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Adoption and Maintenance of Regular Participation in Leisure Time Physical Activity in Women with Fibromyalgia

by

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ABSTRACT

Background: Fibromyalgia is a syndrome of chronic widespread pain, fatigue, and impaired sleep affecting 3.5% of adult women, which is associated with reduced physical fitness and difficulty adopting and maintaining regular participation in leisure time physical activity (LTPA).

Purpose: The purpose of the study was to develop a substantive theory that identifies and describes the processes and factors that explain varying levels of participation in LTPA among women with fibromyalgia.

Method: The study used a grounded theory research design with semistructured interviews supplemented by questionnaires and a physical activity log. The researcher conducted a constant comparative analysis of the interview transcriptions aided by NVIVO software to develop a substantive theory. Quantitative data were analyzed using STATA software. Memo writing, code checking, and member checking were used to ensure acceptable rigor.

Results: A sample of twenty consenting women with a diagnosis of fibromyalgia (median age = 53) was recruited from Saskatoon, Saskatchewan, between Sept. 2002 and July 2003. An emergent theoretical framework was developed that specifies that a pattern of regular participation in LTPA is achieved by accumulating sessions of LTPA through five phases of participation: uncommitted, beginner, intermediate, mature, and integrated. A session is the basic unit of the process and it consists of five ordered stages: forming intent, deciding, planning and preparing, starting, and doing. The stages and the phases are influenced at each juncture by barriers, facilitators, strategies, and outcomes. Disruptions in the process may occur at any stage or phase. The theoretical framework

was compared to three theories of Health Behaviour Change and was found to be complementary rather than antipathetic to them.

Conclusions: The emergent theoretical framework provides detail regarding expected outcomes, barriers, facilitators, outcomes to LTPA experienced by women with fibromyalgia that could serve: a) to formulate appropriate measurement tools for important concepts of the predictive theories, and b) to fashion interventions that are sensitive to the needs of this population. It also uncovers particular issues related to participation in LTPA not emphasized by the general theories including the particular difficulties experienced with starting a session of LTPA.

Keywords: leisure time physical activity, fibromyalgia, grounded theory, qualitative research, health behavior, behavior change, transtheoretical model

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"Quit wasting time, quit procrastinating. Just do it. Sometimes I don't though!" (Liza)

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DEDICATION

This work is dedicated to those individuals who suffer with fibromyalgia. In particular, it is dedicated to the women who participated in this study: to Liz, Jackie, Ceci, Isabella, Pete, Kaluha, Adelchia, Sarah, Sheena, Alicia, Meme, Kayla, Laura, Penny, Kathy, Minnie, Allie, Irene, and Liza in appreciation what they have taught me about living with fibromyalgia.

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FIQ	Fibromyalgia Impact Questionnaire
LICO	Low Income Cut-off
LTPA	Leisure Time Physical Activity
MET	Metabolic Equivalent

1 INTRODUCTION

1.1 General Introduction

Jackie, a slim 58 year old woman sits across the table from me. She is well groomed and alert. She can hardly wait to get started. She leans first on her right elbow, then her left, frequently shifting herself in the chair as we talk. She is direct and open in her communication, speaking quickly and excitedly at times, and slowly and reflectively at others. She carries me with her deep into her experience of pain, fear, and loss. A sensitive and proud woman she is, busy now with tending to two young grandchildren three days a week - busy, in pain too, but happy. The joy, the surprise, the humour they have brought, she explains, has been like an elixir washing away the defeat, the pain, the sorrow, and the desperation of those horrible times 4 years ago. She laughed freely, thinking about the children, but she cried too as she described the struggle she had had trying to keep up with her office job, embarrassed, hiding her exhaustion, holding it in. And again she cried when she described a failed holiday with her husband. She had felt so guilty when pain and stiffness had forced them to turn back … four days of misery ... his holiday ruined ... that was the hardest part. Exercise was her saviour, she said. She walks religiously every evening – hour long walks … that, and standing, moving, shifting … never still, not even to eat … to hold the stiffness and pain at abeyance. And then she acknowledged, “Oh, yes, I forgot about that, I use my exercise bike – about 12 times a month” … four days a week! She’d gone to Vancouver on that bike, her husband said. He had checked the odometer. And lately this pain – a burning searing sharp pain in her legs – it scared her – what was it? What if she couldn’t carry on? She wanted just

another four years to see both her grandchildren off to school. She had to hang on, she just had to. It would be unbearable to have to withdraw from their lives.

Fibromyalgia, a syndrome of unknown cause, is believed to be helped by participation in regular exercise. Exercise is reported to help reduce tenderness, improve physical function, reduce depression, and improve general wellbeing (as rated by study participants). Pain, sleep, and anxiety do not seem to improve. High drop out rates – up to 66%, are encountered in randomized controlled trials studying the effects of exercise in individuals with fibromyalgia. What is happening to those who drop out? What do they experience? How can general well being be improved but pain unchanged? Are there some who improve and some who worsen? How active are these women in their daily lives? In what ways does the experience of those who are active differ from those who are inactive? How can some people in pain exercise regularly while others can not? Indeed, how can some people who live with chronic pain adhere to a regime of regular exercise, while many who have no pain adhere so poorly? What can we learn from these people? These were the questions I had at the beginning of this study.

This dissertation describes the grounded theory study that was developed to explore these questions. It begins with a description of fibromyalgia, the purpose and research question, the rationale, definitions, delimitations, limitations and assumptions of the study. Chapter 2 presents a review of the literature organized to address issues of participation in leisure time physical activity (LTPA) in women with and without fibromyalgia and to lay the theoretical foundations for understanding and explaining adoption and maintenance of LTPA. Chapter 3 describes the methods for the study.

Chapters 4, 5, and 6 provide the results of the study – Chapter 4 provides the quantitative results and analysis, Chapter 5 is an overview of the emergent theoretical framework, and Chapter 6 provides a detailed the analysis of the qualitative data. Chapter 7 provides a discussion of the results with emphasis on an analysis of the emergent theoretical framework and how it converges and diverges with established theories of health behaviour. Chapter 8 describes the implications of the emergent theoretical framework and provides recommendations for clinicians and researchers. Chapter 9 briefly summarizes the conclusions of the study.

1.2 Background

Fibromyalgia Syndrome (fibromyalgia) is a common[1] and disabling[2] condition characterized by widespread pain and tender points.[3] It is associated with a wide array of signs and symptoms including physical deconditioning,[4-8] and decreased muscle strength and endurance.[9,10]

Fibromyalgia affects both men and women, but the prevalence rate in women is far greater than in men. The prevalence of fibromyalgia in the general public, across all ages, has been reported to be 3.4% in women compared to .5% in men.[1] A Norwegian study reported the prevalence in women aged 20 - 49 years to be as high as 10%[11] In individuals who seek medical attention, the condition is chronic and frequently non-remitting, with symptoms affecting every aspect of life including work, family life and leisure.[12-17] Physical exercise has gained acceptance as an important component of management of fibromyalgia.[18-23]

1.2.1 Purpose and Research Question

The purpose of this research was to develop a substantive theory that explained the role that physical activity plays in the lives of women with fibromyalgia, with particular emphasis on factors that contribute to habitual physical activity participation patterns. The research question, which gained clarity as the study unfolded was:

> **What are the processes and factors that explain varying levels of participation in LTPA among women with fibromyalgia?**

In answering this question, the experiences, beliefs, and attitudes of women with fibromyalgia were explored to identify the process of adoption and maintenance of routinized physically active behaviours.

1.2.2 Rationale

Although improvements in physical fitness, tenderness of fibromyalgia tender points, and self-perceived general wellbeing are commonly observed in subjects assigned to a variety of exercise protocols in randomized controlled trials, improvement in symptoms such as pain, fatigue, sleep or psychological well-being have only been observed in an inconsistent manner.[24] Attrition rates among those assigned to exercise groups even over the relatively short interval of the studies (6 weeks to 3 months) are high. The proportion of drop outs from exercise interventions in sixteen randomized controlled studies of exercise for fibromyalgia averaged 25.1% (SD=19.0, range: 0 - 67%) versus 12.5% (SD=8.3, range: 0 - 33%) in non-exercising comparison groups ($p = 0.031$).[25] Norregaard and associates noted: "Many of the patients in the aerobic training

intervention reported a deterioration of symptoms and did not want to complete the study." [26 (p76)] Despite the high drop out rates and poor adherence to recommended exercise intensities in these studies, few adverse effects were reported. It appears that these quantitative studies do not adequately capture the perspectives of individuals with fibromyalgia and that there may be effects and issues related participation in physical activity that have gone completely unobserved by the researchers. A qualitative study is needed to validate the findings of the quantitative research and to uncover factors that may have until now gone unobserved.

To date, no other qualitative studies have attempted explain the participation in LTPA among women with fibromyalgia using grounded theory. Just one other qualitative study, Mannerkorpi and Gard (2003),[27] a phenomenological study, has examined the experiences of participants of a pool exercise program for women with fibromyalgia. Clearly, a qualitative study that has the potential of explaining the adoption and maintenance of LTPA in this poorly understood condition is needed.

1.3 Definitions, Delimitations, and Limitations

1.4 Definitions

To clarify the focus and scope of the study, three fundamental terms: physical activity, leisure time physical activity (LTPA) and exercise are defined below.

Physical Activity. Physical activity is a fundamental feature of human life linked to survival, enjoyment, health, and autonomy. It is defined as "any bodily movement produced by contraction of skeletal muscle that substantially increases energy expenditure."[28 (p. S364)] Physical activity can be categorized into occupational physical activity, household physical activity, care-giving physical activity, transportation

involving physical exertion, leisure time physical activity, and other physical activity such as activities of daily living (e.g., eating, and grooming) (see Figure 1.1).

Leisure Time Physical Activity (LTPA). LTPA is defined as "A broad descriptor of the activities one participates in during free time, based on personal interests and needs. These activities include formal exercise programs as well as walking, hiking, gardening, sport, dance, etc. The common element is that these activities result in substantial energy expenditure, although intensity and duration can vary considerably." [28] (S364) In this study, the term LTPA was expanded to include transportation involving physical activity (e.g., walking, cycling) since individuals often engage in this form of physical activity by choice to improve or maintain aerobic fitness.

Exercise. Exercise is defined as "planned, structured, and repetitive bodily movements that are performed to improve or maintain one or more components of physical fitness."[28 (p. S364)] Exercise is a subcategory of LTPA.

In this report, the terms exercise, LTPA, and physical activity are not used interchangeably, but because the participants did not necessarily perceive the distinction, as frequently evident in the transcripts, there may be some unavoidable confusion. In addition, the glossary (Appendix A) defines other relevant terms and concepts.

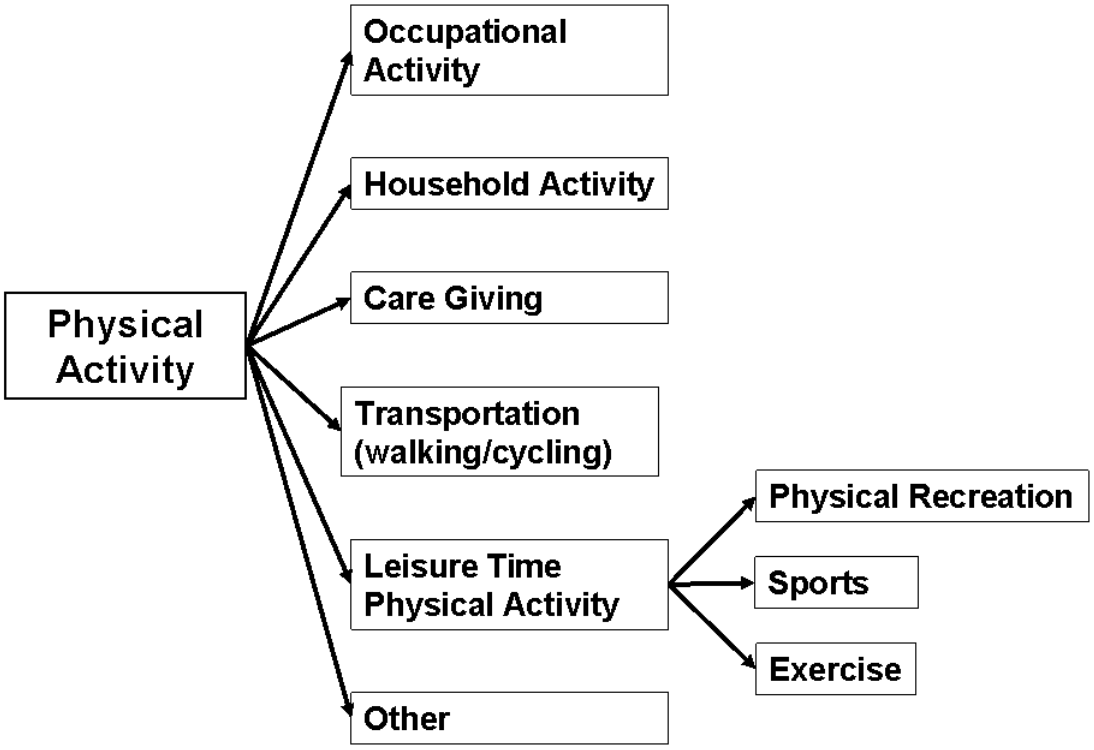

Figure 1-1 Components of physical activity.

1.5 Delimitations

This research deals with a focused area of knowledge and a sample (women with fibromyalgia) drawn purposively using theoretical sampling from a restricted setting (a midsized Canadian prairie city) within a confined time frame (data collection occurred over 10 month period from October 2003 to July 2004). Thus, it is bounded by time and place. The theory generated in this study is described as substantive rather than general.

A wide range of data were obtained in the interviews. In developing the theory, decisions were made to limit the scope of the analysis to that which contributed directly to the research question cited above.

1.6 Limitations

Records confirming diagnosis by a rheumatologist were available for 15 of the 20 participants. The remaining five participants reported that they also had received a diagnosis from a rheumatologist; however this was not verified as part of the study.

Despite attempts to recruit women from age 20 and over, only two individuals were under age 40.

1.7 Assumptions

The assumptions associated with the qualitative research paradigm are applicable to this research. It is assumed that the researcher's perspective will influence the findings of this research. All individuals hold many perspectives based on professional, family, cultural and religious affiliations that affect interpretation of the world around them. Although an effort was made to identify and appraise the impact of these perspectives, any or all of these characteristics may have affected the conduct and the interpretation of this research. The perspectives of the researcher as a physical therapist with more that 23 years experience as a health care provider, as a middle aged Caucasian woman, and as a quantitative researcher in the area of fibromyalgia for the past eight years almost certainly acted at least to some extent as a filter. Thus it is acknowledged that opinions, beliefs, and attitudes related to these perspectives undoubtedly have unconsciously yet inextricably affected the planning, implementation and interpretation of this research.

2 LITERATURE REVIEW

2.1 Introduction

This review is divided into three sections. The first deals with participation in physical activity among healthy women. The second focuses on participation in LTPA among women with fibromyalgia. This section will examine recommended and actual level of participation in LTPA, expected benefits attributed to adhering to recommended levels and issues affecting participation among women with and without fibromyalgia. The final section addresses theories dealing with behaviour changes, specifically those that address adoption and maintenance of health behaviours – with emphasis on three theories that have been applied to adoption and maintenance of leisure time physical activity. This chapter ends with a brief summary of the key features of the literature reviewed and describes how they apply to the current study.

2.2 Participation in LTPA in Healthy Women

Since the early 1950's, epidemiologists have been reporting that physical inactivity is associated with increased risk of many chronic diseases such as coronary heart disease, certain forms of cancer, and Type 2 Diabetes Mellitus.[29,30] To reduce these health risks, current guidelines hold that, "adults should engage in moderate-intensity physical activities for at least 30 minutes on 5 or more days of the week."[31] However, current estimates (Canadian Health Survey 2000/2001) indicate that the majority of Canadians women (59%) are inactive and fail to meet recommended criterion (i.e., equivalent to walking a total of half an hour a day).[32] It is remarkable that such a high level of physical inactivity exists among Canadians despite the fact that most Canadian adults reported that they very strongly believed that being physically active regularly

prevents heart disease (66%), relieves stress (65%), and maintains functional ability with age (64%).[32] This report identifies the three most common barriers to LTPA as lack of time, energy, and motivation and notes that women were more likely to cite lack of energy or lack of skill as barriers to physical activity than were men.

Several researchers have suggested that women have unique challenges to participation in regular LTPA[33-35] related to role overload[36] and participation in occupational and household physical activities[37]. Some researchers have suggested that women may not be as inactive as statistics suggest. Since surveys and questionnaires often rely heavily on measurement of LTPA, the benefits of other forms of physical activity may be overlooked. This may be particularly problematic in women as they may be involved in several forms of physical activity (e.g., occupational, household, and care-giver activities). Friedenreich (2001)[38] categorized the physical activity reported in a survey of Canadian women (n = 1237) as follows: 29.8 hours of occupational physical activity, 22.3 hours of household activity, and 3.7 hours of recreational activity for an average total of 55.7 hours per week. Broken down by intensity, 18.8, 22.4 and 5.8 hours of were low, moderate, and vigorous physical activity respectively.

2.3 Participation in LTPA by Women with Fibromyalgia

There is some controversy about the level of physical inactivity in individuals with fibromyalgia as compared to healthy individuals. Some researchers have indicated that people with fibromyalgia report higher levels of LTPA than do healthy populations[39]. However, this observation is incongruent with the lower levels of physical fitness measured in people with fibromyalgia.[40] The discrepancy may be due to inaccurate perception of exercise intensity by women with fibromyalgia.[39] In fact, a general

criticism of self-report methods for measuring physical activity is that individuals who have a low level of fitness tend to over-estimate the exercise intensity.[41] Experts acknowledge that many individual factors affect evaluation and recall of physical activity on self-report instruments.[42-46] It is possible that factors associated with fibromyalgia (e.g., poor physical fitness, pain, fatigue, anxiety, depression) influence recall of physical activity and distort estimations of intensity and duration and frequency of physical activity events recorded on self-report instruments.[47] These perceptions, even if regarded as "faulty" by researchers and clinicians, will have important implications for participation in LTPA.

2.3.1 Effects of LTPA in People with Fibromyalgia

One assumes that women with fibromyalgia who meet the public health recommendation for LTPA described above will reap the same long term health benefits as others; however this has not been tested. In addition to the possible long term preventive general health benefits, several short term fibromyalgia-specific benefits of exercise have been described. A systematic review of randomized clinical trials of exercise training has reported that short-term aerobic exercise training can improve aerobic performance and some symptoms of fibromyalgia, including pain threshold of tender points, and global feeling of well-being.[25] Modes of aerobic exercise used in reviewed studies were cycle ergometry[48], aerobic dance[49], whole body aerobics[50] and walking indoors[51]. Based on the findings from these studies aerobic exercise was recommended [24] as an important treatment component in the management of FMS. Improvement in aerobic performance, tender points, and global well-being were well supported; improvements in pain intensity, fatigue, sleep, and coping gained limited

support; and positive outcomes in psychological variables (depression, anxiety) were not found. In the past 5 years, several new randomized controlled trials have been completed reinforcing the evidence of benefits of LTPA for individuals with fibromyalgia.[52-69] Among these studies, a few have provided evidence of a beneficial effect of exercise on mood,[55] depression,[55,60] anxiety,[55,60] attitude,[58] mental health,[67]and coping.[60]

Most researchers investigating the effects of LTPA on fibromyalgia have attempted to implement protocols using exercise intensities that will induce physiological adaptations (i.e., cardiovascular or muscular adaptations),[70,71] but recently protocols involving less vigorous intensities have being tested. For example, Mannerkorpi and associates (2000, 2002)[72,73] evaluated the effects of an exercise program at participant-selected intensities in 58 women with fibromyalgia and demonstrated both short term benefits[72] (improved aerobic performance, reduced fibromyalgia severity, and improved quality of life) and long term benefits[73] (reduced symptom severity, improved physical function and improved social function two years after the completion of the intervention).

Although there is now abundant evidence for the benefits of aerobic exercise for individuals with fibromyalgia, there is also growing evidence that other forms of LTPA are also beneficial for this population. Evidence is accumulating that indicates strength training may be beneficial for individuals with fibromyalgia; reduced pain, musculoskeletal performance, and psychological function have been reported.[57,60,74,75] Although it is common practice to recommend exercise to improve flexibility in individuals with fibromyalgia, the few randomized clinical trials that have examined the effectiveness of exercise for flexibility [48,60,67] have not demonstrated significant effects on fibromyalgia symptoms. Researchers[53,76] are beginning to explore LTPA interventions

which focus on enhancing body awareness and correcting faulty movement patterns in individuals with fibromyalgia. Researchers investigating an intervention involving correction of muscle imbalances and movement problems in individuals with fibromyalgia have reported improvement in symptoms.[76] In another study, though, mindfulness meditation and qigong intervention did not result in significant effects for individuals with fibromyalgia.[53]

Dzewaltowski,,Estabrooks, and Glasgow (2004) [77] have proposed a new framework for extending research beyond the setting of controlled efficacy studies. Such methods have not yet been applied to research on LTPA or exercise for fibromyalgia. Therefore, despite the growing body of literature demonstrating the short-term efficacy of LTPA for individuals with fibromyalgia, it is unknown whether the degree of efficacy of physical activity interventions demonstrated in controlled conditions generalizes to or can be sustained in the real-world conditions of individuals with fibromyalgia.

2.3.2 The Lived Experience of Physical Activity in People with Fibromyalgia

Although several qualitative studies have dealt with the experience of living with fibromyalgia,[15,17,19,78-89] only one[27] has focused specifically on the experience of physical activity in the lives of women with fibromyalgia. In a phenomenological study of 19 women, Mannerkorpi and Gard (2003)[27] reported that participants experienced and valued the embodied learning process associated with their participation in a group pool exercise and education program. The participants acquired new relationships with their bodies; they gained new understandings about their bodies, their physical capacity for exercise, how to relax their bodies, and how to deal with stress.

In another qualitative study, a substantive grounded theory on coping with fibromyalgia,[79] researchers described physical activities (walking, bicycling, swimming) as substantive codes under the descriptive category "self-initiated activities." Other researchers have described the sense of loss associated with inability to pursue leisure time physical activities (e.g., walking, tennis)[88] and Henriksson, Gundmark, Bengtsson and Ek (1992) stated "more willpower and motivation is needed for any activity because of the feeling of tiredness and of being unrefreshed when waking up in the morning; the experience of pain throughout the day and during rest periods; and the perception of most tasks being strenuous to perform."[78 (p. 144)]

Henriksson (1995),[15] in a phenomenological study of strategies for daily life in women with fibromyalgia, recognized the role of LTPA in the lives of women with fibromyalgia under the themes of "morning routine" and "regular physical activities." She reported that the women tried to find suitable physical exercise sometimes substituting lighter activities in place of activities that had become too difficult. Even women who did not like physical exercise observed that they felt better following physical exercise, and some women incorporated physical activity into their daily schedules.[90 (p. 82)]

2.4 Theories Related to Adoption and Maintenance of Health Behaviours

The recognition that changes in lifestyles can lead to profound improvements in health and avert future human suffering and health care expenditures both on an individual and population basis came into vivid focus in Canada in 1974 with the release Marc Lalonde's report: A New Perspective on the Health of Canadians.[91] Although the Lalonde report is recognized as a milestone document, its narrow focus on lifestyle and

personal responsibility for all aspects of health has fallen into disrepute. The current theoretical framework for health promotion has been broadened as apparent in proceedings of international meetings on health promotion (i.e., the Ottawa Charter, 1986; the Jakarta Declaration,1997).[92,93] The focus has shifted to population-based health promotion (e.g., healthy communities initiatives) and to a socio-environmental framework that acknowledges the importance of the determinants of health.(e.g., shelter, education, income).[92,93] Nevertheless, the Lalonde report provided an important impetus to governments, health agencies, and Health Care Professionals to respond to the question: how can we facilitate adoption and maintenance of healthy lifestyles among individuals?

2.4.1 The Proliferation of Health Behavior Theories

The focus on healthy lifestyles has spawned an urgency to understand the factors that influence health behaviours. Research which seeks to generate and verify health behaviour theory is important because it identifies and clarifies the factors (e.g., beliefs, experiences, social pressures, and past behaviours) that influence decisions regarding the adoption and maintenance of health behaviours and specifies models that predict behaviour.[94] Such research helps to guide the development of effective interventions[95] which should result in lifestyle change and improved health on both an individual and a population basis.[96]

In a review of 24 journals published between 1992 and 1994, Glanz and associates (2003)[95] identified 66 different health behaviour theories. This proliferation of health behaviour theories confirms the level of interest in, the lack of consensus about, and the complexity of the topic of health behaviour change. Brawley and Culos-Reed

(2000)[97] stated that of the many theories of health behaviour, the five that have been researched to the greatest extent are: the Health Belief Model, the Protection Motivation Model, the Theory of Reasoned Action, the Theory of Planned Behaviour, and the Social Cognitive Theory. In another review, Glanz, Rimer and Lewis (2003) narrowed the field even more when they concluded that Social Cognitive Theory and the Transtheoretical Model were "by far, the two most dominant."[98 (p. 33)]

Although popularity does not ensure validity, the support of a substantial body of research provides several advantages. Most of the research is associated with: a) the level of refinement of the theory and its concepts, b) development of greater sophistication of instrumentation, and c) application of the theory through descriptive and interventions research to a wide range of settings and populations.

Of the many health behaviour theories that have been postulated, several have been applied to adoption and participation in LTPA and exercise in health and selected chronic diseases.[96] Health behaviour change theories appear to have applicability to exercise in healthy populations; observational studies of the social cognitive models (e.g., Health Belief Model, Protection Motivation, Self-efficacy Theory, Theory of Reasoned Action, Theory of Interpersonal Behaviour, Theory of Planned Behaviour) account for as much as 35% of the variance in exercise behaviour.[99 (p. 131)] The Transtheoretical Model, which has been embraced by numerous Health Care Professionals, has yet to be rigorously validated in the sphere of promoting adoption and maintenance LTPA in healthy populations[100] or those with chronic illness.

2.4.2 Classification of Health Behaviour Theories

Weinstein and Sandman (2002)[101] addressed some conceptual and methodological issues regarding health behaviour theories. They introduced a useful classification: continuum theory and stage theory. They described continuum theory as follows:

> … because significant changes in behavior seem to require conscious decision making, the theories used most frequently to explain individual preventive health behaviour (e.g., theory of reasoned action, theory of planned behavior, health belief model, protection motivation theory, subjective expectancy utility theory) view action as the outcome of a cognitive process in which expected benefits are weighed against expected costs. … The theories combine the variables they have identified in an equation that is either prescribed by the theory or derived from collected data. Each theory has a single numerical formula for each individual, and this value is interpreted as a relative probability the individual will act. Thus the prediction places each person along a continuum of action likelihood, and such theories might be labelled continuum theories.[101 (p. 17)]

In their analysis, Weinstein and Sandman (2002) identified that a major shortcoming of commonly used continuum theories is that they prescribe one set of factors to be applied to both adoption and maintenance of change. Thus, continuum theories do not differentiate the factors and processes needed in prediction models and interventions for adoption of change versus maintenance of change. As such, continuum-theory-based interventions seem to be effective at promoting adoption, and weak at achieving maintenance.[101] Rothman (2000)[102] pointed out that none of these theories are able to account for the disassociation between rates of successful initiation and maintenance, and that this is not surprising because: a) adoption depends on outcome expectations while maintenance depends upon satisfaction with outcomes, b) intervention to facilitate adoption may result in increasing outcome expectancies to unrealistic levels which, if unfulfilled will reduce maintenance, and c) adoption is motivated by desire to reach a certain state (an approach-oriented process) whereas maintenance is motivated by

a desire to avoid an unfavourable goal-state (an avoidance-oriented process). Each of these arguments suggests that because continuum theories specify a single set of variables and a single prediction formula, they may be overly simplistic to address both adoption and maintenance.

According to Weinstein and Sandman (2002)[101] another class of theory - stage theory - approaches behaviour change by specifying an ordered set of categories into which people can be classified with respect to their engagement in the health behaviour. The theory then identifies factors that could induce individuals to move from one category to the next.[101] Two theories that meet the classification criteria for stage theories are: the Transtheoretical Model and the Precaution Adoption Process Model. The former has been applied with some success to the adoption and maintenance of LTPA[100] (see below); the latter has not.[103] The Precaution Adoption Process Model is most applicable to behaviours that have a single motive (e.g., the early detection of cancer is the single motivation for having a mammogram)[101] and that deal with confined behaviours (e.g., testing one's home for radon gas). Both of these factors limit the successful application of the Precaution Adoption Process Model to the adoption and maintenance of LTPA. First, there are many reasons one might participate in exercise (enjoyment, social interaction, prevention of heart disease, management of symptoms), not all related to prevention of a single health problem.[101,103] Second, the adoption and maintenance of regular LTPA involves the "gradual development of a habitual pattern of behaviour"[101 (p. 20)] which Weinstein and Sandman (2002) suggested falls outside the scope of this theory.

2.4.3 Review of Selected Health Behaviour Theories

Of the many health behaviour theories, three theories will be examined in this review: a) Theory of Planned Behaviour (a continuum theory), b) the Social Cognitive Theory (a continuum theory), and c) the Transtheoretical Model (a stage theory). The latter two were reviewed during the proposal development phase of this study. They were selected based on the abundance of literature in which they were applied to LTPA. The third, the Theory of Planned Behaviour, which was reviewed following the data collection phase of the study, was selected due to the importance of the concept -- *intention* both in the Theory of Planned Behaviour and in the emergent theoretical framework.

a) The Theory of Planned Behaviour

The Theory of Planned Behaviour is a continuum theory which was developed in 1991 by Icek Ajzen as a refinement to the earlier Theory of Reasoned Action. Ajzen (2001)[104] summarized the theory as follows: "people act in accordance with their intentions and perception of control over the behaviour, while intentions in turn are influenced by attitudes toward the behaviour, subjective norms, and perceptions of behavioural control."[(p. 43)] This theory which has been applied to many health behaviours (e.g., condom use, getting hormone replacement therapy, adhering to medications, eating low fat foods, smoking cessation) has also been applied extensively with fairly good success to prediction of LTPA behaviour in healthy populations and clinical populations (e.g., cancer, cardiovascular disease, low back pain, pregnancy, lower limb disability).[105] Experts have recommended that the Theory of Planned Behaviour be modified to better explain the adoption and maintenance of LTPA, suggesting that: a) *social support* should

replace the concept *subjective norms*,[106] and b) past behaviour should be added to the model.[105]

b) Social Cognitive Theory

Social Cognitive Theory, introduced by Albert Bandura in 1977,[107] is a broad theoretical framework with cognitive, social, personal, and environmental dimensions.[108] Using Weinstein's categories, it can be classified as a continuum theory.[109 (p.18)] It includes powerful modifiable concepts which can be used to explain, predict, and facilitate behaviour change. Social Cognitive Theory states that "behavior change is mediated through cognitive processes (e.g., thinking, perceiving, and believing), that cognitions (e.g., attitudes and beliefs) about a behavior are altered most easily through actual performance or observed performance of the behavior."[110 (p. 321)] Among the variables and relationships described by Social Cognitive Theory, two that are highly emphasized by Bandura are self-efficacy – "beliefs in one's capabilities to organize and execute the courses of action required to gain attainments,"[111 (p3)] and outcome expectations – "a judgment of the likely consequence of (one's) performance"[111 (p21)] Godin (1994)[99] suggests that self-efficacy mediates all behaviour change and explains that it is learned by experience (good or bad) and modeling. According to Godin, self-efficacy determines: a) whether an individual attempts a task, b) the degree of persistence the individual will exhibit when difficulties arise, and c) the ultimate success related to the behaviour change.

Social Cognitive Theory has it roots in Social Learning Theory replete with concepts of operant learning and conditioned learning. However, Social Cognitive Theory has steadily moved away from conceptualizing human learning as a process

chiefly dependent upon and shaped by reflex responses to exterior events, to viewing it as a process that is internally initiated and shaped according to the volitional control of the individual. The vestiges of the Social Learning Theory evident in Bandura's 1977 description of the theory (e.g., symbolic desensitization, symbolic exposure),[107] no longer appear in Bandura's 1997 redesign of Social Cognitive Theory.[111] Emphasis on concepts such as *triadic reciprocal causation* (a continuing three-way interaction among the environment, the person, and the behavior in which "the interacting determinants influence each other bidirectionally")[111 (p. 6)] and *cognitive self-regulation* (the exercise of influence over one's own motivation, thought processes, emotional states and patterns of behaviour), demonstrate that Social Cognitive Theory now strongly affirms a central role for place of human agency in behaviour.[111] Bandura places self-efficacy and outcome expectations in the causal pathway of behaviour change. Self-efficacy, the pre-eminent construct of this model is seen as malleable, responding to social, cognitive, and personal factors. As Bandura (1997) states: "The stronger the efficacy beliefs the intervention instils, the more likely people will enlist the personal resources and sustain the level of effort needed to adopt and maintain health-promoting behavior."[111 (p.286)]

In describing the determinants of self-efficacy, Social Cognitive Theory provides many possible strategies for facilitating behaviour change including: a) *performance accomplishments* (participant modeling, performance desensitization, performance exposure, and self-instructed performance), b) *vicarious experience* (live modeling and symbolic modeling), c) *verbal persuasion* (suggestion, exhortation, self-instruction, interpretive treatments), and d) *emotional arousal* (attribution, relaxation, biofeedback, symbolic desensitization, and symbolic exposure).

Since it was introduced in 1977, Social Cognitive Theory has been applied to many behaviours including LTPA.[112] Refinements have be made to clarify the concepts and more recently to narrow the range of variables to give a pre-eminent position to the concept -- self-efficacy.[111] Researchers have demonstrated persuasively that among healthy adult populations, Social Cognitive Theory variables (chiefly self-efficacy) predict current levels of LTPA behaviour,[113-115] and maintenance of LTPA behaviours for up to 2 years.[116-118]

c) Transtheoretical Model.

Unlike the Theory of Planned Behaviour and the Social Cognitive Theory, the Transtheoretical Model[119] is a stage theory.[109 (p.19)] In keeping with stage theories, the Transtheoretical Model both specifies an ordered set of categories which can be used to classify people according to behaviour change, and identifies the factors that induce movement from one category to the next.[94]

According to the historical account in the book by Prochaska, Norcross and Diclemente (1994): Changing for Good,[120] Prochaska describes the origins of the Transtheoretical Model. He explains that the Processes of Change (see below) were developed first through a comparative "cross-cultural" analysis of the major systems of psychotherapy (psychoanalytic, humanistic/existential, Gestalt/experiential, cognitive, behavioural).[120 (p. 26)] Based on his research, Prochaska identified essential principles used to facilitate change in clients in each of the psychoanalytic systems and distilled these into Processes of Change. He defined a process as "any activity that you initiate to help modify your thinking, feeling, or behaviour."[120 (p. 24)] Prochaska and Diclemente then interviewed 200 self-changers (individuals who had tried to stop smoking mostly

without professional help) to determine how frequently people used the Processes of Change on their own. The exact nature of these interviews was not described, but the following quote suggests that the interviews were somewhat impromptu: "We had progressed from primitive interviews to sophisticated studies and complex data sets."[120 (p. 52)] An unexpected outcome of this research was the discovery that "change unfolds in a series of stages";[120 (p. 37)] these stages they labelled as Stages of Change (see below). Although, it was rooted in psychotherapy and originally focused on smoking cessation, the Transtheoretical Model was rapidly applied to a wide range of health behaviours including weight control, changing delinquency, safer sex, mammography screening, using sunscreens, and exercising.[120,121]

The Transtheoretical Model covers both the adoption and the maintenance of health behaviour and even provides a mechanism for examining relapse. It integrates five main components:

(i) Stages of Change -- The Stages of Change[121 (p.101)] recognize the adoption and maintenance of a health behaviour as a progression through five stages: a) Precontemplation – the individual has no intention of taking action within the next six months, b) Contemplation – the individual intends to take action within the next six months, c) Preparation – the individual intends to take action within the next 30 days and has taken some behavioural steps in this direction, d) Action – the individual has changed overt behaviour for less than six months, and e) Maintenance – the individual has changed overt behaviour for more than six months. Convergent evidence for the validity of the stages-of-change within the domain of LTPA is provided by Cardinal (1997)[122]

who showed that stage of exercise behaviour was related to body mass index, cardiorespiratory fitness, exercise behaviour, relapse, barriers, and self-efficacy.

(ii) Decisional balance – Drawing upon the Model of Decision Making (Janis and Mann, 1977), the Transtheoretical Model conceptualizes a decisional "balance sheet" of comparative pros (potential benefits of changing) and cons (costs of changing). The balance between the pros and cons will vary depending on the Stage of Change.

(iii) Self efficacy --The self-efficacy component consists of two constructs: confidence in the ability to change despite different challenging situations, and temptation to engage in unhealthy behaviours across different challenging situations.[121] (p. 101)

(iv) Processes of Change -- Change processes are covert and overt activities and experiences that individuals engage in when they attempt to modify problem behaviours. Each process is a broad category encompassing multiple techniques, methods, and interventions drawn from a diversity of other theories. Successful behaviour-changers use different processes at each particular Stage of Change. The ten Processes of Change are: consciousness raising, counterconditioning, dramatic relief, environmental revaluations, helping relationships, reinforcement management, self-liberation, self-revaluation, social liberation, and stimulus control.

(v) Treatment Matching – In the interviews with self-changers that Prochaska and Diclemente conducted to determine how self-changers use the Processes of Change, they observed that, not only did the self-changers use the Processes of Change, but the processes were used selectively based on the Stage of Change[120]. This exciting observation gave rise to treatment matching - matching the Processes of Change[121] to the

Stage of Change. Marcus and Forsyth (2003) provided the following explanation of the application of treatment matching to the adoption and maintenance of physical activity:

> Programs based on the stages of motivational readiness for change model match treatment to the individual's stage of readiness for change. For example, individuals in the early stages of change … might focus on use of the cognitive processes. Thus the program might address topics such as increasing awareness of the benefits of physical activity and encouraging thinking about becoming active. Materials designed for individuals in the later stages … can focus more on the behavioural processes.[123 (p.18)]

Researchers studying the adoption and maintenance of exercise behaviours in the domain of physical activity have garnered support for the validity of: the Stages of Change,[122,124] the use of the Processes of Change,[125] and even the differential use of the processes across stages.[126] However, Adams and White (2002),[127] in a critical review of research on physical activity promotion interventions based on the Transtheoretical Model, reported that the studies have demonstrated, "an intervention effect of stage of activity change without a concurrent effect on actual activity levels"[127 (p. 113)] They also noted that most studies have been too short (i.e., less than 6 months) to observe effects on maintenance of physical activity, and that the studies have not been structured to determine "whether stage matching is particularly important."[127 (p. 113)] Prochaska and Marcus (1994) acknowledged problems in applying the Processes of Change to Stages of Change as specified by the Transtheoretical Model and speculated that the poorer performance of treatment matching that they observed in studies of adoption of exercise as compared studies of the cessation of smoking could be attributed to the discrepancies in the nature of the target behaviour (i.e., acquisition vs. cessation).[100]

2.4.4 Applications of Health Behaviour Change Theory to Fibromyalgia

Oliver and Cronan (2002) followed 444 individuals with fibromyalgia participating in a larger study to identify predictors of exercise behaviour. They observed that self-efficacy for exercise[128] was a strong and consistent predictor of regular performance of moderate LTPA (i.e., 3 times/week for at least 20 minutes per time in the last six months) in cross-sectional and longitudinal analysis at baseline, 6 months, 1 year, and 18 months.[129] Although this study explored a number of potential predictors, the researchers did not relate the selection or the results to any specific theory of health behaviour.

In contrast, Culos-Reed (2000), undertook a series of studies,[130] to examine the applicability of the Theory of Planned Behaviour for the prediction and promotion of LTPA in individuals with fibromyalgia. She developed and tested several tools to appropriately objectify the constructs of the Theory of Planned Behaviour for use in fibromyalgia research. She demonstrated that two variables of the Theory of Planned Behaviour (i.e., perceived behavioural control, and intention) were strong predictors of LTPA behaviour. She also demonstrated by using a discussion group intervention that it was possible, at least in the short term, to affect the variables of the Theory of Planned Behaviour in individuals with fibromyalgia. Despite the refinements in instrumentation, these studies did not verify the hypothesized role of attitudes, subjective norms, or the mediating role of intention specified by the Theory of Planned Behaviour as applied to LTPA behaviour in this population.

Most of the research on examining the effects of exercise on fibromyalgia has been atheoretical. Self efficacy has been measured before and after the interventions in

studies examining the effects of exercise on fibromyalgia,[51,55,59,65,131-133] but typically a general measure of self-efficacy (e.g., arthritis self efficacy[134]) has been used; exercise-specific self-efficacy has not been measured.

Although the application of the Transtheoretical Model to adoption or maintenance of LTPA in fibromyalgia has not been documented as yet, Jensen and associates (2000)[135] examined the ability of the model to predict self-management strategies for coping with chronic pain (including exercise behaviours) in a mixed sample (i.e., diverse chronic pain: n = 110, fibromyalgia: n = 119). They quantified the coping behaviours using the Chronic Pain Coping Inventory.[136] Exercise is represented on the inventory by a number of simple physical exercise tasks. They found that exercise behaviour was significantly predicted by Pain Stages of Change Questionnaire.

2.5 Summary of the literature review

Despite the widely recognized general health benefits of regular participation LTPA, the majority of Canadian women have been categorized as physical inactive. It is not known if women with fibromyalgia are more or less physically active than healthy women but it is known that as a population, they are less physically fit. Very little is known about the experience, perceptions, and expectations that women with fibromyalgia have in relation to LTPA. Researchers using rigorous methods have studied the effects of exercise in individuals with fibromyalgia and have reported a variety of short term benefits (improved physical fitness, decreased pain pressure threshold, improved general wellbeing, improved symptoms, and improved mood) some of which are retained for up to 4 years. Concurrently with recording significant positive effects, high drop-out rates are also reported.

Studies of the effects of exercise on fibromyalgia have almost exclusively used quantitative methods. Knowledge about the way women experience LTPA through the use of qualitative methods will enable a broader perspective and illuminate some of the psychological (e.g., attitudes, coping, and mood) and social correlates (e.g., perceptions about social support) which are difficult to quantify. This study was designed to capture these elements and to generate a theory that explains habitual participation in LTPA among women with fibromyalgia who participate in spite of adversity (e.g., pain, fatigue). This knowledge could be used by women with fibromyalgia to guide and strengthen their attempts at adoption and maintenance of LTPA. It could also be used to help design programs and promotion strategies that may help others with and without similar obstacles to adopt and to maintain recommended levels of regular LTPA.

3 METHOD

3.1 Study design

The grounded theory research design was used to develop a substantive theory of the role of LTPA in the lives of women with fibromyalgia. Grounded theory is a "general methodology for developing theory that is grounded in data systematically gathered and analyzed. Theory evolves during actual research, and it does this through the continuous interplay between analysis and data collection."[137] The data used to generate the theory were obtained primarily through semi-structured interviews. The interviews were carried out on a theoretical sample of 20 women with fibromyalgia from Saskatoon, Saskatchewan. Emergent concepts, categories, and models were developed using standard coding methods developed for use in grounded theory studies. Supplementary quantitative data was obtained through questionnaires and a 7-day log of physical activities. The data collection was conducted between September 2003 and July 2004.

3.2 Research Team

The study was conducted by the author (a doctoral student), the student's supervisory committee who provided consultative support, a transcriptionist, and two research assistants. The research assistants were graduate students who were employed to help with code checking for a total of 60 hours collectively. In this report, the doctoral student, the supervisory committee, the transcriptionist, and the research assistants are loosely labelled the "research team".

3.3 Grounded Theory - Theories and philosophical assumptions underpinning the study design

The purpose of grounded theory is to generate new theory or to elaborate on, extend, or verify existing theory.[138] Strauss and Corbin define theory as: "a set of well-developed categories (e.g., themes, concepts) that are systematically interrelated through statements of relationship to form a theoretical framework that explains some relevant social, psychological, educational, nursing or other phenomenon."[139 (p. 22)] The quest for a unitary explanation of a phenomenon would seem to suggest a philosophical espousal of a single reality. Nevertheless, by its nature, theory is tentative and provisional. By claiming that "knowledge is linked closely to time and place," Strauss and Corbin (1994) provide a backdrop of multiple realities to grounded theory. In acknowledging the condition-situation-specific nature of grounded theory, they "… eschew claims of idealistic versions of knowledge, leaving the way open for further development of our theories."[137 (p279)] In developing grounded theory, Glaser and Strauss (1967) recognized a complementary relationship between quantitative and qualitative data in developing theory. They stated: "there is no fundamental clash between purposes and capacities of qualitative and quantitative methods or data."[140 (p17)]

Grounded theory draws upon the theoretical perspectives of symbolic interactionism, which has been summarized as follows:

> an important and unique perspective that regards human beings as active in the environment; an organism that interacts with others and self; a dynamic being; a being that defines immediate situations according to perspectives developed and altered in ongoing social interactions. In taking this stand, . … we do not simply respond to our environment, but we define, act toward it, and use it.[141 (p. 40)]

Expanding on this, Charon (2001) explained: "we can understand what is going on only if we understand what the actors themselves believe about their world." [141 (p. 206)] In keeping with this principle, grounded theory makes use of participants in their own environment speaking of their own experiences and interpretations. It attempts to remain faithful to the everyday realities of a substantive area through careful induction based on diverse data.[137] Grounded theory gains authenticity and applicability by using everyday realities as its source. Strauss and Corbin (1994) insist that interpretation "must include the voices of the people whom we study."[137 (p274)] The essence of grounded theory is that the categories and concepts are rooted in the ideas and concepts presented by the participants themselves; the theory must emerge from the words of the participants. Furthermore, the words of the participants are the data of the research.

The commitment to the emergent nature of the data which is fundamental to this form of research presents challenges with respect to the influence of prior knowledge and perspectives derived from the literature review. While knowledge of the literature can be an aid in "enhancing sensitivity to subtle nuances in the data,"[139 (p. 49)] care was taken in this study to ensure that the concepts were "truly emergent and relevant."[139 (p. 50)] The researcher attempted to stay true to the voices of the participants by: a) suspending the literature review when enough information had been processed to develop the proposal for the study, b) refraining completely from conscious use of concepts derived from the literature during the first interviews with participants, c) seeking reflections of participants on concepts derived from the literature, during the second interview, only after most categories had been saturated[a], and d) collecting quantitative data that included

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[a] Saturation of most categories had occurred by the 18th participant.

concepts from the literature after the first interview (also see Section 3.5.3 Data Analysis and Use of the literature).

In the grounded theory method, the researcher carries a central role. As stated by Strauss and Corbin (1994),[139] "researchers assume the responsibility of interpreting what is observed, heard, or read." This interpretative work, which involves a constant comparative analysis, drives and shapes the entire process. Sampling and data collection are modified in a purposeful manner to challenge and verify current impressions and to follow-up new leads. The design therefore is a fluid one in which even the research problem itself may be modified to the meet the demands of the emerging theory.

There is a lively debate how to evaluate qualitative research[142-150] and what terms to use for attributes of quality.[145,148] To reflect the specific character of qualitative research, an alternate model for describing aspects of methodological quality of research has been proposed for qualitative research as compared to quantitative research. For example, parallel to internal validity are the terms trustworthiness,[151] truth value,[148] and credibility which are "tied to how well the researcher has established confidence in the truth of the findings based on the research design, informants, and context."[148 (p. 215)] Parallel to external validity (or generalizability) of the quantitative paradigm are the terms: applicability, fittingness, or transferability.[148] As stated by Krefting,(1990), "research meets this criterion (transferability) when the findings fit into contexts outside the study situation that are determined by the degree of similarity or goodness of fit between the two contexts," and further, "it is crucial that researchers provide dense background information about the informants and the research context and setting to allow others to assess transferability the findings are." [148 (p. 216, 220)]

3.4 Sampling and Recruitment

3.4.1 Sampling

The principles of theoretical sampling were used. This form of sampling is often used in grounded theory studies[152] and involves "finding examples of a theoretical construct" [153] to allow examination of the construct. Selection of participants is "driven by a conceptual question, not by a concern for *representativeness*."[153 (p. 29)] In practice, because the phenomenon – participation in LTPA - was so broad, most women were able to supply an abundance of data for a wide range of emergent concepts and categories. Thus, a convenience sampling approach was able to supply sufficient data for concepts and categories except barriers related to social role (childcare); theoretical sampling was used to supply participants in this category.

The sample size (n = 20) was chosen based on: a) achievement of theoretical saturation for the most categories, b) time taken for recruitment, and c) availability of participants. Theoretical saturation is defined as: "the point in category development at which no new properties, dimensions, or relationships emerge during analysis."[139 (p143)] In fact, because the emergent theoretical framework was so broad, timing became the major consideration leading to the halt of data collection; some aspects of the theory were only thinly developed.

Adult women living in or near the study center (i.e., Saskatoon, Saskatchewan) with a diagnosis confirmed by a rheumatologist were potential participants. Women with any serious disease other than fibromyalgia affecting ability to participate in regular moderately intense physical activity were excluded. The decision to exclude males from the study was based on the small number of males with this condition.

3.4.2 Recruitment

Four specific recruitment activities were employed to enlist participants to the study. Two activities involved contacting participants of two recently completed randomized controlled trials, one activity involved a recruitment presentation, and one involved posting notices.

- A recruitment poster (Appendix B) was mailed to 143 women with fibromyalgia who had participated, between January 1997 and July 1998, in a randomized controlled trial;[65] comparing two 16-week progressive low-impact aerobics programs to an untreated control group. One individual responded to the mail-out and was recruited.
- Phone calls were made to 19 of the women with fibromyalgia who participated in randomized controlled trial (Busch et al, unpublished) conducted between January 1999 and March 2001 comparing the effects of 12 weeks of community based exercise to physical therapy to an attention only controlled group inviting them to participate in this study. Seventy-one of these women had provided written consent to be contacted regarding future research on fibromyalgia. With two exceptions, the phone calls were made in a sequential manner starting with the women at the top of the list and moving to the bottom of list. Women known to be under age forty were contacted out of sequence. 14 participants were recruited to current study using this source including the two women under age 40.
- Participants were recruited during a presentation to the Saskatoon Fibromyalgia Support Group meeting; two participants were recruited at the meeting.

- Participants were recruited by posting the recruitment posters at the university and at a fitness facility; interested individuals were invited to contact the researcher. Four participants responded to the poster invitation and were recruited.

Phone screening was conducted for all interested individuals. A phone screening form (Appendix C) was used to identify characteristics considered to be relevant to participation in LTPA (e.g., age, duration of disease, current physical activity patterns, marital status, living arrangements, employment, receiving disability insurance, education and income). All participants had a diagnosis of fibromyalgia confirmed by a rheumatologist. Only four women, across all recruitment sources, declined to participate. These women declined because of time constraints. Thus, the sample was recruited using convenience sampling; the use of theoretical sampling was very limited and involved only the preferential recruitment of younger women.

3.5 Data Collection

3.5.1 Types of Data

In this study both qualitative and quantitative data were collected. The qualitative data (in the form of interviews of women with fibromyalgia) had primacy, as these data were used to generate the substantive theory. Quantitative data were used to describe the socio-demographic, fibromyalgia-related, and physical activity-related characteristics of the sample, to examine selected concepts identified in previous research, and to provide a different perspective (i.e., triangulation[154]) thereby enhancing the rigor of the study.

3.5.2 Procedures

Aside from the data collected during the phone screening, all data were collected in a three week interval. In this interval two face-to-face interviews were conducted at

the research office, and a package of questionnaires and a seven-day physical activity log was completed by the participant at home (see Figure 3.1). Participants were given the option of coming to an office at the University of Saskatchewan for the interviews or suggesting another site; all participants opted to come to the office.

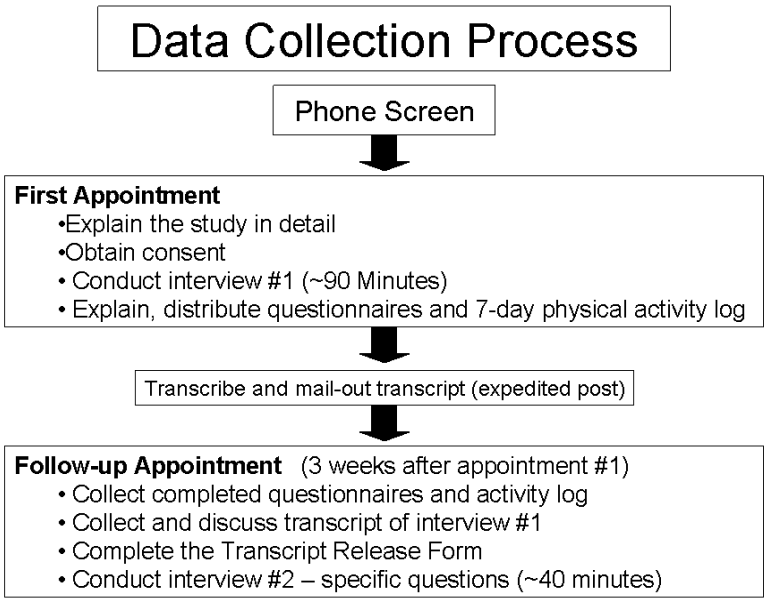

Figure 3-1 Data collection process.

3.5.3 <u>Interview Appointment #1</u>

- Consent forms were completed (Appendix D)
- A semi-structured interview was used, the structure of which evolved during the course of the study to address concepts that emerged from earlier interviews. The initial interview guide (Appendix E) was modified as needed by adding, modifying, or deleting questions to gather data on emerging concepts. The interviews took between 30 – 90 minutes. All interviews were audio-taped and transcribed (verbatim).

- Participants were given the option of choosing a pseudonym to be used by the research team during data analysis and when presenting the findings of the study. The women were encouraged to stand, walk around, or stretch as needed for comfort at any time during the interview.
- Field notes were written during and immediately following each of the interviews to record any significant non-verbal behaviour (e.g., gross motor activity, eye gaze, gestures, and body orientation) of the participant during the interview. The researcher also recorded any reflections she had about the effect that her assumptions, her choice of words, or her own behaviours might have had on the interview (reflexive memos).
- The questionnaires and a physical activity log were distributed. Participants were asked to complete the questionnaires and the seven-day physical activity logs over the course of the next 3 weeks.
- The follow-up appointment was arranged.

3.5.4 Preparation and Distribution of the Transcripts

The transcripts were produced by a skilled secretary and subsequently reviewed and corrected by the researcher (AB). The transcripts of the first interview were mailed using Xpresspost, an expedited postal service offered by Canada Post which delivers documents the next business day locally and regionally. Therefore, participants received the transcripts at least one week prior to the second interview. In keeping with the procedures recommended by the University of Saskatchewan Advisory Committee on Ethics in Behavioural Science Research participants were told that they could add, delete, or modify any of the content in the transcript that they wished.

3.5.5 Follow-up Appointment #2

- Study materials (questionnaires, the activity log, and the transcript of the first interview) were collected. The data (questionnaires, log, and transcript) were briefly reviewed for completeness and clarification by the participant was obtained as needed.
- The purpose of the second audiotaped interview was to obtain new data on the emerging categories and to clarify ambiguities from the first interview. The researcher (AB) used a participant-specific interview guide, which she had drafted while reviewing the first transcript.
- The Transcript Release Form (Appendix F) was administered.

3.5.6 Quantitative Instruments

a) The Fibromyalgia Impact Questionnaire (FIQ)

The FIQ (Appendix G) was used to describe disease severity and symptoms. The FIQ was designed for use with individuals with fibromyalgia to measure: a) physical functioning (10 Likert items), b) work missed (number of days in the previous week), c) well-being (number of days felt good in past week), and d) pain, pain at work, fatigue, sleep, stiffness, anxiety, and depression (using 10 cm visual analogue scales). The FIQ has been tested for validity and reliability; test-retest Pearson's product moment correlation coefficients for six 1-week administrations for individual items ranged from .56 (pain) to .95 (physical function).[155]

b) The Kaiser Physical Activity Survey

The Kaiser Physical Activity Survey (Appendix H)[35] is a self-report participant-completed questionnaire which has been adapted from the Baecke Physical Activity

Questionnaire.[156-158] The Kaiser Physical Activity Survey measures physical activity in 4 domains: occupation, exercise and sports, active living, and household and childcare. The time frame used is 1 year. By including the categories *occupation* and *household/childcare activities*, this questionnaire overcomes some of the deficiencies related to measurement of physical activity in women which were identified by a recent consensus meeting of an expert panel.[45] A study using a sample of 50 women (predominantly white, well-educated, and employed) suggested that the Kaiser Physical Activity Survey was reliable; intra-class coefficients for test-retest reliability at one-month were greater than .79 for all subscales except care-giving, and .83 for the 4-component summary score (sports/exercise, occupation, active living, and housework/care-giving). [159] The researchers demonstrated strong convergent evidence for validity for the Kaiser Physical Activity Survey; age-adjusted Spearman's correlation coefficients between the Kaiser Physical Activity Survey and data obtained using physical activity records, motion detectors, cardiorespiratory fitness testing and measurement of percent body fat were: .35, .49, .59, and -.53 (respectively).[159] When the Kaiser Physical Activity Survey was administered to a diverse sample of 2,636 women,[35] the researchers found that 29% of respondents made one error (missed items and errors in following skip patterns), and 9% made at least 2 errors. Increasing age, non-white ethnicity, and having young children at home appeared to contribute to an increased likelihood of making errors, while being employed was associated with lower likelihood of making errors. In the current study, errors of missing data were avoided by checking data with participants at the second interview appointment.

c) 7-day Physical Activity Log

In this study, a 7-day physical activity log (Appendix I) was used to measure energy expenditure and physical activity patterns. Activity logs and diaries such as this have been used extensively in research related to physical activity and are treated like a "gold standard"[160] to provide evidence for convergent validity for other tools. A log was chosen instead of a more detailed physical activity record because logs are easier to complete and score.[161] Participants recorded the number of minutes they spent in each hour of the day in each of seven physical activity categories: (1) sleeping or lying down, (2) sitting or standing, (3) very light activity, (4) light activity, (5) moderate activity, (6) heavy activity, and (7) driving or riding in a moving vehicle. The time spent in each category was summed over the day and converted to MET-minutes using the following conversion constants[160] for each of the seven categories respectively: 1, 1.5, 2.45, 3.91, 7.08, 10.38, and 1.5. The MET-minutes corresponding to the seven categories were then summed to produce an estimate of energy expenditure over the whole day (i.e., MET-min·day^{-1}).

d) Planned Behaviour Variables Questionnaire

The Planned Behaviour Variables Questionnaire (Appendix J) is a questionnaire[130] developed for individuals with fibromyalgia was used to measure variables from the Theory of Planned Behaviour. Self-efficacy is reported to be the most potent predictor of adopting physical activity.[162] Using ten items, each with an 11-point scale, individuals rate their confidence to engage in physical activity over the next month at specified frequencies, intensities, and symptoms. Cronbach's Alpha levels for test-retest reliability for physical activity efficacy based on data from 68 women with

fibromyalgia tested twice (1 month apart) were reported to be .91 and .71 for frequency and intensity of physical activity, respectively.[130] Physical activity intention is assessed using a single item in which individuals are asked to estimate how regularly they plan to engage in their favourite physical activity in the next 4 weeks. No reliability data were reported for this item.[130]

e) Exercise Perseverance and Barriers Instrument

McAuley and Mihalko (1998) advised that at the very least "exercise performance measures and barriers to self-efficacy should be employed in studies that attempt to predict long-term exercise behavior."[162 (p 379)] Nevertheless, the development of instruments to measure barriers is not very advanced. Debates[163,164] about the conceptual formulation of this construct demonstrate a lack of maturity in this area of measurement. Among the profusion of relatively simple tools for measuring barriers to exercise or physical activity appearing in the literature, the Exercise Perseverance and Barriers Instrument (Appendix K) shows promise. This tool, which was used in this study, has been subjected to intensive analysis (i.e., Rasch Analysis)[164,165] to determine optimal scaling of the 23 items making up the test. Participants use a three-point scale (very often, sometimes, never) to indicate how often barriers in six categories have prevented them from participating in exercise or moderate-intensity physical activity. The six barrier categories are: resources and skills, psychosocial, personal well-being, time, weather or inconvenience, and family or friend support. In addition to confirming the appropriateness of scaling, a study of 219 women, most between 40 and 60 years of age, demonstrated evidence for test-retest reliability. Pearson product moment coefficient was

.68 between tests conducted 6 months apart according to personal communication with researcher.[166]

f) Exercise self-schema

Self-schemata can be viewed as implicit theories used by individuals to make sense of their own past behaviour and to direct the course of future behaviour. A self-report questionnaire (Appendix L) as described by Kendzierski & Sheffield (2000)[167] was used to classify individuals into three categories: "exerciser schematics (those who see themselves as exercisers), aschematics (those without a self-schema with respect to exercising, and nonexerciser schematics (those who see themselves as non-exercisers)".[167 (p 2)] The questionnaire was first used in a sample of 220 (152 female, 68 male) university students. The concepts *exerciser schematics*, *aschematics* and *nonexerciser schematics* corresponded to commitment to exercise regularly and to the number of plans made by the participants to help exercise regularly.[168] In subsequent studies, all involving university students, the questionnaire was used to explore the links between self-schemata, exercise behaviour,[169] and lapses from exercise.[167] There are no studies of the reliability of the questionnaire, nor are there reports of applications to the fibromyalgia population.

3.6 Data Analysis

3.6.1 Overview of the process for analyzing the interview data

The process of data generation and data analysis proceeded simultaneously (see Figure 3.2) following the processes recommended by Strauss and Corbin[137]. The process was cyclical with five main steps: a) Recruitment, b) Data Collection, c) Reflection, d) Primary Coding, and e) Iterative Coding. The final three steps were the critical steps in

the analysis of the interview data. After the interview, the researcher listened to an audio recording of the interview at least twice. Then, aided by the audio recording, the researcher examined the written transcript. During this process, a specialized form of memo, a participant summary, was written. Next, a line-by-line analysis of the transcripts was carried out. Initially, open codes were assigned, then using constant comparative analysis, categories and higher level concepts were developed. QSR NVivo software (version 1.2.142, © 1999-2000 QSR International Pty. Ltd.) was used to manage and organize the coding. Theoretical memos were written during the coding phase, which described the researcher's reflections and interpretations regarding the properties, dimensions, significance, appropriateness, and patterns among the codes and categories. Upon completion of coding a transcript, iterative coding of previous interviews was conducted to determine if new codes were present in the previous interviews. Often, new codes were generated during these iterations. When iterative coding was complete, the process varied depending if this was the participant's first or second interview. If this was the participant's second interview, the codes and categories were scrutinized to identify which categories required further development and to determine what type of individual might best supply the information needed. Recruitment followed. Alternately, in the case of the participant's first interview, the researcher simply proceeded with the participant's second interview.

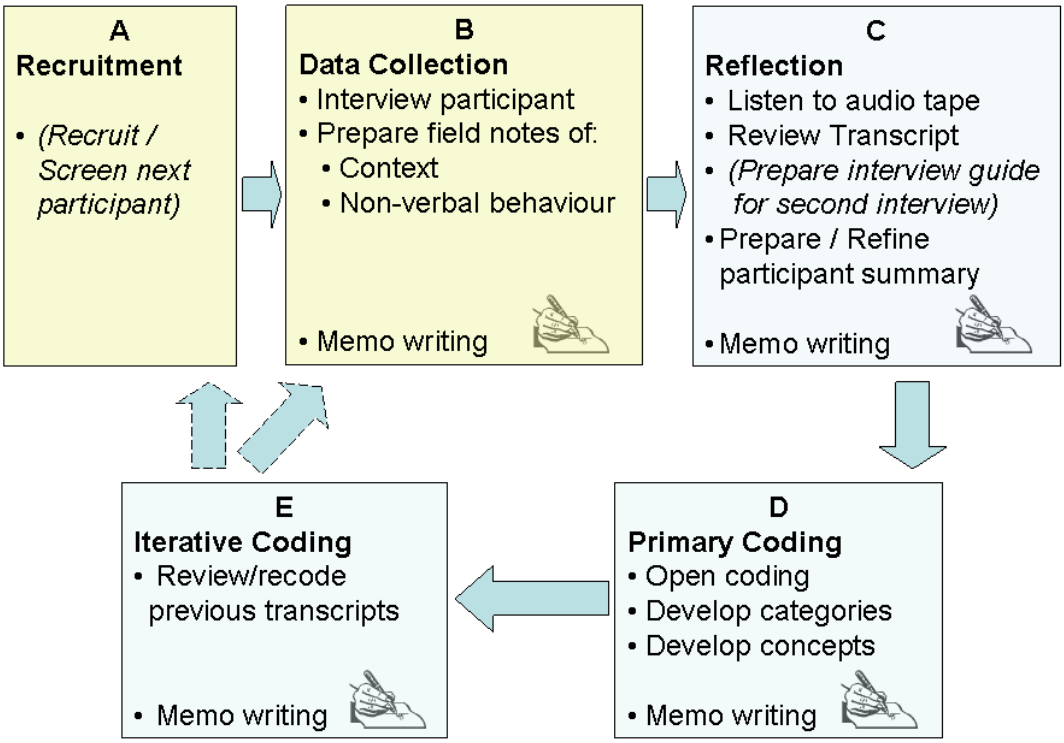

Figure 3-2 Process of data generation and data analysis of qualitative data. Steps A and B are concerned with data generation, while Steps C, D, and E constitute the data analysis of the interview data.

After all the study data had been collected, interview data on present and past LTPA participation was quantified using researcher-defined ordinal scales.

3.6.2 Constant Comparative Analysis and Theoretical Sampling

Creswell (1998) described the constant comparative method as "the process of taking information from data collection and comparing it to the emerging categories."[152] (p.57) According to Glaser and Strauss (1967) the constant comparative method is applied at every stage of the data analysis and is used: a) to assign data to codes and codes to categories, b) to define the properties and dimensions of the categories, c) to integrate categories into components of a theory, e) to delimit the theory and its categories and to form high level concepts, f) to compare higher level categories to concepts found in the literature, g) to assess consistency of the categories with the decisions recorded in the

theoretical memos, and h) to confirm and refine the categories of the emergent theory prior to presentation of the theory.[140 (p. 110-115)]

The following paragraph describes in practical terms how the researcher (AB) applied the methods of constant comparative analysis and theoretical sampling in this study. As each interview was completed, each block of text was scrutinized by the researcher using sensitizing questions (e.g., what is going on here? who is involved? what does it mean to them?) and theoretical questions (e.g., what is the relationship of this to ___? how is this the same as/different from ___?). Codes or labels (i.e., open coding) were assigned to the block of text. From the moment that the first code was assigned to a block of text, the researcher began a process of continuous comparison; data newly coded were compared with subsequent or previous data. As the codes began to accumulate, they were scrutinized to determine if they could be grouped into categories. The categories were likewise compared to identify the properties and dimensions of the categories and to determine if higher level concepts could be formed. The questioning/coding process used with the first interview were repeated with each subsequent interview, but now, the researcher also compared the data in the interview being assessed with codes, categories, and concepts generated in previous interview(s). Reports (i.e., listings of the codes and categories) were produced on an ongoing basis during the study (after coding of the interviews of the 1st, 5th, and the 9th participant, then after interviews of each successive participant). These reports facilitated the tracking of changes to codes and categories and the progress of the analysis. As the concepts began to mature and theoretical relationships were established, the researcher constructed numerous theoretical diagrams to help formulate a model.

3.6.3 Data Analysis and Use of the Literature

While there is some debate about when to use the literature in qualitative research, in grounded theory there is an imperative to allow the theory to emerge from the data. Glaser advises: "In our approach we collect the data in the field first. Then start analyzing it and generating theory. When the theory is sufficiently grounded and developed, *then* we review the literature in the field and relate the theory to it through integration of ideas."[170 (p. 31)] This was the general approach taken in this study. Although the researcher was acquainted with the literature on health behaviour change and had written two term papers dealing with theory of adoption of health behaviours in the year preceding the study, no further reading was conducted on the topic until the model had been developed. Two theories were emphasized in this work – the Transtheoretical Model and the Social Cognitive Theory; these were examined in preparing the study proposal. In the final phase of the study, after the theoretical framework was constructed (i.e., while writing Chapter 8 of this document), the researcher returned to the literature to view the theoretical framework in the light of published general theory, to seek out similarities and differences and to consider implications for further development and research. In so doing, the insights of Neil Weinstein and his colleagues[94,101] regarding the nature of health behaviour theory (i.e., continuum vs. stage theory) was encountered. Upon reflection, two additional theories that seemed relevant were explored – the Theory of Planned Behaviour and the Precaution Adoption Model. Description of the new work was added to the Literature Review section in this report and considered in the Discussion section (see Chapter 8).

3.6.4 Code-checking

Coding was done by the researcher (AB). During the data collection phase of the study, she reported on the coding in monthly progress reports submitted to the research advisory committee. In addition, thorough collaborative critical review of the codes was conducted several times during the study. Detailed code checking was conducted by two research assistants. Both research assistants were graduate students; one was a physical therapist (BB) with seven years clinical experience and the other (EP) was an experienced kinesiologist. The two carried out three detailed line-by-line comparisons of interviews for Participant 1 (BB), Participant 13 (EP), and Participant 14 (EP) with good agreement between the researcher (AB) and the assistants (i.e., there was concurrence between the researcher and assistants for about three quarters of the codes).

Two members of the student's research advisory committee also participated in code checking after the researcher had coded the interviews of the 6th, 12th, and 18th participants. The committee members independently coded selected passages of the interviews and then in three one-to-one meetings (two between AB and SL and one between AB and MV) they compared their codes with the codes and categories generated by the researcher.

Many listings of codes/categories and text reports for specific nodes were generated over the course of the study. Memos were also written during the coding and code-checking process to record the theoretical problems under consideration and any interpretations or decisions regarding them. The listings of codes, text reports for individual codes, theoretical memos, and reflexive notes kept by the researcher provided an audit trail[171 (p. 177)] and were used to ensure consistency of analysis.

3.6.5 Analysis of Quantitative Data

Descriptive statistics of quantitative data were produced using Intercooled Stata 7.0 for Windows 98/95/NT (Stata Corporation, College Station, TX). The FIQ was used to describe severity (FIQ Total) and pain intensity (10 cm visual analogue scale). The activity logs and the Kaiser Physical Activity Survey were used to describe the quantity and pattern of physical activity. The activities recorded in the Kaiser Physical Activity Survey and the physical activity logs were assigned a MET level using the Compendium of Physical Activities[172]. The compendium, which classifies and assigns rates of energy expenditure to 605 activities, is commonly used to provide these estimates. Estimates of energy expenditure (MET-mins·week^{-1}) derived from the log and the questionnaire were compared.

Except for a limited amount of between-method comparisons of four variables (i.e., fibromyalgia symptoms, barriers to exercise, self efficacy for exercise, level of. participation in LTPA, exercise self-schemata). Because the quantitative data were not used for theory development in this study, the study does not qualify as a Mixed Methods Design as described by Creswell, Clark, Gutmann and Hanson (2003).[173]

3.7 Rigor, Dependability, and Credibility

A variety of steps were taken to ensure the dependability and credibility of the research.

1. Prior to beginning data collection, the researcher examined and recorded her "motivations, assumptions, and interests in the research as a precursor to identifying forces that might skew the research in particular directions."[174 (p536)]

2. On an ongoing basis during the course of the study, the researcher attempted to uncover and record any previously unrecognized potential sources of bias arising from her motivations, assumptions, and interests.
3. The constant comparative method is a rigorous and demanding process which in itself provides some assurance of the credibility of the emergent theory. Because the "data are analyzed as collected and interpretations clarified in each subsequent interview with the same or different participants," Wuest (1995) likens the process to "test-reliability as the researcher tries out hypotheses derived from previous interviews in subsequent ones." [175 (p. 131)]
4. As a requirement of the University of Saskatchewan Advisory Committee on Ethics in Behavioural Science Research, each participant was given the opportunity to review the transcript of her interview and was given the opportunity to add to, subtract from or otherwise modify her account. Providing this opportunity to the participants constitutes a form of member checking.[176] by allowing participants to clarify ambiguous text, to expand upon the ideas in the transcript, or to correct errors. Nevertheless, the process carries with it some risks; participants may opt to remove important data which they are embarrassed about, or upon reflection, no longer wish to share. Such risks were not an issue here, because only a few participants chose to make any revisions and the revisions that were made were not substantial; three participants wanted to correct grammar (e.g., substitute the word "yes" for "yeah") and another participant asked that specifics about where she worked be generalized. Other forms of member checking used in this study included: a) a presentation of the results given by the researcher to Saskatoon Fibromyalgia Support Group to which

participants were personally invited, and b) critical appraisal of the thesis by two participants of the study.

5. Code-checking[153 (p64)] was conducted several times during the course of the study as described above. The rationale for code checking was to "approach the research question from a different angle" so as to allow exploration of intellectual puzzles presented by the data "in a rounded, multifaceted way."[177 (p190)] As such code checking is an important procedure used ensure rigor; it helps the researcher to avoid bias.

3.8 Ethical Considerations

At the initiation of the study, the potential for two research sites was considered. Ethical approval was obtained from the University of Saskatchewan Advisory Committee on Ethics in Behavioural Science Research (June 4, 2003) and the Conjoint Health Research Ethics Board, Office of Medical Bioethics at the University of Calgary (October, 2003). The reason for obtaining approval from the latter was to ensure an adequate supply of study participants; however use of the Calgary, Alberta site was not necessary; all participants were recruited from Saskatoon, Saskatchewan.

Procedures developed to ensure that high ethical standards were implemented in all aspects of the research. These procedures related to:

- recruitment practices - with the exception of individuals who had previously consented to be contacted, interested individuals were invited to contact the researcher
- confidentiality procedures – participant-selected pseudonyms were used on all study documents (e.g., transcripts, questionnaires, data tables) except for

the consent form, the registration form and the honorarium requisition form and the researcher was the only who had access to these. All identifying details (e.g., name of employers, names of children) were removed from the transcripts.

- avoidance of coercion – individuals were informed that they could withdraw from the study without any repercussions of any sort verbally (during the screening and at the interviews), and in writing (consent form),
- storage and disposal of records and audiotapes – standard procedures recommended by the University of Saskatchewan Advisory Committee on Ethics in Behavioural Science Research were followed, and
- dissemination of findings – All details that might result in the participant's identity being recognized, (e.g., name of participant, name of employers, names of children) were omitted/will be omitted on any reports or presentations of the study findings.

An honorarium of $15 per appointment was offered to all participants to pay for parking or other expenses incurred related to their participation in the study.

4 RESULTS – THE QUANTITATIVE DATA

Quantitative data were collected to provide a comprehensive description of the participants to enhance transferability (i.e., generalizability), and to gain another perspective from the participants. In this chapter, socio-demographic characteristics, fibromyalgia symptoms, participation in and barriers to physical activity are described. In addition, the relationship between symptoms and energy expenditure is explored.

4.1 The Participants

Twenty-six women with fibromyalgia were screened. Five were excluded during screening: three had other serious medical conditions (i.e., rheumatoid arthritis, coronary artery disease, recovering from abdominal surgery) which would interfere with participation in LTPA and two declined due to time constraints and personal reasons. One woman (Id#7) was excluded at the first interview because, in addition to having fibromyalgia, it became apparent that she had several active concomitant diseases including ischemic heart disease, asthma, gout, and renal failure which significantly limited her ability to participate in regular LTPA. Therefore, twenty women were recruited and formed the sample. Fifteen women had participated in a previous study, three women responded to notices posted on bulletin boards, and two came forward after a recruitment presentation at the local fibromyalgia self-help group meeting.

4.2 Socio-demographic Characteristics of the Participants

The demographic data are summarized in Table 4.1 and listed for each individual in Table 4.2. All except three participants were married. The 20 participants ranged in age from 32 to 61 years of age (median = 53). Five of the 19 women had children living at home; only one, had children under the age of six. The women reported having

symptoms of fibromyalgia between 6 and 60 years (median = 14.5 years); 14 women indicated that they had had symptoms for 10 years or more. Fifteen women had at least high school education (i.e., completed grade 12) and ten were engaged in paid work.

According to the low income cut-offs (LICOs) for 2004 published in the Poverty Profile 2001[178] three of the participants were classified as living below the poverty line (as noted in Table 4.2). (Note. The Poverty Profile report uses the before-tax version of Statistics Canada's LICOs[179] as its measure of poverty.) The criteria used in establishing the LICOs involve a combination of three factors – household income, family size, and population of the community of residence.

4.3 Fibromyalgia Status

Using the 10-centimetre visual analogue scales of the FIQ, participants recorded the highest intensity for the following symptoms: not feeling refreshed upon waking (median = 7.5), feeling of stiffness (median = 7.3), feeling fatigued (median = 7.1), and pain (median = 6.2) (see Table 4.3). Despite this level of symptoms, the impacts on physical function and mood (depression and feeling anxious) were relatively low (medians = 2.5, 2.7, and 3.7, respectively).

4.4 LTPA Participation and Physical Activity

The data collected using the Kaiser Physical Activity Questionnaire were used to describe participant's current participation in LTPA (see Table 4.4). Ten of the 20 women reported that they currently participated in LTPA at least 2 times per week with the most common form of regular LTPA being walking (n = 8). Other forms of LTPA that women performed regularly were stationary bike, dancing, and physically playing with children, each of which were reported by one individual.

The 7-day physical activity logs were completed by 18 participants (see Table 4.4). One participant (Pete) had difficulty understanding how to complete the log and another participant (Irene) was not able to complete it due to time constraints. The median daily energy expenditure for the 18 participants was 2415 MET-minutes per day (1st and 3rd quartiles: 2289 - 2556) (see Table 4.3, Column 11). This is similar to the sample of 50 healthy women (age 20 to 60 years) who participated in an instrument validation study by Ainsworth and associates[159] in which the mean energy expenditure using a physical activity record was 2464 MET-min per day (1st and 3rd quartiles: 2327 – 2588). It is important to note that the 7-day physical activity log data do not discriminate among the types of physical activity (i.e., occupational versus LTPA). This may explain why three individuals (Allie, Penny, and Sheena) classified their participation in LTPA as completely inactive, yet were in the highest quartile among the participants in the study for energy expenditure. For example, in her interview, Penny described doing housework, household renovations, and working (irregular hours demonstrating retail products for a marketing firm).

4.5 Exercise Perseverance and Barriers

The data from the Exercise Perseverance and Barriers Instrument are listed by category in Table 4.5 and frequency data are provided in Table 4.6. Pain or discomfort was the most frequently occurring barrier with 90% of participants (n = 18) reporting that it prevented them from participating in LTPA at least some of the time and 50% (n = 10) designating it as preventing LTPA participation very often. Thirty percent of participants indicated that lack of time and weather prevented them from participating in moderately intensive LTPA very often, and 25% were very often prevented by lack of self discipline,

bad health, and exercise intensity. Conversely, the resources and skills category of barriers appeared to be of the least concern to the participants; lack of facilities was never cited as more than an occasional barrier to moderate intensity LTPA. Most participants were not deterred by lack of support from family of friends, although as with most barrier categories, some individuals did report having difficulties very often.

4.6 Association between Energy Expenditure and Fibromyalgia Symptoms

The mean daily energy expenditure did not correlate significantly with any of the fibromyalgia symptoms or FIQ total scores. The magnitude of the Pearson's product moments varied between -.077 and -.307 indicating that less than 10% of variance in energy expenditure could be accounted for by any of the symptoms (see Table 4.7).

4.7 Intention and Self-efficacy for LTPA

Using the Planned Behaviour Variables Questionnaire, ten individuals reported that they were completely confident that they could exercise twice per week, six were completely confident that could exercise three times per week, and four were completely confident they could exercise more than three times per week over the next month (see Table 4.8). In the face of fibromyalgia symptoms, eight women were completely confident that they could exercise two times per week over 2 weeks; but only three were completely confident in the face of fatigue (see the final two columns in Table 4.8).

Some of the data collected using the Planned Behaviour Variables Questionnaire[130] was inconsistent with answers to similar questions derived using other measures. For example, one individual (Kayla) reported low self-efficacy for exercise despite describing a consistent and regular pattern of LTPA; conversely, Allie reported

high self-efficacy despite describing herself as completely inactive. The data indicated that fatigue had a stronger impact on self-efficacy for exercise than did other symptoms.

4.8 Kendzierski & Sheffield's Theory of Exercise Self-Schema

These results are found in Table 4.9. Using the self-report questionnaire as described by Kendzierski & Sheffield (2000),[167] two participants (Jackie and Isabella) were classified as "exerciser schematics", none were classified as "exerciser aschematics" (those without a self-schema with respect to exercising), four were classified as nonexerciser schematics (Sheena, Alicia, Kathy, and Maya), and the remainder (n = 14) were *unclassified* according to the method described by the originators of the test.[167] These results were somewhat disappointing and point to the need for further development of this measure, at least with respect to classifying individuals with fibromyalgia.

Table 4.1 Summary of Selected Characteristics for the Study Participants (n = 20).

	n
Age (years)	
≤ 35	2
36 – 45	2
46 – 55	9
56 – 65	7
Marital Status	
Married	17
Separated	1
Never Married	2
Duration of Fibromyalgia	
0 – 4	1
5 – 9	5
10 – 14	5
15 – 19	5
20 or more	4
Education	
Less than Grade 12	5
High School	4
Trade School or Community College	4
Some University	1
University degree	5
Graduate Degree	1
Work	
Paid Fulltime	5
Paid Part-time	5
Unemployed	2
Housework	2
Disabled	4
Retired	2
Income	
< 15 K	2
16 – 29 K	2
30 – 59 K	10
60 – 99 K	3
> 100 K	2
Missing	1

Table 4.2 Listing of the Socio-demographic Characteristics and Duration of Fibromyalgia for the Study Participants.

Id#	Pseudonym	Age	Marital Status[a]	Depend-ent Children	Duration of fibro-myalgia	Ethnicity[b]	Education	Household Income (x $1,000)	Work Status
1	Liz	53	Married	0	41	Caucasian	Trade school or college	60 – 99	Disabled
2	Jackie	58	Married	0	17	English-German	High school	30 – 59	Retired
3	Ceci	45	Married	2	20	Caucasian	High school	30 – 59	Commission Sales, Part-time
4	Isabella	47	Separated	2	15	Anglo-Saxon	University degree	30 – 59	Paid-Fulltime
5	Pete	55	Never Married	0	14	White	< Grade 12	<15 [(c)]	Disabled
6	Kaluha	53	Married	0	15	Canadian	< Grade 12	30 – 59	Commission Sales, Part-time
8	Sarah	53	Married	0	6	Métis	High school	>100	Paid-Fulltime
9	Sheena	32	Never Married	0	18	Russian	Trade school or college	16 – 29	Paid-Fulltime
10	Alicia	64	Married	0	60	British:Eng-Irish-Scot	< Grade 12	30 – 59	Housework
11	RoseMarie	57	Married	0	7	Ukrainian	University degree	30 – 59	Disabled
12	Meme	51	Married	0	14	French	University degree	30 – 59	Disabled
13	Kayla	44	Married	2	10	Canadian-Ukrainian	Trade school or college	60 – 99	Paid-Fulltime
14	Laura	57	Married	0	8	Belgian-Swedish	University degree	30 – 59	Paid-Part time
15	Penny	55	Married	0	10	Russian	Trade school or college	30 – 59	Paid-Part time
16	Kathy	61	Married	0	6	German	< Grade 12	Missing	Unemployed
17	Minnie	59	Married	0	?	Scotch-Irish	< Grade 12	<15 [(c)]	Paid-Part time
18	Allie	61	Married	0	20	Icelandic-English-First Nations	Some university	30 – 59	Retired
19	Maya	48	Married	4	13	British Isles	Graduate degree	>100	Paid-Part time
20	Irene	32	Married	3	19	Caucasian	University degree	16 – 29 [(c)]	Unemployed
21	Liza	47	Married	2	6	Canadian (Ukrainian)	High school	60 - 99	Paid-Full time

[a] Marital status – Married includes common law relationships.

[b] Participants were asked, “What is your ethnic background?” and whatever they responded was accepted as stated.

[c] Income level is below the 2001 poverty line based on the participant’s family size and the population of Saskatoon[180]

Table 4.3 Listing of Results of the Fibromyalgia Impact Questionnaire for the Study Participants.

		Fibromyalgia Impact Questionnaire Scores (Scores range from 0 – no symptoms or problem to 10 very severe symptoms or problem)							
Id#	Pseudonym	Impairment	Pain	Fatigue	Not Refreshed on Waking	Stiffness	Anxiety	Depression	FIQ Total
1	Liz	2.3	6.4	6.3	4.5	5.9	5.9	3.7	5.5
2	Jackie	1.7	7.1	5.3	7.1	7.2	7.3	4.1	5.5
3	Ceci	1.3	2.8	4.1	6.4	4.6	4.2	2.6	3.6
4	Isabella	0	0.2	3.1	1.7	1.3	2.5	2.1	1.5
5	Pete	7	8.9	9.7	8.8	9.7	5.7	8.7	8
6	Kaluha	5.3	9.7	4.7	5.8	9.7	0.5	2.8	6.1
8	Sarah	4.3	7.4	7.5	9	8.6	0.8	0.8	5.8
9	Sheena	1.9	5.4	10	10	8.6	10	6.3	7.4
10	Alicia	4	8.8	9.2	9.1	9.5	3.1	2.9	7.1
11	RoseMarie	5	10	10	10	10	4.9	4.8	7.6
12	Meme	3.7	6	6.1	2.1	8.1	2.3	0.5	3.8
13	Kayla	1.7	3.9	8.3	6.1	5.2	4.6	3	4.6
14	Laura	3.8	1.7	8	8.8	0.7	1.4	1.8	4.5
15	Penny	2	4.4	4.9	7.3	4.5	2.6	4.6	4.3
16	Kathy	3	10	10	10	7.3	7.7	7.3	7.8
17	Minnie	4	3.6	6.7	4.4	6.6	6.7	0.4	4.4
18	Allie	0	2.7	5	6.2	0.4	0.3	0.3	1.9
19	Maya	2.7	6.9	9.5	8	9.3	7.2	0.5	6.2
20	Irene	0.4	8.2	7.9	8.3	9.5	1.1	1.5	5.9
21	Liza	1.4	1.3	6.6	7.6	2.8	.1	.1	2.7
Median		**2.5**	**6.2**	**7.1**	**7.5**	**7.3**	**3.7**	**2.7**	**5.5**
1st Quartile		**1.6**	**3.2**	**5.2**	**6.0**	**4.6**	**1.3**	**0.7**	**4.1**
3rd Quartile		**4.0**	**8.5**	**9.4**	**8.9**	**9.4**	**6.3**	**4.4**	**6.7**

Table 4.4 Current Participation in Physical Activity of the Study Participants based on data from the Kaiser Physical Activity Questionnaire (Columns 3, 4,and 5) and the 7-Day Physical Activity Log (Column 6)

Id#	Pseudonym	Activity(ies)	Duration (months)	Time (hrs/ wk)	Daily Log Data[a] (MET-min/day)
1	Liz	Treadmill walking	> 9	≥2 but <3	2141
		Aquacise	4 to 6	≥1 but < 2	
2	Jackie	Walking	> 9	≥2 but <3	2674
3	Ceci	Curves	> 9	≥1 but <2	2462
		Walking	> 9	< 1	
4	Isabella	Walking (dog)	> 9	≥ 4	2541
		Swimming	4 to 6	< 1	
		Canoeing	1 to 3	< 1	
5	Pete	Walking	7 to 9	≥1 but <2	missing
		Aquacise	1 to 3	≥1 but <2	
6	Kaluha	None	-	-	2361
8	Sarah	Curves	> 9	≥1 but <2	2884
9	Sheena	Dancing	1 to 3	< 1	2581
10	Alicia	Walking	4 to 6	≥2 but <3	2087
11	RoseMarie	Pole walking	> 9	≥3 but <4	2407
		Dance	< 1	< 1	
		Badminton	< 1	< 1	
12	Meme	Walking	4 to 6	≥ 4	2397
13	Kayla	Walking	> 9	≥3 but <4	2393
14	Laura	Stationery bike	> 9	≥ 4	2423
15	Penny	Dancing	< 1	< 1	2890
16	Kathy	Square dancing, round dancing	7 to 9	≥ 4	2032
17	Minnie	Aquacise	4 to 6	≥2 but <3	2289
		Bicycle	1 to 3	< 1	
18	Allie	Yoga	4 to 6	≥3 but <4	2556
19	Maya	Walking	4 to 6	≥2 but <3	2506
		Aquacise	7 to 9	< 1	
		Yoga (home,gentle)	1 to 3	≥2 but <3	
20	Irene	Playing (with kids)	> 9	≥ 4	missing
		Callanetics	4 to 6	≥3 but <4	
		Bowling	4 to 6	≥1 but <2	
21	Liza	Pilates	1 to 3	≥1 but <2	2131

[a] MET–min / day with base equal to 1440 .

Table 4.5 Listing of Barriers to Exercise and Physical Activity for the Study Participants as reported on the Exercise Perseverance and Barriers Instrument.

Id#	Pseudonym	Resources or Skills	Psychosocial	Personal Well-Being	Time	Weather or Inconvenience	Family or Friend Support	Total Barrier Score [b]
1	Liz	1.2	0.6	1.6	1	0.7	0	21
2	Jackie	0	1	0.4	1	0.7	0.5	12
3	Ceci	1.2	1	1	2	1.3	1	26
4	Isabella	0.8	0.8	0.8	2	0.3	0.5	18
5	Pete	1.8	1	1.6	1.5	1.7	2	34
6	Kaluha	0.4	1.4	1	2	1.3	2	26
8	Sarah	0	0.8	0.4	1	0.3	0	9
9	Sheena	0.8	1.4	1.6	1.5	1.3	1	28
10	Alicia	1.2	1.8	2	0	1.7	1	32
11	Rosemarie	1.4	1	1.4	1	1.3	0.5	26
12	Meme	1.6	1	1	0.5	0.7	0	21
13	Kayla	0.8	1	1	1	0.7	0	18
14	Laura	0.6	1	0.4	1	0.3	0	13
15	Penny	0.4	1	0.8	1	0.7	0.5	16
16	Kathy	0.4	1	0.6	0.5	0.7	0.5	14
17	Minnie	0	0.8	0.2	0	1.3	0	9
18	Allie	0	1.2	1	0.5	1.3	0	16
19	Maya	0	0.4	1.2	1.5	0.3	0	12
20	Irene	0.2	0.2	0.6	2	0.7	0.5	12
21	Liza	0	0.4	1	1	0.3	0	10
	Median	**0.5**	**1**	**1**	**1**	**0.7**	**0.5**	**17**
	1st Quartile	**0**	**0.8**	**0.6**	**0.75**	**0.5**	**0**	**12**
	3rd Quartile	**1.2**	**1**	**1.3**	**1.5**	**1.3**	**0.75**	**26**

[a] Participants used a three-point scale (0 = never, 1 = sometimes, 2 = very often) to respond to the question: "How often have the following prevented you from getting exercise or doing moderate- intensity physical activity? Moderate-intensity physical activity was explained as: such activities as recreational swim, gardening, and heavy house cleaning.

[b] Category scores are medians for the items in category. Total scores were calculated by summing items scores. Total scores can vary from no barriers = 0 to 46.

Table 4.6 Frequency Distribution for the 23 items of the Exercise Perseverance and Barriers Instrument for the Study Participants (n=20).

Barrier Category and Items[a]	Never	Sometimes	Often
Resources and skills			
Lack of equipment	10	9	1
Lack of skills	11	6	3
No facilities	10	10	0
Not know how	11	7	2
Lack of transportation	17	2	1
Cost of exercising	8	8	4
Time			
Lack of time	2	12	6
Lack of a block of time	5	10	5
Psychosocial			
Self-conscious	10	8	2
Lack of self-discipline	0	15	5
Lack of enjoyment	4	13	3
Discouragement	5	13	2
Lack of interest in exercise	3	13	4
Personal well-being			
Bad health	1	14	5
Pain or discomfort	2	8	10
Fear of injury	8	8	4
Fear for safety	12	6	2
Exercise intensity too high	5	10	5
Weather or inconvenience			
Weather	0	14	6
Too hot or too cold	5	9	6
Inconvenience, perspiration, combing hair	15	2	2
Family or friend support			
Lack of company	12	5	3
Lack of family support	13	5	2

[a] For each item, participants responded to the question: How often has _____ prevented you from getting exercise or doing moderate- intensity physical activity? Moderate-intensity physical activity was explained as: "such activities as recreational swimming, gardening, and heavy house cleaning."

Table 4.7 Pearson's Coefficients for Correlations of Mean Energy Expenditure with Fibromyalgia Symptom variables of the Fibromyalgia Impact Questionnaire (n = 18)

	Mean Daily Energy Expenditure
FIQ Total	-0.191
Impairment	-0.173
Pain	-0.170
Fatigue	-0.307
Stiffness	-0.077
Anxiety	-0.116
Depression	-0.081

Note. * $p < .05$.

Table 4.8 Listing of Results of the Planned Behaviour Questionnaire[130] for the Study Participants

Id#	Pseudonym	Favourite LTPA	**Intention** *"During the next 4 wk, I will engage in LTPA …"* *(times/wk)*	**Activity Level** *(past 6 mo)*	**Intensity** *"How hard do you exercise?"*	**Self-efficacy for Frequency** *"How confident are you that you could exercise __ times/wk over the next month?"*			**Self-efficacy for participation at least 2x/wk over 2 weeks in the face of specific difficulties**	
						2x/wk	*3x/wk*	*>3x/wk*	*Symptoms*	*Fatigue*
1	Liz	Walking	three to four	regularly	moderate	10	10	5	10	8
2	Jackie	bicycling & walking	five	regularly	moderate	10	8	6	10	9
3	Ceci	exercise at curves	three	regularly	moderate	8	7	3	4	4
4	Isabella	Walking	five to six	regularly	moderate	10	10	10	10	3
5	Pete	Walking	two	sporadically	low	3	2	1	3	5
6	Kaluha	work (sales)	one to two	sporadically	low	4	1	0	2	1
8	Sarah	Walking	three	sporadically	moderate	10	10	10	10	7
9	Sheena	Walking	two	sporadically	moderate	6	3	1	3	1
10	Alicia	tai chi, flexibility	one	inactive	low	4	4	2	4	2
11	RoseMarie	walking, exercising	three to four	regularly	moderate	9	8	5	3	0
12	Meme	Walking	seven	regularly	moderate	10	10	10	10	10
13	Kayla	Walking	-	regularly	moderate	1	2	1	4	1
14	Laura	stationary bike	three to four	regularly	moderate	10	8	6	8	5
15	Penny	Walking	-	regularly	moderate	5	5	1	4	4
16	Kathy	Dancing	-	regularly	low	8	5	0	6	2
17	Minnie	Swimming/aquacise	two	regularly	moderate	10	missing	missing	10	10
18	Allie	Walking	two	sporadically	low	9	9	6	9	8
19	Maya	Walking	three to four	regularly	moderate	10	8	2	10	6
20a	Irene	playing with kids	seven	regularly	moderate	10	10	10	10	10
20b	Irene	Callanetics	three	regularly	moderate	10	10	5	5	2
21	Liza	pilates/walking	three	sporadically	moderate	4	4	2	7	6

TABLE 4.9 Listing of Self-Schema data for the Study Participants.

		Personal Descriptor: I Am Someone who … (1 = does not describe me, 10 = Describes me)			Importance Descriptor I think ___ is Important (1 = not important at all, 10 = very important)			Classification Of Self Schemat[a] [168]			Congruence Ratio
Id#	Pseudo	Exercises Regularly	Keeps in Shape	Is Physically Active	Exercising Regularly	Keeping in Shape	Being Physically Active		Self Schema Score	Value Placed on PA	(Ex Behaviour / Value for PA)
1	Liz	10	5	5	10	8	8	Unclassified	6.7	8.7	0.77
2	Jackie	8	8	8	10	10	10	Exerciser Self-Schema	8	10	0.8
3	Ceci	6	2	5	9	9	9	Unclassified	4.3	9	0.48
4	Isabella	8	6	8	10	10	10	Exerciser Self-Schema	7.3	10	0.73
5	Pete	8	9	9	7	7	7	Unclassified	8.7	7	1.24
6	Kaluha	1	1	1	2	2	2	Unclassified	1	2	0.5
8	Sarah	4	3	3	5	5	5	Unclassified	3.3	5	0.67
9	Sheena	1	1	1	9	9	9	Nonexerciser Schematic	1	9	0.11
10	Alicia	1	1	1	8	7	8	Nonexerciser Schematic	1	7.7	0.13
11	Rosemarie	5	5	5	10	10	10	Unclassified	5	10	0.5
12	Meme	6	5	5	9	9	9	Unclassified	5.3	9	0.59
13	Kayla	7	5	4	6	6	6	Unclassified	5.3	6	0.89
14	Laura	5	3	6	5	4	5	Unclassified	4.7	4.7	1
15	Penny	3	2	5	6	6	10	Unclassified	3.3	7.3	0.45
16	Kathy	3	1	7	7	8	10	Nonexerciser Schematic	3.7	8.3	0.44
17	Minnie	10	5	5	6	5	8	Unclassified	6.7	6.3	1.05
18	Allie	1	1	1	4	4	4	Unclassified	1	4	0.25
19	Maya	4	2	8	8	4	10	Nonexerciser Schematic	4.7	7.3	0.64
20	Irene	7	7	7	7	9	8	Unclassified	7	8	0.88
21	Liza	2	2	2	6	6	6	Unclassified	2	6	.33

[a] **Exerciser Self-schema** must rate: at least two of the personal descriptors as very self-descriptive (8-11), and at least two of the importance descriptors as very important to self image (8-11),

Non-Exerciser Self-Schematic: at least two of the personal descriptors as extremely nondescriptive (1-4), and at least two of the importance descriptors as very important to self image (8-11),

Exerciser Aschematic: at least two of the personal descriptors as somewhat self-descriptive (5-7), and at least two of the importance descriptors as relatively unimportant to self image (1-7)

5 OVERVIEW OF THE EMERGENT THEORETICAL FRAMEWORK

5.1 Introduction to the Emergent Theoretical Framework

The emergent theoretical framework was formulated using the interview data and describes the development of a pattern of enduring participation in regular LTPA in women with fibromyalgia. In examining the experiences of the 20 participants, two distinct vantage points were taken, and the emergent theoretical framework deals with both. First, the focus centers on the minute-to-minute experiences of a woman with fibromyalgia during a single session of LTPA; then it shifts to her experiences during the gradual maturation of the behavior over several days, weeks, months, and years. To accommodate this shifting focus, the framework specifies two levels – a *session-specific level* which examines a single session, and a *pattern-specific level* which outlines the formation of a habitual pattern of LTPA participation. The emphasis given to the session-specific level and minute-to-minute experiences within a session contrasts with previous theories of health behavior change which tend to emphasize behaviors on a larger scale. Although the process described has two levels, a number of categories of influential factors (e.g., barriers, facilitators) are common to both levels.

The purpose of this chapter is to provide a thumb-nail sketch of the emergent theoretical framework. In this chapter all the major concepts of the emergent theoretical framework will be briefly introduced including: a session-specific level with five stages, a pattern-specific level with five phases, and a number of determining factors (goals, barriers and facilitators, strategies, and outcome). In the next chapter (i.e., Chapter 6) the

framework will be described in more detail and the supporting data for the theory will be provided.

5.2 Session-specific and Pattern-specific Levels

The framework has been divided into two levels: a session-specific level and a pattern-specific level. The session-specific level deals with the basic unit upon which the whole framework rests: a single session of physical activity. Each session is composed of five stages: *forming intent*, *deciding*, *planning and preparing*, *starting*, and *doing it* (see Figure 5.1). A set of factors influence each of the stages that make up each session. As the woman with fibromyalgia completes a session, the *outcomes* (and her experiences) associated with that session combine with the other influential factors (e.g., her *goals*, the *strategies* she uses, and the *barriers* and *facilitators* she experiences), to determine the likelihood of whether she will undertake the next session.

The pattern-specific level deals with the formation of a regular pattern of physical activity. In the pattern-specific level, sessions are accumulated and a woman moves from an *uncommitted* phase, to a *beginner* phase, to an *intermediate* phase, to a *mature* phase, and ultimately to full *integration* of LTPA into her lifestyle (see Figure 5.2). However, not all women with fibromyalgia go through all these phases. Successful progression through the session-specific and pattern-specific levels depends on a number of positive and negative influential factors which determine the continuity of the process. If the negative factors outweigh the positive factors, lapses (disruptions) can occur. The accumulation can be depicted as a growing spiraling elevation, each new session linked to the experience of the previous session. The process can be disrupted at any point, within or between sessions, and within or between phases. Depending on the length of

the lapse, a woman with fibromyalgia may return to *square one* and need to begin the accumulation anew to re-establish a pattern of regular participation. However, if she sustains the pattern of regular participation for long enough, LTPA may become so integrated into her lifestyle that she no longer sees it as a separate activity.

To assist the reader two aids have been developed – a brief description of the stages and phases in the process (Table 5.1) and a set of illustrations showing the session-specific level and the pattern-specific level (Figures 5.1 and 5.2).

Table 5.1 The levels, stages and phases of the emergent theoretical framework.

Level	Stage or Phase	Description
Session-specific Level	Stage 1 – Forming Intent	This stage involves the formation of the intent to undertake action to achieve goal(s) she values.
	Stage 2 – Deciding	The individual weighs options and evaluates barriers and facilitators of action to decide on a course of action which includes LTPA.
	Stage 3 – Planning and Preparing	The woman with fibromyalgia formulates a plan that includes type and intensity of physical activity.
	Stage 4 – Starting	The transition between thinking and doing.
	Stage 5 – Doing it	The doing-it stage focuses on executing the plan for LTPA. This stage involves woman's step-to-step experience of the LTPA. It concludes with the completion of a single session.
Pattern-specific Level	Phase 1 – Uncommitted Phase	This phase involves no participation or intermittent participation in LTPA with many missed sessions and long lapses.
	Phase 2 – Beginner Phase	This phase consists of an unbroken series of regular LTPA sessions up to, but not crossing a naturally occurring boundary (e.g., end of season, end of program).
	Phase 3 – Intermediate Phase	This phase consists of an unbroken series of regular leisure time physical activity sessions that crosses a naturally occurring boundary (e.g., end of season, end of program).
	Phase 4 - Mature Phase	This phase consists of an unbroken series of regular LTPA sessions that includes several naturally occurring units (e.g., seasons, years).
	Phase 5 – Integrated Phase	In this phase, LTPA blends into one's lifestyle to the degree that it is no longer considered to be special or separate.

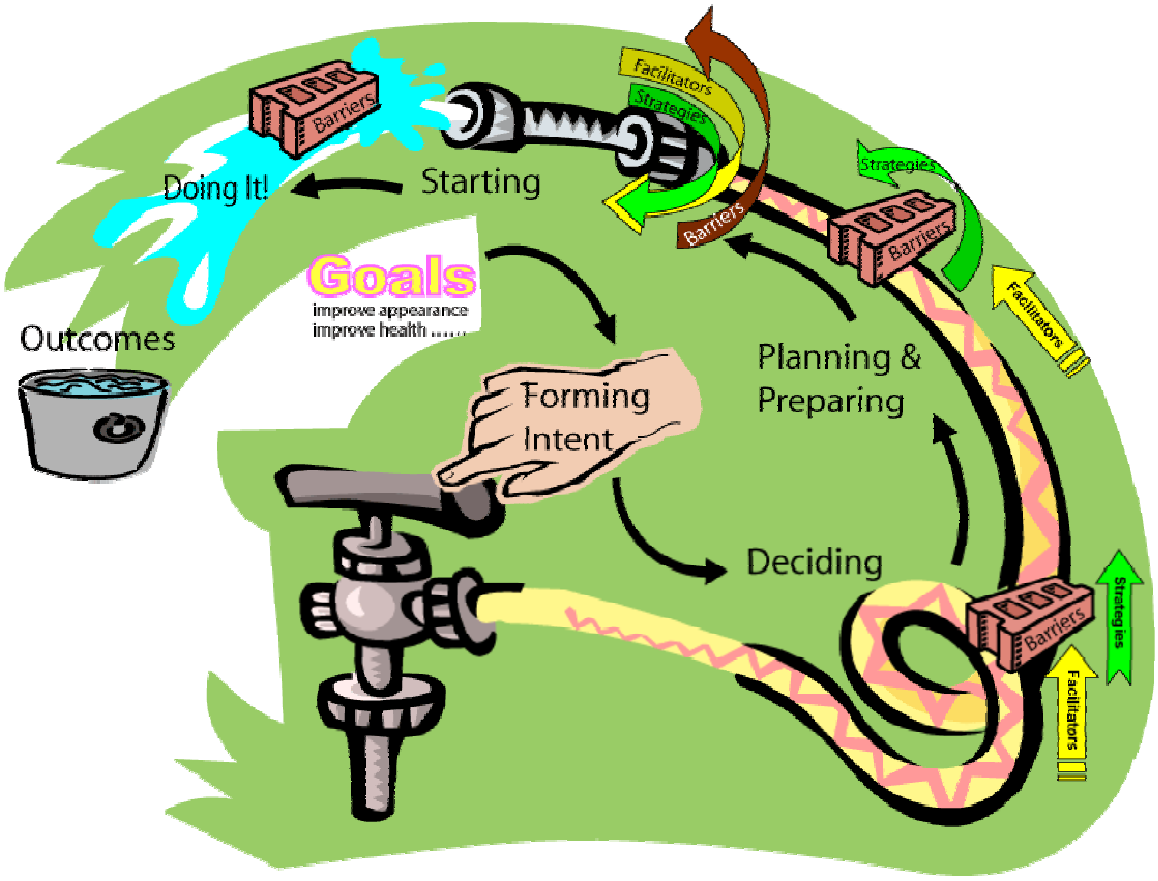

Figure 5-1 The session-specific level of the emergent theoretical framework

The session-specific level is here depicted using a metaphor of a garden hose (see Figure 5.1). The process begins with goals. The goals lead to intent which is depicted as a hand poised ready to turn on the water supply. Depending on the strength of intent, a varying amount of pressure can be released (through opening the faucet). Immediately a decision must be made, depicted by the loop in the hose – the flow of the pressurized water is first in one direction and then in the other (representing an internal dialogue in which the goals are considered, the types of action that can be taken and the barriers and facilitators; the individual first favours action and then inaction). If the loops are too tight, the flow will stop completely and the force of the intent is

overcome. If however, the loop is loose or if the individual is so determined as to "take the decision out of it" altogether, the force of the intent pushes on forward – strengthened by facilitators and strategies and weakened by barriers (depicted as a brick blocking flow). The force of intent takes one next to preparing and planning. Barriers and facilitators both continue to affect the movement towards LTPA. Strategies grow at the planning and preparing stage. A major challenge is reached at the starting stage – where the intent can be totally overcome if the nozzle is turned off. If alternately the nozzle is open, the force of the water pushes out in the *doing it* stage to fill the bucket which represents outcomes. Even at the *doing it* stage there may be barriers, facilitators and strategies. This implies that the relationship between the two levels is not a simple one.

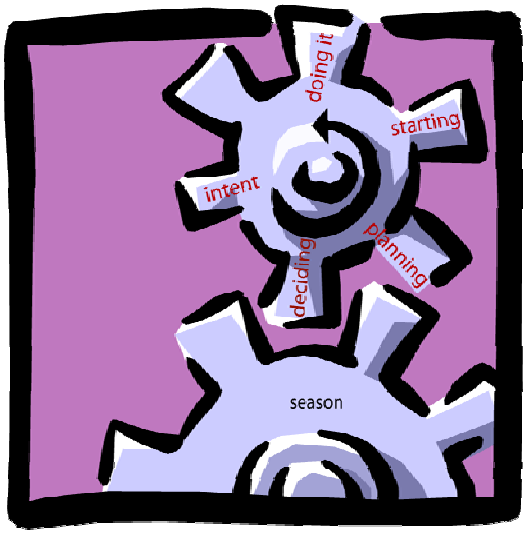

Figure 5-2 The relationship between the session-specific level and the pattern-specific level

The relationship between the Session-specific Level and the Pattern-specific Level is depicted as gears with the Session-specific Level represented by the small gear which drives the system. Each cog in the wheel represents one of the stages (intent, deciding, planning, starting, or doing it). One revolution of the small gear represents a single session. If the small gear stops at any given point the whole process comes to a halt. The actual scale is such that the small

gear must turn many times to effect a revolution of the larger gear which represents a full season.

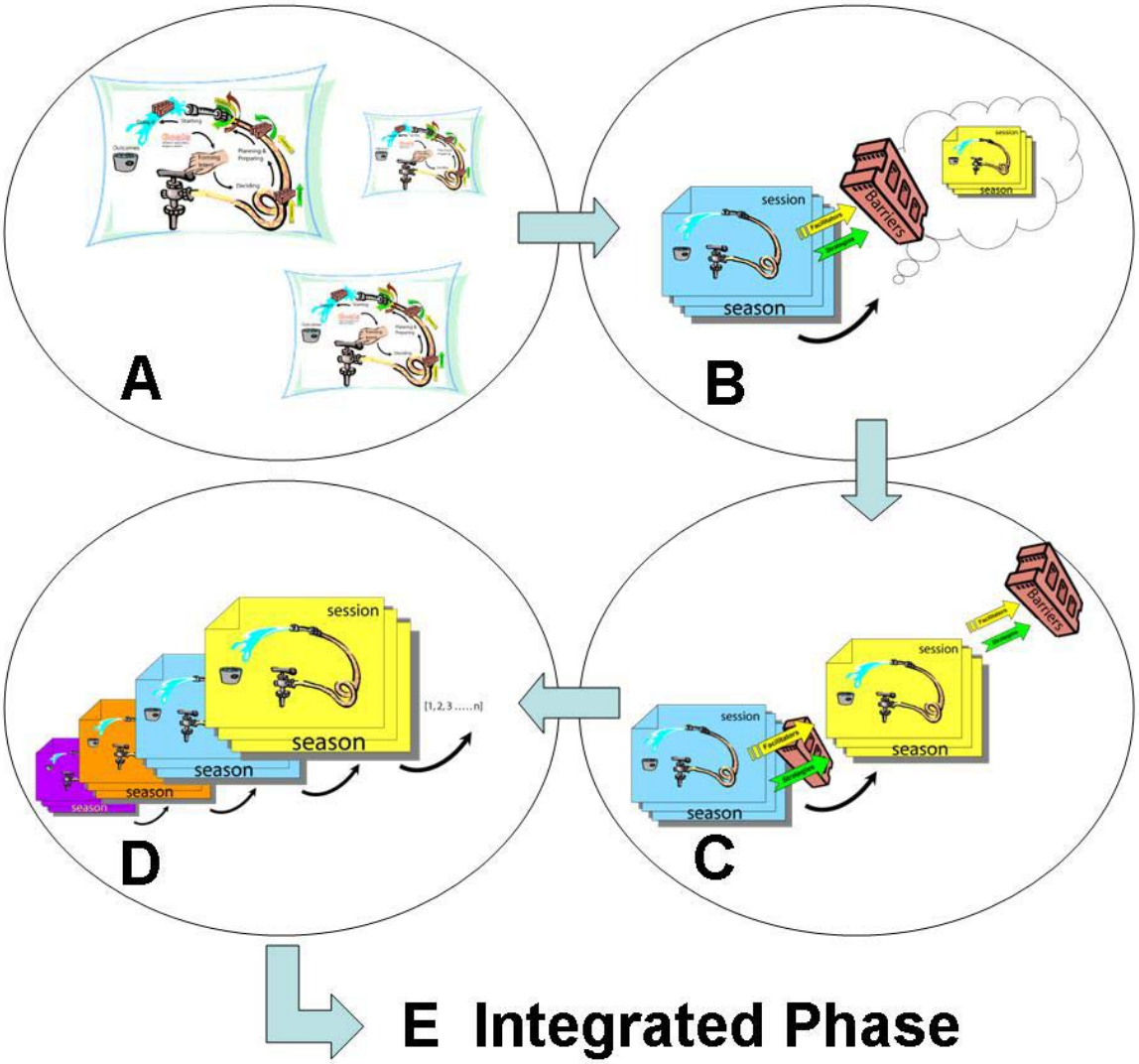

Figure 5-3 The pattern-specific level of emergent theoretical framework

A – The uncommitted phase characterized by limited and sporadic participation in LTPA,
B – The beginner phase showing the completion of participation of a series LTPA sessions within a single season or program,
C - The intermediate phase consisting of a series of LTPA sessions across two seasons (or programs),
D – The mature phase composed of a growing accumulation participation in LTPA forming an unbroken series of sessions across several seasons (or programs).
E – The integrated phase in which LTPA ceases being recognized as separate from other daily activities.

5.3 The Session-specific Level -- the Core Elements of a Single Session

5.3.1 Forming Intent

The first step in the process is the formulation of the intent. Intent is the desire, resolve, and commitment that the woman with fibromyalgia manifests toward the attainment of a personal goal. Intensity is an important property of intent; an involved habitual behavior such as regular participation in LTPA is unlikely to occur in the presence of weak intent.

5.3.2 Deciding

This component of the process is seen as an internal dialogue within the individual (see discussion of symbolic interactionism in Section 3.2). The woman with fibromyalgia enters this stage of the process with a degree of intent and a range of facilitators, barriers, and options. Options might include participation in LTPA, taking medications, going for massage, adopting a special diet, using a combination of methods, or doing nothing. In the deciding stage, the woman now considers her goals, her barriers and facilitators (see below) and her options.

5.3.3 Planning and Preparing for LTPA

In this stage, the woman with fibromyalgia selects the mode or type of physical activity (e.g., walking, aquacize classes, soccer, workouts at the gym), determines the quantity or volume of physical activity (i.e., the duration of a session and intensity of the activity), and formulates strategies to help ensure that she will succeed.

5.3.4 Starting

The starting is seen here as the interval including the few minutes preceding the decision to begin an LTPA session to the execution of the first step (as in walking), repetition of exercise (as in a single biceps curl) or revolution (as in cycling). It is the transition from inactivity to activity. For women with fibromyalgia the starting is a critical part of the process; during this brief stage, fibromyalgia-related barriers (e.g., lack of energy, pain, stiffness, depression) can wreak havoc on motivation

5.3.5 Doing It

The doing-it stage refers to execution of steps, repetitions, and/or revolutions to form a complete session. During this stage women with fibromyalgia experience barriers (including noxious stimuli) and negative outcomes which may be specific to fibromyalgia or general in nature. These barriers and negative outcomes may bring the doing-it stage to a premature halt at any point resulting in, at a minimum, a truncated session or, at worst, a lapse from LTPA which may last days, weeks, or months. On the other hand, women with fibromyalgia also experience facilitators and positive outcomes which help to sustain the doing-it stage. The strategies that a woman forms in the planning and preparing stage are tested in the doing-it stage, and if effective they will help her overcome the barriers to completing the session.

A key feature of the doing-it stage is the minute-to-minute experience of exercise. The doing-it stage, therefore, focuses on the repetition of the elemental movements (e.g., the steps, revolutions, repetitions) that added together make up a complete LTPA session. Thus this part of the process extends from the moment the woman begins a session of

physical activity to the moment she completes the session. Features to be considered in this stage of the process are:

- the processing of the flood of stimuli (e.g., mechanical, thermal, proprioceptive, kinaesthetic, and biochemical) that bombard the woman on a minute-by-minute basis during the session informing her about the internal (e.g., exertion, fatigue, pain) and external environment (e.g., temperature, sights, and sounds). Important here are the intensity and tolerance for the stimuli, and whether the woman interprets the stimuli as noxious or pleasurable.
- The contextual factors (e.g., social environment, beliefs, attitudes, motivation) that color the interpretation of the stimuli and help to determine if the woman will complete the session as planned.

At the conclusion of the session, women with fibromyalgia may observe positive, negative, or mixed outcomes which impact the decision to continue to engage in regular physical activity. Outcomes include any state or event perceived by the participant that the participant attributes to the LTPA; outcomes can be either negative or positive. Among the negative outcomes are what might be termed adverse incidents, including injury resulting from participation in LTPA.

The step-to-step processes are repeated at every session the woman with fibromyalgia undertakes. Each physical activity session will bring with it a myriad of stimuli and outcomes to be ignored, attended to, and interpreted. If the overall experience together with its stimuli, outcomes and contextual elements is favourable, the woman is more likely to conduct subsequent sessions than if the experience is unfavourable.

5.4 The Pattern-specific Level -- Forming a Habitual Pattern of Participation in LTPA

5.4.1 Uncommitted Phase

This phase involves no participation or intermittent participation in LTPA with many missed sessions and long lapses. A variety of factors were at work in this phase including inconsistencies in level of intent, absent or ineffective strategies, and overwhelming barriers – fibromyalgia-related symptoms, life events, and time issues.

5.4.2 Beginner Phase

This phase consists of an unbroken series of regular LTPA sessions up to, but not crossing a naturally occurring boundary (e.g., end of season, or end of a 3-month program). Of particular importance are short term positive and negative outcomes, facilitators (program-related facilitators, and social and environmental supports), and strategies to manage and overcome barriers related to fibromyalgia symptoms.

5.4.3 Intermediate Phase

This phase consists of an unbroken series of regular LTPA sessions that crosses a single naturally occurring boundary (e.g., end of season or program). This concept in the framework focuses on the challenges, strategies, and outcomes to the accumulation over several workouts or sessions of LTPA across weeks and months. Important features at this level are seasonal patterns of physical activity, health outcomes that require weeks and months to manifest, and refinement of strategies. Facilitators and barriers discussed earlier continue to influence the maintenance of physical activity at this level. Durability of goals and strength of intent are important considerations.

5.4.4 Mature Phase

This phase consists of an unbroken series of regular LTPA sessions that includes several naturally occurring units (e.g., seasons, years). The affinity for LTPA (facilitator), mature and varied strategies (e.g., use of a range of LTPA options, priorities, mind tricks and self-management), and are important at this stage.

5.4.5 Integrated Phase

This concept pertains to the establishment of LTPA participation as an integral part of the woman's lifestyle. For most women with fibromyalgia, this concept represents a goal rather than something they ever achieve. After years of regular participation in LTPA, a phenomenon of integration seems to occur whereby the woman with fibromyalgia no longer considers the activity as something she is striving to do but rather views the LTPA session or workout as part of living. This was manifested when women being interviewed would overlook a regular activity (e.g., going for daily walks) when describing their participation in LTPA. When the omission was pointed out, they would respond – "Oh, well I don't really think of that as exercise, its just part of living."

5.4.6 Lapses

Individuals can discontinue the process (i.e., lapse) at any point within a cycle, or between cycles. The lapses can sometimes be conscious, but more often they are an unconscious "dwindling out." Lapses can be brief lasting only days, or intermediate lasting weeks, or extended lasting months or years.

5.5 The Five Determining Factors

There are five categories of factors that can influence the process at any level and therefore determine the success or the failure of the development of a pattern of habitual

participation in LTPA for the participants. These five factors may be viewed as covariances – "connected variables" that do not force "the idea of cause."[170 (p. 74)]

5.5.1 Goals

Goals are important for the formulation of intent. The participants identified a number of goals for undertaking LTPA. Some goals were internally driven (e.g., enjoyment) while others originated as a result of outside agents (e.g., advice from physician). They also ranged in terms of time from the immediate (to relieve stiffness) to months or years in the future (to prevent heart disease). Many of the goals described by participants related to control of symptoms of fibromyalgia, but other categories of goals were: weight loss (physical appearance), enjoyment, social interactions, prevent disease, and other (e.g., guilt). Underlying the forming of intent and the subsequent stage of deciding were the beliefs and values held by the woman's profession, family, and community; her attitudes toward physical activity; her physical activity history; and her current state of physical and emotional health.

5.5.2 Strategies and plans

Ten categories of strategies emerged. Although the stage of planning and preparing was a reflective stage where most of the plans and strategies were generated, strategies and plans were used at each stage of the process. For example, some cognitive strategies seemed to be employed at the intent stage; these cognitive strategies seemed to intensify the intent to participate in LTPA. Important subcategories of the concept "strategies and plans" were self-management and coping.

Strategies were tested in the "doing it" stage, and as problems were encountered during the *doing it* stage that impeded any of the processes, women with fibromyalgia

sometimes formulated new strategies, refined old strategies, or discarded unsuccessful strategies. Not all strategies were effective.

5.5.3 Barriers and facilitators

A barrier was defined as anything real or imagined that disrupts or interferes with the participation in LTPA. A facilitator was defined as anything real or imagined that supports or motivates the participation in LTPA. These two opposite concepts were seen as positive and negative factors that supported, assisted, or accelerated (facilitators); or that impeded, retarded, or undermined (barriers) the process of developing an enduring participation in LTPA. These factors influenced every stage of the session-specific level and every phase of the pattern-specific level. Eight parallel categories of barriers and facilitators have been classified. That is, for each category, two clusters of factors were assembled; the positive factors (i.e., facilitators) and the negative factors (i.e., barriers). The eight categories of barriers and facilitators are:

- Fibromyalgia symptom and impacts (pain, fatigue, disturbed sleep, trigger points, mild cognitive dysfunction)
- Attitudes (beliefs, feelings, and actions)
- Life events, time issues, work
- Health and medical (body weight, fitness level, general wellbeing, age/aging)
- Physical activity history, experience, knowledge and skills
- Social (norms, role models, roles, support, perspectives)
- Personality
- Other (weather, facilities, programming, fate, cosmic forces)

5.5.4 Outcomes

For women with fibromyalgia, outcomes become a potent factor in the progression from session to session, from season to season, and from year to year. Numerous positive and negative outcomes were described; some were immediate, others followed lengthy durations of regular LTPA. Negative consequences related to *overdoing it*, a special subset of negative outcomes will be examined because this phenomenon - *paying for it after* adversely affected the achievement of a pattern of regular participation in LTPA.

6 RESULTS - THE INTERVIEW DATA

This chapter presents the analysis of the data from the interviews. The chapter begins with a brief description of the interviews (i.e., number of interviews, nature of the interview data). This is followed by a detailed description of the data used to construct the theoretical framework; here the data will be presented using the structure of the theoretical framework as laid out in Chapter 5; the reader may wish to refer to Figure 5.1 and Figure 5.2 and Tables 5.1 to provide a frame of reference. This chapter is much more detailed than the previous and includes the concepts, categories, subcategories and in some cases codes (see Table 6.1). The chapter concludes with a section addressing convergence and divergence of the findings derived from the various sources of quantitative data (within method) and between the quantitative data and the interview data (between method).

Table 6.1 Concepts, categories and subcategories of the emergent theoretical framework

Concept	Category	Sub-category
Session-specific Level	Forming intent	• Goals • Level of desperation • Affinity for physical Activity • Focus
	Deciding	-
	Planning and preparing	• General preparation • Social Issues • Specific planning • Developing strategies • Preparing equipment and accessories
	Starting	-
	Doing-it	- Step-to-step
Pattern-specific Level	Uncommitted phase	-
	Beginner phase	-
	Intermediate phase	-
	Mature phase	-
	Integrated phase	-
	Lapses	-
Determining Factors	1. Goals	-
	2. Strategies	-
	3. Barriers	• Fibromyalgia symptoms • Negative attitudes and beliefs • Life events and time issues • Health and medical • Physical activity history, experience, and knowledge • Social (norms, role models, support) • Personality • Other
	4. Facilitators	• Fibromyalgia symptoms • Positive attitudes and beliefs • Life events, time issues, work • Health and medical • Physical activity history, experience, and knowledge • Social (norms, role models, support) • Personality • Other
	5. Outcomes	• Positive
		• Negative

6.1 The Interview Data

Thirty-nine interviews were conducted; two interviews for each of the first 18 participants and one each for the last three participants. The coding of the data yielded 850 nodes (781 free nodes and 69 nodes organized in tree structure). The free nodes were organized into sets which eventually emerged as the elements of the theoretical framework which are described below.

During the interviews, the participants responded to questions and prompts freely, laughing frequently during the interviews, but also sharing experiences of great sadness. Often their responses, although usually relevant to the general topic, did not correspond directly to the question; this was noticed both by the researcher and others including the participants themselves as they reviewed the transcripts. Only one participant (Kathy) seemed nervous and ill at ease; she requested two breaks during the first interview. Nevertheless, her interview was very productive. One participant (Penny) seemed very depressed; at the conclusion of the second interview the researcher gave her information about counseling resources in the community; however, it is not known if she followed through. All participants reviewed the transcript of their first interview; only very minor changes were requested and those were chiefly to correct grammatical errors in their responses. Many of the participants' comments were moving, intriguing, colorful, persuasive and instructive and worthy of repetition, but in order to maintain acceptable brevity in this document, the use of direct quotes will be limited. Data, including direct quotes supporting the concepts which make up the theoretical framework, are referenced using participant pseudonyms; pseudonyms will be identified using brackets.

Code checking produced confirmatory evidence for the credibility of the results. In addition, reactions of those attending the presentation to the Saskatoon Fibromyalgia Support Group and the staff of the Department of Rehabilitation Therapies at the University of Alberta Hospitals.

6.2 The Session-specific Level

While considering the interview data, it became apparent to the researcher that there were important and distinct stages that the women experienced during the execution of a session of LTPA. Thus, the process of adopting and maintaining regular participation in LTPA was separated into two primary concepts. The first concept, the session-specific level, was composed of stages within a single session; the second concept, the pattern-specific level – was composed phases in the accumulation of many sessions. The stages (categories) in the session-specific level were: forming intent, deciding, planning and preparing, starting, and doing it. These stages will now be examined.

6.2.1 Forming Intent

Forming intent was seen as the first stage in the session-specific level (a session). The intent to engage in LTPA varied among the participants; some participants expressed great determination (Sarah, Meme, Jackie), others were moderately determined but not necessarily successful (Sheena, Alicia, Penny, Irene, and Liza), one was ambivalent (Kaluha), and one denied any intent to undertake LTPA under the present circumstances (Allie). RoseMarie, Allie, and Jackie recognized that intent was an important prerequisite to success in establishing new behaviours like LTPA participation. RoseMarie stated:

> I remember when I first decided that I had to get this weight off, I didn't think I could do it and that's, I think, where I have to be very strict with myself, "this is going to happen." (RoseMarie)

The strength of intent was aligned with the goals of participation, the level of desperation, the attitude of “putting me first,” and the affinity for physical activity.

a) Goals

Participants had formed strong intent around several different goals. For some, control of symptoms (Jackie, Maya, Liz, Pete) was critical, whereas others voiced strong intent related to present and or future social integration (e.g., ability to participate in family events, activities and relationships; Kayla, Sarah), weight control or loss (Laura, Ceci, RoseMarie), physical, mental and/or spiritual health (RoseMarie, Meme), securing a healthy future (Sarah), and enjoyment (Isabella, Kathy, Minnie, Meme). Although one participant stated that she started exercising for the purpose of weight loss; when unsuccessful, she continued because she found that outdoor walks were healing. Two participants used strongly positive terms when discussing the control of symptoms stating that physical activity is: “both physically and psychologically my salvation” and “a lifesaver” (Maya and Jackie, respectively).

Allie described how change of goals affected her resolve to continue with yoga. After accruing impressive benefits from yoga, which she had done faithfully for several months with the goal of controlling her symptoms, she stopped attending yoga classes. She no longer had a purpose to go once she had achieved her goal. One assumes that if her symptoms recur to the previous intensity, she may form the intent to restart. She explained:

> Well I think I just was feeling so much better and I wasn’t hurting as much and I was more active and I was feeling better and that’s a pattern of my

> life (laughing) as far as those kind of things go. … (I do it) on a need basis part (laughing). I don't do it as a prevention. I do it as a cure. (Allie)

b) Level of Desperation.

Some individuals described having reached a state of profound dysfunction (attributed to fibromyalgia), which affected their quality of life, their personal goals, and their families. Over time, mounting dissatisfaction with the situation culminated in an intense level of desperation. Intense desperation is evident in a pivotal conversation Meme had with her husband in which they discussed her level of dysfunction and need for taking action:

> "We had a good heart-to-heart talk. He said, "I don't know what to do for you. You've got a husband, you've got two kids; you'd better start fighting it, looking into what can be done." (Meme)

For Meme and for others (Isabella, RoseMarie, Liza), desperation provided the impetus for the decision to take matters in hand. As RoseMarie started:

> "And it was time, it was time to…. I was maybe ready to let go of my job totally then and accept, "okay, you're not going to go back to work and you have to do something with your life. You can't just be at a stand still." (RoseMarie)

In order to overcome their desperate state, several women talked about the need to change their thinking. Sarah summarized her thoughts on it this way:

> Changing the way you view life. It is a hard thing to do. To completely flip-flop. Really, because that's what you really do. … I don't want to live the second half of my life, however long it's going to be, 10, 15, 20, 30 years, an invalid. I want to move forward. I'm getting to the best years of my life really. … I won't be working anymore and I'll have more time to spend on just me. I want to be healthy to do that. It does make you think about that. … I have just made a decision, this is the way I want to be and this is what I've go to do. (Sarah)

c) Affinity for Physical Activity

Within the sample, about half the participants (n = 10) had a long history (prior to the onset of fibromyalgia) of physical activity dating to childhood, and vocalized an affinity for physical activity. Qualitative data pertaining to past history of physical activity obtained during the interviews were transformed to ordinal data and are presented in Columns 4 and 5 of Table 6.2. At the time of the study, seven of the ten had recovered a pattern of regular LTPA. The three exceptions (Sheena, Irene, and Liza) were women who were very active in other domains of physical activity (household, child care, and/or occupation). These participants shared the belief that regular participation in physical activity is an essential component of health. Four individuals attributed the high value for physical activity at least in part to their professional training (e.g., Liz - nursing, RoseMarie and Meme - teaching, Maya - physical therapy).

Three of the participants with a strong affinity for physical activity had experienced an abrupt onset of fibromyalgia subsequent to the combined experience of two serious but unrelated traumatic events: a motor vehicle accident coupled with either the death of a parent (RoseMarie, Meme) or marriage break-up (Isabella). Despite the strong affinity for physical activity, each of these individuals described extended periods (i.e., 5, 2, and 10 years, respectively) of depression and extreme inactivity. In each case, this period of desolation was curtailed by a dramatic and emotional turning point with the participant forming a firm unyielding intent to change their situation.

Some participants had less affinity for LTPA but had formed an intent to begin regular LTPA. For example, Ceci described having to overcome an aversion to exercise that seemed to be associated with three factors: a) experiences of injury while

participating as a child in sports, b) a natural dislike of competition, and c) a longstanding repulsion to sweating. She was able to surmount this aversion and become a regular exerciser by the capitalizing on the group excitement generated when two siblings and her mother began clipping coupons from the free weekly newspaper to join a woman's gym.

(Note. The affinity or lack of affinity for LTPA is also applicable as a barrier or facilitator as the case may be.)

Table 6.2 Pattern of Past LTPA for Each of the Participants

		Recent LTPA [a]	Distant Past Pattern of Regular LTPA (at any time more than 6 months prior to the study)[b]	
Id#	**Pseudonym**	**Pattern**	**Pattern**	**Type of LTPA**
1	Liz	active	sporadic	aerobics (shift work)
2	Jackie	active	unknown	enjoyed LTPA – hockey
3	Ceci	active	inactive	n/a
4	Isabella	active	active	aerobic, swimming laps
5	Pete	active	inactive	n/a ("not a sports fan")
6	Kaluha	sporadic	inactive	one 3-month aerobic program
8	Sarah	inactive	active	walk! like an army sergeant
9	Sheena [c]	sporadic	active	soccer
10	Alicia	inactive	active	athletic as child, various LTPAs
11	RoseMarie	active	active	strong – varied
12	Meme	active	active	curling, baseball, broomball, playing sports at recess with her pupils
13	Kayla	active	active	soccer, bike riding, walking, volleyball
14	Laura	active	sporadic	bowling (mother of seven)
15	Penny	sporadic	sporadic	walking
16	Kathy	active	active	square dancing
17	Minnie	active	sporadic	bowling
18	Allie	inactive	sporadic	archery (stopped, back pain)
19	Maya	active	active	skiing, biking
20	Irene [c]	inactive	active	callanetics
21	Liza [c]	inactive	active	mixed (soccer, downhill skiing, walking, social dancing, Pilates)

Key: Active = engages in LTPA at least twice a week, Sporadic = engages in LTPA less than twice a week. Inactive = does not engage in LTPA

[a] In the six months immediately preceding the study. These data were derived from screening interview. Categories pertained to LTPA only.

[b] Data were derived from interview #1 or #2.

[c] These individuals reported being very active in other domains of physical activity (e.g., household, child care, and occupational).

The activity level data collected based on the probe (i.e., "How physical active have you been over the past 6 months?") during screening varied with the data collected using the questionnaires (compare Column 5 of Table 4.8 with Column 3 of Table 6.2).

d) Incentive (external - internal)

Most of the participants described an internal motivation for undertaking exercise with a few using very direct words to sum it up like “I do it for me” (Meme, Liza) or “I'm the motivator for myself because what I do, I get the benefit of” (Sarah). Several participants stated that in order to feel right about taking time for LTPA, they needed to change from always attending to others’ needs first and learn how to “put me first.”

Two participants described an externally derived incentive for participation. Penny describing the incentive for regular walking despite severe foot pain (plantar fasciitis), stated “like I just had to do this because I did it for him” (her ailing father whom she took for regular walks). Kaluha also described engaging in exercise as part of a study to please her mom. It is interesting to note that despite gaining excellent benefit (less pain, improved self-esteem, better endurance) from participation in a 12-week program of exercise three times per week, she stopped immediately after her commitment to the study was over. Later in the interview, she suggested the importance of external agents in helping her motivationally:

> So if you said, "in three months, come back March 10th and show me what you've done,” (text omitted) I'd probably say, "I'd love to do that for you.” (Kaluha)

Beliefs. The beliefs regarding LTPA did not appear to be influential in the forming of intent. Most participants framed their beliefs about exercise using phrases like: “exercise is a must for the rest of my life,” and “exercise is part of a healthy lifestyle.” Even the participants who were most ambivalent and resistant toward LTPA acknowledged that: “exercise is a good thing,” and “I <u>know</u> that it is important” for the maintenance of good health. Isabella described how when she completed the study

questionnaires, she became aware of her low level of physical activity and formed the intent to take action.

> I looked at those little charts and I spend so much time sitting. And I thought, "oh my goodness! This won't do." (laughing) Although I feel relatively healthy, when you see that you think, "woah - I should be doing a whole lot more." Kind of a wake up call (laughing). (Isabella)

6.2.2 Deciding

Knowing or even believing that LTPA is good for one's health does not seem to be enough to ensure that one will engage in LTPA. Depending on the participant's goals, fibromyalgia management options other than LTPA were frequently chosen. Some participants chose to be physically inactive despite believing LTPA is important, while others chose to fulfill their health and condition-related goals by using one or more of the following: massage therapy, chiropractic, physical therapy, Reiki, medications, light therapy, heating pads, and liniments. Some participants considered LTPA as one component of the management of fibromyalgia. Kayla stated, "… I rest and I try and eat healthy and I try and walk." Laura suggested before embarking on LTPA, one also should ensure that they are receiving medical attention for other conditions such as thyroid and allergy. Because of the range of symptoms (e.g. inflammatory bowel disease) associated with fibromyalgia, Sheena advocated a holistic approach to management that would include several different treatments (e.g., massage therapy, herbal medicine and natural remedies, physiotherapy, exercise). Many participants referred to the need to decide and that the decision was one which the person had to make for herself. Minnie explained: "And it would have to be you making the decision."

Although some participants stated that there was no outside influence on their decision to participate in LTPA, others spoke of group interactions as influencing their

decision. Ceci spoke of the excitement ignited when her sister suggested that their mother and two sisters should each search out coupons for a women's fitness facility and join up together. Ceci, who had never been fond of LTPA, found herself joining in with the group planning and making a one year commitment to regular LTPA. Although several participants appeared to be influenced by others in their decision to become more physically active, no other participant described such a dramatic episode.

In coming to a decision to begin or maintain LTPA, the many items described as barriers and facilitators (see Section 6.9 and 6.10) influenced the decision to engage in LTPA and these were expressed by some (Kayla, Penny, Kathy) in a very rational manner as pros and cons of activity versus inactivity. Kayla comments exemplified this weighing of effects of activity against the effects of inactivity:

> … how long do you think people would listen to that? Like, "I can't do this and I can't do that." And you know, if you go on and on about that and then you just seclude yourself and you never do anything, what kind of life is that? (text omitted) I just made a decision and said, "I'm still going to do this no matter if I hurt, or I'm tired." Because I could sleep 24 hours a day and what's that going to do for me? Like gain 150 lbs? That's not good either. (Kayla)

6.2.3 <u>Planning and Preparing for LTPA</u>

This category deals both with general planning activities such as finding information and with specific planning for undertaking LTPA such as determining the form (i.e., mode) and quantity of LTPA (time of day, intensity, duration, and frequency).

a) General Planning

When asked how they learned about LTPA, several participants stated that they had searched for information specific to fibromyalgia through various means: reading (Kayla, Sheena, Liz), using the internet (Alicia, Meme), attending self-help groups,

seminars, (Kayla, Meme) and receiving expert advice (clinics: Liz, family doctor: RoseMarie, staff at commercial gyms: Ceci and Laura), and participating in research interventions (Penny). Others had obtained how-to information through: activity lessons (square dancing: Kathy, golf: Kayla; Tai Chi or yoga classes: Alicia, Sheena, and Allie), watching others (aquacise: Penny), video taped exercise programs (yoga: Sarah, Allie, Liza, Laura; Pilates: Sarah and Liza; aerobics: Alicia; and callanetics: Irene), and even watching a pet do stretches on awakening (Alicia, Meme).

b) Social Issues

In formulating plans for LTPA several opinions, solicited and unsolicited, were voiced with respect to preferences related to social characteristics of the structure and type of LTPA. Some participants preferred solitary activity -- others preferred to do LTPA with an exercise partner or group (See Table 6.3); some liked competition -- others did not. Some seemed to need a structured social approach (e.g., classes twice a week with an instructor) – others who had changeable demands from one day to the next were able to "work it in."

The need for a structured social approach was described by Allie:

> I'm much better going to classes. (laughing) Having someone tell me to do it. (laughing) (text omitted) I'm not very good with home stuff (text omitted) I honestly can't tell you why. And I mean it isn't just walking, it's like yoga, "oh yes I'm going to do this every day" maybe it's the fact that I think I have to do it every day, where when I'm going to a class, I know it's two nights a week and so I just go and thoroughly enjoy it. Maybe it's the social aspect too, I don't know. But to do it on my own is very difficult for me. (Allie)

The availability or lack of availability of a suitable LTPA partner(s) or access to an LTPA group, depending on the participant's preference could provide either a facilitator or a barrier. Participants who preferred to do LTPA alone or those who were

ambivalent about having an LTPA partner(s) obviously were less vulnerable to failure of partner-dependent LTPA plans than those who preferred cooperative arrangements with LTPA partner(s).

Table 6.3 <u>Recent Pattern of LTPA and Preference for Performing LTPA Alone or with Others.</u>

Id#	Participant	Recent LTPA Pattern[a]	Preference (data derived from interviews)				
			Alone	With a Partner	With a Group or Class	No Preference	Unknown
1	Liz	Active	x				
2	Jackie	Active	x	x			
3	Ceci	Active			x		
4	Isabella	Active	x				
5	Pete	Active			x		
6	Kaluha	Sporadic		x			
8	Sarah	Inactive	x	x			
9	Sheena	Sporadic				x	
10	Alicia	Inactive			x		
11	RoseMarie	Active	x				
12	Meme	Active	x	x			
13	Kayla	Active		x			
14	Laura	Active			x		
15	Penny	Sporadic					x
16	Kathy	Active			x		
17	Minnie	Active			x		
18	Allie	Inactive			x		
19	Maya	Active		x	x		
20	Irene	Inactive	x				
21	Liza	Inactive	x				

[a] In the six months immediately preceding the study. Data derived from screening interview. Categories pertained to LTPA only. Active = engages in LTPA at least twice a week, Sporadic = engages in LTPA less than twice a week.

c) Selecting a Mode

Aside from the decision to engage in LTPA, there are numerous other decisions to make. Choices that face the individual are – what type of LTPA, how often to engage in LTPA, how much to do at one given time (i.e., technically these are referred to as mode, frequency, and time, respectively). It has been estimated that there are over 600 modes of LTPA, and over their adult lives the participants (collectively) had tried numerous activities either before or after the onset of fibromyalgia. The many modes of LTPA identified by the participants can be loosely grouped into five categories: exercise, meditative physical activity, physical recreation, sports, and walking. The women had engaged in:

- Exercise including low impact aerobic exercise programs (aquacize, community fitness classes, televised/videotaped programs, stationery bicycling), Pilates (see glossary), step aerobics, callanetics (see glossary), stair climbing, exercising at a gym (circuit weight/aerobic training), resistance exercise (free weights, gym equipment, home exercise machines, exercise ball), and individualized supervised rehabilitation programs (clinic-based).
- Meditative physical activities including tai chi and yoga (community classes or videotaped programs).
- Physical recreation including dancing (social, ball-room, square, or round dancing), bowling, swimming, golfing, camping, skiing, skating, outdoor cycling, and gardening and yard work.
- Sports including curling, soccer, and other sports.
- Walking including outdoor walking, walking the dog, pole walking, mall walking, walking classes, and treadmill walking (using manual or electronic treadmills).

Having many options produces a situation akin to shopping. Alicia conjured up an image of the shopping metaphor when after having difficulty with low-impact aerobics (poor coordination skills and discomfort due to jarring) she said: “I just struck that off

my list." Alicia believed that "it's important for everybody with fibromyalgia to try and find a program that works for them."

The women considered a variety of factors when selecting an LTPA mode; some factors were related health and some were more general.

Health related criteria for selecting a mode of LTPA

The health related factors that the participants considered when selecting a mode of LTPA included: (1) effect on pain, (2) adverse effects on fibromyalgia and/or arthritis, (3) accounts for physical limitations, (4) involve programming for fibromyalgia, and (5) effect on mood and spirit.

(1) Effect on pain. Certain activities were selected or avoided because the effect that they had on pain. This was a rationale given for walking (Jackie, Maya) and dancing as compared to cycling (interspersed rests between dances seems to keep pain from getting as intense as when bicycling outdoors) (Kathy).

(2) Effect on arthritis and adverse effects. Several participants (Kathy, Minnie, Maya, Isabella) indicated that they had arthritis in one or more joints. The effect of the mode LTPA on their arthritis was considered when selecting a mode. Kathy indicated that bike riding caused less impact on her arthritis (feet) than walking. Minnie recommended aquatic activities because "you're more buoyant," and bone spurs are less of a problem with aquatics than with walking. Maya also found the buoyancy helped "so much especially since a lot of my dysfunction is in my sacroiliac joints and I am prone to plantar fasciitis (text omitted) and yet I find resistance the water gives me (text omitted) helps me a lot." Isabella also referred to the beneficial effect of buoyancy.

Several participants experienced increased pain with activities that involved jarring, and consequently, they were wary of or avoided a variety of activities including: aerobic dance (Sarah and Alicia), floor exercise at Curves (Penny), water aerobics (Maya and Alicia), and outdoor walking (Sarah).

(3) Accounts for physical limitations. Some participants talked about having to rule out activities based on limitations acquired as a result of having fibromyalgia. Minnie summed it up: "I just don't think I could do it (exercise on land instead of exercise in the water), so I just haven't tried." Maya reported, "I still don't know if I'll ever downhill ski again which I would love to do." Two participants suggested that programming needed to match the person's abilities. Kaluha said, "but, I would want to (exercise) with someone that wouldn't say, 'well today I expect you to do everything I'm doing.' I mean I wouldn't be able to do that," and Sheena pointed out, "You can't just say, 'for fibromyalgia, everybody should run a marathon' (laughing), it has to be individualized."

The perceived ease or difficulty of the activity was also a factor in selection. On this basis, RoseMarie was a strong advocate of walking:

> … for me, probably the best exercise is walking. Using the poles, I'm working out my whole body in more of a relaxed fashion instead of where you have to use weights to increase your strength and exercise repeatedly. I might not have the strength but I have the endurance maybe. (RoseMarie)

Kayla and Minnie also made selections based on this criterion. Kayla said, "It just seems to limber you up and it's not strenuous on the body or on your muscles." Minnie concurred stating, "I have never gone because they said it's quite strenuous."

(4) Programming for fibromyalgia. Isabella was very pleased with the fibromyalgia aquatics program and highly recommended it for others with fibromyalgia. She stated,

> It was a fantastic program especially for fibromyalgia patients and that helped immensely. It was very gentle, the pool was warm and it involved a lot of stretching, gentle stretching and then an aerobics part in the deep end. (Isabella)

This program was only mentioned by one other participant (Minnie). Sarah advised: "If somebody was trained and dealt with people with fibromyalgia, I think they could take that all into consideration because we do have limitations."

(5) Effect on mood and spirit. Walking was also selected by some for psychological and spiritual reasons (Meme, Maya, RoseMarie). As stated by Maya, "Walking is my salvation both physically and psychologically" and RoseMarie, "I find the walking not only stimulates me physically but mentally because physically I tend to feel a little better and sort of a boost of energy."

Other more general criteria for selecting a mode of LTPA

The general factors considered by the participants when selecting a mode of LTPA included: (1) feeling social acceptance, (2) comfort and convenience of facilities (3) experience of nature, (4) interest, enjoyment, and variety, (5) achieving a balanced workout, (6) availability of childcare services, (7) holistic programming, and (8) fear of falling (e.g., while using the treadmill).

(1) Feeling social acceptance. For Ceci, an important criterion for selecting LTPA was feeling social acceptance. She explained:

> I'd tried other gyms and stuff but I just didn't feel comfortable there you know? If you're overweight, you feel self-conscious and then it's with males and females where this is just females. So this is a good

> environment because a lot of them are there to lose weight too and there's all sizes there. (Ceci)

(2) Comfort and convenience of facilities. Comfortable water temperature of community pools (Pete, Kathy) and location of the facility (or program) within walking distance (Laura, Allie, Kaluha, Sheena) were attractive features that influenced the decision to participate in a particular mode of LTPA. Cost also seemed to influence the decision about which mode to use: "You know, I think if you could go to these fitness places and you didn't have to pay so much, to go there, I think people would do it a lot quicker." (Kathy)

(3) Experience of nature. Several participants talked about the positive effects and enjoyment of nature during outdoor walking. Examples of the comments made are: "it clears your mind when you're out there walking" (Kayla), "I just loved the sun on my body" (Isabella), "we have a whole field that we can see them (the Northern Lights) when they're dancing and I love that" (Maya), "out in the fresh air" (Kayla), and "I would rather walk outdoors because you also get the oxygen in the lungs" (RoseMarie). Meme was perhaps the most eloquent advocate of nature:

> I've seen sunsets that just blow your mind from purples and blues to pinks to even a little bit of green in there. It's just fabulous. I got a real kick out of the snow banks and the way the wind would swirl them around to make them look like a big dollop of whipped cream on top of your dessert. (Meme)

(4) Interest, enjoyment, and variety. Several participants commented that interest and/or enjoyment were important criteria when selecting a mode for LTPA (Sheena, Allie, Laura, Meme, Kayla, Isabella, Minnie). This reverberated in Laura's advice for others with fibromyalgia, "I guess the first thing that I would say is, find something that you really like to do and see how you can incorporate that into your daily activities."

Maya and Sheena talked about wanting variety. Sheena was most expressive about this stating that she liked to have a variety activities and options; however she observed that it was not easy to find a fitness center that offered the degree of variety she would have liked:

> So, if you find a gym that can accommodate that and has - like this gym didn't have extras. They didn't have an aerobics class, they didn't have yoga or Pilates or anything like that. I think that if they have something different like that, so that you can feel like, "okay, I can't do this today but maybe there's something else - I can go and do this, light yoga and some stretching," a combination like that. I think that would be a lot better. (text omitted) I'd have to have a bit of variety because I'm not a boot camp kind of girl. '50 push ups'! (Sheena)

Meme tried to build variety into her daily walking by changing her body position (looking up) and by focusing on nature, and Sarah thought that variety may be good but not a critical factor.

(5) Achieving a balanced workout. A few individuals talked about trying to find activities that gave the upper body a work-out and indicating that the inclusion of work for the upper body was desirable (Aquacise - Liz, gym equipment – Laura, pole walking – Rosemarie).

(6) Availability of child care services. Only one participant spoke of availability of childcare. Laura, a mother of seven, spoke of having been able to take her young pre-school aged children with her to a community fitness program. Without this service she would not have been able to participate.

(7) Holistic. Two participants (Maya, Sheena) suggested that the mode of LTPA should be holistic. Maya suggested the particular benefits to be derived by individuals with fibromyalgia from such activity:

> I really always have been a strong believer in the holistic approach to health and I find things like Tai-chi and yoga really make me aware that what this fibromyalgia disease has done is that it has put fissures between my physical, mental and spiritual self. And - and what things like yoga and Tai-chi do is I sort of feel like I'm gathering home all my energy, you know, and it just sort of, "okay great"! (Maya)

(8) Fear of falling. Kaluha was the only participant to indicate that she would avoid an activity because she was afraid to undertake it. She said, "for myself, I'm petrified of those treadmills."

d) Practical Planning Related to the Scheduling and Quantity of LTPA

Aside from selecting a mode of LTPA, several practical decisions were needed regarding scheduling and timing, and determining the volume of LTPA (intensity, time and frequency).

Scheduling. The level of planning for LTPA sessions used by participants varied; Liz, Maya, and Laura described advanced planning using to-do lists or daily calendars; in contrast, Kayla, a regular exerciser described a haphazard approach where she and her exercise partner, a neighbor who did shift work, used a flexible system. Kayla talked about trying to add other fitness activities to her day-to-day life but she did not have a pre-planned approach to this either: "I go on a whim and then I'll get sore and I'll quit doing them (sit-ups on an exercise ball) again.".

Selecting a time of day. The preferred time for engaging in LTPA was mixed with five participants preferring morning, five preferring noon or early afternoon (before 3PM), six preferring the evening, one preferred night, and five participants not specifying a preferred time (Alicia and Maya suggested two times). For most participants this was merely personal inclination but two participants indicated a more specific reason for their preference. One participant (RoseMarie) who had to quit work, shifted the time of her

daily walks with the school schedule to avoid encounters with former coworkers and pupils at the school. Another participant (Laura) stated that she had read “somewhere” perhaps in literature on seasonal affect disorder that exercising in the morning was not healthy, so she exercised in the evening.

Several participants (Alicia, Liz, Pete, Isabella), indicated that at three o’clock in the afternoon they had to stop everything for 20 to 90 minutes because of lack of energy. As stated by Pete: “I have been keeping myself busy from the time I got up in the morning until about 3 o'clock in the afternoon and then I have to go and crash.”

Determining the intensity of LTPA. The women seemed to have difficulty knowing how intense the physical activity should be and most used trial and error. Even when advice was sought, the experts did not always have a better system than trial and error to guide the participants (Jackie). The trial and error method did not appear to be very reliable however, as it seemed that a given intensity of exercise might lead to severe pain on the following day on one occasion and be just fine on another occasion.

Only a few participants seemed to be familiar with methods for determining the training intensity range described in public health recommendations (using pulse rate and effect on breathing, sweating) and no one exercising outside of fitness classes took her own pulse. Although description of breathing pattern associated with moderate intensity aerobic exercise given by Meme was very close to the description of the ACSM, many participants were at a loss to describe what the ideal intensity ought to be or what methods they could use to determine to the level of intensity of an activity, as Kayla revealed in the following series of questions and answers:

Researcher: And to you, what does that mean, brisk walking?

> Kayla: A little more than slow. Sometimes I have to tell her to slow down because she's going too fast for me.
> Researcher: And do you have any cues or anything like that or has anybody taught you how to figure out what's brisk or not brisk?
> Kayla: No, we just walk. (laughing)
> Researcher: You don't take your pulse or you don't watch your breathing or anything like that?
> Kayla: No. (Researcher and Kayla)

Determining the appropriate intensity for LTPA was bewildering for most due to variable post-exercise soreness after a given exercise load (post exercise soreness on one occasion and not on others), difficulty trusting their body, lack of knowledge about how to monitor intensity (level of breathlessness, pulse rate), and lack of clear advice from professionals. Ceci's comments are an example dealing with the unpredictable post-exercise soreness at given intensity:

> Yeah, it was hard when I started. I probably wasn't used to doing exercising and I was sore and I still am sometimes too, so I didn't know how much to push. Like some days you work real hard and then you're really sore and other days, not quite as much and you're sore but not as bad. I don't really know, I guess I just go according to how I feel, how much I want to push it. (Ceci)

When describing a failed attempt to establish a regular pattern of LTPA, Meme related that she thought, "that the more tension I put on, the faster my legs will trim." In contrast, many participants indicated that the best approach was not to worry about intensity and go at their own pace. As Kayla said, "I don't care if I'm walking very slow or walking moderately or brisk, I just like to get out and I think it helps me … to function."

Time and Frequency. Other than those participating in structured programs, the length of an LTPA session was highly variable but ranged from 10 minutes (Laura – stationery bicycle with resistance) to 90 minutes (also Laura – stationery bicycle without

resistance). Kathy, who was the only participant to talk about taking breaks or rests during an activity, described her response to square dancing as follows: “I get tired very quickly though, my legs get tired. So when I get tired we just sit for a while.”

The frequency of LTPA sessions was also highly variable, from completely sporadic to daily, but when asked what they would advise others with fibromyalgia, most recommended that engaging in LTPA twice or more times a week was ideal.

Volume and Limits. The concept of exceeding one’s limits and paying for it after were two strong themes unanimously emphasized by the participants. Several participants talked about not being able to “trust” one’s body to determine limits. Isabella’s comment below suggests that fibromyalgia affects the reliability of one’s perception of exertion.

> Oh it was just experience over a few years of knowing what I could do. Say it was a good day, I couldn't trust my body anymore. I had to trust my brain. You know when you're doing something and you feel really good and you go for a walk and you walk for miles because you feel good and you think you can and it doesn't hurt. Well that's when everything's normal. (Isabella)

Meme described the notion of a “fine line” symbolically demarking a tolerable quantity of physical activity from a quantity that would be associated with severe effects (also see outcomes). She related how it had taken her considerable time to understand her limits:

> In fact at that time I didn't even know what fibromyalgia was all about. I guess it's not knowing (spoken slowly) how much exercise that fibromyalgia people can do and then back at that time too, I wouldn't have known about that fine line. I just thought, "Okay, the normal should be ten minutes really heavy going and then quit." But it was ten very, very, hard minutes and then I just hurt myself more. (Meme)

Kahula described two situations – in one she strove to surpass the expected volumes of exercise and in the other she seemed to refuse to try to achieve the expected volume. In a one-to-one supervised setting she described her approach as follows: "Everything that they asked me to do, I did that and I maxed because I said, 'this is going to be good. I'm not just going to do what they said. I'm pushing myself to the limit and I'm going to do over that.' " However, in a group LTPA session, she described her response to direction as follows: "Like they wanted you to do ten jumping jacks in the water, well I could only do five, but that was better than doing none."

e) Developing Strategies

Developing strategies was an important part of the preparation for LTPA. Although not all strategies were effective, the more seriously the participant approached problem solving and strategizing related to the challenges of regular LTPA, the more likely a participant was to achieve her goal. The participants described over 40 strategies to help overcome the barriers to participation in regular LTPA. These were organized into 10 categories (see Section 6.6.2 and Table 6.5).

The participants who were more skilled in self regulation: a) controlled their mood (stayed positive), b) controlled their schedules (use of routines, scheduling strategies), c) maintained focus on distant future goals stronger (purpose oriented), d) controlled their inner dialogue ("I took the decision out of it," Sarah, "get-off your butt," Liz), and seemed to be more successful in moving through the phases to become mature in their ongoing participation in regular physical activity. Nevertheless, even strong self regulation skills were seen to break down in the presence of pain.

f) Preparing equipment and accessories

Although not all participants were asked about exercise equipment, it seemed that most participants (n=14) had access to exercise equipment in the home. The most common pieces of equipment were bicycles (n= 8 stationery bicycle, n=3 outdoor bicycles), followed by treadmills (n = 2, manual treadmill; n = 2, electric treadmill). Equipment described was as simple as a pair of 3 pound dumbbell weights to as substantial as a swimming pool. Five participants used home equipment regularly (bicycle – Laura, Jackie, Kathy; treadmill – Liz, dumbbells - Sarah). The remaining nine used their exercise equipment only infrequently or not at all.

Clothing. Although weather was seen as a challenge, judging by their tone of voice and physical bearing, several participants seemed to see facing the cold of the Saskatchewan winter with a sense of pride. These excerpts are examples of this sense of triumph: "I like to walk a little bit and get a little bit of fresh air even if it's brisk or cold. I bundle up pretty good and I really enjoy that" (Sarah) and "I go out even when it's very cold, even when it's in the minus 40's" (Meme). Several women spoke of "bundling up" in a variety of winter apparel including ski pants, mitts, boots, hoods, and scarves wrapped around the face leaving only the eyes exposed. Some used specialized articles of clothes such as a "leather zip-up turtleneck" dickey (Meme) and a balaclava[a] (Kayla).

Shoes and insoles. A variety of footwear was described: walking shoes (Kathy), custom-made orthopedic boots (Pete), heel cushions (Kathy), costly brand name shoes (Saucony, Inc.) with custom insoles (Penny), good runners (Kayla), orthotic inserts

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[a] A balaclava is a close-fitting knitted covering for the head and neck, leaving only the face, or parts of it exposed

(Sarah). Penny, who had debilitating plantar fasciitis, reported that the expensive shoes and custom made orthotic inserts did not help.

6.2.4 Starting

The stages in the session-specific process described to this point, intent, deciding, and preparing; take us right to the threshold of action. For an individual who has a history of inactivity, the strength of intent, the outcome of the internal dialogue of deciding, and the process of preparation all lead to the magical moment, where, to borrow a few terms from physics, potential energy is released and transformed into kinetic energy. One would think there is little to say about this moment of transition itself. Viewed globally, starting may consist of the first several sessions of LTPA, where one learns the skill, monitors early responses and makes adjustments. However, within the context of the session-specific level, "starting" is viewed as one of the key recurrent elements. It is as real for the experienced as it is for the neophyte. Starting as viewed here is not just a feature of the first several iterations of the LTPA experience, but a distinct stage that is part of each day-after-day iteration of LTPA. For the researcher, the realization that the process of adopting a pattern of regular LTPA is not linear, not an all-or-none phenomenon was perhaps the most important conceptual hurdle to be overcome in developing the emergent theoretical framework. It wasn't until the interview with RoseMarie (the twelfth participant) that it suddenly became clear that an all-or-none view was incorrect. Despite severe headaches, pain, and fatigue, RoseMarie pole-walked religiously for an hour each day. When I asked how she could do this, she replied that with each step, she said the words, "this too shall pass."

This was an important moment in the analysis. Once this was identified, it became clear that the process was not about adopting a practice the way you might adopt a child – an all-or-none event, but about the accumulation of hundreds (or thousands) of individual steps per day (i.e., with a session), and then thousands of sessions over the course of years. Reflecting on this further, each entity within the process, even down to the smallest unit – a step (or repetition, revolution), has, embedded within it, a cycle and each of these tiny cycles has a starting point – the point at which cognitive intent is transformed into physical energy.

The pivotal importance of "starting" as a recurring phenomenon within the cyclical process required for habitual patterns to evolve was first identified during Allie's second interview (the eighteenth participant). When we were discussing forming habits, Allie reflected on how she had been able to do yoga consistently for several months. She clearly identified starting as a distinct and critical phase of the activity. She reflected:

> Allie: Yeah and it wasn't doing the poses, it was getting started and doing them. Does that make sense? (text omitted) And that applies to a lot of things in my life. "Oh well, I really should do….well, I'll just start, see how far I get." Once I start I'm fine. It's the starting.
> Researcher: And each time this comes up, how likely is it that you will do it, would there be a 50/50 chance that you'll do it each time? Is that what you are saying?
> Allie: Oh, in fact, if I start, there's probably a 99% chance that I'll finish. It's the starting of a project, or even a chore, that is the problem.

After identifying *starting* as a significant recurring event, the data collected prior to that point were reviewed to see if this concept had been mentioned earlier and several instances were found. Sheena's description of the getting ready to go for a walk was an excellent practical example of this.

> Sometimes your head goes, "you know, oh, it's so beautiful outside and the weather's great and all the Christmas lights are on. Oh, I should go for a walk. Okay, get your coat on and get your shoes on and, you know, and then you just "aaaaah" and you're like - and I sat there in my coat with my shoes on and I'm going, "well I'd better take my coat off or actually go outside." (Sheena)

At subsequent interviews, participants were asked about their experiences regarding this part of the process. Maya and Liza strongly concurred with the opinion that starting is a pivotal component of the process. Not only is there a transitional aspect to each session (transition from inactivity to activity), but the quality of the experience in the first few minutes of LTPA differs from the quality of experience once one is beyond the first few minutes. In the next two excerpts, Maya described the essence of this recurring starting in two ways – preparation and overcoming inertia:

> And so part of that is physical, but part of it is, ‘yeah, I can. I can get up’. (text omitted) I think it’s truly preparation. I would call it preparation. (text omitted) It’s preparing yourself in all your spirits, physically, mentally, emotionally, to do it. That you’re ready. (text omitted) One of the challenges for physical fitness is going to be a head thing, not a physical thing. It’s going to be, how do we get through that block at the start? (Maya)

In the following excerpt Maya describes the transitional nature of starting and invokes a powerful metaphor (the Berlin wall):

> It’s the hardest part of the whole exercise, is the initial few minutes, you know? And then once you get your body moving, once you get actually doing the activity, then things get easier and so I think there’s this huge block. (text omitted) To me it’s like the wall separating Germany, you know, East and West Germany, I visualize it as there’s this ugly cement wall with razor wire at the top and you just have to plow through it but that’s the intensity that I see this wall being. (Maya)

These descriptions are consistent with the symptom of fatigue; however the next two excerpts would indicate that the experience of pain may be at the heart of the difficulties encountered in starting.

> … sometimes it's so HARD just to get MOVING because of the pain" (text omitted) And it's sort of like, my mother would say, "I'm working out the kinks" and it's that sort of working out the kinks type of thing but as you progress through the exercise or through the walking, I find that that initial pain diminishes. (Maya)

> Yes, at the beginning it does for maybe the first three minutes of the walk. Let's say for the start of my walk, if my legs were sore in the morning, sure I'll be galump-a-lopping along and then once I get into the motion of things the muscles release a little bit and then I'm okay. (Meme)

6.2.5 Doing-it

As described in the previous section, LTPA should not be viewed as a unitary thing but as the composition of sessions, and sessions ought to be viewed as a composition of smaller units – such that each step is an act in itself requiring intent, decision, preparation, and starting. Thus, in the presence of fibromyalgia symptoms (pain or extreme fatigue), the execution of a session of LTPA takes on a fragmented nature. When she was in pain, RoseMarie had to summon her will for each step and each step became a separate entity. The enhanced effort needed to overcome pain was confirmed by the several other participants (Liz, Jackie, Penny, and Pete), Maya validated that in the presence of pain and exhaustion, sessions become fragmented into single steps:

> Yeah and you see, I applaud that woman because she probably went for a walk on a day where I would say, "I can't go." So maybe if I did actually get out there on those days that's how those walks would have been. And I have had a few times where I've gone with my husband to the Field House and have felt so exhausted that every single step was hard. (Maya)

This seems to imply that the fragmentation of the *doing it* stage depends on severity of symptoms and is variable. As the symptoms abate, the steps begin to blend together so that, eventually only one *starting* is needed for the entire session. On a physiological level, individuals receive numerous sensory stimuli with each step. Noxious stimuli such as pain have a role as just described, but likewise so do pleasant

stimuli – visual stimuli (beauty of the northern lights, a sunset, the pattern in the snow), auditory (birds, rustling of the leaves, crunch of the snow underfoot), thermal (warmth of the sun), and sensory and olfactory (feel of a gentle breeze, smell of the outdoors). The social environment may also operate as a stream of stimuli that may impact on the step-to-step experience. For example, Allie reported, “Initially when I first went, again, I got such encouragement from the other people in the class and it was wonderful and I felt good.” Thus, just as symptoms can give meaning to each step, so can these pleasant sensations.

The acuity of awareness to the multitude of transient stimuli may be more intense (and therefore the fragmentation of the session more intense) during the initial sessions of LTPA, during which individuals monitor their internal and external environment more closely. Consistent with this, are Jackie’s comments about her early experience with yoga:

> I remember thinking after the first couple of weeks, how can this possibly help? Because some of those positions when they - you know, you hold and hold and hold and think, "Oh, my every muscle in my body is just crying to relax. (Jackie)

Jackie also seems to indicate that the level of awareness may dwindle with time: “after you've had it so long, you just fail to notice a lot of these little things.” However, <u>all</u> of the participants described fibromyalgia as unpredictable and puzzling. The changeable nature of fibromyalgia served to maintain a heightened level of awareness of the step-to-step stimuli. Indeed, most participants described pain during the LTPA. These are the comments of Sarah, Alicia, RoseMarie, Penny, Meme, Liza, and Maya:

- Like the back pain seems never to go away, the stiffness and I tried to work with that. (Sarah)

- And my left hip often became so painful I'd have to stop walking. (Alicia)

- It depends on the day. If it's a day full of pain then when I walk I'm really grumbling but I still do it. (RoseMarie)

- I'd say that I was pain free when I was doing it, but no, I wasn't. I had some discomfort, and some pain, but I did it. (Penny)

- You're going to have pain regardless of what you do but if you do some exercises that pain will lessen. (Meme)

- I try to walk but there's a lot of pain involved. (Liza)

- … sometimes I'll start walking and even just moving my legs forward, I will have pain in the leg that I'm moving forward, I will have pain on just moving the leg forward and so what we do is we walk slower. (Maya)

Barriers, noxious stimuli, and negative outcomes may bring the *doing it* stage to a premature halt at any point resulting in, at a minimum, a truncated session or at worst a lapse from LTPA which may last days, weeks, or months. Obviously, strategies for controlling or coping with symptoms are important in this stage. Modifications are occasionally made within a session. The successful completion of a session, as determined by the participant, can bring many immediate rewards. Some participants reported feeling less pain and stiffness, and more alert, refreshed, and energetic. Some also experienced a sense of achievement and enhanced self esteem upon completing an LTPA session. However, these effects were not universal across participants, nor were they consistent for a given participant from one session to the next.

6.3 Pattern-specific Level

The accumulation of many steps, repetitions, or revolutions to form a session completes a single layer in this theoretical framework for formation of habitual participation in LTPA in women with fibromyalgia. We are now ready to move beyond

the completion of a single session (Stages of the Session-specific Level: Intent ➔ Deciding ➔ Preparing and Planning ➔ Starting it ➔ Doing it) to the accumulation of many such sessions crossing days, months, seasons, and years to eventually form a habitual pattern of LTPA participation (Phases of the Pattern-specific Level: Uncommitted ➔ Beginner ➔ Intermediate ➔Mature ➔ Integrated). These phases will be described below. Diagrammatically the Session-specific Level of the theory involves the building of layer upon layer of linked sessions such that the process forms a spiral rising from a base of the first LTPA session and extending upward either endlessly or until the spiral is interrupted either within a session or between sessions (see Figure 4.1b) in which case it can return to the base and begin again. The participants were distributed among the phases of participation (see Table 6.3).

6.3.1 Consistency of the qualitative data with the quantitative data

A few points of clarification are in order. First, sessions are not necessarily identical – some will entail greater or lesser emphasis on intent, deciding and preparing/planning. Second, disruptions in the process (lapses) can occur at any time. If a lapse is of a short duration, the spiral may continue uninterrupted, however if the lapse is lengthy, the individual goes “back to square one” and must begin to build again. This phrase “back to square one” was spoken with dread by Liz and RoseMarie.

In all but a few cases (Sarah, Pete), the quantitative LTPA data was consistent with the qualitative data. Sarah who classified herself as completely inactive on the screening questions, indicated in the interviews and the Kaiser Physical Activity Questionnaire that she exercised at Curves between 1 and 2 hours per week and on interview that she walked “at a very fast” pace with a friend every day for an hour a day

for a year. The discrepancy was explained by timing of an episode of bronchitis. The episode disrupted her participation during the 6 months prior to the screening, but a pattern of regular LTPA had been re-established for a sufficient duration by time the questionnaires were administered. This issue was resolved on reviewing the transcripts.

Table 6.4 Phase of Participation in LTPA Categorized using the Emergent Theoretical Framework applied to the Interview Data.

Id#	Pseudonym	Current Phase
1	Liz	Mature
2	Jackie	Integrated
3	Ceci	Intermediate
4	Isabella	Mature
5	Pete	(Uncommitted)
6	Kaluha	Uncommitted (past experience as a beginner)
8	Sarah	Mature
9	Sheena	Uncommitted
10	Alicia	Uncommitted
11	RoseMarie	Beginner
12	Meme	Beginner
13	Kayla	Mature
14	Laura	Mature
15	Penny	Uncommitted
16	Kathy	Mature
17	Minnie	Beginner
18	Allie	Uncommitted (past experience as intermediate)
19	Maya	Integrated
20	Irene	Uncommitted
21	Liza	Uncommitted

Pete had classified herself as regularly active and described her daily exercise as a three block walk to and from a coffee shop where she visited with friends. However, she indicated that this activity, in fact, was quite irregular, because it depended on how she was feeling and lately (most days in the past 6 months) she had not been feeling well. She had difficulty recalling how many times she had done this in the past 2 weeks.

6.3.2 Uncommitted Phase

This phase involves, at best, intermittent participation in LTPA with many missed sessions and long lapses. For women with fibromyalgia, completing a single session may be, in itself, a significant event. However, a single session is the smallest functional unit of process and must be repeated hundreds and thousands of times to become a pattern of regular participation in LTPA. A variety of factors are at play in this phase which interrupt the accumulation of sessions needed to establish a pattern of regular participation in LTPA. Study participants in this phase exhibited the following factors: absence of goals, inconsistencies in level of intent, absent or ineffective strategies, and overwhelming barriers (e.g., symptoms, life events and time issues). Participants in the uncommitted phase were Allie (sated goals, wavering intention), Kaluha (external motivation, severe pain, ineffective strategies), Penny (unresolved injury from walking on a treadmill), Irene (time constraints), and Sheena (very physical occupation, time constraints). Allie's level of participation was sporadic:

> Allie: Like I get into these little, "okay, I have to do this" and I do it, until I lose interest. (laughing)
> Researcher: And how long would that take?
> Allie: Oh it depends how determined I am. It might be a week; it might be a month …

Kaluha talked about plans to engage in LTPA but did not follow through. Penny, Irene, and Sheena stated that they wanted to be more regular; nevertheless, their participation in LTPA was infrequent and sporadic.

6.3.3 Beginner Phase

This phase consists of an unbroken series of regular LTPA sessions up to, but not crossing a naturally occurring boundary (e.g., end of a season or time limited program). As each new session is approached, participants in the beginner phase carry the outcomes and strategies developed in the previous session(s); these combine and interact with the other influential factors (goals, barriers, facilitators) to support or detract from intent in the new session. For the individuals with fibromyalgia, the fluctuating symptoms of fibromyalgia are always an important factor influencing the initiation and execution of each successive session. Depending on the interaction of all five influential factors, the individual will undertake and complete the new session, and the next, and so on.

In the early experience of LTPA, learning the technical aspects of the LTPA becomes an important challenge, which if not attended to, may result in injury that may completely curtail the process. Even with supervision, some participants experienced injury (e.g., RoseMarie, Penny, Ceci, and Sarah). Most injuries were transient, but for some injuries became quite incapacitating (Penny). The injuries described by the participants were: a foot injury (Ceci – exercise machine at Curves), plantar fasciitis (Penny - treadmill at physio), a back injury (Sarah – shoulder press machine at Curves, RoseMarie - weight lifting at a rehab center), a painful hip (Meme - exercise bicycle in her home), a cervical spine injury (Allie – during yoga class), and a shoulder injury (Isabella - Swimming). As Ceci pointed out, “I was thinking of quitting then because I

kept thinking it was going to go and on and on, you know? They corrected my technique kind of thing. I was a little worried that I wasn't going to be able to do keep up with it."

Although at present Kaluha is at the uncommitted phase, she provides excellent retrospective data for the beginner phase. She had completed one naturally occurring unit (a 12 week program) but had been unsuccessful in moving beyond this stage. Prior to this experience, Kaluha had never been involved in regular LTPA as an adult. In this instance though, Kaluha had participated faithfully in exercise as a participant in a 3 month study achieving very positive outcomes (e.g., increased energy, increased physical function, weight loss, increased self-esteem). Nevertheless, she had stopped all LTPA abruptly at the conclusion of the 12 weeks. The following factors seemed to be important in her discontinuation of LTPA: severe pain (barrier), reliance on external motivation (insufficient intent), difficulty at the planning phase, and ineffective strategies (maybe tomorrow).

Minnie was another participant who had reached the threshold of the intermediate phase, at the time of the interview. Minnie, like Kaluha had little or no prior exposure as an adult to regular LTPA. She was just completing an unbroken series of aquacise sessions (attending the "Women at Large" group at the Y). Minnie, unlike Kaluha, seemed to be internally motivated and had recruited exercise partners. At the time of the interview, she did not rate her pain as high as Kaluha did (i.e., Minnie rated her pain as 3.6 compared to Kaluha who rated her pain as 9.7 on the 10 cm. visual analogue scale, see Table 4.3). These factors give us some confidence that perhaps Minnie will move on to the intermediate phase.

6.3.4 Intermediate Phase

Individuals who were able to amass an unbroken series of sessions and who were able also to successfully meet the challenges at the naturally occurring boundaries of the first series of sessions (i.e., change of season, end of program) moved on to the next phase – the intermediate phase. This concept in the framework focuses on the previous influential factors, but now also includes challenges posed by: a) end of program and/or change of season (e.g., getting the bicycle down from the rafters), and b) the impact of outcomes to LTPA performed across weeks and months (e.g., especially any accumulating negative effects). Ceci exemplifies individuals at this stage. She had just completed a one year contract at Curves). She had overcome two seasonal challenges – the challenge of maintaining regular LTPA in the month of January because she always felt depressed during that month, and maintaining regular LTPA during the summer months because her family always went to a lake. She was quite pleased that this past year; since joining Curves, she had been successful in meeting these seasonal challenges stating, "It (Curves) sort of got me into an exercise habit." Despite her regular participation over the previous year, Ceci was uncertain about her future participation; a major facilitator – financial commitment associated with annual dues was no longer applicable as an incentive because clients of Curves at this point are billed on a month-by-month basis.

6.3.5 Mature Phase

This phase consists of an unbroken series of regular leisure time physical activity sessions that includes several naturally occurring units (e.g., seasons, years). Two considerations seemed to characterize the individuals at this stage. Participants at this

phase, Sarah, Kathy, Laura, and Kayla, demonstrated a high level of determination, effective and resilient strategies, concentration on positive outcomes, comfort with a range of LTPA activities, and in most cases a strong social network and an affinity for physical activity. The tenor of the interviews of participants at this phase was captured in this excerpt from Sarah's interview:

> Research: Do you have any fear of "dwindling out" or sort of just getting out of the routine altogether?
> Sarah: No. No, I don't. And you're talking about exercise, activity? No. That's never going to happen to me. I think I'm a positive person. I've had a lot of barriers and struggles in my life and this is just one of them but I've learned to accommodate. I may not go gung-ho in what other people view as exercise but I continue to be active. Maybe when I'm a senior citizen and I can't get around anymore, that's what's going to stop me but I don't see that happening before. I don't. I just set my mind. I am stubborn.

The influencing factors still operate at this phase but as noted by Sarah, individuals at this phase have acquired experience, skills, and strategies that help them deal with the barriers challenges that present themselves; nevertheless, participants can succumb to these challenges. Alicia had been at this phase having participated in a walking class at the community center for four years, but negative outcomes to LTPA were becoming more pronounced over time. At the time of the interview, she had discontinued LTPA and was searching for an appropriate type of LTPA. Technically speaking, she had returned to the uncommitted phase.

6.3.6 Integrating LTPA into Daily Life

This is the final phase of the process. In this phase, LTPA has been integrated into one's lifestyle to the degree that it is no longer considered to be special or separate. Maya and Jackie appeared to be in this phase. Both exhibit the greatest marker of success; Jackie forgot to mention that in addition to walking daily, she used the exercise

bicycle three times per week because she didn't consider it significant and Maya didn't remember to mention that she walked regularly (i.e., at least four times a week) because they considered this to be everyday living. In Maya's words, "I don't even classify my walking three times a week as exercise; it's just part of my every day."

6.4 Lapses

Individuals can discontinue the process (i.e., lapse) at any point within a session, or within phases. Sometimes there was a conscious decision to stop as with Minnie, "If the water gets much colder at the Y, I will be quitting." However, more commonly there was no clear decision to discontinue, but rather a *dwindling out* as described by Isabella, Allie, Liza, and Kayla. For example, Isabella stated, "I tried going swimming, and I found that the water was quite cool at the pool and I was worse, much worse in the cold water so eventually I dwindled away at it until I quit."

Lapses occur when intent is eroded by barriers and negative outcomes, or when goals are revised or achieved. There were instances of participants who quit because they were in too much pain (RoseMarie, Liza) or too "depressed" (Pete) and conversely because they were so much better that they did think they needed to continue (RoseMarie, Allie, Isabella). There were examples of participants who quit because the structure of the program they relied on collapsed or an instructor moved away (Laura). Kathy failed to make the transition from a supervised group program to unsupervised LTPA at home.

Frequently lapses occurred several months into the program when expectations were not met. Minnie and Sarah had hoped that they would "shed some weight, but it didn't work" (Sarah). Kathy expressed her disappointment more strongly, "I kept hoping

that it would strengthen my muscles but it didn't seem to, I don't know, they always tell you to do exercises to strengthen your muscles but I was really disappointed that it didn't strengthen them like I thought it would." Penny was close to tears as she described her disappointment in the results of her attempts at LTPA (aerobics, walking, strengthening exercise). She had hoped that LTPA would help her, but, in fact, it had caused her pain and injury. Alicia, Penny, and Kayla had believed that LTPA would improve their fibromyalgia, but they came to the conclusion that the activities they were engaging in (walking, aquacise, and soccer respectively) "seemed to make it worse" (Penny). Alicia had demonstrated great persistence – attending walking classes at a community center faithfully for four years. She stated, "I kept hoping it was going to get better. That I would feel better. I know we have to have a certain amount of exercise but it didn't work that way. I never did feel any better." At the time of the interview, Alicia was checking out a videotape of aerobic exercises for use in her home, but a lapse of over six months had occurred since discontinuing her pattern of regular walking. Kayla, had discontinued soccer and the exercises she had been doing, but she continued to engage in regular walking, and Penny categorized herself as "completely inactive."

The duration of lapses varied from a few days to several months or years. Kayla talked about missing a day, Liza a few weeks, Penny a year, and Kaluha simply stopped and didn't have plans to restart.

6.5 The Five Determining Concepts

6.5.1 Goals

Goals have previously been discussed. The value placed on goals, and the level of commitment and desperation related to them influence the strength of intent. Although

goals are fundamental to forming of intent, goals were relevant at all stages of the process. For example, Laura who had a goal of weight loss used the indicators on her exercise bike to watch the number of calories she was burning. Meme whose goal for participation in LTPA was "finding miracles" was focused on this as she walked. In these two cases, goals were used to assist with the *doing it* phase.

6.5.2 Strategies and plans

The participants described over 40 strategies to help overcome the barriers to participation in regular LTPA. These were organized into ten categories (see Table 6.5). No attempt has been made in this study to rate the effectiveness of the strategies or to match the strategies to various stages, phases, or barriers.

Table 6.5 Strategies described by the Participants to Enable Regular Participation in LTPA Grouped into Ten Categories.

1. Strategies dealing with time o Using schedules o Developing routines o Building it in o Watching the clock tick down
2. Social strategies o Finding partners o Using pets o Joining groups
3. Strategies dealing with goals o Finding a purpose o Goal setting, meeting challenges o Starting small (*a little is better than nothing*)
4. Cognitive strategies (mind over matter) o Distraction o Ignoring pain (*don't think about it*) o Focusing, putting my mind to it o Using a mantra (*this too shall pass*) o Using affirmations
5. Strategies involving novelty o Trying everything o Incorporating variety

6. Attending to needs o Listening to your body (*mindful of limits*) o Getting enough sleep (*resting when needed*) o At your own pace o Putting me first o Finding an ideal format o Finding an ideal intensity, duration o Finding an ideal time of day o Taking a cell phone for personal safety
7. Focusing on positives o Feeding on positive energy o Thinking positive, focusing on positives o Using humor, surprise, miracles o Having fun o Using treats, rewards o Attending to positive outcomes
8. Self-Management o Pacing o Taking one day at a time o Building piece by piece o Fighting it, not giving up
9. Commitment o Vocalizing the plan o Financial commitment o Setting rules for self (*no excuses, no debates*) o Deciding
10. Strategies dealing with control of symptoms o Preparing muscle / body o Using massage o Using heat and ice o Using medications

The participants who were more skilled in self regulation: a) controlled their mood (stayed positive), b) controlled their schedules (use of routines, scheduling strategies), c) maintained focus on distant future goals stronger (purpose oriented), d) controlled their inner dialogue ("I took the decision out of it", "get off your butt"), and seemed to be more successful in moving through the phases to become mature in their ongoing participation in regular physical activity. Nevertheless, even strong self regulation skills were seen to break down in the presence of pain.

6.5.3 Barriers

There were several categories of barriers at work across the stages and phases of the process. Some barriers impeded at many stages/phases of the process; others seemed to affect only one stage/phase of the process. Of all the categories of barriers, the most common and most pervasive appeared to be fibromyalgia symptoms, time issues, and physical environment.

a) Fibromyalgia symptoms and impacts (barrier)

While interviewing the participants, the heterogeneity of this condition among individuals was observed. The pre-eminent symptoms were pain, fatigue, disturbed sleep, stiffness, and depression. With the exception of stiffness, all of these symptoms were cited numerous times as barriers to LTPA. Invariably, the experience of stiffness was a stimulus for keeping active sometimes in the form of exercise but also in the form of postural shifts and stretching. (Note. Stiffness is discussed in the next section as a facilitator.) Because fibromyalgia symptoms were such potent barriers to LTPA, several examples from the interviews are provided in the next few pages.

Pain. Fibromyalgia is a condition of chronic pain; therefore it is not surprising that all participants reported having pain except Isabella, who described herself as having recovered from fibromyalgia. Laura made a point of emphasizing that although she had pain, her pain was not drastic or limiting; her chief problem was fatigue. When requested to do so, the participants provided detailed and frequently graphic descriptions of pain.

Three special types of pain were described: headaches, trigger points[a], and burning pain. Pain as a barrier affected chiefly the deciding, the planning and preparing, the starting, and the doing stages within a session. It was influential enough to cause disruptions and lapses in the larger process at all three phases including the mature phase.

Pain as a barrier to stages in the Session-specific level:

> *Deciding:* "When I get my headaches back, my muscles just ache all over, (text omitted) I can't go out there and walk and I cannot join my friends for anything." (RoseMarie)
>
> *Planning and preparing:* "When I started having pain this summer, I knew that I had to back up." (Sarah)
>
> *Starting:* "But I also find that if I can work through the - the initial soreness and over-achiness then I feel – I feel better …" (Maya)
>
> *Doing:* "And yeah, it was painful, I'll tell you, (that's the truth). … I have suffered." (Penny)

Pain as a barrier to phases in the Pattern-specific level:

> *Beginner Phase:* "After that well, I kind of got - this was over, I'd done the 12 weeks and everything. I kind of got back in the old behaviour where I wanted to keep going but I didn't for the reason that that pain started to settle in again, quite intensely." (Kaluha)
>
> *Intermediate Phase:* "Now I'm having to cope with more pain and trying to start over from scratch again." (Liz)
>
> *Mature Phase:* Kathy discontinued walking after 4 years because pain on walking seemed to be getting continually worse.

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[a] This is the participant's term; it was not clear if the participant was using the term according to the accepted medical definitions. The medical literature uses the term "tender points" for the pain observed at specified locations in the body on tactile pressure in fibromyalgia [3] and differentiates between tender points from trigger points. Pressure on a trigger points produces pain in a typical referral pattern. Tender points of fibromyalgia do not connote referral of pain[181]

Fatigue. Fatigue was an important barrier to LTPA and, indeed, to other forms of physical activity, too. Liz, Meme, and Kayla described the profound impact of fatigue. Meme reported: "My body seems to shut down. (text omitted) for the first two years, I couldn't get off the couch, I didn't have the energy to even go see a doctor. I had no energy - period." The effects of fatigue seemed to be very significant at the decision stage. Isabella's perspective as having "recovered" from fibromyalgia was persuasive. She placed a high degree of emphasis on the disabling and perpetuating effect of fatigue:

> (I thought) "If I just got my act together, I could get off the couch." It wasn't until the energy came back that I realized that I needed the energy to do that. It didn't take long once I got going again, to get back in shape again. (Isabella)

Depression. Several participants identified depression (sometimes referred to as feeling down, feeling low, or being discouraged) as an important barrier to participation in LTPA. In fact two individuals had been treated for clinical depression – Allie and Pete. Maya and Pete described their experiences with depression and its impact upon LTPA as follows:

> And for me, it's not the level of pain that stops me, it's the fatigue element and probably how down I'm feeling or how low I'm feeling. (Maya)

> I had started with the aquacizes at the YW but I just got to the point where I had a case of depression and I just couldn't do that either, so I gave up. (Pete)

Combination and interaction of fibromyalgia symptoms. The participants commented on the interaction of the symptoms – describing how pain seemed to be magnified in the presence of either fatigue or depression or both. The increased severity of a number of symptoms simultaneously which was sometimes referred to as a bad day

or a flare-up, often led to the participant going to bed and certainly acted as a barrier to undertaking LTPA. Meme described her experience as follows:

> If I was to describe it, it is just a continuous intense ache. My whole body feels extremely heavy. It feels like there is a storm inside my body. I feel edgy, caged in, not in full focus. My energy level is non-existent. I'm so tired. I cannot sit in a chair. I must lie down and close my eyes. If I need to get up, I test my legs to make sure I won't fall. (Meme)

Fibro Fog. One participant attributed difficulty starting and performing LTPA to "fibro fog." Fibro fog is a term used in some of the popular literature on fibromyalgia describing a condition of mild cognitive dysfunction associated with fibromyalgia which includes forgetfulness, difficulty with word finding, and difficulty concentrating. Sheena described fibro fog as follows:

> Sometimes you have fibro fog. You feel great from the neck down, you're like, and you're body's like, "okay, hey, oooh!" (Participant thumps on the table with her hands.) It's like your cells are talking to each other, "Let's go exercise!" And in your head, you are somewhere else. And so I mean it doesn't - a lot of times there isn't that balance. (Sheena)

Sheena was the only participant to use the term fibro fog. It is not clear if the others had heard of this phenomenon, but it is possible that others had experienced a similar phenomenon because they (e.g., RoseMarie, Meme, Laura, Jackie, Maya) talked about a body-mind mismatch; however no one else identified the state as a barrier to LTPA so clearly as Sheena had. Sheena indicated that for her this was the most significant fibromyalgia-related barrier to physical activity; it affected both the beginning of a session and the maintaining of an adequate level of intensity within the session.

Other fibromyalgia symptoms. Although participants identified other fibromyalgia symptoms (e.g., disturbed sleep, nausea), they did refer to them as direct barriers to LTPA.

b) Negative Attitudes (beliefs, feelings, and actions) (Barrier)

If we define the concept, attitude, as a manner of thinking, feeling, or acting that shows one's disposition, expressions of a negative attitude would include: a) voicing negative affirmations about LTPA, or voicing pessimism and hopelessness about the LTPA or the future in general, b) describing a feeling of dislike or repulsion for LTPA, and c) unwillingness to seek solutions, to try new approaches, to discard or modify ineffective approaches, or to participate in other health behaviours (e.g., healthy diet).

A few subtle comments conveyed a mildly negative attitude in terms of thinking; Laura characterized working out at the gym with her daughter as, "we did the fitness thing," and Ceci seemed to suggest that at one time she had regarded LTPA as self-indulgent play. Nevertheless, most participants voiced strongly positive affirmations about physical activity. These affirmations were not always in alignment with their behaviours suggesting dissonance among the beliefs and behaviours. A few participants stated that they really weren't sure if LTPA was good for them as it might make their fibromyalgia worse; nevertheless most participants had very positive beliefs about LTPA and its general health benefits. A few participants, who had stated that they believed LTPA was good, concurrently expressed negative feelings about LTPA and unwillingness to act on the positive beliefs. Allie, for one, stated emphatically that she believed that LTPA was good and beneficial in many important ways for fibromyalgia and for health in general, yet she also stated emphatically that she did not like LTPA and that she did not want to do any.

> My personal attitude is I don't care! (laughing) I don't want to do it. (laughing) I don't have to do it. I don't care. And that's it. (laughing) I know I should. I know that it would beneficial, I know all that, but I don't want to. (Allie)

Two other participants expressed a negative attitude toward LTPA in the domain of feeling (feeling of dislike or aversion for LTPA). Laura described pedaling on her exercise bike as fast as possible, so she could finish as soon as possible because it is “no fun at all” and Kaluha stated, “I really don't like exercise.”

It is not surprising that two characteristics, laziness and procrastination, arose to impede regular participation in LTPA. Allie, Kaluha, Kathy, Kayla, and Liz used the term “lazy” to explain nonparticipation or occasional lapses in their routine of LTPA. Kayla, Minnie, Ceci, and Kaluha spoke of procrastination using the terms such as “I'll go tomorrow" (Kayla), “I’ll have to one of these days” (Minnie), “not really, really getting down to it period” (Ceci) and “maybe tomorrow will be much better and I could go tomorrow" (Kaluha). For Kaluha, this theme came up repeatedly in her interview.

A change in attitude was observed between the first and second interviews (note, the interviews were spaced three weeks apart). At her first interview, Liz seemed comfortable with the way things were. She was taking positive action which included regular exercise and attending information sessions, seeking out new methods, “I try everything, because there might just be some magic thing that might just work for me, that doesn’t work for somebody else.” Although, her attitude could not be described as effervescent, she was quietly positive. Three weeks later, at her second interview, Liz was in quite a different frame of mind; she was defeated and discouraged. She had been through what she termed as a “brutal” experience – a Functional Capacity Evaluation (a 5-day work-simulation assessment) at which she performed physically challenging tasks. Both Jackie and Ceci described similar reversals of attitude from the first appointment to the second, also in response to worsening in symptoms following being challenged by

physical demands associated with increased child care responsibilities (Jackie) and acquiring a puppy who was “just like having a baby (to attend to) again” (Ceci). All three were more pessimistic and had reduced their participation in regular LTPA over the three-week interval.

Other negative attitudes which impeded participation in physical activity that were expressed by the women included: “babying myself” (Kayla) and “feeling sorry for myself” (Kaluha). Fear of injury was another barrier that surfaced in the interviews (Kayla, Maya, and Minnie); it did not affect the global decision to perform LTPA, rather, it influenced decisions about specific forms of LTPA (soccer, skiing, bicycling, respectively).

c) Life events, time issues, work (Barrier)

It is not in the least unexpected that time constraints would be identified as an important barrier to participation in LTPA. Indeed many participants (Kathy, Laura, Irene, Liza, Sheena) identified the lack of time as their most important barrier, either at the present time or in the past, to participation in regular LTPA. Time constraints were associated with extensive family duties or raising young children (Ceci, Laura, Irene), working long, unexpected or irregular hours (Liza, Sheena, Isabella), or simply a busy schedule (Kathy). Despite good intentions, the realities of time as a barrier are apparent in this passage from Liza’s interview: “But I don’t want to get up at 5:00 in the morning when I work late at night. (text omitted) With my type of lifestyle, with my job, sometimes I’m working 14, 15 hours a day.” Time constraints associated with the uncontrolled demands related to social roles (especially childcare) and occupation acted

as a barrier to the accumulation of a series of sessions – so affected the phases of the process.

d) Health and Medical (Barriers)

Another barrier that emerged was the dulling effect of medications taken for mood problems or for pain. Liz described this, "And then the more drugs you take, the more you don't feel like doing anything because then, you know, you just get feeling blaah." Isabella concurred with what Liz had said in the following excerpt:

> I lived in a funny state, almost like a fog but not a real fog. It (the elavil) had taken away my edge. It had taken away my desire to improve myself and it had taken away my desire to get a better job. I was content to just mosey along the way I was. (Isabella)

Other medical conditions such as osteoarthritis (Kathy, Maya) or spondyloarthritis (Maya), old sports-related musculoskeletal injuries with imperfect results from surgical ligament reconstruction (Liza), and allergies (Laura) were identified barriers to exercise sometimes limiting the amount and or influencing the mode of LTPA.

e) Physical activity history, experience, knowledge, and skills (barrier)

The effect of limited involvement in LTPA prior to developing fibromyalgia was discussed in the previous section (Section 6.2.1 – Forming Intent). In addition to limited or negative experiences with LTPA, limited knowledge about LTPA as it relates to fibromyalgia and limited skills (e.g., ability to perform LTPA, athleticism) can also pose a barrier to LTPA.

Limited Knowledge about LTPA and Fibromyalgia. *(also see 6.2.3 –Planning and Preparing)* Fifteen of the women had been part of randomized controlled trials during which they had received fibromyalgia-specific information about LTPA both in verbal and written form. Still others had interacted with physicians and other Health

Care Professionals regarding their condition and or fibromyalgia symptoms. Nevertheless, most women denied having received any practical information on fibromyalgia and physical activity. Perhaps, timing was an issue as Jackie stated:

> I think if I would have got that right off the bat, that would have helped a lot. (text omitted) For a while what was bothering me the most at that time was my neck and my arms. And I think if I had been really encouraged into that right at the beginning for a couple of weeks, I think I would right away noticed the possibility there of improving the situation. That wasn't really stressed at all to me, you know that you should really try and get into an exercise program. I was just searching myself. (Jackie)

Despite searching for information, participants described receiving only the most limited amount of information about LTPA and fibromyalgia. Even participants who exercised regularly were unable to suggest an ideal starting level for others. When asked how much LTPA she would recommend, Meme, a regular walker, responded,

> I don't know how to answer that because that's the stage I'm at now because I am going to be doing exercises, so I don't know. I'm assuming ten minutes, 15 minutes. I know with the walking, I can do half an hour and I have no trouble but when it comes to other exercises, I don't know. But the walking, start 10 or 15 minutes a day as a goal. (text omitted) it's all trial. (Meme)

Kathy another long-term exerciser was even more uncertain in her knowledge. When she was asked what LTPA she thought would be appropriate for others with fibromyalgia, she said, "But I don't know really what to do to improve it to tell you the truth."

Limited Skill Level. Individuals with fibromyalgia may have some impairment of motor skills. The participants described many movement disorders (e.g., poor coordination, slow or limited movement) and they indicated that these self-perceived deficits affected the choice of LTPA. Other movement disorders were transient and occurred especially on arising in the morning (poor balance, buckling of the knees on

getting out of bed) or when the fibromyalgia was “flare-up” (inability to dissociate the movements of the pelvis and hips). Several participants described and were observed by the researcher using altered movement patterns for getting up out of a chair and reaching the hand forward and up (i.e., glenohumeral joint flexion).

f) Social (norms, role models, roles, support, perspectives) (barrier)

Social factors other than those described under time constraints did not seem to pose a serious barrier to participation in LTPA. Only three individuals identified social factors as barriers to regular participation in LTPA. Minnie commented that she had avoided joining programs because facing unknown situations daunted her and she didn’t like going alone. Kaluha identified the lack of an appropriate exercise partner as a barrier to regular LTPA and Allie stated that she had insufficient motivation to exercise at home. Except for a few participants, spouses rarely were consistent exercise partners. When this was discussed it seemed to be due to inadequate motivation of spouse and participant (Allie), differences in physical fitness levels (Kaluha), or differing preferred activities (Jackie, Alicia). While most spouses appeared to be quietly supportive of the participant’s involvement in physical activity, a few spouses may have been overly solicitous or protective (Kathy, Liz), angry or disappointed in the lack of participation in activities such as boating or snowmobiling (Jackie), and in one instance as evaluated by the researcher, devaluing of the participant’s efforts (Penny). The latter was based on Penny’s comment: “My husband said, ‘you’d better quit fooling around in the water because it doesn’t seem to be doing you any good.’ ”

g) Personality (barrier)

Except where individuals revealed a preference for sedentary activities over physically active recreation (e.g., Allie, Laura), it is difficult to speculate whether personality acted as a barrier to deciding to undertake or to continue LTPA. One woman, Kaluha admitted she had a defiant disposition stating that if she were told to do something, she would do the opposite. During the course of her interviews, she described two instances of this. The first was when she believed her husband did not think she was capable of exercising, and the other was when her mother suggested she should exercise. In the first instance she drove herself hard to succeed at a 3-month program of LTPA, and in the second, she refused to undertake even leisurely walking. Thus, this disposition would sometimes operate as a barrier, and at other times, as a facilitator.

Two individuals stated that they found the perspiration and dishevelment associated with moderate or vigorous physical activity distasteful. Ceci attributed this to liking things to be in control coupled with a tendency toward perfectionism. She stated, “I kind of avoided it. And I don't like sweating! (laughing).”

h) Other Barriers (Environmental, facilities, programming)

A variety of environmental factors were identified as barriers to LTPA, however, most environmental barriers that the participants identified were limited to specific activities. For example, participants identified several barriers to walking outdoors (a popular choice of LTPA). These included: icy conditions, darkness (feeling unsafe walking alone), allergens (molds), cold weather, windy conditions, hot weather, and walking surface (cement, rough terrain). Although cold weather was described by several

participants as a barrier, others were not deterred by the cold; Kayla, Meme, RoseMarie, Maya, and Liza described "bundling up" and walking even on the coldest days.

Facilities did not seem to be a major barrier overall but three participants described the cold water at the pools as a barrier to their participation in aquatic activities. Isabella, who described herself as a "water person" remarked:

> I tried going swimming, and I found that the water was quite cool at the pool and I was worse, much worse in the cold water so eventually I dwindled away at it until I quit. (Isabella)

The loss of continuity of programs due to unavailability of instructors was identified as a barrier to participation for two participants (Alicia – TaiChi instructor quit, Allie – yoga instructor moved away); however Allie stated that if she had really wanted to continue with yoga, she could have driven in to the city. Three participants (RoseMarie, Meme, and Allie) did not live in the city, but were close enough that they were able to access programs and facilities if they wished. One rural participant (RoseMarie) did comment on the additional costs of transportation as a deterrent.

6.5.4 <u>Facilitators</u>

a) Fibromyalgia symptoms and impacts (facilitator)

Although strictly speaking, no symptoms acted to facilitate physical activity, reduction of pain and stiffness were among the strongest goals of pursuing physical activity. These symptoms (i.e., pain and stiffness) could be said to facilitate participation in regular physical activity only in that they continually drew the participants' attention to the need for physical activity. There were numerous references to the need to keep moving to reduce stiffness. The majority of participants adopted active living habits (park and walk, using stair rather than elevators, breaking up periods of immobility with

physical activity), however this was not universal. Several participants (Jackie, Ceci, Pete, Kaluha, Sarah, Maya, Alicia, Kathy) described the need to keep moving to avoid mounting stiffness, which they associated with being physically inactive. Jackie was especially intolerant of inactivity; she described standing to eat despite requests from her children "will you please sit down" Her high level of daily energy expenditure relative to the others (see Table 4.3) corroborates this pattern of continuous physical activity.

b) Positive Attitudes (beliefs, feelings, and actions) (facilitator)

Numerous examples of the concept *positive* were found; these were categorized using the three domains of attitude: *thinking* (positive affirmations about LTPA and expressions of optimism and hopefulness about the future), *feeling*, and *acting* (actively seeking solutions, trying, and performing healthy behaviours). The *feeling* category included expressions of affinity for LTPA (see Section 6.2.1 – Forming Intent).

Thinking. Among the many affirmations expressing the belief that regular participation in LTPA is good were: "exercise is a good thing" (Laura, Kathy, Minnie, Kaluha, Allie), "exercise is a must for the rest of my life" (Sarah, Jackie), "exercise is good for everyone" (RoseMarie, Minnie, Sheena), "exercise is a part of a healthy lifestyle" (Sarah, Penny, Kaluha), and spoken with great energy "PHYSICAL ACTIVITY HELPS!" (Liza). Other nodes that provide evidence for this concept as important were: I have to, walking is my salvation, I know deep down (benefit), (it's) something wholesome, a little is better than nothing, use it or lose it, walking just part of living. trying - I would-will do anything, and so hepped up (about exercise).

Among those who expressed hopefulness and optimism were Sarah, Meme, Kayla, and Maya. They described themselves as: being a positive person (Sarah), having

a positive attitude (Kayla, Meme), and focusing on the positive (Maya). Sarah's comment is typical of these four participants, "I think I'm a positive person. I've had a lot of barriers and struggles in my life and this is just one of them but I've learned to accommodate."

Feelings. Many participants spoke of their feelings about LTPA in positive terms. Maya, Meme, RoseMarie, and Liza were the most enthusiastic, using the expression "Love it!" to describe their feelings about participation in physical activity (also see Section 6.2.1 c).

Actions. The third component of attitudes is the area of actions (behaviours). Many behaviours of varying magnitude and frequency have been documented in this report. Many participants noted that their capacity for action varied from time to time and from situation to situation. They also noted that sometimes, doing even a little could be a substantial challenge particularly when one is experiencing pain and other symptoms of fibromyalgia. Several women recognized this saying: a little is better than nothing.

c) Life events, time issues, work (facilitator)

More often than not this category is a barrier, but instances of falling away of role-related activity, work or other time consuming responsibilities and instances of opportunity served as facilitators. One woman, Penny, reported that as a result of moving to a new residence, she consequently changed her work; her new job was part time which allowed her to increase her LTPA. In Alicia's case, we have an example of how changing roles facilitated LTPA. During the interview, it became clear that Alicia, a woman with a long history of fibromyalgia, had begun participating in a number of different physical activities at a specific point in time about 15 years ago. She attributed

this change in her pattern of participation in LTPA to her children growing up. She said, “I didn't have to run to hockey games with the children. I had more time and I started doing things more for me.”

The concept of a *window of opportunity* arose in a few interviews. Ceci’s initiation of LTPA was facilitated by the surge of excitement within her family to embark together in LTPA stimulated by a release of coupons in the free weekly newspaper. Isabella described her experience in relation to taking charge of her condition and simultaneously adopting several new health behaviours (e.g., diet, Reiki, and physical activity), invoking the concept of a window of opportunity. She said, “It was like a window opening and it would have closed real quick (laughing) had I not found that book that day. That's another thing. Everything came together.”

Another participant, Sarah, described how the location of her work facilitated LTPA participation. She worked in an office located in a large mall and was able to use her breaks and noon hour to walk in the mall.

d) Health and medical (facilitator)

There were only a few references to health or medical conditions as a facilitator. RoseMarie observed that since losing weight, it was easier to exercise, and Isabella stated that it was so much easier now that she is feeling well. Several women described the sense of energy and freedom they experienced on a good day, however at such times they talked of exceeding their limits and overdoing it. However, usually the spurt of increased energy was not spent pursuing LTPA, but rather in catching up on household chores.

e) Physical activity history, experience, knowledge and skills (facilitator)

Many participants, who had a strong orientation towards LTPA established in childhood (parental role models, pleasurable experiences during childhood) and maintained this in young adulthood, formed a strong intent, not only to initiate participation in LTPA, but also to continue it when afflicted with fibromyalgia and other health problems. As indicated above (Section 6.2.1 c – Forming Intent - Affinity for LTPA, and Table 6.2) LTPA participation patterns prior to developing fibromyalgia seem to contribute to the level of intent to participate after developing fibromyalgia. Some participants (Maya, Liza, Kayla, Alicia) had given up or reduced involvement in some sports (downhill skiing, soccer, curling, golf, dancing, skating) that they had loved for health reasons (fibromyalgia, arthritis). However, it seemed that for several women, the pattern and love of LTPA was so strong that they had sought out and maintained another form of LTPA. As stated by Sarah, "or if that doesn't work for me, okay I'm just going to try something else. I mean it may not be the typical exercise that people think about as exercise, but."

There was one instance in which knowledge about fibromyalgia served as a facilitator. Maya, a physical therapist, stated her knowledge about the nature of fibromyalgia served to reduce her fear of participating in LTPA. She said:

> I really liked once when I read that fibromyalgia was a pain dysfunction because, what it did was it eased my mind. It made me think, 'okay, my body's telling me that I have pain but maybe I don't really have pain, it's just that my body is teasing me.' (Maya)

Regarding prerequisite skills and ability, most participants were confident that they had the skill to participate in some form of LTPA, even though they could not perform all types of LTPA.

f) Social (norms, role models, roles, support, perspectives) (facilitator)

There were numerous passages dealing with how social factors facilitated participation in LTPA in these women with fibromyalgia. This category was very extensive, with contribution from 30 nodes.

Spousal Categories: Major categories related to spousal role as a facilitator were: (a) spousal support with symptoms and disability of fibromyalgia, (b) spousal support for regular participation in LTPA, and (c) spousal participation with the participant in LTPA. Many examples of spousal support with the physical effects of fibromyalgia were found and included: getting ice (Kayla), observing distress/suggesting rest or time off (Penny, Sarah, Meme), finding information (Ceci), installing jet tub (Kaluha), talking (Jackie, Meme, Maya), accepting (Allie, Kathy, Kayla, Alicia), suggesting a reduction in occupation-related physical demands (Minnie), helping with children (Kayla, Maya), helping with carrying and lifting (Kaluha), helping with the household chores and cooking (Liz, Sarah, Kayla), encouraging (Allie, Maya), and motivating (Sarah). As might be expected, among those who were cohabiting with a spouse, there was a wide range in level and type of support for regular participation in LTPA including: imposing guilt for nonparticipation in shared recreation (Jackie), suggesting increased participation (Kathy, Meme, Allie), supportive in some ways/times and not in other ways/times (Ceci, Laura), supportive but not pushy (Sarah, Liz, Kayla, Kathy, Alicia), purchasing exercise equipment or paying fees (Laura, Kathy), and helping adjust exercise equipment (Minnie). At the time of the interviews, spousal participation as an exercise partner varied from: regular (Maya, Kathy), intermittent (Penny, Minnie), rarely or never (Laura,

Kaluha). When asked about exercise partners, the other married participants failed to mention spousal involvement as an exercise partner except during holidays (Liz).

Support and encouragement (from friends and family including adult children): A strong social network seemed to result in better adjustment to the condition and in improved self management including participation in LTPA. Many forms of support and encouragement that the women had found helpful in planning, instituting, or maintaining regular participation in LTPA were described. These included: a friendly word (RoseMarie), warmth and caring from yoga group members (Allie), practical advice (Meme, Kayla, Jackie), inspirational support (Maya, Isabella), role model and mentoring (Ceci, Meme, Liz), and a gift of exercise equipment (Laura).

g) Personality (facilitator)

Being competitive, being stoical, being positive and upbeat, being energetic, liking a challenge, being a "physical person," being an "independent" person, characterizing self as "not a quitter" and having self-esteem, all seemed to be associated with participation in LTPA. For example, Kaluha observed, "I guess I just want to prove to myself that I can do the limit. I can do the requirements that's asked of me." However, Kaluha who was externally motivated was not able to use this characteristic outside of structured settings.

h) Other Facilitators (e.g., fate, cosmic forces) (facilitator)

Allie spoke of the convergence of desperation (felt she had to do something), interest (thinking she would like to do yoga), and opportunity (television announcement about yoga class starting in her community) as cosmic.

6.5.5 Outcomes

The topic of outcomes often arose spontaneously, but the interview guide included open-ended probes regarding the outcomes, so all participants were asked to comment on both the benefits and adverse effects of LTPA as observed in either the past or present. Thirteen participants believed LTPA helped their fibromyalgia, four didn't notice any change in it, and three thought LTPA had made their fibromyalgia worse. Regarding the major symptoms of fibromyalgia:

- Six participants believed LTPA improved their pain, but twelve believed it made it worse (although not always)
- Eight participants believed that participation in LTPA had improved their energy, but eight believed it made them feel tired or exhausted
- Six participants believed it improved their sleep; one thought it occasionally made it worse
- Eight participants believed LTPA improved their stiffness; no one commented on increased stiffness
- A variety of improvements in physical function were attributed to LTPA: improved muscle strength (6), increased flexibility (3), improved balance (2), and improved mobility (2), compared to one participant who had observed deterioration of physical performance despite regular long term participation in LTPA
- Many psychological benefits were attributed to participation in LTPA: improved self-esteem (7), feeling relaxed and less stressed (5), and improved mood (4); compared to one participant who felt discouraged and panicky when she did not notice any improvement

Fourteen participants had incurred injuries during participation in LTPA – some were minor and brief, but others were more disabling and protracted lasting several months. Allie described an injury when doing yoga that was resolved in a week or two: "I was doing a pose, and wow, I pulled, I suppose a tendon -- trying to keep up with a lot

younger people" (Allie), whereas the injury that Penny incurred over a year ago has not yet resolved:

> I don't know if that was the cause of it or not but my foot started bothering me just shortly after I started doing the treadmill. ... Like my foot just bothered me so much, I couldn't walk. I couldn't step on it. I couldn't get out of bed. ...the doctor sent me to a podiatrist and the podiatrist diagnosed plantar fasciitis. (Penny)

The important positive and negative outcomes are summarized in Tables 6.6 and Table 6.7. (Note., Care is advised in interpreting these outcomes – the outcomes were varied in intensity and duration, and were attributed to LTPA, which was also of variable intensity and duration. Some of the outcomes were inconsistent – the participant might have pain following an activity one day and not pain on another. As Pete said of feeling better following participation in LTPA, "sometimes I did and sometimes I didn't.")

Table 6.6 Positive Outcomes Attributed to Participation in LTPA by the Participants.

Positive Outcomes (number of participants who cited the benefit)	**Example**
1. Fibromyalgia - Feel Better (13)	I think I'm better because of what I do, I really do. (Sarah)
2. Social Benefits (10)	I liked the people that were in there and you know, they were all about the same as me. (Minnie)
3. Enjoyment, Play, Sensuous Joys, Fresh Air (8)	Some of my most joyous walks are in the winter when the Northern lights are dancing. I just have loved that. (Maya)
4. Stiffness – Reduce or Avoid (8)	The aquasize at the Y helped so much because it undid all the stiffness. (Isabella)
5. Belief in improved health - Physical, Preventive (Heart Disease, Osteoporosis) (8)	You get your heart rate up so you get some arteries unclogged maybe that might clog up (Minnie)
6. Energy – Increased, rested, energized (8)	I'd get up in the morning and I could go ahead and do some things that I wasn't be able to do other days ... I had more energy, yes. (Alicia).
7. Psychological - Self-esteem, Sense of accomplishment (7)	I hurt but I felt good about being there and trying to do something (Sarah)
8. Muscle Function - Improved Strength, Less tense/cramps (7)	I don't know if the leg strength has increased or what's happening but I find that I can usually do ten now without too much of a problem. (Laura)
9. Sleep Better (6)	It also benefits your sleep. (Ceci)
10. Physical Function - Balance, ROM, Mobility, Briskness (6)	I learned some body control ... I don't understand it but it (Tai Chi) does seem to help. (Alicia)
11. Pain - Reduced (6)	Otherwise my legs would have hurt, aching way too much from sitting at a desk all day. So it definitely in my opinion it’s a life saver, exercise. (Jackie)
12. Health - Mental, Spiritual, Healing, Wholeness (5)	I find the fitness helps me, um get more grounded and just be more myself. (Maya)
13. Psychological - Relieve Stress, Relaxing (5)	And to me it's a good stress release too. (Kayla)
14. Psychological - Maintain Mood, Boost Mood (4)	then when I lifted weights, then I found that there was a little bit of mood boost. (Laura)

15. Psychological - Distraction from Pain (4)	keeping your mind active too with the dancing, that really helps me. (Kathy)
16. Productivity, Able to continue working (4)	I'm a healthier person; you don't miss work as much. (Liza)
17. Flexibility - Increased (3)	After 15 years - Well maybe the flexibility was a little better (Laura)
18. Improved Appearance, Weight Loss (2)	I wanted to be a little thinner. So I walked the month of January and I probably did lose 7 or 8 pounds prior to joining. (RoseMarie)
19. Health - Improvements in Varicosities, Fluid Retention (2)	I try to stay in the water because the hydrostatic tension does help my varicosities, so that's a good thing, (Maya)
20. Fibromyalgia – prevent deterioration (1)	This winter I think I will do something besides that too, because I think I don't ever want to hit that low again if I can possibly help it. (Jackie)

Note. The reader will notice that frequency data have been included in Tables 6.6 and 6.7. Although some qualitative research methodologists maintain that numbers have no place in analysis of qualitative data, other methodologists disagree.[182-184] Sandelowski (2001), for one, stated, "displaying information numerically can make patterns 'emerge with greater clarity'",[184 (p. 231)] and supports the selective use of numbers to complement and enhance narrative.[184] Keeping in mind that all participants were asked about outcome, frequency data have been added here to help readers evaluate the salience, the pattern, and the relative frequency of specific outcomes.

Table 6.7 Negative Outcomes and Adverse Effects Attributed to Participation in LTPA by the Participants.

Negative Outcomes (number of participants who cited the outcome)	**Example**
1. Injury (14)	I would put a little bit too much pressure on the wheel so it would be heavier pedaling and then I realized, "okay, I'm doing myself more harm than good here." I would really hurt my hip area. (Meme)
2. Pain, General Ache, Intense Regional (12)	I felt more tired and more achy, I guess. My muscled ached. My back ached, my hip ached. It came on after we would finish. I felt it more so in the afternoon and I came to the realization that this wasn't working. Its getting worse, it's not helping. (Alicia)
3. Fatigue - Tired, Exhausted (8)	I was so exhausted that when I came home I had to nap for an hour. (Penny)
4. Sweaty (3)	I don't like feeling wet you know. And then to go and have a shower and get all ready again, you know? It's a nuisance. (Ceci)
5. Fibromyalgia - Worse (3)	I have had a flare after that and have not been able to have felt really, my hips have been dysfunctional and I've been really sore and achy, can't sleep well after. (Maya)
6. Decreased Endurance (1)	Towards the end it wouldn't go on an incline as much because I was walking a lot slower because I was finding it harder to do. (Kathy)
7. Discouraged (1)	It almost brought a panic in me that I'm not going to get better. I think part of me had thought, "this is a way to get better." I was so desperately looking for a way to get better and when I found myself getting worse, I got depressed. (Isabella)
8. Hunger (1)	I'm hungry when I get out of the pool. (laughing) Sorry, it's true! Come home and have a cookie. (Minnie)
9. Sleep - disturbed (1)	I've been really sore and achy, can't sleep well after. (Maya)

The participants talked about the problems they encountered when they "overdid it." The women related this to the fluctuations in their symptoms. Several individuals described having had a series of days when the symptoms (e.g., pain, fatigue) were severe (participants called these "bad days"), followed by a day when they felt relatively energetic and pain-free (a "good day"); they often felt compelled to catch up on all the tasks they had neglected during the bad days. Thus some of the women described a pattern of several days of great physical inactivity followed by a day of great physical activity, followed by one or more days of "paying for it." Although most often the terms "over-doing" and "paying for it" were applied to household chores, the terms were also applied to LTPA.

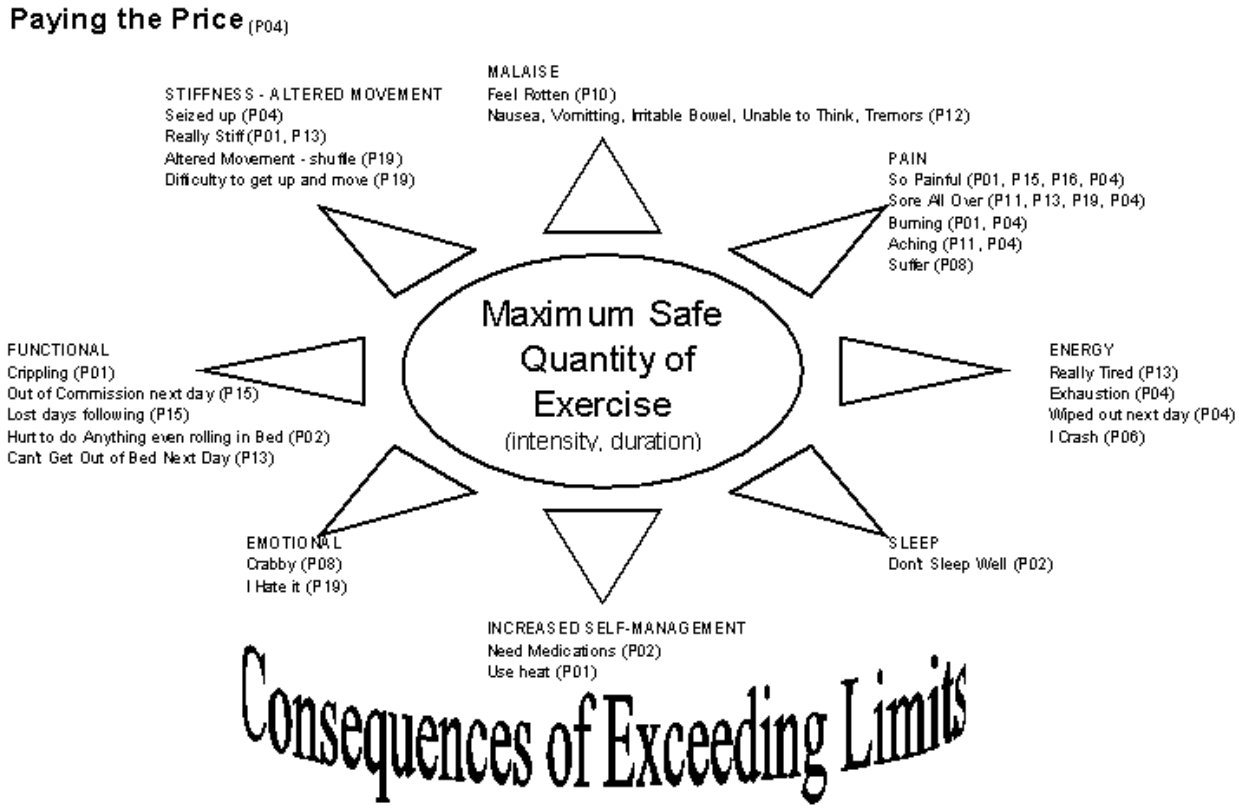

Figure 6-1 Paying the price

The symptoms described by participants that they attributed to undertaking too much physical activity (including LTPA). The numbers following the symptom refer to the participants who described the symptoms.

6.6 Convergence and Divergence within the Data

This study drew upon four sources of data; three quantitative sources (screening questions, questionnaires, and a physical activity log) and one qualitative source (derived from two interviews conducted three weeks apart). The rationale for collecting data from the first three sources was to provide a detailed description of the participants to facilitate transference and to provide a different perspective which will serve to enhance the rigor and credibility of the study. This section explores aspects of consistency and inconsistency within methods (e.g., quantitative vs. quantitative) and between methods

(quantitative vs. qualitative) primarily with respect to the classification and quantification of physical activity participation.

6.6.1 Within Method Discrepancies

Sources of quantitative data on LTPA participation level were: screening, self-schema, Kaiser Physical Activity Survey, and the Planned Behaviour Variables Questionnaire. The question on the screening form: "How physically active have you been over the past 6 months? Completely Inactive, Sporadically Active (participation less than twice a week), or Regularly Active (participation at least twice per week) was used as reference and compared to responses on the other quantitative sources. On the Self-Schema questionnaire, the 12 individuals who classified themselves as regularly active used a wide range of values (range: 4 to 10, where 1 = "does not describe me", and 10 = "describes me") to rate their level agreement with the statement "I exercise regularly". On the Kaiser Physical Activity Survey, these 12 individuals indicated that they had participated in physical activity for at least 1 hour per week for at least 4 months.

(Note. The apparent differences in findings between the 7-day physical activity log data and the screening data was previously discussed in Section 4.4 and will not be repeated here.)

6.6.2 Between Method Convergence

The results on the Exercise Perseverance and Barriers Instrument were consistent with the interview data. On the questionnaire, the most common barriers were pain,

discomfort, lack of time, and weather; whereas lack of resources, skills and facilities were less common. This was similar to findings on the interviews.

The data on fibromyalgia symptoms collected during the interviews seemed to agree with the data of the FIQ – individuals who described severe pain ranked their pain highly compared to those who seemed to be more concerned about stiffness or fatigue. Many participants indicated on the Planned Behaviour Variables Questionnaire that their self efficacy for engaging in their favorite physical activity (at least 2 times each week over the 2 weeks) was much lower when experiencing fatigue than when experiencing pain. The interview data also suggested this pattern.

6.6.3 Between Method Divergence

Using the self-schema questionnaire, four participants were classified non-exerciser schematics. Two of these, Maya and Sheena, had described themselves as having a strong affinity for physical activity and Maya was classified as at the integrated phase.

Of the 12 participants classified as regularly active (beginner, intermediate, mature or integrated phase) based on the interview data, all but one classified themselves as active on screening question (i.e., Sarah classified herself as inactive vs. mature). Conversely, of the eight classified as uncommitted based on the interview data, one participant (Pete) had classified herself regularly active.

Of the 12 participants classified as regularly active based on the interview data, 11 rated their self-efficacy for engaging in LTPA twice a week over the next month at 8 out of 10 (or above) and at 5 out of 10 (or above) for three times per week over the next

month. Kayla, the one exception, rated her self-efficacy at 1 out of 10 for twice per week, and 2 out of 10 for three times a week. Kayla's score was so low and the pattern of her response illogical suggesting that she made an error in reading and using the scales. Of the eight uncommitted participants, six rated their self-efficacy between 1 and 5 for engaging in LTPA at least three times a week over the next month; while Irene and Allie rated their self-efficacy at 9 or 10 respectively.

6.6.4 Conclusions regarding the Convergence and Divergence within the Data

Predominantly there was agreement within and among methods; most participants were consistent across methods. Areas of good agreement were description of fibromyalgia symptoms and description of barriers to LTPA. Nevertheless, discrepancies were found; some between the findings of the various quantitative methods, and some between the quantitative methods and the survey data. These discrepancies were chiefly in the measurement of LTPA. Possible sources of the discrepancies were recall bias, lack of stability of the phenomenon, recording errors, and confusion about the meaning of questions.

Regarding recall bias, there are many ways that recall bias may have influenced the finding including the following: participants may have been inclined to report greater participation levels when interviewed than when completing a self-report measure thinking this response was more socially acceptable to the interviewer, intensity of symptoms may have affected recall, minor cognitive impairments (e.g., fibro fog) may have affected recall, and finally increased awareness on repeated questioning may have facilitated recall (interviews always followed the questionnaires).

The use of two interviews spaced 3 weeks apart provided an excellent opportunity to observe the variability of the condition and its response to physical, social, and emotional demands of life events (e.g., increased hours of work, participating in functional capacity assessment, acquiring a puppy, weather changes). For example, Jackie, when returning for her second interview, stated:

> I did the questionnaires this week and I just thought to myself, ‘In one week, I could have changed all those numbers if it had would have been this week', you know? Like I was saying before, after you've had it so long, you just fail to notice a lot of these little things. But it made me feel good too in a way because it was re-affirming that things can get really bad and then they can get good again. (Jackie)

The areas of convergence are also important to recognize - the between method agreement with respect to barriers was interesting. Likewise, the impression that fatigue may be more powerful as a barrier than pain was significant. However, fatigue may be a consequence of pain and therefore represents prolonged pain. The two symptoms are frequently difficult to separate and according to several participant pain and fatigue interact to destroy motivation for participation in LTPA.

7 DISCUSSION

The objectives of this chapter are: a) to briefly summarize the study findings, b) to classify the emergent theoretical framework, c) to examine the significance of the study in the context of literature on LTPA and fibromyalgia, d) to compare the qualitative findings of the study with selected generalized health behaviour theories, and e) to examine the clinical and research implications of the study.

7.1 Summary of the Study Findings

This study attempted to answer the question, "What are the processes and factors that explain varying levels of participation in LTPA among women with fibromyalgia?" Interviews were conducted to explore the experiences, beliefs, attitudes, and behaviours of women with fibromyalgia and based on these data a theoretical framework was developed which described the process of adoption and maintenance of regular participation in LTPA among women with fibromyalgia. The emergent theoretical framework describes two levels of participation – a session-specific level and a pattern-specific level, and five influential factors (goals, barriers, facilitators, strategies, and outcomes). The session-specific level examines the experiences of women with fibromyalgia as they perform a single session. The researcher is not aware of any published theory that conceptualizes a session-specific level as a distinct entity; however, several of the concepts (e.g., intention, deciding, planning and preparing, barriers, and facilitators) that are described in the session-specific level can be found in other theories. The session-specific level of the emergent theoretical framework specifies that the basic unit of the process (a session) involves five ordered stages: forming intent, deciding,

planning and preparing, starting, and doing. The pattern-specific level builds on the session-specific level. It specifies that as sessions are accumulated, individuals progress through five phases of participation (uncommitted, beginner, intermediate, and mature) culminating in full integration of LTPA into lifestyle. The stages and the phases are influenced at each juncture by barriers, facilitators, strategies, and outcomes. Disruptions in the process (lapses) may occur at any stage or phase.

7.2 Classification of the Emergent Theoretical Framework

The emergent theoretical framework is a substantive theory – it is based on the experiences of a sample of women (adult women with fibromyalgia living in Saskatoon, Saskatchewan, Canada) related to one health behaviour (adoption and maintenance of LTPA). As such it can be used to challenge and clarify ways in which the more general theories of health behaviour apply to this health behaviour in this population (women with fibromyalgia from a midsized prairie city).

The emergent theoretical framework meets the Weinstein, Rothman, and Sutton (1998)[94] criteria for a stage theory. It has: a) a classification system to define the stages, b) an ordering of the stages, c) common barriers to change, facing people in the same stage, and d) different barriers to change facing people at different stages. The first two properties are easily met by the emergent theory; the last properties are present but have not been fully developed. For example, except in a few instances, the emergent theoretical framework does not assign specific barriers and facilitators to specific phases even though it is the impression of the researcher that this could be achieved without "forcing the data."[185 (p81 – 106)]

7.3 Significance in the Context of the Fibromyalgia Literature

This grounded theory study represents the first attempt to develop a theory for the process of adopting and maintaining regular participation in LTPA among women with fibromyalgia. Although other qualitative studies have explored the experience of fibromyalgia in broad terms (e.g., living with fibromyalgia), this study is one of two qualitative studies[27] published to date which have focussed entirely on physical activity in women with fibromyalgia. Mannerkorpi and Gard (2003)[27] explored the experience of participation in a group pool exercise and education program in Swedish women with fibromyalgia (n =19) using a phenomenological study design. The women in their study described an embodied learning experience in which they gained new relationships with their bodies. In our interviews, some women expressed the transforming effect of LTPA in the realm of connectedness of body-spirit. This resonates with the concept "embodied learning[a]" introduced by Mannerkorpi and Gard (2003),[27] but most of our data related to outdoor activities, so it is not clear if the connectedness was related to nature or to physical activity or to both. The women in our study who participated in aquacise spoke very favourably about their experience, but did not provide a picture of the embodied learning as described by Mannerkorpi and Gard.[27]

Other qualitative studies using a variety of methods (e.g., phenomenology[15,27,83,84,186] and narrative[88]), have examined adjusting and coping,[87] maintaining balance,[84] experiencing loss,[88] and living with fibromyalgia[15] in individuals with fibromyalgia. The women in this study shared a range of experiences described in

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[a] Embodied learning is "a process of transformation engaging body, self, and world."[27]

these other studies (e.g., loss, stigma, challenges in understanding and coping with fibromyalgia).

In addition to confirming the findings of other qualitative studies, this study adds abundant new information on the lived experience of participation in LTPA among women with fibromyalgia. This was not a phenomenological study; nevertheless, the emergent theoretical framework was richly influenced by the lived experience in many areas, such as: the decision-making process, the experience of starting LTPA, the barriers and outcomes of the process. Perhaps the most significant new knowledge is the description of a session-specific level and a pattern-specific level in the process of adoption and maintenance of LTPA among women with fibromyalgia. Another area described in this study which has received little attention in previous qualitative or quantitative research is the topic of negative outcomes of LTPA and the experience of *paying for it*. The session-specific and pattern-specific levels, the negative outcomes, adverse effects (including *paying for it*) have important applications in planning and guiding LTPA interventions for women with fibromyalgia and chronic pain conditions who wish to increase their participation in LTPA.

7.4 Comparative Analysis of Theories of Health Behavior Change

This section begins with a comparative analysis of the origins, selected concepts, and structure of four theories: the emergent theoretical framework with three general theories: the Theory of Planned Behaviour,[187] the Social Cognitive Theory,[111] the Transtheoretical Model,[100,188] and the emergent theoretical framework. Following the four way comparison, the Transtheoretical Model, will be examined more closely; the

analysis will include a detailed comparison of the structural features and important concepts drawn from the Transtheoretical Model (e.g., Processes of Change).

7.4.1 Comparative Analysis – Points of Convergence with Other Theories

In this section, convergence of the emergent theoretical framework with the three general theories will be examined. The following concepts will be addressed: personal agency, self efficacy, and intention, and relapse. These concepts have been selected for their salience with respect to: foundational importance (concept -- personal agency), acknowledged impact on behaviour change (self-efficacy), relevance to the emergent theoretical framework (intention, relapse).

a) Personal Agency

Personal agency is an essential tenet underlying each of the four health behaviour theories. Bandura summarizes the concept of human agency as "a perspective in which people function as anticipative, purposive, and self-evaluating proactive regulators of their motivation and actions."[189 (p. 87)] Concepts such as intention (Theory of Planned Behaviour), decisional balance (Transtheoretical Model, Precaution Adoption Process Model) and triadic reciprocal causation (Social Cognitive Theory) are dependent on an agentic perspective.

The emergent theoretical framework also embraces personal agency as a fundamental principle. Moreover it is congruent with the theoretical stance of symbolic interactionism; women with fibromyalgia are seen as re-evaluating and deciding about participation not just upon starting an exercise session, but on a step-by-step basis throughout an exercise session. Symbolic interactionism conceptualizes human beings as

continually defining the ever changing situation around them and constantly making decisions about their actions based on their definitions, their social interactions, and their interactions with self.[141 (p.146)]

b) Self efficacy, perceived behaviour control, and barriers

There is general agreement that self-efficacy is an important predictor of adoption of physical activity and exercise, perhaps the most important.[96,190,191] Despite the widespread agreement on its critical importance for volitional human behaviour,[105,107,191,192] it seems surprising that self-efficacy did not emerge as a concept in the data of this study. How could so central a variable be overlooked? There are three possibilities to consider regarding the absence of this important variable: a) perhaps it is not a major factor in this population, b) perhaps this concept was overlooked, and finally c) perhaps the concept self-efficacy is embedded within another concept. To resolve this question, we must diverge to examine the concept – self-efficacy more closely.

Bandura first defined self-efficacy as "the conviction that one can successfully execute the behavior required to produce the outcomes."[107 (p. 79)] When describing how to design tools to measure self-efficacy, Bandura later stipulated that it is necessary to ascertain "what it takes to succeed in a given pursuit" so that one could endow the instrument with context specific "levels of challenge and impediment to successful performance of the required activities."[111 (p. 43)] He went on to say that "sufficient impediments and challenges must be built into efficacy items to avoid ceiling effects."[111 (p. 43)] So it appears that the nature of self-efficacy has much to do with barriers to performing the behaviour of interest. The interviews produced an abundance of data

related to barriers. In looking back over the data now, several codes might be mobilized from the data to formulate a concept that embodied self-efficacy. Aside from the codes and concepts of barriers and facilitators, ten codes (out of a total of 850 open codes) are framed in the language of self-efficacy (e.g., “Think I couldn't, so have not” and “I'm going to! I can do it”). Despite the fact that these codes found their way into a variety of different categories, the data are not inconsistent with the construct -- self-efficacy.

Turning our attention to the Theory of Planned Behaviour, the construct that parallels self-efficacy is perceived behavioural control.[130,193] Godin (1994) explained that in the first presentation of the Theory of Planned Behaviour, perceived behavioural control was defined as perceived barriers to a given behaviour.[99 (p. 128)] The pervasive role of barriers and facilitators in the emergent theoretical framework is abundantly evident; facilitators and barriers compete for influence literally at every stage and phase of the emergent theory. Although the formulation differs somewhat, there appears to be some convergence between with the concepts in the emergent theory and the important concepts in these two theories.

c) Intention and its antecedents

Intention is a pivotal concept in the emergent theoretical framework. The strength of intention is the driving force, sustaining participation despite numerous obstacles. If intention is sufficiently strong, individuals with fibromyalgia can override the disconcerting symptoms of fibromyalgia and barriers of all types at each of the stages of the session-specific level and phases of the pattern-specific level. Among the established theories, the Theory of Planned Behaviour recognizes and gives a pivotal role to the

concept "intention", designating it as the most proximal variable to behaviour. The concept has been formulated differently in the two theories. The concept *intention* in the emergent theoretical framework has one antecedent – goals; whereas "*intention*" as conceptualized in the Theory of Planned Behaviour has three independent antecedents: attitudes toward the behaviour, subjective norms, and perceived behavioural control.[99] Each of the three antecedents has a place in the emergent theoretical framework – the former (attitudes toward the behaviour) which involves an appraisal of whether the behaviour (LTPA) will result in the achieving the valued goals, is incorporated in to the concept "deciding." The latter two antecedents (subjective norms and perceived behavioural control) are incorporated into the concepts: barriers and facilitators.

d) Relapses - Relapse prevention

Relapses were a common occurrence among the participants of the study. Codes such as "the slippery slope," "going back to square-one," and strategies such as needing to "establish routines" and "prioritizing LTPA" are examples of the ways in which lapses were experienced and avoided by the participants. Lapses are not directly apparent in the Theory of Planned Behaviour or in Social Cognitive Theory. Bandura does explain how Self-Efficacy Theory (i.e., a streamlined version of Social Cognitive Theory) applies to prevention of relapses. He suggests when dealing with self-management of chronic disease, interventions should target not only development of self-efficacy for the primary behaviour, but also self-efficacy for resilience and resistance to relapse.[111]. The Transtheoretical Model has its origins in ceasing harmful behaviours and overcoming

addictions, therefore, the concepts of relapses, temptations, and relapse prevention are recognized. Prochaska and Marcus (1994) stated:

> … we are convinced that no matter what we do, the majority of people will relapse after any single attempt to overcome most chronic behaviour problems. Our strategy is to recycle relapses and to help them take action more effectively on the next attempt.[100] (p. 168)

In the emergent theoretical framework, discontinuation (or lapses) was a major concept that threatened the continuity of the process at numerous points, but it remained peripheral to the stages and phases. By nature it is merely the converse of participation – thus the emergent theoretical framework tells us as much about relapse as it does about participation.

7.4.2 Comparative Analysis - Points of Divergence with Other Theories

Although the emergent theoretical framework appears to share several concepts with the selected generalized health behaviour theories, important differences are apparent as well. Divergence will be addressed related to: a) Origin and Scope -- grounded and substantive versus inductive and general, b) Focus and Structure -- session-specific and pattern-specific stages versus pattern-specific stage, and c) Refinement -- development of the concepts. Because a detailed analysis comparing the emergent theoretical framework and the Transtheoretical Model is undertaken Section 7.4.3, this section will emphasize the Theory of Planned Behavior and the Social Cognitive Theory.

a) Origin and Scope

The Theory of Planned Behaviour and the Social Cognitive Model) have arisen from a "logical positivism paradigm … (which has) two central features – (1) an emphasis on the use of induction, or sensory experience, feelings, and personal

judgements as the source of knowledge; and (2) the view that deduction is the standard for verification or confirmation of theory so that theory must be tested through empiricism and systematic observation of phenomena."[95 (p. 28)] (Note. The origin the Transtheoretical Model has been discussed previously, Section 2.4.3 c, and will not be repeated here.) All three general theories in this discussion are characterized by a high level of abstraction and have proven to be very robust. They have been applied to many health-related behaviours including acquisition and cessation behaviours across the lifespan in the healthy and the ill.[96,98,111,194]

In contrast, the emergent theoretical framework is a substantive theory formulated in a constructivist paradigm using a grounded theory approach. It deals with one health behaviour (the adoption and maintenance of regular LTPA) in a very restricted population (women with fibromyalgia) in a specific location (mid-sized Canadian city). Each of these factors, but especially the experience of fibromyalgia, has shaped the emergent theoretical framework such that it differs in a fundamental way from the generalized models. Often individuals with fibromyalgia must override numerous adverse sensory cues (symptoms) that bombard them, throughout the entire participation; these sensations are not present for most people engaging in LTPA. Pain, depression, and symptoms of fatigue and exhaustion act independently and together to escalate the challenge to the self-regulation of motivation needed to maintain regular LTPA, and even complete one exercise session.

Attending to the experience of symptoms has had the effect of magnifying the process such that each small component of the full health behaviour becomes more

meaningful. This has resulted in the conceptualization of a session-specific level of participation (i.e., session), a feature that is unique to the emergent theoretical framework. The emphasis on the session-specific level provides insight into minute-by-minute decisions, small scale strategies and reveals the complexity of the influence of symptoms such as pain and stiffness on the participation in LTPA (symptoms are sometimes a facilitator and sometimes a barrier). It brings us right into the minute-to-minute ongoing internal dialogue of the experience. By providing a closer fit to the experience of the women with fibromyalgia, the emergent theoretical framework ought to provide fertile ground for the development of interventions and self-help strategies that are more meaningful and effective for those with the daily experience of pain, stiffness and fatigue.

b) Refinement

The three general theories that have been discussed have had more than two decades of development and testing; they have been applied in many settings with scrutiny and comment from many scholars. The concepts and relationships described by these three theories have gained acceptance and have shaped thinking and practice of scholars, health policy experts, and clinicians alike. In contrast, the concepts developed in this emergent theoretical framework are untested and even within the context of this study, further reflection and refinement is needed.

7.4.3 Comparison of the Transtheoretical Model and the Emergent Theoretical Framework

The emergent theoretical framework by virtue of being a stage model dealing with health behaviour change converges closely with the Transtheoretical Model. The two theories have core elements that trace the movement of individuals through stages from inaction to action, and they acknowledge the importance of decision making, barriers and facilitators, and processes and strategies for achieving behaviour change.[100] In addition to many similarities between the two theories, there are many important differences, too. Despite ongoing development and revision of the Transtheoretical Model, its origins (described in Section 2.4.3c) continue to influence its applicability.[100] These origins, therefore, have an important bearing on our discussion and can be invoked to explain many of the differences between the two theories. The Transtheoretical Model, a distillation of theories from the discipline of psychotherapy, was originally developed to explain a *cessation* behaviour – cessation of smoking;[120] the emergent theoretical framework was developed as a substantive theory to explain an *acquisition* behaviour – participation in LTPA. The sample used to develop the Transtheoretical Model was composed of smokers; the sample used to develop the emergent theoretical framework was composed of women with fibromyalgia. The different theoretical perspective, foci, and target populations of the two theories have resulted in differences in: a) the structure of the stages, b) the development of Processes of Change, c) the formulation of key concepts (treatment matching, decisional balance), and, ultimately, d) the applicability to the substantive area.

a) Structure of Stages

To better compare and contrast the structural features of the emergent theoretical framework and the Transtheoretical Model, a triadic view of behaviour is helpful. That is, there are three components (states) to behaviour - an intentional state, a transitional state, and an active state (see Figure 7.1). In the context of this construction, the Transtheoretical Model has two stages in the intentional state (precontemplation, contemplation), one in the transitional state (preparation), and two in the active state (action, maintenance). Turning our attention to the emergent theoretical framework, there are two levels to consider – the session-specific and the pattern-specific levels. At the session-specific level, three stages can be classified as intentional (forming intent, deciding, and planning and preparing), one as transitional (starting), and one as active (doing). At the pattern-specific level, none of the phases are in the intentional state, one phase is in the transitional state (uncommitted), and four phases are in the active state (beginner, intermediate, mature, and integrated).

As might be anticipated, the transitional state is most ambiguous to classify. Three stages have been classified as transitional: starting (a session-specific level stage), uncommitted (a pattern-specific level phase), and Preparation (Transtheoretical Model stage). The *starting* stage is composed of a combination of cognitive and physical components; the *uncommitted* phase is a combination of action and inaction, and, according to the definition by Prochaska, Redding, and Evers (2002), the *preparation* stage is also a combination of action and inaction. They define *preparation* as follows: “Intends to take action within the next thirty days and has taken some behavioral steps in

this direction."[121 (p. 101)] Although none of the *Stages of Change* are identical to any of the *session-specific level stages* and *pattern-specific level phases*, it is probable that several elements do overlap. The greater development of the active phase in the emergent theoretical framework derives largely from the influence of the periodicity of situations that challenge the maintenance of regular participation in LTPA (see below).

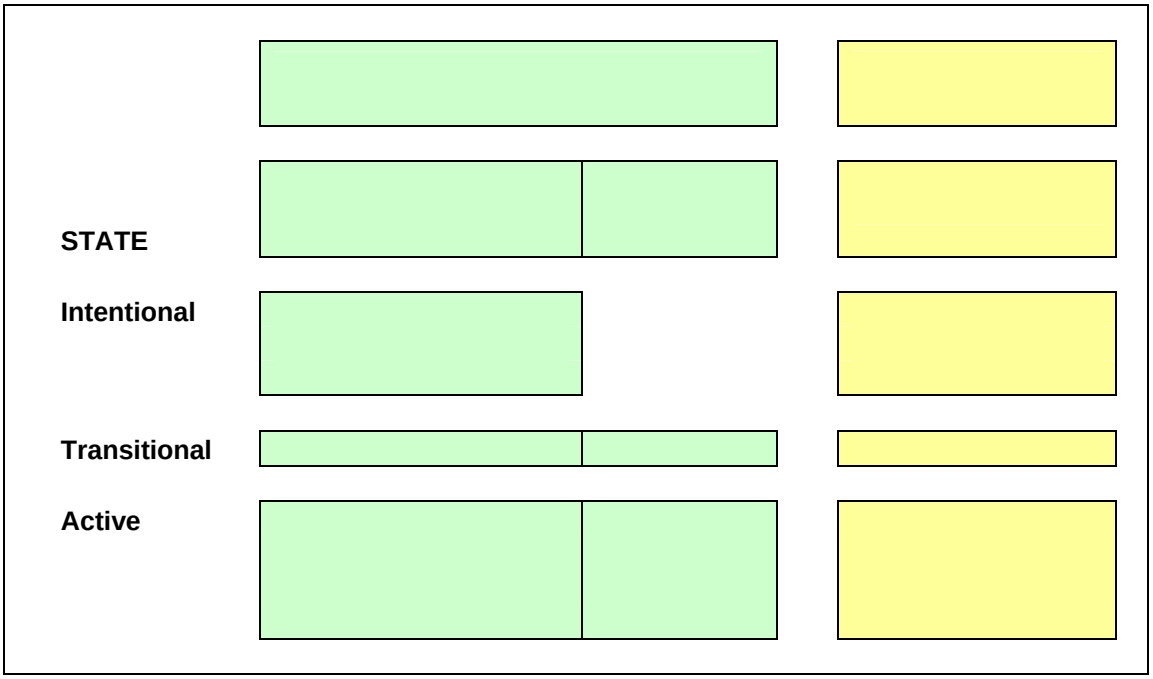

Figure 7-1 Comparison of the emergent theoretical framework to the Transtheoretical Model

[a] Termination is "the stage in which individuals no longer succumb to temptation and have total self-efficacy"[121 (p 102)]

The disruptive effects of seasonal challenges and participation boundaries (e.g., weather, vacation, seasonal affect disorder, end of programs) were influential in the delimiting the beginner, the intermediate, and the mature phases of the pattern-specific level in the emergent theoretical framework. This represents an important distinction between the emergent theoretical framework and the Transtheoretical Model. The Transtheoretical Model was formulated to explain smoking cessation – a behaviour that, until the imposition of laws prohibiting smoking inside public buildings, had little to do with the periodic challenges related to season. Indeed, the boundary between the action and the maintenance stage of the Transtheoretical Model is an arbitrary one. Marcus and

associates (1992) indicated that when applied to physical activity, the lack of clear boundaries between the action and maintenance stages of the Transtheoretical Model did present a problem. They suggested, "it may be helpful to both better define these stages and possibly add an additional stage, perhaps by adding a time referent to the items and subdividing the Action stage."[128 (p.62)] In an articles published later, Prochaska, Redding and Evers (2002) did include a time referent in the definitions for action (i.e., less than 6 months) and maintenance (i.e., greater than 6 months)[121 (p. 101)] however, no justification for the time referent of 6 months was provided.

b) Processes of Change

The Processes of Change which were the first components of the Transtheoretical Model to be developed, were synthesized by Prochaska[120] during a comparative analysis of psychotherapy systems (e.g., Freudian, Skinnerian, Rogerian).[120,121] Since the inception of the Processes of Change in 1979,[195] the wording and definitions of the processes have been modified several times (e.g., compare Prochaska and DiClemente, 1983;[188] Prochaska, Velicer, DiClemente and Fava, 1988;[196] and Prochaska and Marcus, 1994[111]). Prochaska, Norcross and Diclemente (1994) are adamant that processes are not techniques and that "for each process there are dozens, even hundreds of techniques."[120 (p. 32)] In general, the Processes are relatively abstract, they are framed in professional terminology, and they are oriented to the overcoming of addictions. Several of the Processes overtly address the unhealthy behaviour (e.g., counter conditioning, stimulus control, reinforcement management) and the undesirable effects of the unhealthy behaviour (e.g., dramatic relief, environmental re-evaluation). In contrast, the strategies

of the emergent theoretical framework are more concrete, framed in layman terminology, and none of them overtly address the unhealthy behaviour (i.e., physical inactivity or engagement in sedentary behaviours) and its undesirable effects.

Despite these differences, some of the strategies identified in the emergent theoretical framework seem to parallel the Processes of Change. Figures 7.2 and 7.3 compare the Processes and the strategies, and provide the Processes and their definitions (see Figures 7.2 and 7.3, Columns 2 and 1, respectively) and the strategies and examples (see Figures 7.2 and 7.3, Columns 3 and 4, respectively). Four process-strategy pairings have been categorized as similar in nature (i.e., Class A association for the purposes of this study, see Figure 7.2). One Process has been linked to four strategies; the Process of Change, *stimulus control,* appears to be related (i.e., Class B association, see Figure 7.2) to three strategies for avoiding, controlling or ignoring symptoms of fibromyalgia during LTPA (symptoms here are loosely classed as stimuli) and one strategy for increasing the cues (reminders) to engage in LTPA. The final section of the table lists the four remaining Processes and the remaining strategy – these are unrelated (i.e., Class C, see Figure 7.3).

Transtheoretical Model		Emergent Theoretical Framework	

Class A – Similar

Definition[121] (p. 101)	Processes of Change	Strategies	Examples

Class B - Related (stimuli and cues)

Definition[121] (p. 101)	Processes of Change	Strategies	Examples

Figure 7-2 - Similar and related Processes of Change (Transtheoretical Model) and strategies (Emergent Theoretical Framework)

Transtheoretical Model	
Class C – Unrelated	
Definition[121] **(p. 101)**	**Processes of Change**
Substituting healthier alternative behaviours and cognitions for the unhealthy behaviour	**Counter-conditioning**
Realizing that social norms are changing in the direction of supporting the healthy behaviour change	**Social Liberation**
Experiencing the negative emotions (fear, anxiety, worry) that go along with unhealthy behavioural risks	**Dramatic Relief**
Realizing the negative impact of the unhealthy behaviour on one's proximal social and physical environment	**Environmental Re-Evaluation**

Emergent Theoretical Framework	
Strategies	**Examples**
Self-management	Pacing, taking one day at a time, fighting it - not giving up

Figure 7-3 Unrelated Processes of Change (Transtheoretical Model) and strategies (Emergent Theoretical Framework)

Insights that the emergent theoretical framework offers at session-specific level (e.g., starting, doing it, step-to-step) may inform the development of meaningful interventions which address factors that are needed in individualizing LTPA for women with fibromyalgia. Such interventions could lead to achievement of higher rates of adoption and maintenance of this important health behaviour among women with fibromyalgia.

c) Key Concepts (Transtheoretical Model)

Decisional Balance. Among the models and concepts that have been assembled to form the Transtheoretical Model, the decision-making model plays an prominent role

in transitions through the first three stages (precontemplation, contemplation and preparation).[100] A simple two-factor decisional balance instrument (pros – cons) has been applied to guide decision-making.[100 (p. 165)] In this study, many participants talked about their decisions to adopt a pattern of regular LTPA. With striking similarity to the two-factor model used in the Transtheoretical Model, one participant, without prompting, systematically listed the pros and cons of her engagement in LTPA. Barriers and facilitators were weighed against each other, and the effects of physical activity were compared to the effects of physical inactivity. However, for the most part, decision making was not so remote and formalized. Indeed, under some circumstances, decisions about whether to continue or to stop were being made with almost every step of an exercise session. Although this orderly approach was observed in one participant, more often decision making was less orderly. This minute-to-minute decision making is compatible with the conceptualization of decision making described by symbolic interactionist, Joel Charon, since, each step, revolution or repetition seemed to involve an active internal dialogue:

> Any given act along a stream is caused by the individual's decision at that point. A given decision is caused by the individual's *definition of the situation* at that point, including goals, plans, social objects, future consequences, relevant memories, recalled and applied. The definition in turn is influenced by two things: *interaction with self* (thinking) and *interaction with others*.[141 (p. 133)]

Treatment matching. Marcus and Forsyth (2003) proposed that: "matching treatment strategies to people's stage of motivational readiness for change improves the likelihood that they will regularly attend a program, increases their chances of meeting their short- and long- term goals and decreases the likelihood that they will stop

participating in the program or stop reading the materials provided."[123 (p. 16)] If Marcus and Forsyth are correct, treatment matching holds great promise as an approach for promoting and guiding individuals in the adoption and maintenance of LTPA.

The emergent theoretical framework lends itself to similar development. Being a substantive theory, it is heavy with context, so it is anticipated that the physicality of the target behaviour (i.e., participation in LTPA) and factors associated with fibromyalgia (e.g., pain, fatigue, impaired physical function, and disability) will result in greater emphasis on biopsychosocial processes than is evident in the Transtheoretical Model. The strategies of the emergent theoretical framework include a mix of psychological and sociological processes, but three strategy categories (i.e., dealing with symptoms, attending to needs, self-management) have a distinct biopsychosocial focus.

d) Applicability to the Substantive Area

The Transtheoretical Model is a robust theory which combines systems and concepts derived from many sources (e.g., psychotherapy theory, decisional-making theory, social cognitive theory, and direct observation of self-changers).[188] Although it has been applied to numerous health behaviours,[121] the application of the Transtheoretical Model to adoption or maintenance of LTPA in fibromyalgia has not yet been examined.

The session-specific stages emerged from a detailed inspection of the influence of fibromyalgia symptoms on the experience of the LTPA; the definition of a session-specific level stands as a new construction which differs from the Transtheoretical Model, and indeed, the other health behaviour theories. Insights regarding the influential factors at play as individuals progressed through the stages of the session-specific level

could potentially be used in self-guided and practitioner-guided interventions (i.e., stand-alone or therapist-delivered interventions) designed to promote higher levels of LTPA among women with fibromyalgia. Based on what was learned regarding the session-specific level during this study, interventions ought to clarify reasonable LTPA expectations and prevent, monitor, and ameliorate adverse effects of LTPA. Interventions should include self-regulation strategies identified as beneficial by the participants (e.g., time management) and should enhance motivation through helping individuals find personal value in LTPA. Interventions should also address social barriers and facilitators; they should include evaluation and facilitation of desired social support options for LTPA.

7.5 Strengths and Limitations

7.5.1 Strengths

This study derives its strength from the experiences of the participants and the openness and honesty which characterized their expression. The model that has been developed reflects and addresses many important contextual elements experienced by the participants. These contextual elements both confirm and challenge the general models of health behavior change.

Several processes were used to contribute to the rigor of the study and therefore establish the credibility of the results. These included reflexive memos, code checking, and member checking. Member checking (See Appendix M) included a presentation to the fibromyalgia self help group, and obtaining critical appraisal of the thesis in its close to final state. Conducting two interviews allowed for clarifying the meaning of

statements made by participants in their first interview. It also allowed the researcher to obtain different perspectives on data from previous interviews without unduly influencing the participant's primary opinions as such exchanges were not introduced until the second interview.

7.5.2 Limitations

During the process of adopting and maintaining a pattern of regular LTPA, the women in the study encountered a variety of barriers and facilitators, used a number of strategies, and experienced a range of outcomes both positive and negative. It is unlikely that all of these factors were unique to these women. Healthy women, with whom the researcher discussed the study results, commented on encountering many of the same barriers, facilitators, strategies, and outcomes. Thus, some of the factors may be relatively general, others may be specific to unique personal circumstances and attributes, and still others may be related to fibromyalgia. It is beyond the scope of this study to parse out the general from the specific or to identify how the experiences of the participants might compare with the experiences of other individuals (e.g., healthy women, men with fibromyalgia, and individuals with other medical conditions). For example, we know that the reality of time constraints is an important barrier to regular participation in LTPA in healthy individuals. However, we do not know if the symptoms of fibromyalgia interact with this barrier to change its essence and its impact on participation in LTPA for individuals with fibromyalgia.

All of the participants were volunteers. The majority of them had participated in previous studies conducted by the researcher. Volunteers tend to be healthier,[197] "higher

self-disclosers who may be seeking opportunities to talk about themselves",[198 (p. 168)] higher in intellectual ability and need for social approval, more unconventional, younger, and more sociable than nonvolunteers.[D5100) Additionally, based on the responses to a question posed to all participants, most participants stated that they had agreed to participate in the study because they hoped that the research would result in improved understanding by health care professionals and others about the nature of fibromyalgia and how to manage it. Therefore, the participants may have been more altruistic than non-participants. These factors may have implications for the transferability of the emergent theory to other women with fibromyalgia.

It should be noted that this study has emphasized health behaviour theory and LTPA interventions at the individual level. Although some socio-environmental determinants of health behaviour were identified in the interviews, the exploration of these factors was not emphasized and it is acknowledged that there may be an over-reliance on individualistic factors, processes, and perspectives.

Integration of the quantitative and the qualitative data was not undertaken in this study. Although the opportunity for future analysis exists, to meet the principles of mixed methods research outlined by Janice Morse (2003) for a "QUAL ➔ quan" study" each project must be methodologically independent, exquisite, and adherent to its own methodological assumptions."[D0245] [(p. 203)] To meet this criterion, the researchers would need to extend the quantitative component of this study. They would need to attend to the sampling requirements for quantitative research (increasing the sample size, random sampling) to help ensure that a representative sample of women with

fibromyalgia. Adding to the quantitative piece would allow more complete triangulation of results – which would move "the research program along by confirming the earlier qualitative findings". [199 (p. 203)]

7.5.3 Saturation

Given the breadth of the emergent theory, not all concepts have been developed to the same degree. The session-specific level of the emergent theoretical framework has been developed to a greater degree than has the pattern-specific level. The properties and dimensions of strategies require further development. Treatment matching is a conceptual area that holds promise; more data are required to determine what patterns exist between the strategies and stages and phases of the model. Perspectives of young women, women with young children, rural women, and severely involved women may be underrepresented; it is likely that the experiences of women with these characteristics would extend and perhaps, challenge the emergent theoretical framework.

7.5.4 Reflexivity

This study was conducted at a distance from the literature to allow the emergence of codes, categories and constructs from the experiences and words of the participants. The researcher avoided making any comparisons with or references to the general theories until the emergent theoretical framework was nearing completion. However, prior to embarking on this study, as part of the doctoral program course work, the researcher had studied two of the general theories (i.e., the Social Cognitive Theory and the Transtheoretical Model). It is impossible to judge to what extent prior knowledge, perspectives, assumptions, and predispositions of the researcher influenced the data

collection or the analysis, but an attempt was made to focus on the experiences of the participants and to use the words of the participants for codes rather than terms from the theories known to the researcher. Despite some similarities, the differences between the emergent theoretical framework and the general theories do seem to indicate a unique perspective that emphasizes the experience of the participants.

8 IMPLICATIONS AND RECOMMENDATIONS

The clinical and research implications of this research have been compiled in this section. These are presented in the form of recommendations for Health Care Professionals, individuals with fibromyalgia, and researchers.

8.1 Practical Recommendations for Health Care Practitioners and Individuals

By focusing on the properties of the session-specific and pattern-specific levels of the emergent theoretical framework, several stage and phase specific recommendations related to the adoption and maintenance of regular LTPA for individuals with fibromyalgia were formulated. Other recommendations address special issues that emerged in the data including: training needs, injury prevention, the stigma of fibromyalgia, and application of theory to practice.

There were instances of exercise-related musculoskeletal injuries incurred in a variety of settings, both supervised and unsupervised. Most injuries were brief and transitory but at least one was persistent and disabling. Based on the interviews, the following factors seemed to be problematic: overly rigid implementation of treatment protocols, inattention to signs of problems, poor technique using exercise equipment, errors in programming (e.g., attempting overly intensive levels or progressing exercise level too quickly). Only a few of the participants were able to recall having received any help deciding about or designing a program of LTPA. For the most part they described a trial and error process of learning about and adjusting their programs. Many used commercial exercise video tapes to learn how to do various forms of exercise. Consequently it is assumed that the role of Health Care Professional as physical activity

consultants to individuals is underdeveloped. Many of the participants experienced difficulties that might have been avoided if a Health Care Professional had been accessible.

8.1.1 Session-specific Level

a) Forming Intent

A number of community-wide informational interventions (e.g., point of decision prompts, and multicomponent campaigns using television, radio, newspapers, billboards, and mailings) have been shown to be effective for increasing participation in physical activity.[200] Any effective population-based health promotion intervention will have a positive effect on forming intent to engage in the health behaviour among the many subgroups of the population. While these general interventions promoting LTPA are helpful, more directed interventions should be developed. Given the prevalence of fibromyalgia, occasional targeted messages distributed using mass media are justifiable. Judging by the feelings of alienation expressed by most of the participants, individuals with this condition would welcome targeted messages about LTPA for fibromyalgia (e.g., messages about the special benefits of LTPA for fibromyalgia, how-to messages). As well as the validating impact of being targeted, such messages would help to augment the level of intent to participate in LTPA among individuals with fibromyalgia.

Participants cited family events, change of job, moving to a new residence, and reaching an age milestone as stimuli for a turning point in the self management practices including increased engagement in LTPA. The idea of using a personal milestone as a trigger to behaviour change is not new; Prochaska, Norcross, and Diclemente (1994) have

suggested that "supermeaningful events often provide the needed push to move us from one Stage of Change to the next."[120 (p.79)] In addition to the intent-enhancing effect of these personal milestones, this study suggests that growing dissatisfaction with fibromyalgia symptoms (e.g., pain, stiffness, and fatigue), physical inactivity, and social isolation was a powerful stimulus to initiating a behaviour change. Assuming that this dissatisfaction is a common feature of fibromyalgia, perhaps it can be "harnessed" to stimulate a behaviour change. By virtue of their authenticity, the statements that participants used will resonate with others with fibromyalgia and could be used to craft powerful empathic promotional messages for this population. Such statements included: "It was time to start living!" "Life was passing me by!" "Do I want to live like this?" "I had to put myself first." "I had to change my thinking."

Health Care Professionals could also customize promotional messages by highlighting positive outcomes achieved by the women or by acknowledging the goals that were valued by the participants in this study. Again direct statements by the women, attesting to positive outcomes (see Table 6.6) could be used to authenticate motivational messages to individuals with fibromyalgia. Regarding goals, weight loss was frequently cited as a goal for participation. Promoters could emphasize the synergy between diet and exercise.[201] Other goals valued by the participants that could be emphasized were: securing future health into retirement years, maintaining ability to continue social integration (e.g., being able to participate in family events), maintaining independence, and controlling symptoms especially stiffness.

b) Decision

This study suggests that there is value in using a decisional balance to assist individuals with fibromyalgia in their decision of whether to adopt regular participation in LTPA. In addition to guiding clients through a decisional balance, Health Care Professionals could recommend the strategies used by the participants classified at the mature phase: use of positive self affirmations, focussing on positives, and recognizing LTPA as a part of an overall management strategy. Depression and low energy level were major impediments to deciding to participate in LTPA. Diagnosis and treatment for depression and various self-management practices (i.e., pacing of activities, participation in yoga) were also cited by participants as helpful. Several participants reported how important it was to get enough sleep, but the participants themselves had no advice to offer regarding how to improve the quality of sleep. To rectify this, Health Care Professionals should routinely instruct individuals with fibromyalgia in sleep hygiene (i.e., simple behavioural methods to improve sleep).[202-204]

c) Planning and Preparation

The participants indicated that they had little professional help in determining the appropriate mode or dosage levels (i.e., intensity, duration, or frequency) and progression of LTPA. Most participants indicated that they had relied entirely on trial and error to determine mode, dosage, and progressions. Even participants, who had extensive experience with LTPA, had difficulty predicting responses to LTPA or disentangling the seemingly random fluctuations in fibromyalgia symptoms from post-exercise muscle soreness or adverse effects of exercise. Nevertheless, understanding and applying the

evidenced based principles of exercise prescription should minimize problems encountered by individuals with fibromyalgia and help them to sustain their participation in LTPA. Guidance and reassurance is particularly important early phases of participation (Beginner Phase). There are several ways exercise specialists could assist women with fibromyalgia with this stage of the process. They could inform and guide individuals with fibromyalgia regarding the selection of appropriate activities, programs, and equipment. Exercise specialists could help determine and recommend safe dosage levels and progression protocols, and provide training in techniques for LTPAs. They could also discuss strategies, prepare individuals for periods of low motivation, engage the individual in contingency planning, and encourage appropriate goals setting. However, there was data to suggest that the Health Care Professionals with whom the participants did interact were also puzzled about the condition, the indications for LTPA, and the ideal dosage, and the special needs of individuals with fibromyalgia. It appears that there is a need for training for physicians, physical therapists, and other Health Care Professionals with respect to exercise prescription specific to individuals with fibromyalgia. Health Care Professionals who lack the knowledge, skills, or confidence in exercise prescription for fibromyalgia should refer their clients to other professionals who possess these skills to provide consultative service or augment their skills through educational upgrading.

Self-guided instructional pamphlets, internet resources, and other educational materials (e.g., videotapes) should be developed and distributed to individuals with fibromyalgia to guide those who have the desire or need to undertake self-guided LTPA

programs. According to the participants in the study, fibromyalgia specific educational supports for LTPA were either difficult to find or unavailable.

d) Starting

This brief stage, which emerged as pivotal for several participants, warrants special attention by individuals with fibromyalgia who want to adopt or maintain a pattern of regular LTPA and by Health Care Professionals working with individuals with fibromyalgia. To achieve a regular pattern of participation, the barriers to participation associated with this brief stage must be successfully mastered and remastered – with each session. Individuals, either on their own or assisted by Health Care Professionals, should systematically assess the barriers and facilitators to this stage and then plan and implement strategies that will minimize the barriers and strengthen the facilitators. Barriers and facilitators that affect motivation are paramount at this stage. Two sets of barriers seem to be especially important at this stage: fibromyalgia symptoms and time constraints. Fibromyalgia symptoms, especially fatigue and pain, were cited by several participants as sapping their motivation at this stage. Individuals with fibromyalgia should employ strategies in two areas (e.g., attending to needs, controlling symptoms, self management) to improve energy level and diminish fibromyalgia symptoms and thereby improve success at the stage of starting. The barrier of *time constraints* is also critical at this stage; self-management strategies (e.g., contingency planning, anticipation of motivational difficulties) and strategies dealing with time/timing and commitment should be implemented to ensure overcoming this barrier to starting. Conversely, facilitators that help to enhance motivation, such as effective social support,[205] are likely

to be helpful; thus, implementing strategies that strengthen social support hold promise for women with fibromyalgia at the starting stage of the session-specific level.

Community-wide environmental strategies (e.g., making facilities and programs more accessible) will also remove barriers at this stage. Participants suggested increased access (e.g., increased neighbourhood facilities, subsided fees for those with fibromyalgia) and addressing safety concerns (e.g., ice removal on city sidewalks, safety lighting, and neighbourhood walking paths) would remove barriers to participation. Improving access and safety would reduce the situational barriers that can make an important difference in the starting stage. Health Care Professionals can assist with the provision of affordable, accessible environmental supports and programming through referral, providing consultation regarding public policy, and advocacy as the opportunity arises. There is also an important role for fibromyalgia self-help groups in advocacy, consultation, and education of members and the public regarding needs with respect to services, facilities and programs for LTPA that are suitable for individuals with fibromyalgia.

e) Doing it

The doing it stage has several implications for Health Care Professionals. Any improvement in the quality of the experience of LTPA will facilitate ongoing participation. It is particularly important to instruct individuals with fibromyalgia in safe technique, to monitor and correct technique, and to identify hazards, and thus reduce risk of injury. One of the special challenges for Health Care Professionals and clients alike is separating fibromyalgia symptoms from adverse effects of LTPA. It will be necessary to

listen to clients to make the appropriate adaptations to exercise mode and intensity, and to make recommendations regarding equipment, clothing, and footwear. From time to time, it also may be useful to discuss the minute to minute experience of LTPA and the accumulating outcomes. Most participants indicated that they had had very limited access to knowledgeable Health Care Professionals. Thus, again we see the need for increased referral by general practitioners and for enhanced training of Health Care Professionals in the area of exercise prescription and monitoring that meets the needs of individuals with fibromyalgia.

8.1.2 The Pattern-specific Level

A variety of factors were at work in the Uncommitted Phase including inconsistencies in level of intent, shortage of effective strategies, and overwhelming barriers especially related to symptoms, life events and time issues. Health care professionals could help by discussing motivational problems and strategies for dealing with symptom management and time management. Assistance with planning and preparation as discussed earlier will also be relevant here.

Of particular importance in the Beginner Phase are short term positive and negative outcomes, social, environmental, and program-related facilitators and strategies for managing and overcoming barriers related to fibromyalgia symptoms. Roles for Health Care Professionals include helping individuals to identify positive short term outcomes and to celebrate the successful completion of the first season or program. Health Care Professional ought to help correct errors in performance (e.g., stabilize the spine before lifting, avoid inclined treadmill walking to minimize strain on the plantar

fascia, match resistance to strength capacity when weight training), and emphasize gradual progressions to programs to avoid excesses associated with beginner enthusiasm. Health Care Professionals need to develop effective ways of instructing individuals with fibromyalgia regarding realistic goals, how to establish safe programs (intensity and frequency), how to monitor and regulate exercise intensity, and how to recognize the early warning signs of adverse effects. Other important Health Professional functions at the Beginner phase are to assist with problem solving related to any negative outcomes and to help with plans and preparation for seasonal challenges.

In the Intermediate, Mature, and Integrated Phases, Health Care Professionals should help individuals identify long term effects including signs of repetitive strain injury (e.g., plantar fasciitis). They can reinforce any of the positive outcomes including the sense of accomplishment associated with successful completion of the seasonal challenges and assist with problem solving related to any negative outcomes. In these phases, it is important to anticipate and implement appropriate strategies to address potential disruptions due changes in social roles and other potent challenges to regular participation (including "flare-ups" in fibromyalgia). It is also important to attend to motivational fluctuations by reviewing goals and successful strategies and to continue to plan and prepare for seasonal challenges.

8.1.3 Special Considerations

a) The Stigma of Fibromyalgia

The women in this study, as observed in other studies, talked about the stigma of fibromyalgia and about the lack of validation from other individuals including some

Health Care Professionals. Health Care Professionals and students are urged to reflect on the experiences of the participants of this study and other qualitative studies as a means of enhancing sensitivity to the difficulties faced by this population. Furthermore, when interacting with individuals (with any condition) to promote and assist behaviour change, Health Care Professional must be careful to avoid judgemental attitudes; blaming and bullying are inappropriate approaches.

b) Application of Theory when Promoting and Implementing LTPA for Individuals with Fibromyalgia

The management of fibromyalgia has evolved in the context of the biomedical model in which the focus on symptoms drives the design of management programs for individuals with clinical conditions. Although, as observed in this study, the biomedical factors of the condition have an important role in the adoption and maintenance of regular LTPA, psychosocial, sociological, and environmental factors are also very important. Health Care Professionals who are excessively dependent upon the biomedical model when developing and prescribing self-management programs will fail to harness the enhanced outcomes that ensue from the application of health behaviour change theory. They are encouraged to explore the growing treasury of knowledge and research about health behaviour change and to apply these to LTPA the programming and promotion for individuals with fibromyalgia. Although at present there are few documented studies which test these theories in fibromyalgia, fibromyalgia-specific theory-based tools are available for measurement of constructs of the Transtheoretical Model (i.e., readiness for

change)[135] and Theory of Planned Behaviour (i.e., intention, exercise self-efficacy)[130] in the area of participation in LTPA.

8.2 Recommendation for Researchers

The following recommendations have been developed to guide future research.

8.2.1 Expand the Scope of Research into LTPA for Fibromyalgia

To date, the research on physical activity and exercise for fibromyalgia has focussed on quantifying the response to acute exercise and short-term exercise training. Research needs to go beyond the documentation of effects of short-term exercise interventions on individuals with fibromyalgia to design; it must address the design and testing of programs to promote and implement adoption and maintenance of regular LTPA in people with fibromyalgia.

a) Adherence

Based on the findings of this study, research examining the relationships outlined in the Transtheoretical Model (e.g., stages and Processes of Change, treatment matching, self-efficacy, decisional balance), and Theory of Planned Behaviour (i.e., the relationship between intention and maintenance of regular LTPA) would help illuminate the adherence to LTPA in this population.

b) Fatigue and depression

Research examining the impact of behavioural interventions (e.g., exercise, LTPA, sleep hygiene, multimodal interventions) on fatigue and depression should be extended; a wider range of interventions needs to be explored and long term results need to be evaluated. Although pain and fatigue seem to be closely related, the impact of

fatigue and depression seemed to be relatively greater than pain as a barrier to adopting and maintaining LTPA. The relative impact of pain, fatigue, and depression on adoption and maintenance of habitual LTPA should be examined.

c) Adverse Effects

Research on the effects of exercise and physical activity for fibromyalgia should address adverse effects. Adverse effects and mechanisms of injury should be described and interventions designed and tested to prevent adverse effects among women with fibromyalgia who are exercising in supervised and unsupervised settings. New interventions incorporating the strategies identified in this study may have promise for helping individuals safely adopt and maintain regular participation in regular LTPA. Such methods could be developed and tested using randomized controlled trials.

8.2.2 Refine and Develop the Emergent Theoretical Framework

Following the comparison with three health behaviour theories, it is apparent that the emergent theoretical model can be improved. Concepts that require further attention are self-efficacy, intention, self-regulation, and strategies. The analysis could be deepened to gain further understanding of stage-specific barriers, facilitators, and strategies. New data could be added to this study (concatenation); the study could be extended to include men and young people with fibromyalgia. Continuation of the comparative analysis of the emergent theoretical framework to Transtheoretical Model is required to further clarify the differences in cessation and acquisition behaviours. Ultimately testing of the model is needed. Further development of the model holds

promise for improved understanding and management of fibromyalgia and prevention of morbidity.

8.2.3 Description of LTPA Participation among Individuals with Fibromyalgia

LTPA participation (e.g., dosage parameters, patterns of habitual participation, adherence rates) are poorly documented in men and women with fibromyalgia. Descriptive studies using questionnaires, logs, and accelerometers comparing individuals with fibromyalgia to healthy individuals are needed. Case control studies are needed comparing individuals with fibromyalgia with healthy populations with respect to risk factors and outcomes associated with inactivity. Such research will improve the understanding of this condition and will help to determine the status of this population with respect to public health recommendations.

8.2.4 Development of Tools and Interventions Based on the Experience of Individuals with Fibromyalgia

Prospective qualitative studies examining the exercise experience as participants make the transition from inactive to active are needed to further clarify the adoption process. Such information is needed to design more relevant interventions to promote and develop regular participation in LTPA. More qualitative studies are also needed to assess current tools and further the development of tools for measurement the physical activity levels, exercise self-efficacy, outcome expectancy and other important concepts. For example, this study provides extensive data on barriers to LTPA. These data could be used to design better tools for measurement of barriers and related concepts (self-efficacy and perceived behavioural control for LTPA participation).

8.2.5 Examine the Relationship, Training and Role of Health Care Professionals

Education of Health Care Professionals to improve the quality of interactions with and the LTPA prescription practices for individuals with fibromyalgia seems to be warranted.. Research is needed to explore the interactions between individuals with fibromyalgia and Health Care Professionals in view of the feeling of alienation and lack of validation experienced by people with fibromyalgia.

8.3 Dissemination Plan

This research will be disseminated through publications in peer reviewed journals, through presentations at scientific meetings and at local fibromyalgia self-help meetings, and through FM-CFS Canada, a national online association with nearly two thousand registered members. [a]

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[a] FM-CFS Canada (URL: http://fm-cfs.ca/object.html) was created by patients and physicians afflicted with CFS/ME & FM dedicated to advancing Fibromyalgia and Chronic Fatigue Syndrome (CFS) education, research and treatment. The association is dedicated to making educational materials and other useful resources available free to the FM & CFS community, including patients, their care-givers, and physicians.

9 CONCLUSIONS

A grounded theory methodology was applied to semistructured interviews of 20 Canadian women with fibromyalgia living in or near a midsized prairie city to construct a theoretical framework describing the development of habitual participation in LTPA among women with fibromyalgia. The emergent theoretical framework can be classified as a stage theory, as it describes the accumulation of sessions of LTPA to progress through phases to achieve a pattern of regular participation in LTPA. A session (the basic unit of the process) consists of five ordered stages: forming intent, deciding, planning and preparing, starting, and doing. As sessions are accumulated, individuals progress through four phases of participation (uncommitted, beginner, intermediate, and mature) culminating in full integration of LTPA into lifestyle. The stages and the phases are influenced at each juncture by barriers, facilitators, strategies, and outcomes. Disruptions in the process (lapses) may occur at any stage or phase.

The emergent theoretical framework was compared to three general theories of Health Behaviour Change and was found to be complementary rather than antipathetic to any of the three the established theories. It provides greater detail regarding the expected outcomes, barriers, facilitators, outcomes that could serve: a) to formulate appropriate measurement tools for important concepts of the predictive theories, and b) to fashion interventions that are sensitive to the needs of this population. It also uncovers particular issues related to participation in LTPA not emphasized by the general theories – the particular difficulties experienced with starting a session of LTPA.

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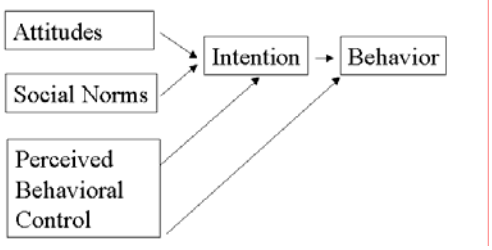
LIST OF APPENDICES

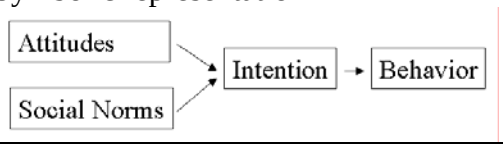
APPENDIX A - GLOSSARY

Aerobic training	Aerobic exercise (training) involves large muscle groups in dynamic activities that result in substantial increases in heart rate and energy expenditure. Regular participation results in improvements in the function of the cardiovascular system and the skeletal muscles, leading to an increase in endurance performance.
Callanetics	Callanetics exercises were developed by Callan Pinckney to combat her own severe back and knee problems. "By isolating muscle groups and using tiny, precise (yet powerful) movements, Callanetics exercises tighten and reshape your body while increasing strength and flexibility." (http://www.callanetics.com/)[206]
Curves	Curves is a fitness and weight loss franchise for women with over 9,000 locations worldwide.207
Dosage descriptors	The characteristics of intensity, frequency, duration, and mode/type are used to describe the dose of physical activity or exercise needed to bring about a particular response. 28
Duration	Duration typically refers to the number of minutes of activity in each session. 28
Energy expenditure	The body's total energy expenditure consists of three bodily functions: basal metabolism, physical activity (15-30%) and digestion and absorption of food.208 The energy expenditure of physical activity consists of energy expended in daily physical activity and exercise. It depends on the frequency, intensity, duration and mode of a person's physical activity. Energy expenditure can be calculated either by objective measurement (direct and indirect)208 or estimated by questionnaires, activity logs and records.209
Exercise	Exercise is defined as "planned, structured, and repetitive bodily movements that are performed to improve or maintain one or more components of physical fitness."[28 (p. S364)]
Facilitate	To make easier[210]
Frequency	Frequency is described as the number of activity sessions per day, week, or month28
Grounded theory	a "general methodology for developing theory that is grounded in data systematically gathered and analyzed. Theory evolves during actual research, and it does this through the continuous interplay between analysis and data collection."[137]
Health Care Professionals	Physicians, physical therapists, occupational therapists, exercise therapists, personal fitness trainers, recreational therapists, nurses and others with formal health sciences training who interact with clients with fibromyalgia.

Health-Belief Model[96]	The theory postulates that the likelihood of adopting a behavior appropriate to the prevention or control of some disease depends on the individual's perception of a threat to personal health and a conviction that the recommended action will reduce this threat. [96] (p.114) - It is not clear as yet if this is an appropriate model for the study of exercise behavior. - This theory probably has most relevance for those already affected by a condition (eg. ischemic heart disease).
Intensity	Intensity describes, in relative or absolute terms, the effort associated with the physical activity. 28
Leisure time physical activity (LTPA)	Leisure time physical activity can be categorized as: recreational activities, sports and exercise. It is defined as "the activities one pursues during free time, based on personal interests and needs."[28] (p. S364)
Metabolic equivalents (MET)	A multiple of the Resting Metabolic Rate. METs are obtained by dividing the oxygen uptake in $mL \cdot kg^{-1} \cdot min^{-1}$ by 3.5 $mL \cdot kg^{-1} \cdot min^{-1}$. 28
Mode	Refers to the type of physical activity. Examples: walking, acquacise, dancing
Physical activity	Physical activity is a fundamental feature of human life linked to survival, enjoyment, health, and autonomy. It is defined as "any bodily movement produced by contraction of skeletal muscle that substantially increases energy expenditure."[28] (p. S364) Physical activity can be categorized into occupational physical activity, household physical activity, leisure time physical activity, care-giving physical activity, transportation involving physical exertion, and other physical activity (e.g., activities of daily living such as dressing, eating, grooming).
Physical fitness	Physical fitness is defined as a set of attributes (i.e., cardiorespiratory endurance, skeletal muscle endurance, skeletal muscle strength, skeletal muscle power, flexibility, agility, balance, reaction time, and body composition) that people have or achieve that relate to the ability to perform physical activity.28

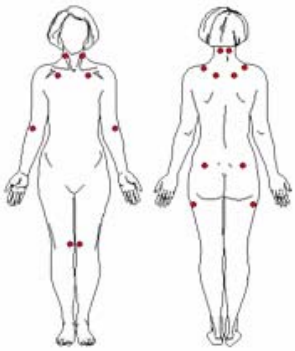
Pilates	An exercise method developed by Joseph Hubertus Pilates (1880 – 1967). The method is based on the movement of animals; everything about the method is based on moving naturally. [211] "Pilates training is intended to improve general body flexibility and health by emphasizing 'core' (truncal) strength, posture, and coordination of breathing with movement. … Advocates report that the exercises can be adapted to provide either gentle strength training for rehabilitation or challenge skilled athletes with a vigorous workout. … Pilates exercises are designed to put participants in a position that minimizes unnecessary muscle recruitment, which could potentially lead to early fatigue, decreased stability, and impaired recovery."[212]
Protection Motivation Theory[96]	The intention to protect oneself depends on: a) the perceived severity of an event, b) the perceived probability of occurrence (of an adverse event), c) the efficacy of the recommended preventative action (response efficacy), and d) the perceived self-efficacy to take the action. [96 (p. 116)] - The theory appears to have limited usefulness for the study of exercise behaviors.
Schema Theory[96]	This theory provides a partial explanation for why some people carry through with the intention to adopt exercise and others do not. If self image (self-schema) as an exerciser is strong - a behavior that is compatible with the self-schema will give immediate reward (through verification of the self schema) and will help with maintenance of the behavior until the other benefits are achieved. An "exerciser self-schematic" will reinforce the adoption and maintenance of exercise behavior. [96 (p. 138)] Measurement instruments have been developed. The theory requires more extensive testing but has led researchers to consider exercise behavior and decision implementation from a new angle.
Self-Changer	An individual who successfully implements a new health behaviour with little of no formal assistance.. (based on DiClemente and Prochaska, 1982)[213]
Self-Efficacy Theory[96]	All behavioral changes are mediated by the belief that one can successfully perform the desired action. [96 (p. 117)] Self-efficacy has been the most successful variable in predicting exercise behavior. Several theorists of other models have modified their theories to include self-efficacy.
Session	A period of activity of any kind – here seen as a single episode of exercise or physical activity.[210]

Sleep hygiene	"Sleep hygiene addresses practices such as an excessive intake of caffeine, vigorous exercise near bedtime, daytime napping, and sleeping in an uncomfortable environment, that are inconsistent with good sleep."[202]
Symbolic interactionism	A theoretical approach in sociology which focuses on social reality as constructed through the daily interaction of individuals and places strong emphasis on the role of symbols (gestures, signs, and language) as core elements of this interaction. http://campus.murraystate.edu/academic/faculty/frank.elwell/prob3/glossary/socgloss.htm#S
Theory of Inter-personal Behavior[96]	The likelihood of undertaking a given behavior depends on: a) the habit of performing the behavior, b) the intention to perform the behavior, and c) the conditions facilitating or discouraging performance of the behavior. The intention is shaped by: a cognitive component, an affective component, a social component and a personal normative component. [96 (p. 123)] -The theory has successfully predicted exercise, but it appears to lack some important elements related to intention and behavior. The affective dimension (perceived enjoyment) more important than cognitive elements.
Theory of Planned Behavior	Similar to the Theory of Reasoned Action but the dimension of perceived behavioural control (PBC) is added. If an individual has limited control, one needs to examine not only the individual's intention but also his/her perceived control over the behavior. PBC can influence intention as can attitude and social norm but it can also influence behaviour directly in concert with intention. [96 (p. 126)] There is partial support for the use of this theory in the prediction of exercise behaviour. Symbolic representation: 

Theory of Reasoned Action[96]	The proximate determinants of intent to adopt a given behaviour are the individual's attitude about performing the behavior and the influence of social factors (such as perceived beliefs of the spouse) [96 (p. 119)] - The basic factors included in this theory only account for a fraction of the variance in adoption of exercise behavior indicating either that measurement methods need to be refined or that other factors not addressed in the model are more important. Symbolic representation 
Trans-Theoretical Model (Stages of Change Model) [96]	The core concepts in this model are: stages of change (pre-contemplation, contemplation, preparation, action and maintenance), processes of change (experiential constructs, behavioural constructs), decisional balance and self-efficacy. This theory postulates that the effectiveness of the different processes used to promote behavior change will depend on the stage of readiness of the individual. [96 (p.161–180)] This model was originally designed for cessation of smoking and addiction behaviors. Measurement instruments for most components have been developed for application to acquisition of exercise behavior. This theory requires more rigorous, longitudinal studies with less reliance on self-report of physical activity. The authors state that interest in this model "has accelerated in recent years." This model has continued to attract great interest and an abundance of research since this book was published.
Workout	A session of exercises[210]

APPENDIX B – RECRUITMENT POSTER

How is Physical Activity important to women with fibromyalgia?



We need women with fibromyalgia living in or near Saskatoon who will tell us about their experiences with exercise, sports, daily physical activities … any type of movement!

The purpose of the study

- To develop a theory about the role and meaning of physical activity (movement, exercise, work, sports) for women with fibromyalgia.
- To attempt to understand why some women with fibromyalgia maintain a pattern of regular physical activity while others do not.

What is involved?

- Participating in two interviews
- Completing 5 or 6 questionnaires, and
- Keeping a detailed record of physical activity diary for one week

If you can help us, please phone:
Angela Busch at 306 966 2545
or email: Angela.Busch@usask.ca

School of Physical Therapy, University of Saskatchewan
1121 College Drive, Saskatoon SK, S7N 0W3 Canada

Telephone: (306) 966-2545 Facsimile: (306) 966-6575

APPENDIX C - PHONE SCREENING FORM

Script: "Thank-you for your interest in this study. You may be exactly the person we will need at some point in the study but right now, we don't know if we will need you to participate. We have a few questions for you now though. This information will help us to decide if you can help us with the information we need. As we go along, if we need someone like you (in your age group, your activity level, your education, or whatever) we will be able to find you. Would you be willing to answer a few questions now over the phone or would you prefer filling out a short questionnaire and mailing back." This will take about 10 minutes over the phone.

Take down:

_____ _____ _____ _____
(Name) Date (d/m/y) Phone (home) Phone (work)

_____
(address)

If the person is willing to answer questions over the phone, complete the following:

1. **AGE** _____

2. **MEDICAL CONDITIONS and DIAGNOSIS:**

Do you have: N Y
Diabetes
Heart disease

Other serious illness _____
Are you taking medication for depression, mood disorder or other psychological problem?
O N, O Y _____

Who made the diagnosis of fibromyalgia?
General Practitioner:_____
Rheumatologist:_____
Other:_____
(Specify name and discipline or profession of the individual)
No formal diagnosis

PHYSICAL ACTIVITY:

3. How physically active have you been over the past 6 months?

O Completely Inactive
O Sporadically Active (less than once a week)
O Regularly Active: How many times a week _____

4. Do you usually nap during the day?

O Never or rarely
O Yes: How many naps: _____
How much time in total _____

SOCIAL / DEMOGRAPHIC

5. How many "family members" live with you in your home? _____(include all significant others)

6. Current Marital Status	*7. With whom do you live:*	*8. Ethnic Background*
O Married	O Alone	What is your ethnic background:
O Separated	O With other adults	_____
O Divorced	O With other adults and children	
O Widowed	O With children only	
O Never Married		

9. *Education –*

O Did not complete Grade 12
O High School
O Trade School
O Some University
O University Degree
O Graduate Degree

We are interested in learning about your employment history and income related to your illness.

10. Please check your main form of work:

O Paid work - Full-time O Unemployed O Disabled

O Paid work - Part-time O Housework O Retired

O Student

11. If employed, what is your occupation: _____

12. Have you received disability or income replacement payments because of fibromyalgia?

O Yes

O No

13. What is your approximate family income including wages, disability payment, retirement income or social assistance?

O < $15,000

O $16,000 - 29,000

O $30,000 – 59,000

O $60,000 – 99,000

O Equal to or greater than $100,000

*** NEW QUESTIONS MAY BE ADDED AS NEEDED FOR THEORETICAL SAMPLING

APPENDIX D – CONSENT FORM

Study: Role of Physical Activity in the Lives of Women with Fibromyalgia

Name of researchers:
Marja Verhoef, Ph. D.
(Professor, Supervisor)
Dept. of Community Health Sciences
University of Calgary, Calgary, Alberta

Angela Busch, M.Sc.
(Ph. D. Student, CHS, UofC)
Associate Professor,
School of Physical Therapy
University of Saskatchewan, Saskatoon, SK

The purpose of the study
The purposes of the study are to develop a theory about the role and meaning of physical activity (movement, exercise, work, sports) for women with fibromyalgia, and to understand why some women with fibromyalgia maintain a pattern of regular physical activity while others do not.

Possible benefits of the study to the participant and to others
By reflecting on attitudes, beliefs and behaviours, participants may gain a better understanding of their behavior. Sometimes this may result in being able set new goals and overcome obstacles. Also, the knowledge gained through this study can be used to help health professionals design better fitness programs for persons with fibromyalgia.

The study procedures
One or two interviews lasting between ½ to 1½ hours in length will be conducted, audio-taped and transcribed. Participants will be given the opportunity to review the transcriptions and make changes. Participants who travel to attend the interviews will receive a flat rate ($15) for transportation expenses.

Participants will complete several questionnaires that describe characteristics such as age, education, employment, the impact of fibromyalgia, and physical activity patterns. This will take about 1 – 1.5 hours. For one week, participants will keep a detailed activity log. At the completion of the study, I will be invited to assist with the development of an educational booklet about physical activity for individuals with fibromyalgia.

There are no foreseeable risks or discomforts that will result from participation in the study.

Freedom to withdraw from the study
Participants are free to withdraw from the study at any time. Withdrawal from the study will not affect the participant's academic status, and/or access to, or continuation of, services provided by public agencies such as the University, hospitals, or social services. If a participant decides to withdraw, she may choose to have her data deleted from the study and destroyed.

Researcher decisions and interpretations
If for any reason the researcher decides that involvement by a participant is not needed or not appropriate, the researcher can choose to discontinue the participant's involvement in the study, in which case the participant's data will be deleted from the study and destroyed.

Confidentiality
A number of precautions will be taken to protect the confidentiality and anonymity of participants. Pseudonyms will be used on transcripts and other study materials; only authorized members of the research team will have access to the real names of the participants. After the transcriptions of the interviews have been checked for accuracy, the audiotapes will be erased. The words used by participants will not be identifiable in any reports or presentations. All study results and associated material will be safeguarded and securely stored by the researcher at the University of Saskatchewan.

Reports and Presentations
The information obtained through the interviews and questionnaires will be used in a number of scientific forms. The information may be used in a doctoral thesis, in articles published in medical journals, and in oral presentations made to groups of researchers, students, persons with fibromyalgia, and to general audiences. Individual quotations taken from the interviews may be used in these presentations. If such are used, the identity of the participant will not be discernable.

Debriefing
At the conclusion of the research, participants will be invited to an information session at which time the study results will be discussed.

Approval of the Research
This research project was approved on ethical grounds by the University of Saskatchewan Behavioural Research Ethics Board on May, 26, 2003 and by the University of Calgary, Conjoint Health Research Ethics Board, Office of Bioethics, Sept. 23, 2003.

Contact Information
Participants may contact any of the following at any time to request further information or to discuss their rights as a participant in this study:

- Dr. Marja Verhoef, 403-220-7813,
- Angela Busch, (Angela.Busch@usask.ca), ph: 306-966-2545, fax (306) 966-6575,
- Office of Research Services, University of Saskatchewan, 306-966-2084. (collect calls will be received)

Availability of Information about this research project

I, _____(name)_____, hereby acknowledge that:

- the study and contents of the consent have been explained to me
- I understand the contents, and
- I have received a copy of the consent form for my own records

and, I hereby agree to participate in the study.

_____ _____
Participant Date

_____ _____
Researcher Date

APPENDIX E - INITIAL INTERVIEW GUIDE

What is the role and significance of regular physical activity in women with Fibromyalgia?
I am interested in the movement, physical activity and exercise that you partake in on a typical day. Let's start by discussing your activities yesterday …

Starting with the morning …
Can you tell me about the types of movement, physical activities and exercises that you do?
… how these make you feel
… how important are these?

Now about the afternoon …
Can you tell me about the types of movement, physical activities and exercises that you do?
… how these make you feel
… how important are these?

Now the evening …
Can you tell me about the types of movement, physical activities and exercises that you do?
… how these make you feel
… how important are these?

Now the night …
Can you tell me about the types of movement, physical activities and exercises that you do?
… how these make you feel
… how important are these?

Preferred Level of Physical Activity
… what would you like to be doing? (preferred) … why?
… what accounts for the difference

… what accounts for your success/inability to meet the preferred

Potential Level of Physical Activity
… what do you think of your potential in this area … what is your potential in this area?
… what accounts for the difference between your present and your potential

APPENDIX F - TRANSCRIPT RELEASE FORM

Study: Role of Physical Activity in the Lives of Women with Fibromyalgia

(to be used after the participant has had the opportunity to review and make additions, deletions or changes to the transcripts)

I,_____, have reviewed the complete transcript of my

personal interview with Angela Busch on _____, ____.

(date)

I have been provided with the opportunity to add, alter, and delete information from the transcript as appropriate. I acknowledge that the transcript accurately reflects what I said in my personal interview with Angela Busch (the researcher). I hereby authorize the release of this transcript to Angela Busch (the researcher) to be used for research purposes described in the consent form. I have received a copy of this Transcript Release Form for my own records.

_____	_____
Participant	Date
_____	_____
Researcher	Date

APPENDIX G - FIBROMYALGIA IMPACT QUESTIONNAIRE

Directions: for questions 1 through 10, please circle the number that best describes how you did **overall** for the past week. If you don't normally do something that is asked, cross the question out.

	Were you able to:	Always	Most Times	Occasionally	Never
1	Do shopping?	0	1	2	3
2	Do laundry with a washer and dryer	0	1	2	3
3	Prepare meals?	0	1	2	3
4	Wash dishes/cooking utensils by hand?	0	1	2	3
5	Vacuum rug?	0	1	2	3
6	Make beds?	0	1	2	3
7	Walk several blocks?	0	1	2	3
8	Visit friends or relatives?	0	1	2	3
9	Do yard work?	0	1	2	3
10	Drive a car?	0	1	2	3

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

0 1 2 3 4 5 6 7

12. How many days last week did you miss work because of your fibromyalgia? If you don't have a job outside the home, leave this item blank.

0 1 2 3 4 5 6 7

Directions: For the remaining items, place a mark like this / at the point on the line that best indicates how you felt **overall** for the past week.

13. When you did work, how much did pain or other symptoms of your fibromyalgia interfere with your ability to do your job?

No problem with work — Great difficulty with work

14. How bad has your pain been?

No pain — Very severe pain

15. How tired have you been?

No tiredness — Very tired

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

Awoke refreshed — Awoke very tired

17. How bad has your stiffness been?

No stiffness — Very stiff

18. How nervous or anxious have you felt?

Not anxious — Very anxious

19. How depressed or blue have you felt?

Not depressed — Very depressed

APPENDIX H - KAISER PHYSICAL ACTIVITY SURVEY

SECTION I. HOUSEHOLD AND FAMILY CARE ACTIVITIES

First, we want to know about your activities at home, not including activities you may do at your home or other people's home for pay.

1. Caring for a child or children under 2 years of age

O None or less than 1 hour a week
O ≥ 1 hour but < 20 hours a week
O ≥ 20 hours a week

2. Caring for a child or children between 2 and 5 years of age

O None or less than 1 hour a week
O ≥ 1 hour but < 20 hours a week
O ≥ 20 hours a week

3. Caring for a disabled child or elderly person (only count time actually spent in feeding, dressing, moving, etc.)

O None or less than 1 hour a week
O ≥ 1 hour but < 20 hours a week
O ≥ 20 hours a week

4. Preparing meals or cleaning up form meals on weekdays?

O None or less than 1/2 hour a day
O ≥ 1/2 hour but < 1 hour a day
O ≥ 1 hour but < 1 ½ hours a day
O ≥ 1 ½ hours but < 2 hours a day
O ≥ 2 hours a day

5. Preparing meals or cleaning up form meals on weekends?

O None or less than 1/2 hour a day
O ≥ 1/2 hour but < 1 hour a day
O ≥ 1 hour but < 1 ½ hours a day
O ≥ 1 ½ hours but < 2 hours a day
O ≥ 2 hours a day

6. Doing major cleaning, such as shampooing carpets, waxing floors, or washing walls or windows?

O Never or less once a month
O Once a month
O 2 – 3 times a month
O Once a week
O More than once a week

7. Doing routine cleaning such as dusting, laundry, vacuuming, or changing linens?

O Never or less once a month
O Once a month
O 2 – 3 times a month
O Once a week
O More than once a week

8. Going grocery shopping and pushing a shopping cart?

O Never or less once a month
O Once a month
O 2 – 3 times a month
O Once a week
O More than once a week

9. Doing gardening or yard work, such as mowing the lawn or raking leaves?

O Never or less once a month
O Once a month
O 2 – 3 times a month
O Once a week
O More than once a week

10. Doing heavy outdoor work, such as chopping wood, tilling the soil, shovelling snow, or baling hay?

O Never or less once a month
O Once a month
O 2 – 3 times a month
O Once a week
O More than once a week

11. Do major home decoration or repair, such as plumbing, tiling, painting or building?

O Never or less once a month
O Once a month
O 2 – 3 times a month
O Once a week
O More than once a week

SECTION II. OCCUPATIONAL ACTIVITIES {Study investigators to decide if this section is to be completed by individuals working part-time as well as full-time.}

Now, some questions about your employment situation.

12. What is your occupation? (if more than one job, describe your occupation for the job with the most hours per week)

_____

13. What is the name of your employer, business or company?

_____

14. What kind of business or industry is this? (For example, hospital, newspaper publishing, mail order house, auto engine manufacturing, etc.)

_____

15. What are your most important specific activities or duties? (for example, selling cars, keeping account books, etc.)

1. _____

2. _____

3. _____

16. Which best describes your current occupation:

- O Employee of private company, business or individual for wages, salary, or commissions
- O Employee of Federal government
- O Employee of provincial or local government
- O Self employed in own business, professional practice or farm
- O Working without pay in home, family business or farm

17. In comparison with other women your age, do you think that your work is physically …

- O Much lighter
- O Lighter
- O The same as
- O Heavier
- O Much heavier

18. After work, are you physically tired? O Yes O No

19. When you are working at your current occupation, how often do you do each of the following:

a. Sit

- O Never
- O Seldom
- O Sometimes
- O Often
- O Always

b. Stand

- O Never
- O Seldom
- O Sometimes
- O Often
- O Always

c. Walk

O Never
O Seldom
O Sometimes
O Often
O Always

d. Lift heavy loads

O Never
O Seldom
O Sometimes
O Often
O Always

e. Sweat from exertion

O Never
O Seldom
O Sometimes
O Often
O Always

SECTION III. ACTIVE LIVING HABITS
This next section asks about the general level of physical activity involved in your daily routine during the past year.

20. How many minutes a day so you usually walk and or bicycle to and from work, school or errands?

O < 5 minutes
O ≥ 5 but < 15 minutes
O ≥ 15 but < 30 minutes
O ≥ 30 but < 45 minutes
O ≥ 45 minutes

21. Did you watch television?

- O < 1 hour a week
- O ≥ 1 hour a week < 1 hour a day
- O ≥ 1 hour a day but < 2 hours a day
- O ≥ 2 hours a day but < 4 hours a day
- O ≥ 4 hours a day

22. Did you walk (for at least 15 minutes at a time)?

- O Never or less once a month
- O Once a month
- O 2 – 3 times a month
- O Once a week
- O More than once a week

23. Did you bike (for at least 15 minutes at a time)?

- O Never or less once a month
- O Once a month
- O 2 – 3 times a month
- O Once a week
- O More than once a week

SECTION IV. PARTICIPATION IN SPORTS AND EXERCISE

This next section asks about the general level of physical activity involved in your daily routine during the past year.

24. In comparison with other women your age, do you think that recreational physical activity is …

- O Much less
- O Less
- O Same as
- O More
- O Much More

25. Did you play sports or exercise?

O Never or less once a month
O Once a month
O 2 – 3 times a month
O Once a week
O More than once a week

26. Did you sweat from exertion during sports or exercise?

O Never or less once a month
O Once a month
O 2 – 3 times a month
O Once a week
O More than once a week

27. During the past year, did you participate in any of these activities or any other similar activities not included in the list?

Yes	No	
O	O	Aerobics, Step Aeorbics, Water aerobics
O	O	Dancing
O	O	Stationary bike, rowing machine, treadmill
O	O	Swimming
O	O	Bowling
O	O	Softball, slow pitch
O	O	Other: _____
O	O	Other: _____

If yes …
28. Which sport or exercise did you do most frequently?

_____

29. How many months in this past year did you do this activity?

O < 1
O 1 to 3
O 4 to 6
O 7 to 9
O > 9

30. How many hours a week did you usually do this activity?

O < 1 hour a week
O ≥ 1 but < 2 hours a week
O ≥ 2 but < 3 hours a week
O ≥ 3 but < 4 hours a week
O ≥ 4 hours a week

31. Did you do any other exercise or play any other sport in this past year?

O Yes
O No

If yes …

32. What was the second most frequent sport or exercise you did?

_____

33. How many months in this past year did you do this activity?

O < 1
O 1 to 3
O 4 to 6
O 7 to 9
O > 9

34. How many hours a week did you usually do this activity?

O < 1 hour a week
O ≥ 1 but < 2 hours a week
O ≥ 2 but < 3 hours a week
O ≥ 3 but < 4 hours a week
O ≥ 4 hours a week

35. Did you do any other exercise or play any other sport in this past year?

O Yes
O No

If yes …

36. What was the third most frequent sport or exercise you did?

_____

37. How many months in this past year did you do this activity?

O < 1
O 1 to 3
O 4 to 6
O 7 to 9
O > 9

38. How many hours a week did you usually do this activity?

O < 1 hour a week
O ≥ 1 but < 2 hours a week
O ≥ 2 but < 3 hours a week
O ≥ 3 but < 4 hours a week
O ≥ 4 hours a week

APPENDIX I - 7-DAY PHYSICAL ACTIVITY LOG

Directions:
For each column, write the number of minutes spent on each activity during the hour indicated. For each column, the total number of minutes should equal 60. For example, if you spend 30 minutes walking fast, 10 minutes driving, and 20 minutes eating during a one hour periods, you would put:
30 in the "moderate activity" column
10 in the "moving vehicle" column
20 in the "sitting or standing" column

Sleeping = sleeping or lying still relaxed.

Sitting or standing = sitting or standing still (such as sewing, writing, eating)

Very Light activity = carpet sweeping, sweeping floors, washing dishes-standing, clearing dishes from table, cooking or preparing food or serving food, making bed, mowing lawn (riding), walking on job, dressing, undressing whirlpool (sitting), fishing from a boat (sitting)

Light activity = stationery bicycling (at easy pace) food shipping with cart, raking lawn, gardening, walking or walking downstairs carrying objects of less than 25 pounds, golf, scrubbing floors on hands and knees.

Moderate activity = aerobics, carrying groceries upstairs, moving household furniture, raking, mowing lawn (hand mower), horse grooming, shoveling, digging ditches, truck driver (loading and unloading), basket ball game, jumping rope slowly, roller skating, kickball, climbing a ladder, backpacking, swimming laps free style

Heavy activity = ski machine, moving household items upstairs, fire fighter climbing ladder with gear, boxing, competitive football, competitive soccer, water polo, speed skating.

Moving vehicle = driving or riding in a moving vehicle (car, bus, scooter, motorcycle, roller coaster).

PSEUDONYM_____ Day _____ Date: _____

EARLY MORNING

Activity	12 AM	1 AM	2 AM	3 AM	4 AM	5 AM
Very Light						
Light						
Moderate						
Heavy						
Moving Vehicle						

MORNING **Waking up Time _____**

Activity	6 AM	7 AM	8 AM	9 AM	10 AM	11 AM
Very Light						
Light						
Moderate						
Heavy						
Moving Vehicle						

AFTERNOON

Activity	12 PM	1 PM	2 PM	3 PM	4 PM	5 PM
Very Light						
Light						
Moderate						
Heavy						
Moving Vehicle						

EVENING Bed Time _____

Activity	6 PM	7 PM	8 PM	9 PM	10 PM	11 PM
Very Light						
Light						
Moderate						
Heavy						
Moving Vehicle						

APPENDIX J - PLANNED BEHAVIOUR VARIABLES QUESTIONNAIRE

Variables: Physical Activity Behaviour, Efficacy, Intention

1. How physically active have you been over the past six months? (Please check one)

O Completely Inactive
O Sporadically Active (less than twice a week)
O Regularly Active (two or more times a week)

2. What is your level of physical activity exertion? How hard do you exercise? (Please check one)

O **Low Intensity** (such as slow walking)
O **Moderate Intensity** (such as brisk walking)
O **High Intensity** (such as fast walking)

3. What is your favorite, or most common, physical activity that you engage in at the present or that you would like to engage in?

_____

4. How confident are you that you could engage in your favorite physical activity the following number of times <u>each week over the next month</u>:

a) One time per week

0	1	2	3	4	5	6	7	8	9	10
Not at all Confident				Moderately Confident					Completely Confident	

b) Two times per week

0	1	2	3	4	5	6	7	8	9	10
Not at all Confident				Moderately Confident					Completely Confident	

c) Three times per week

0	1	2	3	4	5	6	7	8	9	10
Not at all Confident				Moderately Confident					Completely Confident	

d) Four or more times per week

0	1	2	3	4	5	6	7	8	9	10
Not at all Confident				Moderately Confident					Completely Confident	

5. How confident are you that you can engage in your favorite physical activity each week over the next month:

a) At a low intensity (similar to slow walking or light water exercises)

0	1	2	3	4	5	6	7	8	9	10
Not at all Confident				Moderately Confident					Completely Confident	

b) At a steady, moderate intensity (similar to brisk walking or aerobic exercise)

0	1	2	3	4	5	6	7	8	9	10
Not at all Confident				Moderately Confident					Completely Confident	

c) At a moderate intensity with some "spurts" of increased intensity (similar to fast walking or challenging workouts)

0	1	2	3	4	5	6	7	8	9	10
Not at all Confident				Moderately Confident					Completely Confident	

6. <u>During the next 4 weeks</u>, I will regularly engage in my favorite physical activity(s) _____ times <u>each week.</u>

7. How confident are you that you can engage in your favorite physical activity at least 2 times <u>each week over the 2 weeks</u>:

a) In the face of your fibromyalgia symptoms:

0	1	2	3	4	5	6	7	8	9	10
Not at all Confident				Moderately Confident					Completely Confident	

b) When you are fatigued:

0	1	2	3	4	5	6	7	8	9	10
Not at all Confident				Moderately Confident					Completely Confident	

c) When you are experiencing severe tenderpoint pain:

0	1	2	3	4	5	6	7	8	9	10
Not at all Confident				Moderately Confident					Completely Confident	

_____

APPENDIX K - EXERCISE PERSEVERANCE AND BARRIERS INSTRUMENT

How often have the following **prevented** you from getting exercise or doing moderate-intensity physical activity? (Note: Moderate-intensity physical activity includes such activities as recreational swim, gardening, and heavy house cleaning)

A. Self-conscious or embarrassed about my looks when I exercise or do physical activity
   a. Never
   b. Sometimes
   c. Very often

B. Lack of interest in exercise or physical activity
   a. Never
   b. Sometimes
   c. Very often

C. Lack of self-discipline
   a. Never
   b. Sometimes
   c. Very often

D. Lack of time
   a. Never
   b. Sometimes
   c. Very often

E. Lack of company
   a. Never
   b. Sometimes
   c. Very often

F. Lack of family support
   a. Never
   b. Sometimes
   c. Very often

G. Lack of enjoyment from exercise or physical activity
   a. Never
   b. Sometimes
   c. Very often

H. Discouragement
a. Never
b. Sometimes
c. Very often

I. Lack of equipment
a. Never
b. Sometimes
c. Very often

J. Weather
a. Never
b. Sometimes
c. Very often

K. Lack of skills
a. Never
b. Sometimes
c. Very often

L. No facilities or space to exercise
a. Never
b. Sometimes
c. Very often

M. Not knowing how to exercise
a. Never
b. Sometimes
c. Very often

N. Bad health
a. Never
b. Sometimes
c. Very often

O. Lack of transportation to get to place to exercise
a. Never
b. Sometimes
c. Very often

P. Pain or discomfort
a. Never
b. Sometimes
c. Very often

Q. Fear of injury
a. Never
b. Sometimes
c. Very often

R. Cost of exercising
a. Never
b. Sometimes
c. Very often

S. Inconvenience of perspiration and/or combing
a. Never
b. Sometimes
c. Very often

T. Fear of safety
a. Never
b. Sometimes
c. Very often

U. Lack of a block of time for doing exercise
a. Never
b. Sometimes
c. Very often

V. Exercise intensity required to improve health is too high to me
a. Never
b. Sometimes
c. Very often

W. When it is too cold or hot
a. Never
b. Sometimes
c. Very often

X. Other _____
a. Never
b. Sometimes
c. Very often

APPENDIX L - EXERCISE SELF-SCHEMA QUESTIONNAIRE

Circle the number that corresponds best to how well each of the statements describes you.

	Does not describe me									Describes me
1. Someone who exercises regularly	1	2	3	4	5	6	7	8	9	10
2. Someone who keeps in shape	1	2	3	4	5	6	7	8	9	10
3. Physically active	1	2	3	4	5	6	7	8	9	10

Circle the number that corresponds best to how important each of the following characteristics is to you.

	Not at all important									Very important
1. Exercising regularly	1	2	3	4	5	6	7	8	9	10
2. Keeping in shape	1	2	3	4	5	6	7	8	9	10
3. Physically active	1	2	3	4	5	6	7	8	9	10

_____

APPENDIX M - REPORT OF MEMBER CHECKING ACTIVITIES

1. Saskatoon Fibromyalgia Support Group Meeting - Nov 2, 2004 (7:30 to 9:00 PM)

Attendance

In addition to the researcher and the recorder, 22 people, 20 women, 2 men attended. A personal invitation had been mailed to all of the study participants; five participants attended (Laura, Allie, Sheena, RoseMarie, Meme).

Description

Using a Powerpoint presentation with some embedded sound clips supplemented by a handout, the researcher presented the results of the study and the analysis to that point. A colleague attended the meeting and assisted with set-up and took notes.

The audience was very interested; several women were taking notes. There were no questions during the presentation but animated discussion followed the presentation.

One woman (Laura) speculated that the role of personality might be very important in forming and acting on the intention with some people being more laid back and others more driven. Some women who had not been in the study described their experiences with physical activity.

The researcher took the opportunity of asking for help with specific the naming of categories/ concepts (e.g., naming the category which included taking specific actions to reduce discomfort associated with LTPA by taking actions before physical activity such as massage. The participants were asked if they had a better name for the category than “Technical Strategies). To which one woman responded “body works, body support, and complementary methods.”

The researcher asked the audience specifically what they thought of the cyclical process (an early iteration of the Session-specific Level – Pattern-specific Level Theory). Several women spoke up and commented that they thought the “cyclical process” was “correct”. They liked the “pump” image better than the gears. The most important comment here was that “stopping” had been described as a response to obstacles or negative outcomes. One woman pointed out that, instead of stopping, she had taken another option – that of modifying the activity.

After the meeting, a participant of the study (RoseMarie) commented on how much she had enjoyed the presentation. She stated that she was willing to be help in any way with the research and that if the researcher wanted to talk to her, she should just phone.

The recorder was a qualitative researcher. After the meeting, she had a few good suggestions. She suggested that during the presentation, the researcher should have more clearly communicated to the audience that direct quotes would be used and that the individuals in the study had given consent, to avoid the possible perception of voyeurism.

All in all, this was a very positive experience, very beneficial to my analysis. The self-help group organizers have given me an open invitation to come back again when I am further with this.

As a result of this presentation, no new concepts emerged; this could be construed as evidence of saturation.

2. Member Checking – Reading of the Thesis

Two participants, RoseMarie and Maya, read drafts of the thesis to provide comments on the credibility of the study findings. (Note. The drafts were close to final.)

a) Report of a phone conversation between RoseMarie and the researcher (prepared on June 7, 2005 by the researcher using notes taken during the conversation.)

Description

On June 2, 2005 - RoseMarie was given *Draft:050601* to review. She phoned to report her impressions of the thesis. RoseMarie reported that she had read the thesis – her husband had been away for the past 2 days and the house was quiet – she read 3 hours on June 6, and she finished with another 3 hours on June 7. She said she had hung on every word and that she had her dictionary out and looked up everything. She said several times during the conversation, "it's really good."

RoseMarie pointed out 5 sentences where she didn't agree with the wording. These wording problems were in the literature review and in the implications sections of the Thesis and are as follows.

- Chapter 2 – Literature Review, p. 17: *strength training is beneficial*. RoseMarie's impression was that it made her worse, but she said, "That's my comments, other might be OK, but strengthening exercise usually set me back."
- Chapter 2 – Literature Review, p. 16: She did not like the connotation of the word "distorted" – in the phrase *"It is possible that factors associated with fibromyalgia (e.g., poor physical fitness, pain, fatigue, anxiety, depression) influence recall of physical activity and distort estimations of intensity and duration and frequency of physical activity events recorded on self-report instruments."* She thought that the way this was worded might imply that people with fibromyalgia distort things on purpose. It should be pointed out that any inaccuracy is not intentional.
- Chapter 8 – Implications, p.175, *"It appears that there is a need for training for physicians, physical therapists, and other Health Care Professionals with respect to exercise prescription specific to individuals with fibromyalgia*." RoseMarie found this sentence awkward. She thought that the point was that exercise needs to be individualized – each person has their own needs.

- Chapter 8 – Implications, p. 170, *"Other goals valued by the participants that could be emphasized were: securing future health into retirement years, maintaining ability to continue social integration (e.g., being able to participate in family events), maintaining independence, and controlling symptoms especially stiffness."* The thought stiffness was not the only symptom that should be noted here – pain and immobility should be added here.
- Chapter 8 – Implications, p.177, *"The impact of fatigue and depression seemed to be relatively greater than pain as a barrier to adopting and maintaining LTPA. The impact of interventions to reduce fatigue and depression on adoption and maintenance of habitual LTPA should be examined."* Rosemarie: "This is not quite accurate. The pain is important. It's the pain that drains me, it grinds away at you the whole day. That's what causes the fatigue and depression"

She agreed that the experiences recorded in the thesis were credible and that she empathized with the other participants. She commented on a few examples:

- About fear of falling "That's true about walking on a treadmill. Walking on a Treadmill when you feel so painful is frightening."

- Fibro Fog – "yes, its like that. Little things are big – like even to make something to eat. But doctors think it is in your head. They think they have to get you on antidepressants"

Other more general comments were:

- AB: "Did this ring true?" RoseMarie: "Oh, yes! You didn't just pick one type. You have people who did every type of exercise. Even people who like exercise and people who didn't. You covered everything. A good balance." AB explained saturation, and then asked: "Do you think I go saturation?" RoseMarie stated, "yes, I think so. I think you got enough."

- "I found this good. It made me take a new look at myself. I have slacked off a bit – the roads are mucky this week because of the rain and I used that as an excuse. I have got to get back. When the roads are bad, instead of walking my usual route, I walk back and forth in my yard." She added a few more comments on walking. She said, "Walking is so easy. You don't need much equipment. You can do it anytime. You can bundle up when it's cold. Will power is all that is needed. And after thirty times – it becomes a habit. If you don't go, you feel like you are missing something."

- "Something strange happened when I finished … It's embarrassing, but I will tell you. When finished reading it, I closed the book, and I said, 'Umph! I can do this.' It just felt that I could." She had the feeling that she had potential not being used. She thought that she, herself, could have written about this topic, but she

quickly explained that the academic style of the writing was beyond her. Nevertheless, the topic felt familiar, something she understood.

b) Maya's Response to reading Draft 050606

From an email dated: June 8, 2005

What I did is I sat down to read the document in two sittings and ended up having to stand and move around a lot to prevent from getting too stiff as I am in a stiffness phase at the moment; but I had a notepad by me and as different thoughts came I wrote them down. Your main question was "does it ring true?" Definitely, so much so that at times I was tearful and at other times very hopeful. I will get into specifics soon.

I was a bit apprehensive initially to sit and read the document because as I have mentioned before, part of my coping mechanism is not to focus on my fibromyalgia.

I agree very strongly with the fatigue factor being a strong impact on self-efficacy. It is interesting that you felt that you had not covered this topic because I felt many of the comments that the participants made were in the realm of self-efficacy (as you did mention in the end of your thesis)

I liked your water hose and gear analogies. I found as I was reading the pattern-specific-level 5.4 I began strategizing how I could raise my level even more. I must confess I was pleased that you think I was in the integrated phase, but with lapses I think I move between the mature to the integrated phases. I also found that on p. 79 I became tearful - emotional. I think I'm crazy sometimes but actually it just re-enforces how difficult and challenging this disease is to live with. By p. 105 I was emotionally draining to face my reality. I had to stop reading, take a big breath and walk around. It was interesting that my legs were aching more. It was like my mental block of not

perceiving the pain had been moved. On the other hand, I found p. 118 and 119 - strategies - very reassuring. Yes there are techniques that I use and can use more of to be successful.

p. 122 - I was also treated for depression about 6 years age for about 3 months in the winter. By p. 156 I had to stand to read as sitting so long was hard on my hips.

Thank you for asking me to read this thesis. We need more research and acknowledgement that this condition exists and although most of its symptoms are "hidden" they are very real and challenging to those of us who want to live physical lives. God Bless you for your work.