ORIGINAL RESEARCH STUDIES

Toward Improving Physician/Patient Communication Regarding Invisible Chronic Illness (ICI): The Potential of mHealth Technology in Instructional Communication

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Abstract: Patients that suffer from invisible chronic illness (ICI) such as autoimmune conditions, neurological conditions, and gastrointestinal problems often struggle to obtain a proper medical diagnosis due to a lack of objective indicators to help health-care providers diagnose patients with ICIs. Thus, researchers conducted interviews with 21 participants with Postural Orthostatic Tachycardia Syndrome (POTS) to determine what messages they received from health-care providers as they pursued a diagnosis, how they interpreted those messages, and what role mHealth technology may play in improving patient/provider communication and effective diagnosis/treatment of ICIs. Several themes regarding potential instructional communication intervention content emerged from the interview data, including physician communication to patients, patient interpretation of physician communication, and information-seeking via mHealth technology. Directions for future research and implications for patient and provider instruction and training, including utilizing the IDEA model, are discussed.

Invisible chronic illness (ICI) refers to a broad range of neuropathic and nociceptive illnesses characterized by "chronicity and symptoms that are not externally manifested" (Donoghue & Siegel, 2000, p. 4). ICIs include, for example, lupus, rheumatoid arthritis, fibromyalgia, HIV infection, multiple sclerosis, chronic fatigue syndrome, irritable bowel syndrome, epilepsy, and Postural Orthostatic Tachycardia Syndrome (POTS) (Donoghue & Siegel, 2000).

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Although millions of people around the world suffer from ICIs, obtaining an accurate diagnosis is difficult because symptoms are often both unobservable and immeasurable (Donoghue & Siegel, 2000). For example, a patient with chronic fatigue syndrome may describe relentless fatigue; however, the fatigue is not necessarily measurable via currently available diagnostic tests. Thus, physicians must rely on systematically ruling out other disease possibilities. Consequently, ICI patients often end up seeing numerous physicians and paying for many costly tests in their attempt to diagnose the condition. Moreover, when ICI tests come back negative, physicians often conclude that the symptoms are caused by stress, exhaustion, hysteria, or even conjured up in the patient's head (Donoghue & Siegel, 2000). After months and sometimes years searching for accurate diagnoses, many patients stop trying to find answers due to exhaustion and frustration.

Thorne and colleagues (2004) argue that the most significant challenge may be rooted not in diagnostic testing (although that is certainly a factor), but in communication failures based on perceptions of legitimacy. In other words, because no objective indicators exist to diagnose ICIs, these "invisible diseases" lack medical and social legitimacy. To clarify, "healthcare professionals disbelieve your symptomatic reports and interpret your complaints as psychosomatic" (p. 304). Thorne et al. (2004) also suggest that "the relationship between objective indicators and social legitimacy seems to be a potent variable influencing the experience of individuals with chronic diseases and their communication with professional health care providers" (p. 305). As Allen (2008) explains, these "serious, complex, and often debilitating medical disorder(s)" are often trivialized as being "in the patient's head" due, in large part, to misperceptions among health-care providers based on lack of awareness and empirical research (p. 289). Consequently, patients begin to doubt themselves, which may, in turn, adversely impact self-concept and self-esteem (Larun & Malterud, 2007). Thus, it seems plausible that instructional interventions could reduce misunderstandings, improve communication, and increase medical legitimacy about ICIs among health-care professionals.

The perception among health-care providers that ICIs are not legitimate physical illnesses often leads to stigmatization of patients seeking treatment. Goffman (1963) describes stigma as "an attribute that is deeply discrediting" (p. 2). Patients with ICIs are stigmatized as having "blemishes of individual character, [which are] perceived as weak will, domineering or unnatural passions, treacherous and rigid beliefs, dishonesty" (p. 2). In essence, health-care professionals may stigmatize patients as malingerers or suffering from mental illness rather than as someone who is, in fact, physically ill (Donoghue & Siegel, 2000). As a POTS patient, Mel Pruett explains, "At 16, I woke up, and I was just sick. I spent years being undiagnosed, being told it was all in my head" (cited in Layne, 2020, para. 2–4). She further claimed that the worst part is "the stigma with an invisible condition makes you feel invisible" (para. 9). Consequently, many stigmatized patients like Mel Pruett not only pay exorbitant fees and face long diagnostic delays, but also suffer from emotional trauma (Collins, 2019). Emotionally traumatized patients may experience additional complications that also affect quality of life among their families and caregivers (Kira, 2001).

One particularly difficult ICI to diagnose is POTS. As is the case with many ICIs, these patients often face long diagnostic delays because they rarely "look sick." When POTS patients describe a variety of symptoms, including lightheadedness, palpitations, weakness, exercise intolerance, and fatigue, they are misdiagnosed as psychosomatic rather than legitimate (Kavi et al., 2016). For example, in a large cross-sectional study of POTS patients, Shaw and colleagues (2019) found that, on average, POTS patients struggle for 4 years and see an average of seven different physicians in their attempt to get an accurate diagnosis.

Tori Foles and her spouse (Super Bowl LII MVP Nick Foles) recently brought attention to the toll diagnostic delays and misdiagnoses have on patients and their families in an interview conducted at the annual meeting of Dysautonomia International, a nonprofit organization devoted to patient empowerment via research and education (LaMotte, 2018). Tori, a POTS patient, explained how doctors tried to attribute her symptoms to a mental health issue, like anxiety or depression (LaMotte, 2018). Some doctors also suggested Tori may have a virus, but as the former Arizona Wildcat volleyball player explained, "I had never heard of one where you are dizzy all the time. There were a lot of times I couldn't get out of bed" (para. 2). In fact, according to research conducted by the Mayo Clinic, POTS affects patients much like "what is seen in congestive heart failure or chronic obstructive pulmonary disease" (para. 8). As her spouse, Nick, explained, "It's crazy, we spent a whole month at the Mayo Clinic" where they also got engaged before having a courthouse wedding. They never had a wedding ceremony or a honeymoon (para. 15–16).

Tori and Nick Foles are not alone in these kinds of struggles. POTS affects 1 to 3 million Americans (and millions more around the world); most of them young, healthy women (Tori was 23) (Dysautonomia International, n.d.). Because so few doctors are educated on the symptoms, many dismiss POTS and other ICIs as psychological (e.g., depression, anxiety, hypochondria) or as a "woman thing" or that they were merely seeking attention. One comprehensive study conducted by Kavi and colleagues (2016) revealed that this "psychiatric mislabeling" was common among POTS patients. In fact, 3,471 (or 77%) of the participants in Shaw and colleagues' (2019) POTS study were misdiagnosed with a psychiatric condition prior to eventually being diagnosed with POTS. For these reasons, POTS is called the most common condition no one has heard of (LaMotte, 2018).

Unfortunately, this problem is not unique to POTS patients. For example, this "psychiatric labeling" and struggle with legitimacy has been noted in studies on patients with a variety of ICIs, including temporal lobe epilepsy (Beletsky & Mirsattari, 2012), chronic fatigue (Kralik et al., 2005), fibromyalgia (Sim & Madden, 2008), lupus (Brennan & Creaven, 2016), and irritable bowel syndrome (Jones et al., 2009). Participants in these studies suffered from misdiagnoses, perceptions of illegitimacy, as well as being stigmatized by physicians as having a mental health issue rather than a physical condition (Thorne et al., 2004). Clearly, a communication breakdown between health-care professionals and patients suffering from ICIs is occurring. Consequently, patients experience delayed diagnoses, misdiagnosis, stigmatization, and emotional trauma, as well as a significant reduction in quality of life (Csecs et al., 2020).

With the expansion of internet technology and web-based tools, a wealth of resources are now available to patients seeking information beyond what they learn in the doctor's office (Voruganti et al., 2017). Most are intended for patient self-management and are based on the assumption that patients are aware of them, have access to them, and are proficient in using them (Granja et al., 2018). They range from telemedicine for routine office visits to patient portals that provide 24/7 access to medical reports. Unfortunately, however, based on their systematic review of 221 articles, Granja and colleagues (2018) discovered that as many as "75% of implemented eHealth should be considered a failure" (p. 2). To improve success, they conclude that eHealth communication interventions must focus on "quality of care, with particular attention given to improved diagnosis, clinical management, and patient-centered care ... at the earliest possible stage" of implementation with ongoing assessment from that point forward (p. 10).

One promising development in the eHealth area of the health-care industry is mobile health technology (mHealth). Most of the literature on mHealth technology focuses on increasing knowledge about health issues and changing health behaviors. For example, Tarver and Haggstrom (2019) found that tailored patient-centered technologies were effective at increasing cancer-specific knowledge among underserved populations and increased cancer screening behaviors for those populations. Other studies found that mHealth technology affected health behavior change related to physical activity (Hardeman et al., 2019). Several systematic literature reviews reveal similar effects of mHealth technology on chronic disease management as well as medication adherence in cardiovascular disease patients (Ah-Le et al., 2018; Gandapur et al., 2016). mHealth technology has also demonstrated its utility in detecting and managing heart rhythm changes and atrial fibrillation among undiagnosed populations (McConnell et al., 2018).

Patient testimonials also support the argument that mHealth may be useful in improving ICI diagnostic accuracy and treatment. For example, when then-prominent New York lawyer Lauren Stiles contracted POTS 4 days after a snowboarding accident, her doctors dismissed her symptoms as being all in her head (Stieg, 2018). She went to the internet and printed 30 journal articles about POTS. When she handed them to her neurologist, he told her not to go on the internet and took them home to read. When he came in the next morning, "he said 'Holy s***! You have POTS'" (cited in LaMotte, 2018, para. 29–30). In essence, mHealth technology could aid in the diagnostic process by providing patients with objective evidence to communicate with their physicians. This may, in turn, increase legitimacy, decrease time to diagnosis, and reverse quality of life consequences faced by stigmatized patients and their families.

To achieve these outcomes, we argue that instructional communication interventions be developed and implemented with physicians and other relevant health-care professionals, as well as with patients experiencing ICI symptoms and their families. To date, no empirical research exists to examine patient-provider communication as it may serve as instructive communication mitigating misdiagnoses and stigmatization of ICIs. In this manuscript, we explore perceptions of 21 POTS patients regarding the patient-physician communication they experienced. Ultimately, this exploratory study may lay important groundwork for developing effective instructional interventions to help medical professionals ask questions and interpret responses in ways that encourage legitimacy about their disease and, in the process, reduce the tendency to stigmatize patients suffering from these ICIs.

Theoretical Grounding: IDEA Model

Sellnow and colleagues (2015) argue for expanding the scope of instructional communication research beyond conventional classroom contexts. More specifically, they suggest doing more research in health contexts, as well as in technology-enhanced environments. One theoretical model they advocate for doing so is the IDEA model (Sellnow & Sellnow, 2019). IDEA is essentially an acronym standing for the four key elements in effective instructional messages as they occur beyond conventional classroom settings. These elements are internalization (perceived value/utility/relevance), distribution (master narrative delivered via multiple communication channels and trusted sources), explanation (accurate science translated intelligibly to diverse audiences), and action (specific action steps for reducing risk and mitigating harm).

Although the model was originally conceived to predict and explain instructional communication best practices in risk situations and crisis events, its utility has been demonstrated in other contexts including health contexts (e.g., Frisby et al., 2014; Miller et al., 2017; Schraedley et al., 2020; Sellnow-Richmond et al., 2018). For example, the IDEA model has been used to design effective messages and interventions

that improve compliance rates around food safety, biosecurity, health epidemics and pandemics, agricultural biotechnology, as well as natural disasters and human-induced ones. We argue that the IDEA model may also serve as an appropriate framework for developing instructional interventions focused on improving patient/provider communication. More specifically, the IDEA model provides a guideline for interventions regarding the nature and impact of invisible chronic diseases (affective learning), use of mHealth to reduce misunderstandings that lead its misdiagnoses and stigmatization (cognitive learning), and reduced time required to obtain an accurate diagnosis and develop an effective treatment plans (behavioral learning).

We contend that mHealth technology may play a significant role in improving communication through instructional interventions using the elements in the IDEA model. First, it may be a fruitful resource for empirical data that motivates health-care providers to take invisible symptoms seriously. Second, patients and providers could rely on mHealth as one channel for communicating accurate science around ICIs. Third, mHealth technology presents accurate data-driven science in language that a layperson can understand, which can improve communication among patients using the resource and providers following frameworks for communicating science more successfully with patients and families. Finally, mHealth technology may serve as a resource for patients and families seeking actionable instructions while seeking diagnoses and for health-care providers to create action plans to share with patients and families.

Research Questions

This study focuses on the types of messages POTS patients receive from their physicians, as well as how they interpret those messages. We were also interested in possible relationships existing among mHealth technology information and physician/patient communication regarding ICIs. Therefore, we posed the following research questions:

> **RQ1a:** What messages did POTS patients receive from health-care providers as they pursued a diagnosis for POTS?

> **RQ1b:** How did POTS patients interpret the messages received from health-care providers as they pursued a diagnosis for POTS?

> **RQ2:** What role might mHealth technology play in improving patient/provider instructional communication interventions and effective diagnosis/treatment of invisible chronic illnesses (ICIs)?

Methods

Participants

Participants included United States residents diagnosed by a physician with Postural Orthostatic Tachycardia Syndrome (n = 21). Of the 21 total participants, 15 were female, and six were male. Participants' ages ranged from 19 to 70 (mean age = 37). All participants identified themselves as Caucasian except two that identified themselves as multi-racial. These demographics align with statistics reported by the National Institute of Neurological Disorders and Stroke that 80% of the cases are diagnosed in Caucasian women aged 15–50 years (Collins, 2019).

Participants reported having experienced a wide range of symptoms consistent with POTS (e.g., dizziness, pre-syncope or syncope, tachycardia, gastrointestinal problems, low blood pressure, visual disturbances, circulation problems, headaches/migraines, brain fog, fatigue, shortness of breath, trouble sleeping, nerve pain). Participants also reported having seen a number of different health-care providers (some as many as 100) including primary care physicians, cardiologists, neurologists, gastrointestinal specialists, allergists, endocrinologists, pulmonologists, hematologists, immunologists, rheumatologists, geneticists, ear nose and throat specialists, infectious disease physicians, chiropractors, and pain management specialists. Finally, participants reported having numerous medical tests including extensive bloodwork, various types of imaging tests (MRIs, CT Scans, ultrasounds), EKGs, holter/event monitors, echocardiograms, electrophysiology studies, EEGs, EMGs, vision tests, allergy tests, gastrointestinal procedures (endoscopy, colonoscopy, barium swallows), skin biopsies, balance tests, sleep studies, and various autonomic nervous system function tests (tilt table test, QSART).

Procedures

Participants were recruited via social media, the Research Match database, and advertisements on a large Southern public university's website. Study advertisements were approved by the university's health-care system and Institutional Review Board. Interested participants were directed to contact the primary investigator of the study. A screener was conducted with the participant via email or phone to ensure he or she had been diagnosed by a physician with POTS and was over the age of 18. Participants were also notified that they would be paid $25 for their participation in the study. After the participant met the study inclusion criteria, a virtual interview was set up for a later date between the participant and one of three research team members.

Semi-structured qualitative interviews were conducted with participants via Zoom. Once the Zoom interview began, the consent was read to the subject, who then verbally agreed to participate in the study. Interviews were also recorded in Zoom so that they could be later transcribed. Interviews varied in length and ranged from 45 minutes to 90 minutes and produced 330 pages of transcribed data. Participants were asked a variety of questions focused on their experiences and interactions with the health-care system and health-care providers as they pursued a diagnosis for POTS. Sample interview questions included asking participants to describe when they first began experiencing symptoms they now know are related to POTS; to recall when they first saw a physician for those symptoms; to describe the communication that occurred between the physician and themselves; to list what tests, if any, the physician ordered; what aids may have been used to facilitate communication between physicians and patients; and other related questions.

Data Analysis

One coder used an open coding technique to analyze the 21 interview transcripts to identify initial themes or categories (Lindlof & Taylor, 2002). The coder developed and defined a tentative codebook and met with three other coders to review the codebook. All four coders used the codebook to independently code one interview transcript. Codes for all four coders were entered into an Excel file to examine agreement among coders. Coders agreed 85% of the time. Coders met to discuss the interview and resolve any disagreements or discuss categories/themes that needed to be added to the codebook. Coders then independently coded the same additional four interview transcripts to ensure agreement about themes and items categorized within them. This is also when coders determined whether any

new themes or categories needed to be added to the codebook. Then, each independent coder coded an additional four interview transcripts to complete the coding process for the entire sample.

Results

Several themes regarding potential instructional communication intervention content emerged from the interview data. We arrange these themes under the headings of physician communication to patients, patient interpretation of physician communication, and patient information-seeking via mHealth technology. The data revealed both harmful and helpful communication by physicians. Harmful communication consisted of comments dismissing the legitimacy of the symptoms, stigmatizing the disease as a mental health issue, and attributing the symptoms to some other pre-existing condition. Helpful communication consisted of compassionate caring and validating patient symptoms as real. Patient interpretations focused on two areas: giving up and relief. Patient information-seeking focused on mHealth and is illustrated through the experience as described by two patients with POTS.

Physician Communication to Patients

One theme that emerged from the data was physician communication to patients. This theme is divided further into two subthemes: harmful and helpful messages.

Harmful Messages From Physicians

Lack of Concern. Nearly every participant talked about physicians being dismissive about their symptoms signaling any legitimate medical condition. These comments typically occurred after medical test results came back normal or negative. For example, Ashley stated,

> I mean, I probably saw 20 doctors there [medical center]. I saw a neurologist, an ophthalmologist, another cardiologist, a rheumatologist, a dermatologist, like, every doctor they had, and every single one said, 'you seem fine. All of your tests are normal. There's nothing wrong with you.'

Similarly, Ava described an experience when she could hear physicians speaking about her outside of the exam room before entering. She explained, "I could hear them, like, just saying that, you know, I thought something was wrong with me, but nothing was wrong with me." POTS patients often look healthy so physicians do not always believe something is wrong. For example, Paula discussed an interaction she had with a cardiologist and said, "He was very dismissive, and um, you know, sort of almost laughing at the fact that I was describing these symptoms. Because, I was in my twenties, I looked very healthy, and it was difficult to be taken seriously." Paula went on to say, "I would say, generally speaking, doctors don't like it when they can't come up with an answer. And, if they can't come up with an answer, eventually they're going to just wash their hands of you. So, you get pretty good at preempting that and just moving on." Essentially, participants struggled to gain legitimacy with physicians because they often did not appear sick.

Participants also expressed concern that physicians did not listen to them. For instance, Blaire exclaimed, "She [cardiologist] did not, like, she came in and wouldn't listen to me. And she never did any tests." Similarly, Blake reported:

> They [neurologists] would definitely listen the least. So, each of them would do an MRI, which you know, is fine. That's their [neurologists'] protocol. And if they didn't really see anything from there, they almost seem to not be interested at that point. You know, either it was beyond their, you know, normal expertise or they just didn't think that it was a big enough problem.

As a result of perceiving health-care professionals as not listening or as trivializing their symptoms, participants felt misunderstood, which led some to give up pursuing an accurate diagnosis.

Misdiagnosis. Many participants talked about medical professionals misdiagnosing their symptoms and attributing them to something other than a physical illness. For example, many physicians attributed symptoms to a mental health issue, such as anxiety or depression. For example, Callie recalled a period of time when she saw a cardiologist during her high school years. She remembers the cardiologist speaking to her mother, "oh, sometimes children, they can just get a little anxious and scared and they just think something is wrong with them, even though it's not. There's nothing wrong." Callie went on to say,

> Unfortunately, it [the experience with the cardiologist] was kind of just a prelude to what was going to happen the next couple of years. Because, I went through a lot of cardiologists where they've told me, 'oh, it's all in your head.' They've [cardiologists] told my parents, 'oh, she's just looking for attention and that's why she's passing out.'

Similarly, Ava described seeing a cardiologist and said, "I think he [cardiologist] just did an EKG and that was it. And then he said everything was fine. So, he put me on some, like, anxiety medication—he said it [symptoms] was like anxiety and depression." Joyce described her journey through the health-care system and stated,

> Throughout all this [seeing various physicians] I'm getting a lot of mentions of depression and anxiety. So, I went to see a psychiatrist to get an assessment, just so I would know. And, I could also have that information to provide to other doctors. It'd be nice to have something to show them.

Katie had a similar experience with a primary care doctor that made her visibly emotional during the interview. She said, "He literally said, 'there's nothing wrong with you. We've tested everything. Here's a, you know, referral to see the psych department and a prescription for benzos [benzodiazapines].'"

Many participants in this study felt like Joyce did, in that they needed to prove that they did not have a mental health issue with each physician they saw.

Although both male and female participants experienced physicians attributing their symptoms to a mental health issue, females experienced this more often especially during an initial visit (during an emergency room or primary care physician visit for example) than males did. During initial visits, physicians tended to attribute male participants' symptoms to other issues, as described below.

Often, participants' symptoms were attributed to other issues, such as obesity, exhaustion or stress, or some other physical issue. Although women experienced some of these attributions, men were more likely to experience them. For instance, Blake discussed his initial visits with three different general practitioners and stated, "they [physicians] would say things that were just so generic. They would all go, 'you know, it's chronic fatigue or you know, you're just out of shape or something.'" Similarly, Blaire

noted when visiting with her cardiologist, "she [cardiologist] came in and 100% assured me that I don't have POTS and I should look into losing like 10 pounds. What she saw was just like, my body type, which I didn't need to lose 10 pounds. It was just a very long appointment for no reason."

Physicians also attributed males' symptoms to exhaustion or stress. For instance, Eli described an experience when he passed out in a motel room while traveling for work. He said,

> I got real lightheaded. And the next thing I know, I'm laying sideways in a motel room, and 45 minutes later, the maid calls an ambulance for me. I couldn't move a muscle in my body, except for my eyes. When I got to the hospital, the doctors wrote it off as exhaustion because of the number of hours I was working.

Eli went on to describe the second time he passed out, during a vacation. He recalled, "I knew I wasn't exhausted then. So I made an appointment with my family doctor. My family doctor wrote it off as vasovagal syndrome. You know, that was just another answer. And another week went by and I was back on the road [for work]."

Both male and female participants reported physicians dismissing their symptoms. However, female participants' symptoms were attributed to mental health issues more often than male participants. Also, male participants' symptoms were more often attributed to other issues, such as obesity, stress, or exhaustion. Although participants in this study overwhelmingly described harmful messages from physicians, all of them did eventually find their way to a diagnosis. During this process, most at least had one positive experience with a physician.

Helpful Messages From Physicians

Listens and Validates or Believes the Patient. Participants appreciated when physicians listened to their concerns and allowed the participants to have a voice in their own care. For instance, when Blaire was speaking about the neurologist who eventually diagnosed her, she said,

> He usually doesn't make me do things that make me super uncomfortable. So, it's really nice to have that kind of choice. Where if I say, 'I don't want to do that; it's not of great value to me,' he just was like, 'Okay. Your boat, you steer it.' He's definitely been my rock through the whole thing.

Ava also described positive communication behaviors that one of her physicians exemplified,

> Whenever it is time to like, sit and listen, he [cardiologist] does that. And so, the way, so his, the tone of his voice. He sits there and listens and soaks everything in. You can just tell, when you're talking to him, you can just tell he's soaking everything in, and like, trying to think of the best way to help. He's so sweet. You get to see it in his face.

Katie also eventually found a physician who listened. She stated, "So, um, the DO [doctor of osteopathy], I felt was the first person who actually allowed me to tell my story, um, and like, here are all the things wrong with me." Katie went on to describe her experience with that physician and stated, "it was the first time in that decade that I felt somebody was like, 'I'm listening to you. You're right. I admit that I can't help you and am sending you to someone else.'"

It was very important for participants to feel like their physicians believed them. Many found that experience relieving or validating. For instance, Igor discussed his childhood pediatrician and explained,

> He didn't really have any background in this [POTS] but he never, never wavered in believing that you know, everything I was saying was really what I was experiencing. He never suggested psychological treatment. He referred me to the doctor that eventually made my diagnosis.

Igor went on to suggest that physicians should "put their egos aside and accept that the person who has the most insight into what is happening is the patient." Participants appreciated physicians who listened and believed them but they also appreciated when they felt like physicians cared for them, even if they could not help them achieve a diagnosis.

Caring and Responsive. Participants also really appreciated when they perceived physicians cared about them, even if they were not certain what the problem was. For instance, Callie spoke about one of her physicians and said,

> I absolutely loved that doctor. He was a really caring guy, really respectful, very knowledgeable as well. And he was able to put things in a vernacular that I could understand. But, he was respectful enough to know that, since I knew enough about my health at that point, that he could tell me things that normal doctors wouldn't.

Eli also described a positive experience he had with one caring physician. Specifically, he stated,

> The only one, and this is the honest truth, the only one that actually cared, and was willing to figure out what was wrong with me was Dr. [name of physician]. He did not give up on me until he figured it out. All the other ones just went through their, you know, went through their spiel and wrote ya off and sent you on your way.

Ava described specifically asking for a physician that she knew to be caring. She recalled,

> I personally asked for Dr. [name of physician] because I knew that he was, he cared, and that, he like, he really just genuinely cared about his patients. He would always take the time to listen and you know, he had very good bedside manner.

Although many physicians were helpful to the participants in meaningful ways, harmful messages from physicians were often very challenging for participants in ways that negatively affected their journeys through the health-care system.

Participants' Interpretation of Physician Communication

Not surprisingly, participants experienced many positive and negative emotions related to the messages they received from physicians. For instance, participants often gave up on seeking a diagnosis as a result of messages they received from their physician. However, participants often felt validation from physicians as well. These themes are described in more detail below.

Giving Up and Questioning Self. As mentioned earlier, participants in this study often spent years seeking a diagnosis to explain their symptoms, only to face their physicians not listening to them, being dismissive, or attributing their symptoms to a mental health or other issue. As a result, participants often gave up on the process. For example, Callie stated,

I actually stopped seeing doctors about my condition and I was lying to my mom and not telling her that I was passing out, because no one was helping. So, like, I'd pass out at school and they're [school officials] like, 'well, you know, your parents know about this?' I'm like, 'oh yeah, you know, my parents know it's pretty normal.' And I just wouldn't tell my mom when I got home.

Similarly, after hearing physicians dismiss her condition outside of her exam room, Ava said,

I actually got my feelings hurt by that, and I was just like, I'm not gonna say anything to anybody anymore. I'm just going to forget about it. So, I kinda let it, I kind of just brushed it [symptoms] off for awhile.

Katie was also emotional when she described a physician referral to see a psychiatrist (described earlier in this manuscript). She stated, "And that was, you know, probably the most influential doctor who led me to stop seeking treatment."

Participants often described sadness or frustration over the process. For instance, Eli mentioned having a conversation with his wife. He said,

After about the fifth or sixth year [of seeking a diagnosis], I'd just gotten so depressed with it all. I told my wife, 'I'm not going to any more doctors. I'm done.' And then I went for, I don't know, maybe a year and a half, and it [condition] started getting worse. And that's when I went back to the doctor. I probably cycled through 20–25 doctors.

Participants did not just give up after several negative meetings with physicians. They even questioned their own sanity. For example, after being misdiagnosed multiple times by different physicians, often with a mental health issue, Laura said,

I had many doctors suspect that [mental health problem], although none of them were psychiatrists. So, I actually went to a psychiatrist. So, like, maybe I am losing my mind, you know? You have enough people telling you that, you start to internalize it and believe maybe this is what's happening to me.

Ava described a similar feeling after seeing many physicians that attributed her symptoms to anxiety and depression. She said, "I didn't even want to try, cause I was like well, maybe I am crazy. Like, maybe there isn't anything wrong with me, you know?" Although messages from physicians often left participants feeling defeated, participants felt relieved when they were listened to or diagnosed properly by their physicians.

Validation or Relief. Participants often felt a sense of validation or relief when they finally found someone who could help them or who believed them. For example, Katie explained her experience with an integrative medicine specialist,

He's like, 'people come to see me all the time who have been mentally and emotionally damaged by doctors telling them there's nothing wrong with them, when there's obviously something wrong with them. So many people come to me with this exact story. It's terrible.' It made me feel heard and seen.

Angela also described a positive interaction with the physician that diagnosed her. She recalled,

> He basically asked me to tell my story from the beginning. [He] listened to all of it, validated everything I was saying. He said, 'yeah, I'm pretty sure you have POTS, it sounds like you have POTS.' It was amazing. It was like a breath of fresh air.

Because participants often felt the need to "prove" their illness to their physicians, many tried to find aids that helped them communicate with their physicians so that the physicians would listen and believe them.

Patient Information Seeking Via mHealth Technology

One theme that resulted from this study was participants' use of mHealth technology and its perceived impact on their diagnostic processes. More specifically, during two of the 21 interviews, participants discussed their use of mHealth technology and its perceived impact on each of their diagnostic processes. The two case studies described below highlight how mHealth technology may aid patients in obtaining a diagnosis and achieving legitimacy with their physicians more quickly than their peers. Participants' names have been changed to protect confidentiality.

Case Study 1: Amy. Amy is a 28-year-old Caucasian female who began experiencing symptoms of POTS in August 2017. She is physically fit and enjoys running for exercise. Amy purchased a Fitbit a few years prior to the onset of her symptoms because she enjoys running and wanted to track her heart rate. Amy had just completed a half marathon when she began noticing symptoms of POTS. She noticed that her resting heart rate was much higher than it typically was. Her resting heart rate was 160 bpm and would increase from there when she ran for exercise. Amy also began feeling badly even after light exercise. She experienced cramps, problems with her balance, and brain fog.

Amy showed many of the graphs of her heart rate from her Fitbit to her primary care physician to demonstrate her higher than normal heart rate. Amy's primary care physician became very invested in her case and referred her to several specialists, including a neurologist and cardiologist. Those specialists ordered several tests for Amy, including bloodwork, an MRI brain scan, a Holter monitor test, stress test, and balance test, among many others. Many of Amy's tests came back normal, except her Holter monitor test, which showed anomalous tachycardia as well as her balance test, which confirmed her balance challenges. Amy eventually saw a dysautonomia specialist who diagnosed her officially with POTS. Although it took 2 years for Amy to be officially diagnosed with POTS, she believes that the initial data from the Fitbit she provided to her primary care physician expedited the process for her. For example, in her interview, Amy said,

> I think it helped a lot that I brought actual data to back up the things I was saying. It wasn't just me walking in saying, 'I feel like crap a lot.' I had graphs with my heart rate data compared to my, like, running speed, and it just showed this really sharp incline.

Unlike other study subjects, Amy reported that her primary care physician never mentioned anxiety and/or depression to her as a possible cause of her symptoms. Amy attributes this directly to the data she acquired from her Fitbit that demonstrated her high heart rate and heart rate fluctuations. She went on to say, "So, that was kind of hard for them [health-care providers] to say, 'Oh, it's all in your head,' or, 'Oh, that's anxiety.' Like, um, you know. It's hard to argue with the graph." Amy's Fitbit provided some

objective data for her to give to her physician. In sum, Amy believes this decreased the amount of time it took her to achieve a diagnosis for her symptoms and does not know if she would have a diagnosis today without the Fitbit.

Case Study 2: Alan. Alan is a 28-year-old Caucasian male who serves in the military. Alan first began experiencing symptoms as a teenager when he passed out unexpectedly. He still experiences dizziness upon standing, low endurance, and struggles with his military training. He began paying attention to his heart rate because his smartwatch indicated his heart rate stayed in the maximum range for too long. His resting heart rate stayed at about 115 bpm and it would increase up to 200 bpm during exercise and would stay in that range for too long. Alan used an app on his smartwatch called Samsung Health and he was able to read American Health Association information about prolonged increased heart rate. During his interview, Alan stated,

> I've noticed my heart rate was, like, in the maximum range. So every time we'd [military] go out and do a run, cause we run like three to four times a week. My heart rate would be any-where from 185 up to 200 beats a minute, like during the run. And they [smartwatch] even have a section on the App they call like Samsung Health I think, [which] is what I was using. And according to the American Heart Association, you're not supposed to be staying in your max heart rate for very long because it causes like long term stress on your heart. And so that's why I'm like, okay, I should probably talk to somebody about this.

Alan finally spoke to a physician about his symptoms in 2017. He showed the physician screenshots from his smartwatch that demonstrated the types of exercises he engaged in and how long his heart rate stayed in the maximum range. At first, his physician did not take his symptoms very seriously and attributed the high heart rate to a medication Alan was taking. However, after looking at Alan's screenshots again, the physician agreed that Alan's symptoms were not normal. Alan explained that his physician said, "Okay, this is pretty weird." Alan continued and stated, "like, he [physician] finally admitted [that there was a problem] during that appointment, so he wrote me a referral to go see a cardiologist." Alan saw two cardiologists and two neurologists and endured several tests, including bloodwork, an ultrasound of his heart, an MRI, a stress test, and a tilt table test. It took 2 years for Alan to obtain a diagnosis but eventually a neurologist diagnosed Alan with POTS based on his tilt table test results.

Both participants obtained a POTS diagnosis within 2 years of their initial visit with a physician. The average time to diagnosis for the total sample in this study was approximately 5 years. This is consistent with previous studies conducted on POTS patients. As mentioned earlier, participants' average time to diagnosis in the large POTS study conducted by Shaw and colleagues (2019) was 4 years. One of the primary differences among the two cases described in this manuscript from other participants in the same study was the use of mHealth technology to aid the participants in their diagnostic journey.

Participants in this study described grueling symptoms that fueled often years-long journeys through the health-care system to achieve diagnoses. It seems that messages from physicians can leave patients feeling stigmatized and affect their journeys through the health-care system. In those cases, mHealth technology may help patients gain legitimacy with their physicians and assist them in achieving a diagnosis. Messages from physicians can also be helpful to patients as they navigate the health-care system. Better training for both patients with ICIs and physicians treating patients with these potential diagnoses may result in positive experiences for patients and physicians alike.

Discussion

Although patient/provider communication is improving through research and professional development programs, results from this examination reveal several important conclusions. First, physician communication continues to be ineffective based on patient expectations, perceptions, needs, and desires. This conclusion confirms Thorne and colleagues' (2004) claim that perhaps the most serious challenge comes in the form of failed communication based on misperceptions among health-care providers who refuse to consider these invisible diseases legitimate physical illnesses. Consequently, nearly 20 years later, we continue to struggle with obtaining accurate and timely diagnoses of these "serious, complex, and often debilitating" medical conditions (Allen, 2008, p. 289). Our results revealed that ICI patients continue to spend on average 5 years pursuing an accurate diagnosis and treatment plan. This extends the IDEA model theoretical perspective to suggest that, much like novel diseases (e.g., COVID-19), one must explain science in terms of both what is known and unknown, as well as what is being done to find out (Sellnow & Sellnow, 2019). Such transparency would avert health-care providers from sharing misinformation and the negative consequences of doing so.

Second, most ICI patients are misdiagnosed by medical professionals who continue to claim the symptoms are psychosomatic or "in the patient head" (Allen, 2008, p. 289). This is particularly troubling because these misdiagnoses may lead to patient's doubting themselves and even giving up the search for an accurate diagnosis and treatment. This stigmatization of ICI patients may, in turn, adversely affect self-concept and esteem, as well as patient/family quality of life (Csecs et al., 2020; Larun & Malterud, 2007). This study supports Yang and colleagues (2007) argument that stigma is "a social, interpretive, or cultural process" that threatens "what is most at stake for actors in a social world," that is, "lived value" (p. 1524).

Third, results of this study extend existing research by exposing the positive affect when patients believe health-care providers are truly listening and sincerely believing them and their stories. Participants concluded that these providers genuinely cared about them, which softened the blow of having to pursue additional testing. The IDEA model of effective instructional risk and crisis communication purports that demonstrating compassion through effective listening is critical to success (Sellnow & Sellnow, 2019). Conclusions from this study extend that theory to health-care diagnosis and treatment of invisible chronic illnesses (ICIs).

Finally, when used appropriately, mHealth technology may save time, money, and frustration for both health-care providers and patients by tracking symptoms in real time. The patients in this study reported, on average, about 5 years of testing before reaching an accurate diagnosis. However, the two patients (Amy and Alan) that reported using mHealth devices (Fitbit, smartwatch) achieved accurate diagnoses and treatment plans in less than half the time. More specifically, both participants had a POTS diagnosis a full 2 years sooner than the average for most POTS patients (Shaw et al., 2019). It seems plausible that the objective data provided by participants may have contributed to physician perceptions of medical legitimacy and, thus, reduced time to diagnosis for these participants. A shorter time to diagnosis could also improve other health outcomes such as stress and financial burden. These findings have several implications for future work in this area.

Implications

Results from this study illustrate the role health communication interventions could play to improve outcomes for both patients and providers dealing with ICIs. Clearly, reducing the time it takes to confirm an accurate diagnosis of these invisible diseases ought to be a primary goal among health-care providers. However, results of this study confirm research pointing to improved communication may play a vital role in doing so. Although research has suggested doing so, a gap remains in moving these recommendations to applied practice (e.g., Brennan & Creaven, 2016; Jones et al., 2009; Kralik et al., 2005).

One theoretical model that could fill this gap is the IDEA model for effective instructional risk and crisis communication (Sellnow & Sellnow, 2019). To clarify, the internalization component of the IDEA model illustrates the role of conveying care and compassion to motivate participants to trust spokespersons (Sellnow & Sellnow, 2019). Regarding ICIs, providers could learn to begin by asking patients to share their stories, engaging in active listening, and responding that they believe patients are suffering from a medically legitimate condition that is difficult to diagnose because many of the symptoms are unobservable and immeasurable (Donoghue & Siegel, 2000). The explanation component argues that accurate science needs to be shared transparently in terms of what is known, unknown, and being done to find out, as well as translating information intelligibly to disparate publics. Patients can learn to use mHealth technology to collect empirical data in real time, which can be shared with their health-care providers. Providers can learn strategies to encourage patients to use mHealth technologies through well-designed actionable instructions.

In fact, the World Health Organization held a summit in Cape Town in 2011 and recommended creation of a "national eHealth development toolkit" that would include a section on "global mHealth best practice" (Kay et al., 2011, p. 69). If designed and implemented effectively, such instructional communication interventions could improve perceived legitimacy among health-care providers and reduce stigmatization of ICI patients. By making mHealth technology instruction a key component of these interventions, it is plausible that time required to obtain an accurate diagnosis could be reduced substantially and patient quality of life could be improved sooner (Donoghue & Siegel, 2000; Kavi et al., 2016; Thorne et al., 2004). Other researchers that have observed the issue related to legitimacy for patients with ICIs have also discussed the need for improved training for health-care providers.

Limitations and Suggestions for Future Research

The present study was exploratory in nature and based on a small sample size. Although the experiences of the 21 participants in this study provide important insights into this topic, studies that include larger and more diverse samples would be useful in moving this research trajectory forward. Also, because the study participants were recruited only from social media support groups and a university health-care studies website, we can assume that all were actively seeking information related to POTS. It would be helpful to expand the sample to include POTS patients that are not motivated to actively seek information about the ICI. Finally, this present study focused on the potential uses of mHealth technology among POTS patients. However, recent research reveals that COVID-19 "long-haulers" are experiencing POTS-like symptoms (Nguyen, 2020). mHealth technology should be examined as it may function in other health conditions that are novel, difficult to diagnose, and in many ways unobservable and immeasurable.

Conclusion

Individuals who suffer from invisible chronic illnesses (ICIs), such as many autoimmune disorders, chronic pain, fibromyalgia, epilepsy, and postural orthostatic tachycardia syndrome, often struggle for years to obtain an accurate medical diagnosis. Because the symptoms of these complex medical conditions are unobservable and immeasurable using existing procedures, health-care providers often conclude that the symptoms are psychosomatic rather than illustrative of a legitimate medical condition. Consequently, patients report feeling invisible and stigmatized as imagining the symptoms in their heads. Accordingly, patients and their families suffer from diminished quality of life for years.

Conclusions from this study are encouraging, however, in that they point to the potential of instructional communication health interventions based on the IDEA model theoretical framework as a best practice to address these challenges. Interventions would focus on improving communication via internalization (e.g., listening, believing, compassion/care), distribution (e.g., in-person, synchronous online webinars and chat rooms, asynchronous web-based modules), explanation (e.g., accurate science about what is known, unknown, and being done to find out, as well as translated intelligibly), and action (e.g., specific instructional action steps for using mHealth technology to collect empirical data that may inform speedier diagnosis). As a result of such instructional interventions, patient-provider communication could be improved and mHealth technology be utilized not just as a cool gadget but as a useful tool for tracking symptoms in real time, enriching health-care practice, improving patient quality of life, and saving lives.

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