

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



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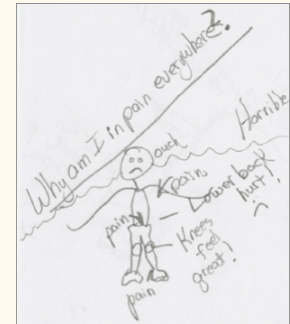
THE UNIVERSITY  
of NORTH CAROLINA  
at CHAPEL HILL

## 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.



P14

## Main Themes

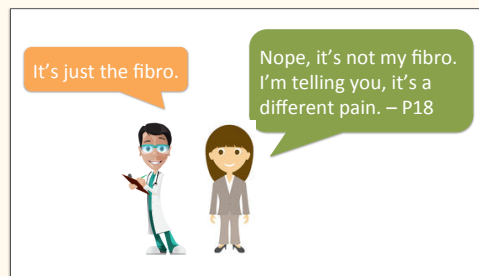
### Distinguishing Fibro Pain and Communicating It to Physicians

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



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

### Learning Triggers

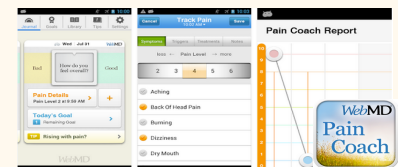
People learned their food triggers through:

- Elimination/rotation diet
- Trial-and-error

Information interactions:

- Paper and pencil
- Mobile apps
- Worked with clinicians

...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



### 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

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

"[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

### 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?

### Acknowledgments

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