

**WHAT HINDERS AND HELPS INDIVIDUALS ACCESSING HEALTHCARE
SERVICES FOR FIBROMYALGIA: A CRITICAL INCIDENT STUDY**

by

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Abstract

Fibromyalgia (FM) is a complex condition characterized by chronic diffuse pain and increased sensitivity to pain, chronic fatigue and sleep disturbance, cognitive difficulties, as well as a range of co-occurring conditions. While FM presents with severe and often debilitating symptoms, it has no known aetiology, and cannot be identified by any objective tests; as a result, it poses diagnostic and treatment problems within the conventional biomedical healthcare system, often leaving patients struggling to find adequate care. While a growing body of literature has explored the topic of FM, it is largely focused on either biomedical perspectives, or ways the condition impacts individuals' lives. To date, little research has explored healthcare experiences for individuals with FM.

The present study used the enhanced critical incident technique (ECIT) to explore the hindering and helping experiences of healthcare of 14 individuals diagnosed with FM, as well as what these individuals believe would have been helpful had they been available. Results identified 16 categories, further organized across the five environmental systems of the ecological systems theory (EST). The EST can be visualized as five concentric circles, representing systems or spheres of influence, with the individual, or person, at the centre. The outermost layer, the macrosystem, which encompasses the cultural environment in which a person lives, contained two categories: clinical understanding of FM, and prejudice. The second layer, the exosystem, which encompasses the larger social system, contained four categories: financial and economic security and affordability of services, models of healthcare delivery, accessibility and flexibility, and diagnosis making. The third layer, the mesosystem, which encompasses interactions between parts of a person's microsystems, contained one category:

continuity of care. The fourth layer, the microsystem, which the person's direct relationships, contained five categories: therapeutic alliance, informed consent, iatrogenic suffering, validation, and counselling and psychotherapy. The innermost layer, the person, which encompasses a person's personal characteristics, contained four categories: internalization of adverse healthcare experiences, medication, exercise and physical activity, and active coping and social support. These results can serve to inform counsellors and other healthcare providers who work with patients with FM, as well as future research.

Lay Summary

Fibromyalgia (FM) is a complex medical condition, involving chronic pain, fatigue, and other co-occurring conditions. Despite the debilitating impacts of FM on the lives of those living with it, and the challenges of treating this condition, little is understood about the healthcare experiences of people with FM. In this study, 14 people diagnosed with FM were interviewed about what they found hindering, helping, and what they wished for in their healthcare experiences with FM. Results from these interviews were grouped into 16 categories: clinical understanding of FM, prejudice, financial and economic security and affordability of services, models of healthcare delivery, accessibility and flexibility, diagnosis making, continuity of care, therapeutic alliance, informed consent, iatrogenic suffering, validation, and counselling and psychotherapy, internalization of adverse healthcare experiences, medication, exercise and physical activity, and active coping and social support. These results contribute to an improved understanding of the healthcare needs of individuals with FM.

Preface

This thesis is the original work of the author, R. Nishikawara, conducted under the supervision of Dr. I. Z. Schultz. All data collection and analyses were conducted by R. Nishikawara, and approved by the University of British Columbia's Behavioural Research Ethics Board, certificate number H15-02109, entitled "FM and Healthcare". This research was supported in part by funding through the University of British Columbia Faculty of Education and Counselling Psychology and Special Education Graduate Student Research Grant.

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List of Abbreviations

Fibromyalgia (FM)

Fibromyalgia Syndrome (FMS)

Critical Incident Technique (CIT)

Enhanced Critical Incident Technique (ECIT)

Fibromyalgia Syndrome (FMS)

Irritable Bowel Syndrome (IBS)

American College of Rheumatology (ACR)

Tender Point (TP)

Central Nervous System (CNS)

Ecological Systems Theory (EST)

Social Ecological Models (SEM)

The Canadian Guidelines for the Diagnosis and Management of Fibromyalgia Syndrome (Canadian Guidelines)

Chronic Fatigue Syndrome (CFS)

Cognitive-Behaviour Therapy (CBT)

Acceptance and Commitment Therapy (ACT)

Complementary and Alternative Medicine (CAM)

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Chapter 1:

Introduction

I don't remember when the stones started growing in my back – calcified tissues collecting around my rhomboids, and along the perimeter of my shoulder blades, caught in the myofascia; that “tissue of movement” which covers the body like “a continuous weave of material [...] that has no beginning or end.” The stones roll around in there it seems, displacing my joints, and muscles, and bones with weighty burden. When I shift my shoulder it click, click, clicks back into place, stirring the stones into a flurry of rhythm, a drumroll. The stones keep life metronomic in a sense, offering a reliable and unrelenting meter to which my body capitulates: the weight of the stones pressing, the readjustment of their weight, the brief pause of relief, the anticipation of their pressure, until their weight presses down once again. I am alive to every microsecond that my body is living.

...

She puts hands cold with almond oil onto my tender neck, finding each of the smallest stones, and pressing down with careful precision. “How painful is that, between one and ten?” she asks, maintaining the pressure. This is a question I never know how to answer. My relationship to pain long ago exceeded the possibility of numeric delineation. Its qualities became too diverse and multiplex. I have not yet discovered the right language to describe the sensations, so that another person might truly understand. Partly, it's that sometimes I cannot even remember the feeling until I feel it again. Memory is tricky this way, duplicitous even.

- mia susan amir, *Geologic Formations*

Fibromyalgia (FM)—also referred to as Fibromyalgia Syndrome (FMS)—is a complex condition, characterized by chronic diffuse pain, hyperalgesia (increased sensitivity to pain), chronic fatigue, and cognitive difficulties including memory and concentration problems (sometimes referred to as “fibro fog”) (Arnold et al., 2008; Okifuji, 2008; Okifuji & Hare, 2013; Okifuji & Turk, 1999; Wolfe & Hauser, 2011; Wolfe & Walitt, 2013). In addition to these key features, people with FM often experience a range of other co-occurring conditions and physical symptoms including headaches, sleep disturbances and unrestorative sleep, bowel and bladder conditions such as irritable bowel syndrome (IBS) and interstitial cystitis, as well as mood disorders and other psychological conditions including depression, and anxiety (International Association for the Study of Pain, 2003).

FM is a commonly occurring pain disorder; some rheumatologists even name it as the most common condition they see in their practices (White, Lemkau & Clasen, 2001). Prevalence estimates range from one source to another with the most frequent estimates projecting that FM impacts between 2 to 5 percent of the general population, (Okifuji & Hare, 2013; Vekuru & Colburn, 2009). According to Okifuji (2008), these variations in estimates might be the result of methodological differences across studies. Estimates are also likely to be impacted by the differing approaches to diagnosis, disagreement in the field around diagnostic criteria and their applications, and differences in sample populations (White, Lemkau & Clasen, 2001). Women are impacted as much as ten times more frequently than men (Vekuru & Colburn, 2009; White, Lemkau, & Clasen 2001).

Johnson (2008) describes FM as “an illness of middle age” (p. 92), however, it is found among younger individuals as well. While the age of onset for FM is between the ages of 29 and 37, the average age for diagnosis is between 34 and 54. This years-long discrepancy between the onset of symptoms and eventual diagnosis speaks to the complexity of the diagnostic process as well as the subjective experience of individuals with the condition, which will be outlined further on.

FM is frequently described as complex and challenging for a number of reasons. As suggested by the brief description above, FM appears to be a heterogeneous illness, presenting in varying levels of severity and with a range of symptoms and associated conditions, making it difficult for medical professionals trying to accurately diagnose and treat (Johnson, 2008; Okifuji & Hare, 2013). Additionally, FM poses a range of challenges to medical researchers for whom FM, along with many other chronic pain conditions, have defied explanation within the conventional biomedical framework. While there are distinguishing characteristics of the

condition, there are no objective tests or labs to identify it, and as such, diagnoses are frequently made through process of elimination. Finally, FM brings with it deep and diverse impacts on the lives of individuals living with the condition; these impacts include and are very much influenced by their experiences seeking support (Zotterman, Skär, Olsson, & Söderberg, 2016).

While there is no documented cost of the impact of FM, the costs associated with chronic pain are staggering. Chronic pain has been cited as the primary reason people seek medical treatment (Endler, Corace, Summerfeldt, Johnson, & Rothbart, 2003; Canadian Pain Society, 2014). According to the Canadian Pain Society (2014), the estimated costs of chronic pain are at least 56 to 60 billion dollars annually. Additionally, Lofgren (2014) writes that chronic musculoskeletal pain is among the three most common reasons for long-term illness-related absences for employees, with FM being one of the common diagnoses given to women with musculoskeletal pain. In addition to the emotional toll on patients, repeated visits associated with FM come with direct healthcare costs of over \$4,000 Canadian per year—30% higher than non-FM patients (Fitzcharles, Ste-Marie, Goldenberg, Pereira, Abbey, ... & Shir, 2012). Furthermore, despite the prevalence of chronic pain and its associated economic burden of chronic pain, pain research is markedly under-funded, receiving only 0.25% of total funding for health research (Canadian Pain Society, 2014). A clearer understanding of patient experiences of FM treatment will contribute to increasing benefit and mitigating harm from the delivery of healthcare services, as well as provide feedback toward more cost-effective treatment.

Purpose and significance

Because FM symptoms and their etiology are poorly understood and subject to misdiagnosis, these patients commonly access healthcare repeatedly regarding FM symptoms for years prior to diagnosis, with diagnosis often doing little to guide or clarify the treatment process

(Chen, 2012; Juuso, Skär, Olsson, & Söderberg, 2011). Many patients report feeling questioned, dismissed, and abandoned, in part because their symptoms defy current biomedical conceptualizations of disease (Lempp, Hatch, Carville, & Choy, 2009).

While recent years have seen increased research about chronic pain (Gatchel, Peng, Peters, Fuchs, & Turk, 2007), and FM specifically is gaining more recognition in the medical field (Arnold et al., 2008), the majority of research continues to focus on seeking an aetiological explanation or viable treatments; the subjective experiences of individuals with this condition have gone largely undocumented. Where qualitative research has been conducted around experiences of FM, studies have largely focused on experiences of symptoms.

A comprehensive understanding of the healthcare experiences for patients with FM is important for a number of reasons (Madden & Sim, 2006). FM is commonly associated with psychological conditions such as depression, anxiety, and post-traumatic stress disorder. Because of the extensiveness and severity of the symptoms of FM, the impacts throughout the lives of those living with it can be profound. The onset of FM symptoms frequently requires restructuring and renegotiating many aspects of one's life, including work, hobbies, social commitments, responsibilities to home and family, and expectations of oneself. In addition to their embodied symptoms, these individuals face social stigmas of invisible disability.

Despite the important role of healthcare in managing this debilitating chronic condition, few studies have addressed healthcare experiences that individuals have found helping or hindering. Furthermore, the available research demonstrates that while support from healthcare professionals can improve patient quality of life, patients frequently report feeling unsupported and disbelieved (Briones-Vozmediano, Vives-Cases, Ronda-Pérez, & Gil-González, 2013; McMahon, Murray, Sanderson, & Daiches, 2012). They report feeling discredited, trivialized,

and invalidated by others who disbelieve the extent of their struggles because they lack visible or testable symptoms. Individuals with FM describe health professionals dismissing their symptoms as “normal life events or as minor ailments” (Madden & Sim, 2006, p. 2969). In addition to detracting from the healthcare encounter itself, these adverse experiences hinder appropriate assessment and treatment, as well as leading to emotional distress, which fuel negative health outcomes (McMahon et al., 2012).

According to McInnis, Matheson, and Anisman (2013) the perception of social support has direct influences on a person’s health. Believing oneself to be supported can help buffer against the detrimental impacts of stressors, while feeling unsupported can usurp an individual’s capacity to cope. When one is in a position to reasonably expect support—such as when accessing a healthcare service—but does not receive it, or the support offered is inadequate, it can lead to negative mental health outcomes. The neuromatrix theory, which will be described in the literature review, suggests that increases in stress also exacerbate pain symptoms (Melzack, 2005).

Considering that part of symptom management is stress management, it is detrimental to patient wellbeing to elicit a stressful healthcare experience (van Ittersum, Wilgen, Hilberdink, Groothoff, & van der Schans, 2009). By failing to provide—at minimum—a sense of support for individuals seeking care for FM symptoms, these patients are potentially being harmed by the services they are accessing for help. In their exploration of the factors influencing women’s abilities to maintain sustainable work while living with FM, Palstam, Gard, and Mannerkorppe. (2013) found that “to receive support from health-care services when needed was described as being important for managing work” (p. 1627). Similarly, Underland and Malterud (2007) found that “significant turning points can emerge with meaning acquired through belonging, doing, and

understanding the self or the world. Hence, meaning in the context of chronic illness is as important for patients and clinicians as is the treatment of symptoms” (p. 250). In order to have confidence in the healthcare treatment that people with FM are receiving, we need to have clear understanding of the helping and hindering factors based on patient experiences. Given the complex, subjective nature of FM is hoped that an exploration of helping and hindering incidents will help provide some tangible factors to contribute to the literature on healthcare access for FM (Dennis et al., 2003; Sim & Madden, 2008; White, Lemkau, & Clasen., 2001).

Situating the researcher

As per the convention in qualitative research, I would like to acknowledge some of the life events that influenced my interest in this research and situate myself in relationship to this topic. I trace my interest in FM, and chronic pain research more broadly, to three particular experiences: my work as an office manager at an orthopaedic clinic, my experiences as a crisis line volunteer, and my lived experience with chronic pain.

Prior to returning to graduate studies, I managed an orthopaedic clinic that served many patients living with chronic pain. Because I typically worked at the reception desk I had the opportunity to talk to patients while they waited to see a clinician. During these conversations many patients shared about challenges and frustrations with their healthcare experiences, particularly in finding lasting pain reduction. Many of these patients had been living with pain for years, and had seen numerous healthcare providers prior to attending the clinic where I worked. As a crisis line volunteer, I spoke with many callers living with chronic pain, and was further exposed to the struggles of individuals living with untreated chronic pain. In this context I became acutely aware of the mental health implications of chronic pain, and the interrelationships between chronic pain, and anxiety, depression, and suicidality. I also became

further attuned to the critical role healthcare providers hold in helping individuals with complex and co-occurring conditions navigate the healthcare system. Finally, having firsthand experiences with chronic pain and accessing healthcare for these symptoms afforded me insight and empathy into the experiences of participants, which I believe aided in development of trust and rapport during interviews.

Having both heard and experienced how the impacts of chronic pain can ripple through people's lives, and also having heard about and experienced the challenges and rewards of accessing healthcare for these symptoms, my desire was to contribute to an improved understanding of what hinders and what helps patients in the pursuit of healthcare for chronic pain. I ultimately focused on FM in this study because of the ways it intersects with so many other important conversations related to disability justice and healthcare.

Chapter 2:

Literature Review

“We comprehend the world through our body; hence, the world itself is perceived differently from the body with pain.”

- Mieko Homma, Yoshihiko Yamazaki, Hirono Ishikawa and Takahiro Kiuchi,
“This really explains my case!”: Biographical reconstruction of Japanese people with fibromyalgia meeting peers, *Health Sociology Review*

Healthcare access refers to the extent to which an individual seeking care is able to command appropriate use of services in a timely and relatively easy fashion (Gulliford, 2002; Evans, Hsu, & Boerma, 2013). Encompassed in this definition are a wide array of factors including the existence of relevant services, the ability of the individual to gain access to these services, and the quality and appropriateness of the care provided to meet the patient’s healthcare needs. Therefore, answering the research question “*What are the helping and hindering factors for individuals accessing healthcare services for Fibromyalgia?*” requires an examination of all these dimensions of healthcare experiences. Determining the existence of relevant services requires an understanding of both the condition itself as well as models of healthcare delivery to determine compatibility. The ability of individuals to gain access to relevant services, should they exist, incorporates issues such as physical accessibility, financial affordability, and the ability to receive referrals to relevant services, and the timeliness of all these factors. Finally, quality and appropriateness include factors relating to the relationship between the healthcare provider and patient, in addition to treatment response to the patient’s symptoms.

This literature review will first present a summary of the research on FM from patient perspectives and then it will summarize the history and evolution of relevant diagnostic criteria. Medical understandings of pain and illness, and the corresponding medical models they inform, will be presented to situate the diagnostic and treatment

challenges of FM. This will then lead to a discussion of models of healthcare delivery, current recommended approaches to the management of FM, and issues related to quality of care for treatment of FM.

Subjective experiences of FM

In their focus group study of patient perspectives on the impacts of FM on quality of life and functioning, Arnold et al. (2008) identified the following key domains of concern: pain, fatigue, sleep, cognitive impairment, emotional impact, functional and quality of life impact, and other symptoms. Participants reported living with constant pain described as “achiness” and “all over,” and several explain their muscles are “constantly tense” (p.117). Fatigue was cited as one of the most interfering symptoms. Participants spoke of their need to conserve energy—that fatigue was a constant presence accompanying the constant pain—because their energy was limited and frequently unpredictable. Some individuals discussed being so exhausted they “can’t even talk” (p. 117). Additionally, sleep was described as low quality and unrestorative. Another significant domain of impact is cognition; participants report challenges in focusing and expressing themselves clearly, referred to in FM communities as “fibro fog” (p. 117). As a result of these, and other, symptoms, participants report that their friendships, romantic partnerships, and connections with family often suffer. Many participants had to reduce work hours, change jobs, or leave work entirely, and experienced financial loss, as well as loss of identity and autonomy as a result.

In another qualitative study, Lempp, Hatch, Carville and Choy (2009) interviewed a sample of patients attending a rheumatology outpatient clinic in the UK as well as randomly selected volunteers from a departmentally held database. Participants in their study provided powerful descriptions of the physical influences of FM on their lives. In

this study, pain was cited as the most commonly used key word, and had four main features in common: (1) it was experienced all over the body, from head to toe; (2) it took a physical and mental toll on participants' lives; (3) it caused people to behave differently; (4) it was a constant presence. One participant describes the physical consequences of trying to stay involved in life:

“FMS just feels sometimes engaging with life from behind it, a big screen of glass where you can see things going around you and you think: I want to be a part of that, I am going to want to be a part of that. And to do that, you have to kind of smash the glass through, but obviously you'll get hurt, there is going to be a bit of pain or consequences if you do sort of smash through” (Life before and after diagnosis section, para. 5).

This study by Lempp and colleagues (2009) also echoed findings by Arnold and colleagues (2008) that unrestorative sleep and fatigue is often more debilitating than the pain experienced. Findings also included significant impacts from co-occurring conditions, as well as psychological challenges such as suicidality, anxiety, and depression; and neurological challenges, like cognitive difficulties, and lack of coordination. All of these experiences compromise work, social, and family life. Most participants described being less able to go out, and enjoy time with friends and family. Some of the negative impact was attributed to lack of awareness of FM, and experiences of stigmatization, discrimination, and invalidation.

Stigmatization occurs when negative attributes become associated with an individual or population based on differences or qualities that set them apart (Sabik, 2010). The diagnosis of FM has become stigmatized for a number of reasons, which will be outlined throughout this chapter, many of them connected to the invisible nature of the condition, and thus challenges recognizing and treating it. FM is often described as a controversial or contested diagnosis; this kind of illness contestation may leave the

individuals struggling with the debilitating symptoms at the centre of the controversy having to prove their suffering (Werner & Malterud, 2003).

The onset of chronic illness often comes with significant disruptions to a person's daily life, and resulting in disruptions of their overall identity (Clarke & James, 2003; Sabik, 2010). Previously enjoyed activities or hobbies may become impossible; sometimes people require assistance for chores that didn't use to require a second thought; people may avoid activities, or engage in them knowing they will pay the price of days of fatigue afterward. And through all these changes, relationships are impacted as well. Yet, while colleagues, friends, and family members are impacted by the changes in the individual with FM, the condition itself is invisible to them. This can leave a person feeling isolated, when they most need understanding, empathy, and support. Isolation may become a way of adapting to the shame, guilt, grief, and other losses associated with FM, and lack of available supports (Sabik, 2010).

In a narrative study interviewing 10 women with FM, McMahon, Murray, Sanderson, and Daiches (2012) found that each of the participants described the daily struggle with FM in terms of a battle against the pain. FM was conceived of as an enemy that impeded participants' abilities to preserve the lives they had designed for themselves, and undermining their sense of control and self-sufficiency. Over the course of the 10 narrative interviews, descriptions of FM were personified as: controlling, taking hold, taking the fun out of things, getting in the way, causing suffering. Some described experiencing internal battles between wanting to maintain a sense of efficacy and accomplishing tasks, and knowing that they might suffer for days afterward if they pushed themselves too hard. Others described avoiding tasks for fear of making their symptoms worse. In the discussion of their findings and clinical implications, McMahon and

colleagues highlight that it is common for people with FM to experience repeated encounters with healthcare providers where they do not feel heard or believed, and that these encounters both hinders access to appropriate treatment for the condition, as well as leading to distressing emotional responses, which worsen their wellbeing. These findings aligned with those by Egeli, Crooks, Matheson, Ursa, and Marchant (2008) who attributed many negative patient experiences to overall lack of resources, in terms of educational materials, time, support, treatment options, and referrals, leading to loss in hope and trust, and worsening of symptoms. McMahon et al. emphasize the importance of healthcare providers' awareness and understanding of FM, and timely referrals to relevant supports. They also suggest a crucial role for pain acceptance—working with the pain, rather than against it—in patient quality of life.

Defining Fibromyalgia

The most common description of FM found in the literature references the 1990 American College of Rheumatology (ACR) criteria that require the presence of chronic widespread pain; to be considered “chronic” pain has to be present for at least three months; to be “widespread” pain has to exist above and below the waist, and on both sides of the body (Lawrence et al., 2008; Okifuji, 2008; Wolfe & Hauser, 2011). The 1990 ACR criteria also required sensitivity in at least 11 out of 18 identified “tender points”. This succinct description—found time and again in the literature—gives the impression that FM is a relatively straightforward diagnosis; however, a clear understanding of FM is frequently more elusive than this description indicates. In the words of Frederick Wolfe (2014), one of the world's leading authorities on FM who spearheaded the development of the ACR criteria “We should not be fooled into thinking that we have a clearly definable entity” (p. 970); thus far, FM continues to be classified as medically unexplained.

History of the diagnosis. Although it is a relatively common condition, FM continues to be a controversial one. Its definition has changed multiple times since FM was first described in the medical literature at the beginning of the 20th century. These fluctuations link to some of the confusion around the FM diagnosis, and attitudes and beliefs that continue to influence the medical community and seekers of treatment today (Wolfe & Walitt, 2013). With this in mind, the historical progression of conditions leading to the current description of FM is presented below.

FM is not a new condition (White, Lemkau, & Clasen, 2001, p. 46). An illness very similar to FM known as *fibrositis* first appeared in medical literature in the early 1900s. This condition—meaning inflammation (*itis*) of the fibrous tissue—referred to localized painful areas known as tender points (TPs). These TPs stood out because they were particularly sensitive to pressure when palpated. Apart from TPs, patients generally presented as “normal” during clinical examination. Although many individuals with FM experience severe pain, fatigue, and other symptoms, there are no objective tests that can be run to identify it, and it has no known aetiology. While there are long lists of what FM supposedly is *not*—a musculo-skeletal disorder, a systemic inflammatory disease, the result of sleep disturbance, a mental disorder (Gur, 2003)—what it *is* proves more difficult to answer.

The name *fibrositis* was eventually replaced with *fibromyalgia*—meaning painful (*algos*) condition (*ia*) of the muscle (*myo*) fibers (*fibro*)—because no evidence of inflammation was found in those with the condition. Piece by piece, understanding of fibrositis evolved from the limited perception of a “regional pain disorder” to being understood as a “multiple symptom disorder” (Wolfe & Walitt, 2013, p. 751). By the time the name *fibrositis* was abandoned and *fibromyalgia* was formalized by diagnostic criteria

in 1990 by the ACR, the disorder retained the TP criterion but also included widespread pain throughout the body and incorporated a number of additional somatic symptoms (Wolfe & Walitt, 2013). The 1990 criteria are credited with identifying the two key features of FM outlined above: (1) a lowered pain threshold, and (2) chronic widespread pain (Wolfe & Hauser, 2011, p. 4).

Since publication of the ACR criteria in 1990, these criteria have become the research standard (Okifuji & Hare, 2013; Okifuji & Turk, 1999; Wolfe & Walitt, 2013; Wolfe, Walitt & Hauser, 2001). The ACR definition is the one referenced in the overwhelming majority of literature about FM. However, the ACR criteria are not without their challenges. The TP criterion that has come to characterize the 1990 ACR definition of FM is one of the areas of on-going debate. The validity of the TP criterion has been challenged due to questions about its ability to effectively discriminate FM from other conditions involving chronic widespread pain. It has also been found that examiners are inconsistent in how much pressure they apply when palpating the points, thus leading to inconsistent diagnostic processes (Wolfe & Hauser, 2011). The TP criterion was dropped in the 2010 revision of the ACR diagnostic criteria. However, it continues to be cited as a distinguishing characteristic of FM in much of the descriptive literature, suggesting that it is still a key feature of many researchers' understanding of the condition.

In the 2010 revisions of the ACR criteria, the focus on TPs was replaced with a “widespread pain index” documenting regions of the body the patient reports as painful (Wolfe & Hauser, 2011). A “symptom severity scale” was also added, which notes severity of key symptoms commonly associated with FM: fatigue, unrestorative sleep, cognitive difficulties, and numerous co-occurring conditions. The new criteria are heavily dependent on in-depth patient interviews and assessment by self-report, thus continuing to contribute

to the complexity inherent in this illness (Wolfe & Walitt, 2013). In order to make an FM diagnosis, complete physical examinations are recommended. As a part of a complete exam, it is expected that patients will receive orthopedic and neurological examinations and blood tests, to rule out other diagnoses that could present with similar symptoms as FM (International Association for the Study of Pain, 2010).

Theoretical Models

As shown above, understandings of FM have fluctuated in accordance with changing medical beliefs about its causes. The most recent ACR criteria begin to shift away from a focus on objective measures, moving instead in the direction of subjective experience. Although there is of yet no medical consensus on the aetiology of FM, the 2010 diagnostic criteria updates reflect (albeit in a delayed fashion) changing theoretical explanations for FM, and corresponding healthcare approaches to working with the condition.

Biomedical model. The biomedical model continues to feature as the prevalent model of healthcare delivery. The foundational theory underlying many of the original—and still present—assumptions in the biomedical model was proposed by Descartes in the 17th century (Melzack, 1996). This model proposed a divide between mind and body, and described human bodies as working like machines, with linear cause and effect pain relationships; where pain is concerned, this leads to the concept of a “straight-through sensory projection system”, which presumes the existence of specific pain fibres that follow dedicated pain pathways to a localized pain centre in the brain (Melzack, 1996, p. 128). The specificity theory thus presumed a direct correlation between peripheral injury and the level of pain experienced, “like the bell-ringing mechanism in a church: a man pulls the rope at the bottom of the tower, and the bell rings in the belfry” (Melzack & Wall, 1983, p.

196). The basic assumptions of specificity theory fit with what later emerged as positivism: concerned with clear-cut cause and effect and the premise that all necessary information can be collected through objectively measurable data, positivism has come to define the scientific ideal (Alderson, 1998).

Although the biomedical model often applies well to those with acute injuries or conditions, it is less informative for complex chronic conditions such as FM (Schultz, Stowell, Feuerstein, & Gatchel, 2007). In basing conceptualization of illness on direct cause and effect between identifiable pathology and symptoms, the conventional biomedical model leaves no room for the influence of factors such as previous experiences, perceived meaning of an event, attention, or other complex interrelationships between the physical body and psychosocial, emotional, and ecological factors.

Because it does not encompass the complexity of the human experience of illness, treatment for chronic conditions based on the biomedical model tends to be limited. Healthcare providers expect to follow a linear path of testing—diagnosing—treating (J. Owens, personal communication, July 4, 2017), and when this is ineffective, the patient is frequently blamed (Melzack & Wall, 1983). As recently as the 1950s, patients who experienced pain without an apparent injury were considered “psychologically disturbed” and were sent to see psychiatrists for treatment in this model, patients who don’t respond to treatment continue to be viewed as noncompliant, or the condition seen as “in their heads” (Schultz et al., 2007).

More nuanced understandings of illness, and consequently, healthcare provision have evolved; however, the conventional system of healthcare provision has yet to make this shift. As a result, many individuals living with FM continue to be treated within a healthcare system that does not adequately recognize and respond to their condition.

Biopsychosocial models.

The gate-control theory of pain. The gate-control theory of pain was proposed by Melzack and Wall in 1965; it evolved from a growing awareness of the role of the brain in the pain process. In this ground-breaking reconceptualization of the pain process, Melzack and Wall shifted attention away from the periphery of the body toward incorporating the role of the central nervous system (CNS) in the pain experience. They also advocated for a more nuanced understanding of the transmission of pain messages (Melzack, 1996; Melzack & Wall, 1983).

The gate-control theory maintained the understanding that injury creates nerve impulses, which are transmitted from the injured area along nerve fibres (known as small-diameter fibres) carrying the message into the CNS. This theory proposes that a mechanism in the dorsal horn (in the spinal cord) acts like a gate, which modulates the level of intensity of the pain message. These spinal gates are influenced by large-diameter fibres descending from the brain; in short, they are influenced by cognitive processes. These gates can increase or decrease the intensity of the signal being transmitted and thus the level of pain experienced. This modulation allows for variability in pain perception, like occasions when injury occurs without pain and pain that is experienced without injury. The greatest victory of gate-control theory was highlighting the central role of CNS mechanisms in the understanding of pain, allowing for an awareness of how psychological factors can inhibit, increase, and otherwise filter pain messages.

The gate-control theory built on specificity theory, incorporating the knowledge that injury activates pain receptors in the periphery of the body. It guided us away from the exclusive association of pain and injury. Pain was no longer seen as a predictable outcome, but rather a possibility. Where in specificity theory, stimulation of a small-diameter nerve

fibre *will* lead to the experience of pain, in gate-control theory it *can* lead to pain, but there are other factors involved as well—notably, perceptions, prior experiences, and other psychological factors (Melzack, 1996; Melzack & Wall, 1983).

The neuromatrix theory of pain. Melzack's influence on understandings of pain did not stop after the gate-control theory. While the gate control theory raised awareness of the active role of the brain in the human experience of pain—filtering, selecting, and modulating inputs—it did not explain *how* all this occurred. Phenomena like phantom limb pain and other forms of chronic pain—where sensations (including pain) are felt in the absence of any possible stimulus from the periphery of the body—were inexplicable by gate control theory. This signaled to Melzack that a more nuanced understanding was still needed. More than two decades after the gate control theory of pain was put forward, Melzack proposed a new theory: the neuromatrix theory of pain (1989). The neuromatrix theory proposed an altogether new understanding of pain as a multidimensional experience—with the possibility of causation through multiple channels, rather than exclusive causation at the periphery of the body.

In describing the foundations for this new theory, Melzack outlined four conclusions stemming from his analysis of phantom limb phenomena that helped him develop this enriched understanding of how pain occurs (1989; 1999; 2004). Firstly, based on the fact that the phantom limb or other body part feels just as real as other body parts, Melzack concluded that the way we experience our bodies cannot simply be the result of inputs from the body; while sensation is usually activated by inputs from the body, it can also be experienced without inputs. Secondly, all sensory experiences generally triggered by inputs from the body can be experienced independently of these triggers as well. This lead to the conclusion that the patterns of sensations we experience must originate from

neural networks in the brain; inputs from the body may trigger these sensations, but they are not created in the body. Thirdly, the body is perceived as a “self”, which is whole, separate and unique from others and surroundings. Finally, the neural network that determines how the body is experienced is genetically determined, although it is modified by experience. The *neuromatrix*, as Melzack (2004) called it “comprises a widespread network of neurons which generates patterns, processes information that flows through it, and ultimately produces the patterns that is felt as a whole body” (p. 87). The neuromatrix was thus described as a template for the body-self.

The neuromatrix theory contributed to the understanding of FM in that it more fully accounted for the contribution of psychological factors in the pain experience, particularly the role of stress. Melzack (2004) reminded that:

“We are so accustomed to considering pain as a purely sensory phenomenon that we have ignored the obvious fact that injury does not merely produce pain; it also disrupt [*sic*] the brain’s homeostatic regulation systems, thereby producing “stress” and initiating complex programs to reinstate homeostasis” (p. 89).

Through including the role of stress into the mix, we are provided with a crucial piece of the puzzle in the quest to understand chronic pain (Melzack, 1999; Melzack 2004). When a person sustains an injury, the body alerts the brain, which engages a sequence of reparative and protective responses. The sympathetic nervous system is activated, which is responsible for the body’s fight or flight response. Simultaneously, the *perception* of injury sets off another sequence of responses. Of particular relevance is the release of cortisol into the blood stream. Cortisol is necessary to survival during emergency; however, prolonged exposure to cortisol can wreak havoc on the body. It can lead to myopathy (muscle disease, associated with cramps, stiffness, and spasming), weakness, fatigue, and suppressed

immune system, among other outcomes. Melzack suggested that some forms of chronic pain may be the result of the damaging effects of sustained cortisol output.

Melzack (2004) described that an understanding of the role of stress is one of the keys to understanding FM. He argued that “By recognizing the role of the stress system in pain processes, we discover that the scope of the puzzle of pain is vastly expanded and new pieces of the puzzle provide valuable clues in our quest to understand chronic pain” (p. 89). He went on to hypothesize that for some individuals, the body-self neuromatrix’s stress response remains activated even after the threat has passed; this leaves the individual in a state of hypervigilance, a sustained state of preparation against threat. In addition to the detrimental impacts of long-term cortisol exposure, this state of hypervigilance leads to chronic muscle tension and can result in muscle fatigue; this could potentially explain the pattern of TPs found in individuals with FM.

It is clear from the literature that the chronic pain and other symptoms associated with FM have extensive impacts on the lives of sufferers, not just from the symptoms themselves but all the other challenges and stresses associated. Chronic illnesses like FM impact and are impacted by biological, psychological, and sociocultural factors—including, as mentioned above, stress. A comprehensive understanding of this illness must therefore take each of these and their interrelationships into account. Chronic illness wreaks havoc on a person’s system—depleting emotional reserves (Turk & Monarch, 2002); and exposing the body to prolonged periods of stress, wherein the body responds to the incoming pain messages as if it is under constant threat (Gatchel et al., 2007). The continual state of suffering and unpredictability can result in feelings of helplessness, demoralization, hopelessness and depression. Pain itself can also result in a range of emotional experiences including depression, anxiety, and anger. Given that no person lives

in isolation, the suffering of one person will also inevitably impact that person's social circle. Emotional distress can predispose someone to pain, it can trigger pain, it can be a perpetuating factor in pain, or it can be a modulating or inhibiting factor in the severity of pain. Finally, as previously mentioned, chronic pain leads to enormous societal costs in terms of medical care and lost productivity (Gatchel et al., 2007; Turk & Monarch, 2002).

Melzack's theories—first the gate control theory, and then the neuromatrix theory—have helped inform biopsychosocial understandings of pain and disability, and have guided interdisciplinary research and approaches to healthcare provision for chronic pain conditions. These approaches were informed by the recognition of the complex relationship between pain, emotion, psychosocial factors, and functioning—and their ability to interact in a cyclical manner, perpetuating and augmenting each other over time if left untreated (Schultz et al., 2007).

Ecological models. Ecological models of health take yet a broader, more complex view, incorporating the multidimensional interactions between the individual and the concentric layers of environmental systems that influence their life. The individual is placed at the centre of the model, which also attempts to capture the influences and role of society on illness and healthcare provision. Where the conventional healthcare model is a reductionist one, social-ecological models (SEMs) have been widely used to structure public health policy to address healthcare needs across multiple levels, including adaptations by the Centers for Disease Control and prevention (Centers for Disease Control and Prevention, 2013, Centers for Disease Control and Prevention, 2015), and UNICEF (UNICEF, 2013). Further, an ecological view on health shifts the discussion away from an absence of injury (as in the biomedical definition) and disease *prevention* and encapsulates social dimensions of health, including collective wellbeing and health *promotion* (Stokols,

1992). Additionally, validated applications of ecological models have been developed for return to work models (Schultz et al., 2007). Ecological models of return to work have been in part based on Bronfenbrenner's Ecological Systems Theory (EST), originally developed as a framework for understanding child development (Bronfenbrenner, 1979; Schultz et al., 2007), advocating that "the ecology of human development lies at a point of convergence among the disciplines of the biological, psychological and social sciences as they bear on the evolution of the individual in society" (Bronfenbrenner, 1979, p.9).

While SEMs have been widely recommended to guide public health practice (Golden & Earp, 2012) the use of Bronfenbrenner's EST in these applications is less common. However, given its demonstrated applications in return to work models for disability—with grounding in many disciplines including sociology, anthropology, social work, industrial/organizational, health psychology, nursing, and occupational health and therapy (Schultz et al., 2007)—as well as its more specifically relational, and developmental (an individual's trajectory over time) framework, a specific focus on EST will be further explored. Bronfenbrenner (1979) built on ecological models, which looked at the different settings in which events took place, and incorporated a relational aspect to them—arguing that "interconnections can be as decisive for development as events taking place within a given setting" (p. 3), thus in a sense integrating biopsychosocial, and ecological perspective, along with a temporal element.

EST places the individual *person* (including characteristics like individual biological traits, and mental, and emotional resources) at the centre of the framework (Bronfenbrenner, 1979). Moving outward from the centre, ecological systems are viewed as concentric layers, each one viewed relationally with respect to the individual. The person has the most direct interactions with the layers closest to them and is able to directly

influence these closest layers; moving outward, the person's interactions become increasingly indirect; while the person is impacted by the outmost layers, they have little personal influence over the decisions that take place within them. The second layer, the *microsystem*, describes the system closest to the person. The person has direct contact with this system (direct relationships such as family, peers, or in a healthcare context, healthcare providers), which is characterized by bi-directional relationships; thus, this is the system the person has the most direct impact on. The third layer is the *mesosystem*, which encompasses interactions between parts of a person's microsystems (such as communications between a person's healthcare providers); while the individual does not directly interact with these systems, they are nonetheless profoundly impacted by them. The fourth layer, the *exosystem*, is the larger social system; the person is not involved in the exosystem as an active participant, but is still affected by its impacts on the mesosystem and microsystems (including policy decisions). Finally, the fifth layer, the *macrosystem*, describes the cultural environment in which the person lives, and all of the other systems that affect them (including belief systems and cultural values, the economy, and societal structure). An additional system, the *chronosystem* encompasses changes or transitions that occur over the course of time.

Applications to healthcare access for FM

The conventional biomedical model is a reductionist one, which assumes the mind and body function separately and independently from one another. In his landmark challenge to the medical field, Engel (1977) argued that "all medicine is in crisis" (p. 129) due to the failings of this dualistic construction; he called for the integration of psychosocial factors to account for the development of somatic and mental illness, and

syndromes. Engel argued as if speaking directly to the challenges of people with FM when he stated:

The boundaries between health and disease, between well and sick, are far from clear and never will be clear, for they are diffused by cultural, social, and psychological considerations. The traditional biomedical view, that biological indices are the ultimate criteria defining disease, leads to the present paradox that some people with positive laboratory findings are told that they are in need of treatment when in fact they are feeling quite well, while others feeling sick are assured that they are well, that is, they have no “disease” (p. 132).

Moseley (2007) posited that a reconceptualization of pain and relevant treatments are needed, based on modern scientific understandings about the biology of pain. He stated that pain is not a straightforward issue, with four key points: 1) that pain does not provide a measure of the state of tissues; 2) that pain is modulated by many biopsychosocial factors; 3) that the predictability of the relationship between pain and tissues decreases as pain persists; 4) “that pain can be conceptualized as the conscious correlate of the implicit perception of threat to body tissues” (p. 172). A model of disease will only be effective in providing understanding of a person’s experience and leading to appropriate treatment options if it is multidimensional, exploring the intersections and underlying determinants of health within biological, psychological, and sociocultural factors (Fielding, Teutsch, & Breslow, 2007; Gatchel et al., 2007; Winfield, 2000).

Critiquing the manner in which the medical system responds to chronic pain patients Hadler (1996) inquired, “What is it like to feel ill and not be believed that you are ill?” (p. 2397). People with FM frequently describe experiences of stigmatization (Sim & Madden, 2008). Because of the invisible nature of FM, and also its lack of objective pathology, those with FM struggle with the dissonance between their subjective experiences of suffering and their external appearances, which those around them perceive as “normal” and “healthy”. In their metasynthesis of 280 qualitative studies, Sim and

Madden highlighted common themes in the subjective experiences of people with FM; a number of themes dealt directly with the symptoms of the illness and coping, while the others focused on the process of seeking and receiving a diagnosis, and questions of legitimacy.

Lempp and colleagues (2009) described an “informal hierarchy of medical specialties,” which prioritized conditions that can be investigated or treated with cutting edge technology. According to this ranking system, conditions like FM are the bottom of the barrel, leaving patients heavily stigmatized. Many individuals diagnosed with FM report feeling abandoned by their healthcare practitioners, and frustrated with their attempts to receive care (Lempp et al., 2009). From a healthcare provider perspective, these individuals are often cited as being challenging, and even unfulfilling to work with (Arnold, Crofford, Mease, Burgess, Palmer, Abetz & Martin, 2008; Okifuji & Turk, 1999; Sim & Madden, 2008).

The lack of objective tests puts the onus on individuals to effectively articulate their symptoms and make a case for themselves (Arnold, Crofford, Mease, Burgess, Palmer, Abetz & Martin, 2008; Okifuji & Turk, 1999; Sim & Madden, 2008). Because the experience of FM can't be objectively confirmed, some clinicians may not recognize the signs and symptoms, others may not consider it a viable diagnosis, while still others may begin to believe the individual is experiencing a purely psychological condition and question his or her credibility. Seeking treatment seems an almost unavoidably complex process that is reported as long and stressful for those seeking consultation and support for their symptoms. At the same time, all the uncertainty associated with FM makes it crucial to access the right kind of support (Juuso, Skär, Olsson, & Söderberg, 2011).

Management of FM. Given the challenges associated with FM, and the lack of identifiable causal mechanisms, treatment guidelines for FM focus on symptoms management (Fitzcharles et al., 2012; Velkuru, 2009). The Canadian Guidelines for the Diagnosis and Management of Fibromyalgia Syndrome (Canadian Guidelines) (Fitzcharles et al., 2012) state: “There is currently no cure for FM and treatment recommendations should be directed to reduction of symptoms and maintenance of optimal function” (2.1). Perhaps most notably, their treatment guidelines emphasized the importance of “active patient participation fostered by a strong patient-centred locus of control” (2.1), stating that patient self-efficacy will lead to improved outcomes. Underscoring the heterogeneous nature of FM, they recommend a multimodal approach, including pharmacologic and non-pharmacologic treatment. Non-pharmacologic treatments include education around pacing of physical and other daily activities, and helping improve patient autonomy and self-efficacy, as well as incorporating psychological therapy, and exercise therapy.

Psychological interventions. Psychological interventions are recommended to address both comorbid psychological concerns that impact quality of life, as well as bolstering coping and improving pain-related behaviour (Fitzcharles et al., 2012). Findings attribute benefits to various psychological interventions, including: cognitive-behaviour therapy (CBT) treatment, motivational interviewing, emotional expression, psychomotor therapy, meditation-based stress reduction, and biofeedback, as well as chronic pain self-management programs, hypnosis, and guided imagery. A meta-analysis of psychological treatments for FM by Glombiewski, Sawyer, Gutermann, Koenig, Rief, and Hofmann (2010) found that while the effects of psychological treatments for FM are relatively small, they are robust and their efficacy is comparable to findings for other treatments for the condition. Their examination of 23 studies showed that CBT yielded the best results in

reducing pain intensity in the short-term, and CBT with relaxation/biofeedback was most effective in reducing FM associated sleep problems. All treatments were found to be equally effective in decreasing depression. It should be noted that divergent conclusions do exist about the efficacy of CBT for FM (Bennett & Nelson, 2006; McCracken & Vowles, 2014; van Koulil, Effting, Kraaimaat, van Lankveld, van Helmond, ... Evers, 2007). Another study by McInnis, Matheson, and Anisman (2014) compared the effectiveness of various coping styles among women with Chronic Fatigue Syndrome (CFS) and FM suggested that given the unique challenges that women with these conditions face, problem solving approaches that are typically seen as adaptive among other individuals may not be as beneficial to women with CFS and FM. McInnis and colleagues (2014) posited that interventions focused on reducing emotional distress might be more advantageous.

Eccleston (2011) sought to counter the “abnormal psychology” interpretation of pain by focusing on a “normal psychology of pain” (p. 422). He argued that pain is more than just a private mental event—it also serves a communicative purpose. Expression of pain functions as an alarm, not just to the person feeling it, but also on a social level, to alert others of danger. As a result, understanding pain requires an understanding of both the person, and the social function of the behaviour. Through this lens, pain can be viewed as having an “interruptive function” (p. 423), interrupting current concerns to update about environmental threats and shift social priorities toward escape or avoidance. Viewing pain as a warning system—and chronic pain as a warning system delivering false alarms—we can view chronic pain as an active process of searching for solutions. Depending on the presentation, this understanding of chronic pain leads to different treatment recommendations: fear exposure for hypervigilance; CBT for shifting rigid pain beliefs

from needing a cure to managing a chronic condition; and acceptance and commitment therapy (ACT) for accommodating life which is impacted by pain.

Exercise. Exercise is recommended as the first step of a multimodal treatment approach, and is stated to have benefits for global wellbeing, physical function, pain, and emotional wellbeing (Fitzcharles et al., 2012). While the results of numerous studies have advocated the benefits of exercise for FM, they also demonstrate a need for more long-term research. Understandably, symptoms of FM may be deterrents to participation in exercise programs. Fitzcharles and colleagues acknowledged that FM patients report poor exercise capacity, and that experiences of pain may pose barriers to exercise; however, there appears to be little research addressing ways to engage individuals with FM in exercise while reducing adverse impacts.

Fear-avoidance research by Leeuw et al. (2007) contributes to understanding the reluctance of some individuals with FM to engage in exercise as part of their treatment plan. The nature of pain is a signal of injury, warning the individual to adjust their behaviour to allow for recovery time. However, when pain becomes chronic, interpretations of these messages need to be reassessed, since avoidance of pain can lead to deterioration and perpetuation of pain over time as a result of restricting movement.

Complementary and alternative medicine (CAM). CAM encompasses an array of medical and healthcare practices and products that are not generally considered part of conventional medicine (Terry, Perry, and Ernst, 2012). What constitutes CAM in a given context is politically, and socially defined, and thus the boundaries between what is CAM and what is conventional medicine are fluid and changing. Rates of CAM use are high among individuals with FM, with studies reporting that over 90% use at least one form of CAM to manage their symptoms (Fitzcharles et al., 2012; Terry, Perry, & Ernst, 2012).

CAM use has been found to be much higher among individuals with chronic pain and FM than the general population, with use among these individuals being the highest reported of any population (Aveni, Bauer, Ramelet, Kottelat, Decosterd, ... Rodondi, 2016; Jong, et al., 2012). It has been conjectured that use among chronic pain and FM patients is a reflection of dissatisfaction with, and the failure of, conventional medicine to treat these conditions (Terry, Perry, & Ernst, 2012). Conversely, evidence-based research of these treatments has yielded mixed results, and healthcare providers in the conventional biomedical model have varying degrees of familiarity and acceptance toward these treatments (Aveni et al., 2016; Fitzcharles et al., 2012; Terry, Perry, & Ernst, 2012).

Further complicating matters, while many conventional healthcare providers do not integrate conversations about CAM in their appointments with chronic pain and FM patients, treatment guidelines for FM suggest tailored approaches to managing FM (Fitzcharles et al., 2012), and specialized treatment programs for FM and other complex chronic conditions take integrative care approaches (Terry, Perry, & Ernst, 2012). These often contradictory attitudes toward CAM create barriers for patients, who are attempting to cope with their symptoms by any means possible. Studies of CAM use show that while many patients will not disclose CAM use to their physician, many patients would like to be able to have these conversations to be more informed and supported in their care, and believed that collaborative decision-making between themselves, their physician, and their CAM providers, was important in helping ensure the best treatment approach (Jong et al., 2012).

Pharmacologic treatments. The Canadian Guidelines (Fitzcharles et al., 2012) recommend incorporating pharmacologic approaches to symptom management for FM, by identifying and treating the most bothersome symptom(s), with an ideal approach being a

medication that addresses multiple symptoms. Pharmacologic treatments might include analgesics (pain relief medications, including acetaminophen, nonsteroidal anti-inflammatory drugs, opioids, and cannabinoids), tricyclic antidepressants, other antidepressants, gabapentinoids, dopaminergic agents, and sleep modifiers. Regardless of the medication prescribed, monitoring is recommended, with careful attention to continued benefit or side effects, particularly given that side effects can mimic symptoms of FM. However, although medication is recommended for FM, preliminary research shows that finding a helpful medication can be a long and challenging process (Durif-Bruckert, Roux, & Rousset, 2015). In the study by Durif-Bruckert, Roux, and Rousset (2015), participants talked about encountering lack of understanding of relevant treatments for FM, attempting multiple prescriptions, and facing significant side effects.

Quality of care. In their investigation of the challenges and barriers in the timely diagnosis, treatment, and management of FM, Hadker and colleagues (2011) identified that it takes an average of five years for patients to be diagnosed with FM, and that they are often dissatisfied with the recommended course of treatment. They also highlighted that while FM is the second most common disorder rheumatologists encounter in clinical practice, American rheumatologists provide care for less than 20% of FM patients, leaving primary care physicians attempting to manage these complex cases. A study in a Mexican context by Colmenares-Roa et al. (2016) found that rheumatologists may even refuse to work with FM patients, resenting how challenging these patients can be, and expressing disbelief in the condition. In their hybrid qualitative-quantitative study involving surveys and focus groups with primary care physicians, Hadker and colleagues' findings revealed that primary care physicians themselves perceived significant barriers in the diagnosis of FM. These barriers included uncertainty when diagnosing FM, and lack of standardization

for diagnosis and for monitoring patient progress. Symptom reduction was seen as a priority, indicated by the use of medications in treatment. Findings indicated an average of three drug or dose modifications were needed before some improvement was noted with these patients. Only half of these primary care physicians' FM caseload was identified as experiencing moderate or marked improvement.

Lempp and colleagues (2009) interviewed 12 patients about their experiences living with and receiving treatment for FM. This study highlights findings related to participants' perceptions of the quality of care they received. Themes related to lack of regular contact and time with healthcare providers, unresponsiveness to their needs, and that care seemed limited to prescribing medication. They also revealed that challenges with hospital outpatient care focused on the inadequacy of professionals' attitudes, and organizational challenges with programs. They described ambivalence toward medication, which was found to address symptoms only in superficial ways, rather than treating the underlying problems. Additionally, many found that prescription medication was ineffective.

Continuity of care. Continuity of care is concerned with the quality of care over time (Delva, Kerr, & Schultz, 2011). It is frequently referred to as a cornerstone of medical practice, and is associated with improved patient outcomes. Since the concept was first introduced to family medicine in the 1980s, the practice of medicine has changed, incorporating more specialized care and integrative teams. These changes in the practice of medicine have created uncertainty around what continuity of care actually includes. According to the American Academy of Family Physicians, continuity of care “is the process by which the patient and his/her physician-led team are cooperatively involved in ongoing care management toward the shared goal of high quality, cost-effective medical care” (2015). Inherent in their definition is a long-term patient-physician relationship,

allowing early identifications of problems, and new information and decisions to be integrated into the care plan. An alternate definition more specific to chronic and complex care needs was suggested by Shortell (1976) highlighting the need for coordination and consistency between different providers and settings. Whereas most aspects of quality of care focus on specific interactions or moments in time, continuity of care incorporates a chronological element.

Drawing from the American Academy of Family Physicians' definition, Gulliford, Naithani, and Morgan, (2006) contends that the concept of continuity of care merges two core concepts: continuity as a “seamless service” and a “continuous caring relationship” (p. 249). Elements of a seamless service focus more on informational continuity, such as timely communication of information, follow ups, and record keeping and relevant sharing of records, and management continuity such as the degree of consistency and coordination between primary care and different specialists (Delva, 2011; Gulliford, 2006; Haggerty, Roberge, Freeman, & Beaulieu, 2013). Haggerty and colleagues (2013) underscore that while healthcare providers may be aware of these factors, patients are not necessarily conscious of them; rather, coordination of care is assumed, and inferred when no problems have occurred. Where chronic conditions are concerned, continuity may come to involve management support, case management, and multidisciplinary and integrative approaches, highlighting the “coordination” aspect of continuity of care. In fact, according to the Canadian Guidelines (Fitzcharles et al., 2012) care of FM may require a team of individuals, rather than relying on an individual healthcare provider, in order to treat the condition from multiple angles, an approach which is also recommended by Durif-Brukkert, Roux, and Rousset (2015). In these contexts, the previous definition of a

“continuous caring relationship” becomes less feasible, as care is delegated out to various specialists.

Therapeutic alliance. While the practice of medicine is changing with general practitioners increasingly working into multi-partner practices, research on experienced continuity of care (i.e. continuity of care as experienced by the patient) reveals that continuity of care is directly experienced in part through having an ongoing relationship with a trusted clinician (Haggerty et al., 2013). In a metasummary of qualitative studies on continuity of care, Haggerty and colleagues (2013) discussed the importance of trust across studies, which was identified in two-thirds of the studies they reviewed. When patients see a number of clinicians, such as is often the case in care for complex chronic conditions, a single trusted clinician becomes particularly important. They found that the importance of this single trusted healthcare provider is so important that “some patients trade off the clinical expertise of specialists for the security of being looked after by a known and trusted family physician” (p. 267).

This study by Haggerty and colleagues (2013) goes on to discuss patients’ desire to be active agents in their care, and for collaboration, touching on a number of facets. They found that patients wished for more than just a caring relationship; they thought of the relationship with their healthcare providers as a partnership. They wished to share power in the therapeutic relationship, wanted to be taken seriously, wanted to be empowered to share in decision making, and wanted their contributions to be recognized. This includes the transition and discharge planning, to support a sense of continuity when patients are being transferred between healthcare providers or settings. Findings from this study demonstrate that patients often experience a sense of discontinuity and vulnerability during such transitions. Additionally, patients were shown to desire care plans that were more integrated

into their lives, showing a desire for more informed consent in the process. According to this study, receiving written information about a care plan did not constitute a “functional care plan” (p. 267). A functional plan is one that informs patients of the trajectory of their condition, explains the content of care, and incorporates contingency plans for when things go wrong.

According to a study on doctor-patient relationships between individuals with FM and rheumatologists in Mexico, relationships with healthcare providers are of particular importance to individuals with FM (Colmenares-Roa et al. 2016). Patients with FM were found to expect a close and trusting relationship with each of their doctors, including the right to ask questions and receive clear explanations. These close relationships had a subsequent impact: based on the trust in their healthcare providers, these patients followed their instructions. Another study by Zotterman and colleagues (2016) examining primary care experiences among people with long-term illness found that continuity of care, as well as having time to engage, were prerequisites for developing a relationship with a healthcare provider. Furthermore, they found that positive relationships with healthcare providers were characterized by: respect, kindness, and having their needs addressed. These kinds of relationships led to patients feeling more energized, and appeared to support general health and wellbeing.

Mattering. These descriptions of patient desires for caring, close relationships with their healthcare providers allude to a need to *matter*. While mattering does not appear to be a commonly discussed construct within healthcare literature, it is more prevalent within counselling and mental health literature. Building the work of Schlossberg, Lassalle, and Golec, Amundson (1993) explored four dimensions of the perception of mattering: (1) attention: the feeling that another person notices or is interested in you; (2) importance: the

feeling that others care about what you want, think, and do; (3) dependence: the feeling of being a contributing member and that others are counting on your participation; and (4) ego-extension: the feeling that others are interested in your successes and disappointments, and actively follow your progress. These four dimensions bear striking resemblance to the desired trusting, caring, collaborative healthcare relationships described by Haggerty et al. (2003).

The importance of mattering should not be underestimated. In their exploration of the mediating role of mattering in recovery and stigma among individuals with serious mental health conditions, Pernice, Biegel, Kim, and Conrad-Garrisi (2017) highlighted the connection between the perceptions of *not* mattering and risk for social isolation, and subsequently, associations between social isolation and poorer self-reported physical health, psychiatric symptoms, and internalized stigma. They wrote that stigma, lack of social support, isolation, and inadequate resources can exacerbate mental health conditions and impede recovery, all of which are also factors cited in the literature as challenges for individuals with FM (Lempp et al., 2009; McInnis, Matheson, & Anisman, 2013; Undeland & Malterud, 2007; Werner & Malterud, 2003). Furthermore, Pernice et al. highlight that while social support and mattering are related, they appear to be distinct constructs; while social support is defined as the giving or receiving of forms of assistance, mattering is the sense of being acknowledged by another who has an interest in one's welfare. Findings from their study suggested that the experience of mattering may be a protective factor in mental health, reducing internalized stigma and increasing the likelihood of seeking professional support.

Iatrogenic suffering. Another construct that appears in healthcare literature, but not specifically in FM literature is iatrogenic suffering. Iatrogenesis—from the Greek

iatros meaning healer or physician, and *gennan* meaning the product of—refers to any adverse effects on the patient resulting from healthcare experiences. In the above study by Lempp and colleagues (2009), many participants were referred to physiotherapy, which was also remembered with ambivalence. While it was helpful to some, it worsened pain for others. Ultimately, many participants stated they tended to self-manage, relying on their own intuition and coping strategies rather than on medical advice, which seemed misaligned with their subjective experiences and risked worsened outcomes. These findings aligned with those outlined above in the article by Juuso and colleagues (2014), where women stated that not being listened to or seen as credible led to them feeling sicker after their healthcare interaction than they had before, thus, demonstrating adverse effects of emotional injury as well as symptom exacerbation. These types of iatrogenic experiences are supported by psychological research which recognizes the role of emotions as modulators of pain experiences (Lumley, Cohen, Borszcz, Cano, Radcliffe, ... Keefe, 2011); specifically, high levels of emotional arousal (intensity) in unpleasant emotional states can exacerbate pain. Additionally, Lumley and colleagues (2011) address the importance of emotional communication between patients and caregivers, suggesting that patients may be unintentionally communicating through pain-related emotions and associated behaviours, which contribute to relationship challenges as well as the pain they experience, while Barker (2005) writes about how the cycle of experiencing doubt as a result of invalidation, can become internalized, progressing to self-doubt, and leaving people questioning their own identities.

Iatrogenic suffering has been notably written about by Kuhl (2011), whose research and work as a palliative care physician enabled him to identify the interrelationships between iatrogenic suffering, communication, and time. While Kuhl's research related

specifically to terminal illnesses, the psychospiritual patient experiences he describes may also be relevant to experiences of FM, particularly insofar as it relates to the “constant reality of pain” (p. 46). As suggested by the research on continuity of care (Gulliford, Naithani, & Morgan, 2006), Kuhl’s research points to the importance of timeliness of medical communications, citing the anxiety and chaos of waiting, which can lead to experiences of lost control, progression of the illness in the interim, and exacerbation of suffering. In describing the outcomes of his research, Kuhl highlighted that it challenges healthcare providers to “respond to expressed psychological and spiritual needs with appropriate sensitivity and skills while suspending judgment” (p. 50). Kuhl further encouraged the importance of healthcare providers reflecting on the complexity of the relationships between healthcare providers and patients, and how lack of communication skills might be adding to patient suffering. From the ample descriptions of distressing healthcare interactions in the FM literature (Juuso et al., 2011; Lempp et al., 2009; Sim & Madden, 2008), the concept of iatrogenic suffering—suffering caused by healthcare experiences—and reminders about the importance of communication and relationship appear necessary and significant.

Placebo response. In the medical field, the concept of the “placebo response” is often invoked in discussions of the therapeutic effect of the relationship between physicians and their patients (Brody, 2000). According to Brody, the placebo response refers to “a change in the patient’s health or bodily state that is attributable to the symbolic impact of a medical treatment or the treatment setting” (p. 650). Recognizing that change can be positive as well as negative, Brody also addressed the possibility of iatrogenic suffering, and warned that if physicians do not understand the placebo response they risk causing patients harm. A meaning model suggests that a positive placebo response is most likely to

occur if the meaning of the illness experience is positively changed. A change in meaning occurs with at least one of the following: (1) the patient feels listened to and receives a coherent explanation of the illness; (2) the patient feels care and concern from those around them; and/or (3) the patient feels an enhanced sense of mastery and control over their symptoms. Brody highlighted how this will occur more often if physicians are able to spend adequate time with their patients, citing that good health outcomes correlate with the length of primary care visits.

Based on findings from studies of the placebo response, Brody (2000) recommended maximizing on the placebo response through sustained partnership between patients and physicians, including: showing interest in the whole person; knowing the patient over time; showing care, sensitivity, and empathy; demonstrating trustworthiness and reliability; adapting treatment goals to the patient's needs and values; and encouraging the patient's full participation in decision-making.

Accessibility. As outlined in the introduction to this chapter, accessibility of healthcare is multidimensional. Gulliford and colleagues (2002) describe four dimensions of access: (a) service availability, including adequate service availability and geographic availability; (b) utilization of services and barriers to access, including personal barriers such as recognition and acceptance of the patient's belief they need services, consent to services, and awareness of services; financial barriers, including willingness and ability to pay for out of pocket services, as well as travel costs and other financial inconveniences to accessing care; and organizational barriers, such as long wait times, and referrals; (c) relevance and effectiveness, i.e. "the right service at the right time at the right place" (p. 187), which is influenced by the other factors described, and (d) equity, including fairness and social justice in access to services. The need for relevance and effectiveness is

reinforced by findings by Haggerty and colleagues (2014), which suggest a need for predictability and stability, balanced with flexibility and adaptability; for example, that appointment frequency can be increased if needed.

Already, the lack of fit between the symptoms of FM, and conventional conceptualizations of illness and available treatment models presents multiple barriers to access in that it demonstrates inadequate supply of appropriate services. This definition also demonstrates that healthcare access includes far more than simply the availability of services; many factors are at play in influencing whether or not a prospective patient is able to make use of an existing service as needed, when it is needed.

Financial factors. Research on the financial burden of FM demonstrates significant out-of-pocket expenses for both conventional and CAM treatments (Annemans, Le Lay, & Taieb, 2009; Lacasse, Bourgault, & Choiniere, 2016). Repeated visits associated with FM come with direct healthcare costs of over \$4,000 Canadian per year – 30% higher than non-FM patients, while chronic pain costs an estimated \$56-60 billion annually in Canada (Canadian Pain Society, 2014). While little research appears to have specifically endeavoured to address the financial burden born by patients related to FM healthcare, findings on the economic burden of FM show that it is not only very costly for society, but also for individual patients (Annemans, Le Lay, & Taieb, 2009; Skaer, 2014; Vervoort et al., 2016). FM frequently results in significant loss of function, which in turn leads to loss of productivity; individuals often need to change their work situation, reducing hours, changing jobs, or stopping work entirely (Annemans, Le Lay, & Taieb, 2009). Simultaneous to these changes in work status and corresponding changes in income, patients are also burdened with significant expenses related to FM. These expenses include informal care, household assistance, prescription and non-prescription medications, and

CAM, including physiotherapy, herbs, vitamins, dietary supplements, and assistance supporting activities of daily living (Annemans, Le Lay, & Taïeb, 2009; Skaer, 2014). The study by Lempp and colleagues (2009) discussed the impact of disability benefits.

Participants described that it was both a challenging, complicated bureaucratic process, while also benefitting their quality of life, improving independence, mobility, and comfort.

Diagnostic Challenges with FM. A number of criticisms have been levelled against FM as a diagnosis. It has been argued that FM lacks clear distinctions from other conditions like chronic fatigue syndrome, IBS, and headache syndromes—many of which are also reported among individuals diagnosed with FM. In a synthesis of studies on FM, Johnson (2008) delineates findings on patients who meet both the FM criteria and a related condition. Notably, a reported 70% of FM patients also meet the Centre for Disease Control and Prevention (CDC) for CFS. Among individuals who meet the diagnosis for CFS, often the only differentiating factor between them and FM patients is the degree of pain experienced. Johnson suggests that it is likely that the processes behind both conditions are the same. As a result, Johnson wonders about the legitimacy of providing individual diagnoses to these conditions, and other “functional somatic syndromes” (2008).

Similarly, some consider FM a “wastebasket” diagnosis, arguing it is vague and unproven, or even that it is a manifestation of psychological illness and therefore not a “real” disease (Le Page, 2005; White, Lemkau, & Clasen, 2014). Despite many promising theories over the years, there is as yet no agreed upon neurological, physiological or psychological root of FM. There are additionally no objective tests clinicians can run to confirm a diagnosis. In the absence of an objective pathology FM is considered a “syndrome”—a set of associated symptoms—as opposed to a “disease”, which requires a known aetiology.

Hadler (1999) critiques the focus on pathophysiology in the medical literature, which continuously seeks to “ferret out an answer from the muscle or endocrine or nervous systems” of FM sufferers (p. 2398). Hadler argues instead that we must cease the reductionist diagnostic process, and move toward accepting the assertions of patients who, he argues, “are paying a substantial price for the scientific method” (p. 2399). With the shifts from the 1990 diagnostic criteria to the 2010 criteria, the burden is placed even more on the physician to make diagnoses through careful interviews and self-reports of the individual’s symptoms, as well as through exclusion of other possible conditions (Wolfe and Hauser, 2011). Hadler (1996) contends that the intense scrutiny FM sufferers experience at the hands of the medical system, which continues to try and “prove” objective illness can only serve to make people more ill; if we are to truly provide care, the disputative diagnostic process must be abandoned.

Making meaning of the diagnosis. From a patient perspective, a lot hinges on the diagnosis as well. A study by Madden and Sim (2006) explores a need for a reinterpretation of the role of diagnosis. Through a negotiated order lens of illness identification, one of the key functions of the healthcare system is to legitimate an individual’s social claim to illness with a diagnostic label. (Without such a label, an individual can be considered malingering.) In turn, a diagnosis is expected to give meaning to the illness experience, allowing the individual to develop a sense of order and reclaim control of the illness experience. Madden and Sim argue that receiving a diagnosis is not a singular event, but is instead an unfolding process of meaning making that takes place over time.

In their semi-structured interviews with 17 individuals diagnosed with FM, Madden and Sim (2006) explored the process of diagnosis through a lens of interactionism, where

interpretation and meaning-making of the social world take place through interaction. Six major themes were identified: (a) discovering a disease; (b) FM as an empty diagnosis; (c) uncertainty about the cause of FM; (d) biomedical ambiguity and definition of FM; (d) symptom discussion; (e) invisibility of FM; and (f) patterns of “acceptance”. In their findings, biomedical understandings of illness informed participant understandings of illness, contributing to some of their challenges with the condition. The identification of TPs provided some initial “objective” confirmation of the individual’s experience of illness. Uncertainty emerges (or is renewed) around why the diagnosis had not been put forward sooner in the consultation process, since individuals tended to have sought multiple consultations before diagnosis.

Additionally, the FM diagnosis “conveys information, but little understanding” (Madden & Sim, 2006, p. 2966); thus it provides some validation of illness, but little more. This leaves individuals seeking further information, particularly to locate some explanation for why they had developed the condition. Further, the broad array of symptoms, and ambiguous descriptions contribute to uncertainty. Despite all of this, findings indicated that healthcare providers tended to prevent discussion of FM with patient, leaving them to cope on their own with their uncertainties, rather than exploring and discussing with them. Differing descriptions of FM lead patients to question the legitimacy of the diagnosis, since the expectation is that a diagnosis by definition would have some consistency and uniformity. The need to have pain—and its severity—acknowledged by the healthcare provider was a dominant theme in this study; individuals frequently felt trivialized by information provided. Finally, all of these factors influenced the individual’s ability to accept the diagnosis.

The themes found in Madden and Sim were supported by the focus group study by Arnold and colleagues (2008), wherein the groups were in agreement that the road to diagnosis was “long and stressful” (p. 117). Many participants received misdiagnoses, and others had to educate themselves and become the driving forces behind receiving a diagnosis. They found public awareness of FM to be lacking, and reported that this made it more difficult to receive support. The symptoms, their severities, and their presentations are different for each person; this wide range of manifestations contributes to the confusing nature of FM and the controversy around the diagnosis.

Similarly, in a Scandinavian qualitative focus-group study Undeland and Malterud (2007) interviewed eleven women about their experiences and the consequences of being diagnosed with FM. They highlight the experiential distinction between the lived reality of a person with a given diagnosis and the medical world’s conceptual framing of the condition. While the hope is that diagnosis will pave the way for relief for the patient through increased understanding and plausible treatments, this study found the experience of diagnosis to be largely unhelpful to the participants. Experiences of illness are heavily impacted by the social context in which the individual lives, and the meanings attributed to the diagnosis and symptoms. There were descriptions of doctors acting hesitant and dismissive about the FM diagnosis, or reluctant to diagnose FM since there is “nothing to be done about it” (p. 252).

In the above study by Lempp and colleagues (2009), the stories that emerged from the study about their experiences living with FM focused on two central themes: social identity and illness intrusiveness. Echoing some of the concerns described in the study by Undeland and Malterud (2007), the participants in this study drew a distinction between *life before* and *life after* diagnosis. The experience of diagnosis was similarly mixed for almost

all participants, involving a combination of relief, ambivalence, and distressing emotions (Lempp et al., 2009). Also similarly, almost all of the participants commented on the lack of information they were provided with about their diagnosis, leaving them searching on their own to try and uncover something to help them understand their experiences.

Subsequent to receiving the diagnosis of FM, participants' lives and health identities seemed to become increasingly defined by the illness (Lempp et al., 2009). Participants described the condition as unpredictable, feeling unable to rely on their bodies in the ways they had come to expect. The combination of the physical, social, emotional, and cognitive impact consistently undermined their self-confidence and overall sense of self.

Credibility. Once the diagnosis was given, many participants initially experienced some relief at having a name for what they were going through; however, this relief was often tempered or followed by negative attributions like awareness of stigma and fear of dismissal (Undeland & Malterud, 2007). Participants described feeling disrespected when others challenged their experiences of symptoms, stating they didn't "look ill enough" (p. 252). All eleven participants stated they had hoped their doctors would talk with them about the consequences of the illness. A number of them also experienced frustration around the lack of explanation for their suffering. Upon realizing that there were few treatment options and the possibility of lifelong symptoms, many participants experienced feelings of sorrow and despair; they described their process as a lonely one.

The challenge of credibility was powerfully stated by Juuso and colleagues (2011) in their study about the meanings of pain for women with FM; they wrote about the "double burden" of living with FM, that is, living with an unpredictable, debilitating pain, while being doubted by others because of its invisible nature. In order to support women with FM, they emphasize the necessity of understanding and believing their experiences of

pain. A subsequent study by the same authors (2014) focused on the meanings of being received and met of women with FM. Emphasizing the research that demonstrates the importance of support in managing chronic illness, they argue the centrality of taking patients seriously and validating their experiences. A study of experiences of chronic illness by Baxter (2013) shows that supportive encounters with healthcare providers contributed to patients feeling believed in, while unsupportive experiences, lacking in understanding, left patients feeling abandoned.

When seeking support from healthcare professionals for FM, women in the study by Juuso and colleagues (2014) described not feeling listened to or taken seriously, which they attributed to the lack of objective results from lab tests. These experiences of being ignored took emotional and physical tolls; participants shared that experiences of being ignored left them feeling sicker than before. They believed that lack of engagement and interest in helping uncover the causes of their symptoms allowed their condition to worsen, and these experiences delayed getting appropriate help. These women contrasted experiences of accessing healthcare for FM compared to other more objective conditions (like a tumour), and stated that for FM they were not seen, whereas with other diagnoses they were seen quickly, listened to, and respected.

Gender. In her book *The Fibromyalgia Story: Medical Authority and Women's Worlds of Pain*, Barker (2005) argues for what she calls the “present absence” of sex and gender in discussions of FM (p. 45). She highlights that while women live longer than men, they are disproportionally suffering from chronic ailments, pain, and dysfunction. The history of FM, women’s “somaticism”, and women’s relationships with the conventional biomedical system are entwined, tracing back to the late 19th century, and diagnostic classifications of hysteria and neurasthenia. While each disorder has its own

unique trajectory stemming from its particular historical context, the connections between both the symptoms and patient experiences of FM and CFS, and historical diagnoses of hysteria, and neurasthenia are significant. Each included pain, fatigue, headaches, cognitive difficulties, mood or emotional elements, bowel irregularities, and sleep disturbances. Women were also disproportionately diagnosed with these historical, and present day conditions, all of which are and were poorly understood, and subject to contested legitimacy, and imperfect treatments.

In their study examining the (often emotional) labour undertaken by women to be viewed as credible by healthcare providers, Werner and Malterud (2003) interviewed 10 women with chronic muscular pain. They found extensive research on the relationships between physicians and patients, most of them focusing on physician perspectives of—and coping with—so-called difficult patients. In their literature review, they found few studies which took gender and sexuality into account. Building on a foundational understanding of discrepant gender role expectations in society, and power imbalances in physician-patient relationships, Werner and Malterud argue that the biomedical model of disease and corresponding medical relationships are themselves gendered, where “concepts of dignity and shame highlight women patients’ management of gender, body, and sexuality in a broader sense, when consulting the doctor” (p. 1411). In exploring these themes, Werner and Malterud also associate themes of hegemonic masculinity in medicine, the welfare state, and living conditions for women living with chronic pain conditions.

Werner and Malterud (2003) interviewed participants about their medical encounters: whether their experiences had been positive or negative, how they had prepared for them, and activities during medical consultation, and focused on the gendered aspects of these interactions. Their findings reveal a great deal of work on the part of women patients

to be perceived as a “credible patient” (p. 1412), as well as broader struggles for self-esteem and dignity as patients and as women. Three dominant themes emerged around (a) appropriate assertiveness; (b) appropriate surrender; and (c) appropriate appearance. When discussing assertiveness, participants in these studies talked about conducting extensive research and consulting with multiple professionals to find out all they could about the condition, and described the strain of having to repeatedly explain their chronic, invisible condition. Some also talked about being assessed for mental, rather than physical, conditions. Many described the necessity of self-advocacy to ensure examinations were properly conducted, and referrals and treatments provided. Alternatively, participants also described the necessity of ending medical relationships, or surrendering to inadequate relationships because replacing them or protesting would do more harm than good. In these conditions, participants described discretely paying out of pocket for private practitioners to provide second opinions, keeping silent so as not to further exacerbate the problems, silently tolerating comments, and enlisting a male partner to advocate on her behalf. Finally, after repeated appearance-based comments such as “You don’t look ill,” and “You are so young,” (p. 1413) participants wondered about the impression they were making with healthcare providers. Rather than feeling like compliments, these comments prompted them to strategize around their appearance for appointments; they considered their clothing, their physical fitness, their make-up, and other appearance factors, not wanting to look “too strong” to be taken seriously as ill in their appointments.

Tied to the subject of appearance, several participants found that age had been a problematic factor; young age was seen as a disadvantage in diagnosis, treatment planning, and disability application, and middle-age was seen as a disadvantage in that the symptoms were attributed to menopause, or menopause was used to dismiss their symptoms as mental

in nature (Werner & Malterud, 2003). Many of these findings were also supported in the study by Juuso and colleagues (2014), summarized in their two themes: being seen as a malingerer, and being acknowledged. In their discussion, Werner and Malterud (2003) moved beyond the physician-patient dynamic, to consider the broader meaning and implication of women's health behaviours. They explored constant balancing and negotiating between impossible extremes. They highlighted the dual impact of legitimization and stigmatization through having one's moral characters called into question, in addition to being "psychologized" by healthcare providers—being illegitimated within a biomedical frame on the one hand or dismissed as having "mental problems" on the other.

Summary

Surveying the historical and current literature on FM and related conditions, and the state of healthcare service provision for chronic conditions, the complexity of the conversations around healthcare experiences for individuals with FM become apparent. FM is a condition that lies at the intersection of multiple social and medical debates. Where FM is concerned, the conventional biomedical model—which focuses on objective pathology to test, diagnose, and treat a condition—falters, but more holistic, collaborative, and integrative approaches appear to have much to offer.

Chapter 3:

Method

The literature on FM indicates that healthcare experiences related to this condition are characterized by uncertainty, confusion, and dissatisfaction—for helping professionals and individual sufferers alike (Asbring & Narvanen, 2003; Chen, 2012; Perrot et al., 2012). The few studies that have focused specifically on the healthcare experiences of people with FM demonstrate that continued investigation on this topic is needed to better understand what those accessing care find helping and hindering in order to improve quality of care (Briones-Vozmediano et al., 2013; Sims & Madden, 2008; Underland & Malterud, 2007).

History of the Enhanced Critical Incident Technique: CIT to ECIT

The roots of ECIT are in industrial and organizational psychology, where it was originally developed to analyze and identify critical requirements for successful role performance in a number of jobs in various industries, including its formative use in the Aviation Psychology Program in the United States Army Air Forces during World War II where it was used for selection and classification of aircrews (Butterfield et al., 2005; Flanagan, 1954). The Critical Incident Technique (CIT) was originally described by Flanagan (1954) as a set of procedures for systematically collecting data “in such a way as to facilitate their potential usefulness in solving practical problems and developing broad psychological principles” (p. 327). The method enables researchers to elicit critical incidents from accounts of factual happenings—what participants saw, heard, felt, and did that helped or hindered the phenomenon being studied.

The ECIT diverges from the CIT in some fundamental ways. Firstly, while CIT as explained by Flanagan placed an emphasis on direct, observable behaviour, its use has been expanded to applications based on retrospective self-report (Butterfield et al., 2005;

Butterfield et al., 2009; Flanagan, 1954). Secondly, in addition to pinpointing critical incidents, wish list items are also identified. Wish list items are “those people, supports, information, programs, and so on, that were not present at the time of the participant’s experience, but that those involved believed would have been helpful in the situation being studied” (Butterfield et al., 2009, p. 267). The addition of contextualizing questions at the outset of the interview to ground both participant and interviewer in a common understanding of the interview content has also been added (Butterfield et al., 2009). Finally, the ECIT aims to bolster the credibility of the research by incorporating nine credibility checks (Butterfield et al., 2005); these credibility checks will be outlined below in Step 5: Interpreting the Data and Reporting the Results.

Methodology

The ECIT was chosen as the methodology for the present study for a number of reasons. Although the CIT initially had a behavioural focus, it has since emerged as a means to furthering understandings of psychological experiences. In her paper describing the CIT, Woolsey (1986) outlined its strengths and applications to the field of counselling. She highlighted the flexibility of the method and its usefulness in the early stages of research on a given topic, in that it generates “both exploratory information and theory or model building” (p. 252). Woolsey also describes how the critical incident method can be applied to studies across a wide range of topics. Of particular relevance to the present study is the CIT’s usefulness in collecting data on relationships, decision-making, qualities or attributes, and identifying differences and turning points. Its combined ability to elicit descriptions of critical elements of job performance, as well as psychological experiences, makes it an excellent fit for a study of healthcare experiences, which pertains to both. Kemppainen (2000) also describes the appropriateness of the CIT in studying the quality of

healthcare services, stating that the CIT has been used effectively by health services researchers to “provide meaningful information about patients’ experiences in health care settings and to determine their views about health care services” (p. 1267), as well as to identify those behaviours on the part of health service providers that led to the satisfaction or dissatisfaction of service users. Its strengths in aiding the understanding of human interactions and experiences, decision-making, and experiences of healthcare settings all make the ECIT a fitting method for the present study.

The ECIT is an inductive method, described as being exploratory in nature and thus particularly suitable for studies aiming to generate information about under-investigated or little-known topics such as this one (Butterfield et al. 2005; Butterfield et al., 2009; Woolsey, 1986). Unlike other qualitative methodologies, which focus on describing phenomenon, the CIT was designed to be used in an applied manner, to assist in solving practical problems; its ability to identify specific helping, hindering, and wish list factors aligns well with the needs and design of the present study and will make it useful for analyzing the complex factors relating to helping and hindering experiences of healthcare services and identifying areas for quality improvement (Flanagan, 1954; Kemppainen, 2000). While the method is reductive in its nature and will not retain all of the subjective detail of some other qualitative methods, it is designed to build descriptive categories that can be pragmatically used, which makes it a fit for this type of healthcare study allowing for tangible recommendations for changes based on the research findings.

Finally, given that research findings on FM frequently describe how undermined and invisible individuals with this condition tend to feel (Juuso et al., 2014; Le Page, 2005; Sim & Madden, 2008), a qualitative interview method was desired that would be flexible and would enable participants to tell their story in a meaningful way. The flexibility

offered by the semi-structured interviews of ECIT are consistent with the values and skills of counselling psychology and have been found to be applicable more broadly to other healthcare professions (Kemppainen, 2000; Woolsey, 1986). Additionally, since this method only requires that the same content areas be covered in each interview—but not in the same order—the interview format was deemed flexible enough to provide a respectful and accessible experience for participants should they need to pause for a break during the interviews.

Recruitment of participants

A total of 14 ($n = 14$) adult women and men from the Lower Mainland who had been diagnosed with FM participated in the present study. The primary inclusion criterion was that participants must have received a formal diagnosis of FM; details about inclusion criteria and the participant screening process will be outlined below in the ECIT methodology description. Since participating individuals were required to have received an FM diagnosis, the sampling procedure was non-probabilistic and purposive.

Participants were recruited through a combination of approaches. First, recruitment letters (Appendix A) outlining the proposed study were emailed to the researcher's professional contacts and social network, as well as a number of relevant organizations across the Lower Mainland (e.g. Pain BC, Change Pain, Women's Health Collective, and the ME / FM Society of BC). Contacts were asked if they would be willing to send an introductory letter (Appendix B) to anyone they knew who might be interested in participating; contacts were also provided with a recruitment poster and asked if they would be willing to place the poster in their place of work for prospective participants to see. Emails were sent out in June 2016 and a first round of interviews were conducted between July 2016 and October 2016. Further recruitment emails were sent out in March 2017,

along with recruitment posters posted on relevant social media sites and the researcher's social media pages. Additional interviews were conducted between March 2017 and May 2017. Snowball sampling also occurred, as a number of participants shared the recruitment information among their networks. Prospective participants contacted the researcher by phone and email, with a total of 23 individuals expressing interest in participating in the study. Further details will be provided in the description of data collection procedures. Among the recruitment avenues, the researcher's personal and professional networks yielded 12 prospective participants, social media recruitment yielded another six, and five prospective participants were reached through snowball sampling; no participants were obtained through related organizations. For confidentiality, the researcher was not provided with identifying information about the individuals to whom the recruitment information was sent.

Given the often stigmatized nature of FM, significant attention was placed on the ethics of privacy and confidentiality, and accessibility throughout this process. All interviews were scheduled for at least one week post the initial contact, and a reminder phone call or email was offered. This was to allow participants the opportunity to further reflect on participation and withdraw if desired. Participants were reminded of the nature of the interview when selecting an interview location; to accommodate their access needs as well as privacy, participants were encouraged to select somewhere they would feel physically and emotionally comfortable. Transparency was used with participants around recognizing the fluctuating and often unpredictable nature of FM, and their right to withdraw or reschedule as needed—without needing to provide an explanation—was emphasized. The researcher also informed participants of the interview process and had individual conversations about how accessibility needs might be addressed together,

including the ability to pause or stop the interview, and that participants could meet in their own homes to eliminate travel impacts. Prior to meeting, participants were given a verbal overview of the study, and sent a copy of the study consent form by email; participants were also offered a summary of the interview questions in advance as desired.

Data Collection Procedures

The ECIT is conducted in five steps, which were adhered to as outlined below. Once the research focus and questions were identified, and ECIT was deemed to be an appropriate method, the steps were as follows: (1) ascertaining the general aims of the activity being studied; (2) making plans and setting specifications; (3) collecting the data; (4) analyzing the data; (5) interpreting the data and reporting the results. The fifth step included nine credibility checks to increase the trustworthiness of the results (Butterfield et al., 2005; Butterfield et al., 2009; Flanagan, 1954).

Step 1: Ascertaining the General Aims of the Activity Being Studied. The first step of the ECIT is “ascertaining the general aims of the activity being studied” (Butterfield et al., 2009). This step can be fulfilled by answering two questions: (a) what is the objective of the activity, and (b) what is the person expected to accomplish who engages in this activity? (Butterfield et al., 2005; Butterfield et al., 2009). The primary purpose of this research is to identify what helps, what hinders, and what might be helpful if it were available for people with FM when accessing healthcare services: those factors, strategies, behaviours of others, or services that are experienced as helpful or hindering as they navigate their healthcare experiences with this complex chronic illness. These facilitators and barriers were explored with an aim to inform healthcare providers working with this patient population.

According to the research, people accessing healthcare for FM are often seeking a combination of outcomes from their experiences: information, such as diagnosis, understanding symptoms and causes, and treatment options and recommendations; support, including validation and compassion; and treatment, including symptom reduction and management, and restoration of function (Egeli et al., 2008). Healthcare experiences are complex, encompassing a number of intersecting facilitators and barriers including adequate supply to meet the demands for services, which are subsequently mediated by affordability, physical accessibility, and adequacy of services (Gulliford et al., 2002). Participants were chosen for their experiences accessing healthcare services with FM.

Step 2: Making Plans and Setting Specifications. Upon being contacted by a prospective participant, the researcher determined eligibility based on the following screening questions:

1. Based on the literature review of FM, receiving diagnosis can be challenging and individuals can live with symptoms and tentative diagnoses or self-identify as having FM for years before receiving a formal diagnosis, which was described as a very different stage in the illness process from having a formal diagnosis (Lempp et al., 2009). For this reason, the primary inclusion criteria for the study was: “Have you received a formal diagnosis of Fibromyalgia?” This question was used to ensure that the participant was diagnosed with FM, the focus of the study.
2. “Are you 18 years old or older?” “How old were you when you received this diagnosis?” These questions were used to ensure all participants were adults, and diagnosed as adults. While Juvenile Fibromyalgia exists, FM is generally described as a condition of “middle age” and more commonly diagnosed among

adults (Johnson, 2008). Participants were required to be over the age of 18 and have received diagnoses in adulthood, to control for possible differences in juvenile and adult experiences with FM.

3. “Do you have any co-occurring conditions?” FM is frequently associated with a number of accompanying conditions including sleep disturbance fatigue, anxiety, depression, gastrointestinal symptoms, headache, CFS, IBS, irritable bladder, interstitial cystitis, temporomandibular joint disorders (International Association for the Study of Pain, 2003). Because these conditions so frequently overlap with FM, and by some definitions are part of the “syndrome” of FM, participants with these associated conditions were not excluded. Non-associated conditions were explored further for severity and current management to determine eligibility. Individuals with non-severe, and well-managed co-occurring conditions were discussed with the researcher’s supervisor to determine inclusion.
4. “Are you able to meet in person for an interview of one to two hours?” This question was designed to identify participants for whom an in-person interview would not be feasible, or for whom the duration of the interview might be a barrier. Remote interviews were excluded from the present study since the CIT has been found most effective with an in-person interview format (Butterfield et al., 2009).
5. “Do you read, write, and speak English fluently?” This question was designed to ensure that participants were able to understand the informed consent form, able to provide written consent to participate in the study, and able to understand and respond to the oral interview questions.

Additional details. All efforts were made to include participants across age groups, years with FM symptoms and diagnosis, and gender identities. These factors influenced which participants were offered an interview, versus placed on a wait-list. While diversity of ages and years with symptoms and diagnosis were achieved in the present study, it was challenging to find a gender diverse population.

All but one prospective participant was deemed an applicable participant for the present study. The individual who was screened out lived out of the country, and could not meet for an in-person interview. One participant had a co-occurring condition and should have been screened out at this stage, but wasn't identified by the researcher until the interview. The interview protocol was followed for this participant, and all efforts were made to focus on this participant's healthcare experiences with FM exclusively. This participant's results were analyzed independently and were going to be included as a "special case", however, her data were found to contain the same themes as the other participants. This was determined by placing the participant's incidents into the existing categories once all other data had been analyzed; since no new themes emerged from this process, it was decided to incorporate this participant's data into the general results. Three individuals were placed on a wait-list; two prospective participants agreed to participate but had to withdraw (one due to FM symptoms, the other for reasons undisclosed), and three were provided further information and did not follow up to schedule an interview.

The researcher developed an interview protocol (Appendix D) to ensure consistency in the content areas explored across interviews, as well as to facilitate the identification of critical incidents and wish list items, and supporting details for each item, during interviews.

Interviews began by building rapport; putting the participant at ease; reviewing informed consent, including reminding the participant that they could withdraw from the study at any time; completing the study consent form (Appendix C); and reviewing the purpose of the study and describing the structure of the interview process. Next, the participants were asked to complete a demographics questionnaire (Appendix E), which the researcher offered to scribe for participants if they preferred. Participants were reminded of their right to leave questions blank at their discretion, and similarly could pass on questions during the oral interview. Informed consent also involved consideration of the unique needs of the participants, based on the ways they are impacted by FM. Because FM involves intense chronic pain and (often) chronic fatigue among other symptoms, lengthy interviews may be particularly challenging for participants. Participants were reminded that they could pause the interview to take breaks as needed, and could stop the interview at any time; no participants chose to stop the interview once begun.

Of the 14 participants, 12 identified as female and two identified as male. Participants ranged in ages between 22 and 76 years old. Participants had lived with FM symptoms between 1.5 to over 50 years, and had an FM diagnosis for between less than one year to 36 years. Eight participants disclosed that they were not currently working due to FM symptoms, while six participants were currently working or in school; all participants stated that their work status was impacted by FM symptoms. All participants had some form of post-secondary education. An oversight in this study was the omission of the inquiry about participant ethnic background. Table 1 provides a summary of participant characteristics.

Table 1

Summary of participant demographic information

Demographics	Participant information
Gender	Female = 12 Male = 2
Age (in years)	Range = 22 – 76 Mean = 48.5 Median = 50
Years with symptoms	Range = 1.5 – 50+
Years with diagnosis	Range = less than 1 – 36
Work status impacted by symptoms	All
Employment status	Not working = 8 Working / In school = 6
Education	Some college/university = 3 Undergraduate degree = 7 Graduate degree = 3 Doctoral degree = 1 (currently enrolled)

Table 2 provides a more detailed breakdown of how participants' work statuses have been impacted by FM symptoms.

Table 2

Summary of participant work status

Work status	Years since employment	Impact on work status
On disability	4	Lost employment due to symptoms.
On disability	5	Lost employment due to symptoms.
On disability	6	Lost employment due to symptoms.
On disability	6	Lost employment due to symptoms.
On disability	19	Medically discharged. Unable to work.
On disability	22	Unable to work.
Part-time	1 since full time	Job search impacted by symptoms. Job loss possibly accelerated by undiagnosed pain.
Part-time; Self-employed	N/A	Previously unable to work. Previously left employment due to symptoms.
Self-employed; Flexible schedule	N/A	Lost employment due to symptoms. Self-employment allows flexible schedule.
Part-time; Multiple jobs	N/A	Unable to work single full-time job.
Full-time; Student	N/A	Transitioning to part-time studies due to symptoms. Previous medical leave. Symptoms impact productivity.
Self-employed; Full-time	N/A	Structured work life to minimize impacts of illness
Full-time; Contract	N/A	Job search impacted by symptoms.
Full-time	N/A	Unpaid sick days due to symptoms.

In the demographics form, participants were asked about treatments and services used, based on frequently cited healthcare services used for FM (Fitzcharles, et al., 2012; International Association for the Study of Pain, 2003; International Association for the Study of Pain, 2010). Table 3 shows a summary of forms of treatment or services participants had tried, and were currently using at the time of their interviews.

Table 3

Summary of participant treatment history

Treatment history	Number of participants tried	Number of participants still using
Medication	12	10
Physical rehabilitation / Physiotherapy	10	5
Exercise / Personal training	12	6
Naturopathy / Natural medicine	6	3
Yoga	9	3
Chiropractic treatment	9	0
Psychological counselling	10	3
Massage therapy	10	3
Occupational therapy	5	0
Pain management (integrative program)	11	4
Marijuana	7	4
Meditation / Mindfulness	9	7
Acupuncture	7	0
Psychiatric treatment	5	0
Other:		
Infrared sauna	1	1
Aromatherapy	1	1
Education	1	0
Hydrotherapy	2	1
Pilates	1	0
Osteopathy	1	0
Intramuscular stimulation	2	0
Dietary changes	2	1
Supplements	1	1
Academic accommodations	1	0
Rheumatologist	1	1
Additional specialists	1	0
Traditional Chinese medicine	1	0
Hallucinogenic substances	1	1

Once informed consent and demographics questionnaire forms were completed, the oral interview started by collecting contextual data, as described by Butterfield et al. (2009). These contextual data provided a foundation for understanding the context in which the critical incidents occurred. The following contextual questions were asked:

1. “As a way of getting started, I’d like to go back to the beginning. Tell me briefly how long have you had FM and what you first noticed happening for you?”
2. “Who did you first go to when you became concerned about your health? What were those early experiences like for you?”
3. “Tell me about receiving a diagnosis for FM. When and under what circumstances were you diagnosed?”

These questions were designed to begin developing rapport with the participant, and allow the person to begin telling their story and feel heard before expanding on helping and hindering factors (N. Amundson, personal communication, March 17, 2016). These questions were informed by the literature that demonstrated that patients frequently feel they don’t have an opportunity to tell their story in healthcare contexts, and desire the opportunity to be heard and treated as a whole person (Egeli et al., 2008).

Subsequently, the critical incident portion of the interview was explored. Following the trajectory of the contextualizing portion of the interview, the researcher asked participants about hindering incidents first. Follow up probes and questions were used, consistent with CIT, to elicit further information describing the importance and a specific example of each incident. In addition to adding richness, these details provide trustworthiness to the data, by fulfilling the criterion for accuracy of retrospective self-

report. As stated by Butterfield et al. (2005) based on findings by Flanagan (1954) and Woolsey (1986), “If the information provided is full, clear, and detailed, the information is thought to be accurate” (p. 481). The critical incident portion of the interview began with the prompt, “Tell me about an unhelpful healthcare experience related to FM that really stood out for you.” To elicit hindering incidents, the researcher further explored: “How was it unhelpful? What contributed to the unhelpfulness of that experience?” and probed for more detail by asking “How did it impact you? Can you give me an example of how it was hindering?” The same process was followed for helping incidents, first with the statement “Tell me about a helpful healthcare experience related to FM that really stood out for you,” and exploring supporting details. The final component of the critical incident interview involves eliciting wish list items. This was accomplished by asking the questions “Is there anything that wasn’t available or didn’t occur that you think would have been helpful?”

The researcher conducted two pilot interviews. The first generated feedback that the researcher’s probes focused too heavily on identifying a timeline of events and specific kinds of practitioners the participant interacted with, rather than critical incidents about what was found to be hindering and helpful to the participant. As a result, the data from the first pilot interview were not incorporated in the results of this study. The researcher adjusted the kinds of probes used in order to focus on the critical incidents. The interviewer conducted a second pilot interview, and received feedback that the questions were understandable, allowed the participant to describe what was meaningful to them, and elicited the kind of information the researcher had hoped for from these interviews. Because this interview elicited rich responses and accomplished the purpose of the study, these data were included in the study results.

Step 3: Collecting the Data. As described above, data collection for all 14 participants took place through in-person interviews. All interviews were conducted by the researcher, for the purpose of consistency and adherence to the interview protocol, and also because this allowed the researcher to stay involved with and familiar with the data collection process. Of the 14 participants, 12 chose to meet in their homes, one chose to meet on UBC campus, and one chose to meet in a coffee shop. As emphasized by Butterfield et al. (2009), rapport between the participant and the interviewer is key so that participants feel comfortable and heard, and are open in telling their stories. Interviews began with building rapport, reviewing consent and the interview process, and answering participant questions. The consent forms were signed by both participant and interviewer once the participant's questions had been satisfactorily addressed, and participants were given a copy of the consent form for their records. Participants were also offered a summary of the interview guide to follow along if they desired. The interviews concluded with an open invitation to contact the researcher with any additional incidents or wish list items, or should any questions arise subsequent to the interview. All interviews were audio-recorded, supplemented by hand-written notes by the researcher.

During their interviews, many participants expressed appreciation that research was being conducted about the healthcare experience of individuals with FM, and hoped that this research could improve circumstances for others; this was often paired with a wish to see more of such research taking place. A list of local counselling and pain related resources were compiled and made available for participants, in the event that the interview elicited strong emotional reactions.

Following feedback from the first interview fidelity check (outlined in Step 5: Interpreting the data and reporting the results) after the first batch of three interviews, the

researcher began incorporating summaries at the end of each interview section, an emerging approach to ECIT interviews (N. Amundson, personal communication, August 17, 2016) inspired by the work of Gilligan, Spencer, Weinberg, and Bertsch (2003) on the “listening guide”. Using this approach, the researcher summarized the incidents identified by the participant at the end of the hindering, helping, and wish list sections of the interview. These summaries served the triple purposes of verifying understanding of participant experiences; prompting recall of missing incidents and ensuring completeness of interview sections; and tracking the emergence of categories over the progression of the interview phase of the study. Incorporating these summaries did not impact the interview protocol, and added credibility to the process. Because the ECIT allows for some flexibility to ensure a natural flow of conversation this method actually supported the interview protocol, in ensuring the same content areas were covered in each interview.

With ECIT, interviews with participants continue until exhaustiveness is reached in the data. While exhaustiveness was achieved after seven interviews, the researcher elected to continue interviews to enhance credibility, in part due to the heterogeneous nature of FM. This also fulfils the additional trustworthiness criteria recommended by Amundson, Borgen, & Butterfield (2014), where additional interviews are recommended amounting to a minimum of half the original number of participants.

An interview protocol was developed for the second interview with participants to fulfil to the seventh of the credibility checks outlined below (Appendix F), based on the questions outlined by Butterfield et al. (2009):

1. Are the helping/hindering CIs and WL items correct?
2. Is anything missing?
3. Is there anything that needs revising?
4. Do you have any other comments?
5. Do the category headings make sense to you?

6. Do the category headings capture your experience and the meaning that the incident or factor had for you?
7. Are there any incidents in the categories that do not appear to fit from your perspective? If so, where do you think they belong?

These questions are designed to get the participant's input on the critical incidents and wish list items extracted from the initial interview, enlist the participants' feedback about the categories and placement of critical incidents and wish list items, and follow up on questions that emerged about the data from the participants' first interview. They are also a way of ensuring that participants' stories are honoured, and represented accurately (Butterfield et al., 2009).

The second interviews were conducted between two and 10 months after the participant's initial interview. Of the 14 participants interviewed, 10 participated in the cross-checks. Two participants were unavailable for cross-checks due for FM related reasons, one participant could not be reached by any of the contact information the researcher had and further attempts to reach them would have breached confidentiality, and the fourth was unavailable for reasons not disclosed. Of the 10 cross-checks conducted, four participants requested to meet in person, three chose to meet by phone, and three corresponded by email.

Step 4: Analyzing the Data. According to Flanagan (1954), "The purpose of the data analysis stage is to summarize and describe the data in an efficient manner so that it can be effectively used for many practical purposes" (p. 344). This process is described as encompassing three steps: (a) selecting the frame of reference; (b) developing the categories; and (c) establishing the level of specificity or generality to be used in reporting the results (Flanagan, 1954; Woolsey, 1986).

All interviews were audio-recorded, and were transcribed verbatim from the recordings. Transcripts were anonymized, and identified by participant number. The interviews were analyzed using Atlas.ti qualitative data analysis and research software for Mac (version 1.5.4). Before coding, the researcher first read each transcript carefully to familiarize with the participant's individual perspective, content, and the meaning of the statements to the participant. Next, the researcher re-read the transcript, coding anything that appeared to be a critical incident. All initial codes were then re-examined to determine whether the event was sufficiently complete, clear, and its consequences related to the purpose of the study, in order to qualify as a critical incident according to Flanagan's (1954) definition:

By an incident is meant any observable human activity that is sufficiently complete in itself to permit inferences and predictions to be made about the person performing the act. To be critical, an incident must occur in a situation where the purpose or intent of the act seems fairly clear to the observer and where its consequences are sufficiently definite to leave little doubt concerning its effects (p. 327).

Events that did not meet these criteria were noted for follow-up in the participant cross-check for further exploration, and excluded from the final results if these criteria were not met.

Incidents were then divided into three parts, using the process described by Butterfield and colleagues (2009): the context of the incident, the [healthcare] experience described; and the meaning of the incident to the participant, i.e. why the incident was helpful or unhelpful. This process helped clarify the actual incident being described, and thus facilitated grouping them together into categories.

The purpose of the present study was to understand the factors, strategies, behaviours of others, or services that are experienced as helpful or hindering to people with

FM accessing healthcare services. The incidents were grouped using an iterative process until descriptive categories naturally emerged which identified actions on the part of the participant or healthcare provider, services, and policies, which participants found to be hindering or helpful, or wished had been available for them. An initial 43 categories were identified, and were verified using the credibility and trustworthiness checks outlined in the following section. The researcher later re-evaluated the level of specificity-generality of the categories with one of her committee members, and determined that while the level of specificity of the original category scheme was deemed fitting to the participants and experts consulted for the present study, the number of categories were too great to be practically valuable to a healthcare provider wanting to incorporate this information to improve their service provision.

Since the ultimate aim of CIT data is its effective use for practical purposes, the researcher opted to consolidate categories to make them more practically applicable; the 16 categories presented in the following chapter are the result of this process, where categories have been consolidated across hindering, helping, and wish list themes. A chart demonstrating how the original categories map against the final category scheme has been included in the appendices (Appendix G). Because the original categories were grouped together in ways that maintained their original structure, and are contained as subthemes within the broader categories, the researcher considers them to still be reflective of the categories discussed with participants and experts during the credibility checks.

Step 5: Interpreting the Data and Reporting the Results. This step incorporates nine credibility checks to increase the credibility of the research outcomes, particularly in cases such as this where the study is based on subjective perceptions of an experience as opposed to direct behavioural observations (Butterfield et al., 2009). Butterfield et al.

(2009) identified nine credibility checks to increase the trustworthiness of ECIT studies. These nine credibility checks, and the procedures used to fulfil them in the present study, are outlined below.

Audiotaping interviews. Interviews were audio-recorded to preserve accuracy of the participants' personal accounts. Interviews were then transcribed verbatim from the audio recordings.

Interview fidelity. Interview fidelity checks were conducted to ensure the interviewer followed the ECIT method as intended, such as following the interview guide, and not asking leading questions or prompting the participant. The researcher selected a colleague who had conducted an ECIT study for her master's thesis for this credibility check, based on her familiarity with the ECIT method and interview process, as well as her understanding of confidentiality procedures. This colleague listened to every fourth interview conducted, and provided feedback to the researcher to add to the credibility of the interview process, and help increase consistency of the interviews conducted.

Independent extraction of critical incidents. This credibility check provided a secondary confirmation of the critical incidents, wherein 25% of transcripts were randomly selected to be reviewed by an independent coder. This secondary coder extracted what he believed to be the critical incidents and wish list items, which the researcher then compared with her own extracted incidents. The researcher selected a colleague currently conducting research in his Doctoral program using the ECIT, and was selected for his familiarity with the method and coding process, as well as his understanding of confidentiality procedures. The results of the independent extraction were compared with the researcher's extraction of critical incidents to determine the level of agreement. All discrepancies between the two coders' outcomes were discussed and resolved. Five discrepancies related to incidents

identified in the independent extraction that were not directly related to the research question; these incidents were not used in further analysis. Four more discrepancies were differences in the determination of whether or not an incident was helping, hindering, or wished list; these items were flagged for review in participant cross checks.

Exhaustiveness. Critical incidents and wish list items were logged throughout the categorization process, to track the emergence of new categories and determine the point of exhaustiveness in the data. According to this credibility check, when no new categories emerge as critical incidents and wish lists are placed into categories, exhaustiveness is achieved; in this study, exhaustiveness was achieved after seven interviews. As mentioned above, interviews were continued after this point for two reasons. The researcher chose to honour interviews that were in the scheduling process, or had already been scheduled; further, these additional interviews fulfilled the additional exhaustiveness criterion recommended by Amundson, Borgen, and Butterfield (2014). This additional exhaustiveness criterion recommends that researchers reach exhaustiveness, and then do a minimum of half again the number of interviews.

Participation rates. Reporting participation rates contributes to establishing the credibility and strength of a category. Participant numbers were included along with each critical incident during the formation of categories to facilitate this process; participation rates were calculated by totaling the number of participants who indicated an incident in a given category. A minimum 25% participation rate was required in one of the helping, hindering, or wish list segment for each category, which was achieved or exceeded in all categories.

Placing incidents into categories by an independent judge. For this credibility check, incidents are placed into categories by an independent judge. The independent

judge is given a random selection of 25% of incidents from each category, along with the category headings and operational definitions, and asked to place each incident where they think it best belongs. The researcher selected a colleague who was also conducting her master's thesis research using ECIT to fulfil this role. The researcher compared her results and those of the research consultant for this credibility check, and the agreement of 83% met the match rate guideline of 80% or better. Discrepancies were discussed and resolved through reviewing the contextualizing details for discrepant incidents.

Cross-checking by participants. Participant cross-checks were conducted as described in Step 3: Collecting the Data, to incorporate participant perspectives on the interpretations drawn throughout the data analysis process. This credibility check creates the opportunity for further participant involvement, to ensure their stories and voices are accurately and respectfully represented; once the data was coded, analyzed, and categorized, participants were contacted for verification, revisions, or additions if desired. Three critical incidents were added by participants at this stage.

Expert opinions. Categories titles and operational definitions were submitted to two experts to determine congruence with their experience and knowledge of the field. Two experts were consulted for the present study: a clinical psychologist who specializes in pain management and works in an interdisciplinary setting, and a physiotherapist with clinical and research experience with chronic pain, who works in a multidisciplinary setting. Both experts were chosen for their expertise in working with chronic pain and complex chronic conditions, as well as for their experience with interprofessional collaboration across disciplines. When reviewing the categories, they were asked the following questions, suggested by Butterfield et al., (2009):

1. Do you find the categories to be useful?

2. Are you surprised by any of the categories?
3. Do you think there is anything missing based on your experience?

Both experts reviewed the categories and operational definitions and described them as useful, and congruent with their experience in the field, the needs of the patients and clients they work with, and considered them useful in guiding the care of individuals with FM. Additionally, both indicated they were pleased to see how “comprehensive” the results of the study were.

Theoretical agreement. In this final credibility check, the scholarly literature related to the topic was reviewed to determine theoretical agreement of the research findings with the literature. The discussion of theoretical agreement will be outlined in Chapter 5: Discussion.

Ethical concerns. In reporting the results of the present study, additional precautions were considered in protecting participant confidentiality given that individuals with FM already belong to a vulnerable population. Participants disclosed deeply personal aspects of their lives, and many shared stories of maltreatment on the part of employers and healthcare providers. While they expressed a shared desire for their stories to contribute to the improvement of treatment for others living with FM, participants also described a desire for aspects of their stories to remain anonymous for their own security. With this in mind, the protection of identities was prioritized, including anonymizing data including fields of work or study, and healthcare providers, and quotations were omitted that could lead to the identification of a participant.

Chapter 4:

Results

This chapter outlines the results of the ECIT analysis of the 14 interviews conducted with participants. From these interviews, 528 critical incidents—factors, strategies, behaviours, or services participants found to be hindering or helpful in their experiences of accessing healthcare services—were identified, including 297 hindering incidents, 231 helping incidents, as well as 90 wish list items, those items which participants would have found helpful had they been available. All incidents were sorted into 16 categories that consolidate helping, hindering, and wish list items across themes. Operational definitions and examples of incidents from each category are provided to illustrate each category. The categories are grouped into environmental / systemic factors, interpersonal factors, and individual factors, and presented hierarchically: first according to highest participation rate (percentage of participants who identified an incident in this category), then by frequency (number of incidents identified in this category), from most frequent to least. Hindering incidents are presented first for each category, followed by helping incidents, and then wish list items. This organizational structure was chosen because it was most consistent with and reflective of how participants shared their stories.

Categories identify common incidents across participants; however, these groupings are not meant to be rigid classifications since many categories and incidents contained overlap or were interrelated. This was found to be particularly true in the identification of wish list items, where participants tended to describe desired changes integrating unmet needs across a number of categories. Despite these overlaps in content, these themes have been reviewed and endorsed by participants and experts in the field, and have been deemed distinct and descriptive of aspects of healthcare experiences with FM that were thought to

be useful to address individually. Additionally, while higher participation rates or more incidents demonstrate common experiences, they do not necessarily mean that a category is more important to the participants—each incident holds its own intrinsic value. Table 4 provides an overview of the categorization of results, including incident frequency (number of times an incident in a given category occurred) and participation rate (number and percentage of participants who endorsed an incident in a given category) for hindering, helping, and wish list aspects of each category. The 16 categories were also subcategorized according to sphere of impact, with seven categories relating to environmental or systemic factors, five categories relating to interpersonal factors, and four categories relating to interpersonal factors.

Table 4

Categorization of results

Category	Hindering Incidents	Number of Participants	Helping Incidents	Number of Participants	Wish List Items	Number of Participants
	297	(% of total)	N = 231	(% of total)	N = 90	(% of total)
Environmental / Systemic factors						
1: Financial and economic security and affordability	31	14 (100%)	11	8 (57%)	6	6 (43%)
2: Clinical understanding of FM	30	14 (100%)	13	10 (71%)	17	9 (64%)
3: Accessibility and flexibility	23	13 (93%)	16	9 (64%)	11	7 (50%)
4: Continuity of care	26	10 (71%)	22	11 (79%)	7	4 (29%)
5: Prejudice	17	9 (64%)	/	/	2	2 (14%)
6: Diagnosis making	15	9 (64%)	12	8 (57%)	2	2 (14%)
7: Models of healthcare delivery	20	8 (57%)	17	8 (57%)	20	11 (79%)

Table 4 (cont'd)

Category	Hindering Incidents	Number of Participants	Helping Incidents	Number of Participants	Wish List Items	Number of Participants
	297	(% of total)	N = 231	(% of total)	N = 90	(% of total)
Interpersonal factors						
8: Validation	32	13 (93%)	15	11 (79%)	/	/
9: Therapeutic alliance	21	11 (79%)	41	14 (100%)	13	9 (64%)
10: Iatrogenic suffering	15	9 (64%)	/	/	1	1 (14%)
11: Informed consent	9	5 (36%)	/	/	/	/
12: Counselling and psychotherapy	6	5 (36%)	11	7 (50%)	4	4 (29%)
Individual factors						
13: Medication and medical marijuana	21	11 (79%)	11	9 (64%)	2	2 (14%)
14: Internalization of adverse healthcare	20	10 (71%)	/	/	/	/
15: Exercise and physical activity	11	8 (57%)	6	6 (43%)	/	/
16: Active coping and social support	/	/	56	14 (100%)	5	4 (29%)

Environmental / Systemic factors

The following categories relate to environmental or systemic factors, impacting participants' experiences of accessing healthcare services for FM.

Category 1: Financial and economic security and affordability. This category pertains to hindering and helping financial and/or economic factors in accessing healthcare. Many of the hindering and helping incidents in this category were interconnected; for example, navigating financial aid and benefits systems leads to stress, as does inadequate financial support and barriers to continued work. At the same time, participants described the financial aid and benefits they do receive as creating some stability, which is essential to their wellbeing, particularly in situations where ability to continue working have been threatened. Within this category, two sub-themes emerged around the presence or lack of

opportunities to establish financial stability, including access or barriers to financial support, and the affordability of treatments and services.

P4: I would say that one of the biggest consequences of the FM is the financial consequences were pretty horrendous for me. I tried to get disability and it wouldn't fly. The medical system wouldn't validate that as a disability, they said I had a pre-existing condition. And I said, "How could I have had a pre-existing condition, I didn't actually have any kind of a diagnosis, and now you're saying, 'Yeah, but you were always feeling that way because we've got a record here that says you reported having these symptoms, so it's a pre-existing condition.'" So there turned out to be a settlement, but it wasn't very much. It certainly wasn't two thirds of my income, let's put it that way. ... I took a couple of months off of work totally. And I wish I could say it did me a lot of good but it didn't. I ended up going back to work, and things were really deteriorating as far as my ability to function. I was just so demoralized and I felt like I didn't fit anymore. I was square peg in a round hole and, so when the opportunity came to get bought out I was so happy. I thought, "Finally I can get out of this situation."

P7: There's not really any support. They can tell you to stretch and do exercise, but the reality is I have to figure out a place to live, I have to do all the paperwork for the medical system, I have to feed myself, I have to do all of these things that for anyone else they just do it, but getting groceries for me like could throw me out. And that comes in with the financial aspect. When you don't get answers for eight months, you've got to make it that eight months, you know?

Hindering incidents (100% participation rate; 31 incidents). All participants described financial barriers as playing a hindering role in their healthcare experiences. In this category, participants identified the adverse financial consequences of FM, compounded by the stresses of navigating financial aid systems, including repeated assessments to qualify for and maintain healthcare benefits, assumptions about malingering, insufficient financial support from benefits programs, and paying for costly out-of-pocket services. These two sub-themes were often connected in that participants described having access to limited financial aid in addition to limited coverage for needed services at which point appointments would have to be paid for out of pocket. To that end, descriptive quotations have been selected that demonstrate the interrelatedness of the sub-themes:

Financial support (e. g. medical benefits, disability benefits, extended health coverage, medical leave), and Affordability of treatments and services.

P14: It's a terrible choice to have to make. I felt that way when I had to choose [to change medications] ... It's not that the province is saying I won't pay for your meds, it's that the province is saying we're not going to pay for this thing you need to have any quality of life. I was really, really lucky that the [medication covered by healthcare] worked, because if it didn't, I would be paying a lot of money for those meds out of pocket. Or I would be stuck in jobs that provide benefits. That's the other conversation I have with myself all the time... Even if I am in a job that isn't satisfying or isn't healthy for me if I have benefits through it, or even if working as much as I am working has direct negative consequences on my health, I can't leave that job or work. ... I just don't think that the income assistance that is available for folks who have chronic illness is all that helpful. If I were to spend all the time that I should and want to spend on my health, I would have to be very poor, and very much dependent on a system that doesn't treat people with disabilities well and doesn't give them enough support, enough money to survive.

P13: Until I was able to access a free physio, physio was not an option for. It was limiting before I had to stop working too. I was spending upwards of \$500 a month on uncovered stuff. It was half my cheque I was spending on medical coverage, I never had savings. I was using my whole check to pay for food and rent and medical stuff and I had nothing left. And that was even when I had a decent job like I should have had better places to live and been able to do more things, or buy more things, but everything was getting dumped into my health care. ... I would max out my med coverage and my and extended benefit coverage for physio, massage, chiropractic, and I maxed all them out between three and six months into the year. And then had to pay everything out of pocket after that.

Helping incidents (57% participation rate; 11 incidents). While financial barriers were described as hindering or even traumatic, the existence of financial aid was described as being essential to participant wellbeing. A number of items in this category feature address the struggles of economic viability and maintenance of quality of life that speaks to how challenging life is when employment is threatened due to disability.

P6: I was offered medical leave. And of course, medical leave was like this incredible gift. 'Somebody's giving me this?!' I was drowning. That saved my life, honestly. Because there was no way I could have continued under the stress I was under.

P8: The initial medical leave showed me that they were willing to support me, that they stood behind me and stood behind my diagnosis. Because dealing with an

insurance company is no small feat. ... They were assisting with paperwork, and signing off on a yearly basis.

P12: I lost my way of living and my family relationship changed. My depression increased trying to wait for disability. The money train was off. I couldn't do it anymore. I had private insurance and that was the only thing that really saved me.

One participant also described how healthcare providers offered discounted services and barter systems to make services affordable that she would otherwise not have been able to access.

P13: I only access massage through a friend who is a massage therapist. He swaps cross stitch for massage. ... If it weren't for [him] being open to trades like that I wouldn't have access to massage at all.

Wish list items (43% participation rate; 6 incidents). The wish list items in this category reflect many of the sub-themes outlined above. Participants shared desires for financial aid that allowed for a better quality of life, and more specifically, that enabled them to access the healthcare services they needed in order to achieve it. A notable finding emerged in terms of participants' wishes for CAM to be more financially accessible. (This issue will be further addressed in Category 7: Models of healthcare delivery.)

P14: If disability [funding] was more accessible [that would be helpful]. So that means: if it were easier to get on, if it actually paid for the cost of living, if you could go off and on it more easily—because sometimes I do better than other times, sometimes I am healthier than other times—if you could make more money while still maintaining your disability payments, if you could have “disability sabbaticals”—like going to work for four months, have a month to recover from that, work for four months, have a month to recover—then I could make these decisions about my health and not have to worry about not paying the rent or being financially ruined for it.

P12: I'd like to see more financial support for alternative healthcare. It costs a lot of money to get the therapies I need.

Category 2: Clinical understanding of FM. This category pertains to incidents where participants described presence or lack of belief in the legitimacy of FM as a

diagnosis, and subsequent presence or lack of understanding about FM in medical interactions.

Hindering incidents (100%; 30 incidents). The concern about clinical understanding of FM was shared by all participants, who perceived that doubts about the existence of FM and poor understanding of FM and chronic pain on the part of healthcare providers negatively impacted the care provided. Incidents in this category include examples of healthcare providers' disbelief in the existence of FM; healthcare providers being unable to help them better understand their symptoms, condition, and illness trajectory; healthcare provider and patient experiences of feeling confused and overwhelmed; and encountering healthcare providers who were unaware of treatment recommendations for FM.

P1: Every doctor I've talked to about it has differences in the ways that they portray Fibromyalgia, the treatment options, and discussions about it. I guess it's different because every person has a different form of fibro—it's not consistent. ... I've been living with fibro for 10 years now, and I'm more confused than ever about how to live with it.

P5: What made me feel that I didn't want the Fibromyalgia diagnosis was the lack of understanding of the mechanism, as well as the treatment of the symptoms that are broadly categorized as Fibromyalgia. ... We have no knowledge whatsoever of anything.

P9: The healthcare system is supposed to provide me with the information I need, but it's a huge uphill battle to get the information. Then it's another uphill battle to get accommodations. I'm not even going to bother trying to focus on government disability stuff. And none of these things communicate. So you have to do this process over and over and over again. ... So now you're trying to take all the information in, you're trying to process what you're experiencing, which is hard. ... And then it's like, holy shit, now I've got to try and put this together. I can't imagine doing this without having had such traumatic—dramatic—I almost said traumatic, but it feels like that sometimes—dramatic experiences with the healthcare system.

These challenges were grounded in a recognition that the medical community continued to question the actual existence of the condition.

P10: Everyone was always so careful. The impression I got is that even people who were really working with FM were trying to be so careful, because the broader medical community was still so unaccepting and dubious. The vast majority of people [with FM] had gone through years of struggling with no one believing them, with virtually everyone thinking they had drug seeking behaviour, or we're a bunch of hypochondriacs.

Helping incidents (71% participation; 13 incidents). Some participants described instances where they observed improvements in clinical understanding of FM. Some of these examples were indirect, such as hearing advertisements for FM medications on television; others were direct, such as noticing improvements in healthcare provider responses to the condition or their ability to offer useful information about the condition. While physician awareness was seen as most desirable and directly applicable to their wellbeing, both types of scenarios offered evidence of progress and ongoing research, which in turn generated hope for continued change for participants.

P1: I feel like things have come a long way. I remember the stories my mom has of people in healthcare saying she was an overanxious child wanting attention. It's so much better now. Because even though I don't have really good things to say about the healthcare system that I've experienced, I was never blatantly told that I was overanxious or seeking attention, or overreacting or what I was feeling wasn't valid. I've felt that was, but I wasn't directly told that.

P5: My doctor was willing to diagnose me as having Fibromyalgia. That was comforting to me in that she is aware of it, and she's educated herself about it, and she's not judgmental or prejudiced about it. So I was relieved that she didn't have any kind of stigma.

P12: Nowadays it has changed quite a bit thankfully, but there still needs to be a great deal more change to have the whole community understand what is going on. My father for instance, until he saw Lyrica ads on TV, which was only about two years ago, he didn't really believe in Fibromyalgia, because, he says, "Well, you're walking fine."

Wish list items (64% participation; 17 incidents). As suggested by the previous quotation, while participants described observing some positive improvements in clinical understanding of FM, they also commonly perceived a need for more research and

awareness that extends beyond pain specialists into general practice medicine, and society more broadly. Among these wish list items, three sub-themes emerged: de-stigmatization of FM, training for medical providers, and specialized services.

De-stigmatization of FM. This sub-theme related to experiences of FM as a stigmatized condition, and the desire to see healthcare provider attitudes shift towards more acceptance of the condition and the individuals living with it.

P1: I want to break that stigmatization of what it's like to live with Fibromyalgia. It's not something that I should be embarrassed of, and it's not something that I can help. People tell you to buck up and just get over it, but it's not one of those things. That's something that's really prominent and painful, and that's stigmatization.

Training for medical providers. This sub-theme addressed participants' perceptions that healthcare providers are not receiving adequate training in how to manage complex chronic conditions such as FM, and that more specific instruction in the medical world about how to support individuals with FM would help address these concerns.

P8: I think there's still a long way to go, starting with knowledge and understanding about FM. ... Teaching it in med school, giving it more airtime. ... Developing knowledge about what not to do when someone's sitting across the desk from you, like dismissing you, not having any options to follow through, not taking you seriously, or having a belittling attitude, not saying "there's nothing wrong with you".

Specialized services. This sub-theme involved participants' wishes to have more access to and ongoing support from specialists.

P13: To me the idea of someone who is specialized and knowledgeable in chronic health conditions working with me forever is so appealing. That's what I really need. Like my GP—I love her and she's great—but she just maintains the things my specialists give me. She doesn't have the expertise; I need somebody who is an expert in chronic health problems to work with me on an ongoing basis the way a GP does.

Category 3: Accessibility and flexibility. This category describes the presence or lack of operational solutions made by healthcare services and providers to ensure that

patients can access services when and as needed. While a broad look at healthcare access has been taken throughout the present study, this category specifically addresses access and flexibility related to spatial accessibility such as travel factors that might impede patient access to services, physical accessibility such as physical layout of clinical settings, flexibility and access accommodations, and appropriateness of recommended treatments relative to patient symptoms. Service equity—incorporating the notion of social justice—also emerged as an accessibility factor, wherein specific services were made available to meet the needs of populations who might otherwise not be served by the conventional healthcare system.

P14: Their mission is something along the lines of “We are a group of interdisciplinary service providers who want to meet the community’s needs that go unmet in mainstream medicine.” So they take folks who other practices won’t touch. ... It’s a collective that has decided, “We’re going to do the hard thing even though it’s hard. It’s going to take humility, but we’re going to do it.” ... They’re trying to make it a one-stop-shop for folks, to make it accessible.

Length of appointment times also emerged as an important flexibility factor.

Other accessibility factors relating to models of healthcare delivery and recognition of the diagnosis FM—including understanding of FM, continuity of care, and affordability of services—have been included as distinct categories for content specificity, but should be noted in this category as accessibility issues by definition.

Hindering incidents (93% participation; 23 incidents). Hindering incidents related to accessibility and flexibility encompassed a number of challenges: bureaucracy and administration; lack of spatial accessibility, which encompassed inaccessible geographic location of healthcare services relative to the patient, and lack of available transportation, in combination with lowered capacity to commute due to symptoms; physical inaccessibility of spaces, which encompassed factors such as the physical layout of a clinic, and

considerations such as elevators, scented environment, and uncomfortable seating; inflexible cancellation policies; and incompatibility of recommended and provided services with patient's symptoms.

In many cases these factors were interrelated, and compounded challenges with access, for example, attending regular appointments was seen as a challenge, further complicated by scheduling, and the process of commuting.

P7: Going to appointments is exhausting; they're always on the other side of town. An hour appointment for me takes up half a day to get there and back, and be in the appointment. ... I often can't keep up with doing stuff like phone calls ... often the bureaucratic process was delayed because I couldn't keep up. And then the impact of pain on your ability to do things; I just find when I'm in pain everything is way more stressful. Like if the bus is ten minutes late then that's ten minutes more that I have to stand in the rain and in excruciating pain. Everything feels so sharp. If the appointment is 20 minutes late, I feel it in my body. It's really tangible.

Participants further described inflexible policies as challenges, impeding their ability to make use of services that could otherwise have been beneficial to them.

P13: I was trying to access home care support—very unsuccessfully. One of the things they wanted to do instead was send me to [local pain program] but I couldn't get there. ... I am not opposed to going to this program—in fact I think it would be really helpful for me—but if I can't get there, or I am in such agony by the time I get there that I can't focus or just cry the whole time, how am I going to benefit from the supports that they have to offer? I have to be in a lower level of pain than red alert to be able to benefit from these kinds of things, and they just wouldn't listen to me. ... In addition to that, before you can even access stuff at the pain clinic, you have to go through one- to two-hour psych assessment. I requested to do that over the phone so I could stay home, and they won't, and they won't come here, they won't do it by Skype. They don't have any alternative ways to do it.

P14: I don't ever really know what my body is going to do when I wake up in the mornings. Keeping morning appointments is really hard. One pain clinic, you had to go to a pain management workshop as you were getting the treatment in order to continue getting the treatment, but they only had morning availability. It was a lot, and I couldn't make it. And then they said, "You have cancelled the day of," and it's like, "Of course I did, I woke up with a migraine! I don't know what tomorrow is going to be like with my chronic pain, that's why I'm at your clinic!" And they said, "Because you cancelled day of, in order to reschedule you have to pay a \$75 cancellation fee." So I stopped going to that clinic. I get that this is inconvenient to

you, yet you have the power as a service provider ... it's not my job to pay you for your own shitty disability politics.

Short appointment times also emerged as a flexibility issue, wherein participants described feeling rushed, and unable to cover the multiplicity of factors impacting their health in the brief time allotted for their visits.

P13: Trying to deal with chronic health problems in a ten-minute doctor's appointment is just absurd. Or having to limit your issues to no more than two. Most people I know with chronic health conditions have co-occurring conditions, they don't just have one. It's impossible to get appropriate care if you can't talk about everything that is going on, like the interrelating ways that you're not aware of, but your doctor will know. But they're not going to know if you can't talk about everything that's happening.

Helping incidents (64% participation; 16 incidents). These items refer to operational solutions by individual healthcare providers or organizations that made services accessible to participants who would not otherwise have been able to access those services. These included examples like offering home visits, flexibility in offering longer appointments, and explicit efforts to provide services to marginalized communities.

P3: My doctor was very open to coming to see me. She knew the symptoms I had and if I couldn't get out there she would come to see me. For instance, I remember one time I got really sick—the combination of what was going on plus the FM meant there was no way I could get across town to the doctors, so she came and made a house call.

While short appointments were hindering factor in accessibility and flexibility, over half of participants had positive experiences of specific providers who offered ample time for appointments. These incidents emphasized the importance of time in the context of a complex, chronic condition, where additional time and appointments are needed—beyond the standard 10 to 15 minute appointments—to discuss diverse symptoms, and intersecting impacts on patients' wellbeing.

P13: My doctor was a very compassionate person. He gave me lots of time. He wasn't trying to solve everything in ten minutes, which is so frustrating—to get a

ten-minute appointment where you are only supposed to bring one issue, and you're like, "Technically it's only one issue, but it's affected like 45 parts of my body so I don't know how to unpack this!" My appointments lasted between one and two hours. It makes a difference when you have time. When they have time for you. ... My issues are complex and they overlap, and Fibromyalgia alone is a difficult piece to chew off, but that doesn't mean you should shoo me out the door just because you don't know what to do.

P14: What has been really wonderful about her is she takes oodles of time. We never have a 15-minute meeting; we have 20, 30, 40 minute meetings, and she is happy to book me in for multiple sessions. ... I suspect that she takes time before every meeting to review my chart. ... I don't have to remind her of the context of my illness. She does that work. And we can spend our twenty minutes actually talking about next steps.

Wish list items (50% participation; 11 incidents). Accessibility and flexibility wish list items focused on a combination of specific desired services like Occupational Therapy, and Social Workers; outreach services or the ability to access services remotely; modularized services; and more flexible financial aid programs that allow individuals to stop and start employment as their health fluctuates.

P13: I wanted supports that could either come to me or I could use the phone, or Skype, or Medio, or some sort of online media to access. ... I had this problem with the [program], which I found shockingly appalling, because their targeted market is people that are really disabled and they had no accommodations at all. I don't understand why there was no lateral thinking for how people may need help to access supports.

Category 4: Continuity of care. Continuity of care relates to the presence or lack of care over time by an individual healthcare provider or team of healthcare providers. Items in this category address factors that are barriers to or facilitative of timely communication of health information, such specialist referrals and referral wait times, and whether or not a patient has a consistent doctor overseeing their care.

Hindering incidents (71% participation; 26 incidents). Barriers to continuity of care included difficulty finding a family doctor; accessing care through walk-in clinics where participants could not rely on a consistent physician to oversee their care; and long

wait times for referrals to specialists, which can take several months to years between the initial referral being sent and a patient having a specialist consult; a lack of healthcare provider follow up with the patient, such as after specialist appointments or lab tests; and gaps in communication between healthcare providers. Discontinuous care contributed to participants' sense of confusion and feeling "bounced back and forth" (P13) in the medical system, as well as a decline in health throughout the elongated process.

P7: I've seen like 20 different specialists in the last six years. And going from the GP to the specialist is eight to nine months of waiting. Then you don't even know if that specialist can help you, because each specialist focuses on their system. So if you don't fit into their ten-step criteria of what illnesses they treat then all they say is, "I can't help you because you're not part of my system." They also don't tell you where to go or how the system works. I think the main thing for me was how slow it went. And as time went on I was getting sicker and sicker. It spread to my hands, my hips, I was walking with a cane at 20. And just getting no answers. So then I eventually I went to physio, I went to chiro, I went to acupuncture—I did all this stuff while waiting for the main medical system stuff. I was lucky that I had coverage with the university.

P13: I didn't know you couldn't just go back to somebody after you've left, and second of all even if you could do that, he had closed his practice and became an ER doctor, and he wasn't even there to go back to. So I came back to Vancouver with no GP again, and it took me two years of active searching and being desperately in need of immediate care to find a GP. I basically spent two years getting bounced around between walk-in clinics and the ER, because the walk-in clinics are like "This is too much, this is too serious for us to deal with," and the ER is like "You're not dying so go to your GP," and I am like, "I don't have a GP," and they're like "Go to walk-in clinic". And I just got bounced back and forth and I couldn't get referrals because I don't have a GP, so I couldn't see anyone who could actually help me. It was a nightmare.

Another shared concern emerged around poor communication and loss of information. In instances where a patient is being transferred from one healthcare provider to another, the data held within that patient-provider relationship are not reliably transmitted into the next one.

P11: There's no progression, no continual investigation. ... I had one blood test, and one of my values is really high, and even when we re-tested it was still really high and it's supposed to indicate muscle breakdown. Nobody's explained it. And that

was a time when my family doctor switched from one locum to another locum, and then the original doctor came back, so there's definitely information lost there. ... Like in a sense that sounds like, what they're trying to do, in the medical system in general is like "Well, we're going to leave the follow up with the family doctor," which is actually isn't a bad idea. But then that means there should be a report from the specialists to the family doctor about what to follow up on. I don't think that's there.

Helping incidents (79% participation; 22 incidents). Helpful contributions to continuity of care involved healthcare providers who provided referrals to appropriate specialists and programs, and a sustained relationship with a specific provider over the course of treatment.

Two participants mentioned instances where walk-in clinics allowed them to request the same doctor on return visits, thereby mitigating some of the barriers to continuity of care resulting from accessing care in this way.

P9: With enough persistence, I had something put on my file so that I could actually request the same doctor, because otherwise there is a policy you couldn't request a doctor you just came in and saw whoever was available. So that was where things started to get a little better, because I had somebody who was overseeing things.

As mentioned above, referrals were another example where incidents were found to be both helpful and unhelpful, depending on how they were handled; many participants described being referred from one provider to another and not receiving follow up. However, when referrals were carefully considered and provided from one trusted provider to another, they were found to be helpful aspects of participants' healthcare experiences.

P3: I've always had a really good GP, and therefore they refer me to good specialists.

P10: Pretty early on, my doctor said, "You're on sleeping medications that are classified drugs. I don't think we're hurting you, but I want there to be a person who is more appropriately monitoring this." She never acted remotely like I was crazy, or suggested that I needed mental health services, but she wanted to make sure I received the right care. She hand-picked the psychiatrist, and I know why she picked him, because this man was just wonderful.

Wish list items (29% participation; 7 incidents). Wish list items in this category were similar to the helping factors above, however, an added component of adequacy and effectiveness of care was articulated. While a consistent relationship with a provider over time, within a supportive structure allowing for longer appointment times and reliable follow ups, was seen as helpful, participants also expressed a need for access to providers who can help them navigate the complexities of the medical system, and providers who are specifically informed about FM and chronic illness more broadly.

P2: It depends on the mindset. Their expectation is that within so many sessions I'm going to be cured, and that's a fallacy. Recognizing this as chronic would be helpful.

P7: There needs to be some sort of support outside of the simple patient-doctor interaction. Administrative support, in order to give the space for the patient-doctor interaction to be respectful, caring, and considerate, and an opportunity to open the interaction instead of closing it—deeming you not fitting into the box and therefore you're out kind of thing—it's almost like a trial, you get in or you don't. The doctors are the doors to the medical system, right. ... You need a counsellor almost—like a guide. "This is how the medical system works. Here are your options. Here's a list of specialists." I had no idea, and grappling at it makes it take way longer too.

Two participants also highlighted the importance of collaboratively creating transition plans, and equipping patients with necessary supports between set appointments or when service provision needs to end, such as a healthcare provider going on leave or retiring.

P13: [My naturopath] basically came in one day with this schedule, weaning me off of her completely, without talking to me about it. This was the first I had heard about. And I just never went back. I was so upset, and so hurt, and our relationship just got permanently damaged. I felt abandoned. I wish she had approached it in a different way. The rational part of me knows that when you have these professional relationships, they don't last forever, even when they're working and they're great. People don't always keep doing the same things. Their professions grow, and they change, and that's totally okay. But I needed her and I had no one else and I didn't know what was wrong with me, and she just told me she was leaving. It wasn't a dialogue at all, she presented me with this schedule with no discussion of who was going to take over my care or anything. I had no GP, I had no one else. It was really

hard.

Category 5: Prejudice. While prejudice takes many forms, participants in the present study largely focused on two forms of prejudice: sexism—negative attitudes toward patients of the female sex—and ageism—negative attitudes toward patients based on their age, in these cases, their youth. One participant also described an instance of homophobia; and two participants talked more generally about “stigma” toward pain-related conditions. In many cases, participants described these prejudices as being inherently linked to the FM diagnosis itself, which is most common among middle-aged women, thus implicating age and gender biases. There is also some overlap between this category and Category 8: Validation, wherein experiences of invalidation resulted from prejudicial attitudes; however, items in Category 5: Prejudice, while experienced interpersonally, reflect a perception of a more systemic occurrence.

P3: It wasn't until I came out as lesbian that I recognized the violence and the stupidity in the “There, there dear”, and how females are treated, and how often the professionals are male. A doctor asked me at one of our meetings if he could ask me a personal question. ... “Why, if you were having sexual problems, didn't you go to a doctor?” And I puzzled for a minute and I said, “What makes you think I had sexual problems?” “Well isn't that why you have sex with a woman?” ... Like, what an idiot!

Hindering incidents (64% participation; 18 incidents). There were no helping incidents identified in this category. Participants spoke of prejudicial attitudes creating barriers to care in ways that undermined them, and created imbalanced power dynamics in their healthcare relationships.

Sexism. Among the 12 female-identified participants, eight identified sexism and misogyny as barriers to their care. Sexism was understood by the participants who endorsed this sub-theme as embedded within the history and practice of medicine. Three

participants linked the treatment of women with FM to the residual effects of women's distress being dismissed as hysteria.

P10: I did run into those doctors—and continue to run into them—who really have problems with women. The sexism is so deep. I mean, we can document how it's a part of the medical practice going way back. It's inconvenient to say the least that this disorder has affected 90 percent women. It certainly made it really easy for some doctors to go back to the Freudian “women are crazy” attitude. Even if it's not much in your awareness, if you've got attitudes like that operating it's going to be really difficult to take anyone seriously coming in with this kind of crazy stuff.

In light of this tenuous history linking women, inexplicable illness, emotionality, and mental health, participants articulated concerns about perceptions of their level of emotionality and pain expression. The question of emotionality and pain expression was described as a dilemma: on the one hand, if participants showed emotion they were seen as “crazy women”, whereas if they did not, they were seen as malingerers—either way, they were met with dismissive attitudes.

P13: I call it “crazy woman syndrome”. Where women's responses to pain are different than men's. I find if I cry in a doctor's office, that shuts off their believing. It's like having water come out of your eyes all of a sudden means that you're crazy. And it's not just that I'm crying because I'm in pain, but I am also crying because I'm losing my home, and I can't afford food. Like I think I have some pretty legit reasons for crying. But all of a sudden they don't want to deal with you, or they just want to send you to someone who deals with mental health stuff.

P4: One of the problems was that I never really looked sick. I would walk into somebody's office and give them my list of complaints, but they would look at me and think, “You look fine,” so that was the problem. I shouldn't have put on any make up.

Participants also contrasted the treatment they received when they attended appointments alone, versus with a male partner.

P7: I went back a year later, with a cane, and my boyfriend at the time. We were in the waiting room and the doctor came out. We stood up and walked towards him—I was closer to him and my boyfriend was a bit farther away. The doctor came up—he didn't look at me—and reached across me and shook my boyfriend's hand. He didn't say a word to me, and then told us, “Come on in.” As we were walking through the door he said, “I see you've brought your boyfriend along so he won't

break up with you.” And the power dynamic makes it so that I can’t say anything back because my life revolves around what this person is going to say or decide about me.

Ageism. Of the five participants diagnosed under the age of 35-years-old, four shared stories of age-related bias being a barrier to their care. These instances were all within the context of healthcare providers’ preconceptions of “young” people as healthy.

P14: I suspect that part of that has to do with women being diagnosed more with fibro. There’s a long history in medicine of women’s subjective experiences being dismissed as hysteria, and I have definitely felt the residual effects of that continuing to happen in medicine. Also being young. I felt very dismissed based on my youth. The growing pains comments for sure, but also, I think that there’s this idea that when you get older you get sick, and young people aren’t sick, unless they are really sick in ways we can see objectively. So if a young person is complaining about something, there has to be some other reason, and maybe it’s that they’re whiney, or entitled or a millennial.

P9: [The rheumatologist] basically said right away, “You’re too young for anything to be a problem.” He said I was a young guy. I was supposed to be healthy. And he said something like he never sees anybody as young as me. That these things are for old people or something like that. I think he was just trying to convince me that I shouldn’t worry about this—that this isn’t anything. ... There’s a very bizarre ageist thing that goes on. I don’t really get it to be honest, because it’s happened a few times with different doctors. I feel like it’s a probability thing. Like they feel like it’s just not as probable—this is not what you’re dealing with because it’s not the general population guidelines for that condition. But that’s kind of a crappy way to go about diagnosing people, right? I mean, sure, it’s less likely, but that doesn’t mean it’s impossible. It also has an assumption built into it that just because you’re younger you’re in perfect health.

Wish list items (14% participation; 2 incidents). In their depictions of facing prejudicial attitudes in healthcare, two participants expressed wishes that the underlying attitudes that contributed to these experiences could be addressed.

Category 6: Diagnosis making. Participants demonstrated a lot of ambivalence in regards to the diagnostic process, and receiving the diagnosis of FM. While participants talked about seeking diagnosis to give them answers and clarity about what they were living with and how to proceed, the diagnosis of FM was often seen as too ambiguous to

provide this; additionally, the process of seeking a diagnosis was frequently filled with doubt and confusion. Incidents in this category address helpful and unhelpful aspects of the diagnostic process, including differential diagnosis, lab tests, and the diagnostic criteria themselves.

Hindering incidents (64% participation; 15 incidents). Chief diagnostic concerns focused on barriers in getting the diagnosis itself, for example, patients being unsure how to respond to assessment questions, the lack of clarity within diagnostic criteria for FM, as well as healthcare providers' reluctance to give the FM diagnosis, and the length of time it took to receive a diagnosis. Participants also addressed the dilemma of barriers to accessing services without a diagnosis, as well as barriers to accessing services once diagnosed with FM.

P11: Fibromyalgia really is a catch-all. It's already kind of nebulous ... and you're muddying it further by not being clear about how it's diagnosed.

P2: [The rheumatologist] had a student working with her who examined me. She was trying to find the trigger points, but she has no clue where they were. She'd say, "Does this hurt?" And I'd say, "Not there, but if you go an inch lower, you'll find something." So I had to direct her to them. And the doctor said, "Your symptoms best fit, or seem to fit." Very tentative. Because nobody wanted to be or were definitive about, "This is what it is, this is what you have." And that contributes to this attitude of it being invented or made up. The inexperience, and the resistance to having [FM] included in [rheumatology]. They don't have a vested interest in being proactive about it, so there's umm distrust, and disinterest, and dismissal, and frustration.

P4: The diagnosis itself really wasn't that helpful, because what it said is, "We can't find anything else to label this with, and we're still doing this provisionally. This is still under dispute and discussion, and there's no treatment." It was a very depressing experience. Very frustrating and demoralizing.

Helping incidents (57% participation; 12 incidents). Despite the challenges described about the diagnostic process, participants did find some benefit in having tests run and receiving a formal diagnosis. Some described the diagnosis as validating, in that it

provided a kind of objective affirmation or official recognition; the experience of having a healthcare provider care for them and believe them enough to go through the process despite inherent barriers also contributed to the experience of validation.

P9: If this was not something that was more rigorously addressed in in terms of the blood work up and the physical examination, I feel like I would have nothing to point to and say, “Here’s a solid base for me to feel okay about how I’m feeling.” It’s like being able to hold a piece of paper and say, “Look, this is official.”

P5: My doctor was very willing to diagnose me with FM, tell me what she knows of it, and that there have been recent discoveries—that I don’t have as grim a future as I may have been reading online.

The process of differential diagnosis and eliminating other conditions also provided some peace of mind, alleviating fears that symptoms might be indicative of a degenerative or life threatening condition, and sometimes established some direction for treatment. Having words to identify and describe the symptoms and condition was found to be helpful as well. Finally, having a diagnosis sometimes created access to supportive services that participants found beneficial.

P11: Information is good for everyone, like explaining that it’s chronic, something you have to manage, forever. To be honest, because of the nature of the symptoms and how they drag on so long, it’s easy to get paranoid and think you have something super serious. And just to have a name to it is nice [RN: right] umm, and to know that, I mean well it’s pain it’s not anything that’s really acute

P7: To have the words ... it’s like night and day. It’s totally different. Now I have access to services, like I have a social worker and all these different things. A diagnosis is kind of like a pass card into the music festival—it gets you in. It’s also weird, because you don’t want a diagnosis—not a bad one anyway. For so long I was desperately pining for a diagnosis and that was taking away from me actually taking care of myself, like eating well and all these things that do help; having the diagnosis became more important to me than all of that. But also, the diagnosis helps me pinpoint the specifics of what I have to do: it’s better to keep moving, I can’t eat nightshades, these times of things. It’s also really validating because then I can read about other people who have the same thing.”

Wish list items (14% participation; 2 incidents). Paralleling the hindering and helping examples discussed above, participants wished for deeper and clearer

understanding of the diagnosis, and for healthcare providers to be more willing to stand behind it when given.

Category 7: Models of healthcare delivery. Over the course of their illness trajectories, most participants were exposed to both the conventional biomedical model—which is the leading approach to healthcare in most Western societies, and focuses on biological factors of health, excluding psychological, and social influences—and the biopsychosocial model that views illness as the outcome and interaction of multiple factors including biological, psychological, and social factors, whereby treatment requires understanding and addressing the whole person and their context in a comprehensive way. Within the biopsychosocial framework holistic, multidisciplinary, and interdisciplinary approaches were identified. Holistic approaches were those taken by individual practitioners, applying biopsychosocial frameworks to their care. Multidisciplinary approaches, where individuals access care from healthcare providers of different specializations who do not necessarily communicate or coordinate with one another, contrast with interdisciplinary programs, which encompass healthcare providers of different specializations who provide coordinated care, integrating their treatment plans. Some participants also accessed CAM. While many incidents identified throughout the study implicitly demonstrated hindering and helping factors related to models of healthcare, those in this category directly reference this systemic awareness.

Hindering incidents (57% participation; 20 incidents). Hindering experiences largely implicated challenges with the conventional biomedical model such as lack of integration between services, inadequate supply of needed services; and barriers caused by the economic underpinnings of the current medical system.

P7: I was always being scrutinized because I wasn't bleeding out of wounds. And that's when I realized the difference between acute and chronic care. I think our healthcare system is really great for acute care, like if you get in a car accident, but anything chronic is like, it's like seen a drain on the system. And there are no services, unless you're like 90% disabled.

P13: Our funding is so limited and these programs are so small and so few, and they are cutting them even further that someone who is on the cusp of losing everything has to wait until they've lost everything before they can access it. ... I'm very much a proponent of proactive versus reactive and waiting until people are in such a hole before helping them really doesn't help them. If you catch people before they fall they don't fall as far and they come out of it much better.

Unable to access comprehensive care through the traditional biomedical model, patients often explore other options such as CAM. While some participants reported helpful experiences with these modalities, others shared about exploitative interactions and feeling manipulated by individuals offering expensive therapies.

P6: So far, there's always going to be people trying to make money off of this. I have to admit, I have very little respect for naturopaths, homeopaths, chiropractors, some of these alternatives. I have tried them but I do not subscribe to them anymore in any way. My life has been saved by Western, modern medicine, and that's where my trust is. I have nothing but skepticism and aversion to this other stuff. My experience has been they are making money off the placebo effect, basically.

Helping incidents (57% participation; 17 incidents). Helpful incidents in this category tended to highlight particular CAM treatments that participants had experienced as helpful; often these treatments were accessed when participants did not get the results they hoped for from the conventional biomedical system. These items are subcategorized into two sub-themes: holistic; and multidisciplinary and interdisciplinary approaches.

Holistic. Many participants referred to “holistic” approaches when describing these incidents, which demonstrate ways that healthcare providers explore the interactions of different elements in patients' lives on their overall wellbeing.

P3: My counsellor-naturopath combined the emotional and physical. She looked at how my thoughts and emotions interacted with each other, and how I could respond

to that in a healthier way. She helped me understand how I could soothe my anxiety, and how that could have an impact on the rest of my symptoms.

P14: My doctor is willing to look at me holistically, so we talk about quality of life, and work, and relationships, and other stresses and trauma and counselling.

Multidisciplinary and interdisciplinary approaches. These incidents described two distinct biopsychosocial models of healthcare that incorporate providers from different specializations working with an individual patient, with varying levels of communication and coordination. In a multidisciplinary model a patient accesses care through a number of different healthcare providers, who may or may not be communicating about the patient's care, and will typically be developing independent treatment plans; in an interdisciplinary model healthcare providers collaborate around common, shared goals; in an integrative setting, all healthcare providers will be housed in the same setting, and co-developing a shared treatment plan for the patient. In the interviews, these distinctions were not made, and terms were often used interchangeably by participants. The following example illustrates experiences in an interdisciplinary setting.

P12: They are taking a multidisciplinary look at my whole being: from an internal medicine doctor, to a nurse provider, to an OT, to a PT, to a dietician, to a pharmacist. There have been numerous providers looking at my situation. ... It's very helpful because...everybody's input has been very interested and integrative; they all know what everyone else knows. ... They all report to each other, so there has been a very good, broad look at who I am and how to look at ongoing care.

One patient also described how her family doctor, who works in an interdisciplinary setting, also integrates discussions about CAM in their treatment.

P14: [My family doctor] is a scientist at heart and as per her medical license she won't recommend or provide treatments that aren't evidence-based. But also, she is open to talking to talking about other things that aren't in the pervue of western medicine. So I can be open and honest with her abut marijuana use. She's of the opinion if someone says to me [sic.], "I am spending all this money at a naturopath and it's really helping me," she's like "Great keep going," and if someone is like, "I am spending all this money at a naturopath, and it's not helping she says, "Well, let's talk about why. We don't have evidence to suggest that it's effective. And also,

sometimes folks will take advantage of people who are desperate for relief from their chronic illness.

Wish list items (79% participation; 20 incidents). This was the most frequently endorsed wish list category in the present study. Of the desired changes to the healthcare model participants recommended, improved integration was a commonality. More integrative services for individuals with chronic illness was the most commonly cited, along with more integrative communication among practitioners, and more practitioners taking integrative approaches within their own practices. In line with the quotation cited by Participant 14 above, another participant expressed a wish for a family physician who would implement a biopsychosocial approach, potentially mitigating a need for referrals to other services.

P7: So if there was a—I hate the word holistic because it’s so overused but just —a full person, full body, full story kind of approach to what you do when you go to a GP, instead of just being referred to specialists—and I mean that’s hard on resources I guess, but it could definitely be possible. That would be life changing.

One participant specifically imagined integration in the form of further development of communication infrastructure to facilitate the transmission of health information among healthcare providers, to remove the responsibility of dissemination from the patient.

P9: ... I give all my information to this person, and now they know what I need. They know that the university needs this information, or they know that the rheumatologist needs this information, and then just have it happen [sic.]. We have the technology to do this. It’s not even cutting edge. They can put it in the mail and have it somewhere delivered by mail carrier, I don’t care, it’ll still get there in like a day, but it shouldn’t take 6 months. ... We have integrated um, biomedical systems. Why am I hopping through all these hoops to do this?

Participants also desired changes to the funding structure that would allow for healthcare providers to allow them longer appointment times, and give them access to home support services, and improved funding for integrative programs, and programs that serve marginalized populations.

P13: I had to wait until I was really, really sick, and really, really poor to access services. A lot of our social services don't kick in until you're really badly off. I think I would have been much better off if I had been able to access some of the stuff before I lost my job, or before I got to sick and forced out of my job. Because once you fall into that pit of poverty and illness, that spiral is really hard to get out of because they perpetuate one another. If you get services and supports before you've gotten that bad, you don't get as bad. You get better.

Interpersonal factors

The following categories relate to interpersonal factors impacting participants' experiences of healthcare access for FM.

Category 8: Validation. The incidents in this category focused on themes of validation and invalidation in participants' interactions with healthcare providers.

Validation refers to the extent to which participants felt received and believed by their healthcare providers.

Hindering incidents (93% participation; 32 incidents). All but one participant shared experiences of invalidation by their healthcare provider. Invalidation was the most frequently identified category in the present study, and a theme which overlaps with many of the other categories described in this chapter. These incidents described encounters with healthcare providers who denied participants' descriptions of what they were experiencing, minimized symptoms, and did not believe they had a "real" condition, as well as healthcare providers explicitly not wanting to work with individuals diagnosed with FM.

P10: My doctor did send me to a rheumatologist, because you're supposed to see one get a diagnosis. ... this woman was utterly dismissive, like, 'Look, you don't have anything physically wrong with you. I've got all these people with rheumatoid arthritis. Get to the gym and get on with your life.' I mean she threw me out. She was really rude and nasty actually. She had no time for anybody with my problems.

P2: The rheumatologist was upset, and in fact, if you read her report she was very angry at my doctor for referring me, because I had seen two other rheumatologists in a span of eight years. She said, "This person should not be sent to another rheumatologist, and I will not see her again." She was very adamant. ... it was very derogatory, and that was upsetting to me. Here I was finally saying, "Okay, maybe

there's new stuff out there that I'm not aware of. Maybe the rheumatologists have figured out what might work." To get that was like being punched in the face. ... I think to rheumatology it's like, "You're wasting my time. I have sick people to deal with."

P1: Even in the healthcare industry I find people don't seem to really get that it's serious—that people live in so much pain. It's not like a physical thing where you have a cut on your body. ... It impeded getting help, which is sad.

"It's all in your head". In addition to the above experiences of invalidation, a specific sub-theme emerged around experiences dismissed as "It's all in your head". This sub-theme contains a lot of overlap with the other examples of invalidation in this category, but is distinct in the underlying belief that FM symptoms are somehow imagined, willfully brought about, or an expression of a mental health condition. This sub-theme is also tightly entwined with the hindering incidents of Category 12: Counselling and Psychotherapy.

P1: I was made to feel like everything was in my head—like it was a mental thing. And because there's still stigma surrounding mental illness I felt stigmatized. ... I felt really weak and like I was a lesser person because I was feeling these things. And then when my doctor heavily tied it to my anxiety ... it dismissed what I was feeling and pushed it under this broad umbrella of something else, when I knew something was really wrong with me, and no one was listening to me. Because she knew I had anxiety, every time I would bring something up, she was like, 'Oh, it's your anxiety.' And it took her a long time to realize that something else could be wrong other than just me having really bad anxiety.

Helping incidents (79% participation; 15 incidents). In these incidents, participants described receiving recognition or affirmation of their experiences and symptoms from a healthcare provider. Many of these incidents stood in explicit contrast to the hindering incidents found in this category in terms of being believed, and treating the condition as real.

P9: At the end of [the rheumatologist's] assessment, he said, "I just want you to know that I don't think you're crazy and that I believe what you're saying. I know that it's not common for people to believe these things or at least state it, so that's why I'm telling you. You don't need to feel crazy." It was really awesome to hear that ... in that he was saying, "I believe you. I'm not just dismissing it the way other doctors have."

P14: The other thing my doctor did was take me seriously. She believed me. I said all these things are happening in my body and they are affecting my quality of life, and she was like, “Okay, I believe you on face value.” You can’t give someone a blood test and see exactly how much pain they are in and then treat them until it’s within normal range. You have to believe the person. And I think a lot of healthcare providers aren’t willing to take that leap of faith.

Wish list items. While participants made no explicit statements that would fit as wish list items for this category, it should be noted here that the desire for validation might have been implicit in a number of other wish list items, such as the following wish list item from Category 2: Clinical understanding of FM.

P9: I feel like it would be really straightforward to tell doctors: “This is a real thing. Stop treating it like it’s not.” I think that would be a small thing that would be completely manageable.

Category 9: Therapeutic alliance

The therapeutic alliance refers to the relationship between a healthcare provider and patient, of which the focus is the health outcomes of the patient. The incidents in this category elucidate participants’ perspectives on the helpful and hindering qualities of their relationships with healthcare providers.

Hindering incidents (79% participation; 21 incidents). Barriers to therapeutic alliance encompassed a combination of factors. Participants who endorsed this category experienced healthcare providers as overly “clinical”, emotionally detached, and authoritarian. Relationships characterized this way had dehumanizing effects on participants, leaving them feeling like test subjects or numbers on a file.

P8: [The rheumatologist] was very efficient. There were no warm fuzzies. It’s not like I felt I could build a rapport with her. I was just another face, another file and that’s what we’re here to do. I found that difficult. I was very nervous, again, that I would be construed as making this up, and it being in my head in the form of seeking attention.

Participants also conveyed that overly clinical and emotionally detached styles made it difficult for them to trust the healthcare provider and whether or not they could be of help.

P11: The internist was—not there. She was not present at all. It gave me low confidence in what they could offer me. I was standing in the waiting room and I saw this lady walk by, and I thought she was a patient because she looked tired, and disengaged, and sad. And then when I went in for the appointment, she was my internist! She basically just went down a list of questions that I believe the nurse had already asked me on my intake.

Helping incidents (100% participation; 41 incidents). Therapeutic alliance was endorsed as helpful by all participants. This category, more than any other, demonstrates the relational elements of healthcare experiences, and the importance of the bonds between patients and healthcare providers in allying with patients in achieving their goals. Healthcare providers in these helpful alliances were described as: supportive, open, empathetic, attentive, understanding, respectful, caring, warm, and collaborative. Participants talked about liking their healthcare provider, and trusting their healthcare provider. These qualities led to experiences of feeling listened to, feeling cared about, and implied experiences of mattering.

P10: The qualities in this situation are the same ones that make any counselling or healthcare experience a good one: support, empathy, and having somebody you feel cares about you. That they believe in you, that you're valued, you're still seen as competent even when you know things are really not good. That you're not blamed. You can get very down on yourself for all this stuff happening, so it is really wonderful when you are supported by people in positions of expertise that are reminding you of all the ways in which you're still trying really hard—helping you stay a little bit balanced and objective in how you're feeling about yourself. That saves you. That is the difference between the demons actually getting you or not. Not to feel like you're totally alone. To have hope.

P13: We had a good working relationship and that made a difference. I think I got better under her care, because she gave a shit about who I was. And it's been like that with all the other people that I have slowly integrated into my team over the years. When it's a good working relationship, when there's mutual trust, and when you matter to them, you do better.

P12: It was amazing because she actually listened to how your life was changing and how you felt emotionally about the way it was changing. She was very kind, and it was so important to me that that appeared in my life in that particular time after this struggle with different providers that didn't listen or have an understanding about what my body was going through, and the emotional impact of what happens to your life when it dissolves in front of you.

Non-expert stance. An important sub-theme surfaced among helping qualities of therapeutic alliances, referencing the ability of some healthcare providers to acknowledge limitations in their knowledge bases and to take initiative in learning about patients' needs, learn about FM, and to persist in working with the patient even when they didn't know exactly what to do to help. Non-expert stance is not to be confused with lack of expertise and training. The benefit of the non-expert stance seemed to transpire from the providers' ability to tolerate not knowing, while continuing to apply their knowledge and training toward learning and experimenting with the patient, rather than becoming discouraged, dismissing or rejecting the patient, or to taking an inflexible or unilateral stance that does not fit for or include the patient. Participants expressed a connection between this type of non-expert stance on the part of healthcare providers and their own sense of hope in living with FM.

P14: What I needed from doctors was for them to hold space for the uncertainty of what was going on, and my doctor now really does that. She is like, "Sure, we don't know what is going to help, what is going to change in the future, but we can try some things. We can learn from what little research there is and anecdotal evidence from other people who survive this condition every day." I find more hope there.

This sub-theme also included examples of providers' willingness to admit that they were wrong, or be transparent with a patient when they didn't know something. Participants expressed appreciation for providers who could acknowledge when the patient presented with symptoms outside the providers' prior experience.

P13: There were some days I would go see my naturopath, and she was like, “You have stumped me. I will go home tonight and do some research, and the next time I see you I am going to have some answers for you,” and I valued that so much. I wish that traditional doctors could be like that. It seems like they want to appear to know everything, so when they don’t they blame it on you. There’s a lot of patient blaming. Instead of having them send me home saying, “There’s nothing wrong with you,” I would like for them to send me home saying, “There’s something wrong with you. I can’t identify what that is right now, but I am going to try and figure it out,” or “I am going to send you to someone I think will help you figure it out,” instead of just being like, “You’re fine because I don’t see what’s wrong.” You can tell when somebody is competent by whether or not they can say, “I don’t know,” when they’re beyond their scope.

Collaboration. Collaborative dynamics were characterized by mutuality, working together, and equality. Providers who were described as collaborative were shown to take patients’ lived experiences into account, and actively solicited their perspectives.

P13: My specialist took a really collaborative approach, where he wasn’t just telling me, “You have to do this,” he was like, “Here are some options. These are the pros and these are the cons for all the options. I will give you all this information to take home and look at and think about, and you can tell me what you want to try. And we’ll try it, and if it doesn’t work, we’ll try something else.”

P7: I feel trusting of doctors who respect me in a way that sees that they have a knowledge base that I don’t have, but I also have a knowledge base that they don’t have because I’ve lived it. And instead of having it like the doctor providing a service and me being a client, it’s more of a teamwork approach ... I think that’s a really good basis of trust with doctors. Even if the doctor is bringing more to the table, just viewing the patient as equally important in the process and getting their insight.

Wish list items (64% participation; 13 incidents). Wish list items largely coincided with participant helping incidents in this category, particularly around the desirability of a non-expert stance from a healthcare provider. These items also emphasized the need for compassion within the therapeutic alliance, and a request that providers recognize that “there is another human at the other end” of the interaction (P9). Participants also desired more transparent communication from their healthcare providers, and that healthcare

providers directly elicit their patients' perspectives in regards to their own healthcare processes.

One participant empathized with protective reasons for disconnecting from patients, while also underlining the impact these kinds of interactions have on patients.

P7: For a lot of doctors it's necessary for them to disconnect from their patients in order to be able to address so many people, and they can't empathize with everyone because at the end of the day they'd be done, so I get that. But one thing that I would like if I were to ask a doctor anything would be to realize that how everything that happens in the doctor-patient interaction, in the medical system, in this whole process, is felt acutely and is extremely painful in our bodies. And that if they can lessen that slightly, it might save someone's life.

Building on this request for recognition of impact, two participants spoke of their desire for more compassion from healthcare providers; one specifically addressed compassion related to the delivery of a diagnosis, the other addressed compassion for the challenges that FM poses in a person's life.

P6: Compassion from healthcare practitioners would have been helpful. FM is very emotionally and psychologically impacted and impacting. The invisibility and chronicity of FM are hard for people to understand.

P14: I think there could have been a lot more compassion on her part, even talking about, "How are we going to frame this for you?" Like, "Okay, let's try calling it fibro from a diagnostic standpoint and work with that for a while," instead of, "I guess you have fibro. Go have your ideas about it." She could also have said "We're going to look through some options, please don't Google this," but she didn't. She just set me free into the world to go be a human being and human beings Google things, even when they know better. ... I guess she couldn't have predicted how I was going to deal with it, but if she had any compassion she could have guessed, and known what other patients have done with random diagnostic words. Like, "I know myself when I don't know something, I Google it. So let me give you some advice human to human."

Category 10: Iatrogenic suffering. Iatrogenic suffering denotes a broad range of adverse, non-intended outcomes from healthcare interactions and treatments. Incidents in this category primarily focused on participants' experiences of treatments that resulted in adverse physical or psychological symptoms, although some definitions of iatrogenic

suffering also encompass things like side effects of medication, medical error and negligence, and financial hardship resulting from medical care, which have been covered in other categories.

Hindering incidents (64% participation; 15 incidents). There were no helping incidents in this category. In some instances, participants attributed distressing experiences to the treatments they received, in other cases they attributed their distress to factors within the relationship itself. Most participants described iatrogenic suffering in the form of worsened physical symptoms or “flare ups” after a treatment.

P13: I have so much anxiety that's specifically around medical professionals and medical environments that I never had before, from the way I've been treated. I go into new medical environments and specialist appointments with a level of anxiety that is not productive just because I've had so much bad treatment that I armor up. I anticipate it now and I am just so anxious about “Is this person going to be good? Is this person going to take me seriously? Is this person going to fuck me up even more than I am to begin with?”

P1: When I went to the chiropractor for the first time, the next day I felt like shit. I felt so sick. Like my whole body hurt, it hurt to have clothing touch my skin, and I was like I never want to do this again. It was super, super painful. And I don't know why because the doctor recommended the chiropractor who I went to. Ever since then I've been a little bit scared to go back and do stuff like that.

Wish list items (7% participation; 1 incident). One participant hoped for healthcare providers to become more conscious of, and responsive to, the impact that their relationships with patients have on patients' wellbeing.

Category 11: Informed consent. This category illuminated experiences related to the importance of receiving full knowledge of possible risks and benefits, prior to giving permission to a healthcare provider to proceed with a given treatment. Although this category has one of the lower participation rates in the present study, a number of these incidents were among the more impactful on participants' experiences of healthcare. When

healthcare providers' fail to provide patients with full knowledge of the possible consequence of treatments the outcomes can be devastating.

Hindering incidents (36% participation; 9 incidents). The incidents in this category were exclusively hindering. Some incidents in this category addressed providers' neglecting to provide adequate explanations to patients about manual treatments and potential exacerbation of symptoms, others involve patients being given medication without being properly informed of side effects, while others involve healthcare providers explicitly disregarding patient requests for how to proceed with examinations and treatments. Participants spoke of power imbalances in relationships with healthcare providers, and how vulnerable they can be in the medical system if providers aren't consciously and carefully attending to patient autonomy. Although participants did not themselves state they felt abused, certainly lack of informed consent risks abusive treatment.

P3: My migraine specialist gave me a drug and didn't explain to me what it was, and didn't explain what could happen with it, and then she went away for a week. By the time she came back I was seriously ill. I could barely stand, and as a result of it a lot of my hair fell out. It also affected my memory, I've never had the same kind of memory that I had before that. Basically I was lithium poisoned. I usually checked all meds when I took them but I mean I was in pretty bad shape at this point so I didn't check this one. ... She just would not get it. And to this day I've never had any kind of an apology or acknowledgement from her.

P14: It feels like I am going to take whatever is provided to me because I am desperate, and what do I have to lose—I am just going to be sick, so I might as well try, even if it is going to make me sicker. So it puts you in such a powerless and desperate position, that you can't actually consent to things.

P2: I had to go through two days of assessments for my benefits. It's not just an independent assessment. What they do is they contract them to take on the person, put them through a three-to six-month rehab program. And it's like, "We'll pay you to get them better, then they can go off benefits." But on the form, there's this tiny little print that says once you sign to work with them, your benefits are terminated, whether you're well or not, at the end of this three or six months. ... In the report, they accused me of not trying [in the assessments]. They said my heart rate didn't raise; well if you can't do an exercise your heart rate can't increase! So that was a ten-month battle I went through to get back on benefits, because they terminated

them.

Category 12: Counselling and psychotherapy. Counselling and psychotherapy was another area where participant experiences were polarized. Several participants reported beneficial counselling and psychotherapy experiences, emphasizing the values of patient-education, cognitive-behavioural pain management strategies, and empathetic care. At the same time, because of the ways invalidating and stigmatizing mental health narratives are implicated in the healthcare experiences of individuals with FM, referrals for this kind of treatment risk further alienation of patients through compounding the implication that symptoms are psychogenic.

Hindering incidents (36% participation; 6 incidents). The hindering incidents associated with counselling and psychotherapy compounded negative messages patients received about FM being “all in your head” (Category 8: Validation) and left patients feeling invalidated about the physical symptoms they were experiencing.

P1: She pretty much said, “It’s really hard to diagnose something like Fibromyalgia, but you do have a lot of the symptoms.” And then she told me to go to counselling. That I needed to talk to somebody. And she kind of made me feel like I was crazy, and that it was all in my head.

P4: I did see a psychologist—that comes back to me because she asked me this question—what was the reward for me being sick, which I found deeply offensive. My career has gone to hell, my money situation is bad, and my man doesn’t love me anymore, so really there hasn’t been any reward. The consequences were all bad.

Helping incidents (50% participation; 11 incidents). Those who experienced counselling and therapy as beneficial talked about receiving compassion and empathy; a supportive other who encouraged them through difficult times, and explored the many ways illness was impacting their lives; and learning about chronic pain, and pain management tools.

P5: I think whenever there's a diagnosis of a long term condition they should send their patients to a mental health profession, like counselling ... for support around what is going on emotionally.

P10: It was very in depth, incredibly empathetic counselling. It wasn't just about chronic medical conditions; it was about all the other things that were happening in my life. ... There's a lot of grief, there's a lot of loss, I mean, I was at the height of my career, at the height of my ability. I was totally taken down, in a way that I could never regain.

P9: I started seeing one of the psychologists on campus as the only work around I had to manage these things. This person was always very helpful and very understanding, and they were very aware of pain management, which I really appreciated. They had former experience with people who had Fibromyalgia. That made a huge difference.

Wish list items (29% participation; 4 incidents). Among those who endorsed wish list items related to counselling and therapy, the emphasis was primarily on emotional support during a time of change and loss. Participants also wished for counselling to be made more financially accessible.

P7: Anyone with Fibromyalgia should have a grief counsellor, hands down.

Individual factors

The following categories relate to individual factors impacting participants' experiences of healthcare access for FM.

Category 13: Medication and medical marijuana. Many participants identified medication—including medicinal marijuana—as being helpful in reducing and managing symptoms; however, there was a lot of ambivalence about medication use due to adverse effects.

Hindering incidents (79% participation rate; 21 incidents). Medication was more frequently identified—by more participants—as hindering than as helping. Medications were found to be hindering when they were ineffective, produced undesirable side effects, caused dependency, and caused withdrawal symptoms. For many participants, these were

not individual experiences, but lengthy processes of trialing different medications in an attempt to find one that helped with symptom management, with as few adverse effects as possible.

P10: What I remember most about that time is a long series of being a guinea pig for just about every kind of medication that is associated with FM—from SSRIs to Amitriptyline and Trazodone—and a lot of really unpleasant experiences. Not only did it just not work, they had terrible side effects. Some of them as bad as me throwing up continuously for 14 hours, being really dizzy, all kinds of things. Finally, although I really didn't want to, I tried benzodiazepines. Bingo, those work! And so I've been on benzodiazepine medication for a long, long time. And although I've been able to cut it down, to this day I'm still using it, and I probably always will be, because it's almost impossible to ever completely come off them.

While medication ineffectiveness might to some be seen as a neutral impact, these incidents were reported within the context of the limited financial and energetic resources described above in Category 1: Financial security and affordability. Additionally, it is important to remember that the medication side effects experienced by participants took place within the context of chronic illness, where patients are already living with debilitating symptoms, many of which are then amplified by the side effects of medication.

P4: If you are in a lot of pain and taking pain medication, you are not on a ball. Everything is slower, your judgement's affected, you make errors in judgment ... you are not really there.

Helping incidents (64% participation; 11 incidents). Some participants did achieve symptom reduction with medication, notably including managing co-occurring anxiety, sleep, and other symptoms of conditions that co-occur with FM, such as IBS and migraines, as well as managing fatigue, and pain. Further, several participants mentioned medical marijuana as being the most helpful medication they have explored.

P3: my doctor was always good at prescribing pain medication if I needed it. It has been really helpful, particularly in managing intense pain in my neck and shoulders that would then trigger a migraine.

Medical marijuana. Five participants described using medical marijuana and found it to be among the most helpful medications for treating their symptoms. Participants described it as helping ease pain, reducing the length of symptomatic periods, easing anxiety, and elevating mood.

P6: I allow myself two grams of marijuana a month, which is not very much. You can get 70 grams or something if you want! My God, I'd be buried alive in the stuff. So it's like a quarter teaspoon a day that I use—I have a one hit a time pipe. That way I titrate it throughout the day. I try to go until 4 o'clock before I use anything, because after only six, seven, eight hits I can't breathe, I start coughing. So you try to find the balance and do the best you can. Harm reduction basically. But honestly, cannabis works the best out of anything I've tried for reducing pain, and elevating my mood.

Wish list items (14% participation; 2 incidents). One participant expressed a wish for effective alternatives to medication, because she did not feel comfortable taking medication, given the ways they impacted her. Another participant wished for more ease of access to medical marijuana.

Category 14: Internalization of adverse healthcare experiences. Internalization refers to the psychological process of an individual integrating an attitude, belief, or perspective held by another and into their own psyche.

Hindering incidents (71% participation; 20 incidents). This category exclusively consisted of hindering incidents that related to participants assimilating invalidating and/or stigmatizing messages from healthcare providers into their self-perception.

P1: I went to my doctor, and I told her symptoms that I'd been having and she wasn't the best at understanding what I was going through. She was a bit dismissive with my symptoms and the pain that I was having, and it made me feel like I wasn't allowed to feel that way. And there's so much stigma, even in the healthcare profession about mental health and pain. It makes you feel like you're weak. I was in there I'm like, "Wow, I'm not a strong person. I shouldn't be feeling this way."

P11: This is the other thing—it sounds really weird—well maybe not weird...I don't want to come off as a hypochondriac, and I get the sense—whether it's true or not—but sometimes I sit there and think to myself, "Does my doctor think I'm a hypochondriac?" You know because when they say, "Oh, you're okay," you start to doubt that sometimes, right?

Category 15: Exercise and physical activity. Exercise and physical activity were described as both helpful and hindering, depending on the context in which they were recommended or explored. While participants talked about feeling fearful and avoidant of exercise because over-exertion and incorrect exercises could lead to a worsening of symptoms, appropriate quantities and kinds of exercise were also found helpful for managing symptoms.

Hindering incidents (57% participation; 11 incidents). Several examples in this category reference healthcare practitioners recommending exercise to patients in ways that were experienced as incongruent with their needs, unsupportive, and invalidating.

P4: [My GP] was like, “You should be doing more exercise.” And I was thinking, “You don’t understand. I can’t exercise. I can barely lift my arms over my head to wash my hair!” That’s how I discovered dry shampoo. That’s how weak I was.

P7: “Just do some exercise,” is a classic. “Just do some exercise. Try running for 20 minutes a day.” Whereas over-exercising is one of the worst things you can do for chronic fatigue syndrome and fibromyalgia.

Helping incidents (43% participation; 6 incidents). When participants were able to find baseline tolerance levels and pace themselves appropriately, they described exercise and physical activity as beneficial to their wellbeing, however, this was generally a process of trial and error through which participants received little expert guidance.

P2: My goal is to balance between pain medication and doing what I can for therapy ... like yoga, and gentle movements, and swimming. This keeps me functioning at a minimum level. ... I’ve tried various combinations, and frequencies, and schedules. It took me three years to be able to build up to swimming three times a week. If I do four times a week, it’s too much. So it’s a fine balance between over-doing and under-doing.

P5: When I started feeling pain I was already stretching, because sometimes I couldn’t even get up without stretching. So it didn’t add to what I was doing, but it validated to me that it actually works. ... I wasn’t 100% sure if stretching was the right thing, but her recommending yoga and stretches it validates that what I was doing instinctually was right.

Category 16: Active coping and social support. Active coping relates to participants' proactive strategies for dealing with their health and healthcare challenges—as Participant 5 stated, “I keep looking, and I keep searching, and I keep putting up my own fight”. Although social support is a form of interpersonal coping, it has been included in this category because it is nonetheless an approach to coping, and was in most cases actively elicited; furthermore, there were insufficient incidents to make this a category unto its own, thus it was deemed more valuable to incorporate these incidents into the coping category rather than remove them from the study.

Helping incidents (100% participation; 56 incidents). This was the largest of the 16 categories, endorsed by all participants. While no hindering items were identified in the theme of active coping and social support, it should be noted that in many cases these incidents were in response to gaps in available care. Further, many of these incidents do not pertain directly to experiences of healthcare access, but rather ways that participants have adjusted to address gaps in the services provided or to manage for themselves in response to the lack of perceived supports from the healthcare system. These incidents have been included to shed light on ways that individuals with FM cope, that could be further supported by healthcare services.

P7: I didn't want to have to figure myself out. I wanted to go to a doctor and for them to tell me what was going on. It wasn't until about two years ago when I really thought I had gotten to the end of the line that I was like, “Okay, this is my responsibility. I can't rely on anybody, because there's no room for me. I fall between the cracks. I am just getting shifted around in this bureaucracy.”

P1: I feel like if I did not bring up the fact that I knew a little bit about Fibromyalgia then I would have gone undiagnosed, and I would have had a much longer road to figuring out what was wrong with me.

Approaches to empowerment and active coping were diverse, drawing from all realms of participants' lives including social supports, spirituality, creativity, self-

education, learning about pain management, hiring others to tend to household management, and food preparation. Incidents have been grouped into five sub-themes: information seeking and education, self-advocacy, social supports, symptom management strategies, and other coping strategies.

Information seeking and education. These incidents related to participants' personal efforts and skills in finding helpful information and resources to inform their treatment plans. Many participants researched their symptoms and brought the provisional diagnosis of FM to their healthcare providers, researched the available evidence-base for FM treatments and consulted with their healthcare providers about what they found, identified possible referral sources they wished to pursue, and read books and took courses on pain management at their own initiative to find ways of living with their symptoms. As stated above, there was some hesitation about this category, since participants' desires were for this information to be provided to them by their healthcare providers. Additionally, they recognized that research could backfire; they were aware that many sources contained misinformation, and did not always feel equipped to identify the most reliable resources. However, participants were driven to address their confusion and lack of answers by seeking out information to better understand their experiences; as stated by Participant 7, "Having information gives you agency and autonomy".

P9: I was bringing literature in with me, like actual research studies from peer-reviewed journals. By this point I had done maybe 100 hours of research. I was a researcher already at that point, so it feels like second nature—and I couldn't not, with no answers from healthcare providers. Normally I would just trust the doctor to provide me with the information I need, but the fact that I wasn't getting any of it meant that I had to do it myself. I needed to get an understanding of what was happening. And it was through that where I started to realize that what I was reading about Fibromyalgia was mirroring what I was dealing with.

Self-advocacy. Self-advocacy was another way that participants responded to feeling disempowered and powerless in their healthcare experiences. These incidents describe active steps taken by participants around relating to medical professionals, including carefully selecting providers they wanted to work with, learning to navigate the healthcare system and new ways of interacting with healthcare providers, and persisting in seeking the care they desired despite undesirable interactions.

P3: I've also stayed very proactive ... I've had friends in the medical profession, so I've learned what their constraints are. I've come to understand what it is they need to hear. It helped my relationship with providers by establishing me as an intelligent, thinking person, and taking some responsibility for my own health.

P12: I learned to stand up for myself. That's the only way that you can negotiate this kind of pattern in your life is to be proactive about your health.

P5: I used to be concerned about me freaking out. So I think the first concern was keeping myself in battle mode—like the samurai—don't let them bother you, upset you. Being centred. They're going to say something that is going to hurt your feelings, and you're going to calmly respond. The other thing is not to yell and scream, but persist in a win.

Social supports. Many of coping strategies included hiring others, or eliciting support from friends or family, to attend to household tasks such as having groceries delivered, laundry and cleaning, and assistance with administrative tasks related to healthcare. This category also included social strategies for emotional coping including building emotional support systems of trusted others.

P4: A lot of things in life is through talking to other people. It seldom comes from the medical community.

P7: I would have given up if it wasn't for my mom, who a lot of times was kind of like my secretary. Should would be like, "When is your next appointment?" And I would be like, "I haven't booked one." And just keeping track of what else you can do, who else you can see, what options you have, who you are seeing.

P14: I think there's an emptiness or a hopelessness or a frustration. I am really lucky that I have cultivated a strong support system, and also my partner of many years and now we continue to have a relationship has also had a lot of these experiences,

so we take care of each other through it. But otherwise, I am sure it would be very lonely. People talk about resilience or they tell people that they are brave for having gone through what they've gone through in terms of like chronic illness or major trauma. But I don't think that's a choice that people make, to be resilient. I think resilience is a product of your access to support, which is usually based on how much privilege you have and some luck.

Symptom management strategies. This category incorporates strategies that account for the interconnectedness of thoughts-feelings-behaviours-sensations, and how adjustments in one area can have a beneficial impact on the others. Participants described “learning to listen to [the] body” (Participant 8, Participant 12), as well as cognitive-behavioural strategies for symptom management, including pain, emotional distress, and fatigue.

P14: I took a yoga class for several weeks which was specifically for chronic pain. The thing that was the most helpful out of that was a pain management framework—education about how pain works, and within that, the emotional management of pain. I was spiraling into panic a lot, like I would have a really bad pain day and I would spiral into this, “I am in so much pain—I am going to be in pain all day long—I am not going to sleep and tomorrow is going to be even worse—I am going to be in pain all week—I am going to be in pain all my life—I will never be able to accomplish anything.” So I learned things like how to hold space for and not judge the panic—a lot of mindfulness—how to say, “Okay, this is the emotion. I am going to accept it for what it is, without amplifying it or trying to get rid of it.” Learning that I have to deal with the emotions that I have in relationship to my pain in order to have a healthier relationship to it.”

P7: [My specialist] told me to wear a heart monitor to keep my heart rate under 118, which is the aerobic zone, instead of the anaerobic zone, because in the anaerobic zone your heart rate is faster and you're in fight or flight and it boosts your adrenaline. If I keep it below that then I don't have to crash—I can keep it steady. ... I also noticed the difference in my heart rate depending on what I'm thinking about. I was sitting in a doctor's office with the heart rate monitor on, and I was sitting there perfectly still thinking about the doctor's appointments I had coming up and it went shooting up—it's that connection between when your brain is stressed and anxious, it makes your heart work harder. It's all connected.

P11: I spoke to a nurse about sleep coaching. ... It's great advice. Things like: no electronic devices, set a routine, nothing but sleep and sex in your bed, keep a sleep diary.

Specifically, a number of patients talked about incorporating mindfulness meditation as a symptom management tool.

P6: Mindfulness. Staying in the present. Not trying to control your thoughts. Just a perspective to own the impermanence of all things, because I'm a control freak. I want to have everything under my control. I had to learn through practice to let some of that go. You can't control these things. You just basically watch them go by.

Other coping strategies. Finally, participants described an array of other strategies that brought joy and meaning to their lives, improved general wellbeing, as well as those that helped manage challenge. These coping strategies included preparation and planning, spirituality, and creative practices. Sex was a coping strategy for one participant, who stated it was a way she could consistently feel good in her body.

P12: I was lucky because I had made some soup the day before. Soup and stew are precious because they're ready.

P3: My spirituality is what underlies everything, because it's about how we relate to things: How do we relate? How does this relate to that? How do I relate to pain? Doctors are more inclined to look at pain and want to know what's causing it. I will look at pain and ask: What is it telling me, and what do I need to do?

P6: I like to have an art project going that I can do for a little while and then come back to it. I find it very emotionally, physically, mentally distracting.

Wish list items (29% participation; 5 incidents). Participants wished for more direct systemic support in improving patient quality of life through services that could help reduce the disabling impact of FM, and improve patients' abilities to stay meaningfully engaged in their lives. Participants also articulated a need for household support like grocery shopping, delivery, and meal preparation; laundry and cleaning services; and support in making their homes more ergonomic and accessible.

P3: I don't think it needs to cost a lot of money to give the services that would make the difference ... grocery shopping and that kind of thing. Thank heavens for Spud because I get organic food and all the non-invasive products that I need. They have the code to my lock box and bring the bins into the kitchen for me. It's amazing that

there are ways for those things to happen. One of my kids comes and changes my bed for me because I can't do it. There's no way I can handle a queen sized duvet or sheet; I'd have to get a single bed, and I don't want to do that. ... My kitchen is designed so that I can prepare food sitting down, so I've got a lot of things covered.

One participant found mindfulness practice to be more valuable in groups.

P9: Meditation and mindfulness is not always accessible. I mean you can do it on your own, but I find it's not as effective. I find that group settings are functional. That's something I think could easily be created and accommodated at a healthcare or institutional level, and they have empirical benefits across different types of illness, not just chronic pain. So that something to go on that wish list.

Finally, while the healthcare system provided certain kinds of care, participants hoped for services that could reduce isolation and support them in staying active in their communities and families.

P2: If there's a way in the system to help build family support for people with Fibromyalgia, that would be a good thing. I've asked if my family wants to come to a therapy session with me because it is about chronic pain mostly, or come to some of the seminars that I've been to, and they can't, it's not the way they're wired. It's like, "Go fix yourself, and then we'll talk to you." But if there's a way in the system to bring families together to understand the nature of the beast, that may be helpful.

As stated by Participant 3, "I'm still pretty resourceful and I'm still pretty functional, but I am getting more tired of having to keep figuring out how to get my needs met, or my wants. Not just my needs but my wants."

Implications, correlations with established literature, limitations, and recommendations for practice will be explored in the discussion chapter.

Chapter 5:

Discussion

The purpose of this final chapter is to locate the findings from the present study within the existing literature on FM, understandings of chronic pain and illness, and healthcare access. This chapter will also show how some of these results might illuminate the field in new ways, or provide new insights from individuals living with FM on experiences of healthcare access for this condition, as well as implications and recommendations for counsellors and mental health professionals, healthcare providers more broadly, and recommendations for future research. This exploration of theoretical agreement between the research findings and the literature also fulfills the final credibility check of an ECIT study.

While there is a growing body of literature on FM, the condition continues to be poorly understood by many healthcare providers (Zotterman et al., 2016). Although the literature frequently acknowledges FM as posing multiple healthcare access challenges, and treatment guidelines are emerging (Fitzcharles et al., 2012), individuals with FM continue to regularly navigate unhelpful healthcare experiences for the condition (Colmenares-Roa et al., 2016; Durif-Bruckert et al., 2015; Juuso et al., 2014). What seems to be missing is research to address hindering and helping aspects of healthcare access as experienced by the patient with FM. The aim of the present study was to identify barriers and facilitators in accessing care, and desired changes individuals with FM themselves desire in order to improve healthcare experiences for this condition. The results of this study contribute to a greater understanding of what is experienced as hindering, helpful, and what *would* be helpful if it were available, for individuals accessing healthcare services for FM.

In sharing their experiences of healthcare access for FM, participants notably addressed hindering, helping, and wish list items factors spanning their immediate environment as well as those they do not directly interact with, demonstrating the complex interrelationships between settings they participate in directly and those they never enter but that nonetheless have significant impacts on their environment and lives. The 16 categories encompassing 528 incidents and 90 wish list items described in *Chapter 4: Results* thus reflect the wide array of direct and indirect influences on patients' experiences of healthcare access for FM. Additionally, the variety of categories elicited in the present study highlight the complexity of this topic, and suggest the need to shift the discourse of healthcare service provision for FM from a primarily conventional biomedical framework, to one that is more collaborative, integrative, and incorporates biopsychosocial understandings.

The thematic complexity of the findings of the present study pointed to a need to ground the discussion of these results in a theoretical approach that recognizes and supports, rather than limits, understanding of the interconnection of environmental settings. Discussing the findings of the present study in this way also allows for a re-contextualizing of the critical incidents and categories developed. According to Bronfenbrenner (1979) in describing the Ecological Systems Theory (EST), “the capacity of a setting ... to function effectively as a context for development is seen to depend on the existence and nature of social interconnections between settings, including joint participation, communication, and the existence of information in each setting about the other” (p. 6). Social-ecological models (SEMs) more broadly are frequently used in discussions of healthcare provision for marginalized populations (Centers for Disease Control and Prevention, 2013; Centers for Disease Control and Prevention, 2015; UNICEF, 2013). However, while the EST

specifically has been used to inform case management and labour-relations models of return to work for individuals with musculoskeletal disorders (Schultz et al., 2007), it does not appear to have been directly applied to understanding healthcare access for FM.

Recognizing the ways chronic illness can influence identity, and the impact of healthcare experiences on a person's adjustment to and experiences of chronic illness (Sabik, 2010)—in addition to its integration of relational and ecological systems—the EST has been selected as a theoretical framework for this discussion. Further, this framework supports the practical application of results by allowing the discussion to be structured according to the layered environmental systems of the EST, addressing the corresponding categories, relevant literature, and recommendations applicable to each systemic layer. It should be noted that while the EST provides a framework within which to discuss the implications of hindering and helping factors, and wish list items, within layers of interrelated systems, as with any model, categories will not always fit neatly within the borders of one system.

The discussion will begin with the outermost layer, the macrosystem, tracing how impacts travel downstream to the individual patient. In recognizing the interactions among all levels of influence, this model also demonstrates the necessity of adjustments at each level in order to achieve lasting change over time. As stated by Bronfenbrenner (1979), “The ecology of human development lies at a point of convergence among the disciplines of the biological, psychological, and social sciences as they bear on the evolution of the individual in society” (p. 13). Since each layer varies in its receptivity to influence and modifiability—with the macrosystem being the least modifiable, and the individual the most—the pressure to adapt to deficits tends to be absorbed by the more flexible systems. Table 5, below, provides a categorization of the results of the present study within the EST

framework. A brief definition of each systemic level, as well as each category, is also provided.

Table 5

Categorization of results according to ecological systems theory

ENVIRONMENTAL SYSTEM	CATEGORY
<p>MACROSYSTEM</p> <p>Describes the cultural environment in which the person lives, and all the other systems that affect them, including: economy, cultural norms and values, belief systems, political system.</p>	<p>2: Clinical understanding of FM: Hindering and helping incidents relating to lack of or presence of understanding of FM in clinical interactions, including healthcare providers' familiarity or knowledge about FM and associated treatments.</p> <p>5: Prejudice: Hindering incidents relating to systemic unjust or prejudicial treatment. Themes relating to sexism and ageism.</p>
<p>EXOSYSTEM</p> <p>Describes the larger social system that does not involve the person as an active participant, but still affects them, including: decisions that have a bearing on the person, but in which they have no participation in the decision-making process.</p>	<p>1: Financial and economic security and affordability of services: Hindering and helping incidents relating to lack of or presence of opportunities to establish financial stability including access to or barriers to continued work, medical benefits, disability benefits, extended health coverage, medical leave, affordable or covered treatments and services</p> <p>7: Models of healthcare delivery: Hindering and helping incidents relating to models of healthcare. Hindering incidents related to challenges with the traditional biomedical model, exploitative experiences with unregulated alternative and complementary treatments. Helping incidents related to biopsychosocial approaches.</p> <p>3: Accessibility and flexibility: Hindering and helping incidents relating to lack of or presence of operational solutions made by organizations and service providers to ensure that clients/patients can access services when and as needed.</p> <p>6: Diagnosis making: Incidents relating to hindering and helping aspects of the diagnostic process.</p>

Table 5 (cont'd)

ENVIRONMENTAL SYSTEM	CATEGORY
<p>MESOSYSTEM</p> <p>Describes the interactions between different parts of a person's microsystem. This is where a person's microsystems are interconnected and influencing each other.</p>	<p>4: Continuity of care: Hindering and helping incidents relating to lack of or presence of care over time by an individual or team of healthcare professionals, and timely communication of health information.</p>
<p>MICROSYSTEM</p> <p>Describes the system closest to the person and the one they have direct contact with. Interactions in a microsystem are bi-directional, so reactions to people in a microsystem will impact how they treat you in return.</p>	<p>9: Therapeutic alliance: Incidents relating to hindering and helping qualities of the relationship between healthcare provider and patient.</p> <p>11: Informed consent: Hindering incidents related to inadequate information about treatment options resulting in unethical and dangerous treatment.</p> <p>10: Iatrogenic suffering: Hindering incidents that involved healthcare interactions or treatments which resulted in adverse outcomes, e.g. a worsening of symptoms.</p> <p>8: Validation: Incidents relating to hindering and helping relational experiences with healthcare providers that contributed to feeling disbelieved and invalidated, or feeling believed and validated.</p> <p>12: Counselling and psychotherapy: Incidents relating to hindering and helping experiences of counselling and psychotherapy.</p>

Table 5 (cont'd)

<p>PERSON (INTRAPERSONAL)</p> <p>Describes the role of personal characteristics play in social interactions, including a person's mental and emotional resources—such as past experiences, intelligence, and skills—as well as things like access to housing, education, or a person's individual biological traits.</p>	<p>14: Internalization of adverse healthcare experiences: Hindering incidents relating to assimilating dismissive and/or negative messages healthcare interactions into one's self-perception.</p> <p>13: Medication: Incidents relating to hindering and helping experiences with medication; when helpful, incidents included a reduction of symptoms, when unhelpful, incidents included ineffectiveness, and hindering side-effects.</p> <p>15: Exercise and physical activity: Incidents relating to hindering and helping aspects of exercise and physical activity.</p> <p>16: Active coping and social support: Helping incidents relating to proactive steps taken to cope with illness and associated distress, including seeking information and resources, self-advocacy, social and hired supports, symptom management strategies.</p>
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Macrosystem

The macrosystem describes the cultural environment in which a person lives, and encompasses all the other systems that affect them (Bronfenbrenner, 1979). The macrosystem thus includes organizing norms and values, and overarching ideologies—the economic system, political and belief systems, and cultural values—that inform social institutions and public policies. Two categories addressed experiences of healthcare access on this macro level: Category 2: Clinical understanding of FM, and Category 5: Prejudice.

Clinical understanding of FM. While the category clinical understanding of FM has some overlap with subsequent systemic ecological environments, discussion of this category has been framed within this higher order environment to reflect participants' perceptions that many of the challenges they face with regards to understanding are

grounded in foundational medical beliefs about disease that lead to “questions about the validity of [FM] being a medical condition” (Participant 2). Hindering incidents related to clinical understanding of FM were shared by all participants, and were among the most commonly cited incidents. Hindering incidents in this category also reflected experiences of systemic problems embedded within the conventional biomedical healthcare model, which influence healthcare providers involving a lack of understanding of FM, and a corresponding stigmatization.

The conventional medical system has long been informed by the Cartesian notion of mind-body dualism and positivist expectations of objectively measurable data (Alderson, 1998; Melzack, 1996). Through this lens of dualism and objective pathology, a complex condition like FM becomes “a medically unexplained illness” (Johnson, 2008), mired in controversy around its existence, legitimacy as a diagnosis, and diagnostic classification (International Association for the Study of Pain, 2010; Wolfe & Häuser, 2011). Thus, aligning with findings from the metasynthesis study by Sim and Madden (2008) this issue of legitimacy becomes a central feature of the FM illness experience, which is directly tied to perceived lack of knowledge about FM. Hindering incidents in this category reflected similar themes, with participants describing the medical community as “unaccepting, dubious” (Participant 10) about FM. Unsurprisingly, this lack of understanding of the condition is also reflected in treatment challenges. The research shows that healthcare providers unfamiliar with FM recommend a variety of treatments, while lacking confidence in their effectiveness (Briones-Vozmeiano et al., 2013; Egeli et al., 2008). In addition to doubts about treatment options, some participants in the present study found that healthcare providers did not know the options available, “Part of doctors not being informed is that

they don't know what the treatment options are," (Participant 9), which corresponded with findings by Egeli et al (2008).

Questions of diagnostic legitimacy and lack of understanding of FM translate into the patient experience, leaving patients with FM feeling ignored and worthless (Egali et al., 2008). This medical paradigm dictates that physicians "probe the experience of illness with questions, examinations, and tests to uncover the root cause, hopefully unveiling some instance of remedial pathophysiology" (Hadler, 1996, p. 2397). This hunt for "an elusive disease, a 'monster that can be locked up with diagnosis'" (Hadler, 1996, p. 2398) leaves countless individuals in a state of uncertainty, and not receiving adequate care. In a bold argument on behalf of change to the contemporary system, Hadler contends: "It is time to dismantle the sophistry. Only then do alternatives reveal themselves" (p. 2399).

As might be expected based on the growing body of literature on FM, participants in the present study did perceive some gradual shifts in recognition of FM. Helping incidents in this category reflected some change toward increased recognition of FM as a medical condition, corresponding healthcare provider recognition of the FM, and decrease in FM being dismissed as a psychogenic condition. Biopsychosocial understandings of pain integrate the role of psychological factors—such as perceptions and previous experiences—in how the brain modulates pain responses (Alderson, 1998; Melzack & Wall, 1965). Research into abnormal pain processing and central sensitization of the CNS in combination with possible genetic factors and triggering events all shed light on the biopsychosocial nature of FM (Alderson; 1998; International Association for the Study of Pain, 2003; Sabik, 2010), while the Canadian Guidelines (Fitzcharles et al., 2012) advocate the importance of multimodal, integrative approaches to treatment. These shifts correlate with the changes participants commented on in terms of movement away from "it's all in

your mind” attitudes in clinical encounters. Five participants also experienced healthcare providers who were informed about FM, and were able to provide some context and explanation about what it was (Participants 5, 7, 11, 9, and 13).

Particularly in light of previous experiences of disbelief and invalidation, participants desired healthcare providers who were familiar with FM. Wish list items called on the need for continued improvement in clinical understanding within the macrosystem that could lead to a de-stigmatization of FM, and influence subsystems through the creation of more specialized services and improved training for medical providers. Findings from this section thus lend support to Sabik (2010) and Traska (2011) in recommending two parallel changes: changes in the definition of FM to make it more credible and acceptable, and improved training in the medical world about chronic pain and related conditions such as FM. The need for improved healthcare provider understanding of FM is also supported by research findings by the Canadian Pain Society (2014) and Egali et al. (2008); despite chronic pain being the most common reason for individuals seeking healthcare services, physicians continue to work within a framework that is not adequately equipped to support and treat chronic pain conditions. As stated by Sabik (2010), “the current ambiguity of cause in this case does not exclude the reality of the condition and the existence of debilitating symptoms” (p. 34).

Understandings of FM need to be adjusted to recognize and validate the experiences of people who are suffering with this condition, despite the lack of confirmed aetiology. In recognition of the limitations of conventional biomedical understandings in addressing the complexity of FM, and distinctions between acute and chronic pain, these findings suggest a need for integration of biopsychosocial understanding of pain into medical training and practice to better equip physicians and other healthcare providers for working with these

patients. Participants of the present study wished for healthcare providers, who they saw functioning as gatekeepers, to be well informed about FM to begin eliminating the stigma surrounding this condition.

Prejudice. Many participants reported incidents of prejudicial encounters with healthcare providers. As with the theme of clinical understandings of FM, while prejudice was experienced interpersonally, participants tended to perceive these encounters not as isolated incidents or unique opinions of individual healthcare providers, but rather as emblematic of values embedded within the biomedical model. Two primary forms of prejudice were cited—sexism and ageism, as well as one instance of homophobia, which was entwined with the participant’s experiences of sexism. Most of the female-identified participants in the present study spoke of experiencing sexism and misogyny (67%), while most of the participants diagnosed under 35 years old spoke of encountering ageism (80%), both of which were found to be barriers to being taken seriously and receiving adequate care.

As outlined above, FM is frequently written about as a stigmatized diagnosis, which stems in large part from the invisibility of the condition that is dissonant with conventional biomedical understandings of illness (Juuso, Skär, Olsson, & Söderberg, 2014). Within this model, both FM patients and their healthcare providers struggle. Due to the unpleasant emotions they evoke in healthcare providers, these patients are sometimes referred to as “heartsick patients” (Malterud, 1999; Perrot, Choy, Petersel, Ginovker, & Kramer, 2012). “Heartsick patients” are those individuals who are seen as “difficult” or “problem” patients because of their inexplicable disorders, leaving their healthcare providers experiencing emotions such as despair, anger, frustration, and powerlessness. Interviews with physicians about their perspectives on patients with CFS and FM demonstrated that when a physician

holding to the positivist ideal encounters a patient with an inexplicable illness, they begin to doubt the patient's claim to illness, and also begin to make moral judgments about the individual's character (Åsbring & Närvänen, 2003).

Further contributing to issues of healthcare access, when medical conditions are poorly understood, they are frequently dismissed as psychiatric in nature—particularly when the majority of sufferers are women (Juuso, Skär, Olsson, & Söderberg, 2014; White, Lemkau, & Clasen, 2014). Juuso and colleagues refer to this devaluing and trivializing of women's experiences of pain as the “feminization” of illness (p. 1386): dismissal based on the condition's association with women, which enables the healthcare profession to control or silence women in clinical contexts. This dismissal will be explored further in the discussion of Category 8: Validation, however, it is mentioned here to highlight some of the ways macrosystem values can impact subsystem experiences.

Sexism. Sexism was perceived by participants of the present study as a longstanding feature of the biomedical framework, which continues to persist and influence modern medical decision-making. Some experiences of sexism were explicit, however, most descriptions demonstrated more implicit judgments, encompassing evaluations of their emotionality, pain expression, psychological state, credibility, and appearance of illness. One participant told of consulting with her physician when a medication increase resulted in her developing suicidal ideation: “He tried to tell me it was PMS,” she said, “I was just like, ‘Umm, no. Not once has my period ever made me feel suicidal. You doubled my dose of meds. Why would you think that this thing I have had for over half my life and is a fairly consistent part of my life is the thing now suddenly causing these symptoms, when we actually just changed something?’” (Participant 9). Further describing her

experiences of physicians in response to FM, expressions of pain, and expressions of emotions, Participant 9 recounted:

I call it “crazy women syndrome,” where women’s responses to pain are different than men’s. I find that when I cry in a doctor’s office that shuts off the believing. It’s like having water come out of your eyes all of a sudden means that you’re crazy. I am crying because I am in pain, but I’m also crying because I’m losing my home and I can’t afford food. I think I have some pretty legit reasons for crying. But all of a sudden they don’t want to deal with you, or they just want to send you to someone who deals with mental health stuff. Can a person not just be really, really sad about some crappy health stuff and not be labeled?

Unfortunately, as many participants in the present study experienced, “The difficult patient, mostly portrayed as a woman, fits neatly into a historical tradition” (Werner & Malterud, 2003, p. 1410). Along the same lines, Participant 6 stated: “Women were always considered hysterical. I went through some of that “It’s all in your head” kind of thing. It’s what our society thinks of gender. In the past we were the “weaker species”, the more emotional and fragile ones.” In the face of “medically unexplained” conditions, which mostly occur in women, many of these beliefs emerge. Healthcare providers working in the conventional biomedical model struggle to manage their own shortcomings; this often results in skepticism toward the patient, belittling and blaming the patient, and discounting the patient’s symptoms as psychogenic in nature (Werner & Malterud, 2003). White, Lemkau and Clasen (2001) suggest an expansion of the definition of knowledge. While the conventional biomedical definition favours “objectivity, value-neutrality, and generalizability” (p. 54), a feminist definition could come to incorporate “subjective experience, personal narratives, and contextual details” (p. 54). Such a paradigm shift might then allow for value to be found in the subjective realities of individuals with FM.

Ageism. While several studies have examined healthcare experiences of FM through feminist and/or social justice lenses (Werner & Malterud, 2003; White, Lemkau, &

Classen, 2001)—examining the roles of power dynamics for individuals accessing care for FM—very few mentions are made of age, particularly those individuals who are younger than what is typically associated with FM (Werner & Malterud, 2003). The study by Werner and Malterud (2003) explored the interconnectedness of age and gender through the framework of exploring women’s challenges of being perceived as a “credible patient” (p. 1412); inherent in these interactions were appearance-based evaluations, such as “You don’t look ill,” and “You are so young” (p. 1413). This theme of relative youth as a barrier to healthcare for FM—independent of gender—may be a unique finding of the present study within the FM literature, since both female- and male-identified patients in the present study reported similar attitudes from healthcare providers with regards to their age, receiving comments such as “You’re too young for anything to be a problem” (Participant 9). It is also possible that these experiences reflect another gendered aspect of FM, wherein the feminization of pain is viewed as contrary to male identity, making it more likely that men will be overlooked with regards to this diagnosis. Similarly, perhaps the combination of FM being considered an “illness of middle age” (Johnson, 2008, p. 92), combined with associations between youth and health, as well as the power imbalance between younger patients and healthcare providers, leaves younger patients at risk of being discounted when attempting to access care for this condition.

For participants in the present study, healthcare provider beliefs that they were too young to be ill resulted in repeated delays in their care, influencing the process of diagnosis making, and resultant treatment planning. Given the multiple years many individuals live with FM before receiving a diagnosis, it is possible that these attitudes play a role in the prolonging of diagnosis (Hadker et al., 2011).

While the macrosystem is difficult to influence, the values held within this system influence policies and experiences of subsequent systems; they were also the place participants in the present study identified the most need for change among their wish list items. These participants did identify a gradual shifting of attitudes toward FM suggesting that research and education efforts on FM are having some helpful impact. This was further supported by findings on the perspectives of physicians, such as that by Åsbring & Närvänen (2003) showed that some physicians hold doubt about the positivist ideal when determining the legitimacy of a condition. Werner and Malterud (2003) call for a deeper awareness of the structures and mechanisms influencing illness, implicating the biomedical model, gender dynamics, and the welfare state in the experiences of people with chronic pain, a call which was echoed by the participants of this study. These findings support those by Sabik (2010), who argued “a deeper understanding of the disease with all of its uncertainties and ramifications is important. ... inappropriate guilt and shame must be left behind” (p. 34). Because guilt and shame often originate in the stigmatizing interactions with healthcare providers, much of this change needs to stem from adjusted understandings, as outlined in the discussion of Category 2: Clinical understanding of FM, recognizing that stigmatization and discrimination in fact lead to distress that worsens FM symptoms, which will be outlined below in Category 10: Iatrogenic suffering (Sabik, 2010).

Exosystem

The exosystem describes the larger social system in which the person lives (Bronfenbrenner, 1979). It is influenced by the organizing norms and values, and overarching ideologies of the macrosystem, and encompasses the resulting social institutions and public policies that subsequent systems function within. Insofar as access to healthcare is concerned, the exosystem pertains to those policies and procedures guiding

healthcare service delivery, including models of healthcare, accessibility and flexibility factors, decisions around diagnostic criteria, and financial and economic factors. The exosystem encompasses four categories from this study, which influence and overlap with one another in multiple ways: Category 1: Financial and economic security and affordability, Category 7: Models of healthcare delivery, Category 3: Accessibility and flexibility, and Category 6: Diagnosis making.

Financial and economic security and affordability. Financial and economic security and affordability was among the most commonly cited of the hindering categories (31 incidents) and was endorsed by all participants. Financial and economic security and affordability factors identified by participants included a range of financial and economic factors related to accessing healthcare, including financial aid and disability benefits that assisted in the face of loss of work and resulting financial instability, and were devastating when they were limited or not available. Financial and economic security might be considered through a cost-benefit analysis, recognizing the costs incurred by seeking or forgoing care, compared to the benefits of doing so (Gulliford et al., 2002). This category also included factors such as extended health coverage and affordability of treatments. While it occurred less frequently as a helping category (11 incidents), those who did mention the benefits of financial and economic security and affordability spoke of it as “the foundation of every other aspect of quality of life” (Participant 6) and that “saved” them (Participants 6, 12) and helped them “survive” (Participant 7).

Despite being one of the most prominent categories in this study, little research exists that documents the patient perspective of numerous financial and economic factors relating to healthcare access for FM, although some studies have explored aspects of the societal economic burden of the condition (Annemans, Le Lay, & Taïeb, Annemans, Le

Lay, & Taïeb, 2009; Canadian Pain Society, 2014; Skaer, 2014; Vervoort et al., 2016). Indirect costs of FM vary depending on severity, and can amount to tens of thousands of dollars annually, involving “losses in productivity, reduced work hours, absenteeism, disability, unemployment, early retirement, informal care and other out-of-pocket costs” (Skaer, 2014, p. 457). Gulliford and colleagues (2002) describe the impact of financial barriers as dependent on “the magnitude of the costs and on the user’s willingness and ability to pay” (p. 187). Drawing from descriptions provided by the participants in the present study, simultaneous to unanticipated loss of income, individuals with FM are also struggling with increased health-related expenses, which appears to pose significant service access challenges. All of these factors mean individuals with FM may require various forms of financial aid to pay for their costs of living in part or in full. Experientially, however, while these financial supports were reported to be essential, they were found to be inadequate in many ways.

Participants in the present study described being in a double-bind with provincial disability funding, where the rationed compensation offered might cover basic needs like food and shelter, but was insufficient to enable them to afford those things that they perceived as necessary for health, such as prescription and over-the-counter medications; CAM, including physiotherapy, massage therapy, chiropractic treatment, acupuncture, dietary supplements and specialized diets; physical training; counselling and psychotherapy; home-care assistance; and mobility aids. Further, many of these desired but unaffordable treatments were recommended by their primary healthcare provider or specialist. Thus, disability income was described as built in a way that perpetuated—rather than aided recovery of—disability. Describing her thoughts about going on disability, Participant 14 stated: “I would have to be very poor, and very much dependent on a

provincial system that doesn't treat people with disabilities well and doesn't give them enough support, enough money to survive.” This participant went on to further describe how she regularly has to decide between holding a job that she recognizes has negative impacts on her wellbeing but provides her with extended medical coverage, and the choice to take time off work, but then being unable to afford treatments that she relies on. Similarly, another participant described attempting to access disability and healthcare services when she was ill, at risk of losing employment due to her symptoms, and subsequently facing housing instability; she reported:

I had to wait until I was really, really sick, and really, really poor to access services. A lot of our social services don't kick in until you're really badly off. I think I would have been much better off if I had been able to access some of the stuff before I lost my job, or before I got to sick and forced out of my job. Because once you fall into that pit of poverty and illness, that spiral is really hard to get out of because they perpetuate one another. If you get services and supports before you've gotten that bad, you don't get as bad. You get better. (Participant 13)

Both participants further outlined how not all conditions will qualify for disability coverage. A diagnosis is required in order to qualify, therefore, someone who is ill but still undiagnosed can't apply for funding; further, some disability insurance companies through employers were cited as not accepting FM as a qualifying diagnosis; thus, financial and economic security becomes directly tied to Category 6: Diagnosis making.

Additionally, several participants (Participants 2, 4, 7, and 13) spoke about conflicts with insurance companies which posed significant barriers to their access to healthcare. Insurance models are historically premised on the biomedical model, through which claimants must prove disability in order to qualify for financial support (Schultz, Crook, Fraser, & Joy, 2000; Sabik, 2010; Schultz et al., 2007). These systems—which seek to ensure malingering is not compensated—have focused on rationing treatment (Schultz et al., 2000). This model places significant bureaucratic burden on the individual to maintain

funding, facing regular re-assessments processes and audits, which cause stress and risk further impairment and suffering (Participants 2 and 13; Schultz et al., 2000). Additionally, this model's tendency to provide limited numbers of sessions for given manual treatments was perceived as only validating those treatments that will "cure" a condition, rather than recognizing treatments as valuable for their ability to improve functioning and quality of life in cases where chronic conditions require long-term management (Participant 2).

In regards to affordability of treatments and services, this is impacted both by income as well as by determinations by the healthcare system around the types and amounts of treatments and services that will be covered. In British Columbia, primary care appointments are covered by basic medical (although above a certain income bracket, there is a premium for this coverage), as are specialist appointments; however, the treatment plans recommended are not necessarily covered, nor are other forms of informal care like household assistance. In a study comparing patients' and professionals' views on FM, Briones-Vozmeiano et al. (2013) found that healthcare professionals support the use of non-pharmacological treatments, however, recognize the challenges in accessing them given that they are not provided by the public health system; furthermore, they found that patients would like access to these services, but many cannot use them due to cost. Despite recognition that out-of-pocket expenses for FM place a significant burden on the individual (Jong, 2012; Skaer, 2014), minimal research has been done to explore this topic.

Moreover, it is not just a lack of CAM coverage that impacts this population. Affordability also impacts medication access, which, despite being an integral part of the conventional biomedical approach is frequently not financially accessible (Gulliford et al., 2002). Participants in the present study described cost being a barrier to medication, which resulted in them needing to make detrimental adjustments in their care choices.

Participants described rationing expensive prescription medications to try and make them last longer, thus not taking them regularly as prescribed and sacrificing their full effect. They also reported being aware that medication options were available on the market with better evidence for treating their symptoms, however, they could not consider these options due to financial inaccessibility.

Finally, a minimally cited but important aspect of financial and economic security relates to the costs of things forgone in order to access care, such as taking time off work or school for appointments, which—as will be discussed below in Category 3: Accessibility and flexibility and Category 4: Continuity of care—are often time consuming and unpredictable.

Thus, while the actual existence of various avenues for financial and economic security were viewed by participants of the present study as essential to wellbeing, the actual working models of these programs and how they interface with people's lives were described as lacking much to be desired. Further, while the helping incidents in this category were relatively few in comparison with the hindering incidents, an examination of their content suggests that this was more representative of the relative scarcity of helping factors related to financial and economic security than its importance to participants. While some participants were able to access CAM through the generosity or flexibility of providers who offered them reduced rates or services on barter systems, these examples were relatively rare and occurred through happenstance rather than being a reliable option.

Wish list items in this category focused on desires for financial and economic disability models that are designed to enable quality of life, including improved access to CAM, improved coverage of prescription medicines, and also more flexible policies that support return to work. One participant expressed a desire to see more correlation between

what primary healthcare providers recommend and what is covered; this aligned with findings by Briones-Vozmediano et al. (2013) that found participants wanted treatments or services recommended by their healthcare providers to be reliably covered by medical. Another participant called for a need to “overhaul” the disability system to demonstrate care for individuals with disability by adequately providing for those who need the support (Participant 14). Counselling and psychotherapy was specifically mentioned as desirable, but unaffordable (Participant 12).

Findings from this category suggest a need for further research on the financial and economic burdens to individuals living with FM. They also represent participants’ calls for the need to reconsider financial aid structures and the economic principles they are founded on. While insurance models are premised on trying to eliminate dishonest use of services—which is often directly tied to needing to prove the existence of a condition (Sabik, 2010)—reports from this study suggest high costs in terms of quality of life and the perpetuation of illness through financial stress. It is possible that applying a more integrative model that accounted for the complex contributing factors to FM might result in a financial aid system that supported individuals to pursue the treatments and lifestyle choices that could significantly alter the cycle of poverty and disability for some individuals.

Models of healthcare delivery. Stemming in part from the macrosystem challenges described above—in combination with the economic structures that determine policies for disability benefits and other financial aspects of healthcare—the conventional healthcare system was largely perceived by participants of the present study as unsuited and detrimental to the lives of individuals with a chronic condition like FM. Several participants acknowledged the distinction in the appropriateness of the biomedical model to

tend to acute care, versus its inadequacy of conceptualizing chronic care: “I think our healthcare system is great for acute care, but anything chronic is seen as a drain on the system” (Participant 7). However, over the course of their experiences accessing healthcare many participants were also exposed to biopsychosocial approaches to healthcare, in the form of holistic, multidisciplinary, and interdisciplinary care.

While the term “holistic” holds some negative associations with unregulated practices, “multimodal” treatment is recommended for FM, which may include multidisciplinary and interdisciplinary specialist care (Fitzcharles et al., 2012). Unfortunately, while the multidisciplinary or interdisciplinary settings were both desirable from a participant perspective and from a physician perspective (O’Rourke et al. , 2007), participants described specialized biopsychosocial programs as “embattled in terms of funding and severely oversubscribed” (Participant 11), and thus difficult to gain access to, making service availability a significant access issue (Gulliford et al., 2002). In terms of hindering incidents in this category, the lack of available biopsychosocial services was predominant, and connected to an overall perception of the (biomedical) system not trusting and valuing the experiences of individuals with invisible disabilities such as FM. Additionally, while CAM was also desirable to many participants, several also had negative experiences with CAM providers, where they paid for costly treatments out of pocket and received minimal if any benefit.

Within the conventional biomedical model, participants experienced care as fragmented, “all these co-existing systems not interacting” (Participant 7) with various specialists who are unfamiliar with each other’s scopes of practice. Describing a patient perspective in their study of views on managing FM, Briones-Vozmediano et al. (2003) described this as a “pilgrimage from one specialty to another” repeated in the search for

treatment (p. 21). They also experienced, as described above in Category 2: Clinical understanding of FM, few services and healthcare providers who understood their condition—and the few that existed were oversubscribed and thus unable to offer them the care they needed in a timely fashion. This lack of care within the conventional biomedical model left individuals searching for supports in an unstructured way, thus reaching out to CAM providers, often with little guidance. Within this context, participants in the present study described becoming more susceptible to unregulated practices.

Conversely, biopsychosocial models approach care from a more integrative way, both on an interprofessional level and in their understandings of illness. Helping incidents related to this category all referenced biopsychosocial approaches to care, with many of them also citing multidisciplinary or interdisciplinary approaches, which coincide with recommendations from the literature on healthcare for FM (Briones-Vozmediano et al., 2013; Fitzcharles et al., 2012). These approaches were appreciated for their ability to help patients understand the interconnectedness of different facets of their lives and wellbeing, and their symptoms, and also enabled them to feel more like “a whole subject instead of bullet point list of symptoms” (Participant 7). A biopsychosocial understanding of FM was also tied to the potential to more readily identify FM, resulting in more appropriate and efficient care, and better use of patient and healthcare system resources.

Participants also referenced an appreciation for healthcare providers who would discuss CAM with them, a finding which is supported by the study conducted by Jong and colleagues (2012) on the integration of CAM in primary care.

[My family doctor] is a scientist at heart and as per her medical license she won't recommend or provide treatments that aren't evidence-based. But also, she is open to talking to talking about other things that aren't in the peruvian western medicine. So I can be open and honest with her about marijuana use. She's of the opinion if someone says to me [sic.], “I am spending all this money at a naturopath and it's

really helping me,” she's like “Great keep going,” and if someone is like, “I am spending all this money at a naturopath, and it's not helping she says, “Well, let's talk about why. We don't have evidence to suggest that it's effective. And also, sometimes folks will take advantage of people who are desperate for relief from their chronic illness. (Participant 14)

Jong and colleagues (2012) found that while 86% of participants (n=416, all diagnosed with osteoarthritis, rheumatoid arthritis, or fibromyalgia) used CAM, of those who responded to the question about disclosure of CAM use to their primary healthcare provider (n=368), only 30% had actually discussed their experiences with CAM with their GP. Furthermore, among those who responded to their preferences toward integration of CAM in primary care (n=416), 92% stated they wanted a GP who would inform them about CAM.

A review of the relevant literature, in combination with findings from this study, suggests the need to shift healthcare delivery for FM toward biopsychosocial approaches. Coordination between professionals and other processes that facilitate communication between all professionals involved in treatment is recommended (Briones-Vozmediano et al., 2012), and was also wished for by participants in the present study. While wish list items in this category displayed significant overlap with other categories, significant themes were more integration, including improved health information networks allowing healthcare providers to share information about common patients, more integration of treatment planning, and biopsychosocial approaches to care, were desirable. Additionally, participants wished to see increased funding for integrative care programs for individuals with complex chronic conditions like FM, underscoring the fundamental accessibility issue of adequate service supply (Gulliford et al., 2002).

Accessibility and flexibility. As outlined in the results chapter, accessibility as it pertains to this category includes issues like spatial accessibility such as transportation that

may impact patients' abilities to access services, physical accessibility such as the layout of clinical settings, and the willingness and ability of healthcare providers to accommodate patient access to services, including remote appointments; flexibility relates to factors like cancellation policies, and appointment times. Gulliford and colleagues (2002) underscore firstly the importance of supply of necessary services as outlined above. However, recognizing that this is a limited measure of access, they go on to discuss accessibility in more detail, distinguishing barriers to access for available services, relevance and effectiveness, and equity. This section addresses what they referred to as the "degree of fit between clients and the health system" (p. 187)—apart from financial barriers, which were discussed above.

Although accessibility and flexibility encompasses a wide range of issues, participants in the present study primarily focused on issues of spatial accessibility, which includes proximity to services, transportation, and the individual's resulting ability to make use of the service offered, as well as alternative access options (i.e. flexibility and accommodations) to meet diverse needs (Gulliford et al., 2002). They spoke of desirable healthcare providers being far away, having regularly scheduled appointments they did not feel they could keep up with, and not having the energy to attend appointments. This was further compounded by delayed appointments, and brief appointment times, and the fact that adding together commute times, appointment delays, and the appointment itself, a single visit to a healthcare provider could take half a day.

All this could be tiring for anyone, but in combination with a condition that is painful and fatiguing by its nature, many participants in the present study described the process of getting to and from appointments as being detrimental to their health in and of itself: "It's tiring to make trips to the doctor. That's to say nothing of the like psychological

taxing weight of having to do stuff when you have certain type of chronic pain things” (Participant 9). Another participant trying to access a specialized pain service described an elongated intake process, which required several hours-long in-person appointments; the participant, who was unable to sit for an hour, hoped to be able to conduct the appointments remotely from her bed, but was denied: “I mean I gave them half a dozen suggestions of alternative ways I could access that program, and they told me no to every single one, and I was like, this is the disability accommodation that I would need to access the support. And they're like “we can't do that” (Participant 13). Participants in the present study also noted that healthcare appointments for FM include a combination of visits for chronic care management, as well as more acute care given the natural fluctuations that come with FM, thus adding to the barriers of access on days where an individual is in a more acute state.

Thus, as stated by Gulliford and colleagues, accessibility is more than a question of supply (2002). While services exist, data from the present study highlight that some individuals with FM are either not accessing, or are ceasing to use services, because they don't exist in a form that supports their health. Further, participants in the present study shared that when they were unable to attend an appointment due to FM related reasons—the reason for which they were accessing the service in the first place—they were often charged costly cancellation fees. While these fees make sense from a service provider perspective, they also pose an equity issue for many individuals with FM for whom flexibility is a necessary accessibility issue given the unpredictable nature of the condition.

Another theme among participant incidents related to flexibility was time—specifically, appointment lengths—which impacted participants' abilities to adequately address issues of importance to them. While many participants had hindering experiences related to short appointment times, they also shared helping experiences of healthcare

providers who allotted additional time for them. Given the complexity of FM and associated co-occurring conditions, standard 10 to 15 minute appointments times were found by Lempp et al. (2009) and Zotterman et al. (2016) as inadequate to address patient concerns, which was supported by participants from the present study. Describing the contrast, Participant 13 stated:

[My GP] gave me lots and lots of time. He wasn't trying to solve everything in ten minutes, which was so frustrating—to get a ten-minute doctor's appointment, where you are only supposed to bring one issue, and you're like, "Technically it's one issue but it's affected 45 different parts of my body, so I don't know how to unpack this."

Equitable access for FM was described by participants as including this kind of flexibility of appointment lengths, where patients could take "as much time as needed" to thoroughly address their concerns (Egali et al., 2008, p. 365).

Perhaps unsurprisingly, this desire for longer appointment times was a key feature in participants wish list items for this category. A unique finding of this study in terms of the FM literature emerged in participants' wishes for access accommodations such as phone appointments or online appointments, providing alternatives to in-person visits. These alternative means of attending appointments could allow patients with FM to more readily access healthcare services when and as needed, while minimizing harmful consequences associated with getting to and from appointments and the appointments themselves. Participants who had been referred to groups or educational programs for help managing FM wished for more flexibility in service design; they suggested that these programs could be delivered in modularized formats so that if a participant was feeling unwell and unable to attend, they could still continue the program and pick up the missing piece at a later date, rather than being removed from the program and having to start again as is often the case.

Another finding that emerged in the wish list items in this category was a desire for specific services or healthcare providers equipped to help patients better navigate the healthcare system. These included occupational therapists to conduct ergonomics assessments in the individuals' homes and help identify activities and movements that cause strain as well as lower impact ways of accomplishing necessary tasks, social workers to assist in guiding individuals with complex care needs through the healthcare system, and more healthcare services offered in an outreach format to attend to individuals when they are most in need and most unable to access care outside their homes. While this specific wish was not addressed elsewhere in the FM literature, this expression of desire for coordination among healthcare providers connects to the concept of continuity of care described by Gulliford, Nythani, and Morgan (2006) and the recommendation by Haggerty et al. (2014) that trust in care is built through coordination. Linked to Category 2: Financial and economic security and affordability, participants in the present study also expressed a desire for increased flexibility of financial aid programs, that could allow them to pause their financial aid payments and work when they felt able without losing access to financial aid entirely and having to start the process all over again.

Diagnosis making. As indicated above, the process of diagnosing FM is influenced by the macrosystem understanding of the condition. While experienced in the mesosystem and microsystem, as well as the chronosystem given that it is a process that takes place over time (Madden & Sim, 2006), diagnosis making is being discussed in the exosystem, given that this is where the diagnosis is defined by the healthcare system. As outlined in the literature review, the diagnostic criteria for FM were amended in 2010 such that FM diagnosis is now primarily a process of patient self-report (Fitzgerald et al., 2012; Wolfe & Hauser, 2011). However, despite these changes and increasing availability of information

about FM, participants in the present study described many healthcare providers as remaining unfamiliar with FM and struggling to make accurate diagnoses, a perception which was echoed by findings by Perrot et al., (2012). Participants in the present study shared both hindering and helping incidents related to diagnosis making, wherein the hindering incidents centred around the confusing and drawn out process associated with making a diagnosis, and the confusing diagnosis itself, and helping incidents related to experiences of validation stemming from making a diagnosis, as well as resultant access to information, treatments, and services when they were available.

In describing their experiences of diagnosis making, participants in the present study reported long processes, with multiple lab tests and physical exams that did not reveal any information. They also reported that diagnosis making was severely impeded by invalidating experiences with healthcare providers who, despite FM being primarily a diagnosis made through self-report, did not listen appear to listen to the patient's experiences, and seemed reluctant to give the FM diagnosis when it was discussed. This will be further explored in the discussion of Category 8: Validation and Category 9: Therapeutic alliance; however, understanding of diagnosis making requires recognition that validation and listening are central to this process (Åsbring & Närvänen, 2003; Fitzcharles et al., 2012). Concurring with research findings, participants of the present study reported that physicians conducted differential diagnosis to rule out other conditions, which involved a sequence of visits, laboratory tests, and physical examinations (Hadker et al., 2011; Madden & Sim, 2006). Participants in the present study related to these tests and examinations with ambivalence: on the one hand they were experienced as helping, in that participants perceived them as necessary to rule out other (potentially degenerative or life threatening) conditions, and also took them as an indication of being taken seriously by the

healthcare provider; on the other hand, they were experienced as hindering, in that test results came back negative or weren't followed up on at all, and they felt they were running out of options.

The Canadian Guidelines emphasize the importance of efficient identification and treatment of FM, however, studies show that diagnosis is frequently a long and disruptive process for individuals, with patients often seeking care for years prior to diagnosis (Perrot et al., 2012; Johnson, 2008). In contrast with other sources (Hadker et al., 2011; Madden & Sim, 2006), the Canadian Guidelines state that FM is not a diagnosis of exclusion, and that unnecessary laboratory examinations can be detrimental to patient wellbeing and should be avoided; findings by Sim and Madden (2008) echo that the process of diagnosis by exclusion has the potential to undermine patient credibility, since it results in a series of negative test results.

Patient descriptions of the process taking years while physicians sought a concrete diagnosis seem to correlate with literature findings with the dilemma around the biomedical model, in which physicians are trained to manage disease—which has an identifiable aetiology—and may feel helpless in the face of illness, which has none (Åsbring & Närvänen, 2003). It is possible that these physician experiences of helplessness, in combination with attachment to biomedical definitions of disease, may be influencing what participants perceived as reluctance to deliver an FM diagnosis. Undeland and Malterud (2007) found similar reports of physicians seeming reluctant to give the FM diagnosis, and unsure of its meaning. Ultimately, several participants in the present study stated that they themselves brought the FM diagnosis to the table with their healthcare providers, which was consistent with findings by Undeland and Malterud (2007).

The ambivalence toward diagnosis shared by participants of the present study is supported by research findings. In their study on meaning-making and FM, Madden and Sim (2006) wrote about diagnosis as serving the function of helping make meaning of an illness experience. However, the unclear nature of the FM diagnosis—as outline in the macrosystem discussion of Category 2: Clinical understanding of FM—is such that it holds little ability to explain the condition and offer a sense of direction as is expected of it (Madden and Sim, 2006). Participant 4 echoes the findings by Madden and Sim (2006), describing the dismay and confusion surrounding her experience of being given the FM diagnosis, as well as the diagnosing physician's reluctance to give the FM diagnosis:

The diagnosis itself really wasn't that helpful ... it was a very depressing experience. Very frustrating and demoralizing. ... We're still doing this provisionally, saying FM but you know, this is still under dispute and discussion, and there's no treatment. So what you are saying is I'm going to feel like this for the rest of my life?

Many participants of the present study shared this hope that diagnosis would resolve some uncertainty, which—from their reports—it was often unable to do. However, Madden and Sim describe that this lack of resolution was also contributed to by healthcare providers, who prevented exploratory discussion about FM, and associated emergent symptoms with the FM diagnosis rather than engaging in further examination and potential revision of the diagnosis, which could be the case for participants of the present study, many of whom reported experiences of invalidation, which will be explored in the discussion of Category 8: Validation.

For some participants, receiving a diagnosis did contribute some understanding; these participants reported that it gave them language to communicate their condition. Undeland and Malterud (2007) described similar participant relief at getting a name for

their condition, as well as a subsequent ability to talk to family members about it. They support the role of diagnosis as helping create coherence and meaning from experiences of illness, as well as diagnosis being an “essential precondition for coping” (p. 254).

Although they go on to discuss the hindering aspects of diagnosis outlined above, wherein a diagnosis perceived as empty contributes its own challenges, this aspect of diagnosis supporting coping was also found valuable. Participants in the present study found that diagnosis provided them with some structure to guide their research, and enabled them to begin identifying behaviours that aggravated and managed symptoms, which will be outlined in Category 16: Active coping and social support.

Undeland and Malterud (2007) also wrote about participant experiences of relief that the condition was a “less serious disease” than what they had previously feared, which some participants in the present study also expressed. Among helping factors, participants of the present study also reported that receiving a diagnosis from a physician contributed to their experience of validation in that a healthcare provider was accepting their claims of illness, another result which corresponded to findings by Undeland and Malterud (2007) which relayed the role of medical labels as validating.

Findings from the present study supported those by Undeland and Malterud (2007) that naming the condition is an important step in the illness process. They highlight the importance of physician’s being able to “tolerate the uncertainty of a diagnostic concept such as fibromyalgia” (p. 254) in order to support the patient in making meaning of the condition and life with FM. In the same vein, Hadler (1996) decries the process of what he calls disability determination, where the process of diagnosis takes on an often moralizing role in determining the legitimacy of illness, with detrimental results to patients.

“Participating as a physician in the disability determination process is an act of

iatrogenicity” (p.2399), he says. This aligns with participant wish list items for this category, where participant desires focused on a combination of more confidence and less reluctance in giving the FM diagnosis, more compassion when giving it, and more willingness to engage with patients around the meaning of diagnosis once it is given. Findings from this category contribute to the call for an adjusted diagnostic concept of FM and improved healthcare provider training, since if a treating healthcare provider does not understand and believe in a condition, appropriate diagnosis and treatment are unlikely to occur (Sabik, 2010).

Mesosystem

The mesosystem comprises interactions between a person’s microsystems (Bronfenbrenner, 1979). In the context of the present study, the mesosystem primarily related to interactions between healthcare providers, although it could also include interactions between healthcare providers, insurance and financial aid programs, employers, and family members. The resounding desire among participants of the present study for more interconnectedness and better communication of health information described above in Category 7: Models of healthcare delivery, while explored in the context of the exosystem, is also a mesosystem recommendation in that participants appear to be looking for improved communication among healthcare providers in terms of pertinent health information like test results, medication interactions, and treatment plans.

These issues allude to recommendations for improved continuity of care, which was Category 4 of this study. Continuity of care is a concept that describes quality of care over time, thus this discussion also comprises a chronosystem dimension. While continuity of care is considered a cornerstone of healthcare, definitions vary from one source to another (Gulliford, Naithani, & Morgan, 2006). In the context of the present study, continuity of

care is limited to the more basic definition of “seamless service” (p. 249), or as described by Bachrach, “the orderly, uninterrupted movement of patients among the diverse elements of the service delivery system” (Gulliford, Naithani, & Morgan, 2006, p. 1449). Some definitions also incorporate patient-centredness and the quality of patient-provider relationships (Gulliford, Naithani, & Morgan, 2006), however, these facets are contained within Category 9: Therapeutic alliance, and will be examined independently .

Continuity of care. Continuity of care was identified as a helping incident, and lack of continuity was identified as a hindering incident, by most participants in this study. Haggerty and colleagues (2013), noted that “coordination is inferred when no problems have occurred” (p. 266), thus, an ideal experience of continuity would feel seamless from a patient perspective. This corresponds to the notion of “experienced continuity” (Gulliford Naithani, & Morgan, 2006, p. 250), which refers to the smooth progression of care from a patient’s point of view. In the descriptions of participants of the present study, smooth progression allowed for diagnosis, and treatment or management of FM symptoms, whereas lack of progression often meant a worsening of symptoms over time.

A key feature of continuity of care in both hindering and helping incidents was the idea of relational continuity—the absence or presence of a key, trusted healthcare provider, who was a stable presence throughout the individual’s healthcare process, a concept also explored by Haggerty et al. (2003), in their research on the experience of continuity of care among patients accessing multiple clinicians. A number of participants reported hindering incidents related to difficulty finding a consistent healthcare provider and needing to access care through walk-in clinics or through a series of locums, which meant they were often seeing a different provider at each visit. These experiences left participants feeling “bounced back and forth” (Participant 13). They also contributed to experiences of lost

information and receiving conflicting information, or needing to repeat conversations, which eroded trust in the healthcare provider's competence, consistent with findings from the literature on FM (Haggerty et al., 2013; Zotterman et al., 2016), and prolonged their process of accessing care. Conversely, two participants of the present study shared experiences where walk-in clinics allowed flexibility in their policies so that they could see the same physician ongoing, which were seen as turning points in their healthcare experiences; these participants described having a consistent healthcare provider overseeing their care facilitated making a diagnosis, and also identifying hindering and helping treatment options.

As outlined above, communication between healthcare providers to facilitate informational continuity was described under models of healthcare delivery, but is also considered a continuity of care issue (Delva, Kerr, & Schultz, 2011; Haggerty et al., 2013). Participants experienced discontinuity in their experiences of specialist referrals, in which they felt "shifted around" (Participant 7) from one healthcare provider to another, often without context or follow up. Specialist referrals typically involved long wait times of months or even years, which frequently involved little care from the referring physician in the meantime. These experiences resulted in extended periods of time with little "progression" or "continual investigation" (Participant 11). It is notable here that specialist referrals in helping contexts still appeared to require long waits, however, the way they were presented to the participants differed, as did the way the healthcare provider managed the wait time with the individual until they could be seen by the specialist. In these situations, participants felt connected to a trusted healthcare provider, who they perceived as making thoughtful referrals for them. Some of these participants described receiving offers of follow up appointments as needed in the meantime, as well as explanations on

why the specific individual being referred to had been chosen. In the study by Haggerty et al. (2013), trust was found to be a key element of experienced continuity, in which respondents felt more confident in their care when connected to a trusted provider who served as a sort of secure base in the healthcare system, which supported findings by Delva, Kerr, and Schultz (2011). Relationship continuity and trust was found to be particularly important for managing sensitive or co-occurring conditions, as is the case with FM.

In the present study, the “care” component of continuity of care took on a particular importance in the context of FM, where so many experiences were characterized by judgment and invalidation. When participants were feeling bounced around, experiences of a provider expressing care, and an interest in working with them on an ongoing basis became all the more precious. As stated by Participant 5, “What was so helpful ... the core of it was [my doctor's] willingness to help. She constantly and consistently showed that.”

The concept of experienced continuity informed Haggerty and colleagues’ discussion of transition planning, where Haggerty et al. issue the reminder: “Professionals often forget that every transition is a new experience for patients, who need transition support,” (2014, p. 267). Wish list items for participants of the present study echoed this theme, emphasizing desires for transition and termination planning when a patient is being referred to a new healthcare provider or the current healthcare relationship is ending. In these items, participants expressed wishes for healthcare providers to recognize the important role they play in their patients’ lives—given that helping manage FM is central to all other facets of life. These wish list items also alluded to the importance of mattering, as discussed by Amundson (1993), particularly insofar as they hint at the dimensions of attention (being noticed), and ego-extension (others are interested in your successes and disappointments and actively follow your progress). Based on Amundson’s description of

job loss as a “non-mattering” experience resulting in feelings of despair, disillusionment, anger, and rejection, the descriptions of terminated healthcare relationships from the present study also appear to be non-mattering experiences, leading to similarly painful emotional experiences. Speaking to this important interpersonal milestone in the healthcare relationship, Haggerty et al. (2013) note that supporting a patient’s transition to a referral, or careful transition planning when a healthcare relationship is ending can make a significant impact on a patient’s continued wellbeing. The importance of continuity of care is further supported by the finding in Zotterman et al. (2016), which suggests that continuity of care, and the ability to spend time in appointments, lays the foundation for developing a trusting relationship with a healthcare provider.

Microsystem

The microsystem(s) describes the system(s) closest to the person (Bronfenbrenner, 1979). A person will have many microsystems in which they directly interact in bi-directional relationships. In the context of the present study, these microsystems referred to various specific healthcare providers. Microsystem categories that emerged in this study were: Category 9: Therapeutic alliance, Category 8: Validation, Category 11: Informed consent, Category 10: Iatrogenic suffering, and Category 12: Counselling and psychotherapy. Therapeutic alliance, validation, informed consent, and iatrogenic suffering will be discussed first as they can apply to any form of healthcare service provided; a discussion of counselling and psychotherapy will follow—recognizing that understanding of the former categories are encompassed within a counselling framework—expanding on how counselling and psychotherapy services are seen as hindering and helpful in the context of healthcare services for FM.

Therapeutic alliance. Therapeutic alliance was one of the largest helping categories identified in this study, and was endorsed by all participants. The helping incidents in this category emphasized experiences of feeling genuinely cared for, supported, and understood in healthcare relationships. Participants also spoke of helping relationships as being characterized by collaboration and non-expert stances on the part of healthcare providers. These qualities were seen as important for trust building, and when absent, participants commented that they mistrusted their healthcare providers and questioned their treatment plans. Conversely, hindering examples from this category described relationships experienced as overly clinical, emotionally detached, and authoritarian. Within these relationships participants described feeling dehumanized, and “like test subjects” (Participant 7), and tended to mistrust their healthcare providers.

Findings from the category of therapeutic alliance shared significant overlap with Brody's (2000) description of sustained partnership as an approach to maximizing the benefits of the placebo response in healthcare interactions. He highlighted interest in the whole person; knowing the patient over time (which in this study is encompassed in Category 4: Continuity of care); showing the patient care, sensitivity, and empathy; demonstrating reliability and trust to the patient; adapting treatment goals to the patient's needs and values; and encouraging the patient to participate fully in health decision-making.

In their study of primary healthcare encounters of people with chronic illness, Zotterman and colleagues (2016) found similar themes. Their study emphasized the importance of feeling “welcomed as a person” (p. 2857) in healthcare encounters, which included exhibiting respect, kindness, attentiveness, and listening. This description aligns with Brody's (2000) recommendation that physicians treat their patients with care,

sensitivity, and empathy, as well as highlighting the importance of his emphasis on listening carefully to their patient's story. Furthermore, this study described continuity of relationship and sufficient appointment time as prerequisites for developing patient-physician relationships, in that they allow the patient to feel they have the person's full attention and therefore fully heard in their visit. These relationships also provided a sense of someone and somewhere to return to as health-related questions emerged over time, as suggested above in the discussion of continuity of care, which lends some support to the present study's findings on continuity of care, as well as the understanding of continuity of care framed within the assumption of a caring and cooperative relationship (Gulliford et al., 2006).

These qualities of therapeutic alliance share significant overlap with the four dimensions of mattering presented in Chapter 2: Literature review: feeling that another person notices or is interested in you; feeling that another cares about what you want, think, and do; feeling that you are a contributing member and part of a team; and feeling that another is interested in your successes and disappointments and actively follows your progress (Amundson, 1993, p. 146), implying that an unspoken feature of these helping incidents were that they contributed to feelings of mattering among participants of the present study. Amundson further states that involvement in mattering experiences enables people to meet their basic needs for relationships and meaning in life, and helps boost morale and self-confidence. Additionally, Amundson states that mattering experiences are critical to coping with the emotional challenges associated with loss of work, which was a factor for most of the participants of the present study.

Non-expert stance. While studies emphasize the importance of healthcare provider expertise in building trust (Colmenares-Roa et al., 2016; Juuso et al., 2014; Zotterman et

al., 2016), a little-cited finding emerged in this study around the importance of a healthcare provider's ability to take a non-expert stance. This was not to say that participants desired that healthcare providers lacked knowledge; however, in working with this complex and often unpredictable condition, participants appreciated healthcare providers who could tolerate uncertainty and not-knowing when they encountered a challenge. This quality was perceived in contrast to what was sometimes described as the "God complex" (Participant 14) displayed by some healthcare providers, who took overly authoritarian stances.

Helping incidents in this sub-theme showed participants feeling more trusting of healthcare providers who could say, "I'm not sure. Let me look into that," (Participant 7). A similar finding was identified by Juuso et al. (2014) in whose study participants shared appreciation for healthcare providers who "dared to show their lack of knowledge about FM" (p. 1385) because this opened up opportunities for knowledge exchange. These kinds of acknowledgments increased sense of collaboration in patients, and also inspired trust in healthcare provider recommendations, believing that they would reflect and research prior to making a recommendation if they were unsure of something.

Collaboration. Further to Brody's (2000) description of incorporating the patient's needs, values, and participation in healthcare decision-making, collaborative dynamics described in findings by Haggerty et al. (2013), and Zotterman et al. (2016), coincided with those described by participants in the present study, focusing on the importance of communication and a sense of partnership, particularly in ways that empowered the patient with information about their illness. Zotterman and colleagues (2016) also found that patients wanted to be involved in their own care, which included having their opinions considered, follow up conversations, and explanations about their illness and care plans. Patients across these studies shared the importance of being able to contribute to the

process through their own self-awareness, ideas, and research, and working “in partnership” (Participant 12) with their healthcare providers and having an “equal relationship” (Participant 3). Findings by Zotterman et al. showed that being able to participate in their care was found to lead to patients’ improved confidence in themselves and their ability to manage their illness, as well as improved confidence in their healthcare providers and the treatment received, while lack of collaboration led to opposite experiences, resulting in uncertainty and anxiety.

Findings from this section illuminate the ways in which individuals with FM value and desire genuine connection with their healthcare provider. Having an ongoing, caring, connected, and collaborative relationships with healthcare providers was an important feature of helping healthcare experiences for individuals with FM. Desired and helping relationship factors included being listened to and the ability to engage in dialogue, where the patient’s perspective was invited and valued; receiving empathy and compassion, and feeling cared for; as well as the healthcare provider’s ability to recognize their limitations and pursue further training or research as needed. Findings from this category further allude to an even deeper meaning in terms of healthcare interactions as potential experiences of mattering, and suggest a possible avenue for further research.

Informed consent. While patients’ desires for information and collaboration were described, informed consent was not explicitly addressed in any of the FM or chronic illness literature reviewed for this study, however connections can be drawn to themes around the importance of communication and collaboration outlined in Zotterman et al. (2016). Although it was a relatively small category that might have been merged with collaboration, the researcher chose to maintain informed consent as a distinct category to highlight it as an independent process, separate from other aspects of the healthcare

relationship and treatment process. Five participants in the present study shared experiences of adverse outcomes that resulted from healthcare providers voiding their consent by dismissing explicit conversations about how to proceed with physical examinations, and not adequately informing them of possible consequences of their treatments.

In one such incident, a participant stopped taking a medication in consultation with his healthcare provider who had not advised him of possible severe withdrawal symptoms that he said “turned my world upside down” (Participant 9). When he sought emergency consultation for the unknown symptoms, the healthcare provider stated she hadn’t thought it would be a “big deal”. Another participant was prescribed a medication without being informed of possible severe side effects, which resulted in her becoming severely ill, while yet another participant went on to explain that her desire to be fully informed was interpreted as non-compliance, and led to the healthcare provider documenting a psychiatric diagnosis in her file without informing her. While Zotterman et al. (2016) did not identify the construct “informed consent” their findings underscore the importance of patients being empowered with information about their illness and their care plans, including receiving information about test results and medications. Furthermore, their findings highlight the need for these explanations to be a continuous process of informing, rather than an event. They go on to elucidate that lack of follow up conversations and continued dialogue left patients with feelings of uncertainty and anxiety, left them feeling unimportant—which might be interpreted as mattering, as per Amundson (1993)—and potentially jeopardized their safety. This coincides with descriptions by participants of the present study, who emphasized how as patients, they place their health, and implicitly their lives, in the confidence of their healthcare providers.

One participant of the present study addressed a hindering experience of desperation and powerlessness that she experienced as virtually nullifying her to provide informed consent, stating: “I am going to take whatever is provided to me because I am desperate, and what do I have to lose like I am just going to be sick so I might as well try even it is going to make me sicker” (Participant 14). This potential state of suggests a need for healthcare providers working with individuals experiencing such states of powerlessness to proceed with caution, to avoid causing further harm, rather than conceding to the patient’s resignation, adding further importance to data highlighting the importance of therapeutic alliance, collaboration, and keeping patients involved in their own care processes (Zotterman et al., 2016).

Iatrogenic suffering. Iatrogenic suffering refers to unintentional adverse effects of healthcare encounters. This category includes both adverse outcomes through relational aspects of healthcare encounters, as well as adverse outcomes from treatments; while adverse outcomes from medications are technically iatrogenic effects, these items have been included in the discussion of Category 13: Medication.

Corresponding with findings by Traska et al. (2011), participants in the present study reported reluctance to access manual treatments such as massage therapy, because touch can be so painful. Findings from the present study also reflected findings by Lempp et al. (2009), that revealed have found certain manual treatments could escalate symptoms. Participants in the present study reported that being touched in a “gentle and intuitive” (Participant 13) way, or feeling “poked and prodded” (Participant 12) could lead to result in them feeling worse off. Participant 1 stated about a chiropractor appointment, “the next day I felt like shit. I felt so sick. My whole body hurt. It hurt to have clothing touch my skin, and I was like, I never want to do this again.” Incidents in this category indicated that

adverse effects of treatments could not only have severe impacts on patients' wellbeing, but these effects could leave someone in "much worse shape for an extended period. It's not just for that day, it's weeks or even months after to get back to where I was before I went to the appointment" (Participant 13).

Building on a core philosophy of medical practice—to relieve patient suffering—Zotterman and colleagues (2016) argue that "being valued as a patient is fundamental to the health process itself" (p 2859). Although descriptions of iatrogenic encounters were minimal, Zotterman and colleagues (2016) found that experiences of connectedness with healthcare providers strengthened experiences of health and wellbeing. Similarly, in their study on experiences of being received and met, Juuso and colleagues identified that the need for healthcare contacts decreased over time when trusting healthcare relationships had been created (2014).

Although briefly mentioned by Zotterman et al. (2016) and Sabik (2010) this category appears to have a unique prominence in the present study. Most participants in this study endorsed incidents in this category, which focused specifically on healthcare encounters that led to a worsening of participants' symptoms. Some participants described iatrogenic suffering as a result of manual therapies that resulted in adverse effects (Participants 1, 13, and 14); however, most of the incidents introduced examples of iatrogenic effects stemming from hindering relational factors such as experiences of invalidation (Participants 2 and 8), and lack of compassion (Participant 14). These incidents described worsening of pain and fatigue, as well as generating anxiety, particularly in response to future healthcare interactions.

Describing one such incident, Participant 8 stated: "Experiences of being invalidated or dismissed by doctors is really painful, and contributes to being in pain, and in

a painful state of mind.” This connection between invalidation and dismissal, and adverse health outcomes, ties back Zotterman et al. (2016), who expressed that not being seen as credible can injure a person’s dignity. Zotterman et al. go on to identify violations of patient dignity as iatrogenic, since they erode the patient’s ability to make use of their internal resources for healing. Similarly, Juuso et al. (2014) wrote that their participants “described that the lack of engagement and interest among health care personnel about the causes and symptoms had worsened their health and affected their entire life” (p. 1384). All of these examples coincide with Kuhl’s (2011) description of iatrogenic suffering, which centralizes communication in the relationship between the healthcare provider and the patient; in his example, when key communications about health are not delivered with care, they can cause patient suffering.

Conversely, one participant in the present study described her relationship with a healthcare provider in a way that seemed to be consistent with the finding in Zotterman et al. (2016) that participants view therapeutic alliance as a factor contributing to their wellbeing, stating: “I had a good working relationship with my naturopath, and I think I got better under her care because she gave a shit about who I was.” This also aligned with research findings by Juuso et al. (2014) who wrote that “To be received in a dialogue, the women’s experiences were in focus and it gave them feelings of security and of being important” (p. 1383). Further underscoring the importance of caring, collaborative relationships, results from Zotterman et al. (2016) and Juuso et al. (2011) identified that when patients experience characteristics of a strong therapeutic alliance with a healthcare provider—such as feeling welcomed and cared for—this contributed to an experience of improved health, while when patients feel an absence of therapeutic alliance feeling insulted and violated—this contributed to an experience of deterioration, suggesting that

qualities of therapeutic alliance might be mediating factors in iatrogenic suffering as well as in overall healthcare outcomes.

Findings from this category contribute to information about adverse effects of treatments, as well as the importance therapeutic alliance. Part of the importance of being able to collaborate and engage in dialogue with their healthcare providers as outlined in Category 9: Therapeutic alliance, related to be able to communicate their own understandings of their bodies and how different activities and treatments impact them. Participants desired that healthcare providers recognize that iatrogenic suffering can have profound impacts on the lives of individuals with FM, and hoped they could “realize that everything that happens in the doctor-patient interaction is felt acutely and is extremely painful in our bodies. If they can make it slightly less then you [sic.] might save someone's life” (Participant 7), which corresponded with Sabik’s findings that stigmatized interactions with healthcare providers can lead to distress and increase FM related problems (2010). Thus, reaffirming the importance of addressing stigma around FM, and improving the quality of relationships between patients and healthcare providers in order to mitigate iatrogenic suffering.

Validation. Validation and invalidation were found to be defining features of experiences of healthcare access for individuals with FM. Experiences of invalidation were the most frequently cited hindering incidents in this study (32 incidents). The importance of these incidents become further accentuated by findings such as those by Zotterman et al. (2016) and Juuso et al. (2014) that correlated validating experiences with positive health outcomes, and invalidating experiences with negative health outcomes. Most incidents in this category related to the macrosystem themes around the validity of FM as a diagnosis, which became translated into microsystem interactions.

Descriptions of invalidating experiences accessing healthcare services are common in the FM literature (Åsbring & Närvänen, 2002; Sim & Madden, 2008; Werner & Malterud, 2003), a finding which was also the case in the present study. As found in the literature, participants in the present study described experiences of feeling rejected, ignored, and told “there is nothing wrong with you” (Participants 1, 8, and 10) and also had their symptoms dismissed as psychogenic (Participants 1, 2, 3, 4, 5, 7, 8, 9, 12, and 13). Consistent with descriptions by Zotterman et al. (2016) and Juuso et al. (2014), these participants found that invalidating experiences eroded trust in their healthcare providers. Furthermore, because the invalidating encounters were so pervasive and perceived as entrenched in the conventional biomedical model, they eroded trust in the healthcare system overall.

It is worth noting here that healthcare provider discomfort with FM patients is not just the perception of individuals with FM. Findings from studies investigating healthcare provider experiences with FM patients support these claims. In a cross-sectional study of over 500 primary care physicians across 12 academic medical centres in the United States, only 1% of respondents reported finding management of chronic pain patients satisfying, which led to the under-treatment of chronic pain (O’Rourke et al., 2007). In the same study, 76% of respondents reported frustration in treating patients with chronic pain. In their anthropological study, which involved interviews with four rheumatologists in Mexico, Colmenares-Roa et al. (2016) received disclosures that FM patients were found to be difficult to treat and time consuming, complicated by psychological symptoms, and yield little improvement, which led to them not wanting to work with these patients. They wrote, “Rheumatologists’ descriptions of their colleagues’ opinions about fibromyalgia patients

include not only the reluctance and refusal to see them but they also have an overt resentful and aggressive attitude toward them,” (p. 1680).

Participants in the present study reported both explicit and implicit experiences of these attitudes when accessing care. Two participants described overt hostility from rheumatologists (Participants 2 and 10), such as:

My doctor did send me to a rheumatologist, because you're supposed to see one get a diagnosis. ... this woman was utterly dismissive, like, 'Look, you don't have anything physically wrong with you. I've got all these people with rheumatoid arthritis. Get to the gym and get on with your life.' I mean she threw me out. She was really rude and nasty actually. She had no time for anybody with my problems. (Participant 10)

Less overt forms of invalidation were experienced through healthcare providers' disbelief in their symptoms, which frequently took the form of dismissing their symptoms as psychogenic.

As stated above in the discussion of iatrogenic suffering, “the lack of engagement and interest among health care personnel about the causes and symptoms had worsened their health and affected their entire life” (Juuso et al., 2014, p. 1384). In addition to being detrimental to a patient's perception of individual healthcare providers and the overall healthcare system, invalidation can also negatively impact an individual's self-perception, as will be explored further in Category 14: Internalization of adverse healthcare experiences. This appeared to be particularly the case with the incidents described in the *“It's all in your head”* sub-theme. This particular form of invalidation invokes the socio-political context of the conventional biomedical model that feminizes pain (Werner & Malterud, 2003), and construes the feminine psychologically weak (White, Lemkau, & Clasen, 2001). Having frequently experienced invalidation of this form, individuals might be sensitive even to well-intentioned recommendations that they seek counselling support

(Hadler, 1996; White, Lemkau, & Clasen, 2001), which will be discussed further in Category 12: Counselling and psychotherapy.

While there were fewer of them, participants did describe experiences of validation (15 incidents). In these examples, as shown in Zotterman et al. (2016), healthcare providers showed genuine interest in helping the participant treat the condition. A finding that did not appear elsewhere in the literature involved examples of healthcare providers making explicit statements in confirmation of the patient's experience, such as described by Participant 9, who's doctor told him: "I just want you to know that I don't think you're crazy and I believe what you're saying. I know that it's not common for people to believe these things like this or at least state it ... so that's why I'm telling you." These expressions of belief in the patient "on face value" (Participant 14) were described as helpful to participants, several of whom shared the desire for more of such responses from healthcare providers.

Findings related to validation in healthcare experiences relate to the "invisibility" of FM by conventional biomedical standards (Sim & Madden, 2008). When lab tests fail to produce objective confirmation of symptoms reported, the patient's credibility is brought into question. In the absence of physical examination and diagnostic laboratory tests, the diagnosis of FM relies on a "detailed and thoughtful interview of the patient" (Wolfe & Häuser, 2011, p. 6). A detailed and thoughtful interview thus requires attentiveness to the patient experience, and a basic premise of believing the patient's experience in order to make a diagnosis. Furthermore, building on previous categories, the role of validation can be seen in its impact on overall patient wellbeing.

Counselling and psychotherapy. Although it holds fewer incidents relative to other categories in this study, counselling and psychotherapy was kept as a distinct category

in part due to the place it holds at the intersection of hindering and helping factors associated with therapeutic alliance; validation and invalidation, especially related to psychogenesis; and coping, which will be addressed further on in the discussion of Category 16: Coping. Furthermore, because the literature review for this study did not yield any research directly addressing experiences of counselling for FM, the researcher determined this category to be of unique importance.

Hindering incidents of counselling and psychotherapy all held some overlap with invalidation in that the therapists described by the participants in the present study believed that the FM symptoms experiences were psychogenic. Helping incidents in this category focused on different aspects of counselling and psychotherapy treatment, addressing the benefits of having an attentive, compassionate, empathetic support; as well as someone who could help them learn symptom management, and other coping strategies.

Addressing an experience held by several participants, Hadler (1996) commented on the practice of referring to counselling or psychotherapy following prolonged, unfruitful examinations within the conventional biomedical model: “medicine is not likely to accept blame for subjecting the patient to months of an exercise that turned out to be flawed in design and iatrogenic in execution. One option is to suggest counseling of some ilk; more often than not, the patient hears, ‘You think it’s in my mind,’ and bridles at the affront to their perspicacity, if not veracity” (p. 2398). This description paralleled the experiences of participants who endorsed hindering incidents in the counselling and psychotherapy category, wherein referrals to counselling and experiences of counselling compounded the invalidating messages they were receiving from healthcare providers. In one such experience, a participant was repeatedly asked “what was [sic] the reward for being sick ... implying that it was psychologically based” (Participant 4). Another was told by his

psychiatrist that his symptoms were psychosomatic—that he was depressed and therefore “perceiving things as painful” (Participant 9). Because of experiences like these, as well as the stigma associated with mental illness and the ways FM have been historically dismissed, individuals with FM may take suggestions that there could be a psychological component to FM as further invalidation (White, Lemkau, & Clasen, 2001). Thus, it is incumbent upon healthcare providers to be familiar with FM and the surrounding contexts, so that such suggestions and subsequent treatment can be carefully addressed (White, Lemkau, & Clasen, 2001).

Psychological therapy is recommended by the Canadian Guidelines (Fitzcharles et al., 2012) for its ability to help educate patients about FM, improve pain-related behaviour, and provide support for associated distress that can come with FM, all of which were described in the helping incidents in this category. Notably, only six incidents identified throughout this study explicitly described a healthcare professional providing education on pain- or other symptom-management strategies; three of these incidents were in the counselling and psychotherapy category. In addition to offering the helping facets of therapeutic alliance described above, helping counselling and psychotherapy incidents also offered de-stigmatizing experiences; empathy; and symptom-management skills, helping patients understand the interconnectedness of emotions, anxiety, pain, and other symptoms, which was consistent with findings by McCracken and Vowles (2014).

Finally, a distinctive finding emerged from this category relating to the importance of support in the face of transition, loss, and grief (White, Lemkau, & Clasen, 2001). One participant spoke of the supportive role her counsellor took during a time that was characterized by significant loss due to FM saying:

It was very in depth, incredibly empathetic counselling. It wasn't just about chronic medical conditions; it was about all the other things that were happening in my life. ... There's a lot of grief, there's a lot of loss, I mean, I was at the height of my career, at the height of my ability. I was totally taken down, in a way that I could never regain. (Participant 10)

Three other participants advocated for counselling and psychotherapy as a support for FM; in two cases these wishes list items addressed the importance of adjusting to change and living with FM (Participants 5 and 11), and the other believed "Anyone with fibromyalgia should have a grief counsellor, hands down" (Participant 7). The role of the counsellor in adjusting the change and grief echoes findings by Sabik (2010) who suggested that "interventions dealing with psychological issues, like stigma and blame, should be developed and implemented" (p. 34). Further implications for the field of counselling and psychotherapy will be discussed below, prior to conclusions.

Person

Finally, at the centre of the concentric, nested systems, is the person (Bronfenbrenner, 1979). Factors related to the person include individual biological traits, as well as mental, and emotional resources. Categories that will be discussed in this section are: Category 14: Internalization of adverse healthcare experiences, Category 13: Medication and medical marijuana, Category 15: Exercise and physical activity, and Category 16: Active coping and social support.

Internalization of adverse healthcare experiences. Internalization of adverse healthcare experiences is a complex, and dangerous occurrence, which has received little attention in the FM literature. Pernice et al. (2017) described self-stigma, or internalized stigma, as the "second illness" because of the additional barriers it creates in social roles

and relationships. In their study interviewing 59 individuals with chronic fatigue syndrome (CFS)—another highly contested diagnosis, often associated with FM—Clarke and James (2003) highlight the ways the “self” is disrupted and changed by experiences of contested illness. They describe the “self” as a sociological concept, which is “constructed through reflexive interaction with others” (p. 1388). This means that the self is acquired, emergent, shifting and changing through interactions. It only follows then, that the self would be changes through experiences of chronic illness and resulting healthcare interactions. Citing Foucault, Clarke and James (2003) observe how dominant discourses—such as those described in the macrosystem section of this study—come to shape definitions of self. As individuals engage in processes of self-policing, dominant discourses are both resisted and internalized as terms of reference. Through this process, interactions with healthcare providers, as well as self-policing based on dominant societal values, become internalized—become part of the person’s self-definition.

A dominant value held by the conventional biomedical model emphasizes overcoming illness (Clarke & James, 2003). This value system focuses on defeating illness as if it were an enemy, and returning the person to “normal” (p. 1389). This internalization process was described by many participants of the present study in their descriptions of negotiating the chronicity of FM, who talked about having taken on values and judgments they were exposed to through adverse healthcare experiences. Examples included: believing they were weak and “shouldn’t be feeling this way” (Participant 1); questioning their realities, and starting to think they were going crazy, manifesting their symptoms, just being lazy, or worrying that they were being hypochondriacs (Participants 4, 6, 7, 8, 9, 11, 13); and internalizing blame and believing they were somehow at fault (Participant 9). These findings appear to be consistent with findings by Lempp et al. (2009) that following

diagnosis, patients' health identities transform, progressively undermining their sense of self.

In some cases, having internalized doubt, these experiences led to participants in the present study feeling reluctant to access healthcare services. They began to question themselves and therefore the legitimacy of their need for treatment. Furthermore, participants discussed hesitance and even unwillingness to take psychotropic medications because of their stigmatized associations with mental health which have been used to delegitimize FM experiences. Finally, participants reported increased hesitance to disclose FM, as internalized stigma resulted in feelings of shame. Findings from this category further underscores the importance of providing validating healthcare experiences for individuals with FM, recognizing that invalidating experiences not only contribute to adverse health outcomes, but also can become incorporated into a person's sense of self. Internalization of adverse experiences in this way can impact a person's willingness to accept treatment options that may be helpful, willingness to seek care at all, and even their belief that they deserve care.

Medication and medical marijuana. According to the Canadian Guidelines (Fitzcharles et al., 2012), "ideal management" of FM includes both pharmacologic and non-pharmacologic treatments. However, participants in this study displayed ambivalence toward pharmacologic treatments. In their study of challenges and barriers in the treatment and management of FM, Hadker et al. (2011) also demonstrated a multimodel strategy, with pharmacologic treatments being most commonly used. However, while participants shared some helping incidents related to medication and medical marijuana, there were almost twice as many hindering incidents in this category.

Findings from the present study supported findings from Durif-Bruckert, Roux, and Rousset (2015), who reported that patients with FM often attempt multiple kinds of medication, struggling to find the correct medication or dose to address their symptoms, and often being impeded by serious side effects. Participants in the present study described a range of challenges with medications including: allergies, addiction, withdrawal, side effects—including some that amplified the symptoms they were seeking to treat, or medications simply not working. In some cases, medications did not address symptoms while also incurring side effects, while in others medications were found to relieve symptoms however they left the participant unable to function in daily life.

Notably, of the 11 helping incidents related to medication, four of them addressed medical marijuana. Three participants found medical marijuana worked better for relieving their symptoms than any of the other medications they tried, and produced less or more tolerable side effects. It was found helpful in a range of symptoms: elevation of mood, managing anxiety, pain relief, and reducing the length of “flares” (periods of increased symptomology). Medical marijuana was a hindering incident for two participants, one of whom also endorsed it as helpful but had side effects with some strains, and another who experienced no benefit from it. Medications in general were found helpful when they were able to address symptoms. However, these experiences tended to require significant trial and error, and healthcare provider willingness to engage in an ongoing process of collaboration and adjustment, as found by Durif-Bruckert, Roux, and Rousset (2015).

A discussion of medications would be remiss without emphasizing the impact side effects have on the lives of individuals with FM. While they are noted in research related to medication (Durif-Bruckert, Roux, and Rousset, 2015; Fitzcharles et al., 2012, Hadker et al., 2011), these mentions do not appear to capture the extent to which these adverse effects

impact the lives of individuals with FM, who are often already severely debilitated by the symptoms of the condition. Furthermore, financial cost is a hindering factor, given that exploring various medications often requires out-of-pocket expenses for costly prescriptions, many of which are not covered (Briones-Vozmeiano et al., 2013). Findings from this category support recommendations of further investigation into pharmacological treatments of FM, and physicians' knowledge of appropriate treatments (Hadker et al., 2011; Durif-Bruckert, Roux, & Rousset, 2015). Participant experiences build on this awareness through emphasizing the importance of caution when attempting medications, and involvement in all collaborative process, including follow-up appointments to monitor medication effectiveness and side-effects, and make adjustments as necessary.

Medical marijuana was a preferred medication for several participants. Although medical marijuana is available by prescription in Canada, the political context is still somewhat gray around marijuana use, given that it is still illegal without Health Canada exemption (Fitzcharles et al., 2012). As a result, some participants expressed concern that use of medical marijuana might lead to negative repercussions in their lives. For this reason, increased attention was paid to anonymity, and participant numbers have not been used in this section of the discussion. Findings from the present study may support preliminary research about the potential benefits of cannabinoid treatments for FM discussed by Fitzcharles et al. (2012).

Exercise and physical activity. In their recommended multimodal approach, the Canadian Guidelines (Fitzcharles et al., 2012) endorse inclusion of “at least one exercise therapy” (section 2.2.2), which they recommend as the first step of a multimodal treatment strategy. Experientially however, exercise and physical activity was discussed with

ambivalence by participants. Some participants reported helping experiences of exercise and physical activity, however more participants reported hindering experiences.

Participant hindering experiences of exercise largely related to experiences of being told by healthcare providers: “Exercise even if it hurts. Find something you can do, and go figure it out ... Get to the gym and get on with your life” (Participant 10). Although they acknowledge that “subjective muscle pain may be a barrier to optimal exercise activity” Fitzcharles et al. (2012) state that findings suggest that “FM patients overscore their perception of exertion” and (section 2.2.4). This kind of framing appears to echo participant descriptions of healthcare encounters related to exercise and physical activity. Participants talked about feeling invalidated by being instructed to exercise, because they felt unable to do so due to pain and fatigue, and that exercise exacerbated their symptoms.

Fear-avoidance research appears to have some valuable contributions to the discussion of exercise and physical activity in FM. The fear-avoidance model describes how chronic musculoskeletal pain can develop or be perpetuated as a result of avoidant and fear based behaviour in response to pain (Leeuw, Goossens, Linton, Crombez, Boersma, & Vlaeyen, 2007). While in the case of acute pain, this response allows the body to recover after an injury, in the case of chronic pain, this response contributes to deterioration through restricting normal use. For this reason, exercise and physical activity is recommended in FM. However, no participants described receiving any such education about fear-avoidance and why healthcare providers might be recommending this approach, nor did they describe receiving any guidance from primary-care providers around how to approach exercise in a way that would be appropriate for their symptoms. Instead, participants described being told to exercise in dismissive ways that closed off dialogue. Furthermore,

while exercise and physical activity may be valuable in addressing symptoms of FM, managing energy levels is also important in fatiguing conditions.

Some helping incidents endorsed exercise and physical activity as helpful, particularly in addressing pain. Among participants who reported helping incidents related to exercise and physical activity, one worked with an instructor who had training in rehabilitation (Participant 4). Another participant described a process of trial and error in which she took three years to build up to an exercise routine that worked for her, stating “it’s a fine balance between overdoing and underdoing it” (Participant 2).

These findings indicate that while exercise and physical activity may be helpful in managing symptoms of FM, the suggestion to incorporate it in a treatment plan needs to be approached with more recognition of why patients might be averse to it. This could include more education and guidance both in understanding why it is being recommended, as well as how to negotiate finding an exercise and physical activity routine that is right for them while mitigating adverse effects.

Active coping and social support. According to a literature review by Annemans, Le Lay, and Taïeb (2009) active coping strategies and social support can improve quality of life among individuals with FM. Although not all the items in this category were related to healthcare interactions, this category was included in order to describe some of the ways the person draws on their own internal resources to adapt within systems that are not meeting their needs. Further, although social support is a form of interpersonal coping and is thereby a microsystem interaction, it was decided to keep these incidents within the coping category since they had more overlap than not.

A study by Traska, Rutledge, Mouttapa, Weiss, and Aquino (2011) investigating symptom management strategies by women with FM found that, while respondents talked

about pharmacologic approaches, they focused more on other approaches, including: pacing and planning, mind-body-spirit approaches and distraction, social support, and pushing themselves. Another study by Egeli, Crooks, Matheson, Ursa, and Marchant, (2008) examining patients' perspectives on improving care for people with FM found that patients cope with negative physician encounters through undertaking research and education, and assertive action. Yet another study, a metasynthesis of qualitative studies by Sim and Madden (2008) found that the ability to understand FM was central to coping, which involved listening to one's body, gaining information, and accepting losses. Findings from the present study were consistent with most of these results, with some minor distinctions: acceptance of loss did not emerge as a form of coping, however, it was discussed by participants in the context of counselling and psychotherapy.; and, while examples of pacing, planning, and pushing themselves to carry on were cited, there were not enough of them to form discrete sub-themes, and as such, they were included in the miscellaneous sub-theme. Active coping and social support sub-themes in this study included: information seeking and education, self-advocacy, social supports, symptom management strategies, and a miscellaneous category which included planning ahead, spirituality, and creative practice.

Consistent with the finding by Sim and Madden (2008) indicating that understanding was central to coping with FM, the dominant sub-theme in the present study related to information seeking and education (15 incidents). In response to the confusion, and the lack of information and understanding provided through accessing healthcare, participants were empowered by acquiring information about FM. As stated by Participant 7: "Having information gives you agency and autonomy." Some participants further reported taking the information they found back to their healthcare providers, and

advocating for their own care, coinciding with findings by Egeli et al. (2008). Another way participants advocated for their own care was through carefully selecting the healthcare providers they wanted to work with, and learning as much as they could about the healthcare system in order to navigate it more smoothly.

Lending support to findings by Traska et al. (2011), the second major sub-theme in this category was symptom management strategies (12 incidents), most of which incorporated cognitive-behavioural strategies based on recognizing the interconnections of thoughts, behaviours, emotions, and physiology, as well as mindfulness meditation, and relaxation training. In this sub-theme, incidents addressed participants' ways of learning to listen to their bodies, and manage their relationships to pain.

While discussion of social support in Traska et al. (2011) primarily focused on shared experiences, social support in the present study addressed task completion, such as keeping track of appointments, and finding out about services. This distinction could relate to the nature of the research questions being asked, however. Four wish list items in this category addressed desires for more social support. One participant wished for family supports to be available, to help family members cope with transition and better understand loved ones with FM (Participant 2); another participant wished for support in staying engaged in her community (Participant 3); while the others desired support for task completion, such as shopping, cooking, and cleaning (Participants 3 and 13). The other wish list item in this category addressed a desire for more mindfulness meditation groups (Participant 9).

Overall, the coping strategies outlined in this category further support to the coping-related strategies outlined elsewhere. These findings also contribute understanding of how people adapt to ensure their healthcare needs are met when these experiences are

dissatisfactory. Sub-theme findings pertaining to information seeking and education, and symptom management strategies are particularly noteworthy, since these were all incidents in which participants responded to a gap in healthcare services through active coping strategies. Further, these sub-theme findings suggest that healthcare services could be better meeting the needs of individuals with FM by moving away from a largely pharmacological approach, toward incorporating education about the condition, and through symptom management techniques.

Limitations

There are some limitations to this study that need to be recognized. Firstly, it is important to acknowledge that demographic data regarding race and ethnicity were not collected in this study; the omission of these data in collecting demographics was an oversight in the study design, and would be important to collect in future studies. Findings from Lempp et al. (2009) indicate that race and ethnicity can be important factors in patients' experiences of trust in their healthcare providers. This experience was articulated by one participant, who identified that her skin colour had been a factor in delayed diagnosis for FM and co-occurring conditions, since healthcare providers are "biased in what FM patients should look like" (Participant 7). She also spoke of the impact of racialized power dynamics, saying "every specialist I have gone to is a wealthy white man at the head of his career". Further research into the experiences of people of colour accessing healthcare services for FM is recommended.

Additionally, while this study included both female- and male-identified participants, many of the studies referred to in this research had exclusively female-identified samples. As suggested by Werner and Malterud (2003), and White, Lemkau, and Classen (2001), FM appears to be a gendered condition, therefore the experiences of male-

identified individuals, which have been studied to a lesser extent, may hold unique experiences. Further research accounting for sex and gender specific factors in experiences with FM are recommended.

Furthermore, this study features a notable demographic characteristic insofar as all participants had some form of post-secondary education, giving this study sample a disproportionately high level of education compared to the general population. The results of this study might be impacted by this sample's relatively high level of education in a number of ways, including the prominence of research as a coping strategy, and participants' articulateness in describing and analyzing their experiences.

Finally, it is notable that the experiences described in this study took place over a broad range of time; therefore these descriptions may not all pertain to the current state of healthcare service provision for FM. However, attention was placed on ensuring participants in this study represented diverse lengths of time living with symptoms for FM, as well as since diagnosis. Furthermore, since categories required at minimum 25% percent participation (and all categories had more than this minimum), these categories are still considered descriptive of applicable themes in hindering, helping, and desired factors, in accessing healthcare services for individuals with FM.

Implications for counselling and psychotherapy

There are several implications of these findings for the field and practice of counselling and psychotherapy. Firstly, recognizing the helping role of therapeutic alliance found in this study, counsellors and psychotherapists appear well positioned to support this need based on the specific nature of the counselling and psychotherapy model. Participants in the present study echoed findings by Zotterman et al. (2016) on the importance of therapeutic alliance—particularly feeling listened to, and welcomed as a person—which is

an integral feature of the counselling and psychotherapy approach, and also alluded to the experiences with healthcare providers as potential experiences of mattering as per descriptions by Amundson (1993).

These findings draw attention to a need to recognize that referrals to counselling and psychotherapy may trigger past experiences of invalidation about the legitimacy of a patient's condition. These findings thus suggest that counsellors and psychotherapists hold this in awareness when meeting new clients, and take steps to actively validate the client or patient's experiences. Validation may also support the development of an alternative narrative to the one perpetuated within the conventional biomedical model, whereby being believed may protect against internalization of adverse experiences. Counsellors and psychotherapists might further address issues of validation by consulting with referring healthcare providers to discuss helpful ways referrals might be made for this client population.

Furthermore, these findings lend support to research by White, Lemkau, and Clasen (2014) pointing to the role of the counsellor in helping clients and patients adjust to illness, and cope with losses associated with FM. In the conventional biomedical model, largely defined value expectation that illness will be overcome, counsellors and psychotherapists have a particular role in helping clients and patients navigate the multiple losses and related grief, and finding acceptance of life with a chronic condition (White, Lemkau, & Clasen, 2014). Counsellors are seen as key facilitators of adaptation to change, and processing loss, making them a support desired by participants in this study. These findings support the recommendation by Sabik (2010) that interventions addressing and blame associated with healthcare experience of FM should be developed and implemented; additionally, findings

from this study indicate the importance of counselling and psychotherapy being sensitive to—and supporting recovery from—internalization of adverse healthcare experiences.

These findings further suggest that counsellors and psychotherapists can support individuals with FM through psychoeducation about the biopsychosocial nature of the condition (Fitzcharles et al., 2012; White, Lemkau, & Clasen 2014). Counsellors and psychotherapists have a role in helping clients and patients understand the interconnectedness of their symptoms, and learn tools for coping with chronic pain and other symptoms. While information and education were found to be helping factors in coping (as will be outlined below in the discussion of Category 16: Active coping and social supports) and desired by participants, psychoeducation around how chronic pain is different from acute pain, cognitive-behavioural approaches to symptom management, and mindfulness and acceptance strategies appear to be infrequently introduced by healthcare providers in the conventional biomedical model.

Finally, over the course of the interviews for the present study, the researcher noted that most participants commented during a break or after the interview on how they were benefitting from the process of the interview. While these comments could not be counted as incidents because they were not recorded and transcribed, they do suggest that something participants were desiring in their healthcare experiences, perhaps being listened to, was being provided through the interview process. The interview process for the present study contained aspects of two out of three of the features of the meaning model described by Brody (2000); while participants did not receive explanations of their illness through the interview process, significant time was spent with each participant, during which the researcher did “listen carefully to [participants’] accounts of their illness” (p.652); additionally, many participants described feeling cared for in the interview process.

Conclusion

The findings of this study contribute to understanding experiences of healthcare access for individuals with FM, by identifying specific categories of incidents that are hindering, helping, and desired by this population. A unique feature of this study demonstrated—through leaving the definition of healthcare open to participants—the breadth of the ways individuals with FM conceptualize their healthcare experiences. Further analysis of these categories shows that individuals with FM are hindered and helped by systemic factors that they do not directly interact with, but that nonetheless have significant impacts on their healthcare experiences and overall individual functioning. The finding of more hindering than helping incidents in this study suggests a number of areas in the healthcare system that could be changed to better accommodate the needs of the participants of the present study, consistent with the literature, which shows that individuals with FM tend to describe discontentment with their healthcare experiences (Briones-Vozmediano et al., 2013; Egali et al., 2008; Juuso et al., 2011). This is further implied in the observation that the largest helping category was Category 16: Active coping and social supports, which involved exclusively participant-driven helping factors, rather than helping factors contributed from within the healthcare system.

Additionally, the EST framework illuminates some of the ways that subsystem categories are potentially being impacted by higher order themes. A critical finding of this study emanates from the manner in which macrosystem factors related to stigmatized definitions of FM influence hindering factors in subsystems. This is particularly evident in parallel findings related to the questioned reality of FM influencing the exosystem, such as policies guiding financial aid (as outlined in Category 1: Financial and economic security and affordability), as well as the ways they impact microsystem factors, particularly those

outlined in Category 9: Therapeutic alliance, Category 10: Iatrogenic suffering, and Category 8: Validation. Invalidation also appears to be a driving factor behind aspects of iatrogenic suffering, and internalization of adverse healthcare experiences. The definition of FM also influenced hindering mesosystem factors, insofar as the search for identifiable pathology leads to patients searching for a healthcare provider who believes and will help them, as well as being referred from one practitioner to another, thus resulting in discontinuous care.

The hindering impact of the conventional biomedical definition of FM at the macrosystem level is thus seen to echo throughout patients' healthcare experiences. These findings were consistent with the literature tying challenges in healthcare access for FM to the conventional biomedical model of disease, and calling for integration of biopsychosocial approaches into healthcare services for FM. Therefore, findings from this study add support to calls for adjusted definitions of illness—and FM in particular—that will validate patients' experiences of illness, remove the need to perform as “credible” or provide “proof” of illness, and recognize FM as an acceptable illness deserving of care (Egeli et al., 2011; Hadler, 1996; Sabik, 2010). Furthermore, the two most frequently cited wish list categories—clinical understanding of FM, and models of healthcare delivery—emphasize and echo research findings on the importance of improving understanding of this condition and adjusting healthcare delivery to better meet the needs of individuals with FM (Engel, 1977; Fielding, Teutsch, & Breslow, 2007; Gatchel et al., 2007; Hadler, 1996; Lempp et al., 2009; Winfield, 2000). This need for improvement will in part require concrete action through improved healthcare provider education and training around FM, in order to equip providers to accept patient experiences, to understand the process and management of chronic pain, and to be familiar with treatments, both pharmacologic and

non-pharmacologic (Canadian Pain Society, 2014; Perrot et al., 2012; O’Rourke et al., 2007). This goes hand in hand with the need for development of more specialized services equipped to manage this complex, chronic condition (Briones-Vozmediano et al., 2013).

Furthermore, incidents related to the prejudice sub-theme on sexism lend support to the literature on connections between the history of the biomedical model and embedded beliefs about women and mental health (Werner & Malterud, 2003). While the sub-theme of ageism was partly addressed by Werner and Malterud, this seems to be another area for further study, examining how healthcare provider beliefs about age and illness influence diagnosis and treatment. Findings from this category also illuminate how the conventional biomedical model of disease questions the legitimacy of FM in the form of stigmatization against mental health conditions. Thus, hand-in-hand with the need to redefine FM as an acceptable and credible condition, findings from this study also point to a need to recognize mental health conditions as credible and to de-stigmatize them.

The theme of financial and economic security and affordability of services—the second most frequently cited hindering category, endorsed by all participants—appears to highlight a gap in the FM literature. While some research addresses the healthcare payer burden and economic impact of healthcare resource used for FM, there doesn’t appear to be research to reflect the financial burden born by patients coping with this condition (Annemans, Le Lay, & Taïeb, 2009; Skaer, 2014). Findings from this category call for a need for improved financial and economic resources for individuals with FM that allows enough economic stability for individuals to care for their health. This also indicates a need for affordable treatment options, since currently individuals with FM report insufficient financial stability to pay for basic costs of living as well as their healthcare needs, leading to a detrimental cycle that worsens their health (Sabik, 2010). Participants believe if they

had sufficient financial stability, their health could stabilize, resulting in less economic burden from FM over time, and in some cases the potential to return to work.

Discussion of models of healthcare delivery, in addition to continuity of care, echo desires for biopsychosocial frameworks in healthcare service delivery, as well as increased integration of services through interprofessional care. Consistent with findings by Briones-Vozmediano (2013), participants specifically desired more interdisciplinary programs, more follow up from healthcare providers, and more complementary and alternative medicine and non-pharmacological treatment options. This could include, as suggested by Terry, Perry, and Ernst (2012) the integration of CAM-related discussions in primary care, helping to reduce harm from unregulated treatments and negative interactions among treatments. Supporting conclusions by Egeli et al. (2008), the combination of desires for improved understanding, treatment, integration, longer appointment times, trusting and collaborative healthcare relationships, and continuity of care, suggests a cumulative desire for long-term treatment plans, a wish specifically articulated by Participant 13, who stated “chronic health issues are chronic. I like the idea of someone who is specialized and knowledgeable in chronic health conditions working with me forever ... what I really need is somebody who is an expert in chronic health problems to work with me on an ongoing basis the way a GP does”.

The theme of accessibility and flexibility of healthcare services for FM appears to be another area in need of further study. Findings from this category support general research in the area of accessibility and flexibility in healthcare; however, there appears to be little research examining accessibility and flexibility factors specifically for individuals with FM. Specific findings from this category demonstrated a desire for longer appointment times—which intersects with helping incidents in validation, therapeutic

alliance, and informed consent. Further accessibility wishes relate to remote access options for attending appointments to reduce adverse effects from travel and wait times and to increase accessibility during times of greatest need, as well as flexibility in scheduling and cancellation policies that recognize the unpredictable nature of FM.

In line with previously stated needs for change in understanding, diagnosis making would be impacted by shifts in awareness and framing of FM. Interrelated with continuity of care and understanding of FM, improved continuity and understanding could lead to a more efficient diagnosis making process, alleviating significant suffering (Egeli et al., 2008; Lempp et al, 2009). Participants and research described that when diagnosis is a years-long-process, people are left suffering and losing hope as their health deteriorates (Egeli et al., 2008; Juuso et al., 2014; Lempp et al, 2009). In addition to improved efficiency, participants wished for healthcare providers that could tolerate the uncertainty of chronic conditions to help reduce their own distress around the uncertainty of the condition.

The importance of therapeutic alliance in healthcare services for FM was one of the more critical findings of this study. Illuminated by findings from Category 8: Validation, Category 10: Iatrogenic suffering, Category 11: Informed consent, Category 12: Counselling and psychotherapy, and Category 14: Internalization of adverse healthcare experiences, the results of Category 9: Therapeutic alliance show that participants desire to feel connected, cared for, listened to by their healthcare providers; they want to collaborate, be informed, and feel a part of the healthcare process; and they want to trust that their providers will take steps to research and consult when they don't know something. These category findings lend support to findings by Brody (2000) and Zotterman et al. (2016) who found that patients desire an ongoing, trusted healthcare provider who knows them well, who serves as a healthcare anchor to whom they can return. The importance of

therapeutic alliance is also shown through support for findings that iatrogenic suffering emerged from relational disconnect as well from treatments that resulted in a worsening of symptoms (Juuso et al., 2014; Zotterman et al., 2016). This provides further support for the desire for collaborative and connected relationships, where patients can discuss informed consent, share concerns, ask questions, and where their previous experiences and self-awareness are sought and valued.

Furthermore, the relative focus on interpersonal and process-related factors, in contrast with biomedical treatment factors, suggests that—similar to results from Traska et al. (2011)—individuals with FM tend to focus less on pharmacologic strategies and more on psychosocial ones. This also correlates with findings from Briones-Vozmediano et al. (2013) who found that to improve healthcare service, healthcare professionals should develop therapeutic alliance with their patients. Findings from this study uphold prior findings that confidence in a physician—as someone who is knowledgeable, supportive, and will listen—improves health outcomes, and positively impacts quality of life (Zotterman et al., 2016). Validation relates to the nature of the condition, as well as the nature of the alliance, and was a key factor in patients' experiences of wellbeing. Support from healthcare professionals plays a key role in adjusting to illness, and information and explanations are key to this process (White, Lemkau, & Clasen, 2014). Participants in this study echoed requests from Egeli et al. (2008) requesting collaborative relationships with patients, including offering more information and collaborative goal setting.

Intriguing findings from Category 11: Informed consent connect informed consent to both collaboration and validation. Incidents in this category demonstrated the importance of patients being able to ask questions, share concerns, and be informed of possible iatrogenic impacts of treatments. They also revealed that when mistakes have

been made or when treatments have led to suffering, patients desire recognition from their healthcare providers for the significant impact these experiences had on their lives.

An essential finding from this study related to internalization of adverse experiences. This outcome does not appear to have been discussed in the FM literature, but supports the premise outlined by Clarke and James (2003) that societal beliefs can become incorporated into an individuals' sense of self through a combination of interpersonal interaction and subsequent self-policing. Patient internalization of adverse healthcare experiences is a dangerous outcome, since it can result in erosion of trust in healthcare services and services providers, hopelessness, and decreased willingness to seek supportive services.

A surprising finding related to the disparity between participant expressed desire for information and non-pharmacologic symptom management strategies, and the availability of these to participants. As a form of coping with lack of information provided through healthcare services, most participants sought education and information independently. Psychoeducation around biopsychosocial factors influencing pain and other symptoms of FM could lead to improved symptom management and patient empowerment, and needs to be made available to individuals seeking healthcare services for FM (Fitzcharles et al., 2012). Ambivalence toward exercise and physical activity could also allude to a need for improved psychoeducation and support in finding optimal levels of exercise unique to the individual.

Furthermore, while pharmacologic treatment may play a role in symptom management, findings from this study support those by Durif-Bruckert, Roux, and Rousset (2015) that medication experiences are tied to relationship factors, and prescriptions are not adequate on their own. Relating back to findings on therapeutic alliance, Durif-Bruckert,

Roux, and Rousset found that patients perceive medication as a framework for partnership with their healthcare providers—a collaborative process in which medication “works as a transitional and transactional space” (p. 2590) where each brings their own expertise, the physician in medicine and medication, and the patient in their experience of their illness and their body. A context-specific finding related to use of medical marijuana as a treatment for FM, which has been minimally addressed in the FM literature. Helping incidents indicating preference for medical marijuana over other pharmacologic treatments suggest that more research into medical marijuana use for FM could be valuable.

Finally, findings from this study suggest that individuals with FM are able to employ extensive, creative coping strategies—including social support, information seeking and education, self-advocacy, and cognitive-behavioural and other non-pharmacologic symptom management strategies—to manage confusion, adapt their lives, and compensate for the absence of needed but unavailable services and supports. However, these strategies are not available to all, and could be more efficiently addressed through healthcare service provision. Consistent with findings by Sim and Madden (2008), Egeli et al., (2008), and Traska et al. (2011), patients with FM desire information, education, and tools for managing their symptoms. Furthermore, participants in this study expressed desires for support in managing activities of daily living, that could enable them to make better use of their energy in ways that would improve their health over the long-term.

In summary, findings from the present study demonstrate the complexity of hindering and helping factors impacting healthcare experiences with FM across multiple spheres of impact. While individuals do not directly interact with higher order systems, findings from this study show that FM patients may nonetheless be aware of the ways in which these systems influence their health and care. Findings from this study further

suggest that patients with FM appear to place a high degree of importance on interpersonal factors in their healthcare experiences, including validation, therapeutic alliance, and informed consent; these interpersonal factors were found to be important even within the brief encounters of primary care settings. Furthermore, the finding of more hindering than helping factors in this study suggests that there are a number of areas in which healthcare services could be improved for patients with FM; the findings from this study may serve to inform efforts to better serve the healthcare needs of individuals with FM.

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Appendix A

Study Recruitment Letter to Colleagues and Friends

Dear colleagues and friends,

I am a MA student at UBC in Counselling Psychology, and have begun recruitment for my thesis research in which I am investigating the experiences of individuals with fibromyalgia (FM) when accessing healthcare services.

I am contacting you in hopes that you may know someone who might be interested in participating in this project. I am looking for adults of any age and gender who are willing to talk about their healthcare experiences with FM. The study will include an in-person interview (average two hours), and a follow up interview by phone or email (approximately one hour).

I have attached three information formats: a poster, a study summary, and a detailed letter to prospective participants. I would be very grateful if you would forward any or all of this information to your networks and to specific individuals who may be interested. I welcome any questions, and will be happy to provide hard copies of these documents as needed.

The goal of this study is to gain a deeper understanding of how people living with FM experience interactions with healthcare services and professionals: what is experienced as helpful or beneficial, what is experienced as unhelpful or hindering, and what might be added to increase benefit. This information can help understand the healthcare experiences of people with FM and help provide recommendations for improvements in services.

Participation in this study will be maintained strictly confidential. With that in mind, please do not tell me the names or information about who you refer to this study; similarly, I will not confirm the names of individuals who contact me or choose to participate.

In summary:

I am seeking adult participants with fibromyalgia, who are willing to talk about their experiences accessing healthcare services for this condition:

- Participation is confidential
- Must be 18 or older
- Must have received a formal diagnosis

The study will include an in-person interview (approximately one to two hours), and a follow up interview by phone or email (approximately one hour). Participants will not be paid for their contribution to the study, however, they will be offered a \$10 gift certificate as a token of thanks.

My sincerest thanks for supporting my research and helping disseminate this to your networks.

Warmest regards,

Ria Nishikawara

MA student, Counselling Psychology

University of British Columbia

Department of Educational & Counselling Psychology, and Special Education

Appendix B

Study Recruitment Letter to Prospective Participants

Dear Prospective Participant,

My name is Ria Nishikawara, and I am studying the experiences of people with fibromyalgia (FM) when accessing healthcare services. This research project is a requirement for the completion of my Master's degree in Counselling Psychology at the University of British Columbia. You have received this letter because one of the individuals or organizations I reached out to thought you might be interested participating in this study.

The goal of this study is to gain a deeper understanding of how people living with FM experience interactions with healthcare services and professionals: what is experienced as helpful, what is experienced as unhelpful or hindering, and what might be added to increase benefit. This information can help understand the healthcare experiences of people with FM and help provide recommendations for improvements in services.

Participation is confidential and entirely up to you. I will not be informed that you received this letter unless you choose to contact me directly.

I am looking for adults of any age and gender who are willing to talk about their healthcare experiences with FM. The study will include an in-person interview (average two hours), and a follow up interview by phone or email (approximately one hour).

If you say "yes" to participating in this study:

Our interview will focus on your healthcare experiences with FM, particularly those instances or interactions you found to be helpful or beneficial, and unhelpful or hindering.

To best focus on what you are saying, I will request your permission to record the interview. Some demographic information will be collected as well. **All information will be kept strictly confidential and all questions are optional to answer.**

In the months following your original interview, I will send you a summary of the results of our interview, for your review. You will be asked confirm whether or not they accurately represent your experience, and will be asked to provide feedback to ensure you are comfortable with how the findings capture your experience.

How we keep this information confidential:

Each participant will be assigned a code number. The audiotapes will be transcribed, removing all identifying information. Participants will only be referred to by the code number (never by name or initials). All paper documents will be kept in a locked filing cabinet, and computer documents will be encrypted and password protected. Only myself and my research supervisors, Dr. Izabela Schultz and Dr. Norman Amundson will have access to the original files.

Contact Information

If you are interested in participating in the study or finding out more information, please contact Ria Nishikawara (Primary Researcher, Co-investigator) at [phone number] or [email address]. This research is being conducted as a component of the thesis requirement for her Master's degree in Counselling Psychology at the University of British Columbia.

You may also contact Dr. Izabela Schultz (Principal Investigator), Professor, Counselling Psychology Program, UBC at 604-822-5251, ischultz@telus.net.

In summary:

I am seeking adult participants with fibromyalgia, who are willing to talk about their experiences accessing healthcare services for this condition:

- Participation is confidential
- Must be 18 or older
- Must have received a formal diagnosis

Again, your participation is completely voluntary. You may refuse to participate in any section of the study, or withdraw at any time without negative consequence or providing an explanation. You will not be paid for your contribution to this study, however will be offered a \$10 gift certificate as a token of thanks.

My sincerest thanks in advance. I welcome any questions you may have, and I look forward to hearing from you.

Warmest regards,

Ria Nishikawara
MA student, Counselling Psychology
University of British Columbia
Department of Educational & Counselling Psychology, and Special Education

Appendix C

Recruitment Poster



Do you live with FIBROMYALGIA?

**We would like to hear about your experiences
accessing healthcare for this condition**

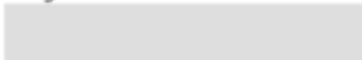
**To be eligible we ask that you have a formal
diagnosis of Fibromyalgia and are 18 or over**

PARTICIPATION:

- Is confidential**
- Involves a 1-2/hr interview
and follow up consultation**
- Helps improve understanding
of the experiences people with
Fibromyalgia have with healthcare
services**

**If you are interested in participating
or learning more please contact:**

**Dr. Izabela Schultz, Primary Investigator
Ria Nishikawara, MA Student
Counselling Psychology
University of British Columbia (UBC)**



Appendix D

Consent Form

Experiences of accessing healthcare services for Fibromyalgia:
Perceptions of facilitators and barriers

Study: Experiences of Accessing Healthcare Services for Fibromyalgia: Perceptions of Facilitators and Barriers

I. Who is conducting the study?

Principal Investigator: Dr. Izabela Schultz, Department of Educational and Counselling Psychology and Special Education, UBC, 604-822-5251, ischultz@telus.net.

Co-Investigators: Dr. Norman Amundson, Department of Educational and Counselling Psychology and Special Education, UBC, 604-822-6757, norman.amundson@ubc.ca.
Ria Nishikawara, Department of Educational and Counselling Psychology and Special Education, UBC, [phone number], [email address].

This research is being conducted as part of the thesis requirement for a Master's degree in Counselling Psychology. Once completed, the thesis will be a public document that will be available through the UBC library.

II. Why are we doing this study?

Purpose: You are being invited to take part in this research study because of your experience living with fibromyalgia (FM). We are doing this study to learn more about the experiences of people accessing healthcare services for FM: what is experienced as helpful, what is experienced as unhelpful or hindering, and what might be added to increase benefit. Your participation can add to our understanding of the healthcare experiences of people with FM and help provide recommendations for improvements in services.

III. How is the study done?

If you say yes, here is how we will do the study:

1. An interview: You will participate in an in-person interview at a location of your choosing. The interview will take between one and two hours. You will be asked to reflect on and describe what was helpful and what was unhelpful in your experiences seeking and receiving healthcare services for fibromyalgia. The interview will be audio recorded so that we can concentrate on what you have to say, rather than taking notes.

2. Demographics questionnaire: You will be asked to provide some basic demographic information. This form will take approximately five minutes.
3. Follow up interview: At a later date, once your interview has been transcribed and analyzed, you will be asked to review the themes to make sure they accurately describe your experience. This can be done by phone or email and will take approximately one hour.

IV. Results of the study

The results of this research will be reported in a thesis that will be accessible to the public. They may also be published in academic journals.

If you would like to receive a final copy of the results, please provide an email address or mailing address where you can be contacted:

V. Is there any way being in this study could be bad for you?

We do not think there is anything in this study that will harm you. However, we understand that you are living with fibromyalgia, and the symptoms can be difficult for you to predict. You may also find that sharing your experiences brings up strong emotions or memories. All questions are optional and you can pause or stop the interview at any time. Please let your interviewer know if you have any concerns.

VI. Will being in this study help you in any way?

You may find it helpful to talk about your experiences accessing healthcare services for FM. Others may also benefit from what we find in this study.

VI. Will I be compensated for my time?

You will not be paid for your participation in this study. You will be offered a \$10 gift card as a token of appreciation for your participation.

VII. How will your privacy be maintained?

Your identity will be kept strictly confidential. Participants will be identified only by a participant number; no names, initials or other identifying information will be used when the results of the study are reported. Only the three investigators identified on this form will have access to the digital recordings and study documents. All digital documents will be encrypted, and password protected and paper files will be kept in a locked filing cabinet. Files will be kept for five years and then will be destroyed. Information that discloses your identity will not be released without your consent unless required by law.

VIII. Questions or concerns?

If you have any questions or want further information about the study, please contact Ria Nishikawara at [phone number] or [email address]. You may also contact Dr. Izabela Schultz at 604-822-5251 or ischultz@telus.net.

If you have any concerns or complaints about your rights as a research participant and/or your experiences while participating in this study, contact the Research Participant Complaint Line in the UBC Office of Research Ethics at 604-822-8598 or if long distance e-mail RSIL@ors.ubc.ca or call toll free 1-877-822-8598.

IX. Participant consent

Your participation in the study is entirely up to you. You may refuse to answer any question, or withdraw from the study at any time without negative consequences and without providing an explanation.

You know your body best. If there is anything we can do that will make participation in this study more accessible to you, please let us know and we will do our best to accommodate your need(s).

☐ I have read the above and I consent to being part of the Fibromyalgia and Healthcare study.

☐ I have received a copy of this consent form for my own records.

Signature: _____

Printed Name: _____

Date: _____

Appendix E

Interview Protocol

The following interview sections will be covered with all participants, however, some wording or order of questions may vary.

Research Question: What helps and hinders the experiences of individuals with fibromyalgia when accessing and using healthcare services?

Interview Sections:

1. Overview and consent: Researcher will go over the interview process with the participant and present the kinds of questions that will be asked. Informed consent for the study will be discussed, including consent to audio-record the interview and inviting the participant to indicate any health or comfort needs they may have for the interview process. Participant will be invited to ask any questions they might have.

If they wish to continue, participants will sign the consent form.

2. Demographics: Participant will be invited to complete the demographics form.
3. Interview: Participant will be invited to share their experiences focusing on the following:
 - a. Contextualization (of their condition)
 - b. Identifying helping and hindering factors
 - c. Identifying wish list items.

Introduction

Thank you for agreeing to be interviewed and for agreeing to have this interview recorded. As you mentioned when you contacted me, you have been diagnosed with fibromyalgia. The topic of our interview today will be about a specific part of your experience with this condition: I would like to know more about your experiences of accessing and using healthcare services for FM, particularly what you found helpful (or beneficial) and what you found unhelpful (or hindering). There are no right or wrong answers, since this is based on your personal experiences.

It is possible that reflecting on these experiences may bring up some emotions for you. Please let me know at any point if you wish to pause the interview or change topic.

Our interview today has three general sections: what you experienced as helpful or beneficial in accessing and using healthcare services for FM, what you experienced as unhelpful or hindering, and whether there is anything that didn't occur that would have been helpful.

It is my job in the interview to listen attentively and encourage you to share your experiences on this topic. I may jump in at times to clarify, or summarize. This is to make sure I am accurately understanding your story, not because what you have shared was unclear or insufficient!

4. Contextualizing (About your condition)

- I'm really interested in your experiences accessing healthcare services for FM and what happened for you.
- Tell me briefly how long have you had FM and what did you first notice happening for you?
- Who did you first go to when you became concerned about your health?
- What were those early experiences like for you?
- SUMMARIZE at end of section

5. Transition to critical incident section: Hindering incidents

- Tell me about an unhelpful healthcare experience related to FM that really stood out for you (or) Tell me about the worst experience with using healthcare services for FM.
- Probes:
 - i. How was it unhelpful? What contributed to the unhelpfulness of that experience?
 - ii. How did it impact you?
 - iii. Can you give me a specific example of how it was hindering?

Unhelpful factor & what it means to participant (What do you mean by ...?)	Importance (How did it hinder? Tell me what it was about ... that you find so unhelpful)	Example (What led up to incident? Outcome of incident?)

SUMMARIZE at end of section

6. Transition to critical incident section: Helping incidents

- Tell me about a helpful healthcare experience related to FM that really stood out for you (or) Tell me about the best experience with using healthcare services for FM.
- Probes:
 - i. How was it helpful? What contributed to the helpfulness of that experience?
 - ii. How did it impact you?
 - iii. Can you give me a specific example?

Helpful factor & what it means to participant (What do you mean by ...?)	Importance (How did it help? Tell me what it was about ... that you find so helpful)	Example (What led up to incident? Outcome of incident?)

SUMMARIZE at end of section

7. About wish list items

- I'm interested in knowing what kinds of interactions or experiences could be helpful to others with FM accessing and using healthcare services. Is there anything that wasn't available or didn't occur that you think would have been helpful?

Wish list item & what it means to participant (What do you mean by ...?)	Importance (How would it be helpful?)	Example

SUMMARIZE at end of section

8. Summary of all critical incidents to end interview and confirm understanding with participant

Closing

Check if participants are noticing any disturbance as a result of the interview.

Thank you so much for meeting with me today and sharing your experiences for this study. In the upcoming months, I will be contacting you with a summary of the themes that came from our interview today. I will be asking you to go over the summary to provide feedback. I will be particularly interested in the summary reflecting your experience as accurately as possible. It is important that you feel your story has been accurately captured and described.

In the meantime, please don't hesitate to contact me if you have any other questions about the study. I look forward to speaking with you at the follow up if not sooner.

Appendix F

Demographics Questionnaire

Experiences of Accessing Healthcare Services for Fibromyalgia: Perceptions of Facilitators and Barriers

Directions: For the following open-ended questions, fill in the blanks to the best of your ability. If you require additional space for your response, feel free to write on the back of the form.

For the multiple choice questions place an X next to the answer(s) that best represent you.

1. **Gender** _____

2. **Age** at date of interview: _____

3. **Onset of fibromyalgia symptoms**

When did you first start experiencing symptoms of fibromyalgia?

4. **Receiving a diagnosis**

When were you diagnosed with fibromyalgia?

5. Treatments

What kinds of treatment or services have you sought for fibromyalgia?

(Check all that apply)

- | | |
|---|---|
| <input type="checkbox"/> Medication | <input type="checkbox"/> Massage therapy |
| <input type="checkbox"/> Physical rehabilitation or physiotherapy | <input type="checkbox"/> Occupational therapy |
| <input type="checkbox"/> Exercise / Personal training | <input type="checkbox"/> Pain management |
| <input type="checkbox"/> Naturopathy / Natural medicine | <input type="checkbox"/> Marijuana |
| <input type="checkbox"/> Yoga | <input type="checkbox"/> Meditation / Mindfulness |
| <input type="checkbox"/> Chiropractic treatment | <input type="checkbox"/> Acupuncture |
| <input type="checkbox"/> Psychological counselling | <input type="checkbox"/> Psychiatric treatment |
| <input type="checkbox"/> Other treatments (please specify): | |

Which (if any) of the above treatments are you currently using?

6. Work status

If you are currently working, please describe your current work status.
(eg. full-time; part-time; self-employed)

If you are not currently working, when did you last work?

Please indicate if your work status has been impacted by symptoms of fibromyalgia:
(eg. lost job due to symptoms; unable to work due to symptoms; on medical leave)

7. Education

Please indicate your highest level of schooling:

- | | |
|---|--|
| <input type="checkbox"/> Elementary school | <input type="checkbox"/> Undergraduate degree |
| <input type="checkbox"/> High school | <input type="checkbox"/> Graduate degree |
| <input type="checkbox"/> Vocational / trades school | <input type="checkbox"/> Post-graduate degree |
| <input type="checkbox"/> Some college / University | <input type="checkbox"/> Other (please specify): |

Appendix G

Participant Follow-up Letter

Dear [Participant Name],

Thank you for participating in this study and for your patience as I prepared this summary of our initial interview. As you may remember, the aim of this study is to explore *what helped and hindered in your experiences accessing healthcare services for fibromyalgia*. The purpose of this follow up is to provide you a summary of my findings so that you can check to see if what I have reported accurately and respectfully summarizes your experience.

I am providing you first with quotations from our interview that outline specific examples of those things that helped, hindered, and what you wished had been available to you.

I am particularly interested in discussing:

8. Are the helping and hindering incidents and wish list items correct?
9. Is anything missing among the helping and hindering incidents, and wish list items listed?
10. Does anything need revising?
11. Do you have any other comments?

Once we have reviewed the quotations, I would like to go over with you the categories I have placed them in. Here, I would like to explore:

1. Do the category headings make sense to you?
2. Do the category headings capture your experience and the meaning that the incident or factor had for you?
3. Are there any incidents in the categories that do not appear to fit from your perspective? If so, where do you think they would more accurately belong?

Your feedback is very important to me. We can add, remove, or make any changes necessary.

Please keep in mind while reviewing that the aim of this study is to explore specifically what helped and hindered in your experiences accessing healthcare services for fibromyalgia. We may have discussed other important aspects of your experiences with fibromyalgia and your life more broadly that have not been included here. While these summaries cannot possibly capture all the depth and richness of your experiences, it is essential to me that these findings honour your story, which you have so generously shared with me.

I also appreciate you not sharing these results for the time being, since they need to be confirmed by all participants first.

My sincerest thanks,

Ria Nishikawara

Appendix H

Comparison of Category Schemes

Table 6, below, displays the finalized category scheme on the left, and the categories it is composed of, on the right. The categories on the right come from the original conceptualization of the data from the present study.

Table 6

Comparison of category schemes

Category	Category Composition
1: Financial and economic security and affordability	HE Financial security/Access to financial support HI Financial instability/Barriers to accessing financial support
2: Clinical understanding of FM	HE Clinical understanding of FM is improving HI Existence of FM questioned HI Lack of education about FM and treatment
3: Accessibility and flexibility	HE Making services accessible HE Practitioners taking the time HI Difficult to keep up with/ get to appointments HI Treatment recommendations or services that are inflexible/inaccessible HI Time factors for accessing care
4: Continuity of care	HE Appropriate referrals HE Practitioners taking the time HI Problems find a doctor
5: Prejudice	HI Ageism HI Sexism
6: Diagnosis making	HE Diagnosis and tests helped HI Diagnosis related difficulties
7: Models of healthcare delivery	HE Holistic approach HE Interdisciplinary/Integrative approach HE Alternative and complementary healthcare HI Systemic/biomedical healthcare problems HI Alternative and complementary healthcare HI Capitalist/Economic structures in biomedical model
8: Validation	HE Validation/Being believed HI Dismissed as "crazy" HI Dismissed/disregarded

Category	Category Composition
9: Therapeutic alliance	HE Supportive, caring relationship HE Collaborative relationship & mutual valuing of knowledge HE Non-expert stance HE Practitioner commitment to client/patient HI Practitioners not attentive to rapport building HI Dismissed/disregarded
10: Iatrogenic suffering	(original category maintained)
11: Informed consent	HI Not being informed and dangerous/unethical treatment
12: Counselling and psychotherapy	HE Counselling and psychotherapy HI Counselling and psychotherapy HI "dismissed as crazy" (counselling specific items)
13: Medication	HE Medication / Medical marijuana HI Medication inefficiencies and side effects
14: Internalization of adverse healthcare experiences	(original category maintained)
15: Exercise and physical activity	(original category maintained)
16: Active coping and social supports	HE Coping and supports HE Empowerment HE Own research and access to information HE Mindfulness and cognitive-behavioural pain management strategies