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

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Background
During the course of an illness, people may come to learn things about their bodies that they did not understand. This poster reports findings from a qualitative study of fibromyalgia patients’ illness journeys, focusing on how they became more attuned to their bodies and adept at managing their condition.

Method
• Qualitative approach based on Grounded Theory and Interpretative Phenomenological Analysis.
• 23 participants were recruited through the University of North Carolina (UNC) at Chapel Hill listserv, social media and face-to-face support groups.
• The participants were interviewed concerning their health history, information use, and illness journey.
• The interviews included the drawing of timelines depicting patients’ illness journeys.
• The study protocol was approved by the Institutional Review Board at UNC Chapel Hill.

Main Themes
Distinguishing Fibro Pain and Communicating It to Physicians

What is fibro?

"Fibro pain is... 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." – P18

Symptoms are often ignored:

"I think that when my body was forced to stop, it was forced to like not be in constant motion, that’s when I first realized that there might be something wrong." – P27

Learning Triggers
People learned their food triggers through:
• Elimination/rotation diet
• Trial-and-error

Information interactions:
• Paper and pencil
• Mobile apps
• Worked with clinicians

Re-interpreting and Working with Physiological Sensations
• Patients may go into “panic mode” when they first begin experimenting symptoms and then, they might be more open to information than they might otherwise be
• Disconnecting the fear reaction from physical symptoms
• Learning one’s limits

Information sources:
• Yoga
• Cognitive Behavioral Therapy
• Mindfulness-Based Stress Reduction
• IBS Protocol
• Buddhism

Discussion and Implications
Needs for supporting “Listening to the Body” skill acquisition:
• Programs that teach patients how to become more attuned to their bodies
• Analysis of where gaps are in existing patient education programs

Explore the potential of tracking applications/mobile apps to assist patients with problem solving
• What can such applications be useful for? Where are the limits of what they might be useful for?

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Image sources:
https://commons.wikimedia.org/wiki/File:Beautiful-woman-silhouette-beach-summer-night.jpg

I filled out all of the health stuff [on the intake form], with have you had any of... But I didn’t write ‘fibromyalgia’... 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." – P12

"[Through yoga]... I learned to evaluate myself, how tired I was getting, and how I was feeling, so I could better pace myself and rest when I needed to." – P17

"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?" – P19

The whole thing is... you have to move.
I was just going through life, cleaning the house, raising kids, doing all the things that I had to do... and... having constant stress.
When I started doing yoga, I started to understand my body more and what’s going on with it, and got more information about fibro. – P18

"It's just the fibro.
I'm telling you, it's a different pain." – P18

"...the Pain Coach one I found very helpful... because I was still really trying to get a grip on what was causing the pain, so I was being really diligent about tracking triggers and stuff like that... I am gluten free at this point because I noticed that it was really causing me issues and it was because of tracking my pain on there that I realized it..." – P24

"Nope, it's not my fibro. 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?" – P19

"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?" – P19