Patients as knowledge partners in the context of complex chronic conditions

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ABSTRACT

This article conveys how taking patient knowledge seriously can improve patient experience and further medical science. In clinical contexts related to infection-associated chronic conditions and other complex chronic illnesses, patient knowledge is often undervalued, even when clinicians have limited training in diagnosing and treating a particular condition. Despite growing acknowledgement of the importance of patients as 'stakeholders', clinicians and medical researchers have yet to fully develop ways to evaluate and, when appropriate, meaningfully incorporate patient knowledge—experiential, scientific, social scientific, historical or otherwise—into clinical practice and research. We argue that there are opportunities for clinicians and researchers to collaborate with patients and colleagues from the social sciences and humanities. We use two examples to demonstrate why patient knowledge should inform medical engagement with chronic and complex conditions. The first comes from a disability studies scholar who describes the social biases that can sideline patient expertise, and the second is from an anthropologist whose reading in medical humanities led to an effective treatment for her recovery. Rather than merely acknowledging 'lived experience', clinical and research teams should include patients with complex chronic conditions as 'knowledge partners'. These patients occupy unique and valuable epistemological positions, and their knowledge should be considered with as much openness and rigour as other forms of medical knowledge. As more medical schools, residency programmes and hospitals emphasise the need for 'deep listening' and patient input, we encourage meaningful engagement with patients whose insights can provide crucial knowledge for clinical and scientific advancement.

INTRODUCTION

In the era of COVID-19 and its postacute sequelae, patient testimony is everywhere: magazines, newspapers, television shows, books, podcasts and documentaries. The scale of Long COVID's impact has brought awareness to infection-associated chronic conditions (IACC), as well as other chronic illnesses that often present with a range of disabling symptoms in the absence of definitive signs. The lack of medical familiarity with and research on these conditions opens up new possibilities for the role of patient knowledge in clinical practice and research. In this short perspective, we use the term 'patient knowledge' to describe both the embodied knowledge of 'lived experience' *and* the scientific, social scientific, historical, and other forms of knowledge that patients, patient-scholars and patient-clinicians can offer (Dumez and L'Espérance 2024). We argue that including patients as 'knowledge partners' in clinical practice and research can not only improve patient experience but also has the potential to further medical science on complex chronic conditions.[1]

We are a collective of anthropologists, historians and rhetoricians engaged in scholarship on Long COVID and other IACC and their related comorbidities, including our first two authors who have lived experience with these diagnoses. Our research has demonstrated how crucial patient narratives are for more fully understanding complex chronic conditions in diverse contexts. These include people living with Lyme disease (Dumes 2020a), amyotrophic lateral sclerosis (ALS) (Carter 2021, 2022), hypermobile Ehlers-Danlos syndrome (hEDS) (Moodie 2018, 2020) and myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS) (Hsu 2023a; Rogers 2022) in the USA, as well as Zika in Brazil (Löwy 2024) and diabetes in South Africa and Kenya (Mendenhall 2019). We write together now to point clinicians to our work and to encourage a social scientific and humanities-based approach to understanding IACC and other complex chronic conditions. Our aim is to foster collaboration between and among patients, clinicians and researchers, particularly in contexts where there are critical differences in race, gender, sexuality and class.

The urgency of including patient knowledge in clinical practice and research dovetails with calls from, for example, the National Institutes of Health in the USA and the National Institute for Health Research in the UK, to attend to patients' 'lived experience'. But it also pushes them further. Patient perspectives have been invited as post facto commentaries or to 'humanize' a particular condition but less often to set research agendas—including and especially the kinds of questions that get asked—or to offer knowledge that is recognised as scientifically valid (Mader *et al* 2018). The rise of patient activism in response to the AIDS epidemic in the early 1980s introduced a new era of patient legitimacy in pushing scientific research forward (Epstein 1998). Patients with ME/CFS and Lyme disease also began to organise at this time, and although they received limited attention at the beginning (Dumes 2020a; Rogers 2022), ME/CFS and Lyme patient activists built the foundation for the rise of Long COVID activism. Indeed,

it was patient activists who coined 'Long COVID' (Callard and Perego 2021; Kaplan and Mendenhall 2024) and who played a role in coining 'infection associated-chronic conditions' (NASEM 2024). An exemplar patient advocacy group focused on research is the Patient-Led Research Collaborative (Assaf *et al* 2020). Their work has subsequently led to commentaries and publications in peer-reviewed journals collaboratively authored by patients and scholars (Davis *et al* 2023; Re'em *et al* 2023). However, this type of collaboration remains uncommon.[2] We argue that incorporating patient knowledge into clinical practice and research should be the rule, not the exception.

In what follows, we discuss why diagnostic uncertainty continues to plague IACC and other complex chronic conditions. This is particularly salient in the first case study, which shows how social bias can impede engagement with patient expertise. Then, we suggest that reading into history—and in some cases old case records and framings—can inform how people with complex chronic conditions are cared for. Thinking deeply across scholarship in medicine, social science, and the humanities is a vital tool for recognising how patient knowledge and questions can drive better care for and research about people living with complex chronic conditions.

Why the diagnostic uncertainty?

Diagnostic uncertainty related to complex chronic conditions like Long COVID, ME/CFS, ALS and Lyme disease is long-standing (Carter 2020; Dumes 2020a; Dumit 2006; Rogers 2022). In conventional medicine, there is a fundamental division between signs and symptoms. When it comes to diagnosis, 'signs trump symptoms' (Dumes 2022). This diagnostic hierarchy dates back to around the early 1800s in Europe and the USA when physicians who had previously made diagnoses based on external symptoms turned their focus to internal pathology (Mol 2002, 126). In 2024, there continues to be clinical uncertainty about how to proceed with diagnosis and treatment in the absence of clear signs, specific biomarkers or definitive tests. Moreover, conditions that present with more symptoms than signs are often ascribed a psychological origin (Atkins 2010; Burke 2019; Dumes 2020b), even when, as in the case of Long COVID, there is compelling evidence to support a condition's biological reality (Al-Aly and Topol 2024; Davis *et al* 2023; Klein *et al* 2023; Peluso *et al* 2024). Women, in particular, have long been dismissed as hysterical in these clinical circumstances (Dumes 2020c; Hsu 2023b; Koerber 2018). The following case studies highlight moments where the incorporation of patient knowledge and experience may have contributed to greater diagnostic clarity and better clinical care.

Case study 1: 'I Don't Need Your Sympathy'

The first doctor whom I ever told I was transgender spent the whole 2 min of my appointment asking about my gender identity. No, I had not started medical transition. No, I did not feel like I just 'needed to be different'. No, I did not think this had anything to do with 7 years of gastrointestinal dysfunction and new-onset vertigo, exertion intolerance and fatigue.

When I asked him to address my symptoms, he took my hand between both of his and said, "I can tell you're very uncomfortable".

I left his office with a diagnosis of IBS and a recommendation that I 'stress less'. Had he asked about my medical history, I could have told him that I'd already been (mis)diagnosed with irrital bowel syndrome. I'd already been prescribed all the standard anticholinergic and antispasmodic medications, and most made me feel worse. Instead, I spent the next year trying to access another gastroenterologist in our town of 80 000, all of whom were either not taking new patients or who turned me away because they 'did not do second opinions'—even though I'd hardly received a first opinion.

He was the first in a long line of doctors who have derailed my care because they could not stop fixating on my trans identity. After I began hormone replacement therapy, physicians began attributing every symptom—including all those that preceded my medical transition—to testosterone. While my medical transition seems like significant information for my providers to have, it is also sometimes the least important fact about me. Once doctors know that I'm trans, I become a concept—too often, a political controversy to be debated—rather than a human being with a specific personal and medical history.

This reduction of the patient to a one-dimensional idea is especially common in any situation with inadequate knowledge—whether due to scant research or social bias. When at a loss, providers (and people in general) rely on dominant narratives to shore up the dearth of adequate knowledge and training (Olszewski 2022). My encounters with healthcare professionals—some of whom have been wonderful, some of whom have been frustrating, none of whom are solely to blame—are then shaped by large gaps in medical knowledge when it comes to complex chronic illness, trans medicine, class stigma and racial bias. I want to emphasise that this is a *systemic* problem—that the solution is not about individual understanding but about a paradigm shift that would enable patients to become informed collaborators in our own care.

In retrospect, I suppose the (extremely uncomfortable) handholding was that doctor's attempt at expressing sympathy. It was a rote performance of 'care' in the absence of meaningful connection. I imagine that care would look very different if he were speaking to a friend, a colleague or someone he could even imagine as a close relation. I imagine that so many of my exchanges with healthcare providers fall short because I do not resemble any person whom they've cared about, and they have no precedent for how to interact with—let alone feel for—me.

The first doctors who took me seriously were ones who work at the university hospital—who are technically also my colleagues, with whom I share some common ground. By then, my long-standing ME had been compounded by two COVID-19 infections and suspected Long COVID. Even though ME and Long COVID remain poorly understood, these providers were far more willing than their predecessors to explore pathways to alleviating my symptoms. They considered my experiences and explained possible avenues for relief. This gave me the chance to describe the treatment methods I had already tried and how I responded to different approaches. With a combination of their expertise, my knowledge of my own body, and a collection of knowledge I'd pulled together from patient scholars and patient activists, we were able to narrow down the options that were most promising for me. I'd like to believe that my care team would approach all patients with equal attention, but I'm also aware that I was only able to get appointments with them through personal connections.

As a chronic illness story, this is not a fable with a feel-good ending. Even with thoughtful and informed care, my condition fluctuates and imposes serious limitations on my life. Because that care is ongoing, though, it is even more important that I work with physicians who are responsive. I need doctors who know that what works today may not work tomorrow, and who are willing to regroup and re-strategise with me when my condition deteriorates. Rather than performed empathy, I need

discussions about the limitations and possibilities of existing medical resources in treating my illnesses. I am relieved to have found a team that can make this journey feel a little less hopeless and isolating, but chronically ill people should not need to network to receive basic treatment. Instead, we need a system designed so that no one's dependent on whether an individual provider can see us as worthy of care.

Knowledge-treatment gaps

This case study reveals a powerful disconnect between a patient's experience and a provider's preconceived notions of how an illness (or gender) should present. It also sheds light on the division between the 'right way to be sick' and the 'wrong way to be sick', which are often correspondingly perceived to be 'deserving' and 'undeserving' of medical attention (Dumes 2020a). For Dr Hsu and other patients who present with more symptoms than signs, being sick in the 'wrong way' means facing a range of barriers, especially when the patient is not a white cisgender heterosexual man. These barriers include clinician bias, a dearth of relevant medical education on complex chronic conditions and health equity, and a diagnosis and treatment framework that is better suited for illnesses that are straightforward and clear-cut. Too often, patients like Dr Hsu are dismissed as too complex or perplexing to treat, let alone cure. But patients with complex chronic conditions may have symptoms that could be alleviated with existing treatment; the challenge is connecting those symptoms with relevant care in the absence of clinician familiarity with relevant diagnosis and treatment (Aronowitz 2001). Without a diagnosis, patients cannot access tests or treatments that may provide a pathway for healing. Being open to considering patient knowledge and concerns may catalyse a diagnosis and treatment plan.

Although access to treatment requires a diagnosis, a diagnosis does not guarantee meaningful treatment, especially in the context of complex chronic conditions. Looking back at successful treatment histories can provide a powerful path for experimentation and recovery when few options are available. Patient communication channels, such as online forums, offer substantial information-sharing that can help patients overcome knowledge-treatment gaps. This is particularly important when a patient has a condition for which there is limited clinician training, on which limited continuing medical education focuses, and for which the clinician may not be aware of the literature. It is important to note that while innovative possible treatments can emerge in these spaces, it is also true that some treatments shared through informal networks (just like treatments prescribed through biomedical channels) can pose risks.

When patients garner knowledge and gather information to bring to their clinicians to consider, we recommend against rejecting patient suggestions outright or identifying a patient who questions clinical authority as a devious or 'noncompliant' patient. We are not arguing that all patient knowledge claims should be embraced as equally valuable—just as not all clinical opinions are equally valid. Rather, we suggest that patient knowledge should be engaged with the same consideration and critical analysis as other forms of evidence. In what follows, we demonstrate how drawing from the medical humanities can provide rich knowledge for patient care and, in this case, result in a remarkable recovery.

Case study 2: Medical progress/amnesia

To the physician or medical student of 2024, Olivers Sacks' 1969 book *Awakenings* might read as a great lesson in medical humanities—that is, how to practice empathetic medicine in such a way that both doctor and patient retain their humanity (Sacks 1999). In rare cases, it might be held up as an example of effective case studies. But it is unlikely to be read for the medical science that it contains. It is too narrative for an era in which time is short, statistics and imaging are paramount, and neuropsychopharmacological science has necessarily 'progressed'. It might also be perceived as too 'historical' to be relevant to contemporary cases. This is not just a problem related to Sacks and his work. Research publication in medicine moves swiftly so that the lessons of the past are supplanted from one graduating medical school class to the next.

As a patient living with an array of comorbidities linked to hEDS who is also a cultural anthropologist trained in archival research methods, I have a relationship to *Awakenings* and its insights unlike that of any doctor I am likely to encounter.

One of the main symptoms of my complex condition is hemispherical dystonia, sometimes also referred to generally as parkinsonism, which to date is only tentatively mentioned in the medical literature on hEDS. One physician, Claude Hamonet, has written about his extensive experience with hEDS-linked dystonia among patients in his clinic at the Hotel Dieu Hospital in Paris. Hamonet treats many of these patients with levodopa (L-Dopa) and describes how it lessens dystonia's more disabling symptoms (Hamonet *et al* 2018).

When my dystonia worsened dramatically almost overnight, the doctors in my small city were stumped. I read Hamonet's clinical reports after they were suggested to me by another patient in an online support space. Though I was sceptical, the reports were also promising, so I showed them to my local doctor and was allowed to trial L-Dopa, given the relatively low risk of side effects. The results were almost immediate and profound: my slurred speech and stutter improved, my gait returned to normal, spasms and tremors resolved or lessened, and my chronic pain (diagnosed as complex regional pain syndrome) abated for the first time in years. One pain management doctor at a nearby research hospital who had been treating me over an extended period said, "It's a miracle. I never in a million years would have prescribed you L-Dopa"; its use for hEDS was far outside the siloes in which she'd been taught to think about chronic pain. She couldn't explain why it worked, but she could see that it did. I have now been stable for nearly 3 years and have gone from being an ambulatory wheelchair user to having the capacity to walk 10 000 steps in a day.

Not all doctors agree with her or with me about what has happened. Another neurologist at a different university hospital who assessed me is convinced that my L-Dopa response is a placebo effect, even though it has been consistent over 3 years and even though dozens of other treatments (with more evidence backing their usage) failed.

When I read *Awakenings* to learn about the history of L-Dopa shortly after I began taking it, I could start to understand why this medication works well for people like me. This is likely related, at least in part, to the way that histamine response disrupts dopamine processing in the brain, but without necessarily damaging tissues or depleting overall dopamine levels that are seen in Parkinson's disease. This was similar to what was seen among Sacks' survivors of encephalitis lethargica, a connection reinforced by the fact that Sacks treated the survivors with anticholinergics (a class of drugs used to treat Parkinson's prior to the introduction of L-Dopa). Given the high prevalence of other dopamine processing-related comorbidities of hEDS, including attention-deficit/hyperactivity disorder (ADHD) and autism, as well as mast cell activation syndrome (Gensemer *et al* 2021), and

given the symptomatic similarity I was able to glimpse through Sacks' incredibly detailed case studies, it seems possible that hEDS-linked dystonia may be linked to a genetic predisposition to histamine-induced breakdowns in dopamine processing.

Sacks' work, coupled with Hamonet's more recent clinical studies, have enabled me to explain my treatment to multiple physicians and other patients, some of whom have also benefited enormously from L-Dopa. This is a form of communication that has been made possible by my experiences as a patient and my training as an anthropologist. A social scientific and historical approach enables us to think beyond the limits of a future-oriented medicine to consider a wider range of possibilities, including the potential promise of 'old' medications. Few physicians today can keep up with the pace of research in their own subfield, let alone across a wide variety of subfields and deep into the historical annals of medicine. This example shows where a collaborative approach between a physician and a patient-historian can yield not only a new treatment option, but also potential insight into the causes of an understudied complication of a complex condition like hEDS.

Expanding expertise to include patient knowledge

This case study reveals how important it is to recognise patient knowledge *as knowledge* and to embrace instances when it may contribute to better treatment. In many cases, clinicians have had limited training in caring for people with Long COVID, ME/CFS, hEDS and other complex chronic conditions, including autoimmune diseases. Introducing these conditions into medical education curricula is a fundamental starting point. Developing large-scale clinician training programmes for complex chronic conditions may be similarly impactful. For example, the #MEAction network has developed a pilot programme with Mayo Clinic for continuing medical education (Grach *et al* 2023). This involves a systematic programme—in partnership with people with lived expertise—for continuing medical education where clinicians are trained to recognise and care for people with complex chronic conditions.

People with IACC and other chronic conditions have a wealth of embodied knowledge from their lived experience. But because these conditions are understudied and patients must often do a significant amount of research to advocate for their own care, many patients also possess broader relevant knowledge about complex chronic conditions. By expanding expertise to include patient knowledge, as our two case studies demonstrate, patients, clinicians and researchers may be able to create novel pathways for diagnosis, treatment and care.

Conclusion

In conclusion, we recommend that rather than including patients merely for their 'lived experience', people living with complex chronic conditions should be systematically integrated into clinical and research teams as knowledge partners. These patients occupy unique and valuable epistemological positions, and their knowledge, from experiential to scientific, should be considered with as much openness and rigour as other forms of medical knowledge.

As more medical schools, residency programmes and hospitals emphasise the need for 'deep listening', particularly for patients living with complex chronic conditions (Bradshaw *et al* 2022), we encourage meaningful engagement with patients whose insights can provide crucial knowledge for clinical and scientific advancement. As large seminars are planned, symposiums proposed and advisory committees formed, patients with and without advanced degrees need to be front and centre. Integrating patients into the line-up is not about making clinical spaces and research programmes more human. Instead, it is about collectively and collaboratively expanding our knowledge about IACC and other complex chronic conditions to improve patient care and find new avenues for recovery.

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NOTES

1. Here, we build on and expand scholarship on 'patients as partners' (Karazivan *et al* 2015; Vanstone *et al* 2023) and patients as 'knowledge workers' (Papautsky and Patterson 2021).
2. See also *Research Involvement and Engagement,* the first journal co-edited by a patient/researcher team (Stephens and Staniszewska 2017).

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