Expert Patients and Networks of Expertise and Ignorance

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Abstract

Patients with rare or understudied diseases often encounter a lack of medical answers about diagnosis or treatment and might seek new ways to obtain answers. The conceptual framework of "networks of expertise" helps analyze such encounters with a lack of medical answers as situations of medical ignorance, which are not necessarily accidental and have been shown to reflect the bias and organization of related networks of expertise. In this context, the paper analyzes and compares public narratives of patients' experiences and suggests three possible patient strategies for responding to the lack of answers. These strategies include establishing external ties with experts and non-experts outside of one's healthcare teams, engaging with patient organizations to affect medical research, and engaging with online communities as an alternative or supplementary network of expertise. In all three cases, patients' efforts are both epistemic and organizational, seeking to (re)shape broader networks of expertise so that they are more likely to generate answers. These organizational dimensions of patients' knowledge production work can be overlooked by the debates on "expert patients" and the relationship of patients' expertise to that of credentialed experts.

Keywords: Patient Narratives, Expert Patients, Networks of Expertise, Ignorance, Rare Diseases, Understudied Diseases

Introduction

The lack of medical answers about diagnosis or treatment is a common problem for patients with rare and understudied diseases. It might take years before patients with, for example, rare genetic disorders receive their correct diagnosis (MacLeod et al., 2015). Many of these patients are children, and their condition is often serious or life-threatening; few of these conditions have curative (or any) pharmacological treatment (Cahan, 2018). Whether their condition is genetic or not, patients or parents of pediatric patients facing a dire health situation and no adequate answers might have to become experts in their condition. In some cases, they might also have to educate doctors, as when a patient is admitted to an emergency room (E.R.) or meets new doctors who lack knowledge about their condition, medications, and side effects (MacLeod et al., 2015; Petersen, 2006). In the words of Mary Dunkle from the National Organization for Rare Disorders, these are "ordinary people who are doing remarkable things because they are suddenly faced with a life-or-death situation" (quoted in Goldberg, 2017).

This paper focuses on patients' responses to the lack of answers about diagnosis or treatment—medical ignorance—in the context where the stakes for getting adequate answers are exceptionally high. Ignorance and its production are important areas of research in science and technology studies (Mills, 2007; Proctor and Schiebinger, 2008; Sullivan, 2007; Sullivan and Tuana, 2007; Tuana, 2006). Much of this research, including my earlier work, points to broader, structural conditions for the production of ignorance (Kuchinskaya, 2014; Kuchinskaya and Parker, 2018). In other words, ignorance is not just a matter of the temporary lack of answers but, more importantly, a result of the broader conditions of knowledge production. Systematic production of areas of ignorance reflects general preferences and biases in how research is done and by whom, and what is funded and prioritized, and who is affected by under-researched conditions. If ignorance can result from systemic challenges of knowledge production, how might it be addressed by individual patients who encounter a lack of medical answers about their diagnosis or treatment?

To address this question, I outline and compare three possible patient strategies seeking to remedy such failure of knowledge production. I focus on exceptional cases of patients who actively engaged with their health care and developed high levels of expertise—often referred to as 'expert patients' (Anampa-Guzmán et al., 2022; Dumit, 2012; Fox and Ward, 2006; Fox et al., 2005; Shaw and Baker, 2004; Tyreman, 2005; Wilson, 2001). I analyze these patients' responses to situations of medical ignorance through the theoretical lens of 'networks of expertise' (Eyal, 2013: 2). Scholars in science and technology studies (STS) have long debated the nature of expertise, including scientific expertise and its relationship to lay knowledges (Collins and Evans, 2002; Kerr et al., 2007; Wynne, 2003). If we adopt the perspective of networks of expertise, expertise can be understood as not simply belonging to experts, medical or lay; rather, it is distributed in broader networks. Patients' encounters with areas of medical ignorance are consequently encounters with medical networks that fail to produce knowledge about diagnosis or treatment that

appears adequate and actionable from patients' embodied perspective. Furthermore, this paper suggests that expert patients' efforts to find answers are simultaneously organizational efforts reshaping relevant networks of expertise.

The paper compares three patient narratives (Segal, 2007) offered by expert patients with rare or understudied diseases. In all three cases, there is more to accounts of expert patients than patients seeking out doctors who can provide answers or increasing their own expertise, thereby becoming scientific experts. These accounts demonstrate organizational efforts affecting the composition of relevant networks of expertise. Comparing these cases reveals three different strategies adopted to affect networks of expertise and the different network configurations that result from these strategies.

Conceptual framework: from 'expert patients' to 'networks of expertise'

Expert patients

Experiencing a lack of medical answers can provide a strong impetus for patients and their families to get more actively involved in their health care. Whether they actually get involved, and what that involvement looks like, depends on many factors, such as resources, skills, competencies, and their health condition. Facing significant challenges, some patients do get involved and even develop a significant level of expertise in their condition. As mentioned above, studies have described them as expert patients but also 'informed patients' (Henwood et al., 2003; Kivits, 2006), 'active patients' (Heldal and Tjora, 2009; see also Gottlieb, 2021; Prainsack, 2017), or, as one clinical scientist writing for a popular audience puts it, 'smart patients' (Topol, 2015). These terms have been used in studies of people with chronic diseases, where patients have to do much of the work, and in studies of patients' use of information technologies.

Critics of the term 'expert patients' pointed to the difference between patients' experience based-understanding of their condition and doctors' education-based expertise (Badcott, 2005; Tyreman, 2005). They argued that the power

dynamic between patients and doctors leads patients to adopt medical terms and overlook broader societal conditions contributing to their health problems (Barker, 2008; Fox and Ward, 2006; Fox et al., 2005; see also Gottlieb, 2021). At the same time, sociologist of science Harry Collins, who sought to defend the special status of scientists compared to lay experts, made a special provision for "small numbers of initially ordinary people [who] can become scientific experts… through… experience of chronic disease" (Collins, 2014: 132). For Collins, these "experience-based experts" have "knowledge about the treatment of those diseases that compares or even exceeds that of their doctors" (Collins, 2014: 64).

Several STS scholars have specifically examined patients' contributions to medical knowledge production, including in contexts where there are no readily available answers. This research offers multiple accounts of patients and patient groups integrating experiential and credentialed forms of knowledge and influencing research (Akrich et al., 2013; Callon and Rabeharisoa, 2008; Epstein, 1995; Kuchinskaya and Parker, 2018; Rabeharisoa et al., 2014; see also Caron-Flinterman et al., 2005; Serrano-Aguilar et al., 2009). As Jeannette Pols (2014: 77) observed for patients with lung emphysema, a chronic and severe disease, patients with such complex chronic diseases are "'medically socialized,' meaning that medical practices and knowledge form an integral part of their experience". Taking patients' contribution to knowledge production seriously, Annemarie Mol (2008: 54, 65) advocated the ideal of "shared doctoring", a way for patients and doctors to "experiment, experience and tinker together."

This paper contributes to the STS discussion of the knowledge production undertaken by patients, including those who experience a lack of medical answers (e.g., Dumit, 2006). Earlier STS research documented lay contributions to medical knowledge production and offered an interpretation of medical expertise as relational, negotiated, and contested. Particularly relevant are Steven Epstein's (1995) classical research on 'lay expertise' and more recent studies on patients' evidence-based activism and approaches to knowledge production (Akrich et al., 2013; Callon and Rabeharisoa, 2008; Jansky, 2023; Kuchinskaya and

Parker, 2018; Rabeharisoa et al., 2014). This paper contributes to this discussion by explicitly relating medical ignorance — a lack of adequate and actionable answers as experienced by patients — to the organization of networks of expertise. The paper demonstrates that the efforts of individual expert patients to generate knowledge about their disease involve organizational work that affects networks of expertise. The broader focus on networks of expertise rather than the individual expertise of specialists or expert patients allows us to compare and analyze patients' approaches to reshaping these networks and to consider the composition of resultant networks.

Networks of expertise

My approach here builds on STS recognition of 'social worlds' that contribute to producing particular types of knowledge and typically include actors whose contributions are not credited. Social worlds depend on particular institutional and material arrangements, tools and devices, classifications, and conventions (Clarke and Star, 2008). Howard Becker provided an influential description of 'art worlds,' pointing out that the production of art depends not just on artists but also on the participation of much broader groups, such as viewers, critics, and various supporting occupations, as well as specific material arrangements (Becker, 2008). For Becker, social scientists' narrow focus on professionals in the arts ignores vast areas of activity of the support personnel and audiences essential to the production of art yet deemed "unimportant or inconsequential" (Becker, 2002: 343; see also Gopnik, 2015). He emphasized the interdependence of the contributions of various actors, the material conditions of this collaborative work, and the role of conventions.

Gil Eyal (2013) offers a similar perspective in the context of the production of medical knowledge. Eyal focuses on expertise rather than experts, proposing a distinction between the two: "on the one hand, the *actors* who make claims to jurisdiction over a task by 'professing' their disinterest, skill, and credibility and, on the other hand, the sheer *capacity* to accomplish this task better and faster" (Eyal, 2013: 869, italics in the original). Medical expertise, then, is not something that is limited to doctors or researchers: it is distributed

in networks "linking together agents, devices, concepts, and institutional and spatial arrangements" (Eyal, 2013: 863). Experts and expertise are not reducible to each other. Indeed, in some contexts where patients might become significantly involved in the process of treatment and research, doctors "may lose jurisdiction, but the network of medical expertise is extended via generosity and dialogue" (Eyal 2013: 976).

Gil Eyal's analysis thus frames the production of medical knowledge as essentially a question of *maximizing expertise*, which depends on the whole network of expertise. This comprises not just experts but patients and other non-experts, as well as "mechanisms by which their cooperation has been secured," tools and devices used, and standards, conventions, and institutional arrangements enabling various contributions (Eyal, 2013: 871). From this perspective, the lack of medical answers faced by patients with rare and understudied diseases is a matter of the organization and functioning of broader networks of expertise.

This paper contributes to broadening conceptual interpretation of the work done by expert patients, demonstrating high levels of expertise and engagement in their health care. The three examples below illustrate that the efforts undertaken by these expert patients in response to the experience of medical ignorance are not exclusively epistemic but also organizational. This organizational dimension does not receive enough attention in the context of research on patients' expertise; the term expert patients tends to emphasize individual levels of knowledge and engagement. As this paper demonstrates, focusing on these patients' organizational efforts in the context of broader networks of expertise provides a way of analyzing and comparing their composition, affordances, and limitations.

Analyzing public narratives of expert patients and the question of medical ignorance

This research was prompted by my encounters with people who had understudied and rare diseases and described their experience of searching for a diagnosis and dealing with the lack of answers. Following my work with an undergradu-

ate student who analyzed her own "journey to diagnosis," I began collecting publicly shared narratives describing patients' experiences of dealing with the lack of answers. A number of them were shared by colleagues, acquaintances, and family members who dealt with undiagnosed, rare, or understudied health conditions and used these accounts to develop a perspective on the situation and their course of action. My particular interest was in stories where patients were willing and able to be actively involved in searching for answers (I include parents of pediatric patients under the term "patients"). In other words, these stories could be described as accounts of people who became expert patients since they developed an unusual degree of expertise and involvement in their health care. These accounts are unlikely to illustrate the typical responses from patients because they described people able to mobilize access to relatively high levels of resources to enable their efforts. They are more likely to be "extreme cases" of patient involvement (Flyvbjerg, 2001: 78).

When analyzing the collected accounts, including the three described in more detail here, I focused specifically on descriptions of networks of expertise and the work done to affect them. I used grounded theory to generate the main themes (Charmaz, 2006; Corbin and Strauss, 1990; Glaser and Strauss, 2017). The three accounts I describe below illustrate these themes, describing different ways of addressing medical ignorance (I return to other examples of patients' search for answers in the discussion). Comparative analysis of these responses points to three different strategies and networks of expertise. These are not the only three ways possible.

The three cases are: (1) Jill Viles, who self-diagnosed her two rare genetic conditions; (2) Sharon Terry, who dealt with her children's rare genetic disorder; and (3) Jennifer Brea, who suffered from an understudied yet relatively common autoimmune condition. Viles told her story in a TEDx talk "about the journey of searching for medical answers at the extremes of biology" (Viles, 2016b, see also 2016a), yet her story gathered much attention after David Epstein's article in *ProPublica* and episode of *This American Life* (Epstein, 2016a, 2016b). Viles's and Epstein's versions are closely

aligned, though my analysis foregrounds Viles's first-person account. Terry's TED talk, "Science didn't understand my kids' rare disease until I decided to study it," has been viewed close to 1.5 million times (Terry, 2017, see also 2015). Jennifer Brea's TED talk, "What happens when you have a disease doctors can't diagnose," has been viewed more than 2.4 million times (Brea, 2016). Brea also described the same experience in the award-winning documentary *Unrest*, available on Netflix (Brea, 2017).

I approach these narratives as an example of patient narratives as public rhetoric (Segal, 2007). Just as medical knowledge is necessarily the production of networks of expertise rather than isolated individual experts, the narratives I analyze are likely to reflect the work not just of particular patients but other uncredited individuals, including, for example, various TED personnel. Indeed, patient narratives as media-circulating public rhetoric are likely to downplay the shared, networked effort on several levels: by making invisible the contributions of media support personnel along with their tools, conventions, and infrastructures; by emphasizing an individual "hero's journey" in the traditions of media storytelling; and overemphasizing the roles of human actors while barely commenting on media, sociotechnical, and infrastructural conditions. By reading the selected expert patient accounts through the lens of networks of expertise, this paper calls attention to what is generally downplayed by these representational strategies. Furthermore, comparing these accounts reveals different strategies for reshaping networks of expertise.

The value of these accounts is that, though highly produced, they are presented from a particular situated and embodied position, and, as such, they offer a kind of 'situated knowledge' (Haraway, 1988: 575; Halpern, 2019). Patients' struggles to find medical answers are at the core of these public narratives. These patients' perspectives are critical because a lack of medical answers is experienced most acutely by patients. In other words, it is a matter of positionality. As the examples below illustrate, while many rare diseases have a generally acknowledged lack of answers and treatments, other conditions—such as chronic

fatigue syndrome or ME—are described by a more complex state of knowledge/ignorance. CFS/ME is more prevalent in women, and commentators note the gendered nature of many understudied conditions, including autoimmune ones (e.g., Cleghorn, 2022; Tuana, 2006). Earlier STS writing described systematic issues with the production of knowledge and challenges experienced by individuals with CFS/ME (Dumit, 2006). Their suffering can be downplayed or explained away as psychological and irrational. What is adequate knowledge from some perspectives might appear as ignorance from the perspectives of people whose suffering is downplayed or systematically ignored in the context of institutional priorities or research agendas (Kuchinskaya and Parker, 2018; Mills, 2007; Sullivan, 2007; Sullivan and Tuana, 2007; Tuana, 2006). The situated, perspective-dependent assessment of areas of medical ignorance calls for the closer analysis of public narratives of patients who speak of their experience with the absence of medical answers and pathways to finding solutions.

The following section provides a summary and analysis of the narrative accounts from Jill Viles, Sharon Terry, and Jennifer Brea.

Findings

Stories of searching for diagnosis and treatment offered by Jill Viles, Sharon Terry, and Jennifer Brea can be read as describing their efforts to develop their own expertise and even conduct their own research. However, they also describe different aspects of seeking to affect networks of expertise.

These accounts represent different historical moments and different approaches to dealing with the absence of medical answers and attempting to affect networks of expertise around a particular disease. Viles's account describes her research in the 1990s, does not refer to the use of new media, and emphasizes Viles's personal search for answers, which still involved reconfiguring some networks of expertise. Terry faced her children's diagnosis in the mid-1990s, but her work is still ongoing. Here the focus is on traditional patient organizing and capacity-building, which I argue below, is also a way of rebuilding networks of expertise (indeed, Terry's TED talk appears to be

an instrumental part of that work). Brea's account documents a search for answers that began more recently. Her narrative refers to online communities, offering, I argue, yet another approach to (re) shaping networks of expertise (Brea's accounts are also part of her advocacy, as I discuss below). Despite their different historical moments and approaches, all three narratives point to some gendered dynamics, including less research about health conditions more prevalent among women and the caregiving roles performed by women (e.g., Cleghorn, 2021; Tuana, 2006).

The following sections summarize the accounts and then reflect on the networks of expertise in each case and efforts to affect these networks.

Jill Viles: One patient's search for answers as network-building

Jill Viles's account, offered in her TEDx talk and as presented by journalist David Epstein (2016a, 2016b; Viles, 2016b), emphasizes the lack of medical answers she faced about her condition and her search for a diagnosis. Her research and insights, the story goes, were at times forcefully dismissed but then repeatedly confirmed by experts. Viles and Epstein offer the following account. Her problems began when, as a young child, she started falling and having difficulty walking. Her father had similar experiences when he was a child, but it was thought to be a mild case of polio. At age 12, Viles lost the ability to ride her bike or skate. Around that time, Viles, her father, and her brother were each diagnosed with muscular dystrophy, but she was the only one constantly falling. She also had unusually little fat accumulation on her hands and legs. Doctors, including experts from the high-profile Mayo Clinic, could not explain any of it.

Frustrated with the lack of answers, Viles studied genetics in college. She also methodically combed through research on muscle dystrophy, eventually finding an article on a rare condition called Emery-Dreifuss. The photos in the article reminded Viles of her own and her father's physique. However, her self-diagnosis was dismissed by a neurologist she consulted. She eventually wrote to researchers in Italy who studied families with Emery-Dreifuss, searching for the underlying gene mutation. The Italian researchers had only found four families

and asked for DNA from Viles and her family. Four years later, in the mid-1990s, Viles received the confirmation of her self-diagnosis.

Viles's story doesn't stop there. While working as an intern in a lab, she found references to another rare condition, partial lipodystrophy, disrupted fat accumulation on parts of the body, especially limbs. She approached specialists at a medical conference at John Hopkins, but they insisted she did not have it. Discouraged, Viles stopped her research. She resumed it only 12 years later, after she got married, had a son, and lost her ability to walk when her son turned one.

The resumption of her research was prompted by Viles's sister, who showed her the pictures of the Canadian athlete, sprinter Priscilla Lopes-Schliep. Lopes-Schliep seemed to be missing fat, though her muscles, unlike Viles's, were incredibly pronounced. Viles suspected that Lopes-Schliep had a different manifestation of the same rare disease. Viles hoped that studying them together might explain why Lopes-Schliep had such developed muscles while Viles suffered from muscle dystrophy. Lacking a way to contact Lopes-Schliep, Viles wrote to the journalist David Epstein after hearing him talk about his book *The Sports Gene*. After Viles captured his attention and proved her expertise to him, Epstein contacted Lopes-Schliep through her agent. It took another year to find a doctor to test Lopes-Schliep; Viles eventually approached a leading specialist on lipodystrophy at a medical conference. The specialist performed genetic testing and confirmed Lopes-Schliep's lipodystrophy.

On the one hand, this is an account of nearly heroic efforts and Viles's personal abilities, determination, and tenacity. Viles could be described as a quintessential expert patient who develops extraordinary personal expertise and insight. However, it is also an account of network-building. Specifically, it illustrates Viles's efforts to establish connections with specialists outside her healthcare team and with non-experts whose contribution would be crucial. Viles contacted researchers in Italy who did genetic research on Emily-Dreifuss, interned at a lab, and approached lipodystrophy specialists at a conference at Johns Hopkins and then another specialist who agreed to test Lopes-Schliep. She also had somebody

help her collect blood samples to send to the Italian researchers (since blood samples were not ordered by a doctor and could not be collected in the Italian researchers' lab). She reached out to Lopes-Schliep, another patient with a different manifestation of the same rare condition, and also sought the help of a journalist (David Epstein) in securing this contact through Lopes-Schliep's agent.

Viles's engagement with the network of expertise around her case was limited to seeking and developing informal "external relations" with specialists outside of her immediate healthcare team (Heldal and Tjora, 2009) and with various non-experts who provided critical support. Nevertheless, Viles's efforts at conducting her own research and network-building—making connections with experts and non-experts—benefitted not only her but also others around her, including her father and Lopes-Schliep; it also changed at least one scholar's research agenda (Epstein, 2016b). According to Epstein's account, Viles's diagnosis of Emery-Dreifuss for herself and her father suggested cardiac problems, which her father was indeed experiencing, and Viles's insistence that a cardiologist see him likely extended her father's life (Epstein, 2016b). Lopes-Schliep received an important warning from the lipodystrophy specialist who did her genetic testing: he discovered that the athlete had dangerously high levels of fat in her blood, despite missing fat in her limbs.

One might observe that Viles's search for answers was both enabled and constrained by her position as a patient. On the one hand, her insights were repeatedly dismissed by experts. A neurologist Viles approached with an article about Emery-Dreifuss disease and later the experts at the Johns Hopkins conference found it hard to believe that Viles could diagnose herself with a rare disease or even two rare diseases. The readers' comments on Epstein's article indicate that this experience of one's insight being dismissed is not unusual for patients with rare diseases. On the other hand, as Epstein puts it: "A person with a rare disease in their family will often have seen more cases and different manifestations of the disease than any doctor has" (Epstein, 2016b). In cases like this, patients and their insights appear poorly incor-

porated into established networks of expertise around these rare diseases. Indeed, Viles stopped her work for 12 years after being dismissed by the Johns Hopkins conference experts, spent a year looking for ways to contact Lopes-Schliep, and another year looking for a specialist who would test her. Viles's narrative thus gives a sense of the time lost due to working from the marginalized position of a patient as a knowledge contributor within these networks of expertise.

At the same time, while Viles's narrative points to these challenges or limitations of the underlying networks of expertise, her efforts did not seek to address the organization of these networks. Rather, Viles effectively expanded them by developing new, informal, personally based connections with outside experts and relevant non-experts who brought their knowledge, experience, institutional resources, and tools (such as taking blood samples or conducting genetic analysis). The two examples below illustrate other strategies based on joining forces with other patients.

Sharon Terry: Organizing to transform old systems

Sharon Terry's TED talk (2017, see also 2015) describes the search for answers that started for her and her husband, Patrick Terry, in 1994, after their children were diagnosed with pseudoxanthoma elasticum (PXE), a systemic, slowly progressing rare genetic disease that causes premature aging and ocular, cardiovascular and other complications. This section summarizes Terry's narrative account and then analyzes the knowledge production work it describes, including the work of developing their own expertise and research and reshaping broader networks of expertise around PXE.

Terry was concerned about the rash on her daughter's neck, which their doctor dismissed as nothing. Terry took her daughter to a dermatologist "without a referral and paying out-of-pocket." The dermatologist diagnosed her daughter and her son, who was with them, with PXE (Terry, 2015). However, doctors had few treatment answers for them as little was known about the disease. Later, the family was approached by researchers studying PXE, asking permission to

sample of their children's blood. The Terrys noted a lack of cooperation among the different teams of researchers: other groups also sought to draw their children's blood rather than sharing samples among themselves. The lack of collaboration did not stop there:

> Pat and I went to the medical school library, and we copied every article we could find about PXE. We didn't understand a thing. We bought medical dictionaries and scientific textbooks and read everything we could get our hands on. And though we still didn't understand, we could see patterns. And it became quickly apparent within a month that there was no systematic effort to understand PXE. In addition, the lack of sharing that we experienced was pervasive (Terry, 2017).

In response, Terry and her husband sought to "collect blood and medical histories [of patients with PXE], and require that all scientists using these resources would share results with each other and with the people who donated" (Terry, 2017). They also established PXE International, a nonprofit dedicated to researching PXE and supporting individuals with the condition. PXE International obtained blood, tissue, and medical histories from more than 100 patients worldwide and eventually found more than 4,000 people with the disease.

Still, Terry and her husband also thought that "shared resources was not going to be enough" and decided to do "hardcore research" themselves, borrowing space from a lab at Harvard, where the postdocs tutored them on how to extract DNA and search for the gene. After a few years of work, they found the gene and "patented it so that it would be freely available" (Terry, 2017). They also created a diagnostic test, conducted clinical trials, and convened a research consortium and patient meetings.

Later, Terry and her husband sought to extend their work by joining Genetic Alliance, "a network of health advocacy, patient advocacy, research and health organizations" (Terry, 2017). In Terry's own words:

> [A]s I learned about all those diseases and all those disease communities, I realized that there were two secrets in health care that were impacting me greatly. The first: *there are no ready answers for people like my kids or all the people I was working with, whether common or rare conditions*. And the second secret: *the answers lie in all of us together*, donating our data, our biological samples, and ultimately ourselves. (Terry, 2017, italics added).

Terry became the president and CEO of Genetic Alliance, making her a leader in the patient advocacy community. Among other things, Genetic Alliance provided infrastructure—the Platform for Engaging Everyone Responsibly (PEER)—for connecting patients and researchers. Genetic Alliance explicitly worked to "transform" old systems where "entities won't share data—data that comes from people who gave their energy, their time, their blood and even their tears" (Terry, 2017). Terry also argued for including and valuing patients' contributions to and knowledge production: "We're part of this system, too. How do we make it so that people can share ideas freely?" (Terry, 2017).

Terry's account is a public testimonial that explicitly connects the lack of medical knowledge about PXE to problems with the organization of networks of expertise around it: the lack of cooperation among researchers and the insufficient inclusion of patients. It is an explicit reflection on how networks of expertise are organized and the role of patients in them, effectively presenting the problem of knowledge production as a problem of organizing.

Nevertheless, Terry and her husband could still be described as quintessential expert patients who achieved exceptional levels of personal expertise and even conducted their own "hardcore research." Just as Viles's research effort required establishing new connections, Sharon and Patrick Terry's knowledge production work arguably required network building: people and institutions had to be approached to gain access to a lab at Harvard and obtain training in how to perform genetic analysis. However, learning to conduct "hardcore research" is more than establishing external connections. It is about becoming integrated into related networks of expertise, which comes with learning to use the equipment and understand the conventions of that practice (Becker, 2008: 57) and, as Terry did, successfully publishing the results of that research — that

is, participating in the defining activities of the network of expertise.

However, Sharon and Patrick Terry's efforts to find adequate understanding and treatment of PXE consistently went beyond their own research. They explicitly sought to change the underlying competition-focused conditions of academic research around PXE and to create conditions that would promote more sharing and patient-centeredness. To that end, Sharon and Patrick Terry began by finding other patients with that rare disease, collecting their samples and data, and making their data collection both a benefit for researchers and a way to incentivize more collaboration and sharing. Terry also joined forces with other patients by establishing a patient organization and then joining a larger one, effectively changing their institutional position vis-à-vis researchers.

Through their collective effort, Sharon Terry and her collaborators at Genetic Alliance could then be said to affect networks of expertise around PXE and other rare diseases in at least two ways: by including more patients and remediating access to these patients' data. The latter included the design of the PEER platform and its later incarnations, which sought to increase researchers' access to patients with rare diseases, incentivize researchers' greater collaboration, and allow patients to "come together" to better advocate for their interests.

In sum, Terry's account is an example of reshaping the organization of networks of expertise around a rare condition by joining forces with other patients, changing their institutional position vis-à-vis researchers, and reshaping researchers' access to patient data by developing a new platform. Terry provides a quintessential example not only of an expert patient but also of a leader in patient organizing, with a career that spanned over 25 years (Frischen, 2020).

Jennifer Brea: "Online we came together"

While Viles's and Terry's children were diagnosed in the mid-1990s, Jennifer Brea describes a more recent struggle with obtaining a diagnosis and treatment. The first part of Brea's TED talk and her documentary *Unrest* tells a story of Brea's journey to diagnosis. It begins as a story of a 28-year-

old Harvard Ph.D. student, about to get married, whose one infection was followed by extreme fatigue, more infections, and then neurological, cardiac, and gastrointestinal symptoms. She became bedridden and went from one specialist to another, though they could not find anything wrong. A neurologist diagnosed Brea with "conversion disorder," which, as Brea points out, is a modern equivalent of hysteria (Brea, 2016). The diagnosis questioned the reality of Brea's illness, suggesting that all of Brea's symptoms, including infections, were caused by distant trauma or recent stress. The lack of answers made Brea think she "had a rare disease, something doctors had never seen." Then she "went online and found thousands of people all over the world living with the same symptoms, similarly isolated, similarly disbelieved" (Brea, 2016, 2017).

Brea found emotional, practical, and informational support in an online community of sufferers of myalgic encephalomyelitis, commonly known as chronic fatigue syndrome, ME/CFS. These interactions helped Brea understand her own condition better. With the help of her online community, she also found specialists who confirmed the diagnosis. After being prescribed antiviral drugs, she was able to walk again. Brea stresses the value of the online community as a place of knowledge production:

> Online we came together, and we shared our stories. We devoured what research there was. We experimented on ourselves. We became our own scientists and our own doctors because we had to be. And slowly, I added 5% here, 5% there until eventually, on a good day, I was able to leave my house […].
> I don't know what would have happened had I not been one of the lucky ones, had I gotten sick before the Internet, had I not found my community. I probably would have already taken my own life, as so many others have done. (Brea, 2016)

Brea started filming her bad days to document her experience for her doctors and then also filmed others she met online, eventually directing her documentary *Unrest*. The documentary and Brea's TED talk explicitly aim to change the public conception of ME/CFS and emphasize the need for funding research. The problems, as Brea

identifies them, include the public invisibility of the suffering caused by ME/CFS and the misconceptions held by many doctors, since "It is not in the textbooks of medicine," and "When we crash, we disappear. So you don't see us at our worst" (Brea, 2016).

Brea's account is thus not about a rare but rather an understudied disease. Brea explicitly reflects on the reasons for systemic medical ignorance about the disease. The reasons, according to her, include the gendered history of ME/CFS, as most sufferers are women, and they frequently receive a psychosomatic diagnosis, which "can never be proven" yet precludes further search for answers. Both the documentary and the TED talk are thus public testimonials, describing a patient's journey to diagnosis and calling for a change in the broader—cultural, institutional, and financial—conditions for research.

In the absence of certified experts who could provide answers, Brea describes relying on a network of other patients, reached through online platforms. Indeed, Brea's narrative emphasizes not her own expertise but the importance of a collective effort (enabled by new media platforms) toward network-building and activism to raise awareness of this condition and demand sustained research: "I used to think that if I looked hard enough, I was going to find a cure… I am not going to find a cure on my own" (Brea, 2017). That network also facilitated Brea's search for credentialed doctors and connected her with knowledgeable and sympathetic medical professionals.

Similar to Viles's and Terry's, Brea's account portrays the experience of somebody who experienced a lack of answers and could be described as an expert patient actively involved in their health care and demonstrating outstanding medical expertise. Like Terry, Brea emphasizes the importance of patients "coming together." However, she provides an example of a different composition of networks of expertise and strategies for (re) shaping them to achieve answers.

Specifically, to find answers, Brea had to find and engage with a different network of expertise — an online community rich with patient participation and patients' experience but relatively poor in terms of its integration with the work and networks of credentialed specialists. The func-

tioning of this network of expertise was made possible and mediated by online social media platforms. These platforms thus acted as de facto "knowledge infrastructures" (Borgman et al., 2013), enabling communication among individuals and accumulation and collective interpretation of their experiences. YouTube and other social media platforms allowed the ME/CPS sufferers to come together—even as their physical state did not permit them to leave their houses. The design of these platforms then affects the knowledge production work of online patient communities. It enables and constrains knowledge production possible but, at the same time, is not under the control of its users and does not necessarily reflect their interests (Van Dijck et al., 2018).

While Brea's account emphasizes the epistemic value of that community, her public-facing TED talk and documentary are explicitly positioned as efforts to affect the organization of academic, publicly funded research. She does that by leveraging the new media tools (that allowed access to other patients with ME/CPS and their experience) to make the problem more publicly visible and attract more funding for research on ME/CPS.

In sum, Brea's account is a more contemporary example of patients' coming together online to perform knowledge production work facilitated and constrained by new media. It is also an example of networks of expertise involving very few credentialed specialists. Finally, Brea's account itself explicitly seeks to affect the organization of networks of expertise around ME/CPS by raising the social profile and awareness of the condition. This account is not just a representation of how networks are formed but also part of the network formation

Discussion and conclusion

This paper analyzed popular, public-facing accounts of three patients—Jill Viles, Sharon Terry, and Jennifer Brea—who faced an absence of medical answers about their own or their children's conditions. Facing dramatic health challenges, they did what "expert patients" might be expected to do. They surveyed extensive amounts of literature and sought to diagnose themselves (as described by Viles), conducted "hardcore

research" (as described by Terry), or experimented on themselves using knowledge and suggestions obtained online (as Brea describes).

Yet the narratives of Viles, Terry, and Brea demonstrate a more complex picture if we consider them through the prism of Gil Eyal's networks of expertise (2013). Medical networks of expertise these women encountered could not generate adequate answers about their or their children's diagnosis and treatment. These patients intervened in the organization of these networks, and they did it in three distinct ways: 1) by establishing external ties with specialists outside one's immediate healthcare team, as well as non-experts and other patients expected to offer critical support or insight (as Viles did); 2) through traditional forms of organizing with other patients to affect the institutional organization of knowledge production (as Terry did); or 3) by engaging with relevant online communities that can serve as an alternative network of expertise in the absence of adequate medical support from credentialed health care specialists (as Brea did). In Terry's case, the organizational efforts included (re) shaping the underlying research infrastructures. In Brea's case, alternative network-building relied on social media platforms. In all three cases, the organizational work of extending and reshaping networks of expertise appears not secondary but essential to dealing with medical ignorance. In sum, these public patient narratives describe not just hero-like efforts to develop personal expertise and conduct research to remedy situations of medical ignorance. They illustrate significant efforts at organizing networks of expertise that would be more adept at generating relevant knowledge.

The contribution of this analysis is two-fold. First, the paper contributes to the discussion of expert patients and lay expertise by pointing at the broader dimensions of expert patient work that transcends their own expertise and knowledge production. In the cases analyzed here, epistemic efforts of expert patients faced with a lack of adequate medical answers about their conditions are also organizational efforts affecting the organization of knowledge production in their case, including who is involved in generating answers and how.

Second, the paper contributes to the earlier STS scholarship on patients' activism (Akrich et al., 2013; Epstein, 1995; Geiger, 2021; Jansky, 2023; Rabeharisoa et al., 2014), which has already suggested an intertwining of knowledge production and activism and organizational efforts of patients. The paper contributes by bringing together the analysis of networks of expertise and STS analysis of the production of knowledge/ignorance -- and arguing that situations of medical ignorance experienced by patients could be interpreted as situations of inadequate organization of relevant networks of expertise. Patients' efforts to generate answers in such situations are both epistemic and organizational. The value of applying the lens of networks of expertise is that it allows for a more nuanced understanding of the composition of these networks and efforts at reshaping them. The paper offered three examples of reshaping relevant networks, drawn from different historical periods, where patients sought to generate answers in different ways: by establishing external ties with specialists and non-experts outside one's immediate healthcare team, through traditional forms of organizing and capacity-building, and through engaging with relevant online communities that can serve as an alternative network of expertise.

More broadly, the analysis suggests that networks of expertise can be described in terms of different aspects of their composition: whether and to what extent they allow contributions by patients, what types of professional experts are included, how these networks are institutionally supported and mediated, what are the affordances and limitations of these media, and what conventions and standards facilitate or limit the work of these networks. However, the through-line for all three cases analyzed in this paper is the question of the integration of patients into networks of expertise around their condition.

Viles, whose account most resembles a hero-like effort to generate her own answers and then affect medical research, still had to do significant network-building. Similar to the expert patient described by Hendal and Tjora (2009), Viles sought to establish external relations with specialists outside her immediate healthcare team. She also made critical connections with

non-experts who helped her efforts and a patient outside her family presenting a different manifestation of the same disease. Her focus was not on broader institutional conditions of knowledge production, even when her position vis-à-vis those networks impeded her search for answers. She lost years after some experts dismissed her suggestions because she was "just a patient." Yet, Viles's and other patients' integration into the relevant networks of expertise appears critical since research on some rare diseases is based on isolated cases. As Epstein points out, Viles then had uniquely extensive knowledge of her own and her family's symptoms and history with the disease. Though that epistemic position enabled her insight, she had no simple way of contributing her insight to the broader networks of expertise around her condition -- and had to reshape her network by forming external relations with various experts and non-experts.

In contrast to Viles, Terry's search for answers about the treatment for PXE was a matter of organizing and, specifically, establishing patient organizations. That traditional organizing and non-profit work made it possible for Terry and her fellow contributors to impact whether researchers collaborated among themselves and what resources were available to them. Perhaps most notably, with the PEER platform, Terry and her collaborators also could achieve these and other goals by organizing and remediating researchers' access to patient data. They increased the data available to researchers of this and other rare diseases — and created the conditions for more patient-centric research and more answers for individual sufferers (as well as more patients' control over their data).

Generally, patient organizing and capacity-building described by Terry might be similar to the work done by other foundations and charities organized and funded by patients. Other public accounts of expert patients describe similar efforts to affect the organization of professional networks around rare conditions by joining or forming such organizations (e.g., Goldberg, 2017). Indeed, patients might continue to engage in organizational work affecting the underlying networks of expertise, in potentially transformative ways, even in areas with relatively high levels of medical knowledge. From the perspective of networks of expertise, it could be viewed as a question of maximizing expertise, assessed from patients' perspective, and remedying inadequacies of health care and knowledge production.

The network of expertise in Brea's narrative was dominated by the online community of ME/CFS sufferers, which Brea credited with helping her survive. This narrative also provides an example of patients' platform-mediated organizing in search of answers. The result of this organizing—online communities of patients—can also be viewed as an important part of networks of expertise around some conditions (see also Griffiths et al., 2012). They are arguably most important when patients, like Brea, feel dismissed by their doctors (e.g., Carroll and Frakt, 2018; Earl, 2017; Kennedy, 2016; Warraich, 2019; see also Kuchinskaya and Parker, 2018).

These alternative, social media-based networks might provide informational support, including information on access to more sympathetic doctors who can provide some care. In these cases, as in Brea's narrative, new media platforms used by various online patient communities—platforms such as Facebook and YouTube or dedicated platforms like PatientsLikeMe.org—might serve as de facto knowledge infrastructures for patients seeking answers. Indeed, how these platforms transform patients' roles and involvement in health care is the subject of recent research (Erikainen et al., 2019; Geiger, 2021; Jansky, 2023). This paper suggests the importance of whether and how the patients and credentialed experts are integrated within the resultant networks. There are reasons to be cautious about the kinds of medical knowledge online communities generate; self-experimentation facilitated by online communities can be dangerous (e.g., Velasquez-Manoff, 2016). However, such collective risky patient self-experimentation might indicate that these patients lack access to adequate support through traditional medical channels. The problem, in other words, might be the isolation of these patients from networks of credentialed experts, their support and resources.

The analysis in this paper is limited by using public, media-circulating patient narratives as its data source. The value of the narratives was their

explicit positionality. However, the analysis is also limited by attempting to make visible what this kind of data generally obscures: the collective, tools- and infrastructure-dependent work. More ethnographic research involving interviews and observations would be needed to account more fully for the complexity of roles that patients might play within networks of expertise and the role and the (re)shaping of the tools that mediate the epistemic work within these networks.

Finally, it is important to recognize that the work done by Viles, Terry, and Brea required skills, access to adequate health care, as well as substantial financial, physical, family, education, and other resources. For many patients and their families, these resources are already depleted by the disease, the work of managing it (Corbin and Strauss, 1988) and of navigating health care. Patients cannot be expected to do more work. Arrangements that require more work, including attempts to integrate patients and specialists around particular conditions, should also consider resources that would be necessary to support patients.

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