Meaning, Information and Online Participation along the Illness Journey:

The Story for Fibromyalgia Patients

Dissertation Proposal

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Abstract

Fibromyalgia is a disorder that is estimated to affect five million people in the United States. Patients experience a range of symptoms including chronic widespread pain, stiffness, fatigue, sleep disturbance, and cognitive dysfunction; 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 are also faced with a difficult, long-term information seeking and sense-making task as they endeavor to understand and manage their condition. However, it is not a condition that has received much attention in terms of either research or health policy.

In my dissertation, I plan to address this gap. My proposed study investigates how patients’ views of illness and of health have changed over time, what role information played, and how these views are related to their participation in online communities, Facebook, Twitter, and other social media. In the first of two interviews, we will explore participants' “illness journeys” – ways in which participants' understandings of illness, life and meaning have changed, and how this is related to information. In the second interview, we will jointly explore participants' online participation histories, through an interface that I developed, the Online Scrapbook. The interface affords patients an interactive temporal visualization of the online content that they have authored. I plan to analyze the data through an integration of Grounded Theory, Interpretative Phenomenological Analysis, and life story approaches.

I hope that this study will inform our knowledge of how fibromyalgia patients, and to some extent, chronically ill patients in general, may change in terms of illness beliefs, information behaviors, and social media participation patterns over the course of
their illness. This knowledge would then provide insight on how we can better support fibromyalgia patients’ needs along their journey. This knowledge might also help people with other chronic illnesses find and consume information, manage their illness, and also provide information to others.

I Introduction

Fibromyalgia is a chronic condition in which patients usually suffer from a variety of symptoms, the most common including chronic widespread pain, fatigue, sleep disturbances, anxiety and depression. Fibromyalgia is estimated to affect a substantial number of people all over the world, including 5 million people in the United States (Lawrence et al., 2008). In terms of economic burden, it has been estimated to be on par with rheumatoid arthritis in terms of health care expenditures (Silverman et al., 2009). However, it is not a condition that has received much attention in terms of either research or health policy.

Given the significant numbers of patients that are affected, the duration, and the cost, 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 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. The nebulous status of fibromyalgia 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.

While even a single snapshot of a fibromyalgia sufferer’s information behaviors is of interest, a longitudinal perspective is even more important. A previous survey showed that fibromyalgia patients’ information needs change over the course of their illness (Chen, 2012a). My dissertation research is intended to provide a richer and more contextualized view of fibromyalgia patients’ illness journeys. The results from this study may inform future research on how we can better support fibromyalgia patients’ needs along their journey. The knowledge that we gain might also help people with other chronic illnesses find and consume information, manage their illness, and also provide information to others.

II Research Questions

The extant literature provides a general sense of how a patient’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).

In the case of fibromyalgia there is much that we do not know about how this re-interpretation occurs: what facilitates this interpretation, and the role that information
plays in this process, e.g., how and what information patients encounter or use on their illness journey, how this information may become integrated into their knowledge structures and result in behavioral changes, and what additional information they would find useful on that journey.

These, then, serve as the basis for my first three research questions:

• How do patients’ perspectives and affective reactions toward illness, life and being change over time?

• How do patterns of information seeking, as characterized by information need and source selection, change throughout patients’ illness journeys?

• What changes are there in information use, as characterized by sensemaking processes and changes in behavior or thought?

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

• How are perspectives and affective reactions, information seeking and information use 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, since there is no immediate threat to life, one might infer that searches might be more focused on symptoms and finding a cure. Previous studies have shown that stress may play an important part in fibromyalgia (Davis, Zautra, & Reich, 2001; Shaver et al., 1998), and that fibromyalgia patients also encounter difficulty in interpersonal interactions, often in terms of lack of understanding and stigma, due to their
condition (Madden & Sim, 2006). Thus, in terms of the illness journey, we might expect that affective components, as well as cognitive components, of information processing and sense-making may be relevant.

To my knowledge, there have been no past studies concerning the use of information by fibromyalgia patients over an extended period. However, theories of information seeking might offer some insight regarding information behaviors over the course of a patient’s illness journey. For example, 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.

In the case of fibromyalgia patients, there may be various 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 failure of a medication, or the “giving up on” a 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).

These models could be used as seeds to probe further about patients’ illness journeys. For example, I could ask patients about the sources that they used to find out about their condition; symptoms, medications, and treatments; how they felt, how they were affected by stress, and how confident they were at various points in the journey.

In recent years, people have increasingly come to rely on the Internet for health information. For example, according to the 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). 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., 2011); 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 that examines online support groups, there are few studies that investigate how patients may participate in online communities over time, and how this may be related to their illness journey. This, then, is the final question to be investigated in the proposed study:
• As people traverse their illness journeys, 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. Only by considering patients’ 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.

III Method

I will interview patients with fibromyalgia in order 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 online. I will recruit participants through online social networking sites, university listservs, and face-to-face support groups. My target sample size is 20-30 participants, and I hope to be able to interview participants that vary in terms of their age, illness duration, and participation style (i.e. “lurking” or reading without authoring posts; infrequent posting; and regular posting).

Participants will be interviewed twice. My interviews are semi-structured, meaning that they follow an interview guide, and I plan for them to take a minimum of
1.5 hours each. The first session will be used to gather information about participants’ health history, information use and the physical, mental and emotional journey they have taken prior to and during their illness. I will bring a sketchbook and colored pencils, and ask participants to tell me about their illness journey as they draw a timeline. The second session will be used to jointly explore their online participation history. Prior to the interview, I will collect any social media content that participants have authored, such as Facebook status updates, tweets, YouTube videos, blogs and so on. These data will be incorporated into an interactive visualization of the participant’s past online activity, supporting the joint exploration of these data by the participant and the researcher.

I will analyze the data through using a qualitative approach developed from the integration of concepts and methods from grounded theory, Interpretative Phenomenological Analysis, and life story approaches. At the outset, I plan to engage in line-by-line coding, followed by identification of themes from the codes. Memos will be used to connect and make sense of the relationships between codes and their overarching themes, and tables of themes will be used to organize and look across themes.

I also plan to analyze the timeline and online artifacts. Given that I endeavor to minimize the “guidance” that I give participants in the construction of the timeline, my analysis method will involve looking for broad conceptual similarities across timelines, such as inclusion of symptom onset, diagnosis and other medical events; symbolism (colors and/or figures that have symbolic meaning); use/non-use of ages and years; shifts in understanding; and involvement of family members and/or other significant figures. Online artifacts may be analyzed using descriptive statistics such as authoring frequency and length, frequency of topics, and media type. They will also be analyzed interpretively.
via automated textual analysis using the Latent Dirichlet Allocation topic modeling method implemented in the MALLET toolkit (McCallum, 2002).

IV Significance

This study is important for various reasons beyond the direct impact of its results on our understanding of fibromyalgia patients’ information behaviors. First, this study proposes to explore how patients’ online interactions are related to other aspects of their lives. This includes not only whether or not they use online resources, but also, their choice of media and how they may use the media at different times and in different ways. The online world is a rapidly evolving space that is actually a conglomeration of overlapping and intersecting spaces. There is potentially a great deal of variation in these spaces and communities, and there is a need for work on how we may analyze and conceptualize interactions in this space and how they may influence the rest of our lives.

Second, there is the conceptualization of patients’ illness experiences as a long-term process of interacting with information that involves behaviors such as information seeking, information encountering, sense-making and information use. Though there is a rich body of literature on illness coping as a long-term process (e.g. Mishel, 1999) and sense-making (e.g. Dervin & Reinhard, 2007), and work on related information interactions such as information encountering (Erdelez, 1999) and evolving information needs (Solomon, 1997; Chen, 2012a), there is still a great need for richer, more in-depth studies on how information processing occurs over the long-term in chronic illness. The integration of Interpretative Phenomenological Analysis and life story approaches proposed here will be an effective approach for analyzing how multiple facets of the illness journey, e.g. cognitive, emotional, physical and social, might be intertwined.
V Outcomes and Implications of the Proposed Study

There are a number of anticipated outcomes of this study. First, this study may extend our knowledge about how fibromyalgia patients, and to some extent, chronically ill patients in general, may change in terms of illness beliefs, information behaviors, and social media participation patterns over the course of their illness. This knowledge will likely fuel additional research and perhaps also form the basis for a theoretical understanding of how illness beliefs, information behaviors and online participation patterns are related in chronically ill populations in general. We may learn more about fibromyalgia patients’ information needs and how information should be delivered to them, particularly in terms of the timing and format of this information.

As far as potential research directions, there are various questions for which there is currently limited information, and I hope that the data collected in this study can begin to shed light on some hypotheses for future research. There are a number of questions that I believe the data might address. How do information needs and online participation differ in a chronically ill population as opposed to a population that suffers from a disease that poses a more immediate threat to life? How are information behaviors related to coping strategies? Are there different subgroups of fibromyalgia patients, in terms of their information behaviors and sense-making processes?

Lastly, I hope that data concerning online health interactions may serve as the basis for design recommendations for health interfaces. For fibromyalgia patients, features that support sense-making and increase users’ sense of social support might be particularly helpful. We may also gain insights into designs for patient expertise locators, trackers and other features that may be useful to health consumers in general.
References


