

REVIEW ARTICLE

Defining patient's experiential knowledge: Who, what and how patients know. A narrative critical review

Arnaud Halloy¹ | Emmanuelle Simon² | Fabienne Hejoaka³ 

¹LAPCOS, Côte d'Azur University, Nice, France

²CREM, Centre de recherche sur les médiations/Mediation Research Center (EA 3476), University of Lorraine, Metz, France

³LPED, Research Institute for Development/Aix-Marseille University, Marseille, France

Correspondence

Fabienne Hejoaka, LPED – UMR151 – AMU/IRD, Aix Marseille Université – Site St Charles, case 10, 3, place Victor Hugo – CS80249, 13331 Marseille Cedex 3, France.

Email: fabienne.hejoaka@ird.fr

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Abstract

Experiential knowledge is today increasingly valued in health-care practices, public health policies and health research and education programs. However, despite popular and institutional success, the concept remains loosely defined with the result of weakening its heuristic scope and paving the way for its commodification. In this article, we seek to provide a finer characterisation of patients' experiential knowledge's features and specificities through a critical narrative review of humanities and social science (HSS) literature published in English and French (1976–2021). Inspired by Jovchelovitch's analysis of social knowledge, we seek to highlight the diversity and plurality of forms and articulations of knowledge that characterise experiential knowledge, as well as the gradual, dynamic and entangled process that leads from experience to knowledge and expertise. Our analysis points to the need for future research to adopt a resolutely pragmatic and situated orientation in the study of experiential knowledge and the new figures of the contemporary patient that they help to create.

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KEYWORDS

epistemic patterns, experiential knowledge, expertise, patients, situated approach

INTRODUCTION

Background

In 1976, Borkman published a seminal work on experiential knowledge in health. Studying mutual aid groups for 5 years in The Netherlands, New Zealand, Sweden and the United States, the American sociologist characterised the dynamics at play in groups such as Alcoholics Anonymous or those for single parents, patients in remission, consciousness-raising groups for women or groups for people who stammer. A typical feature of self-help groups is the sharing of experiential knowledge, defined as ‘truth learned from personal experience with a phenomenon rather than truth acquired by discursive reasoning, observation, or reflection on information provided by others’ (1976, p. 446). Borkman offers a precise empirical description with epistemological guidelines for comprehending experiential knowledge in the field of health. A fundamental point is that experiential knowledge is individual, pragmatic, holistic and applicable to the ‘here and now’. She outstandingly emphasises the role of the group in the sharing of individual experiences and related knowledge. Nonetheless, since all members of a group are likely to have experiential knowledge, the ability to use it varies among individuals. With time, when sharing within a setting group, experiential knowledge may turn into ‘experiential expertise’ expressing the legitimacy and the ability to use experiential knowledge to resolve problems participants encounter (p. 47).

Borkman’s influential article offers a still relevant contribution that inspired many scholars and gave rise to heuristic critiques, nourishing many analyses and concepts about and around what is known today as experiential knowledge. There is extensive literature that explores the production, uses, circulation and validity of experiential knowledge in the context of various conditions such as chronic illness, mental health and disabilities. Furthermore, as patient involvement became a central aim for public health policies, ‘experiential knowledge’ also has become a key concept increasingly considered by patients, patient associations, health-care institutions and national policies promoting patients’ and users’ participation in health care (Jones et al., 2020; Jouet et al., 2010; Näslund, 2020). However, despite popular and institutional success, the concept remains loosely defined with the result of weakening its heuristic scope and paving the way for its commodification. The term ‘experiential knowledge’, as it is currently used, is a polysemous, catch-all concept that applies to myriad definitions. In the scientific literature, the concept is rarely defined explicitly or is solely evoked in a broad and imprecise way as ‘knowledge derived from patient experiences’. These vague definitions—and, more generally, the lack of epistemological analyses—have been noted by several authors. The risk with such conceptual (mis)uses is the weakening of its heuristic scope, leading, as Castro presaged, to ‘poor understanding and miscommunication among researchers, health practitioners, and policymakers’ instead of ‘proposing a conceptual model [...] facilitating implementations in practice’ (2018, p. 307).

Methods

In this article, we seek to provide a finer characterisation of patients’ experiential knowledge’s features and specificities through a critical narrative review of literature in humanities and

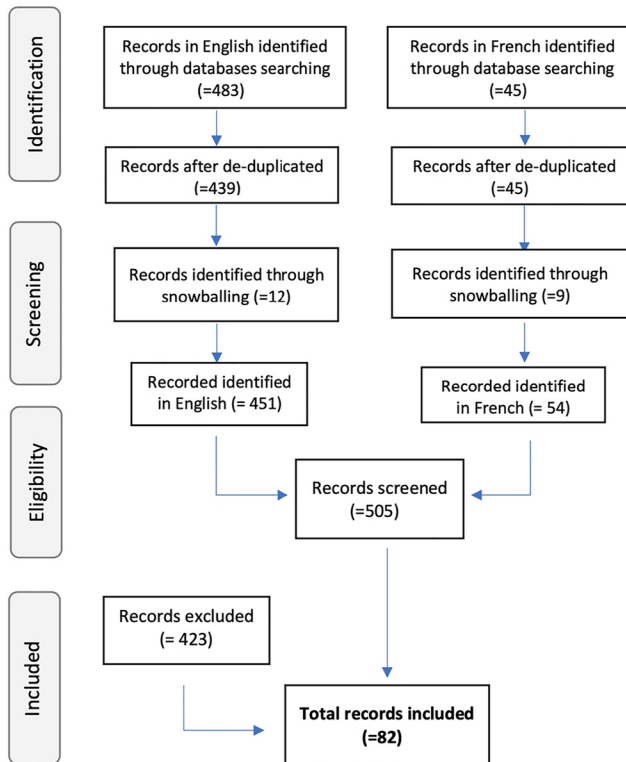


FIGURE 1 Screening of articles to be included.

social science (HSS).¹ As French and Belgian researchers, we wished to broaden the scope of the critical analysis by integrating scientific works published in French that are poorly known or unknown by non-French specialists. Therefore, a search on three electronic databases was performed and completed, including articles published between 1976 and 2021 in English and French. For the review of English articles, two databases were searched (PUBMED and Web of Science); the following words were researched in the abstracts: ‘experiential knowledge’ AND illness/OR disease*. For the review in French, one database was searched (CAIRN) with the following keywords entered: ‘savoir* expérientiel*’ AND maladie*/OR santé. A total of 528 references (483 in English and 45 in French) were identified and imported into the bibliographic management tool Zotero; duplicates were removed. We also identified 21 works, through snowballing techniques. Out of the 505 remaining articles, we screened titles and abstracts to exclude irrelevant records and finally selected a total of 82 full texts for further assessment.

For an overview of the search process and included studies, see Figure 1.

Only publications with a detailed definition of ‘experiential knowledge’, conceptualisation or providing a convincing epistemological analysis were integrated. We only retained articles addressing patients’ experiential knowledge, excluding those exclusively addressing health-care workers’ or carers’ ones. Furthermore, to support the analysis, we occasionally refer to works that use synonymous terms or alternative concepts (such as ‘lay knowledge’ (Popay & Williams, 1996) or ‘expert by experience’ (Barker & Maguire, 2017)). Only references mentioned in the text have been kept in the bibliography.

The 'who', the 'what' and the 'how' of experiential knowledge: An epistemological path

Partly inspired by Jovchelovitch's (2007) analysis of social knowledge, we structured the analysis of the literature review around an epistemological framework based on three dimensions of experiential knowledge: the 'who', the 'what' and the 'how' patients know. The 'who' dimension is related to identity but also to the status and positioning of patients in their social field (Jovchelovitch, 2007). The 'what' of experiential knowledge helps to understand the content ascribed to it as well as its historical and cultural 'anchoring', what Jovchelovitch calls 'the solidity of the symbolic environments' (p. 111). If the 'what' of experiential knowledge is firstly about signification, it is closely 'intertwined to processes of construction of signification' (p. 112), that is, 'the how' of experiential knowledge, our third epistemological step. The 'how' is what links knowledge and context. It is about styles and patterns of communication and how they 'can shape a certain outlook and knowledge of the world' (p. 104). By contributing to the development of a definition of experiential knowledge that is attentive to *who what* and *how* patients know, this article aims to lay a more solid ground for what can potentially be done with experiential knowledge, given the different issues and contexts of its use. Our analysis points to the need for future research to adopt a resolutely pragmatic and situated orientation in the study of experiential knowledge and the new figures of the contemporary patient that they help to create. Contexts, as we defend, are an integral part of experiential knowledge. In other words, what patients know is inseparable from who they are and how they come to know. If experiential knowledge, as we will see, is indeed individual knowledge, it is socially produced.

THE 'WHO' OF EXPERIENTIAL KNOWLEDGE: IDENTITY, VALIDITY AND LEGITIMACY

Over the last 20 years, public health systems in many northern countries have constantly affirmed the relevance of involving users and giving them the opportunity to participate in individual and collective health choices at all stages of the care process. This movement has given rise to a wide-ranging debate on the recognition of new forms of expertise in the field of health—in this case, forms of expertise derived from the experience of living with illness or disability. New figures of the so-called 'contemporary patient' (Bureau-Point & Hermann-Mesfen, 2014; Sarradon-Eck, 2019) and associated stakeholders have emerged, such as lay experts (Akrich & Rabeharisoa, 2012; Rabeharisoa et al., 2014), expert patients (Boudier et al., 2012; Flora, 2014; Klein, 2014), user experts (Jouet et al., 2010), patient-trainers (Flora, 2014), patient-partners (Karazivan et al., 2015) and experiential experts in England (Noorani, 2013; Scourfield, 2010) or médiateurs de santé-pairs (MSP) and patient-intervenants/experts in France (Troisoeufs, 2020). Paradoxically, the knowledge or expertise derived from living with illness that justifies their involvement in care (Vahdat et al., 2014), as well as in research (Harrington et al., 2020) and education (Tourette-Turgis & Thievenaz, 2014) is also what disqualifies them from contributing effectively to the health system (Autès, 2014; Scourfield, 2010).

Recognition and validity are central issues when we ask the question of 'who' holds experiential knowledge. Recognition is about the identity of knowers, their social and professional status, their positioning in clinical practice, health systems, training, clinical trials, as well as their life experience with a health condition. Validity raises the issue of legitimacy, that is, how different forms of knowledge coexist and how the perspective of others is actually taken into account.

Recognising patients as legitimate holders of a certain type of knowledge has never been an easy task as patients are always 'historically and socially situated agents, who meet in public arenas as already constituted ontologies, positioned by social and economic determinants and by a set of social and collective representations that pre-establish the overall conditions in which they meet and upon which they act.' (Jovchelovitch, 2007, p. 139). With regard to experiential knowledge, it is commonly described from the viewpoint of medical knowledge, with a risk of being perceived as inferior (Boardman, 2017). Some authors argue that this most often contributes to rejecting experiential knowledge as 'lay beliefs' (Popay & Williams, 1996) or convictions (Lopes, 2009, p. 39). Emblematic cases are 'medically-ill-defined' conditions or 'medically unexplained symptoms (MUS)' such as fibromyalgia or chronic fatigue syndrome where 'diagnosis relies heavily on the patient's telling of symptoms and practitioners willingness to take the experience seriously and define it as illness.' (Cooper & Gilbert, 2017, p. 338). Who the patients are is largely based on the type of knowledge they are attributed. For Popay and Williams (1996), some patients are carriers of what they call 'lay knowledge' that can help improve understanding of the aetiology of a disease, but it is often dismissed by professionals who reject patient interpretations in the name of science, which is supposedly the only way to gain objective knowledge. They (1996) take a critical perspective of science, in that its hegemonic attitude inevitably leads to excluding certain stakeholders from the debate as well as modes of production of various types of knowledge. They argue that public health should not reject knowledge from other methodological processes outright and should broaden its perspective to include them (p. 766). According to the authors, with respect to public health, the policy of classifying knowledge as either being scientific and therefore valid or as not having a scientific basis precludes the possibility of scientific research that includes the patient's context. In the same vein, Dutch public health researchers Caron-Flinterman et al. (2005) note that disqualifying experiential knowledge because it is contingent upon a particular context means forgetting that all scientific production must be considered within the context from which it emerged. The authors contend that considering knowledge as valid depends on what is understood by both 'valid' and 'knowledge'. In a classic philosophy of science approach, recognising the status of knowledge requires establishing criteria to be able to determine the reliability and validity of such knowledge. They maintain that it would be wrong to consider its validity against the single source of this knowledge, which in this case is illness experience. They assert that 'Experiential knowledge arises when these experiences are converted, consciously or unconsciously, into a personal insight that enables a patient to cope with individual illness and disability' (p. 2576). The authors describe this as 'utility in context'. If a patient's experiential knowledge can be useful in a given context, it can be considered valid in this context even if one might object that it does not *objectively* represent reality. Experiential knowledge, unlike medical knowledge, is strongly related to the identity and positioning of the patient, sometimes leading to a preponderance, as we will see in the third part of the article of the 'how to know' over the 'what is actually known'.

Furthermore, questioning the validity of experiential knowledge is part of broader and potentially more committed research, that is, can patients' knowledge renew and enrich biomedical knowledge in an Evidence-Based Medicine (EBM²)-centred health care system? To understand what EBM and the associated scientific approach in medical studies do *with* or *to* patients' experiential knowledge, we may look to educational science research by Las Vergnas (2014). What Las Vergnas (2014) shows is that bringing experiential knowledge into biomedical science assumes a formalised process for patients or their support network to enable them to share their expertise in EBM protocols: for medical science to consider experiential knowledge, such knowledge must be translated, formatted and even changed into exploitable elements to be incorporated

into protocols (p. 120). The author notes that in most of the protocols that were analysed, patient's organisations play a decisive role. They help formalise experiential knowledge and incorporate it into the institutionalisation process specific to the development of academic knowledge as described in didactics, that is, knowledge that is 'depersonalised, decontextualised, temporalised (...), formulated, formalised, validated and memorised' (Margolinas, 2012, p. 9). As with the didactic transposition of scientific knowledge towards academic knowledge, Las Vergnas introduces the concept of 'protocolised transposition' or 'academic transposition' of experiential knowledge towards scientific or academic knowledge (2014, p. 112). This raises the question of what is actually produced in the process: it is not quite EBM, nor is it experiential knowledge. But it could certainly be defined as 'impure science'—that is, science that directly considers its social and political implications—which was the term Epstein used concerning the AIDS epidemic in the United States in the 1980s (1996). Las Vergnas also argues that in certain specific therapeutic areas (e.g., psychotherapy or fibromyalgia, which are not included in biomedical nosology classifications) for which 'the effectiveness is measured by the patient's experience' (p. 126), individual mediators can perform this 'academic transposition' by sometimes breaking away from EBM-specific methodologies. Then, new protocols have to be invented, and evaluating experiential knowledge requires thinking about the limits of the EBM models (Gill & Cartwright, 2021). Noorani et al. (2019, p. 217) argue that recognising experiential knowledge requires a break with a quantitative approach. Experiential knowledge is difficult to quantify and does not fit neatly into EBM. This also echoes Faulkner's proposals about 'Mad studies', which advocate for the development of a broad spectrum of research (qualitative and narrative research, participatory and user-controlled research) that would allow the emergence of its own experiential knowledge authority. Opening knowledge validation approaches would therefore make it possible to extend and renew our knowledge about the world of illness (Faulkner, 2017).

Our discussion of how experiential knowledge of patients and peer caregivers finds its place in EBM medicine leads us back to the question of recognition and hierarchies of knowledge. Despite fruitful efforts for putting patients at the centre of health-care services, differentials between experts and 'lay' people and between *and* within community groups, continue to persist (Mazanderani et al., 2020, p. 14). Some diseases in the MUS spectrum, such as fibromyalgia or electrosensitivity, for example, are even more likely to be stigmatised because they affect women with a low education level: while complaining from physical pain, they are typically diagnosed with psychological problems; that is, 'whingers' with 'fragile' personalities (Mik-Meyer, 2011, p. 38). In other words, 'the intersection between gender, class and MUS makes certain perceptions of who the "typical" person suffering from MUS is.' (idem: 37). In the case of patients' or caregivers' experiential knowledge, differentials between forms of knowledge are hardly separable from differentials in the recognition and legitimation of individuals, with some of them deemed fit to get 'a seat at the table' (O'Shea et al., 2019), others not (e.g., mad people supposedly incapable of rational thought, Faulkner, 2017).

Autès (2014) describes several mechanisms that can contribute to the disqualification of the bearers of experiential knowledge within the care space; 'maladjustment' due to the lack of codes shared with carers, 'disqualification' by categorisation (e.g., is the knowledge of a 'survivor' useful for patients still in a psychiatric institution?) and the relegation by discussion of a patient's representative capacity for another (his or her experience would speak only for itself). Finally, if it is understood that experiential knowledge presupposes a certain seniority in the trajectory of illness, learning from one's experience is not necessarily within the reach of everyone in so far as, as Dewey understood well, 'we do not learn from experience... we learn from reflecting on experience'.³ What counts as mere experience, knowledge or expertise is closely linked to who holds

that knowledge and its life trajectory. And to understand what gives authority to the experience of a particular actor, it is now time to look more closely at what they actually know and how they know it.

WHAT PATIENTS KNOW: EXPERIENTIAL AND OTHER TYPES OF KNOWLEDGE

The concept of ‘experiential knowledge’ arises from the collusion of two ubiquitous concepts in Western philosophy: knowledge and experience. Contemporary debates about patient’s experiential knowledge, as we saw in our previous section, focus on the concept of ‘knowledge’, questioning the possibility of producing legitimate knowledge from lived experience. We suggest starting our discussion about what patients know with a brief reflection on the second term, namely: what do we mean by ‘experience’?

In French and English research, the idea of ‘experience’ designates mere experience, that is, an individual and intimate experience of the temporal flow as received by consciousness (Bruner, 1986). As Dilthey writes, the experience can also refer to ‘an experience’, meaning a singular event, ‘the intersubjective articulation of experience, which has a beginning and an ending and thus becomes transformed into an expression’ (Bruner, 1986, p. 6). Contrary to mere experience, an experience is a ‘structure of experience’. In other words, the ‘experiences’ to which Bruner refers are notable experiences that are ‘formative and transformative’ experiences at an individual or collective scale. This view of experience directly echoes what Dewey considered to be as a ‘testing’ (‘mise-à-l’épreuve’ in French) of the world and our knowledge of it (2005). For Dewey, our experience of the world is always partial and cannot be confused with a preceding ‘reality’: the only reality is the one experienced by the subject. As Truc emphasises in his introduction to the French translation of Dewey’s article ‘Reality as Experience’, ‘It is not enough to “try something out” to “have experience” as we say; one must have lived through it—in other words, to have suffered, to have endured the consequences of what you went through’ (Dewey, 2005, p. 83). Enduring the consequences of an experience requires ‘situating’ it, that is, seeing it as a pragmatic response to a given problem or situation. Experience, as envisaged in the expression ‘experiential knowledge’, mostly refers to this pragmatic conception of experience as testing of reality that can transform us. An experience, in Bruner’s sense, and not a ‘mere experience’. With patients’ experiential knowledge, such a transformative process would mainly rely on the second term of the equation: the acquisition of knowledge through the living of the experience of illness.

In her seminal paper, Borkman identified four characteristics of experiential knowledge that she contrasted with professional knowledge: First, it is individual: ‘Since this knowledge is the property of the individual, it is self-determining, in that the possessor has to use his judgement making decisions in his area of competence’. Second, it is pragmatic rather than theoretical or scientific in that it is produced from ‘concrete results that “work,” as subjectively perceived by the individual who is going through an experience’. Third, it relates to ‘here-and-now action rather than to the long-term development and systematic accumulation of knowledge’. Fourth, it is holistic rather than segmented, ‘in that it encompasses the total phenomenon experienced’ as perceived by patients or carers. While doctors focus on the diagnosis, patients are concerned about the prognosis, such as when the parents of a sick child worry about the consequences of a diagnosis on their child’s socialisation (1976, p. 449). Experiential knowledge would also contrast with professional knowledge as it is determined by the specific ‘type of information’ on which

it is based: 'The type of information is wisdom and know-how gained from personal participation in a phenomenon instead of isolated, unorganised bits of facts and feelings upon which a person has not reflected. This wisdom and know-how tend to be concrete, specific, and common sensical, since they are based on the individual's actual experience, which is unique, limited, and more or less representative of the experience of others who have the same problem' (*ibid.*, 446). In a nutshell, experiential knowledge is, according to Borkman, individual rather than collective, concrete rather than abstract, related to the here-and-now action rather than long-term accumulation of knowledge, holistic rather than segmented and would rely mainly on subjective reflection (wisdom) and practical knowledge rather than the transmission of propositional knowledge. In the light of contemporary research on patients' experiential knowledge and patient expertise, these different characteristics now need to be qualified.

The first question concerns the nature of the knowledge that makes up experiential knowledge. In 2005, Caron-Flinterman, Broerse and Bunders suggested a distinction between three types of knowledge constitutive of experiential knowledge: 'propositional knowledge' ('knowing that': 'I know that eating fatty foods can have an impact on my health'), 'practical knowledge' or know-how ('I know how to use my inhaler') and 'knowledge by acquaintance'. This last type of knowledge refers to knowledge that is implicit or acquired by a patient's bodily experience ('I know that rheumatoid arthritis in my fingers feels like this'). For Caron-Flinterman, propositional knowledge is an integral part of experiential knowledge as well as knowledge by acquaintance, even if it remains largely implicit as it is not necessarily subject to reflective feedback or awareness.

These authors also describe the possibility of shifts between types of knowledge and consider that each type is not specific to a single category of stakeholders. Patients develop knowledge through acquaintance as they become familiar with an illness and its treatments. They also develop practical knowledge to cope with it. Furthermore, through regular observation and sharing with peers, patients can also develop propositional knowledge. Experiential knowledge, in other words, is composite in nature and, moreover, subject to what we might call forms of knowledge hybridisation. Eve Gardien (2017) indeed, notes that 'an act or practice quite often involves a range of practical and theoretical knowledge that is closely interrelated or even intertwined', independently of a person's awareness of the knowledge that he or she may effectively use during daily activities. Any act of care or self-care, therefore, uses both practical and theoretical knowledge. For example, to regulate their blood sugar, patients with diabetes must learn how to complete a series of technical steps to measure their blood glucose level or modify it by injecting insulin if necessary. But they must also learn to anticipate episodes of hypoglycemia or hyperglycemia to differentiate between rapid- and long-acting types of insulin as well as their different effects, etc. This requires applying a whole range of knowledge and skills, from perception and discrimination of relevant somatic cues to motor skills and propositional knowledge based on reading, testimonies and past experiences.

Thus, the knowledge that makes up experiential knowledge is not only plural but also transformed once it is caught up in the practices in which it is mobilised. We return to this key point in more detail in the next section. Another step aside from Borkman's definition concerns the source of experiential knowledge. While the sociologist identifies wisdom and know-how as the main 'types of information' on which experiential knowledge is based, the anthropologist Mendes Lopes (2009), building on Nichter and Vuckovic's (1994), differentiate between 'spontaneous' or 'empirical knowledge' through trial and error, 'confirmed knowledge' based on examples and 'mediated knowledge' based on information. Experiential knowledge would be organised according to these learning conditions and would provide patients with the necessary

interpretation grid required to internalise biomedical knowledge and make something out of it. These different modes of acquisition reflect the processual nature of experiential knowledge, which can indeed be 'systematically accumulated' over the long term and integrated individually from fragments of information gleaned here and there during the trajectory with the disease.

Whereas almost half a century ago, Borkman drew our attention to the experiential knowledge of patients, the contemporary debate questions the place of scientific knowledge in experiential knowledge, and in particular in relation to patient 'expertise'. Two alternative positions to the opposition of experiential and scientific knowledge (for Borkman, they differ in nature as well as in their mode of acquisition) can be identified. The first, which we adopt in this article, emphasises the plural and hybrid character of experiential knowledge, thought of as a continuum between lay knowledge and biomedical knowledge. The second, which follows the footsteps of Borkman, considers experiential knowledge as one component among a multitude of other types of knowledge, including scientific knowledge. Let's begin with the second approach.

For some authors, patient expertise goes 'beyond' experiential knowledge. According to Gross (2017), expert patients do things that 'aim to fix their environment', relying not only on experiential knowledge (understood by the author as individual knowledge) but also on knowledge and skills acquired collectively. Expert patients are involved in a process of empowerment (group level) that she defines as the ability to influence one's environment and which 'encompasses and extends beyond self-determination' which 'gives people the ability to make their own decisions' (individual level) (2017, p. 27). Because expert patients have knowledge that is more than just experiential, the way they use medical and scientific knowledge is another issue. Three types of expert patients emerge: they may actively seek out health information (scientific and medical), participate in self-help groups or get involved in policy-making. Depending on the type of expert patient, Gross and Gagnayre (2014) suggest that these stakeholders are motivated by 'cognitive passion' (decoding, dissemination, etc. of medical and scientific knowledge) or 'conative passion' (oriented towards action: improving access to care, peer support). The authors present experiential knowledge as being insufficient to respond to the passions that motivate these stakeholders, who use both individual and group experiential knowledge as well as academic knowledge. Passion leads expert patients to push back the boundaries and 'shake up the state of knowledge or the health system' (ibid., p. 49).

In our perspective, any knowledge that is put to the test (*mis à l'épreuve*) of reality in the lives of patients is considered to be part of their experience. This is the case for know-how, life skills and propositional knowledge. All these forms of knowledge, as we have seen, are likely to be integrated into the patient's life, whether it is a question of care as such or of what he or she aims to do with this knowledge, and experiential knowledge is subject to a hybridisation process where the coexistence of different types of knowledge dialogue in the same community and/or in the same individual giving rise to the transformation or creation of new knowledge over time. Prior (2003) argues that while most of the time, lay people can acquire personal knowledge of their disease and master certain medical concepts, they cannot be considered as experts. For Prior, if the focus is on the 'lay' aspect, which by definition means a non-expert, it follows that 'lay expert' is an oxymoron. However, there is more ambiguity if the emphasis is placed on the idea of 'expert', meaning a person with experience. If patients are experts, it would be in line with this second meaning. They may become experts 'on their own bodies and behaviours (or the bodies and behaviours of others)' (p. 49) or on living with their diseases, which is to say, how to best understand and cope with them. That said, their knowledge of the disease and its consequences (knowing that) will often remain quite limited and possibly even erroneous. According to Prior (2003), 'expertise' remains associated with biomedical knowledge and groups of scientifically trained experts and medical professionals.

Over the last 20 years, however, several forms of expertise have been recognised for certain categories of patients in the academic world. We mentioned a series of new figures of the contemporary patient in the introduction to the section ‘The Who of experiential knowledge’ It would require the development of social and communicational skills (which are part of the expert-patients toolkit: Flora, 2015) that consists of being able to put one’s own experience into words and produce a common language to accompany others in their own journey with the disease. From being mere holders of ‘lay knowledge’, some patients now tend to be recognised as experts for others by professionalising their experience of illness, thus shaking up the perimeter of experiential knowledge. Scourfield, in his work on the involvement of ‘experts by experience’ in the Commission for Social Care Inspection in England, describes how the term ‘lay assessor’ has gradually given way to ‘experts by experience’ in the texts of this organisation. This brings us back to the question of ‘who’, that is, the question of the legitimacy and authority conferred by this knowledge? In this context of professionalisation of experience, how can we designate an expert by experience? According to what criteria? And who decides on these criteria? (Scourfield, 2010). Scourfield also emphasises the potential effects of these new patient roles. In a society where expertise is regularly questioned in the public arena, is claiming to be an ‘expert’ for a patient not therefore exposing oneself and increasing the risk of the actors’ vulnerability?

If the two conceptions of experiential knowledge and expertise that we have outlined differ on the boundaries of experiential knowledge, both definitions emphasise the plural and processual nature of patients’ knowledge. Rather than a closed repertoire of available knowledge, experiential knowledge is a matter of ‘practice of knowing’ (Pols, 2013) bounded to everyday life and closely dependent on the contexts and institutions in which they are fostered. In Jovchelovitch’s words: ‘the concrete social conditions within which knowledge develops are intrinsic to the process of knowledge formation and shape the internal structure of knowledge’ (ibid., p. 167). This is why we turn now to the ‘how’ question of experiential knowledge.

HOW PATIENTS KNOW: BUILDING EXPERIENTIAL KNOWLEDGE

Starting once again from Borkman’s seminal work, we learn that it is through ‘public confessions’ and testimonies that the importance of knowledge and experiential expertise is expressed (ibid., p. 47). Borkman hypothesised that by sharing experiences, individuals gain insight into what makes their experience unique as well as what is common to others’ experiences, and in doing so, identify what is useful for coping with the disease. There is today a consensus in the contemporary scientific literature that experiential knowledge is developed through collective and sustained sharing between peers and is the result of personal reflexive work. *De facto* experiential knowledge emerges through interactions between the patient and other patients within different mediation spaces: self-help groups (Borkman, 1976), peer groups (Godrie, 2016a), mutual help groups (Noorani et al., 2019) or the Internet and social media (Akrich, 2010; Aubé & Thoër, 2010; Näslund, 2020). Interaction and communication with others are crucial as they contribute to patient’s lengthy ‘work’ of increasing their awareness, questioning, development, retrospection, reassessment and sharing (Thievenaz et al., 2013). The French language conceptual distinction between *savoir* and *connaissance* can be extremely useful when considering the nature of experiential knowledge and the situations in which it develops. Individual experience, understood as *an* experience, would undergo a shift in status from *connaissance* (the process through which knowledge is acquired) to *savoir expérientiel* or experiential knowledge (a set of collectively validated *connaissances*) through sharing with peers dealing with the same condition

either as patient or carer. Jodelet (2014) compares this action of sharing knowledge to the concept of 'biosociality' developed by Rabinow (2010), which refers to new kinds of social interactions and subjectivity within communities based on a common diagnosis.

We observe that much of the research on experiential knowledge and expertise focuses on peer groups. Their characteristics are now better known (Grundman et al., 2020). But other spaces can also see the emergence of patient experiential knowledge. Authors such as Abel and Browner (1998) broadened the question of sharing experiential knowledge to include carers. They developed two alternative concepts to describe experiential knowledge in action. Based on a study of sources of 'resistance' to or non-compliance with medical advice offered to women, the authors distinguish 'embodied knowledge', which refers to mobilising a woman's bodily experience (here, past pregnancies) and 'empathetic knowledge', which comes from a 'long and close relationship with people under their care'. This distinction between 'embodied knowledge' and 'empathetic knowledge' underlines the need to consider the experiential knowledge acquired by a patient enrolled in a complex support network with a plurality of links and actors: family and friends, peer support specialists, health-care professionals as well as the experiential knowledge of patients about other patients. Social and communicative skills appear to be constitutive elements of experiential knowledge.

Furthermore, sharing knowledge on diagnoses and common experience with peers is neither systematic nor automatic. For example, living with an illness such as osteoporosis—which is often asymptomatic and is considered by many patients to be a normal part of the ageing process—will not necessarily help build experiential knowledge. Indeed, osteoporosis is often perceived by patients as a non-event. For Tourette-Turgis (2013), 'living another life' or making life acceptable with a chronic disease, a mental illness or a disability should characterise experiential knowledge, which depends on the patient's ability to overcome the ordeal inflicted. In certain cases, the non-emergence of this knowledge is a reminder of the need to consider the period during which the disease manifests and patients' care journeys, since experiential knowledge is intrinsically contextual. Certain patients, overwhelmed by the violence of illness, 'lack emotional stability and perspective, which are presented as two important characteristics for being able to use experiential knowledge and help people with similar experiences' (Godrie, 2016b, p. 35). Being diagnosed with an illness, worsening clinical signs, a failed treatment, fatigue or depression caused by the disease or a relapse are all trying events that can limit both the sharing and appropriation of experiential knowledge. As Gardien (2019, pp. 103–104) puts it, there is a 'cost' to producing experiential knowledge; a high *cognitive cost* due to the 'numerical weakness of the holders' and few opportunities for sharing and transmission to the 'difficulty of their elaboration' as well as a 'recurrent doubt about their relevance and usefulness'; a high *social cost* due to the normative gap between the sick person and the healthy as experiential knowledge is (still) not considered, as we have seen, as legitimate knowledge in its own right.

Mazanderani et al. (2012, p. 547) raise another difficulty in turning 'other patients' experiences into a source of knowledge and support'. They call it the process of '*identity work* that takes place to turn other people's experiences into epistemologically meaningful and emotionally manageable sources of knowledge' (ibid). While a common diagnosis is necessary for the identifying process, 'identity tensions' (ibid) may appear, and identity creation is not systematic and may even be impossible or resisted. This can happen, for example, when expert patients have a more serious case or advanced stage of a disease. Patients adopt a partial identity, which leads them to see themselves as 'being differently the same' in order to benefit from their peers' experiences. Blume also highlights identity work, pointing to the fact that for a given diagnosis, an experience with illness tends to be considered 'equivalent in terms of its validity or utility'

(2017, p. 7), irrespective of factors such as gender, age, ethnicity or socioeconomic status that condition identity, as well as a person's access and relationship to the health system and information, and more generally, the everyday experience with illness. Blume also notes that individual experiential knowledge, although based on the daily experience of illness, may be ignored or rejected by others (*ibid.*) based on the person's sociological and/or psychological characteristics, such as a lack of literacy, difficulties of putting their illness into words, over-sensibility or other characteristics of the patient. The lack of medical recognition of the illness, as in the case of 'illnesses that you have to fight to get' (Dumit, 2006), can also contribute to delegitimising the sufferer's voice.

This difficulty in considering the diversity of experiential knowledge within the same group of patients is described by Näslund as the risk of essentialising identity associated with experiential knowledge (2020). According to the author, it is not the experience as such that founds the knowledge but a process, described as narrative, social and political and it is this process that is convenient to describe. Näslund mentions the 'risk of narratives turning into [...] providing voyeuristic insights into intimate and emotional subjects, without any substantial transfer of power taking place' (2020). Sweitzer (2020), in her work on peers' perceptions of experiential knowledge, even speaks of epistemic injustice. Peer helpers speak of a tendency to reduce the political significance of their experience to mere testimony. Many perceive the injunction to tell their stories as a delegation of the dirty work. This requires us to question how sharing patients' experiences in the form of narratives (Borkman, 1976) allows experiential knowledge to emerge? To answer this question, we can turn to the recent work of Noorani et al. (2019). Noorani et al. are interested in another form of heterogeneity in experiential knowledge: heterogeneity of depth. The authors reaffirm that experiential knowledge arises by 'embodied practices of experimentation, whose results are shared amongst other group members' (221). Rejecting a numerical/quantitative approach (see 'who' section), the authors argue that this is not an addition of experience narratives but their setting in a narrative that counts. And over time, 'deep experiential knowledge' (i.e., consolidated and not hegemonic) is shaped, which implies recognising that within a peer group, elders play a prominent role. 'By absorbing the collective stories of the group, the old-timers come to embody the collective in the singular, interpreting the multiplicity through their own lens' (224). These skilled actors can identify what is common and singular in a particular narrative. They are able to ask good questions to help make sense of the experience. They are also able to discriminate between false or at least truncated narratives.

By articulating an interpretative and pragmatic approach, Pols proposes another enlightening analysis of the collective elaboration process of experiential knowledge. Based on a study conducted on patients with chronic obstructive pulmonary disease (COPD), with a cross-disciplinary approach to STS and disability studies, Pols (2013) shows how patient's ability to improvise and be creative has been implemented and improved thanks to a 'caring community' established by the same patients using a network of webcams after their return home (after a 3-month stay in a rehabilitation hospital). Besides 'propositional knowledge' about their illness and how to cope and 'procedural knowledge' incorporated into gestures, ways of taking note of and reacting to certain symptoms, patients had an opportunity to develop and cultivate what Pols calls a 'know-now', which corresponds to a 'context-sensitive' ability to improvise and adapt, which is necessary to cope with the unthinkable aspects of a chronic disease or disability. Rather than a repertoire of knowledge, know-now is a 'repertoire of possibilities to react to a situation' (Pols, 2013, p. 81). The main resource is the patient's body or rather 'a network of bodies that function as "measuring stations" and "sources of knowledge"' (Pols, 2013, p. 82). In this example, the issue is less about identifying a body of knowledge than 'knowing in action' (*ibid.*, p. 75), 'a

form of practical knowledge that does not sit inside textbooks or in heads. It is part of practices, devices, and situations' (ibid., p. 83). Such a more 'pragmatic' approach undoubtedly sheds light on the fragmentary and complex nature of experiential knowledge without seeing it as a weakness, a lack of depth but rather as a strength for dealing with the instability of patients' daily lives (Boardman, 2017, p. 187).

WHAT FOR EXPERIENTIAL KNOWLEDGE? CONCLUSIVE REMARKS

Following Pols and Hoogsteyns (2015, p. 3), we argue that experiential knowledge should be seen as 'interpretive and pragmatic skills' aimed at the best possible life with an illness or disability. Not just a store of knowledge *about* the world but knowledge *in* the world or 'capabilities', that is 'the actual functioning that individuals value, but also the functioning they would have in another situation.' (Gross, 2017, p. 28). Such 'power-to-say', 'power-to-do' and 'power-to-be' (ibid.) are composite and are characterised by the fact that they are experienced in situation, in the sense of a testing of the world, of its knowledge and of what it is possible to do and be in it with an illness or disability. This definition may seem consistent with a key feature of what Castro et al. (2018) mean by 'experiential expertise', that is, 'the degree in which one has integrated the information and is competent to share the knowledge to others'. But it seems to us that the distinction the authors make between 'mostly implicit' experiential knowledge and 'explicit and transferable' 'experiential expertise' (ibid., p. 314) risks overshadowing the diversity and plurality of forms and articulations of knowledge that characterise experiential knowledge, as well as the more gradual, dynamic and entangled process that leads from experience to knowledge and expertise. In our view, the difference between experiential knowledge and expertise is, first of all, a difference of degree, and what Castro et al. call 'expertise' is more a matter of social recognition by peers and/or institutions where 'experts-by-experience' mobilise their experiential knowledge than of *elicitation* of knowledge. In our view, the 'appropriate competencies to articulate experiential knowledge' (attitude, skills and knowledge to put experiential knowledge into action) are an integral part of experiential knowledge. Rather, we suggest that the difference between experiential knowledge and expertise would lie in their level of transferability, that is, the ability to bridge epistemic worlds by translating one form of knowing into another. Expert patients develop such ability by mobilising and connecting distinct forms of experiential knowledge between distinct social spheres, from the microlevel of experience to the meso (social [stigma], care organisation), macro (policies, legislation) and meta (research and education) levels.

Across this continuum, it is possible to identify at least four epistemic patterns or relationships with regard to the lived experience of illness: (1) the patient experience of illness or disability; (2) the individual *knowledge* (*connaissances* in French), the know-how and know-now that are developed based on *an* individual experience; (3) experiential *knowledge* (*savoirs* in French) that tends to be developed and formalised at a collective level; (4) experiential expertise, that is, the transferability of distinct forms of experiential knowledge between epistemic worlds. These epistemic patterns are neither fixed (they may occur at different stages of a patient's journey) nor compulsory (not every health condition necessarily leads to each of these epistemic patterns). However, identifying them makes it possible to better grasp the shifting relationships between experience, knowledge and expertise within the context of illness and patients' care journeys, especially for patients with chronic conditions.

At least two conditions appear to be essential for turning experience into experiential knowledge: the experience must be placed within a specific *context*—*an* experience—and one must

be able to *appropriate*—in order to do something with it. The first condition corresponds to the situated and intersubjective nature of experiential knowledge, which was already present in Borkman's seminal text: intersubjectivity within peer groups, for example, is a critical element in developing knowledge from direct experience. This first condition underlines the need to identify the favourable and unfavourable conditions for the emergence of experiential knowledge. In other words, the need to theorise contexts (Jovchelovitch, 2007). Much research on experiential knowledge and expertise, as we have seen, focuses on peer groups. However, the importance of other learning contexts such as the home, online forums, social networks, health institutions, non-conventional therapeutic practices, etc. should not be underestimated. If peer-to-peer groups play an essential role in building experiential knowledge for many patients, it is necessary to recognise that experiential knowledge is also constructed in a confrontation with oneself, which is generally little mentioned and problematised. The second condition raises the question of experiential knowledge's fundamental functions. At least three of them have been highlighted. First, they offer a grip on reality. On the one hand, they allow patients to make sense of their disease or disability and, on the other, to develop 'logics of care' (Halloy, 2021; Mol, 2008) and coping. Secondly, they do what Jovchelovitch believes to be the main function of all representation, namely 'to deal with the unknown and make the unfamiliar familiar' (2007, p. 112). They reduce the anxiety of uncertainty associated with most chronic illnesses, psychiatric conditions or disabilities and allow the cultivation of a sense of hope, an essential ingredient for coping strategies. Finally, patients develop a sense of belonging within communities of practice, where they learn through participation and sharing with peers. Learning and becoming and the 'what' and 'who' dimensions of experiential knowledge are mutually constitutive in the process of participating and elaborating knowledge from one's experience of illness within communities and social spheres (Lave & Wenger, 1991).

To conclude, if constructing experiential knowledge is inseparable from the contexts in which they are elaborated, these contexts are inevitably traversed by power struggles and the risk of instrumentalisation or even commodification (Lupton, 2014; Mazanderani et al., 2020), as experiential knowledge is today increasingly valued in policies of health services. But here again, we are led to question the places, times, conditions and modalities of the constitution of experiential knowledge and of the epistemic communities they help to establish. The hierarchies of knowledge and their possible commodification are at the heart of discussions on the new discriminations between and within communities in which patients and their relatives participate. These questions encourage us to adopt a resolutely pragmatic and situated orientation in the study of experiential knowledge and the new figures of the contemporary patient that they help to create.

AUTHOR CONTRIBUTIONS

Arnaud Halloy: Conceptualization; Formal analysis; Methodology; Validation; Writing – original draft; Writing – review & editing. **Emmanuelle Simon:** Conceptualization; Data curation; Formal analysis; Funding acquisition; Methodology; Project administration; Supervision; Validation; Writing – original draft; Writing – review & editing. **Fabienne Hejoaka:** Conceptualization; Data curation; Formal analysis; Investigation; Methodology; Project administration; Resources; Supervision; Validation; Writing – original draft; Writing – review & editing.

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DATA AVAILABILITY STATEMENT

Data sharing not applicable to this article as no datasets were generated or analysed during the current study.

ORCID

Fabienne Hejoaka  <https://orcid.org/0000-0002-5205-7282>

ENDNOTES

- ¹ This review of the literature was initially carried out as part of the FAMWEST research project, funded by the Rare Disease Foundation (France). This multidisciplinary study questioning the constructions of experiential knowledge of parents confronting to the West syndrome, a rare and severe type of epilepsy disorder that *appear during infancy or early childhood*. The literature review was also used for the edition of a book directed by Simon et al. (2019).
- ² Evidence-based medicine (EBM) is a method of evaluating clinical practice based on a hierarchy of levels of evidence. In this model, the double-armed, double-blind, randomised clinical trial is the highest level of evidence (Masic et al., 2008).
- ³ For critical history of this well-known quote attributed to Dewey, see Lagueux (2021).

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