Body-As-Information: Learning to Listen to the Body in the Context of Chronic Illness

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ABSTRACT
During the course of an illness, people may come to learn things about their bodies that they did not previously understand. This poster explores how one group of patients with a chronic illness, fibromyalgia, learned to listen to their bodies over time. This work is part of a larger qualitative study of fibromyalgia patients’ illness journeys. Becoming more attuned to their bodies enabled participants to manage their condition better, including the impact it had on the rest of their lives. This poster also describes ways in which fibromyalgia patients acquire knowledge about how to utilize their bodies as physiological information, and considers how information services, resources and tools could be improved to facilitate the process.

Keywords
body awareness, fibromyalgia, health information behavior, patient education

INTRODUCTION
When one thinks of health information seeking, a scenario that often comes to mind is that of a person experiencing a symptom and searching for information about it, or searching for information prior to or after a visit to a physician. This information helps patients to understand more about their condition and what they can do to improve it, or to make informed decisions about treatment options. However, there are other ways in which patients learn about their condition. Patients become more attuned to physiological sensations. There are different types of ways in which patients may come to listen to bodies (or not). The poster considers the concept of “body-as-information” and describes ways in which information services, resources, and tools may support this process.

RELATED WORK
Extant literature has observed that chronic illness may affect life in profound ways. Charmaz (1995) argues that the process as includes: 1) experiencing and defining impairment; 2) identity tradeoffs; and 3) surrendering to the sick self and flowing with the experience. Chronic illness requires extensive management by the patient, and lack of information about how to manage an illness and its outcome, causation and severity can lead to feelings of uncertainty (Mishel, 1999). Obtaining information can decrease uncertainty, and reduction of uncertainty or acceptance of it can lead to increased well-being. Getting to know the illness and engaging in health maintenance can also help people to gain a sense of control.

When patients develop a chronic condition, there is much that they need to learn about the condition and how to manage it. The task of recognizing one’s need for information may be particularly difficult because people are not necessarily adept at knowing what their body needs when they do not have a chronic condition. Often, there may be times when patients are unaware of their need for information (St. Jean, 2012). Wolf and Veinot (2015) have observed that patients gradually get to know their bodies better through their experience of chronic illness.

This poster focuses on a subset of chronically ill patients, those with fibromyalgia. Fibromyalgia is a syndrome characterized by chronic widespread pain, joint stiffness and systemic symptoms (e.g., mood disorders, fatigue, cognitive dysfunction and insomnia) without a well-defined underlying disease (Bellato et al., 2012). Patients with fibromyalgia may struggle with their illness for a long period of time, and as such, this makes the condition an appropriate one for examining how people learn to manage their health and get to know their body over time.

In fibromyalgia, the uncertainty of the effects of symptoms on daily life activities, rather than disease meaning, have the greatest effect on psychosocial adaptation (Anema et al., 2009). Becoming knowledgeable about one’s condition is an important factor in acceptance or “coming to terms” with pain (Lachapelle et al., 2008), and acceptance of pain is associated with less pain, disability, symptomaticity,
anxiety, and depression, as well as with better general health, vitality, physical and social functioning, and greater well-being (e.g., Rodero et al., 2011).

Fibromyalgia patients’ information needs change over the course of the illness, and patients are more interested in learning more about diet and exercise later (Chen, 2012). However, it is not clear if or how fibromyalgia patients become more attuned to their bodies. This, then, was the motivation for this poster.

METHODS
This study employed a qualitative design that was based on interviews with participants focusing on two primary topics: information behaviors over the course of illness and participation in online social spaces.

Sample and Recruitment
The study used multiple mechanisms to recruit a convenience sample of individuals who self-identified that they had fibromyalgia and was diverse in terms of three characteristics: age, illness duration, and social media participation style. The mechanisms included an email contact list from a previous survey; a university faculty, staff and student listserv; face-to-face support groups, health-related discussion forums and Twitter.

Interviews
The first interview was used to gather information about the participants’ health history, information use and illness journey. Participants were also asked to draw a timeline representing their illness journey (Fig. 1). When the exercise was introduced, participants were asked to think about their illness journey and to draw something that represented it. They were told that there were no rules as to what they drew, and that the timeline need not be a “line.” The aim of the prompt was to leave the activity as open as possible, so that participants would feel free to depict the journey as they experienced it.

The second interview was used to jointly explore their social media participation history. Because this poster is not focused on social media participation, this interview is not described here.

Participants were interviewed either once or twice, depending on the extent to which they used social media and geographic proximity to the interviewer. There were three interviews that were conducted via Skype or phone due to issues of geographic proximity. All of the other interviews were conducted in person. Altogether, 37 interviews with 23 participants were conducted.

Data Analysis
The analysis methods were primarily drawn from two approaches: Interpretative Phenomenological Analysis (IPA) and constructivist grounded theory. The primary aim of IPA is to explore how participants make sense of their world and is concerned with the participants’ interpretations of the object or event (Smith & Osborn, 2008). Grounded theory, originally developed by Glaser and Strauss (1967), focuses on the meanings of events and the symbols that are used to convey that meaning (Baker, Wuest, & Stern, 1992). Charmaz (1990) describes her version of grounded theory as social constructionist, having phenomenological and Marxist roots, and coming from a symbolic interactionist perspective. These approaches were selected because they focus on participants’ interpretation of their experience and its meaning. The interview transcripts and a subset of posts authored by participants who engaged online served as the basis for the analysis. The content was analyzed using Atlas.ti Version 1.0.1. The analysis procedure involved line-by-line coding and conceptualization of codes as belonging to themes and subthemes, as is customary in IPA (Smith & Osborn, 2008).

RESULTS
Participant Characteristics
The sample was comprised of 23 individuals who self-reported that they had fibromyalgia. The majority of the sample was White women. This is consistent with previous surveys of fibromyalgia patients in the United States (e.g., Bennett et al., 2007). The participants resided in nine different states; Washington, D.C.; and Australia. There was quite a bit of variability in terms of age (range: 21-79 years) and illness duration (1-58 years).

Distinguishing Fibro Pain
Patients 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 sometimes have difficulty convincing physicians that a symptom that they experience...
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 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).

Learning Triggers
This study showed that participants came to utilize physiological sensations as a form of information. One common step was figuring out food sensitivities and allergies. Some participants, such as P15, researched how to do an elimination diet and carried it out, eliminating items from her diet one by one until she figured out the items to which she was sensitive. P24 tracked her reactions to foods using a mobile app called Pain Coach to figure out that gluten was causing her a problem. Still others, such as P26, underwent lab tests and a rotation diet in order to figure out the foods to which she was sensitive, and she says that she could not have figured out how to do that on her own. These examples show that people may need different types of support to become more attuned to their bodies.

Another part of their path to effective management may involve the learning of 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.

Re-Interpreting Physiological Sensations
Participants learned to interpret physiological sensations differently over time. Due to the intensity of fibromyalgia pain, earlier in their journeys, some participants 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, who initially had a lot of trouble managing her condition, said that as time went on, she found strategies that worked, “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.”

Participants also learned ways to control their physiological sensations. Yoga was particularly helpful for study participants. P18 observed: “When I started to do yoga, I started to understand my body more and what’s going on with it.” P17 put this more concretely: “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.”

DISCUSSION
Reflections on Extant Literature
Extant literature has reported that patients of various conditions, including fibromyalgia, appear to have a hypervigilant pattern of responding (McDermid, Rollman, & McCain, 1996). This study provided context through which we can better understand how participants’ interpret their physiological symptoms and how they make the treatment options work. In this study, patients described a variety of sensitivities, including food, light, sounds and pain, and they found various ways of learning how to deal with these sensitivities.

Study participants found yoga, mindfulness, and to a lesser extent, hypnotherapy effective for health management. These findings are consistent with existing literature, which has reported that yoga and mindfulness are effective for chronic pain (e.g., Büssing, Ostermann, Lüdtke, & Michalsen, 2012; Ferguson, Weinrib, & Katz, 2012). 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 (Zeidan, Grant, Brown, McHaffie, & Coghill, 2012).

Supporting “Listening to the Body” Skill Acquisition
There are different ways in which information services, resources and tools might better support the acquisition of knowledge concerning bodily sensations. Some important points to consider here are the long-term nature of this learning and the nature of the tools used by patients. Patients will need different types of tools to suit their lifestyles and personal preferences. Many participants participated in yoga classes, but not all patients are able to physically attend classes. P26, who spent large amounts of time caring for her ailing mother, learned yoga from videos.

There may be ways in which technology may be used to provide similar affordances, such as offering virtual yoga classes in which students and instructors are able to interact in real time, and through videos that teach patients how to better listen to their bodies. There is a question here, though, concerning how one might facilitate the seeking and finding of videos that help them deal with issues that are relevant to them. There is extant research on health information presented through YouTube videos, including research on issues of quality, credibility and factors predicting interaction (e.g., Syed-Abdul et al., 2013; Oliphant, 2013). However, there is still a need to consider
how systems might index and facilitate retrieval of media on concepts such as “listening to the body” and “getting to know one’s body.”

CONCLUSION
This paper described the ways in which fibromyalgia patients come to utilize bodily sensations as information, including the learning of triggers and learning to re-interpret their bodily sensations. In addition, the paper extends the existing literature by considering how information services, resources and tools might better facilitate patients’ gradual acquisition of skills for “listening to their bodies.”

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REFERENCES


