

UNIVERSITY OF CALGARY

Complementary and Alternative Medicine Decision Making by Women with  
Fibromyalgia

by

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The undersigned certify that they have read, and recommend to the Faculty of Graduate Studies for acceptance, a thesis entitled "Complementary and Alternative Medicine Decision Making by Women with Fibromyalgia" submitted by Annette Vroegindewey in partial fulfillment of the requirements of the degree of Master of Science in Health Research.

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## **Abstract**

**Background:** Fibromyalgia syndrome primarily afflicts women and is characterized by chronic and widespread musculoskeletal pain. Estimated complementary and alternative medicine (CAM) use among fibromyalgia syndrome patients is as high as 90%.

**Purpose:** The purpose of this study was to develop a substantive theory that captures the CAM decision making process in women with fibromyalgia syndrome.

**Method:** Seventeen in-depth, semi-structured, interviews were conducted consistent with a grounded theory study design.

**Results:** Participants went through four phases when making the decision to use CAM: 1) establishing readiness, 2) initiating fibromyalgia self management, 3) getting organized and 4) taking action. These results are presented as an emerging substantive theory.

**Conclusions:** CAM decision making is a process, occurring in phases. By using the Andersen socio-behavioural framework this process of health care utilization can be accurately captured. Understanding these phases will assist health care providers in giving tailored care, specific to the syndrome's stages.

## **Acknowledgements**

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## **Dedication**

This work is dedicated to those suffering from fibromyalgia syndrome. I am thinking especially of the women who generously offered their time for this study. I walked away from each of the interviews having learned something new. I am deeply appreciative for what you have taught me about living life with fibromyalgia syndrome.

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## **Epigraph**

Some people come into our lives and quickly go. Some stay for awhile and leave footprints on our hearts. And we are never, ever the same.

Author unknown

## **Chapter One: Introduction**

### **1.1 General introduction**

*“Just because the fibromyalgia would, uh, it just basically suffocates you”*  
(Participant K)

Little is known about the etiology of fibromyalgia syndrome (FMS) and treatment success rates are generally poor. It is mostly women who are affected by FMS and it has been reported in the literature that many of them resort to complementary and alternative medicines (CAM) (Ernst, 2000). However, many questions regarding CAM use by women with FMS remain to be answered: How do women with FMS decide to use CAM? When do they become interested in CAM? What motivates them to use CAM? Are they influenced by their conventional health care professionals? Where do they get information about these treatments? Is it difficult to start with CAM? Is it difficult to stay with CAM? Responses to such questions may provide important information to women suffering from this condition as well as to their health care providers. A qualitative study was conducted to develop a grounded theory that will assist in answering these questions. In this chapter the background to the study will be presented as well as the study rationale, the study objective, the research question and the thesis outline.

### **1.2 Background**

#### ***1.2.1 Fibromyalgia syndrome***

FMS is characterized by chronic, widespread musculoskeletal pain (Arslan & Yunus, 2003). The American College of Rheumatology states that a person must have at least three months of widespread pain and the pain must be present in at least 11 of 18 tender points to be classified with FMS (Lash, Ehrlich-Jones, & McCoy, 2001). Tender points are at specific anatomical points located on the body, but especially the torso and

upper extremities. Patients with FMS often report other symptoms such as poor sleep, cognitive dysfunction, irritable bowel syndrome, headaches, restless legs syndrome and depression (Arslan & Yunus, 2003). A new consensus document in regards to the classification and treatment of FMS has recently been published (Jain et al., 2004). The expert panel maintains the classification criteria as outlined above, but describes an additional array of signs and symptoms that clinicians can expect in FMS patients. These symptoms range from neurological complaints to cardiovascular concerns. Fortunately, not all patients exhibit these signs and symptoms, nor are they present at all times. Therefore, the main diagnostic criteria remain chronic musculoskeletal pain and the presence of tender points.

The etiology behind FMS is unclear; however certain risk factors have been identified which include a previous history of emotional stress, infection, physical trauma and female sex (Staud & Domingo, 2001). Research is ongoing in this area and central nervous system, neuroendocrine, neurological, growth hormone and sleep abnormalities are all being considered as potential causes of FMS (Staud & Domingo, 2001).

An accepted treatment protocol for FMS is lacking at present in spite of recently published consensus documents (Jain et al., 2004; Rashbaum, Lacerte, Braverman & Ericksen, 2003). The consensus documents maintain that no treatment is universally acceptable for FMS and that the efficacy of treatment must be established on a per patient basis (Jain et al., 2004). Currently, most patients are offered some form of pharmacological therapy, including antidepressants, opioids, nonsteroidal anti-inflammatory drugs (such as Ibuprofen) and plain acetaminophen (i.e. Tylenol). Again, the long-term efficacy of these pharmaceuticals has not been established (Leventhal &

Bouali, 2003; Rashbaum et al., 2003). Gentle aerobic exercise and education around FMS and FMS management are also recommended, with exercise being the most frequently recommended treatment (Meyer & Lemley, 2000; Rashbaum et al., 2003).

### ***1.2.2 Fibromyalgia syndrome prevalence and incidence***

Prevalence of FMS in Canada was measured most recently using data collected from the Canadian Community Health Survey Cycle 1.1 (2000). At that time a total of 1.1 % of the Canadian population reported a diagnosis of FMS, confirmed by a health professional (McNally, Matheson, & Bakowsky, 2006). The prevalence of FMS in the general adult US population is estimated to be 2% (Lawrence et al., 1998). In Canada prevalence of FMS in women is six times higher than in men. It is greatest in Canadian women aged 55-64, in low income brackets, living in BC (McNally et al., 2006). FMS prevalence is the same in rural and urban areas (McNally et al., 2006). Furthermore, the survey showed that immigrant women have significantly lower prevalence of FMS compared to non immigrant women (McNally et al., 2006). Behavioural determinants were measured in this study as well. Higher FMS prevalence rates were reported by women with higher Body Mass Index (BMI), whereas lifelong non-smokers and lifelong non-drinkers reported less FMS (McNally et al., 2006).

There appear to be no recent Canadian studies measuring FMS incidence. However, incidence in a Norwegian study for women aged 26-55, was found to be five new FMS cases per 1000 women per year (Forseth, Gran, & Husby, 1997).

### ***1.2.3 Living with fibromyalgia syndrome***

Much work has been done looking at the experience of living with FMS and the manner in which FMS impacts a person. Asbring (2001) suggests that women with FMS

lose part of their pre-illness identity, which forces women to accept the new person that they have become. This loss of pre-illness identity often revolves around a loss of energy and a subsequent decrease in activity (Asbring, 2001). This loss of energy negatively impacts the women's ability to socialize and to fulfill work obligations. Family life can be heavily impacted as the women find they are no longer able to keep up with its demands (Henriksson, 1995). Soderberg and Lundman (2001) describe living with FMS as learning how to live with negative changes in daily life patterns, work life, family life, and social life.

Chronic conditions can carry varying levels of stigma and FMS is no exception (Asbring & Narvanen, 2002). Most currently, women with FMS report stigma around three areas: first, they often feel as if they are perceived to be exaggerating or being dishonest about their symptoms; second, their health problems are often considered fictitious or due to psychological issues; and third, the diagnosis is often belittled as a "female" condition (Asbring & Narvanen, 2002). Experiencing stigma can lead to suffering and diminished self esteem (Asbring & Narvanen, 2002). The impact of stigma as experienced by women with FMS should therefore not be underestimated.

#### ***1.2.4 Complementary and alternative therapy use and fibromyalgia syndrome***

It is widely established that women with FMS are substantial CAM users. Ernst (2000) suggests that approximately two-thirds of patients with FMS are using CAM therapies. Others have estimated the use of CAM among FMS patients to be as high as 91% compared to the use of CAM in only 63% of patients with other rheumatology disorders (Eisenberg, Davis, & Etter, 1998; Pioro-Boisset, Esdaile, & Fitzcharles, 1996).

### ***1.2.5 Complementary and alternative medicine***

The most universally accepted definition of CAM is provided by the National Center for Complementary and Alternative Medicine (NCCAM) which is funded by the National Institutes of Health. NCCAM defines CAM as, “a group of diverse medical and health care systems, practices, and products that are not presently considered to be part of conventional medicine” (National Center for Complementary and Alternative Medicine, 2002). To allow for further delineation as to what can be considered CAM, NCCAM classifies CAM into five categories: “(1) alternative medical systems, such as traditional Chinese medicine (including acupuncture), naturopathic medicine, ayurvedic medicine<sup>1</sup> and homeopathy; (2) biological based therapies, including herbal, special dietary and individual biological treatments not accepted by the Food and Drug administration; (3) energy therapies such as Reiki<sup>2</sup> therapeutic touch, magnet therapy, qi gong<sup>3</sup>, and intercessory prayer; (4) manipulative and body based systems, for example, chiropractic, osteopathy and massage; and (5) mind-body interventions such as meditation, biofeedback, hypnotherapy and the relaxation response”. These categories of CAM were used in the study, especially during the recruitment process (Appendix A).

### **1.3 Rationale and Purpose**

CAM decision making in women with FMS is a complex issue and remains under explored. FMS is different from many other chronic conditions as it is impossible to verify FMS using objective measures,

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<sup>1</sup> Predominantly used in India, involves ingestion of herbs and minerals.

<sup>2</sup> Used for emotional and spiritual healing.

<sup>3</sup> Involves coordination of breathing techniques with specific body movements.

its etiology remains unclear and an unequivocal treatment strategy does not exist (Asbring & Narvanen, 2002). Since CAM use may have potential risks such as adverse effects from interactions between conventional therapies and CAM therapies, more insight into CAM decision making processes must be gained (Rao et al., 1999). Furthermore, health care providers have a responsibility towards their patients to support them, where possible, in making informed treatment decisions. Health care providers may be better able to assist patients in making safe and informed decisions around their treatment choices if CAM decision making in FMS patients is better understood. Furthermore, potential benefits of CAM use may become evident. Therefore, the purpose of this study is to develop a substantive theory that captures the decision making process in women with FMS when deciding to use CAM.

#### **1.4 Research question**

The following research question was used to guide this study: *What is the process that adult women with FMS go through when making the decision to use CAM?*

The study objective was to build a decision-making model based on the process that women with FMS go through when making the decision to use CAM. Participants were asked to discuss their perceptions of CAM, how they approach CAM decision making and their experiences with CAM.

#### **1.5 Thesis outline**

As complementary and alternative medicine decision making by women with FMS has hardly been addressed in the literature, the literature review in Chapter 2 focuses on CAM decision making in cancer patients and chronic disease patients. Chapter

3 is an overview of the methodology of the study including the study design, recruitment, data collection and data analysis. A discussion of methodological rigour and ethical considerations is found in this chapter as well. Chapter 4 contains a brief description of the study findings. Chapter 5 expands on Chapter 4 and includes a detailed description of the study results. Chapter 6 is used to discuss the manner in which the emergent substantive theory compares to the current literature as well as the Andersen socio-behavioural framework. Implications and recommendations of the results are found in Chapter 7. Chapter 8 contains a brief conclusion of earlier chapters and concludes the thesis.

## **Chapter Two: Literature review**

### **2.1 Introduction**

Literature pertaining to why FMS patients use CAM, i.e. what motivates them to use CAM, is presented first. As the literature on this topic is quite limited, reasons for CAM use in the general population and cancer patients are presented next. Cancer patients are the most widely studied patient population in terms of why patients use CAM; hence they are described here. Since this study is predominantly concerned with the “how” of CAM decision making, this will be addressed next. In other words, how does motivation or intent to use CAM translate into initiating CAM and perhaps even staying with CAM? As there is no literature pertaining to how CAM decision making takes place in FMS patients, CAM decision making in non FMS populations is presented. Cancer patients are described again, as well as chronic disease patients. A number of potential explanations are given as to why the literature is so limited in describing how CAM decision making takes place. A summarizing statement concludes this chapter.

### **2.2 Characteristics associated with CAM use in FMS patients**

There is no literature describing CAM decision making processes in FMS patients. However, three studies have focused on FMS patients’ characteristics associated with CAM use. One study showed that younger FMS patients who reported more pain and higher disability scores were more likely to use CAM than older patients who reported less pain and less disability (Nicassio, Schuman, Kim, Cordova, & Weisman, 1997). Rao et.al. (1999) also found a correlation between severe pain and history, frequency and magnitude of CAM use. Furthermore, patients who were diagnosed with FMS and used CAM were more inclined to discuss CAM use with their physician than

were those with other rheumatologic conditions (Rao et al., 1999). A British study showed that FMS patients who were using CAM, were of a higher socioeconomic class than FMS patients not using CAM (Dimmock, Throughton, & Bird, 1996). These CAM users were dissatisfied with conventional treatment for their FMS, but acknowledged that CAM would not offer a cure (Dimmock et.al., 1996).

Other FMS and CAM studies have focused on the prevalence of CAM use among FMS patients (Pioro-Boisset et al., 1996; Rao et al., 1999; Rao, Kroenke, Mihaliak, Grambow & Weinberger, 2003). Data collection took place through surveys which were done via telephone or in person. The efficacy of CAM treatments for FMS patients has also received some attention in review articles (Berman & Swyers, 1999; Denison, 2004; Ernst, 2000; Ernst, 2002; Field, Delage, & Hernandez-Reif, 2003; Leventhal et al., 2003; Pioro-Boisset et al., 1996; Rashbaum et al., 2003; Rao et al., 1999; Rao, Kroenke, Mihaliak, Grambow, & Weinberger, 2003).

## **2.3 Why patients use CAM**

### General population

There are multiple explanations of why the general population chooses to use CAM. These explanations can be summarized into two categories: 1) patients are “pulled” towards CAM and 2) patients are “pushed” away from conventional medicine (Furnham, 1996). Factors that pull patients towards CAM, i.e. factors that seem appealing about CAM, are philosophical congruence with CAM practices, desiring personal control over treatment, a different relationship with their therapist, accessibility and increased well being (Furnham, 1996).

These factors all appear to be related to the patient anticipating some form of benefit or reward. For example, if a patient chooses to use CAM they may be rewarded with a good relationship with their therapist, control over their treatment and so forth.

Factors that can push patients away from conventional medicine include dissatisfaction with conventional medicine, rejection of conventional medicine, desperation and in some constituents the cost of private conventional medical care (Furnham, 1996). Dissatisfaction with conventional medicine may be due to a number of issues such as ineffective treatments, adverse effects of treatment, waiting lists or the provider-patient relationship (Furnham, 1996). Concerns with the provider-patient relationship may arise from poor patient-physician communication (Furnham, 1996). In contrast to the “pull” factors, these factors are related to the patient being able to remove him or herself from potentially negative or unpleasant situations. For example, if the patient is displeased with his or her conventional physician, using CAM may allow the patient to minimize contact with the physician thus avoiding a potentially unpleasant encounter.

### Cancer patients

There is a plethora of studies assessing why cancer patients use CAM. Verhoef, Balneaves, Boon and Vroegindewey (2005) summarized 52 studies to assess reasons for CAM use as well as socio-demographic and disease characteristics associated with CAM use in cancer patients. They found a wide variety in reasons for CAM use, including “a perceived beneficial response was stated most often (38.4%), followed by wanting control (17.3%), a strong belief in CAM (17.3%), CAM as a last resort (9.6%), and finding hope (9.6%)” (Verhoef et al., p.275, 2005). Surprisingly, in contrast to Furnham’s

findings (1996), only two studies mentioned disappointment with conventional treatment or disappointment with a conventional practitioner as reasons for CAM use. Female sex, younger age, advanced education and a higher income were all found to be predictive of CAM use. Ethnicity and type of cancer did not appear to be significant in predicting CAM use.

#### **2.4 How patients make the decision to use CAM**

Decision making theory is concerned with “how people (and other organisms and machines) combine desires (*or* utilities, personal values, goals, ends, etc.) and beliefs (*or* expectations, knowledge, means, etc.) to choose a course of action” (Hastie, p.655-656, 2001). Decision making describes the process one goes through before settling on a specific course of action.

##### Cancer patients

Three qualitative studies were located looking at how cancer patients make the decision to use CAM (or not). One study assessed CAM decision making in 29 men with prostate cancer (Boon, Brown, Gavin, & Westlake, 2003). Both fixed and flexible decision making factors were identified. Fixed decision making factors included the participants’ “age, co-morbid conditions and disease stage” (Boon et al, p. 475, 2003). Older men with co-existing health issues had limited options in the conventional health care system and they felt this pushed them into looking at CAM. Flexible decision factors included fearing adverse events with conventional treatment, negative experiences with conventional health care providers and a desire to be in control of the decision making process. These were all considered to be motivating factors in trying CAM.

A similar study was done involving 36 breast cancer survivors (Boon, Brown, Gavin, Kennard, & Stewart, 1999). The results showed that patients went through a process of discovery and investigation around CAM when deciding whether to use CAM. This discovery of CAM was either passive (on recommendation from someone from their social network) or active (the patient did her own research). The actual weighing of “pros” and “cons” was described as an individual choice, i.e. patients acknowledged that it was their responsibility. Nonetheless, patients did prefer support from physicians and their social network in making the actual decision. Not enough information and the possibility that a treatment could cause harm were given as reasons not to start CAM. Patients used CAM for a variety of reasons including, 1) doing everything they could to increase survival, 2) having negative experiences with conventional medicine, 3) preventing getting worse and last, 4) feeling that CAM would not cause harm and they therefore had nothing to lose. Cited barriers to staying with CAM were high cost, limited time and poor access.

Montbriand (1995) has created a decision tree model in an attempt to capture cancer patients’ decision strategies when deciding to use CAM, whether for the first time or when trying new CAM. This study involved 300 patients with either a respiratory or digestive system cancer. The author categorized the participants into three groups: 1) high interest (some had used CAM in the past where others had never used CAM yet they were looking to use CAM, 2) regular (had used CAM in the past and would continue on with current CAM, yet no desire to try a new CAM), and 3) biomedical only (were only using conventional medicine and were not interested in CAM). The high interest participants often learned about CAM from their social network and they made it clear

that they wanted a change in health care practices including self management type of activities like changing diet. They indicated that they were stressed and that they preferred to have control over their health care decisions. They also tended to be reluctant to disclose their CAM use to conventional medicine providers. The regular group of participants was less stressed than the high interest group and they did not want to make a change in their health care practices. Unlike the high interest patients, the regular patients were not self motivated to search for information around possible cures.

#### Chronic disease patients

How CAM decision making takes place has been addressed in three other studies. A total of 12 rheumatology patients were interviewed in depth and were queried in regards to their CAM decision making behaviours (Caspi, Koithan, & Criddle, 2004). The types of rheumatologic conditions were not specified by the authors. Of the 12 patients only four patients were using both CAM and conventional medicine. These four patients were initially “pulled” into CAM by close friends and acquaintances. Patients carefully reviewed CAM information once they had identified their CAM choices. Patients felt that treatments had to make sense and they valued the “science” behind treatments more than other people’s opinions. Playing an active role in the decision making process was preferred as well. Staying with CAM was determined by how effective the treatment was, whether the treatment fell in line with their value system and considerations around cost. Barriers to staying with CAM were again cost and the “weirdness” of the treatment (i.e. treatments which patients felt were too strange).

D’Crus and Wilkinson (2005) not only looked at why patients consulted a CAM practitioner, but more interestingly, what made patients initiate CAM and then stay with

it. They recruited patients from a CAM clinic in an urban area, without specifying patient conditions. After analyzing 158 surveys they found that 2/3 of their sample started CAM after a CAM modality was recommended to them by someone from their social network. Furthermore, they report that compliance with CAM treatment was based on 1) improvement in general health status, 2) the relationship with the CAM provider and finally, 3) having met specific expectations in terms of treatment outcome.

Finally, Thorne, Paterson, Russell and Schultz (2002) looked at CAM decision making in chronic illness such as Type 2 Diabetes, multiple sclerosis and HIV/AIDS. They concluded that participants 1) wanted to be involved both in CAM and conventional medicine, 2) wanted to be knowledgeable around CAM, 3) felt that managing their disease was their responsibility, 4) found it important to evaluate the impact or the outcome of CAM and, finally 5) appreciated a healthy dialogue with their physicians around CAM.

These six studies touch on a number of similar concepts around how CAM decision making takes place however, different terminology is used in the different studies. This is problematic for a number of reasons. First, it is challenging to compare the studies side by side. Hence, in an effort to summarize these concepts, the above discussed studies are presented in Table 2.1. The following categories have been used to group the study findings: *role of the social network, decisional control preferred by the patient, role of information seeking, motivators, barriers to starting CAM, reasons for staying with CAM and barriers to staying with CAM.*

Table 2.1

*Summary of current literature on CAM decision making in cancer and chronic disease populations*

Findings	Role of social network	Patients role in decision	Role in information seeking	Motivators	Barriers to starting CAM	Reasons for staying with CAM	Barriers to staying with CAM
<b>Boon et al., 2003 (cancer)</b>		Active		<ul style="list-style-type: none"> <li>▪ Co-morbidities</li> <li>▪ Disease stage</li> <li>▪ Adverse events with conventional treatment</li> <li>▪ Negative experiences with conventional medicine</li> </ul>			
<b>Boon et al., 1999 (cancer)</b>	<ul style="list-style-type: none"> <li>▪ Support</li> <li>▪ Discovery of CAM</li> </ul>	Accountable for choice	Active	<ul style="list-style-type: none"> <li>▪ Explore all options</li> <li>▪ Negative experiences with conventional medicine</li> <li>▪ Treatment not harmful; therefore nothing to lose</li> </ul>	<ul style="list-style-type: none"> <li>▪ Not enough information</li> <li>▪ Potential for harm</li> </ul>		<ul style="list-style-type: none"> <li>▪ High cost</li> <li>▪ Limited access</li> <li>▪ Limited time</li> </ul>
<b>Montbriand, 1995<sup>4</sup> (cancer)</b>	<ul style="list-style-type: none"> <li>▪ Discovery of CAM</li> </ul>	Active	Active	<ul style="list-style-type: none"> <li>▪ Perceived stress</li> <li>▪ Faith in health care practice</li> <li>▪ Preferred treatment methodology</li> <li>▪ Wanting a change in health care system</li> <li>▪ CAM that involved self care</li> </ul>	<ul style="list-style-type: none"> <li>▪ Cost</li> </ul>		
<b>D’Cruz et al., 2005 (various)</b>	<ul style="list-style-type: none"> <li>▪ Discovery of CAM</li> </ul>					<ul style="list-style-type: none"> <li>▪ Improvement in health status</li> <li>▪ Relationship with CAM provider</li> <li>▪ Met expectations in terms of treatment outcome</li> </ul>	
<b>Caspi et al., 2004 (rheumatology)</b>	<ul style="list-style-type: none"> <li>▪ Discovery of CAM</li> </ul>	Active			<ul style="list-style-type: none"> <li>▪ Cost</li> <li>▪ “Weirdness” of treatment</li> </ul>	<ul style="list-style-type: none"> <li>▪ Treatment efficacy</li> <li>▪ Cost</li> <li>▪ Matches value system</li> </ul>	
<b>Thorne et al., 2002 (DM/MS/HIV)</b>		Active	Active			<ul style="list-style-type: none"> <li>▪ Outcome</li> </ul>	

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<sup>4</sup> This only applies to the high interest group (patients who were using conventional medicine, CAM and were searching for information).

Secondly, it is difficult to create a cohesive theoretical framework explaining how CAM decision making takes place when little consistency in terminology is used. For example, Boon and authors (1999) refer to weighing “pros and cons” by breast cancer survivors when they are making the decision whether or not to use CAM.

Another potential factor for the lack of theories is that understanding how CAM decision making takes place is best investigated with a study design that allows for in-depth discussions (such as seen in qualitative research designs) and perhaps has a longitudinal component. Not surprisingly, five out of the six studies used qualitative designs. D’Crus and Wilkinson (2005) were the only authors not using a strictly qualitative design. However, even though their primary data collection tool was a survey, supplemental information was collected through eight semi-structured interviews. As qualitative studies often take more time to complete than quantitative studies, this may also be a contributing factor to why so little work has been done in this area.

## **2.5 Summary of literature review**

At present there is no literature addressing how CAM decision making takes place in women with FMS. How CAM decision making takes place has been addressed in cancer patients and chronic disease patients albeit in a very limited fashion. At best, the literature shows early models of the decision making process in cancer patients (Boon et al., 1999). In contrast to cancer, FMS is a chronic, non-terminal condition. Due to these contrasts in disease characteristics, we cannot assume that these cancer population based decision-making models are applicable to FMS patients. Thus, looking at how CAM decision making takes place in FMS patients, from a qualitative research perspective, is overdue.

## **Chapter Three: Method**

### **3.1 Brief overview of the study design**

A grounded theory design was used for this study. Grounded theory is described as “theory that was derived from the data, systematically gathered and analyzed through the research process. In this design, method, data collection, analysis and eventual theory stand in close relationship to one another” (Strauss & Corbin, p.12, 1998). Individual, in-depth, semi structured interviews were conducted with 17 women diagnosed with FMS. Analysis methods unique to grounded theory methodology were used to generate concepts, categories, and finally the emerging substantive theory, based on the interview data.

Additional data were collected through a short demographic questionnaire which was included in the telephone screening interview and the Fibromyalgia Impact Questionnaire (FIQ). Both questionnaires were used to provide a description of the participants, with the FIQ specifically capturing the impact of the condition. As quantitative data were not used to develop the emergent substantive theory, the study cannot be considered a mixed method study (Creswell, Fetters, & Ivankova, 2004).

### **3.2 Qualitative methodology**

When developing a research question and subsequent study design, the question arises whether a quantitative or qualitative study design should be used. The following discussion briefly summarizes the rationale for choosing a qualitative research design, as well as the assumptions associated with a qualitative research paradigm. Subsequent discussion focuses on grounded theory methodology and the use of literature in a grounded theory study.

The research question is: what is the process that adult women with FMS go through when making the decision to use CAM? Or in other words, *how* do women with FMS make the decision to use CAM? There were no current theories that could be used to answer the research question, nor was it known which variables should be studied. Due to the exploratory nature of the question, an exploratory approach had to be used. This made using a qualitative design appropriate (Maxwell, 1996).

Attempting to capture the actual process of decision making also lends itself well to a qualitative design (Maxwell, 1996). This is difficult to do with questionnaire type data as participants need the opportunity to tell their stories rather than have their experiences forced into pre-conceived categories. The context in which women with FMS make CAM decisions, as well as the influence this context has on their CAM decision making behaviour has to be taken into account as well. Such a multi-faceted concept cannot easily be captured in a questionnaire. Furthermore, the meaning of CAM decision making for women with FMS, including how they make sense of their own behaviour has to be studied. A qualitative design allows for collecting this type of information since the questions asked during a qualitative interview are open-ended and broad (Maxwell, 1996). Finally, as qualitative inquiry focuses on participants' perspectives and uses a style of inquiry that is often more holistic<sup>5</sup>, it lends itself well to studying CAM decision making (Adler, 1999; Adler, 2003).

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<sup>5</sup> The researcher and the participant are on equal terms and the participants' views and thoughts are deeply valued and integrated into the study (Adler, 1999).

### ***3.2.1 Assumptions***

As this is a qualitative study, the assumptions underlying a qualitative research paradigm must be discussed. The main assumption is that the researcher will to some extent influence the study outcomes. In an effort to understand the researcher's attitudes, experiences and perspectives around CAM, CAM use and FMS, the researcher was interviewed prior to the start of the study by one of the committee members. It became evident that the researcher holds balanced views on CAM, CAM use and FMS. For example, there still is much discussion in the literature around the legitimacy of FMS. The researcher holds the stance that whether or not the syndrome exists, patients are accessing health care with the expectation that something will be done for them, and hence health care providers must be ready to care for these patients. Furthermore, the researcher holds the view that CAM may have a place in patients' care plans. Hence, reports of participants outlining the efficacy of their CAM were taken seriously and were considered valid data. These balanced views notwithstanding, the impact of family life, culture, spirituality and so forth, cannot be underestimated in shaping the researchers' views of the situations and concepts that were discussed by the study participants. Bentz and Shapiro frame this most cogently:

“Research is always carried out by an individual with a life and a lifeworld... a personality, a social context, and various personal and practical challenges and conflicts, all of which affect the research, from the choice of a research question or topic, through the method used, to the reporting of the projects outcome” (p.4,1998).

Furthermore, the researcher's professional experiences as a registered nurse will have influenced at least to some extent the manner in which the research was viewed. Since it is impossible to capture all the researcher's attitudes, experiences and perspectives, it

must therefore be acknowledged that these perspectives, however unintended, may have had a subtle influence over the planning, implementation and analysis of this research.

### ***3.2.2 Grounded theory methodology***

A number of questions come to mind when discussing grounded theory methodology. First, why was a grounded theory approach chosen for this study? Second, what is the paradigm or worldview in which grounded theory is situated? Finally, what is theory and specifically what is grounded theory? These questions will be explored in the following paragraphs.

Grounded theory methodology was deemed an appropriate methodology for this study for a number of reasons. First, grounded theory questions are focused towards process and action (Strauss & Corbin, 1990). Strauss and Corbin define process as follows: “the linking of sequences of action/interaction as they pertain to the management of, control over or response to, a phenomenon” (p.143, 1990). This fits with trying to understand what actions women with FMS take (based on their thoughts and intents) and how these actions link together resulting in the decision to use CAM (or not). Also, as discussed earlier, no current explanatory framework or theory exists in regards to CAM decision making by women with FMS. This is also a strong argument for using grounded theory methodology (Wentz, Lindberg, & Hallberg, 2004).

Grounded theory methodology is situated within a constructivist paradigm. This paradigm is based on “a relativist ontology (there are multiple realities), a subjectivist epistemology (knower and subject create understanding) and a naturalistic (in the natural world) set of methodological procedures” (Denzin & Lincoln, p.27, 1998). The methods

used in grounded theory align closely with this paradigm as the focus is on the participants and their “voices” (Strauss & Corbin, 1990). Interactions with participants take place in the participants’ natural setting and the broad range of the participants’ experiences allows for capturing multiple realities around one phenomenon. Thus, the emerging substantive theory comes from capturing the participants’ everyday reality.

Many definitions of “theory” exist in the literature. Kerlinger describes theory as “a set of interrelated constructs, definitions, and propositions that presents a systematic view of phenomena by specifying relations among variables with the purpose of explaining and predicting phenomenon” (p. 9, 1986). Strauss and Corbin describe theory in less abstract terms 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” (p.22, 1998). A well developed theory should not only be able to explain; it should also have predictive power (Strauss & Corbin, 1998). After all, it is a theory’s explanatory and predictive power that guides action (Strauss & Corbin, 1998). One should not assume that a complete and finalized theory is created after studying a particular phenomenon in one context. Theory by nature is flexible and can be verified, extended, or changed (McMillan & Schumacher, 2001).

A grounded theory then, should be “grounded” in the data, rather than deducted from a priori or pre-conceived assumptions (Glaser & Strauss, 1967). The researcher must commit to allowing concepts and categories to emerge from the data rather than use his/her own experiences or speculations in forming concepts and/or categories (Strauss & Corbin, 1998). A substantive theory evolves from studying a phenomenon in a particular

context (Strauss & Corbin, 1990). A substantive theory differs from a formal theory in that a formal theory is used to describe social processes in general. A formal theory emerges after a phenomenon has been studied in many different contexts (Strauss & Corbin, 1990). Once developed, a substantive theory can contribute to a formal theory (Glaser & Strauss, 1967).

### ***3.2.3 Definitions***

Describing the actual process of “doing” grounded theory is inherently challenging as “one learns the nuances of the methodology predominantly by doing it” (Schreiber, 2001). Making this somewhat easier is having an understanding of common terms used in grounded theory. Hence, a number of frequently used terms are presented in the table below.

**Table 3.1**

#### ***Terminology used in grounded theory***

<b>Term</b>	<b>Descriptor</b>
Coding	“The analytic processes through which data are fractured ( <i>broken down</i> ), conceptualized and integrated to form theory” (Strauss & Corbin, p.3, 1998).
Code	Descriptive phrase or word to describe event or idea in the data.
Concept	“Abstract representation of an event, object, or action/interaction that a researcher identifies as being significant in the data” (Strauss & Corbin, p.103, 1998). May become part of a category or be left as a higher level concept (Schreiber, 2001).
Category	A grouping or classification of concepts (Strauss & Corbin, 1998).
Core Category	The central phenomenon around which all the other categories are integrated (Strauss & Corbin, 1998). “In an exaggerated sense it consists of all the products of the analysis condensed in a few words that seem to explain what this research is all about” (Strauss & Corbin, p.146, 1998).

### 3.3 Use of literature

There is an ongoing debate as to how in-depth the literature should be reviewed before engaging in a qualitative study. In grounded theory studies, it is essential to suspend an extensive literature review until a theoretical framework or theory has emerged. Doing an in-depth literature review should be avoided because a sense of analytic paralysis<sup>6</sup> could set in as the researcher is so immersed in the already existing literature. This could lead to bias which may prevent the researcher from discovering new concepts in the data. It therefore “makes no sense to start with “received”<sup>7</sup> theories or variables (categories) because these are likely to inhibit or impede the development of new theoretical formulations...” (Strauss & Corbin, p.50, 1990). This stance was taken in this study and a complete review of the literature did not take place until member or participant validation<sup>8</sup> activities were complete. Nevertheless, in preparing for this study (i.e. writing the study proposal) various literature was read regarding CAM use and FMS. In particular, the manner in which patients are “pulled” and/or “pushed” towards CAM was discussed extensively in the proposal (Furnham, 1996). It should be noted however that this literature is focused on explaining *why* patients in the general population choose CAM, rather than *how* CAM decision making takes place (Furnham, 1996). Literature on CAM decision making specifically in FMS patients is virtually non-existent at present, and the cancer literature only shows initial models of the decision making process (Boon et al, 1999; Boon et al., 2003). Thus, even though literature was read before the study,

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<sup>6</sup> This means that doing an in-depth review may lead the researcher to focus on confirming the existing theories with the data, rather than analyzing the data creatively and with an unbiased view.

<sup>7</sup> Theories that the researcher has accepted to be true and applicable to the phenomenon under study.

<sup>8</sup> The summary of the results used to verify the emergent substantive theory with the participants.

this literature was not used to explain *how* patients with FMS make the decision to use CAM.

### **3.4 Research Team**

The researcher (AV) was predominantly responsible for data collection, data analysis, and she will be responsible for dissemination of the results. Dr. Verhoef reviewed a number of transcripts to review interviewing skills and coding. Dr. Scott reviewed a number of transcripts for coding consistency as well. Dr Scott was also involved in reviewing the member validation summary. Dr. Martin provided clinical insight throughout the study. A research assistant provided administrative support where needed.

### **3.5 Sampling and Recruitment**

#### ***3.5.1 Sampling***

Theoretical sampling is often used in grounded theory studies. The intent behind theoretical sampling is to “maximize opportunities to compare events, incidents, or happenings to determine how a category varies in terms of its properties and dimensions” (Strauss & Corbin, p.202, 1998). This sampling technique is more concerned with representativeness of concepts and how these concepts vary along a dimension, rather than the actual sample being representative of the general population. Theoretical sampling took place to recruit a participant for the 18-24 age category. This was done to assess how age impacts the decision making process, as the literature shows that CAM users are often young. The remainder of participants were recruited through a convenience sampling approach and resulted in a sample of women who had multiple CAM decision making experiences and varied widely in the types of CAM they tried.

They also had many different interactions with CAM providers. Thirdly, the participants presented with different co-morbidities and widely varying FIQ scores. Hence the participants' experiences around CAM decision making were sufficiently diverse and broad to allow for ample variety and density<sup>9</sup> in the concepts and categories. Thus, even though a convenience sampling technique was used, the broad range of data generated was sufficient to create the emergent substantive theory. The decision to stop sampling was based on three criteria. The first and foremost criterion was whether or not theoretical saturation had been reached. Theoretical saturation has been reached when “(a) no new or relevant data seem to emerge regarding a category, (b) the category is well developed in terms of its properties and dimensions demonstrating variation, and (c) the relationships among categories are well established and validated” (Strauss & Corbin, p.212, 1998). This was achieved through the constant comparative method which is explained in section 3.6. Once the point of theoretical saturation had been reached, no more women were recruited. Secondly, the time available for this research necessitated a stop to recruitment after 12 months. Finally, the reality of limited participant availability contributed to the final sample size of 17 participants.

A number of exclusion/inclusion criteria were used to screen potential participants. Men were excluded from this study as the prevalence of FMS among men is low (Buskila, Neumann, Alhoashle, & Abu-Shakra, 2000). Women with FMS who had completely turned away from conventional medicine, were also excluded. It has been suggested in the literature that patients who abandon conventional medicine have

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<sup>9</sup> Depth and detail.

different decision making processes than those patients who use CAM truly in a “complementary” sense, i.e. those patients that use CAM in addition to using conventional medicine (Caspi et al., 2004; Verhoef & White, 2002). Henceforth, since this is the first study looking at CAM decision making in FMS patients, it was deemed sensible to start by looking at truly “complementary” CAM users. Finally, participants had to be over 18 years of age and they had to be current CAM users (in order to limit recall bias). Last, verification of the FMS diagnosis by a physician had to be provided by all participants (Appendix H).

### ***3.5.2 Recruitment***

Participants were initially recruited from a rheumatology clinic. This rheumatology clinic is based out of Foothills Medical Center (FMC) and is part of the Division of Rheumatology. FMC is a large tertiary care referral centre for southern Alberta, south-eastern British Columbia and south-western Saskatchewan. One of the committee members (LM) approached individual patients as they came in for their appointments. Recruitment posters (Appendix A) were posted in the clinic waiting area to increase study visibility. Unfortunately, only four participants were recruited through this method.

In an effort to further increase study visibility, poster advertising was expanded to include the following locations: a family physician office in the community, a health and fitness program at the University of Calgary, notice boards throughout the University of Calgary, the Grace Women's Health Center, the FMS/ME society, a chiropractor's office, a massage therapy office, and a health food store. All these locations were in Calgary, Alberta. The study was also advertised at a CAM conference held in Edmonton, Alberta.

This resulted in a total of four interested participants, two of whom did not meet the inclusion criteria.

Recruitment remained limited and therefore ethics approval was sought and granted to send invitational letters (Appendix B) to patients in the Division of Rheumatology's FMS database. All the patients in this database meet the American College of Rheumatology criteria for the classification of FMS. These patients had at an earlier date given consent to be contacted for possible participation in FMS research projects. Due to the nature of the interviews (face to face) and travelling constraints, the letters were sent out to addresses in Calgary and surrounding area. The addresses were selected in a sequential manner starting at the top of the database and working towards the bottom of the database. One hundred letters inviting patients to participate were sent out. A total of 12 women contacted the researcher indicating an interest in the study. All but one woman met the study criteria; hence a total of 11 women were recruited in this manner. The remainder did not respond resulting in a total of 68 non-responders excluding 20 letters which were returned to the sender. It is not known how many of the non-respondents met the eligibility criteria. In sum, recruitment generated:

- 1 participant from the community through poster advertising
- 1 participant from a CAM conference
- 4 participants from the rheumatology clinic
- 11 participants from the FMS database

The two participants who were not recruited through the clinic or the database confirmed their FMS diagnosis through documentation from their physicians (Appendix H). One woman indicated an interest and subsequently declined to participate. An explanation for

not participating was not provided. A telephone screening form (Appendix C) was used to determine study eligibility for all the interested women.

### **3.6 Data collection**

#### ***3.6.1 Types of data***

Both qualitative and quantitative data were collected in this study. The quantitative data were related to the demographics of the participants as well as disease burden. These were collected to not only provide a comprehensive background of the study participants, but also to consider the context in which decision making takes place.

#### ***3.6.2 Quantitative instruments***

The demographic questionnaire (Appendix C) contained questions about the participant's age, income and ethnicity. This questionnaire was part of the phone screening process hence participants were asked these questions after they had given verbal consent to participate in the study. These questions were included not only to provide a comprehensive description of the participants, but also because the literature suggests that age, income and ethnicity have some impact on CAM use/decision making. Studies assessing FMS patients and CAM use show that older age is correlated with higher prevalence of CAM use (Nicassio et al., 1997). While ethnicity appears to be heavily related to medical decision-making, literature on CAM decision making and ethnicity is non-existent. Ferguson and Candib (2002) found that patients from minority groups are less likely to receive enough medical information and are less likely to participate in medical decision-making. Participants were also asked to disclose educational achievements. This was done because of the well-documented relationship between CAM use and high socioeconomic status (Wootton & Sparber, 2001).

Disease burden was measured through completion of the FIQ (Appendix D). Nicassio and authors (1997) found disease burden to be an important predictor of increased CAM use. The FIQ has been tested for construct validity, test-retest reliability and content relevance elsewhere and has been used extensively in FMS studies (Altan, Bingol, Aykac, Koc, & Yurtkuran, 2004; Burkhardt, Clark, & Bennet, 1991; Kendall, Elert, Ekselius, & Gerdle, 2002; Lindberg & Iwarsson, 2002). This brief, straight forward, self administered questionnaire was designed to measure subjective quality of life and health in FMS patients (Burkhardt et al., 1991). It consists of 19 questions. The first 10 questions assess the respondents' ability to complete instrumental activities of daily living (I-ADL) such as cooking and cleaning. Possible responses with the coinciding numeric scores are as follows: always able to do (0), most times able to do (1), occasionally able to do (2), never able to do (3). Question 11 asks how many days over the last seven days the respondent felt well. Question 12 asks respondents if they were unable to full fill their work obligations because of their FMS. Unemployed participants were asked to skip this question as well as question 14, as question 14 pertains to work obligations as well. Question 13 and questions 15 to 19 asks respondents about pain, fatigue, morning tiredness, stiffness, anxiety and depression (Burkhardt et al., 1991). A visual analog scale (100mm) is used to document respondents' answers.

### ***3.6.3 Data collection process***

After completion of the phone screening process participants were asked to choose an interview time and location convenient for them. Participants had the choice of being interviewed at the University of Calgary offices or at a location of their choosing providing there was a sense of privacy and limited background noise. Most participants

ected to be interviewed in their homes. Two participants were interviewed via telephone due to their geographical location. During the first interview with each participant the following activities took place:

- Overview of the study was given again to participants
- Participants were given the opportunity to ask any questions
- Consent form was given to participants, read and signed (Appendix E)
- The Fibromyalgia Impact Questionnaire was given, read and signed
- A semi structured interview lasting around 60 minutes was completed using an interview guide (Appendix F). The interview guide was modified as the study progressed based on the emerging concepts in the data. All interviews were audio taped and transcribed verbatim

The transcripts were prepared by a transcriptionist and all transcripts were double checked and corrected by the researcher where needed, i.e. if the transcriptionist had made an error in transcribing the researcher would correct the transcript based on the data on the tape. Data collection was an iterative process. This means that after each interview a preliminary analysis of the interview transcript was conducted before the next interview was started. This allowed the researcher to modify or adjust questions based on previous interviews. When analyses on all 17 interviews were complete, participants were contacted for the purpose of answering clarification questions in a follow-up telephone interview. This was done to clarify some areas of the interviews that remained unclear. Participant-specific interview guides were drafted for this purpose. Participants had given consent to being contacted for this follow-up interview on the initial consent form. All the women had given consent to be contacted for the follow-up interview; however the

contact information for one participant was no longer in use. Therefore 16 out of 17 women were contacted for the follow-up interviews. During this conversation participants also indicated whether they preferred to be involved in member validation activities versus ending their participation in the study. All 16 women preferred being contacted for member validation activities.

### **3.7 Data Analysis**

#### ***3.7.1 Overview of the process of analyzing interview data***

Unlike most quantitative data analysis, data analysis according to grounded theory methodology happens simultaneously with the process of data collection. The data were therefore analyzed in the following manner:

The first participant was recruited and interviewed. The interview was transcribed by a transcriptionist. The researcher then listened to the audio tape at least once and wrote a memo of her reflections. The transcript was then read over in its entirety at least once to gain an initial understanding of the data. The transcript was read again line by line. Open coding was then started which ultimately progressed to selective coding. The computer software program NVivo (version 2.0, © 1999-2002 QSR International Pty. Ltd.) was used to sort and track coding. Memos were written during this process to track analytic thoughts, including reflections on the properties, dimensions and relationships of the codes and categories. At the same time the researcher continued to recruit new participants who were then interviewed. As soon as the second interview was completed it was analyzed in the same fashion as just described. However, the first interview would be looked at again after the second interview was done to ensure no codes were missed in

the first interview. This type of coding or “iterative coding” was done throughout the data analysis process. The follow-up interviews were analyzed in similar fashion.

### ***3.7.2 The constant comparative method and the coding process***

The constant comparative method is a central component of grounded theory analysis and therefore warrants further explanation. The constant comparative method means the researcher is constantly comparing differences and similarities between what is being said in the interviews and seeing how it compares to the emerging categories (Strauss & Corbin, 1990). Glaser and Strauss (1967) further describe the constant comparative method as 4 stages: “1) comparing incidents applicable to each category, 2) integrating categories and their properties, 3) delimiting the theory, 4) writing the theory” (p.105). The constant comparison method was first used during open or first level coding (Strauss & Corbin, 1990; Schreiber, 2001). With each block of text or data the researcher asked “What is being said here? What does this mean? Who is involved? Where is this taking place? Aside from these sensitizing questions, theoretical questions such as “What is the influence of this on...? How does this relate to...? Why is this different from...?” were also asked. Open coding was followed by axial or second level coding (Strauss & Corbin, 1998; Schreiber, 2001). Second level coding can be thought of “examining and collapsing codes into categories or higher level concepts” (Schreiber, p.67, 2001). Names for categories were based on the data (i.e. every time participants described how their FMS was affecting their life, these events were sorted into the “Impact of FMS” category). Without looking at the category’s properties and dimensions this category would hold little depth (i.e. one would only know that FMS has an impact). Properties can be described as the characteristics of the category; whereas dimensions are where the

properties fall on a continuum (Strauss & Corbin, 1990). For example, one property of this category was that the impact of FMS is pervasive, meaning there were little to no activities of daily living that were not affected. Placing this on a continuum it was found that this pervasiveness was extensive (i.e. not only were most activities affected, the impact on most activities was extensive). Subcategories were also developed to increase the density of the categories, (i.e. to explain the categories in more detail). Furthermore, the researcher looked at ways in which the multiple categories interconnected with each other and if higher level concepts could be formed. For example, concepts such as “potential discomfort/ pain”, “doubting efficacy” and “cost” could be grouped under barriers to initial CAM. The last step in the analysis was selective coding or third level coding (Strauss & Corbin, 1990; Schreiber, 2001). This process was used to identify the core category (Improving functional self) by relating it to other categories and by validating the relationships between these categories from the data (Strauss & Corbin, 1990). After numerous drafts, the categories were used to formulate the emergent substantive theory. These steps are described in a sequential fashion; however there is definite overlap in the different types of coding. This process started with the first interview. Subsequent interviews were also coded in similar fashion. However, after each interview was done the researcher compared the codes, concepts and categories generated from the interview to all previous interviews. The codes and categories were kept in a list form to allow for tracking of changes as the analysis progressed. The constant comparative method was used throughout all the coding phases.

### ***3.7.3 Quantitative data analysis***

Quantitative data analysis was limited and consisted of scoring the FIQ and tabulating the demographic data. This data were merely used for descriptive purposes and has not been used in the development of the emergent substantive theory.

### **3.8 Rigor**

A number of strategies were used throughout the study to ensure rigor. As this is a qualitative study, criteria appropriate to qualitative research are used to describe the quality of the study and study findings. These criteria are credibility, transferability, dependability, confirmability.

First, credibility which is parallel to internal validity is used to assess whether the researcher's theoretical findings closely match the data ( i.e. do the participants see themselves in the theoretical findings)(Bryman, 2001). Credibility was ensured through member validation activities (Creswell, 1998). Member validation is the process of taking the study findings to the participants in order to check for accuracy of the findings (Creswell, 1998). A summary of the study findings (a one page model and a three page summary) was designed for this purpose (Appendix G). One participant reviewed the summary for clarity and ease of understanding before it was sent to all participants. After the participants had reviewed the summary a brief telephone follow-up was done. Participants were asked whether the model and summary accurately reflected the essence of their decision making experience. All participants felt that this was the case. A few participants had comments; however these were minor and did not warrant changing the model.

Transferability can be likened to generalizability to the general population. We were concerned with the meaning and process of CAM decision making rather than generalizability, hence achieving transferability was not the goal of this study (Creswell, 1998). Nevertheless, the final sample consisted of participants who differed in age, education, FIQ score, past CAM use, and current CAM use. Therefore, it would be reasonable to state that the sample is “maximally varied”. This enhances the transferability of the study findings to the FMS patient population.

The criterion of dependability can be compared to reliability (Bryman, 2001). The concept of dependability concerns the extent to which “the researcher’s theoretical inferences can be justified” (Bryman, p.274, 2001). To enhance dependability, data collection and data analysis procedures for this study are described in detail. This is essential in qualitative studies as there are “no methodological shorthand descriptions such as “interrater reliability” for assessing reliability in qualitative studies” (Krefting, p.221, 1991).

Finally, ensuring confirmability or objectivity was dealt with through numerous strategies (Bryman, 2001). The researcher was interviewed prior to the onset of the interviewing to record her own biases and assumptions around CAM, CAM use and FMS. It was found that the researcher holds balanced views<sup>10</sup> on all three concepts. During the study the researcher made attempts to be sensitive to new biases or biases not uncovered during the earlier mentioned interview. Both the activities of writing memos

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<sup>10</sup> The reader may find it helpful to refer back to the section “Assumptions” for more details

and discussions with supervisory committee members were helpful in looking at the data from many angles rather than with a single, possibly biased focus.

Two committee members (MV and CS) reviewed coding done by the researcher to ensure that the data were appropriately coded. To uncover any poor interviewing techniques the researcher also conducted a practice interview with a PhD student in the department. Some of the language used during the interviews was changed based on the feedback given after this practice interview. One committee member (MV) also reviewed a number of transcripts purely to evaluate the researchers interviewing skills.

The participants mentioned numerous health care providers when discussing their experiences in the conventional health care system. The researcher actively works in the conventional health care system and as such is familiar with some of these health care providers. Therefore, names and other identifying information were removed for all health care providers mentioned by the participants. This was done to diminish the risk of introducing bias to the data analysis.

### **3.9 Ethical considerations**

Ethics approval was obtained from the Conjoint Health Research Ethics Board, Office of Medical Bioethics at the University of Calgary, prior to initiating the study. Ethics approval was also sought and granted when the recruitment strategies needed to be changed (see section 4.2.2 Recruitment). Various strategies for ensuring ethical research practices as recommended by the Conjoint Health Research Ethics Board were implemented throughout the study. These recommendations will be used throughout dissemination as well.

Anonymity is difficult to ensure as face to face interviews were conducted. However, all identifying information was removed from the transcriptions and tapes. The disseminated results will also not contain identifying information. It is possible that the participants recognize themselves in the published data, such as when direct quotes are used. The participants were verbally made aware of the possibility of this occurring before signing the consent form.

Recruitment was also conducted in an ethical manner. Only those participants who indicated an interest in the study were contacted. Participants were informed both through verbal means and written communication (consent form) that they could withdraw from the study at any time without any repercussions.

The majority of the participants did not incur any costs in this study as many chose to be interviewed in their own homes. Reimbursement was given to those participants who did incur parking expenses.

As with any narrative research, the concern exists around the ownership of the data (Smythe & Murray, 2000). This may particularly be the case if participants feel that their individual story has been lost in the larger framework of a phenomenon (Smythe & Murray, 2000). A number of strategies were used to minimize this risk. First, the participants were informed via the consent form that the interviews were not intended to be therapeutic. Second, during member validation activities it was made clear to the participants that the summary was based on 17 women's stories. It was emphasized that the intent of the summary was to verify whether the essence of their decision making experience was accurately captured rather than seeing their own experience described in great detail.

Another concern is that participants may feel taken advantage of if they are not given the opportunity to review the results and provide feedback. Smythe and Murray (2000) recommend that some form of “debriefing” takes place, where the researcher shares the results. Member validation took place to minimize this risk as well. Furthermore, participants were given the opportunity to reflect and comment on any and all aspects of the study prior to the end of their participation. This was done to ensure that participants had an opportunity to share any concerns. A number of participants offered to be contacted again if the researcher were to conduct any FMS studies in the future.

## **Chapter Four: Brief overview of results**

### **4.1 Introduction**

A brief overview of the emergent substantive theory in its totality is given in this chapter (see Figure 4.1). A much more detailed explanation of the theory will be given in Chapter 5, including an in depth discussion of the categories and subcategories.

### **4.2 Overview of the emergent substantive theory**

#### ***4.2.1 Phase 1***

The first phase of the decision making process focuses almost solely on the experience of living with FMS. During phase 1 the women are mostly occupied with being diagnosed with FMS and learning about the syndrome. They are predominantly relying on conventional health care providers for advice and recommendations about their FMS. This continues until they realize that FMS is mostly a self managed syndrome. Once this realization takes place, they become much more active in the decision making process and “take charge” of their health. A sense of readiness is established and this prepares them for phase two of the decision making process.

#### ***4.2.2 Phase 2***

Phase 2 is much more focused on CAM and how using CAM fits into managing FMS. The women are actively engaged in the decision making process and they start planning and preparing for CAM use. This phase ends with the women deciding to start CAM and potentially staying with CAM.

**Table 4.1***Overview of the emergent substantive theory*

<b>Stage</b>	<b>Description</b>	<b>Concept</b>	<b>Categories</b>
<b>1. Context of FMS</b>	This stage describes the context in which the decision making process occurs, i.e. what role do past experiences and present circumstances play in the decision making process?	Establishing readiness	<ul style="list-style-type: none"> <li>✓ Socio-medical context</li> <li>✓ Length of time living with FMS diagnosis or symptoms</li> <li>✓ FMS symptoms and their impact on daily living</li> <li>✓ Disappointments with conventional health care system</li> <li>✓ Co-morbidities</li> <li>✓ Hearing about CAM</li> </ul>
<b>2. Deciding to do something about FMS/feeling unwell</b>	Most options in the conventional system are tried. As these fail, the intent is formed to seek other options.	Initiating FMS self management	<ul style="list-style-type: none"> <li>✓ FMS self management</li> <li>✓ Having had enough</li> </ul>
<b>3. Needing to do more to manage FMS &amp; starting to think about CAM</b>	Not only have the women now heard about CAM, they are now seriously looking into using CAM.	Getting organized	<ul style="list-style-type: none"> <li>✓ Information seeking</li> <li>✓ Motivators</li> <li>✓ Influence of family &amp; friends</li> <li>✓ Role of MD</li> <li>✓ Barriers to CAM</li> <li>✓ Strategies to overcome barriers</li> </ul>
<b>4. Deciding to also do CAM</b>	This is where most of the women go ahead and try CAM in addition to doing their other FMS self management activities.	Taking action	<ul style="list-style-type: none"> <li>✓ Initiating CAM</li> <li>✓ Staying with CAM</li> <li>✓ Improving functional self</li> <li>✓ Barriers to staying with CAM</li> <li>✓ Starting new CAM</li> <li>✓ Information seeking new CAM</li> <li>✓ Barriers to new CAM</li> </ul>

### **4.3 Overview of stages and concepts**

#### ***4.3.1 Context of FMS***

##### Establishing readiness

During any process that involves change, a certain degree of readiness for that change has to be established in order for the change to be successful. The establishment of readiness involves having a number of experiences that pushes the woman to formulate the intent of maintaining a functional self. This intent first pushes her to try conventional treatments for her FMS and ultimately pushes her to form the intent to use CAM. Intent is the end goal one has in mind which allows for the planning of activities to reach that goal.

#### ***4.3.2 Deciding to do something about FMS/feeling unwell***

##### Initiating FMS self management

The woman changes from being a passive participant to an active participant in her illness management, after she discovers that FMS is pre-dominantly a self managed disease. She now adds a range of self management activities to her daily regime and makes other changes to her life style like learning to manage her time better and saying no more often. The woman proceeds with evaluating the outcomes of these activities and finds that her ability to function is still grossly impaired. She decides that this is not acceptable to her and she believes other options must exist.

#### ***4.3.3 Needing to do more to manage FMS and starting to think about CAM***

##### Getting organized

The woman starts by educating herself about CAM by using various information seeking strategies. She learns about the various CAM options as well as barriers and strategies to overcome these barriers. It is during this phase that the woman will often

waiver back and forth as to whether or not to use the CAM. It also becomes obvious to her what importance she attaches to the opinions of her family, friends and conventional health care providers. She ultimately decides on a CAM of her choice and takes the steps needed to get to the first appointment or to buy the product.

#### ***4.3.4 Deciding to also do CAM***

##### Taking action

The woman has now gone to her first appointment or has started taking the product. She is very focused on monitoring if the treatment/product is giving her relief i.e. is it giving her an improved functional self? She weighs this against barriers to staying with the treatment or products. Depending on the outcome she may have to try a new CAM. At this point she would revert back to getting organized to trying a new CAM. If the experience is overwhelmingly negative it may turn her away from CAM for an extended period of time. If CAM gives her the outcome of an improved functional self, she will very quickly become committed to CAM. This is also where she decides how often to use a treatment or product (frequency) and the length of a treatment or the amount of the product (quantity).

## **Chapter Five: In depth summary of data analysis**

### **5.1 Introduction**

This chapter contains a detailed summary of the data analysis. First, a brief overview of the interviews is given. Then, Table 5.2 is presented, which starts with the concepts including their categories and sub categories which will now be examined in greater detail<sup>11</sup>. Direct quotes are provided in support of the concepts presented. Due to length constraints, only the most pertinent quotes are given, which are referenced using the alphabetical participant pseudonyms used throughout the study. The reader will note that many quotes contain expressions such as “um”, “uh” and so forth. Even though this can be difficult to read, these expressions were left in the transcriptions to reflect as accurately as possible the meanings of the participants. For example, some patients were deeply reflective before answering some of the questions which were captured by pauses in their responses.

### **5.2 Interviews**

A total of 17 full length interviews were conducted as well as 16 follow-up interviews. The participants were eager to be involved in the study and shared their FMS and CAM decision making experiences easily. They were quite relaxed, yet at times they would become very sad when they remembered their past experiences. In addition to responding to the questions (Appendix F), participants also responded with FMS

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<sup>11</sup> For ease of understanding it may be helpful for the reader to refer back to Table 4.1 in Chapter 4. The presentation in this chapter will closely follow this table.

information not directly related to the questions. Often this pertained to the impact of FMS on their lives and their suffering due to FMS.

Only one participant needed to take a break during interviewing to take some pain medication. One participant was very depressed (self reported) at the time of the interview. When she was queried on access to appropriate resources, i.e. was she being followed by a health care provider for the depression, she stated that she was getting enough support and that she was working closely with her family physician. She was also the only participant who did not complete the follow-up interview as her contact information was no longer valid at the time of follow-up. The table below summarizes the participants' ages and education. All the participants were Caucasian.

**Table 5.1**

*Ages and education of participants*

<b>Age (years)</b>	<b>(n)</b>
18-24	1
23-34	0
35-44	2
45-54	4
55-64	10
<b>Education</b>	<b>(n)</b>
Some/Completed High School	4
Some/Completed College	7
Some/Completed Undergraduate Degree	4
Graduate University degree	2

**Table 5.2*****Detailed explanation of emergent substantive theory***

<b>Concept</b>	<b>Categories</b>	<b>Subcategories</b>
<b>1. Establishing readiness</b>		
	Socio-medical context	-
	Length of time living with FMS diagnosis or symptoms	-
	FMS symptoms and their impact on daily living	<ul style="list-style-type: none"> <li>• Symptoms</li> <li>• Impact on functioning</li> </ul>
	Disappointments with conventional health care system	Conventional: <ul style="list-style-type: none"> <li>• System</li> <li>• Physician</li> <li>• Medications</li> </ul>
	Co-morbidities	-
	Hearing about CAM	-
<b>2. Initiating FMS self management</b>		
	FMS self management	<ul style="list-style-type: none"> <li>• Diagnosis process</li> <li>• Impact of diagnosis</li> </ul>
	Having had enough	-
<b>3. Getting organized</b>		
	Information seeking	
	Motivators	<ul style="list-style-type: none"> <li>• Therapeutic effect</li> <li>• Taking less medication</li> </ul>
	Family & friends influence	-
	Role of MD	<ul style="list-style-type: none"> <li>• Discussing CAM</li> <li>• MD response</li> <li>• Influence over decision</li> </ul>
	Potential barriers to CAM	<ul style="list-style-type: none"> <li>• Cost</li> <li>• Questioning efficacy</li> <li>• Pain/Discomfort</li> </ul>
	Strategies to overcome barriers	<ul style="list-style-type: none"> <li>• Use in others</li> <li>• Desperation</li> <li>• Control</li> </ul>
<b>4. Taking action</b>		
	Initiating CAM	<ul style="list-style-type: none"> <li>• Choosing type of CAM</li> </ul>
	Staying with CAM	<ul style="list-style-type: none"> <li>• Therapeutic effect</li> <li>• Connection with provider</li> <li>• Complete and tailored treatment</li> <li>• Frequency/Quantity</li> <li>• Strategies used to incorporate CAM</li> <li>• Level of commitment</li> </ul>
	<b>IMPROVING FUNCTIONAL SELF</b>	<b>“CORE CATEGORY”</b>
	Barriers to staying with CAM	<ul style="list-style-type: none"> <li>• No therapeutic effect</li> <li>• Cost</li> <li>• Poor access</li> </ul>
	Starting new CAM	-
	Information seeking new CAM	-
	Barriers to new CAM	<ul style="list-style-type: none"> <li>• Cost</li> <li>• Doubting efficacy</li> <li>• Overwhelmed</li> </ul>

### **5.3 The CAM decision making process**

While analyzing the interview data it became apparent that there was a consistent sequence of stages which the women went through when making the decision to use CAM. This sequence consists of establishing readiness, initiating FMS self management, getting organized and taking action. The main category or “core” emerging category is “Improving functional self”. This concept of improving one’s functioning can be seen in all the stages of the decision making process.

#### ***5.3.1 Establishing readiness***

The participants stated that the following experiences or events were important in shaping their CAM decision making behaviours. The exceptions to this are the two categories of “socio-medical context” and “co-morbidities” as these were induced from the data by the researcher. The participants felt they needed these experiences to establish a sense of readiness or openness towards trying CAM. There was no difference in this category between those participants using CAM prior to their FMS diagnosis and those participants who started CAM after their FMS diagnosis.

##### **a) Socio-medical context**

All the participants were diagnosed in the time period spanning 1990-1999 (see Table 5.4). The American College of Rheumatology introduced the FMS classification (diagnosis) criterion in 1990. These classification criteria were slowly accepted by health care providers. Furthermore, the Canadian Consensus Protocol was only recently published<sup>12</sup>(Jain et al., 2004). However, it is reasonable to argue that more is known

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<sup>12</sup> See section 1.1 for detailed discussion.

about FMS today than in the 1990s. The limited knowledge around FMS had a negative impact on the participants in terms of being diagnosed and treated. As participant P stated:

Um, I did, just because there wasn't hardly any information out there about it. It was very, um, just not well known. Nobody, none of the doctors knew anything about it. And it was hard to accept it because, then, you'd get the odd doctor who was like, no you don't have that. Well, if I don't have that, then what do I have? ...<sup>13</sup> And of course now, it's a lot different, where they basically throw out fibromyalgia for anybody who walks in the door with unexplained pain. And so it's a lot different now, for people going through it.

Thus, the socio-medical environment contributed greatly to the participants' negative experiences in the conventional health care system.

#### **b) Length of time living with FMS diagnosis or symptoms**

At the time of the study, all of the participants had been living with their FMS symptoms for eight or more years. Having spent this time as a FMS patient allowed the women to try most if not all conventional medicine options:

Uh, I don't know, I think you just get to a point after a number of years, where, uh, once I had that diagnosis of fibromyalgia, and I did all my research, and I took all the classes, and I was taking the pills they told me, but it took me about five years to get back to, at the time, what I would have considered pretty good health.  
(M)

They described a certain weariness in learning to manage the disease and the many ups and downs they have had. This contributed to becoming more ready to try CAM, because they tried most of what conventional medicine had to offer without much success.

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<sup>13</sup> ...indicates irrelevant text that has been omitted

### c) FMS symptoms and their impact on daily living

The symptoms<sup>14</sup> of FMS vary widely from one individual to the next. The women in this study were no exception to this. However, the majority of the women mentioned pain, fatigue and sleeping difficulties as their most bothersome symptoms:

I found that I was having a lot of pain, um, couldn't sleep very well, and it got to a point where my doctor asked me to keep a sleeping diary, and so we were basically able to document that I was only sleeping, you know, like two or three hours a, uh, a night, and that even not continuously. (H)

Furthermore, it became clear that: 1) the presence of the pain as well as the characteristics of the pain (constant and widespread), were very challenging, 2) the women did not seem to be able to manage their symptoms with conventional medications or treatment, 3) their symptoms seemed to fluctuate and certain health events like menopause or co-morbidities could alter their symptoms dramatically.

The impact of these symptoms on the women's ability to function was significant.

Even the most basic activities of daily living were described as challenging to complete:

And it's terrible to think, okay, I'm going to get up and I've got to do this and I'm going to do this, and I'm going to do that. And you don't even do the first thing. Like get your breakfast ready, and think, oh okay. I better sit down and eat this, but I'm too damn tired. (D)

Furthermore, a number of women were engaged in gainful employment prior to the onset of FMS, yet had to give up their career due to their limited functioning. Personal fulfillment through leisure activities and such were often described as limited due to lack of energy.

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<sup>14</sup> See section 1.2.1 for review of symptoms.

One participant commented on how she felt after she took her daughter to an amusement park:

So yeah, it was too much, I knew I was going to be in trouble, and of course, the next day, I was right. I stayed in bed for Sunday, Monday, Tuesday, Wednesday, Thursday, Friday, I finally got out of bed again. (E)

Personal fulfillment through social activities became limited and led to isolation for some participants. Furthermore the impact on the participants' families was also significant:

...because it destroys our family, it really does, because I get very, I get tired, I'm in pain, I get very irritated, I scream at anybody and anything that gets in my way, because I just can't tolerate the pain. (J)

Last, some of the women alluded to the stigma related to FMS:

...and I was stressed out with people not believing that I had a problem, thinking, well, I'm not working anymore, and I have a beautiful home, and a wonderful husband, and what do I have to complain about, you know, and a lot of doubting Thomases, and you know, I was getting sicker, and uh, some of my best friends, you know, didn't think I had a problem. (N)

#### **d) Disappointments with the conventional health care system**

Almost all of the participants experienced disappointments in the conventional health care system in three areas: 1) the system, 2) individual conventional medicine physicians, and 3) medications prescribed in the conventional system.

##### The system

This subcategory contains some overlap with the subcategory of individual physicians, however it is separated here to illustrate that the actual restraints of the conventional system contributed to the participants' negative experiences. For example, the women described that they were often offered a narrow treatment plan:

Okay. It's uh, our doctors here, they prescribe, uh, they give you pills, they give you creams, um, they try physiotherapy, and nothing works, well, they're

stumped, and instead of saying, okay, let's try this, let's try that, they don't do that, which, which I find very bad. (C)

One could argue that it is the prescribing physician with whom the participant is disappointed; however the physician is offering treatment within the limits of the conventional system. Most of the women tried many if not all options offered to them, but ran into problems with a lack of resources (i.e. no specific programs for FMS patients) and limited or no treatment efficacy. As participant H commented on trying to exercise as her MD recommended to her:

I can imagine, getting into that first side and swim, and then going back, over here in the northwest, yes, there's the Foothills Pool up here, but it doesn't have a hot tub, and I just find my muscles just turn into cement in the cold water, and it becomes very uncomfortable, I can't do that.

A few of the women, who had extensively used the conventional health care system in the past for other conditions, expressed some bitterness about the system's ability to deal with chronic disease. As participant O stated:

And it's failed me. I don't have any faith or any trust in the medical system when it comes to chronic illness. And they're wonderful for acute illness, but when it comes to chronic illness, they're a complete and utter failure. So I live with, I live with my problems.

The women initially dealt with these disappointments in 2 ways: 1) only using the conventional system if they had to (such as flu shots or prescription renewals) and 2) trying many providers (i.e. trying 5 different physiotherapists, finding new physicians). This ultimately led to the women exploring FMS self management options, which finally led them to including CAM as a self management activity.

### Encounters with individual physicians

The women described a range of experiences in their encounters with their physicians, but the majority of the women commented on the poor communication that took place during office visits. What came up time and time again was the psychological distress of not being believed when communicating about symptoms or side effects of medications:

Um, why would anybody want to stay in pain? Why would anybody want to, to say that something made them sick if it didn't? It's like he was accusing me of lying, or he didn't believe me, that there was something wrong with me mentally. And so, it was just, it was my integrity that he attacked. So I figure, somebody like that, I don't have to have anything to do with that. He just wants to keep giving me prescriptions and prescriptions, and, and not believe me that it made me sick. (D)

Furthermore, the women commented on the very limited time available for an appointment and the limited amount of caring conveyed during communication. The women also commented on the limited collaboration when designing the treatment plan:

I wasn't happy with my new doctor, and he didn't even want to give me my prescriptions. He took them away on me, he wouldn't renew them for me. And I went backwards, probably 100%, and my husband and I were totally disappointed, because I was back at square one. And then he told me later that he wanted to see me at point zero, so he could see what I was like when I wasn't on these prescriptions, and I said, "Well that was at my expense, that was ridiculous, you have no idea how much suffering you have caused me. (J)

### Conventional medications

The majority of the women complained of two concerns: 1) the negative side effects of the medications and 2) the limited or complete lack of efficacy. As participant C explained the effect the medications had on her:

...and in those three years, um, nobody was doing anything except doping me up, and that is one thing that I could not accept, because I couldn't function, I was a

zombie, um, most of those three years are lost to me, there is no memory there at all.

These side effects had a very significant impact on the women's ability to function day to day. The women complained that the medications were only treating the symptoms and not the underlying issue, which they felt was not beneficial in the long term:

I've been on it all, been there, done that, threw it all in the garbage, it just makes me feel even worse. If I don't take it at six o'clock at night, I'm like a wide-awake drunk at two in the afternoon the next day, still. If I take it at midnight, it then, then I'm even worse, I'm the whole day groggy, but I still don't really feel any better. It just covers up, and I'm not helping myself any. (J)

Nonetheless, many of the women were initially quite committed to trying conventional medications. This became evident through the many classes of medications they tried as well as their experimenting with different dosages. Furthermore, they were willing to experiment with conventional medications for long periods of time:

...even at all the medications prescribed, for two years running, I came up with the, you know, somewhat of a dysfunction in the liver, and I'm kind of going, uh, then we'd have to do sort of a three months, it was cleansing, you know, no steroids, none of the rest of them, before we come back to normal.(H)

Not only were the women dealing with the impact on their functioning from the conventional medications and their FMS symptoms, but many of the women were struggling with co-morbidities as well.

#### **e) Co-morbidities**

Almost half of the women in the study were not at a healthy weight. This impacted the women in different ways. One participant was unable to do a number of FMS self management strategies because of her weight. A few participants felt that their weight aggravated their FMS, whereas another participant felt her MD was disrespectful

about her weight, which made her already precarious relationship with her MD even worse:

She is, you know. When somebody turns around to you and says “Oh, does your mom look like you?” Uh, I mean I almost decked her. (K)

This resulted in making her even more determined to avoid encounters with her MD.

Three women in the study considered themselves depressed. Even though depression can be part of FMS, for clarity’s sake it is grouped here under co-morbidities. The impact of depression cannot be underestimated in the women’s ability to engage in either conventional self care activities or CAM. As participant O stated:

But I become so depressed that I give up on all of it for times. And I just stop everything. And I stop, I stop going to the doctors. I stop trying. And it just, and if you let that happen for too long, then it feeds on itself, and it gets you into a pretty bad place.

Certainly, depression or a depressed state of mind was one factor as to why some of the participants experienced disruptions in CAM use. One participant explained that her other health conditions were so significantly impacting her life that this also propelled her to look into CAM.

The participants’ co-morbidities have been summarized in the table below, including their Fibromyalgia Impact Questionnaire scores. The maximum possible score is 100, with the average FMS patient scoring about 50, and severely afflicted patients usually scoring around 70 or higher. The FIQ score measures the impact of FMS has in a patient’s life, i.e. disease burden. These scores are not used in the analysis and are presented here to demonstrate the variance in participants in terms of FIQ scores. The participants also self reported the event or illness that precipitated the onset of their FMS.

**Table 5.3***Summary of self reported precipitating events, co-morbidities, and FIQ scores*

<b>ID</b>	<b>Precipitating event</b>	<b>Co-morbidities</b>	<b>FIQ score</b>
<b>E</b>	MVA	Opioid dependence Obesity Depression	77.78
<b>C</b>	MVA	Obesity	74.40
<b>L</b>	Not known	Osteoporosis	72.63
<b>D</b>	Polio vaccine	Bladder spasticity	69.63
<b>K</b>	Severe stress	Obesity	68.38
<b>N</b>	Repetitive strain injury	Depression	66.16
<b>M</b>	Viral illness	None	64.74
<b>H</b>	MVA	Obesity	63.19
<b>A</b>	Asthma exacerbation Viral illness	Sjogren's Rheumatoid arthritis Chronic Fatigue Syndrome	63.12
<b>F</b>	Viral illness	None	55.37
<b>G</b>	MVA	Primary liver cirrhosis RA	55.29
<b>O</b>	Not known	Depression Obesity Sleep apnoea Asthma Osteoporosis	54.11
<b>Q</b>	Dental work Severe stress	None	46.57
<b>I</b>	MVA	Morbid obesity Atrial fibrillation Hepatitis	46.16
<b>B</b>	Carpal Tunnel Syndrome	Obesity	44.13
<b>P</b>	Headaches	Asthma Early scoliosis	43.12
<b>J</b>	Severe stress	Obesity Osteoarthritis Macular degeneration	16.53

## **f) Hearing about CAM**

The women indicated that they heard about CAM from many different sources including: family (10), friends (10), written materials (internet & books) (9), CAM provider (9), TV (7), conventional medicine provider (5), and support group (1). Clearly the women learned about, or discovered CAM through many different sources. Their social network played an especially dominant role by urging the participants to try different CAM options. Participant C comments on how her daughter encouraged her to try CAM when her daughter noticed her decline in functioning:

No, she's the one that told me. Like, sometimes I'd come home after the physiotherapy, or the, a swim, or a walk, or just trying to play with the dogs, or, and she would see how the pain increases when I did things, and I think, um, when I wasn't able to go up and down the stairs, that's when she told me, she just stopped me and said "Mom, you have to come see the doctor(*CAM provider*), you have to, Mom, because you're too young, and look at you, look what's happening to you...

Since CAM garners consistent popular media coverage, most people will have at some point heard about CAM. Hence, this category was mentioned early on in the decision making process, even though it was obviously not the only point in the process where the participants heard about CAM and did not necessarily mean that the participants acted on this. All but two women first needed to experience FMS self management activities before they consciously did something with this information. This will be discussed in much more detail below.

### ***5.3.2 Initiating FMS self management***

During this part of the decision making process, the women changed from passive participants in their illness experience to active participants. They realized that they would not achieve a satisfactory level of functioning by only trying medications or by

only complying with their narrow treatment plan. Hence the women chose to do to more self management activities such as changing their diet. The table below is included to demonstrate the time lines involved in starting “non CAM” FMS self management versus starting “CAM” FMS self management.

**Table 5.4**

*Timeline of onset of FMS self management and CAM use*

ID	Onset of symptoms (years ago)	Diagnosis (years ago)	Initiation of self care activities after diagnosis	Initiation of CAM after diagnosis	Length of time on current CAM	FIQ score
E	9	9	9 months	3 months	years	77.78
C	16	10	months	1 year	2 years	74.40
L	26	>12	unable to recall time line	unable to recall time line	6-7 years	72.63
D	Childhood	7	unable to recall time line	unable to recall time line	4-5 years	69.63
K	11	11-12	few years	8 years	4 years	68.38
N	Teenager	8	immediately	4 months	6-7 years	66.16
M	15	13	2 years	4 years	6 years	64.74
H	12	12	months	1 year	7 years	63.19
A	16	16	1 year	2 years	14 years	63.12
F	>10	>10	months	10 years	weeks	55.37
G	13	10	months	5-6 years	years	55.29
O	Childhood	7	unable to recall time line	Unable to recall time line	Unable to recall	54.11
Q	10	10	months	3 years	7 years	46.57
I	16	16	immediately	1 year	4 years	46.16
B	15	15	>10 years	3 years	3 years	44.13
P	8	7	5-6 years	9 years	1 year	43.12
J	20	9	2 years	4 years	6-7 years	16.53

**a) FMS self management**

For the purpose of this study FMS self management was defined as a woman taking responsibility for her health, including her FMS. This meant learning more about FMS, and subsequently changing health behaviours as a result of this knowledge. Some of the women collaborated with their physician whereas others tried self management activities on their own.

A few participants used self management strategies based on their MD's recommendations:

Um, because that's what the doctor recommended. At that time, I wasn't seeing a naturopath. I was going by the, uh, rheumatologist. And he did up his report and sent it to the doctor, and the doctor took it from there. And he suggested the arthritis program and everything. (N)

However, the majority of the women encountered physicians who were uncertain as to how to treat FMS and consequently the women started trying FMS self management on their own:

Yes, because, um, well, I'd been dealing with my family's physician at the time. Um, and it really, she was sort of at a loss. And in all that she could recommend, you know, was medications. And rest. And I mean, if anything, we developed a pattern of, I would, um, well, actually I remember she had gotten a tape from Dr. \_\_ and she hadn't had time to listen to it. So she gave it to me and asked me to evaluate it for her. Um, so, you know. (laughs) Um, so learning about people and doing the research on fibromyalgia basically told me that I was going to have to do it myself. (H)

One participant mentioned that CAM was not as common during the early 1990s as it is now, which for her also contributed to trying self management first. There were two women in the study who did not actively engage in self management activities before they tried CAM. Participant B explained that she was simply too overwhelmed with life's demands to spend any time on herself. In the time period that she was diagnosed with FMS she was dealing with multiple family and financial stressors. Her conventional MD prescribed the CAM product for her (none of the other participants experienced this), so using CAM was relatively "easy" for her.

The second participant, who did not follow this sequence, was the only participant in the study whose MD refused to help her with getting time off work due to her FMS symptoms:

Oh well, my GP at the time, which is different than my GP now, I came in and I told her, I can't cope with this problem. I'm very sick. And I, you know, I have I reminded her, I've been diagnosed with fibromyalgia. And uh, I'm needing time off work. I just can't do it. And she said to me, "don't go there...Don't even think about it." And that was the end of it. So, okay, I left. So then I realized, it was then, that I couldn't get any help from a GP. So then after that point, okay, have to help myself. (E)

This participant also had an excellent benefits package in terms of CAM coverage, was quite proactive in dealing with problems and had previously incorporated CAM into her life for non FMS concerns. This participant felt that her tendency to be pro-active played a role in her decision-making.

The women reiterated time and time again that learning about their limitations, letting go of certain expectations or altering expectations and carefully scheduling activities were all important FMS self management strategies. Participant B described it as follows

So now, um, the last two or three years here, I've learned to give myself permission to lay down and have a sleep in the afternoon before I go to my girls. And my day is very regimented, the things that I have to do outside of the home, and just working and taking him where he needs to be. And uh, keep on a fairly even schedule.

The women readily admitted that this process takes a long time to master and that it required a daily commitment. This means it could be very challenging and lonely.

Furthermore, it took access to physical resources and access to finances. One participant described it as follows:

But what, you have to persevere, you have to walk a little bit every day, you have to maybe try to do, vacuum, if you only vacuum one room, if there's one room that needs to be done, do it, and then just leave the rest, if it doesn't have to be done...But you have to persevere, you have to, every day, do something. Because as soon as you quit doing it, it'll get worse, and you'll have to start from square one. (J)

Attending support groups, reading self help books, resting, monitoring one's sleep and blood pressure, changing diet, and initiating or continuing with physical exercise were all FMS self management activities mentioned by the women. It appears to be a trial and error process, moving through different activities until one or several are found which work to either improve functioning or to at least maintain functioning. One participant mentioned that her "intense" personality made it challenging for her to reduce her expectations, hence her personality was somewhat of a barrier to achieving FMS self management. Participant E elaborated here on what FMS self management meant to her:

Um, well, from my experiences around this, I've accepted that there is no cure, I've accepted that there really isn't any treatment out there, and that I have to manage it, and um, if management means sleeping as much as I can through the night, sleeping pills and stuff like that, and uh, taking my heart rate and making sure my heart rate is less, or at least the same as it is at night, otherwise I'm on my way to a crash, um, I monitor on paper, um, my pain level and energy level every day, and so I'm looking for patterns all the time, um, I'm monitoring my food, so I'm on, been trying to eat protein and fresh fruits and vegetables, um, what else am I doing? Yeah, well, I'm still on a program for the psycho-educational, so there's other stuff that we haven't done.

It took anywhere from months to years for the participants to start FMS self management activities after they were diagnosed. There are a number of explanations for this, such as the lengthy diagnosis process some of the women went through. Due to the context in which these women were suffering from FMS<sup>15</sup>, more than half of the women were symptomatic for months to years before actually being diagnosed (see Table 5.4). This led to much uncertainty for the participants:

But until I had a definitive diagnosis, until I was diagnosed, it seemed like I was falling apart. I was in my thirties, and here I was, falling apart. Feeling like an eighty year old woman. And I was going to my doctor a lot. What's wrong with

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<sup>15</sup> See "socio-medical context" for more details.

me? There's this, this, this, this, and this. What the hell is going on here? You know. So she sent me for tests at that time. And when I was seeking to know what was wrong with me, I was at the doctor all the time. (O)

The lack of diagnosis also had a significant impact on the participants' ability to implement self management activities as they did not know the source of their symptoms.

Participant P described the importance of the diagnosis to her:

I had to start doing something to try and alleviate the problems I was having. And so, it's, it's a lot easier sometimes to, okay, where do I go from here? When you actually have a diagnosis.

The other sense of relief for participants was that they finally felt believed in. Another reason participants gave for waiting to do FMS self management, was the sheer time needed to actually become informed about FMS.

Engaging in FMS self management activities was important for the women since it allowed them to be educated around FMS. Secondly, it gave them the determination to take control of their own health care decisions, which allowed them to try many different options in improving their functioning. However, despite engaging in multiple self care activities, their ability to function was still very limited. This led to the women reaching a point of having had enough of the challenges in their day to day living. This will be discussed in detail in the next section.

### **b) Having had enough**

This is the point in the process where all the women declared that they were ready to look at CAM. A few things about this tipping point need to be addressed. First, it appears that the severity of their symptoms and the subsequent impact of their symptoms on their life are what ultimately pushed them to this point. For some women it was one

particular symptom while others had many different symptoms that they were no longer able to cope with:

Um, basically, I was just sick and tired of nothing working. The medications weren't working. I wasn't sleeping at all. And basically I was averaging about two to three hours a night of sleep. And it was really starting to affect my, my life. Like I couldn't, just having more and more problems functioning. (P)

Uh, because I was at a point where I couldn't walk anymore, and the pain was really high, and I was tired of being so drugged, and I had tried so many things. (C)

For some women it was quite a lengthy process before they reached the point of having had enough. They tried most options given to them and had not given up on the conventional system, but they realized that they have reached the end of the road in terms of their options. This demonstrates as well that for virtually all the women CAM took on a secondary role in their treatment plan:

I just thought, you know, I'd come to the end of anything that was working, in particular, so well, okay...Because what else is there for it? Nobody else can do anything for me. (I)

It was also driven by the positive belief that something had to be done and that something could be done about their limited functioning. This was not described as a belief in CAM, but rather a belief that there had to be "something" that could make their situation better:

I mean, it was sort of, ... based on frustration from the doctor not being able to do what I want, and I felt that the answer had to be out there. (M)

...and it seems like everything was negative, uh, but nothing could be done, it's, you got it, and you have to live with it, and, but I was stubborn enough to say no, I can't do that. (C)

Getting to this point also involved a component of long term planning (i.e. there was a realization that functioning like this was not feasible long term).

I don't like living like this until the end of my days, I want to get better. And I'll do anything to, I'll try that list three or four times (*CAM*), and before I make a judgment, no, this is not going to work. (L)

For most of the participants it was a gradual process of getting to this point; however some participants remembered there was a particular impact on their functioning that tipped the balance for them:

And to the point where I couldn't work. I had to stop working. And so it was at that point I started thinking of alternative medicine. (E)

Being severely impacted in their functioning and having heard about CAM, they became interested in seriously looking at CAM. This will be discussed in the next section.

### ***5.3.3 Getting organized***

The participants became informed about CAM by using various information seeking strategies. Their motivations to use CAM became clearer and they discovered the various CAM options as well as potential barriers to using CAM. Strategies to overcome these potential barriers were discovered as well. They felt they were ultimately responsible for the decision to use CAM and they only informed their social network (and their physicians) of the decision after it had been made.

#### **a) Information seeking**

All the women used a variety of different sources to gather information on CAM: Internet (10), friends (8), CAM provider (8), books (7), conventional MD (5), health food store staff (4), and family (2). Of note is that not only did the women often hear about CAM from their social network (see "Hearing about CAM"); they also used their friends as sources of information. Furthermore, the women played an active role in information seeking and they preferred to use many different avenues to gather information:

So I felt, so then I looked more, let's do research and that. I resorted, just in magazines, I have a fibromyalgia magazine, just sort of picked up, and just go to the library, talked to people, just go to the, to the uh, health food store and look, and I settled on St. John's Wort, and that has become my best friend. (J)

The women did not use a linear or systematic process of information seeking, i.e. they did not first go to the library, and then the internet; rather they used multiple resources without paying attention to the order in which they were using these resources. Also, even though they were actively looking for information themselves, they were often offered information by their social network and they learned about CAM passively through popular media such as TV:

Yes. An article. My minister, actually it was a book, my minister gave me a book on it and there were several programs being offered at the time and, er, and I read their literature on it so I knew what it was about. (F)

So it was just sort of by accident, like, I saw a couple things on the TV, I think it was, and they said, oh, it's good for fibromyalgia. (K)

Of interest also is that even though the women often heard about CAM through family, (see "Hearing about CAM"); only two women used their family members as a source of information. Both of these participants had relatives who they stated "believed" in CAM:

Because she is Chinese, um, she doesn't know Western medicine at all, the only medicine that she grew up with was Chinese medicine, and every time she had a problem, um, she was never on drugs, um, it was acupuncture, it was different things, and it would just work for her, and that's, when we did talk, that's what we talked about mostly, and um, then she looked at the pills that I was taking, and she said, "Mom, we don't do that in China."(C)

Even though 10 women used the internet to search for CAM information, the women felt the internet can be complicated to navigate as they had their doubts on the validity of the information. They dealt with this in various ways: 1) simply stop using the

internet for a period of time, 2) discuss the information with a trusted CAM provider, or  
3) use many different sites to assess if the information is consistent:

Um, a lot of the time, if I find something on the internet that I question, or anything, I'd take it to someone at work, or I would actually find someone to talk to about it, just to get clarification of, you know what? Is this legit? Like, is it real? (laughs) (P)

Three out of four women using a health food store for information had overwhelmingly positive experiences. The women were attracted to the fact that the health food store offered readily available, trained staff and that the information offered was complete:

You can read your bottle, know, you know, how many you would be taking, know what the cost involved would be, if you're, you know, cost, like, that is not covered by any health, any, any extra insurance that you get through any workplace, also because I could talk to somebody, rather than just going, when you're reading at the library, something, which I did too, but then you don't have anyone to go and talk to, librarian, but there, I could talk to the person dealing with all, any of the health food stores, there's always somebody there that knows their product, and you can, like I say, you've got all your pamphlets, are right there. (J)

Two participants did not actively engage in information seeking strategies.

Participant E "just" took her sister's advice and changed chiropractic approach and participant F went to an acupuncturist she knew without actively gathering any information beforehand. Both women are longstanding CAM users and they described that they have learned enough about CAM over the years that active information seeking was not necessary for the particular CAM that they were trying.

Clearly, there is more that can be investigated in terms of CAM and information seeking behaviours; in fact an entire study could be devoted solely to this topic. However, as information seeking is not the focus of this study, but rather a component of the decision making process, no further data will be presented on information seeking.

## **b) Motivators**

The concept of motivators for the purpose of this study is defined as anything real or perceived that could promote the use of CAM.

### Therapeutic effect

For all the women the strongest motivator to try CAM was that they hoped for symptom relief which in turn would improve their day to day functioning:

Just because the fibromyalgia would, uh, it just basically suffocates you, I was just feeling miserable and depressed all the time, and that's when I read up and that St. John's Wort seemed to fit, to deal with the fact that if I wasn't in so much, if I was more relaxed, then I wouldn't become depressed, and if I wasn't depressed, I wouldn't feel as, I wouldn't hurt as much, because when you're feeling good, your pain doesn't bother you as much.(J)

I think mostly just to get the headaches under control because it was really bad. I missed, I mean, in grade seven, when it was, got really bad, I missed five months of school. So it was really hard then. Um, so we were basically just trying to get the headaches under control. So that I could go to school, and you know, function. (P)

Absolutely. It's worth it, what if it works and you actually feel better? You're never going to feel good. We just want to feel more functional (chuckles), you know? (I)

Of note here are the relatively modest expectations the women have when they are first contemplating CAM. Their goals are to improve their day to day functioning, rather than cure their FMS. This is the result of engaging in FMS self management as they learned that the chance of curing FMS, no matter with which therapies, is unlikely.

### Taking less medication

For many women being able to perhaps stop or at least reduce the dosage of their conventional medications through using CAM, was also appealing:

The prospect of lessening the pain, of strengthening my muscles, getting off the drugs, um, so many things, good lord. (laughs) So many things...I did, because I

was at a point where, um, it seemed that nothing else was going to work, and I had to get off of those drugs, I really did.(C)

Um, well, it wasn't a pill. It was something that I could, that maybe I was doing wrong, to make things worse. Um, that maybe he could help me without side effects. What a concept. (O)

### c) Family/friends influence

The participants' social network seems to play a role in decision making, first, during the initial discovery of CAM and then again during information seeking. This led to the question: How important *is* the patients' social network in deciding whether or not to use CAM? All the participants strongly felt that even though they use their social network for information, they merely inform the close people in their life of their decision when their decision to use CAM is already made:

So a discussion like this is what I want to do, not "What do you think?"(M)

No, just family and friends. But they didn't, like, just basically telling them that I'm going to try it and see if it works, kind of thing. (P)

The reason why the women informed their husbands was often due to the financial impact of using CAM:

No, because I'm my own person. I don't. I would, I would, no. I have my own convictions. He doesn't read about it, he doesn't know anything about it. The only way that he would, uh, make me think twice is if he worried about the money too much. And so it always comes down to the mighty dollar. (O)

They felt that even if they would receive negative feedback from their social network about using CAM, they would still go ahead.

Well, because I'm the one who's doing it not someone else. ... So um, and I thought that's him. And I need to do this to help me, um. (Q)

It should be noted however that this was a hypothetical question for most of the participants as only two participants experienced direct negative feedback from their social network:

There was quite a conflict, actually, between the two of us. And I was really hurt, um, and so what I did was I decided, okay, this topic is out of bounds, I'm not talking about it with her anymore, I took the supplements off the counter so she couldn't see them when she came over, and I went underground and did it, you know? (E)

The participants were quite adamant in doing what they felt was right for them.

This relates back to their functioning since they feel that *they* are suffering and hence *they* should be the ones to make the decision:

So, you know, but there's a lot of bias there, on their parts. And, but you know, they're not the ones living with the chronic pain, so. (O)

Closely related to the concept of the influence of the social network is the role the physician plays in the decision making process. This will be examined next.

#### **d) Role of the physician**

##### Discussing CAM

Almost all the women discussed their CAM use with their physician. As this appeared inconsistent with previous results, i.e. the women had very negative experiences with their physicians, the data was reviewed again. It was noted that due to the complexity of FMS and the chronic nature of the syndrome, the majority of the women were seeing multiple physicians. Some of the women indeed had healthy relationships with their physicians. This is not to say however, that a healthy relationship with their physician meant that the women shared their CAM use readily. They often considered the

physician's attitude toward CAM and what they thought his or her level of interest in CAM would be:

I think because, er, I don't feel that I'm on that sort of, er, er, how would you say... the level with a physician that they, like I don't know what their spiritual beliefs are so I don't know whether they'd even be interested or, you know, so I just...(F)

They often disclosed their CAM use when they needed something from the MD, i.e. a prescription for a natural supplement or if the CAM they were using influenced their conventional treatment:

...but it made me cautious as to what I said to the doctor, because I knew they weren't really for it. And sometimes you just got to really bite the bullet and do it, like, you know, through the naturopath, we decided I needed, um, natural progesterone, and the naturopath can't prescribe it, you have to get that from your family doctor, so I would have to go to her and say "You know, I've been to the naturopath, this is what she thinks, I've tried it for whatever and it works, can I get a prescription?" And you know, she gave it to me, so you know, in that respect, it was good. But it's been hard, because they don't really want to hear that other therapies, or they're not taught that in school, I don't know, they're just not real open to it. So I don't tell them more than I have to. (M)

The two participants who did not talk to their physician about CAM, were also the two participants who were barely on speaking terms with their physician and wanted to avoid any further aggravation:

I never talk to her about it ever again, because of the reaction I got from her about "don't even use the word fibromyalgia, don't even consider that you have it, just forget about it and move forward". So she didn't, she didn't want to, she made it very clear, she doesn't want to talk about it with me, and I need to put it out of my mind, and I need to just get back to work. (E)

### Influence of the physician

In looking back at the category "Family & friends influence", it was found that the women felt that the decision whether or not to use CAM was theirs to make. Almost

all the women had the same feelings about the role of the physician in the CAM decision making process as they felt the physician could do very little for them anyway:

Um, I really got tired of not doing anything. The medications weren't working. It was, I had to do something. So I would have done it anyways. (P)

I mean, there was none... my doctor prior to that. I don't know if they really had a lot... you know, them saying. Because they know there's nothing they can do for me. (I)

Again, this was a hypothetical question for many of the women as only two participants were told by their physician to not use a particular CAM. Their responses were markedly different with one participant listening to her physician and the other valuing the opinion of her peers more highly:

Um, because one of the group members was really up on it, and thought it was really worthwhile trying. So I went ahead and tried it. And I have found that it has had some positive impact on me. (E)

Clearly, the type of CAM must be taken into account, i.e. is the CAM relatively mainstream such as massage or is the CAM under question much more controversial (which often means more invasive) such as chiropractics? This can impact how the woman weighs her decision. Participant N alludes to this as she describes she would have gone ahead with yoga even if it meant going against her physician's advice, but she did listen to her physician when she warned her against using a cleanse<sup>16</sup>:

Uh, not with yoga, no. Uh, not with yoga. I wanted to do a, um, a, a whole body cleanse, years ago. Probably about six years ago. Or even four years ago. And she just said no. She said your body has been uh, through way too much. And uh, uh, she said no. That I shouldn't do it, um these cleanse, for um, two or three day cleanse. (N)

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<sup>16</sup> Cleanses are believed to detoxify or eliminate harmful substances from the body such as heavy metals or pesticides. Cleanses may involve fasting, special diets, and/or taking herbs and nutritional supplements.

### Reaction of the physician

The women most often dealt with physicians who were either supportive or neutral in their opinion of CAM. The most interesting finding here was that the physicians often left the decision entirely up to the patient. This often seemed based on their limited knowledge about CAM:

And uh, and she is, uh, she felt that she was learning from me. And she had another patient that had, uh, had, has FM as well. And so, you know, what she was, I feel that whatever I was suggesting to her, and I wanted to try this or do that, uh, she would be in agreement. And whatever I felt and uh, cope. Um, so yeah. (N)

Having examined both the role of the social network and the role of the physician, it becomes very clear that the women are internally motivated to use CAM. This internally motivated intent is strengthened even further by their commitment to improve their functioning and the level of desperation they have reached. Notwithstanding this strong intent to use CAM, there were some potential barriers that at times prevented them from using CAM. These will be discussed next.

### **e) Barriers to CAM**

In this study a barrier was defined as anything real or perceived that could interfere or prevent a person from starting or staying with CAM. In other words, what were so called distracters that could inhibit a woman from using CAM? A total of three potential barriers to starting CAM were found. They are potential barriers as the women were able to use certain strategies to overcome them.

### Cost

First and foremost, the cost of CAM seemed to be a significant barrier in starting CAM for the majority of the women:

And so, I can't afford to be stalling out forty-five dollars per treatment. Or whatever the cost is. Um, I think ours is actually quite low compared to that a lot of people will pay for those treatments. So money has a huge, huge impact on, on what my decisions are. (O)

Many of the women were only able to afford CAM through using either their own benefit packages or their husbands' benefits. Of the three barriers, cost seemed to be the most insurmountable, with really few options for overcoming it.

### Questioning efficacy

More than half of the women mentioned a hesitation to use CAM if they were unsure if the CAM worked or not:

Well, uh, I thought, oh, god, this just sounds like a crock of shit, you know? You look at the little lights, and you're going to blink, and I'm, it's going to change my sleep pattern, and it's going to make me feel more energetic. (P)

Their lack of conviction that a CAM would work was especially strong when they could not see the logic or rationale behind it:

Um, ...because they are suggesting some really odd things that just don't make sense to me. It doesn't fit. (E)

So it's a real kind of, it's a juggling act. It is. You just kind of have to go with what you feel makes sense. (M)

### Pain

The potential pain or discomfort a CAM could cause was also a reason that almost half of the women thought twice about using CAM:

It's, it is not a pleasant feeling at all. (laughs) Um, so, I was scared. I was very scared, because I don't like pain. And the last thing I want to do is create more pain. (P)

Keeping in mind that one of the most aggravating symptoms of FMS is pain, one participant explained her hesitation in using a CAM that could cause more pain as follows:

...The pain, I think, now I didn't, you see, you live with so much, with fibro you live with so much, er, discomfort that I just didn't wanna bring any more, even if it was just momentarily, it's just, it's just more invasive.(F)

As all the women in this study are CAM users, clearly there were strategies used by the women to overcome these barriers. These strategies will be discussed in greater detail below.

#### **f) Strategies to overcome barriers**

Strategies are actions/interactions, beliefs, and/or attitudes that would promote the use of CAM. The women employed several strategies to overcome the potential barriers mentioned above, but three were particularly evident.

##### Use in others

By far the most frequently mentioned strategy in overcoming the barrier of questioning the efficacy of CAM, or being concerned about safety, was the fact that CAM was used by others. All the women used the experiences of the people in their social network and beyond, to reassure themselves about CAM use. This strategy was utilized extensively during the information seeking phase. The women preferred to hear from many different people (could be complete strangers) or someone whose opinion they trusted. Furthermore, these CAM users did not need to be using CAM for FMS related symptoms:

And uh, that's why uh, I feel I can, you know, if my friends or their friends have tried it out, then I know that I'm not just a guinea pig for somebody, or somebody else had. (Laughs). (C)

So it's, it's, uh, basically you just talk to people with so many different conditions who have tried it. And it's done wonders for them. So, yeah. (P)

In assessing CAM use in others, the women were attempting to ascertain three things about CAM: 1) is it safe? 2) could it potentially be beneficial? 3) if there are side effects what are they?

And I've seen it help so many people. And it, I had seen it before for, um, different things, that it really didn't concern me at all. And I've never really seen anybody have any effects, like bad effects from it. So it wasn't a huge concern, no. (P)

Other reasons why the women were not concerned about safety included the length of time a product or treatment had been in use and how often it was mentioned in popular media. How easily a product was accessible also played a role in reassuring the women that the product was safe:

Um, not with something like MSM. That had been around for a long, long time, and I'm, pretty well hard to believe that you know, hundreds and thousands of health-food stores and Costco and everybody else is selling it, you can buy it at London Drugs, that it's not safe, right? Any more than buying a bottle of Aspirin that some psycho poisoned, you know? (I)

Furthermore, they started to believe that CAM was safe *after* they had been using the CAM without any side effects, rather than having this belief based on the information they had collected and reviewed.

I haven't had any, any alternative thing do anything harmful to me like that. Nothing... I haven't had any of those side effects from any of this stuff. (G)

### Desperation

More than half of the women also felt that they had little choice but to go ahead with CAM, because they were so desperate for relief:

And you try and figure out what's going to help you because conventional medicine doesn't help. All they offer you are bandages. And symptom relief. They don't offer a cure. They don't offer any hope that, that someday, you're going to wake up and not have this any more. You know? So you've got to just go out there and do your thing. (O)

This is not to say however that they threw caution in the wind. Participant C framed this as follows:

It was a broadcast. Because it was a medical research. It was a medical, uh through this, that channel fourteen, Spokane... They have lots of things on, and it's not just an interview with anybody. It's a matter of all these research things being done. And a couple of my friends, they do a lot of research on the different things. And any time they find out anything alternative, they say, they uh, have you thought about this, have you heard about this? No, it's some kind of weird. And then you listen to it, and then if it still sounds weird, you think about it for three or four days. And then, and even if you are dying in pain, if it still sounds weird, you don't try it. I mean, there are things definitely you don't try just because. (Laughs)

This again demonstrates that the women used many different sources for information, yet they ultimately used their own judgement in making the decision as to whether or not to use a CAM.

### Control

Finally, the fact that trying CAM does not automatically mean staying with CAM was reassuring to a number of women and gave them a sense of control:

And figure, I don't ever have to go back. And I don't like it. And which is actually what we stopped doing, with, with our last chiropractor. I mean, he was good for years, then he had a meltdown and he left for a year. And he had a replacement and I didn't like him and I never went back, so. (M)

The notion of having control over one's treatment is in sharp contrast with how the women felt with their treatment in the conventional system, where they often felt they had few choices.

### 5.3.4 Taking action

Despite the fact that the process of choosing to use CAM is described in a linear fashion here, the actual act of first using CAM is the outcome of the complex convergence between the many different concepts described above. After the participants made the decision to use CAM, they chose a type of CAM and carefully monitored for the outcome of an improved functional self. Through the process of using CAM, they discovered certain barriers to staying on CAM. In the event that CAM was not effective, new information seeking would take place and the subsequent trialling of a new CAM, providing these barriers were overcome, would take place.

#### a) Initiating CAM

##### Choosing type of CAM

The *type* of CAM the women chose was partially influenced by how intuitively attracted the woman was to it:

Because I had the feeling that that would be the fastest way of uh, getting better. (By using acupuncture versus another CAM) (C)

I guess, just reading the different things that it helps with. It just, I don't know, it just hit me... I had pamphlets that could fill the filing cabinet, I said, I would read on different things, but it always came back to St. John's Wort. I put the rest in the back of my mind, and don't even really know what those other alternatives were. (J)

Furthermore, the women acknowledged that there is a trial and error component to choosing a type of CAM:

Like maybe if there had been someone I'd known in my life earlier that, say, did Reiki or maybe even a female who did acupuncture and that I got to know her personally, then that might have happened first, first, well, the yoga was always there but, er, if it's just sort of a random sort of thing. (F)

This is confirmed by the many different types of CAM the women have used (Table 5.5). None of the participants stated that their co-morbidities had an influence on the type of CAM they chose. It was difficult to discern what influence past CAM use for other conditions had in the women now choosing a type of CAM for their FMS.

**Table 5.5*****Overview of current and past CAM use classified by NCCAM categories***

<b>ID</b>	<b>Current CAM</b>	<b>Past CAM</b>
<b>A</b>	<ul style="list-style-type: none"> <li>• Alternative medical systems<sup>17</sup></li> </ul>	<ul style="list-style-type: none"> <li>• Manipulative and body based systems</li> </ul>
<b>B</b>	<ul style="list-style-type: none"> <li>• Alternative medical systems</li> </ul>	<ul style="list-style-type: none"> <li>• Manipulative and body based systems</li> </ul>
<b>C</b>	<ul style="list-style-type: none"> <li>• Manipulative and body based systems</li> </ul>	<ul style="list-style-type: none"> <li>• Alternative medical systems</li> </ul>
<b>D</b>	<ul style="list-style-type: none"> <li>• Alternative medical systems</li> <li>• Mind-body interventions</li> <li>• Energy therapies</li> </ul>	-
<b>E</b>	<ul style="list-style-type: none"> <li>• Manipulative and body based systems</li> <li>• Mind-body interventions</li> </ul>	<ul style="list-style-type: none"> <li>• Energy therapies</li> </ul>
<b>F</b>	<ul style="list-style-type: none"> <li>• Alternative medical systems</li> </ul>	<ul style="list-style-type: none"> <li>• Manipulative and body based systems</li> <li>• Mind-body interventions</li> </ul>
<b>G</b>	<ul style="list-style-type: none"> <li>• Mind-body interventions</li> </ul>	<ul style="list-style-type: none"> <li>• Alternative medical systems</li> </ul>
<b>H</b>	<ul style="list-style-type: none"> <li>• Alternative medical systems</li> </ul>	<ul style="list-style-type: none"> <li>• Reflexology</li> </ul>
<b>I</b>	<ul style="list-style-type: none"> <li>• Alternative medical systems</li> </ul>	<ul style="list-style-type: none"> <li>• Manipulative and body based systems</li> </ul>
<b>J</b>	<ul style="list-style-type: none"> <li>• Mind-body interventions</li> <li>• Manipulative and body based systems</li> </ul>	<ul style="list-style-type: none"> <li>• Energy therapies</li> </ul>
<b>K</b>	<ul style="list-style-type: none"> <li>• Manipulative and body based systems</li> <li>• Alternative medical systems</li> </ul>	-
<b>L</b>	<ul style="list-style-type: none"> <li>• Alternative medical systems</li> </ul>	<ul style="list-style-type: none"> <li>• Manipulative and body based systems</li> </ul>
<b>M</b>	<ul style="list-style-type: none"> <li>• Manipulative and body based systems</li> </ul>	<ul style="list-style-type: none"> <li>• Alternative medical systems</li> </ul>
<b>N</b>	<ul style="list-style-type: none"> <li>• Manipulative and body based systems</li> <li>• Alternative medical systems</li> </ul>	-
<b>O</b>	<ul style="list-style-type: none"> <li>• Mind-body interventions</li> </ul>	<ul style="list-style-type: none"> <li>• Manipulative and body based systems</li> </ul>
<b>P</b>	<ul style="list-style-type: none"> <li>• Alternative medical systems</li> </ul>	<ul style="list-style-type: none"> <li>• Manipulative and body based systems</li> </ul>
<b>Q</b>	<ul style="list-style-type: none"> <li>• Alternative medical systems</li> <li>• Manipulative and body based systems</li> </ul>	-

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<sup>17</sup> Most frequently mentioned NCCAM category

## **b) Staying with CAM**

### Therapeutic effect

Once the participants started to use CAM, there were a number of reasons why they would stay with a CAM. An important incentive for all the women to stay with CAM was if they were achieving the therapeutic effect they sought. Remembering that their three biggest complaints were pain, lack of energy and lack of sleep, it does not come as a surprise that many women were monitoring for less pain and more energy.

Yeah, well, that's about, like from the, I went for three months for this light therapy... for this whatever the heck they call it. And uh, I mean, I was just like a, you know, no pain. Miles of energy. It was just like ahh! (K)

So it actually, I did about ten treatments of that, just for my back. And it really helped. I have not had a problem. I mean, I have still general back pain, but I haven't had a flare up like that since before I started the IMS treatment. (P)

They would continue to monitor for a therapeutic effect on an ongoing basis, however the length of time they were willing to wait for a therapeutic effect to occur varied greatly between the women. One participant used the same time frame for all her CAM (three months, participant I) whereas others were willing to try a CAM for more extended periods of time, i.e. 30 chiropractic treatments (participant N). The women who were willing to try the CAM for much longer stated that what propelled them to do so was hope, i.e. hope that eventually their functioning would improve.

### Connection with provider

The connection with the CAM provider was also raised as an important incentive to stay with CAM. Almost all the women commented on how they felt at ease with the CAM provider fairly early on their treatment. This was partly due to the provider often

being highly recommended by their social network or by other CAM providers. Two participants also knew their CAM provider from their work environment:

Um, and so they said oh yeah, she's the guru of naturopaths, so I wanted to confirm that she had a good reputation, um,...(E)

The women then described how this relationship progressed to feeling a strong connection with their provider:

She's helped my feet. Like she's got me walking again, on all, like not limping. I just felt safe, just thought I could trust her with it. You know, and it's just that type of person. (J)

In contrast to the conventional system, the time allotted for the women in their visits to their CAM provider was something they appreciated greatly. Furthermore, the CAM providers often communicated in a manner that was perceived as caring and "knowing" by the women, i.e. the provider understood FMS and what the women needed:

...and when I first went to the naturopath, it was like, I think an hour, the first appointment, and every appointment after that was half an hour. Half an hour!!! So she gets, you sit down, and you get, it's almost like, I can't say a friend, I mean we don't socialize outside of that, but they get to know what you do for work, what your kids are like. What, do you know what I mean? (M)

#### Complete and tailored treatment

Similar statements were made by the participants about the actual CAM treatment. The majority of the women stated their treatment is often holistic and it is very much tailored to meet their needs:

Um, well, because I had lost, um, you know, a regular exercise program, I just really couldn't do, uh, well squats certain things, say, bicycling, um, walking, uh, walking, for me, it's about a maximum of a half-hour, and that, then I just can't go any further. So I needed something that really was complete. (H)

Furthermore, they felt that the CAM product or treatment was dealing with the cause of the symptoms rather than only treating symptoms:

Okay, so she looks at like what's causing your stress. And what's going on in your family life. And you know, what else is going on. Um, you know, sleep patterns, is that affecting this? Is your bowel movements, is that affecting this? Or, you know, she looks at sort of, your whole body, as opposed to, you go in, complain about your stomach and they just prescribe something for your stomach. Or they prescribe you depression medication. Or do you know what I mean? So, they're not, like when I complain about headaches, the naturopath isn't just thinking there's something in your head. It's (laughs) you know. It could be your back or your neck or whatever. I don't know if I'm explaining it right. But they look at a lot more factors and the cause. Maybe that's what I'm trying to say. They try and find the cause as opposed to covering it up with a drug. (M)

Last, staying with CAM was made attractive due to the relaxing or the “respite” component of CAM as well as the convenience of CAM:

For me, um, like, massage, I like going to massage, I went there Thursday, I feel so good when it's happening, it's like, I get an hour's place, or space, to feel good, you know? And then I get up and leave, and I'm usually exhausted after, so that's the end of that. But I've at least had an hour of some joy. (Laughs) Yeah. (E)

#### Frequency/Quantity

The frequency and quantity of using CAM was dependent on whether the CAM was a product, i.e. like St John's Wort or whether the women were physically seeing a CAM provider. The women often followed the instructions written on a CAM product in regards to dosing and dosing intervals. For those women seeing a CAM provider, in the initial period the CAM provider often recommended the length of a treatment as well as the frequency of the treatment. Once immediate symptoms had abated the majority of the women used their symptoms or level of functioning as a guide as to whether or not to see the CAM provider:

Um, she usually, what she used to tell me, now I kind of go when I'm feeling rotten. I'm actually trying to get off some of my medication right now too. And she's been helping me with that, so. (P)

This demonstrates again that improving one's functional self is truly the outcome that the women were looking for. Furthermore, it must be noted that the cost of CAM again is a limiting factor in the frequency and quantity of CAM the participants could afford to engage in.

#### Strategies used to incorporate CAM

Almost all the women felt that it was easy to incorporate CAM into their lives. Strategies dealing with time appeared to be the most used, in the sense that the women needed to take the time to do CAM. Furthermore, scheduling what time of day to take a product or doing a treatment because of the side effects of the treatment was also mentioned:

Well, sometimes, uh, depending on what I take, um, I'm finding I'll be able, like I have to be conscious of when I take them. Uh, be it twenty minutes before eating. Or waiting two hours after I've eaten. I can't take things like mint, chamomile or lavender. I can't have eucalyptus or lavender in the house or on me. (A)

One participant stated she works more than usual to cover the additional cost of using CAM. Two participants stated that even with using CAM they needed to be aware of not overdoing things and respecting their own limits.

Of interest is that none of the participants mentioned the need for special equipment, specific preparations for food, or specialized clothing. This is a contributing factor to the ease with which the women seem to incorporate CAM into their lives. This resonates closely with the category of "improving functioning self" as the women are using CAM to allow for easier functioning, rather than to complicate their daily life.

### Level of commitment

The majority of the women declared that they were committed to staying with their CAM of choice very soon after starting it. For some women it was as soon as after one or two treatments. This was often directly related to the level of relief found from using CAM:

Oh no, after the first one (*acupuncture session*), and I laid there after a half an hour after finishing, I knew, I knew that was the way to go. (D)

A number of participants also stated that they had to be committed, because they needed symptom relief or they felt they had to commit fully to give the CAM a chance to work. One participant was the exception to this. Participant A was not fully committed until she had been taking homeopathies for a number of months. She was also one of the few women who had had a very negative experience with a CAM provider in the past, to the point where she stopped doing CAM for a number of years. It was not until her CAM provider managed to treat her pneumonia without antibiotics that she felt fully committed to continuing on with the homeopathies. Last, support either from their social network or from their spouses, was not necessary to stay on CAM.

### **c) Improving functional self**

Generally speaking an improvement in functioning for all the women meant an improvement in their ability to carry out activities of daily living as well as completing instrumental activities of daily living. This was the dominant outcome the women gave for exploring CAM options and initiating CAM:

It was, because I don't like to not feel good, because I like to be able to do things, I like to be able to clean my own house, I like to be able to go shopping, I like to go for a walk, not have to turn back after half a block because I can't do it. I like to do my own yard work, and I couldn't do any of that anymore. (J)

I just wanted to be me again, and I think that, you know, sometimes you just sit down and reflect, and okay, where is my life going, where is my body going, it's not following me, you know. (C)

Because what else is there for it? Nobody else can do anything for me, I've got to try to feel as good as I can, you know? I'm not ever going to feel top-fold, but it's much better to be functional than sitting on my butt somewhere and doing nothing. (I)

The women gave numerous examples of what they meant with functioning better including improvements in: mobility, energy, independence, sleep, work, cognition, social activities, intimate relationships, pre-illness identity, inward happiness, leisure activities, and coping skills. This demonstrates that for some women the improvement pertained to a psychological domain where for others it was more focused towards physical improvement.

...now I can do my own work, I can enjoy my grandchildren, I can, you know, I don't do any great things any, I mean, I never did great things, but, you know, I did, I worked a lot and was involved in a lot of things and I can't do that any more but I've got a quality of life which I didn't have before. (G)

I felt so much better. Not healthy but so much better. I still had to rest a lot I could not go for more than a couple of hours without laying down but I was able to walk a few blocks by myself. I even planned our wedding at that time. (A)

The level of functioning deemed acceptable was different for each of the women. For example some women were focused on being able to complete all the activities involved in running a household whereas some women were happy to have two hours of productivity in their day:

And that I have to just take care of myself so I can maybe, maybe get two or three hours of activity in a day to, you know, do things, like laundry or something like that...(E)

It is important to clarify here that when the women were initially exploring CAM options that they were first and foremost looking for an improvement in their functioning.

However, as many of the women have been using CAM for years at a time, their anticipated outcome changed from improving their functioning to maintaining a certain level of functioning.

Yeah. Anything that, like, when (CAM provider) works on, when she, when I miss her, like, she's going away, so I will not get a treatment from her for a couple of weeks, and I will notice the difference. Like, it's maintaining this level of activity that I desire, more than, I'm not going to be cured, so I'd like to keep my level of activity up. (I)

Again this is not static as the women would change their goal from improving their functioning to maintaining their functioning depending on fluctuations in their FMS symptoms and other health events like menopause:

And even now at this point, where you know, I'm probably as healthy as I've been in a while. But still to go to the family doctor, it's like my energy is, you know, two good hours in a day. And that's it. And there's nothing really that they can do for you. So I go back to the naturopath. And we're working on different things. And you know, hopefully we'll see some improvement. (M)

#### **d) Barriers to staying on CAM**

##### No therapeutic effect

A lack of therapeutic effect in its truest sense is not a barrier, but rather a disincentive to staying with the CAM. However for clarity's sake it is grouped here.

All of the participants agreed that they would not stay with a CAM if it was not giving the therapeutic effect they were seeking:

You know, he's doing all this, and it's not really addressing the muscle spasm and the tightness in my muscles you know? So I just walked out, and said, you know, I'm not coming back here any more. It's not working, so. (N)

...but I had gone quite a long time and found absolutely no, no improvement at all so, you know, if you don't find improvement after a while...(G)

Side effects also impacted whether or not the women stayed with CAM. In particular if the women experienced pain due to the CAM, they were often quick to quit it:

Because I had gone to another chiropractor because what this guy did it was not even 5 minutes, he cracked me and left me there I could not even walk !Ok? I was in such pain and that was it. And that was it so then I swore off chiropractors. (A)

### Cost

Not surprisingly, cost again was mentioned. More than half of the women professed that it was challenging to afford CAM over longer periods of time and they recalled instances where they were unable to continue on with a CAM due to the cost:

I'm not going to have the massages often, because it is fifty-five dollars an hour. For half an hour, it's probably not worth it to go to. So you may as well do the hour, but it won't happen very often. Because of the cost. (B)

### Poor access

Twelve of the participants felt that poor access to CAM would prohibit them from staying with CAM. Some participants found driving stressful, or their FMS symptoms impeded their ability to drive. One participant did not drive at all and one participant felt she would be wasting time driving long distances. Ultimately whether poor access was a barrier to staying with CAM was dependent on the woman weighing two things: 1) what impact driving has on symptoms and 2) the benefit of treatment and subsequent improvement in symptoms:

Oh, I don't think I've, I guess if it was really far away, yeah, I'd have to. Because being in the car for, driving in the car for a long time, it's, it sort of negates the effects, the effect of the, um process. I, in fact, stopped going to one alternative

practice because it was all the way in Midnapore from where I live, and it was causing me too much grief to go there. (E)

Some women felt that the impact of the drive was substantially more negative than the benefit of the treatment whereas others felt that they received such benefit from the treatment that they were willing to drive long distances to their CAM.

The impact of weather was also noted by several women; in particular cold weather:

I still struggle with feeling really good and I still struggle immensely with exhaustion so, yeah, for me to, you know, go across the city to my chiropractor when I'm not feeling really good, I just would not bother, especially in the cold nights, the cold affects me greatly.(G)

One participant who lives in rural Alberta pointed out that roads become impassable with the onset of snowy weather; hence she had no choice but to stay in her area.

#### **e) Starting new CAM**

It should be noted that all participants who were non-CAM users prior to their FMS, felt that they became more open to CAM after using CAM for their FMS and all stated that they were now inherently “open” to trying a new CAM. *How* willing they were to actually try a new CAM, was dependent especially on their level of satisfaction with their current CAM (i.e., had they achieved the level of functioning they were hoping for). A number of participants felt that they would only add a CAM if it would not interfere with their current CAM or if their symptoms would suddenly fluctuate:

I would have to take a complete turn-about to square one before I would even change anything at all. Because my prescription medications and St. John's Wort, I've been on all of them now for a good six, seven years, permanently. And they are doing so well for me. (J)

Others felt that they would gladly try another CAM, because they were only just maintaining a functional self. Nonetheless, they would like some assurance that there would be an improvement in functioning:

Er, ...as I said my umbrella is fully open now, I'm open to so many things, I think that there's so many things out there now that the medical world has been so closed minded to, and I put myself in that category, acupuncture, reflexology, all of those things I think are, there's many that I don't even know about but I am open to anything that can give me help. (G)

A few women felt that even though they were open to trying new CAM, they were sceptical that there were any CAM left for them to try:

Um... Well I think, I think I've exhausted all the alternative therapies right now. Um, there would have to be something new that I've not heard of, to consider, but I, I feel like I've completely exhausted them all. (E)

It is again apparent that symptom control and level of functioning are at the core of their decision-making around CAM.

#### **f) Information seeking new CAM**

Keeping in mind that the majority of the women had been with the same CAM for an extended period of time, the question arose if they were still engaged in information seeking. There was a variety of behaviours as some women were no longer actively looking, whereas others were looking for information in order to be prepared for their current CAM no longer being effective. A few women were in the process of changing CAM and were actively looking for which CAM to try next. Of special interest is that all the women stated that they are very much open to hearing from others about CAM, regardless of whether they were actively looking to change their CAM:

I guess, sort of in a way, people tell me what's going on out there, and I don't go, you know, read every new thing that comes out in the health food magazines. (I)

The important role of the women's social network became evident again in this category. This coincided with the women stating that they would use the same information seeking strategies again for a new CAM.

**g) Barriers to starting new CAM**

The majority of participants felt that cost remained a potential barrier in trying a new CAM. However, in contrast to trying an initial CAM, almost half the participants commented on feeling too overwhelmed to start a new CAM. For some this was directly related to their FMS symptoms whereas others simply were busy with life events:

I think I was going through a period of time where so many people were asking for time in my life and I just didn't have any more reserves and so it was like part of me was protecting me and just digging in my heels and saying, "No, I'm not gonna take this on because I know if I do, it's just one more thing I have to give".  
(F)

For two participants it was directly related to the type of CAM they were contemplating, meaning the preparatory work required in order to initiate the CAM. Only a few women commented that their doubts around the efficacy of a new CAM could be a barrier again. (This is not altogether surprising considering all the women stated that they felt more open to trying new CAM now that they have tried CAM in the past). This last category concludes Chapter 5.<sup>18</sup>

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<sup>18</sup> Most health care providers are aware that there are certain patient groups considered "difficult" patients. Adams and Murray describe difficult patients as follows: "patients who are medically challenging, interpersonally difficult, psychiatrically ill, chronically medically ill or lacking in social support" (p.689, 1998). Hence it is not surprising that FMS patients are at times considered difficult patients. However, when reading the above excerpts this may not be the reader's immediate impression. In contrast, the participants appear to be quite well spoken women, who are generally quite proactive. Given these characteristics it is not surprising that these women volunteered for the study. Less proactive women would probably not be interested in participating, making it difficult to recruit them for the study. Furthermore it can be argued that this sample of women is highly educated, which could affect the manner in which they communicate as well.

## **Chapter Six: Discussion**

### **6.1 Introduction**

The following topics are included in the discussion: 1) summary of the study findings, 2) classification of the emergent substantive theory, 3) a comparison between the emergent substantive theory and the current CAM literature, 4) a comparison between the emergent substantive theory and the Andersen socio-behavioural framework for access to health care, 5) delimitations of the study, 6) saturation, and 7) reflexivity.

### **6.2 Summary of study findings**

The purpose of this study was to build an explanatory decision making model based on the process that women with FMS go through when making the decision to use CAM. In-depth interviews were used to discover the participants' perceptions of CAM, how they approached CAM decision making and their experiences with CAM. It became apparent that the participants experienced four distinct phases when making the decision to use CAM: 1) establishing readiness, 2) initiating FMS self management, 3) getting organized, and 4) taking action. Establishing readiness appears to be the result of the convergence of multiple experiences such as being diagnosed during the 1990's, having unfavourable experiences in the conventional health care system, and struggling with the impact of FMS on daily functioning and co-morbidities. These experiences pushed the participants to FMS self management and ultimately to perhaps try CAM. The influence of the participants' social network became evident, as well as the more limited role played by health care providers. During the process of information seeking, motivators and barriers were carefully weighed and strategies to overcome barriers were implemented as well. Taking action initially meant starting CAM. However, during this

phase barriers to staying with CAM as well as strategies to overcome these barriers were discovered also. The participants monitored the outcome of improving their functioning very carefully. If they did not experience an improvement in their functioning or if they were not able to maintain a certain level of functioning, they would quit CAM. Other motivators to stay with CAM were the connection they felt with the provider and the completeness of CAM. If the need arose to try a new CAM, the process of information seeking would start anew and consequentially, potential barriers to new CAM were discovered as well.

### ***6.2.1 Core category: Improving functional self***

As explained in Chapter 3, Table 3.1, the core category is the central phenomenon around which all the other categories are integrated. Hence it receives special attention in this section.

Strauss and Corbin (1998) give a number of criteria that address whether the core category chosen is indeed appropriate (p.147). These criteria are underlined and addressed in the following paragraphs. The concept or category of improving one's functional self came up frequently during the analysis. Every participant discussed the need for improving or maintaining functioning through CAM use. Not only did it appear frequently, all the other major categories can be related to it. This is demonstrated in Chapter 5 through the emergent substantive theory. For example, the initial reason why participants accessed the health care system was because of their impaired functioning and the desire to improve this functioning. Their quest for improved functioning is also what drove them to FMS self management. Their lack of success with improving their functioning through FMS self management in the conventional system drove them to try

using CAM. Once using CAM they based their decision of whether to stay with CAM pre-dominantly on achieving the outcome of improved functioning.

The name of the core category is adequately abstract to be used in future research regarding CAM decision making in FMS patients. For example, do females with other rheumatologic conditions also use CAM to improve their functioning? Last, the core category should hold even when the conditions or circumstance in which CAM decision making takes place vary or in other words, the core category is able to explain variation. For example, some women were interested in trying new CAM and were actively looking for information regarding new CAM whereas others were not. This variation in behaviour can be explained by looking at the level of satisfaction expressed regarding their level of functioning.

### **6.3 Classification of the emergent substantive theory**

A substantive grounded theory evolves from studying a phenomenon in a particular context, such as a specific group of women (women with FMS), living in Alberta, Canada, who have engaged in a certain health behaviour (CAM decision making). To demonstrate the utility of grounded theory, Glaser and Strauss (1967), discuss four distinct properties which all grounded theories should exhibit. These will be briefly discussed (to strengthen the argument that the emergent substantive theory can be classified as an emergent substantive grounded theory).

A grounded theory must fit the phenomenon under study (Glaser & Strauss, 1967). As obvious as this seems, there are many ways in which a researcher can fall victim to trying to force the data to reflect his/her own preconceived ideas. Hence a grounded theory must carefully reflect the everyday realities of the phenomenon under

study (CAM decision making). Numerous steps have been taken to ensure fit and the reader may refer back to Chapter 3 (“Assumptions” and “The use of literature”) for a review of these steps.

A grounded theory must be understandable to people working both professionally with the theory and to lay people who may apply the theory to themselves (Glaser & Strauss, 1967). The majority of participants (16/17) read the member validation summary, and they were all were able to understand and comment on the concepts presented. This manuscript has only been read by two professionals; hence no further comment can be made regarding the ease with which the professional could use this emerging substantive theory.

Glaser and Strauss explain the third property of a grounded theory, generality, as follows: “the categories should not be so abstract as to lose their sensitizing aspect, but yet must be abstract enough to make this theory a general guide to multi-conditional, ever changing daily situations” (1967, p. 242). The categories used in the emergent substantive theory have this property. For example the category of FMS self management conveys that a person takes control of their FMS, but exactly how this is done (i.e. exercise, diet), can be specified by individual.

The fourth property of a grounded theory is the most complex and pertains to the issue of control. Glaser and Strauss (1967) describe this property as follows:

The person who applies the theory must be enabled to understand and analyze ongoing situational realities, to produce and predict change in them and to predict and control consequences both for the object of change and for other parts of the total situation that will be affected (p.245).

Stated *very* simply, control translates into whether or not a theory is useful, i.e. can it practically predict behaviour and can it be built on and expanded on theoretically. These questions are addressed in Chapter 7.

#### **6.4 The emergent substantive theory and current CAM literature**

The components of the emergent substantive theory will now be compared to the existing CAM literature as summarized in Chapter 2, Table 2.1. For ease of comparison, the headings used in Table 2.1 are repeated as titles to the following sections. As mentioned in Chapter 2, there is no FMS literature to which to compare the results. CAM use has been studied extensively in cancer patients and to a lesser degree in chronic disease; hence this is the literature to which the study findings will be compared. This is done to provide some context in which to place the study findings.

##### Role of social network

Similar to findings of existing CAM studies, the social network of the participants in this study played a dominant role in the discovery of CAM. Activities of the network ranged from simply talking about CAM to adamantly “pushing” CAM. This confirms that CAM decision-making should be thought of as a social process. Ohlen, Balneaves, Bottorff and Brazier (2006) come up with similar findings in their recent study looking at the role of significant others in CAM decision making in breast cancer and prostate cancer patients. They identified four main types of decisional involvement by significant others: “creating a safe place for the patient to make the decision, becoming a team or collaborative decision making, moving the patient towards a decision, and making the decision for the patient” (p.1625, 2006). Even though these specific findings relate to

cancer patients, the important role of the social network in CAM decision making in FMS patients cannot be underestimated.

Participants discussed the use of CAM by their social network as a strategy to overcome their own doubts about the efficacy of CAM as well. Boon and authors (1999) found this as well as their breast cancer patients were interested in the personal experiences of other breast cancer patients regarding their CAM use. This is in contrast to the study by Caspi and colleagues (2004), who found that their patients found scientific evidence more important than personal testimony. These authors however did not take into account the different phases of CAM decision making or prior experiences with CAM when evaluating information. Furthermore, it is unclear what types of rheumatologic conditions their four participants had.

#### Patients role in decision making

Notwithstanding the role of the social network in discovering CAM and feeling reassurance about using CAM, the participants felt that they were actively involved in the decision making process and that they were ultimately responsible for the decision. These findings are echoed by the current CAM literature (Boon et al., 1999; Boon et al., 2003; Montbriand, 1995; Thorne et al., 2002; Caspi et al., 2004, D'Crus & Wilkinson, 2005). This is not altogether surprising, as the women are actively using FMS self management at this point in the decision making process. Edworthy (2000) coins self management as the process during which "patients accept responsibility for changing their health behaviours, obtain knowledge of their disease and its treatment and forge meaningful relationships with their health care providers" (p. 705). Hence, the central idea behind self management is that of control, i.e. the patient takes charge in regard to health care

decisions (Edworthy, 2000). This sense of control is carried over into the CAM decision making process.

### Role in information seeking

The active role that FMS patients play in information seeking confirms the literature on CAM information seeking (Boon, et al., 1999; Montbriand, 1995; Thorne et al., 2002). The study participants however, do indicate that they are often hearing about CAM from either their social network or through popular media. This suggests that information seeking can be passive as well.

### Motivators

In this study we distinguished between indirect and direct motivators. Participants discussed direct motivations to use CAM, i.e. a therapeutic effect and taking less medication, however, indirect motivators were also a common theme in the interviews. Indirect motivators were captured under the stage of establishing readiness and included: disappointments with conventional health care, FMS symptoms and their impact on daily living, length of time living with FMS diagnosis or symptoms, co-morbidities, and the socio-medical context. This resonates closely with the findings from the existing literature as the following motivators were found: co-morbidities, disease stage, and disappointment with conventional medicine (Boon et al., 1999; Boon et al., 2003; Montbriand, 1995). The literature includes motivators which were not seen in the emergent substantive theory such as: exploring all options to enhance chances of survival, treatment not harmful therefore nothing to lose, perceived stress, faith in health care practice, preferred treatment methodology, wanting a change in health care, and looking for a CAM that involved self care (Boon et al., 2003; Montbriand, 1995).

However as this literature pertains to cancer patients this is not surprising. FMS is not a life threatening chronic disease whereas cancer is. Hence a motivator such as exploring all options seems more consistent with patients who could succumb to their disease compared to FMS patient who are primarily concerned about day to day functioning.

Using CAM in an attempt to prevent further illness was given as a motivator to use CAM in cancer patients, whereas the FMS patients stated that preventing a worsening in their functioning motivated them to stay with CAM (Boon et al., 1999).

#### Barriers to starting CAM

Barriers to starting CAM such as cost, “weirdness” of the treatment; the potential for harm and not enough information were reported in the existing literature (Caspi et al., 2004; Boon et al., 2003; Montbriand, 1993). Barriers identified in the emergent substantive theory included cost, questioning efficacy and pain/discomfort. These differences are most likely again due to the potentially terminal nature of cancer where a patient may argue that cost is no object in terms of trying to save a life.

#### Reasons for staying with CAM

Staying with CAM was most often reported to be due to the improvement in health status experienced by participants both in the existing literature and in the emergent substantive theory (Thorne et al., 2002, Caspi et al., 2004; D’Crus & Wilkinson, 2005). The connection with the CAM provider was found to be an important motivator in the emergent substantive theory, which coincides with the findings of D’Crus and Wilkinson (2005). Caspi and authors (2004) also found that participants balanced the effectiveness of the treatment with cost as well as the CAM’s compatibility with their value system when staying with CAM.

### Barriers to staying with CAM

Only Boon and colleagues (1999) reported barriers to staying with CAM namely: cost, limited access and time. The emergent substantive theory includes similar findings of cost and poor access. Not surprisingly, a lack of therapeutic effect was included as a barrier to staying with CAM as well.

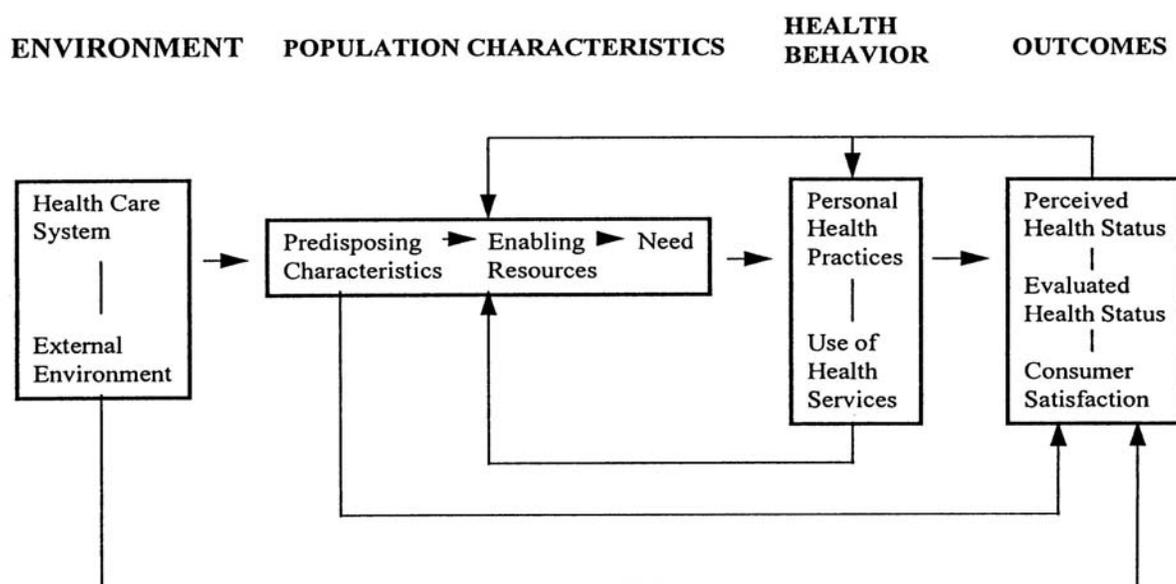
### **6.4 The Andersen socio-behavioural framework: explaining health care utilization**

The socio-behavioural framework was first presented in publication in 1973 with the intent to explain and predict access to health care (Andersen & Newman, 1973). The framework since then has undergone revisions and the last version of the framework was presented in 1995 (Figure 6.1) (Andersen, 1995). Clearly, the scope of this current study does not encompass all the aspects of access to health care as outlined by Andersen and Newman. However, the individual determinants of health service utilization (i.e. population characteristics) are closely linked to the scope of this study; and will be the focus of the following discussion.

This is not to say that other health behaviour theories were not considered. For example, Bandura's (1986) social cognitive theory (SCT) was examined closely to determine if it fit the emergent substantive theory. The concept of self-efficacy is central to SGT. Self-efficacy is concerned with the level of confidence one has in their ability to execute a certain behaviour (Bandura, 1986). Furthermore, SCT "predicts that behaviours are performed if one perceives control over the outcome, few external barriers, and confidence in one's ability" (Armitage & Conner, p.176, 2000). Certain concepts such as "FMS self management" seem to fit in SCT; however the actual decision-making process as a whole could not be accurately captured by SCT.

Multi-stage models of health behaviour were also examined, in particular the Transtheoretical Model of Change (TMOC) which posits that people go through similar stages of change, independent of the type of health behaviour they are trying to change (Proschaska & DiClemente, 1983). There are five distinct stages: precontemplation-contemplation-preparation-action and maintenance (Proschaska & DiClemente, 1983). Again one could see that components of the TMOC could capture the emergent substantive theory. However, the TMOC appears to be pre-dominantly concerned with macro stages of change and would not capture the micro level conditions that are seen in the emergent substantive theory such as indirect and direct motivators or barriers to initiating CAM. Therefore, the TMOC was also not complete enough to capture the emergent substantive theory.

**Figure 6.1 The Andersen socio-behavioural framework: phase 4**



Predisposing characteristics are described as characteristics that a person exhibits prior to the onset of illness, which increase the likelihood of that person accessing health care (Andersen & Newman, 1973). The predisposing properties can be further categorized under demographics, social structure and health beliefs.

Even if a given person is predisposed to using health services, he or she must have the means to access health services. This is captured under the concept of enabling resources, which can be further categorized as personal/family resources and community resources.

For a person to actually gain access to health services there must also be a need felt by this person, regardless of whether this is a perceived need by the individual or an evaluated need by a health care professional. There are a number of factors that will influence this such as the level of disability felt by a person or their general well being. Whereas the predisposing factors are considered to indirectly influence accessing health care, the medical need to access care is considered the most immediate cause of health care use (Andersen & Newman, 1973). In the following sections, a comparison will be made between the emergent substantive theory and the individual determinants of health service utilization. It should be noted that the underlined headings are determinants suggested by Andersen and Newman (1973) unless otherwise indicated.

#### ***6.4.1 Predisposing factors: Demographic***

##### **Sex and Education**

FMS sufferers are predominantly female with only a small percentage of males being afflicted with FMS. As such it is not surprising that the majority of FMS patients using CAM are female (Honda & Jacobson, 2005; Kelner & Welman, 1997; Verhoef et

al., 2005). It is well documented that CAM users are often highly educated (Eisenberg et al., 1998; Kelner & Wellman, 1997; Verhoef et al., 2005). This sample of FMS participants is highly educated as 13 out of 17 women had completed at least some college, with two participants having obtained graduate degrees. Hence, education can be considered a pre-disposing factor to CAM use.

#### Past illness

Andersen and Newman (1973) describe the impact of past illness as a predisposing factor in the sense that people who have experienced illness in the past, are more likely to access the health care system in the future. From a CAM perspective one could argue that CAM use for a previous illness could pre-dispose a person to using CAM again. This was certainly the case in our study as previous CAM use seemed to increase openness to CAM use. Furthermore, all the participants felt that they were *more* open to hearing about new CAM from others compared to when they had not used CAM. This may lead again to using CAM.

#### ***6.4.2 Predisposing factors: Social structure***

##### Social networks

The socio-behavioural framework has been criticized in the past for not addressing social networks, social interactions and culture. However, the creators of the framework have acknowledged that these components should be considered predisposing factors (Andersen, 1995). Certainly the emergent substantive theory makes it clear that a patient's social network plays a pivotal role in the CAM decision making process, especially in the initial discovery of CAM. Patients that are not close to their social network, or whose social network does not endorse CAM may not discover CAM until

much later or not at all. Furthermore, in the process of information seeking, the participants queried their friends for information as well. Hence a patient's social network should be considered a predisposing factor to accessing CAM.

#### ***6.4.3 Predisposing factors: Health beliefs***

##### Values concerning health and illness

The emergent substantive theory addresses values around health and illness through both the concepts of "FMS self management" and "Having had enough". The participants believed that their current health state was not acceptable and hence they felt they *had* to manage their FMS. This is in contrast to patients who believe that managing FMS is predominantly a physician's responsibility and that the status quo is acceptable. It is interesting to note that even though this supports an alternative ideology, the participants did not express an outright belief in CAM. This confirms that even though there is an alternative ideology present, it is much more focused on the patients' *own* awareness in knowing what is best, rather than simply trusting an alternative therapy/alternative provider.

##### Attitude towards health services

Two different attitudes come to mind here, 1) the attitude the person has towards conventional medicine and 2) the attitude the person has towards CAM. The emergent substantive theory certainly captures this. Almost all participants had an underlying faith in the conventional system as they started with trying treatments in conventional health care. It was not until they experienced multiple negative experiences in the conventional system that they choose to use CAM, indicating a positive attitude towards CAM.

Patients who have negative attitudes towards CAM may not take that next step and hence would not access CAM.

#### Knowledge about disease

The emergent substantive theory shows that after FMS self management occurs, i.e. after the patient learns more about FMS, the patient moves on to trying CAM. The participants started to try CAM after learning about the limited treatment options and low success rates in treating FMS in the conventional system. Without this knowledge a participant may continue to try conventional medicine rather than access CAM.

#### ***6.4.4 Enabling factors: Personal and Family***

##### Income /Health insurance

Clearly one must have an income that allows for the out of pocket expenses incurred when utilizing CAM. This was certainly echoed in the emergent substantive theory where the lack of an income, or a limited income, often meant participants were unable to use CAM. Furthermore, a number of the participants stressed the importance of their health care insurance or benefit packages as a vital factor which allowed them to use CAM.

##### Type of regular source of care

All the women in the study had a family physician that they saw for various things like prescription renewals, referrals and annual medicals. Despite this regular source of care, they still accessed CAM. This can at least be partially explained by the type of care they received or perceived to have received, namely inadequate and often uncaring. If their regular source of care had been more satisfactory, they might not have moved on to access CAM.

### Knowledge of available services

The emergent substantive theory demonstrates that it is through the process of information seeking that the participants learn about the types of CAM and where they can access these CAM. Without this knowledge it would be impossible to access CAM. Hence patients need to have at a minimum rudimentary information seeking skills such as accessing a library, or using the internet to learn more about CAM options, unless they have access to a well informed social network.

#### **6.4.5 Enabling factors: Community**

##### Ratio of health care providers and facilities to population

Regardless of whether a person would like to use CAM, if there is a scarcity of CAM providers or CAM facilities, accessing a CAM will be challenging. This is somewhat similar for CAM products as retailers must be in place to sell CAM products, however with the availability and use of internet, a person could access a CAM product on-line. The emergent substantive theory shows that the location of a CAM provider was an important enabling factor for the participants to *stay* with CAM; however it was not mentioned as a barrier or facilitator to *initially* access CAM. All but one participant lived in a large city. Just a simple search for chiropractors in Calgary through the yellow pages revealed four pages of possible chiropractors to choose from, with similar results for acupuncturists and naturopaths. The ratio of CAM providers to population may become adversely affected due to the population boom seen in Calgary; however at present there seems to be a plethora of CAM providers that patients can choose from.

### Urban-rural characteristics<sup>19</sup>

All but one participant in the study lived in urban areas. This certainly enhanced their ability to access CAM compared to the participant who lives in rural Alberta. Not only are there fewer CAM providers in rural areas, driving conditions especially winter driving conditions, can make it challenging to access CAM, if not initially then certainly in the long term.

### Stance of the community<sup>20</sup>

CAM in general seems to be gaining popularity, especially with lay audiences. It seems likely that this supportive stance of the general community on CAM, has some influence on the decision making process. Only two women in the study encountered resistance from their social network regarding their CAM use, hence this needs to be investigated further before any conclusive statements can be made.

#### ***6.4.6 The need for care: Perceived and Evaluated***

The individual determinants in this section emerged from the data analysis and have been added into the framework by the researcher.

### Length of time living with FMS

All the participants in the study had been living/suffering with FMS for eight or more years. This length of time has allowed the participants the time to learn FMS self management strategies including CAM. Patients, recently diagnosed with FMS, may not

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<sup>19</sup> This determinant is not suggested by Andersen and Newman, but rather has been added by the researcher.

<sup>20</sup> This determinant is not suggested by Andersen and Newman, but rather has been added by the researcher.

have had the time to learn these strategies and hence may not yet be participating in CAM.

### Co-morbidities

The presence of co-morbidities can intensify or diminish the perceived need to access CAM. Some of the women were unable to comply with FMS treatments in the conventional system because of their co-morbidities whereas others were unable to initiate CAM or maintain CAM because of co-morbidities.

### FMS symptoms and their impact on daily living

The tremendous impact of FMS on activities of daily living is a recurrent theme throughout the explanatory framework and it is ultimately this *need for improving one's functional self* that drove the women to use CAM. The extent to which a health issue is affecting day to day living certainly seems to be a crucial driving force in accessing CAM.

### Taking less medication

The health care professional may not immediately recognize this as a need for a change in health care. However, the need to reduce the number and doses of medication taken played an important role in the women's decision to use CAM. This illustrates the importance of differentiating between the perceived and evaluated need for care as a patient may prioritize needs differently and may see different reasons to access CAM. An evaluated need for care means that a health care provider has made a diagnosis of some sort versus a perceived need for care where patients themselves identify a need to access care (Andersen & Newman, 1973). A need established by a health care professional may be helpful in accessing care. For example, the delay in FMS self management and the

subsequent delay in accessing CAM, was often due to the lack of an appropriate diagnosis. Once diagnosed, the participants felt that their needs were legitimized, which helped them to move forward towards FMS self management and subsequent CAM use.

### **6.5 The Andersen socio-behavioural framework and current CAM literature**

This is not the first time that CAM decision making has been explained from the perspective of the socio-behavioural framework. Two previously published studies demonstrated that the individual determinants of health service can be used to explain access to CAM. Sirois and Gick (2002) analysed 199 questionnaires completed by patients who accessed either conventional health care clinics or CAM clinics. These questionnaires contained questions regarding health locus of control, satisfaction with conventional medicine, “health aware behaviours” (i.e., engaging in exercise), demographics, personality, medical history, use of CAM and attitudes towards the use of CAM. They compared the results between three groups of patients: conventional medicine use only; new or infrequent CAM user; and the established CAM user. The patients’ health complaints ranged from back problems/muscle strains to chronic pain and the flu. They found that “health aware behaviours and dissatisfaction with conventional medicine were the best predictors of overall and initial/infrequent CAM use, and more frequent health aware behaviours were associated with continued CAM use” (p. 1025). Furthermore, medical need was the best predictor of continued CAM use and committed CAM users reported more health problems than new or non-committed CAM users. Openness to CAM however, was an important factor in initially trying CAM.

Kelner and Wellman (1997) also used the framework to explain how patients come to use CAM. They chose patients who accessed five different types of care: family

medicine, chiropractic, acupuncture/TCM<sup>21</sup>, naturopathy and Reiki. The authors interviewed 300 adults about their health problems and their use of health care services. This allowed them to derive the factors that influenced these patients to seek CAM. The health problems of the patients ranged from musculoskeletal concerns to emotional health issues. They found that some patients used CAM for purely pragmatic reasons and some patients because they believed in CAM. Furthermore, they found that CAM patients relied mainly on themselves for dealing with their health issues and that they took a personal responsibility for their health. Two other interesting findings were that CAM patients suffered longer from their ailments than their non CAM counterparts (9.3 years compared to 6.7 years) and that almost 90% of their CAM patients reported that their health issues affected their daily functioning.

Clearly both these studies are congruent with the findings from the emergent substantive theory. This demonstrates the utility of the socio-behavioural model in explaining how CAM decision making takes place.

## **6.6 Delimitations**

The sample used to generate this research included only women with FMS. These women were all geographically located in southern Alberta with the exception of one participant. Data collection for this study took place over a 14 month time period from February 2005 to April 2006. Hence this research is restricted both by time and setting. The framework generated by this study is therefore considered substantive in nature

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<sup>21</sup> Traditional Chinese Medicine

rather than formal as a substantive theory is generated when a certain phenomenon is studied in “one particular situational context” (Strauss & Corbin, p.174, 1990).

The women in this study discussed a wide range of topics in the interviews. The scope of the analysis was limited to the topics that were pertinent in answering the research question.

### **6.7 Limitations**

All the women in the study were diagnosed seven or more years ago with their symptoms all starting eight or more years ago. This situates their diagnosis and treatment experience predominantly during the 1990s when arguable much less was known about FMS than at present. Despite efforts to recruit a multi-ethnic sample, all women in the sample were Caucasian. It would have been beneficial to have collected income related data as cost of CAM was a frequently mentioned concept. CAM use by type was also not delineated in this study which may have been beneficial.

### **6.8 Reflexivity**

Reflexivity can be described as “an awareness of the ways in which the researcher as an individual with a particular social identity and background has an impact on the research process” (Robson, p.172, 2002). The issue of reflexivity has been addressed in Chapter 3 as it was described there that a complete review of the literature was suspended until the member validation activities were complete. Furthermore, the researchers’ professional experiences as well as family, cultural, spiritual experiences may have had an impact on the study. This too was addressed in detail in Chapter 3 under “Assumptions”.

## **6.9 Saturation**

The phases of the explanatory framework (establishing readiness, initiating FMS self management, getting organized, taking action), reached saturation. The individual categories, such as the influence of the social network, however, require further development. Conceptually the area of women with FMS and CAM decision making is understudied and must be expanded. Certainly in this study alone, the perspectives of young women, women with different family dynamics, (i.e. single mothers, mothers with young children etc.), women with differing social networks, women living in different geographical areas and so forth were underrepresented. Future studies including these women may invariably expand and perhaps even challenge the explanatory framework as presented here. The following chapter addresses the implications of this study and provides further details regarding recommendations for future research.

## **Chapter Seven: Implications and Recommendations**

### **7.1 Introduction**

This chapter contains the practical and theoretical implications/recommendations of this study. Participants were asked to give three recommendations as part of the member validation process. Their recommendations are integrated where appropriate. Theoretical implications of this study conclude the chapter.

As was discussed in Chapter 6, the process of CAM decision making contains distinct phases. This is relevant for physicians as it allows them to provide stage specific care, hence the recommendations will be given per phase of the CAM decision making process.

### **7.2 Phase specific practice implications for physicians**

#### ***7.2.1 Establishing readiness***

##### **1. Education**

A number of recommendations are based on the concept of establishing readiness. An important factor for the participants was their disappointing experiences with the conventional health care system, which included poor communication with their physician. This led to tremendous frustration both for the participants and their physicians, especially in the initial phase of the syndrome when the participants reported vague and non specific symptoms. Therefore, it is not surprising that almost half of the participants recommended more education about FMS for physicians. They felt that if a physician knows more about FMS, communication about the syndrome would be facilitated.

## 2. Treatment options

A common source of frustration for participants was the *limited treatment options* they were offered. The FMS consensus guidelines clearly support a treatment protocol that promotes FMS self management through strategies such as patient education, self development, maximizing sleep, eating a balanced diet, and appropriate body movement and fitness (Jain et al., 2004). The judicious use of pharmacological and non pharmacological products or treatments (including CAM) is also recommended. The consensus guidelines acknowledge that treatment for FMS is patient specific and should be tailored to each individual patient. It is important that physicians are aware of this and, together with the patient, should continue to suggest trying different treatments. This may include treatments provided by other physicians. Hence, whether or not the patient needs to be referred to a specialist should be discussed with the patient. Closely tied to this is that a number of participants were frustrated with the length of time it took to be referred to a specialist:

If your family physician doesn't know how to treat you, what does it take to send you to somebody that knows how to treat you? (Participant O)

Women expressed that it was not until they realized that *FMS is a self managed syndrome* that they were able to take charge of their health. For most of the women it took months to years before they realized this. It would be very beneficial to tell women with FMS early on that FMS is indeed pre-dominantly to be self managed:

Um, I think once a doctor has diagnosed somebody with fibromyalgia, then I would suggest that they have maybe a list of different methods of treatment that are available that other people with fibromyalgia have actually used. And what the, um, possible, uh, side effects are. What the possible hopes are for that particular treatment, and indicate that there really isn't a cure. (Participant E)

Having said this, health care providers must be sensitive to the timing of delivering this message as the patient may be too overwhelmed in the first visit to hear this.

Once patients indicate a willingness to try a self management program; they may not be able to do so due to financial constraints or barriers related to access. Hence a conversation should take place with patients, not only around the level of responsibility that they are willing to take for their health, but also about whether there are any constraints such as finances, to doing so. This allows the patient and the health care provider to set realistic expectations around the type of self management the patient can engage in and the degree of success expected from it.

### 3. Mental health

A number of participants suffered from significant depression requiring pharmacological intervention. They commented on how discouraged they sometimes felt by the lack of improvement in their functioning despite their multiple FMS self management attempts. Hence, mood should be assessed regularly and if needed, treated. It is vital that this assessment is done in a caring manner and that the reason for the assessment is clearly stated. Without this, patients will quickly assume that their FMS is not taken seriously and that their symptoms are blamed on real or imagined mental health problems. Being diligent in screening for depression or other mental health disorders would allow the patient to get the appropriate treatment and support. Participant A comments as follows:

If it is in my mind, you as a doctor should take care of all of me, not just the body. Not just the physical, but the emotional. And don't make it seem like it's something to discard. If it is in my mind, that's like the main engine of my body, right?

### ***7.2.2 Initiating FMS self management***

#### **1. Self management program**

Once the discussion around self management has taken place, the physician can recommend a self management program. One example is the “Living Well with a Chronic Condition” program which is spearheaded by the Calgary Health Region. This program encompasses disease-specific education, exercise and self-management strategies. The program is accessible in all four quadrants of the city and financially accessible for the majority of patients. This program is unfortunately not specifically designed for FMS patients, but rather for patients with diabetes, high blood pressure, heart disease, arthritis, chronic lung disease, chronic pain and other long term illnesses. Hence, this program may not be tailored enough for FMS patients. Furthermore, the potential use of CAM as part of self management is not addressed in this program.

A number of items must be kept in mind when self management is initiated. First, the correct diagnosis must be established (Edworthy, 2000). Second, the physician must caution the patient about getting involved with self management classes or courses where the instructors are pushing their own agenda or product rather than focusing on the actual course (Edworthy, 2000). Third, just because a patient is involved in self management does not mean that the patient now needs less time or care from a physician, i.e. a self management program is a not substitute for access to the appropriate specialist (Edworthy, 2000). Last, the participants were involved in many different FMS self management activities with little consistency between participants. This indicates that there is again a component of having to find self management activities that are effective for each individual patient.

### ***7.2.3 Getting organized***

#### ***1. Social network***

The participants' social network is very important with respect to CAM information seeking. In contrast to the limited information provided by the participant's physicians, their friends and family were active in encouraging them to seek CAM. Many participants felt that their physicians should guide them in this respect as well and recommended that general practitioners receive more education regarding CAM. Ideally, as one participant suggested, patients should be given an information package which includes (where possible) evidence based recommendations around FMS self management strategies including CAM. This allows the patient to have a solid understanding of CAM before hearing multiple, often anecdotal versions of using various CAM.

### ***7.2.4 Taking action***

#### ***1. Collaboration with physician***

When a patient decides to use CAM, the patient will still need support from the physician, as CAM may not deliver the improvement in functioning that a patient had hoped for. The physician should be sensitive to the time and energy involved in certain CAM and caution the patient in perhaps taking on too many activities. Clearly this can only be done if the relationship between the patient and physician is such that sharing of information and frank discussion around multiple treatment options is encouraged. Furthermore, if the physician does not feel confident in advising the patient regarding CAM issues, the physician should refer the patient to a health care provider who is knowledgeable regarding CAM. This should be done at least until the physician has had

an opportunity to expand his or her knowledge base to include potential effectiveness of various CAM modalities.

### **7.3 Practice implications for other health care providers**

#### **1. Communication**

Health care providers such as nurses could play an important role in teaching women with FMS to effectively communicate with physicians. Nurses could be instrumental in encouraging FMS patients to be more clear and persistent about their symptoms and their needs when communicating with health care providers. Fitch and Turner (2006) have described how women with ovarian cancer, whose disease is also characterized by vague symptoms, can be assisted to communicate better with their health care providers. Their recommendations can also be applied to FMS patients, such as 1) help women to prepare questions and write down these questions to ask the physicians, 2) encourage women to search for “appropriate and reputable information” to discuss with the physician, 3) encourage them to have a supportive person with them during the physician visit and 4) encourage women to practice what she will discuss at the appointment (Fitch & Turner, 2006).

Clearly the role of the registered nurse could be expanded beyond teaching effective communication strategies to patients. Advanced practice nurses, which include both the roles of Clinical Nurse Specialists and Nurse Practitioners, have broad scopes of practice. Hence, the potential role of advanced practice nurses in this patient population should be examined more closely. This is expanded on under “Practical Implications for the Health Care System”.

## 7.4 Implications for patients

### 1. Medication use

Most of the participants continued, for some time, to use their conventional medications despite negative side effects. FMS patients should feel encouraged to report these side effects to the prescribing health care provider. This would allow for a timely intervention such as a dose reduction or a change in medications to occur.

### 2. FMS self management

The FMS patient should be open with their physician in regards to their expectations around the role the physician should play in their care. Keeping in mind that FMS is predominantly to be self managed, it would be beneficial to indicate to which degree they wish to be involved in treatment decisions. This should include an assessment of access to the appropriate resources (i.e. fitness facilities) including the ability to finance participation in self management activities. This would prevent the physician from suggesting self management activities which are not feasible for the patient.

### 3. CAM use

Most of the participants relied heavily on their social network for information and advice regarding CAM. It is important that this type of information is supplemented by evidence based information, where possible. This could be in the form of discussions with health care providers or by reading medical journals and so forth. Access to the internet is now available for free at all public libraries in Calgary and area. The Calgary Health Region also has medical libraries that are open to the general public which also

provide free internet access. Hence accessing reputable websites such as NCCAM should be relatively easy.

## **7.5 Practical implications for health care system**

### **1. Integrative health care**

A small number of participants recommended that more energy be directed towards creating an integrative health care system. This means that a patient would not only be able to access both CAM and conventional medicine in one location, but that CAM practitioners and conventional practitioners would work closely together in designing a care plan for a patient. This is clearly not a reality in the Canadian health care system and may not be for some time. However, an initial step would be to provide physicians and other health care providers with opportunities to become more familiarized with CAM. Financial remuneration should be provided as well as continuing education credits for submittal to their appropriate professional bodies.

### **2. Multidisciplinary clinic**

A recommendation that seems more attainable is that of creating a multidisciplinary outpatient clinic for patients with FMS. Such a clinic could be modelled after clinics designed to treat COPD<sup>22</sup> patients and patients suffering from diabetes as these currently exist in the Calgary Health Region. Having such a clinic would allow FMS patients to access appropriate health care providers in one location. This would be beneficial for a number of reasons. First, health care providers at this clinic would have a special expertise in FMS. Second, health care providers such as registered nurses could

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<sup>22</sup> Chronic Obstructive Pulmonary Disease.

complete intake assessments prior to a physician encounter so that the physician visit is utilized to the fullest extent possible. Registered nurses could also play a significant role in patient education both around conventional FMS self management strategies, CAM use and effective communication. Last, since FMS patients have limited energy, the benefit of being able to conveniently access multiple disciplines at one center would be tremendous.

### **7.6 Recommendations for future research**

Testing the model in a variety of situations and populations may allow for the development of the emerging substantive theory into a formal theory. Hence, CAM decision making by women with FMS must be studied in different population such as young women, women with different family dynamics, women with differing social networks, and women living in different geographical areas. This should preferably be done with a sample of women who have been diagnosed within the last five years as this would more accurately capture the current socio-medical context. Furthermore, CAM decision making should be studied in women with other rheumatologic conditions, as this will verify if FMS needs to be studied separately from other rheumatologic conditions or if there is overlap in the CAM decision making process.

More specifically, some of the emerging categories should be assessed in more depth, particularly the *role of the social network* in CAM decision making. Closely tied to this is the *role of support groups* in CAM decision making, which should receive more attention. The impact of *co-morbidities* such as mental health disorders should also be evaluated more fully. Third, a more detailed delineation should be made between *the types of CAM* and how this affects the CAM decision making process. For example, is

there a difference between CAM decision making in women with FMS who only use manipulative and body-based methods, compared to women who only use biologically based therapies? Fifth, *the role of personality* has been understudied in CAM decision making. Last, future studies looking at CAM should use a more consistent approach with at a minimum, *more consistent terminology*. Beyond using more consistent terminology, this study as well as the work done by Kelner and Wellman (1997) and Sirois and Gick (2002) show that CAM decision making can be explained through the use of the socio-behavioural model. Hence, future studies could use *the socio-behavioural model as a framework* from which to clarify the different conditions that determine whether or not a patient chooses to use CAM. This would allow for a more comprehensive comparison between studies which may ultimately lead to the development of a formal theory explaining CAM decision making in women with rheumatologic conditions. It should be noted however that the use of the framework should not stifle the discovery of new determinants as this may lead to an incomplete picture of the actual CAM decision making process.

### **7.7 Dissemination Plan**

The results of this study will be disseminated through publication in peer reviewed journals and through presentations at scientific conferences. The first of such presentations will take place at the 3<sup>rd</sup> Annual IN-CAM Research Symposium: Integrating CAM and Research Practice, held at the University of Calgary in the fall of 2006. Furthermore, discussion will take place between the researcher and Dr. Martin to discuss the potential implementation of the afore mentioned practical recommendations within the Calgary Health Region.

### **Chapter Eight: Concluding comments**

Grounded theory methodology was used to interview 17 women with FMS in regards to their CAM decision making experiences. The intent was to develop an explanatory decision making framework which would capture the decision making process used when deciding to use CAM. The explanatory decision making framework is considered a substantive grounded theory as it evolved from studying a phenomenon in a particular context namely, women with FMS, living in Alberta, Canada, who have engaged in certain health behaviour (CAM decision making).

It became apparent that the participants experienced four stages when making the decision to use CAM: 1) establishing readiness, 2) initiating FMS self management, 3) getting organized, and 4) taking action. Hence it became clear that CAM decision making is a process, occurring in phases. Motivators, barriers, strategies to overcome these barriers and expected outcomes became evident as well.

The emergent substantive theory was compared to the existing CAM decision making literature and congruence was found with most concepts. The emergent substantive theory was also found to be complementary rather than contrasting when compared to the individual determinants of health service utilization as described in Andersen's socio-behavioural framework. Finally, numerous practical implications were identified. These recommendations ranged from improving communication between FMS patients and physicians to providing FMS patients with evidence based information regarding CAM. Recommendation for future research focused especially on testing and validating the emergent substantive theory as well studying CAM decision making with a consistent approach.

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## APPENDIX A: RECRUITMENT POSTER

You are invited to participate in a study to explore decision-making by women with Fibromyalgia who have chosen to use complementary or alternative therapies as part of their treatment.

**Are you a woman with Fibromyalgia who is using complementary or alternative therapies?**

P.I. Dr. Marja Verhoef, Professor, University of Calgary

### Eligibility:

- Diagnosis of Fibromyalgia by a rheumatologist
- Currently using complementary or alternative therapies
- Female gender

If you are interested in the study, please call  
Lana Trojan at (403) 210 - 9608

This study has been approved by the University of Calgary Conjoint Ethics Board

**We are interested in learning about the factors that influenced your decision to use complementary or alternative therapies**

### Participation in this study will involve:

- 1 hour interview in person
- 20 minute interview via telephone
- Completion of a short questionnaire

Your participation in the study will provide us with valuable information. The results will be used to make recommendations about how to best support women with Fibromyalgia who are considering complementary or alternative medicine use.

## APPENDIX B: INVITATIONAL LETTER



FACULTY OF | UNIVERSITY OF  
MEDICINE | CALGARY

Department of Community Health Sciences  
Faculty of Medicine  
University of Calgary  
3330 University Drive NW  
Calgary, AB, T2N 4N1

Dear Madam,

Re: **Complementary and Alternative Medicine decision making in women with Fibromyalgia.**  
Dr M.Verhoef, A.Vroegindewey, Dr L.Martin

We would like to advise you of this research study that is currently underway.  
We are interested in learning how women with Fibromyalgia make the decision to use complementary or alternative therapies.

To be eligible to participate in the study you must **currently** use complementary or alternative therapies. These therapies include **any** of the following: (1) traditional Chinese medicine, acupuncture, naturopathic medicine, ayurvedic medicine and homeopathy; (2) herbal, special dietary and, individual biological treatments that are not approved by regulatory authorities; (3) energy therapies such as Reiki, therapeutic touch, magnet therapy, qi gong, and intercessory prayer; (4) chiropractic, osteopathy and massage; and (5) meditation, biofeedback, hypnotherapy and the relaxation response.

You must also still be using the conventional health care system.

Participation in this study will include the following:

- 1 hour interview in person
- 20 minute interview via telephone
- completion of a short questionnaire

If you are interested in participating in this study or would like more information please call **Dr Marja Verhoef at (403) 210-9608.**

Regards,

Dr Liam Martin, MB

## APPENDIX C: TELEPHONE SCREENING



FACULTY OF MEDICINE | UNIVERSITY OF CALGARY

Hello, my name is Annette Vroegindewey and I am a Masters student with the University of Calgary in the Faculty of Medicine.

**If the participant was recruited through either Dr Martin's rheumatology clinic or through Dr Martin's database, the following script will be followed:**

Dr. Martin is part of my research team and he has told me that you may be interested in participating in a research study about Fibromyalgia. Could I tell you a little more about our study?

Yes     No

**For all other patients the following script will be followed:**

I am returning your call in regards to your interest in participating in the research study about Fibromyalgia and complementary and alternative therapies. Could I tell you a little more about our study?

Yes     No

We are interested in the process that women with FMS go through when they decide whether or not to use complementary and alternative therapies like herbs, mental imagery, meditation, yoga, naturopathy and chiropractics. The purpose of the study is to find out how women with Fibromyalgia decide to use complementary and alternative medicine.

The study involves 2 interviews. The first interview will be done face to face with me at a time and location that is convenient for you. This interview will take about 1 hour. As part of the interview you will be asked to fill out a 1-2 page questionnaire. This will only take a few minutes. The second interview will also be done with me, but via telephone. This is just a short interview and it will last about 20 minutes. This interview will be used to check if I have correctly understood you during the first interview.

**If the participant was not recruited through either Dr Martin's rheumatology clinic or through Dr Martin's database, the following script will be followed:**

We will ask your permission to contact the physician who diagnosed you with Fibromyalgia. You will indicate your permission for us to do so by signing a consent form. Your physician will be contacted for verification of your Fibromyalgia diagnosis **only**.

**For all participants:**

If you agree to participate in this study there may or may not be a direct medical benefit to you. You may find that talking about your experiences with FMS and complementary therapies decision making is helpful. The information we get from this study may help us in giving better care to patients with Fibromyalgia.

Your participation in this study is entirely voluntary. You can stop participating in the study at any time. You would just have to contact me and let me know that you will no longer be participating in the study. Your decision to participate or not to participate in this study will not in any way affect the medical care that you are currently getting.

If I feel that your participation in the study is causes you emotional harm, I may suggest that you withdraw from the study.

There will be no costs for you when you participate in this study. Parking expenses will be covered and I will meet with you at a time and location that is convenient for you. We will not pay you for participating in our study.

Do you have any questions about what I just told you or any other questions about our study?

Yes     No

Do you agree to participate?

Yes     No

Ok, now that you agreed to take part, I need to ask you a few more questions. If after these questions it appears that we can include you in the study, all the information that I just gave you will be given to you again before the actual interview. The information will be on a consent form, which you will be asked to sign before the start of the interview. You will be given a copy of this consent form for your records.

Here are the additional questions that I need to ask you:

1) Are you currently using complementary or alternative medicine? Complementary therapies include herbs, mental imagery, meditation, yoga, naturopathy, massage, chiropractic and many others. These therapies are different than conventional treatments and are usually not prescribed by physicians.

Yes     No

2) Are you currently seeing a family physician, a rheumatologist/specialist or a physiotherapist to manage your FMS?

Yes     No

3) Do you mind telling me your age category?

18-24     25-34     35-44     45-54     55-64     65-74     75+   

4) Do you mind telling me what education category you would put yourself in?

Some/completed high school

Some/completed college

Some university/undergraduate degree

Graduate university degree

5) What is your ethnic background? \_\_\_\_\_

**If patients meet the inclusion criteria the following script will be followed:**

It looks like we can include you in our study. Is it ok to make an appointment for the interview now?

When would be a good time for you? \_\_\_\_\_

Collection of contact information will occur at this time as well.

Name: \_\_\_\_\_

Telephone number: \_\_\_\_\_

Agreed interview time: \_\_\_\_\_

**If patients do not meet the inclusion criteria the following script will be followed:**

Thank you very much for your time, however it looks like we cannot include you in our study at this time. Thank you again and have a good day.

## APPENDIX D: FIBROMYALGIA IMPACT QUESTIONNAIRE

### FIBROMYALGIA IMPACT QUESTIONNAIRE (FIQ)

Name: \_\_\_\_\_

Date:    /    /

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

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

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

0      1      2      3      4      5      6      7

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

0      1      2      3      4      5      6      7

(continued)



## APPENDIX E: CONSENT FORM



FACULTY OF | UNIVERSITY OF  
MEDICINE | CALGARY

TITLE: Complementary and Alternative Medicine decision making by women with Fibromyalgia

SPONSOR: Canadian Interdisciplinary Network for Complementary & Alternative Medicine Research (IN-CAM)

INVESTIGATORS: Dr Marja Verhoef PhD, Dr Liam Martin MB, Annette Vroegindewey RN BN

This consent form is only part of the process of informed consent. It should give you the basic idea of what the research is about and what your participation will involve. If you would like more detail about something mentioned here, or information not included here, please ask. Take the time to read this carefully and to understand any accompanying information. You will receive a copy of this form.

### BACKGROUND

Many research studies have looked at what it is like to live with Fibromyalgia Syndrome (FMS). In this study we are interested in the process that women with FMS go through when they decide whether or not to use complementary and alternative therapies like herbs, mental imagery, meditation, yoga, naturopathy, and chiropractic. These therapies are usually not prescribed by physicians. We hope to recruit 20-30 women.

### WHAT IS THE PURPOSE OF THE STUDY?

The purpose of the study is to answer the following question: How do women with FMS decide to use complementary and alternative medicine?

### WHAT WOULD I HAVE TO DO?

You will be asked to participate in 2 interviews. The first interview will be done face to face with an interviewer at a time and location that is convenient for you. This interview will last approximately 1 hour. The second interview will be done over the telephone and will be about 20 minutes. This interview will be used to check if the investigator has correctly understood the first interview. However, if after the first interview you decide that you do not want to participate in the second interview, you can indicate this by checking off the tick box below this paragraph. The first interview will be audio taped. The interviewer will ask you to describe your experiences around the process of deciding whether or not to use complementary and alternative medicine as part of your treatment of FMS.

I do not wish to be contacted for a second interview via telephone

#### WHAT ARE THE RISKS?

The results of this study will be made public at some point after the study is finished. Some study participants find this difficult, as participants may have discussed sensitive topics with the interviewer. However, your name or any other identifying information will not be used when the results are made public.

Sometimes study participants feel like they have established a therapeutic relationship with the interviewer, even though it is not the intent the interviewer to establish this type of relationship. Study participants may then feel disappointed when the interviews are completed.

#### WILL I BENEFIT IF I TAKE PART?

If you agree to participate in this study there may or may not be a direct medical benefit to you. You may find that talking about your experiences with FMS and complementary therapies decision making is therapeutic. The information we get from this study may help us to provide better treatments in the future for patients with FMS.

#### DO I HAVE TO PARTICIPATE?

Your participation in this study is entirely voluntary. You may withdraw from the study at any time. You can do so by contacting the investigator and letting her know that you will no longer be participating in the study. Your decision to participate or not to participate in this study will not in any way affect the medical care that you are currently getting.

The investigators may also withdraw you from the study. For example if the investigators feel that your participation in the study is causing you emotional harm, they may decide to withdraw you from the study.

#### WHAT ELSE DOES MY PARTICIPATION INVOLVE?

Your participation will be as described above.

#### WILL I BE PAID FOR PARTICIPATING, OR DO I HAVE TO PAY FOR ANYTHING?

You will not incur any costs when participating in this study. Parking expenses will be covered and the researcher will meet with you at a time that is convenient for you. You will not be paid for participating in this study.

#### WILL MY RECORDS BE KEPT PRIVATE?

Your records will be kept locked in a desk at the University of Calgary. The interviewer and Dr Marja Verhoef and Dr Cathie Scott will have access to your records. The University of Calgary Conjoint Health Research Ethics Board will have access to the records as well. A transcriptionist will use the tapes to type up the interview, however, she will not know your name and he/she will sign a confidentiality form as well. All identifying information will be removed from the records. These records will be destroyed 7 years after the study has finished.

## SIGNATURES

Your signature on this form indicates that you have understood to your satisfaction the information regarding your participation in the research project and agree to participate as a subject. Your signature also means that you give us permission to contact the physician who diagnosed you with FMS, but only if we do not have this confirmation already. He or she will be contacted for verification of your FMS diagnosis **only**.

In no way does this waive your legal rights nor release the investigators, or involved institutions from their legal and professional responsibilities. You are free to withdraw from the study at any time without jeopardizing your health care. If you have further questions concerning matters related to this research, please contact:

Dr Marja Verhoef (403) 220-7813

If you have any questions concerning your rights as a possible participant in this research, please contact Pat Evans, Associate Director, Internal Awards, Research Services, University of Calgary, at 220-3782.

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 Participant's Name

---

 Signature and Date

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 Investigator/Delegate's Name

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 Signature and Date

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 Witness' Name

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 Signature and Date

The University of Calgary Conjoint Health Research Ethics Board has approved this research study. A signed copy of this consent form has been given to you to keep for your records and reference.

## **APPENDIX F: INTERVIEW GUIDE**

### Introduction

### Signing of consent form

### Completion of Fibromyalgia Impact Questionnaire

### Explanation of complementary and alternative medicine

- Complementary therapies include non prescription drugs, mental imagery, meditation, yoga, naturopathy, massage, chiropractic and many others. These therapies are different than conventional treatments and are usually not prescribed by physicians.

### Experiences with FMS

- Why don't you tell me a little bit about your FMS?

### Experiences with complementary and alternative therapy

- Tell me a little bit about the types of alternative therapies you are using
- Were you using these therapies before you were diagnosed with FMS?
- What experiences with FMS led you to use these therapies?
- Which therapies did you try first? Why?
- How did you learn (know) about these therapies? What were some of the things that you were trying to achieve?

### Challenges/Benefits with CAM use

- What were some of the things you thought about before using these therapies?
- What made these therapies seem appealing, what attracted you to them?
- Did you have any concerns about these therapies?
- Was there anything that discouraged you from using these therapies?

### Influence of others

- Did you discuss your alternative therapy use with others? Family, friends, other FMS patients, health care providers?
- What was their response?
- What effect did this have on you?
- Did they have concerns about you using these therapies?
- What types of concerns?
- If they had reservations or concerns, how did this influence your decision to use these therapies?
- How did this affect your relationships?
- Did they encourage you to use alternative therapies?
- Were there any other sources that influenced your decision to use these therapies? Internet?

### Reflecting back and final comments

- What might influence you to try other types of alternative therapies in the future?
- What would you like to know about them? From what sources, what people?

Thanking the participant for volunteering for the study

## APPENDIX G: MEMBER VALIDATION SUMMARY



FACULTY OF MEDICINE | UNIVERSITY OF CALGARY

Thank you for taking the time to read through this summary of our study findings of how women with Fibromyalgia make the decision to use complementary therapies or complementary medicines. For the purpose of this summary, Fibromyalgia will be referred to as “FMS” and complementary therapies and medicines will be referred to as “CAM”.

Our summary has two parts. On the first page (Part 1), we have developed a model to show the process that takes place when a woman is trying to decide to use CAM. Following the model, full page summaries (Part 2) describe this process in more detail. You will find that both Part 1 and 2 use the same sub-headings to outline the decision making process.

We know your experience may be a bit different from what is described below, as this summary is a combination of 17 women’s stories. We hope, however, that we have basically understood your decision making experience. When reading this summary, if you feel that we have missed major points in your experience, please make sure to discuss these points when I call you. Again, thank you for taking part in our study. Without your involvement, this study would not have been possible!

**PART 1. Model of Decision Making**

**1. Context of Fibromyalgia**

<b>Length of time living with FMS diagnosis or symptoms</b>	10 + years
<b>Disappointments with regular health care system</b>	Limited treatment options, suboptimal communication, medications had severe side-effects
<b>FMS symptoms and their impact on daily living</b>	Frequent, widespread pain & fatigue. Difficult to do everyday life activities
<b>Hearing about CAM</b>	Friends, family, CAM providers & popular media

**2. Deciding to do something about FMS**

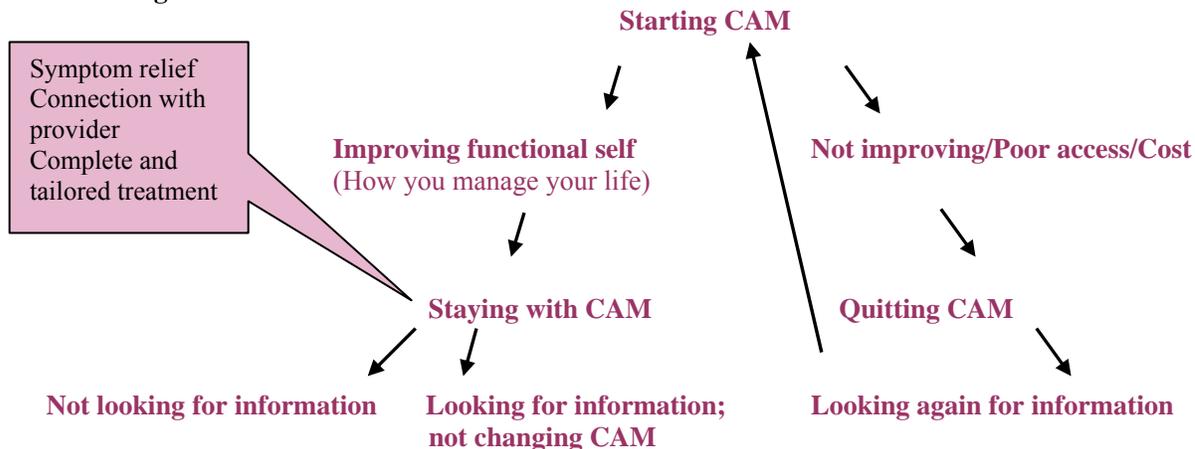
**FMS self management**  
(Diet, exercise, monitoring sleep etc.)

<b>Having had enough</b>	Getting ready to try even more things, because it is still difficult to do everyday life activities
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**3. Needing to do more to manage FMS & Starting to think about CAM**

<b>Goals/Motivators</b>	<b>Looking for information about CAM</b>	<b>Potential barriers to starting CAM &amp; Strategies to overcome barriers</b>
<ol style="list-style-type: none"> <li>1. Relief of symptoms</li> <li>2. Taking less medication</li> </ol>	<ol style="list-style-type: none"> <li>1. Discussions with friends, MD, health food store staff &amp; family. Reading internet &amp; books</li> <li>2. People were often quite persuasive when suggesting CAM</li> <li>3. Safety not really a concern as many people are using CAM</li> </ol>	<ol style="list-style-type: none"> <li>1. Questioning that treatment works, pain/discomfort &amp; cost</li> <li>2. Desperate enough for relief to go ahead anyways &amp; being able to quit at anytime</li> </ol>

**4. Deciding to also do CAM**



Phase 1

Phase 2

## **PART 2. Detailed Descriptions of Decision Making**

### **1. Context of Fibromyalgia**

These are some of the things in the women's past that have played a role in the decision making process.

#### **Length of time living with FMS**

- Living with FMS symptoms or diagnosis for 10+ years, so most of the women in the study have had FMS in their lives for a long time

#### **Disappointments with regular health care system**

- Most doctors had limited knowledge about FMS in general
- Communication with doctors was not always optimal and at times women in the study felt not believed. They also felt that they were given limited treatment choices
- Many of the medications that their doctors prescribed were not tolerated well. The medications usually caused severe side effects and they often did little or nothing to improve symptoms

#### **FMS symptoms and their impact on daily living**

- Having FMS was often described as suffering from frequent, widespread pain
- Virtually all of the women in the study suffer from fatigue, with or without a sleep disorder, making it difficult to do everyday activities

#### **Hearing about complementary therapies**

- Friends & family
- People trained in CAM, like massage therapists & regular doctor
- Reading books about FMS, watching TV or by using the internet

### **2. Deciding to do something about FMS/feeling unwell**

This is the point where the women made a decision to take charge of managing their FMS/feeling unwell. At this point most women were trying options in the regular health care system, because they either did not know what to do or they followed their doctor's recommendations. Only two women tried CAM before trying their options in the regular health care system.

#### **FMS self management**

- Most of the women were and still are, actively trying things like exercise, diet, monitoring sleep, stretching, pacing themselves, reading self help books and many other strategies
- The women in the study found that even when trying to manage their FMS there were still a lot of things they could not do because of their symptoms or because of the bad side effects from the medications

#### **Having had enough**

- Most women struggled unsuccessfully and for a long time, to get their symptoms under control in the regular health care system and have tried many FMS self management options
- Most women realized that they had had enough when their ability to do everyday life activities was still very limited, *even* with all the medications they were on and all the self management activities they were doing

### **3. Needing to do more to manage FMS & Starting to think about CAM**

*Phase 2 starts here.* Not only had the women now heard about CAM, they are now seriously looking into their options. The majority of the women started using CAM after the FMS diagnosis. They have found that since using CAM they have become much more "open" to it.

A few women tried CAM for other conditions in the past and they stated that they have been open to CAM all along. They do say that they “believe” in CAM. Some of these “prior CAM use” women skipped phase 2 of information seeking and went right to stage 4 of deciding to do CAM.

#### Goals/Motivators

- Decrease pain and/or increase energy
- A large number of women also hoped that it would allow them to take less medication, as they believe that taking large amounts of medication is not good and they were tired of all the side effects from the medications

#### Information seeking

- Discussions with friends, the conventional doctor, the complementary doctor, staff at the health food store& family and/or internet and books were used to gather information
- People were often quite persuasive when suggesting CAM
- Not really worried about safety as finding out many people are using CAM

#### Family/Friends influence

- Once the decision about CAM was made, most women did inform family and friends of that decision. This was not done as a discussion but rather the women simply informed them of the decision
- Most of the women felt that even if they had received negative feedback about the decision, they still would have stood by their decision

#### Role of MD

- Most of the women did tell their physician about their CAM use, but often told the doctor only what was necessary, because they were not sure if he/she was all that interested in CAM
- Most of the women felt that the doctor’s opinion about their CAM use was not all that important, as they felt that the doctor could not do much for FMS anyways

#### Potential barriers to starting CAM & Strategies to overcome barriers

- Questioning that the therapy/treatment would actually work
- Cost
- Pain or discomfort with the treatment
- Desperate enough for relief that most women went ahead anyways and being able to quit at anytime was very important for most women

#### 4. Deciding to also do CAM

This is where most of the women went ahead and tried CAM in addition to doing their other self management activities. Most women felt they were committed to CAM from the beginning, often as soon as after a few treatments/doses.

#### Outcome/Improving functional self

- Being able to participate more in everyday life activities
- Symptom relief

#### Barriers to staying with CAM

- No relief
- Cost
- Poor access (i.e. driving long distances to get to treatment)

**Staying with CAM**

- Symptom relief as this helps/helped the study participants to manage their everyday activities
- The connection with the CAM provider is important
- The actual CAM treatment is/was complete and very tailored
- Most of the women did not need support from others to stay on CAM
- Most of the women felt they needed to make little or no changes to their lifestyle to incorporate CAM
- Most of the women based their decisions on how often to go for CAM treatment on their symptoms and cost, i.e. if they could afford to go

**Looking for information**

- Most of the women are not actively looking for information now on new CAM, because what they are currently doing allows them to maintain their functioning
- They are however, still open to hearing suggestions about CAM from other people
- For those women that are not happy with their current CAM, they do look for information again on a new CAM that they can try
- Only 2 women are looking for information (even though happy with their CAM), but it is more to be prepared when the CAM that they are on now no longer works

**Starting new CAM**

- Most of the women would try a new CAM only if they felt it would offer better functioning than their current CAM
- Most of the women felt that they would gather information for a new CAM in the same manner as they did their initial CAM

**APPENDIX H: CONFIRMING FMS DIAGNOSIS**

FACULTY OF | UNIVERSITY OF  
MEDICINE | CALGARY

Department of Community Health Sciences  
Faculty of Medicine  
University of Calgary  
3330 University Drive NW  
Calgary, AB, T2N 4N1

**Subject:** Verification of FMS diagnosis

Dear Dr \_\_\_\_\_,

Ms \_\_\_\_\_ would like to participate in our study titled: Complementary and Alternative Medicine decision making by women with Fibromyalgia (FMS). Ms \_\_\_\_\_ provided us with written consent to contact you for confirmation of her FMS diagnosis.

We respectfully ask for a written confirmation of her FMS diagnosis prior to including Ms. \_\_\_\_\_ in our study. We have included a return envelope for your convenience. We will follow up via telephone in two weeks if we have not received your confirmation at that time.

Ms \_\_\_\_\_ has been diagnosed with FMS

Ms \_\_\_\_\_ has **not** been diagnosed with FMS

Regards,

Marja Verhoef, PhD, Principal Investigator  
Liam Martin, MB  
Annette Vroegindewey, RN BN