News and Perspectives

Online Patient Support Communities as Sources of Support, Risk, and Research for Rare or Contested Conditions

Vanessa Nirode, JMIR Correspondent

Abstract

When research, treatment, and support are scarce, where can people living with rare or contested conditions turn? In this *News and Perspectives* article, JMIR Correspondent Vanessa Nirode reports on the role that online patient support communities play, highlighting People Allergic to Me syndrome as a case study.

Key Takeaways:

- People Allergic to Me syndrome is a rare, contested illness with very little research conducted about it.
- People turn to online communities for support and understanding, particularly in the context of rare or understudied conditions.
- The data from these communities and the analytical processing power available can help bring awareness and motivate further research.

Irene Gabashvili, PhD—biomedical researcher and innovator—has conducted the only clinical trials on People Allergic to Me syndrome (PATM)—a poorly understood phenomenon in which individuals are thought to emit odors or gases that produce allergic reactions (eg, coughing, watering eyes, and sneezing) in people near them. While she didn't have a formal diagnosis (and was able to resolve her symptoms), her personal experience was what led her to cofound MEBO Research, Inc.

One of her trials looked at chemicals in breath. "Some PATM sufferers display a slightly deficient metabolism, meaning whatever they breathe in, they also breathe out through their body," explained Gabashvili.

In 2023, Yoshika Sekine, PhD, conducted a PATM study that profiled human skin gas. The results showed that the gas profiles of those with PATM and those without differed, identifying key gases (especially toluene, hexanal, and octanal) that might play a role in PATM.

"Managing involves time and understanding what your body responds to," said Gabashvili. It's not an easy fix of eating healthy and exercising. Because we all have different microbiomes, "not every exercise nor every healthy food may be good for every individual," she explained. She describes PATM as a combination of genetics, development, and environment, with flare-ups dependent "on the weather, the building you're in, clothing and, of course, psychology."

With so little research and limited medical recognition, those with PATM turn to online support groups or forums—most commonly Reddit. The term *PATM* itself originated online and has stuck.

Uses of Online Forums

Irene Sánchez Rodriguez, a PhD student at IMT School for Advanced Studies Lucca in Italy, researches social media and mental health. "In the case of a contested illness such as PATM, the main objective is validation that you are not 'crazy' and not alone," she said.

Scrolling through the PATM subreddit brings up post after post of people asking if others share their experience and sharing cause and cure suggestions. There are also posts aimed at raising awareness and pleading for more research. Many users document a high level of distress, with one sharing "I have had PATM for 10 years and this disease has evolved in an uncontrollable way and my life has become unbearable, the breaking point is approaching."

Virginia Morini, PhD—postdoctoral researcher in computational social science at the Institute of Information Science and Technologies in Italy—studies the data found on public platforms.

While Reddit users typically remain anonymous, everything, Morini reports, is a "trace of behavior or language." "What people write for tells you more than who they are," said Morini. She analyzed data across 69 English-language Reddit mental health communities, finding that the majority of users typically posted to ask for advice or support (~49% of posts) or to vent (~36% of posts).

Social Dynamics and Psychology in Online Communities

These communities provide a window into how social isolation, stigma, and information vacuums can coalesce in both positive and negative ways.

Maria Sansoni, PhD—psychotherapist, postdoctoral researcher in psychology, and a coauthor of the Reddit study—says that "Social Identity Theory proposes that people draw part of their identity, and part of their sense of belonging, from the groups they identify with."

Online mental health communities can reduce isolation and provide emotional validation, which are two things that most people need. The former, though, can amplify both the benefits and risks of these forums.

"When symptoms are difficult to explain and/or people don't believe in their existence, humans seek recognition, not just information," said Sansoni. These communities can help normalize situations that people may consider shameful. They can help someone make sense of their reality, and they provide access to potentially useful information.

On the whole, research supports the idea that online patient and health communities, even social media like TikTok (Rodriguez' current focus) and Instagram, can "do good." The mental health Reddit communities that Morini and Sansoni studied, for example, appeared to be more supportive and less hostile than many other subreddits within the Reddit ecosystem.

Potential Risks

These communities can also, however, perpetuate anger and hopelessness or expose participants to misinformation and even potential symptom reinforcement, contagion, or social transmission.

"A community that is the only place where you feel understood also tends to become the only place from which you take information, including about treatment," said Morini.

Rodriguez noted that the majority of individuals sharing potential misinformation don't necessarily have malicious intent. For example, she explained, "say, I found this tea that makes me feel better. It's not that I want other people to do something dangerous nor do I intend to give misinformation. I just try to help by posting about it. And if a second person posts, and a third, and a fourth one; then the fifth might think that this is completely true."

Morini and Sansoni's research also showed a worrisome pattern about the "emotional weather of a conversation." In depression communities, they followed how a person's writing changed through time depending on who they'd been communicating with. For instance, after a discussion where the majority of participants wrote from a place of acute distress, a person who before seemed "balanced" was more likely to become more unstable or "fluctuating" in their psychological state.

"And, it does not work symmetrically," said Morini. "Being surrounded by people who were writing from a better place did not reliably pull anyone upward."

> *While there is noise to sift through, the positives [of online support communities] continue to outweigh the negative.*
>
> Irene Gabashvili, PhD

Moderation and Future Directions

Rodriguez has a suggestion for how to manage the potential risks of online support communities: a human in the loop or, at the very least, a moderator.

With respect to misinformation, Rodriguez thinks that algorithmic tagging initiatives should be expanded, for example, to evaluate the validity of a post, so that one touting a "miracle" tea that cures something—without science to back it up—would earn a flag.

Online communities categorized as "support" can play an integral role in treatment pathways, though they should be treated as an addition—not an alternative—to clinical care. Sansoni explained that a community can provide a person with validation, belonging, and a safe place to express emotions among people who genuinely understand that person's experience, while clinicians can help the person process those emotions and make sense of the illness. "And the order matters," she added.

Gabashvili, who has remained in contact with some of her study participants, believes that "while there is noise to sift through, the positives [of online support communities] continue to outweigh the negative."

One additional positive, explained Rodriguez, is the immense amount of data these communities provide. Now, with AI and computational methods, researchers have a way to analyze it all.

"Without all this data, nobody would ever think about conducting more research about something like PATM," said Rodriguez. "These communities show that there is something to be studied, something to research and learn more about," which is exactly what many of the people living with PATM desire most.

Keywords: People Allergic to Me syndrome ; PATM; rare diseases; online support communities; social support; patient support groups

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