

MEANING, INFORMATION AND ONLINE PARTICIPATION ALONG THE ILLNESS
JOURNEY:
THE STORY FOR FIBROMYALGIA PATIENTS

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A dissertation submitted to the faculty of the University of North Carolina at Chapel Hill in
partial fulfillment of the requirements for the degree of Doctor of Philosophy in the Department
of School of Information and Library Science

Chapel Hill
2015

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ABSTRACT

Annie T. Chen: Meaning, Information and Online Participation along the Illness Journey:
The Story for Fibromyalgia Patients
(Under the direction of Barbara M. Wildemuth)

Fibromyalgia is a disorder in which patients experience chronic pain and other symptoms, and annual medical expenditures are comparable to rheumatoid arthritis. Because fibromyalgia symptoms are “invisible,” patients also suffer from a lack of understanding and recognition. They face a difficult, long-term information seeking and sense-making task as they endeavor to manage their condition.

This study explored the illness journeys of fibromyalgia patients, including how patients’ views of illness and of health evolve over time, what role information plays, and how their participation in online communities, Facebook, Twitter, and other social media changes. Participants shared their “illness journeys” through a timeline construction activity, and we explored participants’ participation histories using an interface developed for this study, the Online Scrapbook. The data were analyzed through a qualitative approach drawn from Grounded Theory and Interpretative Phenomenological Analysis.

This study has contributed to our knowledge of information behaviors in relation to fibromyalgia and other chronic illnesses in various ways. The study provided rich detail concerning the illness journey, and illustrated how different phases of the journey were associated with particular types of information behaviors. With regard to information behavior, the dissertation elaborates on the lessons that patients learned, information sources used, patients’ information interactions with others, and online participation.

The study findings have implications for clinical care, information and interface design, and theoretical aspects of the study of information behavior. In terms of clinical care, there is a need to prepare physicians to work with fibromyalgia patients and to promote alternative medicine and lifestyle changes earlier in their illness journeys. In terms of design, there are implications for improving health discussion forums, facilitating analysis of complex clinical histories, and making information accessible and understandable.

This study also has theoretical implications. There is a lack of a framework that describes the interrelatedness of the physical, emotional and cognitive elements of life, with information. A new Evolving Information Ecology model is proposed that conceptualizes the illness journey as a process in which these elements are interwoven. In addition, a taxonomy for conceptualizing long-term information exchanges is proposed.

ACKNOWLEDGMENTS

Well, it has been a journey, and I am thankful to everyone who was a part of it! I would like to begin by thanking all of the members of the committee for their intellectual and emotional support: my advisor, Dr. Barbara M. Wildemuth; and the other committee members, Dr. Stephanie W. Haas, Dr. Claudia J. Gollop, Dr. Gary Marchionini, and Dr. Christine Rini. Each of you has played an immeasurable role in my development, both as a scholar and as a person, throughout my years of doctoral education. You have enriched my journey in countless ways, and I will never forget our discussions. I have the deepest appreciation for your understanding and forbearance, to encourage me to find my own way.

I would also like to thank the participants and pilot participants of my dissertation study and my 2011 survey of fibromyalgia patients' information needs. Without you, none of this would have been possible, and I will do my best to share the experiences and insights that you have shared with me. Thank you for your willingness to contribute. Your experience, first-hand knowledge, and acquired knowledge of fibromyalgia are invaluable, and moving forward, I will do my best to make this information useful to improve health care for fibromyalgia patients and others.

I am also extremely lucky to have had the support and mentorship of Dr. Mike Conway at the University of Utah and Drs. David Gotz, Rob Capra and Jaime Arguello at the University of North Carolina; and the support of friends that I met through the Digital Innovation Lab, including Dr. Pamella Lach and Dr. Marten Düring. I would also like to thank my friends in other places for their support, particularly Dr. Sherri Matis-Mitchell and her husband Kenny

Mitchell, Dr. Beth St. Jean at the University of Maryland, and Dr. Yan Zhang at the University of Texas at Austin; and my friends in Taiwan and Japan, many of whom have not only listened to my stories of my life here in North Carolina over the years, but have also served as inspiration for me in life, in so many ways.

I would also like to thank the SILS community, including faculty, staff and classmates, past and present. I will always cherish the times that we have spent together. I would also like to thank Grace Shin, Dr. Wan-Ching Wu and Dr. Ellen Rubenstein for their input on the slides for my defense.

Last but not least, I would like to thank my family: my parents, Dr. Winston Chen and Chia Ying Chen; my two brothers, Max and Alex; sister-in-law Linda Fee Yue and sister-in-law to be Yi (Grace) Wang; my niece Sophie; and nephew Brendan. Though Sophie and Brendan have not walked with me the entire part of the journey here, the last minute addition of spice and chaos is certainly a welcome one!

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CHAPTER 1 INTRODUCTION

In recent years, there has been increased attention to chronic disease. The World Health Organization (WHO) has reported that non-communicable diseases (NCDs) such as cardiovascular diseases, diabetes, cancer and chronic respiratory diseases accounted for more than 60% of deaths worldwide (World Health Organization, 2011). In addition, NCDs are a priority to be addressed because of their significant impact on society in terms of reducing productivity and increasing health care costs.

In contrast, there are other chronic conditions that receive significantly less attention in both the media and in allopathic medicine. One of these is fibromyalgia, a condition in which most people experience a variety of symptoms such as chronic widespread pain, stiffness, fatigue, sleep disturbance, cognitive dysfunction, anxiety and depression (Goldenberg, 2009). Today, there is still a great deal of ambiguity surrounding fibromyalgia, and the etiology remains unclear. Extant literature shows that the burden of cost for fibromyalgia is comparable to rheumatoid arthritis, at approximately \$11,000 a year (Silverman et al., 2009).

In addition to the great burden of cost, there are other issues of concern. Fibromyalgia is a highly contested illness in which patients suffer from feelings of illegitimacy due to a lack of understanding and recognition of the condition (Barker, 2008). Patients may face numerous difficulties, including a need for information, uncertainty about the meaning of the condition and its effect on their daily lives, and a lack of understanding from medical practitioners and others around them (Madden & Sim, 2006). Patients may struggle for years to obtain a

diagnosis, only to find that it is “empty” – a condition with a name that is unknown to everyone and provides little leverage for treatment.

Given this situation, it is not difficult to imagine patients reaching out to try to find their own answers. And where do they go? Though health care professionals remain a central resource, use of the Internet is also commonplace. According to a Pew Internet and American Life Project survey, 59% of United States adults said that they had gone online to search for health information in the past year (Fox & Duggan, 2013). Indeed, there are those that argue that the complex needs of people today cannot be satisfied through a single point of care, and the solution to this is online communities (Johnson & Ambrose, 2006).

Given the increasing importance of online communities in healthcare in general as well as fibromyalgia specifically, increasing our efforts to understand the needs of fibromyalgia patients that utilize online communities is an imperative. There has been some research on this (e.g. Chen, 2012a; van Uden-Kraan et al., 2008a-c, 2009), but there is a great deal that we do not yet understand about how fibromyalgia patients engage with online support groups, and particularly how that engagement develops longitudinally.

This, then, is the subject of my dissertation research. In my dissertation research, I interviewed patients with fibromyalgia to understand how their views of their illness and of health have changed over time, and how these views are related to their patterns of participating, or not participating, online. I examined how people’s participation in online communities evolves along with shifts in perspective on illness and information seeking. Participants were generally interviewed twice; the first session was used to gather information about their health history, their information use and their physical, mental and emotional journey. The second session was used to jointly explore their online participation history. The data collection also

involved graphic elicitation. In the first interview, participants were asked to draw a timeline of their physical, mental and emotional journey. In the second interview, the researcher and the participant jointly explored the content that participants created online throughout their illness.

Understanding the role that online support groups and other social media may play throughout the course of an individual's illness can be of profound significance to academic, professional and patient communities. Previous work on online support groups and health information seeking has often focused on cancer; there is considerably less work on other conditions, and yet there is an increasingly greater need to improve the lives of those with other conditions as well. This study provides a qualitative account of the information behaviors of fibromyalgia patients along their illness journey, including how it is connected to cognitive, emotional and physical aspects of the journey. Additionally, it explores how fibromyalgia patients engage with online spaces over time. It is my hope that the findings from my research might be used to improve health care for fibromyalgia patients and other patients with chronic conditions by contributing to our knowledge of gaps in existing educational resources, informing the development of patient education resources and physician training programs, and in terms of design of health information systems.

CHAPTER 2 LITERATURE REVIEW

This chapter presents a review of extant literature of relevance to this study. It is comprised of four sections. The first section provides an overview of fibromyalgia, including patients' experiences of the condition, condition management and coping, which is used to set the stage in order to understand the situation that patients face, the information that they have access to, and approaches that they may use to address their problems. The second section describes models of, and empirical literature on, health information seeking that are potentially relevant to fibromyalgia patients. The third section describes the literature on online support groups, with a focus on the ways that they have become a common source of health information. The fourth section, on the design and evaluation of online communities and social interfaces, serves as background to contextualize the design implications that are presented later in the dissertation.

2.1 Fibromyalgia: An Overlooked Condition

Fibromyalgia is a condition in which patients usually suffer from a variety of symptoms, the most common being chronic widespread pain, but patients often also suffer from sleep disturbances, fatigue, irritable bowel syndrome, headache and mood disorders (e.g. Sarzi-Puttini, Buskila, Carrabba, Doria, & Atzeni, 2008). Though fibromyalgia is estimated to affect a substantial number of people all over the world and, in terms of economic burden, has been estimated to be on par with rheumatic conditions such as arthritis in terms of health care expenditures, it is not a condition that receives much attention in terms of either research or health policy.

Given the significant numbers of individuals that are affected, the enormous duration, and the cost – for these reasons alone, fibromyalgia deserves our attention. However, there are other reasons that make it particularly important for us to study from the perspective of information science. If anything, the term “fibromyalgia” is the epitome of a situation in which an anomalous state of knowledge has arisen: a condition that is based on the experiencing of a diverse array of symptoms with no clear cause, for which there are usually no clearly visible outward signs. The average person is unclear what the condition even entails; and thus, if they should befall the condition, they inexplicably find themselves in a state in which they need to find information about something that they may not even know the name of. And yet they start searching – and encounter a confusing deluge of information. All of it may seem relevant and perhaps none of it is; it’s hard to tell. They have plenty of time to search for information, consolidate it and perhaps accept it (or not), over the decades that they may have this illness.

Understanding how fibromyalgia patients cope with their illness should be an imperative simply in order to better the lives of those with fibromyalgia. In addition, the knowledge that we gain from studying how to help those with this chronic illness find and consume information, manage their illness, and also provide information to others, can be invaluable to improving chronic care in general.

There is a considerable body of literature that focuses on non-communicable diseases (NCD), or chronic diseases, and self-management. These are diseases of long duration and generally slow progression, and there are four main types: cardiovascular diseases (e.g., heart attacks and stroke), cancers, chronic respiratory diseases (e.g., chronic obstructed pulmonary disease and asthma), and diabetes (World Health Organization, 2013). Fibromyalgia is not included in this list. There may be a number of reasons for this, including its relatively recent

recognition and continuing controversy regarding its legitimacy as a medical condition, as well as the fact that it does not pose a threat to life in the same way as other conditions, e.g. cardiovascular diseases and cancer, do. However, it can lead to high economic burden, chronic disability, and have otherwise severe impacts on quality of life. Moreover, its nebulous status in allopathic medicine and within society at large may also result in patients having difficulty obtaining the information that they need, whether it be making sense of conflicting information, or even knowing what to look for. Thus, fibromyalgia is a condition that requires our attention.

This section provides an overview of fibromyalgia: what it is, how it affects those who develop it, diagnosis and assessment, treatment approaches, information behaviors, information quality, and coping. The purpose of this section will be to describe what we already know about what fibromyalgia patients experience throughout the course of their illness, so that we may contextualize their information behaviors.

2.1.1 Definition, Etiology and Prevalence

Fibromyalgia is a syndrome characterized by chronic widespread pain at multiple tender points, joint stiffness and systemic symptoms (e.g., mood disorders, fatigue, cognitive dysfunction and insomnia) without a well-defined underlying disease (Bellato et al., 2012). Central sensitization, or increased response to stimulation mediated by Central Nervous System (CNS) signaling, appears to be the main mechanism involved. Recent studies suggest that, in fibromyalgia patients, the sympathetic nervous system is persistently hyperactive, but hyporeactive to stress. Patients with fibromyalgia often have problems with sleep, and fibromyalgia is common in patients affected by autoimmune disease. Other issues that appear to be related are genetic factors, psychiatric aspects, peripheral tissues and trigger factors.

Estimates of the prevalence of fibromyalgia differ, but it is generally between 2% and 3% (Wolfe et al., 1995; Branco et al., 2010; Mas et al., 2008). It is estimated that approximately 5 million individuals of age 18 or greater in the United States have fibromyalgia (Lawrence et al., 2008). It is more commonly found among females, those between 40 and 59 years old, those living in rural areas as opposed to urban dwellers, and individuals with comorbidities (Mas et al., 2008). According to a longitudinal study of 1,555 patients with fibromyalgia followed for up to 11 years, on average there was no clinically meaningful improvement overall (Walitt et al., 2011).

2.1.2 Functional, Psychosocial and Societal Impacts

Patients who have fibromyalgia may experience disruption in many aspects of their lives, including physical, cognitive, social, emotional and work/activity (Arnold et al., 2008). They may also undergo many transitions – in daily life, family life, social life, and working life – and in learning to live with the changes brought about by fibromyalgia (Söderberg & Lundman, 2001). This section will discuss the major impacts identified in the literature.

Fibromyalgia patients experience fatigue in terms of physical tiredness, low energy levels, and greater effort with physical tasks and to overcome inactivity; they experience decreased mental endurance, slowed thinking, aversion to effort and feeling overwhelmed (Arnold et al., 2008). Four aspects of life are most greatly impacted: alertness behavior, sleep and rest, recreation and pastimes, and work (Crooks, 2007). “Fibro fog” or mental haziness has a significant impact on patients’ abilities to function in multiple spheres of daily life. Those who suffer from fibromyalgia tend to have problems sleeping and do not feel rested when they get up. As a result, patients report napping and resting in between their daily tasks to help them manage chronic fatigue and tiredness.

Fibromyalgia patients may also experience increasingly smaller spheres of activity (Crooks, 2007). For example, one woman went from playing tennis outside of her neighborhood, to pool therapy close to home, to going on mile-long walks around the block, and then finally, activity mostly within the home. They may work and volunteer less or quit altogether, and participate in fewer social activities, which in turn leads to smaller social circles and has a significant adverse impact on the way the way patients view themselves.

Fibromyalgia can also have a negative impact on patients' social interactions. In one study involving focus groups of fibromyalgia patients, participants mentioned that, because symptoms are unpredictable, they became reluctant to commit to social activities, feared being judged by others, and faced skepticism from peers and coworkers, sometimes leading to loss of friendships (Arnold et al., 2008). Participants also felt guilt or shame when rearranging their priorities due to fibromyalgia, such as taking care of themselves rather than putting their family and friends first. As mentioned previously, many had to change jobs frequently or reduce their working hours, which in turn has a significant adverse impact on quality of life and social function, not to mention self-confidence and self-identity. Lack of understanding and acceptance of fibromyalgia can also contribute to social withdrawal and isolation. One survey of adults with fibromyalgia also reported that half of the respondents reported mild to moderately damaged relationships with their current spouse/partner (Marcus, Richards, Chambers, & Bhowmick, 2012). However, they did not generally have strongly negative perceptions of relationships; free response statements focused on the loneliness and isolation associated with fibromyalgia, and feelings that they were a burden to others.

Because of the inconsistent, vague and invisible symptoms of fibromyalgia, patients often find themselves in an ongoing struggle for a diagnosis and legitimacy (Sim & Madden,

2008; Thorne et al., 2004). In the course of this struggle, patients may face numerous difficulties, including a need for information, uncertainty about the meaning of the condition in their daily lives, and a lack of understanding from medical practitioners and others around them (Madden & Sim, 2006). Patients and physicians both report difficulties in their interactions with one another (Åsbring & Närvänen, 2003).

In addition to the profound impacts on those affected, the condition also carries with it a large economic burden. One 12-month cross-sectional and retrospective study using claim records from a health care database in Spain showed that patients with fibromyalgia had higher health care, non-health care, and drug expenditure costs as compared to a reference group of non-fibromyalgia patients (Sicras-Mainar et al., 2009). A study comparing the economic burden of fibromyalgia to rheumatoid arthritis (RA) found that patients with fibromyalgia had a higher presence of several comorbidities and greater emergency department utilization than those with rheumatoid arthritis, and that the annual expenditures of the two groups were comparable (Silverman et al., 2009).

As the literature reviewed has illustrated, fibromyalgia patients experience a wide variety of symptoms which lead to disruption of multiple facets of their lives. They end up needing to make adjustments in their daily lives, such as working part-time, not working at all, and doing less or no housework, that may then lead to guilt, shame and social isolation. Aside from the impact on the individuals themselves, the inability to work and high health care expenditures may have an adverse impact on society as well.

2.1.3 History, Diagnosis and Assessment

Though fibromyalgia, as the condition is now known, is a relatively new term, there have been many mentions of similar conditions throughout history. There have been many

terms that have been used to describe similar symptoms, including: muscular rheumatism, neuralgia, muscle calluses (“muskelschwiele”), chronic rheumatic myitis, myofascitis, myofascial pain syndrome, rheumatic myalgia, idiopathic myalgia, lumbago and more (Inanici & Yunus, 2004). One of the most common is “fibrositis”, coined by Gowers in 1904 (Gowers, 1904).

The diagnosis and assessment of fibromyalgia has generally been complicated and time consuming, though in recent years, steps have been taken to simplify this process. The first set of diagnostic criteria was established in 1990 by the American College of Rheumatology (ACR) (Wolfe et al., 1990). It had two parts: individuals have a history of widespread pain present in all four quadrants of the body (left and right sides, above and below waist) and axial skeletal pain; and individuals feel pain in 11 or more of 18 tender point sites upon digital palpation (Clauw & Crofford, 2003; Wolfe et al., 1990; Goldenberg, 2009). There has long been controversy in the medical community regarding the legitimacy of fibromyalgia as a diagnosis, largely due to the subjective nature of the tender point criterion and the lack of a clear etiology (Sim & Madden, 2008; Goldenberg, 2009).

Over the years, various issues emerged concerning these criteria. It became apparent that the tender point count was rarely performed in primary care, and when performed, was done incorrectly (Wolfe et al., 2010). In addition, symptoms that have become known as key features of fibromyalgia such as fatigue, cognitive impairment, and other somatic symptoms were not included in the criteria. Lastly, people who improve or whose symptoms and tender points decrease might fail to satisfy the 1990 ACR classification. In order to address these issues, Wolfe et al. (2010) developed a new set of criteria that incorporates two indices of widespread pain and symptom severity without the use of a tender point examination, and recent

clinical guidelines encourage primary care physicians to diagnose and treat it in the primary care setting, without referral to a specialist, whenever possible (Arnold, Clauw, & McCarberg, 2011). Another alternative, the Fibromyalgia Survey Questionnaire, now exists for survey research and settings in which it would be difficult to evaluate the number of pain sites and symptom severity through interview (Häuser & Wolfe, 2012).

Previous studies have shown that it is important to evaluate health-related quality of life in patients with chronic widespread pain (Salaffi, Sarzi-Puttini, Ciapetti, & Atzeni, 2011). Instruments that are commonly used to assess pain-related quality of life include the SF-36, the Sickness Impact Profile (SIP), the Nottingham Health Profile (NHP), EuroQOL, Fibromyalgia Impact Questionnaire (FIQ), Arthritis Impact Measurement Scales 2 (AIMS2) and the Health Assessment Questionnaire (HAQ). The first four are generic measures that contain items concerning physical, psychological and social aspects of life; the FIQ is specific to fibromyalgia, and the AIMS2 is specific to arthritis. The HAQ is comprised of items concerning difficulties with activities in daily living. A more recently developed instrument, the Fibromyalgia Participation Questionnaire (FPQ) assesses participation and social function in three domains: social life, daily life and work life (Farin, Ullrich, & Hauer, 2013).

Fibromyalgia is also often associated with “fibro fog” or “dyscognition” (Williams & Schilling, 2009). Though no clear definition exists, it usually refers to a composite experience involving slow information processing, difficulties in multi-tasking, failures of memory, poor concentration and clarity of thought, and perceived deficits in executive function. At present, no simple measure of dyscognition is available for patients with fibromyalgia, but the Multiple Ability Self-Report Questionnaire (MASQ) (Seidenberg, Haltiner, Taylor, Hermann, & Wyler, 1994) assesses a number of those domains.

Patients with fibromyalgia may also encounter invalidation experiences. These are defined as the perception that others are denying, lecturing, overprotecting, not supporting or not acknowledging the condition of the patient (Kool et al., 2010). The Illness Invalidation Inventory (3*I) can be used to assess the extent to which patients experience invalidation. The scale consists of eight items that are asked with regard to each of five sources: spouse, family, medical professionals, work environment and social services. Factor analysis of the scale yielded two factors: discounting and lack of understanding.

There is also a tendency for fibromyalgia to be co-morbid with other unexplained clinical conditions such as Chronic Fatigue Syndrome (CFS), Irritable Bowel Syndrome, temporomandibular disorder, multiple chemical sensitivities, migraine headaches, systemic lupus erythematosus, rheumatoid arthritis, depression and anxiety (Aaron & Buchwald, 2003; Weir et al., 2006; Wolfe, Michaud, Li, & Katz, 2010). One study of four rheumatic diseases and their comorbid conditions found two patterns of involvement with fibromyalgia (Wolfe et al., 2010). The first involved depression, mental illness and drug/alcohol problems. The second included symptom and symptom interpretation-related illnesses, such as asthma, allergies, gastrointestinal ulcer, gastro-intestinal symptoms, neurologic and genitourinary disorder.

In summary, historically the diagnosis and assessment of fibromyalgia have been a complicated processes, but there have been recent revisions in clinical guidelines which are likely to result in simplification of this process. Diagnostic and assessment practices of fibromyalgia are still evolving. Fibromyalgia patients often experience a wide variety of symptoms, and as such, multiple types of measures might be used in assessment, including quality of life, dyscognition, and invalidation experiences. The tendency for fibromyalgia to be co-morbid with other conditions may also exacerbate the task of assessment.

2.1.4 Treatment Approaches

Though many approaches have been used to treat fibromyalgia, none have been shown to be universally effective for all fibromyalgia patients (Okifuji & Hare, 2013). Approaches to fibromyalgia treatment are often referred to as: pharmacological, non-pharmacological (lifestyle-oriented) and alternative. Pharmacological approaches may involve antidepressants, nonsteroidal anti-inflammatory drugs, opioids, sedatives, muscle relaxants, analgesics, hypnotic agents and anticonvulsants (Han et al., 2011). The most thoroughly studied non-pharmacological approaches to managing fibromyalgia focus on changing patient activities and beliefs that affect the condition (Friedberg, Williams, & Collinge, 2012). Lifestyle-oriented treatments include patient education, physical exercise and cognitive-behavioral therapy. A wide variety of treatments that fall under the umbrella of complementary and alternative medicine (CAM), e.g., massage, qigong, taichi, acupuncture and hydrotherapy, also exist (Hassett & Gevirtz, 2009). Because of the complex nature of fibromyalgia, it is recommended that fibromyalgia treatment be multidisciplinary, involving a variety of physical, cognitive, behavioral, educational and pharmacological components (Hassett & Gevirtz, 2009; Friedberg et al., 2012; Bellato et al., 2012).

2.1.5 The Role of Information

2.1.5.1 Fibromyalgia-Related Information Seeking

There have been few studies concerning the information behaviors of fibromyalgia patients. The ones that have been conducted suggest that patients obtain health information from a diverse array of sources. These include healthcare professionals, online/websites, organizations (National Fibromyalgia Association and the Arthritis Foundation), magazines, television, radio, library, Internet message boards, face-to-face support groups, health food

stores, and informal sources such as friends, family members and others with the same condition (Bennett, Jones, Turk, Russell, & Matallana, 2007; Daraz, MacDermid, Wilkins, Gibson, & Shaw, 2011a). The health care professionals included family physicians, rheumatologists, internists, massage therapists, chiropractors, physical therapists, mental health professionals, pharmacists, nurse practitioners/physician assistants, nurses, nutritionists/dietitians, and gynecologists.

Studies seem to indicate that the Internet is by far the most frequently used source of information (Daraz et al., 2011a; Chen, 2012a). Though people do not report receiving information from others as frequently as they do the Internet, they appear to value it a similar amount (Chen, 2012a). In a survey of fibromyalgia patients in Canada, the percentage of people that wanted information from health care providers exceeded the percentage that prefer information from the web (Daraz et al., 2011a). What seems somewhat contradictory, however, was that in the same study, online sources, people with the same condition and support groups were perceived as being “most useful”; with doctor(s), health magazines, family/friends and scientific studies, perceived as “somewhat useful.” This may suggest that, although people would like to receive information from health care providers, the information that they receive may not be tailored to suit their specific experiences, whereas it may be possible to find stories online that address their issues more specifically.

Some of the main reasons that fibromyalgia patients may search for information include: to learn more about fibromyalgia, to help make decisions about health, to learn about new research, and for self-management (Daraz et al., 2011a). At time of diagnosis, the most pressing needs are to find out the types of available treatments, who can help them with their

condition, what the usual symptoms are and how to manage them, and possible health outcomes.

Fibromyalgia patients' needs also change over the course of the illness (Chen, 2012a). At first, individuals may be pre-occupied with finding a cure. Searches about what fibromyalgia is, its symptoms and cause remain high through diagnosis and then drop thereafter. Searches for information concerning exercise, medications and research increase over time. Many eventually come to a point where they are satisfied with the information and treatment that they have, and the doctors that they rely on; many then enter a phase where they occasionally look for new research, but are no longer actively seeking information.

2.1.5.2 Quality and Availability of Fibromyalgia Information

Though there is considerable literature concerning the quality and availability of consumer health information, there are few studies that pertain to fibromyalgia. Up to the present, there has been only one study of the quality of websites for fibromyalgia (Daraz, Macdermid, Wilkins, Gibson, & Shaw, 2011b). In this study, the authors used Google to search for fibromyalgia-related websites. They analyzed the top 25 websites returned by keyword search using three instruments: DISCERN, a quality checklist developed by the authors, and the Flesch Reading Ease measure. DISCERN is a questionnaire used to assess the quality of written consumer health information on treatment choices (Charnock, 1998). Daraz et al. found that the most accessible websites on fibromyalgia did not provide comprehensive information, and a substantial portion of these websites did not meet the standards for website quality (assessed using DISCERN and the quality checklist). Only three websites (Fibromyalgia Information, Fibromyalgia Information Foundation, and National Institute of Arthritis and Musculoskeletal and Skin Diseases) had consistently high levels of quality, but they also had

high reading levels (grade 11). Another study analyzed chronic pain websites, found through searches using five key terms (pain, chronic pain, back pain, arthritis and fibromyalgia) (Kaicker, Debono, Dang, Buckley & Thabane, 2010). The average quality of websites, as assessed using DISCERN, was moderate ($M=55.9$, $SD=13.6$) and the average readability by grade level, as assessed using the Flesch-Kincaid algorithm, was 10.9 ($SD=3.9$). Website seals of approval and potential for commercial gain were contributing factors to higher DISCERN scores, while seals of approval and interactive multimedia contributed to lower grade level readability. Though limited in scope, these studies suggest that the information about fibromyalgia that is available through consumer health websites may be variable in quality and require at least a high school education to comprehend.

There are other online resources, such as fibromyalgia-related organization websites and online support groups. Organizations that provide information and resources concerning fibromyalgia include the National Fibromyalgia Association (<http://www.fmaware.org>), the National Fibromyalgia and Chronic Pain Association (<http://www.fmcpaware.org/>), and the American Fibromyalgia Syndrome Association, Inc. (<http://www.afsafund.org/>). The leading organizations that provide information for people with chronic pain include American Pain Foundation (<http://www.painfoundation.org>) and the American Chronic Pain Association (<http://www.theacpa.org>) (Rowe, 2013). There are online websites that offer discussion forums for multiple conditions including fibromyalgia, such as WebMD, DailyStrength and MDJunction. Lastly, there are fibromyalgia-specific sites that one can go to for online support, such as FibroTalk (<http://www.fibrotalk.com>). Section 2.3 provides more detail on health-related online communities.

Though there are many resources for fibromyalgia, patients report being overwhelmed by the amount of information available and its scattered nature; they desire a ‘one-stop website’ for fibromyalgia (Chen, 2012a). Moreover, it has been argued that the volume of information causes confusion and reinforces the patients’ views that they are ill (Armstrong, 2000).

2.1.6 Illness Coping

Coping is arguably an important part of dealing with any illness, and fibromyalgia is no exception. Coping has variously been defined as the cognitive processes through which an individual learns to tolerate or put up with their illness (Bury, 1991), and as the cognitive and behavioral efforts to manage psychological stress (Lazarus, 1993). Individuals who experience chronic pain may employ various coping strategies, including guarding, resting, asking for assistance, task persistence, and coping self-statements (Jensen, Turner, Romano, & Strom, 1995). Information seeking and avoiding have also been observed as coping strategies in the context of illness (Felton & Revenson, 1984).

In my dissertation research, I explored fibromyalgia patients’ illness journeys, including the coping strategies that they have employed. Thus, in this section I review the literature on coping that is relevant to fibromyalgia, first focusing on empirical studies relating to coping in the context of fibromyalgia and/or chronic pain. I also review studies that have employed narrative analysis to study fibromyalgia illness experiences. Additionally, I review theories of illness coping that are relevant to fibromyalgia. This literature suggests that time is an important factor to consider in studies concerning the experience of fibromyalgia patients.

2.1.6.1 Empirical Studies on Illness Coping

For fibromyalgia patients, the path to diagnosis is often a long and stressful one. Patients often wait a long time before presenting their symptoms to a doctor, and even after

doing so, a significant amount of time may pass before patients receive a diagnosis. In one survey of fibromyalgia patients from eight countries, Choy et al. (2010) reported that, on average, patients waited almost a year after symptom onset before presenting to a physician, the mean time to diagnosis was 2.3 years, and that patients presented to 3.7 physicians before receiving a diagnosis. Over half of the respondents in this survey also found it difficult to communicate with their physician. Patients are afraid that they will not be taken seriously, given that the disease has no outward signs (Arnold et al., 2008).

Fibromyalgia patients' difficulties do not end with the diagnosis. In the case of many illnesses, diagnosis can serve to give meaning to an illness experience that has, up to that point, been vague and uncertain (Madden & Sim, 2006). Constructing meaning from the diagnosis and re-interpreting the illness experience are therefore critical to coping with the illness. But in the case of fibromyalgia, initial relief at finally arriving at a diagnosis is replaced by the realization that it is "empty" (Madden & Sim, 2006; Undeland & Malterud, 2007). In many cases, neither patients nor their significant others have heard of the condition, and the condition itself has an unclear medical definition. Thus patients find that "uncertainty based hitherto on a lack of knowledge [is] replaced by a new type of uncertainty, stemming from a diagnosis that convey[s] no meaning, inspire[s] little confidence, and create[s] no real basis for understanding or coping with the illness experience" (Madden & Sim, 2006).

Previous studies suggest that uncertainty plays a large role in fibromyalgia patients' psychosocial adaptation. Johnson, Zautra and Davis (2006) found that illness uncertainty moderated the relationship between increases in pain and coping difficulty. Those with a high level of illness uncertainty found it more difficult to cope with weekly increases in pain than individuals with a lower level of illness uncertainty. Another study found that spiritual well-

being moderated the relationship between uncertainty and psychosocial adaptation (Anema, Johnson, Zeller, & Zetterlund, 2009). When participants were able to find meaning in their lives, they perceived less uncertainty. In the study, the change in activities between the best day and the worst day caused the greatest uncertainty in participants' lives, suggesting that it was the uncertainty of events in everyday life, rather than disease meaning, that had the greatest effect on psychosocial adaptation. Fibromyalgia patients also appear to be more vulnerable to the negative effects of social stress (Davis, Zautra, & Reich, 2001).

The use of coping strategies appears to play a significant role in adjustment. A study of white and female older adults with persistent pain employed the Chronic Pain Coping Inventory (CPCI) to investigate associations between the use of coping strategies, and disability and depression (Ersek, Turner, & Kemp, 2006). The most frequently reported strategies, and those that were associated with better psychological adjustment and physical outcomes, were Task Persistence, Pacing, and Coping Self-Statements. The least frequently used strategies were Asking for Assistance and Relaxation. Another study that examined the results of a multidisciplinary fibromyalgia treatment program found that the following were the strongest predictors of outcome: (1) an increased sense of control over pain, (2) a belief that one is not necessarily disabled by fibromyalgia, (3) a belief that pain is not necessarily a sign of damage, (4) decreased guarding, (5) increased use of exercise, (6) seeking support from others, (7) activity pacing and (8) use of coping self-statements (Nielson & Jensen, 2004).

Büssing, Ostermann, Neugebauer, and Heusser (2010) studied the use of adaptive coping strategies for chronic pain conditions as they related to the concept, locus of disease control. Most patients tended to externalize the process of disease management and thus relied on external sources to control their condition (i.e., Trust in Medical Help and Search for

Information and Alternative Help), but there was also some reliance on internal powers and virtues (i.e., Conscious Way of Living and Positive Attitudes). Positive Attitudes and higher age were predictive of patients' life satisfaction, but none of the other coping strategies were (Büssing et al., 2010). The experience of illness may enhance intensity and depth of life, and thus may explain the association between internal adaptive coping strategies, particularly Reappraisal, and positive interpretations of disease. Therefore, restoring a sense of self-control over pain (and thus congruence with the situation) is a major task in patient care.

Conscious and Healthy Way of Living correlated strongly with Positive Attitudes (Büssing et al., 2010); this may suggest that promoting the adoption of healthier lifestyles may result in positive adjustment. There were no steady courses of adaptive coping strategies but rather, transient trends with strong variances, indicating that individual reasons to utilize a distinct strategy cannot be explained by duration of disease alone but by multiple influences (i.e., acceleration of pain intensity, treatment efficacy, partner support, depression, daily life management, financial situation, etc.).

A number of studies have shown that acceptance of pain may be more successful for predicting adjustment than coping behaviors (Rodero, Casanueva, Luciano, Gili, Serrano-Blanco, & García-Campayo, 2011; McCracken & Eccleston, 2003). Previous research with fibromyalgia and arthritis patients has also found that becoming knowledgeable about one's condition is an important factor in acceptance or 'coming to terms' with pain (LaChapelle, Lavoie, & Boudreau, 2008), and greater acceptance of chronic pain was associated with less pain, symptoms, fibromyalgia impact, anxiety, and depression as well as with better general health, vitality and physical and social functioning (Rodero et al., 2011). Acceptance of pain has a moderate effect on mental well-being (Viane et al., 2003), and also predicts less pain,

disability and distress (McCracken & Eccleston, 2003). Juuso, Skär, Olsson, and Söderberg (2013) found that meanings of feeling well include being in control, having power, finding one's own pace, and feelings of belonging.

There are a few studies that have analyzed the narratives of fibromyalgia patients. In these studies, patients are seen as “active agents who are not only describing their life events, but who are also actively negotiating and reconstructing their life story by choosing and interpreting the events and by emphasizing different aspects of their experiences” (Sallinen, Kukkurainen, Peltokallio, Mikkelsson, & Anderberg, 2013, p. 476). In Sallinen et al.'s narrative analysis of twenty women with fibromyalgia, they identify three representative model narratives, which they have referred to as: “mundane life,” “cumulative life,” and “broken life.” In “mundane life” narratives, patients come to accept fibromyalgia as a part of life, and it only becomes an occasional disruption to life. In “cumulative life” narratives, cumulative life events gradually lead to a situation in which a person's resources are no longer adequate for maintaining well-being, and thus, fibromyalgia is seen as a result of long-term distress and uncontrollable fatigue. “Broken life” narratives were ones in which traumatic experiences permanently changed the course of life. Aside from these main types, Sallinen et al. present two narratives in which the women question the existence of fibromyalgia as a disease. Råheim and Håland (2006) conducted a hermeneutic-phenomenological study of 12 women with fibromyalgia using life-form interviews. They found three themes: “at the will of the treacherous body—powerlessness”; “struggling to escape the treacherous body—ambivalence”; and “caring for the treacherous body—coping.”

Though Charmaz' research did not focus on fibromyalgia patients, she interviewed a total a total of 90 women with chronic conditions (Charmaz, 1991). The conditions for

participant selection included a diagnosis of a serious chronic but not terminal illness and a disease category that poses uncertainty, which are conditions that are also true of fibromyalgia. Thus, her findings are also likely to be relevant for fibromyalgia patients. She presents three ways in which people experience chronic illness: interruption, intrusion and immersion. Gradually, they learn to re-structure their lives through planning, organization, and making trade-offs. Time becomes important for knowing and defining the self. People with chronic conditions learn to structure time differently to suit their health condition and doing so in turn promotes changes in perspective of time. They also create illness chronologies and define certain events as turning points. Thus, their lives may include periods of illness and non-illness, crisis and quiescence, flare-ups and remissions, and attempts to follow rigid regimens and convalescence. Certain events may seem more important in retrospect than when actually experienced. Illness chronologies may become markers of self as well as time.

2.1.6.2 Theories of Coping with Chronic Illness

There are similarities between the literature on fibromyalgia-related illness coping, and coping in chronic illness. This sections reviews two theories, Mishel's uncertainty in illness theory and Leventhal's Common Sense Model of illness regulation, both of which may be useful in understanding how fibromyalgia patients deal with their illness over time.

Mishel (1999) argues that uncertainty in acute illness differs from that of chronic illness. Whereas uncertainty in the former is based on issues of diagnosis, treatment and recovery, uncertainty in the latter results from disruption of daily routines and activities, which influences multiple spheres of life and may ultimately cause a breakdown in a person's view of self and of reality. This results in a time of disorganization, after which a person may emerge with a more

complex view of life and a more complex view of functioning – one in which uncertainty is accepted as a reality of life.

This re-interpretation does not necessarily occur (Mishel, 1990, 1999). In order for uncertainty to be a growth experience, an individual needs the support of those close to him or her as well as from health providers. The individual also needs time to focus on oneself in order for the process of integrating uncertainty into one's view of life to occur. Various factors may lead to uncertainty, such as the variability of illness symptoms, complexity of care and treatment, lack of information, and unpredictable nature of the trajectory of the illness (Mishel, 1988, 1999). Individuals may also employ coping strategies to deal with uncertainty, such as the seeking of information on how to manage their illness, planning one's schedule so as to minimize uncertainty, and controlling one's emotions.

According to Leventhal's Common Sense Model of illness regulation, individuals form cognitive representations concerning their illness based on personal experiences or information from the world around them, in order to make sense of and manage their condition (Hagger & Orbell, 2003; Leventhal, Brissette, & Leventhal, 2003; Petrie & Weinman, 2012). These may include beliefs about the cause/etiology of the illness, its symptoms and label (identity), consequences, expected duration, and the expectation that the person or a health care provider can influence or control the outcome of the illness (controllability/cure) (Stuifbergen, Phillips, Voelmeck, & Browder, 2006).

As illness perceptions influence the strategies that people use to cope with their illness and illness outcomes such as functioning, health care utilization, adherence and mortality, there is a body of research that aims to modify these perceptions (e.g., Foster et al., 2008; Glattacker, Heyduck, & Meffert, 2012). For example, Foster et al. reported that patients who expected their

back pain to last a long time, who perceived serious consequences in their lives, and who held weak beliefs in the controllability of their illness had poorer clinical outcomes. Foster et al. suggest trying to improve patients' perceptions of their personal control and restructuring negative thoughts about the consequences and inevitability of their back problems. In Glattacker et al., information was provided to patients that took into account their illness perceptions. At the end of the intervention time period, those in the intervention group had a greater sense of control and indicated that their information needs were met, more than those in the control group. Thus, it could potentially be useful to pay particular attention to any mentions of illness beliefs among my potential study participants, particularly in regard to controllability and life consequences.

Illness perceptions of fibromyalgia patients have been studied in previous literature. Overall, studies have reported that fibromyalgia patients perceive their illness to be chronic and have serious consequences; in addition, they perceived little personal control and did not expect medical treatment to be effective (Stuifbergen et al., 2006; van Wilgen, van Ittersum, Kaptein, & van Wijhe, 2008). Catastrophizing has also been found to be associated with a limited understanding of the symptoms of fibromyalgia, a perception of a more cyclical nature, and higher emotional representation (van Wilgen et al., 2008).

2.1.7 Self-Management

The process of living with a chronic illness is a continually shifting, non-linear process in which individuals experience a complex interaction between their illness and life context, that may be affected by a variety of factors including the trajectory of the illness and individual-level variables (Schulman-Green et al., 2012). In their qualitative meta-synthesis of research describing processes of self-management in chronic illness, Schulman-Green et al. identified

three main categories: focusing on illness needs, activating resources and living with a chronic illness. Each of these, in turn, was associated with specific processes, tasks and skills. For example, “focusing on illness needs” included the processes: learning, taking ownership of health needs and performing health promotion activities. Taking ownership of health needs, in turn, was associated with the following tasks: recognizing and managing body responses, completing health tasks, and becoming an expert. Each of these was then associated with certain skills; for example, managing/taking medications was associated with completing health tasks.

Though most of the literature on self-management focuses on diseases other than fibromyalgia, there is still potential relevance to my study. Fibromyalgia is a condition in which there are many potential treatments, and in general they involve many of the processes, tasks and skills identified by Schulman-Green et al. (2012). The learning/adoption of self-management processes, such as increased physical exercise and the creation and maintenance of relationships with health care providers, might be mentioned in the interviews or drawn on timelines.

Lorig and Holman (2003) elucidated various skills that were important for self-management: problem solving, decision making, resource utilization, partnering with healthcare providers, action planning and self-tailoring. They also argue for the use of self-efficacy as a mechanism in self-management interventions. Ryan and Sawin (2009) emphasize that self-management is a complex, multidimensional phenomenon that can affect individuals, dyads and families at all developmental life stages. A change in one component (i.e. an individual) can affect all other components of the system (e.g. the family). Moreover, all components of the system are continually evolving.

The notion of individuals as being parts of complex and evolving systems was also useful to consider in my study. Previous studies of fibromyalgia illness experiences have reported that patients experience various problems with others, including social isolation (e.g. Arnold et al., 2008), damage to personal relationships (Marcus et al., 2012), and trouble communicating with physicians (Åsbring & Närvänen, 2003).

2.1.8 Summary

Fibromyalgia is a condition that has impacts on many different facets of life, including impairment in social and occupational function, shrunken spheres of physical and social activity, and illness uncertainty. Moreover, fibromyalgia patients also suffer from invalidating experiences with those around them, resulting in a need for legitimacy and validation, and adverse impact on self-confidence and self-identity. Fibromyalgia patients often suffer from cognitive dysfunction or mental haziness due to “fibro fog.” Previous literature on coping suggest that there are various aspects, e.g. sense of control over pain, a belief that one is not necessarily disabled by fibromyalgia, a belief that pain is not necessarily a sign of damage, decreased guarding, increased use of exercise, seeking support from others, activity pacing and use of coping self-statements, that do improve health outcomes (Nielson & Jensen, 2004).

The information context of fibromyalgia patients is quite a peculiar one. In the case of most diseases, patients obtain information from both their health care providers and the Internet. With fibromyalgia, patients often have trouble communicating with their physicians, and they are also likely to encounter difficulty searching for information on the Internet. There is information available online for fibromyalgia, but the quality of such information is highly variable, and high quality information is usually also at a high reading level. Though there has been limited research in this area, previous studies have reported that fibromyalgia patients

consult a wide variety of information sources and health care practitioners (Bennett et al., 2007; Daraz et al., 2011a), and the volume and scattered nature of this information can be overwhelming (Chen, 2012a).

Given the nature of the condition, fibromyalgia patients usually end up living with their condition for decades. There have been numerous studies that have examined qualitative aspects of patient experience (e.g., Arnold et al., 2008, Crooks, 2007; Madden & Sim, 2006; Thorne et al., 2004); however, none of them have focused explicitly on patient perceptions of their illness over time, what information might be helpful at different points over the course of illness, and how their interactions with information might change in other ways. These, then, became one of the foci of my dissertation research.

2.2 Information Behaviors

As we have begun to see, information plays an important part in the lives of many with fibromyalgia. There is much from extant theoretical and empirical literature in information science that may inform my study of fibromyalgia-related information behaviors. Thus, in this next section, I consider extant literature on health information seeking, needs and use. At the outset, I will consider various theoretical models of health information seeking; then I will review empirical studies that are particularly pertinent to understanding health information seeking. This literature will demonstrate that health information seeking can be considered as a dynamic and evolving process in which needs and perceptions of relevance are constantly evolving, and that use is a function of needs, perception of relevance and contextual factors.

2.2.1 Models for Information Seeking and Use

There are several models of information seeking and use that may be particularly useful for considering the information behaviors of fibromyalgia patients. These include: Kuhlthau's

Information Search Process (Kuhlthau, 1991), Bates' (1989) berry-picking model, information foraging (Pirolli & Card, 1999), Dervin's Sense-Making Theory and Methodology (Dervin & Reinhard, 2007), Wilson's Model of Information Behavior (Wilson, 1997), and the Comprehensive Model of Information Seeking (Johnson & Meischke, 1993). Each model will be briefly described and its applicability to the current study will be discussed.

2.2.1.1 Kuhlthau's Information Search Process

One theory of information seeking that is relevant is Kuhlthau's Information Search Process (ISP) (Kuhlthau, 1991). According to Kuhlthau, information seeking occurs in six stages: initiation, selection, exploration, formulation, collection and presentation. The feelings that an information seeker experiences, their thoughts and actions, and appropriate tasks differ at each stage. They also experience the following feelings alongside the stages: uncertainty, optimism, confusion/frustration/doubt, clarity, sense of direction/confidence and relief/satisfaction or disappointment. In terms of thoughts, they move from general/vague to clear/focused.

An important part of this conceptualization is the principle of uncertainty, which is that it is responsible for affective reactions of anxiety and lack of confidence (Kuhlthau, 1991). Uncertainty is a lack of understanding or a gap in meaning, and it initiates the process of information seeking. The affective reactions of uncertainty, confusion and frustration are associated with vague, unclear thoughts about a topic or question; as an individual's thoughts become more clearly focused, he or she also experiences increased confidence. According to Kuhlthau, current information retrieval systems function well if an individual's information need is clearly defined, but do not function well for situations in which an individual's information need is not clearly defined.

While it was developed by observing students writing term papers, Kuhlthau's model is a useful one for considering the information seeking behaviors of fibromyalgia patients because it provides a framework through which to examine individual growth through information over time. In addition, the ISP model also accounts for the feelings, thoughts, actions and appropriate tasks of the participant at each stage. One central idea that is inherent in the model, that there is an affective component to information processing, seems to fit well with chronic illness experiences; however, the ISP model also seems to suggest a linear process, which does not seem to fit well. It would seem that the process of making sense of information in chronic illness might include stops, starts, sudden jumps, incongruences, and cyclic processes, all of which are not clearly reflected in the model.

Though Kuhlthau's model has previously been employed to study the health information seeking of women in the northeastern United States (Warner & Procaccino, 2004), to date there has been no study that this author knows of considering the applicability of the model to patients with chronic conditions. One question that comes to mind is whether patients ever reach the later stages of formulation, collection, and presentation. Since previous research concerning the trajectory of fibromyalgia shows that it is cyclical (Walitt et al., 2011), it is likely that in many cases, patients do not clearly resolve the specific health problem that triggered the information search.

2.2.1.2 Bates' Berrypicking Model of Information Retrieval

Bates' (1989) "berrypicking" model of information retrieval was presented as a challenge to the classic information retrieval model. In the classic information retrieval model, a query is matched against a set of document representations, and a single document set is returned. Bates posed a number of challenges to this model. First, she argued that the query

does not remain static, but “evolves” as the user is exposed to new information. Furthermore, the user picks up information a little at a time rather than all at once – this is what she calls *berrypicking*. In the process of the search, the user may iteratively employ a wide range of strategies beyond the typical search term and database term match.

Various aspects of this model seem to suit information behaviors in the context of chronic illness. First, those who are chronically ill live with their conditions for a substantial length of time; it is likely that the process through which they come to understand their illness is also one that takes a substantial amount of time, and that they pick up information along the way, little bits at a time. Each piece helps them to understand their condition a little more, and thus any information searches that they conduct will evolve. Lastly, they may encounter information through all sorts of channels – not necessarily the scholarly ones that Bates enumerates, but still through an array of channels. An additional piece that might be added is that, in addition to searches evolving due to user processing of previously acquired information, searches also evolve due to disease progression or changes in health status. Moreover, information is acquired not only through intentional search, but also through information encountering (Erdelez, 1999).

2.2.1.3 Information Foraging

Information foraging is an approach to understanding information seeking, gathering and consumption that is based on the idea that people will modify their strategies to fit the structure of their environment to maximize their information gain (Pirolli & Card, 1999). Some key aspects of the theory include the concepts of *information patch*, *information scent* and *information diet*. The idea behind information foraging is that the environment of an information forager often has a “patchy” structure, where information is unevenly distributed.

One can encounter an area that is richer in information, such as a pile of books on a desk, or an online collection; they may also run into areas with little or no information, such as a clear spot on the desk or a set of websites with little relevant content. There is the idea that individuals will give up some time if they travel from patch to patch, but once they get there, they may be able to find information much more easily than if they had stayed in their original location. Thus, a key aspect of information foraging is that people need to make decisions about whether to move on to a different patch or not.

This is where information scent comes in. Information scent is an individual's perception of whether a resource will be useful or not (Pirolli & Card, 1999). According to information foraging theory, then, people may find an information-rich patch and continue to browse there until they start losing the "scent"; then they may move on and try to find a different patch. In addition, in a situation in which individuals have multiple potential sources of information, they will construct a "diet" that optimizes their gain, taking into account their costs. As can be seen, there are similarities between berrypicking and information foraging; Bates focuses on the actor engaging in information seeking, whereas Pirolli and Card focus on the environment and its influence on the information seeking process.

This model fits well in terms of conceptualizing some of the information seeking behaviors of fibromyalgia patients, and also of health information seeking in general. Information about health conditions, especially information that is *specific to a user's situation*, is not always easy to find or recognize. The information is unevenly distributed and can exist in many shapes and forms. Fibromyalgia patients may look for information on government websites or health portals to get a general idea of what the condition is; they may also look on discussion forums and blog posts to get more personal accounts. Some websites may yield very

little useful information, and in the course of their information search, patients will make multiple assessments about these “patches” and their potential yield. Where the model perhaps does not work so well is that there are changes in fibromyalgia patients’ information needs, but in the foraging of animals, there is perhaps a constant need for food of a relatively consistent quality/kind.

2.2.1.4 Dervin’s Sensemaking Theory and Methodology

Dervin’s Sense-Making Theory and Methodology is another framework for conceptualizing information use. According to Dervin, discontinuity is a fundamental aspect of reality (Savolainen, 1993). One of the major concepts of the theory is the sense-making triangle of situation-gap-uses/helps. In this conceptualization, situations are time-space contexts in which sense is constructed. Gaps are stops or barriers to movement, and as such, cognitive gaps can be operationalized by the questions or information needs of an individual. Gap-bridging may be used to refer to the cognitive strategies that can be used to answer an individual’s questions, and uses/helps are the ways that these answers are used. The helpfulness of information sources can be classified into categories such as: Got Pictures, Got or Kept Moving, Got Support, Got Control, and Got There (Dervin & Reinhard, 2007).

Emotions are inherent within the Sense-Making framework as a bridging sense-making element, along with other elements such as intuitions, thoughts and attitudes (Dervin & Reinhard, 2007). The unit of analysis in the Sense-Making Methodology is “person-in-situation,” and situations are assessed along various dimensions, including: challenging, important, confusing, emotional, unfamiliar and contradictory. The appeal of this methodology is that, in Dervin’s own words, “Sense-Making guided studies are not intended to present essentialist pictures of user behavior as concrete aspects of reality, but rather phenomenological

pictures of how users construe their worlds” (Dervin & Reinhard, 2007, p. 76). Though I concur, the fixed nature of the categories and structure that is inherent in the methodology, in my view, also means that there is the danger that it may not apply to some populations or result in bias in the findings if not properly adapted.

Baker (1998) employed the situation-gap-uses/helps framework and the micro-moment time-line interview technique in her interview study of the information needs and information-seeking patterns of people with MS. She reported that there were gaps in people’s knowledge about physical symptoms that they were experiencing, emotions that they felt, and drugs. In this study, it appears that the Sense-Making Methodology was appropriate for identifying and describing the gaps and barriers to obtaining information. However, Baker reported that there were problems with the use of the timeline because people did not tell ‘neat and tidy stories’ (p. 119). Stories of one incident would be embedded in stories of another. This occurred in the interviews that I conducted as well, but it did not pose as much of a problem because I had expected that this would occur, and employed a flexible interview format in anticipation. Though stories were embedded in one another, and there were tangents taken, all of the data was subsequently analyzed in the process of line-by-line coding.

There are similarities between the Sense-Making Methodology, as applied to the management of chronic illness, and other literature on coping and sense-making in chronic illness. For example, according to the Sense-Making Methodology, patients’ inability to account for their symptoms might be thought of as gaps, and the uses/helps are the ways that patients are able to bridge these gaps and overcome barriers to their health and well-being. Leventhal’s Common-Sense Model of illness regulation links illness representations, or mental representations of their illness, to coping strategies (Hagger & Orbell, 2003). These illness

representations might be thought of as the products of sense-making. In practice, however, research use of the Sense-Making Methodology and the Common-Sense Model are very different, because the Sense-Making Methodology employs an elaborate interview protocol, including the situation-gap-uses/helps framework and the micro-moment time-line interview technique, and most assessments of a person's illness representations involve a scale instrument such as the revised version of the Illness Perceptions Questionnaire (Moss-Morris et al., 2002), which has a fixed set of dimensions representing illness representations.

2.2.1.5 Wilson's Model of Information Behavior

The idea that extant theories in the field of information science do not provide a comprehensive view of information behaviors has been observed by previous researchers (e.g., Spink & Cole, 2006). There are some models that attempt to integrate extant models into a comprehensive model (e.g., Wilson, 1997; Spink & Cole, 2006). Wilson (1997) integrated Kuhlthau's, Ellis', and others' models of information behavior into a single model representing not just information seeking behavior, but information behaviors in general. A person moves from having an information need (modeled as "person-in-context") to information seeking behaviors; in between there are various intervening variables (psychological, demographic, role-related or interpersonal, environmental and source characteristics) and activating mechanisms (stress/coping, risk/reward, and self-efficacy). Information seeking behavior can take the form of passive attention, passive search, active search and/or ongoing search. Following information seeking behavior, one moves to information processing and use, and from then on iterates back to having an information need.

Two aspects of this model are particularly helpful for examining information behaviors. First, like Sense-Making, the framework calls attention to an individual's context; second, the

model explicitly elucidates many variables that may affect information behavior. One that may be particularly relevant to fibromyalgia patients is stress. The relationship between fibromyalgia and stress is a frequently studied question, but studies have also reported conflicting results regarding a causal connection (van Houdenhove & Egle, 2004; van Houdenhove, Egle, & Luyten, 2005; Uveges et al., 1990). Free response answers to my earlier survey (Chen, 2012a) also suggest that self-efficacy may play a role in patients' perceptions of whether they are managing the condition well. In this case, I would argue that management also includes the use of information in management, because the responses suggested that for some, it was a question of knowing enough about fibromyalgia, while for others, it was a question of having experts that they trusted, or both. One drawback of this model is that, while it includes information use, there is not much detail on how this occurs; thus, there is opportunity here for elaboration.

2.2.1.6 Comprehensive Model of Information Seeking

Another model of information seeking that attempts to integrate prior models is the Comprehensive Model of Information Seeking (CMIS) (Johnson & Meischke, 1993), which is based on uses and gratifications theory, the health belief model, and a model of media exposure and appraisal. There are three main components: antecedent factors that determine one's predisposition to seek information from particular information carriers (e.g. demographics, experience, salience and beliefs), information carrier factors (utility and information carrier characteristics), and information seeking actions (Johnson & Meischke, 1993; Johnson, Andrews, & Allard, 2001; Han et al., 2010).

Previous studies have used it to investigate the factors that are important in the appraisal of information sources (Johnson & Meischke, 1993), the factors associated with use of

interactive cancer communication systems (Han et al., 2010), and factors that affect whether patients seek information about cancer (Mayer et al., 2007). Because of the focused nature of the CMIS – Johnson and Meischke (1993) describe the “primary pragmatic benefit” of the model as being an increase in the match between information sources and audiences – I expected that it would be difficult to employ the model to explain the role of information in participants’ illness journeys. However, it was a useful paradigm for considering participants’ selection of information sources.

2.2.1.7 Summary of Models

After considering the preceding models, it becomes clear that each focuses on different aspects of information behavior. Bates’ berry-picking model and information foraging focus on the process of information seeking, and Sense-Making focuses on information processing and use. The ISP model takes a longer view of seeking, but still does not explicitly model use. The CMIS serves as a useful framework through which to consider the characteristics of individuals that may affect their information seeking behaviors, which many of models of information seeking do not do. However, it does not provide guidance concerning how ones’ information seeking behaviors might change over an extended period, nor does it model use. Wilson’s integrated model provides a more comprehensive framework through which to regard information behavior. The model includes information use, but more could be said about how this occurs, the factors that affect it, and individual differences.

2.2.2 Empirical Studies of Information Needs, Seeking and Use

Previous literature has observed that people’s information needs and desires vary considerably depending on where they are in their illness experience (van der Molen, 1999; Squiers, Rutten, Treiman, Bright, & Hesse, 2005; Chen, 2012a). Moreover, as patient needs for

emotional support and information may vary greatly, it is important to try to understand their preferences, offer choices and encourage patient involvement (Beeney, Bakry, & Dunn, 1996). The next section of this literature review examines empirical studies of people's health-related information behaviors, focusing on four themes: channel/source selection, information seeking, information use and evaluation of health information.

2.2.2.1 Channel/Source Selection

As a backdrop against which to consider more specific literature on health information seeking, I will begin with an overview of health information seeking by the general public. Given the ubiquity of the Internet today, people often go online for health information; however, they also continue to rely on traditional channels. When asked about the sources that they turn to for information or assistance in dealing with medical issues, 86% of all adults mentioned health professionals, 68% turned to friends and family, 57% used the Internet, and 54% used print material (Fox & Jones, 2009). Despite increases in the availability of health information on the Internet, at least in the case of cancer, the public's trust of online health information decreased, and trust in health care providers increased, from 2002 to 2008 (National Cancer Institute, 2010).

Health information seeking patterns also vary by individual-level variables such as demographic, health status and distress. A previous meta-analysis of cancer patients found that younger cancer patients and patients who preferred active roles in treatment decision-making express a greater need for information (Ankem, 2006). Those who experience greater psychological distress are more likely to use online support groups, blogs and social networking sites (National Cancer Institute, 2011). Different ethnic groups also vary in terms of the extent to which they engage in health information seeking and the channels/sources that they select;

these differences may be attributed to a variety of factors including health knowledge, trust of the medical community, privacy concerns, insurance, religious beliefs, worldviews and emotional issues (e.g. Kakai, Maskarinec, Shumay, Tatsumura, & Tasaki, 2003; Matthews, Selligren, Manfredi, & Williams, 2002).

2.2.2.2 Information Seeking

In the previous chapter, I mentioned that there have been few studies on the information needs and seeking of fibromyalgia patients, but there is quite an extensive literature on other conditions, particularly cancer. This section will highlight extant literature on the temporal and affective factors that affect information need.

2.2.2.2.1 Temporal Factors

Information needs are likely influenced by temporal factors. In the case of cancer, previous reviews have reported that cancer information needs are largely treatment-related (Rutten, Arora, Bakos, Aziz, & Rowland, 2005; van Mossel et al., 2012), which in turn vary with time. Information needs about the stage of disease, treatment options and side effects of treatment were prominent. Patients may seek information at specific time points in preparation, for example, before visiting the doctor, during investigations, after the diagnosis, when choosing treatments, before treatment, at a short term follow up, and at a long term follow up (Ziebland et al., 2004).

Patterns of information seeking may be contingent upon disease stage, and these patterns also differ depending on the type of cancer (Nagler et al., 2010). In earlier stages, patients with early stage breast or prostate cancer consistently reported more information seeking than colorectal cancer patients, but in later stages, differences between cancer types are not as great. Nagler et al. argued that these differences might be due to variation across conditions in

availability of information, ambiguity in treatment options, number of long-term side effects and the size of lay communities that foster a culture of engagement.

Eheman et al. (2009) conducted a study of patients who had undergone either chemotherapy or radiation therapy. In general, patients were more active information seekers prior to treatment rather than after. They suggested two explanations. Prior to treatment, people actively seek information about treatment options, and thus the need for information decreases once the treatment decision is made. Following treatment, the focus of the information search shifts from medical or technical information about a treatment, to treatment side effects.

Butow, Maclean, Dunn, Tattersall and Boyer (1997) has found that patient needs may vary in terms of desire for information, support and involvement over the course of their care. Prior to the first consultation, patients expressed a need for information such as prognosis, illness and treatment options. Following the first visit, patients' needs shifted to support, with the largest percentage of patients seeking reassurance, hope, and a chance to talk about worries and fears. As time passed, patients were likely to desire less detailed information but greater involvement, except in situations where individuals had follow-up visits in which significant changes in their health conditions were discussed. In such situations, patients were more likely to prefer that their doctor make the decisions.

These empirical findings support the argument that relevance is dynamic and evolving. According to Saracevic (1996), relevance is an “interactive, dynamic establishment of a relation by inference, with intentions toward a context” (p. 5). In Tang and Solomon (1998), it was observed that the information that an individual perceives as being needed (relevance) changes in the process of searching, and hence so does the evaluative process of whether material was

relevant. These conceptions of relevance suggest that it would be important for retrieval systems to be sensitive to searchers' context and mental models.

As this literature review has demonstrated, much of cancer-related information seeking has focused on treatments. Similarly, in the case of coronary heart disease (CHD), it has been observed that patients seem to prioritize information that is pertinent to survival rather than broader lifestyle issues such as exercise and diet (Timmins, 2005). These two examples suggest that, when one faces a threat to one's life, the immediacy of that threat dwarfs other concerns, even when behavioral changes can result in substantial improvements and extensions to one's life. With fibromyalgia, in the beginning, patients appear to be more focused on symptom management and finding a complete cure (Chen, 2012a). Eventually, many patients adjust to the idea that they may have the illness for the long term, and interests shift to illness management and lifestyle changes. How this shift happens, though, is not clearly described in the extant literature, and thus served as a motivation for the current study.

2.2.2.2.2 Affective Factors

Affective factors can play a role in information behavior in various ways: they can motivate or inhibit an individual's desire for information, they can color one's reception of information, and they can also arise from the results of a search. At the outset, I will discuss two methods of coping in response to medical stressors: monitoring and blunting (Miller, 1995). Monitoring refers to attending to, scanning for and amplification of threatening cues, and blunting refers to the avoidance of threatening cues. High monitors tend to be more worried about the seriousness of the problem and exhibit more signs of agitation, pain and discomfort during treatment. Monitors tend to scan for threat-relevant information about adverse medical events and rehearse and amplify them, whereas blunters distract themselves and psychologically

attenuate such information. This behavior also means that blunterners are less likely to be aroused and therefore may have a greater tendency not to adhere to their treatment regimens.

Information avoidance can be associated with various affective factors such as anxiety and fear (Case, Andrews, Johnson, & Allard, 2005). Moreover, worry and risk perceptions can also be associated with information avoidance and age. In one study using a nationally representative sample of the United States population, Persoskie, Ferrer and Klein (2014) reported that for those over 50, those who worried about getting cancer were more likely to avoid seeing a doctor; and for those under 50, those who avoided seeing a doctor were more likely to have high cancer risk perceptions.

Leydon et al. (2000) observed that cancer patients harbored three types of attitudes that would limit their desires for more information: faith, hope and charity. Faith in medical practitioners' expertise precluded the need for more information; hope was a strategy for coping that could be maintained by avoiding potentially negative information; and lastly, charity meant that patients recognized that resources were scarce and there were many other patients in need of help, so they refrained from asking more questions or asking for more assistance.

The seeking of information and/or the reception of information can also have affective consequences. Various studies have shown that information seeking had positive effects on adjustment and wish-fulfilling fantasy had negative consequences (e.g., Felton & Revenson, 1984). A previous review showed that patients who are satisfied with the information that they receive tend to have a better health-related quality of life (HRQoL) and less anxiety and depression (Husson, Mols, & van de Polle-Franse, 2011).

The literature reviewed in this section suggests that the role of affect is often intermingled with risk perception, spirituality, coping and other factors. Understanding an

individual's beliefs about their illness also seem to be critical for understanding their information behaviors, whether it be information seeking/avoidance, or reception of information. In order to provide participants the flexibility to show how all of these factors are related, in the drawing of the timeline I encouraged them to depict these different factors, but did not specify whether these different influences should be drawn separately or together. In doing so, I hoped that, if the factors mentioned in this section are interrelated, that these relationships would naturally emerge in the timeline.

2.2.2.3 Information Use

People search for health information at specific time points in their illness and for specific purposes. With regard to the outcome of health information searches, some of the main impacts that are reported include: the information found affected their decision about how to treat an illness or condition, it changed their approach to maintaining their health or someone else's health, it led them to ask a doctor questions or get a second opinion, it changed the way they think about diet, exercise, or stress management, it changed the way they coped with a chronic condition or managed pain, and it affected a decision about whether to see a doctor (Fox, 2006). As can be seen, many of these impacts dealt with chronic illness management and/or lifestyle behavioral change, and were used to help patients either make a health decision or seek care.

Patients use the Internet for both information and social support (Ziebland et al., 2004). With regard to the former, they used the Internet to learn more and prepare, when selecting treatments, to check that the treatment was optimal, to supplement information from the hospital, to make sense of medical terms, and to find the right questions to ask. In terms of the latter, they used the Internet to combat isolation, to find alternative and complementary

treatments, to access experiential knowledge, to connect with others, to participate in their own care, and to raise awareness of their own condition.

Patients may also use health information to engage in dialogue with physicians. In recent years, patients' bringing information from the Internet into the consultation has rapidly increased (Wald, Dube, & Anthony, 2007). This presents challenges for the practitioner, including dealing with misinformation due to the variable quality of Internet information, possible exacerbation of socioeconomic health disparities, and shifting of conventional notions of the physician-provider relationship in which the practitioner is the "traditional" medical authority. However, there are also potential benefits, such as the opportunity to help patients make informed health care choices, shared decision-making within a collaborative framework, more efficient use of clinical time, augmenting of physician-provided information, online social support, and/or access to patients' own information.

In the case of chronic conditions such as Chronic Fatigue Syndrome (CFS) or myalgic encephalitis (ME) which are "invisible" from a biomedical perspective and debated within the medical community, primary care physicians often are not able to meet patients' information needs (Chew-Graham, Cahill, Dowrick, Wearden, & Peters, 2008). In these situations, patients often rely on alternative sources of information such as the media, websites, and self-help groups, and bring this information to consultations with their family physicians. This information can help them to legitimize their condition to themselves and to others. Aside from biomedical evidence, physicians and patients both have developed a greater sense of recognition and understanding of CFS/ME as they hear increased reports of it through the popular media and from others who know of someone who has it.

The information use styles that a patient develops may be based on a combination of different factors, including experience, health status and health beliefs. Zufferey and Schulz (2009) identified four patterns of use of a patient-centered website for chronic back pain (“Oneself”): selective use, enthusiastic use, magic use, and wait-and-see use. Experienced self-managers engaged in selective use to find tailored information and support for self-management; novice self-managers engaged in enthusiastic use to make a path for self-management; those who were waiting for a definitive solution to chronic lower back pain engaged in “magic use”; and latent self-managers engaged in “wait-and-see use.” To elaborate upon “magic use,” this group of users adhered to the traditional biomedical model and expected their problem to be solved by health professionals. They tended to use the website regularly in the beginning, then become frustrated with it and only return occasionally to see if there was something really new. The group that engaged in “wait-and-see use” was comprised of individuals for whom lower back pain was only a marginal problem; hence, they did not expend a great deal of effort to manage their problem, but they knew that the website would be there if they needed it.

The studies reviewed in this section show that there could potentially be many uses of health information that patients encounter. People may use information to improve their self-management of their condition, or to talk with their health care practitioners about their treatment. Information may not only serve to enrich patients’ knowledge, but also to comfort or encourage. Given the diversity of use styles, paying attention to individual differences could be invaluable in the design of patient education resources.

2.2.2.4 Patient Evaluation of Health Information

The question of how patients evaluate the health information that they find is an important one. It is perhaps not difficult to imagine that patients may have difficulty understanding health information that they encounter. Previous research suggests that heuristics may play an important role. In a study conducted by Sillence, Briggs, Fishwick, and Harris (2007), within a few minutes, patients are able to sift through information, recognize and reject generic portals, sales sites, and sites that they did not trust, based on heuristics concerning the “look and feel” of the site. Along similar lines, Rains and Karmikel (2009) found that structural features (i.e., name, navigation menu, privacy policy, links to external sites, images, physical address and third-party endorsement) were positively associated with website credibility, and message characteristics (i.e., statistics, quotes and identification of authorship) were positively associated with attitudes about the health topic.

Eysenbach and Kohler (2002) reported results that may conflict with the findings of these two studies; they conducted a mixed methods study involving both focus groups and observation. In the focus groups, participants said that when assessing the credibility of a website, they primarily looked for the source, a professional design, a scientific or official touch, language and ease of use. However, in the observational study, none of the participants checked the “about us” sections of websites, disclaimers or disclosure statements, and in the post-search interviews, few participants noticed or remembered which websites they had received the information from.

What might account for the differences in these findings? First, the sample sizes of the studies were fairly limited and most likely differed in terms of demographics, which may account for a difference in knowledge about how to evaluate credibility of health information.

Second, the participants in Sillence et al.'s (2007) study had a vested interest in the information, which was not true of the other two samples. Thirdly, previous researchers have argued that people may pay attention to different features of websites depending on the situation. Lastly, it appears that Eysenbach and Kohler's study was conducted quite a few years before the other two studies; it is possible that over time, people have become more savvy about assessing the credibility of online health information.

Keselman, Browne and Kaufman (2008a) conducted a study in which they had participants search for information about a hypothetical scenario in which a family member had stable angina. They found that, compared to the expert model, participants' knowledge structures involved different concepts, and those knowledge structures were differently grouped and defined. Incorrect or imprecise domain knowledge resulted in participants searching for information on irrelevant sites, often inadvertently seeking out data to confirm their initial incorrect hypotheses.

In the absence of other studies, it is difficult to draw firm conclusions. But the previous literature suggests that people may generally have rules of thumb concerning the reliability and accuracy of health information; however, they may not always adhere to them systematically. Understanding more about when they do and do not could help ensure that patient education resources are designed to promote maximum exposure and comprehension.

Previous work also shows that trust appears to play an important role in the review of health information. Sillence, Briggs, Fishwick, and Harris (2004, 2006, 2007) argued that patients develop trust in health websites in three stages: rapid screening of sites based on heuristic analysis, systematic evaluation of site content, and developing a longer term

relationship with the site. Different content and design factors contribute to the rejection and mistrust versus the selection and trust of websites.

The extant literature in this area suggests that patients do have their own ways of evaluating health information. Various processes may be involved, including heuristic evaluation, systematic evaluation, and long-term relationship building. Search behaviors that may not be helpful, such as selective observation and seeking confirmation of a priori hypotheses may also occur. However, the studies in this area have largely involved small samples, and there is a need for more work in this area. Moreover, it is as yet unclear how people who have had a condition for a long time may or may not evaluate health information differently. Thus, there is a need for caution in applying these findings to fibromyalgia patients.

2.2.3 Summary

This section reviewed the theories of information seeking and empirical literature on health information behavior that are of relevance to this study. With regard to information seeking, there is a rich set of theories that could be relevant to fibromyalgia-related information seeking. Berry-picking and information foraging provide metaphors to consider the process that fibromyalgia patients go through in their search for information: picking up bits of knowledge here and there over time, having information needs shift as their mental models evolve. The ISP model, while perhaps not directly applicable, is an example of how the process of information seeking can also be considered a long-term one, and one in which different points of the process may be associated with different types of affect. There are many aspects in which I find Dervin's Sense-Making Methodology to be potentially useful for studying the experiences of fibromyalgia patients. The approach that she has elucidated leads to an intuitive focus on the "lived experience" of the patient, which I have argued is essential for the study of

the needs of fibromyalgia patients. However, the structured nature of the method might also constrain the directions in which an interview might go; thus, I did not use it as a guiding framework in the current study. Lastly, I reviewed two integrated models of information behavior: the model elucidated by Wilson (1997), and the Comprehensive Model of Information Seeking. These two models emphasize the need to consider contextual factors and perceptions in information use.

The empirical literature on health information behavior suggests that information seeking and use are both highly contextual. People seek out, use and find different types of information relevant depending on a variety of factors, including illness stage and demographic factors such as age and ethnicity. However, much of the extant literature pertains to those conditions that pose a greater threat to life, such as cancer and cardiovascular disease. It is unclear whether/how much this literature applies to fibromyalgia and other, more “nebulous,” conditions.

As there are few empirical studies of fibromyalgia patients’ information behaviors, it is unclear how they process and use information. How do fibromyalgia patients search for information about their condition and/or their symptoms, and how do they evaluate that information once they find it? What role do affective factors play, and how does their role change along the course of their illness? Though there is a rich literature on health information seeking, it is still difficult to answer these questions due to a lack of qualitative studies of fibromyalgia patients’ information behaviors, and a need for more research concerning affective and temporal factors in information behavior.

2.3 Participation in Health-Related Online Communities

There are different types of social media with which people may engage relating to health; in this section, I focus on online communities. Health-related online communities are becoming increasingly common constituents of the tapestry of an individual's health care. These communities come in various shapes and sizes: social networking sites, discussion forums on health portals, theme-based sites of individuals that come together for a common cause such as dieting, fitness, and so on; communities on Reddit, and more.

These communities may play various roles in a given individual's life. First, as Johnson and Ambrose (2006) argue, their widespread use suggests that they fill a void in today's healthcare system. In the past, patients were able to obtain the care that they needed from a single point of care – the physician's office visit. Today, given patients' increasingly multifaceted needs, this is no longer possible. Health-related online communities have emerged to fill this gap.

In addition, health-related online communities are a place for information flow, exchange and storytelling (Johnson & Ambrose, 2006). They can also be a place for group problem solving, insights for research and pervasive memory. Another benefit is that they do not constrain members in terms of spatial or temporal location.

Health-related online communities also play a central role in various contemporary trends, including citizen science (non-professionally trained individuals conducting science-related activities); crowdsourced health research (studies that use web-based technologies to recruit project participants); and participatory medicine (active participation in health care using Web 2.0 technologies; definitions adapted from Swan, 2012). PatientsLikeMe and 23andMe, in particular, have led the way in terms of operating crowdsourced health research studies (e.g.,

Frost, Massagli, Wicks, & Heywood, 2008). Sites such as Quantified Self, Genomera and DIYgenomics also support communities for participant-organized health research studies.

One of the aims of my dissertation research was to investigate the meaning that online health-related communities hold for fibromyalgia patients and how this meaning changes over time. In this section, I provide background on online communities, summarize the types of health-related online communities that currently exist, motivations for use, the kinds of content that are exchanged, and how individuals participate in these communities. As studies that focus specifically on online support groups for fibromyalgia are scarce, my examples draw upon the literature for online support groups as a whole, and I mention the conditions that each of these studies has addressed.

2.3.1 Definitions of Online Communities

Various definitions of online communities exist in the literature. Preece (2000) defined an online community as having four components: “people, who interact socially as they strive to satisfy their own needs or perform special roles, such as leading or moderating; a shared purpose, such as an interest, need, information exchange, or service that provides a reason for the community; policies, in the form of tacit assumptions, rituals, protocols, rules, and laws that guide people’s interactions; and computer systems, to support and mediate social interaction and facilitate a sense of togetherness” (p.10). According to Wellman and Gulia (1999), virtual communities are different from offline communities in that members of online communities are more likely to perceive themselves as close based on shared interests rather than shared social characteristics. The Internet is particularly suited to maintaining intermediate-strength ties between people who cannot see each other frequently.

2.3.2 Types of Health-Related Online Communities

As mentioned earlier, there is a plethora of health-related online communities. Though a complete review is beyond the scope of the current work, I will mention some of the major types. One that readily comes to mind is forums that exist as part of a larger health portal such as WebMD. Health portals are sites that serve as a rich source of health information, and may also offer interactive tools such as checklists, trackers and quizzes. Another type is sites that offer a large number of online support groups, such as MedHelp, DailyStrength and PatientsLikeMe. Some of these may be focused on a particular condition or set of conditions, such as CancerCompass and Beating the Beast. There are also theme-based sites that are dedicated to a common purpose, such as healthy eating or exercise; these include LiveStrong and Fitocracy. Yet another type is health-related groups on platforms such as reddit and Pinterest. There are also interventions with an asynchronous bulletin board component, such as the Comprehensive Health Enhancement Support System (CHESS) (Gustafson et al., 2008; Wen, McTavish, Kreps, Wise, & Gustafson, 2011). CHESS discussion groups are monitored by a trained moderator who ensures that messages are supportive and do not contain inappropriate information.

It may be helpful to identify dimensions along which health-related online communities might be considered. These include: operational model (sponsored, not sponsored or intervention), target user (patient or health care professional), and moderation type (expert-moderated, peer-moderated and unmoderated). Examples are provided in Table 1.

Table 1. Types of Health-Related Discussion Forums

| Attribute | Category | Example |
|-------------------|---------------|---|
| Operational Model | Sponsored | CFvoice http://www.cfvoice.com |
| | Not Sponsored | DailyStrength http://www.dailystrength.org/ |
| | Intervention | CHESS (https://chess.wisc.edu/) |

| Attribute | Category | Example |
|-----------------|--------------------------|---|
| Target User | Patient | Smart Patients https://www.smartpatients.com/ |
| | Health Care Professional | SurroundHealth http://surroundhealth.net |
| Moderation Type | Expert-Moderated | MedHelp Ask a Doctor Forums |
| | Peer-Moderated | UKFibromyalgia Forums http://www.ukfibromyalgia.com/forums/ |
| | Unmoderated | GFCFKids http://health.groups.yahoo.com/group/GFCFKids/ |

2.3.3 Motivations, Benefits and Drawbacks

There are numerous reasons why people might want to use online support groups. Online support groups can offer participants benefits that face-to-face groups often do not: greater accessibility in terms of time and geographic proximity, anonymity, and the ability to obtain information without having to interact with others (Blank, Schmidt, Vangsness, Monteiro, & Santagata, 2010; Klemm et al., 2003). Participation in online support groups can be a source of empowering outcomes such as feeling informed; increased confidence with physicians; increased acceptance, confidence, and optimism; and enhanced social well-being (van Uden-Kraan et al., 2008c; Bartlett & Coulson, 2011). Online support groups can also provide an opportunity to maintain relationships with others, lead to positive behavioral change, and serve as a place to “learn to tell the story” and visualize disease (Ziebland & Wyke, 2012). The process of writing itself can also be therapeutic or cathartic (Esterling, L’Abate, Murray, & Pennebaker, 1999).

Many studies of cancer discussion forums have reported that informational and emotional support are both important components of forum content (Blank et al., 2010; Gooden & Winefield, 2007; Klemm, Reppert & Visich, 1998; Seale, Ziebland, & Charteris-Black, 2006). Health-related online social networks (OSNs) and condition-specific groups on online

social networks such as Facebook have also become important sources of health information and resources for condition management, particularly in the case of chronic illness (Greene, Choudry, Kilabuk, & Shrank, 2010; Seeman, 2008).

In an interview study of participants of online support groups for breast cancer, rheumatoid arthritis and fibromyalgia, van Uden-Kraan et al. (2008c) found the following empowering processes: exchanging information, encountering emotional support, finding recognition, sharing experiences, helping others, and amusement. As a result, patients were better informed; felt more confident in the relationship with their physician, their treatment, and their social environment; experienced improved acceptance of the disease, increased optimism and increased control; and experienced enhanced self-esteem and social well-being.

Many of the study participants mentioned that though they could have found the information available on the forums through another source, the information on the forum was most convenient for them because “it was formulated in their ‘own language’” and tailored to their personal needs (van Uden-Kraan et al., 2008c). All participants said that they felt better informed from participating in support groups. Those who had begun participating in the forums before or soon after they were diagnosed seemed to profit most.

By alleviating patients’ uncertainty about treatment decisions, the forums also seemed to increase the patients’ confidence in their ability to deal with their physicians and their treatment (van Uden-Kraan et al., 2008c). Improved acceptance of the disease seemed to result from the opportunity for social comparison, particularly downward social comparison, in which individuals noted that they were not doing as badly as some others. Participants also felt better and valued when they were able to share their experiences and help others. Some participants also mentioned that participating in the support group had increased the number of social

contacts that they had and helped them to become less socially isolated. Radin (2006) also points out the potential of online support groups for activism and social movements.

However, not all phenomena arising from online support groups are positive. In Barker's (2008) analysis of the online support group for fibromyalgia, Fibro Spot, the users convince others that they need to insist that physicians need to acknowledge patient expertise. However, as Barker puts it, it is an "empowerment without power" in that, though they encourage one another to recognize that they are not at the mercy of doctors, "the only real power they have is the consumer power to search for a less reproachful provider" (p. 30). There are other examples of phenomena that may not be therapeutic, such as "pro-ana" (i.e., pro-anorexia) discussion forums and the reinforcement of seropositivity disclosure in HIV/AIDS forums (Gavin, Rodham & Poyer, 2008; Rier, 2007). Additionally, van Uden-Kraan et al. (2008c) found that the following disempowering processes also took place: being unsure of the quality of the information, being confronted with negative sides of the disease, and the presence of complainers.

2.3.4 Informational and Affective Exchange

One important aspect of online support groups is the informational exchanges and affective interactions that occur among members. This section reviews three ways for thinking about these exchanges: content analysis classification schemes, automated methods, and patient and clinician expertise. This background literature informed my analysis of the interactions among participants in online spaces and my reflections on the value of user-generated content.

Burnett (2000) elucidated a typology for information exchange activities in online communities. At the most fundamental level, there are two types of behaviors: non-interactive and interactive. Non-interactive behaviors are also what is called "lurking"; users read content

produced by others but do not contribute to the conversation themselves. Interactive behaviors are further divided into hostile interactive behaviors (flaming, trolling, spamming, and cyber-rape) and collaborative or positive interactive behaviors. Burnett further divides positive interactive behaviors into behaviors not specifically oriented towards information (neutral behaviors such as pleasantries and gossip, humorous behaviors such as language games and other types of play, and empathic behaviors or emotional support), and behaviors specifically oriented towards information.

With regard to online social support, studies have primarily examined online support groups in terms of support behaviors or self-help mechanisms, and almost all of them have used one of three primary coding schemes, either directly or as a basis for developing one of their own. Interestingly, the first of these originated from a study that was not based on online support groups. In their study of spousal interactions, Cutrona and Suhr (1992) employed a classification comprised of five different kinds of support (informational support, tangible assistance, esteem support, network support and emotional support), which were further subdivided into 23 subcategories. Informational support refers to the provision of knowledge, facts or information to help individuals deal with an issue (Cutrona & Suhr, 1992; Coursaris & Liu, 2009). Tangible assistance involves the provision of material aid or service. Esteem support refers to messages intended to improve the recipient's self-concept, confidence and rights as a person. Network support refers to the expression of belonging to a group of individuals with similar interests or concerns. Emotional support refers to the communication of caring, empathy or other form of emotional support for the recipient.

Two other coding schemes that have been used by subsequent researchers include the 14 categories of helping mechanisms Finn (1999) used in his study of online self-help groups

focusing on disability, and that used by Perron (2002) in his research on an online support group for caregivers of those with a mental illness. The self-help mechanisms that Finn studied were: asks information, chit chat, computer talk, damaging statements, extra-group relationships, expresses feelings or catharsis, friendship, group cohesion, poetry or art, problem solving, provides information, provides support or empathy, taboo topics, and universality. Perron's study included the following ten categories: disclosure, provide information or advice, empathy or support, gratitude, request information or advice, computer issues, friendship, creative expression, structure and negative statements.

There is considerable overlap in the distributions of support types found in the forums. A number of studies have found that the proportion of support provision exceeds that of support seeking. The high proportion of personal experience is salient across a variety of conditions including breast cancer, arthritis and Inflammatory Bowel Disease (van Uden-Kraan et al., 2008a; Malik & Coulson, 2011). Proportions of informational and emotional support are generally greater than that of other support types, though which of the two is more common varies across studies. Though network and esteem support comprise a smaller proportion of discussion content, this may be due to the tendency for posts to be classified by the main type of support offered. Discussion posts may often contain statements such as, "Please keep in mind that there are many survivors just like you..." or "You are not alone..."; they may be part of a much longer discussion, and may thus be categorized as emotional or informational support. In general, there is little or no tangible support; this is most likely due to the tendency for online social networks to be spread out geographically, thus making it more difficult for people to offer tangible support.

Though limited, there have been a few studies that have investigated fibromyalgia patients' use of online support groups. Van Uden-Kraan et al. (2008a) employed content analysis to analyze online discussion content from support groups for breast cancer, fibromyalgia and arthritis. Five hundred posts for each disease condition were assigned to one of 12 topic categories. Regarding the experience of being ill, there were seven categories: diagnoses, symptoms, regular treatment, alternative treatment, regular medication, alternative medication and interaction with health care professionals. The consequences of being ill were captured in four categories: financial issues, vocational issues, social network issues and issues concerning the restrictions patients experienced in everyday life. The last category was chit chat, which referred to off topic, everyday talk.

Chen (2012b) employed cluster analysis to study the content of online discussion related to breast cancer, Type 1 diabetes and fibromyalgia. Overall there were significant overlaps, but because there were 12 categories in van Uden-Kraan et al. (2008a) and 20 clusters in Chen (2012b), the clusters were often more specific than the categories, particularly with regard to specific aspects of condition management. This included clusters on specific medications such as Lyrica and Cymbalta, medications for pain and depression, the side effects of weight gain, supplements, vitamins, diet/food-related issues, sleep and exercise. In addition, in Chen (2012b) there were clusters that were comprised primarily of expressions of support or prayer.

The content that is exchanged among patients may be quite different from clinician expertise along multiple dimensions, in terms of topic (medical, personal or both), type of recommendation (action strategies, knowledge, perspectives and information resources), and style of recommendation (narrative vs. prescriptive) (Hartzler & Pratt, 2011). Clinician expertise is primarily medical in topic, knowledge-oriented in type, and prescriptive in style. As

Hartzler and Pratt observed in their content analysis of online discussion boards and books pertaining to cancer, patients' experiential knowledge focuses on coping with highly personal issues from the context of daily life, and that this "knowledge is gained not through professional training, but rather through the trial and error of managing the lived experience of illness" (2011, p. e62). This work, as well as that of Keselman et al. (2008b) mapping terms from the Open Access Collaboratory Consumer Health Vocabulary to the Unified Medical Language Thesaurus, suggests that conventional medical terminologies such as the Unified Medical Language Thesaurus are not sufficient for indexing patient knowledge.

2.3.5 Participation Styles and Forum Dynamics

There are different ways of participating in online support groups. Some users participate actively in discussion ("posters"), some read the posts but do not post themselves ("lurkers"), and others do not utilize online support groups at all. This next section reviews the literature on participation style, including the research on lurkers and posters, member roles and forum dynamics.

2.3.5.1 Lurkers and Posters

The online communities literature often distinguishes between lurkers, who never post or post infrequently but are known to read the posts, and posters, who participate actively by both reading and posting (Nonnecke & Preece, 1999, 2000). This differentiation is akin to the differentiation between non-interactive and interactive behaviors made by Burnett (2000). Additionally, Ridings, Gefen and Arinze (2006) have distinguished between lurkers, who never post, infrequent posters who posted three or less times per month, and frequent posters.

Previous research has reported similarities between lurkers and posters on health-related forums. According to van Uden-Kraan et al. (2008b), lurkers do not differ significantly from

posters with regard to most empowering outcomes such as being better informed, feeling more confident in their relationship with their physician, increased disease acceptance, feeling more confident about treatment, enhanced self-esteem and increased optimism and control. Their survey included participants of online support groups with three types of diagnoses: breast cancer, arthritis and fibromyalgia, and they did not find significant differences between lurkers and posters based on type of diagnosis. A previous study of participants of online support groups for HIV/AIDS found that lurkers did not differ in self-care self-efficacy, loneliness, depression or optimism (Mo & Coulson, 2010).

However, previous studies of online support groups have also found differences. Van Uden-Kraan et al. (2008b) reported that lurkers are slightly older than active participants and had a shorter disease history. Additionally, lurkers exhibit lower mental well-being than posters. A number of studies have reported that lurkers are less satisfied with online support groups than posters, and that they experience less social support (van Uden-Kraan et al., 2008b; Malik & Coulson, 2011). With regard to information use, a previous study of a breast cancer group suggests that lurkers have less information competence and a greater need for information than posters (Han et al., 2011).

Han et al. (2011) argued that posters seek support online to compensate for relative lack of support from their surrounding environment. Though their study was not specific to online support groups, but surveyed MSN online communities of all different genres, Nonnecke, Preece and Andrews (2004) found that posters visit online support groups more often for social reasons, such as wanting to find out how other members are doing, to enjoy themselves, as part of their daily routine, and because other members expect them to be there.

2.3.5.2 Roles

Numerous studies have investigated the roles played by members of online communities. One general framework is Kim's (2000) model of community membership life cycle. The life cycle is comprised of five stages: visitor, novice, regular, leader and elder. Sonnenbichler (2010) proposed an extension to Kim's model that included the following roles: visitor, novice, active, leader, passive and troll.

There are various studies that have focused specifically on online support groups. Jones et al. (2011) used participation metrics to identify different types of participative stances: "caretaker," "butterfly," "discussants," "here for you," and "people in distress", in discussion forums focused on self-harm. Maloney-Krichmar and Preece (2005) used a coding scheme based on Benne and Sheats' (1948) classification of group membership roles and Interaction Process Analysis (Bales, 1950) to identify group roles and behaviors in the messages that were posted on Kneeboard, an active online community for those who have suffered from knee injuries. The primary roles that were observed were: information-giver, opinion-giver, and encourager. In her content analysis of an online support group for breast cancer patients, Winefield (2006) observed high frequency posters who provided more information than they sought and supplemented the work of the moderators, and suggested that these individuals' roles may fulfill a critical function in sustaining these online support groups.

Pfeil, Svangstu, Ang, and Zaphiris (2011) analyzed the communication patterns in an online community for older people. They combined the findings from a content analysis and social network analysis to develop a taxonomy of social roles in the community. Their typology was comprised of six roles: moderating supporter, central supporter, active member, passive member, technical expert and visitor. Moderating supporters performed an average amount of

self-disclosure and posted a large amount of support content. They tended to welcome and recruit new members, and they were frequent posters and central members of the community. Like moderating supporters, central supporters posted frequently, engaged moderately in self-disclosure and actively in giving support; they differed from moderating supporters in that they were less active and less concerned about activities within the online support community that would strengthen community feeling. Active members posted an average amount of content related to both self-disclosure and support. Passive members participated in self-disclosure but not support. They did not post very many messages, and they were not very central in the community. Technical experts were fairly central, but they mainly provided technical advice. They did not post often, and they did not appear to try to elicit or receive support. Lastly, there were visitors who posted only a few messages and had very remote positions in the community. This typology is quite similar to a general typology of members of virtual communities based on behavior setting theory elucidated by Blanchard (2004).

There are also various typologies of user roles that have been based on discussion forums that were not specific to health. For example, one typology of user roles was developed by Chan and Hayes (2010) and then re-used by Angeletou, Rowe and Alani (2011). This model was comprised of the following roles: joining conversationalists, popular initiators, taciturns, supporters, elitists, popular participants, grunts and the ignored. Viégas and Smith (2004) identified different patterns of behavior in newsgroups: answer person or “pollinator” (high number of days active and low posts per thread ratio), debater (moderate to high number of days active and very high posts per thread ratio), “bursty” contributors (low number of days active and high posts per thread ratio), and newcomers or question askers (very low number of days active and low posts per thread ratio), spammer-like behavior (moderate to high number of days

active, usually initiates threads and then does not follow up on them), and “balanced” conversationalists (initiates about as many threads as he or she replies to and shows about the same posts per thread ratio on both initiated and non-initiated threads).

The preceding section highlights the richness of studies concerning roles. The studies have employed a variety of methods, including content analysis, network analysis and cluster analysis, and yet there are similarities in the types of roles elucidated. Individuals fill a variety of roles in a forum; their contributions might enrich the discussion, provide support for others, increase community cohesion and morale, or simply make a forum more scattered. The studies that have identified participation metrics or profiles, e.g., Jones et al. (2011), Chan and Hayes (2010), and Pfeil et al. (2011), may be applied to other forums in order to examine user participation. Of course, in doing so, care should be taken to ensure that yet unseen participation styles are not overlooked.

2.3.5.3 Forum Dynamics

The previous sections have demonstrated that people contribute to online communities in many ways. Various factors may influence the dynamic, such as user transience, membership duration, membership size, moderation style, and member demographics. Aspects of forum design such as the visibility of lurking and social presence may also affect forum dynamics.

Previous studies have shown that network structure may give rise to different patterns of interaction (Chang, 2009; Bambina, 2007; Pfeil & Zaphiris, 2009). These studies have performed network analysis on posts classified by support category using content analysis. Chang examined a forum for psychosis on PPT, a bulletin board system that is widely used in Taiwan; Bambina studied a forum for breast cancer patients; and Pfeil and Zaphiris, a forum for elderly patients coping with depression. These studies have generally rendered a combined

network comprised of all ties between message senders and receivers, regardless of support type; and separate networks for specific support types. Some of the key findings include: that the networks for informational support most closely resemble the composite network, that the densities of the networks for emotional support were greater than those for informational support, and that central members of the group generally fell into one of two categories – support providers or support receivers. In Bambina's (2007) study, there was a "star" at the center of the network who responded to many individuals who were otherwise not contacted by others. In Chang's (2009) study, cliques formed which exhibited different patterns of interaction and support exchange. Furthermore, central members specialized in different types of support provision.

Other studies have focused specifically on predicting member behavior based on group composition and dynamics. Lieberman, Wizlenberg, Golant and Di Minno (2005) examined the impact of group composition on online support group members' attraction towards and commitment to the group, with group composition being defined as homogeneity or heterogeneity in terms of age and time since diagnosis. The groups in this study were six Internet-delivered Parkinson's Disease interventions. Qiu et al. (2011) found that forum participants change their sentiment in a positive direction through interaction with other participants. Wang, Kraut, and Levine (2012) observed that members who were exposed to greater amounts of nurturant support were less likely to stop using forums. Both of these studies were based on data from large datasets constructed from publicly available cancer discussions (American Cancer Society Cancer Survivors' Network and breastcancer.org, respectively).

There have also been various studies of the effects of different types of forum moderation, on both forum participants and the moderators themselves. Johnsen, Rosenvinge, and Gammon (2002) examined the influence of professional moderators on forum dynamics in a discussion forum for eating disorders. The forum was more active when there was no professional moderation as compared to when there was. Messages posted in the forum with high professional involvement tended to be more starter-centered, and had a greater proportion of explicit replies to the main posts. Lastly, when there was professional involvement, there was more frequent use of phatics and salutations, as well as a higher frequency of asking questions. Coulson and Shaw (2013) conducted a survey of patient moderators across a broad range of support groups. They found that patient moderated online support groups could be empowering for both the moderators and the forum participants.

2.3.6 Participation over Time

There have been numerous interventions with chat room or forum components, and these have generally examined differences in patient populations over two or more time points (e.g., Han et al., 2008; Owen et al., 2005). One study that provided a particularly detailed account of a single individual's online participation in the context of her condition was the study of one woman's participation in Comprehensive Health Enhancement Support System (CHESS) (Wen et al., 2011). Darlene posted 202 messages over her 13 month journey, which ended with her passing. During that time, there were 91 participants total, and Darlene sent messages to 35 of them. Wen et al. identified 19 subthemes and six higher-level themes, including Bonding with Other Breast Cancer Women, Emotional and Spiritual Expression, Cancer Treatment and Physical Updates, Cancer Information and Experience Exchange, Cancer Impact, and Death & Dying. The prominence of these themes varied throughout her journey, as did whether she

played more of an “asking” or “giving” role. The number of messages and the themes of the messages posted by Darlene were clearly related to specific medical events (e.g., recurrence, deteriorating health, needing hospice).

Rodgers and Chen (2005) examined the “life stories” of one hundred women who participated in an Internet support group for women with breast cancer. In this study, the longer women belonged to the discussion board and the more that they participated, the more their stories reflected positive well-being. Rodgers and Chen caution that a single measure of well-being may not detect subtle changes over time in an individual’s mood, happiness, loneliness or coping with breast cancer, and studies that use pre- and post-measures may skew self reports of well-being depending on when the measures were taken.

As mentioned, many of the studies that examined participation over time were part of interventions. Thus, their timeframe was generally six months or less. A few studies that have investigated longer periods of time exist, such as Wen et al. (2011) and Rodgers and Chen (2005), but they have been focused on cancer. There is a need to conduct studies on patients with other conditions to understand if they would utilize online support groups in a similar fashion.

There has also been previous research concerning user lifespan in online communities not specifically related to health. Yang, Wei, Ackerman and Adamic (2010) employed survival analysis to predict individual lifespan in three online knowledge sharing communities. They also explored differences in user participation across sites, and discussed how system design and culture can perhaps explain these differences. Danescu-Niculescu-Mizil, West, Jurafsky, Leskovec and Potts (2013) studied linguistic change in community members. They argued that there is a phase in which users adopt the language of the community, followed by a phase in

which they stop changing, though community norms continue to do so. They also argued that this framework can be used to predict how long a user will stay active in a community.

2.3.7 Summary

This section focused on health-related online communities and the nature of participation in these communities. Patients may utilize online communities for a variety of reasons, particularly information and emotional support. They may play different roles in these communities, and the nature of their participation may change over time. Online support groups can be a source of empowering outcomes such as feeling informed, increased confidence with physicians, and increased acceptance, confidence and optimism, but there are also examples in which they may replicate offline discourses that may not be in patients' best interests.

Various approaches have been taken to studying online support groups. One of these is the classification of online discussion content by the type of support offered, subject matter, and/or nature of expertise (patient vs. clinician). In particular, there has been extensive research that has employed content analysis to categorize posts in terms of social support.

Previous research has also examined participation style and forum dynamics. Members may fill different roles in a given online community, and in turn, online communities may exhibit different types of dynamics. Though there is existing work that characterizes the roles that individuals play in a health forum, there is a need for research that examines participation over time. Moreover, there are questions concerning member roles and forum dynamics that have yet to be answered. For example, are there personal characteristics that predispose forum members to play certain roles? Do some people benefit more than others? How does online participation relate to knowledge acquisition, health behavior change and condition

management? Though the first two questions are beyond the scope of this study, I did gain some insight about the last question.

2.4 Design of Online Communities and Social Interfaces

In my dissertation research, I asked people to discuss their participation in online support groups. Health consumers may use online support groups in different ways from one another, including searching for information, seeking support and interacting with other community members. The design of online communities and social interfaces may shape this interaction. In this section, I review a diverse set of literatures, including studies of and recommendations for online communities, social interfaces and visualization interfaces, because there is knowledge concerning all of these topics that might be relevant in the design of health-related online communities.

2.4.1 Design and Evaluation of Online Communities

There are various guidelines for the design and evaluation of online communities, but there are some commonalities among them. Many of them address the question of what determines communities' success or sustainability. There are also similarities in terms of the important components of these frameworks, such as expression, identity, sense of community and trust. This section describes some of these guidelines.

Berlanga, Rusman, Bitter-Rijkema and Sloep (2009) proposed guidelines for four sets of features intended to foster sustainable online communities: self-management, self-organization, self-categorization and self-regulation. Self-management features, such as profiles, enable participants to create and manage their presence as well as their contributions. Profiles are not mere collections of personal data, but exist to foster interaction and support initial trust formation between forum participants. Self-organization features enable users to

interact with one another and support knowledge co-construction. One example of such a feature would be the discussion forum. Another example that Berlanga et al. offer is Ideasticker, a post-it like tool with structured fields such as proposal, motivation, rationale and position; this tool encourages interaction and supports knowledge co-construction by making it easier to view others' positions. Self-categorization features enable participants to classify and evaluate their own as well as others' contributions; such features might include tags, ratings or rankings. Self-regulation features enable participants to control the level of privacy of their contributions.

Gallant, Boone and Heap (2007) enumerated five heuristics for designing and evaluating web-based communities: interactive creativity, selective hierarchy, identity construction, rewards and costs, and artistic forms. These heuristics were elucidated through a multi-step process involving literature review, concept generation, written concept elucidation and focus groups with heavy users of Facebook and MySpace who were also students. Selective hierarchy is comprised of various concepts, including the insider, outsider, and hierarchical social structures within online communities, as well as selective preferences that users had for information, which in turn lead to preferences for one site over another, as well as selective processing of information. This set of heuristics is quite interesting because it touches upon the subjective, experiential and interactive aspects of a website, as well as its potential to assist the user in self-definition and self-realization.

Preece (2001) identified key determinants of sociability and usability of online communities, which she argues are important in their success. Determinants of sociability include the number of participants in a community, the number of messages per unit of time,

member satisfaction, amount of reciprocity, number of on-topic messages, and trustworthiness. Measures of usability include the number of errors, productivity, and user satisfaction.

Sense of community can be an important factor in the experiences of online community members. Sanchez-Franco and Roldán (2010) administered an offline survey to 278 undergraduate students who use the Spanish social networking site (SNS), Tuenti. They found support for the positive influence of expressive aesthetics on an individual's feelings of membership, identity and attachment to an SNS. Among more innovative members of an SNS, expressive aesthetics and routinised behavior prompts social feelings that lead to community integration, while among less innovative members, expressive aesthetics can serve as heuristics or peripheral cues.

Blanchard and Markus (2004) also argue that sense of community is important, but that this sense of community in virtual communities is not entirely the same as in physical communities. Rather than “feelings of membership” from belonging to and identifying with the group, users create their identity and differentiate themselves from the group. They also identified three types of community-like behaviors and processes: the exchange of support, the creation of identities and identifying other users in terms of personality and opinion, and the production of trust.

Common identity and common bond are another way to consider online communities. Common identity refers to groups in which members become attached to communities by identifying with them as a whole, and common bond, to groups in which attachments are based on bonds with other members (Sassenberg, 2002). Design features can be used to promote different kinds of attachment (Ren, Kraut, & Kiesler, 2007). If the main purpose of the community is the exchange of information, such as in www.tech-forums.net, then it may be

useful to promote identity-based attachment; however, if the main purpose of the community is the promotion of social relationships, such as Facebook, then it may be helpful to promote bond-based attachment. There are also communities with mixed goals, of which online support groups are an example.

Design recommendations on issues such as new members, off-topic discussions, community size, and core members differ depending on the intended community type (Ren, Kraut, & Kiesler, 2007). Attracting newcomers is important for online communities; without them, a community would die out in time due to the departure of current members. However, new members can be disruptive to a community by asking questions and making comments that others have already asked or made by others and not conforming to group norms. Thus, it is important for communities to have strategies for attracting and socializing new members. Identity-based communities often focus on helping new members navigate through forum content, understanding community norms, and encouraging members to contribute in meaningful ways. Bond-based communities focus on helping newcomers connect with existing members, join group interactions, and form lasting relationships.

Community size is another factor that can have a large impact on community experiences. Butler (2001) observed that online communities need to balance the opposing impacts of membership size and communication activity in order to maintain resource availability and provide benefits for members. According to Schoberth, Preece, and Heinzl (2003), as communities increase in size, problems of establishing common ground tend to emerge and social loafing and information overload increase, but the resource pool of the communities, and in turn, their abilities to attract new members also increase. In reaction to increased information load, communication strategies change and influence the communication

activity. The heterogeneity of users' activities grows, and a small minority of users writes an increasingly larger proportion of the postings.

Having a large number of members and high member turnover is less of a problem for identity-based communities than bond-based communities because the primary value of these communities is the content; but if there is a high amount of membership turnover in a bond-based community, members are less likely to form strong interpersonal bonds that keep them coming back to the community (Ren, Kraut, & Kiesler, 2007). Communities can also be designed to promote interaction among subsets of the community. These include guilds in Massively Multiplayer Role Playing Games such as World of Warcraft and the rooms in a traditional Multi-User Dungeon (MUD) site.

Another common lens through which to regard online communities is core vs. periphery. Core members, or the most frequent and loyal posters, are the critical mass in an online community (Ren, Kraut, & Kiesler, 2007). A group of core members can sustain a community for years, but this can also have potentially detrimental effects on community growth by dominating conversations, intimidating new users, and decreasing peripheral members' sense of belonging. One particular design challenge is to recognize and continue to encourage participation from core members, while at the same time encouraging participation from peripheral members (Ren, Kraut, & Kiesler, 2007). Ideas for doing so include downplaying contributions from core members in interfaces seen by the rest of the community, identifying algorithmically resources that peripheral members hold and encouraging them to contribute those, making members more visible to each other, and providing ways for members to visualize their social networks.

Cobb, Graham and Abrams (2010) examined differences in strongly and weakly connected cores in the smoking cessation online social network, QuitNet (<http://www.quitnet.com>). They argue that core groups or key players could facilitate information dissemination, but other groups could enhance network stability, growth or density. Compared to the weakly connected core, members of the strongly connected core were more likely to be female, older, abstinent during the observation period, more active on the site, and members of the site for longer than one year. A larger clique predicts an increased likelihood that a group will grow rapidly, and groups with more individuals outside the largest connected component seem to grow more quickly also (Kairam, Wang, & Leskovec, 2012).

This section reviewed various approaches to considering online communities, including sustainability, sociability/usability, sense of community, common identity vs. common bond, and core vs. periphery. The heuristics suggested by Gallant, Boone and Heap (2007) may serve as a lens for evaluating online communities in terms of interactivity, user experience, and potential for self-definition/self-realization. These approaches illustrate that community management is often not a question of finding an optimum solution to fit all contexts and populations, but rather, designing to support particular contexts and create a nurturing environment balancing the needs of different types of users.

2.4.1.1 Community Lifecycle

When one thinks of a community, the first characteristic that comes to mind is probably not its living nature; however, that is what it is. The nature of online communities is organic. At some moments, a community may appear stable because it is in a state of homeostasis. However, there are undeniably periods in the life of any community, such as growth, maturation, and decline. In my study, I primarily focused on individual members' participation

lifespans in a community, but it is useful to realize that there are these two levels of interest: the community lifecycle, and the individual members' lifespans in the context of the community lifecycle.

Iriberry and Leroy (2009) employed a five stage model of the online community life cycle: inception, creation, growth, maturity, and death. They argued that the success factors that are important to a community are dependent on community type and life cycle stage. In their review, determinants of success in the maturity stage for support groups included permeated management and control (e.g., membership roles, facilitators to monitor and control behavior), subgroup management (e.g., establishing and supporting subgroups within the community, use of channels to segment communications, support for permeable subgroups, narrowly focused discussion forums, flexible gathering places) and member satisfaction management. Conditions that would cause a community to die out included: undersupply of content, poor participation, unorganized contributions, transient membership, weak ties between members, unwillingness to share information, lack of anonymity, concerns about privacy and safety, shyness about public posting and time limitations.

Durant, McCray and Safran (2011) studied the temporal changes and the factors associated with them by comparing forums for six types of cancer on CancerCompass (<http://www.cancercompass.com/>). They identified three phases of growth: a smaller sized phase (phase 1), a transitional sized phase (phase 2) and a larger sized phase (phase 3). They found that four forums (melanoma, renal cell, prostate and ovarian cancer) followed a similar growth pattern (progressive growth from phase 1 to phase 3). The two others, testicular cancer and breast cancer, each exhibited a different growth pattern that included falling back to previous growth stages.

Durant, McCray and Safran (2011) employed a bimodal network model comprised of two types of nodes: threads and members. Based on hub authority analysis, they concluded that treatment topics elicited the strongest response, and hence, the most growth in the forums. It is unclear from this study what it is about treatments that elicits this response; however, this model might be employed with other types of forums to identify influential threads and members, and in so doing, we might also arrive at a better understanding of the topics that elicit strong response from forum communities.

2.4.2 Social Interfaces

2.4.2.1 Design Elements

There are various elements that have been identified as being important in social interfaces and/or online health information systems. Some of these include: social presence, trust, encouraging user participation, fostering social interactions, promoting visibility, and supporting sensemaking. Each of these will be discussed in turn.

Social presence is a construct that has been defined in a variety of ways. A complete discussion and critique is beyond the scope of this paper; for a full treatment one might refer to Biocca, Harms and Burgoon (2003) and Lee (2004). Social presence has been defined as “the extent to which a medium allows a user to experience others as being psychologically present” (Gefen & Straub, 2003). It has also been defined by Short, Williams and Christie (1976) as “the degree of salience of the other people in the interaction” (as cited in Lee, 2004). Cyr, Hassanein, Head and Ivanov (2007) regarded social presence as the perception by the user that a website has human contact, and is personal, sociable, warm, and sensitive. There are various ways that one might increase the social presence of a website; for example, Hassanein and Head

(2006) employed socially-rich text and pictures. An online community platform might endeavor to increase social presence by employing more socially-rich images.

Trust is another important element of virtual communities. The literature on trust has identified many different factors; three of the most common are ability, benevolence and integrity (Mayer, Davis, & Schoorman, 1995; Ridings, Gefen, & Arinze, 2002). Radin (2006) proposed a three stage model of trust development based on a case study of an online community, Breast Cancer Action Nova Scotia. The three stages, corresponding to increasing levels of trust, were: de-lurking or “thin trust,” self-disclosure or “greater trust,” and shared episodes or “thick trust.” A site could endeavor to promote interpersonal trust among its members by building features to promote the exchange of off-task personal information, showing and exchanging personal information on the reputation of participants, showing information about the presence, activities and availability of participants, and showing information about the community (Berlanga et al., 2009).

Leimeister, Ebner and Krcmar (2005) argue that trust can be achieved by incorporating components into the site that support perceived competence and perceived goodwill both among members and between members and the operators of a site. Components that support perceived competence include transparency and quality assured content. Perceived goodwill may be achieved by including differentiation of required and optional fields in the user profile and differing levels of anonymity.

Another important element of social interfaces is encouraging participation. There are various ways of doing this, including recognizing, identifying, attributing and incentivizing participation through rewards that confer reputation and status (Girgensohn & Lee, 2002; Vassileva, 2012). One example of this is the awarding of badges based on user contributions.

These days, many sites offer digital badges, including StackOverflow, KhanAcademy and Wikipedia.

One goal that many forums may have is to encourage those who are reticent to participate, to do so. Ivanov, Erickson and Cyr (2006) argue that non-textual forms of participation can encourage low frequency contributors to participate. They proposed a graphical web poll prototype, called plot-poll, with which users collaboratively construct a series of mini-histograms that depict mood changes over time as they take herbal antidepressants.

Webster and Vassileva (2006) built a system, Relavis, in which users were shown a system that depicted users in quadrants based on their “visibility” to each other (“You see them,” “Unknowns,” “You see each other,” and “They see you”). The objective of the system was to motivate participation in interest-based online communities. It was based on a concept of community energy, and is intended to encourage participation among both core and peripheral members.

Rashid et al. (2006) argued that users may have difficulty in finding opportunities to add value, or in understanding the value of their contributions to a community. They conducted an experiment which demonstrated that people were differentially motivated to contribute depending on who the beneficiary was (self, a group of individuals similar to oneself, a dissimilar group or the community as a whole), and their identification with the groups/communities.

Another important design concern is fostering social interactions. Mechanisms for doing so include common ground, awareness, interaction enablers, and place-making (Girgensohn & Lee, 2002). Fostering common ground involves creating a shared understanding

among collaborators that permits interactions to proceed smoothly. Having users create profiles and maintaining a topic-based discussion forum enables users to build common ground.

Awareness is the state of knowing or being informed, which enables collaborators to interpret each other's actions and to decide on one's own directions. Awareness mechanisms can include personal profiles, activity traces, annotations, updates of new contributions, and a list of scheduled activities. Interaction enablers include polls and forums. Place-making is the cultivation of a cultural and social understanding of the norms and practices appropriate to an interaction setting. Through place-making, discussion forums can be more than a vehicle for information sharing; they can also be a channel for coordinating get-togethers and for construction of a set of norms for using a website.

In order to promote visibility, one can incorporate traces, or information about a person's activities or behaviors on the site (Girgensohn & Lee, 2002). For example, in CHIplace trivia, the interface displayed author attribution as well as an indication of how many items each author has published; this recognizes a person's participation as well as the level of that participation. Social browsing features such as displays of members who recently joined, randomly selected members, directories, and similar members were also used in CHIplace and Portkey.

Heer, Viegas and Wattenberg (2007) argue that sensemaking can be a social process, and thus, visualizations that are meant to support sensemaking should also support social interaction. They presented an interface in which people were able to make graphical annotations. A number of users in the study commented that the graphical annotations were their favorite feature and enabled 'personal expression.'

2.4.2.2 Recommender Systems

I have previously mentioned that one of the key functions in online support groups is information exchange. Online support groups and discussion forums can be a source of patient expertise, which is different from clinician expertise (Hartzler & Pratt, 2011). The incorporation of systems to facilitate these functions can be invaluable for online support groups. One way that this might be accomplished is through the integration of recommender systems. Thus, this section provides a brief review of recommender systems, focusing on social recommender systems. Though at present, I have not often seen recommender systems integrated into online support groups, I do think that this would be a useful direction for development, and the experiences of study participants provide insight into how social platforms might provide personalized recommendations that are helpful to users.

Recommender systems are usually subdivided into two main types, content based and collaborative based (Groh, Birnkammerer, & Köllhofer, 2012; Jannach, Zanker, Felfernig, & Friedrich, 2011). Content based recommendations focus on a user's rating history and similarity between items to derive recommendations; collaborative recommendation systems compare ratings of a given user with other users, and recommendations by similar users, to recommend items to the target user. There are also hybrid systems that combine the two.

Social recommender systems are a subset of collaborative based recommender systems. In such a system, recommendations can be made on social graphs. For example, Karweg, Hütter and Böhm (2011) used a "social relevance" measure that was a combination of trust and engagement, to rank items. In a collaborative information retrieval system called HeyStaks, reputation models are computed for each user based on past actions, and these are used to enhance query retrieval results (McNally, O'Mahony, Coyle, Briggs, & Smyth, 2011).

PeerChooser is a recommender system that enables users to manipulate a graph of their peers at varying levels of granularity and then adjusts predictions accordingly (O'Donovan, Gretarsson, Bostandjiev, Höllerer, & Smyth, 2009). There are also systems that leverage the tag similarity of users in order to make recommendations (e.g. Kim, Alkhaldi, Saddik, & Jo, 2011; Zanardi & Capra, 2008).

In the domain of health, there are many opportunities to personalize the content delivered to users based on their individual needs. Health-oriented social recommender systems may be particularly powerful because of their potential to connect patients with similar health histories/statuses who might otherwise have trouble finding one another. For example, Song, Dillon, Goh, and Sung (2011) developed a social network framework for parents of autistic children.

Social health recommendations can involve the extraction of information from sources such as personal health records (PHRs), textual content, user profiles, forum posts and comments, search queries, tags, photos, videos, ratings, social networks and links, and web usage data (Fernandez-Luque, Karlsen, & Bonander, 2011). Klenk, Dippon, Fritz and Heidemann (2010) proposed a regression-based method that assigns different weights to factors for patient similarity; these were incorporated into a system that provided recommendations to cancer patients. PatientsLikeMe also has features that enable patients to locate other with similar characteristics (Frost & Massagli, 2008).

Online community members may want to locate others with a specific type of “expertise.” For example, a given patient may be experiencing problems from having to take time off of work due to surgery, and may be looking for others with similar experiences to find out how they dealt with that situation. Another example might be that the patient wants to

purchase a wig, and needs advice on what kind to get and how to go about it. Civan-Hartzler et al. (2010) built a system with a patient expertise locator to assist patients to connect with others. Some aspects of the system include individual “knowledge clouds” generated from patients’ answers to questions in the Q&A forum, information in profiles indicating “health situation,” and the ability to select different levels of collaboration, i.e., limit their activity to question answering alone, being directly contacted, or serving as an expert on a particular topic.

Huh and Ackerman (2012) argued that the discussion content is comprised of operationalized patient experiences that can then be used for trajectory alignment. Given that each individual has a different illness history, what works for one individual may not work for another. By considering their peers’ experiences in context, members can come to understand others’ experiences and make their own evaluation of whether an individual’s strategy might work for their own situation.

Mankoff, Kuksenok, Rode, Kiesler and Waldman (2011) explored how competing viewpoints in online content affect how patients with Lyme disease understood their condition. They observed three primary viewpoints, Dominant, Minority and Alternative, and showed how the process of information seeking was a social one, in which members posted information, followed up on information posted by others and tried to convince one another of their own points of view. They argued that systems should be designed to expose multiple explanatory models and help participants make informed decisions through credibility and triangulation.

2.4.3 Visualizing Online Communities

There are various reasons one might be interested in visualizing online communities. For example, one may be interested in knowing how people on the forum interact. What roles do people play? One might also be interested in discussion content. What topics incite lively

discussion, and which ones tend to result in sparse discussion? In this section, I will review visualization approaches for these two purposes: those that visualize communities and user interactions, and those that visualize semantic content.

2.4.3.1 Visualizing Communities and User Activities

This section reviews approaches for visualizing communities, intragroup interactions, and user contributions. There are visualizations that might be directed towards three potential target audiences: health consumers, to encourage participation, help them explore content, and connect with other members; scientists, to assist them as research tools; and forum administrators, to assist in forum design and moderation. Possible uses include the identification of potential forum moderators and volunteer editors (Hansen, Schneiderman & Smith, 2010). In this section, I will focus on two main approaches, those that employ a network approach and those that render a snapshot of user and/or community activity.

Previous researchers have used network visualization software such as Pajek and UCINET to study health-related online communities. In this literature review, a number of examples have been mentioned, including Durant, McCray and Safran's (2011) and Bambina's (2007) studies of cancer forums, Chang's (2009) study of a BBS for psychosis, and Pfeil and Zaphiris' (2009) study of an online community for older people with depression. As these examples illustrate, networks can be used to investigate a variety of questions, including: how do communities grow, mature and decline; the types of users we see in forums, and the roles they play; and the patterns of informational and affective support we observe in forums. The answers to these questions can be helpful for making design decisions to encourage participation, to monitor forums, and to learn more about patients' experiences. With regard to

the last point, understanding patient experiences can be helpful for understanding unmet needs that patients may have with regard to medical issues, knowledge and offline social support.

There are also interfaces that have been designed to visualize social networks. Vizster presents visualizations of online social networks in which nodes represent members of the system, edges represent the friendship ties between them, and keyword searches on profile attributes (e.g., “student”) result in “auras” being rendered around matching nodes (Heer & boyd, 2005). iQuest is a system that facilitates understanding of organizational behavior by mining communication archives such as email and blogs (Gloor & Zhao, 2006).

There are also interfaces that provide a snapshot of individual or community activity. Many interfaces designed specifically for visualizing online community member histories represent user contribution and interpersonal interaction through indicators for time since posting, number of posts, intervals between these posts, responses to their posts, and whether posts are initial or follow-up posts. Examples of such visualizations include Xiong and Donath’s (1999) “PeopleGarden” and Viégas and Smith’s (2004) Newsgroup Crowds, a scatterplot that employs placement, color and size of circles to represent days active, posts per thread, recency of activity and overall posting activity. MacLean and Hangal (2009) “community chromatographs” were based on Viégas and Smith’s (2004) visualizations. Their visualizations showed that in the Lyme disease forum, unofficial leaders made significant contributions, and in Asthma, official leaders did not contribute very much. The chromatographs also depict instances in which people ask a question and never post again, and suggest when there is discursive activity.

2.4.3.2 Visualizing Semantic Content

There are various purposes for text visualization, including exploring change over time, and highlighting semantic similarity/difference. ThemeRiver employs a river metaphor to visualize changes in themes over time (Havre, Hetzler, & Nowell, 2000). The Discussion Forum Visualizer (DifVis) system visualizes the magnitude, popularity, time-related information, turbulence, and importance of threads using color-coded squares (Kim & Johnson, 2006). By abstracting important elements of the conversation, DifVis assists users to pick out major subjects of discussions in a noisy information space. There are also various visualization interfaces and/or studies that integrate text and network analysis, such as Storylines (Zhu & Chen, 2007), iQuest (Gloor & Zhao, 2006), and the Knowledge Space Visualizer (Teplov, 2008).

Interfaces that show how discussion topics change over time and illuminate differences in opinions in discussions could potentially be useful to a variety of audiences. Forum moderators could employ such tools to monitor discussion threads for inappropriate content and/or to promote content of interest that might otherwise get buried. Researchers and clinicians could use such a tool to understand more about patient experiences, and perhaps also uncover bits of knowledge that may be unknown to mainstream medicine. Such an interface could also help patients to explore discussion content. However, here there is perhaps a great need to ensure that interfaces are designed in such a way as to assist patients in the sense-making process, as opposed to simply compounding the complexity and diversity of views that they may already encounter.

2.4.4 Summary

In my dissertation study, one of my research foci was the online participation patterns of fibromyalgia patients. While this is not necessarily related to the design of health-related online communities, the experiences that they shared with me, their motivations for using one social media channel and not another, or different forms of participation across media, provided insight about how these media might be more effective, educational or enjoyable. Thus, I conducted a review of the design of online communities and social interfaces as a foundation for me to better recognize wisps of re-design opportunities when they occurred in my participants' stories.

At the outset, one of the key concepts that emerged was that there are a number of tensions that may occur between design considerations: meeting the needs of individual member vs. those of the entire group; size vs. long-term sustainability; core vs. periphery; and identity vs. bond communities. Though these need not be diametrically opposed, there is often a trade-off between the two. Thus, design of health-related online communities must involve careful consideration of the target population, including the specificity of the group; the intended size; and desired user experience. For example, the founder of an online support group might decide that they want to keep a group small in order to foster group cohesion and ensure that everyone is able to get their questions answered; this can be at the expense of growth, and perhaps there are some members who may become frustrated due to what they perceive as extraneous content. On the other hand, the founder of a social networking site might decide that its aim is to have a large group, even if member turnover is high, and there is a very loose periphery. These are not meant to suggest that these are the only two possibilities.

I also reviewed design concepts for social interfaces that I believe to be particularly relevant to health-related online support groups: social presence, trust, encouraging participation, encouraging contributions, fostering social interactions, and supporting sense-making. In addition, I reviewed the potential use of social recommendation systems in health-related online communities. To conclude, I reviewed different types of visualization interfaces, including those that provide an overview of community/individual activities, and those that visualize semantic content.

Health-related communities offer their members the opportunity to engage in a variety of activities, including information exchange, support provision and community interaction. Because of these disparate tasks, in the design of such communities it may be useful to consider a wide range of design principles, including those for online communities, social interfaces and visualization. In this section, we saw that online communities may afford its members very different experiences depending on their social features and the extent to which they supports members' information seeking and sensemaking practices. Visualization techniques can be integrated into interfaces for consumers, to help them locate content or people, make sense of information, and co-construct knowledge. They can also help scientists to understand more about how patients experience a condition, and for forum moderators and designers so that they can understand how to facilitate a helpful and productive community.

CHAPTER 3 RESEARCH QUESTIONS

In my dissertation, I studied the illness experiences of those with fibromyalgia, with a particular focus on their “illness journey” as it unfolds over time, the role of information along the way, and how this is related to their interactions with others online. Fibromyalgia is a chronic condition with a wide range of symptoms, in which we see little clinical improvement over time (Walitt et al., 2011). However, previous research has shown that acceptance of pain can lead to a moderate effect on well-being, and also less pain, disability and distress (Rodero et al., 2011; Viane et al., 2003; McCracken & Eccleston, 2003).

The extant literature provides a general sense of how an individual’s understanding of their condition, their life and their being may change throughout the course of a chronic illness. For example, chronic illness can serve as a disruption to life (Charmaz, 1991) and result in mental disorganization (Mishel, 1999). Re-interpretation is essential to effective coping. In the case of fibromyalgia and other conditions involving chronic pain, this may involve a re-focusing of one’s energies, not on a cure, but on coping (Chen, 2012a) and acceptance of pain (Rodero et al., 2011).

However, in the case of fibromyalgia there is much that we do not know about how re-interpretation occurs: what facilitates re-interpretation, and the role that information plays in this process, e.g. what information patients encounter and/or use on their illness journeys, how they interact with this information, and how information becomes integrated into existing knowledge structures and results in behavioral change. Moreover, it is unclear what additional information

patients would find useful. These gaps, then, serve as the basis for my first three research questions:

- How do fibromyalgia patients' knowledge of and attitudes toward illness, life and being change over time?
- How do patterns of information seeking and use change throughout fibromyalgia patients' illness journeys?
- How are physiological sensations and affective reactions associated with fibromyalgia patients' illness journeys?

The fourth research question addresses any relationships that may exist among these three:

- How are knowledge, information seeking and information use, physiological sensations, and affect related over the course of illness journeys?

Based on previous research concerning other conditions, we see that, especially when patients are first confronted with knowledge that they have a condition, they tend to direct their information seeking towards the most immediate issues. In the case of fibromyalgia, one might infer that searches might be more focused on symptoms and finding a cure. Previous studies have shown that fibromyalgia patients may be more sensitive to stress, and that they also encounter a great deal of difficulty interacting with others due to their condition. Thus, in terms of the cognitive part of the illness journey, we might expect that affective components of information processing and sense-making may be particularly relevant.

Different theories of information seeking may be useful for considering what happens with patients' information behaviors over the course of their illness journeys. First, Kuhlthau (1991) writes of various types of emotions that may occur during information searches,

including uncertainty, optimism, confusion/frustration/doubt, clarity, sense of direction/confidence and relief/satisfaction or disappointment. Bates (1989) writes that users pick up pieces of information a little at a time (“berrypicking”), and that their information needs change along the way due to the information that they pick up. Information foraging theory (Pirolli & Card, 1999) argues that information is scattered about in patches, and people may seek information in one patch until resources become scarce, and then they move on to another patch.

In the case of fibromyalgia patients, there may be triggers for periods of more extensive searching. At times, more extensive information seeking may be due to the onset of a new symptom, but at others, searching may be triggered due to a renewed desire to know, to find a cure, or just to see if there is anything new out there. There are various resources, online and offline, for people to seek information; thus, at times they may seek information in online support groups and/or health portals, or from their doctors. Through all this, there may be periods of intense frustration, confusion and lack of direction; these emotions may be triggered by failed searches, but they might also be triggered due to the eventual failure of a longtime medication, or the “giving up on” a medication or treatment that a patient is trying out. There may also be periods of optimism, perhaps at the start of a new treatment, or clarity at having figured something out. There is always a context in which a patient is situated, and hence, through which a researcher should interpret patients’ behaviors. There are many potential intervening variables (psychological, demographic, role-related or interpersonal, environmental and source characteristics) and activating mechanisms (stress/coping, risk/reward, and self-efficacy).

In recent years, people have come to rely on the Internet for health information. Patients obtain and make use of information from the Internet, and in many cases, also contribute to that information. In addition, they may become a part of one or more online communities in which they interact with others, exchanging informational and emotional support, engaging in daily banter, and so on. A number of studies have examined the use of the Internet and online support groups, and information behaviors of fibromyalgia patients (e.g. van Uden-Kraan et al., 2008a-c; Chen, 2012a-b; Daraz et al., 2011a); these studies have found that fibromyalgia patients make extensive use of the Internet, and that fibromyalgia-related discussion forums cover a wide range of topics, including allopathic as well as alternative medical treatments, and social and economic difficulties arising from the condition.

Though there is a considerable body of literature concerning online support groups, few studies examine how individuals participate in online communities over time, and how participation patterns are related to illness journeys. This, then, was the final question to be investigated in this study:

- As fibromyalgia patients traverse their illness journey, do they express themselves differently and contribute to online communities in different ways?

Regarding the conceptualization of online and offline spaces, Leander and McKim (2003) observe that participants make meanings of their experiences across these spaces. They might act out problems that they experience in offline spaces, and they might reproduce their identities across these spaces without the separation that is often assumed. Their Internet-based social practices may also shape their offline practices of identification. In such a fashion, online technologies extend rather than replace their offline relationships. Of course, there are also cases in which a person's Internet "persona" may be different from their offline persona

(Markham, 2004), and users might have multiple Internet personas, each different from one another (Takahashi, 2008). Given all of the previous considerations, only by considering individuals' online and offline worlds together, can we come to understand them. It is my hope that, in answering this question, we may not only come to understand how patients support each other in their illness journeys, but also how the design of online health-related communities might be improved.

CHAPTER 4 METHOD

In my dissertation, I interviewed patients with fibromyalgia in order to understand how their views of their illness and of their health have changed over time, and how these views were related to their patterns of participating online. I recruited participants through multiple mechanisms, including an extant email contact list from a previous study, a university listserv, face-to-face support groups, health-related online social networking sites and Twitter. Participants were generally interviewed twice; the first session was used to gather information about their health history, information use and the physical, mental and emotional journey they have taken prior to and during their illness. The second session was used to jointly explore their online participation history. Both sessions involved forms of visual elicitation.

There were three types of data to be analyzed: interview content, the timelines participants drew during the interview sessions, and any online artifacts that they created over time. The data was analyzed qualitatively in order to identify salient themes. The analysis method drew from various theoretical and methodological approaches, including grounded theory, Interpretative Phenomenological Analysis (IPA) and life story approaches.

This study had several expected outcomes. First, I expected that this study would extend our knowledge about how fibromyalgia patients, and to a limited extent, chronically ill patients in general, change in terms of illness outlook, information behaviors, and social media participation patterns over time, and that this extended knowledge would fuel additional research. Second, I believed that we might gain insight concerning fibromyalgia patients' information needs, including the timing and form that the needed information should take.

Lastly, I hoped that interface design recommendations for online communities might emerge from this study.

4.1 Sampling Plan

In this study, I aimed for a target sample size of 20-30 participants who varied in terms of three types of characteristics: age, illness duration, and social media participation style. I relied on extant literature to select dimensions that might be important for observing the range of behavior concerning the phenomena in question, i.e. change in beliefs, information behaviors and online participation over time. In terms of the first characteristic, age differences have been reported in social media and online support group use among adult Internet users in the United States (Chou, Hunt, Beckjord, Moser, & Hesse, 2009), and previous research has also found age differences in the use of coping mechanisms among adults suffering from chronic pain (e.g. Molton, Jensen, Ehde, Carter, Kraft, & Cardenas, 2008).

With regard to illness duration, extant literature has argued that there are certain processes, such as re-conceptualization of illness and re-definition of the self, that are essential to effective coping (e.g. Charmaz, 1991; Mishel, 1989, 1999). LaChapelle, Lavoie, and Boudreau (2008) observed that acceptance of pain was a process of realizations and acknowledgments. As these phenomena are likely to occur over a period of time, illness duration was included as a dimension in the sampling strategy for this study.

The last dimension included in my recruitment strategy was participation style, which referred to the nature of patients' interactions with discussion forums. I expected that participants would fall into four main categories: "nonusers" (no participation of any kind), "lurkers" (reading only), "infrequent poster" (authors posts once in a while, but primarily reads) and "frequent poster" (reading and authoring posts on a routine basis). Lurkers, posters, and to

a lesser extent, infrequent posters, are terms that have been used extensively in previous literature (e.g., Nonnecke & Preece, 1999; Ridings, Gefen, & Arinze, 2006), and in an earlier paper, I observed differences across a number of variables among fibromyalgia patients with different participation styles (Chen, 2015). Thus, it was important to ensure that there was variability on this dimension. Though I did not initially intend to recruit fibromyalgia patients who rarely used social media, there were two such prospective participants who seemed as if they might provide perspectives that would inform my research questions, so I included them in the study.

In my recruitment process, as time passed, there appeared to be a bias in my sample towards those who were further along in the illness journey, had been diagnosed for some time, and had figured out a strategy for managing their illness. I tried to target those who were newly diagnosed more explicitly by adding an extra sentence in my recruitment materials emphasizing my interest in the voices of the newly diagnosed, or even those who did not yet have a diagnosis. I also noticed that those who responded to my study invitation did not include as many individuals who participated actively in discussion forums as I had hoped, so I increased my efforts to post study invitations in online discussion forums, and ultimately my sample did include a number of people who were quite active in discussion forums.

With regard to the first deficiency, a lack of participants who had been recently been diagnosed or were still trying to figure out if they had fibromyalgia, the additional strategies I implemented met with limited success. Part of the reason for this was that, given that my target sample size was 20-30, by the time I realized what the biases were and implemented strategies to address them, I was already close to my target sample size. I think that recruitment through

physicians' offices or clinical facilities might have worked, but I implemented them too late in the process for them to take effect.

However, I do think that there are inherent difficulties in recruiting individuals who are newly diagnosed with fibromyalgia, or who are wondering if they have fibromyalgia. There are several reasons for this. First, a number of people who made contact with me ultimately chose not to participate. Among them, a disproportionate number seemed to be newly diagnosed. I had a few conversations and email exchanges with them, and a key barrier to study participation seemed to be that they were dealing with many issues at the same time, such as problems at work, medical events, and so on. For many, this was also an extremely difficult time emotionally. The circumstances that these prospective participants shared were not unlike those that study participants shared about that time in their lives, in retrospect. By this, I mean that the patients who participated in my study shared stories of their difficulties managing when they were first diagnosed. Thus, I would conclude that patients may be more likely to participate after they find an effective way to manage their symptoms and their lives become more predictable. In the future, one way to try to recruit participants who are newly diagnosed would be to work with a clinic or treatment center, where there may be a higher proportion of newly diagnosed patients.

I had originally intended to conduct all of the interviews in person. Though this meant that I would not be able to interview some people because of where they were located, my primary reasons for doing so were as follows. First, previous research has shown that face-to-face interviews tend to be longer and result in richer data than Skype interviews (Irvine, 2011). Second, the interview protocol involves a fair amount of discussion based on the interviewer and interviewee viewing and manipulating a shared screen and/or hand-drawn timeline; doing

this in addition to trying to view each other through a communication tool such as Skype could not only be challenging, but also distracting and frustrating to the interviewee. While I had planned to limit my data collection to exclude virtual interviews, I still expected to have access to a fairly diverse set of locales because my regular travels take me to different parts of the United States. Ultimately, I did make a few exceptions because of distance, which I elaborate upon in the Results section.

4.2 Recruitment

In this study, I employed a combination of recruitment strategies in order to achieve two aims: to reach the target sample size, and also recruit participants that varied on the three dimensions of age, illness duration, and participation style. The first recruitment method involved the use of a participant pool from a survey of fibromyalgia patients that I conducted in 2011, in which participants had indicated interest in participating in a follow-up interview study. There were approximately 115 email contacts that I had from that initial study; I sent them each an email describing the current study and inviting them to participate (Appendix A).

A second recruitment mechanism was to post study invitations on health discussion forums (e.g., Reddit, ProHealth and HealingWell) and via the university staff and student listserv (Appendix B). In addition to introducing the study, the invitation also asked that anyone who saw it forward it to others who may have fibromyalgia; in this way, it was possible to extend the reach of the invitation outside of the university listserv and discussion forums, and mitigate sample bias. I used this recruitment technique in a previous survey (Chen, 2012a), and I was able to obtain a sample of a suitable size for that study ($N=190$). The demographic of the sample was fairly similar to other studies of fibromyalgia, and the survey respondents provided quite comprehensive and rich information in their free text responses. Once participants

contacted me I sent them a more detailed description of the study, including what would happen in each interview session, and that I would be asking for their consent to collect online artifacts (Appendix C). At the end of this follow-up email, there was a brief screening questionnaire to help me select participants for the study. It was also used to collect demographic data. Once I received their response, I followed up with an email confirming that I had received their pre-study questionnaire, including a message that I would be in touch if they were selected.

Given that in this study participants would need to be more involved than in the previous study, I was not certain that this recruitment method would be effective, and indeed, these two initial strategies did not produce a sufficiently large sample. Thus, I implemented additional recruitment strategies. One of these was to recruit through face-to-face support groups. I recruited participants through one face-to-face support group, at which I introduced myself, gave a brief introduction to the study, and passed out recruitment flyers (Appendix D). I made contact with a number of leaders of other support groups to see if I could visit their support group meetings, and for various reasons I ultimately did not end up visiting any other support groups. However, a few of the leaders I contacted volunteered to participate and also referred another participant, and thus this strategy indirectly led to a number of participants. Another recruitment strategy was to contact individuals who identified themselves on Twitter as having fibromyalgia to see if they would be interested in participating in the study. I recruited through a number of health care practitioners and coffee shops, but ultimately these did not lead to fruitful contacts with prospective participants. I continued recruiting participants through all methods until I had reached the target number of participants, and I had a sample that exhibited sufficient diversity on the three dimensions. The number of participants that was recruited through each mechanism is tabulated in Table 2.

Table 2. Recruitment Mechanisms and Participants Recruited

| Recruitment Mechanism | Number of Participants |
|---------------------------------------|------------------------|
| Participant Pool from Previous Survey | 4 |
| Listserv* | 7 |
| Social Networking Sites | 5 |
| Face-to-face Support Groups | 6 |
| Doctors' Offices | 0 |
| Cafes | 0 |
| Twitter | 1 |

* Includes those referred by someone on the listserv.

4.3 Data Collection

4.3.1 Interviews

The data collection phase of this study generally involved two semi-structured interviews with each participant. There were some exceptions, which will be discussed when the first interview session is described. In semi-structured interviews, interviewers may have a set of topics or issues that they plan to discuss, and perhaps a preferred order, but rather than having the interview be forced to take a certain path, the interview should have the flexibility to take the paths as they arise (Berg & Lune, 2012). I planned to use this type of interview, as there was a set of topics and questions that I planned to ask in advance, but with the exploratory set of research questions that I was investigating, it was not possible to predict all the topics that would arise, and preserving the flexibility to take new paths as they arise can enrich the data considerably.

Given the population that I worked with and the type of content that we discussed (i.e. experiences of chronic illness, that many may find to be a significant part of their lives), it was also important to consider the effect that this conversation may have on the study participants, and techniques that may be most suitable in this conversation. Rosenthal (2003), who has conducted biographical narrative interviews with various populations, including the Shoah, their

children, and their grandchildren, and World War I veterans, writes that these interviews may potentially trigger curative processes, but that a “balancing act” is necessary to prevent narrators from unexpectedly delving too deeply into their sufferings and become overwhelmed. The biographical narrative interviewing method generally involves “narrative-generating questions” that encourage people to narrate about their lives. These may include questions that: address a certain phase in an interviewee’s life, e.g., “Could you tell me about a time when...”; address a single theme, e.g., “Can you tell me about your parents?”; and address a specific situation mentioned in the interview, e.g. “You mentioned x earlier, can you tell me in more detail what exactly happened?”(p. 918). In addition to the use of narrative-generating questions, the biographical-narrative interview technique also employs the “active-listening” technique from client-centered therapy, which involves affirming the interviewee’s stated feelings to signal interest and openness. The interviewer does not pressure interviewees to discuss subjects that they seem hesitant to discuss.

As extant literature has shown, individuals who suffer from a chronic illness often go through a process that is stressful, traumatic and results in mental disorganization, but through which the self may emerge re-defined (e.g. Charmaz, 1991; Mishel, 1988, 1999). This is by no means a process that happens overnight, and thus, I expected to encounter selves in various stages of being re-defined. Thus, I planned to incorporate elements of this technique, most notably the narrative-generating questions and active-listening techniques from client-centered therapy. I did not plan to implement this method entirely, as the interviews would take too much time, and also result in elaboration that would obscure my research foci.

In my study, participants were asked to draw as well as explore, with the interviewer, artifacts that they created. I decided to interview participants in person because, though current

technology mediation could potentially facilitate seeing the participant and sharing the screen at the same time, it would be very unwieldy to also see the paper that they drew on. There are technologies that could support their drawing on the screen, but that might make the interview more difficult, particularly considering the potential interview demographic. Thus, I decided to interview participants in person.

I expected that the first interview would take approximately an hour and a half, and the second, an hour. I pilot tested the interviews with a limited number of individuals ahead of time to check the timing and flow of the interviews and revise the interview guide as needed, based on the pilot tests. The pilot participants were individuals who had a chronic condition other than fibromyalgia and participated in online spaces to varying degrees. Altogether, there were four pilot participants, and their main medical issues were lupus, migraines, rheumatoid arthritis and Chronic Fatigue Syndrome.

At the conclusion of the pilot tests, I decided not to include the first question in the Timeline section of Interview Session I: “What do you think are the five most important events that have occurred on your illness journey?” Originally, the purpose of this question was to facilitate comparison across the sample and to situate participants’ social media participation history. However, the pilot tests suggested that the illness journeys people describe are not always well encapsulated by five events, and so this question was not used in the interviews for the study.

4.3.1.1 Interview Session I

The purpose of the first interview was to collect background information about the participant, including their illness history and their physical, mental and emotional journey to the present day. The first task in the interview was to introduce myself, the purpose of the

study, and then go over the consent form (Appendix E). The participants then filled out a brief set of questionnaires (Appendix F), and then I proceeded with a set of interview questions (Appendix G) on health history, information use, current condition management strategies and social interactions, focusing on aspects that are better captured through narrative as opposed to the initial questionnaires. This interview session also included the drawing of a timeline.

I interviewed each participant either once or twice, depending on the extent to which they participated in social media and geographic proximity. If participants did not participate in social media or participated only to a limited extent, I usually interviewed them only once. If they lived far away and I was only able to make one trip, I often integrated the questions from the second interview guide into the first, and only, interview. There were three interviews, two with the same person, that I conducted via Skype or phone due to issues of geographic proximity. Altogether, I conducted 37 interviews with the 23 participants.

4.3.1.1.1 Questionnaires

Participants were asked to fill out two questionnaires (Appendix F), the Fibromyalgia Impact Questionnaire – Revised version (FIQR) (Bennett et al., 2009) and the Brief Illness Perceptions Questionnaire (BIPQ) (Broadbent, Petrie, Main, & Weinman, 2006). The FIQR provided a general assessment of the impact of fibromyalgia, whereas the BIPQ provided an overview of patients' illness representations. Because previous research has demonstrated that a person's illness representations can potentially have an effect on their coping and information behaviors (Chen, 2015), and further, predict health outcomes (Foster et al., 2008), it was important to include in the study. Given that the focus of the study was on the qualitative content, an important consideration was brevity, in addition to validity and reliability. Study participants were all able to complete the instruments within a few minutes.

The FIQR is an instrument with three domains: function, overall impact and symptoms (Bennett et al., 2009). It is a revision of the Fibromyalgia Impact Questionnaire (FIQ), which was developed over 20 years ago and has become one of the most frequently used instruments in the assessment of fibromyalgia. The FIQR was developed to address various deficiencies in the original instrument, including a cumbersome scoring algorithm that prevented widespread clinical use. The FIQR differs from the FIQ in having modified function questions and the inclusion of questions on memory, tenderness, balance and environmental sensitivity.

A validation study reported that scores on the FIQ and FIQR were well correlated ($r = 0.88$, $p < 0.001$), and it was able to discriminate effectively between patients with fibromyalgia, and those with rheumatoid arthritis (RA), systemic lupus erythematosus (SLE), and major depressive disorder (MDD) (Bennett et al., 2009). A recent evaluation of standardized assessment tools for fibromyalgia recommended the use of the FIQR for the assessment of physical function, overall/global improvement, and multi-dimensional function/health-related quality of life (Boomershine, 2012). The FIQR has been translated into a number of languages, including Spanish, Italian, Persian, Turkish, Moroccan and Arabic.

The Brief Illness Perception Questionnaire is a nine-item scale designed to assess the cognitive and emotional representations of illness (Broadbent et al., 2006). The Brief-IPQ was developed based on the revised version of the Illness Perceptions Questionnaire (IPQ-R), a commonly used multifactorial questionnaire that assesses illness representations (Moss-Morris et al., 2002). The Brief IPQ showed good test-retest reliability in 132 renal patients; concurrent validity with relevant measures in 309 asthma, 132 renal and 119 diabetes patients; and discriminant validity between five illness groups (Broadbent et al., 2006). The scale also

demonstrated good predictive validity in patients recovering from a myocardial infarction (MI). Permission was obtained from the author to use the Brief Illness Perception Questionnaire.

4.3.1.1.2 Timeline Activity

In this study, I employed a timeline construction activity. There was a dual purpose to the timelines. During the first interview, their primary use was as an exercise to facilitate participants' reflections on their own past. They also helped me to form questions to better understand participants' journeys. I elaborate further on my own use of the timeline, but first, I present an introduction to the use of visual stimuli, including timelines, in interviews.

Visual elicitation is the process of using a visual stimulus to draw out a verbal or a visual response (Salmons, 2010); visual stimuli that may be used include physical specimens, maps, drawings, photographs and videoclips (Crilly, Blackwell, & Clarkson, 2006). Closely related are graphic elicitation techniques, which involve the use of diagrams or drawings in interviews (Crilly et al., 2006). Graphic elicitation techniques open up participants' interpretations, enable participants to form a more holistic view of the topics being explored, encourage them to explore different layers of experience, and evoke deeper elements of human consciousness (Bagnoli, 2009; Harper, 2002). Drawing activities can give participants time to reflect, and facilitate creativity and self-expression (Bagnoli, 2009).

Graphic elicitation techniques have been used to study patients' illness experiences (e.g. Thygesen, Pedersen, Kragstrup, Wagner, & Mogensen, 2011; Oliffe & Bottorfe, 2007). There are various reasons why they may be particularly helpful for such studies. Graphic elicitation techniques can support participants to remember "nearly forgotten parts of their experiences and ...[express] emotions associated with those significant experiences" (Thygesen et al., 2011, p.

596). In addition, they are especially useful for eliciting data relating to emotions and emotional experiences (Copeland & Agosto, 2012).

Timelines are a specific technique that can be used in graphic elicitation. Bagnoli (2009) used timelines in the Young Lives and Times study in order to encourage young people to reflect upon the past, present and future. Timelines were also used by Sheridan, Chamberlain and Dupuis (2011) in a study of individuals' weight loss experiences over time. One particularly interesting use of timelines to elicit emotional aspects of disease trajectories is described in Thygesen et al. (2011). In this study, the first author interviewed eight women in an acute period of cancer. She gave these women pieces of paper with preprinted grids in which the x-axis represented time, and the y-axis, degree of emotion, on a scale of 0 to 100%. The major events in a standardized gynecological cancer trajectory in southern Denmark were also printed on the grid. The interviewer asked the participant to draw a line indicating how her emotions changed during the course of the disease trajectory. If the participant did not talk spontaneously as she drew, the interviewer would prompt her to share her thoughts.

Given that participants were being asked to engage in a task, and also to discuss the process as they were doing it, one might think that it resembles the "think-aloud" protocol, a technique that is often used in usability testing. However, I would argue that the technique I used is quite different from the think-aloud protocol (Ericsson & Simon, 1984). Though some writing on the think-aloud protocol has argued that interviewers do not have to take a completely passive role, but rather, should interact with interviewees by taking into account "speech genre" or speech communication patterns (Boren & Ramey, 2000), at the end of the day the standard think-aloud protocol is conceptualized as a data collection technique focused on the capture of cognitions as they occur in the participant's short-term memory. I am focusing on

the use of visual elicitation techniques to invite participants to retrieve long-forgotten memories, see things in a different light, and even embark on a journey of self-discovery during the interview.

The purpose of the timeline activity was to understand how participants' experiences have changed over time. Though I had initially planned on providing patients an instruction sheet that I called the Journey Timeline Worksheet (Appendix H) to guide their drawing of the timeline, I found that it worked much better to explain the exercise to them orally. When I introduced the exercise, I asked them to think about their illness journey and to draw something that represented it. I told them that there were no rules as to what they drew, and that the timeline need not be a "line." It could contain a line if they wished, or it could contain a squiggly line, meandering line, or no line at all. I brought colored pencils and highlighters, and I told them that they could use whatever colors they wished. Interestingly, no one showed any interest in the highlighters, and all participants used colored pencils, so I eventually stopped bringing out the highlighters. I also brought a 9" x 12" sketchpad for participants to use, and they had access to as many pieces of paper as they wished.

Various problems may arise with graphic elicitation techniques. Some people may feel nervous about drawing; however, researchers have also reported that, not only did they not encounter reluctance from participants, but that participants were eager and enthusiastic about engaging in the proposed activities (Copeland & Agosto, 2012). There may also be differences in people's abilities to think spatially (Copeland & Agosto, 2012; Thygesen et al., 2011). Participants may feel that the artifacts 'speak for themselves,' and thus using artifacts may actually hinder verbalization (Meo, 2010). Another drawback of graphic elicitation techniques is decontextuality, i.e., the danger that the graphical data do not make sense without the use of

interviews to probe for contextual details, and that, decoupled from the interviews, the reliability and validity of visual data is diminished (Copeland & Agosto, 2012). Lastly, analysis of the graphical data can be time-intensive.

Inclusion of the timeline can enrich the process of data collection considerably. Thus, I did my best to minimize potential problems by putting participants at ease with the timeline construction activity and letting them know that they could draw it however they wanted. Also, I asked participants to clarify areas that were unclear to me on the timelines, and read out some of the labels so that I would be able to find the respective sections on the recording later.

4.3.1.2 Interview Session II

The second interview was focused on online participation. Broadly speaking, there were three topics of interest: how participants' online participation has changed over time, what role this media played in their lives, and what online community meant to participants (Appendix I). At the opening of the interview, I first asked participants to talk generally about their social media participation. Following this initial discussion, I engaged participants in a discussion about each of the media that they used.

If it was possible to employ the Online Scrapbook interface in the interview, then I would introduce the interface and ask them to reflect upon their social media participation through the interface (Appendix J). This interface has three primary sections. In the uppermost section is a timeline that features each social medium in which the user has authored posts; in the middle, a search textbox; the bottom shows online content, either content retrieved through a keyword search or by clicking on one of the circles in the timeline. When one of the circles is clicked, the posts authored during the corresponding period are displayed.

There were some variations to the protocol outlined in the second interview guide based on two primary factors: the nature of participants' social media participation and geographic proximity. For 11 out of 23 participants, I used the Online Scrapbook interface as I had planned. We discussed their participation in general prior to viewing the interface, and then we examined the interface, as outlined in the second interview guide.

There were four participants for whom there was no social media content to view. Two participants (P07 and P26) did not participate in social media at all, one lurked but did not engage otherwise (P08), and one participated only for non-health related reasons (P21). In the case of these four participants, I asked them about their impressions of online community, but I did not ask them about their participation.

There was another group of participants with whom I discussed their online participation without the use of the interface. This group primarily engaged with blogs, Twitter and Facebook, and I interviewed most of these individuals only once due to geographic proximity. As I will discuss in more detail later, I found that the Online Scrapbook was not as effective as an elicitation technique for viewing blog and Facebook activity, and I often found it difficult to request and obtain social media content prior to the first interview, so I did not use the interface in these interviews. For this group, I integrated the questions from the Pre-Graphic Elicitation section of the second interview guide, which focuses on online participation and participants' impressions of online community, and I used the participants' social media content to inform my interpretation of their participation. This accounted for 7 of the 23 cases.

Lastly, one participant (P22) engaged extensively with two discussion forums where it would have been difficult for me to get access to all of the posts, so I did not use the interface with her. I conducted a second interview with her about her social media participation using the

Pre-Graphic Elicitation section of the second interview guide and used a sample of her posts in the qualitative analysis.

In interviews in which participants had extensive social media content that we did not view through the interface, we discussed their content in other ways. For example, P23 participated in closed Facebook groups for various chronic conditions. We viewed these posts together on her computer at her home. P06 keeps a running blog that reads somewhat like a novel and includes fictional characters that have chronic conditions. I read through parts of this blog prior to our second interview.

4.3.2 Artifacts

In between the first and second interview session, I collected artifacts of the participant's online presence. These included posts that they had authored on discussion forums, tweets, Facebook comments and notes, and in a few cases, health-related email and listserv communications.

In some cases, there were logistical reasons why I did not collect all of the social media that participants had authored. As one might imagine, not all of it continues to be accessible over time. In some cases, it would have been difficult, if not impossible, to locate all of the traces because of the site design. A few participants said that they might have authored a few posts at some point, but they could not recall for sure, and I was not able to find anything authored by them searching on the Internet. For those who had not developed the illness until more recently, their social media participation often started substantially earlier than their illness, and collecting it would only have had limited utility for contextualization.

There are various logistical considerations with regard to the use of artifacts. It is important to make sure to have clear identification for each artifact (Collier, 2001). The

interviewer needs to make sure that they say the identification number of the artifact so as to be able to distinguish it, later, in the interview transcript (Meo, 2010). As I conducted interviews, I emphasized the identifying characteristics of posts and other social media artifacts as we were talking about them so that I would be able to distinguish them later.

4.3.3 Consent

Though the Internet could potentially be a very rich source of data, there are also many issues that may arise from conducting research on the Internet. Ess (2007) enumerates many of these issues. From the perspective of the medical and/or social sciences, the author of online discussion content may be considered a human subject, so it is important to consider issues such as anonymity, confidentiality and consent. They might also be considered authors, so the concerns might be copyright protection, fair use and attribution. Other issues include the expectations of the participants (i.e., is the space public or private to them), increased risk due to research being online rather than offline, and methodology-specific issues such as a greater need for quotes in certain types of analytic methods.

Many researchers believe that the notions of public and private are not strictly dichotomous (McKee & Porter, 2009). First, these notions are always relative to their context; and whether a space is public or private may depend on whether one is considering a broader or a narrower context. Second, people may share extremely private details of their lives with people that they do not know offline, but not with those that they know well; and they may upload videos and photos to a public space, but label or name them in a way that only their close friends and family can find (or so they think). Lastly, there may also be cultural differences in notions of privacy. McKee and Porter, however, do point out that even these cultural norms or conceptions of privacy evolve over time, so judgments of whether a space is

public can be moving targets. Various researchers have argued that the decision of whether or not to seek informed consent should be a “nuanced, contextualized decision-making process” that considers whether users view their communications as public or private, the sensitivity of the topics discussed, the degree of interaction between the researcher and potential participants, and the rhetorical, technical, and/or material vulnerability of participants (McKee & Porter, 2009).

One issue that many researchers may face is the question of whether to quote participants in analyses of online content. On this topic, Herring (1996) draws upon her own background as a linguist and the practices of scholars in that field. She argues that, in the collection of naturalistic spoken language data, it is often necessary to forego consent in order to collect authentic data. In the process of analysis, it is customary to use pseudonyms and otherwise obscure the identities of the informants, but at the same time, it is important for researchers to provide sufficient context so that others are able to verify their findings. Thus, the practice that she herself follows is that she anonymizes the individuals, but discloses the names of the groups that she observes. To contextualize her work, she also writes that, because most of the content she analyzes is open-access Listserv groups in which the discourse is ‘strong public, even exhibitionistic’ (p. 159), she finds it appropriate to compare this content to public broadcasts.

Flicker, Haas, and Skinner (2004) also faced this issue in their research. In their design of an online community that they used both for research and health promotion, some of the users of the discussion board had consented to their research, but not all of them. What they decided to do was assume that all data was private, and only posters who consented to be part of the study group could be quoted in analyses. They used the postings of those who did not

consent only as context for analyzing conversations and did not explicitly quote them in analyses.

Allen (1996) argued that the question of how to research ethically in cyberspace should not be pursued from the “top-down,” through the use of the “Golden Rule,” because there is a lot that researchers do not know about what will be harmful in advance. Instead, Allen argues for a bottom-up approach, developing ethical practices in situ, in dialogue with the participants and other researchers, throughout the research and publication process.

There is also the possibility of deductive disclosure, in which the traits of participants make them identifiable in research reports (Kaiser, 2009). Kaiser argues that there are two approaches, the “dominant” approach, and an alternative approach. The premise behind the dominant approach is to conduct the research without compromising the identity of the participants, and confidentiality is primarily addressed during research planning, data collection, data cleaning and dissemination of results. Aside from removal of personal identifiers, the researcher must also use his or her judgment to decide what aspects of participants’ stories or lives need to be changed to maintain confidentiality. According to Kaiser, researchers vary in terms of how much they are willing to change. Changing details of stories can be problematic, because this can alter or destroy the original meaning of those stories. For this reason, some researchers choose to leave data unpublished.

Kaiser (2009) elucidates a series of objections concerning the dominant approach. First, though the dominant approach is likely to prevent outsiders from knowing the identity of participants, it does not prevent “insiders,” i.e., those who are close to participants, from recognizing participants in stories. In addition, researchers carry the burden of deciding what makes data identifiable. Third, there are no provisions for how researchers should dialogue

with participants about confidentiality once the data is collected. Fourth, the promise of confidentiality may prevent researchers from using some of the rich data that they have collected. Lastly, the dominant approach assumes that details in the data can be changed without compromising the meaning of the data.

Kaiser (2009) introduced an alternative approach, which essentially consists of two points: 1) making participants more informed about the uses to which their data might be put; and 2) instituting practical steps to facilitate dialogue with respondents about how their data might be used. The strategy I employed with regard to consent was designed with this in mind. It bears similarities to the procedures that Meo (2010) used in her study employing photo elicitation, in which she asked participants to give different levels of consent, and also offered them the option to specify different types of consent for different photos.

In the case of this study, the consent form offers participants the option to specify different levels of consent for different data sources (Appendix C). The three levels of consent were: consent to download the content but not to use in publication; consent to use, anonymized, in publication; and consent to use as is, without anonymization. There were two types of data that I had planned to include in publications: interview content and online content. The consent form offers participants the opportunity to make separate decisions as to the level of consent for each data type.

In a study such as this, where there are multiple data types, there is the potential that if I refer to different types of data collected from the same participant, and their identity becomes known for one of them, that it will then also be possible to attribute the content in the other medium to them. For example, if I excerpt a post that they have authored and their online identity is public, and I refer to their interview content at the same point in the text, then it

would then become known what this forum member said in their interview. It was important that participants were aware of this possibility and have the opportunity to decide what they would like me to do.

Thus, aside from making separate decisions about each of the data types, I asked that participants consider one final option: “Interview and online content together.” Participants could give consent for me to refer to both their interviews and their online content together in publications (anonymized or de-anonymized, according to their preference). If they did not, then I could still use one or the other data type separately in publications, if they so indicated, but not both. Within the context of this study, de-identification meant that I would use either a participant ID or a pseudonym in place of participants’ names, and an X in place of any characteristics that are removed due to their potential for identifiability.

Content was de-identified prior to insertion in a publication. The reason for this was that, if a participant were shown their own content, de-identified, through the interface, it might appear foreign to them. The purpose of the interface is to assist them to go back in time, and the artificiality of the content may impede that process. In addition, they may have had a hard time piecing together the context that the content depicts. However, access to the interface was password protected, and the content was stored on a secure server (discussed in the next section).

4.3.4 Data Collected

There are four types of data that were acquired and stored during the course of this study: interview content, questionnaires, hand-drawn timelines and online artifacts. In this section, I describe the acquisition and storage of each of these types of data in turn. All of the data was stored in digital form on a secure server and named according to participant ID. A

table listing all of the IDs with the participant names was kept in a different location on the server.

4.3.4.1 Interview Content

As I mentioned earlier, I conducted 37 interviews with the 23 participants. Given that I sometimes covered the content intended for two interviews in a single interview, I am reporting aggregate statistics for the total time with each participant. The mean total interview time per participant was 2 hours and 26 minutes, and the median time was 2 hours and 19 minutes. The minimum time per participant was 1 hour and 8 minutes, and the maximum total time was 5 hours and 13 minutes. The mean times for the first and second interviews were 1 hour 42 minutes and 1 hour 11 minutes, respectively. These means were fairly close to my projected interview times after conducting the pilot tests (1.5 hours for the initial interview and one hour for the second interview).

As I conducted interviews, I recorded them on a portable device. The audio files were transferred to a secure server that was backed up on a regular basis. The interview content was transcribed verbatim. I transcribed 22 of the 37 interviews, and the other 15 were transcribed by a commercial transcription service with a confidentiality agreement. Three interviews that were transcribed by me were only partially transcribed because there were large portions of dialogue that were not directly relevant to the topics at hand.

4.3.4.2 Questionnaires

In general, participants filled out two questionnaires at the beginning of the first interview. The original copies of the questionnaires that participants filled out were stored in a secure location. In the case of P13, whom I interviewed twice virtually, he told me his responses orally.

4.3.4.3 Timelines

During the first interview, I asked each participant to draw a timeline. The timelines that they drew were digitized as soon as possible after the interviews, and digital copies were stored on the server. The originals were stored in a secure location.

4.3.4.4 Social Media Artifacts

I collected as much social media as I could for each participant in the study. There was great variability in the amount and type of content. Some participants did not author any content, while others had enormous amounts of content that were spread out over multiple platforms. Altogether, I collected over 30,000 “pieces” of social media and the collection included Facebook, Twitter, online discussion forums, and blogs. A number of participants also used Instagram, but most did not view it as a social platform, and I did not collect any content that they authored on this platform. The earliest social media collected in this study was from March, 1997.

The social media content was obtained through different methods depending on the data type. In the case of discussion forums and games, I manually saved pages containing online content that participants had authored. In the case of Twitter, I used the Twitter Streaming API to collect the tweets. The Streaming API allows a maximum of 3,200 tweets, and for three participants, I hit this maximum, which indicates that I had an incomplete sample of their content. The first time this occurred, with P11, I asked her to request the archive from Twitter. I had read that sometimes users requested archives and did not receive them, and in fact, this appeared to be the case here. Thus, I decided that the 3,200 tweet sample was adequate for her and subsequent participants for whom I hit this cap. In the interviews, I asked participants to tell me if they believed that their participation had changed over time, and if so, how. In the

case of Facebook pages, I accessed participants' timelines and saved them as HTML files. In the case of blogs, I did not keep a copy of the blog posts, but merely linked to them.

Digital copies of the online artifacts were stored on my personal laptop and on the secure server, which are both password-protected according to university security policies. These digital copies are named according to participant ID and data type. Additionally, the copies of the online artifacts I obtained underwent a pre-processing procedure, in which the web page display code was removed, and the content of participants' posts was inserted into a MySQL database. The purpose of this step was to prepare the content to be used in the Online Scrapbook application and/or subsequent qualitative analysis. The code for pre-processing and database insertion was written in Python using the BeautifulSoup API. The metadata that was stored for each artifact included: Participant ID, Media Type, Data Source, Date, Time, and Text. Table 3 shows the media types and sources that fell under each media type.

Table 3. Media Types and Data Sources

| Media Type | Data Source |
|------------------------|--|
| Blog | Tumblr, Hibiscus Garden |
| Email | N/A |
| Forum | Reddit, MedHelp, ProHealth, Alopecia World, chronicfatigue.about.com |
| Game | Stickpage |
| Social networking site | Facebook |
| Tweet | N/A |
| Other | Facebook note |

4.4 Data Analysis

My study included a number of different types of data: interview transcripts, hand-drawn timelines, and online artifacts. Inclusion of different data types enabled me to glean richer and more complex illustrations of individual lives unfolding over time than would have otherwise been possible through a single medium. My results are primarily comprised of descriptive

statistics on all of the data types collected (4.4.1) and thematic analysis of the narrative content (4.4.2).

4.4.1 Descriptive Statistics

The first section of my results focuses on descriptive statistics. I report aggregate statistics concerning the demographics of my sample, including age, gender, race/ethnicity, education, employment status, and whether or not they received disability. In addition, I report aspects of their illness history, namely, illness onset year, duration, and comorbidities. Illness severity and perceptions were assessed using the FIQR and BIPQ, respectively, according to guidelines provided by the developers of the instruments (Bennett et al., 2009; Broadbent, Petrie, Main, & Weinman, 2006). Scores on the FIQR range from 0 to 100, where increasing score corresponds to increased impact of the illness. In the case of the BIPQ, each of the dimensions is reported separately in the results. Each item is on a 0 to 10 response scale, and that score is directly reported, except in the cases where the author has suggested reverse-coding, and those items were reverse-coded accordingly. The two ends of each item on the BIPQ were anchored with opposites, e.g., for the Concern item, the low end was “not at all concerned” and the high end was “extremely concerned.” Lastly, I present an overview of the timelines and social media artifacts collected. Excel was used in the construction of the tables, and R, in conjunction with the ggplot2 package, for the generation of the figure describing the distribution of illness perceptions.

Descriptive statistics are a critical element of the data analysis in this study. At the outset, they serve as a backdrop, context through which one is able to understand the experiences of the study. The narratives I present later were certainly experienced in light of participants’ backgrounds, health histories and perceptions, and as such, having background

knowledge of the participants facilitates interpretation of their illness journeys and information behaviors. In the Results section, I also report some general characteristics of the timelines and social media participation patterns.

4.4.2 Qualitative Analysis

The crux of the analysis undertaken in this study was in the form of thematic analysis of the interview content, augmented with analysis of timelines. The procedures for this analysis are described in this section. In sections 4.4.2.1 and 4.4.2.2., I set the stage by reviewing the philosophical and conceptual foundations, and methodological underpinnings of the analysis. In 4.4.2.3, I describe the procedures I used to prepare the data for analysis, and finally, in 4.4.2.4, I describe the procedure for thematic analysis.

4.4.2.1 Philosophical and Conceptual Foundations

In this study, I employed a qualitative approach to data analysis that draws from Interpretative Phenomenological Analysis (IPA), constructivist grounded theory, and to a lesser extent, life story approaches. IPA and constructivist grounded theory served as the basis for both a conceptual and methodological integration, and life story approaches provided sensitizing concepts that were used in the analysis of the data. Though I elucidate more specifically in later subsections the analysis that was conducted, in this section I explain how the philosophical roots of these respective traditions are suited to my research objectives.

4.4.2.1.1 Interpretative Phenomenological Analysis and Grounded Theory

Phenomenology focuses on how people make meaning of their lived experience (Starks & Trinidad, 2007). One approach that has often been employed in health psychology is Interpretative Phenomenological Analysis (IPA), which has roots in phenomenology, hermeneutics and idiography (Smith, 2011). The primary aim of IPA is to explore how

participants make sense of their world and is concerned with the participants' interpretation of the object or event, as opposed to producing an objective account (Smith & Osborn, 2008). IPA takes the stance that the researcher plays an active role in the research; interpretation is going on on two fronts, that of the participant and that of the researcher. The researcher is trying to make sense of what is happening to the participants, who are also trying to make sense of what is happening to them – what Smith (2011) calls a double hermeneutic.

Grounded theory, originally developed by Glaser and Strauss (1967), has its roots in symbolic interactionism, which focuses on the meanings of events to people and the symbols that they use to convey that meaning (Baker, Wuest, & Stern, 1992). The grounded theory method is used to inductively generate theoretical explanations of social and psychosocial processes. Charmaz (1990) describes her version of grounded theory as social constructionist, having phenomenological and Marxist roots, and coming from a symbolic interactionist perspective. The symbolic interactionist and phenomenological perspectives lead the researcher to look closely at participants' interpretations of their actions and situations, and Marxist theory encourages the researcher to ask questions about how society affects the individual and how individuals reproduce dominant ideas within society.

In phenomenological approaches, including IPA, the focus is on the meaning of lived experience and how people make meaning of their experiences; the focus in grounded theory studies is on meaning and social processes. In my study, I drew from both IPA and grounded theory because the questions that I investigated concerned both the *meaning of lived experience*, as well as *social processes*. In considering the phenomenon at hand, online participation in the context of illness experiences, it is useful to have both of these foci in mind. On the one hand, the experience of a discussion forum member is very much an individual one; it is their lived

reality, online and offline. On the other hand, what they say and do, and what they do not say and do, become part of someone else's reality. The two realities (and multiple, if one considers other individuals) intersect. What people say to each other affects each other's understanding of their own condition, and may cause them to see their own lives in different ways.

Phenomenology places the focus on the individual's lived experience, and grounded theory places the focus on the self, contextualized within life and social processes. This is the philosophical basis for the synthesis.

4.4.2.1.2 Life Story Approaches

Aside from these two traditions, life story approaches can be useful as conceptual frameworks through which we can consider how people make meaning of their lives and integrate different views that we may have of the same person (through different media) into one richer, more holistic and coherent understanding of that person.

What is a life story? McAdams (1988) argues that people construct life myths or stories which serve as our identities. The stories are not meant to deceive themselves or the world, but rather, "provide a coherent narrative framework within which the disparate events and the various roles of a person's life can be embedded and given meaning" (p. 19). Life stories can be seen as *joint actions*; "a life story depends on others – there must be a teller, but there must also be people who will hear and listen" (Plummer, 2001, p. 399). The stories that others tell remind oneself of who one is. Moreover, as we travel through life, we leave behind "personal props", such as diaries and photo albums, collections of clothes, books and records, and these "can be regathered to enable a telling of a life" (p. 399).

There are various models that have been used to analyze life stories. In the interests of keeping the data analysis process free and open so that themes can freely emerge from the data,

I did not explicitly integrate any of these models into my analysis procedure. However, I did consider them in the design of the interview questions, as well as in the analysis phase, in the interpretation of participants' behaviors.

The two models I draw upon in this study, Alexander's (1988) "principle identifiers of salience," and McAdams' (1993) "nuclear episodes," were also employed in Baumgartner's (2007) study of the incorporation of HIV/AIDS identity into the self over time. Alexander (1988) identifies nine "principle identifiers of salience": primacy, frequency, uniqueness, negation, emphasis, omission, error, isolation, and incompleteness (p. 269). McAdams (1993) argues that there are scenes from our past – "nuclear episodes" – that we reconstruct, subjective memories that come to occupy particularly prominent places in our understandings of who we are (p. 296). In particular, he focuses on high points, low points and turning points.

In addition, Orgad's (2009) integration of Plummer's (2001) life story approach also serves as a conceptual basis for my analytic approach. When researchers use different kinds of data in the same analysis, they may find that there are differences in the stories that the data appear to tell. In Orgad's (2009) study of breast cancer patients' online participation, she collected three different kinds of data: e-mail, online texts from breast cancer websites and face-to-face interviews. She found that participants' email accounts often reified or discounted the role of the Internet. But when she spoke with them in person, she realized that there was much more subtlety and complexity to the role of the Internet and the role it played in participants' coping. For example, one participant told her that the Internet played a limited role in her coping, and yet the online data showed that she actually participated quite actively.

In reconciling these differences, Orgad was guided by Plummer's (2001) interpretative approach to life stories, taking the perspective that when people talk about their lives they

invariably forget, select, exaggerate, become confused and lie, and that it is up to the researcher to recognize and examine these gaps, and distill their meaning. Rather than thinking of one as explaining the other, they should be thought of as contextualizing one another.

Thus, life story approaches may serve as sensitizing concepts of what might potentially be important in the data overall, and as a guide with regard to examining how the different media may complement and contextualize one another.

4.4.2.2 Methodological Underpinnings

The analysis procedure incorporates elements from both IPA and grounded theory. They begin similarly, with line-by-line coding, and then diverge from there in terms of method. However, there are conceptual similarities that underlie these two methods, namely in the sense that they both seek to discover a coherent structure of relationships among codes. I will first describe the two methods separately, and then explain how I integrated them in analyzing my data.

4.4.2.2.1 Interpretative Phenomenological Analysis

In IPA, the researcher generally analyzes cases one at a time (Smith & Osborn, 2008; Storey, 2007). They begin by reading an interview transcript a number of times and commenting upon the text in the left-hand margin. They go through the text line by line; the text is not broken up into meaning units, as is generally the case with phenomenological traditions. Once the researcher has been through the entire text, they then go through the text again and annotate emergent themes in the right-hand margin, by transforming the comments in the left-hand margin into concise phrases. Following these steps, they list the themes chronologically and then begin to cluster, or group them, such that they then have a hierarchy of themes and their subthemes. The next step is to produce a table of themes for that participant,

ordered coherently. This table might have three columns: theme, location in the text, and the quote that represents that text. Once this process is completed, the researcher moves on to the next case. At the end, the researcher compiles a master table listing all of the themes and subthemes, for all participants together.

4.4.2.2.2 Grounded Theory

Grounded theory also begins with line-by-line coding (Charmaz, 2008). The researcher goes through and defines short, specific and active codes about the data. Questions that they might want to ask themselves as they are doing so include: what is occurring, what are people saying and doing, what do their actions and statements take for granted, and what role do structure and context play? Additionally, one might focus on processes: how can I define the process at issue here; under what conditions does this process develop; how does the participant think, feel and act while involved in this process; when, why and how does the process change; and what are the consequences of this process?

Following line-by-line coding, researchers move on to focused coding, when they select from the initial codes the ones that make the most analytic sense (Charmaz, 2008). Then the researchers raise their focused codes to relevant conceptual categories. At this stage in the process, researchers begin to write narrative statements in memos that explain the properties of categories; specify the conditions under which categories arise, are maintained and change; describe the consequences of the categories; and show how categories are related.

Charmaz (1990) emphasizes that the researcher takes an active and dialectical stance in shaping conceptual categories. While raising codes to concepts, the researcher creates an explanation, organization and representation of the data, rather than discovering order within the data. This process involves constant comparisons (of data with data, category with category,

category with data, category with concept, and concept with concept) and continued questioning.

There are various reasons for the use of memos. At the outset, the use of memos in the process of coding can be helpful for the process of sense-making about the data. In addition, Charmaz (2008) argues that: “writing memos without editing them fosters developing and preserving your natural voice”(p. 103). Lastly, memos may serve as a record of the evolution of thought.

4.4.2.3 Data Preparation

In this study, the interview transcripts were analyzed in Atlas.ti Version 1.0.1 (MacOSX version). The corpus that was analyzed was comprised of two types of documents. The first was the set of original transcripts for each of the interviews. The second was a subset of social media artifacts that was chosen for analysis. In the selection of artifacts, I focused on the content from health discussion forums, as that tended to be most pertinent to the health issues experienced by participants. In addition, I endeavored to select a similar number of artifacts from the participants who authored this type of content, regardless of how many posts each participant had authored. Ultimately, I included seven out of the 23 participants in the corpus that I analyzed through thematic analysis in Atlas.ti. An eighth individual was an active participant in multiple Facebook groups, including those for fibromyalgia and other chronic conditions. Because these were closed groups, I did not include them in my sample, though we did look at some sample posts together during the interview.

With regard to the selection of artifacts, my sampling strategy was purposive rather than random. I attempted to select artifacts that captured as much of the subject matter and behavioral variability of participants’ social media contributions as possible. For example,

though P22 often authors posts with very similar content, providing introductory information to new members, rather than replicating this content, I only included one or two examples of different types of introductory information that she would post. In addition, though the number of initial posts is far smaller than the number of non-initial posts in my study, I over-sampled from the initial posts of the study participants, in order to form a greater understanding of this type of behavior pattern.

4.4.2.4 Thematic Analysis

As I have stated, IPA and grounded theory share methodological similarities in that they both seek to develop a coherent thematic structure from coded data. I used a structure that integrates the two. I examined the text line by line and made comments that eventually took the form of focused codes. I conceptualized codes as belonging to categories of themes and subthemes, as is customary in IPA. I used the Code Groups feature in Atlas.ti to arrange the codes in terms of categories of themes and subthemes.

There were various techniques that I used to make the process of structuring the codes into categories easier. First, I created code names that were representative of what their high level categories might be. For instance, most of the codes that ended up referring to the diagnosis point started with the word “diagnosis”. Examples include “diagnosis facilitated info seeking” and “diagnosis facilitated understanding.” There were also sets of codes that started with verbs, such as “learned.” These codes ended up becoming the constituents of the category, “What Participants Learned.” In this manner, the codes would end up next to each other in an alphabetically ordered display.

I also wrote memos that reflected upon connections among the codes and emergent themes, as is customary in grounded theory. As I worked, I periodically went through the text that I had already annotated to compare and refine codes, and go back and re-code as necessary.

The timelines and social media artifacts are important elements for contextualization. As I had anticipated that there would be quite a variety in terms of the types of timelines that participants drew, I proposed an open-ended and exploratory analysis procedure. The primary purpose of the timelines was to complement their oral testimonies. By this, I mean that I used their interview content as the main source of data about their illness journeys, but I also thought about how their drawings might reflect what they spoke of. An example might be P12's use of stop signs to depict road blocks that she encountered.

4.5 Ensuring the Validity of the Research

There were various measures that I took to ensure the validity of my research. In the design phase of this study, I deliberated over issues of descriptive and interpretative validity. In this study, I was concerned with developing a design that would enable me to understand the world as my participants see it. To achieve this objective, I regarded both interpretive and descriptive validity to be important – the former because I am presenting my participants' views, and the latter, to present them with enough detail that they can be understood. Richness of detail enables others to more fully understand participants' thoughts, feelings and actions.

My collection of a variety of different data types is predicated upon this point. In this study, I collect quantitative data, through scale instruments; visual and textual data, through the timeline; audio and textual data, in the form of interviews; and finally, another form of visual and textual data, online artifacts. Most, if not all, individuals would naturally express themselves differently across all these different media, and even across different instantiations

of the same data type, if one considers online artifacts a singular type. This difference of expression need not be seen as contradiction, but rather, as the flexibility and the multidimensionality that most people have. It would be natural to expect that people would express themselves differently if they were talking to a researcher, than to others that they see as peers in an online support environment; and yet again, if they are constrained to making decisions about themselves through a scale instrument. Even though a canvas and colored pencils affords a certain degree of freedom, these initial parameters and the word “timeline”, are themselves imbued with their own set of expectations. People naturally sense-make and tailor their own words and behavior to their context. As researchers of human behavior, it makes sense for us to interpret with this in mind. Thus, I see my own task as one in which I endeavor to make sense of and make meaning of the different forms through which participants have expressed themselves.

During the process of data collection, there is the need for researchers to take care to ensure that participants’ voices are heard. Polkinghorne (2007) cautions that interviewers need to guard against simply producing the texts that they expect by assuming an open listening stance and carefully attending to the participants’ responses. Davies and Dodd (2002) emphasize the importance of reflexivity. In their study of the experience of pregnancy, they had originally planned on asking their interviewees to focus on the pregnancy, not the birth; however, it became apparent that women did not view pregnancy as an isolated incident that they could delimit in the way that they were asked. Rather than stopping the women and keeping them on track, they allowed the women to tell the stories from their own perspectives, and according to Davies and Dodd, the interviews turned out to be far more interesting, rich and complex than they had expected from their “neatly bound research plan”(p. 286).

In conducting the interviews, I also took steps to try to ensure that participants' voices were heard. When I interviewed the participants, I employed an open attitude and worked at being sensitive, to notice which directions participants seemed to want to go in, and to develop a rapport with them. I also worked at developing an interview protocol and a timeline activity that was open and flexible so that participants were able to tell me their story in a way that suited them.

Ensuring the validity of the analytic process was also critical. To begin with, my analysis procedure employed line-by-line coding, focused coding and memoing. According to Charmaz (2008), through the use of line-by-line coding, staying close to the data, and reflexively considering the potential relationships that exist in the data through memos, one can avoid making the mistake of seeing something in the data that is not there, due to one's own biases. Memos not only facilitate sense-making, but serve as an audit trail of the research process.

Additionally, I organized my codes by themes and subthemes. Miles and Huberman (1994) argue that by organizing information into an immediately accessible, compact form, the analyst can see what is happening and draw justified conclusions. The organization of codes by themes and subthemes facilitated systematicity. It also enabled me to ask questions of the data, such as: "Is there a category missing?", "Is there an inconsistency in the themes represented?" and so on.

Another concept that was important in data analysis was convergence and divergence in the data. The concept of portraying subtle differences among participants is one that is in line with the goals of IPA (Smith & Osborn, 2008). One aims to show convergences and divergences in the data, i.e. with any given theme, there is similarity but also variation among

the examples. Smith and Osborn write that, in order to say something meaningful about a group, one should conduct detailed case-by-case analysis of a small sample. Iterative analysis of the cases in light of superordinate themes can thus reveal both theoretical convergence and individual idiosyncrasy.

In this study, the occurrence of convergence and divergence is perhaps particularly interesting due to the nature of fibromyalgia. The participants varied widely in terms of the symptoms that they experienced and in terms of illness severity, as one might expect with this condition. And yet, there were striking similarities – in participants’ experiences interacting with others, the health management approaches that participants eventually adopted, and the beliefs about health and wellness that participants came to hold.

The convergences appeared stark and accentuated against the backdrop of the divergences. For example, almost all participants reported having difficulty interacting with physicians, family members, and others, and they also held in great esteem the physicians with whom they were able to work. There was also concordance in participants’ views that there was a lot of information out there, and that after a certain point, there was little to be learned. Because the convergences were so stark amidst participants’ diversity on other facets, I went back over them to make sure that they were really there, and how participants came to hold the views that they did.

With regard to the presentation of the findings, I have provided verbatim quotes to illustrate themes. This enables readers to see how themes are supported by evidence and also to make their own judgments (Brocki & Wearden, 2006).

Whittemore, Chase, and Mandle (2001) have identified authenticity as a primary criterion of validity, which they describe as the portrayal of the emic, or insider, perspective,

representing subtle differences in the voices of all the participants, while at the same time acknowledging the researcher's own perspective. I agree that acknowledgement of the researcher's perspective is important; and further, that active engagement in reflexivity is important at all stages in the research process. I elaborate more on my perspective in the next section.

4.6 Researcher Perspective

We are all a product of our personal experiences. As researchers, our personalities, intermixed with our pasts, have led to our present-day selves. The role of this “self” in the research process is a wondrous thing. We shape it, and we have the power to see that it makes a difference in the world. In this section, I describe some aspects of my own background that are relevant to the study at hand, and reflect upon how they may have influenced my own interpretation of the data. In particular, there are two sets of experiences that are relevant: my own health experiences, and my past experiences as a fitness instructor.

First, I was diagnosed with Lyme Disease, fibromyalgia and hypothyroidism almost twenty years ago, the summer after my junior year of college. I had been experiencing symptoms without a known cause from about two years prior. Since symptom onset to the present day, I have experienced a diverse range of symptoms and periods of greater and lesser severity. I have had experiences similar to many of those that I write about in subsequent sections. I have also, as a result of seeking a solution to my health issues, acquired a great deal of knowledge and experienced all sorts of treatments, both allopathic and alternative, addressing the diverse range of symptoms that I have and continue to experience.

Fifteen years ago while I was living in Tokyo, an opportunity presented itself for me to work as a fitness instructor. As I performed consultations, listened to members talk about their

daily lives and the problems that brought them there, prescribed exercise regimens, and built relationships with members over time, the striking realization that I came to was that my role was not just providing instruction concerning how to exercise. I came to hold the perspective that one needed to attend, not only to members' physical, but also their mental and emotional states, and social and occupational contexts – in short, the whole person and their reality – and suggest a regimen that worked with their lives, in order for the solutions to work. And then I needed to support them through it.

I am grateful for the opportunities that I have had. I am not glad to have developed the physical problems that I continue to struggle with, but they have resulted in a tremendous amount of self-growth, and my dedication and commitment to helping others be well remains an important part of my life.

Regardless of who we are, we can't hang our background at the door and go about our research. I realize that there is the danger that my biases and preconceptions might potentially influence the way that I see the data. But I have done my best to develop a research design to ensure the validity of the research and minimize the biases that might have been introduced by my own experiences.

CHAPTER 5 RESULTS

In this chapter, I present the results of my dissertation study, in four sections. In 5.1, I present descriptive information about the sample, the timelines and the social media artifacts. This background information is invaluable for helping us to situate the experiences and behaviors of participants; their actions and views are much more easily understood in light of characteristics such as demographics, co-morbidities, symptoms experienced and career aspirations. In 5.2, I describe participants' illness journeys, which serves as context for us to consider their information behaviors in 5.3. In 5.4, I conclude with a discussion of salient issues that were not explicitly discussed in other sections.

5.1 Characteristics of the Sample

5.1.1 Demographics

The sample was comprised of 23 individuals who self-reported that they had fibromyalgia (Table 4). The majority of the sample was comprised of White women. This is consistent with previous surveys of fibromyalgia patients in the United States, in which samples have generally largely been comprised of White women (Wolfe et al., 1995; Bennett et al., 2007). Previous surveys of fibromyalgia have also reported that the prevalence of fibromyalgia is greater among women than among men (e.g. Wolfe et al., 1995; Branco et al., 2010). The participants resided in nine different states: North Carolina (8), California (3), Maryland (2), Delaware, Florida, Michigan, Texas, New York and Illinois; Washington, D.C.; and Australia.

This sample was highly educated, with the majority holding at least a two-year or four-year degree, and approximately half the sample holding graduate degrees. The main reason for

this bias is likely to be that the university listserv was used as one of the methods of recruitment. However, a large percentage of those who responded over social media were also highly educated. An additional reason for this bias might be that those who had graduate degrees may be more likely to have a greater appreciation for the contribution of research to health care, and thus volunteered themselves for the study.

Table 4. Sample Demographics

| Characteristic | n | % |
|--|----|------|
| <i>Age</i> | | |
| 21-30 | 4 | 17.4 |
| 31-40 | 4 | 17.4 |
| 41-50 | 2 | 8.7 |
| 51-60 | 7 | 30.4 |
| 61-70 | 5 | 21.7 |
| 71-80 | 1 | 4.3 |
| <i>Gender</i> | | |
| Female | 22 | 95.7 |
| Male | 1 | 4.3 |
| <i>Race/Ethnicity</i> | | |
| White | 20 | 87.0 |
| Black | 2 | 8.7 |
| Asian | 1 | 4.3 |
| <i>Education</i> | | |
| Some college | 2 | 8.7 |
| Two-year or four-year college degree in progress | 1 | 4.3 |
| Two-year or four-year college degree | 8 | 34.8 |
| Graduate degree | 11 | 47.8 |
| Graduate degree in progress | 1 | 4.3 |
| <i>Employment Status*</i> | | |
| Student | 3 | 13.0 |
| Full-time | 11 | 47.8 |
| Part-time | 0 | 0.0 |

| Characteristic | n | % |
|----------------------------|----|------|
| Retired | 9 | 39.1 |
| Not employed | 1 | 4.3 |
| <i>Received Disability</i> | | |
| Yes | 8 | 34.8 |
| No | 15 | 65.2 |

*Multiple selections possible

The sample had (or previously had) a diverse set of careers, including writing/editing, law, public health research and activism, accounting, childhood education, management, administrative work, laboratory technician, nursing, and film. There were also a few students in the sample, and one person who had been employed in the military. For many, the nature of their occupations played a significant role in terms of their illness journeys, as they needed to come up with ways to overcome the problems that they experienced in their work lives due to their physical issues. Eight out of 23 participants were currently receiving or had previously received disability benefits. A few individuals also mentioned having previously been abused.

5.1.2 Age and Illness History

Among the participants, there was quite a bit of variability in terms of their age and illness history (Table 5). For some, onset was not clear because symptoms developed over a long period of time. Though there were a few cases in which participants were either diagnosed either on their first visit to the doctor or soon thereafter, for most participants the path to diagnosis was long, involving numerous lab tests and multiple health care practitioners.

Table 5. Age and Illness History

| | Age | Onset Year | Duration | FIQR Score |
|-----|-----|------------|----------|------------|
| P05 | 27 | 2008 | 6 | 45 |
| P06 | 49 | 1998 | 16 | 48 |
| P07 | 79 | 1956 | 58 | 41 |
| P08 | 52 | 2000 | 14 | 33 |

| | Age | Onset Year | Duration | FIQR Score |
|-----|-----|------------|----------|------------|
| P09 | 26 | 2006 | 8 | 51 |
| P10 | 32 | 1996 | 18 | 24 |
| P11 | 31 | 1999 | 15 | 51 |
| P12 | 65 | 1985 | 29 | 14 |
| P13 | 21 | 2012 | 2 | 54 |
| P14 | 54 | 2008 | 6 | 53 |
| P15 | 59 | 2009 | 5 | 61 |
| P16 | 66 | 1969 | 45 | 39 |
| P17 | 62 | 1993 | 21 | 50 |
| P18 | 60 | 1989 | 25 | 37 |
| P19 | 37 | 1999 | 15 | 40 |
| P20 | 44 | 2004 | 10 | 80 |
| P21 | 56 | 2004 | 10 | 27 |
| P22 | 60 | 2008 | 6 | 63 |
| P23 | 61 | 1985 | 29 | 64 |
| P24 | 27 | 2012 | 2 | 58 |
| P25 | 51 | 1983 | 31 | 50 |
| P26 | 57 | 1980 | 34 | 52 |
| P27 | 31 | 2013 | 1 | 51 |

The Revised Fibromyalgia Impact Questionnaire (FIQR) was used to evaluate the severity of illness. There was a great deal of variation in the level of illness severity. Among the sample, the mean of the FIQR scores was 47.2 (SD=14.4), and the minimum and maximum were 14 and 80, out of a total possible of 100, with higher scores indicating greater illness impact.

The interview content also reflected the diversity of these scores. Some participants reported little or no impairment in their ability to perform and even excel in their occupations, while others were forced to give up their jobs shortly after developing fibromyalgia. Aside from problems in terms of their work lives, participants who had children often struggled to take care of them. Several participants spoke of emergency room visits, some in previous years, one the previous week.

The range of FIQR scores is also consistent with incidental information I have from interviewing the participants. Two of the younger study participants who have no other diagnosed illnesses walked with the aid of a cane when they came to meet me, and another participant had various ambulatory aids, including a cane and a wheelchair, in her home. Yet another had a migraine on one of the days I interviewed her.

Though this study was focused on patients' perceptions of their illness journey and their information behaviors, it is helpful to have an idea of the diversity in degrees of impairment, because it affects the salience of some elements of participants' stories, such as their experiences in the workplace and at home, in applying for disability benefits, and their psychological state.

5.1.3 Comorbidities

Many participants had conditions other than fibromyalgia. These included: arthritis, Chronic Fatigue Syndrome, alopecia, Irritable Bowel Syndrome, diabetes, hypothyroidism, endometriosis, bipolar disorder, cerebral palsy and hypertension. Their comorbidities influenced the type of information seeking in which participants engaged, the information sources to which they had access, and the treatments and/or management strategies that they researched or used. For instance, one participant was a leader of a support group for Chronic Fatigue Syndrome, and this support group regularly arranged for scientists to give talks relating to the illness. For quite a few of these participants, their information acquisition concerning food was due to symptoms of Irritable Bowel, food allergies, or food sensitivities. Other comorbidities such as arthritis and the order in which participants developed conditions influenced the way that participants reacted to fibromyalgia, which I will discuss in more depth later.

5.1.4 Illness Perceptions and Self-Perceived Causes of Illness

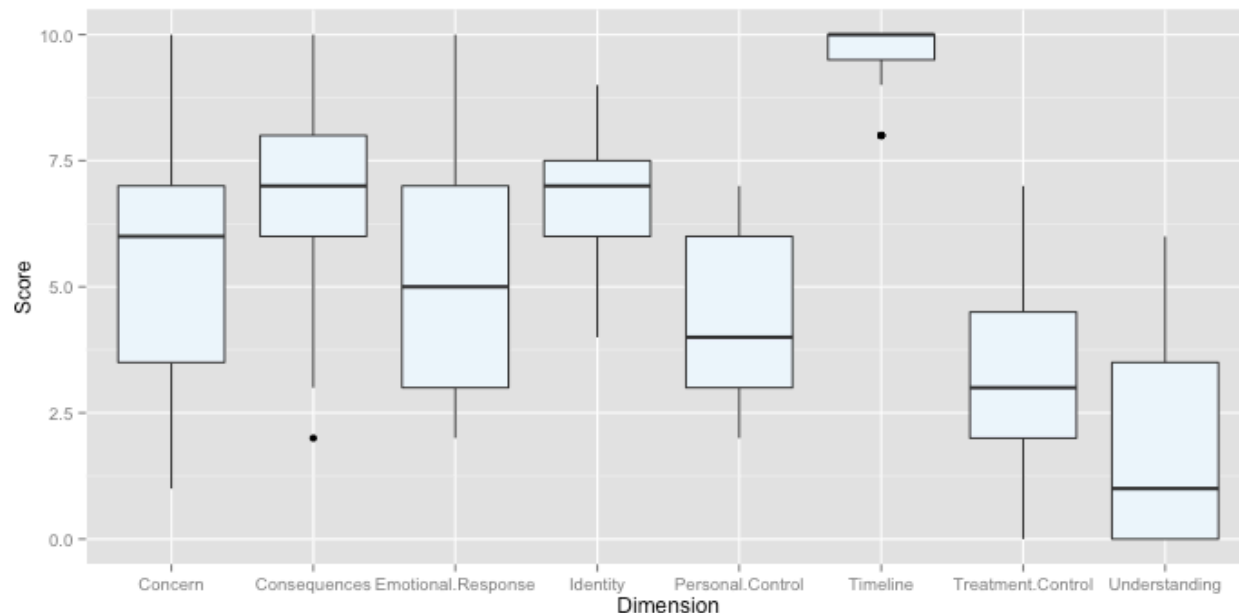
Responses to the Brief Illness Perceptions Questionnaire (BIPQ) provided an overall assessment of participants' illness beliefs (Table 6). Boxplots characterizing the distribution of scores for each dimension are presented in Figure 1. There was one dimension in which the variability was particularly low, the Timeline dimension. The mean was 9.5, meaning that almost all the participants felt that their illness was going to last a long time, and as the interview content later showed – “forever.” The mean of the Understanding item, which was reverse-coded, was 2, suggesting that participants felt that they understood their illness.

Table 6. Brief Illness Perception Questionnaire Scores

| Dimension | Questionnaire Item | M | SD |
|--------------------|--|-----|-----|
| Concern | How concerned are you about your illness? not at all concerned.....extremely concerned | 5.6 | 2.5 |
| Consequences | How much does your illness affect your life? no effect at all.....severely affects my life | 6.6 | 2.1 |
| Emotional Response | How much does your illness affect you emotionally? not at all affected emotionally.....extremely affected emotionally | 5.3 | 2.5 |
| Identity | How much do you experience symptoms from your illness? no symptoms at all.....many severe symptoms | 6.7 | 1.4 |
| Personal Control | How much control do you have over your illness? (R) absolutely no control.....extreme amount of control | 4.4 | 1.7 |
| Timeline | How long do you think your illness will continue? a very short time.....forever | 9.5 | .85 |
| Treatment Control | How much do you think your treatment can help your illness? (R) not at all.....extremely helpful | 3.3 | 1.9 |
| Understanding | How well do you feel you understand your illness? (R) don't understand at all.....understand very clearly | 2.0 | 2.2 |

(R) = reverse-coded.

Figure 1. Brief Illness Perception Questionnaire Score Distribution



Consistent with previous literature that has employed the IPQ-R to investigate illness perceptions among fibromyalgia patients, study participants perceived their illness to be chronic (Stuifbergen et al., 2006; van Wilgen et al., 2008). They appeared to have greater faith in the potential efficacy of treatments than in previous literature, but the comparison of these results to previous work is simply food for thought, given the small sample size. Also, the studies cited here employed a longer instrument for assessing illness perceptions, the IPQ-R. However, I would argue that the sample might harbor a greater belief in treatment efficacy due to successes that they have had in the management of their condition, as we shall see.

In addition to the scale items, the BIPQ also asks participants to indicate what they believe caused their illness. All responses given by more than one participant are listed in Table 7. Those given by only one participant were: thyroid, pancreatic condition, auto-immune dysfunction, metabolic dysfunction, ADHD, ongoing street harassment, poor sleep, shots before deployment, underlying health issue, biological basis, consumption of antibiotics, consumption

of too much milk, smoking, consumption of psychedelic drugs, emotional trauma, prolonged physical over-exertion, and "just unlucky."

Table 7. Self-Perceived Causes of Illness* (N=23)

| Cause | Frequency |
|---------------------------------------|-----------|
| Stress | 12 |
| Genetics | 8 |
| Environmental factors | 4 |
| Work focus | 3 |
| Physical trauma/sexual violence/abuse | 3 |
| Adrenal dysfunction | 2 |
| Hormonal issues | 2 |
| Virus | 2 |
| Food-related | 2 |
| Previous medical treatments/surgeries | 2 |

*Causes mentioned by more than one person.

The high frequency of attributions to stress and genetics is striking. The interview content also reflected these attributions. For example, as they spoke of their illness journeys, they often spoke of situations and events that they found stressful, such as marital discord and stress at work. A number of participants mentioned that someone in their family, most often their mother but sometimes also other relatives, had fibromyalgia and/or were seen as hypochondriacs (P08, P10, P11, P20).

5.1.5 Timelines

All of the participants drew a timeline as they told me about their illness journey. Participants had a great deal of freedom in the drawing of the timelines, and in terms of visual representation, there were perhaps five main dimensions of variability: color/monochrome, line/path, pictographic/text-based, completeness and period of life depicted. Among the dichotomous dimensions, participants tended towards, color, path and text-based representations. In terms of period depicted, some participants started early in life, from when

they believed that their symptoms first began, while others began from where they started noticing symptoms. Some participants projected into the future. Figures 2-5 are examples.

Figure 2. Sample Illness Journey Timeline: P05 [1 of 2]

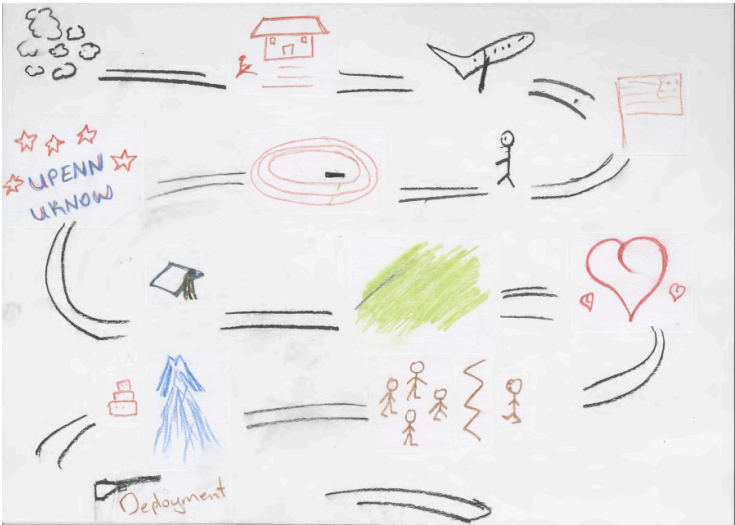


Figure 3. Sample Illness Journey Timeline: P06

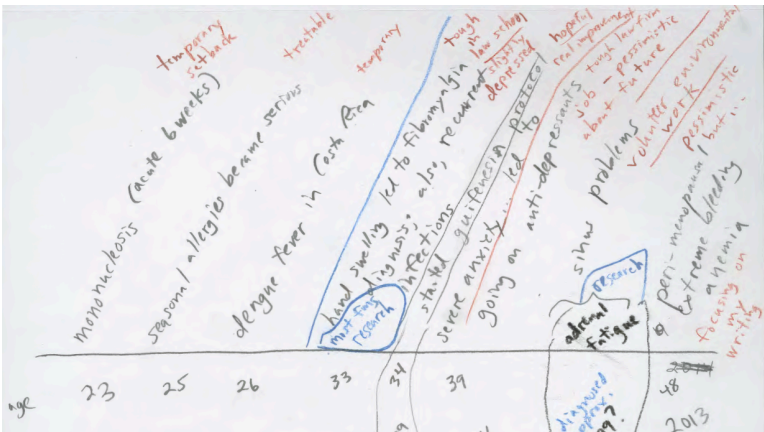


Figure 4. Sample Illness Journey Timeline: P14 [1 of 5]

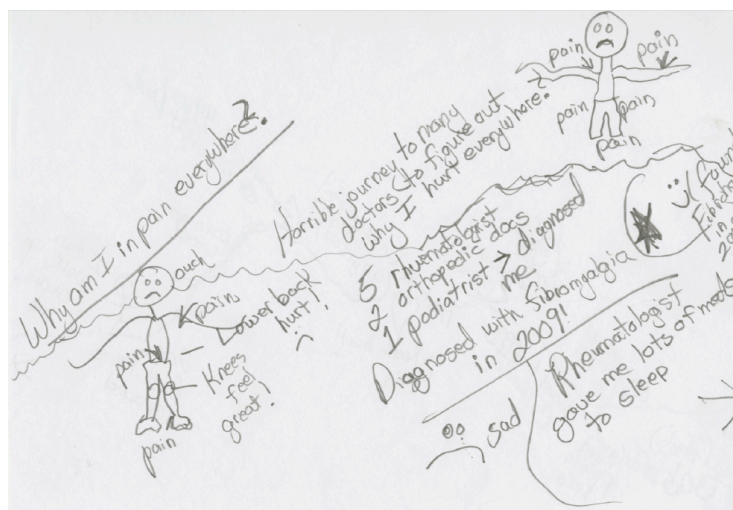
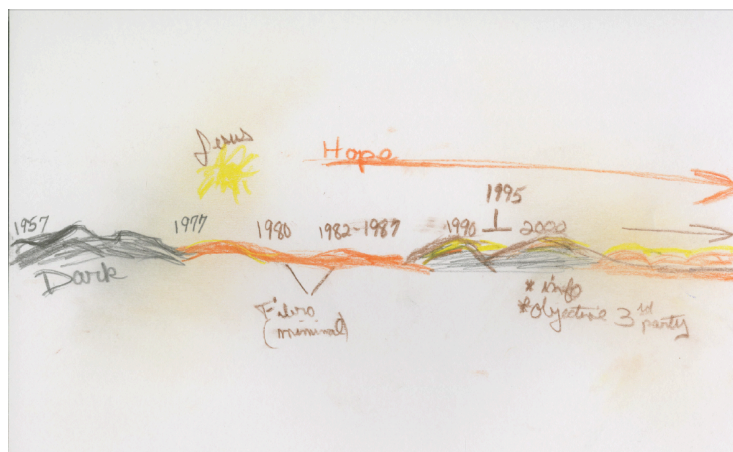


Figure 5. Sample Illness Journey Timeline: P26



Many of the timelines that were drawn involved curvy paths, which seemed to be an apt analogy for the participants in this study. A number of them made comments to the effect that the path they had taken was not a straight line, and so they would draw a curvy path. I think that this analogy is an apt one not just for chronic illness, but for life in general, and could potentially be used to explore other research questions.

In many cases, events were depicted that were not strictly health-related. In some cases, participants included events because they believed them to be related to the causes of their

illness, whereas in others, participants most likely included them simply because they regarded them as important life events. If asked whether they should include life events that were not health-related, I left the decision up to them, the reason being that I felt that the choice would reflect some aspect of them.

Concepts that were often depicted included: major life events, major health events, symptoms, medications, treatments, other illnesses, alternative healing modalities, health care practitioners, emotions, spirituality, and information sources (Table 8).

Table 8. Concepts Depicted in the Timelines

| Concepts | Examples |
|-----------------------------------|---|
| Major life events | met partner, had a child, divorce |
| Illness events | Symptom onset, diagnosis |
| Symptoms | allergies, sinus problems, hand swelling, knee pain |
| Medications | Lyrica, Cymbalta, Flexeril, Paxil, etc. |
| Treatments and medical procedures | nerve block injection, MRI, surgery, counseling |
| Other illnesses | diabetes, arthritis, hypothyroidism |
| Alternative healing | yoga, meditation, hypnosis |
| Health care practitioners | “multiple doctors”, neurologist, rheumatologist, chiropractor |
| Emotions | anxiety, depression, hope, relief, love |
| Information sources | Internet, books, word of mouth |
| Other | spirituality |

There was quite a bit of use of symbolic representations. For example, one person used stop signs to represent roadblocks on her journey. Another participant used spirals to represent the idea from American Indian thought that experience is often cyclic, meaning that an experience may often repeat, and that, when repeated, if one has not adequately faced it the first time, they will have the opportunity to face it again.

5.1.6 Social Media Participation

There was quite a bit of variability in the ways that participants engaged with social media. Moreover, this social media use did not remain static over the course of illness journeys, but rather, evolved as participant changed in other ways. Some participants did not author any content, while others had enormous amounts of content that were spread out over multiple platforms. We might characterize this variation in terms of three dimensions: *media type*, *volume*, and *time*, or *temporal spread*. The main media types encountered were Facebook, Twitter, discussion forums and blogs. A number of participants also used Instagram, but most did not view it as a social platform, and I did not collect any content that they authored on this platform. One person also mentioned that they had created a YouTube video. The measurement of volume is perhaps very elastic, because it is so dependent on the unit of measurement and sample. For example, one might think of volume in terms of the number of posts in a given time period, or the length of posts. And one might think of oneself as posting relatively infrequently, but he or she might still be seen by others as posting relatively often.

Participants also differed in terms of the time(s) in which they engaged in social media. For instance, some (e.g. P05 and P16) engaged more towards the beginning of their journey, when they were most actively seeking information. Others (e.g., P22 and P23) posted frequently throughout their journey. Yet another pattern was to re-engage with social media when one developed a new symptom or disease, which is consistent with the overall tendency to search more with the appearance of new symptoms. P17's participation is an example of this; her social media traces were the earliest that I was able to find in my dissertation research, dating back to March, 1997, on Google Groups alt.med.fibromyalgia. However, at the time of

our second interview in the summer of 2014, she was participating in a forum for hair loss, called Alopecia World.

Table 9 depicts the main use behaviors observed. I use media type as one level of differentiation, temporal spread (continuous, intermittent, or lurking) to further differentiate the behavior of discussion forum participants, and health related and non-health related to further differentiate Facebook posting and blog authoring. Non-use, or complete abstinence from participation, and lurking, or reading but not posting social media, were also considered use types.

Table 9. Social Media Use Behaviors

| Social Media Use Behavior | Health-related/ Temporal Spread | Media Type Total |
|-------------------------------------|------------------------------------|------------------|
| <i>Facebook</i> | | 18 |
| Includes health experiences | 12 | |
| Does not include health experiences | 6 | |
| <i>Twitter</i> | | 7 |
| <i>Discussion Forum</i> | | 10 |
| Continuous | 6 | |
| Intermittent | 2 | |
| Lurking | 2 | |
| <i>Blogs</i> | | 6 |
| Includes health experiences | 4 | |
| Does not include health experiences | 2 | |
| <i>Non-Use</i> | | 2 |

Apart from Non-use, the categories depicted were not mutually exclusive, meaning that participants might exhibit one or more of the use behaviors. For example, P22 generally used the Facebook timeline for non-health related purposes, and engaged extensively with discussion forums. P23 participated actively in health-related Facebook groups. P05 has a long history of Facebook use, intermittent use of health-related discussion forums, and has engaged in sporadic

blogging over time. P11 engaged in Facebook, Twitter and online discussion forums, but was most prolific on Twitter, tweeting over 3,000 times within the span of a year.

5.1.6.1 Social Media Types

5.1.6.1.1 Facebook

The most pervasive social platform in the study was Facebook. Eighteen out of 23 participants used this medium, at least to a limited extent. A number of individuals barely used it, and a number stated that they did not use it for health-related purposes. Two had avoided posting anything health-related, for at least some period of time in their lives, due to work-related reasons. There were also a number of participants that participated actively in Facebook fibromyalgia groups, and others who updated and interacted with others concerning their condition through their Facebook timeline, status updates and notes.

Some participants held back in terms of what they post to Facebook because of concerns that they had about how their network might react. For example, P11 said that the first time that she posted something about fibromyalgia on Facebook, one of her relatives started following a fibromyalgia-related group and constantly sharing things from them on her wall. P11 said that is an example of why she does not use Facebook for “venting.”

5.1.6.1.2 Twitter

The constraint of brevity has perhaps resulted in some rather interesting and unique uses for Twitter. Though not related to health, Twitter was frequently cited as a source for news. Specifically relating to health, expressing short sentiments about whatever issues that they had trouble with at the time was common among some Twitter users. Though all types of symptoms were mentioned, pain and sleep appeared to be particularly common.

P24 searched for others with similar experiences using hashtags. Among her tweets, popular fibromyalgia-related hashtags included “#fibro”, “#fibromyalgia”, “#spoonie”, “#fibrofighters”, “#invisibleillness”, “#chronicpain”, and “#chronicillness”. She also used it to promote her blog and various fibromyalgia related events.

5.1.6.1.3 Discussion Forums

Study participants used a variety of discussion platforms. The platforms that had forums devoted specifically to health topics relevant to the sample included Reddit, MedHelp, DailyStrength, ProHealth, MDJunction, Alopecia World, Facebook and Google Groups. By Facebook, what is meant here is the joining of, and participation in, groups that engage in fibromyalgia-related discussions, such as “Living with Fibromyalgia.”

Among the platforms used, there were sites such as Google Groups, Facebook and Reddit that offered functionality for people to create their own spaces devoted to their topic of choice, and people had created groups for fibromyalgia, chronic pain, Chronic Fatigue Syndrome, and other health issues. There were also sites such as DailyStrength, ProHealth, and MDJunction that were specific to health, but supported discussions on a wide variety of conditions; and then there were more focused health-related sites such as Alopecia World. Those that used Reddit generally participated in multiple subreddits, including but not limited to fibromyalgia and chronic pain. Some participants had participated in forums that no longer exist, or on platforms that still do exist, but they were unclear as to the screen name that they had used, so it was not possible to retrieve their content.

5.1.6.1.4 Blogs

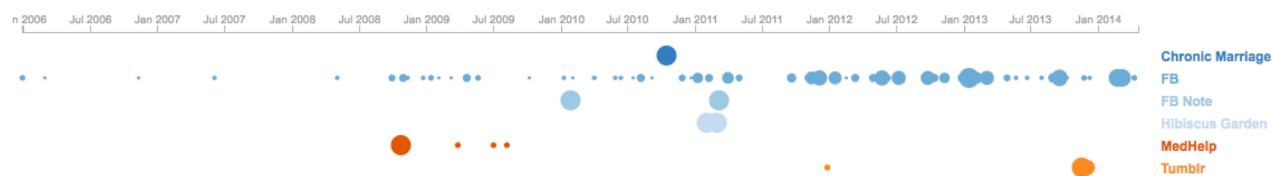
Lastly, there were a number of people who kept blogs. As was the case with the other media types, there were cases in which blogging included health experiences, and cases in

which it did not. Among the blogs that included health experiences, one had the explicit purpose of raising awareness about fibromyalgia; another was a running story about life in Washington, D.C., in which the participant occasionally interwove her own illness experiences in the lives of two of her characters. Lastly, two others were personal blogs in which participants wrote about a variety of experiences, including those related to their illness. In these cases, participants said that they mostly blogged for themselves, and it was not that important to them that they had an audience. One of the participants who blogged for professional reasons said that she was planning on creating a new section of that blog that would be devoted to sharing her experiences with fibromyalgia and building a career for herself.

5.1.6.2 Conceptualizing Participation Patterns: An Example

The Online Scrapbook's rendering of P05's timeline illustrates how a participant's social media participation might be spread out over a variety of media over time (Figure 6). Her Facebook participation includes both health-related and non-health-related postings, and is the longest running of her social media traces. Her posts on MedHelp come early on in her illness journey. She has an email exchange with ChronicMarriage that is focused on her specific issues at that time, and she has two Facebook notes that she employs to share information with her wider network, one that shares her fibromyalgia story, and another that thanks her network for their support. There are also two blog platforms that she has used sporadically, Hibiscus Garden and Tumblr.

Figure 6. P05's Social Media Participation (Online Scrapbook)



The participation patterns that are reflected through the Online Scrapbook seemed to arise from the different motivations that participants had for engaging with social media, and their perceptions of the media types. P11 said that Twitter was her medium for “whining.” Those who engaged in discussion forums for limited periods said that their participation decreased for a variety of reasons, but particularly that their interest in information seeking had waned, that they perceived a lack of new information, they became tired of the repetitiveness of material due to new members joining the forum, they were turned off by the negative attitudes of participants, and/or they felt that the members were not truly interested in learning and being open to new information. Those who posted status updates or wrote notes to those important to them were engaging with their own network. Those who engaged in discussion forums over long periods of time valued the information exchange; additionally, they perhaps valued the community and emotional support more so than those whose participation was transient. This finding is in agreement with a previous study of member retention and attrition in a cancer discussion forum (Wang, Kraut, & Levine, 2012).

5.1.7 Summary and Discussion

This sample, similar to other surveys of fibromyalgia patients in the United States, was primarily comprised of White women (e.g., Walitt et al., 2011; Bennett et al., 2007; Schaefer et al., 2011). There was great diversity of age and illness duration, with the range of illness duration varying from one to sixty years. As we shall see, the variation in age and illness duration was important in terms of understanding the challenges and problems that fibromyalgia patients face over time.

Many of the study participants had multiple conditions, and the ways that they reacted to their illnesses depended partially on what other conditions they had, and the order of onset. The

severity of illness impact and the medications that they took depended on these comorbidities as well. Though the focus of my dissertation is not on participants' treatment regimens, the extent that they were affected by illness and the nature of the medications that they took affected their information behaviors, and thus, it is helpful to know the conditions that participants had.

In terms of their illness perceptions, the lack of variability on the Timeline dimension was particularly striking (Figure 1). In general, one would expect to see a range in people's responses to an instrument, so that in itself is not surprising. But the standard deviation of that item is particularly small, compared to the standard deviation on the other response items (Table 6). In the forthcoming sections, I argue that the belief that the illness would last "forever" is associated with acceptance of the condition, which in turn is instrumental in developing effective management strategies.

Though this is hardly a surprise, the timeline construction activity showed that people's experiences of illness are inextricably intertwined with the rest of their lives. Important elements of participants' lives played a prominent role in how they reacted to situations. For example, stress at work exacerbated the symptoms of P06, which in turn motivated her to search for information on those symptoms. Spirituality was an important foundational component of P26's outlook towards illness and life.

The social media participation patterns in this study varied widely. There were four main types of media use that I observed: Facebook, Twitter, discussion forums, and blogs. Facebook was the most pervasive platform. Twitter was commonly used for news and/or "venting." Participants tended to speak of either blogging for themselves (e.g., P05 and P14) or blogging as a public platform (e.g., P19 and P24). I observed instances of "venting" on Facebook, Twitter, and discussion forums. Though most study participants spoke of engaging

with discussion forums at some point, few were actively participating in discussion forums at the time that they were interviewed. We examine online participation in depth in section 5.3.8.

5.2 The Journey

In this section, I present an overview of the illness journey of fibromyalgia patients, as seen through the interview content and the timelines. Though there were certainly differences across the sample, there were certain points, such as onset, diagnosis, acceptance, and development of a self-management strategy, that were shared by almost all the participants. I first present an overview of the journey and the main phases. Then I elucidate features that I observed in these journeys: non-linearity or cyclical nature, restricted social activity, worrying about dying and being concerned about the future, identity, sense of control, moving out of one's comfort zone, and empathy and understanding. Lastly, I close by reflecting on the journey.

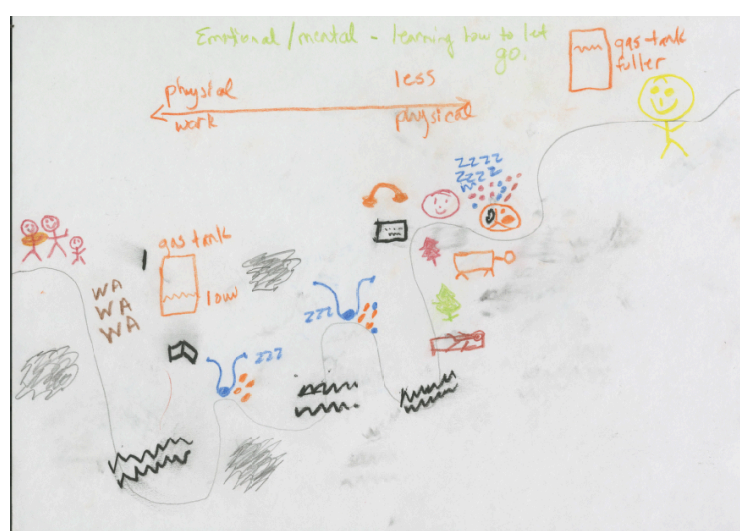
5.2.1 Overview of the Illness Journey

In the first interview, I focused on asking participants to share their story with me. In doing so, I would open with a general question asking them to tell me about “when their symptoms first began.” They would share their story with me, and I would ask questions along the way. Once they appeared to be at a good stopping and/or pausing point in their story, I would ask them to begin drawing. I would tell them to think about their illness journey and to draw something that represented it, and stress that there were no particular rules that they needed to follow. Figure 7 (along with Figures 2-5) show how such a timeline looked.

Some of the salient elements on the timeline in Figure 7 include the stethoscopes, which represent multiple doctors, and medications: “Let me put in some pills here, because that’s what these doctors all want to do is put you on pills” (P21). Gradually she moves towards alternative

medicine and a wellness orientation, which she depicts using a green leaf. Another salient element was her efforts to improve her sleep. P21's timeline also includes objects that depict overall trajectories: an empty gas tank earlier on, and a fuller one later; and directional arrows showing more physical work earlier on, and less physical work later. Lastly, she writes at the top that an important emotional/mental lesson for her was learning to let go and not being such a perfectionist.

Figure 7. P21's Illness Journey Timeline



5.2.1.1 Onset

As the literature review has shown, fibromyalgia manifests in different ways for different people. The participants I interviewed also differed in terms of their symptom patterns; for some, pain was the most salient, whereas for others, it was symptoms of Irritable Bowel, fatigue, migraines and so on. Though for some participants, fibromyalgia onset coincided with a given event, such as a surgery or immunization, a more predominant pattern was perhaps the experiencing of symptoms for quite some time, before the recognition that the symptoms were not to be ignored (e.g., P09 and P27). From there, participants tend to

experience continued health problems and decreased ability to function, until they develop an effective management strategy.

Participants experience a period of uncertainty in which they may see multiple health care practitioners and take a multitude of lab tests before being diagnosed. P05 remarked somewhat facetiously, “It was really crazy, because of... a lot of ER visits, um, got to know doctors very well – all kinds of specialists... and I sit there, and I was like, I should have been a doctor. Because at this point, I have done almost every test you can think of.” Because many of them did not know what illness they had, how to manage it, and what was in store for their future, they experienced a variety of negative emotions including frustration, anxiety, fear and panic. Many of the participants in the study had a history of pain, fatigue or other health issues prior to being diagnosed with fibromyalgia.

5.2.1.2 Diagnosis

Though there were a few cases in which participants were diagnosed fairly quickly after presenting their symptoms to a physician (e.g., P18), for most participants, it was years after onset that they were diagnosed. There appear to be various reasons for this delay. In many cases, participants themselves did not seek medical assistance right away. For example, P27 had a fast-paced lifestyle with a schedule full of events that she was committed to, so she ignored her symptoms until “[her] body was forced to stop.” In retrospect, she said:

thinking back on how long I’ve been feeling a little bit tired or feeling a little bit achy and thinking of all the ways that I made excuses for that, I realized that probably my symptoms have been going on a lot longer than I thought that they have, probably up to a year and a half longer than I thought they had. But I just said, well this is what it’s like

to be an activist, like you're just always tired because you're always doing stuff for the movement or for the community so just push through it. – P27

P09 experienced fatigue for years prior to developing symptoms of pain, but she did not seek help because she thought she was just being lazy. So it was not until she started experiencing pain that she sought the opinion of a physician.

Other than the fact that patients often waited before seeking the advice of a health care practitioner, there were other reasons why diagnosis took a long time. As mentioned earlier, physicians tended to diagnose the condition only after excluding other possibilities through laboratory tests, which often took a long time. There might also be reticence on the part of physicians to diagnose the condition. Some participants felt that it was because the physician did not take the condition or them seriously; in other cases, it appeared that physicians might have been trying to prevent patients from being labeled. For whatever reason, there tended to be a delay. For example, in going back over her medical records, P19 noticed that a physician had written “Fibromyalgia?” in his notes, four years prior to her actually being diagnosed.

Participants' responses to diagnosis varied greatly. Many participants did not want to be diagnosed with fibromyalgia. This sentiment appeared to be due to the impressions that participants had previously had of the condition. P15 said of the moment when her physician gave her a preliminary diagnosis of fibromyalgia:

I remember thinking, ‘No!’ That’s one of the things I never wanted to have, because... it’s like, Chronic Fatigue Syndrome or back problems... you can’t really see it, and nobody believes it’s real. And it’s one of those things that makes people out all the time from work, and... people think you’re faking it... and I thought, ‘Oh God! Of all things!’

A couple of participants mentioned that their mother or other close relative had had fibromyalgia or chronic widespread pain. In fact, the possibility of a genetic basis to fibromyalgia, as well as the observation of familial occurrences of fibromyalgia, has been observed in previous literature (Neumann & Buskila, 2003). P20's mother had been diagnosed with fibromyalgia, and she remembered that she hadn't really believed her: "I thought that something had just happened to my mom, that she was making it up. Because this was in the '70s, when she was diagnosed with fibromyalgia. And I'm like, what kind of made up stuff is that?" So when P20 was diagnosed, she thought: "Please don't give me that. Anything but that."

At 24, P11 had thought that she might have had fibromyalgia and brought it up to a doctor, but was told that she didn't have it. She subsequently went through the next six years having lab tests and saw lots of doctors. In a Reddit post, she wrote of her diagnosis, which occurred at 30: "For me, it was relief, to finally have an answer (an answer I thought was RIGHT, as I'd thought it was fibro for a while, but had never brought it up) but also a bit sad as I'm stuck with this for the rest of my life!"

Being diagnosed with fibromyalgia was bittersweet for more than one participant. In the case of P24 who also went through a period of frustration at the lack of answers, she said of the time when she and her physician finally found something that was working, "So that visit with her was kind of bittersweet because it was like, great, something's working, I have an answer – but it's fibromyalgia, and I'm going to have this for the rest of my life."

Extant literature on fibromyalgia has reported that patients often experience a sense of relief after being diagnosed (e.g., Madden & Sim, 2006). There may be various reasons why the phenomenon of relief was less common among my sample. First, many participants seemed to

already have guessed (or had physicians suggest) that they had fibromyalgia prior to being formally diagnosed. In between this initial piece of information that they “might” have fibromyalgia and a formal diagnosis was often a period of seeing specialists or taking lab tests to exclude all other possibilities, so they actually had a long, gradual period of “getting used to the idea” that they had fibromyalgia. Second, given the relative newness of fibromyalgia as a condition, participants in prior studies may have been less likely to hear of fibromyalgia as a condition, and thus experience a greater feeling of legitimacy and validation following diagnosis. There were quite a few who experienced a feeling of dismay or dread upon hearing or guessing their diagnosis because they had already heard of fibromyalgia and had negative impressions of it.

There were a few participants who were less concerned because they had pre-existing health conditions that overshadowed any effects that they might have felt from fibromyalgia. P10, for example, had always considered her pre-existing arthritis condition to be the more serious, because she had to take “hard-core drugs” which had severe, long-term consequences to treat the arthritis, and this was not the case for fibromyalgia. P25 had suffered from Chronic Fatigue Syndrome prior to developing fibromyalgia.

Though most participants did not seem to experience relief, being diagnosed was important for many in the sample, because the diagnosis often helped them to move forward in terms of figuring out how to manage their condition.

5.2.1.3 Acceptance

After participants were diagnosed, it often took time for them to move towards acceptance of the diagnosis, and of acceptance of the illness. In terms of the diagnosis, participants seem to come to accept it because their symptoms matched clinical descriptions of

fibromyalgia. P10, for example, initially did not believe that she had fibromyalgia. However, she said that: “as time progressed, and I had other symptoms, like migraines... and other symptoms that went along with fibromyalgia, as I read more about fibromyalgia, I kind of accepted that I had fibromyalgia” (P10). Thus, coming to acceptance may be a gradual process that involves both information consumption and sense-making.

In the beginning, some participants felt that the illness was temporary, and they were looking for a way to “fix it,” for the “magic pill” (P05) or the “magic bullet” (P17). Later, most came to accept that the illness was here to stay. Previous literature has observed that there is a “grieving process” one goes through when one develops a chronic illness, in which one must grieve the loss of their old self (Löfgren, Ekholm, & Öhman, 2006). P15 described her experience dealing with this process in this way:

I decided in 2012, that 2013 was going to be my year of... health... it was going to be the year that I got myself back. Yeah right. But, at a certain point, I adjusted to be a year of concentrating on wellness, instead of just, ‘Oh, I’m going to be... cured.’ Because I kind of felt like, ‘I’m going to cure myself!’ (Said very flamboyantly.) And that’s as much as I’m optimistic about that... I think it’s kind of like a pipe dream that some people like me will cling to and... I need to accept... I think you have to grieve like you have to grieve any other loss or death. Like you have to go, ‘Okay that’s the old me,’ and ‘This is the new me.’ So, to do that, I have to accept that I have fibromyalgia, and that in itself is a process.

Eventually, all of the study participants reached a point where they had accepted or recognized the need for acceptance of their condition. P12 described her current state in this

fashion: “I think now it’s kind of a notion of: you’re not trying to fight it; you’re trying to accept it, and it’s part of who you are. So, there’s probably more of a peacefulness to it.”

Though most of the study participants had some difficulty dealing with the illness and/or the diagnosis, not everyone did. For example, P18 said, “I didn’t really look into it [fibromyalgia] ... I just kind of accepted it for what it was and didn’t worry about it.” For those who had a condition that pre-dated fibromyalgia such as Chronic Fatigue Syndrome, there also seemed to be less of an impact. This process seems to get easier if one goes through it more than once. For example, P08 said of being diagnosed with Type 2 Diabetes: “it makes it easier every time I get a new disorder. Really. I hit the ground running with diabetes. No issues. I was devastated. I was stunned for a week, and then I was like, okay. Done. Hit the road... And I remember being distraught for easily, more than a year, with fibromyalgia. ‘Cause that was my first big thing.”

5.2.1.4 Self-Management

“...basically what I have learned is that you just manage your life.” – P21

The state of acceptance and self-management perhaps go hand-in-hand. The concept of self-management does not mean the elimination of symptoms, but rather, reaching a point where patients feel like that they are able to manage their symptoms, and that the extent to which they experience symptoms is “acceptable.” For many, this may mean “wellness”, a concept that I will examine in more depth in section 5.3.2.2.3.2. This is more of a homeostatic rather than a static state, in which patients may experience “flares”, but not to the extent where they are constantly in and out of the ER, as was the case with P05 early on in her journey, or experiencing pain or bowel issues and no perceived recourse to mitigate those issues. In actuality, the level of functioning for each individual might differ significantly, as there were

some that perhaps were able to function at a level similar to their prior performance, and others who were not able to work at all.

Though the participants in the sample had all reached some level of acceptance of their condition, they varied in the extent that they continued to work on various aspects of the management of their condition. Some participants, such as P09 and P11, were working with their physicians to develop and/or adjust treatment strategies; others, such as P13 and P15 were actively engaged in information seeking and management strategy implementation on their own, in addition to working with their health care practitioners.

As far as health management was concerned, all participants without exception, made changes to their lifestyles. Many made dietary changes to avoid specific trigger foods; others had strategies such as having nuts on hand to avoid hypoglycemic episodes. Many found that exercise was helpful; the only type of exercise that was very commonly mentioned by the sample was yoga. Participants also employed alternative strategies such as massage therapy, acupuncture, meditation, and hypnotherapy. Meditation and hypnotherapy appeared to be effective for both pain management and emotion regulation.

As far as medical treatments, there were a fair number of participants that took medications on a regular basis, though for some of these participants, the medications might be related to other conditions that they had, such as arthritis. Many participants had either been loathe to use medication from the start, or gradually moved away from medication.

5.2.2 Distinguishing Features of the Illness Journey

There were various features that tended to be common across participants' illness journeys: non-linearity or cyclical nature, restricted social activity, worrying about dying and

being concerned about the future, identity, sense of control, moving out of one's comfort zone, and empathy and understanding. I discuss these features here.

5.2.2.1 Non-Linear, Periodic or Cyclical Nature

First, the journey was not a smooth or a linear one. It was not as simple as starting out at a point where participants did not have control of symptoms, and moving gradually towards controlled management. Rather, participants had periods of better or worse control, or greater and fewer “flares.” Negative experiences with medications were common, as was the iterative testing of medications to find treatment regimens that worked. The illness journey might also be thought of as “periodic” or “cyclic” in the sense that, at times, patients thought that they had gained control over problems that they were experiencing, only to go through a subsequent worsening of symptoms. In some cases, this was triggered by another event, such as the fender bender that P24 was in, or stress at work (e.g., P06). In other cases, the reasons were unclear (e.g., P09).

Participants depicted this non-linear or cyclic nature in various ways. Some participants depicted this on timelines through the use of a wavy path, others used words such as “control” and “worse” to convey these ups and downs, and still others drew pictures to depict treatments tried, information consumed and pain. More often than not, this was simply conveyed orally in the interview, rather than on the timeline.

5.2.2.2 Restricted Social Activity

Having fibromyalgia affected the social interactions that participants had with others. For some, that meant not attending as many social engagements due to their physical condition (e.g., P12 and P24), whereas others became self-conscious and avoided social interactions due to cognitive deficits that they experienced: “I avoid situations where you have to talk to people,

because of it [fibro]... If I have to have an intelligent conversation, forget it... when we have to have our scout meetings and stuff like that, I always try to get busy doing side work or messing with the boys – keeping them straight, so that I don't have to have adult conversations" (P20).

Some participants were able to re-introduce social interactions over time as their level of self-management improved. For example, P08 said that at one time, she had a relationship that she was not really satisfied with, but she maintained it because that was all the social activity she could manage: "I went from a fairly active social life, to a very restricted social life... that would be another reason why I let the boyfriend be with me. Because he was my primary social activity... I had various parts of my social life just fall off for various reasons. I really couldn't maintain it, and be as sick as I was." As she started to feel better, she also started making changes in her life, like breaking up with her boyfriend and actively seeking new relationships. P05 went from a period of having a negative outlook on her own future, thinking, "Nobody's going to want to be with a sick girl," to a positive outlook on her future, drawing a "yellow brick road" on a timeline, depicting herself as "skipping along."

However, it is important to understand that each person's experience of illness is unique, and that though some people are able to return to a higher level of social and physical activity, this does not necessarily mean that this is possible for everyone. Moreover, most participants were able to come to terms with their illness even if they were not able to return to a higher level of functioning.

5.2.2.3 Worrying about Dying and Concern for the Future

There were a number of study participants who wondered if they were going to die at some point. P27 said, "I was like, what the hell's happening to my body? I can't figure it out and I could be dying." When P26 was first diagnosed, one of her first questions was, how long

she had to live, because, “I was just positive that you couldn’t feel that bad and live for long so I thought it certainly had to be some kind of terminal thing.”

Even after patients came to accept that what they had was fibromyalgia, there were still some that worried about the future. This concern seemed to be more common among those who took a high level of medication. For example, P20, who was at the highest recommended dose for Lyrica, said, “I’m like, when the Lyrica stops working, if it does -- which I’m praying it doesn’t -- but when it stops, is that how I’m going to be, again?” P11 shared in a Reddit post, “I’m on SO much medication and it does worry me about that at such a young age... I also haven’t had to raise from the lowest dose since I started... it’s good to know eventually [that] when I’m sure I will [raise from the lowest dose], I’m not ‘running through the doses quickly’ if that makes sense, thinking long term.” This excerpt shows that P11, who is thirty, is looking ahead and trying to select treatment options and health management strategies that are sustainable in the long term.

This outlook on the future can be very different for fibromyalgia patients who experience a great deal of pain early on, but are later able to develop effective management strategies. For example, P19 believes that she went through the lowest point with the condition in graduate school, and that her fear has declined over time: “I know that for most people, as they get older, they experience more pain, ‘cause you just tend to experience more pain as you age. But the longer I go, the less fear...”

In general, use of complementary and alternative forms of treatment was common among my sample. This usage also appeared to be tied to this concern for the future. For example, P27 talked about how she started looking into alternative treatments due to her concern about the long-term effects of medications:

I'm... not like necessarily interested in like chemical and medical, like Western medicine treatments for fibromyalgia, but thinking about the ways in which I can change my lifestyle or do things differently in order to treat myself, because if this is something that's going to be chronic for the rest of my life... I don't want to have to be on a pill for like the next 60 years of my life and not knowing what the pill might do to my body.

5.2.2.4 Identity

For many participants, their illness caused them to have to deal with fundamental aspects of their identity, and who they saw themselves to be. P21 said that, in the past, she had seen herself as a very active person, someone who was able to do what they wanted. The illness called this image into question, and it took her some time to adjust to this change:

I used to be very active. When we went on trips... we might go out to Colorado and go hiking and rafting and physical stuff, you know, and so I just had to -- that's not who I'm going to be able to be. So I got to readjust that, and it was very difficult, very depressing, cause that's not -- I didn't want to be somebody with some kind of disability, I wanted to have 100 percent healthy body that did whatever I wanted to do whenever I wanted it to do. So that was probably one of the hardest things, readjusting that and feeling okay with it. – P21

As mentioned earlier, P15 went through a grieving process in which she needed to accept the loss of the “old me”, and accept the “new me.” Often, this is difficult because the “new me” appears to call into question aspects of our lives and ourselves that we consider fundamental. For example, P05 developed severe fibromyalgia symptoms while in graduate school. She was in and out of the emergency room, had lots of laboratory tests and clinical consultations with many doctors. She has struggled with the illness on many fronts, but one of

the most difficult issues was that “[she] wanted to be independent, and that was the toughest part... that I felt that I could never be independent, that I would always have to depend on people.”

P20 had a career in the military, and she had wanted desperately to retire after 20 years of service. Her information seeking was motivated by questions of what would happen to her career if she made certain decisions, for example, refusing the requisite third anthrax injection after having problems with the second one, going through the medical board, and talking to the mental health department. Not being able to retire at 20 years left her “feeling broken,” and moreover, she had to re-conceptualize herself and her life: “I’ve got to figure out who I am, now that I’m done with the military. Because I’m like, that’s been my life for the last forever” (P20). However, over time, the participants in this section were able to, with the help of information and sense-making, adjust their perspectives on life, wellness and the self and develop fulfilling alternative approaches, as we shall see in the upcoming sections.

5.2.2.5 Sense of Control

One of the key issues that participants dealt with over the course of their illness is sense of control. This surfaced early on in their illness journeys, when participants went through extensive periods of testing and did not seem to come any closer to a resolution to their health issues. P05 found that period to be “a very frustrating time, because nobody could give me clear answers,” and P09 said that, “During all the diagnostic testing, I was frustrated because there was nothing I could do about it.”

Participants eventually adjusted to this in various ways. Many participants derived some sense of control from the diagnosis. P27 observed, “[The diagnosis] helps me feel like I’m in control of my body in a way, that like I understand what’s happening and that I can also like

make a path – I can make this pathway from thinking about the ways in which fibromyalgia happens chemically and physically in your body.” P19 gradually learned how to manage her condition better, and with that, “[these days] I also feel like I have a lot more control over knowing what I can do to feel better, and not feeling like I’m grasping at straws.”

Participants also learned to be more accepting of not being in control of everything. For example, P24 said:

I still have days where I just want to throw something because I want to be in control of it and I’m not, but I’m getting a lot better about letting go of that and listening to my body and letting my body be in control of it, rather than my mind... I’ve gotten a lot better about it, and it’s affected other parts of my life well because of that. I am okay with being less in control of things now.

What did P24 mean when she said that being less in control had affected other aspects of her life? She said that she was better about being spontaneous; she would not “freak out” as much if something came up unexpectedly that she had to do at work, and she was more easygoing about plans in her social life. In short, “it’s made me a little bit more laid back because there’s plenty of other things for me to worry about” (P24). Thus, grappling with sense of control has helped participants to grow in ways that they see as beneficial in the rest of their lives also.

5.2.2.6 Moving out of One’s Comfort Zone

A number of participants said that having fibromyalgia and perhaps other illnesses has led them to reach out to others in a way that they naturally were not used to doing. For example, P18 said, “I finally stepped out of my real comfort zone and I joined a Meetup group,” which she now runs. P05 has taken steps towards “being more vocal”, including sharing her illness with her Facebook network.

5.2.2.7 Empathy and Understanding

The difficulty of fibromyalgia and other “invisible illnesses” is that no one else can see your pain, which, as we will see, leads to lack of understanding and stigmatization. On the flip side, the testimonies of study participants suggest that having the illness made them more sensitive to the needs of others, and perhaps also had indirect benefits for those in helping professions. For example, P23 was a nurse, and she often had difficult times at work due to her physical condition. After describing an incident at work, she remarked, “I think, in a way, it made me a better nurse because I experienced pain without physical symptoms. Everybody’s pain is theirs in how they perceive it, and you can’t judge it really.” P08 observed, “I do think it [fibro] has actually widened my understanding of the work that I do, in understanding that it is a chronic illness for the family or chronic illness for the person.”

P20 is one participant who has become more understanding of the need to slow down, both for herself and others: “when I was healthy-healthy, I was like, ‘Oh, quit with your whining.’ I think I’m still kind of like that, with quit with the whining. But I’m more understanding if somebody has... if somebody is moving a little bit slower... I don’t like to say, ‘slow down’ because of me. But I understand if somebody else needs to slow down. Because I know. I understand it now.”

5.2.3 Summary and Discussion

In general, I observed four common features in the illness journeys described: onset, diagnosis, acceptance, and self-management. Many participants experienced onset as a gradual process of realization. Though a few were diagnosed fairly quickly after presenting their symptoms to a physician, most went through a prolonged period of having lab tests and seeing different physicians prior to being diagnosed. Participants had various attitudes toward

diagnosis. Some did not want to be diagnosed with fibromyalgia because of their own negative perceptions of it. A few experienced a sense of bittersweet relief. Following diagnosis, participants move towards acceptance and self-management, which may actually be tightly coupled and/or simultaneously occurring processes.

Rather than being discrete events, these phases were often periods that people would slip into gradually and transition out of gradually, and the phases would bleed in and out of one another, and even overlap. I would argue that this is due to the interrelatedness of what perhaps is often thought of as different spheres of activity: the physical, emotional and cognitive. Regardless of the nature of physical onset of illness, participants often did not act upon onset immediately, often because they had not mentally recognized it (e.g., P09, P11, and P27). Acceptance and self-management are closely linked; there is a cognitive component, recognition that one has the condition and that one must deal with it. Then there is emotional acceptance of it, through which comes peace. Being able to manage one's physical symptoms can be both causally and consequentially related to acceptance. Acceptance that one has the condition and must deal with it can pave the way for the person to develop a self-management strategy, and making progress in terms of self-management can help a person to adjust to it mentally and emotionally.

There were various themes that tended to be common across participants' illness journeys: their non-linearity or cyclical nature, restricted social activity, worrying about dying and concern for the future, identity, sense of control, moving out of one's comfort zone, and empathy and understanding. Participants' journeys were not linear, but instead were cyclic or periodic in the sense that they often experienced periods in which their symptoms became better and then worsened. There were various reasons for these fluctuations, including chance life

events, the development of comorbidities, and the natural process of aging, and there were also situations in which the reasons were unexplained. People appeared to get better at dealing with this variability over time.

The journey often caused participants to face issues and grow in ways that they might not have otherwise. Changes in their physical selves often called into question fundamental aspects of their identities and attribution of self-worth. Some of the lessons that patients learn, such as being okay with being less in control, and moving out of one's comfort zone, may tend to occur naturally over time, and thus, the longer one has had chronic health issues, the more likely it becomes that they have engaged in these behaviors. But life circumstances may also play a prominent role in whether or not people grow in these ways. P18, for example, ended up "moving out of her comfort zone" when she started attending support group meetings and became a leader of a Meetup group. She did not start making these life changes until she divorced, almost two decades after she was diagnosed.

In closing, this section described the illness journey overall, including the main phases I observed and prominent features of many of the journeys. These serve as context through which we can consider the information behaviors of participants across these journeys in the next section.

5.3 Information Behavior

In this study, I had an opportunity to examine the understandings that participants formed over extended periods of time. What I witnessed was the products of information interactions over periods sometimes as short as a span of months, but more often years, and perhaps decades. Participants took in information from a variety of sources, including media, people, and themselves, which they then made sense of. Some participants engaged more

actively with external sources; some engaged in sense-making of information received from external sources and/or endogenously, from their own physical sensations. Others were less active information seekers, but learned from information that they encountered. Aside from receiving and processing information, participants also engaged in other information behaviors, such as the sharing of information and co-construction of knowledge with their health care practitioners and other fibromyalgia patients online. Information played multiple roles in people's lives, sometimes leading to confusion and negative thoughts, but also resulting in positive outcomes such as increased understanding of one's condition and ability to manage it.

In section 5.3.1, I present an overview of information behaviors along the illness journey, in which I show that participants generally moved from a period of active information seeking to passive monitoring. Then, in 5.3.2, I discuss the topics on which participants sought information and what they learned. In section 5.3.3, I explore their information seeking and use, including motivations and contextual factors for information seeking, their approaches to seeking information, and how they made use of information. In sections 5.3.4 and 5.3.5, I explore physiological and emotional aspects of information behavior. In section 5.3.6, I describe participants' interactions with print and digital sources, and in section 5.3.7, I explore participants' information interactions with people and their environments, focusing on family and friends, health care practitioners, and workplaces. In section 5.3.8, I explore how participants interact in online spaces, and then conclude with a summary and discussion.

5.3.1 Information Behaviors along the Illness Journey

In general, participants engaged in active information seeking toward the beginnings of their illness journeys, when they first became aware of their symptoms and/or were diagnosed. Prior to knowing what they had, participants searched for their symptoms. Some participants,

such as P15 and P20, looked for conditions that had symptoms similar to what they were experiencing in order to try to figure out what illness they might have.

Some participants came to suspect on their own that they had fibromyalgia and suggested it to their doctors; others learned of it from their doctors. In either case, once participants had an idea that this was what they had, they would engage in more extensive information seeking on the condition. P17 said that when she was first diagnosed, she read “everything [she] could get her hands on,” and P11 “googled everything on creation.” Most of the participants had multiple conditions and symptoms, and each new symptom and/or condition would trigger additional searches. For example, P17 has been diagnosed with a number of conditions including Chronic Fatigue Syndrome, Fibromyalgia, and Alopecia. Her participation in online discussion forums has varied over the years, but after the diagnosis of both fibromyalgia and alopecia, there were periods in which she was much more active on online discussion forums.

There usually follows a period of lacking clarity as participants continue to search for information and find that there are no clear answers. One reason appears to be the lack of clarity surrounding fibromyalgia. Many of the participants go through multiple doctors and countless lab tests before being diagnosed. As it is customary to eliminate other possible explanations for patients’ symptoms before diagnosing them with fibromyalgia, patients such as P19 had “this battery of tests for, you know, we call it the symphony of catastrophic diseases? Lupus, MS...”

Another reason is that clinical encounters with health care practitioners are unproductive. P05, who read and sought out a lot of information both through books and online, had had encounters with numerous health care practitioners, including a pain specialist,

physical therapists, chiropractor, and rheumatologist. One doctor thought it was fibromyalgia, but another had said arthritis, and “they’re like, we’re not exactly sure. So it was a very uncertain time in terms of figuring it out because it wasn’t getting any better” (P05). At one point, P06 was experiencing multiple health problems, and the encounters with health care practitioners did not appear to be leading towards a clear resolution. Thus, she ended up trying to figure things out herself: “And then I was doing research on my own and realizing that there was no medical consensus about what fibromyalgia was or how to treat it, so I really ended up doing a lot of research on my own” (P06).

Being diagnosed or having some idea of what they had was helpful for many participants. In the case of P09, it helped in her search for information: “Once I had a name, I searched for fibro communities. Before that, I kind of trawled the Internet looking for places where other people talked about it... I searched for the symptoms, ignored what the forum was, and just sort of talked in various forums.” Participants found it extremely frustrating not to know what was happening with them, and active information seeking often continued through the point of diagnosis. Some people also found the diagnosis empowering in that it enabled them to do something to help themselves (e.g. P19).

Not all of the participants’ energies were engaged in external information seeking; there was also a lot of internal sense-making. For many, it was frustrating that there were so many unexplained symptoms, and they were constantly trying to figure out the root cause of their problems. As P14 said, “If you have any intelligence at all and you want to get better, you want to try to figure out why you woke up feeling so bad. So I would go back and go through all the foods that I ate and go through everything. Did I go through these stresses? Did I go through any blah blah blah? That just takes time to try to figure that stuff out, I think.”

Eventually, study participants came to accept their illness and learn to manage it. Along with these changes, participants also came to do less information seeking. There appeared to be various reasons for this. First, because information seeking was often symptom-driven, as participants were able to get their symptoms under control and/or learn to manage their condition better, they felt less of a need to continue seeking information. For example, when asked if she currently searches for information, P09 responded: “The symptoms fit the diagnosis, and while it’s frustrating to have that diagnosis and I don’t like it, and I wish it were something that were curable, I’ve mostly stopped, um, because the current treatment regimen is helping.”

Many participants reached a point where they felt like they knew enough, and they just wanted to move on. P14 described this point by saying:

For me, you just kind of reach a point where it’s like (sigh), ‘It is what it is. I’m going to continue to eat as healthy as I can. I’m going to continue to walk every day. I’m going to continue to lead as healthy a life as possible. But I really am kind of done trying to figure it all out. I just want to get on with my life... now, it’s like I’m just enjoying life. When I have a bad day, ‘Oh well,’ I don’t really question it anymore.

P05 said that, eventually, she reached a point where she searched for information on an “as needed” basis, searching for information on particular problems, such as migraines, sitting for long periods of time, pain from walking, and so on: “[I] started looking for specific things for specific problems... And less just like how fibro... So stuff like that... I wanted to piece what would cause different areas of the symptoms, instead of looking at it as a whole, ‘cause then it was just overwhelming.”

Another reason that participants stopped seeking information is that they felt that they knew what was out there, and there was no new information to be found. P06 said, “I occasionally get back online and kind of look up and see where the research is at. Every now and then I’ll see a research study highlighted about fibromyalgia and I’ll read it just to see if there’s any major breakthroughs [chuckle], but there never are.” Most of the participants who reach this point do, however, try to maintain some level of awareness of the state of fibromyalgia research through “passive monitoring” – subscribing to e-newsletters from services such as Medscape.

Earlier on in her illness journey, P12 had been more active in seeking information and had subscribed to various e-newsletters, but eventually, she says, “I stopped subscribing, but I’ll check Facebook pages, and occasionally we’ll see if there’s anything there, anything different.” Even if participants have long since stopped reading newsletters on a regular basis, there is a tendency to stay subscribed: “I’m still signed up for a couple of newsletters, but I don’t look at them on a regular basis. They flood... they come to my Inbox and I don’t want to... um... unsubscribe... ’cause there are moments... sometimes I just want to see latest conversations, and latest research, things like that. So I keep them, and I...you know, they all go into a folder...” (P05).

5.3.2 Information Needs and Lessons Learned

Over the course of participants’ illness journeys, they interacted with many different types of information and emerged with many new understandings. This section describes their information needs and what they eventually learned.

5.3.2.1 Topics on Which Participants Sought Information

Participants sought information on many different topics and from a wide variety of sources, including people, print, and digital sources. In the beginning, many people often had trouble getting diagnosed, so they sought information to figure out what illness they had by finding out which conditions manifested in terms of symptoms similar to the ones that they were experiencing. There were some individuals that did not have trouble getting diagnosed, and even received a fibromyalgia diagnosis the first time that they presented their symptoms to a physician, or soon thereafter. But even in these cases, people often engaged in information seeking in order to understand their illness. People also wanted to know the cause of their illness, though as time went on and they gradually came to accept the illness, they became less interested in the cause and more interested in effectively managing it.

Another common topic was medications and/or treatments. With regard to medications, some people were interested in learning more about their efficacy and/or side effects. With regard to treatments, some participants were interested in learning more about the different types available. Quite a few participants mentioned that they were sensitive to medications, and therefore were particularly interested in finding alternative ways to treat their condition. Other participants, particularly those who were younger, were concerned about the long-term effects, or eventually reaching a point where the medications no longer worked.

Some participants were more oriented towards treatment options from allopathic medicine, while others were more interested in alternative, integrative and/or preventative approaches. With regard to the latter, topics that arose in the interviews included yoga, acupuncture, meditation, exercise, diet and supplementation. The longer that participants had had their condition, the more likely they seemed to adopt an approach involving a combination

of traditional and alternative approaches, and usually involving lifestyle changes such as diet, exercise, sleep hygiene, and stress reduction.

Other topics included work, disability, and how others dealt with fibromyalgia in everyday life. P05 described it in this way: “... nobody tells you what the day-to-day is... for me, in terms of my research, finding information about how people are living with it, or how are they finding out other treatment options, how they’re selecting the treatment options, what are their interactions with their doctors, how do they select their doctors...” Often, questions in this realm were specific to participants’ backgrounds and life situations, such as being black or being in the military; thus, participants often desired information from others of the same background.

5.3.2.2 What Participants Learned

Over time, the illness appeared to result in information acquisition on a diverse array of topics and the development of new understandings and skills in many different facets of life. Participants emerged with different management strategies, and many of the lessons that they learned spilled over into non-health-related parts of participants’ lives. The lessons that they learned are briefly summarized in Table 10. These included developing new understandings of fibromyalgia, health and wellness; learning strategies to manage their condition effectively; acquiring knowledge of how to obtain access to health care; developing approaches to achieve their work- and career-related goals; and learning how to communicate and interact with others. In this section, I elaborate upon these lessons.

Table 10. Lessons Learned

| Category | Lesson |
|--------------------|---------------------------------------|
| About Fibromyalgia | The Illness Will Last Forever |
| | No Consensus in the Medical Community |
| | What Fibromyalgia Is |

| Category | Lesson |
|-----------------------|---|
| Management Approaches | What Treatments Options Exist |
| | Exercise and Self-Care |
| | Figuring Out One's Triggers |
| | Respecting One's Limits |
| | Taking Charge of One's Own Health |
| Re-conceptualizations | Re-conceptualizing One's Approach to Illness, Life and the Self |
| | Conceptualizing Health and Wellness |
| Other | How to Navigate the Health Care System |
| | How to Apply and Obtain Disability Benefits |
| | Building/Shaping One's Career |
| | Negotiating Work Situations |
| | Interacting and Communicating with Others |

5.3.2.2.1 About Fibromyalgia

As participants engaged in information seeking, most interacted with a variety of sources, including print and online sources, and people that they knew. The diversity of sources and content concerning fibromyalgia often led them to various realizations about the condition. First, as discussed earlier, participants realized that the illness was going to last forever.

Second, participants realized that the medical community did not have all the answers. The nature of this realization and its subsequent implications for patient behavior played out somewhat differently in different individuals. The most common reaction was to stop looking at some point because individuals came to feel as if they knew “all there was to know” (e.g. P25, on BIPQ).

Participants came to understand fibromyalgia in different ways. P05 spoke of her coming to know the concept space: “I know the biology and the science behind fibromyalgia, what they say about it, the causes they don't really know about it...” Many came to know fibromyalgia in terms of the symptoms and how it felt: “Mostly when I was still learning what fibromyalgia is, I was looking at symptoms and stuff like that. I was just kind of looking

around, at all these different websites explaining what is going on, and what is its effect, and how people with fibromyalgia are going to feel”(P13).

P13 approached the disease by reading online information to understand the perspective of allopathic medicine, and then switched to Chinese medicine when he realized that there were limitations to the knowledge of allopathic medicine concerning the condition: “After I was diagnosed, I looked more at the basic information about what fibromyalgia is, and trying to figure out exactly what Western medicine knows about it. It didn’t take me long to realize that it doesn’t know much at all... from there, I kind of shifted my focus more to just concerning on learning Chinese medicine...”

Many participants pointed out that though they did not question allopathic medicine from the outset, they came to realize that it had its limitations, at least when it came to fibromyalgia. P06 observed that there was no consensus in the medical community, and P13 observed that, while Western medicine was able to address acute conditions, it did not know what it was doing with regard to conditions such as fibromyalgia. P12 mentioned a time when a physician had admitted to her that physicians are trained to deal with a limited subset of health conditions, and the rest of the time, they were guessing. However, despite realizing that allopathic medicine did have its limitations, participants still recognized its value and were more interested in using it in combination with other modalities.

5.3.2.2.2 Management Approaches

Over the course of their illness, participants gradually increased their knowledge and found ways to manage their health. This was generally a process of trial and error as participants tried a variety of treatments to find out what worked. It was also a cumulative process, and one with a feedback loop, in that participants would try one thing, and it might or

might not work, but then they would learn from it, and it would help them to do more research and try yet another alternative. There were solutions in which almost all participants tried to engage, such as exercise and dietary change; and there were families of solutions that a subset of participations employed, such as alternative medicine and allopathic medicine. In this section, I describe the main types of knowledge acquisition relating to management approaches: exercise and self-care, learning triggers, respecting limits, and taking charge of one's own healthcare.

5.3.2.2.2.1 Exercise and Self-Care

Movement was a key element in participants' management strategies. Exercise is a tricky issue for fibromyalgia patients, because many of them suffer from fatigue. The story from P17, who also suffers from Chronic Fatigue Syndrome, is a case in point: "At the time, they were suggesting that I needed to do more aerobic activity for the fibromyalgia... I got myself an exercise bicycle, and ... I worked up to ten minutes a day... but then the other 24, 23 hours a day I was in the bed. So I figured that's not going to work." Thus, participants often needed to experiment to find the right combination of exercise type and amount in which they were able to engage.

Participants in this study found various types of exercise helpful. P07 went to the gym several times a week and engaged in light exercise with a friend, with whom she shared and discussed health and exercise-related information. P05 and P26 both mentioned that walking was very helpful to them. P13 engaged in light exercises that bear similarities to tai chi and meditation. For many participants, yoga had made an enormous difference in their lives. P18 summed it up as: "The whole thing is, you have to move."

Three participants discovered that exercise was enormously beneficial to their health management relatively late in their illness journey (P07, P17, and P18). For all three, the discovery was perhaps largely serendipitous, but they all acknowledged that it had greatly improved their condition.

Lastly, many participants became aware of, and made time for, self-care activities. For example, P19 said, "...part of my... self-care every day is stretching and soaking in the hot tub, and meditation, and that takes a lot of time." This "self-care formula" may be different for everyone: "I try to avoid unnecessary stress, and get a lot of rest, and eat really healthy, and do my yoga, and take the dog for walks when I can..." (P17).

5.3.2.2.2 Figuring Out Triggers

Another common management step was figuring out food sensitivities and allergies. Some participants, such as P15, researched how to do this on their own, and then carried it out. She went on an elimination diet and gradually figured out the items to which she was sensitive. P24 used a mobile app called Pain Coach to figure out that gluten was causing her a problem, and then eliminated it from her diet. Still others, such as P26, underwent lab tests and a rotation diet in order to figure out the foods to which she was sensitive.

Patients of various conditions, including fibromyalgia, appear to have a hypervigilant pattern of responding that extends beyond the pain domain, for example, to auditory stimuli (McDermid, Rollman, & McCain, 1996). Thus, another part of their path to effective management may involve the learning of their pain triggers. For P05, learning how to manage triggers was an important part of coming to feel like she could manage fibromyalgia:

For once in a very long time, I felt like I could handle the fibromyalgia. I don't think I had ever felt like I could handle the fibromyalgia... or the flare-ups, but I was starting to

realize: ok, it's a part of my life, and I started noticing some of the triggers a little bit better, also the best way to manage some of the symptoms, and also not being so mad at myself or my body.

Thus, for P05, we see that the learning can perhaps be thought of as occurring in multiple ways: in terms of concrete management skills, learning to listen to one's body better, and dealing with the illness emotionally. This was a gradual process, in which knowledge and confidence were built incrementally.

5.3.2.2.2.3 Respecting Limits

...as long as I stay in my little box, I do okay. If I go outside the box, then I'm going to pay for it. – P17

Many participants spoke of learning one's limits and learning to respect those limits. A number of them explained this through analogies to a limited set of resources. For example, P21 said: "It's kind of like getting up in the morning with a full tank of gas in your car and you know you've got ten things on your to-do list and you've got to get it done with that tank of gas, so you can't add an extra thing or you're going to run out of gas." Other analogies that were mentioned included having a limited set of pencils or spoons¹ (P23).

Among the sample, respecting one's limits appeared to be particularly difficult because of participants' expectations for themselves. Participants used language such as "perfectionist" and "superwoman," suggesting that they and others had high expectations of themselves, and they spoke of how this was a major lesson that they had to learn. P21 depicts this lesson on her timeline, with the following description: "So here's me, and I'm feeling much better. Like not

¹ The spoon analogy comes from the Spoon Theory (Miserandino, 2003).

being such a perfectionist, you know, trying to get everything done and being a perfectionist about it, learning that other people can do the same job... let it go.”

However, many participants realized that they were sensitive to stress and learned to plan their schedules to reduce their stress levels. Extant research has argued that stress may play an important role in the etiology of fibromyalgia (van Houdenhove & Luyten, 2006), and stress was also by far the most commonly mentioned perceived cause of illness in the participants’ responses to the BIPQ. There were various ways that participants might reduce stress. For P05, this meant being strategic: “Grocery shopping has to be strategic; going out has to be strategic; everything has to be strategic.” For many of the participants, it meant not having more than one activity a day, and resting for several days ahead of major events.

Some study participants gradually stopped working after they developed fibromyalgia. There were quite a few participants, however, that continued to work full-time, and among these, participants often reported that they cut down on their social activities, which can be frustrating too: “I cancel plans with people far more than I would ever like to. I'm a very social person. I hate saying no to plans. I hate missing out on stuff. It's been really difficult for me to learn how to set limits and know that it's okay to say no to plans or it's okay to say I just can't make it tonight” (P24).

Although all of the study participants became cognizant of their physical limits and made adjustments to their lives accordingly, their decisions did not mean simply cutting activities out of their lives to eliminate pain. For example, P09, whose involvement in gaming is very important to her, said, “the video games that I play seem to make my hands hurt more than they would statically, but there is a static level of pain... a base level of pain that I wake up with. So... I feel like my options were to sit in bed and hurt and bitch about it, or to...hurt and

do things I enjoyed, and at least I would have the things I enjoyed." Thus, participants came to know their own bodies and made decisions that took into consideration their values and priorities.

It often takes some experimentation, some trial-and-error, to figure out the right combination of activity and rest that works, and as P22 observed, it is difficult to live with these limits even if you have set them:

I think you have to experiment in the beginning to see how far you can get and because it's such a variable condition, then you have to become sensitized to those little variables that are going to impact you in a bad way if you keep going. Once you figure all that out, and put it together, then you say to yourself, 'Okay, this is the formula that I have to live by,' but a lot of fibromyalgia patients struggle with that continually. – P22

P25 characterizes respect for limits as a strategy to facilitate stability and minimize the ups and downs that patients of fibromyalgia and Chronic Fatigue Syndrome experience. In her role as a support group leader, she has often encountered people who are newly diagnosed, and she says that:

one of the things that I tell people... is that you can learn coping skills that will make it so that you're not doing a roller coaster ride. But you're not really better, and don't call yourself cured. Most of the people that say that they're cured, they're cured in their limited little world because they've learned to cope with it. And if they stay in their little box, they're okay. But if they venture outside of it, they're going to get just as sick as they were before. – P25

It is interesting that P17 and P25 both used the metaphor of the "little box." P25 also presents her perspective on claims of being cured. Like many others in my sample, she felt strongly that

the task before patients was to learn strategies to reduce their symptomatology, not cure their illness.

5.3.2.2.2.4 Taking Charge of One's Own Health

Though, as has been discussed, participants usually have ended up with a team of health care practitioners that they trust, what many of them have realized is that they need to take charge of their own health care. There are various reasons for this. At the outset, one reason is the lack of a standard, efficacious treatment: "There wasn't any gold standard for treatment. It was either hit-or-miss. This works for one person... And I just sort of figured that I needed to kind of figure it all out myself and see what I could do" (P17).

Moreover, though health care practitioners may be experts in their respective areas, patients are likely to have a more intimate understanding of their own body. P22 said that earlier on, "I've had other doctors tell me, 'Well, this is ridiculous. You should be able to take this or that or do this or that,' and this was when I was younger. I basically let them bully me into it and then as a result, I'd get violently ill, whether it's a GI issue, or I just flat pass out and end up in the ER." So now, she said, "When I have somebody that's just insisting and pounding on the desk that I have to do this or that, then I'm going to examine it from all angles. I'm going to sit back and go, 'Maybe I will and maybe I won't,' because I live here, and I know what goes on."

P12 has had similar experiences. For example, a doctor had insisted that she take statins; she had tried to explain to him that her blood pressure habitually fluctuated in such a way that sometimes it would be above normal range, but most of the time it was within normal range, and so taking statins would drop her blood pressure too low. He still insisted, so she followed his directions and became ill as a result. Thus, she stressed the importance of

providing to physicians one's own knowledge of one's body, and making informed decisions about one's health care: "Doctors know some things, and you know some things. And you've got to have somebody who lets you put that together, 'cause you're the expert on your body, and they might be the expert on some treatments, but then you're the one that has to sort of be your own case coordinator, and monitor your body" (P12). This was not a role that participants naturally took on, and so it took time to learn: "It took me a long time to be the manager of my own health system. I expected doctors to kind of manage my life for me. It took me a long time to realize that, no, I'm in charge of this. The doctors that work for me are a team, and I manage that team" (P14).

Aside from the strong relationships she has with her healthcare team, P26 has also learned a lot from her physicians and on her own, to develop an approach towards her multiple comorbidities that works for her. In her opinion, recommendations for how much fibromyalgia patients should exercise are too low. She engages actively in two forms of exercise, walking and yoga, which she learned from videos while serving as the primary caregiver for a relative. She believes strongly that people can improve their own health situation by taking charge: "I don't think that people understand how much they can actually help themselves by taking the reins" (P26). Given the wide range of ways in which patients experience fibromyalgia, I do not believe that all patients can adopt P26's approach. However, the point that I am making here is that exercising agency in one's healthcare may be extremely beneficial.

5.3.2.2.2.5 Summary of Management Approaches

In summary, the process of becoming able to manage fibromyalgia is a gradual one that can involve many different components. Some of these are more concrete strategies, such as implementing an exercise regimen and figuring out one's food and pain triggers. There are also

more mental strategies, such as respecting one's limits and taking charge of one's health. In P12's case, her nutritionist helped her to come up with an integrated health plan for health maintenance: "So, and that's part of all that we've put together holistically, is: diet, energy, breathing, mental focus, and then which parts of medicine maybe will help to do things."

5.3.2.2.3 Re-conceptualizations

As participants learned or developed skills to manage their condition, they also came to see many things in a fundamentally different light. Their views of illness, life and themselves changed, as did the meanings that they held for health and wellness. These changes in outlook facilitated their abilities to implement the health management strategies that they were learning.

5.3.2.2.3.1 Re-conceptualizing One's Approach to Illness, Life and the Self

One important lesson for many participants was to re-conceptualize their outlook and approach to their illness. For example, P12 needed to learn to "stop fighting":

One of the nutritionists that I was working with said, "Stop fighting. You're putting all your energy into fighting. You don't feel good, and you have some part of you that feels like you have to fight, but you're wasting your energy fighting." And I was like, "But I've had to fight this. That's what you've been told... don't give in. Fight it!" And she said, "No! You need to take... you need to take all your energy and put it towards something, towards growth!"

P12 said "that was a really big turnaround, to think about: 'This isn't about battling something.' Which that's always the word we use medically, always. You're 'battling' cancer. You're 'battling' heart disease. It was more like, how do you make it part of you, but you're still growing and thriving? It's just a piece of you."

P12's re-conceptualization is perhaps on a more abstract and conceptual level; P15 has a story that illustrates how the same sentiment might play itself out in terms of concrete changes in approach to a health problem: dealing with sleep issues. She mentions that some information encounters she had with a sleep researcher "changed my life, because I no longer thought I needed to work on this insomnia. I need to try to figure out this insomnia. And I just started to accept that, and know that I needed to find a job and make my life fit with this, instead of fighting against it, to work with it" (P15).

One lesson that appears to go along with this re-conceptualization is the idea that, regardless of what they are experiencing on any given day, they will get past it. As P12 said: "That's what I think I've been trying to accept, that if I've got a stabbing pain in my neck for a while, it's not the whole day, or the whole week that that's been. So my stomach's bothering me this morning. But it'll stop; it always does. I just have to remember that."

This may perhaps seem like common sense to some, but the severity of pain may lead participants to be extremely fearful and uncertain of the future. P19 said, "Early on, I remember being diagnosed, and I would just get this intense stiffness, and the stiffness was so bad I couldn't walk, that... I'm like, am I going to be able to walk in ten years? And now it's like, I know on my bad days, it's like, 'Crap! I can't really move that well today. I'll be okay in a week. I'll just keep doing yoga, and keep soaking in the hot tub.'" Thus, an important part of participants' journeys is learning to re-interpret information that their bodies are giving. Instead of seeing these as acute signals that trigger worry and anxiety, they learn to approach them as problems that they try to address as much as they are able.

Accepting and "working with" an illness does not mean giving up; rather, it means coming up with alternative ways to achieve their goals. P05 came to the realization that, "I can

still work in public health, and also do innovative work like I want to do, but I'm going to have to re-think it." For many of the participants in this study, developing fibromyalgia led them to question fundamental aspects of their identities. P20, too, went from, "I've got to figure out who I am," after being forced to retire from the military due to her illness, to finishing a Master's degree and realizing that, "You can still do things; you just have to figure out a different way to do it."

Participants had a tendency to be very demanding of themselves, and many of them said that, despite their illness, they would expect things of themselves that they did not expect of others. They would also have a tendency to be frustrated with themselves and their inability to maintain the schedules and workload that they once did. Thus, being gentler on themselves was an important lesson to learn: "I'm handling it better than before because I'm also letting myself rest and not like, beating up on myself too much, and being so mad about having fibromyalgia and how it's affecting my life" (P05). P19 spoke of how, throughout most of her life, she used to push herself through her work despite the pain, and it was only a couple of years ago that she had started to change: "I have a sense of humor about it, and I'm kinder about it, and I don't do those things to my body anymore. But that's really just the last couple of years, and I think, had I not really just learned to step back, and say no, and not take things on... I think I would have reached a point where I couldn't do my job."

As mentioned earlier, the illness often calls into question participants' views of themselves. Participants sometimes felt that there was something wrong with them, and that they needed to fix it. A change in orientation away from thinking that they needed to "fix themselves" can help participants to move towards successful management of their condition. With regard to her problems with sleep, P15 said:

I kept feeling like there's something wrong, and I need to fix it... I finally accepted, I don't need to fix myself, really. There's nothing really wrong with me, and so I can stop being stressed out about that, and I can just work on fixing my... it's like, making accommodations for yourself if you have... one leg... or have a wheelchair... or you have a... mental illness or something. It's like, well, I could just keep trying to fix that, or I could try changing... you know, where I keep hitting my head against things, or I could try to put cushions there...

One final, poignant example was related to me by P17. She had gone to see her neurologist, an older, Chinese man that she thought was extremely wise, and she had said to him, "I don't understand why I'm not getting better. I'm trying so hard." And the neurologist said, "Perhaps you should try softer." She said it took years for her to understand what he meant.

5.3.2.2.3.2 Conceptualizing Health and Wellness

...wellness is pretty much the whole emotional, spiritual, and the physical. It's like everything together. – P20

Being ill often caused participants to view health and wellness differently. When asked how they defined health and wellness, one commonly held view was that health was the ability to do what they wanted to do, and that they had lost that capability.

Health and wellness gives you the flexibility to do pretty much anything you'd like to do at any given time. When you don't have it, then you have to make choices about what you can do at any given time and for how long. It's not an easy thing to live with when you don't have those options, and I don't think that people really -- I don't think I really appreciated being well until I wasn't... – P22

P25's notion of health bears similarities; she says that it means, "I would be free to do what I want to do rather than... feeling the need [to be careful]... like, with this IBS, I can't go to a restaurant and order whatever I want. I have to follow a diet or pay the consequences." She remarked, "I have to be more careful than my mom was when she was dying, practically. And that kind of carefulness shouldn't be... I wouldn't be well, unless I could do what I wanted to do" (P25). Thus, quite a few participants thought of health as a state in which they would be able to do what they wanted without having to consider their condition.

Many participants' conceptions of health and wellness evolved along their illness journeys, moving away from a focus on health, to a focus on wellness. As mentioned earlier, P15 had originally been determined to 'cure herself', and later changed her resolve to one of wellness. A key part of this process, as she saw it, was coming to accept fibromyalgia.

P21 also sees herself as having made a shift from health to wellness. She describes this as a move away from eradicating the physical manifestation of fibromyalgia, and focusing on all the different aspects of her life: "At the beginning I was looking more at just health, 'cause I had symptoms and I wanted them to go away, you know? So I was looking at health. And as I've gone on the journey, it's changed to a more wellness focus, because there's no one thing that fixes fibromyalgia, it's a combination of managing your life and all the different components."

For P24, developing fibromyalgia helped her to realize that there was more to health than weight, and the need to adopt a more holistic perspective. She also came to understand the connection between the mind and the physical body:

It's really become more of a holistic, whole-picture thing for me whereas it used to probably just be weight... Let me go on this diet that's probably only going to last a month... I now think about every aspect of it from the water I drink to the food that I

put in my body and the supplements. I'm trying to improve my reactions to pain... and try to control inflammation and the acupuncture and try to stay relaxed and not get stressed and all of that, because I know that it all contributes to the physical response that my body has. And I never really thought about it before. I definitely never thought about how stuff that happens emotionally and mentally can affect your body until it all came to a head for me... It's definitely a completely different vision of health than I used to have.

The concept of treatment and the purpose of it, while different from health and wellness, is related. P17 reflects upon what this means to her in relation to various conditions that she deals with:

About whether a treatment is successful or not... it depends on how you define success. I mean, success for hair loss: does that mean, your hair re-grows, or does that mean you're not losing as much... Success with the CFS: does that mean you're managing better? You're going to get your life back to where you were before? I don't think so. With the FM, a treatment may be successful because somebody feels marginally better, or has, you know, some amount of reduced pain, but that doesn't mean that they're cured. So I guess that's the nature of chronic illness. You live with it and learn how to manage it and stuff.

These examples demonstrate that, after developing fibromyalgia, participants often end up also developing a more complex and holistic view of health, in which all different aspects of life are considered. They also become more attuned to how non-physical aspects of their lives may affect their physical sensations.

One aspect of conducting research on fibromyalgia (that is not unique to fibromyalgia) is the preponderance of comorbidities. Though the next example I present is of an experience that a participant had due to her having a different condition, I would argue that it is relevant because the nature of fibromyalgia, and in fact, the human condition, is that we all are a product of multiple “conditions” (a few of us perhaps have the lucky disposition to believe that they have the condition of “health”).

Due to her having a rare pancreatic condition, P26 had an opportunity to visit Korea to undergo a stem cell treatment. Not having had any knowledge of Korea previously, she was extremely struck by what she viewed as an entirely different approach to health and wellness. She argued that in Korea, they approached health from the standpoint of wellness, whereas Americans approach health from the standpoint of pharmaceuticals. She believes that:

...in America we have grown to accept... disease but I don't think that's necessary. I think you can live – now maybe not in this [country] because we've damaged our environment so much... but I think there was a point in time and I think that it still exists in other countries, especially countries like Korea and China and Japan that have practiced wellness for thousands of years and have just a different view than we do, I think that the God-given view was life, the beginning of life, life and death and that there was a natural decline and decay but I don't think that it necessarily had to involve disease. – P26

What does that mean, to live without disease? P26 gave an example: “My husband's grandmother died at the age of ninety-seven. Her hearing was shot. Her vision was shot. She had lost most of her teeth but... one day her heart just gave out... she wasn't disease ridden and

that is so extraordinary in America... I think we've accepted... that disease is a part of that decay and dying process. I don't accept that as being a necessary truth."

5.3.2.2.4 Other Lessons

Other than conceptual knowledge about what fibromyalgia was, how to manage it, and also high-level re-orienting around concepts such as health, wellness, life, and the self, participants were also learning how to navigate certain spaces, like the health care system and social security, and developing new ways of navigating spaces that they had previously been accustomed to, such as career, work, and social relationships. I elaborate more upon participants' specific approaches in terms of obtaining disability benefits, career and work in later sections; in this section, I focus on what they learned about these topics.

For most participants in the study, the experience of fibromyalgia led to them becoming familiar with the health care system and how to navigate it. For most participants, this learning occurred early on, when they first developed fibromyalgia and had the least control over their symptoms. One type of knowledge that many participants acquired was which practitioner to see. This knowledge might be gained in various ways, e.g., random selection, word-of-mouth, and deduction based on online information sources. It is perhaps important to mention that there is quite a bit of trial-and-error involved here; P10 commented that one of the practitioners that has worked out best for her and her mother has been a practitioner that she picked out of a phone book, whereas she once chose a highly respected practitioner at a university that did not work out at all for her. P26, who hardly ever uses the Internet, has been successful for years in locating practitioners simply by word-of-mouth.

Other than knowledge of health care practitioners, participants also learned or developed knowledge about how to pay for medications and/or treatments. This knowledge included the

use of health insurance, which sometimes would only partially cover their medical expenditures (e.g., P11). P18 spoke of attending free meditation sessions at the Chopra Center and finding deals for acupuncture sessions. Thus, over time, participants developed knowledge of how to manage their health care within their financial constraints.

One final area in which participants learned about paying for health care involved obtaining disability benefits. In the case of P24, this involved short-term disability, but for most participants who obtained benefits in the study, this meant long-term disability benefits. Participants learned that they had to show a “path of illness” in order to get disability (P14). P22 said that she saw two physicians, including one pain specialist, on a regular basis, and “they don’t really do anything for me. I keep them on my roster because I’m on Social Security disability, and it’s necessary to have specialists because if they decided to review me, if you don’t have a specialist, they frown on that.” P14 said that she had “obviously decreased going to doctors... because I feel like unless there’s something really traumatic going on that requires attention, I pretty much know how to manage”, and then had had difficulty getting approved for disability benefits.

After participants developed fibromyalgia, they often had to make adjustments in terms of their career objectives/directions. For some participants, such as P14, P17 and P20, it eventually meant the end of the careers that they once had, while for others (e.g., P05, P10, and P13), it influenced the career decisions that they made. With regard to career and work, there appears to be a synergistic effect of age and illness severity; some of the participants for whom fibromyalgia set in at an older age were able to retire and move on to developing a new life routine that did not involve working full-time (e.g., P14), whereas other study participants generally tried to find a way to adjust their career objectives to suit their physical situations.

Other than changing their career aspirations, participants also learned strategies for managing their work lives, including negotiating with employers, which I discuss in section 5.3.7.3.

Participants, as well as their friends and family, often had a lot to learn also in terms of how to interact and communicate with one another after the onset of illness. It is difficult for those around fibromyalgia patients to realize that they may not be feeling well, as patients themselves often try not to let on. For example, P14 said that her spouse was a person who was never ill, and was always full of energy. So, for example, he might come home and ask how her day was. Even if she had had a really tough day, instead of saying, ‘It was really crappy. I was sick all day,’ she would say, ‘It was okay.’ Then he might want to go out and do something, and then she would say no, and he would be confused. She had to learn to tell him when she wasn’t well, and she had a hard time with that. To sum it up, P14 said, “He needed to pick up on clues, but I needed to also realize that he can’t read my mind, that I need to share with him when I’m feeling really bad. We’ve learned how to do that.”

It can also be difficult for children of fibromyalgia patients, because their parents may not be able to accompany them to events in which parents normally participate, and may not be able to give children as much attention as they might if they did not have fibromyalgia. Among the sample, participants who relayed these types of challenges included P17 and P20.

5.3.2.2.5 Summarizing What Participants Learned

In terms of information interactions over the illness journey, study participants generally moved from first endeavoring to understand what fibromyalgia was and how to manage it, then how to manage the different spheres of their work and social lives. As participants started to feel that they had gained some ability to manage their health, quite a few started to look outward

in terms of how they might help others. Their efforts in this area, in terms of advocacy and raising awareness, are discussed in section 5.4.3.

5.3.3 Information Seeking and Use

Over the course of their illness journeys, people sought information for a variety of different reasons. In this section, I first describe their motivations for information seeking, and then I describe the strategies that they used to find information, and how their strategies changed over time. Lastly, I describe how participants reasoned with information to try to address the problems that they were trying to solve.

5.3.3.1 Motivations and Contextual Factors of Information Seeking

5.3.3.1.1 Getting at “That Underlying Thing”

Many participants wanted to understand the nature and/or cause of their illness. They spoke of wanting to get “to the bottom of everything. What’s the underlying thing? I want to know what it really is” (P15). P12 spoke of her feelings at the time of diagnosis: “I don’t remember feeling relieved as much as I was puzzled. Like, is this something different? Or is this a name that you put everything under? ... I wouldn’t say I found relief. I think it sort of started me more on a quest to try to put pieces together.”

5.3.3.1.2 “Fixing It”

Many of the participants were very solutions-oriented in terms of their approach to their illness; they just wanted to “fix it.” P20 mentioned that she had little patience for the Cognitive Behavioral Therapy (CBT) course and the health discussion forums she visited, because she found them to be a bunch of “woe of me,” whereas, her way of thinking was, “I want you to fix it. I don’t want to sit here and listen.” Thus, she engaged very actively in information seeking, targeting the problems she encountered, e.g. what her illness was, how long she should wait

before getting pregnant a second time after her anthrax injections, what to do about her medical situation with respect to her military career, whether she had hypothyroidism, and so on.

P15 engaged in information seeking and then solutions implementation to address each of her problems. She identified different issues and then tried solution after solution to address them:

I've found that I have adrenal issues, and I had hormonal issues, and... Trial and error, so many things I tried. Try this; this doesn't work or this has a negative result. I tried this; this works. Doing therapeutic doses of things, all on my own, because my doctor's like, 'You know, you can go ahead and do that.' She's kind of like got a smile on her face. 'You know, it's just going to come out in your urine.' – P15

P15 said that the solutions she tried involved nutrition, exercise, physical therapy and more.

Participants often came to re-define the notion of “fixing.” Many came to realize, as I mentioned earlier, that “there's no one thing that fixes fibromyalgia, it's a combination of managing your life and all the different components” (P21). P19 said of hypnotherapy, one of the solutions that she found worked for her: “I really read about hypnotherapy, and I understood that this wasn't a quick fix, but this would... you know, very likely, disconnect the physical symptoms from the fear reaction?” Thus, returning to the concept of the illness journey and information behavior, participants gradually found solutions that enabled them to manage their condition better in the long-term, and as they did so, their information seeking lost the sense of urgency it had had before, so they shifted to a pattern of monitoring.

5.3.3.1.3 Frustration with the Lack of Answers

Prior to diagnosis, motivations for information seeking included wanting to know what was going on, and waiting for and lack of progress to a concrete diagnosis. Thus, in cases

where the diagnosis is prolonged, so is the information seeking. Participants were also motivated by other factors, such as the desire to corroborate and/or counter information that they encountered accidentally.

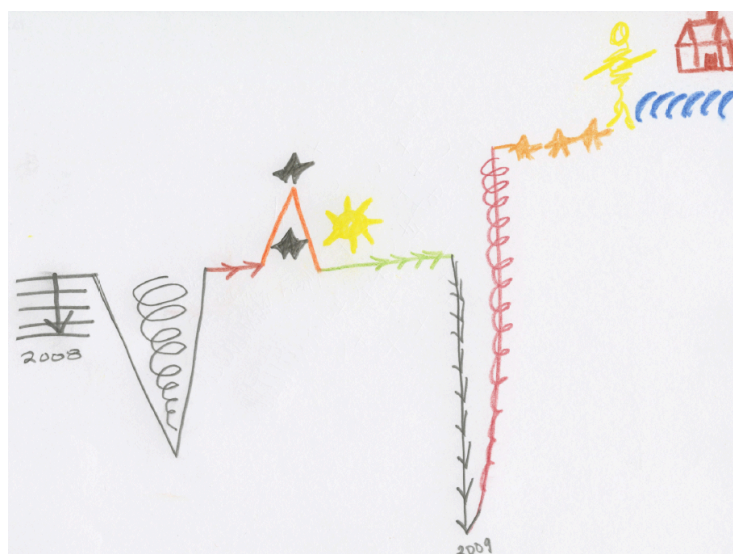
The lack of concrete outcomes in medical visits often serves as motivation for patients to become more actively involved in determining what their illness is. In the case of P13, he said that the lack of progress in his medical consultations led him and his mother to actively seek information: “We were both just digging around because the doctors were being completely unhelpful. So we were trying to find out what’s actually going on so we can be prepared with options to suggest to the doctor when we actually go there.” Eventually, it was his mother who found information about fibromyalgia online; P13 thought it sounded plausible and brought it up to his general practitioner, which subsequently led to the diagnosis.

P22 also became fed up with the lack of progress in terms of her health situation, and so made a decision to seek information from a particular health practitioner to see if she could bring an end to the impasse she perceived in her situation. As she drew a cyclone on the timeline (Figure 8), she described her perception of the situation at the time:

I decide that I’ve had enough of these suggestions from my physicians about what to do, and... I have to figure out what’s going to work or not work and what’s wrong because I’m obviously getting no place, and I don’t like that. I want to move on. I either want to be better or at least understand what the problem is and what can be done about it, not this holding pattern where everything seems to be just piling up, and we’re getting nowhere. We’ll make a cyclone in the middle of this because there’s a lot of confusion, a lot of information coming and going, and nothing is happening. It’s just sort of destruction. – P22

In order to rectify the situation, she decided to go see an orthopedic specialist that she had seen for a long time for advice. He referred her to a rheumatologist who diagnosed her with fibromyalgia, which she called a “green light” because it confirmed what she already thought she had. She drew a sun to indicate the light that had been shed on the subject and the move forward to figure out what kind of treatment will work for her.

Figure 8. P22’s Illness Journey Timeline



5.3.3.1.4 To Corroborate, Understand and/or Prepare for Clinical Encounters

There were times in which participants would search for information prior to or after a clinical consultation. After an office visit, participants would sometimes search for information to clarify what a physician had said. For example, P07 said that she’d never been a person who was really curious, so earlier on in her illness journey, she did not really look for information. However, in recent years, as she has come to use the Internet more because of her interest in genealogy, she has also started to look up words that she hears when she goes to the doctor that she does not understand.

Sometimes, patients do not explicitly engage in information seeking regarding what a physician has said, but they inadvertently come across information that clarifies an issue that

they were confused about. P06 said that earlier on in her illness journey, she had been prescribed antidepressants for pain and she was confused why that was. It was not until she had done research on her own about fibromyalgia that she learned that antidepressants are routinely prescribed for pain.

Among the sample, there were many participants who did research to try to figure out what condition they had. This process was often prolonged because participants took multiple lab tests to rule out conditions, and it might have also taken some time to get an appointment with the physician. For example, P15 said that when she was tested for lupus, she waited two months for her appointment. Regarding her motivation, she recalled, “I thought, I want to be prepared. So if they say I have lupus, I want to know what’s my prognosis and what are the possible treatments and what kinds of things can I do on my own, and what’s my life possibly going to be like, what kind of changes I might have to make...” (P15). So she did a great deal of research to make sure that she was prepared.

5.3.3.1.5 “Re-Grounding” or Guarding against Unwanted Information

Participants sometimes had to guard against information that they encountered that they did not agree with. For example, at one point, P08 regularly came into contact with an individual with Chronic Fatigue Syndrome that was quite adamant about her views about what causes the condition. She perceived this information as contrary to her own understanding, and thus found herself searching on the Internet in order to confirm her own understandings, “There was a period of me looking into more information around her, just to get myself re-grounded, so I could cut that information off” (P08). Another participant said, “What got me started thinking about fibromyalgia was the stupid Lyrica commercials that I hate because it makes it look like fibromyalgia just means that you can’t go run and play. No. Fibromyalgia means that I can’t

get out of bed sometimes. So the stupid commercials are probably what really triggered me to start looking at it and researching it” (P24).

5.3.3.1.6 Interest and Enjoyment

Many of the participants in the study seemed to enjoy the process of information seeking. P16 said that she has always been interested in information “in and of itself”, and P17 said that she still enjoyed looking to see what kind of research was out there. P12’s account of her story also suggests that she experiences a certain level of engagement in the process of reflecting on her own health experiences. She says, “I’ve always been a questioner, from the very beginning. Not the why is me, or woe is me, but what is this really? Which has always been my interest in it” (P12). She speaks of her “fascination” with the similarity between the symptoms of conditions such as fibromyalgia, hypothyroidism, adrenal issues, and Addison’s Disease, of “untangling” these as a “puzzle” and a “mystery,” and of her diagnosis starting her “on a quest to try to put pieces together.”

5.3.3.1.7 Diversion

Lastly, seeking information appeared to reduce stress because it diverted participants’ attention from various negative emotions to more positive orientations and constructive activities. For example, P27, who attributes the onset of her fibromyalgia to sexual harassment, said:

I think after every kind of emotional, like, stage that I’ve gone through, my brain has also tried to seek solutions, and so that has kind of dissipated, like the emotional stress I felt. So thinking about the ways in which to address street harassment as, like, a public health issue has helped me not be as angry about this. And then thinking about ways

that I can modify my job schedule, like taking medical leave, has helped me be less stressed about, like, continuing to work.

5.3.3.2 Ways that People Sought Information

There was some variation in participants' information seeking strategies. For the most part, participants engaged in simple keyword searching using Google, though a few participants also used Pubmed. These participants had all received training while they were in school concerning how to search for academic articles.

In the beginning, many participants tried the "learn everything" approach. They tried to read everything that they could. Another related, but different strategy was to seek out a single resource that would provide them a general overview of fibromyalgia and related issues. *Fibro for Dummies* was an example of a book that was helpful to a number of participants, and was also routinely recommended by P22 to others.

Over time, participants' searches became more focused and directed as they learned more about the condition and learned to navigate the information space. P05 describes this progression:

[At first] I was looking broadly at stuff... it wasn't really specific in terms of what I was looking for. Now... I try to be more focused in my approach, so I can delve into it a little bit more? I'll review a lot of things at the same time, so instead of trying to review fibromyalgia as a whole, I'm looking for support groups, and only support groups, and the same type of support groups. Or I'm looking for...things that alleviate back pain. I'm more specific... in the beginning, I wanted to know everything, and it wasn't very helpful. Because I didn't know how to focus.

Some participants engaged in information sharing and discussion. Those who did so primarily participated in online discussion forums such as Facebook, DailyStrength, and Reddit. For many, the periods of information seeking, sharing and discussion were intermittent or brief, spanning a couple of months or less, as patients struggled to figure out a strategy to deal with a new symptom that emerged. There were cases, though, of participants who stayed actively engaged in discussion forums for years, such as P22 and P23.

One participant, P07, engaged in this activity in person, with her “exercise buddy.” They subscribed to different print newsletters and magazines, traded with each other, and discussed them as they exercised together. P07 said that she did not learn how to manage her condition until recently, and she was very enthusiastic about what she had learned about taking care of her health.

Lastly, once participants had reached a point at which they felt they knew everything there was to know or that there was no new information, they often ceased actively seeking information, and engaged in passive monitoring through newsfeeds and Facebook. In most cases, participants either read the newsfeeds very infrequently, or not at all.

5.3.3.3 Making Use of Information

In this section, I examine the process by which participants integrated information that they received from different information sources, combining information from external sources with information that they had gathered about physical, emotional, spiritual and other aspects of themselves, and then found ways to make this information work for them. This might mean in terms of helping them to make sense of the illness and life; it might also mean in terms of developing ways of “making things work” in life.

How do fibromyalgia patients do this? For some, the process may be akin to a feedback loop in the sense that participants find and/or encounter information that leads them to try a new treatment, and then based on that process they progressively make adjustments and/or engage in new information seeking based on evolutions in their thoughts and often, also their symptoms. P15, for example, has engaged in information seeking on a variety of issues, including exhaustion. Over time, she researched various potential causes, including hypoglycemia and vitamin B-12 deficiency, and tried a series of different potential solutions. As she was trying all of these solutions, she incrementally added to her knowledge. She described it as peeling back layers:

Like with the nutrition, say I have an issue with certain types of foods, if...that's one thing, and then I am getting better nutrition, not the processed things... more organic stuff, and that's peeling off another layer... and getting better exercise and more movement, of the proper kinds of movement that don't cause me to have pain. That peels off another layer. And that exposes something else. – P15

P12 also thinks of the journey as being cumulative: “I think all of these pieces along the way, you learn from, so you're always growing. So maybe it's really a spiral. Because you're not just, oh, that didn't work, well... you're kind of learning things from each step. So you can kind of reflect on it” (P12). Thus, we see that there may be an iterative experience of information consumption, use and reflection occurring in participants' lives.

P05 mentioned that her ability to find and assess information improved over time. She provided an example in which she combined the use of multiple sources to help her decide whether to use a device called a Transcutaneous Electrical Nerve Stimulation (TENS) unit:

I know how to look up and review – ‘cause I would review different websites, see something that a lot... a lot of valid sources have discussed... you start looking at whether it would fit in. When I was trying to decide whether to use a TENS unit... I went online first to PatientsLikeMe... ‘cause they list out different treatments people have used, and their thoughts. Then I went online and read about how people used TENS unit and how it affects pain management... pros and cons, then costs. – P05

Thus, she used different sources to put together different parts of the puzzle.

P20’s information seeking behaviors and subsequent processing of the information she found illustrates a process of judicious identification of the information she needed, and of careful consideration of this information to make decisions. For example, she started experiencing medical problems when she received a series of anthrax injections prior to military deployment. She had an extreme reaction to the second one, and thus was concerned about getting the third injection. She looked up information then to find out what percentage of people had reactions like hers, and what would happen after the third one. Then she also tried to find information on what would happen to her career if she refused to have the third injection. Ultimately, she decided to have the third injection, which she received a week later, and was then deployed.

Many of the participants in this study read extensively concerning fibromyalgia and synthesized across sources. For some such as P05, it involved consumption of both print and digital sources. P13 and P27 engaged in another type of synthesis, involving the comparison of explanatory perspectives on fibromyalgia. As mentioned earlier, P13 very quickly realized that allopathic medicine’s explanation of fibromyalgia did not satisfy him and moved on to study Chinese medicine. P27 said, “As soon as the doctors are thinking, okay this might be

fibromyalgia, I started doing research on the Internet, but then also checked out at least ten fibromyalgia books from the library, just to read different perspectives on what fibromyalgia is and like differing ways that you can treat it.”

Participants also made connections between pieces of information that participants had at their disposal for a long time. P10, whom I have mentioned did not initially believe that she had fibromyalgia, but ended up coming to believe it over time, referred to her thinking of her health condition as a process of “untangling.” Regarding how this happens, she says, “I don’t consciously think, oh, I need to sit here and untangle all of my health issues... maybe it’s one of those things that just happens over time... you have these light bulb moments that... well... that all fits together” (P10).

It surprised me that I did not see as many examples of putting information to work as I had expected. Reflecting on this process, I ultimately decided that there were two main reasons. First, I think the “light bulb” does provide some insight into this matter. For many people, the process of drawing connections and making sense of information is a cumulative one in which thoughts and feelings may have fermented for a long period before one day, they have a “light bulb moment.” That moment may be hard to capture, especially since, for many of the individuals in the sample, I was interviewing them long after they had developed some form of acceptance of their condition. Second, the study was designed to examine the big picture, and thus focused on higher level knowledge formation processes and sense-making, rather than lower-level processes of knowledge formation and acquisition. Even though I did ask questions that were intended to get at incongruence, such as, “Were there particular points in your journey when you felt confused?”, “Do you recall receiving any information that left you confused?”, and more generally, “How did you feel at different points in your journey?” and “Can you tell

me how your understanding of fibromyalgia changed along the way?”, to get at lower-level processes, it would be more appropriate to conduct a follow-up study on particular points in illness journeys and delve more deeply into information interactions at those points.

5.3.4 The Role of Physiological Sensations in Information Behavior

This study showed that participants came to utilize physiological sensations as a form of information. First, participants learned to employ their physiological sensations to learn more about their bodies and consequently, improve their ability to manage their condition. For example, P15 went on an elimination diet, and P24 tracked her reactions to foods, in order to learn what they were sensitive to. P11 mentioned that she came to be able to tell when she was about to have a migraine, and then she would go to get a trigger point injection.

Participants learned to interpret physiological sensations differently over time. As mentioned earlier, there were study participants that, early on, wondered if they were going to die. Over time, they learned that these sensations would pass, which helped them to cope effectively with the condition. P19 said, “Especially using mindfulness, and using the Buddhist techniques of sitting with your pain, and holding with your pain, and not being afraid of your pain, and not letting your pain cause you to do stupid s**t and go buy candles and that kind of stuff.”

Patients also learned to distinguish fibromyalgia pain from other types of pain. P18 described it as: “Fibro pain is... it’s like... it’s always there; it hurts. When you have a flare, it hurts more, but it’s like... just under the surface, burning, like a smoldering fire.” Being able to differentiate it from other types of pain can be helpful for them, because then they know when they can employ the management strategies that they have learned over time to whatever they are experiencing, and when they need to seek outside assistance. However, patients may

sometimes have difficulty convincing physicians that a new symptom that they are experiencing is worth paying attention to. For example, when P18 had had a serious fall that turned out to be a herniated disk requiring surgery, her physicians did not believe that there was anything wrong, and just told her that it was “just the fibro.” She had trouble convincing them, “Nope, it’s not my fibro. I’m telling you, it’s a different pain” (P18). P18 said that, “Once you tell them you have fibromyalgia, they attribute everything to that”; some patients, such as P12, may therefore choose not to tell physicians about fibromyalgia in order to obtain more information from the physician about what may be wrong.

Participants also learned to read their bodily signs and use techniques to control their physiological sensations. Yoga appeared to be particularly helpful for the participants in the study. P18 observed that: “When I started to do yoga, I started to understand my body more and what’s going on with it.” P17 put this in more concrete terms: “I learned to self-evaluate myself, how tired I was getting, and how I was feeling, so I could better pace myself and rest when I needed to.” Overall, previous research has also shown that yoga is effective for pain- and pain-associated disability (Büssing, Ostermann, Lüdtke, & Michalsen, 2012).

Mindfulness is another technique that participants mentioned as being useful, and has also been shown to be effective in previous research for chronic pain (Ferguson, Weinrib, & Katz, 2012; Morone, Lynch, Greco, Tindle, & Weiner, 2008). Previous research on mindfulness has found that it attenuates pain through enhanced cognitive and emotional control and modification of the contextual evaluation of sensory events; moreover mindfulness medication-related pain relief is associated with unique appraisal cognitive processes depending on expertise level and meditation tradition (Zeidan, Grant, Brown, McHaffie, & Coghill, 2012). Theoretical work has argued that mindfulness is useful for chronic pain management because of

six factors: environment/social variables, brain states, cognitive content, cognitive coping, behavior, and emotion and affect, which operate through mechanisms such as increased pain management self-efficacy, reduced pain catastrophizing, increased pain acceptance, pain beliefs, positive treatment expectations, increased approach-oriented coping, improved task persistence, increased resilience, and improved emotion regulation (Day, Jensen, Ehde, & Thorn, 2014).

The self-reported experiences of study participants show that illness affects many different dimensions of life, including cognitive, emotional and physical aspects. Moreover, as the testimonies of the participants show, and previous research corroborates, yoga and mindfulness meditation techniques may modulate and alter patients' pre-existing pain pathways and lead to pain reduction and improved overall well-being. There were other treatments, such as cognitive-behavioral therapy and hypnotherapy, that were mentioned by a few participants, and may operate through similar mechanisms.

5.3.5 The Role of Emotions in Information Behavior

This study showed that emotions played an important role in information behavior. Aside from serving as an impetus for information seeking, emotions affected the way that incoming information was perceived and outgoing information was expressed. Even in situations where information was not exchanged, emotions often led to changes in cognition and knowledge structures. Upon confronting the reality of the illness, patients experienced fear, anger, sadness and other negative emotional reactions; positive affective experiences such as validation, confidence, and hope also appeared to be important (Table 11).

Early on, participants were often fearful and/or frustrated. In the earliest stages, there was the uncertainty of experiencing very visceral pain and not knowing what it was. Patients might even fear for their lives, which may seem odd to a bystander knowing that someone has

fibromyalgia, but to the experiencer, in many cases given the extremity of the pain, it seems as if it must be serious and life-threatening. This fear would surface in other ways, including being fearful that they would not be able to take care of themselves or hold a job, and being fearful of what was in store for their future medically if the medicine(s) that they took stopped working.

Table 11. Emotions and Their Relationship to Information and Cognitions

| Emotions | Implications for Information Seeking, Perception and Processing, and/or Cognition |
|--------------------------|---|
| <i>Fear</i> | |
| Fear | Fear engenders trust in information sources that are not credible. Information withholding to prevent others' fear. |
| Concern about the Future | Concerns about taking medications. |
| Panic | Information helped her learn how to learn how to control her emotions, and in turn, her body better. |
| <i>Anger</i> | |
| Anger | Health situation caused anger and frustration. |
| Frustration | Not having answers was frustrating. Not being able to figure things out caused frustration. Lack of control causes frustration. Communication issues caused frustration. |
| <i>Sadness</i> | |
| Denial | People may not learn from information that they receive if they are overwhelmed or otherwise not ready to take it in. |
| Disappointment | One feels disappointment because he/she cannot do the things that they used to. |
| Sadness | Placing limits on the self is saddening. |
| Depression | Had to re-conceptualize the self, and that was depressing. Confrontation of the reality is associated with depression (prior to acceptance). |
| Grief | A grieving process needs to occur. |
| <i>Positive Emotions</i> | |
| Empowerment | Finding out that she could seek out and access information to improve her own situation was empowering. |
| Confidence | Experiences led to increased confidence and knowledge. |
| Validation | Recognition of the condition leads to validation. |

| Emotions | Implications for Information Seeking, Perception and Processing, and/or Cognition |
|----------|---|
| Hope | Online support groups are validating. Optimistic that she can figure out how to manage. Information = hope. |

These fears might be intertwined with frustrations: the lack of clarity in the situation, perceived inability to take control or improve their own situation, and communication issues with others. The gradual elimination of other, perceived to be severe, conditions such as arthritis or lupus, led to constant mental re-adjustment on the part of participants that was bittersweet: relief but also continued frustration because they were no closer to an answer.

Participants differed in terms of their approaches to finding a solution to their health problems; some primarily sought answers from their doctors, while others tried a combination of information seeking through their doctors and online information seeking; still others tried to “figure out” the cause of their health issues and find solutions for them. However, it was striking that, despite their different approaches, there were similarities in why they became frustrated: their seeming inability to make a difference in their own situation. One example in which a participant tried to reason through her situation was expressed by P14:

It was for me, what the hell did I do to have such a great day? What the hell did I do to have such a bad day? The fact that they can be right next to one another was so frustrating. It was so frustrating to be eating the same thing, no change in medication, no change in exercise, no change in atmosphere, no change in diet, blah, blah, blah and one day you feel great and the next day you feel like hell.

Though this problem is common with fibromyalgia, there are various solutions that could perhaps be emphasized with this community, including the use of trackers to help patients

identify subtle differences in their day-to-day situations and triggers that might be causing their flare-ups.

One point to be discussed in more detail later is that participants also experienced frustration due to the stress of their health situations and/or interactions with others, and for some, they found online environments to be good for expressing their frustrations. P14, who keeps a blog on Tumblr, said that for a while she and her husband were having some difficulties interacting due to her condition, and then she engaged a lot in online spaces: “I had a lot of frustration with communicating with him about my illness. We were having a hard time with it, so that provoked a lot of writing on my end.”

Fear and frustration had various effects on information behaviors. First, fear and continued concern about one’s health situation often served as motivation for active information seeking. Frustration with the lack of progress towards a diagnosis and perceived lack of control of their health situation, in the face of serious medical events, led participants to search for information and to be persistent in their interactions with health care practitioners (e.g. P13). This pressure dramatically lessened once those fears were alleviated (e.g. P09). Fear also led to greater receptivity and trust of information sources than participants might have had otherwise (e.g. P19).

Participants gradually came to experience the impacts of their illness on different aspects of their lives, and in the process, they also experienced different emotions and affective states, such as denial, disappointment, sadness, depression, and grief. Denial in the context of an illness is a state in which the experiencer does not acknowledge to themselves that they have an illness or the effects that may result from it. This phenomenon was not as prominent in the

sample, since, as I have mentioned, it appeared as if participants generally felt that they had reached a state in which they had “figured things out,” or were on the road to doing so.

Disappointment, sadness and depression were common, as participants came to realize that they could not do all the things that they used to do. For some, the emotional impact was not as severe. For P12, it was more like a feeling of sadness: “I’ve never used the word depression, ‘cause I don’t think I get depressed, but I can get sad. And I think I probably did more of that where, I might limit myself to something, and I’d feel sad about it.” For others like P21, as described in section 5.2.2.4., it was a much deeper, more fundamental re-conceptualization in which she had to come to terms with seeing herself in a way that she had not originally wanted to, and for P15, it involved grieving the loss of the “old me.” There was a need for participants to accept that they could no longer do what they could previously do and because, for many of these participants, their identities, and often, their work aspirations, were tied to their capabilities, this had an enormous impact on their emotional state.

Participants also had various experiences that engendered or increased positive affect. For example, many participants took comfort in the knowledge that there were others like them when they went online and read content by others who experienced similar symptoms and health problems. This might mean validation in terms of feeling that someone believed them, that there were others out there that had similar experiences, or both. The feeling of validation might also come from health care practitioners, patients’ friends, family and co-workers. P14, who had had social security disability benefits denied several times and then obtained them, spoke of how “there was this amazing sense of joy and like, at least somebody believes me now. Somebody gets it. The government gets it. It wasn’t even really about the money for me, I think it was just about, quit telling me I’m crazy...”

Apart from validation, there were other experiences that led to a heightened sense of confidence and ability to manage. For many, this began with the knowledge that they “could research and learn and access things that were good for me” (P19). Confidence grew incrementally with each small success that they had, in terms of learning their food triggers, negotiating with employers and other steps. Many of the participants also learned various skills along their illness journey, often as part of their efforts at information seeking, that became part of a “toolkit” which enabled them to manage their emotions and outlook. These tools, coupled with greater knowledge of fibromyalgia, management strategies, and health in general, paved the way for improved management. Thus, P26 equated information to hope:

It just seems like, to me, that once you have that knowledge and you have information, then you can equate that to hope and I think that that’s what makes the difference... it’s like when I asked [my doctor] how long do I have to live, in my mind I had already decided that whatever this was that I had certainly had to kill me because I felt so bad, and I couldn’t imagine living a lifetime like that. There was a hopelessness to that, but then there was hope in the information, the knowledge of what it was and then the information of what you actually can do, because it’s not like you’re sitting here totally subjected to your illness. There are things you can do to help yourself. There are things you can do that will improve. – P26

Considering the relationship between affect, information and cognition at a high level, we might observe that there are some common underlying factors. First, lack of control and lack of closure were persistent sources of negative affect, and they often led to information seeking behavior. In many cases, positive information encounters, whether self-initiated or not, would lead to a positive feedback loop in which participants would increasingly build

confidence, sense of control and skills to manage their condition effectively. There is a triadic relationship between information, affect and cognition.

There are ways in which this study corroborates and differs from previous work. On the one hand, this study corroborates previous work that has found that information seeking has positive effects on adjustment (e.g., Felton & Revenson, 1984). In addition, a previous review has found that patients who are satisfied with the information that they receive tend to have a better health-related quality of life (HRQoL) and less anxiety and depression (Husson, Mols, & van de Polle-Franse, 2011). In this study, on the whole participants were satisfied with the practitioners and the information that they ended up with, and this seemed to be related to their health-related quality of life. Though previous work has reported that some participants avoid information in health-related contexts, this behavior was not observed in this study; rather, what seemed pervasive among the sample was a persistent seeking of information and desire to know or “get to the bottom of” their health problems. Given the limited size of my sample and the retrospective nature of the analysis, it is not possible to conclude what the root cause of this desire was, but in most cases, it seems likely to be due both to the constant lack of answers, as well the innate curiosity and desire to know that many of the participants appeared to have.

5.3.6 Information Interactions with Print and Digital Sources

There was great diversity in the media types and information sources that participants used in their search for information. Table 12 summarizes the main information source types and provides examples. Appendix K lists all of the information sources mentioned by participants.

Though, as one might expect, the Internet was a common resource, books too were extremely common. Earlier on in their illness journeys, many participants went to Barnes &

Noble, Amazon, or the library and read everything that they could find on fibromyalgia. Print materials were used even among those who were younger and recently diagnosed, like P05 and P27. The use of print can be observed from Table 12. Three of the physician authors/researchers listed have authored popular health-related print books, and the book, *Fibro for Dummies*, was also commonly mentioned.

Table 12. Information Source Categories and Types, with Examples*

| Information Source Category/Type | Examples |
|--|--|
| <i>People</i> | |
| Physician Authors/Researchers | Dr. Devin Starlanyl, Dr. Jacob Teitelbaum, Dr. Paul Cheney, Dr. Charles Lapp, Dr. R. Paul St. Amand, Dr. Oz |
| Other People | Parker Palmer, Thomas Merton |
| <i>Informational and Emotional Support Exchange Venues</i> | |
| Conferences | The Wellness Conference |
| Courses | Mindfulness-Based Stress Reduction |
| Face-to-face Support Groups | CFIDS, FibroHaven |
| <i>Print Media</i> | |
| Newsletters | |
| Magazines | |
| Books | <i>Fibro for Dummies</i>, <i>From Fatigued to Fantastic!</i>, <i>Osler's Web: Inside the Labyrinth of the Chronic Fatigue Syndrome Epidemic</i> |
| <i>Online Information Sources</i> | |
| Twitter | |
| Informational Websites | National Fibromyalgia Association, CDC, Mayo Clinic, WebMD, CFIDS |
| Online Discussion Forums | Facebook, Reddit, DailyStrength, ProHealth, Yahoo Groups, PatientsLikeMe |
| Blogs | Tumblr |
| Webinars | |
| E-newsletters | MedScape, FM Aware |
| E-books | |
| <i>Other</i> | |
| Commercials | |
| Radio | |
| Television | |

*Examples that were mentioned by more than one participant are in bold.

The participants also frequently mentioned the same informational websites. Mayo Clinic, WebMD and Medscape were often mentioned as trusted sources. A few national organizations, such as the National Fibromyalgia Association and Chronic Fatigue and Immune Dysfunction Syndrome Association of America, and governmental websites such as the National Library of Medicine and the Center for Disease Control, were also mentioned. The e-newsletters that participants subscribed to included Medscape and FM Aware. Given the limited size of the sample, it is not possible to draw any conclusions, but it may be worth exploring whether print and online information sources that are more widely known among fibromyalgia patients and others that are available, provide high quality fibromyalgia-related information.

Content not specific to fibromyalgia, but relevant to other conditions participants had or to alternative treatment options, was also mentioned. For example, P17 mentioned a book by Hillary Johnson called, *Osler's Web: Inside the Labyrinth of the Chronic Fatigue Syndrome Epidemic*. Two of the researchers in Table 12, Dr. Cheney and Dr. Lapp, are known for their research on Chronic Fatigue Syndrome. One explanation for this may be that, a number of the study participants suffered from Chronic Fatigue Syndrome in addition to fibromyalgia. Another might be that, because fatigue is also one of the symptoms commonly experienced by fibromyalgia patients, those who are seeking information to better their health might also consume health information on Chronic Fatigue Syndrome.

Books which present a broad introduction to fibromyalgia seemed to be helpful to many participants because they provided fairly comprehensive introductions to relevant topics within a single volume. Because fibromyalgia is a complex condition and participants tend to find

information associated with it confusing (Chen, 2012a), it is helpful to have a lot of this information in one place. P08 said that she bought two books that she “wore out.” However, P27 felt that these books tended to approach fibromyalgia from the perspective of Western medicine, and that they did not go very deep.

Though it is perhaps true that these resources are simply an overview of fibromyalgia, it appears that they do serve an important role in introducing fibromyalgia patients to their condition. There is a great deal of information on the condition, and the preponderance of symptoms (and hence manifestations) does not improve the information horizon that patients face. Participants appear to be interested to varying degrees in researching their condition. For those who desire more, these resources may serve as a base from which they can begin more in-depth searching.

Participants appeared to read few, or no, journal articles, and a number expressed little desire to do so. One participant said she did not want to bother with anything that difficult to read (P08), and another said that she would probably not understand them (P17). Yet another said that they read them but found that there was no consensus across them (P06). At the same time, many participants mentioned that they did want to know what research was out there. There were a few individuals who told me about studies that they had read about and found interesting; some were from secondhand sources such as Medscape. Thus, in terms of the accessibility of research to health consumers, the sentiments of these participants suggests there is a need to increase public access to current research, and also to make this research available in forms that lay health consumers are able to understand.

There were cases in which information exchange occurred on a regular basis with the same source, over an extended period of time. Online support groups are one example that I

will discuss in more detail in section 5.3.8. Other examples include face-to-face support groups, patient education courses, or participation in classes or events held by a particular organization, like a yoga studio or meditation center. These interactions appeared to play significant roles in the journeys of participants in many ways. Those who engaged in support groups for an extended period found them to be useful sources of informational and emotional support (P14 and P25). Other individuals took courses that they found extremely useful because the courses gave them tools that they could use to deal with particular situations and/or problems (P05 and P19).

5.3.6.1 Source Credibility Assessment

Overall, participants were aware that the information they encountered was not necessarily accurate, and they employed different heuristics for making judgments about the sources and information that they used. As one participant put it, they engaged in active “weeding” to “[find] those books that seemed to be reasonable, and not full of hocus pocus and outrageous thoughts about where the illness comes from” (P08). Participants tended to discount information that claimed to be able to cure fibromyalgia: “I ignored the sort of things where people said... this thing will cure you. I didn’t trust people who promised cures; I trusted people who promised mitigation” (P09).

There was a great deal of concordance in terms of the online consumer health sites that were cited (i.e. WebMD and Mayo Clinic), and often participants would say that, because of their education and/or profession, they were aware that they should consult authoritative sources. Overall, the participants appeared to believe strongly in evidence-based research and differentiated it from the patient-generated information on the Internet. As one participant said of Reddit, “... these are people’s stories. They’re not actual research where if someone

handpicked a bunch of people and did a study on interactions between Lyrica and Cymbalta and followed them the whole way through” (P11). The extent to which they seemed to find source authoritativeness and evidence important was striking, despite the fact that in their searches for treatments that worked, many of them had ventured out into alternative healing modalities, which do not necessarily have a strong evidence base.

One participant described an approach that combined source authoritativeness with her own intuitive sense of whether the content made sense: “I look at the source and then I look – because it could be even just somebody posting some thoughts about fibromyalgia or something, and they might have some interesting points. I’m looking to see if they’re accurate about the basic mechanics of how it works” (P22). It is perhaps important to observe here that P22’s judgment is predicated upon her own understanding of how fibromyalgia works, which is itself a product of time.

Dr. R. Paul St. Amand and the guaifenesin protocol he developed were also mentioned by a number of participants. This example differs from the books previously mentioned in that participants who came across this information appeared to have done so through both print and Internet channels. One participant (P06) found that the protocol really worked for her, and she mentioned that she had not only read Dr. St. Amand’s book, but also done a lot of research online on the protocol. Though this participant, like many others, found that treatment information on the Internet and online discussion forums did not seem to suggest there was one solution that everyone agreed upon, she felt that the guaifenesin protocol seemed to be the solution that the most people were reporting as working.

Other participants also looked for concordance among multiple information sources. For example, P27 said, “So when I read something on the Internet about an illness, I’ll generally

only believe it if five different websites are saying the same thing.” In addition, she said, “I’m looking for things that are, like, the same from different people, because then that means that it’s probably something that, like, works or is utilized.”

Though overall, participants seemed to believe in the use of reputable sources, there also appear to be times when fibromyalgia patients were more receptive to sources that were less authoritative. P19 stated that she went through a “panic mode”, in which she felt that she was “grasping at straws.” She believes that her fear led her to be more open than she might otherwise be toward unconventional information sources: “I was afraid I was not going to be able to have a career, let alone the personal life that I wanted, and I was really grasping at straws. And I think very, very gullible and susceptible to any and every hoaxy solution...” At that time, she said, “I had people give me crystals and be like, ‘Put this in your window. You’ll feel better!’ And I’m like, ‘Really?’” She would have conversations with employees in organic food markets, and “whatever the current supplement that would cure anything, whether or not there was any research behind it,” she would take it and try it. She also had “literally dozens of books that were sort of junk science books on healthcare, especially on diet and nutrition.” Ultimately, she came upon two educational programs, one on mindfulness and the other, Irritable Bowel Syndrome, that helped her to manage her condition more effectively: “[They] enabled me to reconcile this condition with the fact that I’m a scholar, and I research, and I rationalize things through.”

5.3.6.2 Mobile Device and App Use

Though mobile app use was not pervasive, a fair number were mentioned (Table 13). Participants talked about two main uses of mobile apps: information organization and tracking, and mindfulness. P27 said that since she had been experiencing problems with her short-term

memory, she had looked into different Personal Health Records (PHRs), and ended up selecting Microsoft HealthVault, which enables her to keep track of all her test results, the contact information for her physicians and emergency contacts, and the hospitals and pharmacies that she goes to. She takes constant notes with it, and it has syncing ability among devices. P24 used Pill Monitor to help her remember when to take her medications and check off that she took them.

Table 13. Mobile Apps Mentioned

| Purpose | Category | App Name |
|-------------------------------------|---------------------------------------|----------------------------------|
| Information Organization & Tracking | General, Personal Health Record (PHR) | Microsoft HealthVault |
| | Medications | Pill Monitor |
| | Pain Tracker | Manage My Pain, MyRA, Pain Coach |
| | Fitness | MyFitnessPal |
| Mindfulness | Mindfulness | Mindfulness, Altered States |

A number of apps for tracking information of all different types, was mentioned. In particular, pain trackers were common, and it was interesting to observe that an app for a different condition, Rheumatoid Arthritis, was also among these, suggesting that to some degree it would be possible for people who have different chronic pain conditions to use the same app. P24 ended up going gluten-free because use of Pain Coach helped her to realize that her flares were coinciding with when she ate bread, pizza and other similar items.

One participant mentioned that she wanted to try using mobile apps to practice mindfulness. In a discussion post on Reddit, P11 mentioned that a relative had suggested two apps called Mindfulness and Altered States to help her sleep. Though not an app, P18 went to SoundCloud (<https://soundcloud.com>) and listened to meditations there.

A number of participants also used their mobile devices in their search for information. For example, P11 said that she downloaded various sources to her iPad, including an e-book on fibromyalgia and e-magazines published by FM Aware. P20 said that having a cell phone has enabled her to look up information when she is not at home. If someone mentioned something that triggered an information search, she could look it up and save the page in the appropriate folder (she had several on fibromyalgia).

5.3.7 Information Interactions with People

In this section, I elaborate upon on information interactions that participants had with others. These include family and friends, health care practitioners and employers.

5.3.7.1 Information Interactions with Friends and Family

Family and friends were an important part of participants' interactions. Sometimes, they engaged in information seeking on behalf of the participant. Participants took care in terms of how they communicated about their illness to those close to them, and there were also times in which participants' health condition resulted in friction between the participant and those close to them. I elaborate upon these interactions here.

5.3.7.1.1 Announcing the Illness

Aside from getting used to the idea that they had fibromyalgia, participants often had to decide whether to disclose this to others. In this study, there were two individuals who chose to share their story with their online network and provide them information about the illness (P05 and P24). P05 shared her story in a Facebook note, and also announced the launch of a candle business to raise awareness about fibromyalgia. She said that this also opened the door for future conversations about fibromyalgia, because those who were in her network were more likely to then ask how she was doing or share any information that they had.

P24 wrote to her friends and provided them information about fibromyalgia. P24 said that practically all her friends sent back a note of support. However, it does take some adjustment, because she is not able to go out as much as she used to, which is a problem in her interactions with some but not others. However, P24 did realize that people did not necessarily understand, and so she has set out to devote her skills as a writer to this cause: “I think that’s part of why I started writing the blog... I wanted to help people understand it more, because there are people who, when I told them I have this chronic illness, they were like what does that mean? Who are you? I’m still the same person.”

P27 is an active social media user with an extensive Facebook network. She posts often about a variety of things that she cares about, including her health. Because her illness history has been relatively short, the posts on her Facebook timeline tell the story of her path to diagnosis. As was the case for many others, there was not really a definitive day in which she was diagnosed, but around that time, she mentioned her rheumatologist’s suspicion and her feelings on the subject, and also posted a picture of all the fibromyalgia books that she checked out at the library. Quite a few people posted in response, and she said that since then, she has had many people share with her that they also have the condition.

In general, participants seemed to exercise care in considering what the ramifications of their communications might be. Many participants exercised caution concerning what they disclosed to their families about their illness. For example, P19 said that early on she did not say much to her parents, because she did not want to worry them, especially without concrete information from the medical community: “My friends here were very aware and very supportive... I wouldn’t say that I was trying to mislead my parents as much as I was trying to tell them when I had something to say.” This meant that she also had to shoulder the financial

burden of expensive diagnostics such as colonoscopies and MRIs herself: “I wanted my parents to retire and to not worry, and in part, I didn’t want to tell them what was going on because they would have been terrified.” There were a number of participants who avoided posting too much information about their health issues on Facebook due to concerns of worrying their family.

5.3.7.1.2 Understanding and Support

In their interactions with those close to them, participants met with a variety of reactions. Some met with disbelief. P08 said of her former partner, “He really couldn’t believe, like, he would actually not believe that something hurt. Like it couldn’t possibly hurt. You couldn’t be serious.” P13 said that, earlier on in his illness journey, “My dad was not thinking that I was sick at all. He thought I was a hypochondriac or something, so that was a bit discouraging.” P22’s ex-husband divorced her because she was too sick to take care of work around the house, and “right up until the end, [he] was insisting I could work.”

Many participants felt that their families did not understand why they were not able to do the things that they once did or that they should do. In some cases, families seemed to have an image of participants as being “superwomen”, and they were not able to accept the change (e.g., P23). P05 said that her ex-husband was supportive or concerned at first, because he thought that the illness “would go away,” and then he became unsupportive as time passed. P23 also spoke of this gradual change: “Of course, your family can’t see anything. They get to the point where they think that you’re faking it because they can’t see anything. They all start out really concerned, but then they kind of get tired of it and they think you’re kind of like – and it doesn’t go away. It doesn’t heal.”

People have a tendency to make suggestions to try to fix problems, which can be frustrating for patients and create a lot of tension. P05 said of her parents: “They just didn’t

know how to deal with it. They were trying but they just didn't know what to do. Because they couldn't fix it." It was as if everyone had a list of things that they thought she try: "'If you did this, you would feel better.' 'Or maybe you're not trying hard enough.' 'Have you... are you sure? Are you eating enough of this?' 'Have you taken this vitamin?'" The testimonies in this study have shown that participants tried a lot of their solutions and aggregated a great deal of knowledge on their own in their day-to-day efforts to deal with their health condition. Moreover, this process of repeatedly trying solutions that may not work is emotionally taxing. The addition of having to field suggestions from those around participants, many of which can be redundant, can be extremely frustrating. P05 said that, "Not everybody understands what chronic really means. They think you're not trying hard enough."

Despite these issues, it appeared that many participants' families were extremely supportive. P17 said that, "[Her husband] has been wonderful... he never once tried to push me to do something I didn't feel like doing. He's never once, you know, told me it was all in my head or get over it. He's been great." As mentioned earlier, P14 and her husband have had to work on communication and understanding, and this included going to counseling to work on this. Since then, she said, "He has changed tremendously and grown and matured and I have too. He's been a wonderful source of comfort for me since we've started. Well, he always has been, but especially since then. He's learning how to make it work, and I'm learning how to make it work." Some family members were very supportive and sought information on the participant's behalf. P05's sister bought her recipe books for people suffering from chronic pain.

5.3.7.1.3 Collaborative Information Seeking

Those who were close to participants often became involved in the search for information. For example, P09 has played games online regularly for many years, and has become close to the people that she plays with. She talks to them about her symptoms, and her symptom also affect her performance in the games, to different degrees on different days. These fellow game players are thus keenly aware of how she is feeling on any given day, and show their concern by engaging her in discussion about how she was feeling, searching on her behalf, and passing along information that they find. In fact, in her case, she first found out about the tender point examination² because one of these fellow gamers suggested it to her.

A couple of participants found informational and emotional support in friends that had a similar condition. P15 had a friend who had multiple sclerosis, and she talked with her at various points, first to see if it might be what she had, and then later, to find out what treatments she had undergone. P24 knew someone with cystic fibrosis who also helped refer her to information.

5.3.7.2 Information Interactions with Health Care Practitioners

Health care practitioners played a prominent role in the interviews of all the participants. Participants generally established long-term relationships with multiple healthcare practitioners, and there was a great diversity in the types of practitioners that they saw. In terms of allopathic traditions, patients generally saw general practitioners, rheumatologists, and neurologists, though other specialists such as gastroenterologists, orthopedists, physician's assistants, and

² The tender point examination was elucidated in the American College of Rheumatology 1990 Criteria for the Classification of Fibromyalgia, and thereafter used in the diagnosis of fibromyalgia (Wolfe et al., 1990). The diagnostic criteria were revised in 2010 (Wolfe et al., 2010).

nutritionists also were mentioned. Alternative medical practitioners included chiropractors, acupuncturists, massage therapists, physical therapists, and naturopaths. Over time, participants generally assembled a team of healthcare practitioners that they relied on; for some, this includes a team of primarily allopathic practitioners, and for others, a combination of practitioners of various traditions and perspectives, including allopathic, alternative and integrative. This section explores how participants forged those relationships and engaged in co-construction of knowledge and management strategies with their physicians.

5.3.7.2.1 Vetting Doctors and Partnership Medicine

‘Cross that one off! That’s the wrong one!’ – P12

‘If I don’t like that GP, I’ll keep going. I’ll find somebody else.’ – P19

Though participants in the study eventually found practitioners that they liked and trusted, getting there was not always easy. There were cases in which physicians exhibited skepticism regarding patients’ symptoms. For example, P06 had woken up one day to find her wrist extremely swollen, and a sports medicine doctor had looked at it and referred her to a rheumatologist. By the time she had been able to see the rheumatologist, the swelling had gone down, and the rheumatologist had told her he thought it was ‘all in [her] head’ (P06). Speaking of his own experiences with doctors, P13 said, “They either thought I was being a hypochondriac or something or didn’t believe me at all.”

The assembling of the healthcare team is no small task. Over time, participants develop a list of things that they look for in doctors. Two of the most basic are that physicians take the time and effort to listen to patients, and that they are open to questions. The participants speak of ‘interviewing’ doctors and counselors, of spending the first appointment just chatting with doctors rather than having a physical, to see if the relationship is going to work. P05 and P06

both mentioned that they appreciated physicians going through their medical history with them on the first visit. Another characteristic that participants looked for was open-mindedness, providing information, and leaving it up to participants to make their own decision:

...when I'm vetting a doctor, I'm looking for someone who's open-minded, looking for somebody who's not going to just pooh-pooh acupuncture, or alternative practices, but also someone who's not just going to like, "Here. You need these 50 tests..." I really appreciate people who give me information, give me options, and then let me decide for myself. Because like, I want to understand; I don't want to be told. I also want to choose for myself. – P19

Participants also appreciated a soft touch and a desire to share information: "She relates to me. She doesn't just try to push medicine on me. She'll suggest something and I'll say yea or nay, and she's good with whatever I decide. I never feel like she's rushing. I never feel like she has not got time for me. She's just been a really wonderful source, and she educates me. I think doctors need to share" (P14).

The theme of physicians pushing pain medication was common and undesirable among the sample: "I'm very fanatic in some ways, about vetting doctors, because I don't want to be with someone who's just going to throw pills at me" (P19). They are looking for "partnership medicine", not "here it is, go do it" (P12). There are things that patients can do to make the most of the appointment:

In a seven minute appointment, they're going to listen to you for the first two minutes, and then they've already drawn their conclusion. That means as a patient, I need to go in clear and concise, not wandering... 'cause I've only got his attention for two

minutes... I take paper in with me always. Sometimes I've written things down I want to ask ahead of time, and then, I take notes. – P12

Thus, P12 believes that partnership medicine involves a relationship in which both parties have responsibility. Finding the right person can be of great benefit and result in tremendous self-growth. P14 said of her counselor: "I want somebody who's compassionate and who can help me be a stronger, better, healthier person."

5.3.7.2.2 Information Gaps

As I considered the interactions of patients with their health care practitioners, I observed various gaps in communication. In the context of their interactions, these gaps seem to occur under three main circumstances: patients desired information that practitioners might not have been able to give, practitioners could have provided information that could potentially have helped patients but were not cognizant of the information need, and patients deliberately withheld information from physicians.

When asked about information that they received from practitioners, many said that earlier in their journey, they did not receive much information. Among those was P05, who said, "It was a very frustrating time, because nobody could give me clear answers. They were like, oh, we think it's fibro, and once they tell you it's fibromyalgia, then that's it... They were like, okay, that's it. Don't have much to do for you."

There were pieces of information that were omitted by physicians that perhaps would have made the journey easier for participants. For example, two participants mentioned situations in which they were prescribed antidepressants for pain, and they did not really understand why. One found out later on her own as she read more about fibromyalgia that antidepressants were routinely prescribed for pain (P06). The other was not told about the

medication she had been prescribed, although she was also told not to stop taking it without consulting the physician (P16). She found out about it a year or so later, when she heard on the radio of someone overdosing on it.

Sometimes participants did not tell their physicians that they had fibromyalgia. In some cases, this was because participants perceived that fibromyalgia had a tendency to become the physician's explanation for a phenomenon that the patient was experiencing, and that this explanation did not fill in any knowledge gaps for the patient. For example, when P12 consulted a physician about some health problems she was experiencing, the explanation turned out to be hypoglycemia, though her lab values were within normal range. She did not tell her physician that she had fibromyalgia, but her physician ended up asking her if she had fibromyalgia. When I asked P12 why she did not tell the physician initially, she replied: "... it's not that you're embarrassed by it, but you're like, what do they think? Do they treat you differently? And in that case, I was really trying to figure out what was wrong. I didn't want somebody to say, 'Oh, it's fibromyalgia; don't worry about it.'" Aside from this idea of wanting to get to a more robust medical explanation, P12's testimony hints at something that P16 states much more directly: "[The orthopedist's] quote was: 'People with fibromyalgia just get tendinitis for no reason' ... that attitude of people with fibromyalgia, as though we were some weird class of people, just get tendinitis." Thus, fibromyalgia might be used as an explanation of some symptom that patients were experiencing, but this explanation was not only empty, it also left patients feeling that they had not been treated with respect by health care practitioners.

5.3.7.2.3 Information Exchange

Though participants do encounter situations in which physicians provide little information, the interview testimony showed that over time, patients often engage in rich information interactions with physicians. A number of participants mentioned that physicians might mention something that they did not understand, and they would go home and look it up on the Internet. Other participants mentioned that their physicians would tell them about recent research.

Many participants also did their own research and brought information to the consultation room. A number of participants brought up the possibility of fibromyalgia to their doctor or another health care practitioner (e.g., P07, P08, P09, P13, and P24). Interestingly, there were also quite a few that said that they thought they had fibromyalgia, but they did not tell their physicians because they knew that they were not supposed to self-diagnose.

Participants who encountered information about fibromyalgia on their own did so in a variety of ways. P08 said that her co-worker had taken her symptoms and entered them into a WebMD search, and that the symptoms had suggested fibromyalgia as the condition. P20 also entered her symptoms into symptom checkers: “You know how you go on... medical websites, and you can do like the questionnaire things to where you get a diagnosis? So I did just about every one of those that I could find.” P09 was told about fibromyalgia and the tender point examination by a fellow game player who had found the information online, and P13 was referred to online information about fibromyalgia through his mother. P07 had learned of fibromyalgia through a paper newsletter, and P24 came to suspect that she had fibromyalgia through various online information sources she had read. Thus, information exchange with physicians was often part of a larger chain of information seeking and/or exchange.

5.3.7.2.4 Collaborative Information Seeking/Problem Solving with Physicians

Many participants reported interactions with physicians that could perhaps be viewed as collaborative information seeking and/or problem solving. P17, for example, had learned of an experimental medication for alopecia, and she mentioned to her dermatologist that she was interested in taking it. The physician said that the medication had not been approved for women, and that she was not comfortable with prescribing it. She ended up trying something else on that visit, and the next time she went back to see this physician, the physician had done her own research, and was then willing to prescribe it. By then P17 had thought it over, and decided it was too risky for her.

This example illuminates several points. First, it is clear that both parties are engaged in the information seeking process, and that their actions are dialogic: information seeking and communication on the part of one results in reflection and subsequent information seeking on the part of the other, and vice versa. The physician is open to receiving and processing information offered by the patient, and the patient also reflects upon the physician's opinion. The parties explore the information together and ultimately arrive at a decision, with the ultimate responsibility for that decision resting with the patient.

Besides this type of iterative process of information seeking, participants also mentioned looking up information online with physicians in consultation, and one participant also said that she looked at her electronic health record with her physician. Another participant, P05, said that she had a good team of physicians because, though "everybody was targeting different things... they all knew of each other." Moreover, her primary care physician would do research on how she could support her patient.

Another example of a collaborative process towards diagnosis was related by P13. He became acquainted with his physician because he was a classmate in the Chinese medicine program in which he studied. He had already had numerous previous negative interactions with Western trained physicians, so when he met this practitioner through the program, he thought that the physician must have been pretty open-minded to be studying Chinese medicine. So he started seeing this physician as a patient. When P13 found out about fibromyalgia through his mother's referral to a website describing the condition, he thought it seemed plausible, and mentioned it to the physician, which eventually led to the diagnosis. An additional point was that P13 had undergone numerous lab tests to explore many different issues. Ultimately, the physician told him that he fit the criteria for both Chronic Fatigue Syndrome and fibromyalgia, but diagnosed him with fibromyalgia because it encapsulated more of his symptoms.

5.3.7.3 Information Interactions with Employers

The participants in the study demonstrated that there was great diversity in terms of how people dealt with fibromyalgia in their working lives. There were some, such as P12 and P16, who experienced minimal or no disruption due to their health condition, and so did not perceive a need to ask for accommodations. Others, such as P08, said that her workplace was very understanding of people's health issues.

Telling employers about one's condition and asking for changes to make the environment easier to work in is another strategy. P11 searched for information on the Internet relating to fibromyalgia, bookmarked it, and printed it out to show to her employer. At first, P05 was reluctant to ask for changes in her work environment, but she became better at this over time: "I had them come and move the light. I had to be okay with asking them to come

and move me a couple of places. Before I never would have... I would have just been miserable, and not been as productive.” She also learned how to have these conversations:

When you’re talking to an employer as well, you have to give them the solutions ... It’s not just like, ‘Oh, I have fibromyalgia, and I need a flexible schedule.’ It’s like, ‘So... I have fibromyalgia. I need a flexible schedule, and this is the kind of schedule that will work for me... And we can test it out, and we can make sure that I’m still accomplishing the work that I need to complete, and if you feel that it’s not happened, let’s have a conversation at a two-week mark,’ you know, to make sure that it’s working for both people.” – P05

However, these are not easy conversations to have, and not all participants felt comfortable having them. P15 waited until she had made herself indispensable at work before asking if she could come in later, due to problems with sleep.

P19 said that she did not disclose that she had fibromyalgia at first because she worked at a university where there was a high profile individual who had fibromyalgia and used it as “an excuse not to do [her] job.” Thus, she wanted to prove herself as someone who worked hard and was good at her job. Now that she has tenure, she has been much more willing to speak out on issues concerning work conditions.

5.3.8 Online Spaces and Online Participation

Participants used a diverse array of online media throughout their illness journey. In my dissertation, I collected as much social media that participants authored as I could. For the most part, I focused on health-related social media, but in most cases, to contextualize participants’ social media use, I also collected media from generic platforms such as Facebook and Twitter.

In this section, I first describe topics that were commonly addressed, and then I examine major themes in the content examined.

5.3.8.1 Topics of Discussion

Common topics of conversation include sleep, medications, food allergies, supplements, migraines, coping, being diagnosed, disability, and possible connections between fibromyalgia and other conditions. Sources mentioned by the group included government-issued informational material, links to other web pages, and news articles. Other recommendations included supplement vendors. Sometimes, forum participants cut and pasted information from other sources.

5.3.8.2 Common Themes

5.3.8.2.1 Seeking out Others with Similar Experiences

Participants in the study often used social media to seek out others with similar experiences. There were various reasons for doing so: to know that they were there, to connect to them, and to seek out examples of how to manage. At the outset, it was comforting for participants to know that there were others out there who shared their experiences, regardless of whether they actually connected. Knowing that there were others was, in and of itself, a form of validation: “I do like them because number one, it validates you. I’m not the only one like this. I’m not crazy” (P23). Of course, patients also interact with one another. For example, in one thread in which P11 participated, one young poster had shared frustrations as she was on the brink of diagnosis, and other young posters had responded with their own histories.

Often, participants were not able to find others in their immediate network who had the condition, and there were some who tried to attend face-to-face support groups and found that they couldn’t relate. For example, P05 yearned to find someone with whom she shared

similarities in terms of age, race and career aspirations. She attended a support group for a while, but had trouble relating to the other members of the support group “because the support group that I went to was mostly old people who had fibromyalgia and had now the luxury... they don’t need to work... Some of them had families... some of them had people to take care of them... they’ve lived their life. And I was like, I am just beginning my life, and all of you guys are in a place where we can’t relate.” Of the members of the support group, she said, “they were nice, but imagine, they were all... except for one, older women. Older White women, to be specific. And for me, it was just like, I can’t even – we don’t even have a shared experience.”

P05 said that, “that would be amazing, to see more examples [of women who are living with it]. Especially women of color, because to me, that’s my reality.” She acknowledged that part of the reason she had not met as many was most likely a difference in how vocal people are about the condition in different ethnic groups: “When it comes to fibromyalgia, I have not met a lot of Black women... I know it has to do with how people perceive and talk about illness. Especially in Black communities... it’s the same with certain conditions, but fibromyalgia’s one of those where, given its history, are also... how people perceive it... affects how people are going to talk about it.”

However, P05 found sites online, such as ChronicBabe and the National Fibromyalgia Association, that were helpful in terms of providing stories of how others were doing: “The National Fibromyalgia Association at one time had little stories of people living with fibromyalgia and telling their story. I read those... it was just nice to have the interaction... people just interacting and talking about their different experiences, and kind of like, either what

they're doing to cope, or just around that realm.” It was helpful for her to see these examples of how people were making it work, as that was what she was trying to do.

P24 found it difficult to deal with fibromyalgia because of the disconnect between her age and her initial perception of fibromyalgia as being a condition that older women develop:

The biggest part for me was being so young and dealing with it... this is something that was really difficult and has been helpful to be able to find some people online who are the same age as me, or in the same general age group, because a lot of the times when you look up fibromyalgia information, it's pictures of old ladies doing water therapy exercises... They have it too, but it's completely ignored that you can be a very active young adult who has supposedly everything going for you in your life and then this happens and brings everything kind of to a screeching halt.

Thus, online spaces afford an additional opportunity for patients to find others with similar experiences.

It is useful to note that having similar experiences does not necessarily mean having the same condition. Among the sample, there were individuals who were able to connect with, support and exchange information with others who had different conditions from the ones that they had. For example, P09 often shared her experiences with another fellow game player with a different, but also “invisible”, condition. In addition, in a thread that she started where she shared her experience of having fibromyalgia with others, the others who responded to this thread had many other conditions, including ME/CFS, Multiple Sclerosis, Crohn's Disease and cerebral palsy.

There is an inherent power in the feeling of similarity. For example, in one thread, forum members discussed how their body condition can change dramatically even in a short

period of time. The initial poster asked: “Has anyone experienced fluctuating Pain and/or Fat[i]gue in the same day? It’s strange, I can feel good part of the day and then all of the sudden it changes and I have difficulties walking.” Another forum member echoed these sentiments: “I have this problem too. I can feel ok and then just ‘crash’ very quickly. I don’t seem to be able to sense it coming on or be able to predict when it’s going to happen. It sure is frustrating!” Thus, we can see that participants read about others’ experiences online and empathize with each other.

5.3.8.2.2 Seeking Answers

There were various ways that participants sought answers online. Some participants, such as P17 and P22, participated actively in terms of reading, responding and initiating questions. According to P23, the Facebook groups that she participates in often engage in collaborative problem solving, in which one person asks a question, and then others brainstorm to help them think of potential solutions.

P08 said that she sometimes read the content in health-related discussion forums, but she never posted anything on the Internet about herself because she knew of someone who had posted information online in the late 1990s, and that information could still be found. But she also observed that there was no reason to post anything online, because what she wanted from these support groups was validation that someone else was experiencing the same thing, and she could get that just from reading. P05 had made observations along similar lines, saying that a lot of times she did not need to post anything because what she had wanted to know had already been asked.

Many participants seemed cognizant of differences in the nature and quality of information that a particular site might offer, and interacted with the sites differently based on

these impressions. As previously mentioned, P05 used a variety of different resources in her search for information, lurking on some sites and posting on others.

5.3.8.2.3 Sharing of Experience

Online platforms can be useful environments for participants to share their experiences with others. A number of participants did this on Facebook through status updates, and on Twitter through tweets, and in discussion forums, mostly devoted to health topics, but also sometimes through discussion forums that were not health-related. For example, P13 had frequented Stickpage for years, and occasionally would share his illness experiences on that platform. Though the community was dedicated to a completely different activity, in this situation the individual considered themselves connected to the community and thus, it was a natural environment in which to share his experiences.

Even when people are happy about their lives, there may be times when they need to express their frustrations. A number of participants found discussion forums to be useful platforms for “venting”. Reddit can be a good place to go because posting or reading subject matter that is not meaningful can be a good way to let go of one’s frustrations:

It’s a really good outlet when you’re ticked off about something, but there’s no way to fix it. You’re stuck with this pile of frustration, and sometimes it’s about being in pain, sometimes it’s about being tired. Sometimes it’s completely unrelated to the illness, but it’s good to get it out. Which is why I like games kind of: you can kill pixels, there is zero negative effect in the real world, but you feel better. Same thing for this. Posting stupid stuff or reading stupid stuff actually does make me feel better. – P09

In one case, P09 started a thread on a discussion forum that told the story of her experience of her illness. She received many responses expressing empathy and offering

suggestions. In one of her responses to these posters, she thanked them for their advice and said, “Make no mistake, I'm not giving up on my life. I have a pretty great one all the venting aside. I just needed to get it out so I wasn't unnecessarily cranky at the people who are around.” Thus, this example shows that forums offer participants an opportunity to release their frustrations in a way that does not cause pain to others around them.

Some study participants made efforts to provide useful information to newer members, or to direct them to such information. This might mean directing them to forums that would be of use to them, recommending content for reading or products to try, or trying to fill in the gaps in fibromyalgia information. P22 mentioned that she often encounters patients in the forums that appear to be lacking basic knowledge about fibromyalgia. She gave an example:

They don't tell fibromyalgia patients that when they start taking medication it could be a month before they notice a change in their symptoms... why would you not tell your patient that? I mean most people assume okay, I'm taking a pill, I should feel better in forty-five minutes. I should feel a lot better and when it doesn't happen they're like well why not... – P22

Some of the topics that P22 appeared to post on most frequently included sleep, artificial sweeteners, common co-morbidities of fibromyalgia, and the *Fibro for Dummies* book recommendation.

P22 found herself being very repetitive, and though she found it annoying, she saw this work as a necessity:

I just feel doctors don't do a very good job communicating period and I do get annoyed having to repeat the same information over and over again but at the same time I will do it because people have to be educated and if the doctors aren't going to do it,

somebody's got to do it so they understand what's going on and I don't think as far as I'm concerned with the medical profession and the prices that we pay for care that that's too much to ask but it doesn't happen most of the time.

There were also study participants who posted in forums, but less frequently. Among those who characterized themselves as being less active, they gave various reasons for the times in which they did participate. These included feeling that they needed to “add a voice” (P05), and feeling bad for the poster.

5.3.8.2.4 Change in Participation over Time

There were differences in whether, and to what extent, those who participated in online communities continued to do so over time. Though some, like P22 and P23, have continued to participate for extended periods of time, more often than not, participants engaged for a limited period of time, and then their participation tapered off. There were various reasons why this occurred. For many, their primary motivation in engaging in discussion was to find information that they considered useful. As time wore on, the benefits from this interaction decreased. In the case of P17, her participation in the fibromyalgia Google Group decreased as her interest in fibromyalgia-related information waned. She also mentioned that she became tired of the repetition. As each time a new member joined, the same conversations were often repeated. In the case of P13, as time wore on, he came to feel that there was a lack of substance in the forum discussion.

5.3.8.2.5 Meanings of Online Community

The interviews showed that participants held different views of what online community meant. At the outset, online communities could help participants to feel that they were not alone: “I think anybody with a chronic illness who uses it would say that it really helps us to not

feel so isolated” (P14). P24, who developed fibromyalgia and was diagnosed within the last two years, said about ‘gentle hugs’: “Cheesy little sentiments like that really do mean a lot when you’re sitting there miserable or it’s three o’clock in the morning and you can’t sleep and you’re scrolling through Twitter or Instagram and see that other people are up and having the same problem and they’re in pain too. It really does create this little bond that you have.”

Online communities also afforded a sense of perspective about one’s situation, the opportunity to help someone else, and to have some contact with others, which may be important for many with fibromyalgia because they are restricted in terms of their social activities. P22, who does not leave the house often, explained this in the following way:

I think it’s contact with the outside world. I think that it gives me a better perspective on my own situation because I can look at somebody else and go, ‘Well, thank God, that isn’t me – at least not today. It gives me some degree of pleasure to be able to share information and help someone who is really struggling, and I just think it gives me a sense of balance because I can see where other people are at, and I know where I’m at...

I guess I draw some comfort from that.

Yet another view was as a series of stories being told: “When somebody tells anecdotes like I told here [on Reddit], they’re adding to this larger story” (P09).

Online communities were regarded as a source of informational support, emotional support, or both. P23 said that she enjoyed engaging with fibromyalgia support groups on Facebook. People would bring up issues they were having, and the group would offer suggestions and support: “Especially when I don’t feel good, I can at least talk with somebody that will support me and say, ‘I know how that feels. I’m sorry you’re having a bad day.’ It’s

nice to communicate like that. ‘Did you try this? Did you try that? Did you try a hot shower?’ Sometimes that helps. ‘Did you try an ice pack or did you try different things?’” (P23)

Online community might not only mean different things to different people: even for the same person, it might have a different type of significance depending on the situation. For example, I have mentioned the case of P17, who participated in a fibromyalgia forum in 1997, and at the time of the second interview, was participating in a forum for alopecia. She observed that the meanings that these two online communities held for her were different:

I think when I first started using the FM site, I viewed it a lot as a support group.

Information and support. But I think now, with the FFA, it’s more to research information, and less about support... it felt like I needed more of the support and information when I was first diagnosed with the FM, because I was really having a hard time. I had small children, and I had the CFS in addition, and it was just very difficult.

Those things were life-altering. This is not. – P17

5.3.8.2.6 Community Atmosphere

The participants’ experiences with online communities illustrate that communities often differed in terms of atmosphere, and that these differences might determine which communities participants chose to join, and how long they continued to remain active. Different factors may contribute to community atmosphere, including community size, frequency of postings, prominence of and style of leadership, and member interactions.

People may gravitate towards different platforms due to their own preferences for community atmosphere and information content. For example, though P22 participates in two online communities, DailyStrength and MDJunction, she prefers DailyStrength because it has a

larger volume of traffic and “better mix of people,” and the core and peripheral members are more knowledgeable and supportive. The core group serves as de facto moderators:

there are specific people that I think of as moderators, they’re probably not officially moderators... [but if] somebody is getting out of line or abusing the site in some way or being nasty to somebody else, they’ll step in immediately and say, ‘Listen, this behavior is not appropriate and if you continue, then you’re going to get reported,’ or they do report them. There’s a core group of people that are very active... We kind of moderate ourselves for the most part. There are moderators that work in the background but they generally don’t get involved unless it’s absolutely necessary. – P22

P11, on the other hand, prefers Reddit to DailyStrength because she feels that there is more of a focus on information, and less on feelings:

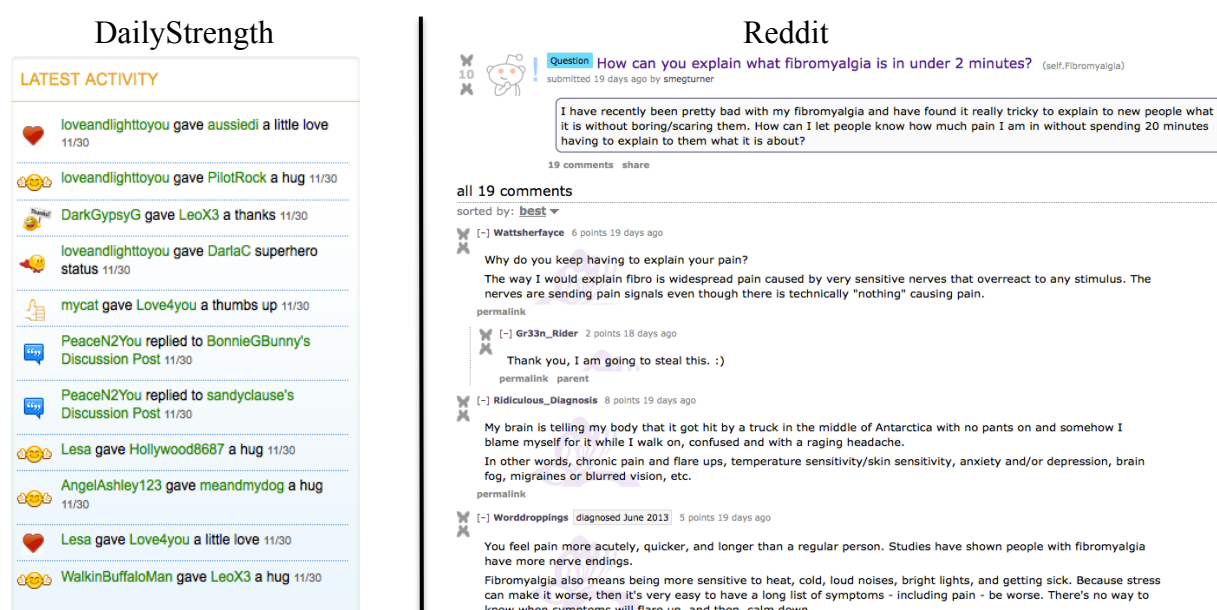
When I found the board I was actually really impressed and I kind of liked their attitude more...[than DailyStrength] because they were a little too happy for me. People would whine, ‘Oh, my life is so horrible,’ and then people would cheer them up and it was like a constant cycle of that. I do feel that the Reddit board is more informative and there’s a little bit of, ‘I’m having a bad day,’ but when it happens, it’s like I’m really having a bad day. It’s serious and not I had a bad day yesterday, and I had a bad day today, and I’ll have a bad day tomorrow... it’s a better board overall. – P11

These two examples show that people may form different impressions of the same board, and that this may arise due to their own preferences. Though P22 is interested in fibromyalgia-related discussion, she is also interested in engaging with others as a community, and open to unrelated discussion. For example, she said that she enjoys the daily “check-in”

post that one of the members writes, which she often finds amusing and entertaining. P11 is more interested in fibromyalgia-centric discussion and less interested in emotional support.

It is useful to consider here how differences in site design may lead to differences in community atmosphere. DailyStrength facilitates affective interaction by offering functionality for members to interact with others through actions such as giving love, hugs, thanks, “thumbs ups”, and “superhero status.” These actions are visible through a “Latest Activity” display (Figure 9a). Reddit features a nested comment display that enables readers to easily follow and respond to conversations point by point (Figure 9b).

Figure 9. (a) DailyStrength Latest Activity (b) Reddit’s Hierarchical, Nested Display



Another factor that may affect the feel of a community is its size, and this in turn may affect members’ willingness to post and/or the content of their postings. P17 says that one of the forums that she has participated in, Alopecia World, is not as large as some other forums, and in this forum she has posted comments that were a bit humorous, which she might have been more reluctant to do if it were a bigger group. The characteristic of community size is

perhaps a particularly important one to consider, as fibromyalgia-related discussion forums are more likely to be larger because of the lack of a tendency to partition fibromyalgia further into subtypes, as has been the case with other conditions such as cancer. However, it is also important to observe that members may still view communities as being personal despite their size, as in the case of P22 and DailyStrength. Thus, forum features may be designed strategically to foster personal interaction.

There may be tendencies for certain discourses to be more popular than others. For example, in a thread in which P16 participated, a poster describes a negative experience she has with her doctor. This thread started off primarily sympathetic towards the poster and remained so throughout, but after one person mentions the possibility of “firing” doctors, the subsequent posts take on a much harsher tone, with three of four of them continuing to use the word “fire” and with parts of the posts written in all capital letters. This suggests a kind of affective or emotional contagion, and also illustrates how certain types of patient “ideologies” might be propagated through online spaces.

5.3.8.2.7 Negativity Online

Many study participants felt that there was a great deal of negative sentiment expressed online. For example, P20 said: “Like on Facebook, I know I’m a member of one of those pages. But you go on there, and it’s more, ‘Oh, woe is me.’ And I’m like, ‘Stop with the oh, woe is me.’ I don’t know. Just tell me what makes you feel better.” Participants make a conscious decision to minimize their exposure to negative information:

I don’t participate in it a bunch because I’ve noticed a lot of them [fibromyalgia groups on Facebook] are, from what I can tell, a lot of negative stuff, people just on there complaining about it, and I don’t really like to inject more of that into my life. Yeah,

this thing sucks and we can all talk about that, but I don't want to continue that negative barrage of information into my life. – P24

Another participant observed that information from fibromyalgia groups often made her feel worse: "... the funniest thing with receiving the journal... I recognized that I would read it, and then I would feel worse the whole week after. 'Cause I was like, focusing on it, instead of focusing on other things" (P12). These examples show that many participants realize the effects that negative stories had on them, and consciously make decisions to reduce their consumption of such information.

5.3.9 Summary and Discussion

In this section, I described the information behaviors of patients along their illness journeys. Study participants learned a great deal along their illness journeys, and their knowledge acquisition might be said to cover different realms, including foundational knowledge of fibromyalgia, health and wellness; skills-based knowledge in terms of how to find and evaluate health information; knowledge of emotion and mood management; knowledge of how to interpret physiological signals; and a contextualized type of knowledge concerning how to navigate life and society given their illness.

In considering patients' information behaviors and knowledge formation, consideration of time is essential. The knowledge and understandings that they develop do not form overnight, nor does their skills acquisition. In the beginning, participants' information seeking behaviors are more diffuse and unfocused. They first respond reactively to their symptoms, searching for them using symptom checkers, and/or trying to match up their symptoms to diseases on their own. Once they learn of the name "fibromyalgia," they start searching for everything they can find on the condition. Eventually, they stop searching actively and enter a

phase of monitoring. There are many reasons why they stop searching – they want to move on, they come to believe that they will not encounter new information, they search for information on an “as needed” basis. In reality, for most study participants, multiple reasons were true.

It is interesting that many patients started off searching for information on particular symptom, then transition from this to searching for information on fibromyalgia in general, and eventually return to searching for information on specific symptoms again. Does this mean that it was not useful for them to go through the “middle stage” of searching for information on fibromyalgia? I would argue that this is not necessarily true. In some ways, this period of searching for information about “fibromyalgia in general” served as an opportunity to build an intellectual and emotional foundation from which they could then move on. The disease that we call fibromyalgia today has been called many names in the past. Tomorrow it may be called something else, but today, under the term of fibromyalgia, patients encounter information that addresses diverse facets of health and wellness. This information serves as a wide conceptual base from which they can decide – “This is all I need” – or continue to do research on specific topics, as suit their physical, emotional and intellectual dispositions, and their situations in life. Even if they eventually go back to searching for information on specific symptoms, they do this with the conceptual backdrop and through the wider lens that they have acquired.

Many participants spoke of trying to “figure out” what was going on, getting at the “underlying thing,” the problem that was causing their physical symptoms. Why was this phenomenon of trying to figure things out so common? On the one hand, there were probably multiple factors in the sample that made them predisposed to doing so, like affinity for information (e.g., P16 and P17), training in a health-related field (e.g., P05), and natural curiosity. However, the very visceral feeling of the pain and the fear of one’s mortality instilled

by it (described in section 5.2.2.3), the drawn-out nature of the diagnostic experience, and the lack of answers most likely adds to it. Many of the younger and more recently diagnosed participants (e.g., P13, P24, and P27) voiced frustration at this.

The statement, “no news is good news” does not necessarily apply to this population. P24 related an experience in which she had gone to have a test done:

I remember when I came out of the nerve conduction study and they told me all right, everything looks great. I walked out, and my dad was sitting there in the waiting room, and I just burst into tears. He goes like, ‘What happened?’ I’m like, ‘Everything’s fine.’ ‘So why are you crying?’ ‘Because everything’s fine.’

To sum it all up, P24 said, “It was all such a bittersweet thing. You’re like great, nothing really serious is wrong with me, but I’m still in the worst pain I’ve ever been in my life and no one can tell me why, and no one can fix it.”

Another important aspect of participants’ illness journeys was their information interactions with others. This included family and friends, health care practitioners, and employers. Some family members were supportive and/or engaged in information seeking with the participants. Others did not believe the participants, thought that they were faking, or that they were hypochondriacs. Some participants also reported that family members were uncomfortable seeing them in a different way from which they had known them previously. Participants took care in terms of when, how and what information to disclose to family and friends, and the decisions that they made were often influenced by previous interactions with those family and friends.

Interactions with health care practitioners were varied as well. Participants reported various negative experiences, including practitioners not taking participants’ medical histories

into account, having practitioners use fibromyalgia as a generic explanation for their health issues, being told that they were seeking drugs, and not being believed. However, in the long run, participants generally found practitioners that they were able to work with. Regarding those practitioners that participants were able to work with, participants had very positive evaluations, including that the practitioners spent time with the participants to go over their medical history, that they provided them information and engaged in collaborative problem solving with them, and that they were open-minded. Some participants really appreciated that physicians were frank with them in discussion and helped them to problem solve to the extent that they were able.

With regard to family, friends, and health care practitioners, one of the most common causes of problems appears to be the invisibility of the illness. People tend to believe in what they can see or feel themselves. In this study, there were participants who had seen their mothers/relatives as hypochondriacs or not believed that they had fibromyalgia. Even those who are supportive of patients do not necessarily know how those patients feel, and thus misunderstandings arise. In this study, there were cases in which family and friends worked at trying to support each other, and were eventually able to do that, even if they could not actually experience what the other person was feeling. Participants seemed to be very appreciative of instances in which family, friends and practitioners did show them this type of support.

With regard to interactions with physicians, it seemed that there were aspects of physicians' behavior that appeared to exacerbate reactions that patients were had as they dealt with uncertainty. As we have seen, a diagnosis of fibromyalgia is, in itself, not always an easy one to obtain. There is often a long period of uncertainty, and even after it has been diagnosed, patients do not find themselves on solid ground in terms of getting on an efficacious treatment

protocol. In the testimonies of the patients in this study, when physicians acknowledged that they did not know the answers but attempted to engage in problem solving with patients, the patients seemed to appreciate these efforts. When physicians “threw pain pills” or did not listen to patients, patients became frustrated.

Another issue that was called to attention by the experiences of study participants was the duration of patients’ relationships with physicians. Fibromyalgia patients generally experience a wide variety of symptoms that are interrelated with one another. As such, it is unlikely that a physician will be able to grasp them all within the course of a single clinical visit. Thus, it is helpful for patients to stay with the same physician for a long period of time, so that the physician can develop a more complete understanding of patients’ clinical histories. But both patient and physician need to allow this to occur. Patients need to understand that physicians cannot understand everything in a single visit, and physicians need to acknowledge that this is true.

This study also explored how fibromyalgia patients participated in online spaces. Study participants exhibited a wide range of participation patterns. Which media types they used most often, if at all, seemed to be determined by both their own needs and their perceptions of different media types. Participants sought out others with similar experiences and engaged in the sharing of their own experiences; they also had needs for different types of information. They differed in their impressions of online communities, and there were participants in my study who had used the same communities and formed different opinions of them. Most study participants had either lurked or participated on a health discussion forum at some point, but few were currently using them on a regular basis at the time that I interviewed them.

Was negativity the main reason why participants did not use them over sustained periods of time? I would argue that, though this was one reason, there were other ones. For example, as I mentioned, many of them gave up searching for information at some point for various reasons. For many, this was probably also the point at which they gave up participating in discussion forums, and it would naturally follow that they would. The exception would be if they saw themselves as a member of the community, as P22 and P23 did.

5.4 Salient Issues

There were several issues that often came up in the interviews and are important in the lives of fibromyalgia patients, but were not specifically addressed by my research questions. Though I have mentioned them tangentially in other sections, I elaborate upon them here. The three issues I discuss in this section are: work and career, obtaining disability benefits, and promoting awareness of fibromyalgia.

5.4.1 Work and Career

Developing fibromyalgia often makes it difficult for participants to maintain the life and work that they had up to that point. Among the sample, over half of the participants had considered their condition in their decision of where to work and what kind of position to take, had made career changes, or had retired on disability. In terms of where to work, when P10 looks for a position, she gives preference to ones where she does not need to take a bus, because this often results in a situation where it is necessary to walk, which can be difficult for her. Another, P11, selected a position that involved a later start time than others she might have had to choose from.

There were also instances in which participants' physical conditions influenced their career decisions. For example, P10 said, "How much did my illnesses impact my decisions? I

like to think that they didn't, but they probably did. They most likely did, because... I don't think... when I was thinking about the medical school hole... I was thinking that there's no way under the sun that I can do something that rigorous..." Another participant, P13, made a decision to study Chinese medicine after developing fibromyalgia, partially because he recognized that he was not going to be able to continue the profession he had originally been preparing for, which would have entailed sitting at a desk all day, and partially because of his frustration with the traditional health care system. P21, who trained as a nurse, stayed in the same field, but moved to a position involving less physical labor, and also was more in line with what she was learning due to her experience of fibromyalgia. Thus, in both of these cases, the decisions of participants were motivated partially by participants' physical limitations, and partially by changes in knowledge beliefs due to the condition.

P05 has learned a lot about how to manage her condition. She has realized that she cannot be in a stressful work environment, and that she *needed* to define her work environment. Though having these conversations with employers is difficult and initially took her out of her comfort zone, she has learned a lot about how to have these conversations to create situations that work for both parties.

P17 became very ill with a condition other than fibromyalgia when she was in her mid-30s, to the point where her physicians were not sure she was going to live. She eventually did recover, but she never really recovered fully, and continued to have health problems after that. She tried to go back to her full-time job as a lawyer and was unable to do so, and so eventually had to cut back to part-time. She found that she was still unable to continue that work, so she retired on disability. However, she has continued to take on short-term projects, so that she is

able to use her skills to some extent. Because they involve very few and short, in-person appearances, her illness does not interfere, and she does not need to disclose her conditions.

These examples demonstrate some of the diverse set of outcomes that may result from having fibromyalgia and having a productive and satisfying work life. The job that a person holds is a product of a diverse set of inputs, including his or her life situation, career aspirations, and personality. As such, the ways in which an individual deals with illness on the job may differ greatly from another individual, and even for the same individual in different work situations. However, the examples here illustrate possible approaches. They also perhaps accentuate the need for greater awareness of the need for flexible working conditions.

5.4.2 Receiving Disability Benefits

Though research on being on disability was not a main focus of this study, many study participants obtained recognition and support for being disabled at some point in their lives. The difficulty of the process differed greatly among participants. Some, like P22, had no trouble, whereas others, like P14, had a much more difficult time. P17 received disability checks for five years, and then had her benefits taken away upon re-evaluation. She then wrote an appeal letter and had her benefits re-instated.

The subject of obtaining disability benefits is discussed quite a bit in online discussion forums. One of the most common questions is how to apply for disability benefits. In her Google Groups content, P17 recommended that patients call the Social Security Administration directly to set up an appointment; P22 recommended that patients call Allsup. In the following post, she responded to a question from a poster about having her disability application denied twice:

I'm sorry that you find yourself in this position. The system is overwhelmed with people trying to get disability. Some of them are people who cannot find work. They are trying to get any source of income possible... nine months is not a long time in the wait for SSDI. Many people wait for years. Since you have been denied twice, you might want to seriously consider getting a new advocate to handle your case. I used Allsup and had a very good experience. You can find them online. Don't give up! Get the benefits that you are entitled to from working and paying into the system. Take care. – P22

P17 has participated in a number of conversations online about disability benefits, and in those discussions, she has shared her experience of appealing the Social Security Administration's decision that she was no longer disabled. Another forum participant had asked her to elaborate on what she included in her appeal letter. In response, she shared the following:

The first part of the letter was an explanation of why my first report failed to adequately describe my situation - cognitive difficulties and all that, you know. I went back and outlined all the the tx's I had tried - biofeedback, PT, meds, etc, w/out success. The second part of the letter went into excruciating detail about my daily living - a lot of "yes, but" type answers. Yes, I am able to bathe and dress myself but I often have to wait until later in the day when I feel better and sometimes that is all I am able to accomplish that day. – P17

There were various tips about obtaining disability benefits that participants mentioned. A number of participants mentioned that it was easier to obtain it if you could show “a path of illness” (P14). In the case of P17, this meant a history of repeated attempts to work, and in the case of P14 and P22, having specialists to confirm their disability.

5.4.3 Working towards Patient Education and Public Awareness

We're like the red-headed stepchildren of the medical field. – P22

As participants gradually learned how to manage their own condition, many of them started to focus their attention on how they might help others or raise awareness. A number of them, such as P19 and P24, have considered starting, or already started, blogs. In the case of P19, her intention was to devote a section of her existing blog to writing about how she was able to build a career and manage her work life with fibromyalgia. In the case of P24, her blog shares her own stories or those of other patients in order to raise awareness and understanding of fibromyalgia. P15 designed a course to help others manage their illness.

For other participants, it was not so much of an intentional effort, but rather, sometimes unintentionally finding themselves in the role of helping others that shared their condition. For example, one participant, P25, was selected as the leader of a Chronic Fatigue Syndrome support group. Another participant, P26, was routinely asked by her physicians to speak with patients who did not have as extensive an illness history, to try to help them along. Lastly, P22 often provided information to “newbies” on discussion forums because, as she saw it, “somebody’s got to do it.”

Participants also made various efforts to increase awareness about fibromyalgia. P05 started a candle business to raise the awareness of fibromyalgia. P18 started a Facebook group to raise awareness about fibromyalgia and other causes, such as Crohn’s Disease, lupus, cystic fibrosis, eating disorders, domestic violence, adoption, bullying, and homelessness. She also serves as a moderator for the Facebook page of a fibromyalgia support group.

Reflecting upon this phenomenon, one might think of participants as communicating, or having an awareness of communication on two levels: interpersonal and general public. Some

messages, such as P05's Facebook note and P24's email, were meant for their immediate network. Others were meant as a communication for a broader group, those that participants did not know personally, and thus were meant to encourage public awareness of fibromyalgia.

CHAPTER 6 CONCLUSION

6.1 Main Contributions

This study has contributed to our knowledge of information behaviors in relation to fibromyalgia and other chronic illnesses in various ways. First, this study provided rich detail concerning the illness journey of fibromyalgia patients, including physiological, cognitive and emotional dimensions. Second, the study illustrated that different phases of the journey are often associated with particular types of information behaviors. The information behaviors in which participants engage are inextricably tied to these physiological, cognitive and emotional dimensions. Keeping this in mind can be important in terms of research, as a contextual view can illuminate connections not otherwise apparent, and in resource development contexts, as considering the other elements of a patient's environment can facilitate the development of resources that suit patients' needs better.

This study also explored aspects of information behaviors relating to chronic conditions, including the information sought and lessons learned, information interactions, and patients' activities in online spaces. Patients may interact and exchange information with a variety of sources, including print materials, online sources and people, over the course of their illness journey. In some cases, they control the process more deliberately by making explicit decisions about the amount and type of information to consume; in others, they may encounter information accidentally.

Descriptive information about information sought, resources consulted and credibility assessments of those sources, may inform future resource development. The experiences

reported in this study concerning participants' information interactions may also be considered in the design and evaluation of communications courses for patients, family and friends; and in the development of ways to facilitate patient-provider communication. If patient and practitioner are both more prepared for clinical encounters, the encounter might be more pleasant, productive and educational. Moreover, tools that facilitate this communication, such as electronic health records and interfaces that visualize and facilitate interpretation of patient data, may aid communication prior to, during, and after the clinical encounter. This study also identified ways in which online spaces might support patients' needs better.

6.2 Reflections on the Methods

There were aspects in which the methods used in my dissertation research were novel or addressed particularly difficult challenges. In this section, I discuss four elements of my methods: recruitment strategies, the use of timeline construction as an elicitation technique, the Online Scrapbook interface as an elicitation technique, and conducting face-to-face vs. virtual interviews. With regard to each topic, I critically examine the methods that I chose, discussing strengths and weaknesses of relevant options, and assess how well they worked. Lastly, I conclude with a brief discussion of study limitations.

6.2.1 Recruitment Strategies

In this study, I used multiple recruitment strategies. The three most productive strategies, the university listserv, online discussion forums, and face-to-face support groups, were all effective for recruiting participants, but there also seemed to be sample bias associated with each. The participants recruited using the university listserv led to the largest part of the sample; however, these participants did not tend to be active in health-related social media.

Recruiting via online discussion platforms was also fairly productive, and these participants were generally active in health-related social media, at least to some degree.

I also recruited participants by visiting a face-to-face support group and contacting face-to-face support group leaders. This was an effective method for reaching a population that often encountered health information in their daily interactions with others. Though I have no way of ascertaining this without further investigation, my sense is that the acquisition of health information by this subsample was higher than usual among face-to-face support groups, because the groups that my study participants participated, or had participated in, actively promoted information exchange by offering yoga classes in conjunction with support group meetings, and also by engaging regular speakers. The participants also spoke of a lack of involvement on the part of other support group members, thus acknowledging that not everyone was engaged to the same degree that they were.

Though I ultimately only recruited one person via Twitter because I reached my quota in terms of sample size and target sample characteristics of interest, I believe that Twitter would have been an effective mechanism for a larger scale recruitment. The method that I used was to identify individuals who had disclosed publicly through social media that they had fibromyalgia, introduce myself and the study, and ask them if they would be interested in participating. In many cases, it was possible to acquire some sense of where prospective participants were located geographically and thus engage in targeted recruitment efforts. In addition, it would have been possible to tweet study invitations and potentially reach a large audience. The effectiveness of such a recruitment strategy would be determined by a combination of factors including the potential for re-tweets of the study invitation, the number

of followers the initial study invitation tweeter(s) have, and the potential findability of the tweet study invitation through the use of keywords and hashtags.

Because I was interested in recruiting participants who engaged with health-related social media in all sorts of different ways, including not interacting with it at all, the combination of recruitment strategies I employed was effective for achieving that diversity. However, one population that was perhaps missing in my study was online discussion forum leaders. In this context, what I mean by “leader” is a person who has some role in setting the climate of the discussion forum, regardless of whether it is a formally appointed role or not. As such, I am making a distinction between “leaders” and “moderators”, in the sense that the latter have a more formally recognized role. Though P22 was an active participant in several discussion forums, she did not identify herself as one of the “leaders.”

Though initially I was interested in having participants in my sample that were “leaders”, in retrospect, I think it would have added an additional element to my data that would have made it less cohesive. Some of the potential themes of interest with regard to discussion forum leaders would be their concerns, goals and approaches to their leadership role, which would be distinct from their own illness journeys. While outside the scope of the current study, this would be an interesting question to pursue in a future study. To conduct such a study, I might employ recruitment and interview methods different from those I used in this study. For example, trust is likely to be an important element. Thus, being a member of the community at the time of the study, or knowing someone who could provide an introduction (“gatekeeper”), might be helpful. In addition, online community leaders might be more comfortable with virtual interview methods, since they are likely to be comfortable in the online space.

6.2.2 Timeline

There was a great variety in terms of the timelines that participants drew, and the exercise certainly showed that people have varying abilities to express themselves through different media. Some were able to draw timelines with vivid pictures; others constructed more traditional, linear timelines. Use of color also varied, with some timelines in an array of vibrant colors, and others in a single color. There were also participants who told their story better verbally, either on paper or orally. In engaging participants in the timeline construction activity, I made it clear that artistry was not important, and I felt that the activity successfully engaged participants in the telling of their stories, which was the main motive.

At the outset, I had considered other ways of structuring the timeline activity, including having a straight line across the page; having multiple trajectories, as in Thygesen et al.'s (2011) work; and using Dervin's micro-moment timeline. All of these designs involve a more structured set of instructions and visual guides on the page. However, I found that the lack of a more structured set of guidelines seemed to lend itself well to the topic I was exploring – a person's life journey.

Overall, participants appeared to be at ease with the exercise. I believe that the lack of guidelines and emphasis on artistry not being a concern helped to put participants at ease, which could potentially be stressful and/or difficult for some if it were more structured. A few participants did seem uncertain about what to do without a clear set of instructions, and for those participants I did generally elaborate and offer more suggestions about what to include. In particular, I might ask at what points they had experienced emotions along the way, or engaged in more or less information seeking, and to indicate these on the timelines. If one intends to perform a content analysis of timeline elements, providing participants different amounts of

guidance would not necessarily be desirable, since this would mean that there would be a level of inconsistency across interviews. However, in this case, I intended to and did use the interview content as the primary content type for analysis. The timeline doubled as supplemental data and a medium for elicitation of participants' thoughts and reflections during the interview.

Participants seemed to enjoy the timeline exercise and the process of telling their story. Many said it was helpful for them in terms of thinking about their own history. I believe that the exercise also helped participants to remember the past, as there were times when, as they were constructing the timeline, they would ask themselves whether the chronology was correct, think a bit more deeply about what actually had happened, or engage in other dialogic behavior which provoked them to work with their own mental representations of the past.

One final strength in terms of the timeline as an interview elicitation technique is that it enables the viewer, whether it be the researcher, the participant, or someone else, a more contextualized view of participants' experiences. What is illness? What is life? The person and the illness are not one and the same, and one's illness certainly is not one's life, but they are related. Experiences of the illness can become important events in one's life, and the events of one's life can also affect one's illness. Take P22's timeline as an example (Figure 8). The two major downward trajectories depicted on that timeline are: 1) the cyclone; and 2) the divorce. The second is a life event, but the participant has depicted it on the timeline. Why is it there? Perhaps it is there because the participant sees it as an event that followed from her illness, or perhaps it was there because it was salient in her experience of life. Here, I am not speaking about her actual intent in depicting this event, but rather, I am speaking abstractly of how life events that are not necessarily illness-related might end up on a timeline focused on illness

histories. The events of life will always be there, as well they should, interspersed with the events of illness, and if we are to understand the experience of illness, the events of life will inevitably be part of the picture. Thus, asking participants to depict whatever they thought was relevant, including the events of life, led to a more complete picture of the role that illness and wellness plays in people's lives, and is also consistent with the goal, in IPA, of helping us to understand the "person-in-context" (Larkin, Watts, & Clifton, 2006).

There were some issues associated with the use of the timeline. For example, there was not always a clear point in the interview when to bring up the timeline, because some participants told their story in great detail without the use of the timeline and did not come to a natural stopping point. Others needed more direction in terms of what to put on the timeline. Because of these and other differences across participants, it makes it difficult to compare across timelines. However, as a tool to facilitate the interview, it was very effective. Usually, asking participants to draw the timeline after providing an overview of their journey led to additional insights as they drew. Additionally, as I have just discussed, it also enabled the researcher to better interpret the participant's experience within their life context.

6.2.3 Online Scrapbook Interface

6.2.3.1 The Interface as an Elicitation Technique for the Interview

In addition to the timeline, I used an experimental interface, Online Scrapbook (Appendix J), to facilitate a conversation about the content that participants authored on social media. The interface enables participants to view and explore their social media over different media, across the span of their illness journey. Many participants remarked that they liked the interface and that they found it interesting to look at their own content in that way. I believe that it was helpful because it enabled us to look at the participants' content, which might be

scattered across several social media platforms and over time, through a single view. The interface also facilitated ready access to material that participants had often forgotten. Even participants who had been diagnosed relatively recently and had authored content regarding their condition relatively recently (i.e. within the last couple of years) had trouble recalling what they had posted. It also facilitated a comparison in terms of frequency of participation.

Though it was useful to be able to see in a single visualization how individuals participated across a range of social media, creation of this visualization did present challenges. It necessitated collecting all these different social media artifacts and in addition, figuring out the best way to insert them into the database and display them in the interface itself. Though the code I created was reusable, there was a lot of custom coding involved. Generally, a different script was written for every platform. It was difficult to decide how to import certain media types, such as Tumblr and other blog platforms. For those, scrolling downwards and viewing them as if they were all part of one story seemed to make more sense than viewing them through the interface alongside other social media. In some ways, this makes sense, as participants who used Tumblr seemed to view it primarily as a means of expression rather than dialogue.

Also, participants did not seem to interact readily with the interface. I attribute this partially to my not foregrounding the interface enough in my interview as I had done with the timeline, and partially to the need for more attention to be paid to certain aspects of its usability. For example, I noticed after the study had begun that many of the older participants in the study used iPads and tablets, and I think that if I had designed an interface that could be accessed on such a device, it would have been more intuitive to them. Also, in the case of Facebook, it might have been easier to find the content that they were looking for on the Timeline rather than

on the Online Scrapbook, because they were already used to the interface and might have remembered where the content was that they were looking for.

6.2.3.2 The Interface as a Research Tool

As a researcher, I found the tool extremely useful for reviewing participants' online participation histories. The timeline visualization facilitated an overview of the different media in which participants engaged. In particular, the line-by-line display of media served to illustrate how participants might choose to use a certain medium at a given time, and another at a different time. Participants might also come back to a medium after a period of non-use, for a completely different reason than the one that influenced their earlier use. The inclusion of Facebook helped me to consider how participants' online participation might have related to the rest of their lives. For most participants, their health-related Facebook posts only comprised a small proportion of their overall Facebook posts, but it reminded me of how their participation might relate to other important events in their lives. The embedding of links back to the original posts also enabled me to quickly jump back to the context of these posts and cut and paste as necessary into Atlas.ti for qualitative analysis. The full-text search was also useful for identifying posts and topics that featured prominently in participants' testimonies.

There were various aspect of the Online Scrapbook that could be improved as a research tool. The interface, as it currently exists, does not facilitate analysis across cases. In order to visually compare illness journeys, one would need to take screenshots of the timeline visualizations for each participant and juxtapose them. It would be useful to incorporate features to facilitate comparison of timelines, visually but perhaps also algorithmically, using algorithms that compare illness journeys on a set of variables that have been reported in this study to be important in the illness journeys of fibromyalgia patients.

In addition, the current visualization emphasizes certain characteristics of participation, such as frequency and amount, as defined by the number of posts. There are other aspects of online participation which are not captured, such as the semantic content of posts and the length of posts. While it is not possible for analysis tools to facilitate analysis on all dimensions, it is important for the researcher to realize these limitations and seek alternative means to perform these types of analyses if they are relevant to the research question.

6.2.4 In-person vs. Virtual Interviews

In this study, I conducted interviews face-to-face and virtually. I chose to interview my participants in person whenever possible, though there are various advantages and drawbacks of each method. Table 14 presents a comparison of face-to-face vs. Skype video interviews.

Table 14. Comparison between Face-to-Face and Skype Interviews*

| | Face-to-Face | Skype Video |
|--------------|--|--|
| Cost | Could be expensive to travel to the participants' locations. | Free if both parties have Skype; minimal cost if participant does not have Skype. |
| Interaction | It may be easier to establish rapport in a face-to-face interview. However, some participants may feel more comfortable being able to interact with the interviewer in person, others not. | Body language and facial cues may not be as clear. Participants may be nervous about being on camera. It may be difficult to show participants artifacts and see them well at the same time. Participants may find it odd when interviewers look down to see their notes (Bertrand & Bourdeau, 2010) |
| Technology | | There may be problems with connectivity. It would be very difficult to see a piece of paper that a participant is drawing on (as I would have needed to do in my study). |
| Availability | | Participants are generally able to schedule at shorter notice than for a face-to-face interview (Hay-Gibson, 2009). It is necessary to consider time zones in scheduling. |
| Reach | | It may be easier to access hard-to-reach populations, and to recruit from a wider geographical area (Opdenakker, 2006). |

| | Face-to-Face | Skype Video |
|-------------------|--|---|
| Data | Interviews tend to be longer, and data richer, when conducted in person. | Extrapolating on previous research concerning phone interviews, Skype interviews might be shorter and result in less participant talk (Irvine, 2011). |
| Recording Quality | | The sound quality of the virtual interviews might be worse than those recorded in person. |
| Confidentiality | | Participants might be concerned about confidentiality of the video recording (Bertrand & Bourdeau, 2010). |

* Positive; Negative; Mixed

Overall, I found that face-to-face interviews were very effective for establishing rapport. When one conducts interviews in this mode, it may be easier to read body language and facial cues. In this study, it also led to richer, more highly contextualized data because, in some cases, it enabled me to see firsthand, and thus better understand, the life worlds of the participants.

I asked participants to select the location of the interview in order to help them feel comfortable. The locations that participants chose fell into one of three categories: home, restaurant or coffee shop, and office. In cases where participants selected a restaurant or coffee shop, peripheral noise was sometimes a problem, but the quality of the recordings was still substantially better than the virtual interviews that I conducted.

In the situations where participants selected their home or office, I was often able to see how they navigated their computers and any mobile devices that they owned. If they wanted to show me their Facebook page or show me other information, this was a much easier task. To a limited extent this was also true in the virtual interviews, where a participant was able to show me books on the shelves. In the interviews I conducted in homes and offices, I was better able to understand participants' physical limitations through the spaces and the tools that they used in order to make their lives easier. As I walked over to use the restroom in one participant's

house, I encountered a cane, a walker, and a wheelchair, all of which the participant said that she might need on any given day, given her physical condition.

There was a strong logistical reason for conducting interviews in person: the first interview involved the drawing of a timeline, and that this might be difficult as a virtual activity. Two exceptions were made to the study. In one case, one of the participants I interviewed was too far away for me to interview twice in person, and in the other, the participant was too far away for me to travel to. However, I decided to include these two participants because there were aspects of their background that suggested that they might relate experiences that would be a unique and useful addition to my data.

There are various problems that may occur with virtual interviews conducted with Skype or a similar tool. These include the possibility of participants being nervous about being on camera, problems with connectivity and/or the quality of the recording, and collecting data that is less rich. In the three virtual interviews that I conducted in this study, I did not have problems establishing rapport with the participants due to the connection, but there were problems with the connectivity and the quality of the recordings. In the case of the participant that I interviewed twice virtually, it was a decision between having some data or none, and given those two options, I chose the former. The quality of the transcripts was adversely affected by the quality of the recording, but I still regard the data I collected as being extremely valuable. Of course, had I planned to interview all of my participants via Skype, I might have found a more reliable technological solution.

The exceptions that I made, however, do provide some insight concerning the practicality of virtual interviews that involve additional “props.” One exception was made in the study because, upon my saying that I was conducting all my interviews in person because of

the timeline exercise, the participant said that they were well-versed in multimedia techniques and would have no trouble drawing a timeline online. This participant did, in fact, succeed in drawing the timeline online with no direction from me in terms of software. This singular experience perhaps did result in some useful observations concerning methodology. It does not lend support to the idea that timeline drawing is a viable form of data collection in a virtual interview, since the participant was more highly trained in this area than the average participant might be. However, it does suggest that the activity is possible if the software is easy enough to use and participants receive training in advance. In this study, I did not think it a viable option due to considerations of the population to be studied (possibly advanced age, cognitive fog and memory deficits, etc.) and the length of the interview protocol even without training. However, it might be possible under other circumstances.

An additional point was that, in this interview, the participant had prepared a list of points to depict in the timeline. Undoubtedly, having prepared this list facilitated the process. I did not ask participants to do this, in the hopes that the activity would be more spontaneous and organic. However, I do think that it worked well in this particular case, and might be advisable if one were to attempt to guide participants in drawing timelines virtually. This does mean, however, that one loses the opportunity to witness a participant's natural recollection processes at work.

6.2.5 Limitations of this Study

There were various limitations of the study. As is true with any study, there was bias in the sample. In this case, there were perhaps several obvious sources of bias. One was that most of the participants had completed a high level of education. Many had a profession, or had previously held a position, having to do with health care, and had had exposure to concepts such

as evidence-based medicine. There were quite a few that had said that they liked information, were good at finding information, or knew how to search for information. The familiarity of this population with concepts of evidence-based medicine and with how to search for information is not likely to be representative of patients with fibromyalgia in general.

In terms of the broader concepts that patients came away with, such as the focus on wellness and the need for lifestyle change, these changes in knowledge and orientation occurred irrespective of education level. Moreover, given that, with fibromyalgia, patients often have very few satisfying answers, even those who do not have extensive training looking for information may develop some level of expertise, especially considering the long duration of illness. With this also comes the question of whether formal training in evaluation of information quality affects the likelihood of errors in the consumption and synthesis of information, such as the inadvertent tendency to confirm incorrect hypotheses observed by Keselman et al. (2008a). In short, more research is needed to examine the impact that education level may have on illness journeys.

Another limitation of the study was that there were few newly diagnosed patients in my sample, and even those who were recently diagnosed appeared to have reached a point of acceptance of their condition and passive monitoring. Though many of the study participants reported times in the past in which they were panicking or felt out of control, at the time of data collection, they no longer felt that way. While interviewing these participants was extremely interesting and led to great insights about their journeys, it is unavoidable that due to the erosion of memory, some aspects of their journey are not going to be as clear to them. Thus, in the future, it would be useful to recruit a sample of newly diagnosed patients and learn more about information needs and seeking processes earlier in a person's illness journey. In order to

understand participants' experiences earlier in their illness journeys, including the time period in which they are seeking a diagnosis, it would perhaps be desirable to include those who are not yet diagnosed, but suspect that they have fibromyalgia. Though they may not end up being diagnosed with the condition, it would still be useful to have their experiences inform the question of how one goes about figuring out if they have fibromyalgia.

Another limitation of the study is that I did not ask participants to perform searches in front of me, so I am not able to offer insight into specific aspects of how they engaged in searching behavior. I made this decision because I was more focused on the meta-level questions of the types of information that they were searching for, the types of information that they found, how they were able to obtain such information, and how their knowledge and mindsets changed. These subjects were ones that took a great deal of time to understand, and the interviews in my study already required quite a substantial amount of effort on the part of the participants. As this is also a population that tires easily, I did not want to inconvenience them even further. However, given that this condition is one that participants have for decades, I chose to focus on the meta-level questions concerning overall information intake and reception as opposed to the day-to-day, for this initial study. Moreover, though I was aware that using this protocol, I would not necessarily be able to understand specific aspects of participants' search behaviors, I believed that the social media traces would provide some insight, because they serve as a residue through which I could understand some of the places that participants sought information.

6.3 Reflections on Extant Literature

In this section, I reflect upon extant literature in three areas, in light of implications of the study findings. The first area, illness coping, is an important area of concern with regard to

fibromyalgia and chronic conditions in general. The second area is forum dynamics. Patients who visit discussion forums are walking into an ecosystem and they become part of that ecosystem; thus, it is useful to consider potential impacts of their “encounter.” The third and last area that I reflect upon is the value of online information, a subject of pertinence given the increasing interest in mining user-generated content and data.

6.3.1 Illness Coping

There was great concordance between the experiences of the participants and previous literature on illness coping. For example, in the literature review, I mentioned that Nielson and Jensen (2004) reported that various coping behaviors were strong predictors of outcome. They argued that this did not mean that fibromyalgia was a purely psychosocial disorder, but that there was an important psychological component to it, and that cognitive-behavioral treatment programs were well-suited to address fibromyalgia.

In this study, some participants had a persistent desire for a sense of control, and they often felt frustrated or depressed when they did not have this sense of control. Many participants reported that their mental and physical state improved after engaging in yoga, and many also learned that pacing their activities helped them to manage effectively. There were cognitive aspects of the improvement in their health management. For instance, P19 spoke of how she learned that hypnotherapy could “disconnect the symptoms from the fear reaction” and P05 spoke of learning her pain triggers. Participants also limited their social activities (e.g., P08, P12, P24) or planned their schedule to reduce the burden it placed on their system (e.g., P05). These examples lend support to a cognitive-behavioral model of fibromyalgia in which changes in participants’ knowledge and beliefs affect their management strategies, which in turn lead to improvements in health management.

This study also provides food for thought concerning the relationship of coping strategies and locus of disease control. In previous work exploring these constructs among individuals with chronic pain, it was reported that patients tended to rely on external sources to control their disease, such as *Trust in Medical Help* and *Search for Information and Alternative Help* (Büssing, Ostermann, Neugebauer, & Heusser, 2010). In this study, it appeared that participants engaged extensively in *Reappraisal: Illness as Chance*, meaning that the illness caused them to reflect on what is essential in life and the meaning of illness, and that the illness became a chance for development and elicited appreciation of life. Moreover, participants made extensive use of strategies that were considered external: *Trust in Medical Help* and *Search for Information and Alternative Help*; as well as strategies that were considered internal: *Conscious Way of Living* and *Positive Attitudes*. Spirituality and religion were also important to some participants, suggesting a possible correlate in *Trust in God's Help*.

The overlap in themes that were expressed in this study, with those of the scale, suggest that the instrument may be useful for characterizing fibromyalgia patients' coping behaviors. However, the results of this study also raise questions concerning the definition of the construct, locus of disease control, the relationship of external vs. internal adaptive coping styles, and whether certain styles are internal or external at all. For example, P12 and P26 actively engaged in dialogue with physicians, demonstrating faith in an external locus of disease control, but their engagement also demonstrated an internal locus of disease control. Moreover, both of these participants indicated that spirituality and religion were important elements of their illness journey. In fact, the results of my dissertation study seem to suggest that adaptive coping is a result of relying on both internal and external loci of disease control, and that the two loci are not necessarily opposing.

We also saw concordance between this study and previous literature in terms of participants' reactions to uncertainty. As previous literature has reported, not knowing the cause of one's symptoms is extremely stressful, as was the unpredictability of one's daily function (e.g. Mishel, 1999; Johnson et al., 2006). Planning one's schedule to reduce this uncertainty and pacing oneself was helpful in this regard.

6.3.2 The Intersection of Illness Journeys and Forum Ecosystems

In the literature review, I described past studies that have examined the roles that participants played in online discussion forums. In this section, I consider the implications that people's interactions with discussion forums have in light of extant literature on member roles and forum dynamics.

We may perhaps think of each of these interactions as the intersection of a traveler on an illness journey, happening across different forum ecosystems, each one visited by a unique set of other travelers. These travelers play different roles in the ecosystem depending on where they are in their own illness journeys, their informational and emotional support needs, and their own habitual uses of the Internet.

A number of study participants used discussion forums early on in their illness journeys, prior to being diagnosed, after diagnosis and for a while after. Those who suspect that they have fibromyalgia or are simply unable to figure out what is wrong with their body may appeal online communities for help. The reader may recall, for example, that P09 "trawled" discussion forums looking for people with similar symptoms until she had a name for her condition. In P05's case, there was a time when she was in a lot of pain and her doctors kept telling her everything was normal; at that time, she posted her history online so that she could ask others for feedback.

After participants are diagnosed, they may reach out to the community for support. Though I did not observe any of my study participants posting immediately after being diagnosed, I did observe two of them (P11 and P22) commenting to support other members who were newly diagnosed. For example, in one thread a member had initiated, which they had posted the day they were diagnosed after 15 years of symptoms, P11 responded with congratulations, the sharing of her own sentiments on her 15 year journey to diagnosis, and suggestions for managing.

Once participants begin participating in discussion forums, it appears that they engage for a while, and then gradually taper off as their need for information declines. During this period, they often engage in both seeking and providing informational and emotional support. There were different ways that participants might provide informational support. One of these was to share one's own experiences with problems. For example, P16 shared her own personal experiences with specific problems, such as endometriosis, bug bites and guaifenesin, for the initial poster to digest. P17 tended to provide factual information and engage directly with other posters for more information when she read something that she previously did not know.

Participants might also engage with others on more personal and emotional levels. P11's posts are often empathetic in nature: "I understand where you are coming from, I went to my family doctor with my mom at 15 with fibro symptoms and was told I was crazy, and was finally diagnosed by my doctor now, who is excellent, at 30." She often refers to some aspect of herself that she has in common with the poster. P11 and P22 would comfort forum members who posted to introduce themselves or posted in despair. A number of individuals sought the comfort of knowing that there were others like them, but did not feel the need to connect with them directly. This phenomenon suggests that online discussion forums that are publicly

available provide an invaluable contribution because they supply this type of reassurance to the “silent”, as Nonnecke and Preece (2000) refer to them.

Though for the most part, forum participation in this study appeared to be transient, there were also participants for whom this was a more long-term behavioral pattern. P22 is one of these examples. She sees an online community as a replacement for physical community, and it has become a part of her life. P09 engages actively with the Internet in both work and leisure time, and thus her health-related participation is simply a natural component of her everyday life.

There are parallels between the participation patterns of study participants and extant literature on the roles that participants play in online discussion forums. In particular, I would argue that we saw examples of behavior that fit the categories of novice and active members in Kim (2000), Sonnenbichler (2010), and Pfeil et al.’s (2011) typologies. These two categories perhaps elicit a greater focus on structural aspects of participation, e.g., how long a person has been a member and how frequently they post.

Some of the other literature addresses the nature of this participation. For example, I might consider P22 either an “answer person” (“pollinator”) or a “balanced conversationalist”, according to Viégas and Smith’s (2004) categories, because she participates often and engages the same amount on all threads, regardless of whether she has initiated them or not. She answers more threads than she participates in, but it seems to me a “balanced conversationalist” should be someone who initiates a fair amount of threads and also participates extensively, rather than someone who has a 1:1 ratio. There were also a number of participants (e.g. P11, P16 and P17) that were perhaps “joining conversationalists” (Chan & Hayes, 2010) or “discussants” (Jones et al., 2011).

We have seen that individuals may play a fairly consistent role in an online community for a given period of time. This argument is consistent with previous literature employing network analysis on online support groups, in which it has been shown that individuals often play particular roles in networks (e.g. Chang, 2009; Bambina, 2007; Pfeil & Zaphiris, 2009). There may be different “currents of activity” in the same forum; Pfeil and Zaphiris generated different networks for various types of social support, and found that they had very different structures.

6.3.3 The Value of Online Information

The value of the information generated by patients in online discussion forums is an issue that has been examined in numerous studies. For example, Hartzler and Pratt (2011) performed a content analysis of different sources of patient and clinician expertise, and argued that content authored by patients fill an information need unmet by clinician sources. Kazmer et al. (2014) described how patients discover and share knowledge from disparate sources about Amyotrophic Lateral Sclerosis (ALS).

Participants in this study, as well as in previous studies (e.g. Chen, 2012a), have indicated a need for better ways to find information that is specific to their needs. One way that this might be done is by finding ways to label content with tags that are intuitive to participants and making these tags searchable. There are bits of knowledge that are useful, which are not likely to be present in curated information, such as “I’ve recently found ‘humibid’ in 400 mg tablets, which are actually easier to split than the blue Mucinex pills...also found them to be cheaper when I calculated the cost/mg” (P16, on *ProHealth*). Another example that received 30 responses was the question: “Can fibromyalgia cause weakness in your hands? For example, sometimes dropping objects that you are holding?” In the first example, the poster is informing

the other members is comparing pills in terms of how “splittable” they are, and in the second example, the poster is asking about weakness in the hands, which people might not normally think of as a symptom. If this content is properly indexed, it can be more easily findable in discussion forums, and can also serve as the seed for future research.

The question of how to increase the findability of this information remains a challenge. There have been efforts to build resources such as the Consumer Health Vocabulary (CHV), which is comprised of words that lay people use to describe health phenomena (Doing-Harris & Zeng-Treitler, 2011). Recent efforts have employed an n-gram approach to augment the existing CHV with words from PatientsLikeMe data. However, it is unlikely that an n-gram approach would have extracted concepts such as the “splittability” of medications. Other solutions include the use of other text mining approaches such as topic modeling, crowdsourcing and human curation.

Aside from knowledge of strategies and physiological sensations of fibromyalgia, patients are also able to provide skills-based knowledge to one another. For example, in one thread on ProHealth, a poster shares her story about the difficulty she is having with her doctor with regard to pain medications. Many others provide support, some by sharing their experiences as a way to make suggestions, others by providing advice specific to the poster’s situation, and others, simply emotional support. Collectively, the group expresses a variety of ideas: that the member deserved to be treated better; that she should try to get referred to a pain specialist; that she should try to document what happens in case she needs to apply for disability; that patients are in control of their health, they “pay for doctors’ knowledge” and the poster has the ability to “fire” her doctors; and that patients and doctors need to work together as a team to achieve results.

There is certainly valuable experiential knowledge here; forum members are helping the poster address her situation, and at the same time, providing information on how to manage her relationships with her physicians. Though they are giving her advice on her specific situation, they actually speak more broadly, on what types of relationships patients should have with their doctors. Thus, they are imparting a sort of skills-based knowledge. In addition, it may be useful to have the information in narrative form, as information may lose its power, pertinence or relevance out of context.

Social media may also provide information that may not readily be accessible through a person's physical surroundings. For example, P17 said that it was helpful to know what people were doing in other countries, giving an example in which she had found out about a treatment that was being used in Greece to treat alopecia, and another example in which friend was researching a drug that was being used to treat Chronic Fatigue Syndrome in France, that had not yet been approved in the United States.

In summary, it is useful to observe that though there is great potential value in health-related online discussion, efforts to utilize this power will meet its own challenges. Asking users to provide tags for information or developing ways to generate tags by mining this data will produce tags that are useful as well as those that are not, and then there will be a need to address this issue. Finding ways to connect people with information can be useful, but this does not lessen the problem of judging the quality of information that is out there, or ameliorating the potential for overload, which can overwhelm patients. These are all challenges that we will face as we endeavor to increase the usability of patient-generated discussion content.

6.4 Clinical Implications for Fibromyalgia-Related Health Care

The findings of this study have various implications for the treatment of fibromyalgia. First, the experiences of the sample illustrate that the clinical presentation of fibromyalgia does vary a great deal between individuals. However, despite this, there were also striking similarities among participants. For instance, the results of the Brief Illness Perception Questionnaire demonstrated that there was very little variability in how long participants thought that their illness was going to last – almost everyone thought it was going to last “forever.” Almost all the participants went from a period of confusion, in which they sought and consumed a diverse array of information sources, and at some point reached a point of personal reconciliation with the illness. At some point also, they developed personal management strategies, found practitioners that facilitated management of their condition, and entered a state of information monitoring.

There are ways in which support for this process might be improved: efforts to improve the diagnostic experience, strengthening of training of health care practitioners to work with fibromyalgia patients, promotion of fibromyalgia awareness in workplaces and among the general public, improved assessment and evaluation of fibromyalgia-related information sources, improved patient education courses, promotion of alternative healing modalities, and lastly, development of tools to assist patients and clinicians in the comprehension and analysis of the complex clinical histories that are common among fibromyalgia patients. I discuss each of these in turn.

6.4.1 Improving Diagnostic Procedures

As a group, the participants in this study have experienced at least three different periods in the development of the definition and diagnostic procedures for fibromyalgia: prior to the

establishment of the 1990 diagnostic criteria, after the 1990 criteria was established but prior to the revision in 2010, and after the revision in 2010. This section reflects on patients' diagnostic experiences in light of these changes over time. In 6.4.1.1, I reflect on what patient experiences suggest in terms of clinicians' adoption of clinical guidelines; in 6.4.1.2, I elaborate on patient' impressions of fibromyalgia and the clinical climate, and in 6.4.1.3, I discuss diagnostic implications.

6.4.1.1 Changes in Diagnostic Experience over Time

In this study, many patients had difficulties in getting diagnosed. These included having to undergo multiple lab tests and/or see multiple physicians, and long periods to obtain a diagnosis. For most patients, this can take more than a year, and usually spans multiple years, which can result in a great deal of stress on the part of the patient. Moreover, because multiple doctors and laboratory tests are often involved, there is an enormous burden of cost. In recent years, there have been efforts to shorten this process, and the timing of this study is opportune in the sense that it afforded a view of interim effects of changes in the diagnostic criteria for fibromyalgia.

As mentioned in the literature review, it has been recognized that problems exist with diagnostic procedures, and a revised set of criteria was developed (Arnold et al., 2011; Wolfe et al., 2010). Current guidelines for diagnosing fibromyalgia do not require that a specialist be involved. Among my sample, there were a number of individuals who were recently diagnosed, and had been diagnosed by their general practitioner, which is in accordance with the revised guidelines for diagnostic procedures. However, there were also instances in which this was not the case. There was great variability in the diagnostic experiences, and the lack of a clear relationship to time (e.g. there were those who were diagnosed in the last several years who still

had had numerous lab tests and seen specialists, and there were also those who were diagnosed decades ago on their first visit to a doctor). This suggests that there is an incomplete adoption of clinical guidelines. It is not surprising that there would be a lag in the adoption of new procedures, particularly for a condition in which physician acceptance is not widespread.

I had a number of participants who were diagnosed prior to the diagnostic criterion being established for fibromyalgia in 1990. Among these, one was diagnosed on her first visit to a doctor (P18), while a few others were not diagnosed on their first doctor's visit, but switched physicians or were referred to specialists, where they were eventually diagnosed on their first visit. P12 speaks of having tests "for everything imaginable", even though she was diagnosed prior to 1990.

Among those who were diagnosed prior to 2010, there were participants who went through this process of taking multiple lab tests to exclude other conditions, such as P19. There were those, such as P15 and P24, who were diagnosed relatively recently and by their general practitioners. Among those who were diagnosed in the last two years, there were also participants who saw multiple specialists prior to being diagnosed, and for whom diagnosis took many years, such as P05 and P11.

Given the extent of variability and the limited size of my sample, it is not possible to draw conclusions about the state of adoption of clinical guidelines. But my impression is that prior to 1990, it might have been easier to obtain a diagnosis because of the lack of a formally established criterion. Between 1990 and 2010, we had a period in which people often saw multiple specialists and took multiple lab tests prior to diagnosis. In the last several years, we have started to see the new diagnostic procedures being performed by some physicians, but by no means all.

6.4.1.2 Patients' Impressions of Fibromyalgia and Diagnostic Experiences

Extant literature on fibromyalgia has previously reported that patients experienced an initial sense of relief and validation when they were diagnosed with fibromyalgia, which was later replaced with a realization that it was an “empty diagnosis” (Madden & Sim, 2006). Because patients and those with whom patients interacted often had not heard of the condition, it was not helpful, to themselves or to others, as an explanation of what they were experiencing.

In this study, most participants appeared to have heard of the condition, or at least after they began suspecting that they had it, soon encountered negative information about their condition and developed a negative impression of it. Participants had impressions of fibromyalgia being seen as an invisible condition that people did not believe was real, that made people miss work all the time, and that fibromyalgia patients were believed to be “faking it” (e.g., P15). There were quite a few participants who did not want to be diagnosed with fibromyalgia for various reasons, including that they had a relative with fibromyalgia or some other nebulous condition, and that they knew it was a stigmatized condition. Participants were afraid of labels. P15 did not want to disclose that she had fibromyalgia at work, and P20 resisted going to see a therapist because of what she knew it meant for her career.

Participants reported that, in consultation, physicians had made comments about the participants or about fibromyalgia, comments that indicated that they did not believe in the existence of the condition, or harbored negative opinions about it. For example, participants were told that various physiological phenomena they described were “all in their heads” (e.g., P06 and P12), an experience which was also reported by the online support forum participants that Barker (2008) studied.

However, there were also participants who stated that they believed awareness and recognition of fibromyalgia has improved. These participants felt that, in the past, fibromyalgia patients were made to feel as if it were all in their heads, but that this is no longer true. P21, who sees people with fibromyalgia as a part of her work, says:

Back then, fibromyalgia was so new that a lot of doctors didn't know about it and they just thought, here's some woman that's... you really felt like nobody was validating how you felt, that well, it's just emotional. Now I think it's much better, because it's been recognized, they have medication specifically for fibromyalgia, and doctors know what it is and how to diagnose it and do something for it.

P26 argues that not only has the diagnosis of fibromyalgia become more common, but that it now serves as a catch-all diagnosis in a way that may be dangerous, because physicians may miss diagnosing another, more serious disease:

The danger I think we're in right now is... we go through periods of time in history where different ailments start becoming catch-all... now that the medical world and society has decided that fibromyalgia and chronic fatigue are real... maybe they're throwing too many people... I have encountered multiple patients who have had undiagnosed or misdiagnosed Lyme's Disease with very serious consequences and a huge majority of them were told they had fibromyalgia when indeed they may have it on top of that, but that was not what they initially had...

Given the relatively short history of fibromyalgia in terms of its recognition as a condition, it would not be surprising that patients who developed symptoms at different times may have had very different experiences with health care providers and in terms of information seeking. In particular, the sheer amount of information has changed. Many of the older

participants who were diagnosed earlier mentioned that very little information was available at the time that they were diagnosed.

Because many participants who were diagnosed more recently had relatively shorter times from onset to diagnosis (e.g., P24 and P27), it may lend support to the idea that physicians are more aware and more willing to diagnose fibromyalgia. However, these participants also indicated that they were extremely aggressive in pursuing diagnoses. Moreover, there were participants who were diagnosed relatively recently that had trouble with physicians thinking that it was all in their heads (e.g., P13 and P22). Thus, the testimonies of the participants suggest that while awareness concerning fibromyalgia is increasing, it is not ubiquitous.

6.4.1.3 Implications for Addressing Patient Needs

The experiences of participants in this study suggest that, though progress has been made in terms of shortening times to diagnosis, the number of lab tests that need to be taken, and the physicians seen, adoption of these changes is still in progress. Though this study involved a small, non-representative sample, the variability in times to diagnosis among the sample, regardless of the timing of diagnosis, suggests that there is still a ways to go towards more consistent practice of the diagnostic protocol.

It would be helpful if diagnosis and treatment of fibromyalgia were consistent across practitioners. The participants in this study reported a wide variety of attitudes among practitioners regarding fibromyalgia, and spent significant amounts of time finding practitioners whose orientations fit their own. While issues of patient-practitioner fit are certainly not unique to fibromyalgia, efforts should be made to ensure that health care practitioners are adequately trained to deal with fibromyalgia.

In terms of patients, it was evident from this study and a previous survey of fibromyalgia patients (Chen, 2012a), that patients experience a great deal of confusion and anxiety prior to and just after diagnosis. Many patients go into “panic mode” or wonder if they are dying; it is important to alleviate these fears as well as provide the information that patients need in a way that they are able to digest. In my interviews with P22, she argued that it was not useful to present information to patients at the diagnosis point, but rather, that such information could perhaps be presented afterwards in classes that patients could take. The task here is to find the right balance and way of discussing the condition with patients early on, so that they are not overwhelmed but have enough interest and motivation to reach out and seek additional information when they are ready. Lastly, having information resources that patients are able to access on their own time and that are written in supportive language could alleviate pressure that patients may feel from hearing that they have fibromyalgia and processing that news during the clinical encounter.

Another potentially beneficial practice would be to recommend that participants adopt changes in lifestyle earlier, even prior to diagnosis. The initiative displayed by a number of participants suggests that this may be useful to patients on a broader scale. In the case of P15, she realized that there was no point in waiting for the diagnosis to implement lifestyle changes, since she had already decided that, even if she were diagnosed with fibromyalgia, she was not going to take medication. P13 experienced a great deal of difficulty in obtaining a diagnosis, and ultimately decided to study Chinese Medicine partly because he did not want to rely on a healing modality that depended on having a diagnosis.

Extant research literature has recommended that treatment of fibromyalgia be multifactorial. In my dissertation study, all of the participants eventually implemented lifestyle

changes, and most of them also incorporated alternative healing modalities. Thus, I would argue that it would be useful to provide chronic pain patients with information resources concerning lifestyle changes and alternative healing modalities earlier on, prior to being diagnosed. I would also add that it is important for practitioners to speak more specifically about how this might be accomplished, as saying that one should change one's diet or exercise more is likely to not be enough for patients to know how to implement the suggested changes.

Lastly, there are many different types of health care practitioners that may treat fibromyalgia, including rheumatologists, neurologists and pain specialists; thus, it may be helpful to have increased coordination and exchange of patients' medical history among clinicians. Among the sample, this coordination seemed to occur in cases where practitioners already had a working relationship with one another. Since this is not always the case, it would be useful to facilitate information exchange through electronic health records or through the patients themselves, perhaps through histories that they may carry on mobile devices. Some of the patients already carry their health histories in binders and/or mobile devices, but having applications that ensure completeness of medical history, into which physicians could also transfer information from patients' medical records, could potentially be quite helpful.

6.4.2 Training for Health Care Practitioners

The participants in my study reported that they had extensive interactions with practitioners, and in this section, I consider the implications that their experiences have for the training of health care practitioners. The extent to which participants valued practitioners was striking. Many had had problems with health care practitioners in the past, but at the time of the interviews, all of them had at least one, and usually multiple, practitioners that they trusted and went to for their different areas of expertise. Overall, the patients seemed satisfied with the

health-related knowledge that they had acquired, and the information to which they had access. Though health care practitioners were by no means their only source of information, it appears that they were an important part of the puzzle. Patients made extensive use of other channels such as the Internet, but having a supportive set of health care practitioners whom they could consult with appeared to be invaluable for this population.

At the same time, study participants also employed and practiced a wide variety of alternative healing modalities, such as yoga, mindfulness-based stress reduction, hypnotherapy, massage, and acupuncture, and made extensive changes to their lifestyles in terms of diet, exercise and sleep hygiene. Through these activities, they often developed relationships with practitioners of those modalities, and received information from them as well.

Participants did not appear to see allopathic and alternative traditions to be in contradiction, though the ways that they integrated multiple modalities into their lives differed. For example, P12 described herself as, in recent years, having gone the route of “alternative medicine.” She has altered her eating habits and introduced supplements to control the hypoglycemic symptoms that she was experiencing, she engages in meditation, and has a massage therapist. She credits a physician’s assistant as the main person to have “put all of those pieces together,” but the reader may remember, P12 also has great esteem for her physician, and says that he practices “partnership medicine.”

Other examples of participants who have integrated multiple modalities include P15, P19, and P24, all of whom saw a general practitioner and an acupuncturist. P13 saw a Western-trained physician who also studied Chinese medicine, and a practitioner of Traditional Chinese Medicine (TCM), who prescribed herbs to treat his symptoms. P13 said that he had also learned some simple tai chi-like exercises from the practitioner of TCM, and that he and his general

practitioner would “talk to each other, and get ideas from each other, [and] see what options are available as options.”

The findings have various implications for patient-provider interactions. First, the multifactorial approaches taken by study participants corroborate extant literature, which has argued that treatment approaches involving multiple components is optimal (e.g. Hassett & Gevirtz, 2009). Second, the integration of alternative healing modalities need not be detrimental to relationships between physicians and patients. Quite to the contrary, patients in this study viewed physicians that they built relationships with over time as “partners” who provided them a wealth of information and with whom they engaged in collaborative problem solving processes, often involving other information and other types of resources. Thus, one implication of this is the need to develop support for physicians engaging in these processes by providing them information that they may in turn pass on to their patients.

In this study, as time passed on participants’ illness journeys, they often learned a great deal about health and wellness, and this new knowledge resulted in them taking different approaches to health management. They often picked up concrete strategies/skills for dealing with their illness, including learning how to interpret bodily signs and regulate emotions differently. These strategies seemed instrumental to participants’ abilities to manage and cope with their health conditions. However, participants frequently mentioned that, in discussions with physicians, often the only recourse offered was pain medication, and that there was very little advice about how to manage using other approaches. Thus, physician training in terms of how to advise fibromyalgia patients of other alternatives would be helpful.

The extant literature suggests that many primary care practitioners still feel that they are not adequately prepared to diagnose or treat fibromyalgia. In one mixed-methods study of

general practitioners ($n=189$) and specialists ($n=139$) in Canada, general practitioners reported insufficient knowledge and skill in diagnosing and treating fibromyalgia, with not all believing it was a diagnosable condition (Hayes et al., 2010). Attitudinal issues included frustration and negative profiling of fibromyalgia patients. A large-scale study ($N=1,622$) of six European countries, Mexico and South Korea reported that over half of physicians reported difficulty in diagnosing fibromyalgia and that they felt that their training was inadequate to do so (Perrot, Choy, Petersel, Ginovker, & Kramer, 2012). There have not been surveys of physicians' attitudes and approach to dealing with fibromyalgia in the United States. Thus, other than the need for physician education to address fibromyalgia, there is a need for foundational research to improve our understanding of physicians' attitudes towards and knowledge concerning fibromyalgia.

6.4.3 Promoting Fibromyalgia Awareness

This study has demonstrated that there is a greater need to promote awareness of fibromyalgia. The need for awareness exists in many circles, including among health care practitioners and the health care industry as a whole, in workplaces, and among the general public. As I have discussed, there were signs that awareness of the condition has improved over the last several decades: a number of participants mentioned that they believed that physicians were more willing to diagnose fibromyalgia, and for the most part, participants who were diagnosed more recently tended to report that they were aware of the condition and did not want to be diagnosed with it, rather than a complete lack of awareness of the existence of the condition.

The findings of this study suggest that there is a need to promote greater awareness of the need for flexible work conditions and support for employees. Participants made efforts to

alter their work conditions in various ways, including asking for the lighting to be changed, to be allowed to work flexible hours, and to work at home. They felt that these conditions increased, rather than hindered, productivity. They advocated for these changes in different ways, and their experiences suggest that movement towards more healthful workplaces may best be achieved through collaborative efforts from both employers and employees.

Lastly, the perceptions that study participants had of fibromyalgia and their stories suggest that there is still a lack of understanding of fibromyalgia among the general public. There have been, and still are, perceptions of fibromyalgia patients as “drug seekers,” “lazy,” or otherwise being capable but unwilling to contribute to society. The testimonies of the participants demonstrate that these perceptions can have a negative impact on fibromyalgia patients’ success in seeking out effective care, as well as their general well-being. Efforts to alter this public perception, as well as to educate family members about fibromyalgia, could potentially improve the quality of patient lives.

6.4.4 Assessment of Existing Information Resources for Fibromyalgia

This study showed that, over the course of their illness journey, participants came into contact with many types of information sources, and these information sources provided different types of value. For example, many participants used books to acquire an overview of the condition and treatment approaches; they went to discussion forums to seek answers regarding specific questions, or for reassurance that there were others like themselves. This study shed light on the motivations, topics and circumstances of participants’ use of specific information sources.

However, it remains unclear how well particular sources suit fibromyalgia patients’ information needs. Extant analyses of fibromyalgia information sources are limited. Examples

include an assessment of the quality of websites for fibromyalgia by Daraz et al. (2011b), and for chronic pain, by Kaicker et al. (2010). A more extensive analysis of subject matter coverage and quality of information in different sources, and perhaps of popular print material on fibromyalgia, could potentially be of great benefit.

6.4.5 Patient Education

The results of this study have demonstrated that fibromyalgia patients may turn to a wide variety of resources for help. Aside from health care practitioners and online information sources, many found long-term and/or group educational programs helpful. In this section, I summarize recommendations for areas that these programs might emphasize.

6.4.5.1 Encouraging “Active Patients”

Many study participants stated that though they initially did whatever their physicians advised, they eventually realized that they needed to take a more active role. Being more active might mean various things, including doing research on their own, taking an active part in discussion with physicians, and ultimately, being responsible for their treatment plan. As a patient, being active might entail knowing ahead of time what one wants to ask, making sure to clarify information if one is unclear about what the physician has said, and bringing information into the discussion as necessary. As P12 pointed out, physicians do not know everything, and even though they have expert knowledge, patients are likely to know things about their own bodies that their physicians are unaware of. Bringing up this information can help the physician to make recommendations that suit the patient better. Lastly, patients can be encouraged to be responsible for their treatment plans. That would entail not only understanding the treatments, but also making a conscious decision that they want to try a given treatment plan and then to carry it out – in short, to own it. P26 said, “I don’t think that people understand how much they

can actually help themselves by taking the reins.” Though a variety of resources exist for fibromyalgia, there is a need to ensure that this information presents constructive ways for patients to select and carry out their treatment plans.

6.4.5.2 Teaching Patients How to Search and Access Information

Many study participants mentioned a desire for additional resources that would help them find current research. Those who had experience finding information appeared to exercise those skills, but there were others in the study who might have benefited from instruction on how to search for and read scientific information once they found it. For example, P13 mentioned that, prior to enrolling in a program to study Chinese Medicine, he did not know how to search for articles on biomedical research. In the Google Groups alt.med.fibromyalgia group in which P17 participated, listserv members regularly shared news articles. In response to one of the shares, she posted, “All of this stuff is so confusing! CFS researchers have been saying for years that CFS is likely the result of an ‘upregulated’ immune system – one that activates to fight off some kind of infection then doesn’t shut itself off properly. Does anyone know what they’re talking about?”

Having focused lessons on locating and reading relevant articles, how to judge the articles, and what other information they might seek to add to the discussion might be enjoyable to some patients. Not all patients would be interested in learning these skills, but it seemed that a subset of the participants in this study would have been interested in a group like this. Moreover, online discussion forum participants periodically introduce articles to the groups in which they participate. Though, of course, this can be informative and useful to the entire group, the discussion itself might be more focused and become developed further if it were in a forum dedicated to discussions on articles. The lack of depth and advancement of knowledge

was also a reason why some study participants stopped participating in discussion forums, so encouraging focused discussion might increase the retention of these types of members. While an article discussion forum might be worthwhile on its own, it might be more interesting and effective to develop an educational program featuring lessons on locating and reading scientific research and an additional chat component with a moderator to discuss relevant articles.

6.4.5.3 Diversification of Information Provision

An overarching goal in the design of information resources is to develop resources that focus on understanding, utility and patients' abilities to help themselves. Participants in this study learned a great deal about their illness through the course of their journeys. This information, turned into knowledge, enabled them to manage their illness better. The lessons that they learned included factual content about their illness, but it also included a variety of other lessons, such as how to read their body signs, how to communicate with others, and many more. As has been demonstrated, participants came to learn these lessons through a variety of different channels. In the planning of patient education for fibromyalgia patients, it is important to continue to provide different forms of information access, as the diverse information seeking patterns of this population, likely arising from demographic and other differences, have resulted in very different paths to mastery of relevant management skills for their condition(s). It would also be useful to provide information at varying levels of difficulty, as patients may seek explanations at differing levels of complexity.

Moreover, these lessons are likely to be ones that require multiple exposures before being learned, and often require experiential learning. Thus, patient education resources should be designed so that they can be repeatedly accessed over time and include features to facilitate retrieval of information that is tailored to patients' situations and backgrounds, level of

knowledge and emotional state. For example, perhaps a patient is feeling guilty about his/her inability to meet family expectations, or to pay attention to his/her children. Other patients' stories about this could be grouped together and presented to the patient. In terms of knowledge level, an interface might be designed so that patients could quickly drill down deeper into a topic if they are familiar with it. Of course, the information could also be organized as individual courses to begin with, but sometimes a person's knowledge is deeper in one subject than another.

6.4.5.4 Supporting the Entire Family

Fibromyalgia is no different from any other condition in that the illness can affect the entire family. Examples from section 5.3.7.1, in particular, illustrate that there can be a great deal of tension between fibromyalgia patients and their families. Because it is an "invisible illness," it is difficult for family members to understand, and in some ways, the remarks from some participants that they themselves had thought that their family members were "hypochondriacs" and that they were "making it up" are a testament to how difficult it may be for those who do not experience the condition to understand it.

It is important to realize the inherent difficulties on both sides. On the one hand, patients are often struggling to find a solution that works, a process that is both psychologically and physically taxing, at a time when support is tantamount. By the same token, it is difficult for those around the patients to understand what they are going through, and their lives are also disrupted because they may have increased household or childcare responsibilities or not be able to go out as often with their partner as they had in the past. Thus, there is a great need to focus on programs that focus on patients and their families.

Previous literature on fibromyalgia patients and their partners has argued that the disability felt by a patient is likely to be significantly related to the partner's sense of burden, which can in turn lead to partners reacting by being supportive, overprotective and discouraging of activity (Reich, Olmsted, & van Puymbroeck, 2006). In this study, I came across examples of all of these types of behaviors, and sometimes within the same set of partners. In a narrative analysis of five men married to women with fibromyalgia, Söderberg, Strand, Haapala, and Lundman (2003) observed seven main themes in terms of the changes in the life of the partner: increased responsibility and work in the home, being an advocate for and supporting the wife, learning to see the woman's changing needs, changing relationship between spouses, changing relationships with friends and relatives, deepening relationship with the children and lacking information and knowledge about fibromyalgia. Sylvain and Talbot (2002) proposed a model of synergy towards health based on three elements: professional support, personal development and spousal support, in which the spouse's needs are also taken into consideration.

Thus, the current study and prior work have identified the need for educational programs to support and educate entire families. However, the relationship between patients and their partners, as well as with the rest of their family, can be a complicated feedback loop involving a variety of factors including illness uncertainty, level of disability, partner's perceived level of burden and others (Reich et al., 2006), and there is still a lack of educational resources and programs for the entire family.

6.4.6 Promoting and Facilitating Use of Alternative Healing Modalities

If nothing's going to work, why take it? It's just a band-aid. – P18

In this study as well as in Chen (2012a), patients were more likely to report seeking information on alternative treatments later on in their illness journey. Patients mentioned

various modalities, such as acupuncture, yoga, meditation, Chinese medicine, dietary change, supplementation and exercise that were particularly effective for improving their overall health status.

Previous literature has shown, and this study has corroborated, that alternative medicine use is common among patients (Barnes et al., 2008). Given that patients may use information on CAM to decide what treatment to utilize and how to do so, it is important to consider the nature of information that is available on CAM online and elsewhere. However, there is much that is unknown about the quality of the information resources that are available online. While there has been some evaluation of online CAM information sources for conditions such as cancer (Brauer, El Sehamy, Metz, & Mao, 2010), and Irritable Bowel Syndrome (e.g. Breckons, Jones, Morris, & Richardson, 2008; Promislow, Walker, Taheri, & Bernstein, 2010), little is known about online CAM information for most other conditions, including fibromyalgia.

P27 raised the point that introductory information sources for fibromyalgia are often authored by physicians or other individuals with a health care background, and approach the subject from the perspective of Western medicine. Though, to my knowledge, there has not been a relevant study investigating print sources of fibromyalgia information, many of the sources cited by study participants were authored by those coming from a Western medical perspective, and it seems likely that introductory information sources for fibromyalgia—and often, patients’ first outlets for information on fibromyalgia, their physicians – are more likely to present a traditional medical perspective. Consequently, patients may not encounter information regarding the use of alternative healing modalities as a treatment option unless they specifically look for it. In this study there was little mention of print or online resources on alternative medicine, despite the relatively pervasive use among the participants.

P22 speculated on possible reasons for the relative lack of coverage of these topics in online discussion forums. She attributed it to two reasons, suspicion about “things like acupuncture are voodoo” and lack of insurance coverage: “alternative therapies when it comes to fibromyalgia are not discussed as much as it should be, and I think part of that is just because there’s no coverage for it, so if it’s not available to you at a reasonable copay, then it’s kind of not within the realm of possibility.” Thus, with regard to CAM, there is both a need to consider the possibility of making it more affordable, as well as to investigate the availability, quality and suitability of CAM information on the Internet, as it may pertain to fibromyalgia and other conditions.

6.5 Design Implications for Information Resources

In this study, participants reported accessing a wide variety of information sources. Earlier on in the illness journey, most participants were interested in learning about what research was out there, and later on, many of them continued to subscribe to e-newsletters in order to keep up with new research. Though there is an abundance of information resources for health consumers, it is still a challenge for patients to navigate what is out there, and the experiences of most study participants reflect this. In this section, I discuss some major recommendations concerning the design of information resources that emerged from the study. Many of these recommendations may apply to chronic illness in general, rather than to fibromyalgia specifically.

6.5.1 Health Discussion Forums

This study raised issues that may be useful to consider in the design of online discussion forums. In this section, I describe some of the problems that participants reported and design

recommendations to address them. A summary of the recommendations, problems and aims achieved is presented in Table 15.

Table 15. Forum Design Recommendations, Problems Addressed, and Feature Aims

| Recommendation | Problem Being Addressed | Aim Achieved |
|---|--|---|
| <i>Information Presentation: Filtering and Grouping Posts</i> | | |
| Difficulty level | Repetitiveness of content, information overload | Easier for members to find content of interest, less likely for members to be confused or overloaded by irrelevant content or content that is too difficult |
| Emotional support vs. informational support | Exposure to content that is not of interest | Easier for members to find content of interest |
| Task or Skill | Patients have trouble understanding how information is applicable to their situation | Easier for patients to apply information to their lives |
| Symptom | Information overload | Easier for members to find content of interest |
| <i>Content Management</i> | | |
| Content creation by moderators to guide discussion directions | Negative online interactions between forum participants, paucity of content on a given topic | Increase topic diversity |
| Linking to external content | Paucity of content on a given topic | Increase topic and source diversity, introduce forum members to other content and information sources |
| <i>Community Atmosphere</i> | | |
| Clear posting of community guidelines and scope | Negative online interactions between forum participants | Reduce conflicts between members, create a more pleasant online environment, help new members orient themselves |
| Option to filter posts of negative emotional valence | Exposure to content that is depressing or discouraging | More positive community atmosphere |

6.5.1.1 Information Presentation

In health-related discussion forums, the inclusion of a diverse set of filters and multiple ways to display information can help patients, caregivers, and others find content of interest to

them. In this section, I describe the rationale and mechanisms through which this might be achieved.

In health-related discussion forums, you can have patients come together with varying levels of health knowledge. On the one hand, in a forum that has existed for some time, there may be members who have been participating for years. On the other hand, in most public discussion forums there is a constant stream of new members who may or may not participate in the forum long-term. As P22 described, in her experience there are many members who ask basic questions that have been asked before, but are nevertheless important to answer.

Those who are new to a health-related community may not read posts that have previously been authored and inadvertently ask the same questions, which in turn leads to the creation of a great deal of repeated content. Though some members do not find it problematic and often re-post information that they have previously posted, a number of study participants mentioned this repetitiveness and the lack of new information as reasons why they stopped participating. In order to reduce this repetition, it might be useful for these types of websites to implement functionality to filter out some of this content or to group it together. Grouping the content by subject can also help new members to notice that there may already be an answer to a question that they want to ask.

In addition, functionality to minimize the display of similar, repetitive posts might also encourage participants to post more in-depth content for those who need it. For example, the book, *Fibro for Dummies*, was often recommended by P22 for new members. While this may be a good book for new members, there may be other sources that are worth recommending. Reducing repetitive posts might unearth other posts on different topics that are worthwhile for participants to discuss.

In addition, it may be helpful to provide the option to group posts by type of content, e.g., emotional support vs. medical information. Though quite a few participants in this study found it frustrating that a lot of posts seemed to be “whiny,” there were others who saw these posts as comforting and supportive. There are some fibromyalgia patients who do not desire to read emotionally laden posts; perhaps they would be more inclined to visit discussion forums if there were a way to filter out these posts and just focus on the medical ones.

It may also be useful to implement features on discussion forums that facilitate views based on topic specificity and/or degree of experience with the condition. One approach would be to try to create filters for the content based on topic and/or condition experience, so that forum members could view posts of different levels based on their experience and mood or inclinations at the time.

In addition, many participants mentioned that they were interested in acquiring practical tools to help them manage their condition. It may be useful to group discussion posts that focus on particular skills, such as mood management, listening to one’s body, learning triggers and so on, to help patients to more quickly identify relevant posts and also understand how to apply the information to the problem that they are trying to solve. Having a more “action-oriented” interface to access content might make it more approachable, intuitive and helpful for patients.

Finally, fibromyalgia patients suffer from a diverse array of symptoms; thus, patients browsing the posts in fibromyalgia-related discussion forums may often encounter discussion content about symptoms that they do not experience. Filters might be used to help forum members to focus on symptoms that are relevant to them. Of course, customization and flexibility in the application of the symptom filters would be essential, since patients do experience a diverse set of symptoms.

The filtering and clustering of content can be done algorithmically, so that the content can be presented in different layouts to suit different audiences. This automatic generation could be achieved through machine learning algorithms, using a combination of supervised and unsupervised techniques. For example, one could use extant knowledge about fibromyalgia to develop high level categories, or identify novel categories of interest through cluster analysis (e.g., Chen, 2012b) or topic modeling. Machine learning techniques could also be used to classify content by difficulty level, which could then be used in filtering or clustering.

People visit the same online space for different reasons and see the content through different perspectives. The use of text mining techniques and interactive interface controls can enable patients to retrieve content that they are interested in, at a level that suited to their own experience.

6.5.1.2 Content Management

There are also recommendations for content creation and management on health-related discussion forums. P13's experience raising a question about Chinese medicine in a generic fibromyalgia forum provokes some thought. Those who responded were not favorably disposed to Chinese medicine, and this resulted in several negative interactions through the course of the thread.

Though this was a singular account, it perhaps raises the question of "patchiness" in topical coverage in discussion forums. Patchiness or spare coverage of topics may be particularly pronounced in cases of topics that serve a niche audience, such as Chinese medicine. Coverage of topics is inevitably uneven, but it may be useful for forums to link out to or draw in information not generated by patients to supplement what is already there, which may also help to present a more balanced set of viewpoints. For example, they might link out to

relevant pages on Medline Plus or the Drug Information Portal on the National Library of Medicine website. There are inherent difficulties in terms of maintaining the currency of the links, but these are challenges that could potentially be overcome.

6.5.1.3 Community Atmosphere

Though conflicts inevitably occur in online spaces as they do in real life and in face-to-face support groups, P13's experience with the Chinese medicine subreddit underscores the need for forum designers and moderators to consider how to nurture a supportive environment. Forums could encourage supportive content by posting forum guidelines prominently in the page layout or nurturing this through their own posts. Of course, there may be the risk of sounding overbearing or controlling, and forums perhaps need to experiment a bit in order to develop a supportive but open space. Providing functionality to filter out posts of negative emotional valence could also be helpful.

6.5.2 Mobile Applications

Another potential area for improvement of tools for chronically ill patients is mobile devices. Mobile devices may be useful to fibromyalgia patients for various tasks, including tracking of health behaviors and health status, engaging in a healthful behavior such as meditation, information seeking, and information management.

A number of participants in this study had experimented with mobile applications to track the pills that they were taking, the foods that they were eating, the amount that they were exercising, and pain levels. Participant 27 used an app to keep track of her test results, contacts that she needed to manage her health, like her physicians and her friends, information about the hospitals that she has been to, and the pharmacies that she visits. A few participants also

mentioned considering the use of, or actually using apps on their phone to support the practice of meditation.

Most of the time, their use of these applications was transient – until they remembered their medication regimen, or they were able to get their diet under control. Participants said that it did help them accomplish certain goals, like remembering to take their medications and identifying their triggers, but it would be helpful to further investigate users' motivations for ceasing to use these apps, and whether there are features that should be introduced to meet the needs of those who have reached more of a maintenance stage in terms of managing their condition.

There might be other tasks that fibromyalgia patients perform, such as note-taking and information seeking, which could be integrated into mobile apps. Several participants made notes that they would take to the doctor so that they would not forget what they had intended to say. Some participants mentioned that they brought their medical history, research that they have found, and questions that they wanted to ask physicians about, to the consultation; and a few mentioned that they kept binders of information (P11) and/or used a mobile app, HealthVault, due to losses of short-term memory (P27). P20 mentioned that she kept several folders of information that she has found online on her mobile device. There are particular problems that fibromyalgia patients may experience, e.g., having to keep track of and managing large amounts of personal health information and consumer health information, and dealing with cognitive problems and memory loss, in which mobile apps could potentially be of great benefit. Future research investigating current use practices and use gaps could potentially be very useful.

6.5.3 Facilitating Analysis of Complex Clinical Histories

Extant literature on fibromyalgia has often commented on the complexity and variability of its presentation. This study certainly highlighted this, as I observed great variability in the illness histories and comorbidities of the participants. Moreover, a change in any one area, such as sleep or diet, can have effects on multiple aspects of health and life, which complicates the tracking and managing of one's health. This is true regardless of the condition, but perhaps particularly in the case of chronic conditions. There is an extensive list of variables that may be involved, in multiple domains such as the physiological, cognitive and affective. As such, it is difficult to understand and keep track of patients' illness histories, and there is a need for interfaces and models to assist both patients and clinicians to make sense of and analyze these variables.

It is particularly important to develop interfaces that assist patients in the management of their own condition. Patients are the ones most intimately connected to their own bodies, though they are not always aware of them, and this is where interfaces can help. Interfaces can help them to track and draw causal connections, such as in P24's realization that she was gluten intolerant, which came from her use of a mobile app to track her food intake. In some ways, what some of the study participants here were doing resembles an $N=1$ clinical trial (van der Greef, Hankemeier, & McBurney, 2006). Providing them better tools to help them detect patterns in the physiological states, and identify causal connections, could potentially reduce cognitive overload.

What shape and form might these interfaces take? In fact, there is a great deal of prior work upon which we can draw. Extant work in the design of interfaces for visually analyzing electronic health records (EHRs) has recognized complexity as a critical issue, and thus,

reduction of complexity has been a goal of various development efforts. However, a development area for increased emphasis would be the modeling of data that one traditionally does not find in EHRs but is critical to fibromyalgia and many other chronic conditions: lifestyle variables.

Many of the participants in this study eventually engaged in long-term efforts to make changes to their sleep, diet and exercise patterns, and integrated regular treatments involving alternative healing modalities such as massage, acupuncture and chiropractic. How do we represent these variables in a health record, and moreover, integrate disparate variable types into analysis? For example, take an exercise recommendation such as “20-30 minutes of exercise, three times a week.” The type of exercise would likely matter a great deal in the effect that executing this recommendation would have, particularly for a person with CFS or fibromyalgia. Moreover, the way that this recommendation is executed would then affect other variables such as sleep and metabolic function.

Though this may sound like common sense, first, we must ensure that we are actually capturing this content somewhere, and then, we must implement ways of analyzing it. Though this information is not captured in a great deal of depth in most EHRs (occasionally there may be a physician’s note that may mention these details), of late there has been great interest in the use of mobile devices to track sleep, diet and exercise patterns, as well as other types of health indicators. There is still a need to consider whether our data representation facilitates the types of analyses that might be useful to patients.

To this point, I believe that there is an opportunity here to consider integration of alternative analysis algorithms. For example, P13 mentioned that his body temperature tends to be particularly low in the early morning and rise at approximately 11am. He also mentioned

that a focus on the suitability of eating certain foods, according to the principles of Chinese Medicine energetics, has been helpful to him in managing his health. It might be interesting to have systems that could employ a knowledge framework based on allopathic medicine and others based on alternative modalities, to see how the recommendations might differ. Chinese Medicine energetics is certainly one; another might be Ayurvedic traditions. Returning to the point about data capture and representation, we would then need to ensure that at time of collection, the required types of data are collected.

6.5.4 Metadata for Consumer Health Information

In the assessment of these resources, aside from inclusion of more traditional measures for evaluating information quality such as coverage, evidence base, and readability, it may also be useful to note other characteristics of a source, such as its temporal utility, the ways in which it might be used, and its perspectivity. In this study, I explored the consumption and use of information over long periods of time, in some cases as short as a couple of years, but in most cases, as long as decades, among fibromyalgia patients. Different pieces of information played different roles in their lives. Some pieces of information led to trigger moments in which participants experienced epiphanies, or engendered a radically different outlook or behavioral management strategies. Information that was often accessed at one time, such as books or online discussion forums on fibromyalgia, would often come into disuse over time, or sporadic use. This is somewhat reminiscent of Zufferey and Schulz's (2009) concept of "information use styles". Though it may be difficult to predict temporal utility directly, there may be other measures that get at this indirectly, such as specificity vs. breadth of a source, its subject matter, and perspectivity. For example, if a source is very general and covers a wide range of topics, it

may be useful for someone who is just beginning to learn about their condition, but not as useful later on.

The question of author perspective is an important one in the case of information. In the evaluation of health information, we often seek to ascertain that information is objective and comes from an authoritative source. While the logic of this is understandable, particularly with regard to subjects where there are many unanswered questions such as complementary and alternative treatments, it may not make sense to emphasize one argument or another (e.g., their efficacy or not), to the same degree. Rather, it might make more sense to provide clustering and summarization features for articles, tagged with metadata about the authors and/or views being expressed, to aid in interpretation and contextualization. Doing so would leave the reader free to make his or her own judgments.

In closing, it may be useful to consider what kind of metadata might be provided. For example, in a discussion forum, post characteristics such as temporal utility, author background, and viewpoint could be made searchable, so that patients are able to access posts of interest more easily. At present, few health discussion forums offer many more features than a full-text search. The posts might also be made available through a display that is meant to be browsed, for people not inclined to search. For example, if we could automatically tag discussion posts by temporal utility and/or other characteristics, we could incorporate tags such as “The Basics”, “An Overview”, “Newly Diagnosed”, “Learning to Deal with Doctors”, “How to Tell Your Family”, “Whether to Disclose at Work”, “Adjusting Your Diet” and “Exercising” into a browsable interface, or an interactive decision-based patient education resource. There could be options to alter post display priorities based on post author characteristics.

Posts with conflicting or opposing viewpoints could also be juxtaposed to help people understand different ways of looking at a problem. One example is medications. People often have had very different reactions to medications such as Lyrica, for example. Dividing these reactions into positive and negative alone could be helpful, but often, as I argued in a previous paper, a much more nuanced view of medications is needed (Chen, 2013). People's experiences with a medication can change over time, and it may be helpful to distinguish these experiences by "temporal phase" of medication use, as well as by side effect. Aside from medications, employing visualizations to tease out nuances in discussion text might be accomplished for a whole range of topics, such as food sensitivities, obtaining disability benefits, negotiating work conditions, and back pain.

6.5.5 Facilitating Patient Understanding of Health Information

This study showed that participants became quite knowledgeable about fibromyalgia over time. They often consumed and synthesized information from a wide variety of sources. Though many participants in this study appeared comfortable with this process, some did allude to difficulties (e.g. P11, P20, and P23). These might be due to cognitive and memory problems, as fibromyalgia does often present with cognitive difficulties, or "fibro fog." They might also have to do with the inherent complexity of fibromyalgia.

This process could be made easier through intuitive interfaces that facilitate patients' seeking, processing, storing and organizing of information. Participants in the study managed this process through various analog and digital tools, including use of a binder (P11), bookmarking (P11), and storing information in separate folders on mobile devices (P20).

Though there is no denying the value of analog tools such as pads and binders, it may be useful for participants to have the option of digital tools for engaging in these information

seeking and organizing tasks. There are various potential benefits of using a digital platform. First, it would be possible to semantically link ontological resources that explain medical terminology to patients. Of course, this is no easy task, and there are very great challenges here in terms of linking to or automatically integrating text that is written for consumers. Additionally, the interface could facilitate sense-making, by supporting higher-order sense-making processes by grouping similar studies; identifying conflicting findings, perspectives and views; summarizing text; and tagging text by level of difficulty. In their study of available online information concerning Lyme Disease, Mankoff et al. (2011) also raised the argument that there was a need to develop interfaces that highlight different viewpoints on issues. Lastly, there is the option of making this information readily accessible to a particular patient's physician(s) and any other(s) involved in the patient's care.

6.5.6 Designing for Accessibility

Most participants in this study relied upon books, consumer health websites, and/or secondary information sources such as Medscape for health-related information. Overall, they did not appear to be interested in reading reports on clinical studies themselves, and a number of participants expressed the sentiment that the articles were likely to be too difficult. One participant mentioned that it might be helpful to have a resource that provides summaries of current research, "to really help people be aware of what their options are, and what seems to work and what doesn't" (P13). Before he enrolled in a program to study Chinese Medicine, he said, he did not know how to look up journal articles.

Though there are information sources such as Medline Plus and Medscape to help people learn of and keep up with current research, many people are not aware that they exist. Though there were a number of study participants that subscribed to Medscape, my sample was

comprised of a high proportion of individuals that were working in, or had previously worked in, a health care environment, and the proportion of fibromyalgia patients who are familiar with these resources is likely to be lower. Thus, it would be helpful to promote the use of these resources among fibromyalgia patients. Moreover, it might be useful to automatically link the text to semantically relevant queries in health-related search engines, and/or link to definitions and additional information from authoritative sources.

Related to this is the need to examine the extent to which sources of health information cover topics of relevance to fibromyalgia patients. Daraz et al. (2011b) have examined the quality of websites that address fibromyalgia. Overall, they found that the websites with higher quality information tended to be less readable. Moreover, the websites that were rated as having the highest quality (Fibromyalgia Information, Fibromyalgia Information Foundation, and the National Institute of Arthritis and Musculoskeletal and Skin Diseases) were hardly mentioned by participants.

In addition, though Daraz et al. (2011b) examine the extent to which different types of information were available, it would be useful to have more information concerning the level of detail of this information. For example, though it is useful to know that diet and alternative therapies are discussed, it would also be helpful to know the depth with which they are discussed. A cursory overview may not be enough for someone who is interested in pursuing these avenues, and there appears to be considerable interest in these two topics among fibromyalgia patients, as both the results of this study and other prior work (Chen, 2012) have shown.

6.5.7 Long-Term Information Exchange

This study also showed that participants engaged in long-term information exchanges in various contexts, including patient education courses, exercise classes, face-to-face support groups, and online discussion forums. It may be useful to consider the characteristics of these long-term information exchange relationships. There is some ambiguity in the term, “long-term information exchange”, but the aim is to propose a taxonomy for studying information interactions that are continuous, intermittent, episodic or otherwise extend over a period of time, particularly in such a way that information is exchanged over multiple interactions. What makes them successful or not, and in what ways do they address participants’ information needs? There are various characteristics we can consider that these sources have in common: planned/not planned, content focus, subject matter, size of group, group cohesion, leader characteristics, frequency and mode of meeting, and duration and nature of the information exchange relationship (Table 16).

Table 16. Dimensions of Long-Term Information Exchange Resources

| Dimensions | Examples |
|--|--|
| Planned/Not Planned | Planned: Structured course. Not planned: Face-to-face support group in which participants go around a circle and share with each other their experiences. |
| Content Focus | Focused on a specific topic. Covers a broad range of topics. |
| Subject Matter | Health management strategies, coping, yoga. |
| Size of Group | A few people to thousands. |
| Group Cohesion and/or Sense of Community | Little or no sense of community. Strong sense of community. |
| Leader Characteristics | Physician, nurse, other health care practitioner, patient, etc. |
| Frequency of Meetings | Daily, several times a week, weekly, monthly. |
| Periodicity of Meetings | Regular or sporadic. |
| Mode of Meetings | Face-to-face or online. |

| Dimensions | Examples |
|---|-------------------------|
| Duration of Information Exchange Relationship | Weeks, months or years. |
| Nature of the Information Exchange Relationship | Structured or not. |

In any given case, there may be an issue of fit between individual patient characteristics and group characteristics. For example, some patients might prefer a course that is general and covers a wide variety of topics so that they can acquire an overview of the range of options that they have before them. Others might prefer a focused course on a particular topic such as mindfulness, and have little patience for broad overviews. A newly diagnosed patient might prefer the general course, but not necessarily; there are likely to be individuals who like to delve deep, and have no patience for broad overviews even in the beginning.

Many of the characteristics in Table 16 may be related to one another. For example, smaller groups may tend to have a stronger sense of community. This was an observation that was made by both P13 and P17. The longer a resource is intended to be used, such as health discussion platforms like DailyStrength, the less structure it may have, to accommodate the needs of the users. Online discussion groups associated with interventions that are limited in duration might be run by experienced moderators and have a more focused agenda.

In the case of chronic illness, long-term information exchange is perhaps a common phenomenon. However, information science has primarily focused on short-term information seeking and use models. Some models, such as Bates' berry-picking model and Dervin's Sense-Making model, can be applied to some of these information exchange relationships, as the search for information is often a meandering one that evolves as patients' cognitive structures do, and information seeking is often initiated to address an information gap perceived by the patient. In many cases, the lesson(s) learned may be one that takes a great deal of time or

is a continuous one involving continuous feedback from the self and/or others. P19's practice of mindfulness and engaged Buddhism may be considered as an example:

So the acupuncture, the yoga practice, and ultimately, really surrendering to practicing Buddhism really helped me to approach this differently and sort of prioritize being kind to my fear and prioritize the fact that especially early on, I didn't know what would make me feel better, but that was okay... and in time, I have figured out, usually, what makes me feel, you know, better.

In some cases, the motivation(s) that lead participants to engage in this long-term information exchange relationship might not be a perceived gap of knowledge. It may be a desire to engage in exercise or simply to connect with others, sometimes in conjunction with a desire for information but not always, which inadvertently intimates continuous information exchange. Participating in a yoga class, a face-to-face support group, or an online discussion group are examples of long-term information exchange interactions that might arise from these motivations.

6.6 Theoretical Implications

In this section, I examine the extent to which the models of information behavior that I introduced in the literature review apply to the phenomena at hand – the information behaviors of fibromyalgia patients. I consider six models: Kuhlthau's (1991) ISP Model, Bates' (1989) Berrypicking Model, Information Foraging (Pirolli & Card, 1999), Dervin's Sensemaking Theory (Dervin & Reinhard, 2007), Wilson's (1997) Model of Information Behavior, and the Comprehensive Model of Information Seeking (Johnson & Meischke, 1993). Because each model places emphasis on different aspects of information behavior, they have different strengths and weaknesses when applied to the problem at hand. Lastly, I present a model that

emphasizes the interrelatedness of cognitive, emotional and physiological experiences with information behavior over time, which is not emphasized in the other models.

6.6.1 Kuhlthau's Information Search Process Model

As this study has illustrated, uncertainty and emotions play important roles in the information behaviors of fibromyalgia patients. In addition, participants move from a general/vague understanding of a subject, associated with confusion and frustration, to a clear/focused understanding, and their confidence increases at the same time. In these ways, my data suggest that Kuhlthau's model applies to the information behaviors of fibromyalgia patients. However, there are also aspects of the ISP model that do not appear to apply as well to chronic illness information behaviors. As mentioned in the literature review, the ISP model appears quite linear, whereas "trial and error", detours, roadblocks and cyclical processes were prominent in the illness journeys described by participants.

Moreover, the later stages of the model – formulation, collection and presentation – were not usually observed. There were some cases in which one could argue that the essence of these stages did occur: for example, in P22's posts to the discussion forums she participated in, or P15's design of a educational program for managing fibromyalgia. In both of these situations, there was some circumstance that served as an impetus for the information seeker to go through these stages. Without these, a formal process of formulation, collection and presentation generally does not take place. This inconsistency is not surprising, given that the students in Kuhlthau's studies were engaged in a task that culminated in a presentation.

I am not arguing, however, that there is no experience of closure on the part of participants. Much to the contrary, I believe that participants either found the answers that they

sought, or became reconciled to the idea that they had learned as much as they could, and then worked at letting the issue go.

6.6.2 Bates' Berrypicking Model of Information Retrieval

Bates' "berrypicking" model of information retrieval appears to be well-suited to modeling the process of information seeking in chronic illness. As the results of the study have shown, users' information needs evolve gradually as they pick up bits of information. In addition, Bates (1989) enumerates six strategies that users may use for searching: footnote chasing, citation searching, journal run, area scanning, subject searches and author searches. Though these strategies more aptly describe academic contexts, one might consider whether they also apply to health information seeking in more everyday situations.

In the context of health information seeking, I believe that there is some argument for the applicability of the last four strategies. One might think of a journal run as a search for other useful material within the same website, as opposed to a journal. This might happen when an individual encounters a health discussion forum through a Google search, finds an interesting post or set of posts, and then decides to browse through more of the site. Area scanning might be thought of in terms of examining a group of web pages that occur together in a set of search results. One might also engage in subject or author searches online. One example of this in this study was P06's reading of other materials by Dr. St. Amand and regarding the guaifenesin protocol once she had heard of it.

The berrypicking model seems an apt analogy to consider in the design of information sources for chronic illness. Overall, though participants' understandings and information needs evolved over time, most participants did not appear to keep track of and organize the material that they found, other than perhaps keeping their medical information in a binder or in a folder

on their computer or phone. They did, however, think and reason about this information in their heads. But as we have seen, fibromyalgia-related information may be complex and difficult to understand; thus there is the danger that reasoning about it in one's head may result in errors in understanding, and there is also the danger of erosion of memory. Technologies that support information management could help users to organize the information that they have found and avoid inadvertently making errors in reasoning about the material.

Thus, one take-away is that it would be useful to design applications to help participants organize the information that they acquire from their online information seeking, help them to understand and sense-make about this information, and also facilitate the monitoring of information with which many participants engage after they stop actively seeking information. This might be in the form of “intelligent” interfaces that extract information from web pages, suggest additional relevant resources, and summarize resources that a user has flagged as being relevant. Lastly, interfaces might also offer features that enable users to compare and synthesize information from multiple sources. Provided that article metadata is available, the system could also provide a temporal visualization of the dates in which the web pages that they bookmarked were published or retrieved. If the content of various articles is conflicting, it may be because more recent research has changed the medical community's understanding of a phenomenon.

6.6.3 Information Foraging

Prior to conducting this study, I expected that information foraging would be an apt analogy for the process of information seeking in the context of fibromyalgia. In large part, the interviews have confirmed this to be the case. Participants sought out information in different patches, which we might consider to be information sources such as health care practitioners,

health care portals, health discussion forums and so on. One might say that this landscape appears “patchy” in the sense that some sources appear to be richer than others, and participants may move on because they feel that the “information scent” in a particular patch is weak. There were examples of this in the interview content – P13 stated that his interest in discussing Chinese Medicine on Reddit had started to wane because he did not feel that the users were truly interested in learning more about Chinese Medicine, and multiple study participants saying that patients should move on if they did not feel that a physician was going to take them seriously and work with them. The concept of an information diet also works in this context if one considers it as the different types of information that participants consumed over the course of their journeys.

We can employ the analogy of information foraging to consider participants’ interactions with various information sources over time. The concept of information foraging suggests that resources become depleted in patches over time, and there were cases in which participants lost interest in a patch over time. In many cases, participants felt that they had thoroughly consumed the resource, and that there was nothing new to be learned from it.

When I asked P06 why she stopped searching for information, her answer suggested that she had sized up the lay of the land: “the first couple years, I felt like I had figured out as much as I could... and everything else online. There were people who had tried various things... different kinds of massage... there were people who said that they had connected issues, like Irritable Bowel Syndrome...” She goes on a bit further to describe her assessment of the different groups and recommendations that she had seen online, and the ones that she had tried. Thus, her conclusion was that she had gleaned what was useful from the source, so there was no need to keep going back to it. In this situation, if we think of a resource as not just

“information”, but “novel information”, then the analogy of foraging works. Participants gradually use up “novel information” a.k.a. “resources”, and then, they move on.

However, there were also instances in which participants interacted with a source rather extensively in a short period of time, and then lost interest in it because it had not turned out to be what they expected or hoped. P13’s interactions with Reddit are an example. At first, he had hoped to engage in substantive discussions about various topics, including Traditional Chinese Medicine, on Reddit, but after interacting online for a short period of time, he came to feel that there was very little substantive content there, so the time he spent participating on that platform tapered. Thus, the motive to stop grazing may not be depletion of the resource, but “disillusionment” with it – apparently, it was not as delectable as initially anticipated.

In the case of physicians that participants felt were useful, participants most often did not end up “running them dry” and moving on, but rather, continued to work with the same physicians over time, and were extremely enthusiastic about the value of the information that their physicians provided. A few participants also engaged long-term with online communities. However, in the cases of the few long-term health-related online participation histories I have in my sample (P09, P22, P23), other non-information related benefits, such as sense of community and having an outlet for “venting”, appeared to have been more important motivators for participation. These long-term relationships perhaps take us out of the analogy of foraging, to a concept of an ecology in which different parts of the ecosystem interact symbiotically. Though it may be a stretch also to argue that patients and providers have a symbiotic relationship, in some ways, realistically and idealistically they do, and P12’s statement that her physician practices “partnership medicine” approaches this idea as well.

Lastly, I would like to examine the case of passive monitoring. As reported earlier, participants tended to engage in active information seeking until they got to a point at which they felt that they had enough information, and then they switched to passive monitoring. Though one might think that this situation is akin to the notion of a patch becoming depleted, I would argue that this is not the case. Rather, the equivalent situation would be that an animal has become satiated and continues to feed on an occasional or periodic basis with no great drive.

6.6.4 Dervin's Sensemaking Theory and Methodology

As expected, there were aspects of Dervin's conceptualization of Sense-Making that seemed useful for considering how fibromyalgia patients make sense of their situation. Fibromyalgia was experienced as a discontinuity – many participants were unable to understand what was wrong with them and/or why they had developed the illness (e.g., P12 and P15). Moreover, the physiological effects left many mentally, emotionally and otherwise at a loss for how to manage their lives, and led to a fundamental questioning of their self-identity and self-worth (e.g., P05 and P20).

In Sense-Making, the outcomes of information use might be considered *helps* or *hurts* (Savolainen, 2006). Study participants reported various situations in which we can observe these practices. For example, information sources enabled people to “get a picture” of what was going on, receiving support or validation from others enabled people to “keep moving”, and encountering information about treatments, and/or taking part in yoga or patient education courses enabled participants to “get control.” In fact, this orientation towards the outcomes of information use as specified in Dervin's theory is consistent with the study findings because there was a strong focus on outcomes among study participants and, likely, patients of fibromyalgia and chronic illnesses in general. Once participants accept the idea that they will

have an illness “forever”, the important question becomes whether they are able to function, or “do what they want to do”.

Emotions are an inherent part of the Sense-Making framework, and they certainly played a role in the illness journeys of participants in this study. Early on in their journeys, participants often experienced confusion, both in terms of what was happening to them, and as they endeavored to find answers through health care practitioners, books and online information sources. Fear and anxiety concerning their physiological state was also an inherent part of their mental state as they sought control over their symptoms.

6.6.5 Wilson’s Model of Information Behavior

Wilson’s Model of Information Behavior endeavors to integrate multiple models into a single model of information behavior. As mentioned in the literature review, people are embedded in contexts in which there are intervening variables (psychological, demographic, role-related or interpersonal, environmental and source characteristics) and activating mechanisms (stress/coping, risk/reward, and self-efficacy) influencing them; and their information seeking, processing and use are affected by these variables. This can be an iterative process.

I now examine the information behaviors of study participants through the paradigm of this model. According to this model, the concept of an information need is at the heart of information behavior (Wilson, 1997). A person experiences different types of information needs due to their own physiological, affective and cognitive states, their social roles, and their environment – in short, the context of the information need.

This study provided rich detail about elements of the context that influence and shape patients’ information needs. How patients perceived their information needs, i.e., the questions

that they needed to answer, was very much shaped by their life situations. For example, much of P06's information needs were driven by her need to manage pain in her work, which involves long hours working on the computer. P20's information seeking was very much influenced by the desire to preserve her military career.

Structural aspects of the health care system also influenced information seeking. Participants sought information to obtain access to the health care that they needed, for example, to learn how they might pay for medications and get approved for disability benefits. Going through the process of getting approved for disability benefits was a subject that came up in many of the interviews, and it was also a pervasive topic of discussion in the online discussion content that I examined.

The physical experience of fibromyalgia was also critical. For most patients, their experience of pain is persistent and therefore demands their attention. There were a number of participants who, at some point, thought that they were going to die. These types of factors all exacerbate the perception of urgency of the information need. For many participants, once they had managed to achieve some level of control over their symptoms and reached a state in which they were not pain-free, but stable, they stopped actively looking for information.

Activating mechanisms such as stress and self-efficacy (suggested in Wilson's model) play an important role in fibromyalgia patients' information behaviors, decision making and illness management. At onset, fibromyalgia patients may be overwhelmed by their symptoms. They may struggle to understand what it all means and to keep up with the demands of their work and family obligations. All of these factors can lead to a great deal of stress and have an impact on their decisions and information seeking behaviors. For example, P05 was concerned

about how she was going to pay for her health care; she had also thought that no one would “want to be with a sick girl,” and these factors played a role in the life decisions that she made.

Aside from stress, self-efficacy also played an important role. For P05, being independent was paramount. At first, her health issues called into question her ability to be so and resulted in extreme levels of anxiety and anguish. However, she eventually was able to figure out her own strategies for managing her physiological condition, work, and other aspects of her life. This was a gradual process involving many pieces of information consumption and use, including learning how to manage her triggers, working out an effective treatment strategy with her doctors, negotiating with her employers, and adjustments to the ways in which she and her family and friends interacted with one another. With each small gain, her belief in her own ability to achieve her goals increased, which in turn increased her motivation to continue making progress. Thus, P05’s experience serves as an example of how incremental increases in self-efficacy operate in a feedback loop to help a patient to continue moving forward.

Intervening variables modeled in the context are important. Contextual factors that facilitated this, such as the connection that many of the participants had with academic environments, in which looking up information on the Internet is encouraged, facilitated their extensive use of online information sources. Indeed, some of the participants had a natural affinity for the Internet and/or information.

Another intervening variable that Wilson enumerated was the environment. Though comparison across countries and/or cultural systems was out of the scope of the current study, it is likely that there would be great differences between the way fibromyalgia patients seek information and what they seek information about, based on these differences. Some of the study participants’ experiences, which are imbued with belief systems and health practices

outside the paradigm of allopathic medicine, suggest this. For example, many study participants placed great importance on alternative healing modalities. P26 argued that a pharmaceutical-driven health care system was not a necessity.

Wilson (1997) also argued that information seeking and acquisition might occur in various forms: passive attention, passive search, active search and/or ongoing search. Examples of *active search* were prominent in the sample. Almost all participants engaged in active search intermittently in their journeys. Common motives to engage in active search were the appearance of a new symptom and being diagnosed with a new condition. Whenever there was not a pressing need for information, consumption of health-related information became an activity involving *passive attention*. Participants occasionally glanced at newsfeeds that they subscribed to, but very rarely engaged in search.

Ongoing search occurred less frequently. There are perhaps two main reasons for this. First, information seeking was generally motivated by pressing needs. Participants sought help only when they were not able to carry out the functions of their daily lives (e.g., P27). When they were on treatment regimens that were working, they did not engage in such active information seeking (e.g., P06 and P09). The second reason is that participants reached a point in which they did not believe that there was information (that would be new to them) to be had. Thus, there may be a question of whether ongoing search occurs when these two conditions are not true (i.e., when participants do not reach a state of effective management, or satisfaction with the information at their disposal). One might suppose that they would continue to seek information, but other factors might also cause them to pause or put an end to their search (e.g., a feeling of powerlessness or life circumstance), or impede the progress of their search. I did not see any clear examples of this, but this does not mean that such events do not occur. There

may be various reasons why I did not come across such examples, including selection bias (many people in my sample believed that they were very good at finding information) and the method of retrospective recall.

The phenomenon of *passive search*, and its manifestation in participants' illness journeys, is perhaps one of the most interesting to consider. Wilson (1997) defined passive search as "those occasions when one type of search (or other behaviour) results in the acquisition of information that happens to be relevant to the individual"(p. 562). McKenzie (2003) proposed a two-dimensional model of information practices, including the mode *active scanning*, defined as "semi-directed browsing or scanning in likely locations (for example, doctors' offices or bookstores... and active listening to conversations or questions in likely locations (e.g. group discussions in prenatal classes or multiple birth association meetings)"(p. 26), which she argues is akin to Wilson's concept of passive search.

There were various examples of passive search in the sample. There were participants who sought books on fibromyalgia in bookstores and libraries (e.g., P11 and P27). As mentioned earlier, prior to learning of the condition called "fibromyalgia", P09 looked broadly over different social media platforms, seeking out individuals and reports of symptoms similar to hers. McKenzie (2003) observes, "Accounts of active scanning involved the recognition of a particular location as a likely information ground, or of a particular source as likely to be helpful, although the seeker may not describe having an expectation of finding anything specific"(p. 26). The term, "fibromyalgia", in fact, appears to engender an expectation of non-specificity.

6.6.6 Comprehensive Model of Information Seeking

As mentioned earlier, the Comprehensive Model of Information Seeking has three main components: *antecedent factors* that determine one's predisposition to seek information from particular information carriers, *information carrier factors*, and *information seeking actions*. This model makes the inter-related nature of these three components explicit, and in the context of this study, is useful to a limited degree for examining the information seeking behavior of participants. At any given point, participants' selection of information sources is a product of their own personal characteristics (antecedent factors) and characteristics of the information sources (information carrier factors). For example, a number of study participants tended to seek out what they perceived to be reputable sources of online health information, such as Mayo Clinic, rather than other sources such as discussion forums, which they found to be depressing (e.g., P12) and negative (e.g., P20).

Though the CMIS is an apt model for examining the match between information sources and their audiences, this model has limited applicability to the study of illness journeys. There are perhaps two primary issues. First, time is not explicitly incorporated into the model. Second, though the model is fairly comprehensive in its elucidation of antecedent and information carrier factors, utility and information seeking action are fairly simplistic in their conceptualization. As we saw in the examples in this dissertation, participants' appraisal and use of information sources changed over time. P05, for example, engaged with different online platforms differently, and her level of engagement changed over time.

6.6.7 Applying Information Behavior Models to the Illness Journeys

Each of the models that I have reviewed has certain strengths and weaknesses for examining illness journeys. One of the greatest challenges with the study of this phenomenon is

the passage of time. I would argue that Bates' berrypicking model and information foraging afford conceptualizations that are closest to that of the illness journey, because they depict a path that is not necessarily linear, that is organic and evolving. Dervin's Sense-Making Model is not necessarily in contradiction with this idea; however, the way that the Sense-Making Methodology is instantiated places the foci on particular points of information seeking, use, or sense-making, rather than on the big picture of the journey.

Another salient aspect of illness journeys was that the journeys were shaped by a complex set of interactions among physiological sensations, emotional states, cognitive understandings, and incremental effects of consumed information. Though the models do not explicitly include physiological sensations or emotional states, it would be possible to include them in certain models, such as information foraging, Wilson's (1997) model, and the CMIS. Cognitive understandings are perhaps difficult to model to any degree of specificity without incorporating a more complex model focused specifically on the type of cognitive understanding of interest. In this study, I incorporated the Common-Sense Model to provide a brief assessment of an individual's illness representations (Leventhal et al., 2003; Hagger & Orbell, 2003). However, the point remains that the preceding models of information behavior do not readily facilitate analysis of the complex interplay of physiological, emotional, cognitive and information-related factors over the course of an individual's illness journey.

6.6.8 An Evolving Information Ecology: A Conceptual Model

The preceding models of information seeking and use each provide a useful way to examine aspects of information seeking in the context of chronic illness. However, none of the models is readily amenable for depicting this journey. Thus, I propose a model, the Evolving

Information Ecology (EIE), for conceptualizing this illness journey that incorporates the elements just described.

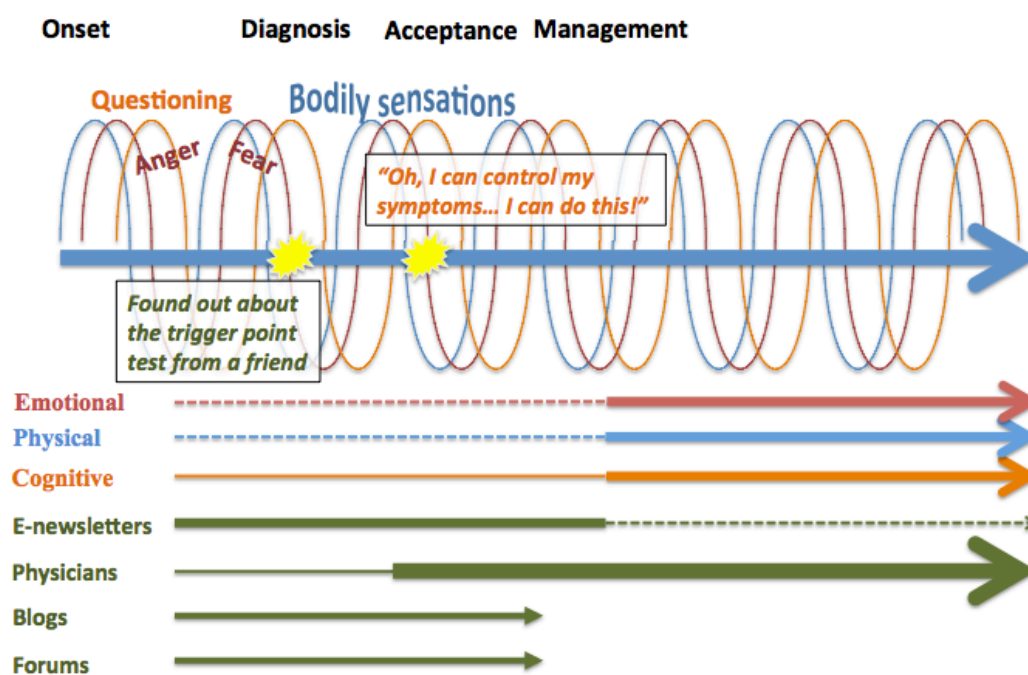
6.6.8.1 EIE Model Description

We may think of people as traveling through an information ecology that evolves as they do. As they travel along through life, people consume from and share information themselves, through various channels. The type or extent of consumption of these sources may also change over time. For example, earlier in patients' illness histories, many searched online for information and read what other patients shared in online discussion forums. Later on in their journeys, patients often did not seek information as proactively, and developed ways of passively monitoring information through news feeds. There were others, though, that kept up active information exchange routines through their physicians or through online discussion forums. Patients' own cognitive understandings and perceptions evolve as a result of their interactions with the ecology. Moreover, their subsequent actions, in response, also lead to shifts in the ecology, resulting in a feedback loop.

Figure 10 is an example of how the information ecology might look for a given individual. The width of the diagram represents the flow of time, such that the leftmost point is the earliest part of the illness journey, and the rightmost point is the point farthest in the future. The crux of this model is the individual's journey, depicted in black, and three inextricably intertwined dimensions: the physiological (blue curve), emotional (red curve), cognitive (orange curve). At any given time, a person is engaged in information consumption and sense-making. Throughout their journey, they come into contact with information sources (green), some short-term, some long-term, and some that they have proactively sought out and others that they have encountered serendipitously. The thickness of the lines reflects the amount of activity. With

regard to information, at certain points, the information that patients receive from a given source may be very little (thin green lines), and at other points, considerably more (thick green line). Dashed lines represent implicit or passive activity. For example, towards the end of this individual's journey, she stops actively seeking information, but she does occasionally glance through the newsletters that she continues to receive. Earlier in the journey, this person was not that aware of her own body or her emotions, and thus, the implicit nature of these inputs is indicated with a dashed line.

Figure 10. An Illness Journey through an Evolving Information Ecology

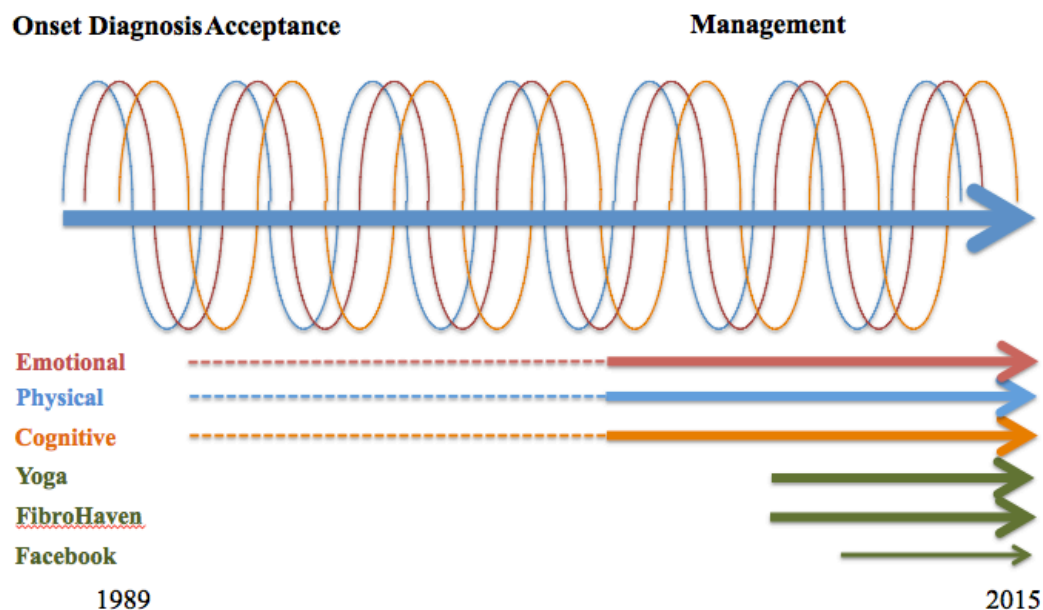


Early on in this person's journey, they experienced a period in which they felt scared and angry about what they were going through. They questioned what they were being told, and they went online to see what they could find, reading somewhat aimlessly through blogs and discussion forums. Gradually, they picked up on little patterns in the seemingly senseless ups and downs in their health condition. Though this was a gradual process, they realized that they could control some aspects of their condition at a particular time, and had a "light bulb

moment.” Meanwhile, they had initially been with a physician that was not very helpful, but along the way, a family friend had referred someone that they went to and tried out. This new physician helped the patient implement some lifestyle changes that eventually enabled the patient to manage their condition effectively. The patient gradually settles down to a pattern of passive information monitoring.

The different elements of the model might be modified to reflect the specific aspects of a given person’s journey. For example, P07 and P18 accepted their illnesses early on, with little or no information seeking. Later on, they both ended up learning much more about their illness. Figure 11 depicts how P18’s illness journey might look, depicted using the Evolving Information Ecology model. The primary information sources for P18’s cognitive growth were yoga and FibroHaven, the support group in which she participated, both of which became part of her journey in the last decade. She did not mention having any light bulb moments, only gradual changes in understanding.

Figure 11. P18’s Journey Depicted using the Evolving Information Ecology Model



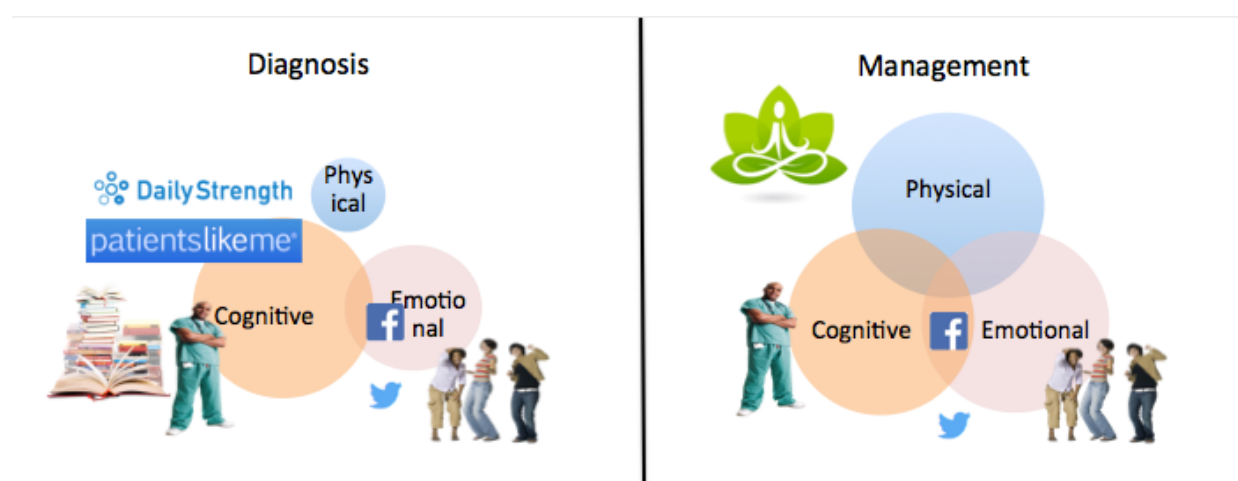
The model that I have proposed could potentially be useful for illustrating many of the key patterns that I have observed in this study. Early in their journeys, many participants read everything they could get their hands on, because they were not sure what they had. Even if they had a name, “fibromyalgia,” they needed to read more to understand. Over time, many participants became more adept at consuming and evaluating information across a variety of different media. They eventually came to a point where they developed a personal understanding of the term that they were satisfied with, and reached a ceiling where they did not feel that they were accessing new information. They had a sense of what they were looking for and recognized it when they saw it. Whether a treatment or strategy that they adopted was effective was still a matter of “trial and error”. Once they reached this point, they usually ceased actively seeking information. Most attributed this to the lack of new information, but this change might also be because they had cultivated channels and reflexes to be able to acquire and process information more seamlessly.

6.6.8.2 Snapshots of the Evolving Information Ecology

It is perhaps useful here to consider what cross-sections of the EIE model might look like. Essentially, each would be a snapshot in time, of the information ecology at that moment. Figure 12 depicts an example of how two of these snapshots might look for a given patient. At time of diagnosis, this patient is trying to understand as much as she can about the illness, so the orange circle depicting her cognitive input is fairly large, while the physical and emotional inputs (blue and pink, respectively) are smaller. The volume of emotional inputs is still greater than that of physical inputs, because the patient is also reacting to what she is feeling. The patient reads a lot of books, has a fair number of interactions with physicians, and is also looking around online, on various discussion forums. She is also interacting with family and

friends. Most of these interactions are affective in the sense that people are providing emotional support, but they are not providing information that helps the patient to learn about the condition, as the physician is (and hence, the different positioning of the icons). Facebook is a source of both emotional support as well as information, as the patient sometimes sees stories in her newsfeed that inform her understanding of her condition. Twitter is present, but rather tangential.

Figure 12. Information Contexts along the Illness Journey (Diagnosis, Management)



As the patient reaches a point in which she is effectively managing her condition (the second snapshot in Figure 12), the physical, emotional and cognitive elements of her illness journey come into balance. Through yoga, the participant has become more aware of her body, as many participants (e.g., P05 and P17) spoke of. She has stopped actively seeking out information on discussion forums and in books, but still sees her physicians on a regular basis and receives information from them. Facebook, Twitter, and family and friends remain part of the equation.

Stepping back from the snapshots, there are two observations that might be made. First, the snapshot of the diagnosis point suggests a situation of information overload, which participants mentioned. Second, the participant's increasing awareness of her own body and

ability to regulate her own emotions are key aspects of her becoming able to manage her condition. In depicting this journey thusly, I am not suggesting that every journey will take this form, but these snapshots were inspired by the testimonies of particular participants in this study.

The cross-sections of the EIE bear similarities to various extant models for studying information seeking behavior, including the concepts of information horizons (Sonnenwald, Wildemuth, & Harmon, 2001) and information fields (Johnson, Case, Andrews, Allard, & Johnson, 2006). The most significant difference between the EIE model and these two concepts is the explicit modeling of time. The information horizon map has been used to study the information behaviors of lower socio-economic students (Sonnenwald et al., 2001), archaeology professionals (Huvila, 2009), and environmental activists (Savolainen, 2007), among others. Johnson et al. describe information fields as being “static” and the “starting point for information seeking”(p. 570), and as such, the conceptualization of the information field is quite different from a cross-section of the Evolving Information Ecology. The concept of the “pathway” is proposed in Johnson et al., but this conception does not refer to the information context, but rather, the path that an individual takes in their information seeking, and is similar to the concept of an information processing chain that I discuss in section 6.6.8.4. The other major difference between the EIE model and these two concepts of information seeking behavior is the triadic conception of physical, emotional and cognitive growth that occurs along the illness journey, in step with an individual’s information seeking behavior in their evolving information ecology.

6.6.8.3 Applying the EIE Model to Research

This model might be employed in research in various ways. First, a researcher might draw this out themselves in order to make sense of the different factors at play in an individual's illness journey. Second, they might provide participants a worksheet and colored pencils, and provide instructions on how to complete it. Worksheets with timelines have been used in various health-related studies (e.g., Sheridan, Chamber, & Dupuis, 2011; Thygesen et al., 2011; St. Jean, 2012). All of these studies provided more structured guidelines than those that I used. In this study, I deliberately gave participants very open-ended instructions so that I could form a better understanding of what was important to participants along their illness journeys. The data from this study served as the foundation through which I identified important variables to include in the model, which can then be used in future research.

Lastly, this model might also be used in quantitative studies, using time series analyses or structural equation models. The most straightforward way would be to operationalize the variables in terms of dichotomous or interval/ratio variables representing whether a variable is present or absent, or the magnitude of the variable. For example, one could represent the information sources this way, to indicate whether or not, or to what degree, a person used information from a source, and also use variables to represent the extent to which participants experienced physical discomfort or emotional reactivity, at different time points. As mentioned earlier, the cognitive representations would be more difficult. One might represent this simply in terms of amount of knowledge, or use a more multidimensional construct, such as the illness representations I used in this study. By operationalizing all these variables in such a fashion, one could then study the ways in which information consumption, physical status and knowledge are related to an individual's emotional reactivity.

Variables might be operationalized in more complex ways to model them more faithfully. For example, patients may not react the same way to all symptoms; there are some that they might find more pressing than others. The model might include different categories of physical issues that trouble patients, rather than lumping them all together in a single variable. This might also influence which sources they choose to use.

6.6.8.4 Applying the EIE Model to Systems Design

This model might also be useful for informing the design of systems for chronic illness information seeking and use. People may differ in terms of various aspects of the information that they consume: the healing modalities that they prefer, the amount and type of information that they consume, and the extent to which they would like to “direct” their own care plan. Applications should enable participants to customize their information diet by tailoring the type and amount of information that they retrieve, consume and store from diverse sources. For example, applications might download and summarize information from Twitter, Facebook, online discussion forums, and other sources. Users could select the sources from which they would like to see information, and exclude the ones in which they are not interested. Channel, source and subject matter filters could facilitate the information retrieval process, such that those who are seeking information on pharmaceutical products as opposed to alternative treatments, and vice versa, would receive the appropriate type of content. Text mining techniques and information source metadata could facilitate subject matter, perspective, and viewpoint identification. Lastly, applications could link to other sources to provide background information about complex material to help users understand what they are reading.

In addition, applications should also take into account changes in patients’ cognitive understandings and information exchanges over time. For example, in this study participants

generally became quite knowledgeable about fibromyalgia over time, and they also tended to gravitate more towards alternative treatment modalities. Labeling recommended information sources by specificity level (general to specific) and subject matter tags could facilitate information selection in browsing, and the same metadata might be used to automatically generate recommendations.

Aside from differences in the amount and type of information from different sources, there were also information processing chains, in which participants might obtain information about a subject from one source, and then employ another source to find out more about it, or to corroborate the information obtained. For instance, as mentioned earlier, P13 and P24 found information on the Internet and then asked their doctors about it, which then led to their diagnoses of fibromyalgia. On numerous occasions, P17 found information about a treatment over the Internet and then asked her doctor if she could try the treatment. There were also participants received information from their physician and then went online to learn more (e.g., P07), and P16 was told that “people with fibromyalgia just get tendinitis for no reason”, which she disagreed with (and argued in futile with the physician about), so she went online to see if she could find any evidence regarding the matter.

There were instances involving more complicated chains, such as P15 using information to solve one problem, only to realize that there was another “underneath” that she would then go and do research to solve. P13 and his physician bouncing ideas off of each other and iteratively running lab tests is another example. The example of P17 finding information on the experimental drug and bringing it up to her practitioner, but ultimately not deciding to take it is particularly interesting, because both go off and seek information and then come back and act upon the results of their information seeking, forming a double loop. (As a reminder, the

practitioner had said no at first, but then conferred with another physician and changed her mind, at which point the participant had decided it was too risky.)

6.7 Future Research

This study has identified a number of directions for future research. These include more research on the role of physiological, emotional, and temporal aspects of information behavior; the degree to which the information behaviors of fibromyalgia patients may be similar to those of other chronic conditions; the design of mobile apps and devices to support chronic illness management; how day-to-day information exchanges incrementally lead to knowledge formation; and the diffusion of popular and “academic” versions of knowledge about fibromyalgia and other illnesses. I elaborate on each of these in turn.

This study showed that temporal, physiological, emotional and cognitive factors are inextricably bound up in information behavior. Fibromyalgia patients often exhibited particular information behaviors at different points in their illness journey. There were also physiological and emotional factors, such as fear and concern for future health, and concern about their work and careers that influenced participants’ information behaviors. These issues may potentially have a great impact on patients’ lives – in terms of whether they seek out information at all and from where, how they communicate with others, the treatments that they choose, and the management strategies that they adopt. Thus, temporal, physiological and emotional factors are an integral part of health information behavior and, likely, information behaviors in general. As such, there is a need for more research into these factors and their influences on information behaviors.

Another important direction is to consider how the findings from this study are applicable to other conditions, i.e. how the illness journeys of fibromyalgia patients, their

information needs, and information seeking behaviors compare to those of patients with other conditions. Though each disease experience is different, there are also great similarities between the experiences of fibromyalgia patients and patients of other conditions that have a pain component, such as arthritis. Fibromyalgia patients often need to make significant changes to diet, and living and work situations; and need to develop a constant awareness of their physical and emotional state. All of these lessons could also result in significant personal and/or even spiritual growth. While the sample here was comprised of fibromyalgia patients, the challenges that fibromyalgia patients face in terms of being responsible for their own long-term care and how to develop a way to do this successfully, are challenges that patients of any chronic condition are likely to face.

The results of this study also suggest that there may be similarities between the experiences of fibromyalgia patients and those of other chronic conditions. Because of the complexity and multiplicity of symptoms experienced by fibromyalgia patients and usually, the concomitant presence of comorbidities, there are aspects of patient experience in this study that are similar to what patients of other conditions experience. In particular, study participants went through a period of psychological adjustment and implemented various lifestyle changes, which is common among those who suffer from chronic conditions. Thus, there may be tools and information resources used by these populations that would be useful for fibromyalgia patients, and vice versa. For example, participants in this study used MyRA and MyFitnessPal. The first tool is one that was developed for a different condition, but could be useful to fibromyalgia patients, and the other is a more generalized tool for fitness tracking. Examining tools for condition management and their cross-applicability could result in greater utilization of

available tools, as well as insight into areas where applications need to be tailored for specific populations.

This study also demonstrated that the use of mobile devices for health has become increasingly common. This is consistent with extant survey research, which has reported that 31% of cell phone owners said that they had previously looked for health or medical information using their phone (Fox & Duggan, 2012). The participants in this study used their mobile devices for a variety of tasks, including remembering their medication regimen and reminding them of it; tracking pain, diet or exercise routines; keeping track of their illness history; and performing and saving the results of searches for health-related content. These apps could potentially be very useful for fibromyalgia patients to identify their pain and food triggers, figure out how much and what type of exercise they might be able to engage in, and assist them in their information exchanges, prior to and during the clinical encounter, and also in their independent information seeking. However, there is also a need for more research concerning such apps' usability and effectiveness. One previous review of smartphone apps for pain management reported that there is little evidence to support their efficacy (Rosser & Eccleston, 2011). Quite a few of the participants had used or were currently using mobile apps at the time of the study, but there was not sufficient time to explore their usage habits in depth. It would be worthwhile to conduct in-depth interviews of fibromyalgia and other chronic pain patients to investigate what types of devices they have used, how they selected them, their impressions and evaluations of the features, and walk-throughs of their use, to understand the motivations and usability issues involved, and inform design improvements and innovations.

A third potential research direction would be to investigate more closely how patients interact with information sources. One of the goals of this study was to understand how

fibromyalgia patients' understandings of the illness change over time, and the information sources that they employed along the way. The findings of this study suggest that patients who suffer from a long-term illness such as fibromyalgia may become quite knowledgeable about their illness. A number of participants observed that they became more efficient in their searches. However, given that the focus of the study was not on their specific information interactions, it was unclear how participants' search strategies might have changed, how their ability to understand and evaluate individual sources might have changed over time, and to what extent these changes may reflect changes in health-related mental models. Future research could ask users to engage in search sessions using the think aloud protocol at different time points longitudinally, to investigate whether patients' search strategies and methods of consuming information change over time. An alternative method might be to ask patients to record any information they encounter or seek through a diary collection method. Lastly, patients' health-related mental representations might also be assessed at these points.

It would also be useful to conduct a survey of both the popular and academic literature concerning fibromyalgia. In my study, it became apparent that there were resources and pieces of information that were popular among patients, particularly *Fibro for Dummies* but also others, that are not necessarily read by academic researchers and clinicians. How do these resources differ? Moreover, how does the popular literature of this condition intersect with that of other conditions that tend to be comorbid with fibromyalgia? Research of this nature could help us to understand the nature of information diffusion among lay health consumers.

APPENDIX A. RECRUITMENT EMAIL TO PREVIOUS RESPONDENTS

Email subject line or thread topic: Thanks for your participation in my fibromyalgia survey...and an update!

Content:

Dear all,

My name is Annie Chen, and I am a Ph.D. student at the University of North Carolina at Chapel Hill. Thank you for participating in the survey I conducted two years ago. With that survey, I learned about your information needs at three points in your illness journey, and I was able to publish an article. I hope that many people will read the article, and that resources of fibromyalgia information will continue to improve for all!

Last time, you left me your email to be contacting for a follow-up interview study, and now, I am beginning that study. In this study, I would like to hear your story!

I would like to find out about your “illness journey.” How did you get where you are today? What role did information and the Internet play?

I would like to conduct two interviews with you. In the first interview, I will ask you to draw a “journey timeline” showing me the path you took (don’t worry, no artistic talent required). In between the first and second interviews, I will try to collect the content that you’ve posted online, from as far back as we can go. In the second interview, I hope that we can explore this information together through an interface I’ve built: “The Online Scrapbook”.

The stories that you and other fibromyalgia patients share with me may be helpful for the health care community and for other patients to understand more about the information you needed to get where you are now, and the information you still need. In this way, I hope we can work together to better the lives of fibromyalgia patients everywhere!

Will you join me?

If you would to contribute to this study or would like to know more about it, please contact me at atchen@email.unc.edu. In addition, if you know of someone else who might want to participate, I would appreciate it if you would pass my invitation on.

Thanks, and I look forward to hearing from you!

Best,

Annie

Please note: This study has been approved by the University Institutional Review Board (#_____).

APPENDIX B. RECRUITMENT EMAIL AND POST

This is a template of the content that I plan to use in the recruitment email/post. I plan to use the same template for both. There may be a need to modify it slightly depending on the requirements of the particular listserv or health-related website that I post to. (In 2011 when I used a similar recruitment email, very little modification was needed.)

Email subject line or thread topic: Share your illness journey?

Content:

Dear all,

My name is Annie Chen, and I am a Ph.D. student at the University of North Carolina at Chapel Hill. I have been conducting research on fibromyalgia for a number of years, and in my dissertation, I am interested in studying the path you took to where you are today: your “illness journey”. For example, did you visit health discussion forums? Did you author discussion posts? Do you post about fibromyalgia on Facebook or tweet about it?

I am interested in your story! I would like to conduct two interviews with you. In the first interview, I will ask you to draw a “journey timeline” showing me the path you took (don’t worry, no artistic talent required). In between the first and second interviews, I will try to collect the content that you’ve posted online, from as far back as we can go. In the second interview, I hope that we can explore this information together through an interface I’ve built: “The Online Scrapbook”.

The stories that you and other fibromyalgia patients share with me may be helpful for the health care community and for other patients to understand more about the information you needed to get where you are now, and the information you still need. In this way, I hope we can work together to better the lives of fibromyalgia patients everywhere!

Will you join me?

If you would to contribute to this study or would like to know more about it, please contact me at atchen@email.unc.edu. If you don’t have fibromyalgia but know someone who does, I would appreciate it if you would pass my invitation on.

Thanks, and I look forward to hearing from you!

Best,

Annie

Please note: This study has been approved by the University Institutional Review Board (#_____).

APPENDIX C. FOLLOW-UP EMAIL TO SCHEDULE

Dear _____,

Thank you for your email. I would like to tell you a bit more about the study, and ask you a few brief questions. These questions are to help me understand a bit more about your background and select a diverse group to interview. I will send a confirmation email to everyone, and then follow up with those who are selected to schedule some times to work with you. I appreciate all of you for your interest, and I am sorry that I am not able to interview everyone.

First, this is an interview study about participation, and non-participation, in online support groups. I am interested in hearing about how you participate in online support groups, e.g. which ones you participate in, when, for what reason, and so on. I am also interested in hearing your story if you read, but don't post anything online. As part of the study, I would like to ask you to share with me some of your history with your illness; this will help me to understand your participation, past and present.

In addition, I will ask you to let me collect some or all of the content that you have created online. For example, I would like to collect your forum and blog posts, tweets, and so on. For those media that involve passwords, I will need your help! For example, I may ask you to provide me your tweets. These can be requested from Twitter, and I can help you to figure out how.

I will enter this information into a system, "The Online Scrapbook," which I have built for this study. We will explore your content through this interface. A snapshot of this interface appears at the end of this email.

During the interview, I will also ask you to annotate a timeline with things that have been important to you in your journey.

The purpose of the study is to explore how we change over time with fibromyalgia, and how and when it affects our participation online. I hope that this information can help us improve health care for fibromyalgia.

If you would like to help with this study, I would appreciate it if you would reply to this email with the following information:

Sex:

How many years you have had fibromyalgia:

Please place an "X" to the left of the category below that best describes how you participate in online discussion forums:

___ I read posts, but I've never written any.

- ☐ I read posts, but I rarely write them (less than 5 this year).
☐ I both read and write posts.
☐ Other (please explain _____)

Where have you posted content relating to your illness? Here are some health-related websites to get you started (place an X for all that you have authored content on):

- ☐ National Fibromyalgia Association
☐ WebMD
☐ MedHelp
☐ DailyStrength
☐ HealingWell
☐ Other (please specify _____) Add as many of these as you need!
☐ Other (please specify _____)
☐ Other (please specify _____)

How many posts do you think you have (a guess is fine): _____

Do you use other types of social media such as Twitter, YouTube, etc.? If so, which ones?

City and state in which you would want to be interviewed _____

Thanks so much for your help! Once I receive your answers, I will contact you soon.

Best,

Annie

Illness Journeys and Online Participation: A Study of Fibromyalgia Patients' Experiences

Hi everyone!

I am a Ph.D. student at the University of North Carolina at Chapel Hill. In my dissertation, I am interested in studying the path you took to where you are today: your "illness journey".

I am interested in your story! I would like to conduct two interviews with you. In the first interview, I will ask you to draw a "journey timeline" showing me the path you took (don't worry, no artistic talent required).

Before the second interview, I will try to collect the content that you've posted online. I hope that we can explore this information together through an interface I've built: "The Online Scrapbook".

The stories that you and other fibromyalgia patients share with me may be helpful for the health care community and for other patients to understand more about the information you needed to get where you are now, and the information you still need. I hope we can work together to better the lives of fibromyalgia patients everywhere!

Will you join me?

If you would to contribute to this research study or would like to know more about it, please contact me. Even if you have not been diagnosed with fibromyalgia, but think you may have it, or if you are newly diagnosed, I would like to hear from you!

Thanks!

Annie

Annie T. Chen, Ph.D. Candidate
University of North Carolina, Chapel Hill
Email: atchen@email.unc.edu
Phone: 949-872-3761

APPENDIX E. CONSENT FORM

University of North Carolina at Chapel Hill Consent to Participate in a Research Study Adult Participants

Consent Form Version Date: _____

IRB Study # 13-2420

Title of Study: Participation in Online Support Groups among Fibromyalgia Patients

Principal Investigator: Annie Chen

Principal Investigator Department: School of Information and Library Science

Principal Investigator Phone number: 9498723761

Principal Investigator Email Address: atchen@email.unc.edu

Faculty Advisor: Barbara Wildemuth

Faculty Advisor Contact Information: wildemuth@unc.edu

What are some general things you should know about research studies?

You are being asked to take part in a research study. To join the study is voluntary.

You may refuse to join, or you may withdraw your consent to be in the study, for any reason, without penalty.

Research studies are designed to obtain new knowledge. This new information may help people in the future. You may not receive any direct benefit from being in the research study. There also may be risks to being in research studies.

Details about this study are discussed below. It is important that you understand this information so that you can make an informed choice about being in this research study.

You will be given a copy of this consent form. You should ask the researchers named above, or staff members who may assist them, any questions you have about this study at any time.

What is the purpose of this study?

The purpose of this research study is to understand how fibromyalgia patients participate in online support groups over time. The information that is learned during the study may go towards helping medicine understand what information and support needs fibromyalgia patients may have over the course of their illness, and this, in turn, may lead to improved information and support services, and even treatments for fibromyalgia patients.

Are there any reasons you should be in this study?

You should be in this study if you have fibromyalgia, and if you have ever used social media.

How many people will take part in this study?

There will be approximately 20-30 people in this research study.

How long will your part in this study last?

You will be asked to participate in two interviews, each lasting approximately 1.5 hours. If necessary, I may contact you to follow-up on what we talk about in the interviews by email or phone.

What will happen if you take part in the study?

There will be two interviews. This is what the two interviews will include:

1. History of your experience with fibromyalgia. During this interview, I will ask you to fill in a timeline with notes about this history.
2. I will ask you to talk about your participation in online support groups and how that has changed over time. If you agree, I will also collect artifacts of content that you have posted online, for example, forum or blog posts, tweets, YouTube videos, etc. and ask you to talk about them.

What are the possible benefits from being in this study?

You may discover something interesting when you tell me your story. Also, what you tell me may contribute to advancements in fibromyalgia-related research, which could ultimately benefit you and others with fibromyalgia.

What are the possible risks or discomforts involved from being in this study?

There is a minimal risk of deductive disclosure. What this means is that, even if I remove your name and other particular personal characteristics from your data, someone may still guess who you are. There is also the possibility that, if they read an excerpt from what you have written online, that they will also learn what you talked about in your interview, if I refer to you both times by the same pseudonym. If you choose to remain anonymous (you will have the opportunity to decide this on the next page of this consent form), I will do my best to mitigate this risk by not quoting directly from your online content and removing personal characteristics that could lead to inadvertent identification, but I cannot remove this risk completely.

In addition, you may recall some aspects of your past that cause you distress. There may be uncommon or previously unknown risks. You should report any problems to the researcher.

What if we learn about new findings or information during the study?

You will be given any new information gained during the course of the study that might affect your willingness to continue your participation.

How will information about you be protected?

During the study, I will collect various types of information about you. This information will be stored on a secure server and on my laptop, which is also password-protected. Only I will have access to your data.

Your name and contact information will be stored separately from other information I collect about you, such as the online artifacts that you have created, the audio recordings of our interviews, and the timelines. These will be named according to participant ID number.

You have the opportunity to give different types of consent for how I use each type of information.

For each of the data types listed below, you have the option of selecting: a) okay to use in analysis of the interviews, but do not include in publication; b) okay to use in publication in anonymized form; and c) okay to use without anonymization. By anonymization, I am referring

to the removal of the 18 classes of PHI cited in the Health Insurance Portability and Accountability Act (HIPAA). Examples of these identifiers include: person names, ages greater than 89, geographical locations, hospital and healthcare organizations.

| | Okay to use in interviews and analysis, but do not include in published materials. | Okay to use in published materials in anonymized form. | Okay to use in published materials as is (without anonymization). |
|---|--|--|---|
| Interview content | | | |
| Online content | | | |
| Interview content and online content together | | | |

Participants will not be identified in any report or publication about this study unless they have given consent. Although every effort will be made to keep research records private, there may be times when federal or state law requires the disclosure of such records, including personal information. This is very unlikely, but if disclosure is ever required, UNC-Chapel Hill will take steps allowable by law to protect the privacy of personal information. In some cases, your information in this research study could be reviewed by representatives of the University, research sponsors, or government agencies (for example, the FDA) for purposes such as quality control or safety.

Though every attempt will be made to anonymize the content that you provide during the interviews, there is still a minimal risk of deductive disclosure. What this means is that a combination of various characteristics about you may be included in a publication, and that someone reading it may deduce who you are based on the combination of those characteristics.

What if you want to stop before your part in the study is complete?

You can withdraw from this study at any time, without penalty. The investigators also have the right to stop your participation at any time. This could be because you have had an unexpected reaction, or have failed to follow instructions, or because the entire study has been stopped.

Will you receive anything for being in this study?

You will not receive anything for taking part in this study.

What if you have questions about this study?

You have the right to ask, and have answered, any questions you may have about this research. If you have questions about the study (including payments), complaints, concerns, or if a research-related injury occurs, you should contact the researchers listed on the first page of this form.

What if you have questions about your rights as a research participant?

All research on human volunteers is reviewed by a committee that works to protect your rights and welfare. If you have questions or concerns about your rights as a research subject, or if you would like to obtain information or offer input, you may contact the Institutional Review Board at 919-966-3113 or by email to IRB_subjects@unc.edu.

Participant's Agreement:

I have read the information provided above. I have asked all the questions I have at this time. I voluntarily agree to participate in this research study.

| | |
|--|---------------|
| _____ Signature of Research Participant | _____ Date |
|--|---------------|

Printed Name of Research Participant

| | |
|--|---------------|
| _____ Signature of Research Team Member Obtaining Consent | _____ Date |
|--|---------------|

Printed Name of Research Team Member Obtaining Consent

APPENDIX F. SESSION I QUESTIONNAIRES

REVISED FIBROMYALGIA IMPACT QUESTIONNAIRE (FIQR)

Last Name:

First Name:

Age:

Directions: For each question, place an "X" in the box that best indicates how much your fibromyalgia made it difficult to do each of the following activities during the past 7 days

| | | | |
|--|----------------------|--|-----------------------|
| Brush or comb your hair | No difficulty | <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> | Very difficult |
| Walk continuously for 20 minutes | No difficulty | <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> | Very difficult |
| Prepare a homemade meal | No difficulty | <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> | Very difficult |
| Vacuum, scrub or sweep floors | No difficulty | <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> | Very difficult |
| Lift and carry a bag full of groceries | No difficulty | <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> | Very difficult |
| Climb one flight of stairs | No difficulty | <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> | Very difficult |
| Change bed sheets | No difficulty | <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> | Very difficult |
| Sit in a chair for 45 minutes | No difficulty | <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> | Very difficult |
| Go shopping for groceries | No difficulty | <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> | Very difficult |

Function sub-total
(for internal use only)

Directions: For each question, check the one box that best describes the overall impact of your fibromyalgia over the last 7 days:

| | | | |
|---|--------------|--|---------------|
| Fibromyalgia prevented me from accomplishing goals for the week | Never | <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> | Always |
| I was completely overwhelmed by my fibromyalgia symptoms | Never | <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> | Always |

Overall Impact sub-total
(for internal use only)

The Brief Illness Perception Questionnaire

For the following questions, please circle the number that best corresponds to your views:

| |
|---|
| How much does your illness affect your life? <div style="display: flex; justify-content: space-between; width: 100%;"> 0 no affect at all 1 2 3 4 5 6 7 8 9 10 severely affects my life </div> |
| How long do you think your illness will continue? <div style="display: flex; justify-content: space-between; width: 100%;"> 0 a very short time 1 2 3 4 5 6 7 8 9 10 forever </div> |
| How much control do you feel you have over your illness? <div style="display: flex; justify-content: space-between; width: 100%;"> 0 absolutely no control 1 2 3 4 5 6 7 8 9 10 extreme amount of control </div> |
| How much do you think your treatment can help your illness? <div style="display: flex; justify-content: space-between; width: 100%;"> 0 not at all 1 2 3 4 5 6 7 8 9 10 extremely helpful </div> |
| How much do you experience symptoms from your illness? <div style="display: flex; justify-content: space-between; width: 100%;"> 0 no symptoms at all 1 2 3 4 5 6 7 8 9 10 many severe symptoms </div> |
| How concerned are you about your illness? <div style="display: flex; justify-content: space-between; width: 100%;"> 0 not at all concerned 1 2 3 4 5 6 7 8 9 10 extremely concerned </div> |
| How well do you feel you understand your illness? <div style="display: flex; justify-content: space-between; width: 100%;"> 0 don't understand at all 1 2 3 4 5 6 7 8 9 10 understand very clearly </div> |
| How much does your illness affect you emotionally? (e.g. does it make you angry, scared, upset or depressed?) <div style="display: flex; justify-content: space-between; width: 100%;"> 0 not at all affected emotionally 1 2 3 4 5 6 7 8 9 10 extremely affected emotionally </div> |
| Please list in rank-order the three most important factors that you believe caused <u>your illness</u>. The most important causes for me:- <div style="margin-top: 10px;"> 1. _____ 2. _____ 3. _____ </div> |

© All rights reserved. For permission to use the scale please contact: lizbroadbent@clear.net.nz

APPENDIX G. SESSION I INTERVIEW GUIDE

This interview is intended to take 1.5 hours.

Introduction (10 min.):

Hello, I am Annie Chen. Thank you again for agreeing to this set of interviews.

Before we start, I would like to go over some information with you concerning the study procedures. (Go over consent form.)

We've talked about this before, but I'd like to go over with you again the schedule for our meetings. Today, we're going to talk mainly about your life journey with the condition. I'm going to ask you to draw a timeline that depicts this journey.

Next, I'd like to ask your permission to collect content that you have created online. By this, I mean, for example, if you've read something online and then commented on it, or if you've tweeted before, or if you keep a blog. I'm happy to collect any or all of this, as long as you say it's okay.

Once I've collected all of this, I'd like for us to meet again, and for you to tell me about this content: why you created it and what it means to you.

How does that sound? (Pause to discuss and answer questions.)

Good! Now let's proceed.

There are different types of consent. You can opt not to give your consent for me to obtain certain types of information, or you can opt to give me consent to obtain it, but not to publish it. Please put an "X" next to the one you want.

Thanks! That looks great.

Pre-interview questionnaire (10 min.):

Now I'd like to ask you to fill out a basic questionnaire to help me understand your background and health history.

(Ask them to fill out survey.)

Opening questions (10 min.):

Now let's proceed with some questions about your health history.

1. Can you tell me when your health issues first began?
(probe further) Can you tell me more about that?

2. How did you feel at the time?
3. What sources did you go to for help? (This can refer to medical help, social support, or information.)
4. How were those initial experiences?

Timeline activity (30 min.):

(Give sheet with timelines.)

I'd like to ask you to think back, to when you started experiencing health issues, or further, if you think it's relevant. Think about the path, the journey you took, to get to today.

I'd like to ask you to represent what happened on the timeline you see printed on this sheet.

You can use different colors to represent different aspects of your experience.

(Take out or point to colored pencils and highlighters.)

If you need more paper, we can attach an extra sheet.

Please talk aloud as you are drawing the timelines. You can just talk to me about what you are drawing, why you are drawing it, anything that occurs to you. The purpose of me asking you to talk aloud is to help me understand what matters to you, and also to understand your memories as you do.

Prompt the participant if he or she falls silent.

Some possible probes include:

Could you tell me about what happened then?

Could you tell me about what you're drawing now?

Could you tell me about that change?

Suggest that the participant add the following to the timeline:

Emotions

Turning points

Gradual changes (e.g. periods of frustration, periods when you felt that things were going well)

Important events ("What would you say is an important event?")

Ask the participant:

1. What do you think are the five most important events that have occurred on your illness journey?

2. Thinking back to your illness journey, at what points do you think information came into play? Can you note these points on the timeline?
3. (probe) In what ways did information come into play?
4. Throughout your illness journey, what information was most important to you?
5. Did you look for information? (If yes, why?)
6. Did you receive information from practitioners or people around you?
7. How did you feel at these times? (Frustrated? Hopeful?)
8. Do you remember anything that you learned, or any information that you received, that changed the way you viewed your illness, your health or your life?
9. Do you remember anything that you learned, or any information that you received, that changed the way you do things or manage your illness?
10. From what sources did you receive information? Have these changed throughout the time that you have had your condition(s)?

(After the participant is done, ask them some questions to try to clarify points that may be unclear, if any, on the timeline.)

Follow-up questions (30 min.):

11. Do you feel that you have generally received the information that you needed to know how to deal with your condition?
12. Today, do you feel that you still need information about your condition, and if you do, how do you go about finding what you need? (Make sure that they touch upon the sources that they use, how they conceptualize the search, and their search strategy.)
 - a. What sources did you use?
 - b. How do you go about looking for information?
13. Now can you tell me about how you manage your condition today?

What do you see as your priorities?
14. Has your management strategy changed over time?
15. Do you see this changing in the future, and if so, how?
16. How do you feel about your health now?

17. What do you think that health and wellness mean?

Has this changed for you over time?

18. Do you feel that those around you are supportive of you?

19. Where do you personally go for support?

20. Is there anything else you want to tell me about your illness journey?

This is all I have for today. Thank you so much. Before our next interview, I will collect the content that you have authored online, and then we can review it together. Thanks again, and I'm looking forward to our next meeting!

APPENDIX H. JOURNEY TIMELINE

Please draw whatever you want to illustrate your illness journey. This can include **thoughts, emotions, information needs** and **sources, health-related activities**, and whatever else you think is important.

You can use colors to help you differentiate between different aspects of your experience.

The “time” when something happens doesn’t have to be one point; it could be a straight line, a squiggly line, etc.!

You may want to include these:

Thoughts (...on life, illness, well-being, etc.!)

Emotions

Information (needs, sources, etc.)

Health-related activities

Do you want to include these events?

- Symptom onset
- Diagnosis

APPENDIX I. SESSION II INTERVIEW GUIDE

This interview is intended to last one hour.

Pre-Graphic Elicitation Questions (30 min.):

Thank you again for your time. I'm looking forward to our time together here today. We will begin by talking about your experiences participating in online spaces.

1. Can you start by briefly talking about the online spaces that you participate in? (Might want to probe with: "For example, do you use Twitter, Facebook, etc.?" It would be helpful to have the information from the pre-screening questionnaire on hand.) Why do you participate in online spaces?
2. What does "online community" mean to you? Has this meaning changed over time?
3. Do you obtain information from the online community you participate in? Can you give some examples?
4. Do you give information to the online community you participate in? Can you give some examples?
5. Do you feel that the members of the online community support each other? Can you give some examples?
6. What do the members of the online community mean to you? When and how do you interact with them?
7. How has your participation in online support groups changed over time? Can you give some examples?

(If, in answering the questions above, the participant has not touched upon multiple communities/platforms, but their pre-screening questionnaire indicates that they do participate in multiple media, it would be good to ask them about that.)

Graphic Elicitation Session (30 min.):

In the last session, you agreed to let me collect some of the content that you've authored online. Now I'd like to show you some of this content, and for us to explore it together. Okay? (wait for the participant to agree)

(Access the *Online Scrapbook* application.) This is an application that I've developed for this study. It's called the Online Scrapbook. Here's how it works:

At the top, you'll see there is a timeline. There is one row for each social media type that you told me about in your pre-screening questionnaire. There is a circle for each month that you participated; the bigger the circle, the more you participated during that time. If you click on the circle, you can see all of the content you authored during that month.

You can also search for your posts that contain a certain keyword. So if you think of something that you might have written about, that you want to tell me about, you can type the keyword in the box and hit the "Go" button.

Would you like to explore? (Hand the computer over to them and see how they interact with it.)

Here, it would be useful to see what they might naturally do with the interface before trying the probes below:

Is there anything that stands out to you about this timeline? (Ask them to elaborate on the reasons why the artifacts stand out to them.)

Are there any pieces that were particularly meaningful for you when you wrote them? Why?

Are there any pieces that are particularly important to you now? Why?

Are there any topics that you remember writing a lot about in the past? Why?

In the past, when you have written of your own experiences, have you had any responses back that were particularly meaningful to you?

Depending on the situation, did you tend to use different types of social media to communicate with others?

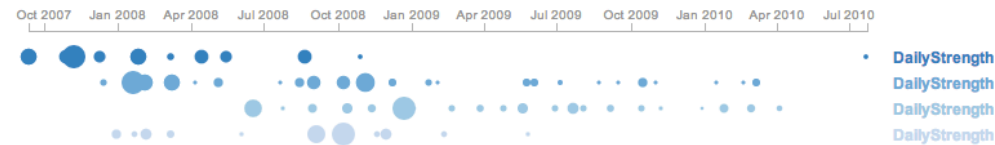
This concludes our interview. Is there anything else you would like to share with me?

Thank you for participating in this study!

APPENDIX J. ONLINE SCRAPBOOK INTERFACE

The Online Scrapbook: Visualizing Participation Histories

The timeline below shows the extent to which you participated online per month. The tick marks are set at 3 month intervals, but each dot represents one month. The bigger the dot, the more posts you authored that month. Click on the dot to reveal the posts for that month.



2008-01-21 113354
Enter term to search for:

10 2008:

| |
|---|
| that DR better be finding out what fibro is, his head is in the sand! How ridiculous! Take fibro in children infoto him. Is there another clinic like that somewhat close to you so you can take her elsewhere? |
| I haven't participated but I have read from other that have...that when you participate the researchers normally take you off all of your medication. You then get the actual drug they are trying for 6-8 weeks or you get a placebo for the same time. Nobody knows if you have the drug or the placebo. I want to have new drugs available to us but I am finally doing well with the meds I am on I cannot quit them to hope I get to try another. My luck, I would get the placebo sugar pill! |
| I really like it! I take it with Adderall. It really helps my awful fatigue. |
| When I asked my DR if Provigil interacted with other medications, he said no. I take a number of meds for different reasons, and Provigil doesn't interact with anything. I wonder if your DR just told you that to close the subject. If I were you I would then ask him about Adderall or Ritalin or Concerta. They are widely used and usually don't interact with the drugs we take either. They all help with energy and have been used for years. All Concerta is is a time released Ritalin. |
| I just know how much fatigue affects us as it is my biggest problem, I don't want DR's giving you the run around on these energy meds because they have changed my life and I usually feel pretty normal most days until the evening when I am tired. I want to see others benefit from these meds also. There are others on the board who use them too, I am not the only one. They gave me my life back and I work full time and have a toddler. |

APPENDIX K. INFORMATION SOURCES

Newsletters

Magazines

Books

Fibro for Dummies

From Fatigued to Fantastic!

Total Recovery

The Fibromyalgia Solution

Book of Secrets

Osler's Web

E-books

Commercials

Prominent Physicians

Dr. Cheney

Dr. Lapp

Dr. Mercola

Dr. Oz

Dr. St. Amand

Dr. Starlanyl

Dr. Teitelbaum

Dr. Weil

Other Personas

Parker Palmer

Thomas Merton

Twitter

Informational Websites

NFA

Fibromyalgia Network

FM Aware

CDC

NIAMS

NLM

Mayo Clinic

WebMD

CFIDS

Cleveland Clinic

RxList

Lyrica website

Online Discussion Platforms

Facebook

Reddit
PatientsLikeMe
DailyStrength
MDJunction
FibromyalgiaSymptoms.org
Pheonix Rising
ProHealth
Google Groups
ChronicBabe.com
ChronicMarriage

Blogs

Tumblr
Hibiscus Garden

Other Online Sources

Wikipedia
SoundCloud

E-newsletters

Radio

Conferences

Webinars

Courses

MBSR
CBT

Centers

Chopra Center

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