacity for physical and mental activities (Sharpe & Wilks, 2002). To date, the impact of activity and participation on fatigue (and vice versa) has been referred to but there has been limited examination of this aspect of the definition. Packer, Sauriol and Brouwer (1994) studied the severity of fatigue via The Fatigue Severity Scale (FSS) and assessed activity level via The Human Activity Profile (HAP) in 28 people with Post Polio Syndrome (PPS), 13 people with Chronic Fatigue Syndrome (CFS), 9 people with MS and 11 healthy people. Using the Mann Whitney U test, all participants had significantly higher scores on the FSS than the control group, but the correlation between the FSS and the HAP was not addressed in this study. Packer, Foster and Brouwer (1997) continued researching activity patterns of a CFS group (17 people) and the healthy group (11 people) using the Activity Record (ActRe). People with CFS spent less time in productivity and greater time in rest than those in the control

group. Schreurs and colleagues (2002) attempted to study fatigue correlates in people with MS using the Multidimensional Fatigue Inventory (MFI), the Beck Depression Inventory (BDI), and the Sickness Impact Profile (SIP). Regression analyses found that physical fatigue contributed to the prediction of physical disabilities ($R^2 = 0.45$, $p < 0.01$) and mental fatigue contributed to the prediction of depression ($R^2 = 0.35$, $p < 0.01$). Structural equation modelling found that depression did not predict mental fatigue, but predicted two subscales of the MFI ('physical fatigue' and 'reduced activity') at one year follow up. This study highlights the impact of depression on fatigue and activity.

Frequency of physical activity and participation, sleep quality, and smoking have also been examined. No effect of these variables was found on the mean fatigue score in people with chronic conditions (Franssen et al., 2003). Mathiowetz (2003) found moderate correlations between fatigue (via Fatigue Impact Scale, or FIS) and HRQoL (via SF-36®). Pearson's correlations demonstrated significant relationships: physical functioning and the physical impact of fatigue ($r = -0.57$, $p < 0.01$), and social functioning and the psychosocial impact of fatigue ($r = -0.62$, $p < 0.01$). This study, however, did not clarify the contribution of activity and participation to the impact of fatigue. However, a gap still exists in our understanding of fatigue and aspects of activity and participation. These correlations demonstrate significant relationships between fatigue and some aspects of activity and participation including physical and social activities (Ware, 2003; Ware & Kosinski, 2002; Ware & Sherbourne, 1992b).

It is known that leisure is an important component of activity supporting health (Caldwell, 2005). Australian people spend an average of 22% of their time on leisure activities. This can be compared with work/education (32%), and necessary activities (sleeping, eating, and personal hygiene) (46%) (Australian Bureau of Statistics, 1998a). For people with FSCI, only one study (Packer, Foster, & Brouwer, 1997) has compared mean percentage of time spent in leisure activities between people with CFS (24.72 $\pm$ 10.65 %) and those without CFS (16.22 $\pm$ 7.54%). A two-sample t test revealed no significant differences in the mean percentage of time spent in leisure activities by those two groups. This result suggests that living with chronic conditions may not influence total time in leisure participation. Pentland and her

colleagues (1998) measured time allocation within rest and leisure, personal care, productivity, and sleep in 312 people with spinal cord injury. Using regression analysis, the time allocation of each type of activity did not predict health and well-being. Robinson (1999) and Lynch & Veal (1996) also noted that many people have different patterns of time use in non-free time activities (productivity, personal care and sleep) and free time activities (rest and leisure).

The previous paragraph reviewed attempts to examine percentage of time in all leisure activities compared to work, rest, and other activities. Other researchers have examined specific leisure activities. Physical leisure activities (Da Costa et al., 2003; Eriksen & Bruusgaard, 2005; Franssen et al., 2003; Garber & Friedman, 2003; Guinn & Vincent, 2002; Kasser & Stuart, 2001; Sharpe & Wilks, 2002; Wendel-Vos et al., 2004) have been the most frequently examined. There has been less focus on the impact of different types of leisure and/or leisure satisfaction on health. One possible explanation is that the meaning of leisure activities is based on individual opinion (Parker, 1996). This makes the meaning of leisure difficult to measure due to individualized perceptions (Griffin & McKenna, 1998; Harvey, 1993; Lynch & Veal, 1996; Taylor et al., 2003). This may be the reason why many researchers measure frequency of leisure participation. Other possible explanation that research has focused on physical leisure activities is the knowledge that physical activities have on health outcomes (Caldwell, 2005).

A number of leisure studies have addressed health benefits in different populations (Coleman, 1993; Passmore, 2003; Tinsley & Tinsley, 1986). People who experience leisure activities are more likely to experience feelings of social support (companionship and friendship) and capacity for self-determination (perceived freedom and intrinsic motivation). This may buffer negative life events and maintain good physical and mental health (Coleman & Iso-Ahola, 1993). In considering leisure participation in people with chronic illness, Zimmer, Hickey and Searle (1995) categorized leisure activities in people with RA by selecting ten common leisure activities and inviting 225 people with RA (females aged 60-104) to rate their frequency of participation. Using principal component factor analysis, these activities were described as social (23.7% of variance), physical (16.7%), and solitary (13.3%). The results of regression equations indicated that well-being was influenced by social

leisure activities, severity of arthritis, social satisfaction, age, and income (at 26% of the variance). Leisure participation in social activities then may have a reciprocal relationship to well-being. This has also been found in the general population.

While some advances have been made; for example, we know that physical and social leisure activities have a positive impact on health (Hilleras et al., 1999; Zimmer et al., 1995), gaps still exist in understanding the relative contribution of different types of leisure participation in people with FSCI. The present study was designed to further understand the three key components of the fatigue definition (physical, psychological, and activity and participation) across chronic conditions. The study examined the contribution of leisure activities (type, frequency, and satisfaction) to the impact of fatigue (physical, cognitive, and psychosocial) and the physical and mental health domains of HRQoL.

6.3 PURPOSE OF THE STUDY

The previous studies in this thesis have set the stage for the final phase of the study, which was to determine the contribution of leisure participation and satisfaction to the prediction of fatigue and HRQoL. Use of the term 'fatigue' instead of 'the impact of fatigue' and 'physical and mental health' instead of 'SF-36® PCS and SF-36® MCS' are for easy reading in the thesis. The first step was to examine the relationship between leisure participation and fatigue (physical, cognitive, and psychosocial functions); leisure participation and HRQoL (physical and mental health domains); fatigue and HRQoL; fatigue and other variables (age, duration since diagnosis, pain; depression; and social support); and HRQoL and other variables (age, duration since diagnosis, pain; depression; and social support). The other variables were included based on evidence presented in the literature review. The second step was to determine which variables above are significant contributors to the prediction of fatigue and HRQoL. From the literature review, it was hypothesized that the inclusion of frequency and leisure satisfaction would further elucidate our understanding of fatigue and quality of life in women with chronic conditions.

6.4 RESEARCH QUESTIONS

This research was conducted to answer the following research questions:

1. Do frequency of leisure participation and leisure satisfaction correlate with HRQoL and fatigue?
2. Do frequency of leisure participation and leisure satisfaction contribute to the prediction of HRQoL?
3. Do frequency of leisure participation and leisure satisfaction contribute to the prediction of fatigue?

6.5 RESEARCH DESIGN AND PARTICIPANTS

This study employed a cross-sectional design using standard self-report scales and the CLP Scale. Mailed questionnaires were used in this study (See Appendix 4). Data collection was conducted concurrently with that undertake with respect to validate the CLP Scale. The same 102 women with chronic conditions who participated in the study of development of CLP Scale (See details in Chapter 4) participated in this phase.

6.5.1 Power Calculation

Two methods were used to calculate sample size. Firstly, the required number of participants (N = 100) was determined using the common recommendation of statisticians (Dawson & Trapp, 2001b) for ten times the number of participants as the number of independent variables in the study. Power and sample size tables were then used to determine the power of the regression at the 5% level of significance (Cohen, J., 1988 cited in Portney & Watkins, 2000c, p. 726). This table estimates the lambda value$_f$(λ), which can be converted to the multiple correlation coefficient squared (R^2) by this formula (Portney & Watkins, 2000c, p. 715):

$$\lambda = \frac{R^2}{1-R^2}(N)$$

Finding the value for lambda requires a calculation of the number of residual degrees of freedom, df_{res}, in the analysis of variance of regression (equal to N-k-1, N = number of participants and k = number of independent variables). So that, df_{res} = 89

when $N = 100$ and $k = 10$. Using the closest value for the calculated df_{res}, that is 60, yields 23.8 for the lambda value at 90% power in the regression analysis. From the above formula, the lambda value of 23.8 was converted to $R^2 = 0.19$.

Secondly, the calculation for R^2 was reconfirmed using PASS (Power Analysis and Sample Size) software version 2002 (©2002 J. Hintze, Kaysville, UT). This software offered the same finding as the first calculation. Thus, to detect at least 19% of the variance in the association between the independent variables and the dependent variables, a sample size of at least 100 was required at 90% power and a 5% level of significance.

6.6 VARIABLES AND MEASUREMENT TOOLS

6.6.1 Demographic Data

Demographic data (e.g., age, education, employment, marital status, and duration since diagnosis) were collected (Appendix 4).

6.6.2 Physical, Social and Passive Leisure

The CLP Scale was used to measure frequency of leisure participation in the physical, social, and passive domains. Instrument development and psychometric properties were described in Chapter 4 and 5.

6.6.3 Leisure Satisfaction

As noted in the literature review, satisfaction with leisure activities is one specific dimension of leisure participation. The short version of the Leisure Satisfaction Survey (LSS) was used to measure the quality of leisure participation. This is a standardized, self-report inventory with six subscales: psychological, educational, social, relaxational, physiological, and aesthetic. The LSS uses a five-point graphic response scale with 24 anchoring statements/items. The items are rated from 'Almost never true for you' to 'Almost always true for you.' It has Cronbach Alpha Score of 0.93 and its content-related evidence of validity has been previously stated by 160 researchers undertaking work in the field of leisure (Beard & Ragheb, 1980), demonstrating strong support.

6.6.4 Pain

The Numeric Rating Scale (NRS), a single item scale, was used as a self-report measure of pain intensity. The scale uses a 0 (no pain) to 10 (worst possible pain) rating scale (Hartrick, Koran, & Shapiro, 2003). Its short form is a valid, frequently used scale, which is easy to complete and interpret. It has been widely used clinically for the assessment of pain. Using Spearman correlations, moderate to good construct validity was found between NRS and The Visual Analogue Scale of Pain (VAS) while resting (r = 0.38 to 0.41, $p < 0.001$) and during activity (r = 0.50 to 0.68, $p < 0.001$). The value 4 or greater indicates clinically important painful symptoms or analgesia (Hartrick et al., 2003).

6.6.5 Depression

The short version of the Depression Anxiety and Stress Scales (DASS-21) was used as a standard self-report measure of negative emotions (Lovibond & Lovibond, 1995). It is more acceptable, in both clinical and non-clinical samples, than the full version of the DASS (Henry & Crawford, 2005). Twenty-one statements are rated on a scale from 0 (did not apply to me at all) to 3 (applied to me very much, or most of the time). This short version has strong internal consistency (Cronbach's Alpha of 0.73 to 0.81), tested in 2,914 Australian people (Lovibond & Lovibond, 1995). A summation of the depression subscale (items 3, 5, 10, 13, 16, 17, and 21) was calculated in this study. Strong construct validity of the depression subscale has been shown when compared to the Beck Depression Inventory (BDI) (r = 0.75, at $p < 0.01$) in 241 people with mental illnesses (Brown, Chorpita, Korotitsch, & Barlow, 1997). It has been normed on the Australian population. The mean depression score for Australian women is 6.14 (SD 6.92) (Lovibond & Lovibond, 1995).

6.6.6 Social Support

The Duke Social Support Index (DSSI) was used as a standard self-report measure of social support (Landerman, George, Campbell, & Blazer, 1989). The short form of the DSSI (Koenig, Westlund, & George, 1993) consists of an 11-item scale. It captures how individuals feel about social interaction (4 items) and satisfaction with close relationships (7 items). Increased values demonstrate higher social support (true norms = 33). This measurement tool, used with 117 Australian older people,

has demonstrated good internal consistency (α = 0.77), and test-retest reliability (correlations of 0.70 to 0.81). Moderate construct validity was found between the DSSI and the Interview Schedule for Social Interaction (ISSI) (Goodger, Byles, Higganbotham, & Mishra, 1999).

6.6.7 Physical and Mental Health

The Medical Outcome Study Short Form-36® Health Survey ((MOS) SF-36®) is a self-administered questionnaire designed to assess generic HRQoL (Ware & Sherbourne, 1992a). It covers 8 health domains including 4 domains of physical health (physical functioning, physical role limitation, bodily pain, general health), and 4 domains of mental health (emotional role limitation, vitality-energy/fatigue, mental health, social functioning). The scoring method for these domains is outlined in the SF-36® manual (Ware & Kosinski, 2002). Scores on each of the 8 domains are transformed into standard scores ranging from 0 (worst health status) to 100 (best health status). The standardized scores are then calculated into SF-36® PCS and SF-36® MCS scores. This measurement tool has strong internal consistency (0.81 to 0.92) in Australians (Sanson-Fisher & Perkins, 1998). This study received a license agreement (F1-021305-21457) for use of the SF-36® (Australian version) shown in Appendix 3. The norms of SF-36® PCS and SF-36® MCS for Australian women are 49.50 (SD 10.40) and 49.40 (SD 10.30), respectively (Australian Bureau of Statistics, 1997).

6.6.8 The Impact of Fatigue on Cognitive, Physical, and Psychosocial Functions

The Fatigue Impact Scale (FIS) was used to assess the impact of fatigue on an individual's life. The FIS assesses the impact of fatigue on cognitive, physical and social functioning (Dittner et al., 2004; Fisk, Pontefract, Ritvo, Archibald, & Murray, 1994; Fisk, Ritvo et al., 1994). Subjects were asked to rate the extent that fatigue caused problems for them in relation to 10 items of cognitive functioning, 10 items of physical functioning, and 20 items of psychosocial functioning. The rating scale consisted of 0 = no problem, 1 = small problem, 2 = moderate problem, 3 = big problem and 4 = extreme problem. The maximum FIS score is 160. It has strong psychometric properties: internal consistency (α = 0.93), and convergent validity (r = 0.51) with the Sickness Impact Profile (a measure of general health status based

on a patient's description of how his/her functioning has been affected by their disease) (Fisk, Ritvo et al., 1994). This scale is able to detect a significant decline in the impact of fatigue when compared with a 'baseline' (near zero) level of 'normal' daily fatigue over a period of days (Fisk & Doble, 2002).

6.7 DATA ANALYSIS

6.7.1 Data Screening and Normality Tests

All data were entered into and managed via the SPSS software for Windows version 11.5 (© 2005 SPSS Inc., Chicago, Illinois). Box plots for all variables in this study were inspected first. The Box plot represents the median, 25th (lower boundary) and 75th (upper boundary) percentile. If the data is normally distributed the median should be positioned in the centre of the box (Coakes & Steed, 2005), consistent with the assumptions of one-sample *t* tests (Portney & Watkins, 2000g) and Pearson's correlation matrix (Portney & Watkins, 2000b). Outliers and normality were also checked by inspecting the residual scatter plots and the normal probability plots for the regression standardised residuals (Hair et al., 1998; Pallant, 2005). These graphical methods have been recommended as a part of testing assumptions for the use of regression (Coakes & Steed, 2005; Hair et al., 1998).

6.7.2 Descriptive Analysis

The mean and standard deviation (SD) for the interval data, and percentages for the categorical data were computed via the SPSS software for Windows version 11.5 (© 2005 SPSS Inc.) for each questionnaire. One-sample *t* tests (Portney & Watkins, 2000g) were used to compare data to the available norms: depression (norms = 6.14), social support (norms = 33), SF-36® PCS (norms = 49.50), and SF-36® MCS (norms = 49.40) as provided in their respective manuals or references.

6.7.3 Univariate Analysis

The Pearson's correlation matrix (Portney & Watkins, 2000b) was then used to determine the bivariate correlations between fatigue (cognitive, physical and psychosocial functions) and other variables including age, duration since diagnosis, leisure participation (physical, social and passive domains), leisure satisfaction, pain, depression, and social support, and HRQoL (physical and mental health domains).

Correlations were also used to examine the relationships between HRQoL (physical and mental health domains) and all other variables. In addition to statistical significance, the strength of association (via Pearson correlation coefficients, r) can be interpreted as weak ($0 \leq r > 0.25$), moderate ($0.25 \leq r > 0.50$), strong ($0.50 \leq r > 0.75$), or very strong ($0.75 \leq r > 1$) (Dawson & Trapp, 2001a; Portney & Watkins, 2000b).

6.7.4 Multivariate Analysis

After confirming the normality of the data and checking for outliers and collinearity, multiple regression (Pallant, 2005; Portney & Watkins, 2000c) was then used to determine the significant contribution of the independent variables (as mentioned in the previous section) to the prediction of two outcome variables: HRQoL (physical and mental health domains) and fatigue (on cognitive, physical, and psychosocial functions). This analysis is a statistical technique to determine which independent variables is the strongest predictors of the dependent variable, at the 5% level of significance (Dawson & Trapp, 2001c; Portney & Watkins, 2000c). Each scale of the outcome variables was run separately, on the SPSS software for Windows version 11.5 (© 2005 SPSS Inc., Chicago, Illinois), using multiple regression (stepwise method). Stepwise multiple regression includes a new variable at each step if it meets set criteria; that is, the test of its regression coefficient (Adjusted R2 value) is significant (Portney & Watkins, 2000c). Additional independent variables are selected in terms of the incremental explanatory power they can add to the regression model (Hair et al., 1998). The greater explanatory power of the regression equation the higher the value of Adjusted R2 and the better the prediction of the dependent variable. Standard error of the estimate (SEE) was reported to reflect the prediction accuracy of the multiple regression (Hair et al., 1998; Portney & Watkins, 2000c).

This study also calculated the standardized regression coefficient (β) as an indicator of how much each independent variable contributed to the predicted value for the dependent variable (Coakes & Steed, 2003; Hair et al., 1998; Portney & Watkins, 2000c). To ensure collinearity of predictor variables did not occur, all variables were included in the analysis; none were eliminated on the basis of the univariate analysis. The collinearity diagnostics option was also used. This option gives useful additional output that allows assessment of whether the data has a problem with collinearity.

The tolerance values are a measure of the correlation between the predictor variables and can vary between 0 and 1. The closer to zero the tolerance value is for a variable, the stronger the relationship between this and the other predictor variables. SPSS will not include a predictor variable in a model if it has a tolerance of less than 0.01 (Hair et al., 1998; Portney & Watkins, 2000c).

The inclusion of independent variables as potential predictors was based on theoretical relevance of leisure, fatigue, and HRQoL. This study used multiple regression to test five models: physical health, mental health, cognitive fatigue, physical fatigue, and psychosocial fatigue. Due to the known relationships between the independent and dependent variable demonstrated in previous research. The five models were run separately. In different models some variables acted alternately as predictors and outcomes. For example when HRQoL was the outcome it was not used as a predictor, however, when fatigue was the outcome HRQoL was entered as a predictor. This is consistent with convention that allows any predictor to be included (Coakes & Steed, 2003; Hair et al., 1998; Portney & Watkins, 2000c). For the HRQoL outcome, there were 10 independent variables of interest including pain; depression; social support; cognitive fatigue; physical fatigue; psychosocial fatigue; physical leisure; social leisure; passive leisure; and leisure satisfaction. For the impact of fatigue outcome, there were 9 independent variables of interest including pain; depression; social support; physical health; mental health; physical leisure; social leisure; passive leisure; and leisure satisfaction. As the contribution of age and duration since diagnosis to HRQoL is known (Ford, Gerry, Johnson, & Tennant, 2001), the addition of these time-related variables was entered into each model if the Adjusted R^2 remained significant.

This study also calculated the standardized regression coefficient (β) as an indicator of how much each independent variable contributed to the predicted value for the dependent variable (Coakes & Steed, 2003; Hair et al., 1998; Portney & Watkins, 2000c).

6.8 RESULTS

6.8.1 Participant Characteristics

Demographic and clinical characteristics of the study participants are presented in Table 4.3 (See Chapter 4).

6.8.2 Variables of Interest

All data were normally distributed via the Box Plots. For testing assumptions for the use of regression, there were no extreme deviations from a centralised rectangle in the given models of fatigue (cognitive, physical, and psychosocial impacts) or HRQoL (physical and mental health domains) indicating that then there were no outliers. There were clear relationships between the residuals and the predicted values, consistent with the assumption of linearity for regression.

Table 6.1 provides means and standard deviations (SD) for all variables used in the correlation matrix and regression models. When compared to the published norms, the sample in this study had statistically lower SF-36® PCS ($t = -11.589$, $p < 0.001$) and SF-36® MCS ($t = -3.851$, $p < 0.001$) scores. There were no differences between this sample and published norms on social support or depression.

Table 6.1

Participants' mean score and standard deviations (SD) on the variables of interest

Instruments	Variables	Mean (SD)	Maximum score
1. The Numeric Rating Scale (NRS)	Pain	2.98 (2.56)	10
2. The Depression Anxiety and Stress Scales (DASS)	Depression	5.25 (4.88)	21
3. The Duke Social Support Index (DSSI)	Social support	34.36 (5.27)	47
4. The Fatigue Impact Scale (FIS)	Impact of fatigue on		
	- cognitive function	14.55 (10.88)	40
	- physical function	19.64 (10.48)	40
	- psychosocial function	28.58 (18.87)	80
5. The Medical Outcome Study Short Form-36 ® Health Survey ((MOS) SF-36®)	SF-36® PCS	36.82 (11.05)	100
	SF-36® MCS	44.47 (12.94)	100
6. The Classification of Leisure Participation (CLP) Scale	Physical leisure	1.58 (0.68)	7
	Social leisure	1.48 (0.53)	7
	Passive leisure	3.54 (1.09)	7
7. The Leisure Satisfaction Survey (LSS)	Leisure satisfaction	82.44 (18.55)	120

6.8.3 Correlates and Predictors of Physical Health

According to the intercorrelation matrix of the study variables (see Appendix 5), the collinearity diagnostics found that correlations amongst the predictor variables had a very high tolerance. Thus, there was no influence of these correlations on the stepwise regression models. As shown in Table 6.2, correlational analysis demonstrated strong associations between the NRS pain score and the SF-36® PCS score ($r = -0.54$, $p < 0.001$); and the FIS physical score and the SF-36® PCS score ($r = -0.69$, $p < 0.001$). Participants with more pain or greater fatigue (physical function) had poorer physical health. Better physical health was associated with younger age, shorter duration of diagnosis, greater social support, and more engagement in physical and social leisure.

Table 6.2

Prediction of physical health (SF-36® PCS) using univariate and multivariate analysis

Variables		Univariate	Multivariate	
Outcome	**Independent**	**Pearson correlation coefficients (*r*)**	**Standardised regression coefficients (*β*)**	**Adjusted R^2**
Physical health (SF-36® PCS)	Age	-0.33**	-0.22***	0.67***
	Duration since diagnosis	-0.26*	NS	
	Pain	-0.54***	-0.34***	
	Depression	-0.05	-0.26***	
	Social support	0.29**	NS	
	Impact of fatigue on cognitive function	-0.38***	NS	
	Impact of fatigue on physical function	-0.69***	-0.57***	
	Impact of fatigue on psychosocial function	-0.47***	NS	
	Physical leisure	0.29**	0.16*	
	Social leisure	0.18	NS	
	Passive leisure	-0.10	NS	
	Leisure satisfaction	0.06	NS	

*Note. *p < 0.05; **p < 0.01; ***p < 0.001; NS = non-significant.*

Using stepwise regression, fatigue (physical function) was the strongest predictor of physical health ($\beta = -0.57$; $t = -7.999$, $p < 0.001$). The other contributors to the prediction of physical health were pain, depression, and physical leisure. Without the inclusion of physical leisure, three variables (pain, depression, and the impact of fatigue on physical function) explained 65% of the variability in physical health *(Adjusted $R^2 = 0.65$; $F_{4, 97} = 47.229$; SEE = 6.570, $p < 0.001$)*. The addition of physical leisure improved the model, explaining a further 3% of the variance *(Adjusted $R^2 = 0.67$; $F_{5, 96} = 41.457$; SEE = 6.379, $p < 0.001$)*. Thus, more

engagement in physical leisure activities was identified as a positive predictor of physical health in women with chronic conditions.

6.8.4 Correlates and Predictors of Mental Health

There were strong correlations between the DASS depression score and the SF-36® MCS score, the FIS psychosocial and cognitive score and the SF-36® MCS score, as indicated in Table 6.3. Participants with more depression or greater fatigue (psychosocial and cognitive functions) had poorer mental health. The LSS leisure satisfaction score was also positively associated with the SF-36® MCS ($r = 0.39$, $p < 0.001$).

Results of the regression analysis accounted for 54% of the variance when age, depression, and the impact of fatigue on psychosocial function were included *(Adjusted* $R^2 = 0.54$; $F_{4, 97} = 29.318$; *SEE = 8.882,* $p < 0.001$*)*. The strongest predictor of mental health was fatigue (psychosocial function ($\beta = -0.38$; $t = -4.419$, $p < 0.001$). When satisfaction with leisure participation was added to the model, 56% of the variability was accounted for the prediction of positive mental health *(Adjusted* $R^2 = 0.56$; $F_{4, 97} = 32.580$; *SEE = 8.623,* $p < 0.001$*)*. This was an increase of 2%. Thus, greater satisfaction with leisure participation contributed 2% to the prediction of better mental health for this population ($\beta = 0.21$; $t = 3.047$, $p < 0.01$).

Table 6.3

Prediction of mental health (SF-36® MCS) using univariate and multivariate analysis

Variables		Univariate	Multivariate	
Outcome	**Independent**	**Pearson correlation coefficients (r)**	**Standardised regression coefficients (β)**	**Adjusted R^2**
Mental health (SF-36® MCS)	Age	0.22*	0.23**	0.56***
	Duration of diagnosis	-0.10	NS	
	Pain	-0.23*	NS	
	Depression	-0.59***	-0.34***	
	Social support	0.40***	NS	
	Impact of fatigue on cognitive function	-0.59***	NS	
	Impact of fatigue on physical function	-0.39***	NS	
	Impact of fatigue on psychosocial function	-0.63***	-0.38***	
	Physical leisure	0.11	NS	
	Social leisure	0.14	NS	
	Passive leisure	-0.03	NS	
	Leisure satisfaction	0.39***	0.21**	

*Note. *p < 0.05; **p < 0.01; ***p < 0.001; NS = non-significant.*

6.8.5 Correlates and Predictors of the Impact of Fatigue on Cognitive Function

As shown in Table 6.4, univariate and multivariate analysis of independent variables and the dependent variable (the FIS cognitive score) are described. Pearson correlation coefficients indicated strong correlations between the FIS cognitive score and the DSSI social support score and the SF-36® MCS score. The higher the cognitive fatigue, the poorer the mental health experienced and the less social support reported. Participants with more fatigue were less satisfied with leisure participation.

Standardised regression coefficients of this model indicated three predictors of cognitive fatigue; social support, physical and mental health. The strongest contribution to the prediction of the cognitive impact of fatigue was mental health *(β = -0.53; t = -7.016, p < 0.001)*. The model, including all these predictors, predicted 56% of the variability in cognitive fatigue *(Adjusted R^2 = 0.55; $F_{3, 98}$ = 41.470; SEE = 7.329, p < 0.001)*. Participants with poorer physical and mental health and less social support tended to report higher cognitive fatigue. Although depression, pain and leisure satisfaction were correlated with cognitive fatigue in the univariate analysis, they did not however significantly contribute to the regression model.

Table 6.4

Prediction of the impact of fatigue (FIS) on cognitive function using univariate and multivariate analysis

Variables		Univariate	Multivariate	
Outcome	**Independent**	**Pearson correlation coefficients** *(r)*	**Standardised regression coefficients** *(β)*	**Adjusted R^2**
Impact of fatigue on cognitive function (FIS)	Age	-0.06	NS	0.55***
	Duration of diagnosis	0.01	NS	
	Pain	0.36***	NS	
	Depression	0.47***	NS	
	Social support	-0.53***	-0.22*	
	Physical health	-0.38***	-0.35***	
	Mental health	-0.59***	-0.53***	
	physical leisure	-0.15	NS	
	social leisure	-0.17	NS	
	passive leisure	0.05	NS	
	leisure satisfaction	-0.25*	NS	

*Note. *p < 0.05; **p < 0.01; ***p < 0.001; NS = non-significant.*

6.8.6 Correlates and Predictors of the Impact of Fatigue on Physical Function

As shown in Table 6.5, correlational analysis resulted in a strong negative association between the FIS physical score and the SF-36® PCS score. The poorer the physical health, the higher the fatigue reported. Higher levels of fatigue (physical function) were associated with more depression, less social support, poorer mental health, and less engagement in physical leisure.

The stepwise regression revealed physical health was the strongest predictor of the impact of fatigue on physical function *(β = -0.72; t = -12.380, p < 0.001)*. Mental health was the other unique contributor to predicting the impact of fatigue on physical function. The model, including physical and mental health, predicted 67% of the variability of physical fatigue *(Adjusted R^2 = 0.66; $F_{2, 99}$ = 99.211; SEE = 6.109, p < 0.001)*. No other variables showing associations in the univariate analysis were unique contributors.

Table 6.5

Prediction of the impact of fatigue (FIS) on physical function using univariate and multivariate analysis

Variables		Univariate	Multivariate	
Outcome	**Independent**	**Pearson correlation coefficients** *(r)*	**Standardised regression coefficients** *(β)*	**Adjusted R^2**
Impact of fatigue on physical function (FIS)	Age	0.14	NS	0.66***
	Duration of diagnosis	0.14	NS	
	Pain	0.40***	NS	
	Depression	0.37***	NS	
	Social support	-0.40***	NS	
	Physical health	-0.69***	-0.72***	
	Mental health	-0.39***	-0.44***	
	Physical leisure	-0.29**	NS	
	Social leisure	-0.11	NS	
	Passive leisure	0.11	NS	
	Leisure Satisfaction	-0.15	NS	

*Note. *p < 0.05; **p < 0.01; ***p < 0.001; NS = non-significant.*

6.9 DISCUSSION

This chapter provides the first report of the impact of leisure participation and leisure satisfaction on fatigue and Health-Related Quality of Life (HRQoL) in women with various chronic conditions. Univariate and multivariate analysis enabled five major findings: (1) relationship of age and duration to fatigue; (2) non-leisure factors related to fatigue and HRQoL; (3) relationships between fatigue and HRQoL; (4) relationships between fatigue and leisure; and (5) relationships between leisure and HRQoL.

6.9.1 Relationship of Age and Duration to Fatigue

In the univariate analyses, age and duration since diagnosis were not associated with fatigue. Sharpe and Wilks (2002) also reported that high levels of FSCI were not associated with age. Interestingly, physical health was negatively associated with age and duration since diagnosis, whereas mental health was positively associated with age. Possible explanations are that physiological changes due to ageing and living with chronic conditions may cause poorer physical health, but better mental health may reflect positive adjustments to living with chronic conditions in older persons. Multivariate analysis in this study found age was a positive predictor of mental health for women with chronic conditions, which is in contrast to the study of Ford and his co-researchers (2001) who found that age was a negative predictor of QoL (via Leeds Multiple Sclerosis Quality of Life scale, LMSQoL) in 180 people with MS.

6.9.2 Non-Leisure Factors Related to Fatigue and HRQoL

Univariate analyses in this study indicated that the higher the fatigue the poorer the HRQOL and the less social support reported. Higher fatigue and poorer HRQoL were also related to more pain and depression. It is worth noting, however, that pain, depression and social support seem to be confounding factors of the two outcome variables (fatigue and health) in women with chronic conditions. A confounding factor can be explained as any variable that is associated with both the dependent and independent variables. This study confirms relationships found in the previous studies: fatigue and pain (Ci Ciccone & Natelson, 2003; Crosby, 1991; MacAllister & Krupp, 2005); fatigue and social support (Barnwell & Kavanagh, 1997; Schwattz

6.8.7 Correlates and Predictors of the Impact of Fatigue on Psychosocial Function

There was a strong correlation between the DASS depression score and the FIS psychosocial score; the DSSI social support score and the FIS psychosocial score; and the SF-36® MCS score and the FIS psychosocial score, as indicated in Table 6.6. Participants with more depression, less social support, and poorer mental health had higher scores on the FIS (psychosocial function). The LSS leisure satisfaction score was also negatively associated with the FIS psychosocial score (r = -0.26, $p < 0.05$). There was a weak relationship, but significant between the CLP physical leisure score and the FIS psychosocial score.

Results of the regression analysis accounted 74% of the variance when depression, social support, physical and mental health were included *(Adjusted $R^2 = 0.74$; $F_{4, 97} = 71.067$; SEE = 9.713, $p < 0.001$)*. The strongest predictors of the impact of fatigue on psychosocial function were physical *($\beta = -0.44$; $t = -8.098$, $p < 0.001$)* and mental health *($\beta = -0.44$; $t = -6.645$, $p < 0.001$)*. Leisure variables were not predictors of the impact of fatigue on psychosocial function in this population.

Table 6 .6

Prediction of the impact of fatigue (FIS) on psychosocial function using univariate and multivariate analysis

Variables		Univariate	Multivariate	
Outcome	**Independent**	**Pearson correlation coefficients** *(r)*	**Standardised regression coefficients** *(β)*	**Adjusted R^2**
Impact of fatigue on psychosocial function (FIS)	Age	0.03	NS	0.74***
	Duration of diagnosis	0.07	NS	
	Pain	0.35***	NS	
	Depression	0.61***	0.26***	
	Social support	-0.58***	-0.17*	
	Physical health	-0.47***	-0.44***	
	Mental health	-0.63***	-0.44***	
	Physical leisure	-0.22*	NS	
	Social leisure	-0.19	NS	
	Passive leisure	0.10	NS	
	Leisure Satisfaction	-0.26*	NS	

*Note. *p < 0.05; **p < 0.01; ***p < 0.001; NS = non-significant.*

& Fronhner, 2005); and fatigue and depression (Benito-Leon, Morales, Rivera-navarro, & Mitchell, 2003; Ciccone & Natelson, 2003; Crosby, 1991; MacAllister & Krupp, 2005).

In the multivariate analysis, pain did not contribute to any of the models. Social support contributed to the prediction of cognitive and psychosocial fatigue. These results are supported by earlier studies (Huyser et al., 1998; Riemsma et al., 1998; Schwartz & Frohner, 2005). Huyser at al. (1998) found social support (via Social Relationships Questionnaire, SRQ) was a significant predictor of fatigue (via Piper Fatigue Self-Report Scale, PFS) in 73 people with RA. This finding was similar to the study of Riemsma et al. (1998), which measured severity of fatigue (via Visual Analogue Scale, VAS) and problematic social support (via a Dutch version of an instrument developed by Revenson et al., 1991) in 229 people with RA. Schwartz & Frohner (2005) used the Modified Social Support Survey, MOS and Fatigue Impact Scale, FIS – short version to demonstrate a negative contribution of social support to the prediction of fatigue in 69 people with MS.

In this study, depression also contributed to the prediction of psychosocial fatigue across diagnoses. This result is supported in many previous research studies conducted in one particular chronic condition (Belza, 1993; Garber & Friedman, 2003; Huyser et al., 1998; Kasser & Stuart, 2001; Pollard et al., 2006; Schwartz et al., 1996; Wolfe et al., 1996), but contradicts one study of Schreurs and colleques (2002). It is also important to note that these earlier studies included participants with clinical depression; this study excluded those participants.

Not all factors related to fatigue in the univariate analyses contributed to the multivariate analysis. Social support was correlated with, but not a predictor of physical and mental health, indicating that those correlations may not be strong enough to be selected in the models of HRQoL. Depression was also not correlated with, but contributed to the prediction of physical health. One possible explanation is that all correlated and non-correlated variables were included equally in the regression model, and stepwise regression identifies the smallest number of independent variables (Coakes & Steed, 2005; Portney & Watkins, 2000c) as significant contributors to the given outcome. Some identified variables may not be

unique contributors, instead they may share an association with other contributors in the same model. For example, depression was related to physical fatigue, which, in turn, contributes to a negative perception of physical health.

6.9.3 Relationships between Fatigue and HRQoL

In the univariate analyses, this study found a negative relationship between fatigue and HRQoL. This result confirms previous research conducted with people with MS (Merkelbach et al., 2002) and chronic conditions (Swain, 2000). This study compared the data of the SF-36® PCS and the SF-36® MCS with the Australian norms (Australian Bureau of Statistics, 1997). Women with chronic conditions or FSCI had very poor scores of the SF-36®. Furthermore, use of multivariate analysis in this study detailed the strongest contribution of fatigue to the prediction of HRQoL (and vice versa): the SF-36® PCS score was predicted by the FIS physical score, and in turn, the FIS physical score was predicted by the SF-36® PCS and the SF-36® MCS scores. The FIS psychosocial score was a marked predictor of the SF-36® MCS, and in turn, the SF-36® PCS and the SF-36® MCS were marked predictors of the FIS psychosocial score. Interestingly, psychosocial fatigue was correlated with and a contributor to mental health, indicating that the strongest correlate would become the strongest predictor in the model. It should be acknowledged that the SF-36® PCS includes the vitality subscale (fatigue), however, items are focused energy. The vitality scores is only one of four subscales that contribute to the SF-36® PCS. While some overlap of constructs is possible, this does not explain the relationship with the SF-36® MCS. From the findings, not all subscales of the FIS could be selected as a predictor of the SF-36® PCS.

6.9.4 Relationships between Fatigue and Leisure

Pearson correlations found negative relationships between leisure participation in physical activities and fatigue (physical and psychosocial functions); and leisure satisfaction and fatigue (cognitive and psychosocial functions) in this study. Previous research may help to explain these results. Fatigue may cause physical inactivity (Da Costa et al., 2004; Janssens et al., 2003; Wikström & Jacobsson, 2005), reduce frequency of leisure participation (Eriksen & Bruusgaard, 2005; Wikström & Jacobsson, 2005), and decrease satisfaction with leisure participation (Taylor, & Kielhofner, 2003). Also, people with FSCI seem to participate at less intensity and

lower frequency in physical leisure than those without FSCI (Da Costa et al., 2003; Eriksen & Bruusgaard, 2005; Franssen et al., 2003; Garber & Friedman, 2003; Guinn & Vincent, 2002; Sharpe & Wilks, 2002; Wendel-Vos et al., 2004).

However, stepwise regression showed that neither frequency of leisure participation nor leisure satisfaction were significant contributors to the prediction of the impact of fatigue. These results suggest that leisure participation is not an independent predictor of fatigue. In this study women consistently reported low levels of physical leisure. This may have reduced the overall contribution of leisure to the predictive value of fatigue.

6.9.5 Relationships between Leisure and HRQoL

In the univariate analyses, this study found that physical leisure participation and leisure satisfaction had positive relationships with HRQoL in women with FSCI. These relationships are consistent with previous theoretical literature that reports people who engage in leisure activities may have better physical and mental health (Coleman & Iso-Ahola, 1993) and perceive greater satisfaction with leisure participation (Mannell & Kleiber, 1997; Tinsley & Tinsley, 1986). This study also measured leisure participation (via the CLP Scale and the LSS) based on individual interpretations (Lee, Dattilo, & Howard, 1994; Parker, 1996), perceptions of leisure activities (Harvey, 1993; Lynch & Veal, 1996; Taylor et al., 2003), and satisfaction with leisure participation (Griffin & McKenna, 1998).

In the multivariate analysis, physical leisure and leisure satisfaction were selected predictors in the regression models of physical health and mental health, respectively. These results agree with previous theoretical papers (Caldwell, 2005; Kleiber, Hutchinson, & Williams, 2002; Pondé & Santana, 2000), which reported the positive role of leisure in coping with chronic conditions. For example, Kleiber, Hutchinson, and Williams (2002) reported that leisure plays a major role in the personal transformation of living with chronic conditions. Individuals are learning to live in a new way, and developing the skills needed for positive adaptation and engagement in leisure activities.

It is noteworthy that social and passive leisure did not contribute to perceived levels of physical health. Physical, social, and passive leisure did not contribute to mental health. These results are in contrast to the study of Zimmer, Hickey, and Searle (1995), which found social leisure contributed to QoL in people with RA. Possible explanations are that living with a chronic condition may influence perceptions of gaining better physical health from physically active leisure participation rather than other types of leisure participation (Pattie, et al., 2002; Petajan, Gappmaier, White, Spencer, Mino, & Hicks, 1996). An enhancement of mental health in this population, then, may have been derived from the effect of satisfaction with leisure participation, regardless of type and frequency (Lloyd, King, Lampe, & McDougall, 2001).

6.9.6 Limitations and Recommendations for Future Research

This study has run a single multiple regression for each outcome model. All five outcome models were separately analyzed and not linked into one model. So that the total number of the participants (N = 102) as per the expected power calculation was achieved; however, recruitment bias from use of a convenience sample via membership bulk mailing may have occurred. True representation of people with chronic conditions around Australia is required in order to improve the ability to generalize data to a wider population. Recruitment of 15 participants per predictor in the model, as a good rule of thumb suggested by Stevens (1996), would enable multiple analyses leading to Structural Equation Modeling (SEM). Moreover, a cross-sectional design does not allow determination of causal pathways or mechanisms of the actual contribution of leisure participation (physical, social, and passive domains) and leisure satisfaction on fatigue and HRQoL. To answer this, a longitudinal design is required for future research.

Lastly, the results of frequency of leisure participation in each domain illustrated mild to moderate relationship or contribution with the outcome variables. The total score of the CLP Scale had stronger internal consistency than those of the domain score, but this study has required use of domain scores to answer the research question. It is recognized that the somewhat low internal consistency values may have reduced the power of the multiple regression model. Future studies may be able to refine the items of the CLP Scale to increase internal consistency of domain scores. The total score may be suggested for a further research investigating

frequency of leisure participation in a combination of physical, social and passive domain. As seen from the preliminary studies on the CLP Scale, it is clear how this scale was carried out in terms of classifying leisure activities.

The leisure domains in this study have been investigated, to some extent, in previous studies (Christensen & Mackinnon, 1993; Hilleras et al., 1999; Iwasaki et al., 2005; Katz et al., 2003; Savage et al., 2003; Wikström, 2005; Zimmer et al., 1995). The difference between the CLP Scale and all previous attempts to describe leisure activities is the systematic inclusion of perceptions of women with chronic conditions and the use of Hierarchical Cluster Analysis to create the domains. It was originally expected that the CLP Scale would measure four components of leisure participation, but women with chronic conditions did not categorize any of the potential items as educational/creative compared with those without chronic conditions. Items expected to be included in this category (interest group/club, going to the library, going to art/craft classes/group) instead were classified as social activities. This is inconsistent with previous qualitative studies of women without chronic conditions (Coleman, 1997; Lynch & Veal, 1996; Parker, 1996) who addressed mental or psychological benefits of leisure participation into a single "educational or creative" category. It may indicate that women with chronic conditions, who often experience social isolation, value the social component more than the educational component of these leisure activities. However, one limitation of the CLP Scale is that counting the number of days per week of engaging in a given activity could not be referred to someone who did leisure activities everyday for minutes or hours. This rating scale may have to be modified for that purpose. The other limitation is that some activities are more or less likely to be engaged in frequently (e.g., walking occurs daily while getting petrol rarely occurs). As known that getting petrol was previously classified into social and leisure category (via the ACS-Australia version), the research may ask why this item is leisure and have difficulty for interpretation of this scale which may be limited to leisure domains rather than each leisure item.

CHAPTER 7

DISCUSSION AND CONCLUSION

7.1 INTRODUCTION

This chapter has three parts. The first section is a discussion of the relationship between fatigue, HRQoL, and leisure. The second section discusses correlates/predictors of HRQoL and fatigue; and, finally, section three describes implications for practice.

7.2 RELATIONSHIP BETWEEN FATIGUE, HRQOL AND LEISURE

Univariate analyses in this study found relationships between fatigue, HRQoL, and leisure participation in women with FSCI (Figure 7.1). These results are consistent with previous research that has found a negative relationship between fatigue and HRQoL (Da Costa, Dritsa, Ring, & Fitzcharles, 2004; Merkelbach, Sittinger, & Koenig, 2002); a negative relationship between fatigue and leisure (Da Costa, Lowensteyen, & Dritsa, 2003); and a positive relationship between leisure and HRQoL (Da Costa et al., 2004).

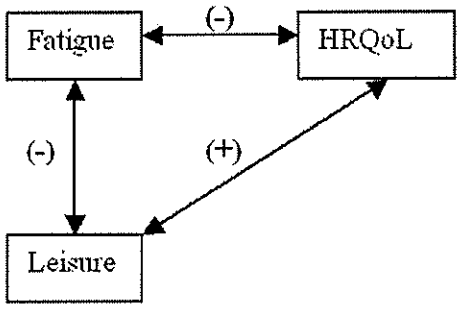

Figure 7.1. Relationships between fatigue, HRQoL, and leisure (univariate analyses).

When using multivariate analysis, some relationships shown in the univariate analyses changed (Figure 7.2). Similar relationships between fatigue and HRQoL, and leisure and HRQoL were found but not leisure and fatigue. Multiple regression was able to more clearly demonstrate the direction of relationships through predictor variables. For instance, participation in physical leisure activities was a positive predictor of physical health while leisure satisfaction was a positive predictor of mental health. This information supports the argument of Coleman and Iso-Ahola (1993) that leisure promotes physical and mental health in people who are

experiencing negative life events. It also supports the finding that leisure promotes mental health in Australian adolescents (Passmore, 2003). However, neither social nor passive activities were found to be contributors to HRQoL. This result is consistent with the study of Wikström and Jacobsson (2005), but different to other research that found a positive contribution from social leisure (Zimmer, Hickey, & Searle, 1995).

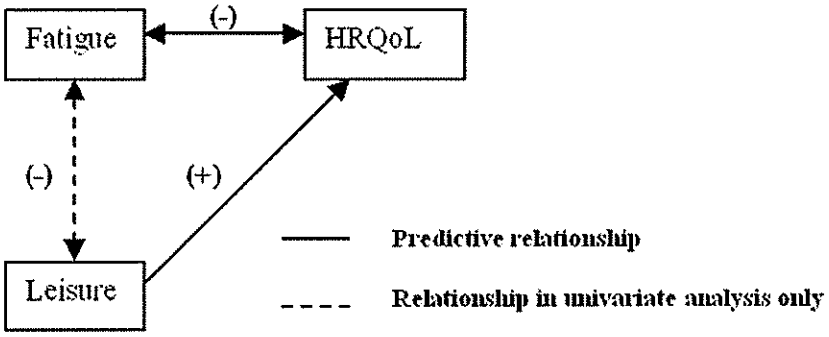

Figure 7.2. Relationships between fatigue, HRQoL, and leisure (multivariate analysis).

Interestingly, none of the leisure variables contributed to the prediction of fatigue, indicating a possible indirect influence of leisure on fatigue. In other words, the univariate relationship found between leisure and fatigue did not form part of the predictive model. Perhaps leisure influences fatigue through its relationship to health. People living with FSCI may have changed life patterns, including the manner of engagement in leisure activities, which may directly improve HRQoL and, at the same time, indirectly reduce fatigue.

Three more possible explanations are persisted. First, many people instinctively know how to cope with negative life events when they do occur, but leisure participation does not come naturally to everyone (Caldwell, 2005); for instance, women with FSCI may avoid exercise and participate in passive leisure activities to alleviate fatigue (Sutherland & Andersen, 2001). Second, leisure participation may vary from individual to individual, in terms of the amount of physical and mental effort involved, regardless of the impact it may have on their fatigue (Taylor & Kielhofner, 2003; Wilhite, Keller, Hodges, & Caldwell, 2004). However, whether

fatigue is the cause of the physical inactivity (Sharpe & Wilks, 2002; Swain, 2000) or the result of chronic conditions (Packer, Foster, & Brouwer, 1997) is uncertain, even if two negative relationships (physical leisure and physical fatigue; and leisure satisfaction and psychosocial fatigue) were found in this study. Third, participants in this study may not have performed leisure activities at sufficient levels to gain benefit; for instance, they engaged in physical leisure less than 2 days a week (see results in Chapter 6). In contrast, people without FSCI spend 16.22 to 22.10 % of each day (more than 2 days a week) on leisure activities (Australian Bureau of Statistics, 1998a; Packer, Foster, & Brouwer, 1997).

7.3 CORRELATES/PREDICTORS OF HRQOL AND FATIGUE

This study has examined the three themes found in the definition of fatigue across diagnoses: the physical aspect, the psychological aspect, and the aspect of activity and participation (focused on leisure). Results of the univariate analyses (Figure 7.3) are supported by recent research (Ci Ciccone & Natelson, 2003; MacAllister & Krupp, 2005; Schwattz & Fronhner, 2005), which has reported a positive relationship between fatigue and pain/depression; and a negative relationship between fatigue and social support/leisure participation. The same variables were also correlated with HRQoL however all were in the opposite direction. These results are also consistent with previous research (Forbes, While, Mathes, & Griffiths, 2006; Rupp, Boshuizen, Dinant, Jacobi, & van den Bos, 2006; Schwartz & Frohner, 2005).

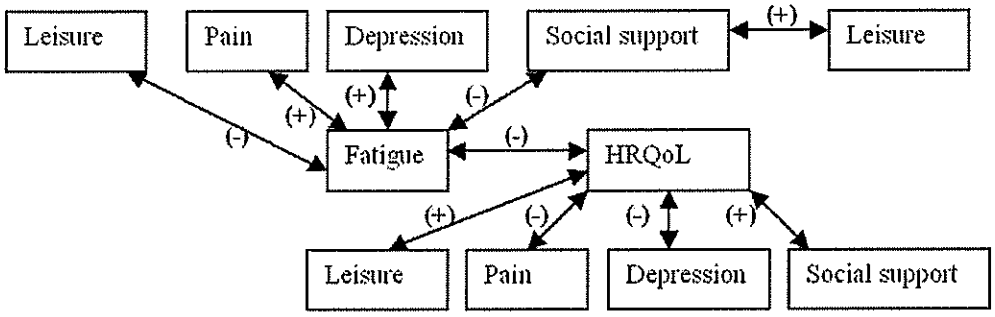

Figure 7.3. Correlates of HRQoL and fatigue (univariate analyses) with additional analysis of social support and leisure.

When using multivariate analysis for the model of HRQoL (Figure 7.4), pain and depression contributed negatively to the prediction of HRQoL. Pain has been shown to be a predictor of HRQoL in a study of people with RA (Rupp, Boshuizen, Dinant, Jacobi, & van den Bos, 2006) and depression has been shown to be a predictor of HRQoL in a study of people with MS (Forbes, While, Mathes, & Griffiths, 2006).

In this study, leisure also contributed positively to the prediction of HRQoL. This finding is consistent with previous research conducted with people without chronic conditions (Coleman, 1993; Iso-Ahola & Park, 1996; Iwasaki, Mannell, & Butcher, 2002; Iwasaki, Mannell, Smale, & Butcher, 2005) and people with orthopaedic disabilities (Zoerink, 2001).

For the regression model of fatigue, it has found that depression contributed positively to the prediction of psychosocial fatigue (Figure 7.4). This result has been previously reported in people with RA (Huyser et al., 1998; Riemsma et al., 1998) and MS (Schwartz, Coulthard-Morris, & Zeng, 1996). These studies suggested that the relationship between fatigue and depression might be due, in part, to overlapping symptoms. Social support also contributed negatively to the prediction of fatigue (cognitive and psychosocial). This result confirms the study of Prins and co-researchers (2004) that identified lack of social support as a perpetuating factor of fatigue and a negative impact on cognition and behaviour of the individuals with FSCI.

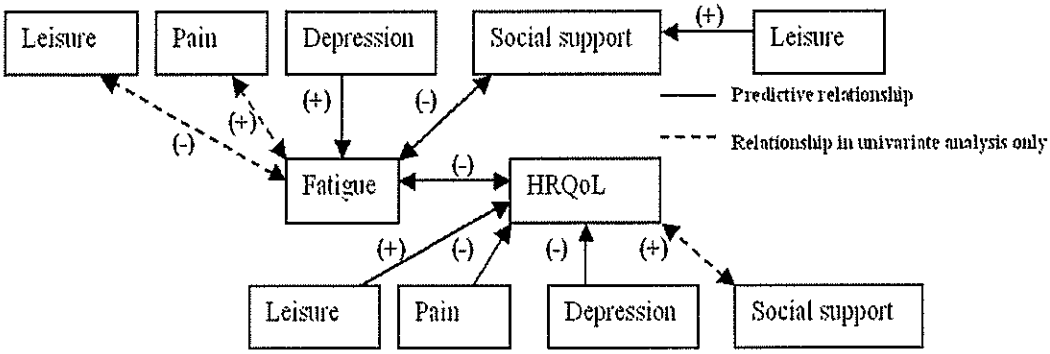

Figure 7.4. Predictors of HRQoL and fatigue (multivariate analysis) with additional analysis of social support and leisure.

In the multivariate analysis, leisure participation was not an independent predictor of fatigue. Social support was a predictor. As previous research has shown a relationship between leisure and social support (Coleman, 1993; Iso-Ahola & Park, 1996) this relationship was further explored, even though it was not a stated objective of the research. First, univariate analysis found two positive relationships: physical leisure and social support ($r = 0.20$, $p < 0.05$); social leisure and social support ($r = 0.31$, $p < 0.01$). Second, multivariate analysis was conducted on social support as an outcome variable. Independent variables entered into the model were age, duration since diagnosis, pain, depression, cognitive fatigue, physical fatigue, psychosocial fatigue, physical health, mental health, physical leisure, social leisure, passive leisure, and leisure satisfaction. Two predictors were selected in the model of social support: social leisure and psychosocial fatigue. Social leisure contributed positively to social support ($\beta = 0.20$, $p < 0.05$) whereas psychosocial fatigue contributed negatively to social support ($\beta = -0.54$, $p < 0.001$). Together these predictors explained 37.7% of the social support. These are important findings suggesting that leisure influences fatigue through social support and confirming the findings of Coleman & Iso-Ahola (1993) and McAuley, Jerome, Elavsky, Marquez, & Ramsey, (2003).

7.4 IMPLICATIONS FOR PRACTICE

The study results have implications for health practitioners. Education could be provided to clients, their families and health service providers regarding the role of a healthy leisure lifestyle in maintaining better health when living with a chronic condition (Caldwell, 2005). Some leisure activities may be more important or more meaningful to individuals than others, and the specific meaning attached to activities may affect the impact on chronic conditions. An understanding of the different contributions of leisure satisfaction, type of leisure activity and frequency of leisure participation to HRQoL and fatigue impact levels may guide interventions and advice provided to those with FSCI, with a possible consequent effect on HRQoL. However, given the nature of this cross-sectional study, cause and effect of those contributions cannot be demonstrated. Future research should investigate the

possibility of leisure participation as a mechanism or an intervention to effect positive change in HRQoL and fatigue over time.

The findings of this PhD research have demonstrated possible pathways to examine the effectiveness of leisure interventions. For example, leisure and fatigue predicted HRQoL (physical and mental health). Leisure and fatigue also predicted social support even though leisure did not predicted fatigue. Thus, people with FSCI may be able to reduce fatigue and improve HRQoL by participating in leisure related social support. With regard to the three tasks of self-management outlined by Corbin and Strauss (1988) this suggests that leisure may assist in symptom management, similar to CBT and self-management.

Furthermore, this PhD research demonstrated the contribution of one's perception of depression to their perception of psychosocial fatigue. Importantly, leisure satisfaction, depression, and psychosocial fatigue predicted mental health. Therefore, people with FSCI may reduce depression and improve mental health by increasing leisure satisfaction. Again with regard to the tasks of CBT and self-management, leisure may assist with management of emotional consequences. However, there has been no evidence of leisure participation in role management for people with FSCI.

7.5 RECOMMENDATIONS FOR FUTURE RESEARCH

Future research should explore the effects of leisure on fatigue compared to other fatigue management strategies? What are the effects of leisure if it is combined with other fatigue management strategies? A longitudinal design investigating the effectiveness of leisure participation would further our understanding. A clinical trial may also provide beneficial interventions in different populations with FSCI. With the significant findings, the CLP has application for a number of professionals in a number of settings. Health professionals, recreation providers, and community agencies will be able to monitor changes in leisure participation over time or in response to specific intervention strategies. Their relationship to changes in health status and/or quality of life can be measured. By examining the differential impact of different types of leisure on health, innovative programs may result. This is particularly important as women with chronic conditions often find physical exercise

difficult or painful. Alternatives avenues to maintain health would be of value and would guide both health providers and local governments in providing locally available programs.

7.6 CONCLUSION

This PhD research has examined leisure participation related to health in women with FSCI. Leisure participation in this research means engagement in different types of leisure activities, including satisfaction. A small validation study found that women with chronic conditions viewed leisure activities differently than women without chronic conditions. Women with chronic conditions did not classify leisure activities in an educational/creative way. The CLP Scale for women with chronic conditions systematically measured frequency of participation in physical, social, and passive leisure. Psychometrically, the CLP Scale has good face validity, mild to moderate construct validity, and moderate internal consistency for the total score.

Based on the fatigue definition, physical and psychological aspects (including pain, depression, and social support) have been found to impact on fatigue and HRQoL. This study found that leisure participation in the physical domain was a predictor of physical health; and leisure satisfaction was a predictor of mental health. Both physical and mental health domains of the HRQoL were strong predictors of fatigue, but leisure participation was not. A positive relationship between leisure and social support was found as well as a positive contribution of leisure to social support. This study suggests leisure influences fatigue through HRQoL and social support. Therefore, finding a way to reduce the impact of fatigue may be more difficult than an enhancement of HRQoL through leisure activities.

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APPENDICES

APPENDIX 1: TELEPHONE INTERVIEW FORM

patterson JOB # 5176

Telephone Interview Form

Metro 1
Country 2

	Date	By:
Edit		
Valid		

TIME COMMENCED _____
TIME COMPLETED _____
TOTAL MINUTES _____

Introduction

Hello, my name is (...) from Patterson Market Research. I am conducting a survey on behalf of a PHD student from the Centre for Research into Disability & Society at Curtin University. Are there any women in your home between ages 25-64?

Yes > 1 **continue:** "Can I please speak to that person?"
No > 2 **thank & terminate**

NB, If more than one women aged 25-64yrs then randomly select the one who will next have a birthday.

REINTRODUCE THEN:
I would like to ask you some questions about the demands of a list of leisure activities. This should take about 10 minutes. Do you have a few minutes to help the PhD student with his research?

Yes > 1 **continue**
No please call back another time > 2 **book appointment**
No/refused > 3 **thank & terminate**

Federal Privacy laws protect the confidentiality of any comments you make in relation to this survey. Your responses will be used solely for research purposes and while we prefer you to answer all questions in the survey, you do not have to.

Q1. Do you have any of the following medical conditions as diagnosed by a physician? **READ OUT ACCEPT MULTIPLES**

Rheumatoid Arthritis (RA)	1 (YES) – mail survey note & terminate
Chronic Fatigue Syndrome (CFS)	2 (YES) – mail survey note & terminate
Multiple Sclerosis (MS)	3 (YES) – mail survey note & terminate
Post Polio Syndrome (PPS)	4 (YES) – mail survey note & terminate
Anaemia	5 (YES) – terminate
Clinical depression	6 (YES) – terminate
Severe respiratory deficit	7 (YES) – terminate
None of the above medical conditions	90 (NO) – continue at Q2

If participants say YES for Number 1-4 at Q1, please ask for their agreement to complete mail survey, as follows: "The PHD student from Curtin would like to mail-out a survey for you to complete. This will take approximately 45 minutes. You will be asked to return the questionnaire booklet within one week. The PHD student may call you to remind you. Even if you agree to participate, you are free to withdraw from the study at any time for any reason".

If they agree, please record the following and then close the survey:

Name_____Phone number_____
Postal Address_____ Postcode _____

If participants say No (code 90 at Q1), please continue; otherwise go to close and do not count as interview.

Firstly a few questions to check that we are speaking to a good cross section of the community. Please remember all these details remain confidential and you will not be individually identified.

Q2. Your present age: _____ **years**

Q3. What is your marital status?

Married/long term relationship	1
Divorced/separated/widowed	2
Never married	3
Refused **DO NOT READ OUT**	89

Q4. How many adults are currently living in your home? **USE 89 for Refused**

_____

Q5. Are you currently **READ OUT:**

Employed	1
Unemployed	2
Retired	3
Full-Time Homemaker	4
On Leave From Employment	5
Refused **DO NOT READ OUT**	89

Q6. Which is the highest level of education that you have completed?

Primary School	1
Year 10 High School	2
Year 12 High School	3
TAFE or other diploma	4
University degree	5
Refused **DO NOT READ OUT**	89

Q7. Consider each of the following activities. Please decide whether they are mostly physical, social, educational/creative, or passive leisure? **READ OUT OF STATEMENTS OVERLEAF ONE ONLY FOR EACH STATEMENT**

Q7 Statements (ROTATE ORDER)

Activities	Physical	Social	Educational /Creative	Passive
1. Going to place of worship	1	2	3	4
2. Volunteer work	1	2	3	4
3. Interest group/club	1	2	3	4
4. Community/civic activities	1	2	3	4
5. Going to children's or grandchildren's activities	1	2	3	4
6. Storytelling with children	1	2	3	4
7. Marriage/relationship	1	2	3	4
8. Entertaining at home or club	1	2	3	4
9. Travelling	1	2	3	4
10. Parties/picnics/BBQ	1	2	3	4
11. Family gatherings	1	2	3	4
12. Visiting with friends	1	2	3	4
13. Going out for a meal or drinks	1	2	3	4
14. Taking a day trip	1	2	3	4
15. Doing favours and helping out	1	2	3	4
16. Talking with family and neighbours	1	2	3	4
17.Gardening/growing flowers	1	2	3	4
18. Watching movies (theatre or home)	1	2	3	4
19. Watching television	1	2	3	4
20. Listening to music	1	2	3	4
21. Sitting and thinking/reminiscing	1	2	3	4
22. Cards	1	2	3	4
23. Computer (email, games)	1	2	3	4
24. Collecting	1	2	3	4
25. Crosswords and word games	1	2	3	4
26. Puzzles	1	2	3	4
27. Spectator Sports	1	2	3	4
28. Recreational Shopping	1	2	3	4
29. Sewing	1	2	3	4
30. Hand crafts	1	2	3	4
31. Reading magazines/books	1	2	3	4
32. Reading newspapers	1	2	3	4
33. Letter writing	1	2	3	4
34. Going to the library	1	2	3	4
35. Attending concerts	1	2	3	4

Q7 Statements continued...

Activities	Physical	Social	Educational /Creative	Passive
36. Going to the theatre	1	2	3	4
37. Bowling	1	2	3	4
38. Golfing	1	2	3	4
39. Walking	1	2	3	4
40. Exercising	1	2	3	4
41. Knitting/crocheting	1	2	3	4
42. Going to beach	1	2	3	4
43. Having morning or arvo cuppa	1	2	3	4
44. Listening to radio	1	2	3	4
45. Bingo	1	2	3	4
46. Lawn Bowls	1	2	3	4
47. Gambling	1	2	3	4
48. Going to art/craft classes/groups (folk art, sewing)	1	2	3	4
49. Preparing for outing/trip	1	2	3	4
50. Getting petrol	1	2	3	4
51. Taking care of a pet	1	2	3	4
52. Talking on the phone	1	2	3	4
53. Shopping in a store	1	2	3	4
54. Driving	1	2	3	4
55. Visiting friends who are ill	1	2	3	4
56. Resting	1	2	3	4
57. Beauty/Barber shop	1	2	3	4
58. Care-giving (grandchildren, family/friends who are ill/disabled)	1	2	3	4
59. Using public transport	1	2	3	4
60. Going to the post office	1	2	3	4
61. Health-related activities (health appointments, aqua-aerobics, walking)	1	2	3	4

Thank you for your time. That completes the actual survey, but in case my supervisor needs to check my work could I please have your name and a contact number. **These details are only for our checking procedures. Apart from the checking process, you will not be contacted again after this survey, nor will your name be recorded on any database.**

NAME _____ TELEPHONE NO _____

INTERVIEWER NAME _____ INT NO _____

I hereby certify that these interviews are accurate and complete, taken in accordance with my instructions and the ICC/ESOMAR international code.

INTERVIEWERS SIGNATURE _____ DATE _____

APPENDIX 2: ADVERTISEMENT

Curtin
University of Technology

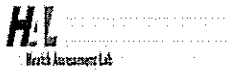
Study Volunteers Needed

Do you experience Fatigue?

A doctoral student from the School of Occupational Therapy is seeking 100 women diagnosed with **Rheumatoid Arthritis, Multiple Sclerosis, Chronic Fatigue Syndrome, or Post Polio Syndrome** to participate in a pilot study to explore frequency of leisure participation, satisfaction from leisure activities, physical health, mental health, and the level of fatigue impact in these chronic illnesses.

For more information, please contact:
POP (Supalak Khemthong)
E-mail supalakpop@hotmail.com
Or
Linda Whitby or Heather Mearns
Tel. 9266 4651, Center for Research into Disability and Society

APPENDIX 3: PERMISSION TO USE THE SF-36®



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APPENDIX 4: INFORMATION SHEET, CONSENT FORM, AND QUESTIONNAIRE BOOKLET

Curtin
University of Technology

CENTRE FOR RESEARCH INTO DISABILITY AND SOCIETY
SCHOOL OF OCCUPATIONAL THERAPY

GPO Box U1987 Perth
Western Australia 6845

TELEPHONE: +61 8 9266 3606
FACSIMILE: +61 8 9266 3636

CRICOS Provider Code 00301J

Information Sheet

Thank you for responding to our request. We have invited you to participate in this study because we are interested in finding out how your experience of fatigue impacts on your participation in leisure and social activities. Through your involvement, we anticipate you will gain a greater understanding of how leisure and social participation can relieve your feelings of fatigue, and you may be better able to manage the impact of fatigue. These outcomes may enhance not only your quality of life, but also contribute positively to people with chronic illness throughout the world.

If you agree to participate, you will receive a questionnaire to complete. This will take approximately 45 minutes. You will be asked to return the questionnaire booklet within one week. The researcher may call you to remind you. Even if you agree to participate, you are free to withdraw from the study at any time for any reason.

There are no known risks to participating in the study and the information gained will assist therapists and researchers to understand fatigue and its impact on activity performance. This information will also assist in the future development of a fatigue management program. Your participation will be kept confidential. Your name will not be used on the questionnaire but a code will be used so that we can make a reminder call to you. All information and data will be stored in a locked cabinet. When the results are published only group information will be reported – you will not be identifiable.

This research is being done by Supalak Khemthong, doctoral student in the School of Occupational Therapy and is being supervised by Professor Tanya L. Packer.

Further information about the study can be obtained from the researchers:

1. POP (Supalak Khemthong), supalakpop@hotmail.com

School of Occupational Therapy-PhD Research Lab

Curtin University of Technology, Phone 9266 3605

2. Linda Whitby or Heather Mearns

Centre for Research into Disability and Society, Phone 9266 4651

This study has been approved by the Curtin University Human Research Ethics Committee. If needed, verification of approval can be obtained either by writing to 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 2748.

Consent Form

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 I will be asked to complete a questionnaire booklet and to return the completed questionnaires to the researcher within one week. If required I may be contacted with 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 also understand that I will gain no personal benefit from participation, but people with fatigue secondary to chronic illness generally may benefit from the results.

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: _____

Questionnaire Booklet

ID Number: ☐☐☐☐☐

Demographic Information Sheet

We would like to know some information about you.

Please complete to the following questions and tick the box/es that best match your response.

1. Your present age: _____ in years

2. What is your marital status?

   ☐1 Married/long term relationship

   ☐2 Divorced/separated/widowed

   ☐3 Never married

3. Are you presently:

   ☐1 Employed

   ☐2 Unemployed

   ☐3 Retired

   ☐4 Full-Time Homemaker

   ☐5 On Leave From Employment

4. Which is the highest level of education that you have completed?

   ☐1 Primary School

   ☐2 Year 10 High School

   ☐3 Year 12 High School

   ☐4 TAFE or other diploma

   ☐5 University degree

Please turn page and continue.

1

5. Have you been diagnosed with any of the following conditions?

☐1 Rheumatoid Arthritis (RA)

☐2 Chronic Fatigue Syndrome (CFS)

☐3 Multiple Sclerosis (MS)

☐4 Post Polio Syndrome (PPS)

☐5 Anemia

☐6 Clinical depression

☐7 Severe respiratory deficit

6. Please tell us when you were diagnosed with:

RA Month:_____ Year: _____

CFS Month:_____ Year: _____

MS Month:_____ Year: _____

PPS Month:_____ Year: _____

7. How many adults is currently living in your home? _____

Please turn page and continue.

We would now like you to complete the following seven questionnaires.

Please follow the instructions carefully for each questionnaire.

1. Numeric Rating Scale (NRS)

On a scale of zero to ten, where zero means no pain and ten equals the worst possible pain, what is your current pain level?

Please circle one number only.

|---|---|---|---|---|---|---|---|---|---|---|

0 1 2 3 4 5 6 7 8 9 10

No pain — Mild — Moderate — Severe — Worst Possible Pain

Please turn page and continue.

2. Duke Social Support Index (DSSI)

This section is about the support you may receive from your family and friends.

Please tick one box only.

1. How many persons in this area within one hours travel, do you feel you can depend on or feel very close to? Do not include people in your own family.

☐ 0 persons ☐ > 2 persons

☐ 1 – 2 persons ☐ no answer

2. How many times during the past week did you spend some time with someone who does not live with you? (For example, you went to see them or they came to visit you, or you went out together?)

☐ no times ☐ > 2 times

☐ 1 – 2 times ☐ no answer

3. How many times during the past week did you talk to someone - friends, relatives or others - on the telephone? (either they called you, or you called them)

☐ none - 1 time ☐ 2 – 5 times

☐ > 5 times ☐ no answer

Please turn page and continue.

4. About how many times in the past week did you go to meetings of social clubs, religious meetings or other groups that you belong to?

☐ none - 1 time ☐ 2 – 5 times

☐ > 5 times ☐ no answer

5. Does it seem that your family and friends (that is, people who are important to you) understand you?

☐ never ☐ no answer / not applicable

☐ hardly ever

☐ some of the time

☐ most of the time

☐ all of the time

6. Do you feel useful to your family and friends?

☐ never ☐ no answer / not applicable

☐ hardly ever

☐ some of the time

☐ most of the time

☐ all of the time

Please turn page and continue.

7. Do you know what is going on with your family and friends?

- ☐ never
- ☐ no answer / not applicable
- ☐ hardly ever
- ☐ some of the time
- ☐ most of the time
- ☐ all of the time

8. When you are talking with your family and friends, do you feel you are being listened to?

- ☐ never
- ☐ no answer / not applicable
- ☐ hardly ever
- ☐ some of the time
- ☐ most of the time
- ☐ all of the time

9. Do you feel you have a definite role/place in your family and amongst your friends?

- ☐ never
- ☐ no answer / not applicable
- ☐ hardly ever
- ☐ some of the time
- ☐ most of the time
- ☐ all of the time

Please turn page and continue.

10. Can you talk about your deepest problems with at least some of your family and friends?

- ☐ never
- ☐ no answer / not applicable
- ☐ hardly ever
- ☐ some of the time
- ☐ most of the time
- ☐ all of the time

11. How satisfied are you with the kinds of relationships you have with your family and friends?

- ☐ extremely dissatisfied
- ☐ no answer / not applicable
- ☐ very dissatisfied
- ☐ somewhat dissatisfied
- ☐ mostly satisfied
- ☐ always satisfied

Please turn page and continue.

3. Depression Anxiety and Stress Scales (DASS)

Please read each statement and circle a number 0, 1, 2 or 3 which indicates how much the statement applied to you over the past week. There is no right or wrong answer. Do not spend too much time on any statement.

The rating scale is as follows:

0 Did not apply to me at all

1 Applied to me to some degree or some of the time

2 Applied to me to a considerable degree, or a good part of time

3 Applied to me very much or most of the time

1. I found it hard to wind down	0	1	2	3
2. I was aware of dryness of my mouth	0	1	2	3
3. I couldn't seem to experience any positive feeling at all	0	1	2	3
4. I experienced breathing difficulty (e.g. excessively rapid breathing, breathlessness in the absence of physical exertion)	0	1	2	3
5. I found it difficult to work up the initiative to do things	0	1	2	3
6. I tended to over-react to situations	0	1	2	3
7. I experienced trembling (e.g. in the hands)	0	1	2	3
8. I felt that I was using a lot of nervous energy	0	1	2	3
9. I was worried about situations in which I might panic and make a fool of myself	0	1	2	3
10. I felt that I had nothing to look forward to	0	1	2	3
11. I found myself getting agitated	0	1	2	3

Please turn page and continue.

The rating scale is as follows:

0 Did not apply to me at all

1 Applied to me to some degree or some of the time

2 Applied to me to a considerable degree, or a good part of time

3 Applied to me very much or most of the time

12. I found it difficult to relax	0	1	2	3
13. I felt down-hearted and blue	0	1	2	3
14. I was intolerant of anything that kept me from getting on with what I was doing	0	1	2	3
15. I felt I was close to panic	0	1	2	3
16. I was unable to become enthusiastic about anything	0	1	2	3
17. I felt I wasn't worth much as a person	0	1	2	3
18. I felt that I was rather touchy	0	1	2	3
19. I was aware of the action of my heart in the absence of physical exertion (e.g. sense of heart rate increase, heart missing a beat)	0	1	2	3
20. I felt scared without any good reason	0	1	2	3
21. I felt that life was meaningless	0	1	2	3

Please turn page and continue.

4. Fatigue Impact Scale (FIS)

Rate the extent that fatigue has caused problems for you over the past month for each of the statements below.

Circle the appropriate response for each.

Because of my fatigue I feel:	No problem	Small problem	Moderate problem	Big problem	Extreme problem
1. Less alert	0	1	2	3	4
2. I feel that I am more isolated from social contact	0	1	2	3	4
3. I have to reduce my workload or responsibilities	0	1	2	3	4
4. I am more moody	0	1	2	3	4
5. I have difficulty paying attention for a long period of time	0	1	2	3	4
6. I feel like I cannot think clearly	0	1	2	3	4
7. I work less effective (this applies to work both inside or outside of the home)	0	1	2	3	4
8. I have to rely more on others to help me or do things for me	0	1	2	3	4
9. I have difficulty planning activities ahead of time	0	1	2	3	4
10. I am more clumsy and uncoordinated	0	1	2	3	4

Please turn page and continue.

Because of my fatigue I feel:	No problem	Small problem	Moderate problem	Big problem	Extreme problem
11. I find that I am more forgetful	0	1	2	3	4
12. I am more irritable and more easily angered	0	1	2	3	4
13. I have to be careful about pacing my physical activities	0	1	2	3	4
14. I am less motivated to do anything that requires physical effort	0	1	2	3	4
15. I am less motivated to engage in social activities	0	1	2	3	4
16. My ability to travel outside my home is limited	0	1	2	3	4
17. I have trouble maintaining physical effort for long periods	0	1	2	3	4
18. I find it difficult to make decisions	0	1	2	3	4
19. I have few social contacts outside of my own home	0	1	2	3	4
20. Normal day-to-day events are stressful to me	0	1	2	3	4

Please turn page and continue.

Because of my fatigue I feel:	No problem	Small problem	Moderate problem	Big problem	Extreme problem
21. I am less motivated to do anything that requires thinking	0	1	2	3	4
22. I avoid situations that are stressful to me	0	1	2	3	4
23. My muscles feel much weaker than they should	0	1	2	3	4
24. My physical discomfort is increased	0	1	2	3	4
25. I have difficulty dealing with anything new	0	1	2	3	4
26. I am less able to finish tasks that require thinking	0	1	2	3	4
27. I feel unable to meet the demands that people place on me	0	1	2	3	4
28. I am less able to provide financial support for myself and my family	0	1	2	3	4
29. I engage in less sexual activity	0	1	2	3	4
30. I find it difficult to organize my thoughts when I am doing things at home or at work	0	1	2	3	4

Please turn page and continue.

Because of my fatigue I feel:	No problem	Small problem	Moderate problem	Big problem	Extreme problem
31. I am less able to complete tasks that require physical effort	0	1	2	3	4
32. I worry about how I look to other people	0	1	2	3	4
33. I am less able to deal with emotional issues	0	1	2	3	4
34. I feel slowed down in my thinking	0	1	2	3	4
35. I find it hard to concentrate	0	1	2	3	4
36. I have difficulty participating fully in family activities	0	1	2	3	4
37. I have to limit my physical activities	0	1	2	3	4
38. I require more frequent or longer periods of rest	0	1	2	3	4
39. I am not able to provide as much emotional support to my family as I should	0	1	2	3	4
40. Minor difficulties seem like major difficulties	0	1	2	3	4

Please turn page and continue.

5. SF-36 HEALTH SURVEY

This questionnaire asks for your views about your health, how you feel and how well you are able to do your usual activities.

Answer every question by marking the answer as indicated. If you are unsure about how to answer a question, please give the best answer you can.

1. In general, would you say your health is:

(circle one)

Excellent.....1

Very good.....2

Good.....3

Fair.....4

Poor.....5

2. Compared to one year ago, how would you rate your health in general now?

(circle one)

Much better now than one year ago.....1

Somewhat better now than one year ago.....2

About the same as one year ago.....3

Somewhat worse now than one year ago.....4

Much worse now than one year ago.....5

Please turn the page and continue.

3. The following questions are about activities you might do during a typical day. Does your health now limit you in these activities? If so, how much?

(circle one number on each line)

ACTIVITIES	Yes, Limited A Lot	Yes, Limited A Little	No, Not Limited At All
a. **Vigorous activities**, such as running, lifting heavy objects, participating in strenuous sports	1	2	3
b. **Moderate activities**, such as moving a table, pushing a vacuum cleaner, bowling, or playing golf	1	2	3
c. Lifting or carrying groceries	1	2	3
d. Climbing **several** flights of stairs	1	2	3
e. Climbing **one** flight of stairs	1	2	3
f. Bending, kneeling or stooping	1	2	3
g. Walking **more than one kilometre**	1	2	3
h. Walking **half a kilometre**	1	2	3
i. Walking **100 metres**	1	2	3
j. Bathing or dressing yourself	1	2	3

Please turn the page and continue.

4. During the past 4 weeks, have you had any of the following problems with your work or other regular daily activities as a result of your physical health?

(circle one number on each line)

	YES	NO
a. Cut down on the **amount of time** you spent on work or other activities	1	2
b. **Accomplished less** than you would like	1	2
c. Were limited in the **kind** of work or other activities	1	2
d. Had **difficulty** performing the work or other activities (for example, it took extra effort)	1	2

5. During the past 4 weeks, have you had any of the following problems with your work or other regular daily activities as a result of any emotional problems (such as feeling depressed or anxious)?

(circle one number on each line)

	YES	NO
a. Cut down on the **amount of time** you spent on work or other activities	1	2
b. **Accomplished less** than you would like	1	2
c. Didn't do work or other activities as **carefully** as usual	1	2

Please turn the page and continue.

6. During the past 4 weeks, to what extent has your physical health or emotional problems interfered with your normal social activities with family, friends, neighbours, or groups?

(circle one)

Not at all 1

Slightly 2

Moderately 3

Quite a bit 4

Extremely 5

7. How much bodily pain have you had during the past 4 weeks?

(circle one)

No bodily pain 1

Very mild 2

Mild 3

Moderate 4

Severe 5

Very severe 6

8. During the past 4 weeks, how much did pain interfere with your normal work (including both work outside the home and housework)?

(circle one)

Not at all 1

A little bit 2

Moderately 3

Quite a bit 4

Extremely 5

Please turn the page and continue.

9. These questions are about how you feel and how things have been with you during the past 4 weeks. For each question, please give the one answer that comes closest to the way you have been feeling. How much of the time during the past 4 weeks .

(circle one number on each line)

	All of the Time	Most of the Time	A Good Bit of the Time	Some of the Time	A Little of the Time	None of the Time
a. Did you feel full of life?	1	2	3	4	5	6
b. Have you been a very nervous person?	1	2	3	4	5	6
c. Have you felt so down in the dumps that nothing could cheer you up?	1	2	3	4	5	6
d. Have you felt calm and peaceful?	1	2	3	4	5	6
e. Did you have a lot of energy?	1	2	3	4	5	6
f. Have you felt down?	1	2	3	4	5	6
g. Did you feel worn out?	1	2	3	4	5	6
h. Have you been a happy person?	1	2	3	4	5	6
i. Did you feel tired?	1	2	3	4	5	6

Please turn the page and continue.

10. During the past 4 weeks, how much of the time has your physical health or emotional problems interfered with your social activities (like visiting with friends, relatives, etc.)?

(circle one)

All of the time 1

Most of the time 2

Some of the time 3

A little of the time 4

None of the time 5

11. How TRUE or FALSE is each of the following statements for you?

(circle one number on each line)

	Definitely True	Mostly True	Don't Know	Mostly False	Definitely False
a. I seem to get sick a little easier than other people	1	2	3	4	5
b. I am as healthy as anybody I know	1	2	3	4	5
c. I expect my health to get worse	1	2	3	4	5
d. My health is excellent	1	2	3	4	5

Please turn the page and continue.

6. Classification and Frequency of Leisure Participation (CFLP) Questionnaire

Please consider each of the following activities and decide whether you think they are mostly physical, social, educational/creative, or passive leisure.

Please tick only one column	Physical	Social	Educational/ Creative	Passive
1. Going to place of worship	☐	☐	☐	☐
2. Volunteer work	☐	☐	☐	☐
3. Interest group/club	☐	☐	☐	☐
4. Community/civic activities	☐	☐	☐	☐
5. Going to children's or grandchildren's activities	☐	☐	☐	☐
6. Storytelling with children	☐	☐	☐	☐
7. Marriage/relationship	☐	☐	☐	☐
8. Entertaining at home or club	☐	☐	☐	☐
9. Travelling	☐	☐	☐	☐
10. Parties/picnics/BBQ	☐	☐	☐	☐
11. Family gatherings	☐	☐	☐	☐
12. Visiting with friends	☐	☐	☐	☐
13. Going out for a meal or drinks	☐	☐	☐	☐
14. Taking a day trip	☐	☐	☐	☐

Please turn the page and continue.

Please tick only one column	Physical	Social	Educational/ Creative	Passive
15. Doing favours and helping out	☐	☐	☐	☐
16. Talking with family and neighbours	☐	☐	☐	☐
17. Gardening/growing flowers	☐	☐	☐	☐
18. Watching movies (theatre or home)	☐	☐	☐	☐
19. Watching television	☐	☐	☐	☐
20. Listening to music	☐	☐	☐	☐
21. Sitting and thinking/reminiscing	☐	☐	☐	☐
22. Cards	☐	☐	☐	☐
23. Computer (email, games)	☐	☐	☐	☐
24. Collecting	☐	☐	☐	☐
25. Crosswords and word games	☐	☐	☐	☐
26. Puzzles	☐	☐	☐	☐
27. Spectator sports	☐	☐	☐	☐
28. Recreational shopping	☐	☐	☐	☐
29. Sewing	☐	☐	☐	☐
30. Hand crafts	☐	☐	☐	☐

Please turn the page and continue.

Please tick only one column	Physical	Social	Educational/ Creative	Passive
31. Reading magazines/books	☐	☐	☐	☐
32. Reading newspapers	☐	☐	☐	☐
33. Letter writing	☐	☐	☐	☐
34. Going to the library	☐	☐	☐	☐
35. Attending concerts	☐	☐	☐	☐
36. Going to the theatre	☐	☐	☐	☐
37. Bowling	☐	☐	☐	☐
38. Golfing	☐	☐	☐	☐
39. Walking	☐	☐	☐	☐
40. Exercising	☐	☐	☐	☐
41. Knitting/crocheting	☐	☐	☐	☐
42. Going to beach	☐	☐	☐	☐
43. Having morning or arvo cuppa	☐	☐	☐	☐
44. Listening to radio	☐	☐	☐	☐
45. Bingo	☐	☐	☐	☐
46. Lawn Bowls	☐	☐	☐	☐

Please turn the page and continue.

Please tick only one column	Physical	Social	Educational/ Creative	Passive
47. Gambling	☐	☐	☐	☐
48. Going to art/craft classes/groups (folk art, sewing)	☐	☐	☐	☐
49. Preparing for outing/trip	☐	☐	☐	☐
50. Getting petrol	☐	☐	☐	☐
51. Taking care of a pet	☐	☐	☐	☐
52. Talking on the phone	☐	☐	☐	☐
53. Shopping in a store	☐	☐	☐	☐
54. Driving	☐	☐	☐	☐
55. Visiting friends who are ill	☐	☐	☐	☐
56. Resting	☐	☐	☐	☐
57. Beauty/Barber shop	☐	☐	☐	☐
58. Care-giving (grandchildren, family/friends who are ill/disabled)	☐	☐	☐	☐
59. Using public transport	☐	☐	☐	☐
60. Going to the post office	☐	☐	☐	☐
61. Health-related activities (health appointments, aqua-aerobics, walking)	☐	☐	☐	☐

Please turn the page and continue.

6. Classification and Frequency of Leisure Participation (CFLP) Questionnaire

How many days in a week do you usually do the following activities?

Please circle only one number.

1. Going to place of worship	0	1	2	3	4	5	6	7
2. Volunteer work	0	1	2	3	4	5	6	7
3. Interest group/club	0	1	2	3	4	5	6	7
4. Community/civic activities	0	1	2	3	4	5	6	7
5. Going to children's or grandchildren's activities	0	1	2	3	4	5	6	7
6. Storytelling with children	0	1	2	3	4	5	6	7
7. Marriage/relationship	0	1	2	3	4	5	6	7
8. Entertaining at home or club	0	1	2	3	4	5	6	7
9. Travelling	0	1	2	3	4	5	6	7
10. Parties/picnics/BBQ	0	1	2	3	4	5	6	7
11. Family gatherings	0	1	2	3	4	5	6	7
12. Visiting with friends	0	1	2	3	4	5	6	7
13. Going out for a meal or drinks	0	1	2	3	4	5	6	7
14. Taking a day trip	0	1	2	3	4	5	6	7
15. Doing favours and helping out	0	1	2	3	4	5	6	7
16. Talking with family and neighbours	0	1	2	3	4	5	6	7
17. Gardening/growing flowers	0	1	2	3	4	5	6	7
18. Watching movies (theatre or home)	0	1	2	3	4	5	6	7

Please turn the page and continue.

19. Watching television	0	1	2	3	4	5	6	7
20. Listening to music	0	1	2	3	4	5	6	7
21. Sitting and thinking/reminiscing	0	1	2	3	4	5	6	7
22. Cards	0	1	2	3	4	5	6	7
23. Computer (email, games)	0	1	2	3	4	5	6	7
24. Collecting	0	1	2	3	4	5	6	7
25. Crosswords and word games	0	1	2	3	4	5	6	7
26. Puzzles	0	1	2	3	4	5	6	7
27. Spectator sports	0	1	2	3	4	5	6	7
28. Recreational shopping	0	1	2	3	4	5	6	7
29. Sewing	0	1	2	3	4	5	6	7
30. Hand crafts	0	1	2	3	4	5	6	7
31. Reading magazines/books	0	1	2	3	4	5	6	7
32. Reading newspapers	0	1	2	3	4	5	6	7
33. Letter writing	0	1	2	3	4	5	6	7
34. Going to the library	0	1	2	3	4	5	6	7
35. Attending concerts	0	1	2	3	4	5	6	7
36. Going to the theatre	0	1	2	3	4	5	6	7
37. Bowling	0	1	2	3	4	5	6	7
38. Golfing	0	1	2	3	4	5	6	7

Please turn the page and continue.

39. Walking	0	1	2	3	4	5	6	7
40. Exercising	0	1	2	3	4	5	6	7
41. Knitting/crocheting	0	1	2	3	4	5	6	7
42. Going to beach	0	1	2	3	4	5	6	7
43. Having morning or arvo cuppa	0	1	2	3	4	5	6	7
44. Listening to radio	0	1	2	3	4	5	6	7
45. Bingo	0	1	2	3	4	5	6	7
46. Lawn Bowls	0	1	2	3	4	5	6	7
47. Gambling	0	1	2	3	4	5	6	7
48. Going to art/craft classes/groups (folk art, sewing)	0	1	2	3	4	5	6	7
49. Preparing for outing/trip	0	1	2	3	4	5	6	7
50. Getting petrol	0	1	2	3	4	5	6	7
51. Taking care of a pet	0	1	2	3	4	5	6	7
52. Talking on the phone	0	1	2	3	4	5	6	7
53. Shopping in a store	0	1	2	3	4	5	6	7
54. Driving	0	1	2	3	4	5	6	7
55. Visiting friends who are ill	0	1	2	3	4	5	6	7
56. Resting	0	1	2	3	4	5	6	7
57. Beauty/Barber shop	0	1	2	3	4	5	6	7

Please turn the page and continue.

58. Care-giving (grandchildren, family/friends who are ill/disabled)	0	1	2	3	4	5	6	7
59. Using public transport	0	1	2	3	4	5	6	7
60. Going to the post office	0	1	2	3	4	5	6	7
61. Health-related activities (health appointments, aqua-aerobics, walking)	0	1	2	3	4	5	6	7

Please turn the page and continue.

7. Leisure Satisfaction Scale (LSS)

Please circle the response that best matches your response.

How true are each of the following statements for you?

Statements	Almost never true	Seldom true	Sometimes true	Often true	Almost always true
1. My leisure activities are very interesting to me	1	2	3	4	5
2. My leisure activities give me self-confidence	1	2	3	4	5
3. My leisure activities give me a sense of accomplishment	1	2	3	4	5
4. I use many different skills and abilities in my leisure activities	1	2	3	4	5
5. My leisure activities increase my knowledge about things around me	1	2	3	4	5
6. My leisure activities provide opportunities to try new things	1	2	3	4	5
7. My leisure activities help me to learn about myself	1	2	3	4	5
8. My leisure activities help me to learn about other people	1	2	3	4	5
9. I have social interaction with other through leisure activities	1	2	3	4	5
10. My leisure activities have helped me to develop close relationships with others	1	2	3	4	5
11. The people I meet in my leisure activities are friendly	1	2	3	4	5

Please turn the page and continue.

Statements	Almost never true	Seldom true	Sometimes true	Often true	Almost always true
12. I associate with people in my free time who enjoy doing leisure activities a great deal	1	2	3	4	5
13. My leisure activities help me to relax	1	2	3	4	5
14. My leisure activities help relieve stress	1	2	3	4	5
15. My leisure activities contribute to my emotional well being	1	2	3	4	5
16. I engage in leisure activities simple because I like doing them	1	2	3	4	5
17. My leisure activities are physically challenging	1	2	3	4	5
18. I do leisure activities which develop my physical fitness	1	2	3	4	5
19. I do leisure activities which restore me physically	1	2	3	4	5
20. My leisure activities help me to stay healthy	1	2	3	4	5
21. The areas or places where I engage in my leisure activities are fresh and clean	1	2	3	4	5
22. The areas or places where I engage in my leisure activities are interesting	1	2	3	4	5
23. The areas or places where I engage in my leisure activities are beautiful	1	2	3	4	5
24. The areas or places where I engage in my leisure activities are well designed	1	2	3	4	5

Please turn the page and continue.

Please put completed questionnaires into the pre-paid postage envelope enclosed and post it back to the researcher.

Thank you for completing this survey!

APPENDIX 5: INTERCORRELATION MATRIX OF STUDY VARIABLES

	1	2	3	4	5	6	7
1	-						
2	0.18	-					
3	0.14	0.17	-				
4	0.07	-0.03	0.20	-			
5	-0.03	0.03	-0.24*	-0.42***	-		
6	-0.07	0.01	0.36***	0.47***	-0.53***	-	
7	0.14	0.14	0.40***	0.37***	-0.40***	0.67***	-
8	0.03	0.07	0.35***	0.61***	-0.58***	0.84***	0.84***
9	-0.33**	-0.26*	-0.54***	-0.05	0.29**	-0.38***	-0.69***
10	0.22*	-0.10	-0.23*	-0.59***	0.40***	-0.59***	-0.39***
11	0.01	-0.12	0.08	-0.04	0.20	-0.15	-0.29*
12	0.05	0.07	-0.01	-0.06	0.31*	-0.17	-0.11
13	0.15	0.01	0.17	0.05	-0.06	0.05	0.11
14	0.11	0.11	-0.14	-0.18	0.29*	-0.25	-0.15

	8	9	10	11	12	13	14
1							
2							
3							
4							
5							
6							
7							
8	-						
9	-0.47***	-					
10	-0.63***	0.07	-				
11	-0.22*	0.29**	0.11	-			
12	-0.19	0.18	0.14	0.38***	-		
13	0.10	-0.10	-0.03	0.35***	0.34**	-	
14	-0.26*	0.06	0.39***	0.25*	0.38***	0.17	-

*Note. 1 = Age; 2 = Duration of diagnosis; 3 = Pain; 4 = Depression; 5=Social Support; 6 = Impact of fatigue on cognitive function; 7= Impact of fatigue on physical function;8 = Impact of fatigue on psychosocial function; 9 = Physical health; 10= Mental health; 11= Frequency of leisure participation in physical domain; 12 = Frequency of leisure participation in social domain; 13 = Frequency of leisure participation in passive domain; 14 = Satisfaction of leisure participation; *p < 0.05; **p < 0.01; ***p < 0.001.*