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Engage and withdraw: The role of peer-led online communities in the configuration of knowledge on chronic illness

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ABSTRACT

Background: Living with chronic conditions and the dependencies for continual treatment make some citizens turn to peer-led online communities (PLOCs) to seek care and information about their illness. **Aim**: This article explores the role of PLOCs in the configuration of knowledge on chronic illness and unfolds how temporality of illness influences this process. **Methods**: A qualitative analysis using a thematic coding process was performed on transcripts from 20 semi-structured interviews conducted in 2022 with people living with various physical chronic conditions and using PLOCs. Within the theme of 'knowledge', three sub-themes were identified: peer, medical, and experiential knowledge. **Results**: The article finds that knowledge on chronic illness is configured by (1) information from peers in PLOCs, (2) medical expertise from doctors and (3) own experiential knowledge. **Discussion**: The article further discusses how this configuration of knowledge is influenced by temporality and thus is steered by the onset of a diagnosis. **Conclusion**: The PLOCs play a significant role at the onset of a diagnosis and make a 'new chronic patient' engage more, while an 'experienced patient' tends to withdraw from PLOCs. The article concludes by outlining the potentials of recognizing PLOCs as spaces where the joining together of various knowledge forms is made possible.

KEYWORDS

Chronic illness, configuration of knowledges, peer-led communities, social media, temporality

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Introduction

> When the doctors are groping in the dark for answers it can be a relief to turn to the group online. To see if anyone has had similar progress and found a good solution. To see if there is hope ahead. (F39)

Searching for knowledge elsewhere than in the established healthcare system is not new, and if you are living with a chronic condition, seeking answers and knowledge on your illness through new pathways than the established medical healthcare system – as some sort of reassurance – seems even more pressing. In Denmark, approximately 3 million people are registered with one or more chronic diagnoses (Denmark Country Health Profile, 2021). Chronic illness is often described as living with one or more bodily disorders lasting longer than 12 months that increases the need and dependencies for continual care and treatment (Hvidbjerg et al., 2020). For some, it may take up to several years before getting a diagnosis and, in the meantime, jumping from one specialist to another, spending a lot of time waiting for test results or for things to get better (or worse) can be frustrating. In sum, these factors make some citizens turn to peer-led online communities (PLOCs), like the thirty-nine-year-old female suffering from the inflammatory bowel disease, colitis ulcerosa, quoted above did, “to see if there is hope ahead” (F39). These PLOCs provide both care and support from peers as well as information on specific illnesses, special treatments and recommendations on medicine and specialists across the country (Stage et al., 2023). However, partaking in PLOCs is not necessarily about turning one’s back on the established medical system; rather, it is part of a configuration of the knowledge needed when struggling with chronic conditions and this configuration appears to be shaped by a trinity of sources of knowledge depending on the onset of the diagnosis. These sources of knowledge – produced both inside and outside of PLOCs and which co-exist in the PLOCs – are: The experiential knowledge understood as the individual experience of the ill body; the medical expertise understood as the medical knowledge provided by the doctor and the established health care system; and information shared by peers understood as illness narratives, information on medicine, care strategies and recommendations of specific treatments or practitioners provided by peers in PLOCs. Thus, PLOCs both become sites for sharing knowledge as well as a source of knowledge in itself; peer knowledge. The key argument of this article is thus that PLOCs constitute special spaces for configuration of knowledge allowing a holistic sharing of knowledge, where experience, peer information and medical knowledge can coexist, and that this configuration is steered by a temporal logic of illness. From the interviews that this article draws from, a pattern emerges in terms of how the interviewees tend to engage with and seek out information from peers in PLOCs at the onset of their diagnosis, while a tendency to withdraw from PLOCs shows when they render themselves more experienced – more knowledgeable about their illness. Hence, we argue that PLOCs should not only be seen as spaces for shared experiences of illness and wellness, but rather as temporal spaces where different forms of knowledge are tested and held up against each other in different phases of an illness’ trajectory. Our study contributes to existing research with new perspectives on the importance and use of PLOCs when living with chronic illness.

Thus, in this article, we ask:

R1) How is knowledge on chronic illness configured in PLOCs?

R2) What role is played by temporal structures of illness in this configuration?

Literature review

Online peer-led communities

The digitization of health has also seeped into social media, rendering social media as a place to search for and share healthcare information for many different groups of patients (Castleton et al., 2011; Eysenbach, 2008), changing health care research (O'Connor, 2010) and improving chronic care management to make it more effective (Pousti et al., 2014). Other scholars have a more patient-focused perspective and have explored the potential of social media and online communities as places for body-hacking, exchanges of knowledge and peer support focusing on online communities as places to navigate your illness, and places to connect and receive care (Kingod et al., 2017; Lolholm Gammelby, 2021; McCosker, 2018; Tucker & Goodings, 2017). From a biopolitical perspective, peer-based communities can be seen as places for developing and constructing the responsible self-improving patient seeking out information on their own health (Ajana, 2017). This speaks to a neoliberal idea of a society turning more towards individualism and the responsible and digital patient (Lupton, 2014). An exploratory study from 2016 investigates health activism by analysing the bottom-up sharing and co-production of health knowledge in online communities and finds that experiential knowledge and medical authority are equally valued in these processes (Vicari & Cappai, 2016). This article's ambition is to contribute with a perspective that looks deeper into the significance of 'the temporality of illness' in the configuring of this different knowledge, suggesting that the phase of the trajectory of illness the individual finds themselves in seems to affect which source of knowledge – peer-based, expert-based or experiential – they tend to draw from the most.

Configuring knowledges from 'somewhere'

"Knowledge is power" wrote Frances Bacon in his *Meditations Sacrae* (1597). Centuries later the French philosopher, Michel Foucault, claimed that knowledge is related to history, that history sets boundaries for what we can know and that all knowledge on humankind is provisional and historically conditioned. Foucault defined this as episteme (Foucault, 1988). In 1988, the feminist scientist, Donna Haraway, challenged the positivist ideal of scientific knowledge production – what she defines as "the trick of God" or the idea of a knowledge production completely cleansed of all kind of subject positions and subjective meanings. Instead, Haraway offers a knowledge production that is situated and bodily anchored, claiming that production of knowledge is never neutral, but always already influenced by the subjects anchoring in time, space, historical hegemonic relations and bodies. Thus, Haraway replaces the notion of a universal human identity (the white male perspective) with a knowledgeable subject able of inhabiting various positions in correlated and transformative constellations with others. According to Haraway, knowledge is situated and partial, simply because we cannot see everything from where we stand, noting that “vision is always a question of the power to see” (Haraway, 1988, p. 585). Haraway claims that the concept of situated knowledges forms the grounds for what is defined as feminist objectivity created by “the joining of partial views and halting voices into a collective subject position that promises a vision of the means of ongoing finite embodiment, of living within limits and contradictions of views from somewhere” (Haraway, 1988, p. 590). Drawing from Haraway, we want to explore theses “situated and embodied knowledges” and understand how they are configured. Thus, this article is situated within Haraway’s feminist line of thought and her way of thinking in and thinking with various forms of figurations. The way Haraway insists on connecting both human and non-human entities and rendering them equally responsible – as for an instance with her figuration the Cyborg: a cybernetic organism, a provocative and visionary boarder figure between human and animal, organism and machine. A creature incapsulating both the social, the real and the fiction. ‘Configuring knowledge’ becomes a way of understanding the complex interplay between various sources of knowledge, how they form connections of value and importance for the person living with chronic illness. We understand the online peer-led communities as spaces where various entities, knowledges and representations of human bodies can co-exist. Thus, like Haraway, we will use the plural form of ‘configuration of knowledges’ throughout the rest of the article to emphasize this multiplicity.

Gender theorist Nina Lykke (2008) explains how feminism as a research discipline largely stems from the women’s movement, visualized with the book project *Our Bodies Ourselves* from The Boston Women’s Health Book Collective (1971). This movement emerges and evolves in the early seventies in the US and later spreads to the rest of the world. The book was – and still is – considered a milestone in women’s emancipatory liberation process because it became a way of “taking back the body” from the patriarchy. Up until then, the knowledge on women’s bodies in terms of reproduction and health was dominated by male doctors and medical experts. By creating a collection of knowledge about the female body and women’s life – as a collective project between women, from women and to women – this hegemonic knowledge position was challenged (Lykke, 2008).

These historical notions and perspectives on knowledge production, on who can know and on who renders knowledge become evident when looking at online communities as potential spaces for the configuration of experiential knowledge, medical encounters and information shared by peers. The configuring of knowledges in PLOCs – e.g. co-creating knowledge on lived experiences of being chronically ill by exploring, sharing and caring for one another – somewhat mimics the movement that arose around The Boston Women’s Health Collective in the seventies. In PLOCs, the challenge of knowledge claims ‘from nowhere’ occurs by bridging medical expertise with own experiential knowledge and shared narratives from peers. Given the fact that the majority of users in the PLOCs behind this study are women, constructing and exchanging complex configurations of knowledges makes this parallel even more evident. Following Science, Technology and Society (STS) scholar Lucy Suchman (2012), we understand ‘configuration’ as relational and created by different entities, discourses, norms – the sociotechnical constellation of people living with chronic illness and the PLOCs they encounter, produce and engage with. In other words, it is a configuration of phenomenologically experienced and understood bodily knowledge and the medium that mediates and unifies this configuration. Or in Suchman’s words, they “join together” (Suchman, 2012, p. 48). Thus, the configuration of knowledges is influenced by the expert knowledge provided by the doctors and healthcare system, the individuals own experiential and embodied knowledge and the shared information from peers accumulated in the group over time. Needless to say, other factors play a part in this configuration of knowledges such as personal relations, resources and time. The latter appears to be very important when deciding on how to bridge the experiential knowledge with information from peers and medical expertise. In other words, it is deciding on which source of knowledge one ascribes most value to at a given time in the development of the illness.

Time and the chronically ill body

The philosopher Drew Leder offers an interesting phenomenological notion on the sick body (1990) by stating that our perceptions of our own bodies is shaped by what he calls 'corporeal absence' (Leder, 1990, p.1). Leder draws from Merleau-Ponty's uncompleted work *The Visible and the Invisible* where Merleau-Ponty introduces the idea and concept of the lived body as 'flesh'. To Merleau-Ponty, the body, then, is a medium through which the self and perspectives on and experiences of the world are formed. However, Leder expands this concept of 'flesh' to 'flesh and blood', and he does so to go beyond the surface (flesh) of the body to include what lies underneath: "The term flesh and blood suggest a dimension of depth hitherto unspoken … Beneath the surface flesh, visible and tangible, lies a hidden vitality that courses within me" (Leder, 1990, p. 66). By pointing to the fact that our bodily sensations mostly build on the outside of our bodies, that we have difficulties sensing the inside and therefore our felt experiences of our bodies are highly shaped by external factors, Leder also challenges the cartesian dualism and offers a new way of seeing and trusting the body as a whole (Leder, 1990). On the onset of chronic illness, the body that used to be – in Leder's terminology – absent or simply forgotten – is now showing itself via illness and pain. These (new) bodily sensations become important as something the individual can use as a guidance and – in time – as an experience or biography of illness. Physical chronic illness might differ in, for example, pain, severeness, symptoms; however, chronic illness shares the specific common thread of time, meaning that temporal structures are evident for the citizen living with one or more chronic conditions. A narrative review from 2016 explores how scholars have chartered the relationship between time and chronic illness and finds that four key temporal structures are evident when living with chronic illness: "calendar and clocked time, biographical time, past–present–future time, and inner time and rhythms" (Jowsey, 2016, p. 1100). Calendar time includes the time spent in waiting rooms, waiting for doctors, and scheduling appointments and medicine to be consumed at a specific time each day; biographical time "reference[s] the summative period of time allotted to an individual during the course of their life" (Jowsey, 2016, p. 1095); Past-present-future time is a socially understood temporal construct; and Inner time and rhythms are bodily messages that tell us when we need to sleep, consume food or medicine, e.g. when diabetes patients feel the lack of insulin.

In an article from 1982, the sociologist Michael Bury coins the concept 'biographical disruption' conceptualising chronic illness "as a particular kind of disruptive experience" (Bury, 1982, p. 178). He builds his research on an interview study with rheumatoid arthritis patients at the onset of their diagnosis. He explores what happens at that very early point of 'becoming' chronically ill in terms of recognizing and coping with the life changes and ditto circumstances that change when facing an altered situation. For example, when young people get a diagnosis of rheumatoid arthritis, it confronts their cultural perceptions of arthritis as being an illness for the elderly. As such, the diagnosis marks "a biographical shift from a perceived normal trajectory through relatively predictable chronological steps, to one fundamentally abnormal and inwardly damaging. The relationship of internal and external reality was upset" (Bury, 1982, p. 171). Simon Williams problematizes this biographical notion of illness as disruption, arguing that illness can be there from birth or be expected, e.g. someone has a genetic predisposition (Williams, 2000). What we have learned from the interview data behind this article is that the onset of a diagnosis is most important compared to whether it is an innate illness or a biographical disruption later in life. This is the moment when some steer towards PLOCs and start engaging with peers looking for answers and searching for information on their specific illness. During this time, it becomes clear what to search for "to see if there is hope ahead" (F39).

Methods

This article builds on parts of a larger study carried out in 2022 focusing on peer-led communities for and by citizens living with chronic conditions. In particular, we draw from 20 semi-structured and in-depth interviews (Kvale & Brinkmann, 2009) with citizens living with chronic conditions and who follow the public Instagram profile *Kroniske Influencers* (Eng: Chronic Influencers, CI) with 10,000 followers, or are a member of the closed Facebook group *Kroniske Smertepatienter* (Eng: Chronic Pain Patients, CPP) with 3,600 members. Both communities were founded and are administered by people experiencing chronic conditions themselves.

Interviews and ethical considerations

The interviewees were recruited via a survey distributed in both CI and CPP and 40 respondents signed up with email agreeing to be contacted to participate in an individual interview. Out of the 40 respondents, we sampled for maximum variation and diversity in terms of gender, age, and choice of social media community. This resulted in 21 interviewees being selected: 16 women and 5 men (20 interviews in total as one interview had two participants). The interviews were conducted in April and May 2022, and the same interview guide was used for all the interviews structured around five core issues (1) the experience of living with chronic conditions; (2) the overall experience of the healthcare system; (3) the engagement in peer-led online communities; (4) the experience of care in peer-led online communities; and (5) the patients' demographic information. All interviews were conducted by the same interviewer and lasted approximately one hour each. We have chosen to use direct quotations in this article to make sure that the narratives of our interviewees truly come forward. Thus, every quote has been translated meticulously from Danish into English. The collection of interview material was based on informed consent, meaning that the interviewees could withdraw from the project at any time without sanctions, and the study follows and complies with GDPR guidelines. All interviewees are anonymized in the material and are represented after a quote by either ‘M’ (male) or ’F’ (female) referring to their gender followed by a number referring to their age.

Several ethical considerations were continually discussed throughout the research. Most importantly, we did not want to cause any negative physical or psychological effects (Franzke et al., 2020). To ensure this, we initially let the informants choose the interview setting as well as the schedule for the interviews to respect different needs, including their current level of energy due to their illness and need for privacy. The 20 interviews were conducted as follows: in the homes of the informants (two interviews); at the researcher’s office (one interview); by phone (five interviews), via Zoom in the informant’s home (11 interviews); via Zoom at the hospital during the informant’s treatment (one interview).

Coding process

All 20 interviews were transcribed followed by a thematic manual coding of the material (Braun et al., 2006; Tracy, 2019). We coded for ‘continuity’, ‘publics’, ‘care’ and ‘knowledge’, and this article explores the latter. Within the theme of ‘knowledge’, three sub-themes were identified: ‘peer knowledge, ‘medical knowledge’ and ‘experiential knowledge’. The qualitative research tool NVivo was used for categorizing the themes and to create an overview of the transcriptions. All researchers participated in the coding process to ensure inter-coder reliability (Tracy, 2019), and the coding themes were thoroughly discussed to ensure a common ground of understanding of each theme. In the coding process, it quickly emerged that all sub-themes were infused with the concept of ‘temporality’, and the difference between being a ‘new patient’ and an ‘experienced patient’ became obvious. Being a new patient suggests that up to quite recently, this person was not yet a patient. Likewise, an experienced patient indicates a temporal structure of having occupied the role of patient for some time. In the following section, we will outline the results of our study and show in what way temporality interferes with the configuration of knowledges on chronic illness.

Results

Time and the ‘new chronic patient’

According to our interviewees, it becomes clear that living with a chronic condition demands a certain individual drive to master their own illness and to test and seek out possible solutions, medical treatment and wellness strategies to cope with everyday life challenges, e.g. pain related to their diagnosis. It also shows that this configuration of knowledges is an ongoing process – changeable and adaptive to the life circumstances of the individual and the development of the illness. Furthermore, the changeability influences the source of knowledge the individual struggling with chronic conditions chooses to rely on the most. One interviewee describes how information from peers shared in PLOCs becomes a valuable source of knowledge:

> It basically means that you can gain knowledge about your illness from those who know best. You cannot get a better partner to discuss things with than one who has had the illness himself. And in particular if it is

> a person who has lived with the illness for several years… that person has likely spent a great deal of time researching how to get well, and all that information is just right there in front of you (M35).

Peers matter when you are newly diagnosed and just finding your way around this new world of yours that is now inhabited by one or more chronic illnesses causing frustration and despair. As one interviewee describes the moment she received her chronic diagnosis: "I felt very, very, very, very, very alone! Completely alone" (F39). Another interviewee adds to the sense of loneliness that pushes you to take control over your situation and react to the situation of being newly diagnosed: "No one tells you in the beginning. It is something that you have to figure out along the way. It is like with life in general; you can collect knowledge and, in that way, help each other" (F20). When one is at the onset of a diagnosis of a chronic illness and feeling alone and somewhat lost, the PLOCs offer a place to seek knowledge and information about the diagnosis, possible treatment for it, others' experience with that particular illness and treatment. It accommodates the need to find "lived knowledge" instead of abstract medical knowledge. One of the interviewees describes getting a chronic diagnosis like having to "go through a lot of phases because your life changes completely." She is forty-six years old and has been diagnosed with fibromyalgia. She went from hard manual labor working as a butcher to a sedentary office job – and that simply triggered the illness:

> I didn't know anybody with fibromyalgia, so I trawled the internet, Facebook, everything! And suddenly it all made sense – I had like a real diagnosis, right? So now I have found several groups because I needed to talk to someone (F46).

Another interviewee shares how she turned to the internet and a PLOC just after getting diagnosed with Crohn's disease, asking questions such as:

> I need some help. I need some knowledge on how to live with this and how to manage my everyday life. What impact does it have on your day-to-day life – both positive and negative, right? This is knowledge that someone who does not experience this in their everyday life would never be able to provide you with (F20).

At the onset of the illness – not necessarily newly diagnosed, because one can have lived with illness for several years before getting a diagnosis – everything changes in an instant. The biographical disruption, as described by Bury, alters the perspectives and concepts of the individual getting a diagnosis and suddenly experiences the world in a completely different way. Then the questions follow of how to cope with this in everyday life and which strategies to implement to live as "normal" as possible alongside the chronic conditions. This is something the peers in the PLOC can help answer. However, learning how to best live a life with chronic illness our informants make clear that you cannot draw from one source of knowledge alone. The endless search for answers and hope can feel like you are trapped in a maze and thus you might believe that you suffer from something that you do not. In such cases, the medical expertise helps the individual to navigate the land of diagnoses. One interviewee suffering from a rare heart disease describes how she at one point was sure she had another more common diagnosis based on shared knowledge on that specific diagnosis from peers in a PLOC – because she was so desperate to find out about her ill body and at the same time to feel a sense of belonging to a community around a diagnosis: "when you have an illness less known you tend to wish for another diagnosis that is more known. One time my doctor had to tell me 'hey, this makes no sense at all'" (F21). And even though she had experienced being seen by others and being cared for in the PLOC, where they seek peers sharing experiences and illness narratives, she sometimes thinks there is "too much room for alternative ideas", and that the lack of evidence and scientific approval sometimes makes her wish "that someone would just step in and moderate things a little" (F21).

Based on the interview material, we can see how the 'new chronic patient' tends to seek peer-based information online to (1) understand the diagnosis given from the doctors and (2) to figure out how to navigate everyday life as a person living with chronic conditions. This suggests that when the 'new chronic patient' is entering and partaking in this configuration of knowledges, they will rely mostly on medical expertise and on information shared by peers. With Leder's phenomenological accounts in mind, this is the exact time where the body is showing itself through illness. Becoming aware of its existence throws the individual out into an unknown and uncontrolled land of illness.

Time and the 'experienced chronic patient'

Being more experienced at living a life with chronic conditions also means knowing the ill body at a deeper level – expanding the concept of body to include not only flesh but 'flesh and blood', as Leder (1990) would put it, and simply being more focused on bodily sensations and signals and thus drawing more from experiential knowledge when entering the configuration of knowledges on the chronically ill body. The sensation of the illness becomes more known, and the individual comes to trust the body over information shared by peers and instead supports their own experiential knowledge with medical expertise. From the interview data, a pattern emerges in terms of how the interviewees tend to withdraw from PLOCs when they render themselves more experienced – more knowledgeable about their illness, as a patient explains: "Well, I know a lot. That's one of the benefits, right? I have really learnt to know myself and my physical condition" (F52). Another interviewee explains: "I can feel when my blood pressure is high, I can feel all sorts of things, so I measure my blood pressure and then I call my doctor telling him something is wrong" (F39). She has been suffering from a rare blood disease all her life and describes herself as a "pretty seasoned patient" who has been "reading scientific articles" since she was twelve years old – just to be as informed as possible and to ensure that the doctors take her seriously and involve her in all the steps of the process when being hospitalized or trying out new medication or treatment. Another interviewee, who has also struggled with chronic illness since childhood, explains how it is in fact a great thing being "part of the decisions… having something to say and defining how I want to live with this chronic illness" (M24). One interviewee who has been living with chronic illness for ages uses her experience to help others by volunteering as a mentor answering calls from a hotline where people can call for help when struggling with pain. A fifty-two-year-old interviewee who is "having a good period now" from her Crohn's disease explains how she tries in the PLOCs "to give advice and care the best I can to the others because I know it can be difficult" (F52). This supports the concept of peer mentoring coined by McCosker (2018). In his work on online communities for people living with mental illness, McCosker shows how peer mentors with certain resources or abilities can "transform the aversive affects of their own encounters with mental illness into a mechanism for connecting – or connecting with others" (McCosker, 2018, p. 4757). These examples show the strong, resourceful and responsible patient providing help to others in need, seeking out health information on their own, and not being a burden to society (Ajana, 2017; Lupton, 2014). However, it could be that this is more of a coping strategy rather than a free choice, as the interviewee with the rare blood disease concludes, “it takes its toll on being a patient in the Danish healthcare system” (F39).

Returning to Bury’s study on rheumatoid arthritis patients, he finds that when patients come to realize the limits of medical knowledge and the regimes of treatments provided, e.g. a certain amount of exercise and rest that are difficult to maintain, all they are left with is their diagnosis. This realization that medical knowledge can be failing and incomplete “throws individuals back on their own stock of knowledge and biographical experience. The search for a more comprehensive level of explanation, a more certain basis of coping with the illness is often a long and profound one” (Bury, 1982, p. 174). Today, more than forty years later, the search for explanation and coping strategies also takes place among peers in online communities. The interview data implies that ‘time of lived illness’ has an impact on how the configuration of knowledges is balanced: Having lived with chronic conditions for years establishes an experiential knowledge based on several years of bodily sensations and symptoms of illness that you learn how to deal with.

Other influential factors

It is evident that other factors are at play when choosing to engage with or withdraw from PLOCs in addition to being a new patient or a more experienced one. These factors vary from change in illness, to living in close relations, e.g. living together with partner or being a child and therefore supported by parents, equipped with or lacking resources such as communication skills. From the data, we saw examples of how sudden improvement in illness trajectory can cause withdrawal. Like when one of the interviewees explains how she at some point finds herself “feeling too well to be part of this community” (F32). Another example is living with a partner who can take part in difficult appointments with doctors or hospitalization or just having “one by who also listens to what the doctor explains” (F32). One interviewee explains – slightly angrily – how not having someone nearby for support or not possessing the resources needed to demand that the system be better can drive some people to write desperate posts on the PLOCs “and sometimes I really feel sorry for those who do not have the resources and who can’t articulate what they need and what they are entitled to” (F49). A thirty-four-year-old interviewee, living with chronic pain since he was thirteen, has had some difficult experiences with what he refers to as “the system”, and quite early in the interview shows a form of epistemic resistance where medical expertise is not to be trusted. He emphasizes the importance of “sharing experiences with those who have the disease themselves” instead of “seeing an expert who might not believe that you are sick at all”. Ultimately, it all comes down to that “you have to go find out stuff yourself”. Later in the interview, when asked how he would feel about online communities for chronic patients being administrated and facilitated by healthcare professionals, his response is quite clear:

> It would be difficult for me to trust it. Talking to someone who lives with an illness and has done everything to get well and have researched on that illnesses, I would much rather have knowledge from that person (M34).

However, these factors do not change the overall pattern showing that use of PLOCs for chronic illness is highly influenced by temporality in terms of phases of illness that the individual finds themselves in; they simply offer nuances to the argument. In the following, we will discuss our findings.

Discussion

Analyzing data from 20 individual interviews with men and women living with chronic illness of various kinds, we have found that knowledge on chronic illness is configured by the joining together of three sources: Medical expertise (coming from the doctor and the established healthcare system), shared information from peers (coming from the PLOCs) and experiential knowledge (the individuals' own embodied knowledge and experience of illness).

With a healthcare system somewhat challenged alongside an increasing number of citizens being diagnosed, it becomes paramount to go somewhere else to look for answers and information than from the established healthcare system. Acknowledging that medical knowledge sometimes can be failing and that the "doctors can be groping in the dark" (F39) corroborates Bury's claim that this "throws individuals back on their own stock of knowledge" (Bury, 1982, p. 174). Individuals are expected to go find knowledges from somewhere, as Haraway suggests, both to be an expert on one's own illness and to live a life as close to that lived by the non-sick citizens. A significant factor in this configuration of knowledges is temporality; it matters whether you are recently diagnosed and living with chronic conditions is new to you – being a 'new chronic patient' as opposed to being an 'experienced chronic patient' having been living with these conditions for years – potentially all your life. Being a 'new chronic' often means seeking out help and information and asking for support – engaging more in the PLOCs and relying on peers' shared experience. Being an 'experienced chronic' means sharing and giving information and support – and to some extent withdrawing from the PLOCs and relying more on own experiential knowledge and medical expertise. Being an 'experienced chronic' potentially also means having a diagnosis to rely on, to be part of a patient community focusing on a specific disease, and knowing how your body reacts to treatment, medicine and everyday life activities. Other factors are resources and relations: what matters is who you are, your ability to communicate what kind of chronic conditions you struggle with, and if there are others with your specific diagnosis with whom you can engage. Moreover, the kinds of relations you have are vital: are you alone, do you live with someone, do you have strong relations to family who can join you for difficult encounters with the system or simply stand by you in difficult times?

PLOCs contributing to the configuration of knowledges on chronic illness – and in particular at the early phase of a diagnosis – can be seen as supporting a challenged healthcare system.

PLOCs provide a place for the 'new patients' to engage with peers and to look for answers and information on a diagnosis they are supposed to live with for the rest of their lives. The information shared by peers in these spaces then functions as support and a primary source of knowledge alongside the medical expertise until they render themselves experienced enough to withdraw to rely mostly on their own experiential knowledge.

Withdrawal as a transformation of knowledge

Scholars in the field of self-tracking have made interesting contributions on how temporality, knowledge and engagement with self-tracking technologies are interconnected. In their article from 2022, Clark et al. argue that self-tracking persists even after the device is removed.

Building on the Deleuzian concept of 'habit', the authors challenge what they call 'the myth of discontinuance' suggesting that tracking continues – in different forms and shapes – after the user-app relationship formerly stops (Clark et al., 2022). Another article looks at the user-device relationship by simply removing the device and study what kind of new knowledge building practices occur in its absence (Homewood et al., 2020). These findings resonate to some extent with what we find in the study at hand, considering that self-tracking practises and engaging in a PLOC are both non-linear and somewhat unpredictable practices. It is both a matter of seeking and inhabiting knowledge and – to some extend – sharing information, and both practises are deeply shaped by temporality.

Conclusions

PLOCs not only function as counterpublics for epistemic resistance but also as spaces for epistemic negotiation and co-construction of knowledge on illness/wellness. This function is highly steered by temporality and the peers in PLOCs seem to be used as a source of knowledge at certain times in the trajectory of chronic illness: PLOCs play a considerable role at the onset of a diagnosis of chronical illness. Thus, the configuration of knowledges is an ongoing process. One that is changeable and adjustable to a trajectory of chronic illness that holds phases of various character – the disease flares up at times; other times it seems to be in abeyance. However, the onset of chronic illness is unchangeable – in Bury's terminology, a 'biographical disruption' – that calls for a certain configuration of knowledge to draw from, thereby allowing a feeling of safety. This configuration changes alongside the emerging diagnosis, resources and changes in relational circumstances which naturally shifts the balance between drawing from medical expertise, from peers and from experiential knowledge. Ultimately, the patient must determine whether to engage with or withdraw from the various sources of knowledge.

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