



**Anna Charko,  
MSc**

works professionally as a psychologist and psychotherapist. A board member of the "People and Medicine" Foundation. Teaches students at the SWPS University of Social Sciences and Humanities how to design health-oriented solutions based on research. Takes an academic interest in psychosomatics, body-mind science, and patient-centered innovations.  
ania.charko  
@ludzieimedycyna.pl

# WHOSE VOICE IS MISSING FROM THE HEALTHCARE DEBATE?

Patients with chronic conditions are experts regarding their own health and should have their voices heard – not just about medical treatment but also about the everyday challenges they face.



WELLPHOTO/SHUTTERSTOCK.COM

**Anna Charko**  
**Robert Statkiewicz**

“People and Medicine” Foundation,  
University of Łódź  
SWPS University in Warsaw

When you hear the phrase “healthcare debate,” what comes to mind? A heated discussion in parliamentary chambers? People in white coats sitting around a long table? A professional conference featuring renowned experts from the medical and governmental sectors? Perhaps these are not the only images we should consider.

Imagine this: amidst serious discussions about healthcare policies and treatment methods, an unexpected voice breaks through: “I generally do not tell people that I’m sick. The truth is, society doesn’t view illness favorably. At first, there’s sympathy, but soon enough, people tend to distance themselves from someone they see as impaired. Illness is a kind of impairment – why would anyone want to associate with someone weak like me?” This isn’t the voice of a politician or a doctor. It’s a statement from Zbyszek, a 65-year-old who has lived most of his life managing type 1 diabetes. His words reflect sentiments shared by many participants in the research for the *Patients for Patients* app – voices that reveal a sense of exclusion and misunderstanding. Does today’s health debate have room for perspectives like Zbyszek’s?

### Three dimensions of illness

We believe that patients’ perspectives provide a fresh and often overlooked viewpoint in discussions about healthcare policies, support programs, and medical procedures. To better understand this multifaceted perspective, it is helpful to draw upon a concept central to both medical anthropology and health psychology: the classic triad of illness dimensions proposed by anthropologists and psychiatrists Arthur Kleinman, Leon Eisenberg, and Byron Good, reflected in the English terms *disease*, *sickness*, and *illness*. While all three refer to aspects of being unwell, their underlying definitions differ significantly.

*Disease* refers to the biomedical dimension. It invokes the language of medicine to describe physical (and mental) changes in the body, establishing standards and limits for biomedical norms. This dimension forms the foundation of modern biomedical knowledge. *Sickness*, in turn, represents the social dimension of illness. It reflects how disease is perceived culturally and socially, as well as the attitudes society holds toward individuals with certain conditions.

*Illness*, by contrast, captures the personal, first-hand experience of being unwell. It includes reflections, emotions, and embodied knowledge derived from living with a condition. The second-person perspective – often represented by caregivers or allies – adds complexity to this framework (while Kleinman, Eisenberg, and Good categorized this perspective as part of *sickness*, contemporary qualitative research often aligns it more closely with *illness*).

In most healthcare debates today, the focus tends to be on *disease* and *sickness*. These discussions influence legal frameworks and societal norms, which, in turn, impose a rigid structure on the everyday realities of living with illness. Yet, this framework is too narrow, uneven, and incomplete. The subtle realities of living with illness often stretch beyond these confines, fraying at the edges. The creators of legal and social systems fail to see the full picture, and patients are left without the tools to convey their lived experiences effectively.

As Joyce Lee MD observes, patients are frequently excluded from the “culture of healthcare” because they are perceived as unable to contribute knowledge or innovation in this field. She argues: “To move forward, we must overcome the current healthcare culture, which insists that only doctors are experts, not patients. It maintains that only certified professionals



**Robert Statkiewicz, MSc**

applies expertise in anthropology to practical research in the areas of health, technology, and culture. Facilitates design thinking processes and participatory design, lectures at SWPS University, and is pursuing a PhD at the Doctoral School of Humanities at the University of Łódź. A board member of the “People and Medicine” Foundation. Has a research focus on inclusive studies and medical anthropology.  
robert.statkiewicz  
@ludzieimedycyna.pl

Medical anthropology and health psychology offer valuable insights into the everyday lives of people living with illnesses. They enable us to see beyond the patient as merely a client, a citizen, or a body with a disease.

can define health, in a one-way system where health is created solely by doctors for patients.”

### Chronic illness as poverty

While that quote may seem like an oversimplification, its essence is reflected in the extensive literature on the lives and needs of individuals living with illness and disability. People with chronic illnesses often face various forms of social exclusion, as highlighted in Zbyszek’s story above: distancing, stereotyping, having their voices silenced or invalidated, and segregation.

In 2017, Dubin et al. conducted a study examining the attitudes of medical students toward patients

with disabilities. The findings indicate that stigmatization is present even within healthcare education, suggesting that being ill is still perceived by some as a consequence of one's actions. Notably, up to 26% of medical students doubted the possibility of leading a happy life with various forms of disability, including chronic illnesses. A report by the AMICUS Psoriasis and Psoriatic Arthritis Foundation on the experiences of individuals in Poland living with chronic skin conditions (e.g., atopic dermatitis, psoriasis) sheds more light on this issue: 68% of respondents reported that they avoid social interactions out of fear of rejection or stigmatization, while 56% said their illness caused disgust or discomfort among their loved ones.

While we are seeing significant changes in healthcare, these changes often focus on the delivery of services (e-visits, teleconsultations) rather than rethinking the role of patients within the system or addressing

Medical anthropology is more than an academic discipline. It is an applied science, a tool for dialogue, and a way to develop practical solutions to real-world challenges.

the broader socio-psychological dimensions of illness. For example, the report estimated that around 44% of individuals with chronic skin conditions need psychological support. However, the majority – nearly 80% – reported never being informed that such resources were available. This gap highlights the need for a fundamental shift in how we view chronic illness – not just as a medical condition but as one with profound social and psychological implications

## Medical anthropology and health psychology

The approaches known as *medical anthropology* and *health psychology* offer valuable insights into the everyday lives of people living with illnesses. They enable us look beyond the patient as merely a client, a citizen, or a body with a disease – instead helping us see the whole person as someone navigating complex circumstances, without reducing their experience to oversimplified statistics. They allow us to explore the thoughts and emotions that accompany individuals at different stages of living with an illness (not just

during hospital stays). These perspectives also draw attention to “everyday knowledge” and the specific needs related to various support and care programs. This is particularly important when we consider that illness, in some form, will affect most of us at some point in our lives.

Medical anthropology, alongside design approaches such as participatory design, human-centered design, and user experience design, seeks to balance the voices of all key stakeholders: medical professionals, policymakers, and, most importantly, patients. Medical anthropology goes beyond simply bringing these perspectives into dialogue – it helps create effective solutions.

These approaches complement the current healthcare system, where “patient-centered care” is frequently discussed but often focuses narrowly on the body as an object requiring attention and optimization. Even within this framework, medical anthropology and health psychology can drive meaningful improvements. For example, while the concept of *intersectionality* is still gaining traction in healthcare discussions in some regions, it has already been successfully applied in other parts of the world, such as Canada, where it has shown considerable promise. Intersectionality examines the cultural and social contexts of patients, enabling better adaptation of programs and optimization of treatment methods. This perspective has already highlighted significant gaps, such as the lack of diversity in clinical trial populations for new medications. A person living with a chronic illness might also be a parent, a person with a disability, a member of a linguistic minority, or part of a socially or technologically marginalized family – and these factors may have a profound impact on the procedures and systems we design.

Research shows that some of these factors – or rather, some of categories an individual with an illness fits into – can have an even greater impact on their quality of life than the particular illness itself. Medical anthropology and human-centered design help us identify the areas of life most affected by ill-



ROMAN SAMBORSKIY/SHUTTERSTOCK.COM



PEOPLEIMAGES.COM – YURI/ A/SHUTTERSTOCK.COM

ness while also distinguishing those shaped more by a person’s status of belonging to a marginalized or privileged group.

## Inclusive design for patients

At the “People and Medicine” Foundation (a Polish NGO established in 2018 that supports individuals with chronic illnesses), we believe that in a world where the recipients of healthcare programs are so diverse, meaningful solutions cannot be created without genuine dialogue. Our work aims to address a gap in the healthcare landscape by focusing on the socio-emotional dimensions of illness and recovery. We actively listen, engage in conversations, and invite the individuals we serve to participate in decision-making. This approach helps us understand the varied attitudes people have toward their illnesses, the available forms of support, and the unique challenges that have often remained unmet.

We have developed a range of projects to support the daily lives of individuals with chronic illnesses. These include: set of “greeting cards for difficult circumstances,” a free app *Patients for Patients*, co-created with individuals living with chronic conditions to foster mutual support, a Critical Thinking Map to help people navigate the maze of (mis) information, and the program Taming the Illness, designed for parents of children with chronic con-

ditions. Additionally, we conduct our own research to better understand the realities of those we serve. We share insights and inspiration from medical anthropology by teaching design courses at SWPS University. Through research and development initiatives, we assist organizations focused on health and illness in better understanding the needs and expectations of their audiences – for instance, with projects like *On Menopause: A Short Guide* for the HelloZdrowie platform. Finally, we are committed to amplifying the voices of marginalized groups that are often underrepresented in Poland.

One of our colleagues at the foundation, who joined a project utilizing the participatory design process, once shared that she had never imagined, as a patient, that she would ever be able to create, contribute, and effect change – for herself and for others. Her experience is a powerful testament to how the methods we use, even within the foundation itself, are fostering real transformation.

For us, medical anthropology is more than an academic discipline. It is an applied science, a tool for dialogue, and a way to develop practical solutions to real-world challenges. It represents an opportunity for meaningful change and active participation in a rapidly evolving healthcare landscape. We believe that through this approach, the complex reality of living with chronic illness can finally be fully understood and addressed. ■

---

### Further reading:

Dubin S.N., et al. 2018. Transgender health care: Improving medical students’ and residents’ training and awareness. *Advances in Medical Education and Practice* 9, 377–391.

Kleinman A., Eisenberg L., Good B., 1978. Culture, illness, and care: clinical lessons from anthropologic and cross-cultural research, *Annals of Internal Medicine*, 88(2).

Lee J., Participatory Design and the “Making” of Health, TEDxDetroit, [www.youtube.com/watch?v=HyVaEASftF8](https://www.youtube.com/watch?v=HyVaEASftF8)