



From ‘parallel world’ to ‘trading zone’: How diabetes-related information from social media is (not) discussed in clinical consultations

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ABSTRACT

In today's digital world, people with type 1 and 2 diabetes turn to peers on social media to access and share information. Some studies have addressed how such information is discussed in clinical consultations, but conceptual nuances are needed to account for the different ways information is discussed. In this article, we draw on semi-structured interviews with 19 clinicians and 25 people with diabetes to examine how diabetes-related information from social media is discussed in Danish outpatient clinical consultations. The data were collected from September 2020 to January 2021. We conceptualise how these discussions fall on a continuum of (dis)engagement with social media information represented by three metaphorical concepts: parallel world, border zone, and trading zone. On one end, social media resembles a parallel world disconnected from clinical consultations: people with diabetes do not bring up social media information and clinicians do not invite them to discuss it. The middle of the continuum is represented by a border zone in which people with diabetes present social media information and clinicians' reactions can either push back, maintaining social media as a parallel world, or support the formation of a trading zone. On the other end, clinical consultations resemble a trading zone: clinicians are open to social media information, invite people with diabetes to discuss it and acknowledge the value of social media. Furthermore, these discussions are often characterised by negotiation in which different perspectives are exchanged. We discuss the benefits and challenges of moving from the parallel world to the trading zone, arguing that discussions about social media information may help clinicians learn what people with diabetes gain from online peer interactions and enable them to offer their expertise to support people with diabetes as they navigate a complex world of online information.

1. Introduction

1.1. Social media and online health information: a challenge to medical authority?

Social media has become a ubiquitous part of our world. Given that an estimated 4.7 billion people use social media (Statista, 2022), it is not surprising that online environments have facilitated information sharing among people with chronic conditions such as diabetes. People with type 1 and 2 diabetes interact with peers on platforms such as Facebook, Twitter and Instagram (Kingod, 2020; Lewis et al., 2018; Litchman et al., 2018; Tenderich et al., 2019). For example, interactions revolve around the demanding self-management of blood glucose levels, diet, exercise and technological devices, all of which are elements of daily ‘chronic living’ with diabetes (Wahlberg et al., 2021).

Since the advent of the internet, social scientists have debated what patients' access to online health information implies epistemologically for healthcare and involved actors, particularly whether it entails a challenge to clinicians' expertise and authority (Broom, 2005; Hardey, 1999, 2001; Kivits, 2006; Maslen and Lupton, 2018; Nettleton and Burrows, 2003; Stevenson et al., 2021a, 2021b; Zieband, 2004). Medical expertise is considered an epistemic authority, understood as holding the power to distinguish between valid and invalid knowledge claims about health (Parsons, 1951; Pierson, 1994; Stivers and Timmermans, 2020). However, in the 2000s, growing access to online health information was anticipated to challenge the epistemic authority of clinicians (Broom, 2005; Hardey, 1999, 2001). Patients were expected to become informed citizens, enabled by online health information to present their problems in ways that empowered their position when negotiating access to treatment in clinical encounters (Broom, 2005). In

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this sense, the internet was expected to democratise medical knowledge and transform relationships between patients and clinicians. Predictions of the internet's diminishment of medical authority were contested and empirically debunked. For example, rather than democratising medical knowledge, Fox et al. (2005) argued that the internet appeared to strengthen the authority of medical expertise. People adopted medical terminology to discuss their health experiences online, fuelling a medicalisation in which more aspects of human life became subject to medical expertise (Fox et al., 2005). From another point of view, the assumption that the internet would alter relationships between patients and clinicians was criticised for being technologically deterministic (Nettleton and Burrows, 2003; Timmermans and Berg, 2003). In other words, scholars were hesitant about attributing the force of social change to technologies such as the internet. Consistent with this critique, empirical studies stressed that clinicians still claimed great authority in their interactions with patients, leaving little space for patients to negotiate treatment options based on information obtained online (Henwood et al., 2003; Imes et al., 2008; Kivits, 2006). As Henwood et al. (2003) pointed out, some patients made suggestions that were promptly rejected and others were simply happy to leave decisions to their clinicians. In short, access to online health information did not appear to revolutionise clinical consultations in practice.

Although this debate emerged before social media became widely adopted, more recent literature echoes similar findings and arguments. Studies that address how information obtained online is discussed in clinical encounters have predominantly done so from the perspectives of patients. For people with diabetes and other chronic conditions, online peer interactions have been suggested to help prepare for clinical consultations, including sharing advice on how to advocate for specific treatments (Benetoli et al., 2018; Litchman et al., 2018; Maslen and Lupton, 2018; Townsend et al., 2015). This indicates a strengthening of patients' positions in clinical encounters, a potential challenge to medical authority. At the same time, information obtained through social media is often carefully evaluated, and sharing such information with clinicians can help appraise its credibility (Benetoli et al., 2018; Jacomet et al., 2020; Litchman et al., 2018; Maslen and Lupton, 2018; Townsend et al., 2015). In this way, patients may place trust in medical authority and seek out clinicians' expertise to navigate information.

However, recent studies also suggest that patients tend not to inform clinicians about their online information-seeking and engagement with peers (Luo et al., 2022; Stevenson et al., 2021b). They may perceive discussing information obtained online as wasting clinicians' time or fear that clinicians do not take the information seriously (Benetoli et al., 2018; Kingod, 2020). Making explicit references to social media in consultations can be controversial because some clinicians react with scepticism and disapprove of social media as a valid source of information (Benetoli et al., 2018; Kingod, 2020). Clinicians may also perceive patients' presentation of such information as a threat to their authority, causing some to respond defensively and assert their expertise (Stevenson et al., 2021a, 2021b; Townsend et al., 2015). These findings emphasise how such disclosures can be subject to conflict and that information obtained online may therefore remain unarticulated or require a careful introduction to keep the consultation running smoothly (Stevenson et al., 2021a, 2021b).

Matters of knowledge legitimacy and authority are indicated to be at stake when information from social media and other online resources is discussed in clinical consultations. However, a need exists for theoretical concepts to help understand these discussions in ways that capture their nuances and dynamics. In this article, we explore how diabetes-related information from social media is discussed in outpatient clinical consultations from the perspectives of people with diabetes and clinicians. Drawing on the work of Peter Galison (Galison, 1999, 2010), we conceptualise how these discussions fall on a continuum of (dis)engagement with social media information represented by three metaphorical concepts: parallel world, border zone, and trading zone. Along this continuum, we identify dynamics and reasoning that shape how

social media information is and is not discussed in clinical encounters.

2. Theoretical framework

2.1. Trading zone: establishing a common language and culture across worlds

Historian and philosopher of science Peter Galison introduced the metaphorical concept of trading zone to denote the exchange of expertise between actors located in different social worlds (Galison, 1999, 2010). For example, interactions between different academic disciplines—Galison's focus—entail the potential formation of a trading zone. However, involved actors may have radically different languages and cultures, emphasising the need for establishing ways to communicate. Trading zones thus entail varying degrees of actors sharing their expertise and building a common language and culture for doing so (Galison, 2010). Scholars in science and technology studies have since elaborated on the concept of trading zone, including variations (Collins et al., 2007, 2019). Differing values and power positions among actors challenge the formation of a trading zone, and actors are not necessarily equal partners. For example, one actor may hold a privileged position or infuse a set of values into the trading zone (Collins et al., 2019). Indeed, actors may not even agree on the significance of the substance being traded, but the need for establishing a language and culture remains crucial to the formation of a trading zone (Galison, 2010).

In our analysis, we use the concept of trading zone as one end of the proposed continuum of (dis)engagement with social media information in clinical consultations. Clinical consultations resemble a trading zone when clinicians are open to social media information, invite people with diabetes to discuss it and acknowledge its value. The opposite end of the continuum is denoted by the concept of parallel world, a metaphor for disengagement with social media information. The concept of border zone represents the intermediate position which is a modified trading zone. We will show how clinical consultations are pushed into the border zone when people with diabetes explicitly introduce social media information and clinicians' reactions can either push back, maintaining social media as a parallel world, or support the formation of a trading zone. In this sense, the continuum entails varying degrees of discussing social media information and establishing a common language and culture for doing so in clinical consultations.

Inspired by Galison (1999, 2010) and Collins et al. (2007, 2019), we pay particular attention to how differing values and power positions among people with diabetes and clinicians may challenge the formation of a trading zone. To discuss the benefits and challenges associated with moving along the proposed continuum, we also draw on the work of philosopher Vinciane Despret (2004). Despret presents the concept of authorisation to describe a relational form of authority that depends on mutual learning and caring among actors, in contrast to authority as a form of domination and control (Despret, 2004). This concept helps us connect three identified forms of (dis)engagement with social media information to questions of authority and ethics in clinical care.

3. Methods

3.1. Data collection and ethics

The first author collected the data from September 2020 to January 2021. All study participants were recruited using a purposive and snowball sampling strategy and were not required to have experiences of discussing social media information in clinical consultations. To recruit clinicians, project information was emailed to nurses, physicians and dietitians from two diabetes outpatient clinics in the Capital Region of Denmark. Eleven clinicians initially agreed to be interviewed, and another eight were recruited through follow-up emails, allowing the inclusion of more nurses. In total, 19 clinicians were recruited, including nine nurses, seven physicians and three dietitians.

Eligible participants with diabetes were aged >18 years, diagnosed with any type of diabetes, and receiving outpatient care services in the Capital Region of Denmark. Project information was emailed to 179 potential participants meeting these criteria who had agreed to receive written information about diabetes research projects; 16 participants were recruited. However, most participants were aged >50 years, and additional snowball recruitment through Facebook was undertaken to include younger individuals. A total of 25 participants with diabetes were recruited; 72% (18) were women and the median age was 49 years (range, 22–76 years). Seventeen participants had type 1 diabetes and eight participants had type 2 diabetes.

All interviews were semi-structured and carried out in Danish. Interviews with 32 participants were carried out face-to-face in clinical settings or private homes. Due to the COVID-19 pandemic, the remaining 12 participants were interviewed through online videoconferencing. Clinician interviews lasted 30–45 min, and interviews with people with diabetes lasted approximately 60 min. Interviews with clinicians focused on exploring how social media information was discussed in clinical encounters and how they perceived this information. The interview guide for participants with diabetes centred on exploring reasons for retrieving information from social media, how they evaluated the quality of that information and how it was discussed in clinical consultations. All interviews were recorded, transcribed verbatim and anonymised. Quotes presented here have been translated into English and all names are pseudonyms. Verbal consent was obtained before interviews. The study was evaluated by the Danish Data Protection Agency (Rec.no.:21015640) and did not require ethical approval.

3.2. Data analysis

We analysed data according to the principles of an abductive analysis (Timmermans and Tavory, 2012). The two-phase analysis consisted of inductive data coding centred on identifying how and why social media information was and was not discussed in clinical consultations and deductive analysis to conceptualise the findings using theory.

All transcripts were first read through as a whole. Both authors independently developed codes based on four interviews, organised in Nvivo 12 software, and discussed and revised codes together. The first author coded the remaining interviews and consulted the last author to revise the codes slightly based on new insights. Coding clinician interviews identified various forms of (dis)engagement with social media information in clinical consultations and reflections about their professional and authoritative role as experts. Coding of interviews with participants with diabetes also highlighted diverse experiences of presenting social media information in clinical consultations, various strategies for evaluating social media information and reflections about what type of information was useful. The analytical meanings of the initial findings were discussed, going back and forth between empirical data and theory (Timmermans and Tavory, 2012). This served to generate concepts that could capture the diverse findings, eventually leading to the three points on the continuum. The parallel world concept stemmed from an interview with a physician who used this metaphor to describe the consequence of clinicians' disengagement with social media information. As discussed earlier, trading zone originated in a theoretical concept, and the border zone represented a modified trading zone that connected the outer points on the continuum.

4. Results

4.1. Parallel world: disengagement with social media information

On one end of the continuum, social media resembles a parallel world disconnected from clinical consultations: social media information is not explicitly presented by people with diabetes or invited as a potential discussion topic by clinicians.

4.1.1. People with diabetes: "I don't think I have ever mentioned it"

Most interviewed participants with diabetes had not disclosed social media as the source of diabetes-related information in clinical consultations. For example, when 27-year-old Nina with type 1 diabetes was asked if she had ever told clinicians that she often used social media to access information, she paused before replying:

I don't think I have ever mentioned it [that social media is a source of diabetes-related information]. It's not like it's a secret or that I'm scared to tell them [clinicians] – I expect to be taken seriously no matter what kind of information I present.

Nina stated that she did not fear potential negative reactions from clinicians but had not talked to them about her online interactions with peers. When asked why this might be the case, she responded that it had not seemed relevant to mention the source of the information and she could not recall clinicians ever asking her if she used social media. However, later in the interview, Nina explained: "I don't think that physicians perceive it [social media] as a support. As a physician, you probably view things in a medical way, and they focus on achieving the best possible outcomes". This indicated her uncertainty about whether clinicians would recognise social media as a resource and important to achieving good outcomes, suggesting that clinicians would not find it relevant to discuss. In this sense, social media resembled a parallel world that did not belong in clinical consultations.

The uncertainty about whether clinicians would recognise social media as a resource was echoed by many participants with diabetes. Ally, a 56-year-old woman with type 2 diabetes, also reported that she had not disclosed her social media use in clinical consultations. She had recently participated in a patient education course and had been eager to show a Facebook group to the nurse in charge of the course. She hoped the nurse would encourage others to join the group, but the nurse responded that she did not like Facebook. Ally explained:

I told her [the nurse] that I've sourced so much information from this Facebook group, but she replied that we [people with diabetes] should consult our clinicians instead. I explained that I'd found answers to many questions and that this group is available 24/7 – these people aren't physicians or nurses, but they usually know something about your issue or they'll advise you to call and ask your physician.

Although this conversation took place at a patient education course, it indicated that social media was not considered a potential asset in diabetes self-management. Without such legitimacy, social media was relegated to a parallel world.

Participants with diabetes provided many examples of sourcing information from social media to support daily self-management and inform treatment preferences. For example, 35-year-old Emma with type 1 diabetes had recently used social media "to figure out her options" when she needed to choose between different insulin pumps provided by the outpatient clinic. She had investigated Facebook groups to obtain information from peers using the insulin pumps, which had informed her decision. Emma explained, "It [information from peers on social media] has guided me towards a specific decision, but I haven't talked to any health staff about it". When asked to elaborate, Emma paused for a moment and replied that she had not been asked how she had sourced information about the insulin pumps, even though this was an important decision. In this way, social media had remained a parallel world that clinicians did not gain insight into.

Interactions with peers on social media were also invoked as tacit knowledge that supported participants with diabetes in negotiating treatment options in clinical encounters. This was exemplified by 43-year-old James with type 1 diabetes:

Social media is very helpful! You can learn how much you should talk about your hypos and your awareness [incidents of very low blood glucose levels and ability to sense blood glucose fluctuations] — if you want to get a Dexcom [continuous glucose monitor], you've

got to indicate that you need this device, but if you say too much [about your inability to sense blood glucose fluctuations], it will be noted in your medical records, and they'll suspend your driver's license.

Online interactions with peers could underpin such arguments, but the source of information would often remain undisclosed. The statement thus indicated potential benefits of maintaining social media as a parallel world that clinicians lacked insight into.

4.1.2. Clinicians: "I haven't explicitly asked"

The majority of interviewed clinicians had not initiated discussions about social media information in clinical consultations. Among these clinicians, several could hardly recall any situations in which social media information was discussed, and some also questioned the extent to which people with diabetes utilised such online resources. For example, one nurse, Erin, did not recall a situation in which people with diabetes had referred to social media. She stated:

I can only imagine, but it doesn't seem like they get it [information] there [from social media], at least they don't tell me, right? And no, I haven't explicitly asked them if they go online to look for information on social media.

Although her use of "only imagine" suggested a speculative response, Erin questioned whether people with diabetes obtained information from social media. Erin explained that she assumed that social media use was more common among young individuals and less common among the people with type 2 diabetes for whom she primarily provided clinical care. Several clinicians echoed this perception. They described some elderly patients as not owning smartphones and some, especially people with type 2 diabetes, as unmotivated in terms of self-management, which made it seem unlikely that they would engage with peers online. Regardless, social media was relegated to a parallel world, assumed to be irrelevant to clinical consultations.

The tendency of clinicians to not ask about social media use can be viewed in light of a more general tendency of clinicians to not inquire about how people with diabetes obtain information about their condition. Kate, a physician, stated, "I am not that good at it [asking how people with diabetes acquire information] – actually, I don't do it – I normally don't go into details about how patients get their information about diabetes." She explained that she forgot to ask and often lacked time to do so, a perspective echoed by other clinicians. When asked why discussions about social media information might not take place, Kate indicated that this was also a matter of authority and power asymmetry:

I just don't talk about it [social media], it's very likely that if I asked about it, they [people with diabetes] would be more open about it, but no matter what, you may say that I own the consultation – I'm the expert, I'm the one who knows – I mean, to put it in crude terms, you can try to establish an equal relationship, but it's difficult.

Critically, this statement addressed the perception of clinical consultations as infused with asymmetric power and, as Kate described it, beyond her individual control, even if she wanted to mitigate it. Interestingly, she also indicated that clinicians had the power to make social media a legitimate discussion topic, although she did not do so.

Other clinicians indicated that social media belonged to a private sphere outside clinical consultations. This was exemplified by another physician, Pia:

It somehow doesn't really matter to me if they [people with diabetes] engage in an online forum [pause]. Unless, of course, it's good if these forums are moderated by Diabetesforeningen [patient organisation] [...]. If people feel lonely, need support and need to talk to peers, that would be really nice for them.

This statement suggested that the legitimacy of social media as an asset in diabetes self-management was restricted to emotional support

that would optimally be moderated by patient organisations. When asked whether social media was relevant for clinicians to know about, Pia responded that she would not mind informing patients about online groups upon request. She paused and clarified that she would emphasise that "treatment is taken care of in consultations" but what people with diabetes decided to do in their daily lives was beyond her control. Taken together with her previous statement, this suggested that the emotional aspects and challenges of living with diabetes could be separated from those related to medical treatments. Emphasising only the potential emotional benefits of social media consigned it to a parallel world.

4.2. Border zone: pushing back towards the parallel world or moving towards the trading zone

The middle of the continuum is represented by a border zone. People with diabetes push the consultation into this zone by explicitly introducing social media information. Clinicians' reactions can be viewed as pushback, maintaining social media as a parallel world, or a move towards what we later describe as the trading zone.

4.2.1. People with diabetes: "they often get suspicious"

Nearly half of the interviewed people with diabetes had at some point introduced social media information, pushing a consultation into the border zone. However, several of these participants described how clinicians responded in ways that did not encourage them to talk openly about social media, maintaining the parallel world. As noted earlier, 43-year-old James with type 1 diabetes described social media as a useful resource for obtaining diabetes-related information. He also reported how clinicians had reacted when this source was revealed:

If you mention it [social media], they [clinicians] often get suspicious – the relationship is very asymmetrical in terms of power, so it quickly seems controlling and like they throw suspicion on you; especially in terms of devices, they'll interrogate you. I cannot stress this enough; clinicians – no matter how good your intentions are – you must remember that this is an asymmetrical relationship. I wish they [clinicians] would not control things but provide information about online groups, keywords to find them and encourage the good use [of social media].

Clinical consultations were described as characterised by asymmetrical power; clinicians' scepticism regarding social media both felt intimidating and increased the reluctance of people with diabetes to share information. As James expressed, he did not want clinicians to supervise social media groups for people with diabetes, but he wanted them to support the existence of the online world through open-minded dialogue and encouraging social media use.

Revealing social media as the source of information was also invoked as entailing the risk of being rejected by clinicians. This was exemplified in the account of 64-year-old Arthur with type 2 diabetes:

Interviewer: "During consultations, have you ever had any questions that relate to something you've read on social media?"

Arthur: "Yes."

Interviewer: "Do you say that you've read it on Facebook?"

Arthur: "No, I don't tell them that because then they say that they don't have time for that."

Interviewer: "They respond that?"

Arthur: "Yeah, well, they are so busy."

Interviewer: "Yeah, but they are also there to help you?"

Arthur: "Yes, but they take all kinds of tests and tell me what the results show, right? That's what it's all about."

Arthur had explicitly introduced social media information, but

clinicians seemed to regard these discussions as less important than test results, making him hesitant to reveal that his questions stemmed from online interactions with peers. This showed another way in which clinicians' reactions could resemble pushback, maintaining social media as a parallel world.

Several participants with diabetes described consulting clinicians about social media information to appraise its credibility. As exemplified in the account of 56-year-old Eva with type 2 diabetes, clinicians had responded differently to such inquiries. Eva had read on Facebook that some people had been able to reverse their diabetes through a healthy diet, and she was curious to know whether this was true. She had recently asked the physician and described what happened: "She [the physician] never really answered my question, I think. She just told me that I should not buy into that and that I should not believe everything I read online." When asked how she felt about the physician's reaction, Eva explained that she had decided to consult the nurse instead. She had asked a question that arose from reading peers' interactions on Facebook:

Eva: "I've had problems with high blood sugar levels, and some people [peers] were discussing whether you need to exercise or eat bread [to lower the blood glucose level], so I thought I had to ask about it, so I asked the nurse, and she said exercise."

Interviewer: "Did you tell her that you've been discussing it on Facebook?"

Eva: "Yes."

Interviewer: "And how did she react then?"

Eva: "Well, she was like, 'oh, that's great, that's good you're doing that.'"

Interviewer: "How did you feel about that?"

Eva: "It was so nice, it's kind of like they acknowledge that we use those groups – that they actually exist."

The nurse had made no further inquiries about online peer interactions, but she acknowledged their existence. In contrast to the physician's response that could maintain social media as a parallel world, the nurse's response could support future sharing of social media information and facilitated a move towards the trading zone, as we describe later.

Although clinicians could help appraise the credibility of social media information, their engagement would often be restricted to appraisal. For example, as 67-year-old Lily with type 2 diabetes explained, she had read about diets on social media and been in doubt about whether specific kinds of food would impact her blood glucose levels negatively. Lily had consulted the nurse and dietician. When asked how they had responded to the fact that she had used Facebook to obtain information from peers, she stated:

They think it's a good idea as long as no one is sharing any medical advice, and we [Lily and her peers in the Facebook group for people with type 2 diabetes] are not allowed to do that anyway.

This response indicated that both clinicians and the Facebook group set boundaries about information considered appropriate for people with diabetes to exchange online. However, neither the nurse or the dietician had inquired further about online peer interactions and, in this sense, their engagement was restricted to appraisal. Lily explained that she appreciated clinicians answering her question, but it would be nice if they knew more about what information was shared online. "They [clinicians] could actually learn something", as Lily stated. This indicated a need for clinicians to be more curious about the online world, a different form of engagement than a simple appraisal.

4.2.2. Clinicians: "I've also kind of heard that we need to be careful about the stuff that's on there"

Although most interviewed clinicians had not initiated discussions about social media information, most recalled that people with diabetes had presented such information, pushing the consultation into the border zone. Clinicians generally described people with diabetes as consulting them to appraise the validity of social media information. One nurse, Amy, stated:

It's like they [people with diabetes] want to refute or confirm something they've read or heard, they'll say like 'I've heard that' – and I can't always tell if it's from social media. [...] but it's like they are confirming whether this information is correct or not.

People with diabetes seemed to seek her professional authority and expertise, but Amy did not think they were necessarily confident about referring directly to social media. When asked why, Amy had noticed her colleagues' varying opinions about social media; some were familiar with different online groups and others were sceptical and considered social media harmful. As Amy explained, this could influence clinicians' reactions to such information. She reflected upon her own position: "I have to admit that I don't know much about those online groups." Amy elaborated: "Knowing more about it would probably give me a better understanding of what patients find important – they wouldn't use Google or engage in online groups if they didn't need it". In this way, she addressed both her limited insight into social media and the value of being curious about it.

Clinicians also found themselves confronted with questions of professional and ethical responsibility when social media information was introduced. One physician, Sara, recalled how people with diabetes would sometimes refer to peers' experiences they had read about online. This information was difficult for her to engage with. "I can't go into stories concerning another person's treatment – that's the job of that individual's clinician", she stated. Further, Sara raised concerns about sharing misleading advice online, a concern echoed by other clinicians even though few provided examples of it. Sara had once discussed social media information with a woman who had decided to stop taking insulin as part of what she had read could cure her type 1 diabetes, and she had felt worried and powerless, trying to convince the woman not to do so. Sara elaborated:

When you know how stuff can flourish online, you can imagine that someone might share an idea that other people could get really sick from trying out, so it will always be my fear that bad advice is shared in an online group and no one is there to delete the bad stuff.

Sara expressed a fear of potential harm related to social media use, invoking her professional and ethical responsibility for the care of people with diabetes. At the same time, her statement indicated feelings of scepticism and ambivalence clinicians may have about social media being used for sharing diabetes-related information that could influence their reactions to the information.

Ambivalence was also invoked as several clinicians were hesitant to encourage people with diabetes to interact with peers online. One nurse, Lisa, explained that she thought "a lot of good stuff" was shared on social media, and she knew that some of her colleagues would sometimes inform people with diabetes about Facebook groups. However, when asked if she had done so, Lisa stated:

I haven't really done that, and I've also kind of heard that we need to be careful about the stuff that's on there [social media], and I know they [colleagues] also tell them [people with diabetes] that you have to be careful about everything you read, no one is supervising these groups to check if the information is correct. But I've heard that the stuff that's shared is not always the kind of advice you would vouch for as a healthcare professional.

She addressed ambivalence about whether it would be professionally responsible to encourage people with diabetes to interact on social

media because inappropriate advice was also shared. Being confronted with questions of professional and ethical responsibility could influence how clinicians respond to the introduction of social media information, potentially in ways that could be viewed as pushing it back into a parallel world. At the same time, clinicians' curiosity about social media could facilitate movement towards the formation of a trading zone.

4.3. Trading zone: acknowledgement and negotiation

On the other end of the continuum, clinical consultations resemble a trading zone: clinicians are open to social media information, invite people with diabetes to discuss it and acknowledge its value. Furthermore, these discussions are often characterised by negotiation in which different perspectives are exchanged.

4.3.1. People with diabetes: "social media is part of our world now"

Few participants with diabetes described clinicians as open to social media. Among these, 49-year-old Liv with type 1 diabetes appreciated discussing social media information with the nurse:

I've got such a great nurse, we've got a super good communication, and I'm so lucky that I've got her, so I'm definitely holding onto her. And she's just so open towards everything — it's not always that she agrees with the things I suggest, but then we just discuss it, and she's completely aware that social media is a part of our world now — it's not just books.

The nurse welcomed social media information, and Liv did not perceive this as a given, as indicated by the phrase "I'm so lucky that I've got her". Liv provided a recent example in which she had changed her diet after reading about low-carb diets on social media. She had informed the nurse about it but did not expect a dialogue to follow. However, the nurse had assured her that she respected her decision and wanted to hear more about it. "I got so excited, and our conversation just flowed", Liv explained. During the dialogue, the nurse advised Liv against strictly limiting carbohydrates and suggested a consultation with a dietician to support her in balancing meals with insulin. Liv explained:

I didn't want to do that at first [consult the dietician], but I eventually agreed to it. My past experience is that dieticians are not as open-minded, they must follow official dietary guidelines with a lot of carbs. [...] When you eat low-carb, you eat a lot of meat and vegetables, and when I talked to the nurse about it, she said that we've got to start taking this [diet] seriously, but she didn't know everything about it.

This example represented how a consultation could become a trading zone: the nurse had inquired about social media information, acknowledged its relevance and contributed her perspectives, although her knowledge about low-carb diets was limited. As a result, Liv had agreed to consult a dietician. In this way, the trading zone was characterised by acknowledgement and negotiation. However, the formation of a trading zone took time and effort. Paul, a 76-year-old man with type 2 diabetes, described how he had persistently asked questions that would often relate to social media information. When asked to elaborate on his experiences of bringing up such information in clinical consultations, he stated:

It was difficult in the beginning, it's not anymore, but the physicians also used to be different, and they were not used to people asking questions. [...] Now, some of the physicians have said to me: 'Oh, so what questions do you have for me today that I don't know the answer to and have to look up?' But that's certainly a response!

As Paul described it, he was now invited to ask questions that his clinicians acknowledged were often complex. Paul also attributed this to a shift in training of physicians that made it more acceptable for patients to ask questions. Nonetheless, asking questions related to social media information was still described as requiring effort. As 25-year-old Sif

with type 1 diabetes explained, clinicians used to react with scepticism when she brought up social media information. She described presenting them with "a different kind of knowledge" than they were used to, and they sometimes had to consult a colleague or look up the answer to her questions. The fact that her questions arose from social media had become acceptable, but Sif still emphasised the general need for clinicians to understand how social media influences people with diabetes:

They [clinicians] need to understand this kind of influence [of social media] — it's actually more important than them trying to know what it feels like [to live with diabetes], because they will never understand that, but it's important to understand the things that influence us, and social media is one of them, so they cannot just ignore it.

Critically, she addressed the need for clinicians to acknowledge the importance of social media, describing it as part of living with diabetes and thus necessary for clinicians to know about and engage with. In other words, acknowledgement was essential to forming a trading zone.

4.3.2. Clinicians: "I think it's important to discuss it"

Some clinicians had initiated discussions about social media information and emphasised the importance of doing so. One nurse, Sally, reported that she usually began consultations by asking whether people with diabetes had read something online they would like to discuss. She stated:

I ask them if they've read something because I think it's important to discuss it. The information might not be correct, but it may also be correct, and, fortunately, it very often is, and then it's important to say 'that's great, just keep doing that and listen to them [peers on social media]'.

Consistent with the border zone, discussions about social media information could serve to appraise its credibility. However, as Sally emphasised, it was important to initiate the discussion and acknowledge when information was accurate, as it often was. Initiating such discussions was also invoked to help mitigate asymmetrical power relationships, as noted by Andrew, a physician. He stated, "You actually need to invite the conversation [about social media information], because there is still, I mean, at least in the population of people with type 2 diabetes, there is still a kind of fear of authority." Social media needed to be a legitimate discussion topic in clinical settings, as Andrew described:

Perhaps we should put a note on the consulting room door stating that it's completely legitimate and okay [to obtain information from social media] — otherwise, we'll live in some sort of parallel worlds in which we've got the medical point of view on the one side and the user populations' [people with diabetes] point of view on the other side.

Critically, Andrew used the metaphor of parallel worlds—providing a central inspiration in our analysis—to explain the consequence of clinicians' disengagement with social media information. He thus hinted at its negative consequences for relationships between people with diabetes and clinicians.

Clinicians who initiated discussions about social media information also described having these frequently. One dietician, Ida, stated, "It's very often that they [people with diabetes] have read something on Facebook. There are just so many Facebook groups with different topics." Ida was aware of several Facebook groups for people with diabetes, suggesting she had been curious to learn what they could offer. She and a few other clinicians advised people with diabetes to interact with peers online. When asked to elaborate why she would often encourage people with diabetes to engage online, Ida responded:

If you are guiding a patient in something, like from a theoretical perspective, and it's not working too well and the patient needs support, you can encourage them and suggest 'try to look in some of

those online groups, there are probably other people who feel like you do, and I am sure you can gain some inspiration there'. Then many patients respond 'I'll try that', and then, of course, I tell them 'remember before you try out something radical, please come and talk to me about it first'.

When theory did not work in practice, Ida involved social media to support people with diabetes. Still, she established her professional authority by emphasising the importance of her input into decisions based on social media information, urging people with diabetes to consult her before trying out "something radical". In this way, she also indicated a shared responsibility for negotiating the usefulness and quality of the information. As Ida explained, it was important to acknowledge people with diabetes for going online and researching ways to handle self-management. "You get much further when it's their own suggestion compared to when we [clinicians] inform them about a diet, guideline or whatever it might be", she stated. She provided an example:

People who have a tight [blood glucose] management and eat very low-carb are used to resistance [from clinicians], but then they just stop listening, so you've got to acknowledge some aspects and then offer other perspectives. I sometimes have to say, 'I don't recommend that, and I have to inform you about it', but then I explain why and also acknowledge that their blood glucose levels are really good, remind them about a few things and encourage them to consult us again.

Ida addressed how acknowledgement was part of negotiations in which she offered her professional perspective, an example of how a trading zone took shape. The formation of a trading zone also gave rise to clinician reflections about professional authority and expertise. One nurse, Sophie, explained that she very often discussed social media information and described social media as playing a "major role" for many people with diabetes, especially for those with type 1 diabetes. Sophie reflected upon what this meant to her professionally:

I feel like we [clinicians] often lag behind [...]. The flow of information online is so big, they [people with diabetes] often know things before we do, and that's challenging because this requires us to be professionals in a different way. We are schooled to be the expert and sometimes I am just not the expert. I mean, I am not an expert per se, but this issue about them knowing things before we do, that can actually be really challenging.

Sophie addressed the ambivalence that she and other clinicians may feel towards their role as experts when people with diabetes can easily access information from peers via social media. As she indicated, they mobilised a collective knowledge that she was confronted with in clinical consultations, challenging her role as the expert. Her statement also emphasised that clinicians had to acknowledge that this was now part of their professional work.

5. Concluding discussion

5.1. From parallel world to trading zone

People with diabetes and clinicians discuss social media information in ways that can be considered to fall on a continuum of (dis)engagement. Three metaphorical concepts—parallel world, border zone, and trading zone—connect this continuum, and we have identified dynamics and reasoning related to each that shape how social media information is and is not discussed in clinical consultations. The words 'world' and 'zone' invoke spatial domains that represent social media and the physical location of clinical consultation rooms. As touched upon earlier, the clinical encounter is infused with a tradition of specific epistemic roles, privileging clinicians in terms of expertise and authority (Parsons, 1951; Pierson, 1994; Stivers and Timmermans, 2020). The

clinical encounter therefore involves certain power relationships and logics that shape the practices and ethics of clinical care (Mol, 2008). Further, clinical consultations are restricted to a specific time frame and centre on prescribed actions such as discussing test results and documenting medical records. Collectively, these factors inevitably shape interactions between people with diabetes and clinicians, but they also influence the establishment of a language and culture for talking about social media information that are crucial to forming a trading zone (Collins et al., 2007, 2019; Galison, 1999, 2010).

On one end of the continuum, social media resembles a parallel world disconnected from clinical consultations. Denoting social media as a parallel world both captures empirical findings that point to disengagement with such information and hints at social media as a vast online world of information. Participants with diabetes generally describe social media information as supporting daily self-management, informing their treatment preferences and reasoning when seeing clinicians, as suggested in other studies (Litchman et al., 2018; Maslen and Lupton, 2018; Stevenson et al., 2021a; Townsend et al., 2015). Although social media has become an asset for people with diabetes, they may not articulate its use and value. They may not find it relevant to mention and, when advocating for access to specific treatments, there can be certain benefits to preserving social media as a parallel world that clinicians lack insight into. However, maintaining social media as a parallel world is also fuelled by uncertainty about whether clinicians understand and acknowledge its value. Although clinicians may have the power to initiate integrating social media and clinical consultations by asking directly about social media, they are not necessarily aware of this or prepared to do so. Lack of time and perceptions that older adults and people with type 2 diabetes do not use social media or that social media is a private domain useful only for emotional support are all reasons invoked by clinicians that underlie disengagement. This points to the absence of a common language and culture for talking about social media information in clinical consultations.

Moving along the continuum to the border zone, people with diabetes explicitly present social media information. As described in other studies (Benetoli et al., 2018; Jacomet et al., 2020; Litchman et al., 2018; Maslen and Lupton, 2018), people with diabetes may seek clinicians' expertise when in doubt about the credibility of information. Navigating a vast online world of information is a demanding task, and people with diabetes may find themselves confused or overloaded with information from peers (Kingod and Cleal, 2019). However, bringing up the information in clinical consultations entails the risk of clinicians responding in ways that could be viewed as pushing back to maintain social media as a parallel world. Such pushbacks include clinicians dismissing social media information as irrelevant or reacting to it with scepticism, consistent with findings of other studies (Benetoli et al., 2018; Kingod, 2020; Maslen and Lupton, 2018; Stevenson et al., 2021b; Townsend et al., 2015). Clinicians may find themselves ambivalent when confronted with social media information and find it difficult to engage with such information, especially in ways that go beyond simple appraisal. Consistent with other studies (Barney et al., 2011; Kim and Kim, 2009; Townsend et al., 2015), we also found that clinicians express concerns about harmful advice being shared online. Such concerns can be tied to the ethics of clinical care in which authority and accountability are intertwined (Peräkylä, 1998). In contrast to peers on social media, clinicians can be held accountable for their advice. Clinicians may therefore be reluctant to encourage online peer interaction or engage in discussions about it unless it is presented in conjunction with a serious problem for the patient. Nevertheless, such reluctance still places the responsibility for initiating social media discussions on people with diabetes. In addition, because people with diabetes may only present information when in doubt about its credibility, clinicians gain distorted insights into this online world.

Finally, the formation of a trading zone takes place when clinicians are open to social media information, invite people with diabetes to discuss it and acknowledge its value. While discussions may still be

focused on evaluating the credibility of information, they are also often characterised by negotiation in which different perspectives are exchanged. Whereas traditional forms of medical authority rest on the expectation that individuals should follow prescribed instructions (Parsons, 1951; Pierson, 1994), an alternative form of authority is to *authorise* people with diabetes. Despret proposes the concept of authorisation to describe a relational form of authority that depends on mutual learning and caring among actors, as contrast to perceiving authority as a form of domination and control (Despret, 2004). To help establish a common language and culture for discussing social media information, clinicians can authorise people with diabetes, legitimising their online search for information. As we have described, some clinicians express the importance of making social media information a legitimate subject of discussion, and some find it relevant to guide people with diabetes towards potentially useful social media resources. These are examples of how clinicians both authorise people with diabetes to present their information in clinical consultations and authorise the value of social media by endorsing its existence. At the same time, clinicians may also establish their professional authority by emphasising the importance of their input into decisions based on social media information, indicating a shared responsibility for evaluating its quality and usefulness.

Moving from the parallel world to the trading zone may appear to be a simple matter of asking about social media information. However, as our findings show, this movement is complex and gives rise to challenges. It forces clinicians to reflect upon their professional role. For example, discussions about social media information can be time-consuming, give rise to questions that one is unable to answer or lead to a sense of one's knowledge being out of date because information travels quickly on social media. Secondly, clinicians are faced with ethical questions of professional accountability due to concerns about online sharing of harmful advice. These are complex dilemmas, emphasising that movement along the continuum is not necessarily an easy task. Nonetheless, maintaining social media as a parallel world abandons people with diabetes to navigating the online world of information alone and places the responsibility for initiating discussions about such information entirely on their shoulders. While this study focused on how social media information is discussed in clinical consultations, it is unknown how many people with diabetes use social media to acquire information. Statistically representative studies are needed to explore this. Future qualitative studies should include observations of clinical consultations to provide further insight into how social media information is discussed, a limitation of this study. Future studies could also recruit participants in person to minimise self-selection bias. Finally, clinicians should be trained in communicating about social media information to help move from the parallel world to the trading zone.

Credit author statement

Emilie Mølholm Kjærulff: Conceptualisation, data collection, formal analysis, writing and editing. Henriette Langstrup: Conceptualisation, formal analysis, writing and editing.

Data availability

The authors do not have permission to share data.

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