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'Online boundary-work': How people with diabetes negotiate what counts as legitimate knowledge in Facebook peer support groups

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ABSTRACT

People with chronic conditions such as diabetes use social media to interact with peers. While these online interactions allow them to exchange advice and gain insight into how others cope with their condition, concerns about 'misinformation' being shared are persistently raised, especially among medical professionals. Rather than assessing whether information shared on social media is 'correct' from a clinical perspective, we explore how people with diabetes negotiate what counts as legitimate knowledge as they interact in Facebook groups. Empirically, we draw on a six-month observation of interactions in two Danish Facebook groups for people with type 1 and 2 diabetes, including a data sample of 300 posts and 7797 comments. Observations were carried out in 2021. Guided by the concept of boundary-work (Gieryn, 1983), we analyse how members of the Facebook groups demarcate legitimate knowledge from what they deem illegitimate, enacted as they scrutinise peer advice and knowledge claims. We refer to this ongoing process as 'online boundary-work' and draw out three distinct negotiations, specifying how group members (a) recognise sharing of personal experiences as useful but do not necessarily accept them as valid forms of self-management advice, (b) support each other in evaluating medical issues but delegate certain treatment decisions and responsibility to professionals and (c) do not necessarily agree on the most accurate answer but mobilise scientific or professionally managed sources to legitimise or question claims. Our work contributes to the science and technology studies (STS) literature on how social media facilitates a collective space for people with chronic conditions to 'diagnose' issues in daily self-management and reflect on solutions, especially through sharing personal experiences. By demonstrating how these activities involve an ongoing, collective task of negotiating what counts as legitimate knowledge, we elucidate the effort people with diabetes put into upholding peer support groups as digital spaces for solidarity and knowledge useful to daily self-management. However, as we highlight, online boundary-work does not necessarily result in consensus, prevent certain types of advice from being shared or guarantee that answers are considered useful to members or 'correct' from a clinical perspective.

1. Introduction

Although concerns about misleading health information on social media are far from new, this issue has received tremendous attention over the past few years. One cause for concern is the fact that people outside the medical profession share health information on social media (Basch et al., 2021; Reidy et al., 2019; Swire-Thompson and Lazer, 2019; Wilson and Wiysonge, 2020). Online communities can mobilise thousands of people and advocate specific agendas, some of which run counter to prevailing clinical consensus: anti-vaccine advocacy during the COVID-19 pandemic is a recent, well-known example (Basch et al., 2021; Wilson and Wiysonge, 2020). Furthermore, certain individuals may gain 'expert status' among their peers and provide advice on medical issues (Bellander and Landqvist, 2020; Mazanderani et al., 2020). Such dynamics fuel concerns, especially among medical professionals, about the promulgation of misleading advice and potential

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harm (Reidy et al., 2019; Kjærulff and Langstrup, 2023).

Medical and public health research has adopted concepts such as misinformation to analyse the content being shared online (Swire-Thompson and Lazer, 2019). Misinformation, understood as "information that is contrary to the epistemic consensus of scientific communities regarding a phenomenon" (Swire-Thompson and Lazer, 2019), entails a binary distinction between true and false. It also implies that this distinction is negotiated and established in scientific communities, providing certain criteria for evaluating what counts as legitimate knowledge. This epistemic stance extends to research in online peer support groups for people with diabetes, typically using clinical practice guidelines to assess if the content is 'correct' and whether the groups are 'safe' for patients to use (Cole et al., 2016; Greene et al., 2011; Van Berkel et al., 2015). However, clinical practice guidelines provide a narrow perspective on information shared online among people with diabetes and other chronic conditions, supporting only analyses of medical accuracy and implying that clinical criteria predetermine what is considered relevant and legitimate knowledge.

Scholars in the field of science and technology studies (STS) have argued for recognising the relevance and legitimacy of patients' knowledge, especially in the context of chronic conditions such as type 1 and 2 diabetes that require people to engage in extensive self-management (Jansky, 2024; Kingod, 2020; Mazanderani et al., 2020; Mol and Law, 2004; Pols, 2014). Contemporary healthcare systems and policies around the globe encourage patients to take charge of their health and, by implication, become less reliant on medical services (Øversveen, 2020; Petrakaki et al., 2018). While people with chronic conditions often receive professional support and patient education, they are expected to develop the skills necessary for managing daily treatment. In diabetes management, medical advancements and a growing array of digital health technologies enable fine-tuning blood glucose levels but also engender a highly individualised responsibility for administering medication, interpreting data and making decisions about actions to take in response (Øversveen, 2020). The STS literature elucidates how individuals build knowledge from engaging in daily self-management and how patient knowledge is increasingly constructed through peer interactions on social media (Jansky, 2024; Kingod, 2020; Maslen and Lupton, 2019; Mazanderani et al., 2012, 2013, 2020; Petersen et al., 2020; Pols, 2014). In particular, STS scholars have highlighted the ability of social media to provide a collective space for people with chronic conditions to 'diagnose' and reflect on solutions to issues in daily self-management, especially through sharing personal experiences (Jansky, 2024; Kingod, 2020; Pols, 2014).

In this article, we draw attention to the effort people with diabetes put into upholding online peer support groups as digital spaces for solidarity and knowledge useful to daily self-management. Building on the STS literature, we explore how people with type 1 and 2 diabetes negotiate what counts as legitimate knowledge as they interact in Facebook peer support groups. Our analysis is guided by the concept of boundary-work, which originally refers to the constant effort of scientists to demarcate what counts as science from 'non-science' (Gieryn, 1983). In our case, we analyse how people with diabetes demarcate legitimate knowledge from what they deem illegitimate, enacted as they scrutinise peer advice and knowledge claims shared in the Facebook groups. We conceptualise this ongoing effort among people with diabetes as 'online boundary-work' and specify the various negotiations it comprises. Before discussing our conceptual approach, we first situate our analysis in the STS literature on social media and patient knowledge.

1.1. Social media and patient knowledge

Since patient organisations and self-help groups began to unite online in the early 2000s, STS researchers have been interested in how social media facilitates and mediates peer support for people with chronic conditions (Akrich, 2010; Barker, 2008; Jansky, 2024; Kjærulff and Langstrup, 2023; Kingod, 2020; Maslen and Lupton, 2019; Mazanderani et al., 2012, 2013, 2020; Petersen et al., 2020; Pols, 2014; Whelan, 2007; Ziebland, 2004). Although this research is extensive and draws upon different conceptual ideas (Borkman, 1976; Brown et al., 2004; Epstein, 1995; Haas, 1992), certain arguments are overarching. Scholars have pointed out how sharing personal experiences is central to peer support; it both engenders a sense of solidarity and provides a common ground for learning how to interpret symptoms and engage in self-management. Since fellow patients often deal with similar issues, they can help 'diagnose' problems and provide advice based on their personal experiences (Jansky, 2024; Kingod, 2020; Pols, 2014). Furthermore, social media platforms afford specific options for peers to discuss and document their experiences through posts, comments, pictures and videos, allowing ways for them to accumulate knowledge within the community (Akrich, 2010; Maslen and Lupton, 2019; Mazanderani et al., 2012, 2020; Petersen et al., 2020).

To recognise the knowledge and skills people with chronic conditions develop from self-management as a distinct epistemology, Jeannette Pols has proposed the term 'patient knowledge' (Pols, 2014). Pols (2014) describes how individuals mobilise elements of practical, embodied, emotional, technical and medical knowledge as they manage their condition. For example, although there are major differences between type 1 and 2 diabetes and the specifics of medical treatment regimens, people with both conditions rely on managing blood glucose levels to keep them as stable as possible. In addition to diet and exercise practices, sensing blood glucose fluctuations, testing glucose values and interpreting the results can be viewed as various practices and elements of knowledge mobilised to manage glucose levels (Mol and Law, 2004). According to Pols (2014), patient knowledge – especially in the context of medically recognised conditions such as type 1 and 2 diabetes – cannot be understood apart from medical knowledge because patients must learn to manage treatment. While self-management practices may be developed from individual experience and continual guidance from medical professionals, social media provides a collective space for patient knowledge to be articulated among peers (Jansky, 2024; Kingod, 2020; Pols, 2014).

Because individuals engage in medical practices and mobilise elements of medical knowledge to manage their chronic conditions, medical knowledge also forms an integral part of peer interactions on social media. Engagement with medical or scientific knowledge in online peer support groups takes different forms (Armstrong et al., 2012; Jansky, 2024; Kingod, 2020; Maslen and Lupton, 2019; Mazanderani et al., 2012, 2013, 2020; Pols, 2014). For example, people able to explain complex medical matters are often viewed as resources among their peers (Maslen and Lupton, 2019; Mazanderani et al., 2013, 2020). Such skills are potential ways for individuals to gain 'expert status' or demonstrate authority, including by questioning the opinions of professionals or challenging scientific claims (Armstrong et al., 2012; Maslen and Lupton, 2019; Mazanderani et al., 2013, 2020). However, fellow patients also make medical or scientific knowledge more accessible; in addition to expressing it in simpler terms, they 'translate' instruction manuals and guidance from clinicians into practical application to everyday life (Jansky, 2024; Kingod, 2020; Pols, 2014). Such interactions can involve people with diabetes sharing how they experiment with their devices (Jansky, 2024) or different solutions when facing issues counting carbohydrate intake (Kingod, 2020). On social media, peers can adapt their input to specific questions or situations to help find solutions, allowing them to cultivate new insights together (Jansky, 2024; Kingod, 2020; Pols, 2014).

At the individual level, STS scholars have addressed the work associated with navigating information and peer advice on social media, including the 'inappropriate' or 'disturbing' content (Kingod, 2020; Maslen and Lupton, 2019; Mazanderani et al., 2012; Petersen et al., 2020). Interview participants have described being faced with emotionally upsetting pictures and stories about health complications (Kingod, 2020; Mazanderani et al., 2012) and voiced concerns about potential 'misinformation' or 'anti-scientific' views being shared

(Maslen and Lupton, 2019; Petersen et al., 2020). At the collective level, tensions over what counts as legitimate knowledge in online peer support groups have been framed as a matter of transforming common experiences into a collective illness narrative, especially to advocate for better treatment options (Akrich, 2010; Barker, 2008; Whelan, 2007). In response to concerns about 'misinformation' being shared, other researchers have also reported that people with diabetes engage in self-policing of online peer support groups (Armstrong et al., 2012; Litchman et al., 2018). Litchman et al. (2018) describe self-policing as resembling professional content moderation as group members correct misinformation and prevent sharing medical advice. This hints at an effort among people with diabetes to enforce boundaries around what is considered legitimate to share online. However, as indicated in the STS literature, what constitutes 'medical advice' may not be clear in practice if online interactions focus on self-management issues and sharing experiences tends to be intertwined with advice about possible actions to take in response. Furthermore, correcting information and preventing the sharing of medical advice are outcomes; specifying how such epistemic negotiations take form in practice calls for further empirical analysis.

2. Conceptual approach

2.1. Boundary-work: the ongoing effort of negotiating boundaries

Sociologist Thomas Gieryn introduced the concept of boundary-work to describe the ongoing effort that scientists engage in to uphold science as a domain in opposition to 'non-science' (Gieryn, 1983). By attributing specific characteristics to what science is and entails in practice – its methods, practitioners, values, purpose or institutional organisation – scientists demarcate the boundaries of what counts as science in the pursuit of goals, e.g., a monopoly of professional and epistemic authority. In the attempt to gain certain resources and favourable positions in society, scientists engaging in boundary-work promote themselves at the exclusion of others. As Gieryn (1983) demonstrated, science is not a single or fixed entity; its boundaries are the result of constant negotiations. With this analytical attention to epistemic negotiations, we turn our focus towards the empirical context of social media.

The concept of boundary-work has informed analyses of other researchers at the nexus of social media and health (Phillips, 2019; Zimdars, 2023), articulating ways in which people outside the scientific community engage in epistemic negotiations. Based on a qualitative survey, Phillips (2019) analyses how people with multiple chemical sensitivities debate treatment in online patient communities. She demonstrates how patients' treatment experiences and knowledge claims are often scrutinised with respect to scientific criteria, arguing that boundary-work ultimately relates to the struggle for medical and political recognition of their contested condition (Phillips, 2019). Zimdars (2023) explores how Instagram users debate the fat acceptance movement, focusing on how Instagram affords certain ways for users to moderate what content is being shared through boundary-work. This takes the form of users repeatedly promoting what they perceive as 'true' and 'correct' information with the hashtag #fatacceptance on Instagram. For example, when users refer to medical research to claim that the fat acceptance movement increases obesity rates, other users argue with both the discourse and scientific evidence underpinning obesity research (Zimdars, 2023). Zimdars argues that engaging in this content moderation is about both veracity of information and reinforcement of a specific group identity by creating a digital space on Instagram for solidarity with the fat acceptance movement (Zimdars, 2023).

In our analysis of Facebook groups for people with diabetes, Gieryn's concept of boundary-work (1983) guides our exploration of how group members demarcate legitimate knowledge from what they deem illegitimate, enacted as they scrutinise peer advice and knowledge claims. However, by using the term online boundary-work for these efforts, we highlight that negotiations take place on social media. In our case, Facebook enables people to create peer support groups where members can contribute posts, comments, pictures, links and use emoji reactions (Maslen and Lupton, 2019). As we demonstrate, the sociotechnical affordances of Facebook shape the opportunities for people with diabetes to negotiate what counts as legitimate knowledge, including options for moderating peer advice and knowledge claims. For example, group members may intervene if they disagree with specific advice or 'like' comments expressing a certain opinion. Finally, in contrast to the analyses of Phillips (2019) and Zimdars (2023), we attend more broadly to the question of how people with diabetes negotiate what counts as legitimate knowledge, as opposed to how they distinguish science from 'non-science'. Building on the STS literature, we pay attention to how the Facebook groups facilitate a collective space for 'diagnosing' self-management issues and reflecting on solutions. We elucidate how these activities constantly fuel online boundary-work as Facebook groups interconnect thousands of people with diabetes with diverse experiences and solutions to self-management issues.

3. Methods

3.1. Selection of Facebook groups and ethics

In 2021, we selected two Danish Facebook groups for observation: one for people with type 1 diabetes (65% women, approximately half of group members were aged 35–54) and one for people with type 2 diabetes (70% women, approximately half of group members were aged 55 and above). Upon request, demographic data were provided by group administrators who had access to bar charts displaying members by age groups without percentages. The groups were selected as part of a wider Danish research project exploring social media use among people with type 1 and 2 diabetes (Kjærulff and Langstrup, 2023). They collectively had more than 10,000 members, frequent interactions (500–1000 posts per month) and did not focus on a specific topic, such as exercise.

Our study was evaluated and approved by the Danish Data Protection Agency (Rec.no.:21015640), which requires adherence to ethical procedures securing data anonymity and confidentiality. Our data collection method complied with the European General Data Protection Regulation (GDPR) law; we copied no content and collected no personal data (e.g., quotes, pictures or names) that could identify individual Facebook group members (Thompson et al., 2021). Obtaining informed consent from individual members was not required, but we considered other ethical aspects (Lathan et al., 2023; Sørensen et al., 2024; Thompson et al., 2021). EMK contacted the group administrators to present the study, asking for their permission to join the groups to conduct it. She then informed group members about the study via a detailed post that included her contact details and instructions for blocking her from seeing their profiles and content if they wanted to (Sørensen et al., 2024).

3.2. Data collection and analysis

Data collection and analysis occurred in three phases. First, EMK spent six months unobtrusively observing peer interactions, drawing on the method of online ethnography (Hine, 2015). She browsed through posts and comments daily, noting the types of information discussed and how it was negotiated. The latter was reflected in consensus and controversy about what was considered legitimate information expressed in phrases such as 'I agree that it is necessary to consult your physician' and 'your advice does not translate to others because our bodies respond differently to medicine'. Five categories of negotiations occurring across the Facebook groups were identified: different personal experiences; the body's response to medicine, food and exercise; the role of medical professionals; acute health issues and information accuracy. These categories served as a coding scheme for further data sampling.

In the second phase, data samples were collected using keyword

searches to retrieve posts. This phase was inspired by summative content analysis, in which searching for a specific word within a text provides insight into the frequency or context of its use (Hsieh and Shannon, 2005). However, rather than searching for posts in which people with diabetes discussed specific topics (e.g., exercise), we wanted to retrieve a broad selection of posts using interrogative keywords. To do so, EMK individually entered six keywords into the search interface of each Facebook group. Each search generated approximately 100 posts featuring use of the keyword in the post or comments. Repeating the search yielded different content, suggesting that not all content displaying the keyword could be generated at once. For each keyword search, the content of the first 25 posts, including comments, was summarised descriptively and anonymised. Summarising and anonymising the data preserved group members' anonymity (Lathan et al., 2023). Descriptions were initially coded into the five categories noted in the previous paragraph or as 'other' if the content did not reflect any of these. The number of comments and emoji reactions (e.g., thumbs-up 'like' emoji) were also noted. Keywords and dates/years of retrieved posts are withheld from this article to protect group members' anonymity. EMK consulted with MAN to summarise the data. The final data sample comprised 300 posts and 7797 comments. The descriptions of data presented here were translated into English and contain no direct quotes.

The third phase was inspired by abductive analysis (Timmermans and Tavory, 2012). First, data were read through as a whole. EMK and HL discussed theoretical concepts that could help elucidate how online interactions among people with diabetes reflected continual negotiations of whether information or specific advice shared in the Facebook groups was considered legitimate. As described previously, Gieryn's concept of boundary-work (1983) inspired us to analyse how members of the Facebook groups demarcate legitimate knowledge from what they deem illegitimate. During this analytical process, the five preliminary categories were reorganised into three types of negotiations occurring across both Facebook groups. As noted, our attention was also directed towards how the sociotechnical affordances of Facebook shaped negotiations, leading us to use the term online boundary-work for our conceptual lens.

4. Findings

Our analysis elucidates how people with diabetes engaged in online boundary-work, involving negotiations with distinct foci: the usefulness of personal experiences, the need for professional assistance and the most accurate answer.

4.1. The usefulness of personal experiences

Although topics varied widely, Facebook group interactions consistently involved sharing personal experiences. Because posts often requested input to help with a specific self-management challenge, anyone with relevant insight was invited to share. In that way, living with diabetes and dealing with daily self-management was the ticket to participating in discussions and contributing insights. However, certain ways of sharing experiences appeared to be perceived as more legitimate than others. In the following example, the original poster (OP) described how some peers sharing their experiences on Facebook did not seem to consider people's differences and simply contributed to a vast and sometimes irrelevant flow of information.

> Post: The OP states that they joined the Facebook group to learn more about diabetes, but they often feel confused and have realised that not all information is useful to them. The OP explains that peers within the Facebook group seem to have good intentions when they share their experiences to guide others but stress that people are different and urge group members to keep that in mind when sharing advice.
>
> Comments: Peers describe finding the Facebook group useful but skipping irrelevant posts, such as those about medication they do not take. Person 1 suggests that peers should state relevant information about their own treatment and diet when providing advice to others as there are often different answers to questions because people have different preferences, diets and medication—the OP and 18 others 'like' this comment. Peers also comment that bodies are different and respond differently to medicine and food, so people with diabetes must figure out their own ways to manage their condition because there is no universal guide.

The OP and commenters addressed the individual work involved in navigating the information exchanged in the Facebook group, raising the question of what made sharing personal experiences useful. The online boundary-work reflected in their interactions implied that the individual experience of living with diabetes did not represent general knowledge about 'what works' for others in terms of self-management. Thus, including relevant information about one's treatment and diet was suggested as a specific way to uphold legitimacy when sharing personal experiences, and the number of 'likes' indicated that others agreed. As group members further argued, bodies are different and respond differently to medicine and food, pointing out the need to consider biological differences. These interactions hinted at members alluding to their common responsibility for diabetes self-management but acknowledging the task of figuring out 'what works' was profoundly individual.

Different types of medication were discussed within and across Facebook groups. However, because medical treatment varies between people with type 1 and 2 diabetes *and* between individuals, members of both groups invoked similar arguments as they engaged in online boundary-work. For example, the argument about biological differences was invoked among people with type 2 diabetes to take issue with personal experiences presented as a general truth applicable to all:

> Post: The OP states that they do not know whether metformin is the best medication for them and if they even have a choice about taking it.
>
> Comments: Person 1 comments that the OP should not take metformin because it causes stomach aches and diarrhoea—person 2 emphasises that people respond differently to metformin, so it is not okay to advise against metformin based on negative personal experiences—person 1 responds that they simply stated their experience but did not advise against metformin—person 2 replies that peers should not provide guidance about medication in that way, and a lot of people within the Facebook group are pleased with metformin.

Although the identified side effects of metformin may be common among group members, the way in which these experiences were presented as general truth was disputed as illegitimate. As the comments indicated, peers pointed out how sharing personal experiences in this way neglected a range of other equally 'true' and relevant experiences. These interactions suggested the importance of describing personal experiences as subjective, especially when sharing advice about such medical issues. In contrast to giving prescriptive advice, emphasising subjectiveness implies that the advice does not necessarily work for others and that other suggestions could work equally well.

Engaging in online boundary-work also appeared to question whether certain experiences should be articulated at all, as could be the case when group members shared unsolicited advice about self-management. To disagree with this type of input, group members sometimes referred to their long-term experiences of living with diabetes, stressing that they knew what self-management worked for *them*. Because many interactions revolved around 'diagnosing' specific problems and possible actions to take in response, simply stating a personal experience could appear as inappropriate advice to others. For example, interactions among people with type 1 diabetes often concerned various types of insulin; these discussions tended to focus on why blood glucose

levels may fluctuate and how they could be brought into 'normal' range. However, people with diabetes have different insulin-to-carbohydrate ratios, i.e., the amount of carbohydrates 'covered' by one unit of insulin. Due to biological differences, certain personal experiences were viewed as dangerous for others to transfer into practice:

> Post: The OP is struggling with very high blood glucose levels (a picture of the OP's blood glucose levels is attached). They explain that they recently switched to a different brand of rapid-acting insulin and ask what they can do to get their blood glucose level under control.
>
> Comments: Peers are familiar with this struggle and advise the OP to try a new insulin pen because the one being used might be defective or go out for a walk to lower the blood glucose level from exercise. Some peers state how many insulin units they would administer to lower blood glucose levels like those the OP shared. Person 1 asks whether the OP is stressed or sick because this may increase the need for insulin—the OP responds that they have not been feeling well the past couple of days. Person 2 describes often struggling with high blood glucose levels and usually needing a double dose of insulin to get it under control but stresses that this is only their experience. Person 3 states that the insulin-to-carbohydrate ratio might be wrong—person 4 agrees and explains that the insulin-to-carbohydrate ratio is different for each person, so any advice about specific insulin dosages is not applicable to other people. The OP responds that they appreciate the answers. Other peers continue to describe how many insulin units they would need to lower similar blood glucose levels.

Some peers simply shared how many insulin units they would administer to lower blood glucose levels similar to those illustrated in the picture of the OP's glucose data. However, by pointing out that insulin-to-carbohydrate ratios differ, others called out these statements as potentially dangerous advice to follow and stressed that these specific experiences did not translate to others. Thus, group members engaging in online boundary-work moderated specific pieces of advice in these interactions. Although this did not necessarily stop people from sharing similar statements, expressing criticism drew attention to the point that personal experiences were no longer considered useful and could be potentially harmful to share online.

4.2. The need for professional assistance

As noted, posts in both Facebook groups reflected members reaching out to peers to 'diagnose' and evaluate various issues related to self-management and medical treatment. Some posts criticised professionals for inadequate knowledge about diabetes self-management and failure to provide medical guidance, making it necessary for them to ask for help on Facebook. However, group members sharing their opinion about an issue often encouraged others to consult with medical professionals, statements that were sometimes followed by members explaining that they were not experts or professionals. While sharing personal experiences was also part of interactions, online boundary-work involved negotiating whether group members could legitimately handle medical issues on their own or if professional assistance was needed. As suggested below, posts asking for guidance about treatment decisions could call into question whether group members were considered qualified to help:

> Post: The OP states that they were recently diagnosed with (type 2) diabetes and their average blood glucose level has dropped from 96 to 43. They ask peers whether they should reduce their metformin dose.
>
> Comments: Several peers advise the OP not to reduce their metformin dose unless a physician advises them to do so—the OP replies that they know that but still wanted to hear what group members think before consulting their physician. Person 1 explains that they stop taking metformin when their average blood glucose level is as low as the OP's because they do not benefit from it at that point. Some peers explain that they started out with a high metformin dose which they and their physician agreed to slowly reduce but that they still take metformin because it also has beneficial effects for the heart—others 'like' these comments and state that they agree that it is necessary to consult a physician. The OP responds that they appreciate all the answers and that they will discuss it with their physician.

Group members had tried reducing or discontinuing metformin, but, as most of their comments emphasised, thought it was essential to consult a physician first. In another post with a similar question, commenters responded that 'physicians must be consulted about medication because they have access to medical records and are responsible for treatment'. These examples suggested specific ways that group members ascribed authority to medical professionals based on their access to restricted information and legal responsibility. Having access to professional support also implied an obligation for people with diabetes to use this resource when necessary. Thus, as Facebook group members delegated the responsibility for certain treatment decisions to clinicians, they made a collective judgement about using professional resources. As suggested in the first example, such judgements could be presented in conjunction with insight into possible outcomes of negotiating treatment options with clinicians, thus supporting the OP in navigating healthcare services. Such navigation could also involve the specific kind of professional to consult with. In one case, the OP was trying to treat a foot wound, but group members promptly urged them to get a medical appointment:

> Post: The OP explains that they have had a great deal of pain in one foot for several days and that it is swollen and discoloured (a picture is attached to the post). They state that they have tried foot baths but do not know what else to do about it.
>
> Comments: Peers suggest calling emergency care services because it seems urgent—each comment of this type receives 6–9 'likes'. Some peers propose calling a wound clinic or a podiatrist—the OP explains that they are worried about the increasing pain—person 1 replies that calling a podiatry clinic will probably not help much because it looks like it requires immediate medical treatment. Person 2 explains that they had a toe amputated due to an infection and strongly encourages the OP not to take foot baths because it can make it worse. Peers continue to encourage the OP to get a medical appointment. The OP later provides an update that they have consulted professionals, got medication and is thankful for the help—peers 'like' the update and some respond that they appreciate the update.

Facebook enabled the visual presentation of the OP's issue. Peers emphasised that foot wounds must be taken seriously and require professional care, comments that were endorsed by multiple 'likes' indicating support for the online boundary-work emerging from these statements. Furthermore, the OP was warned against taking foot baths. Taken together, these comments suggested that peers in the Facebook group considered neither the OP or themselves capable of dealing with this concern, invoking the need for professional knowledge and skills. However, establishing such a consensus was not necessarily easy. Another example from the Facebook group dedicated to people with type 1 diabetes illustrates that an issue may seem serious to some and manageable to others:

> Post: The OP states that they accidentally took 30 units of rapid-acting insulin instead of long-acting insulin. The OP explains that they have calculated how many grams of carbohydrates they need to consume (to avoid low blood glucose) and asks if there is anything else they need to consider.

Comments: Peers have tried this too and encourage the OP to eat and drink juice. Peers advise the OP to keep testing their blood glucose level and advise them to still take their long-acting insulin. Person 1 comments that they would call diabetes outpatient care services right away because they would die from that amount of rapid-acting insulin units—the OP explains that they will probably be fine because their blood glucose level has been around 11 for a while—person 2 agrees that it sounds like the OP will be fine then. The OP later provides an update that the blood glucose level did not drop below normal range—peers respond that they appreciate the update.

Injecting rapid-acting insulin instead of long-acting insulin can cause a rapid decrease in blood glucose. In this case, the OP managed the issue, but commenters evaluated the situation differently: some 'would die from that amount of insulin units' whereas others could consume enough carbohydrates to keep their glucose level stable. These conflicting responses resulted in further negotiation in which the OP stated their current blood glucose value to justify that they did not need professional assistance. As part of online-boundary-work, sharing data like glucose values could both substantiate such arguments and enable group members to re-evaluate the situation.

In contrast to commenters advising the OP to seek professional assistance, the OP sometimes rejected commenters' advice, stating that they would rather consult with professionals. Furthermore, asking rhetorically whether commenters were experts or medical professionals appeared to invalidate uninvited advice sharing by bringing closure to interactions. However, simply making a reference to medical professionals did not automatically preclude negotiations. In one example, interactions among people with type 1 diabetes concerned the result of a ketone test. Although some ketones in the blood may be normal, high levels can be life threatening. The following comments were part of a discussion in which the OP's level of ketones was greater than 4:

Comments: Person 1 advises the OP to eat and take extra insulin to avoid building up ketones due to lack of carbohydrates and reports that clinicians gave them this advice but also told them to be careful if the ketone level was higher than 3—the OP replies that they just tested their ketone level and it is even higher now. Several peers comment that they would never try to treat such high levels of ketones on their own, and they urge the OP to call diabetes outpatient care services immediately—one of these comments receives 12 'likes'.

Group members passed on advice from clinicians about reducing ketone levels, indicating that reporting its origin among professionals may have lent it legitimacy. Although this commenter also noted the potential danger of ketone levels higher than 3, other group members established the urgent need for professional help, emphasising that the advice should not be put into practise. Commenters placed themselves in the OP's situation by saying that they would never try to treat such high ketone levels on their own. The online boundary-work emerging from these statements indicated that these commenters did not consider the situation safe for any person with diabetes to handle on their own. In this way, seeking emergency care was not simply a suggestion, it was an instruction, reinforced by multiple 'likes'.

4.3. The most accurate answer

Posts often contained questions inviting answers to reflect upon specific issues for which different answers could be considered equally 'true' or relevant. However, in certain contexts, negotiations among members in both Facebook groups appeared to suggest that certain answers to questions were more accurate than others. Although these negotiations could entail establishing a single 'correct' answer, negotiations typically evolved from group members trying to 'diagnose' an issue by negotiating different claims to establish a credible explanation. To legitimise or question different claims, group members often mobilised external knowledge resources such as websites or scientific publications to argue their case. In one example, interactions among people with type 2 diabetes indicated that sharing links to online knowledge resources could serve multiple purposes:

Post: The OP states that their blood glucose level is usually about 10 when they wake up in the morning. The OP asks if there is anything they can do to avoid high blood glucose levels in the morning.

Comments: Peers state that it sounds like dawn phenomenon, in which blood glucose levels increase in the early morning hours. Peers explain that they have stopped eating after 6 pm to avoid high blood glucose levels in the morning; some have also reduced the amount of carbohydrates in their diet and others take a walk before bedtime. The OP explains that they are confused because the nurse once advised them to eat bread before bedtime—person 1 responds that eating bread before bedtime will probably not help avoiding high glucose levels in the morning and that eating before bedtime would usually be to avoid low blood glucose levels, especially for people who take insulin—the OP 'likes' this comment. Person 2 comments that it sounds like the dawn phenomenon and includes links to information from scientific and professionally managed sources that describe the dawn phenomenon and that consuming many carbohydrates before bedtime may cause high blood glucose levels in the morning.

Group members shared their ideas on how to avoid high blood glucose levels in the morning, but the advice provided by a nurse conflicted with some of these suggestions. Peers used websites to legitimise the claim that it might be the dawn phenomenon and that eating bread before bedtime was unlikely to help. Although they questioned advice provided by a nurse, group members providing links ascribed authority to professionally managed sources. The online boundary-work emerging from these practices revolved around substantiating certain claims at the exclusion of others, but the interactions did not reveal whether the OP considered the answer useful.

Although some posts contained questions inviting various answers, others included closed yes/no questions, which could evolve into negotiations to establish a single 'correct' answer. In one case, the OP asked whether a specific type of insulin should be stored in the refrigerator:

Post: The OP asks whether they are supposed to keep their opened rapid-acting insulin pen in the refrigerator during the summer.

Comments: Person 1 comments that they keep it in a cooling bag whenever they are outside—the OP responds that they are interested in buying a cooling bag—person 1 provides a link to an online shop. Person 2 explains that this kind of rapid-acting insulin should not be stored in the refrigerator when in use—the OP states that they are surprised to hear that—person 2 provides a link to a website operated by national health authorities which states that it should not be stored in the refrigerator.

Peers provided links to websites operated by national health authorities to support the legitimacy of their responses and, by implication, to express disagreement with other suggestions. Facebook afforded this option for group members to engage in online boundary-work that could help establish the 'correct' answer, especially to yes/no questions. However, making use of these affordances did not automatically imply that all commenters seemed to agree on the most accurate answer:

Post: The OP asks whether they should wear their insulin pump during an x-ray examination.

Comments: Some peers state that it must be removed, but others disagree because they did not remove their insulin pumps during similar examinations. Person 1 states that the devices are sensitive to radiation, so the fact that some people managed to get an x-ray without damaging their devices is pure luck and not valid

advice—the OP states that they will take the pump off. Person 2 explains that they called the medical company and were told that it was okay to wear their insulin pump—person 1 provides a link to information from the medical company stating the opposite—person 3 explains that they have also just worn theirs during an x-ray examination and nothing happened.

In these interactions, certain information was disputed as incorrect; some peers referred to personal experiences of wearing devices during x-ray examinations, but others disagreed that these experiences qualified as credible answers and provided links to information from the medical company to substantiate their argument. While the OP appeared to accept this response as valid, online boundary-work did not seem to result in consensus among all commenters, leaving the 'right' answer open to individual interpretation.

5. Concluding discussion

In the context of contemporary healthcare systems and policies, people with diabetes and other chronic conditions face the responsibility of life-long self-management (Øversveen, 2020; Petrakaki et al., 2018). As suggested in the STS literature, social media may ease the perceived burden of this highly individualised responsibility because it allows peers to connect across physical locations and gain detailed insight into how others cope with their condition, engendering a sense of solidarity (Akrich, 2010; Barker, 2008; Jansky, 2024; Kingod, 2020; Maslen and Lupton, 2019; Mazanderani et al., 2012, 2013, 2020; Petersen et al., 2020; Pols, 2014; Whelan, 2007; Ziebland, 2004). In particular, STS scholars have highlighted the ability of social media to provide a collective space for people with chronic conditions to 'diagnose' and reflect on solutions to issues in daily self-management, especially through sharing personal experiences (Jansky, 2024; Kingod, 2020; Pols, 2014). Our work contributes to this literature by demonstrating how these activities in online peer support groups involves an ongoing effort among group members to negotiate what counts as legitimate knowledge. We have conceptualised this effort as online boundary-work and described in detail negotiations occurring across two Facebook peer support groups for people with type 1 and 2 diabetes. Our analysis elucidates how group members (a) recognise sharing personal experiences as useful but do not necessarily accept them as valid for self-management advice, (b) support each other in evaluating medical issues but delegate certain treatment decisions and responsibility to professionals and (c) do not necessarily agree on the most accurate answer but mobilise scientific or professionally managed sources to legitimise or question claims. As we discuss, these negotiations collectively highlight the effort people with diabetes put into upholding online peer support groups as digital spaces for solidarity and knowledge useful to daily self-management. However, online boundary-work does not necessarily result in consensus, prevent certain types of advice from being shared and guarantee that answers are considered useful to members or 'correct' from a clinical perspective.

Although members of the Facebook groups often requested and highly appreciated sharing of personal experiences, they also addressed the demanding task of navigating different and occasionally confusing input. As Mazanderani et al. (2012) point out, whether a particular experience shared online is considered an epistemic resource depends on the extent to which an individual reader can turn it into something useful; readers can collectively perceive a particular input as both useful and irrelevant. Although usefulness may be essentially individual, the ways in which members of the Facebook groups presented their personal experiences online were not necessarily accepted as legitimate or useful by the community. As our findings reveal, group members questioned the extent to which these experiences translated to general advice or knowledge about diabetes, stressing the importance of pointing out biological differences and emphasising the subjectiveness of personal experiences.

In contrast to research emphasising how online patient communities are focused on identifying similarities or transforming common experiences into a collective illness narrative (Akrich, 2010; Barker, 2008; Whelan, 2007), these findings highlight the importance of recognising differences in peer support. Mazanderani et al. (2012) call attention to how cultivating a sense of differences is necessary for individuals to benefit emotionally and epistemically from online peer support. Although a shared embodiment of the same condition is often a primary reason for valuing and identifying with others' personal experiences, the idea of everyone being different helps individuals negotiate their level of identification with others to sort input (Mazanderani et al., 2012). We extend this argument by noting that Facebook group members' engagement in online boundary-work cultivates a collective sense of differences that may both intensify and ease the task of navigating peer advice online. First, encouraging others to include information about their treatment and diet when sharing advice helps create awareness of differences in 'what works' in diabetes self-management. While the exposure to diverse experiences and solutions to self-management issues can facilitate new insights (Jansky, 2024; Kingod, 2020; Pols, 2014), it may also cause individuals to feel overwhelmed when tasked with figuring out 'what works' for them. Second, invoking the argument about biological differences as a general truth – as opposed to personal experiences – group members take issue with presenting experiences as if they apply to everyone and call out potentially dangerous advice. By enacting such moderation of peer advice, members may support navigation. As noted previously, other researchers have reported that people with diabetes prevent each other from sharing medical advice on social media (Litchman et al., 2018). However, because interactions are often focused on self-management issues, sharing experiences tends to be intertwined with advice about possible actions to take in response. In the context of such interactions, it is difficult to clearly define what counts as 'medical advice' and commenters stating a personal experience might not realise that their input appears as inappropriate 'medical advice' to others. Thus, online boundary-work does not necessarily prevent 'medical advice' from being shared, but it can draw attention to the opinion that personal experiences are no longer considered useful or are potentially harmful to share online.

Because people with diabetes often face issues related to their ongoing medical treatment, another frequent subject of online boundary-work was whether these issues require professional assistance. Although group members may encourage seeking professional help because they feel unqualified to address a specific medical issue, they may still feel an ethical responsibility to show solidarity and help their peers evaluate these issues. Group members share a collective identity of being responsible for self-management *and* for navigating professional care services (Jansky, 2024; Øversveen, 2020). In contrast to contested illnesses where people may be denied access to formal avenues of care, people diagnosed with medically recognised conditions as type 1 and 2 diabetes are expected to seek professional support regularly (Phillips, 2020, 2019). In case of potential diabetes-related complications, seeking timely care may even be considered a moral obligation, especially to avoid placing further economic pressure on healthcare systems (Øversveen, 2020; Petrakaki et al., 2018; Phillips, 2020). Facebook group members negotiate these common responsibilities in various ways through online boundary-work; calling out issues that require professional assistance helps identify the boundaries of individual responsibility for self-management issues *and* the extent to which Facebook group members can take responsibility for guiding others. As members engage in these negotiations, they also connect online peer support groups to the clinical world. This is literally the case when group members advise others to consult with professionals and those individuals report following through on the advice. Members delegating certain decisions or responsibility to professionals convey social approval of using this resource; therefore, they also establish a symbolic connection to the clinical world. These dynamics may, in turn, reinforce seeking timely professional care as a moral imperative, especially considering that our study is situated in the context of the Danish

welfare state where public healthcare services are financed through general taxes (Bertram et al., 2021). Yet, the generally high level of trust in the healthcare system among the Danish population might also increase the likelihood of group members suggesting professional care-seeking (Bertram et al., 2021).

The symbolic connection between peer support groups on social media and the clinical world is further supported as group members link to sources that are scientific or professionally managed. As noted previously, engagement with scientific or medical knowledge among members of online patient communities is frequently described in STS and social scientific research. Much of this research seeks to understand how activistic patient movements emerge online, exploring how social media plays a role in mobilising people to push for the scientific community to include patients' knowledge to promote better treatment options (Akrich, 2010; Jansky, 2024; Mazanderani et al., 2013; Whelan, 2007) or recognise their condition (Barker, 2008; Phillips, 2019). However, few online groups or patient communities transform into activistic movements. Facebook group members mobilised scientific or professionally managed sources to legitimise or question different claims when helping peers to 'diagnose' self-management issues or establish a 'correct' answer. Making use of these affordances, negotiations can turn into a 'trial of strength' between opposing answers (Latour, 1993) and may build towards consensus if group members share the idea of certain sources being valid and authoritative (Maslen and Lupton, 2019). Even so, online boundary-work does not necessarily result in consensus or guarantee that answers are considered useful to members or 'correct' from a clinical perspective. This point leads us back to our introductory remarks about misinformation receiving tremendous attention in recent years, including in research of online peer support groups. Misinformation on social media is indeed a serious threat to public health and society. However, if the narrative conflates social media with such troubling discourses, a risk exists that patients will be more reluctant to discuss social media information with clinicians. Metaphorically speaking, this dynamic contributes to maintaining social media as a 'parallel world' disconnected from clinical consultations rather than establishing opportunities for patients to share what they learn from online peer support groups and for professionals to provide their perspectives to support navigation (Kjærulff and Langstrup, 2023). Although our analysis has drawn attention to the effort that people with diabetes put into upholding peer support groups as digital spaces for solidarity and knowledge useful to daily self-management, the complex task of navigating peer advice and information on social media is not eliminated by online boundary-work.

5.1. Study limitations

Several study limitations deserve mention. Presenting data as summarised and anonymised descriptions of peer interactions protects individuals from being identified (Lathan et al., 2023; Sørensen et al., 2024), but it also introduces methodological and analytical weaknesses. When data are summarised, the exact number and order of comments and use of emojis cannot be consistently reported. Furthermore, these data are not as rich as verbatim quotes, making it more difficult for the reader to comprehend the dynamics of peer interactions and for us to elucidate details in our analysis. In contrast to conducting interviews or surveys, observing online interactions provides insight into only what people decide to write or communicate about through emojis, pictures or links; it does not provide insight into the experiences of those who read without responding. Group members may also simply ignore input they deem illegitimate, rather than calling it out. In addition, the intended meaning of emojis is difficult to interpret. For example, 'liking' a comment can represent endorsement, but it might also serve to shut down interactions or avoid disagreement. As described in other studies, group members get to know each other and develop a sense of who they trust (Maslen and Lupton, 2019; Mazanderani et al., 2020), and Facebook group administrators may delete content or uphold certain community rules (Maslen and Lupton, 2019). However, accounting for specific relations among group members or input from administrators would require identifying individual members and their contributions, which we have chosen not to do. Finally, our focus on two Danish Facebook groups for people with type 1 and 2 diabetes omits other social media platforms and groups in which interactions might have reflected different practices of online boundary-work. Our analysis deals with different Facebook groups for people with different types of diabetes involving different medical treatments. We recognise that people with type 1 and 2 diabetes are also treated differently in public health discourses and by the medical establishment; for example, stigmatising language around type 2 diabetes being a 'lifestyle' condition may reinforce professional care-seeking as a moral imperative (Phillips, 2020), but also deter individuals from reaching out for help. Although focusing on one Facebook group could have supported a more detailed analysis of these aspects, we identify how online boundary-work involves negotiations emerging across groups.

CRediT authorship contribution statement

Emilie Mølholm Kjærulff: Writing – original draft, Methodology, Investigation, Funding acquisition, Formal analysis, Data curation, Conceptualization. **Mette Andersen Nexø:** Writing – review & editing, Supervision, Methodology, Formal analysis. **Chrysanthi Papoutsi:** Writing – review & editing, Formal analysis. **Henriette Langstrup:** Writing – review & editing, Supervision, Methodology, Funding acquisition, Formal analysis, Conceptualization.

Declaration of competing interest

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Data availability

The authors do not have permission to share data.

References

Akrich, M., 2010. From communities of practice to epistemic communities: health mobilizations on the internet. Socio. Res. Online 15, 116–132. https://doi.org/10.5153/sro.2152.

Armstrong, N., Koteyko, N., Powell, J., 2012. "Oh dear, should I really be saying that on here?": issues of identity and authority in an online diabetes community. Health (United Kingdom) 16, 347–365. https://doi.org/10.1177/1363459311425514.

Barker, K.K., 2008. Electronic support groups, patient-consumers, and medicalization: the case of contested illness. J. Health Soc. Behav. 49, 20–36. https://doi.org/10.1177/002214650804900103.

Basch, C.E., Basch, C.H., Hillyer, G.C., Meleo-Erwin, Z.C., Zagnit, E.A., 2021. Youtube videos and informed decision-making about covid-19 vaccination: successive sampling study. JMIR Public Health Surveill 7, 1–8. https://doi.org/10.2196/28352.

Bellander, T., Landqvist, M., 2020. Becoming the expert constructing health knowledge in epistemic communities online. Inf. Commun. Soc. 23, 507–522. https://doi.org/10.1080/1369118X.2018.1518474.

Bertram, M., Brandt, U.S., Hansen, R.K., Svendsen, G.T., 2021. Does higher health literacy lead to higher trust in public hospitals? Int. J. Equity Health 20, 1–15. https://doi.org/10.1186/s12939-021-01528-w.

Borkman, T., 1976. Experiential knowledge: a analysis of self-help groups. Soc. Serv. Rev. 50, 445–456.

Brown, P., Zavestoski, S., McCormick, S., Mayer, B., Morello-Frosch, R., Altman, R.G., 2004. Embodied health movements: new approaches to social movements in health.

Sociol. Health Illness 26, 50–80. https://doi.org/10.1111/j.1467-9566.2004.00378.x.
Cole, J., Watkins, C., Kleine, D., 2016. Health advice from internet discussion forums: how bad is dangerous? J. Med. Internet Res. 18. https://doi.org/10.2196/JMIR.5051.
Epstein, S., 1995. The Construction of Lay Expertise: AIDS Activism and the Forging of Credibility in the Reform of Clinical Trials. Sci. Technol. Human Values 20, 408–437. https://doi.org/10.1177/016224399502000402.
Gieryn, T., 1983. Boundary-work and the demarcation of science from non-science : strains and interests in professional ideologies of scientists author (s): Thomas F. Am. Socio. Rev. 48, 781–795. Gieryn Published by : American Sociological Association Stable URL : https://www.jstor.org/stable/20953.
Greene, J.A., Choudhry, N.K., Kilabuk, E., Shrank, W.H., 2011. Online social networking by patients with diabetes: a qualitative evaluation of communication with Facebook. J. Gen. Intern. Med. 26, 287–292. https://doi.org/10.1007/s11606-010-1526-3.
Haas, P.M., 1992. Introduction: epistemic communities and international policy coordination. Int. Organ. https://doi.org/10.4324/9781315251981-10.
Hine, C., 2015. Ethnography for the Internet: Embedded, Embodied and Everyday, 1st edition. ed. Taylor & Francis Group, Oxford. https://doi.org/10.5040/9781474218900.
Hsieh, H.F., Shannon, S.E., 2005. Three approaches to qualitative content analysis. Qual. Health Res. 15, 1277–1288. https://doi.org/10.1177/1049732305276687.
Jansky, B., 2024. Digitized patients: elaborative tinkering and knowledge practices in the open-source type 1 diabetes "looper community.". Sci. Technol. Hum. Val. 49, 53–77. https://doi.org/10.1177/01622439231170443.
Kingod, N., 2020. The tinkering m-patient: Co-constructing knowledge on how to live with type 1 diabetes through Facebook searching and sharing and offline tinkering with self-care. Health (United Kingdom) 24, 152–168. https://doi.org/10.1177/1363459318800140.
Kjærulff, E.M., Langstrup, H., 2023. From 'parallel world' to 'trading zone': How diabetes-related information from social media is (not) discussed in clinical consultations. Soc. Sci. Med. 320. https://doi.org/10.1016/j.socscimed.2023.115756.
Lathan, H.S., Kwan, A., Takats, C., Tanner, J.P., Wormer, R., Romero, D., Jones, H.E., 2023. Ethical considerations and methodological uses of Facebook data in public health research: a systematic review. Soc. Sci. Med. 322, 115807. https://doi.org/10.1016/j.socscimed.2023.115807.
Latour, B., 1993. The Pasteurization of France. London: Harvard University, Cambridge, Mass.
Litchman, M.L., Rothwell, E., Edelman, L.S., 2018. The diabetes online community: older adults supporting self-care through peer health. Patient Educ. Counsel. 101, 518–523. https://doi.org/10.1016/j.pec.2017.08.023.
Maslen, S., Lupton, D., 2019. 'Keeping it real': women's enactments of lay health knowledges and expertise on Facebook. Sociol. Health Illness 41, 1637–1651. https://doi.org/10.1111/1467-9566.12982.
Mazanderani, F., Locock, L., Powell, J., 2012. Being differently the same: the mediation of identity tensions in the sharing of illness experiences. Soc. Sci. Med. 74, 546–553. https://doi.org/10.1016/j.socscimed.2011.10.036.
Mazanderani, F., Noorani, T., Dudhwala, F., Kamwendo, Z.T., 2020. Knowledge, evidence, expertise? The epistemics of experience in contemporary healthcare. Evidence and Policy 16, 267–284. https://doi.org/10.1332/174426420X15808912561112.
Mazanderani, F., O'Neill, B., Powell, J., 2013. "People power" or "pester power"? YouTube as a forum for the generation of evidence and patient advocacy. Patient Educ. Counsel. 93, 420–425. https://doi.org/10.1016/j.pec.2013.06.006.
Mol, A., Law, J., 2004. Embodied action, enacted bodies: the example of hypoglycaemia. Body Soc. 10, 43–62. https://doi.org/10.1177/1357034X04042932.
Øversveen, E., 2020. Stratified users and technologies of empowerment: theorising social inequalities in the use and perception of diabetes self-management technologies. Sociol. Health Illness 42, 862–876. https://doi.org/10.1111/1467-9566.13066.
Petersen, A., Schermuly, A., Anderson, A., 2020. Feeling less alone online: patients' ambivalent engagements with digital media. Sociol. Health Illness 42, 1441–1455. https://doi.org/10.1111/1467-9566.13117.
Petrakaki, D., Hilberg, E., Waring, J., 2018. Between empowerment and self-discipline: governing patients' conduct through technological self-care. Soc. Sci. Med. 213, 146–153. https://doi.org/10.1016/j.socscimed.2018.07.043.
Phillips, T., 2020. The everyday politics of risk: managing diabetes in Fiji. Med. Anthropol.: Cross Cultural Studies in Health and Illness 39, 735–750. https://doi.org/10.1080/01459740.2020.1717489.
Phillips, T., 2019. 'Mostly accurate with occasional piles of bullshit': patient 'boundary-work' in an online scientific controversy. Health Sociol. Rev. 28, 261–276. https://doi.org/10.1080/14461242.2019.1658537.
Pols, J., 2014. Knowing patients: turning patient knowledge into science. Sci. Technol. Hum. Val. 39, 73–97. https://doi.org/10.1177/0162243913504306.
Reidy, C., Klonoff, D.C., Barnard-Kelly, K.D., 2019. Supporting good intentions with good evidence: how to increase the benefits of diabetes social media. J. Diabetes Sci. Technol. 13, 974–978. https://doi.org/10.1177/1932296819850187.
Sørensen, J.B., Thomassen, J.L., Meyrowitsch, D.W., Kingod, N.R., Konradsen, F., Ploug, T., 2024. Ethical dilemmas in conducting qualitative, public health research on social media: using a study on Facebook as a case. Scand. J. Publ. Health. https://doi.org/10.1177/14034948231219725.
Swire-Thompson, B., Lazer, D., 2019. Public health and online misinformation: challenges and recommendations. Annu. Rev. Publ. Health 41, 433–451. https://doi.org/10.1146/annurev-publhealth-040119-094127.
Thompson, A., Stringfellow, L., Maclean, M., Nazzal, A., 2021. Ethical considerations and challenges for using digital ethnography to research vulnerable populations. J. Bus. Res. 124, 676–683. https://doi.org/10.1016/j.jbusres.2020.02.025.
Timmermans, S., Tavory, I., 2012. Theory construction in qualitative research: from grounded theory to abductive analysis. Socio. Theor. 30, 167–186.
Van Berkel, J.J., Lambooij, M.S., Hegger, I., 2015. Empowerment of patients in online discussions about medicine use Clinical decision-making, knowledge support systems, and theory. BMC Med. Inf. Decis. Making 15, 1–9. https://doi.org/10.1186/s12911-015-0146-6.
Whelan, E., 2007. "No one agrees except for those of us who have it": endometriosis patients as an epistemological community. Sociol. Health Illness 29, 957–982. https://doi.org/10.1111/j.1467-9566.2007.01024.x.
Wilson, S.L., Wiysonge, C., 2020. Social media and vaccine hesitancy. BMJ Glob. Health 5, 1–7. https://doi.org/10.1136/bmjgh-2020-004206.
Ziebland, S., 2004. The importance of being expert: the quest for cancer information on the Internet. Soc. Sci. Med. 59, 1783–1793. https://doi.org/10.1016/j.socscimed.2004.02.019.
Zimdars, M., 2023. Do not use this hashtag: fat acceptance (Mis)information and discursive boundary-work as content moderation on Instagram. Int. J. Commun. 17, 1654–1674.