



Beyond experiential knowledge: a classification of patient knowledge

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Abstract

Patients' experiential knowledge is increasingly documented as a valid form of knowledge in the health sector and is often said to be a source of valuable information to complement the knowledge of health professionals. Although this increased recognition is outlined in the health science literature and formalized in certain organizational and clinical contexts, it remains difficult for various actors of the health ecosystem to contour the different forms of knowledge patients acquire through their experience as well as to consider them as essential in co-building care plans and as an asset to build care relationships. The aim of this review is twofold: (1) to challenge the dominant model of knowledge in medicine and healthcare by making the various forms of patient knowledge more explicit and tangible and (2) to provide a better understanding of what experiential knowledge consists of by classifying the various forms of knowledge patient acquire, develop, and mobilize throughout their care journey. A narrative review allows to classify six types of patient knowledge according to their source of learning: embodied, monitoring, navigation, medical, relational, and cultural knowledge. The three main sources of learning, namely the self, the system, and the community grounds patients' learning process in their health journey.

Keywords Patient knowledge · Experiential knowledge · Epistemic injustice · Patient partnership · Care relationships · Healthcare improvement

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Patients' experiential knowledge is increasingly documented as a valid form of knowledge in the health sector (Gross & Gagnayre 2017; Jouet et al. 2010) and is often said to be a source of valuable information to complement the knowledge of health professionals in clinical settings, medical education, health research, and healthcare management (Pomey et al. 2015). Although this increased recognition is outlined in the health science literature and formalized through frameworks, policies, and guidelines in several organizational and clinical contexts, it remains difficult for actors of the health ecosystem to outline the different forms of patients' knowledge, to consider them as valid and useful in co-building care plans and mobilize them as an asset to build care relationships. In other words, what we call experiential knowledge is not explicit for many of the major actors in the health community, patients included. In a context where patient knowledge is constantly undervalued, patients themselves are not always aware of the variety of knowledge they have acquired and the value it can have in building more equitable care relationships. Patients' participation in the co-production of decisions more consistent with their rights, needs, and interests also often resides in greater recognition of their ability, and even competence, to interact with a healthcare system dominated by experts and professional knowledge. The elasticity of the concept of experiential knowledge also impacts on the general understanding of healthcare professionals. Many concepts of patient-centered practice emphasize the importance of experiential knowledge as the cornerstone of shared decision-making and partnership in care. However, without a clear understanding of what this means, it remains difficult to put this recognition into action, to bring it to life at the heart of care delivery. This reinforces the clear epistemic injustice (Fricker 2007) that remains in healthcare and social services.

We propose a new reading of the literature to give a pragmatic meaning to the concept of experiential knowledge. By clarifying what we mean when using this broad term, we better differentiate the range of knowledge encompassed by this notion of "experience." A narrative review highlights the differences and similarities between different types of knowledge in order to underline their meaning action. As much as patient experiential knowledge is cited as the foundation of patients' expertise, biomedical knowledge is still predominant in the design and implementation of healthcare practices, interventions, and policies. The biomedical establishment is known to give a deflated level of credibility to a patient's narratives (Dumit 2006) and lacks the necessary interpretive resources to make sense of a patient's experience of illness and healthcare (Heggen & Berg 2021). In the healthcare economy of credibility, patients are given less authority by professional hearers when compared to the value usually granted to biomedical, scientific, and professional perspectives. Without highlighting their variety and specificity, patients' experiential knowledge is given a vague meaning in contrast to professionals' skills and knowledge formalized by academic training. This in turn undermines their perceived value in the production of quality care and decision-making. This can, in part, be explained by the lack of coherence between the definitions given to the concept of experiential knowledge and the ambiguity between the explicit forms of knowledge acquired and mobilized by patients in their journey.

The non-recognition of patients' knowledge by the dominant intellectual classes in health care was described by some as epistemic oppression (Dotson 2014) hence



bringing to light one of the many shapes of the power imbalances characterizing care relationships. Patients, caregivers, and medical professionals exchange and interpret the knowledge during medical encounters. Patients report frequently that healthcare professionals do not take their testimonies, interpretations of symptoms, and treatment preferences seriously (Heggen & Berg 2021). For Glasby and Beresford (Glasby & Beresford 2006), neglecting the views and experiences of people who use health services gives a “*false and potentially dangerous view of the world*” (p. 6) bringing them to highlight the crucial contribution that experiential knowledge can bring; a notion taken up by many other authors especially in the field of mental health and chronic disease management (Faulkner 2017; Rose 2009; Russo 2014; Sweeney 2015). They show that the development of experiential knowledge starts with experiencing continuously a phenomenon such as a chronic disease or a disability (Castro et al. 2019), by analyzing, reflecting repeatedly, and sharing stories about this experience (Gardien 2020). This kind of knowledge endlessly develops through observation, imitation, affection, and reflection. Consequently, patients and their support networks are experimenting, adapting, acquiring, and even generating all kinds of knowledge, including scholarly knowledge (Coulter 2011).

In this polysemic context, the aim of this narrative review is twofold: (1) to challenge the dominant model of knowledge in medicine and healthcare by making the various forms of patient knowledge more explicit and (2) to provide a better understanding of what experiential knowledge consists of by classifying the various forms of knowledge patient can acquire, develop, and mobilize throughout their care journey. In our perspective, it is essential to better define patient knowledge to give it its rightful place at the heart of the care relationships, whether it is expert or experiential in nature. Recognition and mobilization of knowledge shape patterns of health care relationships. Who owns it, how knowledge is defined, and who is seen as knowledgeable, all play a vital role in weaving the power dynamics between health professionals and patients at the clinical, organizational, and political levels. It is therefore more thought-provoking to ask the following questions: What are the sources of patient knowledge? What forms do they take? How are they activated and expressed?

The need for a classification of patient knowledge

While the literature highlights renewed acknowledgement that patient knowledge matters (Tambuyzer et al. 2014), it seems to be a poorly understood concept in the current health care context (McLaughlin 2009; Miaskiewicz & Kozar 2011; Scourfield 2010). The concept of experiential knowledge for instance remains vague and is used to encompass many types of experiences. It also tends to be placed at odds with the expert knowledge of professionals, as if patients were not experts of their condition. However, positioning patient knowledge as expert knowledge did not help to bridge the gap either. As Pols presented it, “*the knowledge of the ‘expert patient’ may be assumed to have the shape of up-to-date medical information*” (Pols 2014, p. 73), therefore diminishing the credibility given to them and contributing in fact to perpetuate the epistemic injustice that proponents were trying to counter.



Besides, patient knowledge and professional knowledge in healthcare are both made up of what could be called expert knowledge and experiential knowledge. If professionals have expert knowledge acquired through learning about medicine and science as well as experiential knowledge acquired through their clinical practice, thus patients acquire expert knowledge through learning about their condition and treatments and experiential knowledge through life with their condition and self-care. One or the other of these forms of knowledge is therefore not the prerogative of one of these actors (Akrich 2010; Collins & Evans 2002; Epstein 1995; Jasanoff 2006; Pols 2014).

Broadly, three groups of patient knowledge are described in the health care literature: embodied or bodily, lay, or experiential, and biomedical. Bodily knowledge or body listening is defined by Price (Price 1993) as “*awareness of and attention to understanding and interpretation of one’s body.*” (p. 37) He describes a spectrum of awareness going from precognition or vague attention to full cognitive consciousness. Price correlates this knowledge to specific management activities. Mishel (Mishel 1999) discusses patients’ familiarization with symptoms triggers and signs of oncoming attacks and argues that they are key to self-management. These embodied knowledge, consist of, and are mobilized, as a source of authority (Salmon 2000) by patients “managing their illness through considerable experimentation and testing for variations in body response” (Paterson et al. 2001, p. 336). The patient as a sentinel designation characterizes chronic patients who have learned to perceive symptoms of seizures to perceive the symptoms of crises early on (Crozet et al. 2018). Sentinel patients have developed a personal semiology that allows them to perceive reliable symptoms and act accordingly. According to Crozet and colleagues, the perceptual competence can be improved during the patient education programs by an adapted training on the verbalization of symptoms and listening to the body (Crozet et al. 2018).

As for lay expertise or experiential knowledge, it has been defined as practical knowledge embedded in the patient’s experience of managing and living with an illness. Where “*professionals generally concern themselves with disease processes, ... laypeople focus on the personal experience of illness*” (Brown 1992, p. 267). Experiential knowledge takes a variety of forms in the literature. They are sometimes described as medical, cultural, technical, institutional, methodological, etc. (Kerr et al. 1998) resulting in a strong conceptual blurring and a dissipation of the distinction between embodied knowledge that takes its source in the body, and knowledge acquired from the experience of living with the illness which is rooted as much in the management of oneself health, the interaction with health care systems and actors, as in the acquaintance with the medical disciplines and the care provided by the community. Experiential knowledge, Borkman wrote in 1976, “*is truth learned from personal experience with a phenomenon rather than truth acquired by discursive reasoning, observation, or reflection on information provided by others*” (Borkman 1976, p. 446). Experiential knowledge has contextual, subjective, unconscious, and emotional properties (Boardman 2014) that offer an intimate understanding of the condition. Pols (2014) define experiential knowledge as a “*knowing in action*” (p. 78) understood in terms of its utility or use-value for self-management and for supporting other patients. From this knowledge could stem



compassionate capacities and social values possibly leading to the formation of epistemic communities (Mazanderani et al. 2012, 2020).

Biomedical knowledge, on the other hand, is referred to as formal, professional, and authoritative in the literature. Seen as objective, it is concerned with the disease process and the indisputable “truths” about medical science. Very often, this type of knowledge is considered the sole possession of health professionals. As if patients did not have the capacity to access this knowledge and integrate it into their own disease management. However, another part of the health science literature discusses the growing phenomenon of patients mobilizing the latest scientific advances (or information gathered from the Internet) during their medical consultations, often significantly altering the contours of their relationship with their physicians (Anderson et al. 2003). Patient with chronic fatigue syndrome (Banks & Prior 2001) and more recently patient affected by long COVID (Atkinson et al. 2021; Rushforth et al. 2021) showed how patients use biomedical knowledge to make sense of and describe their symptoms, both to name their reality and to gain medical and public recognition for their condition. The medicalization of individual narratives is well described by Hydèn & Sachs. (1998):

To express one's suffering in terms of illness means that it must fit into and fulfill certain criteria and preconceptions about disease and its treatment... this means that to have suffering recognized as a disease and to obtain relief, patients must transform their suffering in a way that enables them to seek help and be accepted as patients for medical care (p. 176)

Peters and colleagues (Peters et al. 1998) assert that experiential and medical knowledge are not separate systems by describing how patients incorporated medical beliefs into their description of their symptoms to access physical treatment. Thorne argues that people with chronic illnesses are learning as much as possible about how health science and medicine view their condition (Thorne 1993).

While these three categories of knowledge have been well described in the literature, another categorization emerged in France in a group of thinkers adopting a patient-driven approach to the study of patient knowledge and partnership in care. Gross and Gagnayre (Gross & Gagnayre 2017) described five types of experiential knowledge patients acquire in the course of their life with the disease: (1) implicit experiential knowledge that aims at adapting to their own body, (2) explicit experiential knowledge that aims at adapting to their environment, (3) situated knowledge that allows patients to form epistemic communities, and (4) scholarly knowledge that supports the previous ones and can allow them to access (5) expert knowledge. Although we find echoes of the above-mentioned literature in these five types of knowledge, it puts into perspective that a classification of patient knowledge should not necessarily be oriented solely around the attributes of the knowledge, but above all consider the reasons why patient learn and mobilize them. This line of work led us thinking about the sources of patient knowledge acquisition and the patient journey as a learning device. The types of knowledge described by Gross and Gagnayre are all acquired in several ways and take their essence from the experience of the self as much as from the interactions with others and institutions, through immersion, submission, collaboration, and contestation. While highlighting the



relational aspect of putting patient knowledge into action, this framework of patient knowledge does not allow us to fully clarify their intrinsic nature and their primary sources of acquisition.

Thus, we looked at patient knowledge from the point of view of the learner and constructed the classification around sources of acquisition. With the aim to better recognize, expand, and mobilize patient knowledge at the level of care, it felt important to provide mutually exclusive categories of patient knowledge, not only with the aim of expressing what is, but also by providing space for action. By identifying the sources of acquisition, we uncover learning spaces. By uncovering learning spaces, opportunities to teach are highlighted and learning is accelerated by providing keys to patients and professionals along the healthcare journey, supporting empowerment and capacity building. By emphasizing the sources of patient knowledge acquisition, the massive work undertaken by patients taking place outside the health system is made visible which consolidates their primary position within the healthcare team. By delineating the learning spaces, we therefore value the teaching roles of both professionals and patients as trainers (Karazivan et al. 2015) and their (in)ability to effectively transmit one or all of the six types of knowledge we further describe.

Three sources of learning

We classify patient knowledge into three main sources of learning, namely the self, the system, and the community. First, the *self* is a fundamental source of implicit and explicit patient knowledge (Gross & Gagnayre 2017). Patients learn from their body and their mind, and they get to know the many details of their bodily manners, their physical as well as their mental strength and vulnerabilities. Their experience of the sick and healthy body and soul is part of their learning. They get to know what they like, what they need, what feels right and wrong, and define what is their own “natural” state. The self is also a space of observation, reflection, and experimentation. Second, the *system* is a source of situated, learned, and scholarly knowledge. Through their use of health services and their interactions with actors of the healthcare institutions, patients learn how to be (attitude, manners, conduct), how to talk (vocabulary, concepts, and codes), and what to do (gestures, posture, choreography). Patients have “*a particularly nuanced way of applying the often unspoken and sometimes invisible ‘rules of the game’ of healthcare.*” (Willis et al. 2016, p. 209) Despite professional gatekeeping, patients will strategically acquire knowledge that will enable them to adopt the codes and epistemic repertoires necessary to build relationships with health professionals and secure a credible voice around the decision-making table. As they move through their care and service journey, they will learn how to use the structures of the healthcare system to their advantage or how to circumvent structural barriers more effectively to achieve their health goals. Finally, the *community* is the third source of patient knowledge. Learning is thus a relational and situated activity. Patients develop knowledge through meeting others and sharing their stories in peer support and user groups (Faulkner 2017) and through their constant encounter with health care professionals



and caregivers. The community is where the healthcare journey intersects with domestic, professional, academic, and spiritual, etc., journeys. The community is a learning space because it allows for the weaving of links between life with the disease and all the other experiences that build the person's life beyond the disease. The community is the space where links are forged, and care and caregiving take a plurality of forms. We must even consider that the knowledge generated by these relationships can lead to the learning of false information or even knowledge that contradicts recognized care practices. Yet this knowledge materializes into narrative and action repertoires that influence the care relationships of a significant proportion of patients; all the more reason to recognize their existence.

The six categories of patient knowledge

With the three sources of acquisition in mind, we asked: what is the knowledge we acquire through the experience of the self, the system, and the community? Six categories of patient knowledge were, according to our review, described at length by the health science and social science literature: embodied knowledge, monitoring knowledge, navigation knowledge, medical knowledge, relational knowledge, and cultural knowledge (see Fig. 1.)

Embodied knowledge is sensory and grounded in bodily experience, anchored in physical sensations (pain, relief, discomfort, level of energy, etc.) and perceptions of the body and mind. In other words, the body is foundational to making sense of the human experience and the experience of illness and/or disability (Craig et al. 2018). Bodily vulnerabilities and strengths become signals that patients learn to listen to and use as a basis for making decisions. Decoding the world through the body and the mind forges a type of knowledge of the self and of others that shapes the

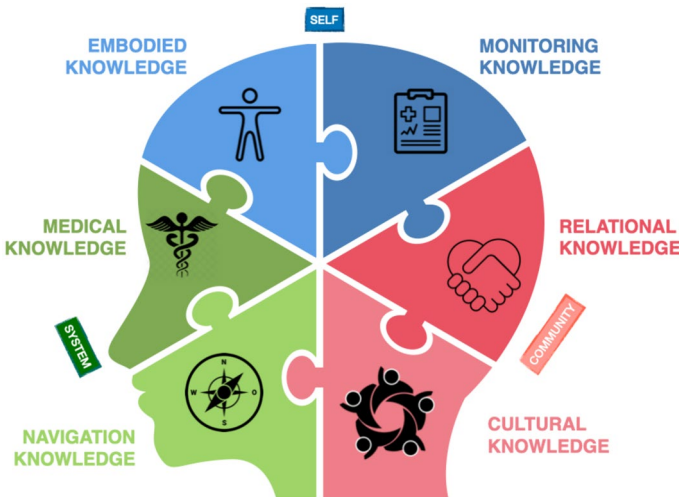


Fig. 1 Classification of patient knowledge by source of learning



way patients will conceive their body, their illness, and their relationship to others. This type of knowledge provides a basis for defining their life experience, resulting in a conceptualization that may be at odds with the broader socially constructed perception of what one's experience is, what one's body feels like. The experience of the sick or disabled body allows for the conceptualization of the self and of others and thus contributes to social positioning. Patients often speak of their embodied knowledge as the only knowledge others will never have full access to, apart perhaps by peers. This knowledge, more conceptual than practical, is inherent to the activity of being.

Everyday life with an illness, taking care daily of oneself or a loved one, tracking vital signs (e.g., through analog or digital devices), taking medication, regulating care, learning care techniques (e.g., injecting, exercising, massaging, clapping, etc.), making choices about one's health, noting feelings and symptoms, etc., are all developing and reinforcing patient *monitoring knowledge* through their care journey. Monitoring knowledge is the capacity to identify with acuity physical, mental, and/or emotional signs either through formal tracking or self-awareness. Patients learn to recognize their symptoms and can make decisions based on bodily sensations, physical and psychological manifestations, etc. Patients develop a sensory perception of symptoms leading to an information processing, resulting in a personalized semiology on which patients base their own diagnosis and treatment plans on a day-to-day basis (Crozet et al. 2018). Monitoring knowledge enables patients to cope with crises but also to better manage their disease. They consist of precision know-how as much as the recognition of sensations specific to their condition. Patients know how to take their blood pressure or glucose levels, know how to inject medication, and know what doses of medication are most appropriate at what time for what purpose, etc. They know how to go beyond standard protocols and apply the "codes" of medicine in a "personalized" arrangement of care based on their knowledge of their body and their own physiological, psychological, and emotional reactions to treatments and care. Monitoring knowledge is learned through the practice of the body. It is acquired by continued management of the body and the illness using standardized medical technologies as much as individually crafted techniques and devices. They are useful in achieving an individual goal of self-care as well as in pursuing the relational goal of seeking care.

Navigation knowledge comes from the repeated use of health care and services, from the repeated experience of institutional access and barriers to health care and services, and from searching and finding resources available within and outside the healthcare network (Willis et al. 2016). Patients develop knowledge to ensure they have access to the basic necessities and benefits. This type of knowledge is learnt by using the system, by being lost in the institutional structures, and by learning where the services are and how to access them most efficiently (Fischer et al. 2007). Service users often have a better understanding of the health system than the professionals themselves, having experienced service breakdowns and barriers to access that cannot be seen from an insider's position. This knowledge is procedural in nature, insofar as it helps patients position themselves within a complex machinery of actors and institutions. They get to know what information is perceived as valuable and how to use it to be viewed as credible to be heard by care and service providers. It



is as much about knowing how to make a medical appointment -for instance where to call, with what information, when—as it is about knowing how to present oneself to obtain the needed care and services—for example, by selecting information or using a specific words during an appointment with a specialist versus a general practitioner.

Medical knowledge is the derivative of two dynamics: (1) meeting with medical practitioners and (2) seeking information about the physiological causes and mechanisms of their illness, their symptoms, the options and types of treatments, the side effects and benefits of such treatments, the drug interactions, etc. Patients understand and use medical language, can initiate a discussion about their care and services with knowledge of the science of their disease or condition, can question treatments or medication choices, know what a diagnosis means, and generate some themselves. Often perceived as the realm of doctors and medical staff, medical knowledge is nonetheless mobilized by patients to bargain for a position of credibility during appointments and to make sense of their illness. Medical knowledge can be useful for telling their own story and therefore for being heard and understood by a larger public. It can become a source of empowerment in the search for a balance between caregivers and patient statuses. Patients become familiar with technical or medical terms, use these terms in an accurate manner, and thus meet the expectations of health care professionals by being “good patients” (Collyer et al. 2017).

Relational knowledge is a set of explicit and situated knowledge that enables patients to know who to turn to within their community to access the care they need, to help them with disease management and support the achievement of their life goals. Patients identify the people and organizations that are part of their care team both outside and inside the health care system. Patients develop and sustain a series of relationships that will enable them to obtain and maintain the care they need, and relationships they will rate on a trust scale ranging from blind trust to no trust at all. Yet these relationships will need to be activated at different times to allow both life within the healthcare system to stay minimal and life in the community to be maximized. Relational knowledge sometimes refers to the codes and norms influential to interpersonal relationships and shaping communication with different parties involved in one’s care journey. Relational knowledge is also to learn about the roles each actor plays within the care team, knowing their specialties and their complementarity, how to coordinate their work or avoid conflict. These are not only tools to develop communication skills, but also tools to build judgment. This requires having the words to say things intelligibility for their different interlocutors and may require a certain “culture” when these interlocutors are health professionals. In peer support settings, this knowledge is used to enter therapeutic relationships and sometimes to influence the learning of other patients so that they gain quality of life and autonomy (Gardien 2020).

Cultural knowledge includes the norms, values, symbols, constructions of reality, and worldviews that influence the experience of life and illness. It shapes what is considered as right or wrong and how to act accordingly. Cultural knowledge can help uncover how perceptions of health and sickness are constructed and thus consist of stratified differentiated experiences situated in time and space



(Aldaheri et al. 2022). Examples of how cultural knowledge can influence health communication are multiple: for instance, kinship, age, and gender can be important indicators of who has the right to know and discuss health information with or about another person. Patients know how that can influence their care and what needs to be taken into consideration for the care they need to be provided with respect, to be safe and of quality, in line with their conception of self and their relationship to their community. Patients can identify which norms and values are central to their care and how these are actualized in their health journey. Here, cultural knowledge lies not only in the knowledge of cultural codes but also in how they influence conceptions and preferences about health, care needs, treatment options, and care relationships.

Recognizing patient knowledge: a first step toward partnership and value creation

This knowledge is acquired progressively over the course of a person's journey. They are not all acquired and made explicit for everyone, nor are they easily mobilized in all contexts. Health and social inequalities and social systems of oppression will affect one's capacity to learn and/or mobilize knowledge. For example, self-help and mutual aid groups, online patient forums, patient associations are created in part to balanced out these disparities and stimulate individual and collective empowerment. These venues and spaces where sharing and naming stories occur contribute to the transformation of experience into knowledge and to the realization that this knowledge can become power when harnessed in the right context. While recognizing that we are not all equal when it comes to learning, that not everyone has the same chances of transforming an experience into knowledge, that healthcare systems produce inequalities, we still propose to change the focus from "who" can or cannot acquire and mobilize knowledge to "what" knowledge can be acquired and "where/when" knowledge is acquired along one's journey. We attempt to redistribute the responsibility of learning, which is often left only to patients, by putting it in the hands of professionals as well. By having a clearer idea of the six types of patient knowledge and three sources of acquisition, professionals and decision-makers are partly responsible for mobilizing, activating, and actively developing them throughout the patient's journey. They can no longer be passive in the face of patient learning once their forms have been clarified and the sources of acquisition are identified.

Recognition of patient knowledge and its nature allows both individuals and institutions to account for the important influence of this knowledge on health, on care and service relationships, and on the creation of value in the health and social services system. In many ways, a classification of patient knowledge provides a clear identification and definition of the array of knowledge acquired by patients, and allows us to better grasp what experiential knowledge consists of and to better position patient knowledge in complementarity with the knowledge of health professionals. Patients' various knowledge draws not only on "*systematic, rational or scientific knowledge, but also on social ideas, religious beliefs,*



situated experiences and specific world views" (Wilcox 2010, p. 55). Defining, differentiating, and classifying patient knowledge enables: (1) the recognition of each form of knowledge as cardinal pillars of building partnership with patients and caregivers; (2) the identification of learning strategies by source of knowledge acquisition; and (3) the development and mobilization of patient knowledge as a vital resource in creating value in the health care system at all levels, clinical, organizational, and political. Therefore, designing interventions to develop patient knowledge early (as a preventive tool) or during the care trajectory allows patients to increase their autonomy and, above all, rebalance the power relationship that historically undervalues the patients' perspectives, experiences, and preferences. Developing patient knowledge early, even before a diagnosis or crisis, could allow for the strengthening of citizens, patients, and caregivers capacities to be an integral part of the care team early in the care journey. This could lead to quality, safe, and accessible care at the right time. Interventions developed in partnership with patients, considering the multiple dimensions of the patient experience, are most likely to strengthen patients' knowledge, while highlighting their value to healthcare professionals throughout the care journey. In this way, these knowledge-based interventions contribute to strengthening the capacity of both patients and caregivers to mobilize their knowledge and make it a driving force behind a more appropriate and value-creating care plan.

Developing patient knowledge and mobilizing it, for instance through therapeutic patient education, can generate great benefits in terms of access to care and continuity of care provided that the complementarity of the health professionals and patients' knowledge is recognized. Describing and classifying patient knowledge take us away from the issue of interests and preferences of involved parties, biases, and evidence, and redefine care relationships around learning, dialogue, and knowledge exchange.

By way of conclusion, a caveat is in order. Many forms of knowledge coexist in the complex ecosystem of healthcare, dominated by well-documented knowledge-power dynamics. For the plurality and diversity of knowledge to exist, it is imperative to recognize it not only as a tool, but also as a way of life. In this sense, the knowledge presented in this classification cannot be detached from the contexts and cultures in which they are embedded. This is the enormous limitation of a classification work such as this. It has the value of defining better, but the limitation of making the six types of knowledge static and of evacuating their positionality and conflictuality with other coexisting knowledge.

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