

ENTER THE SPIRAL: THE ADVERSE CONSEQUENCES OF PROFESSIONAL AND LAY EXPERTISE FOR SUFFERERS' LIVED EXPERIENCES

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ABSTRACT

While professional expertise is often the first recourse for diagnosing and treating personal problems, it cannot always satisfactorily solve them. In such instances, lay expertise can often complement professional knowledge and practices. Due to easily accessible digital platforms, it is increasingly common for people to utilize both professional and lay expertise to solve problems. This warrants further examination of how utilizing both professional and lay expertise co-constitute the lived experiences of sufferers. To answer this question, we qualitatively studied a prominent online community dedicated to reflux disease. We found that, in many cases, both professional and lay expertise proved inadequate in alleviating suffering. The nature of the symptoms faced by the sufferers, the subsequent dependence on and failure of professional and lay expertise to satisfactorily solve the problems led sufferers to experience what we call the spiral. The process of spiraling exemplifies how the sufferers engage with diverse forms of expertise and how this in turn shapes their lived experiences.

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By developing this notion, we contribute to the literature on expertise by showing the combined effects of both professional and lay expertise on the sufferers' lived experience. Our study also highlights the limitations to the complementarity of professional and lay expertise, as well as the potential harms of engaging with lay expertise.

Keywords: Expertise; professions; lay expertise; clients; online communities; suffering

Unable to work, I ended up spending the better part of two months lying in the hammock in my tiny backyard. I could no longer tolerate food with strong flavors, so I subsisted on brown rice, lentils, steamed vegetables and small amounts of chicken breast. At some point, my wedding band slipped off my thinning fingers, lost without my realizing it. One evening, my 10-year-old daughter, the eldest of my three children, burst into tears and said, "I just want you to get better!" (Velasquez-Manoff, 2023)

Science and medicine have turned many previously severe diseases into solvable problems (Greenwood, 2008). However, many health problems – such as the recent example of long-Covid-19 (Au et al., 2022) – remain difficult to diagnose and treat. Many of us have a family member or a friend who is dealing with a longstanding health issue that seems to defy treatments or even diagnosis. Such issues can cause utmost suffering for individuals and their loved ones – as the New York Times science journalist's long-term experiences with gastrointestinal issues show.

Professional expertise, the abstract knowledge held and practiced by credentialed experts (Abbott, 1988) – is often the first recourse in such situations. However, professional expertise may, on occasion, fail to solve clients' problems or meet sufferers' expectations. For example, doctors may be unable to diagnose and treat sufferers' symptoms (Bradley, 2021) or professional expertise might be unreachable due to long wait times or high cost (Siciliani et al., 2014). On other occasions, patients feel alienated by professionals who discount emotional needs (Pilnick & Dingwall, 2011).

In such situations, sufferers can turn to lay expertise to address their concerns (Epstein, 1995). Lay expertise is a collection of hybrid knowledges and practices disseminated and utilized by non-credentialed people in a given issue domain (e.g., HIV/AIDS advocacy). This hybridity originates from lay expertise's diverse knowledge bases, values, personal experiences, and interaction spaces – all of which usually contrast with professional expertise (Epstein, 2023). Prior work has identified several benefits to lay expertise, including its ability to complement professional expertise by filling knowledge gaps through the articulation of sufferers' problems (Au & Eyal, 2021; Eyal, 2013). Lay communities can also provide emotional support and identity for members by acknowledging their experiences and interests (Borkman, 1976; McReynolds-Pérez, 2017; Rabeharisoa et al., 2014).

While this previous work has helped us understand the relations between sufferers and professionals, and sufferers and lay expertise, there has been much less attention to sufferers' lived experiences in relation to *both* forms of expertise. However, there are several reasons why these experiences would be important to

understand. First, when individuals face personal problems that require expertise, they often engage with both professional and lay expertise simultaneously or sequentially (Au & Eyal, 2021; Kraschnewski et al., 2014). However, even when it highlights lived experience at all, the literature on expertise mostly considers lived experience in relation to different forms of expertise in isolation. Second, lay expertise is increasingly accessible through online lay communities organized around shared concerns (Akrich, 2010; Hardey, 1999; Kempner & Bailey, 2019). These lay communities can potentially mediate the influence of professional expertise on lived experience. Finally, while popular depictions of online communities sometimes point to the problematic nature of these groups (Dooley & Ueno, 2022; McAllen, 2024), to date, the academic literature has often focused on the nature of lay expertise itself and its epistemological tensions with professional expertise (e.g., Croidieu & Kim, 2018; Wynne, 1996). We thus know less about the potential “dark side” of engaging with lay knowledge for individual sufferers. Therefore, it is important to understand *how utilizing professional and lay expertise co-constitutes the lived experiences of sufferers?*

To answer this question, we conducted an inductive archival study of an online community dedicated to reflux disease. Drawing on the work of philosopher Ian Hacking (1995), our analysis reveals a process we call *spiraling* that characterizes how the sufferers engage with diverse forms of expertise and how this shapes their lived experiences. In *entering the spiral* phase, sufferers first experience enduring and painful symptoms and a dependence on expertise, raising anxiety about their situation. In the next phase, *deepening the spiral*, the sufferers depend heavily on medical experts. When professional expertise yields little relief, the next phase, *expanding the spiral*, follows, wherein sufferers turn heavily to online lay expert communities for solutions. While these communities acknowledge their suffering, they also offer sufferers perplexing advice, further contributing to adverse experiences of the sufferers. Our study contributes to the literature on expertise by showing how the combined adverse effects of both professional and lay expertise on the sufferers contribute to their experience of a *spiral*. Furthermore, we explicate the boundaries to the complementarity of professional and lay expertise, and the limitations of lay expertise.

The implications of professional and lay expertise for the lived experience of sufferers: Individuals grappling with a variety of problems often seek assistance from professionals (e.g., doctors, priests, and therapists) who draw on their professional expertise to solve these problems (Abbott, 1988; Freidson, 2001). However, professional expertise does not always provide satisfactory solutions. For instance, professionals may not have the knowledge needed to solve sufferers’ problems or they fail to meet people’s emotional needs (Bouchard et al., 2023).

Dissatisfied individuals can then seek solutions through lay expertise (Arksey, 1994; Barker, 2008), a term often invoked, but surprisingly, rarely defined. Usually, it refers to “outsider” knowledge and participation in a domain of professional or scientific expertise (Epstein, 1995; Wynne, 1996). Lay expertise is defined by its structural position, knowledge bases, values, and collectivity (Epstein, 2023). First, it is practiced, initiated, and advanced by relative outsiders beyond the traditional boundaries of established professions or science (see Gieryn, 1983).

Second, lay knowledge is characterized by epistemic hybridity (Epstein, 2023), as it appropriates professionals' primary source knowledge (Collins & Evans, 2007; Epstein, 1995), as well as anecdotes, alternative, and experiential knowledge (Broom & Tovey, 2008; McReynolds-Pérez, 2017). Third, actors engaged in lay expertise may align with professionals on values such as "health," but their priorities are often more personal and urgent (think of a cancer patient versus a cancer researcher). Finally, while lay expertise may draw from individuals' lived experiences, it is constructed in lay communities that range from activist movements (Epstein, 1995) and patient organizations (Rabeharisoa & Callon, 2004) to online communities (Foster, 2016). These collectives are tied together by members' shared experiences and identities (Allsop et al., 2004; Epstein, 2008), rather than shared socialization or institutional credentials – the hallmarks of professional expertise.

Yet, despite important differences, professional and lay expertise are not polar opposites. As Epstein (2023, p. 82) remarks "most of the empirical work on lay expertise speaks to its hybrid character and indicates that lay expertise in practice traverses the boundary between official knowledge and its multiple 'others,' rather than being located purely on the 'alternative' side of the divide."

Lay expertise can draw on professional knowledge, while professional expertise can similarly use patients' experiential knowledge or common sense.

Lay expertise fulfills several roles: it offers emotional support (Radin, 2006), generates experiential knowledge rooted in personal experiences with similar conditions (Borkman, 1976), and helps in navigating established institutions (Foster, 2016). Lay expertise can also contribute to the scientific process (Epstein, 1995) by interpreting and challenging professional norms (Barker, 2008; Wynne, 1996). Lay community members also engage in fact-gathering, data collection, analysis, interpretation, and treatment that do not necessarily adhere to standard professional practices (Campbell, 2021; Hardey, 1999).

However, while the literature has helped us understand the relationship between sufferers and professional experts, on the one hand, or sufferers and lay experts, on the other hand, there has been much less work on the combined effects of sufferers' engagement with professional and lay expertise. Instead, the literature has often focused on portraying relationships between professional and lay expertise as a political, jurisdictional, or epistemological struggle (Brante, 1988; Eyal, 2019; Kendall & Freidson, 1976) while paying less attention to sufferers' actual lived experiences as a result of engagement with expertise.

There are several important motivations to pursue this knowledge. First, individuals rarely engage with either professional or lay expertise exclusively (Kraschewski et al., 2014). As Epstein (2023) notes, the boundary between the two is often porous, with lay experts gathering, interpreting, and disseminating professional knowledge, while at the same time, institutionalized professionals also complement their domain expertise with experiential knowledge. For instance, during the Covid-19 pandemic, online community members were recipients of both official public health messages and the interpretations of lay experts (Au & Eyal, 2021). In many contemporary cases then, simultaneous, or sequential engagement with both professional and lay expertise is the norm rather than the

exception. However, the literature on expertise often considers lived experience in relation to different forms of expertise in isolation.

This leads us to our second motivation: the increased accessibility of lay expertise through online communities. Affordances of technologies such as discussion platforms, smart devices, and wi-fi make lay communities prevalent and accessible (Brady et al., 2016). In healthcare, websites, blogs, and online communities have emerged around a variety of issues (Akrich, 2010; Kempner & Bailey, 2019). Instead of locally and culturally bounded advocacy groups, these new kinds of communities offer knowledge and collectivity without formal organization or the goal of mobilization (Foster, 2016). The accessibility of these communities is in stark contrast to professional expertise, which is often limited by economic, availability, or geographic constraints.

Finally, while there is some reporting on the “dark side” of such online lay communities (Dooley & Ueno, 2022; McAllen, 2024), their potential downsides to participants’ lived experiences have rarely garnered much attention within the broader expertise literature. We thus know little about the potential “dark side” of engaging with lay knowledge for individual sufferers. Therefore, we ask, *how does utilizing professional and lay expertise co-constitute the lived experiences of sufferers?*

To theorize our case, we draw inspiration from the notion of *looping* (Hacking, 1995), which describes how medical diagnosis and patient identities shape each other. This theory suggests that after a medical diagnosis is made and a patient is labeled, this label “loops” back to constitute the patient’s identity. We expand on the notion of looping by formulating the notion of *spiraling*. In our case, the initial loop originates from the nature of the sufferers’ symptoms and the dependence on professional expertise. This, in turn, generates anxiety, creating the *anxious self*. We elaborate on the idea of looping by adding in the third dimension, *depth*, which converts the two-dimensional loop into a three-dimensional spiral. This added dimension of depth is created by the prolonged dependence on professional and lay expertise, and the subsequent failure of both to provide adequate relief to sufferers, resulting in the experience of what we call *spiraling*.

METHODS AND DATA

Research Setting

We examine our research question in the context of online communities dedicated to reflux diseases: GERD (Gastroesophageal reflux disease) and LPR (Laryngopharyngeal reflux). Typical symptoms of reflux disease include regurgitation, dysphagia, burning in the throat and chest, inflammation of vocal cords, postnasal drip, excessive mucus, lump in throat sensation, burping, indigestion, and asthma (see, e.g., Maret-Ouda et al., 2020). Estimates of the diseases’ population-level prevalence range from 9% to 30% (IFFGDAAdmin, 2021). Reflux diseases differ from many others, as they are, on the other hand, not immediately life-threatening (compare cancer) or radically novel (compare Covid-19). This means there is sometimes a lack of urgent acknowledgment and

interest in the disease. On the other hand, reflux symptoms can be severe (compare minor headaches) and long-lasting (compare common cold), which means they can represent a significant shift in the lives of sufferers.

Standard treatments for treating reflux disease include PPIs (Proton pump inhibitors), H2 blockers (Histamine receptor antagonists), and antacids as well as lifestyle modifications (Gyawali & Fass, 2018). Diagnostic tests including endoscopies, Ph-impedance testing, and manometry can be used (Maret-Ouda et al., 2020).

The online communities we studied were founded in the late 2000s and have thousands of members. These communities provide sufferers with information, suggestions, and community. Sufferers often post about their problems and ask for help on topics including diagnosis, treatment, and diet. They also narrate their experiences with medical experts and lay experts alike. The posts are detailed and temporally arranged with terms such as “2 months ago” and “last week.” The lay experts respond to the sufferers’ queries with their own experiences and advice. The posts remain publicly archived on the platform and are available to anyone. While those who find complete relief may leave the forum, many continue to post because they are still suffering despite following guidance from both professional and lay experts. These communities are ideal settings to study our research question since the posts cover the expanse of how sufferers experience the confluence of the disease, and engagements with professional and lay expertise as they search for the elusive relief. Altogether, then, this setting is like many health communities (Epstein, 2008) where shared experiences of pain and suffering bring people together (Allsop et al., 2004; Packard et al., 2004).

Before proceeding, we would like to clarify the difference between “sufferers” and “lay experts.” Individual users in the online community can take different roles at different times. A person can act as a lay expert and advise on a problem while still struggling with the same problem. Also, there is variation in sufferers’ experience and knowledge. Following, Epstein (2023), we do not claim that at a given moment someone is an expert or not.

As the literature on lay expertise would suggest (Epstein, 2023), in our case, lay and professional expertise are not entirely in opposition. Lay experts often draw on professional expertise, as they might discuss – if often critically – gold standard medical practices (Jones & Podolsky, 2015) or less established, emerging treatments proposed by medical professionals. Conversely, professionals may also draw on “clinical experience” of what works for patients (Kahrilas, 2008, p. 1701) or lay knowledge about managing the disease (Ahuja & Ahuja, 2019), and not only systematically collected scientific evidence.

Data Collection and Analysis

We describe data collection² and analysis altogether, as the relation between these two processes was highly iterative. Our data consists of archival materials from a prominent online community for reflux disease that has over 75,000 registered members and, potentially, numerous unregistered users. The online community is open and does not require an invitation or registration to access. The platform provides guidelines and has human and automatic moderation.³ The users have

pseudonyms, but may at times state their age, gender, and location (e.g., “M,39, Atlanta” stands for male, aged 39, living in Atlanta). One interesting observation was that many of the sufferers reported being in their 20s or early 30s, while the average reflux patient is often of middle or advanced age (Lee et al., 2007).

Data collection took approximately 6 months, from April 2022 to September 2022. The data were posted between January 2017 and September 2022 and are primarily text in the form of threaded posts. Each post is timestamped and has temporal guideposts, aiding in understanding the narrative of unfolding events and experiences of the original posters and responders. First, at the beginning of data collection, the first author used the platform’s sorting features, such as “top” and “most commented” posts, to filter the posts. These posts are high in engagement, reflected by the number of comments and upvotes (i.e., likes) they have received. The first author continued initial data collection until reaching the first point of saturation (Glaser & Strauss, 1967), that is, the same types of discussions started reoccurring with no qualitatively different ones appearing. This resulted in a sample of 206 threads.

We initially analyzed the data inductively (Charmaz, 2009). The first author began the analysis by closely reading these texts and open-coding a sample of the posts, searching for emerging patterns. The second author joined the project at this stage to develop data collection and analysis. During initial coding, we observed two interesting patterns. First, sufferers consistently wrote about how persistent their symptoms were as well as their reliance on expertise to solve this issue. We coded examples of these patterns “Encountering painful and long-lasting symptoms” and “Needing to rely on professional expertise.” Second, they described their experiences of engaging with professional and lay expertise and their effects on their lived experience. We focused further data collection and analysis on understanding how the lived experience of the sufferers changed as they engaged with different forms of expertise.

With this focus and emerging categories of professional and lay expertise in mind, the first author collected another 172 threads that provided insight into the sufferers’ experience of their disease and engagement with the two forms of expertise, leading to a sample of 378 threads. While there are posts about positive outcomes, they were rare, and many users wondered if there were success stories at all. Since most of the posts on the forum were about unresolved suffering, we focused on these cases. While the prevalence of negative posts is a boundary condition of our data,⁴ it is also its strength as it provides focused data on how lay expertise, especially through easily accessible online communities, can harm sufferers.

As we continued to analyze the sample, we inductively identified the dimensions through which lived experience is constituted – by the interplay between symptoms, and engagements with medical, and lay expertise. Having settled on key themes, we then moved to focused coding of our empirical materials to uncover additional subthemes, dimensions, and relations between concepts (Emerson et al., 2011). In the case of professional expertise, we noticed that people initially trusted the medical experts for a solution to their suffering, but interestingly, medical experts inadvertently added to the anxiety of the sufferers in two significant ways: first, by conveying the message “You are not sick” and second,

by stating “There is nothing more we can do.” We categorized these instances as “dismissing suffering” and “failing to treat” by doctors. For instances of lay expertise, we coded them thematically too, for example when lay experts said: “I understand what you are going through.” We coded this as “validating suffering.” Regarding lay experts’ diagnosis and treatment suggestions, we found the advice was characterized by a broad variety of suggestions and heated debate on many topics. We coded this as “perplexing with advice.”

Our data analysis revealed that sufferers’ experiences generally followed a certain temporal sequence. We divided the temporal sequence into phases based on the specific nature of the lived experience and the type of expertise with which sufferers were primarily engaged with in each phase. In the first phase, our analysis showed that the mixture of painful symptoms and desperate search for expertise is characterized by experiences of anxiety among sufferers. We labeled this lived experience the “anxious self.” Overall, we call this temporal beginning of the spiral “entering the spiral.” Furthermore, our analysis showed us that in the second temporal phase, the sufferers were dependent on professional expertise to solve their problems, but the medical professionals were often unable to provide satisfactory relief and rejected the existence of suffering. We labeled this phase as “deepening the spiral.” We noticed that after these experiences with professional expertise, sufferers often turned to lay expertise for a solution, initiating the next phase, which we call the “Expansion of the spiral.” Members of the online community readily acknowledge their suffering, but, at the same time, often provide idiosyncratic and contradictory advice. As a result, sufferers reported being bewildered by lay expertise. Finally, we went back to our empirical materials to better understand the consequences of experiencing the spiral. Following similar analytical procedures as before, found three common responses to experiencing the spiral, which we call “resigning,” “adapting,” and “mistaking.” [Table 1](#) provides additional empirical data for each analytical category.

Entering the Spiral: The Symptoms of the Disease and Needing to Rely on Expertise Construct the Anxious Self

Individuals’ engagement with the disease starts with the onset of symptoms. In the following, we describe how sufferers – people who are affected by an illness discussing it in the online communities – describe the painful and long-lasting nature of these symptoms on the online forum, as well as how they contribute to a shift in their identity into what we call the anxious self.

Encountering Painful and Long-lasting Symptoms

In many of the posts on the online forum, the sufferers described experiencing painful symptoms that persist throughout the day, as the following post describes:

The initial weeks of this turmoil were pure hell. I couldn’t eat, I couldn’t sleep, and I had burning in my mouth, throat, ears, and nose 24/7. I want to die just to stop the burning (...) feels like something is “tearing” into my stomach (...) I eat, I suffer. If I don’t eat, I suffer. I’m being bullied by my body.

Table 1. Empirical Findings and Representative Data.

Entering the Spiral

Encountering painful and long-lasting symptoms

“14 months ago, I lived normally, then I developed reflux. Gasping for air every waking moment. I can’t exercise anymore, as it makes shortness of breath 10 times worse. I can’t concentrate on anything anymore. Endlessly gasping and yawning. I only relief when I’m sleeping.”

Needing to rely on professional expertise

“I lose hope. I have suffered from reflux for two years now. My problem continues. I have pain in my throat and difficulty speaking. I don’t know what to do anymore and if I really want to continue. My mental health is dire. I don’t want to suffer anymore. I feel that nothing will change and that I will end up dying because of this disease”

Painful, long-lasting symptoms and needing to rely on expertise give rise to the anxious self.

“I have been on the NHS waiting list for 14 months now waiting to be seen and do not have the money to go private. Today I called and they said it was another 10 weeks until I will be seen (...) I feel like the long-term ingesting of a high dose of omeprazole, the lack of NHS appointments, and my own reckless behavior have put me between a rock and a hard place.”

Deepening the Spiral

Dismissing suffering

“It’s so frustrating dealing with doctors who just say, ‘Take the antacids for 4 weeks then we’ll see what to do next’. They don’t even do a diagnostic test before it. They don’t medicate someone suspect of having high blood pressure without first checking their blood pressure, would they? They look at me like as if my life hasn’t been disintegrating before my eyes. They think that I’m young and otherwise healthy, so it shouldn’t be a problem for me. Why the callousness? I suffer just as much as a 60-year-old with this.”

Failing to treat

“I just had a half-wrap fundoplication surgery which didn’t ease my symptoms and feel very depressed. Still waiting for a follow-up appointment and in an insane amount of pain”

Dismissing suffering and failing to treat intensify the anxious self

“My doctors dismiss me completely. They behave as if nothing is wrong and tell me to breathe deeply and sleep well. As if that is going to solve my problems. They just don’t understand what I am going through. It’s so frustrating !!!!!!!”

Expanding the Spiral

Validating suffering

“As I said, I’m not a doctor. But as a human, I can understand the human side of this suffering.”
“Wow, I felt every word you said. I was at my lowest point too.”

Perplexing with advice

“No one talks to a diabetic and says ‘don’t follow Doctor’s advice! You need to eat a lot of sugars to supersaturate your body and improve insulin production thereby making your body more insulin sensitive! It worked for me and my aunt – don’t give your money to big pharma! No one with a functioning brain would advise that.”

Validating suffering and perplexing with advice contribute to the expansion of the anxious self

“I’d be ok with following the standard advice if there was some fucking consistency! ‘Oh, don’t eat acidic foods’ – ‘Oh no, actually, you need to acidify your stomach to digest your food (Funny thing about PPIs’ if they cause rebound acidity, then wouldn’t that be what the ‘low acid’ crowd want?)’, ‘Take this PPI to treat the symptom (oh BTW it won’t actually heal your LES so good luck dealing with that without surgery).’

Such descriptions of the lived experience of sickness – drawing on dramatic imagery, “something is tearing into my stomach” – are common on the online forum. The second feature of the disease is that, for many sufferers, the symptoms are long-lasting. The following post captures this problem:

I hate this disease. I have suffered from reflux for two years now. My symptoms persist. I have pain in my throat, and difficulty speaking sometimes. My mental health is terrible. I fear that nothing will change, and I will end up dying due to this disease. I'm really trying to not cry as I type all this.

The person reports being afflicted with the condition for “two years now,” yet the problem “persists.” They are exasperated and end up catastrophizing.

Needing to Rely on Professional Expertise

After trying to manage the situation by themselves, the sufferers conclude that they need professional help:

I have so much pain every day. It doesn't matter what digestive enzymes or what I take or what I eat, I end up eating a lot of Tums a day (...) I know I need to see a GI specialist now. This is fucking hell.

When the symptoms have not abated after trying over-the-counter remedies, sufferers desperately seek professional expertise.

Painful, Long-lasting Symptoms and Needing to Rely on Expertise Give Rise to the Anxious Self

Following the sudden onset of the painful symptoms of the disease, it's not surprising that sufferers report fundamental changes to their identity. We call the identity that arises from the experiences with the disease and dependence on expertise, *the anxious self*. The following post captures these altering changes and the experience of anxiety:

Life was so good just 8 months ago. I could do and eat anything. Now I'm on house arrest. I can't socialize. I can't eat. I have never been so depressed (...) I can't believe I went from a happy-go-lucky bourbon drinker and steak eater to a guy holding his chest due to stabbing pain. What is the end game? I dread this might never be cured. I was a healthy social guy now I am a social pariah.

Identities such as “bourbon drinker and steak eater” have been substituted by “house arrest” and “stabbing pain.” The identity of a “healthy fit social guy” has been replaced by the one of “a social pariah.” Similarly, the user who saw themselves being bullied by the disease observed how they were “turning into a very grouchy and depressed person.” These profound changes induce considerable anxiety about the future, with sufferers asking themselves and fellow community members: “What is the end game.” In addition to the symptoms themselves, the reliance on expertise, their lack of accessibility, and the fear of bad news become sources of stress:

Due to the COVID situation, my doctor has informed me that ENTs are not currently available. I am very stressed about the possibility of developing cancer since it will take at least six more months for me to see an ENT.

Here, the sufferer is unable to access an ENT (specialist for ear, nose, and throat), giving rise to fears of the condition progressing. Additionally, when anticipating a meeting with professional experts, sufferers may feel nervous about potential procedures such as MRI scans.

In sum, the painful and long-lasting symptoms, and needing to rely on professional expertise – including their inaccessibility and potential for adverse findings – contribute to experiences of anxiety for sufferers. An anxious self is created by the apprehensions over the open questions of when, how, by whom, and *if* the condition will be cured. Following these experiences, the sufferers depend heavily, at first, on doctors and their medical expertise for help.

*Deepening the Spiral: Experiences with Medical Expertise
Intensify the Anxious Self*

However, sufferers often report that doctors and medical expertise fail to solve their symptoms. Two patterns are prevalent. First, medical experts fail to provide relational expertise as they often do not recognize the suffering of clients. Second – on many occasions – treatments based on medical expertise fail to alleviate the symptoms. These two experiences and the continued experience with symptoms contribute to intensifying the anxious self.

Dismissing Suffering

First, sufferers often share how doctors trivialize their experience and symptoms. Clients are denied the “patient” label and, thus, legitimacy, as shown by this post:

The doctors are so infuriating. My gastroenterologist didn't even think that my burning mouth is a problem. It is my biggest complaint. I explained to him every time I saw him (...) Asshole didn't think that the thing driving me crazy was important enough to add to my notes.

The frustration of the person toward the doctor is clear – “asshole” – as the doctor fails to see the “biggest complaint” as a problem. Sufferers report medical experts disregarding concerns for a variety of reasons. One sufferer explained how they were denied diagnostic tests because of being “young.”

Failing to Treat

On other occasions, sufferers receive recognition for their symptoms and treatments. They describe taking multiple drugs prescribed by their doctors. However, on many occasions, they also report that medical treatments are failing to manage their condition or even trigger side effects:

I am taking 80 mg of famotidine (...) it doesn't work. I stay up for over 24 hours (...) I am constantly bloated, constipated, agitated, and I keep burping up food. On my last hospital visit, I was prescribed pantoprazole 40 mg, but it only made me gassy and caused diarrhea.

Such difficulties in finding a treatment often persist alongside long-lasting symptoms, as sufferers report having the condition for several years, often experimenting with combinations of treatments without qualitative improvement:

I've had Gerd all my life. I don't get why PPIs and H2 blockers are the only medications. Antacids and OTC meds are useless placebos. They don't do a thing. I don't get it, why do so

many doctors keep throwing these medicines at you and expect them to cure everything? (...) The medicines have nasty side effects too.

The sufferers often portray doctors as experts who “throw those types of medicines at you.” But as one sufferer puts it, expert treatments run out over time: “Doctors say they can’t do anything for me [anymore].” In sum, the solutions of professional expertise fail many of these people. Users experience doctors as dismissing pain, and their treatments fail to cure the condition.

Dismissing Suffering and Failing to Treat Intensify the Anxious Self

Sufferers feel that doctors have let them down by dismissing their suffering and giving up on treating them. For example, a sufferer narrates how their concerns were outright ignored by a doctor:

I saw my doctor again, sure that it was GERD. I was hoping they’d be doing tests to check my esophagus. The doctor came in and quickly and said “You don’t look sick. Maybe you need more sleep” (...) What the hell? I felt so disrespected.

Doctors’ dismissal makes the sufferers feel “disrespected.” Such treatment from experts who are supposed to help them not spurn them plunges sufferers deeper into anxiety. Patients chafe at the invalidation from doctors, who think that their suffering “is all in the head.”

The contrast between the suffering and the dismissal by doctors produces frustration. When the treatments fail to produce relief, the sufferers’ anxieties often deepen. In the following post, the sufferer has tried a variety of medicines and lifestyle interventions:

It has been a year since this began. I’ve tried PPIs, all sorts of blood tests, ultrasound, antibiotics, rifaximin, dietary changes, probiotics, and sleeping sitting upright. I even spent 2 months in the hospital with a feeding tube in my stomach (...) every day I’m suffering from burning in my throat (...) I want to live so much, but I really feel can’t do this anymore.

The treatments and tests do not work for many sufferers, who are exasperated with the failure of professional expertise – especially if they feel gaslighted and abandoned.

Expanding the Spiral: Experiences with Lay Expertise Expand the Anxious Self

When medical experts fail them, the sufferers lean more heavily on the advice from other members of the online lay community. However, engagement with the lay community comes with a new complication. On the one hand, the lay community validates the experiences of sufferers as sick individuals. On the other, it provides perplexing advice on diagnosis and treatment, which often do little to alleviate the suffering.

Validating Suffering

While the medical experts often failed to acknowledge the suffering of the people, the lay experts in the online communities provided sympathy and recognition of the suffering. Here, a sufferer who posted about their symptoms and the

difficulties caused by them gets several validating responses from members of the online community:

- a) I'm going through the exact issue!
- b) I felt the same things. I have spent hundreds of hours on research too.
- c) My symptoms also came out of nowhere last month. I'm so confused like you.
- d) I know. It infuriates me too that doctors don't know shit.

Validation takes many forms, from shared experiences of similar symptoms to not being taken seriously by society or doctors. This validation is often welcome: "I get so much support from you people. Doctors did not take me seriously and I thought I was going crazy. But after coming here I feel seen and heard for the first time. I know I am not crazy." Interactions between sufferers and the lay community are, however, not limited to expressions of empathy, but include advice regarding diagnosis and treatment.

Perplexing with Advice

Unlike doctors, lay experts are not bound by clear epistemic boundaries but offer multiple diagnoses and treatment suggestions. The sheer range of suggestions and the lack of organizing epistemic rules make it difficult for sufferers to know what suggestions to engage with and whom to trust. This problem is exemplified by responses to a post where a person asks for help:

- 1) Get tested for h pylori, SIBO, candida, etc.
- 2) This may not be reflux or vocal cord dysfunction. It may be air hunger.
- 3) It's a vagus nerve issue.
- 4) Gluten Intolerance? Perhaps have your stool tested?
- 5) Go get a bravo test or a manometry test
- 6) This may be sleep apnea
- 7) Go see an allergist

This pattern, wherein a single discussion thread the range of possible diagnoses and suggestions ranges from a food allergy to bacterial infection and new diagnostic tests repeats itself often. This range makes it difficult for the sufferers to navigate the information and implement any suggestions. In addition, lay experts' treatment suggestions can be incoherent, as shown by this (partial) list of treatments offered to a user:

- 1) Dgl licorice, slippery elm & d-limonene have been good friends.
- 2) Exercise, drink coconut water, hot showers, no spicy food, and probiotics.
- 3) Probiotics can work wonders.
- 4) I take B-complex. I eat red meat, vitamin C.
- 5) Stay alive. My GERD symptoms reduced merely because my body aged.

- 6) Get on anti-depressants they've helped me.
- 7) For me, I have said goodbye to coffee and spicy food.

Here, users suggest treatments ranging from warm showers to acupuncture, all within a single thread. Furthermore, lay experts' treatment suggestions can be contradictory since what helped one person is often interpreted negatively by others:

I see people around here telling each other to drink ACV for their reflux. What the hell is wrong with such people? I recently had 4 months of PPIs. Now I have my singing voice back and eat without fearing how it's going to mess up my throat. Don't take my word on this. Read the medical literature yourself.

"ACV (apple cider vinegar)," a popular alternative therapy, is attacked by a user who leverages medical and experiential knowledge as evidence. In response, another user extolls the virtues of ACV:

It is a good thing to share your story, but to dismiss other options based on your experience is shortsighted. I've had reflux for 8 years now. But so far, my best success is on ACV. Doctors and PPIs have failed me.

This sufferer calls the stance of the previous post "short-sighted" as they have had a different experience, providing evidence on the effectiveness of ACV while citing the original posts suggested treatment – and the gold standard – PPIs (Proton Pump Inhibitors) as a failure.

Validating Suffering and Perplexing with Advice Contribute to the Expansion of the Anxious Self

While the doctors often disregarded the sufferers' troubles, lay experts provided validation and sympathy for the sufferers. As the following post shows, these interactions encourage sufferers to trust lay community members:

Doctors have done shit for me; they just dismiss my pain. But here I finally find the support and understanding I desperately needed. It's a relief to know that I am not alone. I read your suggestions and will try them soon.

However, sufferers soon see that online community advice is riddled with complications and experience frustration in wading through this information. This contributes to the worsening of their anxiety:

The information is all over the place: A) GERD is from too much acid. No, it's from too little acid. B) ACV will help – No, it won't. Are you crazy? C) PPIs are the best treatment – No, they are dangerous drugs. D) Eat these foods./ARGH! NEVER EAT THAT! Don't eat these foods – PSSH! These foods are fine. Don't listen to those people. E) This expert is great – No, he or she is a quack; this other expert is whom you should listen to. F) This diet is the best – No, it's rubbish, you'll be sorry, try this one instead. G) This supplement is the best – No, never take that one! Try these instead!

The conflicts between epistemic positions are incommensurable ("this is the best thing," "Argh! Never eat that!") and accompanied by fearmongering from different camps ("You will be sorry if you try this," "never try this," "this is

dangerous”). This results in further anxiety as sufferers are unable to figure out what to do:

How do you go through so much information and find what is right for you? I have been trying to know the best diet for many months (...) I just get frustrated trying to make sense of it all.

This inability to choose between the conflicting suggestions feeds anxiety. This is because of the fear that choosing the wrong treatments can worsen their condition: “It’s scary because this is something that can easily turn into cancer if it’s not well controlled, but the process of trying to successfully treat it, is causing more damage.” Due to the idiosyncratic variety of lay advice, sufferers try different diagnostic tests and speculative treatments, only to spend a lot of time, money, and effort for no tangible benefits. In the following post, a sufferer describes the actions they have taken – many on the advice of the online community – and their consequences:

I visited 15 medical specialists – ENTs, GIs, Allergists, etc. I spent a lot of money on testing – Barium X-ray, pulmonary function, manometry, upper endoscopy, EKG, blood panel, etc. An insane dietary plan – Paleo, vegan, vegetarian, keto, Mediterranean, intermittent fasting, etc. I tried blanket fixes or snake oil – Reflux Reboot, Fast Tract Diet. They did nothing. Antibiotics did nothing. Prednisone – Did nothing. Lansoprazole (PPI) – Certainly, didn’t fix me (...) Nexium (PPI) – This really messed me up! Allergy medications – did nothing, Lexapro (SSRI) – did a little to help. Wellbutrin – Did nothing, Ginger – nothing. Throat coat tea – nothing, Gaviscon Advance – fucked me up!

Sufferers end up chasing multiple diagnoses and treatment possibilities to no avail. Ultimately, the benefits of being understood by the online community members wear off while the suffering remains. This drives up the anxiety about their condition and their future after they realize that lay expertise is failing them.

Similar to sufferers’ diminishing trust in professional expertise, sufferers lose trust in lay expertise after being confused by the community advice:

Don’t spend time in online communities, get off these places. I know many of you are here a lot of times. You even feel it’s doing good to you. But seriously (...) stop looking for the cure (...) It won’t happen. This hope keeps you trapped.

At this point, many sufferers recognize that searching for the “cure” from doctors or the internet online communities keeps them in an unhealthy “trap” of hope. In conclusion, after undergoing spiraling, the sufferers are disillusioned and distrustful of the capacity of expertise to solve their symptoms.

Coda: After the Spiral?

Is there an end to the *spiral*? Sufferers often exchange their experiences of coping with their symptoms, prompted by posts such as: “Since when have you been dueling with this? I’ve been dealing with this devilish disease for three years, but it feels like forever.” We observe three broad categories of responses in the community: *resigning*, *adapting*, and *mistaking*.

In *resigning*, people have been disappointed in their search for relief. They are particularly surprised at how modern medicine can fail to treat a simple reflux disease, as articulated in the following post:

With all the advances in modern medicine, you'd think they'd be able to come up with more effective treatments for Gerd. No diet, lifestyle change, or medication (or combination of medications) suggested to me by any medical professional in the over 2 decades since I've been alive has done shit for me, no matter what I do, it's always a matter of time before I'm choking and regurgitating on disgusting burning stomach acid.

People such as this sufferer have been experiencing reflux for extended periods, trying out different professional solutions with no significant improvement in their situation.

Alternatively, when *adapting*, depending on the severity of the day-to-day symptoms, sufferers learn to live with their condition, having better and worse days in the process. They try to give hope to others by highlighting the capability of sufferers to adapt:

The human brain can adapt to a lot. GERD sucks and is a crappy thing to get used to but hell some people go blind or lose their hearing and their new life becomes more normal every day. Eventually it'll just become a new lifestyle and you'll adapt.

This narrative emphasizes that sufferers will get used to the new “lifestyle” with time. Another post echoes a similar sentiment of good and bad “streaks,” where further suffering will have to be stoically absorbed: “(...) as time goes on you will have good streaks and bad streaks. Right now, I'm on a bad streak and can't really eat anything without feeling like crap.”

Finally, some people claim to find a solution that works for them, after having tried many things over a long period of time. They post about how they found a “miracle cure”:

I started taking TCAs (tricyclic antidepressants) like Amitriptyline. They are antidepressants, but they are often used for nerve pain. It was like night and day. My symptoms receded more and more, and I couldn't believe it. Honestly, typing this sounds like some sort of infomercial for a miracle cure. I can't stress enough how relieved I was, after two years of absolute hell.

But often, such reports of a “cure” are temporary. For example, the same person later writes that their “cure” became unusable:

Amitriptyline worked, but due to side effects I switched over to Nortriptyline (...) Nortriptyline did an excellent job of masking my symptoms, but after trying some trigger foods I realized I wasn't healed.

Here, after long-term usage, the sufferer comes to the realization that either they cannot continue with the “cure” or that it was simply masking their symptoms. Other sufferers also report similar experiences of temporary relief only to relapse later with other pharmaceutical agents or invasive surgery like the Nissen fundoplication. We call this narrative *mistaking*, as the sufferers often find relief only to later realize its temporariness.⁵

While there are different responses that sufferers have depending on the severity of symptoms and personal circumstances, generally, they become distrustful and disillusioned with both professional and lay expertise. Sufferers emphasize self-reliance and self-advocacy in solving their problems; they should not “just hand themselves over to the experts and hope that they will take care of everything,” but rather, “Advocate for yourself and do your own research.” They are skeptical

of both professional and lay expertise and find it difficult to immediately say that someone is “right or wrong.” Therefore, after experiencing the spiral, people are critical of any advice they receive and preach caution toward experts of all stripes:

I can't tell you if your doctor is right or wrong (...) The mechanism of action for your reflux may not be the same as everyone else's (...) and if you see someone selling a book, an app, a magical diet plan or exercise regiment, idk!!! Just be skeptical of the asshats that will steer you wrong.

DISCUSSION

This article examines the lived experiences of sufferers as they engage with professional and lay expertise. In doing so, it also sheds light on the important but understudied limits of expertise – particularly when it comes to lay expertise. To understand how the interplay of sufferers’ experience and engagement with expertise unfolds, we developed the notion of *spiraling* (see Fig. 1). This notion elucidates how the symptoms of sufferers, their subsequent dependence, and engagement with both professional and lay expertise shape their lived experience. In particular, our analysis provides a nuanced understanding of the distinct ways in which different forms of expertise shape sufferers’ experiences. We also shed light on the boundaries of expertise, specifically on the “dark side” of lay expertise. Next, we discuss these theoretical contributions in more detail.

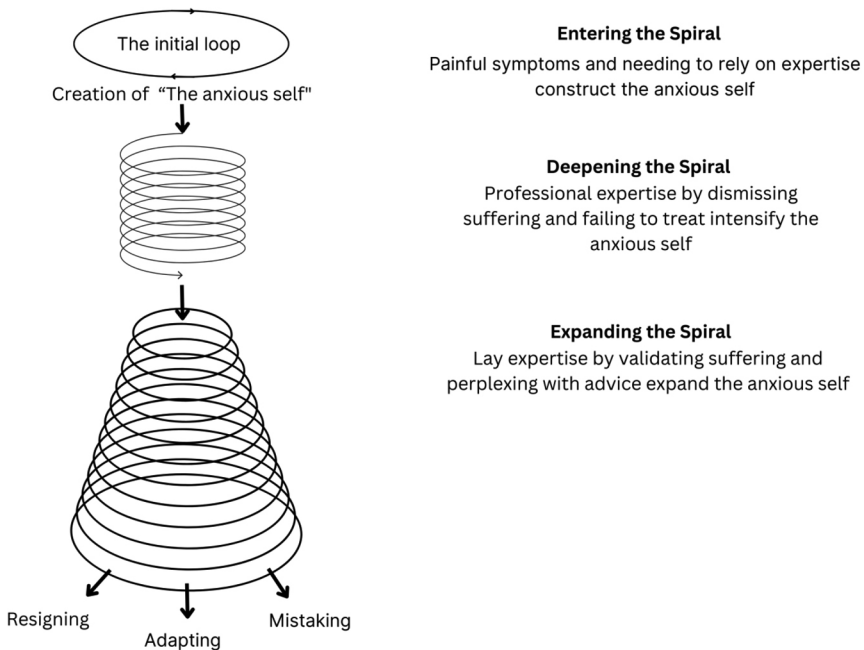


Fig. 1. The Spiral: The Co-constitution of Lived Experience Through Engagement with Expertise.

Theoretical Contributions

First, we advance our understanding of expertise by examining how laypeople utilize different types of expertise and how their lived experiences are shaped by their engagement with these various forms of expertise. Today, many people routinely engage with different forms of expertise sequentially or simultaneously (Hardey, 1999; Van Riel et al., 2017). Online communities in particular have become popular places for those seeking help and knowledge of any kind, largely due to their ubiquity and accessibility (Akrich, 2010; Au & Eyal, 2021). While the existing literature on expertise occasionally documents sufferers' experiences and perceptions, it rarely focuses on explicitly theorizing these experiences. Instead, the literature has examined issues such as how lay expertise helps sufferers in different ways (Campbell, 2021; Foster, 2016; Radin, 2006), how online platforms have changed the relationship between sufferers and professional expertise (Broom, 2005; Hardey, 1999; Trehan & Daluiski, 2016), and the incorporation of lay expertise into professional expertise (Callard & Perego, 2021; Epstein, 1995; Eyal, 2013).

Our research bridges this gap by examining sufferers who experience failure of both professional and lay expertise. This perspective is underrepresented in the literature, which often centers on sufferers' triumphs or disappointments with professional expertise (Bud, 2007; Fraser, 2021; Greenwood, 2008) or their positive experiences with lay expertise (Epstein, 1995; Petersen et al., 2020; Radin, 2006). However, such research gives us an incomplete picture of expertise and client experiences, since many personal problems remain unsolved or persist for extended periods (Charmaz, 2000; Sosnowy, 2014).

Our research suggests that individuals' engagement with both professional and lay expertise in an attempt to address their problems can actually exacerbate their anxiety. We conceptualize this lived experience as a spiral. To theorize individuals' experiences, we draw inspiration from and extend the concept of looping (Hacking, 1995, 2007). In cases such as ours, a loop can be initiated by the presence of an intractable problem that leads to a desperate search for a solution and reliance on expertise. The spiral begins as individuals become increasingly anxious about the persistence of their symptoms, their inability to access expertise, and their fear of unfavorable outcomes. While sufferers expect professional expertise to alleviate their suffering, they often fail to have their problems resolved or their emotional needs met. Thus, the spiral deepens as sufferers are let down by professional expertise. Sufferers' engagement with lay expertise may initially begin on a positive note, as sufferers may feel validated by it. However, because lay expertise is not bound by standards of evidence, the suggestions offered are numerous, difficult to understand, idiosyncratic, and often contradictory. Worse such advice often fails to provide relief, thereby contributing to the expansion of the spiraling. After experiencing the spiral, we suggest that there are broadly three types of responses that sufferers may have to their predicament: resigning, adapting, and mistaking. Going through the spiral gives rise to sufferer's skepticism regarding both professional and lay expertise, and they appear to be more self-reliant and less trusting of expertise.

We suggest such spiraling might be most likely to happen in the case of sticky and intense problems where professional or lay expertise do not have definitive tools and understandings to provide adequate relief. For example, in the field of healthcare, it can occur in cases of addiction (alcoholism, drug addiction), mental illness, chronic illness, new diseases such as long-Covid-19, and under-diagnosed women's health conditions (Au et al., 2022; Cho et al., 2019; Koob & Le Moal, 2001; Moore, 2014). More broadly, personal problems in areas ranging from law and taxation to house renovation and personal finance could have the potential for spiraling.

Second, our study contributes to understanding the dynamics between professional and lay expertise as well as the limits of expertise. The literature has shown the complementary nature of professional and lay expertise, for example, AIDS sufferers who wanted early access to potentially life-saving treatments were helped by lay activism (Epstein, 1995). Lay expertise can also contribute to knowledge when appropriate professional expertise is lacking (Wynne, 1996) and provide experiential, moral, and emotional support that professional expertise may fail to deliver (Radin, 2006; Rushforth et al., 2021; Schrock et al., 2004). In our case, sufferers engage with professional and lay expertise but are often let down by *both*. Our research shows that instead of being mutually beneficial, professional and lay expertise can be mutually detrimental and have compounded negative implications for sufferers. We emphasize the importance of future research in this area to determine how professional and lay expertise fails in myriad ways and what the consequences are for those who seek expertise. Knowing the limits and harms of expertise will allow us to potentially minimize suffering by possibly filling the gaps in the dispersion and consumption of professional and lay expertise. When considering the limits of expertise, it is important to acknowledge that there will always be cases where expertise fails (Buckwalter, 2016; Dismukes et al., 2007). Similar to our case, medical professionals can often face challenges in adequately addressing common diseases, leading to patient distress. Sometimes they deal with this inadequacy by gaslighting patients' lived experiences, shutting them out, or connecting symptoms to anxiety or hypochondria (Au et al., 2022; Fraser, 2021). This can result in patients feeling invalidated or ignored, fostering mistrust toward experts, and potentially leading to abandoning expertise. To retain trust, we suggest that professionals need to acknowledge their limitations, manage expectations, and develop behavioral skills (Hawley, 2015; Teutsch, 2003) to ensure patients feel acknowledged and understood. Recognizing and validating patient suffering, regardless of diagnosis (or the lack of one), could broaden the scope of expertise and mitigate its limitations by keeping patients engaged. Additionally, professionals can improve patient care by being transparent about the limitations and potential inefficacy of standard treatments, thereby setting expectations upfront to prevent further distress when treatments fail. Finally, engaging with online community discussions can provide insight into patient experiences and how sufferers use online resources and lay expertise. This knowledge can help professionals communicate more effectively with patients, build trust, and even prevent harmful self-diagnosis and treatments (Teutsch, 2003).

Even without a cure, professionals can alleviate suffering by empathizing with patients, recognizing their suffering, maintaining open communication, and helping them navigate their health issues. This is how the spiral could be made more tolerable.

Third, we also contribute to understanding the potential dark side of lay expertise by demonstrating how engaging with lay expertise can be detrimental to sufferers. To date, the critical views of lay expertise have been mostly focused on the ways lay actors encroach on professional jurisdictions or how lay knowledge might “dilute” institutionalized expertise (Collins et al., 2023; Prior, 2003). However, understanding the possible limits of lay expertise is important because of the increasing ubiquity and normalization of engagement with it (Epstein, 2023; Hardey, 1999; Kerr et al., 1998; Lamas et al., 2016).

Unlike professional expertise with defined epistemic boundaries and established practices (Abbott, 1988; Freidson, 2001), lay expertise lacks such constraints. While the broad spectrum of alternative practices, personal experiences, idiosyncratic perspectives, and values can be the strength of lay expertise (Bains, 2008; Campbell, 2021), our findings show this “mix” can also have consequences for sufferers. Specifically, the detriment to sufferers begins, counterintuitively, when lay expertise initially provides validation and recognition to sufferers (Callard & Perego, 2021; Radin, 2006). This leads the sufferers to seek help on core professional tasks, such as diagnosis and treatment, from lay experts who offer contradictory advice that significantly diverges from professional standards (Akrich, 2010; Pols, 2014; Wezyk et al., 2023). These suggestions may rely on idiosyncratic, personal experiences, making them difficult to make sense of and costly to act upon. As our findings show, such suggestions often fail to provide relief to sufferers and end up adding to the misery. Therefore, the very things that make lay expertise valuable to sufferers, such as their validation of the suffering and the broad collection of knowledge based on personal experience and research, are the same things that can harm sufferers. These findings contrast with previous literature on advice seeking in online health communities, where sufferers find many positive benefits, including emotional support, community, tacit, and explicit knowledge in such communities that give them dignity, legitimacy, and a voice (Akrich, 2010; Au & Eyal, 2021; Foster, 2016).

Finally, our findings may provide an interesting lens for exploring the so-called “crisis of expertise” (Eyal, 2019; Heimstädt et al., 2024; Nichols, 2017). This phenomenon that captures the increasing – and to an extent, prevalent – distrust of science in the general public, is often seen as a macro-sociological phenomenon. Here, scrutiny and denial of expert advice are primarily driven by forces such as polarization (Reed & Reed, 2023), populism (Brubaker, 2017), or politicization of science (Eyal, 2019). However, such sweeping forces should also be grounded in understanding “what people do, say and think in the actual flow of momentary experiences” (Collins, 1981, p. 984). Looking at the narratives of sufferers’ experiences suggests that the broader mistrust of expertise can be rooted in the suffering of individuals and negative interactions with professional expertise which are then onward mediated by engagement with lay communities. Modern online lay communities bolstered by algorithmic

recommendations (see [Seaver, 2022](#)) might be particularly powerful breeding grounds for macro-narratives that challenge credentialed expertise since they allow people with similar experiences and emotional registers ([Collins, 1981](#)) to come together. Notably, they can do so with less regard for time and space compared to traditional forms of lay activism that were more geographically and culturally bounded (e.g., [Wynne, 1996](#)). However, as our study focuses explicitly on sufferers' experiences, we suggest further research is needed to understand the connections between lay communities and the crisis of expertise.

It's important to note that online community moderation plays a pivotal role in shaping the discourse within these communities ([Roose, 2024](#)). While moderation can uphold institutional positions, it may inadvertently suppress discussions on experimental and alternative practices ([Au & Eyal, 2021](#); [Campbell, 2021](#)). This highlights the double-edged sword of moderation: it can both protect and limit. On one hand, unregulated forums can become breeding grounds for harmful advice and misinformation ([Scheufele & Krause, 2019](#)). On the other hand, moderation could stifle dialog and peer support, potentially driving users to seek out less restrictive platforms ([McAllen, 2024](#)). Overly restrictive platforms may deprive users, many of whom are not bad faith actors, but individuals facing genuine problems, of validation, hope, and potential solutions. Therefore, the challenge lies in striking a balance between regulation and freedom of expression. Thus, future research should explore the effects of moderation, especially the nuanced pros and cons, not based on normative ideals, but on users' experiences. Ultimately, we believe the goal should be to create online spaces that are safe while being conducive to the free exchange of ideas.

In summary, our research expands the understanding of expertise and its impact on those who engage with it, shedding light on the complexities, complementarities, and detrimental aspects of different expertise forms. We examined the lived experiences of sufferers, especially when expertise fails, providing theoretical underpinnings for this critical aspect of expertise engagement. Our findings also challenge the prevailing narrative of lay expertise and emphasize the need to consider the boundaries of expertise, including the dark sides of lay expertise.

NOTES

1. The [Oxford English dictionary \(2023\)](#) defines a "sufferer" as someone "One who suffers pain, tribulation, injury, wrong, loss, etc.; one who suffers from disease or ill health." We use the term to describe the users of the platform who discuss their illness. We do not call them patients since the sufferers can be denied this categorization or may inconsistently engage with healthcare professionals. Our understanding of suffering is further inspired by social theorist Andrew [Sayer \(2011\)](#), who writes (p. 42): "A key characteristic of pain and suffering is that they are not merely states of being, but of frustrated becoming, or continuous yearning for relief and escape."

2. The users of the platform are not "participants" of our study and data is naturally occurring archival data. We obtained ethics approval for the research project from an institutional ethics review board.

3. The community has guidelines about appropriate conduct on the platform. Low effort, gruesome, or promotional posts are highly frowned upon. Instead, detailed narratives and

constructive exchanges are promoted. While the new moderation rules say that no alternative medicine or diagnosis posts are allowed, such posts are rampant. The lay experts usually qualify their advice with (e.g., “I am not a doctor, and this is just my experience so take it with a grain of salt”) to dodge responsibility or moderation.

4. We do not seek to make any epidemiological claims about reflux disease. Rather, in line with a lot of sociological and anthropological research in health and illness, we seek to illuminate the experiences on those (often marginalized) groups that do not experience having their needs met.

5. We do not mean to claim no sufferers find permanent relief. However, mistaking is a common experience of sufferers after the spiral and may eventually lead to other pathways such as adapting or resigning.

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