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

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Abstract

Danish adults with type 1 diabetes value peer-to-peer interaction through the social media platform Facebook as a way to quickly exchange knowledge on essential everyday self-care for chronic illness. In this praxiographic study, following informants into online and offline social dimensions, I explore how they use Facebook to exchange self-care knowledge based on practical experiments and negotiations between bodies, technologies, and daily lives. When in doubt about how to self-care on a daily basis, Danish adults with type 1 diabetes look to Facebook for inspiration and peer support. A synergistic process of online searching and sharing and offline tinkering with self-care generates person-centred knowledge about how to live with illness that is situated to individual needs and unique daily lives. Facebook can be viewed as an online knowledge manual about how to self-care that is co-constructed by peers from their experiences of illness on a daily and ongoing basis. This knowledge addresses all aspects of daily life with illness.

Keywords

Type 1 diabetes, Facebook, doubt, patient knowledge, tinkering, praxiography

Introduction

> *"I have learned from Facebook that there is other information, than what I get at the clinic, and that I should use it! I feel that there is a tendency for doctors to look at diabetics as a puzzle or a mathematic equation. Of course it should be like that, because there is metabolic stuff that is similar; however, it is also my impression that there is a great difference how we react individually. My algorithm is not the same as Karen's or Mary's because we will all end up with different blood sugars. I have to listen to what the doctor tells me, but not necessarily adhere to it 100%. Sometimes, I have to follow what the doctor says and, other times, it is time to tinker. Of course, I have some self-responsibility when saying "let me try this experiment", but it is my life and I am the one who has to live it." (Tanja, 41 years old, diagnosed with type 1 diabetes for 33 years)*

Type 1 and 2 diabetes, with which 422 million adults are diagnosed worldwide, pose an alarming public health problem (Barry et al., 2017). In Denmark, approximately 30,000 people in a population of 5.7 million are diagnosed with type 1 diabetes, and current evidence indicates that national and international incidence and prevalence are on the rise (World Health Organization, 2016). As the quote that opens this article illustrates, self-care with type 1 diabetes calls for experiential knowledge that is difficult to obtain at a clinic. Tanja explains how she decides when to adhere to medical directions and when to tinker on her own. She chooses the latter when she is in doubt about how to self-care in a specific situation and believes that information from healthcare professionals is too general. However, she does not reject the biomedical model; she seeks to supplement it with other forms of expertise and knowledge co-created by her peers on Facebook.

Daily self-care of type 1 diabetes is challenging because more than 95 percent of care is performed by patients without the direct support and influence of healthcare professionals (Funnell and Anderson, 2004). Daily self-care practices build on knowing one's body and how to navigate intrinsic self-care technologies, knowledge that is often developed through tinkering (Mol and Law, 2004; Guell, 2012; Danholt, 2013). As a concept and a practice, tinkering was introduced within healthcare as a way of describing the practice of handling, negotiating, and, especially, experimenting with human and nonhuman actors (Resnick and Rosenbaum, 2013). Don Schoen has described tinkering as a conversation with materials (Schoen, 1983), which is closely related to the way people with diabetes refer to practices of bodily interaction with self-care machinery (Mol and Law, 2004). With a specfic focus on people living with diabetes, Guell describes how migrants in Berlin with diabetes develop tactical decisions about self-care that involve tinkering and puzzling together of various sources of advice (Guell, 2012). To some extent, tinkering is a quintessentially human practice and thus not unique to people living with type 1 diabetes. Nonetheless, tinkering among patients with type 1 diabetes is unique by virtue of the condition's signs and symptoms and the technologies and skills that are required in self-care. With continuous growth in personalised self-care technologies and online social media options, the ways in which patients with type 1 diabetes tinker have changed; concomitant with these changes is an increase in the complexity of the knowledge and skills required for self-care.

The many hours of self-care for type 1 diabetes that are required throughout the day have been stressed in several studies focusing on the complex regimen involved in monitoring and managing self-care technologies on a daily basis (Guell, 2012; Danholt, 2013; Hernandez, 1996; Mol, 2008; Oxlund and Whyte, 2014). Self-care activities for type 1 diabetes have involved some form of technological intervention since treatment first became possible in the 1920s. In recent years, the number and types of devices and drugs available to treat and manage diabetes has expanded rapidly. As a consequence, people with diabetes who actively seek to optimize their self-care practices are challenged to keep abreast of technological developments and new treatment options. New technologies and treatments will, in turn, require people with diabetes to acquire new knowledge and skills for proper self-care (Mol, 2008; Mol and Law, 2004).

Fox describes the types of devices that are familiar to people with type 1 diabetes, such as insulin pumps and continuous blood glucose monitors, as personal health technologies, a concept that captures the way mobile and wearable devices become extensions of people's corporeality (Fox, 2015). By emphasizing the personal, the concept also implies that these devices are designed primarily for use outside of healthcare settings and enable self-tracking and monitoring through wireless technology (Fox, 2015; Lupton, 2016). Due to complicated and technological self-care practices that require skills equivalent to those of a nurse and a technician, Tanja turns to peers on Facebook to obtain guidance and knowledge situated to individual ways of self-caring. This situated self-care requires the tinkering that is the focus of this article. Situated self-care knowledge cannot be extracted from biomedical knowledge or clinical guidelines. It must be generated through a continual and complex interplay between devices, bodies, and affective states.

Previous studies on knowledge creation in daily life with chronic illness have adopted varied approaches. The social scientist Jeannette Pols defines patient knowledge as that which patients create in the course of daily life with illness; it incorporates both know-how and know-now, which patients develop and use to translate biomedical knowledge into something with practical utility (Pols, 2012; Pols, 2013; Pols, 2014). Studies on patient or lay knowledge have focused on noncompliance and the potential threat to doctor-patient relationships that arises when patients do not always follow directions given by their healthcare team (Funnell and Anderson, 2004; Britten and Maguire, 2016; Fox et al., 2005). Pols explores how patients with chronic obstructive pulmonary disease try out strategies, improvise, and develop skills and talents to address a whole range of issues, often without professional advice (Pols, 2013). She notes that the goal of patients is not always to adhere to what doctor's think is best; rather, they want to find solutions to live well with illness (Pols, 2013). In a cross-cultural study, Mattingly et al. (2011) note that expectations and guidelines from healthcare professionals are not integrated fully into the daily lives of patients with conditions for which the vast majority of treatment occurs outside the clinic. The authors define a 'borderland practice' between clinic and home where patients independently find solutions to live well with chronic illness (Mattingly et al., 2011).

Studying how patients create knowledge over the course of daily life with illness has previously been conceptualised in numerous ways; 'experiential knowledge' (Kingod et al., 2017), 'lay knowledge' (Britten and Maguire, 2016; Nielsen and Grøn, 2012), 'embodied knowledge' (Hester, 2005; Broom, 2009), and 'surveillance knowledge' (Lyon, 2010, Lupton, 2012; Fox, 2015). No longer conceived as passive and doing only what they are told by their healthcare providers, patients are identified with attributes emphasising their agency: 'the informed patient' (Kivits, 2004), 'the active patient' (Barbot, 2006; Rabeharisoa et al. 2014), 'the expert patient' (Fox et al., 2005), and 'the expert of experience' (Nielsen and Grøn, 2012). These conceptualizations challenge traditional hierarchical knowledge exchange in healthcare, and they beg the question of how patients collaborate and co-create with scientists through 'research in the wild' (Callon and Rabeharisoa, 2003).

With a Facebook app on her smartphone, Tanja can easily access illness-associated peer support (Chayko, 2008; Kingod et al., 20017). This reflects a trend in healthcare from e-health to m-he alth, in which ‘mobile’ patients have portable healthcare devices and smartphones that are carried around close to the bodies of their users (Lupton, 2016; Ziebland and Wyke, 2012).

In this article, I explore how Facebook transforms the ways in which patients can tinker with their self-care. I investigate complicated processes and practices of online searching and sharing and offline tinkering with self-care. In doing so, I argue that it is a problematic notion that online activity and co-creation of knowledge outside the biomedical realm are equivalent to medical non-adherence. I will discuss the nature of what is at issue as more complex than adherence and non-adherence.

Praxiography: Following practices on- and offline

A praxiographic design was applied in which I followed informants - carriers of practice - into different online and offline social dimensions where self-care and knowledge about self-care are practiced and co-constructed. Praxiography was defined by Mol as ethnography with a focus on practices (Mol, 2002). As with Mol (2012), Buerger (2014) calls for multiple methods under the term praxiography, with observation being one of the main data-gathering methods. The combination of methods I applied to this research were chosen to facilitate a ‘multi-faceted understanding’ of the practice of self-care, tinkering, and co-construction of knowledge through intertwined online and offline processes (Hine, 2015). The use of health-related online communities has gained increasing attention as an object of scientific curiosity, but a tendency remains to view the online and offline worlds as disintegrated social dimensions. Several recent studies stress the inadequacy of this approach. Future studies should integrate online and offline ethnography in chronic illness research (Kingod et al., 2017) because online dimensions should be considered integrated into ‘real’ life (Miller, 2016; Hine, 2000). Consequently, I conducted online and offline praxiography simultaneously, including one year of observation on Facebook, 12 face-to-face interviews, several follow-up conversations, 6 participant observations at peer meetings and 2 focus group discussions. The data discussed here are primarily derived from observations on Facebook and individual interviews.

Fieldwork was conducted between June 2015 and June 2016. Miller et al. (2016) elucidate the importance of studies on Facebook that examine what people post and comment and the consequences of these postings in daily life. Taking a lead from this insight, I was interested in understanding how shared posts on self-care were integrated in daily life. I chose Facebook as an ethnographic site because it is the preferred online space for Danish adults with type 1 diabetes, second only to peer-to-peer offline meetings. Initially, I negotiated access with the administrators of diverse Danish communities on Facebook, who usually required that I demonstrate familiarity with type 1 diabetes. A further condition of access was that I observe 'unobtrusively' to avoid interfering with the natural environment and inadvertently cause members to withdraw from the community. Unobtrusive observations enable the researcher to gather data across perspectives and time and in the natural setting of online social interaction without interfering with it (Patton, 2002; Nørskov and Rask, 2011). Within online communities, it is normal to lurk without posting (Hine, 2012:57), but anonymity was not an option if my goal was to actively engage with members of these Facebook groups. I announced my presence, not least out of respect for ethical issues related to conducting qualitative research in online communities (Eysenbach and Till, 2001; Markham and Buchanan, 2012). Posting about my research project explained and clarified the nature of my 'unobtrusive' presence to other members within the community. I used the same post to recruit members for 12 interviews. I took notes and downloaded data from the communities to understand of sharing knowledge online was integrated into life with illness. Even though I identified a total of 16 Danish Facebook communities for adults with type 1 diabetes, I chose to restrict my in-depth observations to the three most active: 1) a community with a specific focus on insulin pumps, 2) a community focused on exercise, and 3) a generic type 1 diabetes community. Membership in these ranged from 200 to 4000 individuals.

According to Dalgas (2016), long-term ethnographic fieldwork involves engagement and investment in the lives of study participants, and informal conversations and observations are of equal importance to structured interviews. I had ongoing conversations with the same informants through email, during coffee breaks at offline peer meetings, and in their home environments. The 12 interviews were structured to first gain an in-depth understanding of daily self-care, followed by additional semi-structured questions aimed at observing human-technology practices and experiences and stimulating informants to reflect on their actions. Hine notes that observation of media use is helpful to understanding interconnected practices and expectations (Hine, 2015). I used a 'think aloud' method, which provides insights into observed actions and practices connected to Facebook navigation and use of technology such as computers, iPads, and smartphones. This provided data both on how informants would logged onto Facebook throughout the day by primarily using smartphones and, on entering the communities, how online practices and shared content affected daily self-care practices (Patton, 2002; Van Someren et al., 1994). All interviews were transcribed verbatim and anonymized.

Results

This section provides empirical examples of how doubt about self-care motivates adults with type 1 diabetes to turn to peers on Facebook for advice and how they co-construct knowledge on how to live with illness through intertwined practices of online searching and sharing and offline tinkering with self-care.

How doubt about self-care leads to peers on Facebook

Study participants with type 1 diabetes were driven toward peers on Facebook to reduce doubt in their daily struggles with self-care that largely related to decision-making, prediction and controlling practices. I will illustrate this empirically with the case of Lisa.

Lisa, a 44-year-old woman, was diagnosed with type 1 diabetes when she was 8 years old. Sitting outside at a favourite café near her workplace, she explains daily life with her illness, focusing on many daily situations in which she struggles to keep her blood sugar under control. She highlights the daily routines of sleeping, staying awake, being physically active, and eating that all have an impact on her blood sugar in one way or the other. She believes that the consequences of these routines on her body and blood sugar are difficult to grasp for people without type 1 diabetes. Therefore, she tries hard to make me understand her daily challenges, returning repeatedly to a metaphor of walking in a valley with many hills that represent her daily trials with a fluctuating blood sugar she must control. This is exemplified by the 24-hour display on her insulin pump with a graph of her blood sugar level with two red horizontal lines that demarcate the high and low boundaries of the preferred level between 4 and 6 mmol/l. Observing the display, I understand the metaphor of many fluctuations as hills. Some hills rise far above the top line, and others appear as craters well below the bottom line. Lisa explains how, on a daily basis, she tries out various strategies of operating, adjusting and calibrating her life-saving self-care device to stay within the preferred lines. It became clear to me that managing type 1 diabetes is located far less in hospitals and clinics than in the daily lives of people who are diagnosed with it (Mol and Law, 2004).

Lisa explains that, for her, self-care is being able to predict what will happen to her blood sugar in various situations throughout the day and deciding on which practices to apply to control or recover from fluctuations.

> *It is in particularly difficult with exercise. I just cannot figure out how to properly adjust the pump. I am usually too low, but then I suddenly become too high, and I can see on Facebook that I am not alone with this doubt.*

She has many examples of the illness limiting her ability to participate in activities that she feels people without type 1 diabetes take for granted, such as exercising at her local gym, going to a birthday party, buying groceries, or walking. These activities have an impact on her blood sugar that she needs to figure out, which often leaves her in doubt. Lisa addresses the difficulties in keeping her blood sugar well-regulated without a definitive self-care manual on how to live with the illness.

> *We only see a doctor for less than an hour a year and the rest of the time we are left on our own. And we have to decide all the time. We are our own doctor 24/7, and then we have some 'coaches' (referring to the diabetes nurses) 50 minutes a year! That is so unique with our illness. Try to just think about that! That is also why I believe that we should have all the knowledge as if we are our own doctors. (Lisa, 44 years old)*

She expresses a strong need for access to relevant knowledge and support for problem solving about her daily self-care challenges. She refers to the four yearly visits with healthcare professionals, during which interactions are primarily dedicated to routinized biomedical practices, including long-term blood sugar measurements, weight control, blood pressure measurements, and eye and foot examinations. Limited time is dedicated to her concerns about daily life with the illness. These areas of concern emanate from the self-care Lisa conducts outside the clinic, where support is scarce. As another informant states:

> *It is as if they (health care practitioners) are only interested in the illness and the way to treat it. The life with illness or the way you get the best out of it, they care less about (Peter, 60 years old, diagnosed with type 1 diabetes for 2 years)*

Peter pays attention to the way biomedicine treats type 1 diabetes, focusing on the physical manifestations of illness and not on daily life with it. He feels the lack of a manual on how to navigate the domain of self-care to live well with illness. He also describes various situations in daily life where he meets challenges that need to be solved.

The informants constantly searched for information and support beyond that delivered by healthcare professionals. It became evident that doubt related to decision-making, predicting, and controlling blood sugar levels experienced by informants requires a type of knowledge, information and experience other than the one supplied by the clinic. Whyte (2005) states that people with illness will use meaningful modes of acting on a problem to steer in the right direction. In a study of people with HIV/AIDS in Uganda, she describes patients attempting to control the uncertain by 'trying out ideas'. This trying out of ideas represents a practice of tinkering, which will be explored in the next section. The search for ideas and problem-solving knowledge on how to live with type 1 diabetes drives the study informants to health-related communities on Facebook.

To reduce doubt in self-care, Lisa explains that it is all about *knowing* the illness. In a study of people with hypoglycaemia, Mol and Law (2004) argue that knowing the illness is derived from practices of self-care at a daily level, using technologies that have moved from hospitals and clinics into patients' hands and homes. Knowing type 1 diabetes thus encompasses observing, trying out, experimenting, tinkering, attending to, adjusting, and finally *knowing* the practices involved in daily self-care (Mol and Law, 2004). The knowledge about how to control, predict, and decide on what practices to apply for a fluctuating blood sugar as described by the informants of this study can only be derived continual self-care experiments.

What began as predominantly verbal stories of daily experiences of living with type 1 diabetes evolved into detailed explanations and observations of complex overlapping processes and practices of online searching and sharing,and offline tinkering with self-care.

Facebook searching and sharing allows for offline tinkering with self-care

Lisa is most active in the community on exercise because she is often unsure about how to control her blood sugar before, during, and after various kinds of sport. Adjustment and calibration of technology, in combination with carbohydrate calculations and levels of exercise, caused doubt that called for peer advice. In a post in an exercise community, she described her doubt:

> *Can someone please share with me in detail what you do during exercise? Even though I know that it is individual, I would really like to hear your experiences. Today my blood sugar level was 10 (mmol/l) before gym class at 0830, and, just as an experiment, I only took half of my normal dose (insulin given by an insulin pump) for breakfast. As it was relatively hard exercise, I adjusted the basal dose (small continuous insulin doses supplied by a pump) to 75% for 1.5 hours. I landed on 6 (referring to mmol/l of blood sugar level) after the gym hour and after another hour my level is 5,2 (mmol/l). I am very curious about what will happen within a few hours. Yesterday my BS (blood sugar level) was 18,2 (mmol/l) after two hours of yoga class without sweat but with a BS on 3 (mmol/l) after the class and the basal rate adjusted to 50%, ugh! Please tell me what you think and how you act – step by step…my experience is that I am running in a labyrinth blindfolded. (Post on Facebook by Lisa, 44 years old, diagnosed with type 1 diabetes for 32 years)*

Lisa’s post received 11 likes and 15 comments. The latter all contained specific descriptions of the commenters’ tinkering experiments, with descriptions of complicated offline negotiations between bodies, technologies, and daily lives. Lisa wrote two of the replies, requesting clarification of experiments shared by her peers.

The comparison to running blindfolded in a labyrinth in her post illustrates Lisa’s doubt about her ability to figure out how to adjust the insulin pump settings for different types of exercise. After her own experiments with insulin pump adjustments do not lead to the outcome she wanted, she searches for inspiration on how to tinker in other ways. The process of Lisa’s online navigation is primarily one of following; she starts out searching for related posts in the most relevant online community using Facebook’s built-in search function. After she realizes that there is no relevant information, she creates a post about her self-care concern and shares it with peers in the community. As her peers like and reply to her post, she compares their experiments and then initiates a process of discussing how best to tinker with her peers. Lisa finally puzzles together the various pieces of self-care information, including her past embodied experiments, for a next step of offline tinkering in her specific area of doubt. Her typological navigation and negotiation between body, technology, and daily lives was typical of those observed online and directly among other informants.

The informants turned to Facebook to begin a process of assembling information from various sources. They were not necessarily newly diagnosed; they might have recently received a recommendation to use a new self-care device, such as an insulin pump or continuous glucose monitor, which required education and instruction before use. Even though most informants appreciated the ability of new technology to make self-care easier they also perceived the technology and the language related to it as complicated. Informants tended to forget how to adjust and use the devices or doubted their technological skills in situating the device to their life.

Tinkering as negotiations between bodies, technologies, and daily lives

The posts related to tinkering were based on experiments in specific individual contexts and fell into diabetes-specific, inter-related concerns about placing and adjusting diabetes self-care technology, often in combination with issues related to physical activity and food. Informants considered physical activity, which included all types of activity such as walking, biking, and exercise at local gyms, very challenging in relation to regulating blood sugar levels. This was especially evident in three communities on insulin pumps and the three communities on exercise and food I identified on Facebook.

Several communities for adults targeting specific insulin pump brands showed the complexity of adjusting the pump properly to the body and daily life. The insulin pump is a complex piece of machinery used by about 15% of people with type 1 diabetes in Denmark. In comparison to an insulin pen, a pump continuously delivers small doses of insulin through a catheter attached to the body in an attempt to mimic the insulin-producing pancreas of a healthy individual. The patient can adjust the pump to regulate insulin delivery and control blood sugar levels. Some insulin pumps are interoperable with a continuous glucose monitor, also attached to the body, which measures blood sugar levels and automatically transmits them to the pump, which, in turn, adjusts insulin dosing. The informants, inspired by online peer advice, tinkered with insulin pumps and continuous glucose monitors to situate and individualize self-care.

Sisse is 53 years old and was diagnosed with type 1 diabetes three years ago. She recently received an insulin pump and a continuous glucose monitor due to numerous low blood sugars, which caused her to fear going into insulin shock. Although Sisse has completed a four-day patient education course, she remains unsure about how to handle and situate the pump to her daily life.

Sisse describes her daily life as active; she bikes to work and walks her dogs daily and takes weekly spinning classes. She considers herself to be an engaged and active patient because she aims to respond immediately to her blood sugar. She is determined not to let illness control her way of life and has maintained her daily routines since her diagnosis. She explains that one of her major doubts about self-care is during spinning classes where it is difficult for her to sense low blood sugars. She therefore relies on the continuous glucose monitor to indicate rapid drops in her blood sugar with downward arrows on her insulin pump's visual display. This feedback helps her ward off insulin shock by consuming a sugary drink, but she finds it very frustrating when the monitor falls off during spinning class because of perspiration. Her healthcare professional and the medical company supplying the device taught her that it should be attached to the skin over her abdomen. Unaware of other options for placing the device, she often took longer breaks from both the monitor and exercise because of her difficulty keeping it in place. During a conversation Sisse explains to me how a Facebook community for people with insulin pumps inspired her to attach the device somewhere else while she illustrates the new location of the sensor on her upper arm.

> Sisse says: *This is actually something I have learned from within these communities, that you can actually attach it to other body parts. I was just not aware of that possibility. (Sisse, 53 years old, diagnosed with type 1 diabetes for 3 years*)

Sisse describes first trying to attach the glucose monitor to her leg without success; it often fell off while she slept at night and dropped the data transmission to the insulin pump. Sisse searched Facebook for peer knowledge about how to place the monitor in other places using different materials to create a more secure attachment, collecting and puzzling through information from various posts to tinker and negotiate with the machinery, her body, and her specific situation. Initially happy with her result, she posted her tinkering experience with peers in the insulin pump community on Facebook:

> *Daily experiment: Sensor in the arm. I received help in pulling out the needle, but on my own I covered it with two pieces of Medtronic bandage. I am so excited to know how it will work….*

This post received 88 likes and 11 comments. Unfortunately, Sisse developed a rash from the stickers shortly afterward. Turning to Facebook again, she tried out different adhesives inspired by her peers without finding a solution.

Having tinkered with the technology over time by experimenting with information from her peers, Sisse became motivated to carry out her own experiments that went beyond the inspiration she received on Facebook. She bought different types and brands of adhesive material at her local pharmacy. Using a special sports tape, which she attached in a star-like pattern over the sensor, she finally developed a solution that worked well for both her body and her way of living. The continuous glucose monitor did not drop the data transmission to the insulin pump, her skin could breathe underneath the tape, and the device did not fall off during exercise. She again shared her tinkering experiment with peers in the insulin pump community. She uploaded three photos illustrating the old method of attaching the sensor to her upper arm, a photo of her arm with the sensor and sports tape attached in a star, and a photo of the brand of sports tape she used.

Another common tinkering area was adjusting and individualizing insulin pump settings, particularly in terms of blood sugar patterns during the day and levels of physical activity and carbohydrate intake. Adjusting insulin pump settings is usually done in collaboration with healthcare professionals at quarterly appointments; however, as internal and external changes affect blood sugar levels, continuous modifications in self-care are crucial. Various posts on Facebook consisted of tinkering practices related to insulin pump settings and individualization in which complicated experiments included handling, trying out, negotiating, and even hacking the insulin pump to shape and reshape it to bodies and daily lives of individuals with type 1 diabetes. During a conversation with Mia, who is 32 years old and living with type 1 diabetes for 24 years, she explains:

> *I have become aware that I always get low blood sugar levels when I walk. I can see from others in there (referring to a Facebook community) that I just have to adjust the setting to 50% (referring to the continuous small doses of basal insulin). I just haven't thought about that. I have received a lot of tips that my physician could not have given me. It has been a gentle but much needed push in the right direction. (Mia, 32 years, diagnosed with type 1 diabetes for 24 years)*

Mia became motivated to tinker with insulin pump functions to adapt to her exercise routine. She explains that she would not have been confident with this practice without the inspiration of her peers in an insulin pump community. I observe how she scrolls through posts on Facebook to find those concerned with low blood sugars to be used as a guideline to tinker. Mia reveals how her self-confidence about caring for her diabetes has increased as a result of her tinkering. However, she is not likely to reveal this at her quarterly meetings at the clinic, due to previous negative reactions on the part of healthcare professionals to her use of Facebook for support in tinkering.

Discussion

The tinkering m-patient co-creating knowledge on how to live with type 1 diabetes

As revealed by the analysis, self-care for type 1 diabetes is difficult to routinize due to complex and highly individual interactions between physiology, technology, and daily lives that require equally individualized solutions. Observations and interviews with informants revealed that they were often unsure about how to self-care; however, through practices of online searching and sharing and offline tinkering, they were observed to co-create practical and situated knowledge on how to live with the illness. This knowledge was tailored to individual needs and went beyond general knowledge about self-care supplied by healthcare professionals.

Winance (2010) describes the tendency of people to tinker when technology is not properly adjusted to the body it must serve; in particular, Sisse's experience exemplifies this observation. Through tinkering with her body and the technology, she recreated knowledge about how to self-care using her body as a toolbox and arriving at an embodied knowing that she shared with peers on Facebook (Hester, 2005). By tinkering, Sisse negotiated and adjusted the technology until arriving at a functional arrangement, a process necessary to improve care and live symbiotically with the technology. Winance (2010) describes these tinkering practices as continuous until a suitable material, emotional, and relational arrangement is reached. Like Sisse, Mia finally arrived at arrangements that did not compromise either the effect of the technology or her way of living. I refer to tinkering as serious work, inspired by Mattingly et al (2011), to highlight its consequential nature. Although tinkering may possess an element of playfulness in some circumstances, the tinkering I describe here is a highly serious endeavour (Dumit, 2012). Tinkering is hard work and a thoughtful, creative, and exploratory way of engaging with problems in the daily self-care of type 1 diabetes.

The tinkering m-patient is a product of Web 2.0 technologies offering a new time-space dimension that provides easy access to allow patients to tailor and situate self-care at an individual level (Lupton, 2012). Observations reveal that Facebook allows for the embodiment of mobile device users because the app installed on the smartphone links to supporting self-care knowledge from peers. Embodiment of technologies has been described by Fox (2012:181): smartphones and personal digital devices that link one's body to a world of knowledge and communication. These technologies extend what a body can do -

just one click away (Lupton, 2012; Pols, 2012; Fox, 2012). On entering Facebook with a personal profile that gives access to membership of several communities, it is easy to understand how Facebook has become embedded, embodied, and everyday (Hine, 2015).

Informants use Facebook as an online manual for self-care through written posts with uploaded photos and documents that encourage peers to mirror the experiments of others and initiate personal practices of tinkering with bodies, technologies and daily lives. This was evident in the uploaded photos describing Sisse's step-by-step experiments, showing first her failed experiment with the glucose monitor, followed by photos of successful tinkering with her body, self-care technology, and new materials that resulted in a more secure attachment to her body. Informants in this study derived embodied knowledge through a collective sense-making of self-care using new technologies for this endeavour (Broom, 2009). This knowledge arises from bodily responses to tinkering.

Defining the informants as tinkering m-patients, I strive to illustrate how they engage with self-care in highly inventive ways, as observed in individual cases. Online searching and sharing and offline tinkering motivated patients, as in the case of Mia, to take more control of self-care and tinker in new situations. Through digital engagement, informants as tinkering m-patients worked collectively through the communities by encouraging each other to understand more about daily life with illness and how to treat it (Lupton, 2014). The tinkering m-patient eventually becomes what Shaw and Baker (2004: 723) define as the well-informed patient or 'expert patient', someone with 'the confidence, skills, information, and knowledge to play a central role in the management of (his or her) own life with the chronic illness'. They argue against the stereotype of rejecting medical advice and instead describe a concerned and motivated patient. The findings in this study support this view of an engaged m-patient taking control of his or her own care by co-creating patient knowledge through Facebook that is, arguably, as important as biomedical knowledge (Pickard and Rogers, 2012).

Pols (2010; 2013) states that tinkering reflects a creative practice in daily activities of patients that is essential for patients to have a good life with illness - but it does not always adhere to what medical experts define as good patient care. Although Schaffer, Kuczynski, and Skinner (2008) found that parents of chronic ill children trust and value peer advice in online communities more than information from doctors, I argue that using peer advice and finding solutions to situate self-care in their daily lives does not imply that patients reject biomedical knowledge. Informants were still following medical advice given during quarterly clinic visits based on a long-term blood sugar test that indicates appropriate adjustments of insulin levels. However, numeric values and the advice of the medical care team are insufficient to support them in how to live with the illness. What they seek through Facebook is qualitative knowledge generated through years of tinkering with self-care – a certain knowing derived through embodied experiments while living with type 1 diabetes (Hester, 2005). It is a ‘messy’ knowledge, as Pols (2014; 2012) states, involving different techniques, values, and materials, which call for further investigation.

A limitation to this study is its singular focus on patients. Informants were highly active both in terms of their online behaviour on Facebook as well as how they attended to daily self-care. As a result, they may not represent all patients with type 1 diabetes. More study is needed to understand the interactive processes of using social media for self-care support among a broader group of patients, including those who may use social media platforms other than Facebook, as well as to understand the perspectives of healthcare professionals on the topic. Little qualitative research has been conducted on the implications for relationships between healthcare professionals and patients when patients turn to health-related communities on Facebook.

Conclusion

Adults with type 1 diabetes often live in chronic doubt about how to self-care and manage their illness on a daily basis. Necessary practices of decision-making, prediction, and control drive them to Facebook communities to seek guidance and support from their peers and to tailor their self-care to their bodies and circumstances. Facebook provided a source of inspiration to transform and integrate biomedical information into situated patient knowledge and to handle, navigate, and tailor technological self-care devices to individual physical needs and living situations. What emerged was an understanding of a synergistic process of online searching and sharing and offline tinkering that reflected serious work of negotiating with bodies, self-care technologies, and daily lives. Tinkering is a way for patients to adapt self-care to their bodies and daily lives when clinical guidelines do not fully suit individuals' needs; they thus make sense of daily self-care and adapt successfully to a life with illness. Informants were seen as creative tinkering m-patients working as active agents in their serious endeavour to facilitate self-care through self-developed means and practices. The knowledge patients created through intertwined online and offline practices were adapted to their unique experiences of living with illness.

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