Experto crede

Patient knowledge formation in health communities on Facebook

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The article explains the processes involved in knowledge sharing and support giving in an open FB forum dedicated to endometriosis. It builds on the existing understanding of experiential knowledge, as well as adopts Jovchelovitch's (2007) perspective on knowledge diversity and representation which views knowledge construction as an intersubjective process. The analysis looks at the what, the who, and the how of the community in question, focusing in particular on three areas: identity work (self- and other-categorisation); perspective sharing and recognition by "significant others"; and epistemic self-other positioning. The analysis determines the most common strategies of categorisation, identifies ways of constructing shared understanding, as well as reveals that the participants' personal truths are based primarily on their embodied experience and hearsay.

Keywords: community of practice, intersubjectivity, online forum, patient knowledge, stance

1. Introduction

As aptly observed by Jovchelovitch (2007, 1), "[t]he problem of knowledge does not go away." Indeed, the issue of what constitutes genuine knowledge has long troubled philosophers, psychologists and social scientists, and it continues to perplex us today. Early epistemology favoured the view that the knower is separate from the object of knowing, and that certain truth exists, which is fixed, outside consciousness, and distinct from nonknowledge, opinion and belief. More recent approaches, however, suggest that the bases for claim making are to be sought within communities and that "the scientific quest for a universal Truth is no longer a compelling aspiration" (Miller and Fox 2001, 668). Similarly, the positivist

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approach, emphasising logical truth and empirical proof, has given way to an awareness that scientific inquiry is a social endeavour and that, as such, it may be the object of sociological investigation (Miller and Fox 2001, 669). This is all the more relevant in today's unstable world that is facing a range of knowledge concerns including knowledge societies, knowledge economies, and the management of knowledge (Jovchelovitch 2007, 1), as well as novel knowledge production and transmission practices, in addition to redefined epistemic relations. In light of these developments – with the social construction of reality being an accepted fact – communication scholars try to explain how individuals construct and represent the world in dialogic ways, utilizing new tools for both knowledge creation and dissemination. Such investigations include, among other issues, the expert-lay interface and health knowledge formation in online communities, that is on sites where existing hierarchies of knowledge are being challenged and where nonexpert voices are gaining more prominence.

With this in mind, and taking a social constructivist perspective, I argue that the analysis of virtual communities centred around an illness may be a fruitful enterprise that can deepen our understanding of how health knowledge, a "small-*t* local truth" (Miller and Fox 2001), arises in online multi-party interactions. To this end, I take a closer look at a Polish virtual community of FB users addressing the problem of endometriosis, a painful condition affecting millions of women and often making their daily lives extremely difficult. I seek, in particular, to highlight community-driven knowledge formation, i.e. the "how" of the community, involving both information exchange and emotion sharing through goal-oriented dialogic action (Weigand 2021). The investigation covers three areas: identity work (self- and other-categorisation), perspective sharing and recognition by "significant others" (dialogic resonances), and epistemic self-other positioning. It thus offers a unique characterisation of experiential knowledge formation among Polish women suffering from endometriosis.

2. Background

2.1 What is patient knowledge?

The last two decades or so have seen a proliferation of studies focusing on health communication and a re-assessment of the lay understanding of health and illness, as reflected in the use of terms such as "lay expert" (Prior 2003), "expert by experience" (Barker and Maguire 2017), "experiential expertise" (Castro et al. 2018), or, most notably, "experiential knowledge" (Blume 2017; Halloy et al. 2022). Arising from "the collusion of two ubiquitous concepts in Western philosophy:

knowledge and experience" (Halloy et al. 2022, 411), the concept of experiential knowledge was originally conceived by Borkman (1976) as "truth learned from personal experience with a phenomenon rather than truth acquired by discursive reasoning, observation, or reflection on information provided by others" (2022, 446). According to this standpoint, experiential knowledge, unlike professional knowledge, is pragmatic (rather than theoretical or scientific), oriented to the here-and-now (rather than long-term and systematic), and holistic (rather than segmented) (Borkman 1976). Most importantly, as argued by Borkman (1976) citing Hurvitz (1970), experiential knowledge emerges in interactions with "significant others", that is peers who serve as role models for each other and who are able to empathise with each other owing to their shared life experiences. It is thus a self-help resource involving not only information exchange, but also individuals' expressions of feelings about themselves and an evaluation of their circumstances.

Building on Borkman's (1976) seminal work, recent accounts embrace "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" (Halloy et al. 2022, 405). Accordingly, Halloy et al. (2022, 406) underline that an analysis of experiential knowledge has to be pragmatic and situated, and that "what patients know is inseparable from who they are and how they come to know" (Halloy et al. 2022, 408). They go on to stress that "experiential knowledge is developed through collective and sustained sharing between peers and is the result of personal reflexive work" (Halloy et al. 2022, 414) and, further, that its constitutive elements include social and communicative skills (Halloy et al. 2022, 415). Conceived in this way, individual knowledge is socially produced and bound to the context of its production, which means that "the concrete social conditions within which knowledge develops are intrinsic to the process of knowledge formation and shape the internal structure of knowledge" (Jovchelovitch 2007, 167).

Following Jovchelovitch's (2007) characterisation of knowledge diversity and representation, Halloy et al. (2022) propose that experiential knowledge be considered along three dimensions: the "who", the "what", and the "how". As they note, "the 'who' dimension is related to identity but also to the status and positioning of patients in their social field" (Halloy et al. 2022, 408). Thus, when examining the identity of knowers, one should recognise new forms of patient expertise derived from the experience of living with a health condition, as well as the fact that they are legitimate holders of a certain type of knowledge which – although not easily transposed into academic knowledge or incorporated into evidence-based medicine – should be acknowledged and considered valid (Halloy et al. 2022, 408–409). The "what" of experiential knowledge, they say, is about signification and "helps to understand the content ascribed to it as well as its historical and cultural 'anchoring'" (Halloy et al. 2022, 408). In their reflection on the "what", Halloy et al. (2022, 411) follow Dewey (2005), suggesting that experience is a transformative process involving a "testing" of the world and one's knowledge of it, which is possible only if one has endured the consequences of what one has lived through. Just as importantly, they point to the composite nature of experiential knowledge, recalling Caron-Flinterman et al.'s (2005) distinction into propositional knowledge (*knowing that*), practical knowledge (*know-how*) and knowledge by acquaintance, that is implicit knowledge acquired through one's bodily experience (Halloy et al. 2022, 412). Finally, the "how" pertains to "styles and patterns of communication and how they 'can shape a certain outlook and knowledge of the world' (Jovchelovitch 2007, 104)" (Halloy et al. 2022, 408). This means that experiential knowledge is developed through the sharing of experiences: "public confessions" and "testimonies" which allow individuals to understand what is unique about their experience and what is shared with others (Borkman 1976). In this context, Halloy et al. (2022, 415) emphasize that transforming others' experiences into a meaningful source of knowledge involves social interactions, story-telling and identity work based on a common diagnosis, although, as they admit, identity tensions may arise and some identities may be resisted within the communities to which such individuals belong.

Elsewhere, Blume (2017) draws attention to the changing perception of "lay health beliefs", noting the contributions "expert patients" make to decision-making in the healthcare system.[1] Trying to account for this shift, Blume notes the declining status of professional expertise resulting from societal changes – recognised and theorized by sociologists including e.g. Habermas – coupled with the growing need to acknowledge patients' rights to be consulted about their treatment, which has transformed a "patient" into a "health care consumer" (2017, 92). He thus acknowledges a patient's right to autonomy and their ability to articulate the experience of living with a limiting health condition, which inevitably occurs during encounters with the healthcare system (Blume 2017, 93). By the same token, reflecting on the uses of experiential knowledge, Blume (2017, 95) argues that it "has become a form of cultural capital, to be used in legitimating one's

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[1] Different positions on "patient expertise", or the "expertness" of patients, can be found in the literature. For example, Prior (2003) questions the concept of "lay expert", arguing that the term "expert" should be reserved for scientifically trained experts and medical professionals. Castro et al. (2018) draw attention to the fact that expertise is a matter of social recognition by peers and/or institutions. Halloy et al. (2022, 417), in turn, contend that the difference between experiential knowledge and expertise depends on their level of transferability, that is "the ability to bridge epistemic worlds by translating one form of knowing into another" across distinct social spheres (personal experience, care organisation, policies/legislation, research/education).

views or demands" and that therefore "its possession has value". However, at the same time, he voices his doubts concerning the lack of authority accorded to the experiential knowledge of some groups of patients (e.g. autistic or deaf people), contrasting it with the status attributed to (bio)medical knowledge (Blume 2017, 95).

In his re-examination of the concept of experiential knowledge, Blume (2017, 96) echoes claims made in earlier studies: for patients to transform other patients' experiences into a self-help resource and to consider them knowledge, they must be willing to identify with their peers suffering from the same condition. When such identification becomes too painful, he argues, for instance, in the case of neurodegenerative diseases, patients may opt for partial identification, or being "differently the same", in order to benefit from experiential information sharing. Worthy of note is also the notion of "patient knowledge" as conceptualised by Pols (2014), who posits that what patients know comprises the knowledge they utilize to cope with their condition – that is, the practical knowledge they need to lead a reasonably acceptable daily life – which draws both on medical knowledge and their own experience (Blume 2017, 96). A similar view on the relation to medicine is found in Akrich (2010), in which it is stated that experiential knowledge involves a process of abstraction alongside the knowledge regarding individuals' lives, which includes interactions with the medical world, thus making medicine part of what is considered "experience".

Other relevant observations concern the "why" of experiential knowledge, that is its fundamental functions. At the personal level, experiential information sharing enables individuals to get "a grip on reality" and to develop ways in which to manage everyday living (Halloy et al. 2022, 418). At the same time, it offers a means "to deal with the unknown and make the unfamiliar familiar" (Jovchelovitch 2007, 112), thus giving a sense of hope and reducing the anxiety of uncertainty (Halloy et al. 2022, 418). Also, collective experience sharing helps patients to cultivate a sense of belonging within communities of practice, where they acquire knowledge through participation and sharing with peers (Halloy et al. 2022, 418). As to its re-use, or broader utility, individual knowledge can be employed, for instance, by patient organisations seeking to improve the quality of care, rather than simply for the purposes of personal coping (Blume 2017, 96). However, it should be underlined that not everyone's experience is equivalent in terms of validity or utility, and that variables such as e.g. age, gender, ethnicity or socio-economic status should be considered as well (Blume 2017, 97–98). In addition, the relevance and authority of knowledge based on experience may vary from society to society and from one decision-making context to another (Blume 2017, 99). Most importantly, however, as pertinently highlighted by Blume (2017, 99), "experience is treated as authoritative, as worthy of being characterized as "knowledge" only to the extent that it appears compatible with medical knowledge and assumptions."

In conclusion, it should be reiterated that experiential knowledge is intrinsically contextual and perspectival, i.e. "relative to the perspectives of those making knowledge claims" (Miller and Fox 2001, 675). It is thus communicated from a subjective "Somewhere," rather than a value-free "Nowhere" detached from social life, and reflects individuals' projects, histories, and perspectives which to a large extent affect their struggle to make sense of the world (Miller and Fox 2001, 675), as evidenced by their interactions with peers within the communities to which they belong.

2.2 (Virtual) communities of practice and health communication

Though not unproblematic, the term "community" is frequently used in the literature to describe knowledge networks and the management of knowledge. Although difficult to define definitively from a sociological perspective, this notion may however be useful in discourse-analytic studies of knowledge-sharing practices when conceptualized in more narrow terms, for instance, as a *community of practice*.

In their pioneering proposal, Lave and Wenger (1991) position the idea of a community of practice (CoP) as a new model of learning based on social interaction, rather than the process of cognitive transmission, and as "participation in an activity system about which participants share understandings concerning what they are doing and what that means for their lives and for their communities" (1991, 98). As they posit, CoPs can evolve naturally because of their members' sustained interest in mutual engagement, or they can be created for a specific purpose in order to provide a platform for the creation of knowledge (Lave and Wenger 1991). Lave and Wenger (1991) underline that members of CoPs can grow professionally and personally through regular interaction with other members and the concomitant sharing of information, skills and experiences, which may occur at the workplace or in a professional organisation, but which does not necessarily require their physical co-presence or a unified group with clearly defined boundaries.

Taking the concept of a CoP further, Wenger (1998) and Wenger at al. (2002) put forward the idea that CoPs are based on three pillars – the domain, the community and the practice – which distinguish them from other communities and which are inextricably linked to the social construction of knowledge. A community of practice is thus "a unique combination of three fundamental elements: a domain of knowledge, which defines a set of issues, a community of people who care about this domain; and the shared practice that they are developing to be effective in their domain" (Wenger et al. 2002). Accordingly, CoPs pursue a common practice and cohere around a shared domain of interest which, admittedly, may or may not be recognised as "expertise" outside this community (Wenger-Trayner and Wenger-Trayner 2015). Moreover, if we conceive of learning and knowledge building as social participation, then it will also become clear that CoPs are sites of identity formation, where individuals construct their shared identities through engaging in the joint practices of their communities (Wenger et al. 2002). Similarly, in pursuing their goals, members of a CoP develop a shared repertoire of resources: experiences, stories, tools or ways of addressing recurring problems (Wenger-Trayner and Wenger-Trayner 2015), thus collectively seeking solutions and generating ideas, either in groups within organisational boundaries or in those which lack formal ties. The focus on the informality in a CoP is clearly articulated by Wenger et al. (2002, 4), who redefine CoPs as groups of individuals "who share a concern, a set of problems, or a passion about a topic, and who deepen their knowledge and expertise in this area by interacting on an ongoing basis."

The move towards passion and informality, and away from organisations, is vital from the perspective of virtual communities (VC) which come into existence and coalesce thanks to their members' commitment to a domain of interest despite the fact that they are not physically co-present and have no organisational ties. Practical guidelines on how to research VCs are presented, for instance, in Herring's (2004) work which reasserts the utility of this concept, stressing, however, that it should not be used indiscriminately and that the criteria distinguishing VCs need to be appropriately defined. Advocating empirically grounded work, Herring (2004) specifies five distinct parameters which, in her view, indicate a virtual community: structure (jargon, in-group/out-group language), meaning (exchange of knowledge, negotiation of meaning), interaction (reciprocity, extended threads, core participants), social behaviour (solidarity, conflict management, norms of appropriateness), and participation (frequent, regular self-sustaining activity). It is important to note, after Herring (2004), that these indicators represent both structural and semantic phenomena and, further, that they span five domains commonly invoked in computer-mediated discourse analysis (CMDA), namely: Text Analysis, Conversation Analysis, Pragmatics, Interactional Sociolinguistics and Critical Discourse Analysis (Herring 2004).

As one would expect, the notion of a (virtual) CoP has been widely applied in research investigating online health communities (see e.g. Stommel and Koole 2010; Kimmerle et al. 2012; Bellander and Landqvist 2018; Mansfield 2019). What these studies share is a focus on the situatedness of patient knowledge creation, the processes of identity formation, and the resources which patients deploy in dialogue with others to obtain medical information, request practical self-management advice, offer and seek emotional support, and to achieve a sense of empowerment. The issue of empowerment is brought to the fore, for instance, in Mansfield's (2019) study of diabetic discourse, in which he juxtaposes medical news on a popular website with "emotionally-charged, informal, written-to-be-spoken discourse" (2019, 167) shared by diabetic patients joining a related discussion forum. The author concludes that virtual communities are more than sources of health information; rather, they serve to empower patients who may thus become better advocates for themselves (Mansfield 2019, 191). Bellander and Landqvist (2018), on the other hand, compare health blogs and patient forums to demonstrate how parents of children with congenital heart defects share their experiences and attain the status of experts. In their comparison, the authors note that blogs offer spaces which foster resistance to professional care and "are a reasonable way of evaluating experts, with experience used as the main measurement" (Bellander and Landqvist 2018, 11). At the same time, they observe that forum threads are conducive to the construction of mutual stances and the integration of medical knowledge with individual experience, although, as the authors admit, both blogs and discussion forums are channels that seek alternatives to professional knowledge (Bellander and Landqvist 2018, 12). Yet another paper (Kimmerle et al. 2012) addresses knowledge-sharing practices in an outsider nutrition-focused community that would not be accepted by the majority in a society. Combining quantitative and qualitative analysis, the authors identify behaviours which characterise the core members of this community, including their hostile attitude towards people of a "different faith". Kimmerle et al. (2012, 10) highlight that the forum is more than a knowledge-building platform; rather, they argue, it promotes a holistic attitude towards life and propagates an ideological view of the world. More specifically, their study reveals that the core members "put newcomers on the right track" and rebuke participants who do not comply with the group norms in order to ensure the formation of a collective identity (Kimmerle et al. 2012, 12).[2]

Finally, narratives of endometriosis patients sharing their experience of living with chronic pain have been the subject of several studies exploring online communities. For instance, using large-scale data and adopting a mixed-method approach, Lindgren and Richardson (2023) examine the public disclosure of pain and peer validation within two communities on Reddit. Directing their attention specifically to pain-related words and concepts – and the manner in which they contribute to collective knowledge production – the authors conclude that in such

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[2] For a similar discussion of the mechanisms which govern interaction between the established members of a CoP centred around eating disorders and newcomers required to adopt the community's norms, see Stommel and Koole (2010).

communities pain tends to be disguised and underplayed for fear of being misunderstood. In another study, Bullo (2018) uses online forum data and semantic tagging to identify broad themes and discourse relationships within texts produced by endometriosis patients. In her thematic analysis she reveals that the narratives can be linked to a set of discourse fields (e.g. generally abstract terms; language and communication; movement, location, travel and transport) and semantic categories (e.g. evaluation, likelihood, verbal processes, actions, emotions, time markers) which reflect the women's major concerns. Therapeutic affordances of online support groups for women with endometriosis have in turn been explored by Shoebotham and Coulson (2016) who identify four such affordances: connection, i.e. the ability to exchange advice and to support each other to overcome loneliness; exploration, i.e. the ability to look for information in order to gain knowledge; narration, i.e. the ability to share experiences; and self-presentation, i.e. the ability to manage one's presentation online. Although the authors recognise the value of support gained through online interactions, they at the same time voice their concerns related to the possible negative outcomes which may have a detrimental effect on users, i.e. the inaccuracy of information, arguments between group members, or the patients' overreliance on the community.

As shown above, collective knowledge formation and emotion sharing within virtual CoPs gathered around various medical conditions including endometriosis has been addressed in earlier studies. To date, however, no research has been undertaken to examine the online linguistic behaviour of Polish women suffering from endometriosis. This is the niche the current investigation aims to fill by identifying the practices and resources which Polish endometriosis sufferers deploy in their polylogic interactions concerning their experiences of living with the disease.

3. Data and method

The study is based on a corpus of 49 original postings contributed by the forum administrator and 593 comments manually collected from a Polish Facebook group dedicated to endometriosis and described as "an independent portal with a support forum." The data span a fifty-month period, from November 2018 until January 2023, and include all the original postings and all the comments posted during that time. With more than 8,000 members,[3] the portal aims to promote social awareness of endometriosis in Poland. The subject matter is of great social significance given that an awareness of endometriosis among the general public

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[3] As at 1 February 2024.

is somewhat limited. On the one hand, the portal provides information about endometriosis as a medical condition (its symptoms, treatment options, available therapies) and highlights initiatives which benefit endometriosis sufferers, and, on the other, it provides a space for women affected by this condition in which they can share their difficult experiences, as well as seek practical advice and emotional support. The community assembles around a domain which matters to its members because of their shared experience of living with the same disease. In pursuing their interest in endometriosis, the members engage in a multi-party dialogue, comment on the material posted by the administrator, as well as share practical information and offer support.

Given the public nature of the forum as well as the administrator's appeal: "Help us raise endometriosis awareness in Poland", with the general public as the intended audience, no ethics approval was requested. Since the data are readily accessible without the need to register and log in as a group member, they belong to the public domain and do not raise any concerns regarding confidentiality. I did however anonymise the posts to protect the privacy of the participants; I removed the posters' names, as well as those of individual physicians and medicinal products, and, where necessary, marked them as @FP (as a form of address), PH, and MP, respectively. Other elements are reproduced in their original form (including spelling and grammatical inaccuracies), together with their English translations.

The study adopts as its point of departure the concept of community of practice discussed earlier (Lave and Wenger 1991; Wenger 1998; Wenger et al. 2002) and examines the data along three dimensions: the "what", the "who" and the "how" of the community in question. It also accommodates Miller and Fox's (2001) philosophical perspective on "epistemic community", defined as "a group of inquirers who have knowledge problems to solve" and who produce "small-*t* local truth and not big-*T* universal Truth" (2001, 669). In addition, the analysis is guided by Herring's (2004) approach to the online behaviour outlined above, with the five indicators of a virtual community: structure, meaning, interaction, social behaviour, and participation. Finally, the research assumes a polylogic conceptualisation of online multi-party interactions allowing double articulation, that is active participation in text-based polylogues and passive participation by "lurkers" reading the comments (Bou-Franch et al. 2012).

As stated above, the analysis centres on three aspects of knowledge formation, regarded as essential elements of a CoP. First, I consider the "what" (goal structure) of the group in question, paying particular attention to the subject matter around which the members cluster and their motivation for participation. Next, I examine the "who" (role structure), explaining who participates in the community, distinguishing between active and passive (or peripheral) participants. In the final part, I provide a detailed examination of the "how" (communication structure), i.e. community-driven knowledge sharing practices, involving goal-oriented dialogic action, with dialogue being understood as sequences of initiative and reactive acts (Weigand 2021) and as “a mechanism for producing increased understanding” (Weller 2013, 5). I specifically identify the members’ stance-taking practices: epistemological positioning (Bednarek 2006) and elements of emotive communication, which are linked, building on Marín-Arrese (2009), to four categories of stance: (1) experiential (embodied experience, perception); (2) cognitive (inference, deduction, common knowledge); (3) communicative (hearsay); and (4) affective (emotion talk and emotional talk).[4] In keeping with Jovchelovitch’s (2007) approach to knowledge diversity and representation, the investigation of the communication structure (the “how”) is organized around three areas: (1) identity work (self- and other-categorisation); (2) perspective-sharing and recognition by “significant others” (dialogic resonances) and (3) epistemic self-other positioning.

The main findings are reported below.

4. Patient knowledge formation in an open FB forum dedicated to endometriosis

The investigation has shown that the group gathered around the topic of endometriosis has its own distinctive ways in which it builds a shared understanding of the disease. To better capture the relationship between the participants’ experience, knowledge and expertise, let us consider the “what”, the “who” and, most importantly, the “how” of this community (see Figure 1), the “how” being shaped to a large extent by the participants’ identities and local interactional goals.

As already noted, the group is described as “an independent forum with a support group”, and it operates as a non-hierarchical community open to everyone who is interested. The group members fall into two broad categories, i.e. the active participants, including the anonymous group administrator alongside both the anonymous and non-anonymous group members, as well as the passive participants (so-called “lurkers”), that is the general public who do not contribute any material, but have access to the posted content. Among the active participants we mostly find women suffering from endometriosis; however, occasional posters include participants whose identity remains unknown and who recommend therapies and medicinal products.

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[4] In her 2009 study, Marín-Arrese analyses three types of stance: experiential, cognitive and communicative; in the current study, I have added the category of affective stance, as well as included embodied experience as one of the sources of knowledge identified as part of the “experiential stance.”

Characteristics of a CoP	Open FB forum as a virtual CoP
PURPOSE (WHAT) what a CoP does and why it exists	DOMAIN Endometriosis as a medical condition (symptoms, treatment, therapies); Information about events and initiatives related to endometriosis GOAL Raising public awareness of endometriosis; Sharing experience of the disease; Seeking/gathering practical information/advice; Seeking/giving emotional support
PEOPLE (WHO) who participates in the community	Public FB forum with a support group; Hierarchies not strongly pronounced (anonymous administrator; anonymous and non-anonymous group members) PARTICIPANT ROLES: ACTIVE PARTICIPANTS FB group administrator; Endometriosis sufferers (women); Participants advertising therapies/products (including men) PASSIVE PARTICIPANTS Lurkers/general public
PRACTICES (HOW) how a CoP organizes itself; how it communicates	TEXTUAL POLYLOGUE Asynchronous; doubly articulated (active and passive participation); open to the general public: Non-hierarchical self-other interaction: – original posts contributed by the anonymous administrator; – replies contributed by anonymous and non-anonymous participants

Figure 1. Characteristics of the FB forum dedicated to endometriosis as a virtual CoP

The dual purpose of the community is reflected in its dynamics: the administrator posts information which opens a virtual floor for discussion and provides a pretext for the outpouring of emotion, whereas the participants behave reactively by commenting on the original postings or responding to those added by other members (cf. Weigand's (2021) idea of an *initiative act* and a *reactive act* being constituents of dialogic action). In doing so, they co-construct textual polylogues revolving around their personal experiences and more general societal issues (such as, e.g. the operation of the Polish healthcare system) in response to third-party material, rather than on their own initiative. As with similar FB groups, the forum has the form of an asynchronous text-based polylogue that allows "double articulation" (Bou-Franch et al. 2012), that is active and passive participation, which provides space for multi-party interaction. The original posts contributed by the administrator feature e.g. articles related to endometriosis, awareness-raising memes, and images of celebrities or hosts of TV programmes, while those added by the community pertain to their experiences of the disease and serve the purpose of emotion and information sharing.

Of special interest to the current study is the question of how the group members communicate and justify their knowledge and belief, that is how they linguistically construct their experience of the disease, how they assess external sources of information, and how they integrate other-sourced accounts into their own discourse. With this in mind, in the discussion below, I provide insights into their behaviours related to identity work, perspective sharing and epistemic positioning, that is, in broad terms, community-driven knowledge representation.

4.1 *Dawaj wojowniczko (C'mon warrior)*: Self- and other-categorisation

The first set of practices concerns self- and other-categorisation, or collective identity formation. To understand the purposes which acts of categorisation are intended to serve, we must bear in mind that such practices usually perform more than one function. In the examples that follow, I focus on the expressive function, as described by Bühler (1934), or the emotive function, to use Jakobson's (1960) terminology. That is not to say, however, that they should be linked solely to the expression of emotion, or the affective stance.[5] As we will see, the forum members deploy "collections" of category terms and "category predicates", i.e. actions and attributes associated with a category (Schegloff 2007),[6] making them relevant to the ongoing interaction and providing an effective basis for shared identity formation. In the data, several practices have been found to be especially prominent.

To begin with, it is necessary to consider the deployment of inference-rich items from the "family" category. By using terms such as *endosiostra* 'endosister', *endorodzina* 'endofamily', *endomama* 'endomum', thus collectively forming an "endofamily", the participants presumably infer that what is known to be true about family members (in terms of actions and attributes) is also true about the other forum participants (cf. Schegloff 2007). Another discernible feature is the presence of references invoking the category of gender (e.g. *endokobietki*

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5. See Bally (1970 [1909]) who notes two fundamental modes of communication: the intellectual mode and the affective mode which, as he suggests, are not dichotomous but should be thought of as poles on a continuum, with messages being oriented towards one or the other pole.

6. For the original formulation of Membership Categorization Analysis, see Sacks (1972). For later applications, see e.g. Housley and Fitzgerald (2009).

‘endowomen$_{\text{DIM}}$’, *dziewczyny z Endo* ‘girls with Endo’, *panie zmagające się z endo* ‘women struggling with endo’) which combine the focus on being a female with the positioning of endometriosis as a distinguishing attribute. As with the “family” category, this labelling (“a female with endo”) performs a solidarity-building function, too (consider (1)–(4)).[7]

(1) *Walczę z II i podziwiam każdą EndoSiostrę!*
‘I’m fighting 2nd degree endometriosis and I admire every EndoSister!’

(2) *My Endokobiety mamy nieziemską moc zróbmy wszystko abyśmy nie były niewidzialne dla NFZ. EndoMama*
‘We Endowomen have incredible powers. Let’s do everything we can not to be invisible to the NFZ.[8] EndoMum’

(3) *Kochane endokobietki nigdy nie dopuszczajcie u siebie do tego by zyc w bolu ciaglym*
‘Dear endowomen$_{\text{DIM}}$ never let yourselves live in constant pain’

(4) @FP *ja za Ciebie też trzymam mocno kciukacze, jesteś mega dzielna bo podjęłaś decyzję/walkę. Jesteś wielka* 💪💪💪👏👏👏
‘@FP I keep my fingers$_{\text{AUG}}$ firmly crossed for you, you are mega brave because you took the decision/started to fight. You are great 💪💪💪👏👏👏’

(5) *dawaj wojowniczko*💪
‘c’mon warrior 💪’

The postings in (1)–(5) additionally reveal that the interaction is organised around the category of “fight”. Thus, the participants position themselves and their addressees not only as members of the “endofamily” or representatives of the “endowomen”, but also as “(female) warriors”. Being intimately connected, the three types of member-generated categorisations serve to encourage other posters to take action and also to imbue them with a sense of empowerment (cf. Weigand’s (2021) idea of an *initiative action* followed by a *reaction*). As the examples indicate, the directive illocutionary force of these calls for action is strengthened thanks to the use of (often co-occurring) devices such as contextualization cues (Gumpertz 1982) in the form of emoji (as in (4) and (5)), intensity markers (e.g. *My Endokobiety mamy nieziemską moc* ‘We Endowomen have incredible powers’ in (2) or *trzymam mocno kciukacze* ‘I keep my fingers$_{\text{AUG}}$ firmly crossed’ in (4)), or acts of

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[7] The clipped form “endo” (or its capitalized variant “Endo”) was pervasive in the data and acted as an in-group marker. Its use by people having no experience of endometriosis seems much less likely.

[8] NFZ = Polish National Healthcare Fund.

praise (e.g. *Podziwiam każdą EndoSiostrę* 'I admire every EndoSister' in (1) and *Jesteś mega dzielna* 'You are mega brave' in (4)).

The next characteristic of the interactions involve the construction of dichotomies: the *us* vs *them* opposition and the "*me*-before" vs "*me*-after" juxtaposition. In-group and out-group marking can be noted for instance in (6) and (7), where the authors suggest that only women suffering from endometriosis are capable of understanding the terrible pain caused by this disease. Thus, they set "endowomen" (*us*) apart from "non-endowomen" (*them*), and provide the basis for an affinity and shared identity. In the next two examples, in turn, the participants foreground the contrast between divergent states: in (8), the author emerges from "the darkness" and looks into the future, sharing her hope for a positive change, whereas in (9), the poster contrasts her former happy life with the new painful existence. As expected, the data yield many more examples in which the women express negative emotions arising from their experience of living with endometriosis. However, there is also evidence of the expression of negative emotions being accompanied by an appreciation of positive experiences (as in (9) and (10)).

(6) *Ten ból zrozumie tylko druga kobieta chora na endometriozę.*
'This pain can be understood only by another woman suffering from endometriosis.'

(7) *Ja również życzę każdej kobiecie, która nas nie rozumie, tylko jednej takiej menstruacji i wszystkim moim koleżankom, które myślą, że przesadzam i myślą, że jestem mało odporna na ból.*
'I also wish every woman who doesn't understand us just one such menstruation and I wish this for all my girlfriends who think that I'm exaggerating and who think that I have a low resistance to pain.'

(8) *Przez Endo dawna Ja- energiczna, kreatywna, fazująca nie istnieje… została wiecznie skrzywiona, obolała, walcząca o każdy dobry dzień.*
'Because of Endo, former Me – energetic, creative, acting crazy, doesn't exist… what's left is someone who's forever sulky, achy, struggling to have another good day.'

(9) *… szansa na nowe życie, w którym to JA jestem najważniejsza, a MOJE potrzeby są na pierwszym miejscu. To mrok, z którego bardzo chciałam wyjść, by poczuć siłę, energię i radość. Nie wierzyłam lekarzom. Uwierzyłam sobie i póki co jestem na dobrej drodze.*
'… a chance for a new life in which I am the most important and MY needs take priority. It's the darkness which I wanted to leave to feel strength, energy and joy. I didn't believe my doctors. I believed myself and right now I'm on the right track.'

(10) *Bezsilnosc, bol, izolacja, kalectwo, samotnosc, cierpienie, rozpad, odrzucenie, bezrobocie, kryzys… ale tez empatia, bo rozumiem. innych chorych i cierpiących (…)*
‘Hopelessness, pain, isolation, disability, loneliness, suffering, disintegration, rejection, unemployment, crisis… but also empathy because I understand other sick and suffering people (…)’

Summing up this section, it should be remembered, following Stommel and Koole (2010, 368), that membership categorization is not to be taken as a cognitive representation of reality, but as an interactional activity aimed at building inclusion or exclusion. As the examples discussed here suggest, based on the data at hand, acts of categorization serve to unite and mobilize the forum participants against the shared experience of living with the condition, despite the awareness that out-group members may not fully understand their pain.

4.2 *Ja też (Me too)*: Perspective sharing and recognition by “significant others”

To highlight how the participants build a shared understanding of their condition, I will now consider a selection of comments[9] illustrating how they orient themselves dialogically to the claim opening the thread (posted by the administrator) and/or those contributed by other group members, producing sequences of initiative and reactive acts. It is assumed here that by engaging with the words of the prior posters, i.e. by taking stances, the women produce both local (within the current exchange of stance utterances) and remote (across future events and situations) resonances (Du Bois 2007, 140). Needless to say, these dialogic acts, as with the acts of categorisation discussed above, are inseparable from identity forming; however, the *me too*-pattern[10] has been distinguished both to foreground

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[9] **9.** Space does not permit a full presentation of the analysed discussion thread. I believe, however, that the sequences of posts shown in (11), comprising the original posting and the first five replies, aptly illustrate the practices in question.

[10] **10.** In the original posts in Polish, the echoing responses have different structural realisations (e.g. ‘*I also* + verb’; ‘*I don’t* + verb + *either*’; *also* + noun), but they are referred to collectively as the *me too*-pattern. Another fact to note is the use of the 1st person pronoun *ja* (as in ***Ja** walczę już 16 lat* ‘I’ve been fighting for 16 years already’ or ***Ja** brałam MP krótko* ‘I was on MP only for a little while’) which syntactically is not obligatory (Polish is a pro-drop language), but which has pragmatic relevance. Its turn-initial, dialogic use (paraphrasable as “I, in turn, + verb”) suggests that the utterance is not a standalone statement, but that it is responding to prior discourse. This meaning is not reflected in the English rendition which must include the pronoun irrespective of whether it is used dialogically or not.

the significance of intersubjectivity and parallel assessments (Heritage 2011), and for greater analytic clarity.

The relevance of parallel assessments to building a shared understanding of a disease has been addressed in earlier work on support forums. De Cock and Figueras Bates (2023, 306) note, for instance, that "parallel assessments validate the advisee's affective and epistemic states based on the advisor's own lived experience" without intruding into the recipient's life.[11] Further, they posit that peer experts fulfil "a bridging function" regarding professional treatment, stressing the significance of healthcare professionals and explaining medical information in more comprehensible ways (De Cock and Figueras Bates 2023, 308–309). The current study provides similar evidence: "endowomen" utilize parallel assessments to display alignment and affiliation, i.e. epistemic symmetry, or to provide the basis for constructive advice (cf. De Cock and Figueras Bates 2023, 305). To see this more clearly, let us consider the discussion in (11). The woman in the thread-opening meme (initiative act) epitomises "females with endo" and would seem to be one of the group members. Facing the viewer, she "utters" the words: "I'm strong, because despite the everyday struggle with stage four endometriosis, I want to live!", a statement that resonates with other women who respond by sharing their stories (producing reactive acts). As the interaction unfolds (only partly shown here), they empathise with other members and identify with their subjective experience of pain (*Rozumiem i też walczę* 'I understand and I'm fighting, too'). Thus, they engage with the words in the earlier postings, providing echoing responses (Ricento 1987) and creating resonances of stances that build on each other dialogically (Du Bois 2007, 140),[12] with reactive postings becoming initiative postings for those that follow.[13] In their replies, the women also seek help (*Nie czuję się silna tylko słaba, powinnam sobie lepiej z tym radzić w końcu jestem mamą, nie wolno mi się poddać ale też nie wiem jak sobie z tym radzić im dłużej to trwa tym jest trudniej. Jak Wy sobie radziłyście?* 'I'm not feeling strong

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[11] De Cock and Figueras Bates (2023, 295) define shared understanding as "experiential knowledge made available by responders to validate and elaborate on the troubles-telling messages published by the first poster" and they highlight the use of person reference, cognitive verbs, parallel assessments and second stories.

[12] Cf. Du Bois' (2007, 139–140) claim that in order to understand the achievement of stance, we need to consider "a complex web of interconnections linking stance with dialogicality, intersubjectivity, the social actors who jointly enact stance, and the mediating frameworks of linguistic structure and sociocultural value they invoke in doing so." For a discussion of dialogic syntax, see Du Bois (2014).

[13] As aptly noted by Weigand (2023, 13), "each reactive speech act in the sequence can secondarily be again taken as initiative and trigger off another reaction" (cf. action → reaction/action → reaction/action → reaction).

but weak, I should be better at coping with this, I'm a mum after all, I mustn't give up, but I don't know how to cope with this, the longer it takes, the more difficult it gets. How did you cope?') and offer advice (*ja brałam MP krótko bo zaczęły mi się problemy z krwawieniem* 'I was on MP only for a little while because I started having problems with bleeding'), creating what Pols (2014, 82) justifiably refers to as "a network of bodies that function as 'measuring stations'", as well as a source of know-how, or "knowing in action" (2014, 75). Naturally, the posters' attitudes and emotions can be inferred not only from the words, including the echoing utterances (e.g. *Tez 4 otrzewna* 'Also stage 4, peritoneum', *Też mam 4 st* 'I also have stage 4'), informal vocabulary and emotionally-loaded items (e.g. *ale są skutki uboczne tragedia* 'but there are side effects, a disaster', *psychika totalnie w rozsypce* 'I was a total mess'), but also the paralinguistic contextualization cues (as in (11a) and (11b)) which steer the interpretation of the semantic content. Taken together, the comments in the extended thread – forming sequences of actions and reactions – reveal how the group members perspectivize their knowledge claims and validate other members' assessments, performing both linguistic and social acts, in addition to activating locally relevant values "to frame the significance of participant actions" (Du Bois, 2007, 141). Through engaging with the stances taken in the previous comments, the "endowomen" generate dialogic resonances, communicating their knowledge from "Somewhere" (Miller and Fox 2001, 675), the Somewhere being equated with their painful experience of living with endometriosis.

(11)

Endometrioza -Niezależny Portal o endometriozie wraz z forum wsparcia
March 28, 2019 ·

Marta Frej - dziękujemy! ❤

[thread opener: (meme) ‘I’m strong, because despite the everyday struggle with stage four endometriosis, I want to live!]

a. *Tez 4 otrzewna* 😥
‘Also stage 4, peritoneum 😥 ’

b. *Też mam 4 st* 🙁
‘I also have stage 4 🙁 ’

c. *Ja walczę już 16 lat od dwóch lat jestem na zastrzykach ale są skutki uboczne tragedia*
‘I’ve been fighting for 16 years already, have been on injections for two years, but there are side effects, a disaster’

d. *Zaczęłam od 2, miałam laparoskopie przy której wykryto u mnie edno i zrosty które nie zostały usunięte z racji, że można było uszkodzić jajnik a ja chciałam zajść w ciążę, dwa miesiące później udało się zaszłam w ciążę. 11 godzin rodziłam naturalnie po czym lekarz z racji spadającego tętna dziecka zdecydował natychmiastową cesarke, podczas niej usłyszałam że to cud że zaszła w ciążę. Teraz mój syn ma 1,5 roku a mój stan na tyle się pogorszyl że nie umiem normalnie funkcjonować. Jestem na lekach MP…. Nie czuję się silna tylko słaba, powinnam sobie lepiej z tym radzić w końcu jestem mamą, nie wolno mi się poddać ale też nie wiem jak sobie z tym radzić im dłużej to trwa tym jest trudniej. Jak Wy sobie radzilyscie?*
‘I started with stage 2, had a laparoscopy which showed endo and adhesions which weren’t removed because there was a risk that the ovary would be damaged and I wanted to get pregnant, two months later I was lucky and got pregnant. It was a vaginal delivery, I was in labour for 11 hours, but then the child’s pulse was down and the doctor decided on an immediate C-section, during which I heard that it was a miracle that I got pregnant. Now my son is 1.5 years old and my state has deteriorated to the point that I can’t have a normal life. I’m on MP… I’m not feeling strong but weak, I should be better at coping with this, I’m a mum after all, I mustn’t give up, but I don’t know how to cope with this, the longer it takes, the more difficult it gets. How did you cope?’

e. *Na MP u mnie było pogorszenie stanu i psychika totalnie w rozsypce. Zmieniono mi leki i zauważyłam różnicę. Trzymaj się i koniecznie porozmawiaj o tym jak się czujesz ze swoim lekarzem.*
‘When I was taking MP, my condition got worse and I was a total mess. My drugs were changed and I felt the difference. Take care and definitely talk to your doctor about how you’re feeling.’

That being said, instances of unmitigated disagreements following the *me too*-pattern were also identified, although, admittedly, conflictual discourse was not attested. To take an example, in (12), both women disagree with the original posting suggesting that there are long waiting times for surgery. In (13), similarly, the authors take issue with the claim that surgery is needed for a diagnosis. These pairs of comments show that echoing responses, or dialogic resonances, are also generated in the case of divergent opinions and negatively framed information.

(12) *Także sie nie zgadzam. Dostalam skierowanie na operacje to proponowano mi termin nawet na za 4 dni. W koncu operacja po uzgodnieniach odbyla sie po 10 dniach*
‘I don’t agree, either. I got a referral for surgery and was even offered a date in 4 days’ time. In the end, after we agreed on the date, the surgery took place after 10 days.’
(…)
Tez się nie mogę z tym zgodzić 🤔 *ja miałam zabieg nie mal z dnia na dzień* ….
‘I can’t agree with this, either 🤔 I had my procedure scheduled almost overnight.’

(13) *Znowu bzdury że trzeba operacji żeby się zdiagnozowac*
‘The same nonsense again that one needs surgery to get a diagnosis.’
@FP *Dokładnie. Wystarczy usg u dobrego specjalisty + ewentualnie rezonans jeśli są jakieś wątpliwości*
‘@FP Exactly. An ultrasound by a good specialist is enough + maybe also an MRI scan if there is any doubt.’

The postings presented in (11)–(13) are but a limited sample of how the forum participants engage with other members’ experiential and affective stances. The size of the sample notwithstanding, they give a sense of the type of behaviour observed in the forum, revealing how stances are co-created as part of a goal-oriented interactive process. This in turn provides more evidence for the claim that experiential knowledge is intersubjective and perspectival, i.e. dependent on the knowers’ perspectives, and, equally importantly, that the capacity for empathy and affinity arises out of interactions with those with whom the group members share “experiences, activities, places and/or histories”, all of which allows them to identify with the community and to interpret their relationship within broader social categories (Amit 2002, 18).

4.3 *A mówili…* (*And they would say…*): Epistemic self-other positioning

In the final part of the study, I focus on two main sources of knowledge (*self* and *other*) and examine the discursive manifestations arising from the underlying question: *How am I justified in saying X?* As the data confirm (see Figure 2), the participants refer chiefly to their embodied experience, with “the self” being the basis of their knowledge, and use it to validate their claims to truth. Other epistemic assessments concern third-party information (hearsay) and are based mostly on the women's encounters with the Polish healthcare system, with "the other" being the basis of this knowledge.

The most striking feature of the posters' epistemic assessments is their organization around the *I-have-experienced-A,-so-I-know-B* schema, foregrounding the significance of embodied experience. To better understand how the participants claim epistemic legitimacy, let us turn to the examples in (14)–(18). In her comment in (14), the poster admits to knowing the pain that endometriosis causes, saying: *niestety wiem z doświadczenia jak to wygląda* 'unfortunately I know from my own experience what it's like', thus pointing to her lived experience as the basis of her knowledge. In (15), in turn, the participant combines the marking of reasoning with what may be regarded as the communication of general knowledge (*można troche uśpić, ale jak się przestanie brać hormony, to się dziadostwo robi od nowa* 'it's possible to make it dormant for a while, but once you stop taking hormones, this damn thing starts growing again'). The next three examples bring into play third-party opinions: in (16) the poster refers to what she heard from her gynecologist (*nie da się, zrostów nie widać, tak mi powiedział ginekolog* 'that's not possible, you can't see the adhesions, my gynaecologist told me that'), but considers this opinion to be worthless (*absurd* 'it's absurd'); in (17), the author scornfully refers to unspecified "others" claiming that "that was just the way she was" (*A mówili, że to TYLKO okres i że TAKI PANI UROK*❗❗ 'And they would say that it was ONLY my period and that THAT WAS JUST THE WAY I WAS❗❗') and adds that having the knowledge she has now she would not have let the doctors brush her off as they did (*I z tym rozumem, wiedzą itp. co teraz, nie dała bym się spławić lekarzom tak jak kiedyś…*'And having the understanding, the knowledge, etc. which I have now, I wouldn't have let the doctors brush me off as they did'). Finally, in (18), we learn that the woman was advised by her doctors to get pregnant, despite having tubal ligation (*I od lekazy slysze zajscie w ciaze wyleczy gdzie juz mam jajowody podwiazane wlasnie przez ta horobe a teraz mowia o ciazy* 'And I hear from my doctors that getting pregnant will cure me, but I already have tubal ligation, and it's specifically because of the disease, and now they are talking about me getting pregnant'), which she comments upon by saying that, regrettably, Polish doctors still ignore the disease (*to jest przykre jak w pl lekaze lekcewaza ta horobe* 'it's regrettable how doctors in Poland ignore this disease').

What these and other examples demonstrate is that the women base their claims on personal experience, producing unqualified statements without any obvious epistemic markers or qualifying their assertions with signals of an experiential, communicative, or, to a much lesser extent, cognitive stance. As it transpired, the verb *wiedzieć* 'know', marking a cognitive state, tended to be followed by immediate references to experience (e.g. *wiem z doświadczenia jak to wygląda* 'I know from my own experience what it's like', *wiem bo sama niestety choruję* 'I

Self	Other
PARTICIPANT'S EMBODIED EXPERIENCE	THIRD-PARTY MATERIAL IN THE FORUM ADMINISTRATOR'S POSTS
[I have experienced A, so I know B]	[e.g. visuals, press articles, information about TV programmes/celebrities, information about events and initiatives related to endometriosis]
e.g. *niestety wiem z doświadczenia jak to wygląda* 'unfortunately I know from my own experience what it's like' *Miałam endometrioze w bliznie po cc ponad 4 lata … Koszmar* 'I had endometriosis in my C-section scar for more than 4 years… A nightmare'	
PARTICIPANT'S COGNITION AND PERCEPTION	HEARSAY (REFERENCES TO NAMED OR UNNAMED SOURCES IN THE PARTICIPANT'S POSTS)
[I know from inference, deduction and/or observation]	[X/an unnamed doctor said/told me; I heard from X/an unnamed doctor; X believes; I was told]
e.g. *I wydaje mi się ze ciąża sprawiła że zniknął ból zrostowy* 'And it seems to me that the pregnancy caused the pain from the adhesions to disappear'	e.g. *dr PH – guru w dziedzinie operacyjnego leczenia endometriozy twierdzi tak jak napisałam wyżej.* 'dr PH – a guru in the surgical treatment of endometriosis says what I wrote above.' *i ze po porodzie przejdzie … to tez słyszałam* 'and that it would go away after childbirth… I heard it, too'
	COMMON KNOWLEDGE
	e.g. *Brak specjalistów by skutecznie leczyć endometrioze, brak odpowiedniej diagnostyki* 'There aren't enough specialists to treat endometriosis successfully, there's no proper diagnostics' *Operacja pomaga* 'Surgery helps'

Figure 2. Bases of knowledge identified in the forum data

know because unfortunately I also suffer from endometriosis').[14] Thus, the posters let the readers know that what they have communicated with great epistemic certainty was a personal truth, and not objective knowledge grounded in reasoning. At the same time, it was found that signals indicating inference and deduction (e.g. *myślę* 'I think', *wydaje mi się* 'it seems to me'),[15] linked to varying degrees of certainty, were used somewhat sparingly, revealing that in the context under investigation the marking of these modes of knowing was far less important. Further, as regards hearsay, I identified references to both named sources (e.g. *dr PH – guru w dziedzinie operacyjnego leczenia endometriozy twierdzi tak jak napisałam wyżej. Pamiętam to dokładnie z jego webinaru.* 'dr PH – a guru in the surgical treatment of endometriosis says what I wrote above. I remember it clearly from his webinar') and unnamed sources, either individual or unspecified (e.g. *mój lekarz powiedział, z tym trzeba żyć* 'my doctor told me, you have to live with this'; *I że po porodzie przejdzie… to też słyszałam* 'and that it would go away after childbirth… I heard it, too'). Such reported opinions were often followed by skeptical remarks or a negative evaluation. Finally, unqualified statements classified as "common knowledge" were also attested (e.g. *Operacja pomaga* 'Surgery helps').

(14) @FP *niestety wiem z doświadczenia jak to wygląda… leżę czasem przed domem na schodach i kwiczę z bólu* 😣 *chłód zawsze działa*
'@FP unfortunately I know from my own experience what it's like… I sometimes lie on the steps in front of the house squealing in pain 😣 the cold always helps'

(15) *można trochę uśpić, ale jak się przestanie brać hormony, to się dziadostwo robi od nowa, w innych miejscach* 🙄
'it's possible to make it dormant for a while, but once you stop taking hormones, this damn thing starts growing again, in another place 🙄'

(16) @FP *nie da się, zrostów nie widać, tak mi powiedział ginekolog, dopiero laparo ukazuje zrosty, ale i jednocześnie powoduje nowe, absurd*
'@FP that's not possible, you can't see the adhesions, my gynaecologist told me that, only laparoscopy can show the adhesions, but at the same time it causes new ones, it's absurd'

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[14] Interestingly, with only six occurrences, the negated form *nie wiem* 'I don't know' served to convey the women's uncertainty resulting from the assessment of their circumstances, rather than to mark the lack of propositional knowledge (consider e.g. *Nie wiem co robić* 'I don't know what to do' or *No nie wiem bo ja już miałam myśli samobójcze* 'Well, I don't know because I was already feeling suicidal.')

[15] Each of these forms had only two attestations in the data.

(17) *A mówili, że to TYLKO okres i że TAKI PANI UROK* ❗ ❗ *Te dwa stwierdzenia działają na mnie jak czerwona płachta na byka i z tym rozumem, wiedzą itp. co teraz, nie dała bym się spławić lekarzom tak jak kiedyś…*
'And they would say that it was ONLY my period and that THAT WAS JUST THE WAY I WAS ❗ ❗ These two statements are for me like a red rag to a bull and having the understanding, the knowledge, etc. which I have now, I wouldn't have let the doctors brush me off as they did…'

(18) *I od lekazy slysze zajscie w ciaze wyleczy gdzie juz mam jajowody podwiazane wlasnie przez ta horobe a teraz mowia o ciazy to jest przykre jak w pl lekaze lekcewaza ta horobe*
'And I hear from my doctors that getting pregnant will cure me, but I already have tubal ligation, and it's specifically because of the disease, and now they are talking about me getting pregnant, it's regrettable how doctors in Poland ignore this disease'

To recapitulate, the data demonstrate the prevalence of the participants' high epistemic certainty derived from personal experience, most commonly communicated in the form of assertions which lack explicit signals of cognitive reasoning, such as deduction or inference. Other-sourced claims, on the other hand, are indexed with markers of hearsay and co-occur with evaluative or expressive items, providing evidence of the women's positioning of their knowledge and assessment of their circumstances vis-á-vis the expertise of medical professionals.

5. Conclusions

This article has explored the practices of community-driven knowledge sharing in an open FB forum dedicated to endometriosis, at the core of which lies the participants' experiential knowledge and embodied experience. We have seen how knowledge, or "small-*t* local truth", is co-constructed by a group of knowers in a virtual community of practice having its own goals, members and practices.

With respect to the community's goals, it has been confirmed that the women, through their dialogic exchange of stance utterances, express, on the one hand, the need to share their painful experiences and to receive emotional support, and, on the other, the need to find practical advice and concrete medical help. As to the role structure, the analysis has revealed that the community is essentially non-hierarchical and that it involves a large group of active female posters, whose messages presenting personal stories are available to the general public, i.e. passive participants. Crucially, it has been found that the forum in question meets the criteria specified in Herring (2004) as being constitutive of virtual communities. More precisely, it has been established that the group members use in-group and out-group marking (thus positioning "endowomen" against outsiders); negotiate their knowledge claims and strive to have their epistemic competence validated; participate in extended discussion threads and engage with other members' stances; express solidarity and avoid conflictual communication, and, finally, cultivate the community through their commitment and sustained participation.

Most illuminatingly, regarding the community's communication structure, the study has revealed several knowledge-sharing practices reflective of the group members' goal-oriented dialogic action that leads to intersubjective knowledge creation. The analysis has provided evidence of member-generated categorization (*endofamily, endowomen, fighters*), most likely prompted by the women's sense of being misunderstood, and naturally tied to shared identity formation. It has likewise uncovered dialogic resonances, or parallel assessments, revealing how the participants engage in sequential stance-taking acts with a view to sharing their experiences of pain and developing ways of coping with the disease. The presence of these practices aligns with previous research which has emphasized "the symmetry of common concern" (Jacobs and Goodman 1989, 537) and the reciprocity of peer narratives, reinforcing "patient ownership of the pain" (Whelan 2003, 475) and supporting the epistemic authority of the group (Lindgren and Richardson 2023, 8). The current data similarly support the claim that knowledge building is social and intersubjective: it is never "point-of-view-less" or "solo" (Bruner 1991, 3), and it is always communicated from "Somewhere" (Miller and Fox 2001, 675). Lastly, the study has indicated a high frequency of assessments that mark the high epistemic certainty derived from the women's embodied experience, together with the concurrent scarcity of markers of cognitive stance signalling deduction or inference. On the other hand, the posters frequently referred to and critically assessed other-sourced claims, positioning their knowledge anchored in experience against the professional knowledge of medical practitioners, on the one hand, and the lack of understanding by healthcare professionals, colleagues and friends, on the other, thus creating a situation of "we" talking about "they." This observation aligns with earlier research identifying endometriosis patients' narratives about being mistrusted, or even delegitimized by healthcare professionals (see e.g. Lindgren and Richardson 2023 or Bullo 2020).

As a final point, the study shows that virtual CoPs continue to be sites where knowledge is constructed through purpose-driven peer-to-peer interaction embedded in a collective social action. Therefore, it is worth emphasizing the main characteristics of a CoP, as specified by Botha et al. (2008), who note that: (1) learning is a social phenomenon; (2) knowledge is integrated into the culture, values and language of a CoP; (3) learning and community are inseparable; (4) knowledge and practice are inseparable, and, finally, that (5) empowerment is crucial to learning. The research reported in this paper – bringing to the reader's attention the social dimension of health knowledge formation and the dialogic means used to co-create "small-*t* local truth" and to empower women with endometriosis – drew inspiration from this characterisation.

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