Online Patient Work

On the Use of Peer-Led Online Communities to Process and Prevent Discontinuity of Care

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Abstract
Patients in Western countries increasingly experience a lack of continuity of care. The aim of this article is to understand how patients with one or more chronic conditions handle and prevent experiences of discontinuity of care by engaging in collaborative – and most often systemically invisible – patient work in peer-led online communities (PLOCs). The article’s analysis is based on 20 interviews with users of two Danish PLOCs and finds that care continuity is primarily addressed in its absence; that is when it has been lacking in systemic experiences, or when discontinuity is anticipated or feared in future encounters. The analysis shows that the collaborative patient work done in online communities can be understood as patients’ attempts to mend discontinuities produced by health institutions. Three dominant mending practices are (1) to interpret or vent systemic information to increase collective understanding and decrease frustration, (2) to prepare for encounters with the system to enable them to be more effective, and (3) to push the system to improve decisions and services linked to treatment and care. Considering these findings, the article concludes that there is a need to acknowledge the collaborative work of patients in PLOCs as an informal contributor to continuity of care.

Keywords
Care continuity, informal care, patient communities, patient work, social media, systemic mending.
“There is a lot of injustice in this world in relation to getting the support and help that you need as a person with an illness. And access to things… to understand your journals and stuff like that. A lot is missing on that front. In CI we use each other to understand and interpret” (32, female).

In this quote a female chronic patient describes how she uses a peer-led online community on Instagram (called Chronic Influencers; CI) for people with one or more chronic conditions to both understand information given by the healthcare system (e.g. journals) and to share knowledge about how to navigate the system in order to for instance ‘get access to things’. The rationale for this collective interpretation and knowledge sharing process seems to be that something is missing in the system; that the system leaves patients experiencing deficiency in terms of feeling informed and cared for in an effective and meaningful way.

The concept continuity of care is used to describe a situation, where the patient experiences health care in a way which is well-informed, well-coordinated and characterised by relational stability. In Western countries patients increasingly experience a lack of continuity of care, often due to ineffective coordination of treatment (Martin, 2010; Schultz et al., 2019), inadequate sharing of clinical information, and failures of communication (WHO, 2018). Discontinuity of care can be linked both to (1) actually experienced failures (e.g. meeting too many new and under-informed health professionals in relation to one’s treatment) and (2) systemic expectations that make patients take on more responsibility in terms of managing and taking control over encounters with the health care system in order to avoid discontinuity in care experiences.

In the existing literature, continuity of care is usually investigated in terms of the relationship between patients and health professionals or coordination between different healthcare sectors or services. This has the implication that the – often digitally mediated – continuity work performed by patients is not taken sufficiently into account. Due to increasing importance of social media for health-related purposes the article seeks to address this knowledge gap. It does so by exploring to what extent and how peer-led online communities (PLOCs) on social media can be understood as arenas for performing patient work with the aim of producing care continuity and handling care discontinuity. The article will address the following research question:

*RQ*: What is the role of selected PLOCs for users interacting about care (dis)continuity in the healthcare system?

The article’s analysis is based on 20 interviews with users of two PLOCs for people with one or more chronic conditions: the public Instagram profile Kroniske Influencers (Eng: Chronic Influencers, CI) with around 10,000 followers, and the closed Facebook group Kroniske Smertepatienter (Eng: Chronic Pain Patients, CPP) with approximately 4,000 members.

**Theoretical Framework**

*Patient Work*

Research on the active health practices of citizens has presented and developed a range of different concepts such as self-management, involvement, participation, empowerment, and engagement (Bygholm & Bertelsen, 2017; Greenhalgh, 2009). These conceptual approaches
are often based on the assumption that active patient practices are desirable – if guided and informed in the right way – and that health care systems must therefore focus on assisting patients in constructively developing their behaviour as an active patient. This article will not take this point of departure and instead understand active patient practices through the sociological lens of ‘patient work’, which focuses on exploring all the often “relatively unnoted and unrecognized effort by patients” (Strauss et al., 1982, p. 977) in relation to handling their health, interacting with health care and living up to more or less explicit expectations linked to the patient role.

Yin et al. defines patient work as “the tasks (physical and cognitive) conducted by patients to manage their health, as well as the holistic sum of contexts (physical, social, mental and organisational) that influence the work conducted” (Yin et al., 2018, p. 2). They distinguish between medical (e.g. planning appointments), emotional (e.g. dealing with anxiety) and role-related (e.g. balancing family relations) forms of patient work (Yin et al., 2020). According to Strauss et al., patient work generally aims at managing and shaping patients’ “lives in the face of physiological impairment and medical intrusion. They work more or less successfully at controlling symptoms and disease processes, and at carrying out their regimens” (Strauss et al., 1982, p. 978).

Existing research has studied patient work in relation to particular types of disease, like chronic illness and heart failure (Holden et al., 2015) or diabetes (Rogvi et al., 2021), methodological challenges of studying patient work (Yin et al., 2018), the importance of acknowledging the patient work involved in medical intervention and documentation (Bygholm & Bertelsen, 2017), barriers to the work of patients and informal caregivers (Holden et al., 2015), and the different types (e.g. in relation to staff work) and contexts of patient work (e.g. clinic vs. home; Strauss et al., 1982; Werner et al., 2021; Yin et al., 2020).

According to Strauss et al. patient work can be explicit and appreciated by health staff (e.g. when patients do exercises during rehabilitation) or implicit and taken for granted as mere cooperation (e.g. when patients give information on their illness). Patient work can furthermore relate to staff work in multiple ways: by mirroring it (e.g. delivering a requested urine sample), supplementing it (e.g. staying composed during a procedure), substituting it (e.g. delivering information that the staff forgot to ask for), rectifying it (e.g. reporting errors; Strauss et al., 1982).

Patient work can also deal with unintended consequences or failures of health care. Rogvi et al. for instance argue that patient work is sometimes motivated by the fact that “the organization of care leads to patients doing (or not doing) specific things to fill the gaps of formal health care” (Rogvi et al., 2021, p. 2631). A specific type of increasingly prevalent patient work is thus not linked to fulfilling explicit tasks, but to making oneself available for care. This kind of work includes running between medical encounters, coordinating encounters, knowing how to contact health care with the information that will give access to relevant care. “We argue that this work of making oneself available to be cared for involves initiative and self-care. It also involves knowing the system and articulating one’s need for care. Making oneself available for health care takes effort” (Rogvi et al., 2021, p. 2633). Following this, patient work is not only about fulfilling visible tasks or processing emotional challenges, but also linked to navigating the health care system – and to performing what Strauss et al describe as trajectory work (Strauss et al., 1982, 981) – to access care.

Due to e.g. economic or physical restrictions, certain groups (e.g. the chronically ill) will have to do more work than others, or not be able to do the work required, to get help. In that
way patient work depends on resources. In their scoping review of 67 articles on patient work, Yin et al. stress that patient work requires resources like time, energy and support, but also that it can be as much about building as consuming resources. Resource-building can for instance be a collaborative process and take place in support groups, where patients “proactively share their own health information and self-care strategies with others and act to support other patients along the illness journey” (Yin et al., 2020, p. 8).

By using patient work as a theoretical framework, the article contributes to research in two distinct ways: First, it explores how peer-led online communities on social media can also be approached as arenas for doing different types of patient work; second, it focuses on exploring continuity of care – and the rectification or processing of experiences of discontinuity – as a specific objective for collaborative patient work on social media.

**Peer-Led Online Health Communities**

For more than a decade, health research has been exploring the potentials of social media in terms of providing and accessing healthcare information (Eysenbach, 2008; Poisti et al., 2014) and changing health care research (O’Connor, 2010). This article especially focuses on online health communities and define them as digitized social formations based on interaction among peers about health issues. Such communities (linked for instance to a Facebook group, Instagram profile, app, website etc.) can be open or closed, large or small, and more or less thematically demarcated (e.g. to a specific form of exercise, a set of diseases (e.g. chronic conditions) or more general health concerns).

Illness-related online communities are engaged with for various purposes. In a systematic review, Kingod et al. argue that individuals with chronic illnesses use peer-to-peer communities online to process identity changes, to get and provide social support, to share experiential knowledge about illness, and to promote collective agendas to the public (Kingod et al., 2017). Oh et al. have instead explored the forms of social support experienced by users of health-related Facebook groups and distinguish between support focused on objective appraisal of information, building esteem, emotional exchange, and tangible or practical help (Oh et al., 2013).

Existing research on peer-led illness communities on social media has also shown how certain types of authority or mentorship develop as peer users “transform the aversive affects of their own encounters with mental illness into a mechanism for connecting – or connecting with – others” (McCosker, 2018, p. 4757). Another important finding is that these peer-to-peer illness communities exist in a tension between offering new forms of informal care and producing new experiences of insecurity or ambiguity as care is suddenly exchanged in a social space “in which caring for oneself becomes bound up in the ambiguities of caring for others” (Tucker & Goodings, 2017, p. 629). In this process, care responsibility can also shift – or be distributed in new ways – because peers engage in care practices directed at potential strangers.

This article focusses on patient work dealing with issues of (dis)continuity of care in online health communities initiated and run by patients themselves. The article will thus advance the academic understanding of chronic patients’ engagement with peer-led health communities by focusing on the underexplored issue of how these communities are both disconnected from healthcare (in terms of who uses them) and highly entangled with the practices, procedures and problems of formal health care.
Continuity of Care Beyond the Usual Suspects

According to WHO, continuity of care as a concept “reflects the extent to which a series of discrete health care events is experienced by people as coherent and interconnected over time and consistent with their health needs and preferences” (WHO, 2018, p. 9). It has been documented that patients increasingly experience a lack of continuity of care, for instance, due to encounters with too many different health professionals, too much waiting time, too many cancellations, and ineffective coordination of treatment (Martin, 2010; Schultz et al., 2019).

According to WHO, better coordination of care should be a strategic goal with the aim of providing more people-centred care. WHO also notices that a lack of continuity is a “particular problem for people with chronic or complex conditions” (WHO, 2018, p. 9). A qualitative study of Danes with chronic widespread pain documented that this patient group experienced frustrations when treatment was fragmented or specialised professionals did not coordinate with each other, when time was too limited during consultations, or when they had to wait too long between consultations (Schultz et al., 2019).

Continuity of care is often divided into subcategories or key forms. Haggerty et al. (2003) have offered an influential typology that distinguishes between informational, managerial and relational continuity. Informational continuity is produced through knowledge that bridges separate care events (e.g. through documents or the recollection of providers; Haggerty et al., 2003). Management continuity is enabled by the planning and timing of health services in relation to the need of a particular receiver, while relational continuity is produced through coherent and consistent relations to a suitable core of health care staff.

As mentioned, care continuity is most often linked to encounters between patients and systems, but research has also stressed that other agencies can affect the experience of care continuity. Wong-Cornall et al. have for instance explored how informal and family caregivers (e.g. the relatives of a patient) can be crucial in terms of tying treatment processes together and handing over information (Wong-Cornall et al., 2017). Menke et al. (2020) furthermore explored how informal caregivers also seek social support in mediated care relationship networks in order to process the potential burdens and dilemmas of providing informal care to relatives – and how these online networks become even more important if offline relationships are damaged or impaired (Menke et al., 2020).

This article is inspired by these attempts to widen the attention to the plethora of different informal actors involved in producing continuity of care, but it adds to the discussion by looking beyond family caregivers and by asking how self-organising patients themselves engage with the production of continuity of care by interacting on social media.

To sum up, this study is unique by taking an interest in how the collaborative patient work performed in PLOCs are entangled with experiences of (dis)continuity of care. Findings will not least be of importance to health care institutions or professionals interested in a more holistic and nuanced perspective on how their patients engage with health care (and its failures) through social media communities. The project contributes to three existing research fields: (1) Research on patient work by exploring if/how PLOCs on social media can also be approached as arenas for doing different types of collaborative patient work, (2) research on online health communities by focusing on the underexplored issue of how peer-led communities handle experiences of care (dis)continuity, and (3) research on continuity of care by investigating how self-organising patients themselves engage with the production of continuity of care through social media interaction.
This is an important phenomenon to study due to the increasing importance of social and
digital media for issues of health and illness (Lupton, 2013, 2018) – not least for chronic
patients who often have a pressing need to engage with peers about how to navigate the health
care system. The research also helps shed light on a Danish context where coherent health care
is put under pressure by demographic changes (e.g. an aging population and an increasing
number of chronic patients) and institutional fragmentation, which are likely to sustain the need
for system-orientated and collaborative patient work on social media.

Method

The article’s analysis is based on 20 qualitative in-depth mediated or in-person interviews with
Danes living with chronic conditions and using one or both of the social media communities
explored here (Kvale & Brinkmann, 2009; Salmons, 2014). The two communities both focus
on sharing peer-based knowledge and are chosen due to their size (they are examples of large
patient communities for chronic patients in Denmark) and because they are initiated and
administered by patients, but also because of their differences in terms of being public/private
and use of platforms (Facebook vs Instagram).

The interviews focus on five core issues (1) the experience of living with chronic
conditions, (2) the overall experience of continuity in the healthcare system, (3) the engagement
in and knowledge of peer-led social media groups, (4) the experience of care in peer-led social
media groups, and (5) the patients’ demographic information. Informants for interviews were
recruited through a survey shared in the groups, which will be explored in future articles. 40
out of a total of 207 survey respondents signed up to be contacted for an individual interview.
Out of the group of 40, we sampled for diversity in terms of gender, age, and group affiliation
and ended up with 20 interviews and 21 respondents (as one interview was done with two
informants at a time) consisting of four men (between 26 and 55 years) and 17 women (between
20 and 67 years). Approximately half of them are members of CPP, while the other half is
following CI. The interviews give access to the informants’ interpretation of the relationship
between the communities and (lacking) experiences of care continuity (Creswell, 2014). They
were conducted in April and May 2022. The same interview guide was used for all interviews
and they lasted approximately one hour each. The interview guide was created collaboratively
by the three researchers, while all 20 interviews were conducted by one researcher to ensure
consistency in the deployment of the guide.

The collection of interview material followed the GDPR guidelines and was based on
informed consent, meaning that the informants could withdraw from the project at any time
without sanctions. All informants are anonymised in the material and are represented after a
quote by either M or F referring to their gender followed by a number referring to their age. A
range of other 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., 2019). To ensure this, informants could chose the interview setting as well as the duration
of and schedule for the interviews to respect different needs related to their current level of
energy and individual privacy requests.

One factor that cannot be overlooked is the vast majority of women involved – both in the
peer-led social media groups as well as in this study. The share of men among the interviewees
(4 of 21) is slightly larger than how gender is distributed in the social media groups according
to numbers shared by the administrators of the two communities. In CPP the members consist of 14% men and 86% women; in CI 6% of the followers are men and 94% are women. There might be several reasons for this skewing in gender; however, to establish what undergirds the poor representation of men in peer-led social media groups, another study focusing more in depth on men’s (non)engagement with social media communities on chronic illnesses is needed.

All 20 interviews were transcribed and then processed through a closed coding focusing on the core themes of knowledge, care, publics and continuity (Bjørnholt & Jacobsen, 2020; Braun & Clarke, 2006). The coding process was based on a code book (DeCuir-Gunby et al., 2011) that predefined the main criteria for identifying these four central codes in the material. The code book was developed and discussed collaboratively by the three researchers. One of the researchers coded three interviews by using a first version of the code book; then the result was discussed by the three researchers, and the code book was revised accordingly. Then all the interviews were coded by one of the researchers. In this article the interview material linked to the theme of continuity is the key focus of the analysis. This article does not focus on the differences between the two groups as experiences relating to care discontinuity, and the role of PLOCs in relation to this, did not seem to differ across the two user groups.

Analysis

The following analysis will argue that users of the two PLOCs engage in collaborative patient work to process and prevent experiences of discontinuity of care. Before embarking on the analysis, negative encounters with the healthcare system as a general backdrop for engaging with PLOCs will shortly be introduced.

Stories of Discontinuity and Shifting Responsibilities

The informants shared different types of negative experiences with lacking care continuity. In the following example, a female user (20) describes the lack of both relational and informational continuity of care in her encounters with a specific hospital:

“(…) every time I went to (name of hospital), where I was going due to my pain, it was a new doctor every single time. For a long period, I had to go there once a month and meet a new doctor and start all over by trying to explain and then everything would be questioned once again” (20, female).

The female informant emphasises her frustration by highlighting issues with information flow which mean that she herself must be the mediator of information to ensure some sort of coherent narrative about her within the system. The informant describes this as taking on a type of care work that ought to be handled by health professionals:

“No, no one talks to each other at all, and then it becomes your own job as a patient to try to figure things out, and that is not my job, but it has become my job and that is the case for a lot of patients with multiple diagnoses. A lot of doctors avoid these responsibilities” (20, female).

The quote stresses how care labour is experienced as distributed in ways that disrupt a traditional understanding of how doctors and patients enter into a relationship with each other; that is, the idea that the doctor provides care as a health professional, while the patient receives
care as a private, non-professional and embodied subject. The informant in that way articulates a collapse of roles and responsibilities where patienthood (with multiple diagnoses) is framed as saturated by a type of invisible and unwanted work and as linked to an analytical process of figuring things out.

Another female informant reflects on her understanding of why people with chronic conditions often end up not being understood and handled effectively in health care. This is because their treatment requires a type of interdisciplinary work that health professionals are not able to deliver, but also because chronic conditions disrupt the logic of wanting to cure patients once and for all:

“The frustration of not being heard and not being taken seriously or understood. And maybe the frustration that you feel that doctors just want patients that they can fix – to give them some medicine so they can be fixed and go out and live their life. I think people with a chronic condition is a patient group that frustrates many doctors because multiple diseases are involved and interdisciplinary processes, and nobody takes responsibility for that. (…) It requires a lot to be a patient in the Danish healthcare system” (39, female).

The analysis identified a pattern across the material that shows how informants express a kind of muffled-realist critique of the system that simultaneously underlines the need for systemic improvement (based on experiences of care discontinuity) and a no-nonsense recognition of the fact that the system will probably not change overnight and therefore patients must take on the work of rectifying it. One informant for instance expresses her pragmatic acceptance of the fact that her doctor can be too busy to read her journal before meetings or ensure a coherent long-term treatment plan (32, female), while another informant describes how the lack of care continuity is not something “I worry too much about. I think it is because I don’t have very high expectations” (36, female). For these reasons, the informants who are able to do so also seem to take on the task of finding and sharing information about their illness(es) and treatment process(es) to enhance subjective control and agency, but also to make themselves available for care.

The informants quoted above have experienced moments of both relational discontinuity (e.g. too many new encounters), informational discontinuity (e.g. incoherent information flow) and managerial discontinuity (e.g. problems with solving interdisciplinary tasks) and they understand this as linked to processes where responsibility shifts and moves from being handled by the healthcare system to being the patient’s unwanted work. The informants register these shifts – and articulate them as problematic and as indications of a flawed system – but they also seem to take on the task of filling in gaps and mending the system through peer-based and collaborative patient work on social media. The article proposes the concept of systemic mending to designate these patient-driven attempts to collectively gather and share information with peers that increase individual abilities to effectively navigate the healthcare system and thus to avoid the distress and health consequences linked to experiences of care discontinuity.

The following analyses will investigate the three most prominent ways that users articulate their attempts to pragmatically mend the flaws and inconsistencies of the healthcare system through collaborative patient work in PLOCs. These are: (1) to interpret or vent systemic information to increase collective understanding and decrease frustration, (2) to prepare for encounters with the system to enable them to be more effective, and (3) to push the system to improve decisions and services linked to treatment and care.
**Systemic Mending I: Interpreting the System**

PLOCs are used by informants to prepare for meetings with the healthcare system, to find knowledge about treatment options or to ask questions after meetings with the system. In that way PLOCs are arenas for sharing existing experiences of the system, but also for avoiding or preventing certain types of future encounters. A male informant for instance explains how the communities are important to him during moments of insecurity or of feeling abandoned by the system:

“Yes, completely abandoned and not understanding what you are facing and well – that is what you can use these communities for. (…) there you can search for help. That is search ‘What is actually happening in this situation?’ Because hundreds of people have been in the same situation” (35, male).

The informant’s experiences rely on the fact that PLOCs are in a sense vast experiential publics where individual first-time experiences can be transformed into collective knowledge or into a shared pattern of encounters with the system. This also entails that the insecurity of being alone in a situation characterised by information deficit can somehow be mastered by getting access to peer-assessments of how the situation could potentially be handled or develop. Individual differences and insecurities are in that way converted into experiences of collective sameness and potential predictability through the engagement with PLOCs as an experiential resource that can be activated through processes of searching for knowledge (in terms of both reading previous posts or asking questions). These peer-based processes can also be perceived as a kind of collaborative patient work focused on systemic mending in the sense that they help to process and deal with the knowledge insecurities or inequalities that the system unintentionally produces. According to a female informant (32, female) – also quoted in the introduction – the groups thus counterbalance the lack of interpretative help inside the system, e.g. in terms of getting access to and understanding patient journals: “(…) a lot is missing on that front. In CI we use each other to help understand and interpret” (32, female).

Experiences of systemic insufficiency can also be shared for more emotional reasons, e.g. to unload during moments of desperation or pain, where you don’t expect medical authorities to be able to provide help. Distress related to bad news or communication in the wake of acute treatment processes are also mentioned:

“Well I have tried a couple of times to return to my home from the hospital after acute hospitalisation, and you get home and you are still confused and nobody is home. And there you are, you need some sort of place to get it off your chest. If you return from the doctor, maybe with bad news. You need to get it off your chest. And you can do that in the group” (52, female).

Whether or not this is to be perceived as a kind of mending after an experience of care discontinuity is debatable. Returning home after hospitalisation or after having received bad news will often involve an element of potential distress or confusion. But confusion – and the need to share it with peers – might also be a consequence of incoherent communication or of feeling handled by an abrupt system based on quick treatments and hasty discharges from the hospital. This leaves the patient with the task of performing complex emotional work in the wake of interacting with the system.
Following this, it might be helpful to distinguish between continuity work in PLOCs that 1) is directly linked to experiences of systemic care discontinuities in terms of how information flows, relations are maintained, and treatment is managed, or 2) more focused on providing a sense of emotional and existential co-presence linked to e.g. being available for communication around the clock or making social connections possible despite bodily hindrances or immobility.

**Systemic Mending II: Preparing to Meet the System**

PLOCs are also used to prepare for meetings with the healthcare system. This is described by the informants as a form of work equipping them to interact with the system in a constructive, effective, and meaningful way. For instance, a young female informant describes how she uses one of the groups to be able to be more proactive in the actual medical encounter:

“Then I am better equipped to deal with the treatment options I have. (…) And I really like that you get the chance to prepare a little before meeting these doctors. You come across as better prepared, and you are taken a little more seriously, when you have some background information as you enter the room” (20, female).

The informant describes how she uses peer-interaction in a PLOC to be able to perform a certain patient role that is not based on passive submission to medical inspection, but on being informed and taking part in discussing treatment options. Respect within the system is articulated by the informant as directly linked to knowledge and to being well-prepared and thus to being able to take part in more explicit and visible forms of patient work in relation to staff (like asking the right type of questions and making qualified demands). In that way, collaborative patient work in PLOCs can also enable future-oriented attempts to optimise what lies ahead by finding the right type of knowledge to do so.

Using PLOCs to prepare to meet the system is a particular type of mending practice, where the avoidance of future experiences of discontinuous care is key. The informant thus seems to focus on being able to take part in a medical encounter where solid and effective treatment plans are made in collaboration with the medical authorities. Collective sharing practices in PLOCs play an important role in trying to predict and anticipate the types of health care conversations, decisions, and options that the individual will potentially face within the system. In that way, PLOCs not only serve as spaces for building bodily expertise – about e.g. what kind of everyday interventions might alleviate various conditions or illnesses – but also for building systemic expertise as a shared resource based on the broader collective’s experiences with health care institutions and professionals. This underlines Tucker and Gooding’s point that caring for others and caring for the self is often intertwined in peer-based communities. Here users collectively engage in sharing systemic experiences and knowledge to increase each individual’s ability to navigate – and be available for – health care in a way that is effective and meaningful for that person.

**Systemic Mending III: Pushing the System**

An important motivation for preparing to meet the system is to enable users to improve the interaction between themselves and health care professionals and maybe even to rectify or push the system in a desired direction. Talking to the informants, they stress how interaction in PLOCs for instance can have the effect that it widens the individual’s perspective on what can
be asked for in relation to the system or how the system can be approached. A male informant describes how reading about the practices of other patients, when they are shared in a PLOC, has inspired him to consider asking different questions and articulating other types of demands:

“The thing that you are not on your own, and that you, if it was just me… ‘can I really ask for this?’ Then if I see that she asks for it or that he does. Well then I am also able to ask for it” (26, male).

He continues to explain that interaction in the PLOC seems to transfer his own negative experiences with the system from a purely subjective realm to being part of a collective pattern that indirectly validates that the system must change:

“If I were the only one that experienced problems, then I was… I have a tendency to internalise things, and I have always done that. (…) I can find a lot of things that make me indignant because it is not just my responsibility. When so many of us experience the same problems in different ways, then society must do better and solve some of these tasks” (26, male).

This quote stresses that the movement of responsibility and work from health institutions to patients is not only a process of internalization that slowly turns previously institutional responsibilities into individual ones. It can also trigger counter-reactions where a subjective feeling of being responsible is externalised and directed towards other agencies (like society or the system). The informant insists that he cannot make himself responsible for every health problem in his life. In the interview he instead emphasises that society and the healthcare system must provide services of a certain quality and that this has become more difficult due to cutbacks. Therefore, on the one hand, he refuses to treat his health situation as a purely individual project by speaking back to the system, but on the other hand he also takes on the political responsibility of raising this critique and pushing for reforms.

When patients are asked to involve themselves more actively in health issues – in contrast to an older form of compliant patienthood – this can in other words entail both that the patient engages in work focused on illness prevention and in more critical forms of rectification. The articulated desire to push the system can thus be interpreted as an indirect consequence of involving individuals in sustaining and maintaining their own health. A female informant further complicates this by describing how the ability to object and be critical also relies on having access to resources:

“Sometimes you must put your foot down and say ‘This is not good enough. I want something better.’ I feel quite sorry for the people who don’t have the resources and can’t articulate themselves like that” (32, female).

The precondition for raising demands is a basic acknowledgement of the fact that the healthcare system can actually be affected and that different institutions and professionals act differently according to how you engage with them. Therefore, other patients’ experiences become valuable as input on how to navigate different care trajectories in the system and thus on how to co-produce a more coherent treatment process:

“There is not only one way to meet a physiotherapist; there is not only one way to go to the doctor. It is like claiming ownership. The thing is that many people think that there is only one way of being chronically ill. And that health professionals
have this treatment gene, where they just want you to get well and treat a lot of people. Here I think the groups are important because of the way they approach the healthcare system” (26, male).

Following this line of thinking, PLOCs become important spaces for challenging an understanding of the healthcare system as one coherent unit characterised by the same rationality. Instead, the system is understood as differential, as consisting of more or less positive and effective dimensions and thus as a heterogenous – but not necessarily stable – landscape that the patient needs to find her way through. They do so by means of knowledge and experiences produced through collaborative work among peers that have moved through the same or similar landscapes in the past. As a specific example, an informant describes (F_39) how she developed certain techniques for contacting the system in order to get the advice or response that she is looking for (e.g. to be put on the doctor’s call list). Another informant outlines how knowledge can also be linked to finding and demanding treatment options: “There are a lot of treatment options that are a little invisible, and that you need to find yourself, and that you have to find out exist, before you can be referred to them” (36, female). In that way PLOCs are not only experienced as existential lifelines (Lagerkvist & Andersson, 2017), but also as systemic lifelines for building resources that can be used to navigate complexity, tame confusion, and prepare requests.

Discussion

As shown, PLOCs are constantly related to the health care system by being used to process and avoid less successful encounters with it. This is done through various types of systemic mending practices where users of PLOCs engage in collaborative patient work with peers that increase their collective ability to navigate the healthcare system and thus to avoid the distress and health consequences linked to experiences of care discontinuity. Three forms of mending stand out in the material: interaction focused on interpreting or venting experiences of care discontinuity; on preparing to meet the health system in ways that avoid care discontinuity; and on pushing the system to produce more effective treatment or care from the perspective of the patient.

This type of patient work is characterised by (1) being focused on collaboratively producing resources making the individual patient available for care (Rogvi et al., 2021; Yin et al., 2020), (2) having both a medical and emotional dimension by building shared knowledge about the system and processing emotional disturbances (Yin et al., 2018), (3) being invisible from the perspective of health professionals, but nevertheless also focused on enabling users to meet more explicit or implicit tasks within the system (like being able to collaborate in a meaningful way during medical encounters; Strauss et al., 1982) and (4) being engaged in various forms of trajectory work aimed at e.g. rectifying mistakes or insufficiencies (Strauss et al., 1982).

The analysis adds to existing research on online health communities by not only stressing how experiences, support and mentorship are developed and communicated (Kingod et al., 2017; McCosker, 2018; Oh et al., 2013), but also how these publics are used for engaging in patient work that addresses systemic gaps and failures. Peer-led online communities in other words need to be acknowledged as significant publics for trying to mend systemic flaws and for pragmatically trying to improve the users’ ability to navigate health care and facilitate experiences of continuous care.
The material underlines that the participants do not necessarily approach continuity of care as something they can expect to receive, but rather as the potential outcome of a form of undesired, but necessary patient work aimed at making themselves available for the best possible care. If informational and relational continuity is missing, they must co-produce it by telling the same story repeatedly, and if managerial continuity is lacking, they must be well-informed enough to be able to ask the right questions or propose alternatives. PLOCs can be useful in this process of taking an active role in several ways: users can, for example, enhance informational continuity by teaching each other techniques for getting information across to or from health professionals; they can increase the potential for establishing relational continuity by seeking out peer-endorsed health professionals with a good reputation; and they can support managerial continuity by being able to ask about and push for various treatment options. PLOCs in that way serve as arenas for building collective resources of peer-based knowledge that are useful for trying to prevent informational, relational and managerial discontinuity, and as spaces for figuring out and venting discontinuities when they have occurred.

The analysis in that way adds to existing research on continuity of care by emphasising a need to consider, understand and acknowledge a wider array of informal or civil society contributors to continuity of care – and not just the ones (e.g. relatives) able to directly stand in for or mediate the experience of patients when engaging with the system (Wong-Cornall et al., 2017). A key insight of the analysis is thus that interaction on social media can also contribute to how “individual patients experience integration of services and coordination” (Haggerty et al., 2003, p. 1220) by creating an arena that seeks to optimise or process encounters with healthcare.

Limitations of the study are that it explores only two online communities and in a specific national context. It is based on self-selection and includes a smaller number of informants. Therefore, future research on patient work in PLOCs with more participants and in other national contexts would be interesting – not least to understand how system-orientated patient work on social media is performed in contexts with different health care infrastructures. Furthermore, the exact role of peer-led patient communities – compared to patient communities initiated by e.g. patient organisations – in relation to how patient work takes place, would make an interesting contribution. Last, but not least, the relative absence of men in many illness-related PLOCs calls for more research.

**Conclusion**

This article has argued that PLOCs should be considered as spaces, where collaborative patient work, aimed at producing or processing (dis)continuity of care, is performed. Actual experiences of continuity of care are, however, rarely shared by the users of PLOCs who seem to find the communities more useful when trying to tackle existing and potential experiences of systemic failure. The analysis has shown that self-organising patients partly interact in their own digital spaces to improve each other’s ability to navigate a healthcare system that they know and expect can be flawed. This implies that consideration and acknowledgement need to be given to a wider array of informal contributors to continuity of care.
Ethical Approval
The type of data collection reported in the manuscript, according to Danish standards, was considered exempt from needed ethical approval. Following to the ethical provisions by the Danish National Center for Ethics, approval of planned health research by an ethics committee is not required for interview-based studies that do not involve human biological material. However, the reported research was conducted following general ethical standards of good qualitative research: All participants were asked for informed consent at the beginning of the interview and were advised of their right to cancel participation (see section on Method).

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Conflict of Interest
The authors have no conflicts of interest to declare.

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Methodology (design, operationalisation): Amanda Karlsson, Carsten Stage, & Loni Ledderer
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