The Tinkering M-Patient

An (Auto-)Praxiographic Study of Attuning to a Life with Type 1 Diabetes through Online and Offline Support

PhD Dissertation by

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Figure 1: Doubt in self-care of type 1 diabetes and Facebook support

For Olivia

and all individuals who fight with chronic illness
Acknowledgement

Everything we know is co-constructed. This thesis is the result of a year-long (auto-)praxiographic endeavor of following adults with type 1 diabetes into online and offline social spaces where self-care is practiced and knowledge about illness is co-constructed. Innumerable interactions with adults with type 1 diabetes were involved, and I would like to dedicate this work to all those who took the time to share with me your innermost thoughts, stories, doubt, and hope about daily self-care practices and living with illness. You have allowed me to observe your practices of self-care, which include interactions and negotiations with digitalized self-care devices, and I have peeked over your shoulder when you navigated within communities on Facebook. At times, I have both cried and laughed with you during deep conversations throughout the period of fieldwork. I am truly blown away by the strength and patience it requires to live with this illness on a daily basis. I did not share the embodied feelings of a failing pancreas with the consequence of high and low blood glucose levels throughout the day; however, I share with you many similar experiences in relation to self-care for this illness on a daily basis on both a practical and an emotional level.

Exploring the lives and self-care of adults with type 1 diabetes, including their journeys into online and offline social spaces, has in many ways been a journey for me as well. My fieldwork of observing practices of self-care did not stop when I left the field. Ongoing (auto-)praxiography will continue at my home until my daughter is old enough to care for herself. This PhD is also dedicated to Olivia, who was just two years old when she was diagnosed with type 1 diabetes, two months into this research project. Together with your sister, you are my love and light and my biggest inspiration. Olivia, I am amazed by your strength by your strength at handling your life with this illness. I remember a conversation we had some months ago on a day where the illness was too present in your life. I said to you that I wished that I could take your illness. Just take it away from you. You replied that you would not want to inflict this illness on me or anyone else you know. “Just send it far, far away,” you said to me. I also want to thank my husband, who was diagnosed with type 1 diabetes a year before we met each other in 2007. My deepest gratitude for the way you have supported me, not only throughout the completion of this PhD project while I forced you to listen to an academic language distinct from yours and the details of another scientific discipline, but also my deepest indebtedness for the way we came through a major crisis in the wake of our daughter’s illness. Through my research, I believe that I now have another understanding of how it is to live with this illness. I have stopped being the diabetes police, peeking over your shoulder when you check your blood glucose and commenting on your food. Type 1 diabetes is an unwanted companion that will walk with you and with Olivia for the rest of your lives. I have rewritten this section many times because it has a therapeutic and emotional dimension. I do not feel emotional because I am sad but because the process of making this PhD has been such an important journey for me. I feel empathy for all individuals diagnosed with this illness who can never put self-care on hold or take a vacation from it. I am also grateful for the opportunity to write about a topic I find fascinating and important on both an academic and a personal level. An (auto-)praxiography is also so much more than fieldwork. It has also been a highly reflexive endeavor, and I would argue that it has been a therapeutic journey as well.

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PART ONE

CHAPTER 1: INTRODUCTION

I use Facebook more for lurking than posting. But now I have become more engaged on Facebook again because my BG (blood glucose level) is not good, however (it is) not entirely bad either. It is usually too high, and I have no clue why, and I don’t know how to stabilize it. My blood glucose tends to fluctuate during the day. So, I just want to get my act together again and I seek inspiration on Facebook… I can see in the communities that there is much doubt around sensors (continuous glucose monitors) as people experience problems with calibration. They post a lot about this. However, I don’t have one, so I kind of skip through these posts. I have a pump and I like the posts on pump technique in general. I have become aware that I have to feel my way with pump adjustments. And I have become motivated to try again and again. The pieces of advice have had a great influence on how I now carry out self-care… But actually I received a glucometer through one of the communities, you know one of these that also measures ketoacidosis in the blood. Because I lacked one myself, and I just biked to the person who had a spare one. It was very easy. Of course, I could also have ordered it, but this worked well for me. I can’t remember which one of the communities it was. But one of them!… I experience them as offering a supporting hand, and they are used for sharing both good and bad experiences. Like: ‘YES, my average blood glucose finally reached this level!’ And then people ‘like’ it. And there is also a deep respect for the individuality in living with the illness… I feel less sick when I am a part of the communities because I am met with people who have a good life and people who consider it no problem. It is more like a companion. And then I sit there thinking that I am actually doing quite well.

(Lotte, 32 years, diagnosed with type 1 diabetes at age 8)

For a growing number of chronically ill people, the internet has become a resource that is actively mobilized in their everyday life. As Lotte indicates, Facebook is an interactive library on her condition where she can search at her own pace for posts on her specific self-care concerns and receive knowledge and guidance from more experienced peers. In instances of doubt in self-care she both searches through various communities to find the specific information she needs and becomes inspired by the experiential knowledge posted by peers. Facebook demonstrates the possibility of an exceptional network of electronic support conveyed through posts often accompanied with uploaded self-care photos and videos and replied to by emoticons and “likes.” Furthermore, it is a space to bridge knowledge from institutions to
homes (Pols 2013). Thus, in these translation processes, both opportunities and challenges arise when people share and co-create vast amounts of information and knowledge.

Over the last twenty years, the Internet has become an increasingly important source of knowledge about how to care for and live with a chronic illness. Several researchers have pointed to the popularity of the Internet and how it has become an embedded, embodied, and everyday item (Hine 2015; Miller and Slater 2000; Miller 2011, 2016). Searching for information about health was one of the main uses of the Internet right from the early days after its introduction to the public. The development of Internet technology made it possible to establish peer networks and specialization of interests on social media platforms such as Facebook. Since 2008, people with chronic illness have increasingly adopted social media; this popularity is reflected in many recently established communities on Facebook for people with type 1 diabetes. This shift demonstrates that the days when people with chronic illness sat behind their computer screens and searched for information on their condition as isolated individuals have been augmented by opportunities to connect and think together through peer networks on social media platforms.

This PhD dissertation will explore how adults with type 1 diabetes engage in social media as they go about their daily self-care. As the title reveals, I will call the increasing number of people living with type 1 diabetes who actively seek and share support and co-construct knowledge through Facebook “tinkering M-patients.” An M-patient is a user of M-health (also defined as mHealth within the literature) and implies a person with type 1 diabetes who accesses portable self-care support primarily through a smartphone. A tinkering M-patient implies a person with a chronic illness who strives to balance and reduce an augmented focus of the illness in everyday life in ways that often exceed biomedical directions supplied by healthcare professionals. When the illness is too much in the foreground of daily life, an M-patient tinkers to balance and reduce an identification of being a patient to one of being a person for whom the illness resides in the background of daily life.

Lotte is a tinkering M-patient as she enters Facebook several times a day to seek inspiration on how to experiment with her self-care. The way she approaches Facebook for self-care support and guidance is replicable to other informants. As I will show within this PhD study, smartphones and tablets have placed health in the hands of an increasing number of people with type 1 diabetes with unlimited access to health-related communities through a downloaded Facebook app. A primary reason among study informants for using Facebook was the ease of obtaining peer support throughout the day with nothing more than the app. This allows for convenient and continuous healthcare support from peers at all times of the day (Chayko 2008). I observed how easily peer support could be accessed on Facebook, reflecting the very definition of a mobile patient (Lupton 2016; Ziebland and Wyke 2012; Chayko 2008).

I chose an online-offline (auto-)praxiographic research design for several reasons. First, while carrying out a qualitative systematic review on the subject of online peer support, I experienced how a singular focus on online ethnography did not provide insight into the observed intertwined processes and practices. Therefore, I chose combined online-offline fieldwork; I wanted to study the way people move between online and offline settings because my interest has been in the actual ways in which adults with type 1 diabetes engage with and integrate social media into their daily lives.
Second, when lurking within the many communities for adults with type 1 diabetes, I was struck by the many posts expressing doubt about practical areas of self-care involving handling complex digital self-care devices. Praxiography
places in the foreground the pragmatic side of self-caring type 1 diabetes and, in particular, the many micro-practices involved when using technology. Finally, I have bracketed the “auto” in front of praxiography to reveal a reflexive method that has been applied to all stages in the design of this PhD from fieldwork to analysis. It was an influential condition as much as a choice due to my personal entanglement with the illness as a self-care surrogate for a child with type 1 diabetes. Relying on (auto-)praxiography has enabled me to gain in-depth insights on the embeddedness of online support in daily lives of informants. In the method section I define my reliance on (auto-), although bracketed, as a reflexive tool and symbiotic dialogue with the data that allowed me to refine my research questions and build empathy and rapport during fieldwork. I will argue that it has enabled me to show a highly pragmatic side of living with type 1 diabetes that is not easily captured through traditional ethnographic methods. There are few examples of (auto-)praxiography in the literature, so I devote considerable space to elaborating on this approach in the methodology chapter.

I developed the concept of the tinkering M-patient based on analysis of an online and offline (auto-)praxiographic approach to data collection to understand how a group of people with type 1 diabetes engage in self-care through their involvement in various peer communities on Facebook. Tinkering is a term that can be compared to earlier notions of bricolage and covers a wide range of human-technology practices of experimenting with, fitting, adjusting, and applying technologies to bodies and daily lives. This PhD dissertation and the concept of tinkering has been inspired by Annemarie Mol’s approach to studying “doing” as well as Jeanette Pols’ approach to studying “knowing,” both of which are reflected in the analytical chapters of Doing, Knowing, and Attuning. Although the concept of tinkering has been developed during the last ten years, the concept of a tinkering M-patient has not been described before in relation to how a growing number of people with a chronic illness such as type 1 diabetes seek, share, and co-create experiential knowledge on social media platforms such as Facebook in their daily struggle with the illness.

The concept of attuning was developed during analysis when it became apparent that attunement worked as a bridge between doing and knowing. Attunement is a state of fine-tuning and adjusting. It involves practices of filtering information as well as negotiating knowledge from bodies and technologies to fit daily lives. It is a constant balancing process. Thus, the analysis also reveals how living with a chronic illness in the twenty-first century is demanding because people must process enormous amounts of data from their bodies, self-care technologies, and social media to avoid noise as dysappearance, defined as an augmented focus on the illness. I draw on Drew Leders (1990) concept of bodily dysappearance to illustrate how noise as unprocessed information emerging from bodies, self-technologies and Facebook creates an unwanted consciousness of the body. Although I attend to noise as the more challenging face of Facebook, I both acknowledge and challenge how the Internet and social media have been portrayed as problematic spaces filled with alternative facts and fake news. When I generally portray social media as an important space for access to self-care knowledge, as directly derived from the data, I will seek to challenge a one-sided perspective of Facebook as “Fakebook” with insight into what is actually taking place within these closed peer support communities. Facebook use has become an integrated and valuable support tool in daily life with type 1 diabetes, and the increasing number of newly established type 1 diabetes communities indicates that it is here to stay.

In the next section, I will trace the contemporaneous emergence of chronic (self-)care and the rise of the Internet and social media on a global scale with a particular focus on Denmark.
Background and State of the Art

People attach tremendous value to the experiences of others who have travelled a similar road and wrestled with comparable questions. We may not know how people’s experiences become valuable for other people, how experiences come to be treated as knowledge, or something knowledge-like…. But the fact is that they do.

(Blume 2017:100)

According to the World Health Organization, chronic illness prevalence is expected to rise by 57% by the year 2020, placing an increasing demand on healthcare systems worldwide. Chronic illnesses, such as heart disease, chronic respiratory conditions, and diabetes, are by far the leading causes of mortality in the world, killing 40 million people per year and accounting for 70% of all deaths worldwide (WHO 2016). Mortality associated with chronic illness represents a social and economic strain, and ongoing initiatives aim to reduce the prevalence and impact of chronic illness by developing health prevention approaches and cost-cutting models. In relation to diabetes, the “large” economic burden imposed by diabetes affects individuals, households and healthcare systems (Ettaro et al. 2004). With a recent shift from morbid death to morbid living and the ‘governmentality of living’, experiences of living with illness are reflected as an object within global and national health policies (Wahlberg and Rose 2015). Although mortality measures are still prominent, quality of life indicators, as the wellbeing and life satisfaction of individuals and societies, are increasingly investigated and measured.

Diabetes in Denmark

About a third of the Danish population lives with a chronic illness (Flachs et al. 2015), and diabetes is highly prevalent. Diabetes has three major biomedical types: type 1 diabetes (the body fails to produce insulin), type 2 diabetes (the body is resistant to insulin), and gestational diabetes (a temporary condition carrying an increased risk of subsequent diagnosis with type 2 diabetes). However, many sub-types also exist with more indistinct diagnostic profiles, as does the risk category of prediabetes (Smith-Morris 2010).

Recent prevalence data suggest that there are about 32,000 individuals diagnosed with type 1 diabetes in Denmark, which accounts for an estimated 10% of the overall diabetes population (both type 1 and type 2) (Jørgensen et al. 2016). Type 1 diabetes has long been recognized as a juvenile chronic illness; however, the incidence has increased among adults (Due 2017; Bruno, Gruden, and Songini 2016).

Type 1 diabetes mellitus is a chronic autoimmune illness diagnosed by high concentrations of glucose in the blood that result from autoimmune-mediated destruction of beta cells in the pancreas, which then fail to produce insulin. Daily insulin injections are necessary for people with type 1 diabetes to avoid the ketoacidosis produced when the body cannot metabolize sugar and must burn fat for energy; it is a threat to health over time. Long-term complications of uncontrolled blood glucose levels include damage to internal organs such as the heart and kidneys, impaired eyesight,
and nerve damage. Continuous support for daily self-care for type 1 diabetes is crucial; 95% of care is done entirely by patients and families outside clinical practice settings (Funnell and Anderson 2004).

Curing, Caring and Self-managing

There have been two prominent shifts within chronic illness management and self-care. Whereas the first one is a shift from curing to prevention (Lupton 1995), the second are central to public health and represent a shift from caring to managing (Manderson and Smith-Morris 2010). The second shift includes an attention to self-care in health that relates to the activities that individuals, families and communities undertake with the intention of enhancing health, which are derived from the knowledge and skills from both professional and lay experience (Webber, Guo and Mann 2013). I acknowledge that there is a wide field of preventive medicine. Thus, the focus of this PhD dissertation is the micro-management and self-care of type 1 diabetes and the particular strategies to live well with illness.

The Chronic Care Model (CCM) currently dominates health systems in industrial countries. It was developed by Wagner (1998) and incorporates patient-, provider-, and system-level interventions. It has been implemented in health policies to address the needs of an aging population with an increasing prevalence of chronic illness; a hospital-based model of curing must transform to an in-home model of caring as an increasing number of people learn how to self-care and manage illness. Furthermore, it is a concrete tool to improve clinical practice; one of six components is support for self-management of people with chronic illness:

Self-management support involves collaboratively helping patients and their families acquire the skills and confidence to manage their chronic illness, providing self-management tools (e.g. blood pressure cuffs, glucometers, diets, and referrals to community resources), and routinely assessing problems and accomplishments.

(Bodenheimer, Wagner, and Grumbach 2002: 1776)

Within national plans for self-management interventions worldwide, there is a clear focus on tailored solutions to skills training, psychosocial support, and collaboration between healthcare providers and patients to define problems, set priorities, establish goals, identify barriers, create treatment plans, and solve problems. The goal of self-management support is to empower and prepare patients to manage their health and condition, which is primarily accomplished through patient education.
**Self-care and Management of Type 1 Diabetes**

Self-care and management for type 1 diabetes is challenging because it requires the development of knowledge, skills, and ways of knowing the body, many nurse-like practices involved in insulin injections and changing vials and needles, and technological know-how needed to use complicated digitalized devices such as insulin pumps and continuous glucose monitors (Hernandez 1996; Mol and Law 2004; Guell 2012; Danholt 2013). Several studies have examined routinized practices of self-care, such as blood glucose measurements and insulin administration; however, other mediating practices are more difficult to routinize due to individual responses to treatment that will be further reflected upon in Chapter 2.

In the 1980s, monitoring and controlling blood glucose at home became prominent with the availability of the glucometer; people with type 1 diabetes became less reliant on the clinic and more reliant on their own blood glucose monitoring skills (Schilling, Grey, and Knafl 2002). In the early 1990s, the results of the Diabetes Control and Complications Trial (DCCT) indicated that maintaining a near-normal blood glucose level could prevent or slow the development of complications (DCCT 1994). These findings contributed to a shift from a singular reliance on biomedical management at the clinic to supporting individuals to self-monitor their numbers in their daily lives. Another more recent technology used by people with type 1 diabetes in their daily lives is an insulin pump (Hermansen et al. 2003). An insulin pump is designed to replicate the function of a healthy pancreas by dispersing continuous small amounts of insulin throughout the day. It does so because it is attached to the body it must serve. The insulin pump is complex machinery, and patient education on how to use the device is crucial. Insulin pump treatment (Continuous Subcutaneous Insulin Infusion) is usually offered to people who experience poor glycemic control or children with type 1 diabetes. Studies have shown that insulin pump supports stricter blood glucose control and prevents or reduces episodes of hypoglycemia (Pickup and Keen 2002).

One way of supporting people who have been diagnosed with type 1 diabetes is to offer patient education. Patient education schools have existed in Denmark since the 1990s. However, a global 2001 study (DAWN2) estimated that just 49% of people with diabetes participate in diabetes education programs or activities aimed at improving diabetes management (Hansen et al. 2015). An analysis of the Danish data highlights a marked discrepancy between the perceptions of people with diabetes and of healthcare professionals about received care, raising a question of the perceived quality of care experienced by Danish people with diabetes. A recent ethnographic study by Stenov et al. (2017) on Danish patient education confirms problems of reduced attendance reported earlier and emphasizes the stringent focus on generic biomedical knowledge. Although this study examined patient education for type 2 diabetes, the focus on generic biomedical knowledge is applicable to type 1 diabetes as well. Learning about type 1 diabetes is not the same as learning to live with type 1 diabetes, and a focus on the latter is absent in patient education schools (Due 2017).

One aim of the CCM was to focus on quality of care and make patient education more “person-centered” (Grøn et al. 2012). Person-centered healthcare should be understood as “providing care that is respectful of and responsive to individual patient preferences, needs, and values and ensuring that patient values guide all clinical decisions” (Young-Hyman et al. 2016). Thus, studies find that attending to individual needs and preferences within group-based patient education is challenging (Stenov et al. 2017; Grøn et al. 2012; Due 2017). In 2009, a Danish medical technology
assessment included recommendations to establish clear goals and mechanisms of action for patient education (Sundhedsstyrelsen 2009). This has increased the incorporation of theoretical models and frameworks into patient education, evaluation of pedagogical models, and knowledge about how to change practices through methods and theories of self-efficacy, motivational dialogue, empowerment, and action competence. Strengthened current patient education options include schools with more well-developed theoretical and pedagogical foundations; studies have shown that patient education delivered in a person-centered way is more effective in supporting patients in their daily care (Diabetes Care 2017).

The Danish National Board of Health recently announced a strengthened initiative for people with diabetes. This plan, which promotes tailored and user-driven solutions based on individual needs, clearly reflects a person-centered focus (Sundhedsstyrelsen 2017). Although national health plans strive to make patient education more person-centered, meeting individual needs that arise outside clinical practice settings remains challenging (Nielsen and Grøn 2012). The prevailing challenges reside on the comprehensive knowledge adults with type 1 diabetes need to acquire for understanding their illness and being able to perform self-care, management and monitoring of blood glucose levels throughout the day. Understanding type 1 diabetes and the many micro-practices required for proper self-care require time and exposure to various familiar and unfamiliar situations in which people gradually build and integrate their experiences (Due 2017).

Medicalization and Therapeutic Itineraries

Anthropologists have long been concerned with questions of how people with chronic illness seek alternative therapeutic itineraries when biomedical knowledge cannot immediately be translated to daily lives. Alongside the biomedical and public health model of curing and caring, there has been a parallel development within medical anthropology with long contribution of ethnographic accounts of how it is to live with and care for a chronic condition. Classical studies have centered upon the relational complexities between patients and healers (Kleinman 1981; Good 1994; Mattingly 1998), and ethnographic accounts have dealt with structure, agency, and morality when people with chronic illness try to navigate health systems both as patients and customers. Concepts of uncertainty and control have emerged from analysis of chronic illness care and management, especially in the areas of diagnostic techniques, genetic testing and screening for cancer and cardiovascular disorders (Whyte 2005). I will not trace the long, multifaceted, and comprehensive development of medical anthropological research on chronic illness care; I will instead attend to studies that have portrayed challenges in the transition process and integration of biomedical knowledge into everyday lives of concerned and how people with illness have sought out unconventional therapeutic itineraries to live well with illness.

Hanne Mogensen (2005) discusses the different ways medical anthropologist have portrayed biomedicine - on the one hand as being universal, neutral, and hegemonizing and, on the other hand, working in applied anthropology and public health to change the world for the better. She describes how medical anthropologists have critically observed a biomedical Cartesian body-mind dualism, portraying rational willful agents on one side and docile bodies on the other along with ideas about decontextualization:
As long as biomedicine does not work more effectively than it does, as long as it does not release people from the problems of their everyday life – which biomedicine never will – people will not stop considering the larger context of their problems.

(Mogensen 2005: 241)

In relation to the above quote, Mogensen explores what is at stake for young Ugandan mothers when the body/mind distinction is enacted in everyday life, which she suggests is a matter of the biomedical focus on how an illness is inflicted on a person and not the meaning of illness. Through an ethnographic account of a young mother who loses two small children, she introduces a discussion of morality and agency. If going to the health unit do not offer relief and the illnesses continue to recur, the mothers will be more eager to look for insights into the larger context of their problems, which include navigating alternative itineraries to seek guidance and support on health-related problems. Mogensen calls for more studies that deal with the actual ways in which people practice biomedicine and how it becomes part of their social agency.

Susan Whyte’s (1997; 2005) concept of “subjunctivity” relates to how people try out ideas and negotiate uncertainty and possibility as an aspect of subjectivity. Subjunctivity is a form of situated concern that keeps possibilities open (Whyte 2005). Through longer periods of fieldwork in Eastern Uganda, Whyte explores local therapeutic itineraries when people in Bunyole resort both to divination and ritual measures aimed at curing illness and biomedical tests and pharmaceuticals. She described how situated attention to moods such as doubt, hope, will, and potential is brought into action and interaction. With inspiration from both American pragmatism and phenomenology, she unifies the body/mind dualism in her ethnographic account of the pragmatic side of trying out something:

Subjunctivity is about the specific uncertainty that particular actors experience as they try out something that matters to them – as they undertake to deal with a problem.

(Whyte 2005: 251)

Several researchers have studied people’s therapeutic itineraries and experiential practices. Pols states that medical practices cannot be transferred directly to daily lives or lived by the book. It requires an accumulation of tinkering, of bricolage (Pols 2012; 2010). This is evident in the cross-cultural study by Mattingly, Grøn and Meinert (2011), who introduce the concept of “chronic homework” to cover translation challenges of moving healthcare from clinic to homes, describing it as borderland of practice. Through ethnographic accounts from Uganda, Denmark, and the United
States, they describe the border zones between health systems and homes when people with a chronic illness and their family do not strictly follow the “homework” assignments directed by healthcare professionals. They attend to explorations of the multiple perspectives among chronically ill people, their families, and clinicians of the same problem and how biomedical knowledge becomes reconfigured in the transition processes from clinics to homes in rather creative ways.

**Biosociality and Evidence-based Activism**

Whereas the previous section highlighted transition challenges of bringing biomedical knowledge from clinics to homes with concepts of therapeutic itineraries, subjunctivity, and chronic homework, this section will attend to popular concepts of biosociality and how patient organizations are striving to strengthen partnerships between laypersons and professionals by promoting the experiential knowledge of patients.

The tendency of people to group around a specific illness has been called biosociality by the American anthropologist Paul Rabinow (1996) to capture the ways in which mediation of new biomedical knowledge and technologies has become the basis for sociality (Oxlund 2012). Rabinow observed how people with rare illnesses grouped together and offered support and sociality and, in particular, advocated for medicalization of rare genetic illnesses. Biosociality, as a collective and political mobilizing, offers a new way of thinking about group-based sociality with regard to illness and how it shapes individual as well as collective identity formation and knowledge processes. In relation to the latter, Vololona Rabeharisoa, among others, has done pioneering work on the ways in which patient organizations engage in evidence-based activism as a means to understand the development of modes of activism that focus on knowledge production and knowledge mobilization in the governance of health issues (Rabeharisoa, Moreira, and Akrich 2013).

In a 2014 paper, Rabeharisoa and O’Donovan discuss the Europeanization of healthcare policies by European patient organizations (EPO):

> For EPOs, bringing individual patients to the fore, constantly recalling that their experiences matter, are at the core of their politics for transforming ‘patient-sufferers’ into European individuals.

(Rabeharisoa and O’Donovan 2014:14)

The democratization process Rabeharisoa and O’Donovan describe is a form of “euro-pragmatism” in the way that EPOs actively mobilize concerns based on lay people’s experience and knowledge. EPOs are not only lobbying for their interests but also contributing to generating data and statistics that map out health issues as economic, political, and social concerns for Europe.

While much research has been conducted on knowledge processes and mobilization of patient organization, studies of the way in which people group together to share experiential knowledge in the format of peer-to-peer interactions will
be outlined in the next section. Furthermore, with the current rise of social media platforms, new ways of online biosociality and mobilization for advocacy work are apparent but understudied.

**Peer Support, Lay Knowledge and Agency**

I have described how, after receiving a diagnosis of type 1 diabetes, patients are often offered group-based patient education along with lifelong quarterly check-ups at the diabetes clinic. I have also traced how anthropologists have focused on the relationships between laypersons and professionals and therapeutic itineraries and how biosociality can lead to evidence-based activism. Peer (also known as peer-to-peer) support is defined as support from a person who has experiential knowledge of a specific behavior or stressor and similar characteristics as the target population (Brownson and Heisler 2009). It can also be defined as feeling cared for by others and receiving assistance, as well as being part of a social network; peer support reduces psychological distress, anxiety, and depression (Loane and D’Alessandro 2013). Studies comparing people with type 1 and type 2 diabetes have found that social networks and good social support are associated with better care and management of diabetes and reduced psychosocial problems (Hempler, Joensen, and Willaing 2016). Studies of peer support for individuals with type 1 diabetes have shown outcomes of reduced depression and loneliness and improved diabetes management and health behaviors related to diet, exercise, blood glucose monitoring, and medication adherence (Joensen, Tapager and Willaing 2013; Brownson and Heisler 2009).

Although studies have portrayed positive results of peer support, opportunities to interact, share, and co-construct knowledge in a peer-to-peer context have also raised concerns about how existing doctor-patient symmetries change. This is especially evident within the social science literature in the form of discussions about how peer support and interaction have allowed for the emergence of an expert lay person (Britten and Maquire 2015), defined as someone with “the confidence, skills, information, and knowledge to play a central role in the management of life with chronic illness.” (Shaw and Baker 2004: 723). Whereas the definition and development of an expert lay person is closely aligned with the CCM model of empowering patients to become knowledgeable and skillful experts, it has also brought forward issues of compliance and adherence when people with illness acquire knowledge on their own and put it into practice (Shaw and Baker 2004). With a branch of research that focuses on compliance and adherence (Lorig and Holman 2003; Conrad 1985), an emerging focus in the literature shifts the perspective to one of people with chronic illness as knowledgeable laypeople that give rise to new concerns of the changes in traditional professional-layperson symmetries.

A meta-synthesis of early process and adaptation following a diagnosis of type 1 diabetes in adults reveals that learning can take many forms, such as seeking information and developing experiential learning strategies (Due 2017). Offline and online peer-to-peer sharing enable both of the latter. Other means of learning about type 1 diabetes are often through peer support initiatives. Although self-help groups have existed since the 1970s, when Borkman (1976) studied experiential knowledge generated by people with chronic illness, peer support has become more widespread, and studies have shown that it can supplement patient education programs (Carolan 2011).
Although several researchers recommend an increased focus on the promotion of lay knowledge (Britten and Maquire 2015), others attend to a concept of patient knowledge generated through years of experimenting with an illness as posing some challenges within the evidence-based literature. Patient knowledge has often been described as “research in the wild,” as opposed to knowledge generated by specialists through years of experimentation using codified methods and procedures; this dichotomy has given rise to ongoing conflicts of epistemic and moral authority (Rabeharisoa 2017).

I will now attend to how the Internet has recently evolved from a resource for health information into a medium for interaction; the revolution of communication and knowledge exchange among peers is most evident in online communities on social media (Powell, Darvell, and Gray 2003). Studies are lacking on how peer communities on Facebook facilitate knowledge-generating processes.

**The Rise of the Internet and the Transition from E-health to M-health**

The emergence of the CCM and of the public Internet was roughly contemporaneous. The concept of the well-informed or expert patient is framed by a digitalized world in which, since the rise of the public Internet in the 1990s, patients can find information and knowledge about their health conditions. Denmark was quick to embrace the public World Wide Web (WWW) after its public introduction in the early 1990s. In 1996, 11% of the Danish population was on the WWW; within 10 years, this proportion rose to 86%. Initially, it was common to access the WWW through phone modems, which later changed to broadband (ADSL). Now, using a mobile broadband Internet connection is common. Data from 2015 show that 92% of the Danish population has online access and 87% are online on a daily basis. 78% of the adult population has a smartphone and 92% of Danish households have a computer (Tassy 2016).

The first-generation Web 1.0 allowed patients to seek information through search engines such as Yahoo. Some of the first “virtual ethnographies” followed, primarily using Goffman-inspired symbolic interactionism (Turkle 1995). In the mid-1990s, the Internet rapidly became more popular and, increasingly, a public domain. The second generation of web services on the Internet, or Web 2.0, created new opportunities for seeking and sharing information in interactive ways. New research directions followed as interest grew in studying whether the Internet was inherently good or bad and whether online activity should be considered real or virtual. Sosnowy (2014) argues that digital technologies and social media have become so integrated in shaping a cultural paradigm of healthcare that several scholars have adopted the term “Health 2.0.” Health 2.0 covers the use of online communities, blogs, podcasts, Youtube, Twitter, Wikis and more by healthcare professionals, patients, and scientists.

As indicated earlier, self-caring type 1 diabetes is carried out outside the clinic, and a study by Heisler et al. (2010) stresses the importance of self-management assistance between clinic visits. Support at home has been demonstrated in studies on how people with chronic conditions turn to social networking sites when looking for insight into health-related problems, symptoms, and treatments and to connect with others who share the same illness (Barak, Bonniel-Nissim, and Suler 2008; Farmer et al. 2009; Greene et al. 2010). An increasing number of people seek health information and support in online communities, rather than from traditional sources, despite being unable to verify the reliability of the information and clinical evidence available online (Jones et al. 2013; Wikgren 2001). Online
connections expand possibilities for social interaction and communication outside a handful of annual scheduled face-to-face consultations with healthcare professionals (Bjoernes et al. 2012). However, little research has looked into the above-mentioned areas with a focus on type 1 diabetes. Within the domain of diabetes and online interventions, one type of research is driven by healthcare providers and represented by studies on the effect of self-management on hemoglobin A1c (HbA1c), an indicator of long-term blood glucose control. Another type of research focuses on patient-driven solutions across other chronic illness groups, such as online peer-to-peer communities that are not directly influenced by healthcare professionals. I will briefly sketch out important accounts of online peer-led support in the literature with focus on other chronic illnesses.

Some studies of online peer-to-peer interactions have examined potential harmful or beneficial effects and report conflicting results (Eysenbach, Powell and Stern 2004; Dedding et al. 2011). Other studies have shown that people with chronic illness highly value online interactions as a way to quickly and easily obtain advice and support from peers (Demiris 2006; Barak, Bonniel-Nissim, and Suler 2008; Greene et al. 2011; Lian and Nettleton 2015; Brown and Duguid 2000; Chung 2013; Horst and Miller 2012). Research has been conducted into motivations for joining online communities (Ellison, Steinfield, and Lampe 2007), on the relationship between online and offline social dimensions (Ledbetter et al. 2011; Oxendine et al. 2003), and how the amount of online interaction exceeds traditional face-to-face contact (Merolli, Gray and Martin-Sanchez 2013). Relative to the latter, online communication is perceived as flexible and providing social benefit for people with social insecurities. Studies have also centered on how Health 2.0 empowers a new active patient citizen who rebels against the traditional medical patriarchy (Sosnowy 2014). A qualitative systematic review of 13 studies provided a promising account of how online peer communities provide a space for illness-associated identity work, social support, and connectivity, experiential knowledge sharing, and collective voice and mobility (Kingod et al. 2017). Nevertheless, social networking sites such as Facebook remain generally under-examined with respect to health promotion, and few studies have focused on the processes and practices of online and offline peer-to-peer interaction in relation to everyday living with type 1 diabetes.

**Facebook Communities, Virtual Biosociality and the Emergence of an M-Patient**

Social media platforms became popular in the early 2000s, and Health Web 2.0 social media applications are commonly used worldwide by people with illness today. In popular vernacular, “social media” is an umbrella term for platforms and technologies that promote social interaction mediated through the Internet (Jensen and Tække 2013). In recent years, a shift has taken place in the way that people communicate, with an increase in the number of online forums, communities, and social networking sites (Jones et al. 2013). In particular, the social media platform Facebook has become extremely popular as an online space for social interaction (Ellison, Steinfield, and Lampe 2007; Miller 2011). This tendency is obvious both at a national and global scale as Facebook offers an easy way to obtain peer-to-peer interaction and social support for people with various conditions (Bender et al. 2011).

Facebook began as a Harvard University-specific social network in 2004; by 2006, it had expanded to include anyone over the age of 13 with a valid email address. In 2008, Facebook was rated the most popular social networking site. Worldwide, 2 billion people use Facebook, and about 73% of the Danish population has a Danish Facebook account.
(Brügger 2013). In 2010 a new page was launched called “Community Pages”, which allowed for people to group around topics of interests such as a specific illness diagnosis (Brügger 2015), and since then health-related communities on Facebook have been on the rise. Although some online patient portals are designed for peer-to-peer interaction, like the popular American patient network PatientsLikeMe, Facebook is still the most popular site for illness-related interaction in Denmark. The increasing number of online communities for people with type 1 diabetes demonstrates the need to gather information and receive social support for living with the illness in daily life. This perspective is supported by a survey indicating that patients turn online for health-related information more frequently than they raise health-related questions with healthcare professionals (Farmer et al. 2009). With the rise of portable health-related communities through a Facebook app on portable devices such as smartphones, iPhones, iPads, and tablets, a notion of an M-patient becomes pertinent.

![Figure 2: Amount of users per month on social media](image)

Whereas biosociality was originally restricted to the offline realm, a new concept of virtual or online biosociality has arisen to describe a web-based phenomenon of health-related socializing, and Facebook is progressively becoming a natural meeting point for individuals with all kinds of illnesses and conditions. Little research has been done on how Facebook provides the opportunity for people to connect and share experiences about an illness such as type 1 diabetes, which I will further outline in the next section.
This Study

The PhD study examines how a select group of Danish adults with type 1 diabetes practice self-care and how they find support through online and offline peer networks. I chose a combined online-offline (auto-)praxiography, an approach that is rarely reported because ethnographers have typically chosen to study either the online or offline dimensions (Hine 2000). My main analytical interest is in the use of social media, more precisely Facebook, within a Danish context and how processes and practices of online searching and sharing of experiential patient knowledge become integrated into daily life and micro practices of self-care.

With an initial interest in the entangled nature of online-offline peer support in daily self-care, I began reviewing the literature using popular search engines such as PubMed and Web of Science. However, I was unable to find any ethnographic accounts of the use and integration of online peer support in daily self-care of type 1 diabetes. I sought theoretical inspiration in the interrelated fields of virtual anthropology, medical anthropology, and the anthropology of experiential knowledge with emphasis on embodied and bodily skills and practices, which led finally to a focus on practice theory and the development of and reliance on an (auto-)praxiographic approach. My emphasis on self-care as a bodily skill and practice that is developed over time is a response to a call for “bringing back bodies” in studies on health (Pols 2010). This call itself a response to a longer-term development, which Oxlund and Whyte (2014) accentuate, of how the body re-emerged as a research theme in sociology and anthropology in the 1980s and 1990s. Given the recent widespread advances in both technology and digitalized devices, the body today has a new meaning, which calls for a focus on human-technology practices. A research interest in exploring processes and practices of doing and knowing, including how adults with type 1 diabetes use and integrate the digital (in the form of both self-care devices and online social spaces), calls for a theoretical and methodological approach that can apprehend interrelated fields.

At the outset of designing this PhD study, I was unaware of the growing footprint of communities devoted to type 1 diabetes on Facebook. I was hired to explore the use of online support in daily life with diabetes during enrollment in a three-year PhD program. Studies indicated that people with chronic illness use various kinds of online and offline support in daily life and self-care, but it was unclear what type of online tools, networks, or platforms Danish adults with type 1 diabetes were using. In the early stages of the design phase, I puzzled over the research design and whether it should be more similar to an anthropological intervention inspired by a public health tradition with implementation and testing of an intervention or an entirely Kozinets-inspired (2010) online “netnography” (ethnography) of a relevant virtual space.

My interest in an entangled online-offline (auto-)praxiography of self-care began quite unexpectedly and traumatically when, just a few months into the PhD study, my daughter received a diagnosis of type 1 diabetes. It forced me to put this research on hold so I could learn the comprehensive practices that enabled me to function as her self-care surrogate. I use the term “surrogate” to distinguish the self-care of the study informants from the care I performed for my daughter’s illness. From reading articles and books on diabetes, I rapidly accumulated a lot of information. I experienced how I had to attune to a life with type 1 diabetes through my daughter at a level different that of a mother attending to the needs of a healthy child. My attunement involved becoming able to sense what takes place inside her
body to predict and understand her blood glucose fluctuations. The digitalized self-care technology offered me visual cues on her internal state that promoted more practices. I had to work on behalf of her and embody the self-care she was too young to perform herself. I closely observed the pattern of her blood glucose level throughout the day and how her eating and activity routines affected it. I felt that I had to replicate the work of a nurse, a mathematician, a nutritionist, and a pharmacist in many required practices that involved handling needles, vials, and insulin, counting carbohydrates, and checking food labels and diets. I also had to develop my organizing skills to keep tabs on the inventory of her diabetes equipment: How many quick-sets are left for her insulin pump? What about the needles for her finger-pricking device? Do we have enough cartons of juice and packages of dextrose? Is the battery still fully charged in her portable kitchen scale? I had to upsize my handbag to fit her box of equipment (her finger-pricking device, glucometer and charger, extra insulin pump batteries, rubbing alcohol for her fingers, extra needles for her finger-pricking device, a portable kitchen scale, and some dextrose and liquid carbohydrates). Type 1 diabetes is an illness filled with technology and digitalized devices and, most of all, practices.

Throughout the fieldwork, I came to understand that many of my own “self-care” practices resembled the practices and decision-making processes of the informants in this PhD dissertation. This created a reflexive dialogue on the data as mentioned earlier. I have used parentheses for the “auto” in front of praxiography to emphasize the boundaries and intentionalty of both disclosing my personal embeddedness with type 1 diabetes and restraining the self from the primary fieldwork to move my reflection to a higher level in the process of analysis. The bracketing of the “auto” further functioned as a way of protecting and restraining myself and allowing me to keep a reflexive distance on the data. The interplay of the “auto” in all phases of this PhD from design to fieldwork to analysis have allowed me to obtain insights on processes and practices among the informants and self-reflections on my own practices as a self-care surrogate for a daughter with type 1 diabetes. Thus, I suggest that one of the most important assets of my reliance on (auto-)praxiography has been to build informant rapport. I will return to a closer engagement with this argument in Chapter 3 with a discussion of the anthropological literature on auto-ethnography because my main concern was how to ethically position my personal experience with type 1 diabetes in my analysis and writing. Simultaneously living with type 1 diabetes in my family and having the illness as a research focus can both be an advantage and disadvantage as stressed in the literature on auto-ethnography. The challenge was to simultaneously attune myself to an academic perspective on diabetes and to a life with type 1 diabetes in my close family. The self-care practices I observed in the field continued in my own home. On the positive side, new questions arose from these iterative explorative practices; some came in the form of doubts about my micro-practices within my daughter’s self-care, and others rose to an analytical level in the form of questions about how adults would self-care for this illness, how bodies, technologies and daily life interacted, and what kind of support adults with type 1 diabetes searched for.

The inspiration to focus on how adults use peer support on Facebook appeared after I was coincidentally guided to a community on Facebook for parents of children with type 1 diabetes. Finding the community was a great relief after having used the hotline at the clinic for weeks after my daughter’s diagnosis, often with hesitation and rarely finding what I was looking for. I often felt more frustrated after the call than when dialing the number out of doubt about my self-care. I recall the tired voices of the nurses and doctors who had the nightly duty of being in charge of the cell phone at the other end of the hotline number given to the worried parents of newly diagnosed children. On nights when I was
terrified that my unskilled care might negatively impact my daughter’s health, I dialed the number while sobbing, hoping to find comfort and guidance. I found them first on Facebook.

Facebook was an online manual on how to self-care, and it was also an online pat on my shoulder in times of hardship and doubt. After approximately half a year of primarily lurking within a community targeting parents of children with type 1 diabetes, I became aware of newly established communities for adults with type 1 diabetes that represented growing efforts to seek health-related peer support. I became increasingly interested in how to articulate the knowledge that people with type 1 diabetes use and create through social media. The days are long gone when people with illness were viewed as passive and ignorant laypeople, as outlined in the previous section (Pols 2012). I was interested in understanding both whether social media had an impact on self-care and how social media are transforming the ways in which adults with type 1 practice diabetes self-care. This raised an assemblage of analytical concerns about practices, processes, knowledge, and agency. With these analytical questions formulated, the sick leave for my daughter came to an end and was followed by a year of maternity leave with my second daughter. I returned to the study with a personal motivation and analytical interest to focus the PhD dissertation on social media and, in particular, Facebook.

Due to the many self-care practices required in type 1 diabetes, I decided on an (auto-)praxiographic design and framework, inspired primarily by Mol’s praxiographic approach (2008, 2002). An (auto-)praxiography calls for multiple methods in addition to participant observations of practices, and I augmented observations with interviews, focus groups, and several informal conversations. I carried out a year of fieldwork during which I identified 16 communities for adults with type 1 diabetes on Facebook. Many were established during the year I conducted fieldwork and were not always easy to locate. There was an emergence of increasingly specialized communities targeting self-care technologies and ways of living with the illness (Wahlberg 2009). This tendency was reflected in emerging communities on food, exercise, gender, and self-care technology brands, as well as activist and hacktivist communities. The increasing number of new and specialized communities indicates a demand for tailored knowledge. I applied a method of following informants and their self-care practices into online and offline social dimensions, allowing me to observe the translation and integration of online knowledge and support into daily life, which is inseparable from knowledge about how to practice self-care for type 1 diabetes. This also meant that I followed informants as they moved between online and offline contexts.
I mapped out and categorized all areas of support on Facebook during my year of observation. However, my main analytical interest was in the category of experiential knowledge. I observed a complex online-offline interplay, and, upon analysis, it became clear that informants co-created experiential knowledge through complicated processes and practices facilitated by the Facebook social media platform. The knowledge that adults with this illness co-create through Facebook is based on ongoing experiments and negotiations between bodies, technologies, and daily lives. It is a type of practical knowledge that is tested through tinkering with self-care in the various situations of daily life. Through the built-in Facebook calendar, I received announcements about the offline peer meetings across Denmark in which I participated.

**Contextualizing the Offline Field**

I reflected on Miller’s claim that, for anthropologists, there is no such thing as Facebook; there is only the aggregate of its particular usages by specific populations (Miller 2011). I realized that, in order to understand Facebook use in daily life with type 1 diabetes, I needed to include methods other than online lurking. Instead of focusing on the social media platform alone, I chose a methodology of following informants to understand how they use Facebook in their daily lives with illness, which took me both online and offline.

Meeting informants in offline peer meetings was just one aspect of a range of offline methods. Hine (2015) stresses the importance of meeting informants several times to build rapport because online ethnography leaves out important visual cues and gestures that are important to building trust and relationship. She recommends combined online-offline ethnography. When I had established contact with informants through face-to-face interviews, I could follow them
during their self-care itineraries through relevant online support spaces and offline peer meetings located throughout Denmark. Other ways of obtaining access to meetings were to receive notification alerts online. Membership in the communities allowed me to receive notifications of offline events and peer meetings that I could attend. These were often made through the Facebook calendar or directly posted, with links on the Facebook wall. I then asked the organizers if I could attend as a researcher. All the peer meetings I attended were announced and facilitated through the type 1 diabetes communities on Facebook. These meetings were characterized by peer-to-peer interactions with scant, if any, influence from healthcare professionals. Occasionally, the Danish Diabetes Association made a small financial contribution to cover basic supplies, such as bread and coffee. The time, date, and format of peer meetings varied. Some meetings were held every month, often at public spaces used by unions, whereas others were announced more occasionally and occurred at locations requiring no advance booking, such as cafés. Some meetings had a loose conversational structure, and others had predefined themes and, at times, guest speakers. There was a tendency for smaller café meetings to be cancelled more often than meetings facilitated through the larger regional communities. I observed that individuals who took the initiative to announce a café meeting would withdraw the announcement if there were too few attendees. Whereas regular community members often arranged café meetings, Facebook community administrators typically facilitated larger regional meetings. Although the latter type of meeting was rarely cancelled, the number of participants varied.

I will now set the scene with a field excerpt of an offline meeting I participated in. This particular offline peer meeting had the form of a self-help group described by Borkman (2004:428) as “autonomous, voluntary, assemblies of people in similar situations or predicaments, or with the same disease or condition, who join together to cope with and resolve their troublesome issue through sharing knowledge and providing mutual social and emotional support.” In her 1999 book, Borkman defines self-help groups as based on a small number of people (less than twenty) with the same illness who sit in a circle (or around a table, as in the excerpt that follows) and share personal stories of their suffering and how they attempt to cope with it and resolve their problem. One of the most important aspects of a self-help group is that it is entirely peer led, lacking any direct influence from healthcare professionals.

**A Participant Observation of an Offline Peer Meeting**

With help from my smartphone, I link the address posted in the Facebook community to GPS and stroll down the narrow streets in the center of a larger city in Denmark by following the suggested route marked on a map by small blue dots. I arrive at the building, a community house where the offline peer meetings are held every other month. It is a modern-appearing building, where about 200 unions a year have their regular programs. The meeting is at 7 PM, and I notice on the clock on my smartphone that I have arrived half an hour early as planned. I allowed time to find a shop to buy a bag of good coffee as a small gift to this peer group for allowing me to attend. I am standing in front of the building with four women and two elderly men. We must ring a doorbell to be buzzed into the building by the representatives of our community, because building entry is by invitation only. A woman opens the door and, with a big grin on her face and dramatic gestures, dispenses hugs and kisses to the three other women with whom I waited. We all follow her into the building; the four women who are conversing in their own language enthusiastically join seven other women and continue down the hallway. The two elderly men join two people in wheelchairs, and they all move to a
room where other people in wheelchairs are already waiting. There is a vibrant level of activity in the building, and I am beginning to wonder how to locate my group for the evening. As I walk through the lobby, I pass a woman playing a piano for a man and a woman who are dancing a tango. I walk through the hallways downstairs, then upstairs, where a woman in a doorway stops me to ask if I am looking for the epilepsy self-help group meeting. I reply that I am trying to locate the peer meeting for adults with type 1 diabetes, and she advises me to go downstairs where she believes that people with type 1 diabetes are meeting. I begin to think that locating the communities on Facebook is a lot easier than finding the offline meeting as I walk downstairs again. In the lobby, I recognize Karen, whom I interviewed half a year ago, standing with a woman I don’t recognize. Karen greets me and then follows me to a large room with glass walls and an inside balcony that is open to the room upstairs, from which loud music, handclaps, and footsteps from a country dance class emanate. The jumble of sounds from people walking, talking, dancing, clapping, playing, and singing resonates throughout the building, making it challenging to hear each other around a big table that could easily fit 50 people.

A total of seven people are attending this peer meeting, a small number compared to the more than 100 members of the regional Facebook community where the meeting was announced. The Facebook community is newly established, and every week the membership number increases. I ask why more people are not attending, and Karen responds that it varies a lot. Sometimes 20 or more people attend and other times there are only a few. Karen and the other woman, whom I will call Line, discuss whether they should start having themes for these meetings to attract more people. When the offline peer meetings were first established in the online community, Karen asked members about the format; most people replied that they preferred unstructured meetings where they could talk freely about all kinds of matters, especially doubt related to self-care. She explains that they are now questioning this format as they compare attendance at their meeting to other offline peer meetings in communities with more members. Ideas flow through the room, ranging from inviting a psychotherapist to talk about “how to live a good life with type 1 diabetes” to inviting relatives to attend.

Bread, butter, jam, fruit, and pebernødder (a Danish Christmas biscuit) are brought to the table along with freshly brewed coffee from the package I bought on the way to the peer meeting. Participants remove their insulin pumps from underneath their clothing and, for the insulin pen users, glucometers are placed on the table along with a finger-pricking device and a box of lancets. For a moment, a digital chorus of beeping sounds occurs around the table as machines are turned on and blood glucose levels are checked. One person weighs the bread on the small table scale that Karen always brings to the meetings, and another reads aloud the carbohydrate levels on the label of the pebernødder package. John, who sits on my left, is annoyed by the high blood glucose level revealed by his machine and cries out, “Damn!” Everyone except me must inject themselves with insulin, according to the calculated carbohydrate level in the food. After blood glucose numbers are checked, controlled, and stabilized, a round table conversation begins about daily life with type 1 diabetes. This evening, there are two new members at the peer group. One is a woman in her sixties who has been living with type 1 diabetes for nearly all of her life. She took a bus from a small town; it was a two-hour ride to get to the meeting. The other woman, in her fifties, is newly diagnosed. She was invited by Karen but still hasn’t found her way into the Facebook community, so she is unaware of the online themes that are eagerly discussed. Beside me, John is silent because he is not on Facebook. Line jokingly pressures him to “get online. You will not receive important notifications of our meetings,” she says. John is not convinced of the importance of being on Facebook. “I really cannot
be bothered having a Facebook account,” he replies to Line. “I don’t want to read other people’s not-very-important stuff, like what cup of coffee they are drinking or what kind of toothpaste they are using,” he responds in a voice that conveys his disdain for this online content. Karen joins the conversation, saying, “John, I really cannot send you private emails every time we have a meeting. Don’t be so old fashioned. Come join us. A lot of interesting information is posted within the online community. And there are also other good communities for people with type 1 diabetes….like the regional community.” Again, John doesn’t respond, and the conversation turns to the noise that also characterizes Facebook.

Karen wants to have a round of introductions for the new members of the group, as well as for me. Marie, who sits across from me, begins introducing herself and describes being diagnosed with type 1 diabetes three years ago on a vacation when she suddenly lost a lot of weight and felt very ill. All eyes are on her as she tearfully describes her loneliness with the illness and how nobody is able to understand her. It seems as if everyone around the table understands how she feels as they nod in agreement and sigh compassionately in response to her life story. She continues with the everyday struggles of living with the illness, like when she suddenly becomes very low while strolling around shopping and, in an agitated state, has to run into the nearest supermarket and pull a box of juice down from the shelf. On one occasion, she sat on the floor in the shop for a long time until she could feel her blood glucose increase enough to allow her to stand up. While Marie is sharing her story, everyone around the table is nodding and showing their concern. They also acknowledge her statements about wanting to run away from the illness and also often wanting to ignore the fact that she has it. She asks the others if their blood glucose levels are also continuously high because she wants to know if there are good ways to make her blood glucose drop. She reveals that she has a high long-term blood glucose and then further discloses that her health care practitioner has told her that she is only supposed to measure her blood glucose twice a week. “Twice a week!” Jens, sitting on my right, shouts. Lise and Karen look at each other, and Karen then looks at me and explains that it is the second time within a short span of time that they have heard this “nonsense” at a peer meeting. Karen explains to Marie that this information is incorrect and that she should consider changing healthcare professionals. For the next 20 minutes, meeting participants around the table dispense thorough peer advice, and Marie carefully notes every bit of it in a small notebook. When the discussion continues into another area, Marie looks directly at me and tells me that she actually has changed her doctor and that her new doctor is very good and competent and asks her to note down all her self-care: when she eats, what she eats, how much she eats measured in carbohydrates, how much insulin she takes, as well as her levels of exercise. “I really want to be stabilized soon,” she says to me. “It is like I always have this weird taste in my mouth,” she continues. Jens listens in and immediately responds, saying, “It sounds like you might have ketoacidosis, which can be very serious.” Others join in again, voicing their concern about the weird taste in Marie’s mouth. They advise her to check her level of ketones and contact her doctor. Marie wants to know the names of all the Danish Facebook communities for type 1 diabetes because she feels that she lacks a lot of necessary information on how to practice self-care and live with the illness. She is particularly interested in the insulin pump communities because she is waiting for one herself, even though she also fears technology. “I can’t even find the way around my smart phone,” she says, waving a rather old-looking Nokia in front of us.
“See you on The Face:” Contextualizing the Online Field

People have really gotten comfortable not only sharing more information and different kinds, but more openly and with more people - and that social norm is just something that has evolved over time.

(Mark Zuckerberg, Facebook co-founder)

As the peer meeting ends, Line yells to Karen, “See you on the Face,” while she waves to her from the doorway. The “Face” is, of course, Facebook, and, in Danish, “See you on the Face” is “Vi ses på Fjæsen.” Fjæs in Danish is a synonym for face in English; however, its derogatory connotation is more akin to the English word mug. Fjæs is associated with the word fjæs, which originally meant unnecessary noise, discomfort, or hullabaloo, interpretations that reflect the online social noise that study informants describe in reference to the searching and sharing practices on Facebook. “See you on the Face” was used frequently in many of the offline peer meetings I attended because several were announced through the various online communities that were often established before the offline meetings. By using the word “see,” Line suggests a visual interaction where people meet through shared posts accompanied by their profile pictures.

For many informants, online interaction was a daily routine; they visited Facebook frequently when notifications of activities drew their attention to the specific communities, whereas participation in offline meetings with peers remained more limited. As an informant asked me during an interview, “What did people really do before Facebook?” This question indicates how integrated a part of their daily life and self-care this particular social media platform has become. Immediately afterward, she answered her own question: “I think that people just sat alone with all this doubt.”

In 2014, Facebook was the most popular social media platform in Denmark and worldwide. Since Mark Zuckerberg changed digital communication forever in 2004, Facebook has grown to more than two billion users worldwide and has become a central part of the lives of Danish people (Jensen and Tække 2013). The original purpose of the platform was to provide a smaller network for American college students, but “The Facebook” changed into today’s Facebook and is fully integrated into people’s lives through smartphone technology and apps. Facebook connects people across society, similar to the way that media such as radio and television have, and it demarcates new social processes (Jensen and Tække 2013). The first type 1 diabetes community on Facebook was established in 2012; since then, 15 other communities have been created. Many were established during the year I conducted fieldwork; during that year, the membership of the largest community doubled in size from 2000 to 4000 members. This number does not represent the entire type 1 diabetes population in Denmark due to the large number of children who are not on Facebook. It is difficult to estimate the exact number of adults with type 1 diabetes who are active members of the Facebook communities because informants were usually members of several type 1 diabetes communities. Also of note is the fact that relatives and researchers are allowed to join the larger and more general communities and remain as lurkers in the background. I chose to focus only on communities for adults with type 1 diabetes, excluding communities for young adults, although they are also represented on Facebook. Initially I wanted to study the online platform of the Danish Diabetes Association, but it soon became clear that the level of peer-to-peer activity was limited. When I conducted the
first few interviews, I asked informants why they were not part of the online forum “Diabetesdebatten” on the Danish Diabetes Association; replies followed that indicated that Facebook is a preferred medium for sociality around their illness because they are already on Facebook through private profiles linking them to family, friends, and various interest groups and communities. Several sites and log-ins are considered annoying and Diabetesdebatten was not available as an app to be downloaded on a smartphone. Another reason for choosing Facebook over Diabetesdebatten is that the communities on Facebook are entirely peer-led without any influence from authorities. Finally, with limited activity on Diabetesdebatten, the response times to posts were considered too long.

Figure 4: Mapping and categorization of the Danish Type 1 diabetes landscape

As I have already noted, my introduction to the type 1 diabetes communities on Facebook occurred at a critical stage in my life when I was overwhelmed by the many self-care practices. I found solace and inspiration on Facebook and, over time, developed the skills to navigate within the Facebook platform and use built-in functions such as searching, sharing, liking, and accessing and retrieving files and documents uploaded by community members. During interviews, I realized that not all informants knew how to effectively navigate online, which led to one aspect of what I called “online social noise” in the third article. In addition to navigation skills, effective Facebook use required general literacy, the ability to communicate well in writing, and some degree of fluency in the self-care language reflected in the specific community. Clearly, there are both disadvantages and advantages to the use of Facebook for peer support for type 1 diabetes, which is also evident in a current discussion within the media that identifies Facebook as a vehicle for
post-factual half-truths. However, in Denmark, it remains the only option for interactive community-based online peer support.

As stated by anthropologist Daniel Miller, who has extensively researched social media, it is not social media that change the world but the world that changes social media (Miller et al. 2016). This is very true in the sense that the original purpose of Facebook was to connect with people within one’s existing network. In the early days of Facebook, Zuckerberg did not foresee how the platform would also become a valuable space for health-related peer support. Broad descriptions of Facebook have included “social network,” which later changed to a “meta media” as it integrated existing media forms, formats, and genres. Today, it is common to use Facebook to share videos and files from other social media channels such as the video-driven social media platform YouTube.

By default, member profiles within closed communities are only visible to other community members, which created a sense of trust and privacy. Thus, members share freely, with few concerns about a Big Brother watching them, which could also generate concern about who owns the data created by members. I often asked informants if they would share everything within the communities. Even though they generally reported that the atmosphere of the communities was trusting and supportive, they responded that they would think twice before posting in the exact same way that they might converse with others at a peer meeting or even with other people they did not know particularly well. For example, Peter is 44 years old and was diagnosed with type 1 diabetes in his late twenties. During an interview at a café at a central spot in town, he talks about his posting behavior.

Peter: If work has been difficult and it has been a really bad day in terms of controlling my blood glucose. Well at times I just get so agitated when I come home and then I just really need to get it off my chest.

Researcher: Do you do this through the communities on Facebook?

Peter: No, not on Facebook. For me, it is not a medium to express my innermost feelings. I rather prefer to do this face-to-face, even though I know that others within the communities freely share all kinds of feelings. I am just a little skeptical.

In general, informants perceived the atmosphere within Facebook communities as being trustful and empathetic, and any reluctance to post was primarily due to uncertainty about the medium and how data would be stored and distributed in perpetuity.

I will now highlight an excerpt from an interview with 32-year-old Mette, who has had type 1 diabetes for most of her life, in which she describes how much she values a trusting atmosphere where people share all types of emotional and practical matters. She usually checks Facebook notifications on her phone in the morning on her way to work and sometimes posts in the evening from her computer. Her posts generally pertain to more informational and practical
topics, such as the carbohydrate level in a rum ball cake or if she has a very high blood glucose and cannot determine why. She thinks people can relate more to a high blood glucose level than a low or a near-normal one; she would not post about the latter:

I just think it is so nice to share with like-minded (people) who truly understand my concern. It is super cool when people do that. Like when people write; ‘Oh, I am just so high and cannot figure out why, do you know that?’ Then one person answers: ‘Have you tried to change the cord to your insulin pump?’ And this she did not yet try and it turned out that the cord was clogged. And then another one in response to a high blood glucose level got replies that she could reflect upon whether it was the time of the month for her period or if she had a virus in her body.

**Summing Up Chapter 1**

I have traced the development of chronic illness management and self-care and how the popularity of the Internet has created new opportunities for seeking and sharing support in illness-related communities on social media. Social media is a central part of daily life of people in Denmark and around the world, and Facebook is the dominant social networking site. Facebook started as a purely web-based service, but with the launch of the first iPhone in 2007, it developed into an app available for downloading through the Apple app store (Brügger 2013). Since then, Facebook has become a daily routine for billions of people globally. With the availability of portable communication technology, the concept of M-health was introduced, and health-related activities using a smartphone are increasingly prevalent among a growing number of people with chronic illness. However, although the use of Facebook has become routinized and integrated into the daily lives of people, self-care is not something that is easily routinized due to various circumstances. This includes general practices of self-care for type 1 diabetes and interplay of an unpredictable body and living circumstances that make self-care a continuous process to which one must attune. As we will see in the next chapter, individual variations in personal experiences with type 1 diabetes direct both online-offline support and self-care.

While designing this PhD study, I reflected on and questioned the relevance of conducting an ethnographic study of living with type 1 diabetes in Denmark without including Facebook. Although Facebook plays a crucial part in the lives of many people with type 1 diabetes, not everyone with the illness has joined the platform. However, the rapid increase in the number and membership of Facebook communities over the year I conducted fieldwork suggests that Facebook is (and will continue to be) a pertinent part of daily life and self-care of people with type 1 diabetes. I support this assertion with a quote from Miller (2012:159):
The sheer ubiquity of SNS (Social Networking Sites such as Facebook) means that they are likely to become an aspect of almost any area of anthropological study in the future – from economic life and religion to development studies and medical anthropology. But the reason for focusing so tightly upon SNS within the more general realm of digital anthropology is that SNS poses qualities that seem to have a particular affinity with the discipline of anthropology itself.

It was not my initial intention to focus on Facebook use as a new space for online biosociality in daily lives of people with chronic illness. When I joined Facebook because of my personal involvement with the illness and saw the growing peer support communities, I needed to test its relevance before deciding to focus on this social media space. It soon became clear that Facebook had outperformed other social media and online spaces in the ability to form peer groups turning into large communities. I experienced the relative ease of locating various type 1 diabetes communities on Facebook, applying for membership access, and seeking and sharing health-related information online. In light of the M-health trend and Miller’s argument that the digitalized future of anthropology necessitates more studies on Facebook as an “embedded and everyday” phenomenon (Hine 2015), the answer to my question was that it is vital for social scientists to focus on the important ways in which people engage in social media sites such as Facebook.

I chose an online-offline (auto-)praxiographic research design because previous research focused on either online or offline sociality, often in a way in which the online world seemed disintegrated from an offline world. By combining various methods under the umbrella of praxiography, I intended both to obtain a better grasp of the dialectical connection between the virtual and the real life and to bring forward the myriad micro-practices of self-care that give rise to doubt. In Chapter 3, I will return to a more thorough argument for my reliance on (auto-)praxiography, a branch of ethnography that is subject to some criticism.

Note on Terminology

In writing this PhD dissertation, there have been a number of challenges in terms of defining terminology. Various terms are used in distinct ways in the literature, generating ongoing discussions. My selection of specific terms over others also gave rise to critiques from peer reviewers of the research articles, who requested further elaboration. I therefore dedicated this section to a note on terminologies, and I will attend to and reflect upon my choices here.

One of the roles of terminology is organizing concepts of specific domains and relating them through definitions. Conducting an industrial PhD within Health Promotion at Steno Diabetes Center Copenhagen meant that there was often a reliance on terms that were apparently adopted from global and national health and policy guidelines that tended to shift over time, such as from patient-centered to person-centered and the reliance on the use of “persons” rather than “patients”, reflecting a more ethically refined vocabulary.
**Illness versus Disease**

In the clinical lexicon, “disease” provides a biomedical explanation of a malfunction in a body in biologically universal, neutral, and objective terms.

I rely on “illness” throughout this dissertation to reflect the social aspects of practicing self-care for type 1 diabetes that transcend biomedical practices. Helman (1981) defines illness as the psychological, social, and cultural reaction to the disease process. This relates to the distinction that Kleinman (1981) draws between disease and illness, in which biomedical disease is defined as a biological malfunctioning related to a medical realm and illness includes personal and social responses, as well as interpersonal interaction within a social network. This also extends to online and offline peer interaction examined in this dissertation.

Disease is the named pathological entities that make up the medical model of ill-health, such as diabetes and tuberculosis, and which can be specifically identified and described by reference to certain biological, chemical or other evidence.

(Helman 1981:581)

Although distinctions are made between disease and illness, the terms should be seen as overlapping and entangled explanatory models (Helman 1981, 2001). I acknowledge that these distinctions, as well as the narrators behind, have been the target of ongoing criticism on the binary nature of Cartesian body/mind separating. I will nuance this dualism with reflections by Mol.

Mol delineates illness as an important object to be added to a disease’s physicality. Although I have been influenced by early works of medical anthropology that draw some distinctions between illness and disease, I acknowledge Mol’s argument for finding a way out of perspectivalism and into disease “itself” (Mol 2002: 12). With the above description derived from perspectivalism and early American pragmatism, the terms disease and illness no longer contrast physical facts with personal meaning. Instead, they differentiate between the perspectives of doctors on one hand and patients on the other (Mol 2002: 10-11). Both doctors and patients interpret the worlds they live in - but in different ways. I will further elaborate on this in the next section.
Self-Care versus Self-Management

A number of authors have put forward definitions of self-care and self-management, often in opposition to each other; however, generally varying definitions in the literature are often used to refer to the same processes and practices of managing and caring for one’s own health (Schilling, Grey, and Knafl 2002).

I rely on the term self-care, in addition to self-management, for several reasons. In general, self-care is perceived as a broader definition of behaviors and health practices that individuals use to manage and promote health. Within this definition is the more specific aspect of self-management that covers medical management of the illness condition (Peeters, Wiegers, and Friele 2013). When I use the term self-care, I implicitly also refer to self-management of illness through medicalized and technological devices. Self-care has been described as naturalistic decision-making process, which corresponds well to the processes and practices among the informants within this study (Wilkinson and Whitehead 2009). According to Orem (1995), performativity by individuals on their own, relying on various knowledge and skills, represents self-care agency, which is described as the ability to perform self-care activities. It is these activities that I seek to explore in the doing section of chapter 2.

People versus Patients

In this dissertation, “people,” “persons,” or “adults” with type 1 diabetes are used in preference to “patients” as a fixed category. In the scientific literature, there has been a recent switch from “patient-centered” to “person-focused,” in which the latter is described as based on “accumulated knowledge of people, which provides the basis for better recognition of health problems and needs over time and facilitates appropriate care for these needs in the context of other needs” (Starfield 2011:65). With this description, focus is turned toward the whole person (Tornholt, Engelund, and Willaing 2014).

I use “patient” when citing a vocabulary derived from articles or reports, such as “patient knowledge” used by the Dutch anthropologist Jeannette Pols, although I expand it to “experiential patient knowledge.” In this use, patient distinguishes this type of knowledge from biomedical knowledge or that of healthcare professionals. I acknowledge the more nuanced and inclusive terms within the literature on health promotion and diabetes management research with a movement away from patient to more agentic and inclusive alternatives: people, individuals, citizens or users. Thus I have argued how my reliance on the term ‘the tinkering M-patient’ is used to highlight an ongoing attunement, where the practice of tinkering is aimed at bringing the patient to the background and the person to the foreground. I rely on a term of the tinkering M-patient to define an ongoing struggle I observed among the informants. They are per definition patients in the way that they have received a diagnosis of a chronic severe illness that they need to attend to. They cannot run away from neither the diagnose, nor the huge treatment regime. When I state that patienthood is not a matter of identity but practice it is based on empirical grounds rather than ideological. Nevertheless, the informants did not refer to themselves as patients with type 1 diabetes, and many emphasized that they perceived this term as drawing from the biomedical vocabulary to describe a permanent self. They are so much more than their illness, and their illness, although chronic, is just one part of their daily lives. It is exactly this struggle I seek to show within this PhD dissertation. Finally, I used the term informants to refer to participants in the studies reflected in this dissertation.
Facebook Community versus Group

The term “community” has multiple contrasting definitions within anthropology. There are as many varied uses of community as there are of the terms online, digital, virtual, and Internet-based. I use online community to refer to a setting in which groups of people share social interaction and participation, social ties, some sense of belonging and reciprocal familiarity, shared knowledge of behavior, norms, rituals, practices, and a sense of obligation to the group (Blanchard 2007; Blanchard and Markus 2004; Welbourne et al. 2013; Kozinets 2010). The development and use of E-Health and M-health is rather new; the concept of community should be understood as influenced by both traditional kinship factors, such as shared language, discourses, and attitudes, and the rapid increase in the interconnectedness of individuals (Keiting and Egbert 2004). Online communities are always in flux; as relative membership sizes changes, the influence of any one community can be quickly eroded as other sites become more popular or new communities arise and break off of larger ones.

The concept of virtual community was introduced by Rheingold in a groundbreaking book of the same name (1993). I use the term online community because the communities I followed in this study are based on shared interests, goals, and values. The online communities I observed are not smaller groups restricted to people who know each other; however, they are a community in the sense that people join because of their shared interests in a specific illness, lifestyles, and use of self-care technology (divided by brands, food, exercise, and gender), based on a common interest (which is a common definition of a community goal). I define them as communities because they are goal oriented, as evidenced when members want to add something to the community through shared posts as well as emoticons and likes for posts and benefit from it by learning about how to practice self-care in various situations of daily life. In this sense, the online community concept can be defined through how people act. Facebook facilitated different levels of participation, so whether it is a group or a community also relates to the way people decide to be users. The use of community conjures up an image of the family with a common diabetes language used by many informants or a close and friendly neighborhood of support. The family metaphor might work well for some, but for others it would be completely alien; it was not reported by study informants.

Another way of defining a community based on the sociality of a group of people can be found in a study by Olwig (2010), in which she argues that calling the sociality of a group of people a community requires that it encompass routinized sociality. She exemplifies this with observations from her commute between a small town and Copenhagen. She described how, at the level of daily practices, the same people would meet and engage in small talk and frequently check up on each other’s absence. She refers to them as a “small community of travel companions.” Olwig’s argument is a good frame of reference for this dissertation and my argument for the use of the term Facebook community. I observed the same routinization of logging in to the communities several times a day to keep track of the latest community news and following certain persons and interactions though Facebook’s built-in functions. When users did not directly post a text message, Facebook allowed them to respond to posts with social functions such as likes or emoticons. Informants also referred to community members checking up on each other when someone posted about a bad day with the illness.
Outline, Structure, and Summaries of Articles

This dissertation is divided into three parts: 1) a framework, 2) the three articles constituting the foundation of the dissertation, and 3) media publications comprising an op-ed article, blog article, and internet site article.

**Part One** encompasses four chapters framing this dissertation with an introduction clarifying the background, state of the art, and aim of this study, followed by analytical perspectives, methodology, and a conclusion and recommendations for future research.

**Chapter 1** provides an introduction to type 1 diabetes, care, and support in a Danish context. I sketch the general background of this illness in terms of biomedical development and implications and related concepts within medical anthropology and the study of chronic illness care. I provide an overview of existing options for patient education and online and offline self-care support. In tracing the development of the Internet, the Web 2.0 and the rise of many established communities on type 1 diabetes on Facebook, I define a new tendency and opportunity for M-health-enabled peer-to-peer support. I describe my inspiration to adopt an overall focus on the use of social media in the daily life of adults with type 1 diabetes and how this opened possibilities for further exploring this growing phenomenon. I outline my main analytical interest and continue with a contextualization of the offline field of peer meetings and the online field of Facebook communities, with excerpts from the field. This is an industrial PhD dissertation; thus, I argue that the overall aim is positioned both within Diabetes Management Research and Medical Anthropology. Finally, I clarify specific terms used in this dissertation and the research articles.

**Chapter 2** constitutes the analytical and theoretical framework that binds the articles together. Through three sections that reflect a practice theoretical (or praxiographic) approach, I further elaborate on the Doing, Knowing and Attuning discussed in the articles. The theories and concepts from the articles will be brought to life through the empirical data to provide further clarification.

**Chapter 3** provides the rationale for the chosen (auto-)praxiographic study design. Studying practices includes gathering data on both doings and sayings. Therefore, supplementary data collection methods of interviews, informal conversations, and focus group discussions were carried out, along with online observations within Facebook communities and participant observations at offline peer meetings. In the latter half of the chapter, I turn the lens from the informants to myself. Adding “auto” to praxiography, I elucidate the fact that this dissertation also draws on knowledge from own work as a self-care surrogate, which is used as a reflexive tool in all phases of this PhD from the design to fieldwork and analysis. The final section in this chapter focuses on ethical considerations related to data collection, anonymization, and limitations.

**Chapter 4** highlights major conclusions of this PhD dissertation, with an emphasis on the tinkering M-patient attuning to a life with type 1 diabetes, a concept that may inspire future developments in diabetes management research. It concludes by identifying new questions arising from the dissertation that are related to further analysis of the large amount of collected data and the design of new empirical studies. Finally, I conclude by suggestions and recommendations targeting healthcare professionals and patients alike.
Part Two of the dissertation consists of three articles.

**Article one: Online peer-to-peer communities in the daily lives of people with a chronic illness: a qualitative systematic review.**

This article is a review of existing research related to the overarching topic of the PhD study and serves as a background for this dissertation. It also addresses a demand for more qualitative research on how online peer-to-peer interaction affects daily life with a chronic illness, focusing on why it is important to understand how online communities influence people in their daily life with illness. A systematic approach to reviewing the qualitative literature was used to locate relevant findings within the wider body of literature on this topic. The systematic review is based on 13 qualitative articles and employs a thematic analytical approach. The findings of the review indicate that online peer-to-peer interaction facilitates illness-associated identity work, social support and connectivity, experiential knowledge sharing, and collective voice and mobility. Online peer-to-peer communities provide a supportive space for daily self-care related to chronic illness. Further studies are recommended on underrepresented illnesses. The influence of online peer-to-peer communities validates the importance of the two subsequent articles targeting the use of social media among adults with type 1 diabetes.

**Article two: 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.**

This article focuses on how online support available through social media platforms such as Facebook enables self-care of adults with type 1 diabetes. The use of social media in the daily self-care of people with a chronic illness is understudied, even though the number of health-related communities on Facebook is increasing worldwide. Previous reports primarily examine relationships between online platforms enabling peer-to-peer or patient-healthcare provider interactions and psychosocial factors such as empowerment, quality of life, and well-being. These studies rarely include social media platforms. In addition, existing reports tend to study online communities as though they are detached from physical everyday life. The effect of online peer-to-peer interaction on Facebook on the daily lives of people with a chronic illness has received limited attention. Therefore, I aim to address this by drawing on data from a year-long study merging online and offline (auto-)praxiography to follow adults with type 1 diabetes into online and offline settings where self-care is enacted.

More specifically I explore how adults with type 1 diabetes become motivated to join health-related peer communities on Facebook through many instances of doubt about self-care. This doubt arises from blood glucose levels that fluctuate for unknown reasons and challenges in applying and adjusting self-care technologies to bodies and daily lives. I explore how adults with type 1 diabetes turn to peers on Facebook for guidance and support about how to tinker with their self-care in daily life.

This article contributes a discussion of how we can define the knowledge and practices people with chronic illness create in their daily self-care. I attend to a theory within social science called tinkering to define how patients struggle to reduce doubt and find solutions to self-care issues through illness-related peer communities on Facebook. A concept of
the tinkering M-patient is discussed to bring forth an understanding of an emerging performativity among patients of the 21st century with portable access to online biosociality on social media.

Article three: Noise as dysappearance: Attuning to a life with type 1 diabetes

Although Facebook is increasingly used as an online manual for self-care, the growing number of new and specialized communities is also a strategy to reduce noise. Noise is both an emic and etic term, which informants used to refer to the bombardment of information (embodied, technological, and online social) that, when unprocessed, creates an unwanted focus on the illness. The unwanted consciousness of the embodiment of type 1 diabetes is a kind of dysappearance. To reduce an unwanted focus on the illness, informants had to attune themselves to self-care, which involved practices of listening to the body, adjusting self-care technologies, and filtering through posts on Facebook.

Part Three of the dissertation consists of three media articles. The first two are authored by me and the third article is written by a journalist based on an interview with me. I will start this third part with an argument and defend my decision to include a section on media in this PhD dissertation.

My first contribution is an op-ed published in Politiken; one of the largest and oldest daily newspapers in Denmark. The op-ed presents a critical discussion of why people with chronic illnesses such as type 1 diabetes and the metabolic disorder of hypothyroidism turn to Facebook to make sense of daily life and self-care with illness. The op-ed piece critically appraises a recent negative response to social media from the Danish Health Ministry and healthcare practitioners in general. It calls for a more open, inclusive, and person-centered approach to the social media that comprise a substantial part of daily life among people in many chronic illness groups. I juxtapose the analysis of an outside and inside position with academic reliance on (auto-)praxiography of following study informants into online and offline social dimensions and based on my personal experiences as the mother of a child with type 1 diabetes. The second article is a blog article entitled, “Does social media really help people with diabetes?” It is based on collaborative work with Diabetes UK, the London-based English Diabetes Association, which requested an article highlighting my research and the main findings for their blog. This article is a shorter version of a much longer Danish op-ed piece published in Politiken. The third article was developed in the final stage of this PhD dissertation and outlines five concrete recommendations for professionals when confronted with the use of social media by patients (or citizens).
CHAPTER 2: THEORETICAL PERSPECTIVES AND ANALYTICAL INSPIRATIONS

In the previous chapter, I outlined my personal and academic interest in the self-care practices of adults with type 1 diabetes and how this led me to focus on the interconnectedness of online peer communities for adults with this condition on Facebook and offline peer meetings established and announced through Facebook.

In this chapter, I will shape a theoretical framework that can be used to account for and analyze the ways in which people with type 1 diabetes engage with online social media in daily self-care practice. My initial interest was on the concept of doing and knowing and, in the process of analysis; I became aware of a concept of attunement. The theoretical framework is a construct in which three components often overlap: doing, knowing, and attuning.

Doing, knowing, and attuning should be seen as in constant iterative interaction with one another. As a consequence, they naturally overlap and it was challenging to completely distinguish between them, theoretically define their interrelatedness and graphically illustrate their dispositions. Therefore, table three should be considered a work-in-progress. My initial focus was to explore processes and practices of self-care, inspired by the work of Annemarie Mol, and on how knowledge about living with type 1 diabetes becomes constructed through Facebook, with the aim of further elaborating on Jeannette Pols’ concept of patient knowledge. This focus follows recent developments in the anthropology of knowledge that are ethnographic and theoretical investigations into how we learn and how we know.

Attunement is that which emerges out of an interaction between doing and knowing and can be described as a state of fine-tuning information. The way adults with type 1 diabetes fine-tune information is through practices of tinkering, adjusting and sorting out information and knowledge from bodies, self-care technologies and posts on Facebook. Tinkering is a practice that can be fine-tuned over time. The desired outcome is a balanced life with type 1 diabetes. When information becomes noise there is a risk of dysappearance resulting in augmented focus on the illness. This is an unwanted outcome that distorts a balanced life with illness. The informants were seen to apply concrete practices of tinkering, adjusting, re-calibrating and negotiating to overcome doubt and daily challenges in self-care and restore balance. Attunement is a subjective state and it is developed through a constant handling and reading of signals from bodies, technologies and social relations on Facebook.

Figure 5: How attuning emerges out of doing and knowing
Living with type 1 diabetes involves continuous and complex processes and practices of checking up on the body and the technology used for treating it. It demands a constant embodied and technological attunement to life with illness. The many doing-related posts in relation to self-care that were communicated online were evident when I started observing. Posts shared concerns about how to practice self-care in various areas of daily life: how to count carbohydrates in specific foods, apply a continuous glucose monitor to the body, adjust and calibrate the insulin pump, crack the code of blood glucose fluctuations during and after exercise, etc. The purpose of these posts was to gain inspiration about how to balance life with type 1 diabetes and reduce the augmented space it occupied in daily life. Of course, there were also posts that illustrated illness-associated identity work with strong illness narratives and emotionally reciprocal sharing and mirroring (see Kingod et al.’s [2017] definition of illness-associated identity work), as well as sharing and borrowing equipment and ranking healthcare professionals’ ability to listen. What particularly caught my interest was how Facebook facilitated practices of tinkering in daily self-care and how adults with type 1 diabetes would co-construct knowledge on how to self-care and live with illness in daily life.

Attunement is a state of fine-tuning to make self-care easier that includes the development of skills and practices over time. It covers continuous negotiations with bodies, self-care technologies, and daily life to make them fit like a unique self-care bricolage. People with type 1 diabetes all tinker; however, technologies are applied to bodies and insulin pumps are adjusted to daily lives in ways that are as unique as individuals. Blood glucose fluctuations follow patterns that are as unique as fingerprints. In the Attunement section, I will position and discuss my understanding of attunement within this PhD dissertation against related work by novel social scientists and bring them into a comparative dialogue in order to position my own understanding of attunement as it was derived through analysis.

I will briefly introduce the emergence of practice theory, followed by an argument supporting the main analytical interest that guided the design of this doctoral work.

The Practice Turn
Practice theory generally refers to an epistemological position that is concerned with how things get done in everyday life. It embraces different approaches and traditions; what binds them together is the claim that the social is located in practical knowledge and routinized dispositions, such as the current focus on self-care and support-seeking practices.

A practice approach to data analysis is often placed in opposition to classical “meaning-making” phenomenology that emphasizes cultural mentalism, textualism, and intersubjectivism (Reckwitz 2002). Whereas practice theory integrates body and mind, these approaches have an epistemology and ontology of the social as entirely located in people’s minds and often focus on the intersubjective understanding of cognition. I find Reckwitz’s (2002: 249) often-quoted definition of practices useful for illustrating some of the same analytical paths of interest in this dissertation: “a routinized type of behavior, which consists of several elements, interconnected to one another: forms of bodily activities, forms of mental activities, ‘things’ and their use, a background knowledge in the form of understanding, know-how, states of emotion and motivational knowledge.” This differs from a dualistic approach to mind and body, because mentality is located in
practices from which know-how and particular ways of interpreting knowledge and aims connected to doings are constructed (Reckwitz 2002). The individual, as a bodily and mental agent, is a carrier of practices, and these practices are understandable both by the agent carrying them out and by observers (Giddens 1984; Schatzki 2002; Warde 2005).

With a phenomenological approach, the focus of this PhD could have been anchored in a description and experience of illness narratives online or in symbolic interactionism to understand the communication of identities within online communities. When reviewing the literature, I found that these approaches to data analysis were prominent in studies of Internet-based interventions and online communities. Although my data also capture some of these narratives, they could not adequately explore the social dynamics and interrelated processes and practices of self-care that I observed, the comprehensive knowledge-generating activities that take place in online and offline peer networks outside clinical settings, or, in particular, the sharing and integration of knowledge-related activities online and offline.

Practices came to prominence in social theory in the 1970s with key works such as Harold Garfinkel’s *Studies in Ethnomethodology* (1967), Pierre Bourdieu’s *Outline of a Theory of Practice* (1978), and Anthony Giddens’ *Central Problems in Social Theory: Action, Structure and Contradiction in Social Analysis* (1979). More recent influential works within praxiography/praxeology include Judith Butler’s gender studies highlighting performances (1990) and Bruno Latour’s science studies (1991) and laboratory ethnography. Introduced into social theory while still in its infancy, praxiography was generally used as a tool to study and conceptualize social actions with an emphasis on systemic and structural explanations (Ortner 2006). This represented a movement away from phenomenology and the Husserl-inspired ontological study of existence to an understanding of the social as embodied in agents and enacted through practice. Several scholars later used practice theory to explore the various ways in which practices are intrinsically connected to and interwoven with objects (Schatzki 2002; Warde 2005; Mol and Law 2004). The socio-material turn to practice theory also included the study of human-material mediations and entanglements and the dynamics of change in practices, which follow changes in artefacts, such as improvements in digitalized devices for self-care or new features and upgraded functions on the Facebook user interface.

Within this PhD dissertation, a turn to a socio-material analysis of practices includes both digitalized devices vital for type 1 diabetes self-care, such as glucometers and insulin pumps, and smartphone technology used for connecting with peers on Facebook, which is understood as a socio-material space in which artefacts float through posts. All technologies both extend and delimit the possibilities of users and, in turn, become appropriated and embedded in everyday experience. Thus, technologies may sometimes appear cold, alien, noisy, and too complex, causing confusion, doubt, and fear.

I will not devote this chapter to a longer description of social practice theory because it has been described within the literature, including its many directions (for example Reckwitz 2002; Turner 1994; Schatzki 2002; Shove, Pantzar and Watson 2012) and the more recent quantified self or self-tracking field defined by Lupton (2016) and Fox (2015). Instead, I will introduce the term of praxiography. I have defined this PhD as an online and offline (auto-)praxiography inspired by the 2002 work by the Dutch “anthropologist of the body” Annemarie Mol. A praxiographic analysis focuses on bodies, agency, and knowledge. The term praxiography denotes an ethnographic strategy to accentuate practicalities. Mol conducted extensive fieldwork within a Dutch hospital with an analytical focus on practicalities and the ways in
which illness is done. Her point of departure was the illness of atherosclerosis and the different ways in which it was treated. She had a particular socio-material interest in understanding strategies and techniques to capture things and make them knowable. Mol’s aim was to move away from subjective perceptions to highlight practicalities and the multiple ways in which illnesses are produced and enacted. She observed that the way this illness was enacted by doctors differed according to the enactment by nurses at the clinic, whereas the enactment by patients was based on how they engaged in practical matters of living with the illness. This observation led to the conceptual development of the body multiple. She shows us how ontologies are not transcendent but are brought into practice. This PhD dissertation is concerned with a focus on adults with type 1 diabetes; however, the focus is not on the various enactments in relation to care in different clinical settings. Rather, the focus of this work is how adults with type 1 diabetes engage with self-care in multiple ways and through the use of multiple digitalized tools. This will be exemplified in the section on doing later in this chapter.

In a 2008 study, Mol questions the nature of good care, using praxiographic examples of the illness of diabetes with a particular focus on patient-doctor interactions. Using a step-by-step approach, she contrasts the logic of care with the logic of choice:

It is difficult to predict what may work and what will fail. Thus, the logic of care wants us to experiment carefully. Try, be attentive to what happens, adapt this, that or the other, and try again. (Mol 2008:61)

Mol concludes that good care is something that grows out of collaborative and continuing attempts to attune knowledge and technologies to ill bodies and complex lives (Mol 2008). In the section on attuning, I continue on this path with excerpts from my fieldwork that precisely exemplify ongoing strategies and skill-making practices that informants carry out during daily self-care for type 1 diabetes. With a reference to the practice of tinkering that Mol established as a concept in her 2010 study, I show how adults with type 1 diabetes use Facebook as a source of inspiration and an online manual on how to tinker with their self-care. Tinkering is often described as experimentation; although Dumit promotes a playful side to tinkering, other scholars define it as hard work or chronic homework (Mol 2010; Mattingly, Grøn, and Meinert 2012). In the second article, I attend to these human-technology relationships when defining tinkering as ongoing negotiations between bodies, technologies, and daily lives. Whereas Mol was primarily concerned with a clinical setting, her former assistant and current colleague Jeannette Pols focuses entirely on patients. With this shift, we move from the clinic and into the homes and daily lives of people with chronic illness.

Pols is concerned with articulating the kind of knowledge that patients use and produce when living with a chronic illness or disability (Pols 2012; 2014). She also embraces a praxiographic approach, which she calls “knowing in action.” She is inspired by the anthropology of experiential knowledge, including early work by Kleinman, who has been concerned for decades with what sick people know, but Pols prefers the term patient knowledge. For Pols, patient knowledge is a kind of pragmatically derived knowledge that patients use to translate medical knowledge into
something with practical utility. This knowledge is combined with what they have learned both at the clinic and through their own experimentation. Although patient knowledge is a certain type of experiential knowledge based on living with illness, it is something completely apart from medical knowledge and needs comprehensive analysis. One objective of this PhD dissertation has been to explore Pols’ concept of patient knowledge in a Danish context through an entangled online-offline (auto-)praxiography.

Little research has been done on how social media is transforming the ways in which patient’s tinker with their self-care and what kind of knowledge they co-create in peer networks on Facebook. In the section on knowing, I further elaborate on the kinds of knowledge Danish adults with type 1 diabetes use and co-create during their daily lives with illness.

**Doing**

There are so many practices surrounding treating this illness that I don’t understand. And it never stops I think.

(Tina 54 years and with type 1 diabetes for 3 years)

In Mol’s (2002) concept of “ontological politics,” she argues that illness can only be studied by observing practices. She further argues that, because relations between objects are not given but done, they are inevitably done differently in different places and by different actors. Mol claims that ontology is not given in the order of things but brought into being in common day-to-day material practices (Mol 2002). This implies that type 1 diabetes only becomes a reality through the self-care practices surrounding it. Without practices, no illness exists; it comes into being through the practices constituting it. This fits very well with what I observed in the field and is why I have devoted a section to the many doings surrounding this illness. The many comprehensive doings connected to practicing self-care for type 1 diabetes on a daily basis are often referred to by the informants as a fulltime job with very bad working conditions; there are no breaks or vacations during which self-care can be put on hold. Ignoring type 1 diabetes or taking a leave from the daily job of self-care is not an option. Unattended, blood glucose can develop into hyperglycemia and ketoacidosis over the short term and lead to multi-organ complications over the longer term. For study informants, daily life is about reducing noise as dysappearance and fine-tuning their practices of self-care with the aim of pushing an augmented negative focus on the illness into the background of daily life.

Technology is a substantial part of daily self-care. Informants expressed gratitude for continual technological advances, but digitalized self-care devices also often generated doubt. As an example of a self-care practice involving technology, consider a glucometer. A typical self-care tool, it enables accurate measurements of blood glucose levels. This device must be handled in a specific way. First, it must be switched on and then charged like a smartphone when the battery is becoming drained. Many daily measurements are required for informants to stay within the preferred range of 4-6
mmol/L, which may be nearly impossible. Some routines are associated with blood glucose measurements; most informants measured their level before they went to bed, when they woke up, and before each meal during the day. Measurements between these times varied according to sensory perceptions of fluctuations in blood glucose or the predicted effect of physical activity. This is where the mentality of know-how is connected to the specific practices of decision-making, prediction, and control of blood glucose. At all three levels, there is room for doubt. As one of the informants said to me: “What will happen to my blood glucose if I take my bike to work instead of the car? And what if I eat an apple because I am in a hurry instead of my usual cooked oatmeal? I have to keep this in mind all the time.”

Applied self-care practices differed according to whether informants used an insulin pen or an insulin pump. About half of the informants had an insulin pump. Although the purpose of an insulin pump is to enable better control of blood glucose by continuously providing small amounts of insulin to replicate the work of a healthy pancreas, pumps were also considered difficult to operate. An insulin pump must be adjusted to the body it serves (Wance 2010; Mol 2008). The tiny computer allows for programming patterns and intervals by the hour of the day. Most informants had a Medtronic pump, which provides both bolus (used before meals) and basal (given continuously throughout the day) insulin dosages; both need to be adjusted continuously to adapt to situations of daily living.

Figure 6: A new (left) and older (right) version of a Medtronic insulin pump. The new Medtronic 640g gave rise to a Facebook community where knowledge is shared on how to obtain the device and on how to handle, operate, and adjust it
Operating an insulin pump involves learning a specific “language”: small buttons with arrows pointing down and up decrease and increase the basal dose, allowing for more insulin. Perhaps the bolus is set “too hard” and the blood glucose level becomes too low after a meal. The bolus setting must then be higher. This does not sound very logical to a non-user, and it might even be complete nonsense for relatives because the person wearing the pump does the practice of daily operation. Often, the vocabulary for a certain diabetes self-care technology was a reason for joining specific communities on Facebook targeting insulin pump brands; every pump has a different “language” and requires distinct ways of navigation and operation.

**Self-Care for Type 1 Diabetes 24/7: An Omnipresent Illness**

It is a job we all have 24/7 with no day off.

(Mette, 53 years old, type 1 diabetes for three years)

For Mette, daily life with type 1 diabetes is about reducing the time spent on self-care practices in order to live a “normal” life and reduce her identification as a patient. She is a 53-year old woman, diagnosed with type 1 diabetes three years ago, who remembers her life before the diagnosis.

“It is such a time-consuming illness,” she says to me one day over coffee in her house. “I would rather use my time on walking my dogs or normal stuff.” Mette shares with many other informants a concern about the illness taking up too much time in daily life. The chronic illness has forced her to restructure her day to accommodate a new schedule of highly practical care routines. With type 1 diabetes it is demanding and time consuming in relation to the self-care requirements and burdens across other illnesses where consuming a pill twice a day is a completely different practice to full-time self-care (Kleinman and Hall-Clifford 2010). Reducing the time spent on daily self-care involves being able to control the illness and respond appropriately to fluctuating blood glucose levels. Taming a seemingly untamable illness encompasses creating an awareness of time as it relates to her daily self-management routines. There is a time for measuring, for insulin injections, for carbohydrate intake, and for exercise. However, for Mette, controlling diabetes also involves creating an inner awareness of time in relation to when she last ate and how long ago she rode her bike to work and using that awareness to predict whether her blood glucose will rise or fall. These controlling, predicting, and decision-making skills are developed over time, but Mette considers herself a beginner in her diabetes treatment after just three years of self-care experience. When I asked about her Facebook routines, it was evident that she goes online to Facebook throughout the day as notifications appear, signaled by beeping sounds on her smartphone. She describes learning a lot about the illness and required self-care practices just through reading through various Facebook posts during the last year.
To support her in her daily self-care, she has developed a self-care timetable inspired by peers in a Facebook community. She unfolds a piece of A4 paper in front of me, revealing a spreadsheet containing the timetable for the day. My attention is drawn to the first blank row labeled “time,” with a blank space to note down the specific time of day. It is followed by rows for her blood glucose level, continuous glucose monitor readout, carbohydrate intake, and level of exercise. For Mette, the timetable works as a tool for controlling and taming the illness: “Yesterday was a good day as I only measured my blood glucose 5 times. Look here! Today I have already measured my blood sugar 4 times and it is only 10 am!”

She explains that a good day with type 1 diabetes is one on which she takes fewer than six blood glucose measurements. On her timetable, she has written down the preferred time of these measurements: the first is at 7.30 in the morning just before breakfast, the next at 10 am and may be accompanied by a small healthy snack depending on her blood glucose level. The third blood glucose measurement is just before lunch, and the fourth is a few hours after lunch and may involve another snack. The fifth is just before dinner, and the last one preferably before going to bed. The construction of her timetable implies a tidy, consistent linear flow and repetition. Nevertheless, it is apparent how often the illness deviates in dynamic and unpredictable ways, making it impossible to fit into a fixed self-care routine. She considers too much focus on her illness to be unhealthy, so she only uses the timetable during “bad periods.” During these periods, she needs an overview of how her daily activities negatively affect her blood glucose. One of these bad periods describes as a stressful time in her life where she struggled both to understand her fluctuations and especially with many high blood glucose levels. She tries to avoid too much stress as she believes that it has a negative impact on her immune system, overall health and with a negative impact on her blood glucose.

**Predicting and Acting on Unpredictable Numbers**

In a consulting room, the body is not a precondition for the life of the mind that philosophers hold so dear. It lives, the body does, and the ideal for it is to live well.

(Mol 2008:41)

Kira, a 36-year-old woman diagnosed with type 1 diabetes when she was teenager, explains that she has about four yearly visits with healthcare professionals. These visits are mainly dedicated to routinized biomedical practices, including measuring long-term blood glucose control, weight, blood pressure, and vision. For Kira, the four visits each year bring up mixed feelings. On one hand, she looks forward to obtaining insight about the various numbers (blood glucose, vitamin and minerals, weight, blood pressure). However, she fears a number that implies a negative assessment of her skills as a patient. “I just want a good number. I don’t want to be judged,” she says, referring to a test measuring long-term control of her blood glucose level. Also called the “telltale test” by informants, it reveals average blood glucose over the previous three months. For Kira, it is comparable to receiving a grade after a test in school that
involves preparation, practice, and performance. She explains that the result might not be good even though she has invested a lot of time, energy, and practice. And this is where the fear comes in. It is not so much the number that she fears. Rather, she fears that her body reacts in a way that she cannot control, that her blood glucose “goes wild.” This is more problematic in situations in which people are unaware of her condition and she has been unable to sense it fluctuating downward. In these instances, the body suddenly makes unwanted embodied noise. This is a subjective experience; however, if the noise escalates, it can be visible externally through bodily signs such as trembling, acting out aggressively, swearing, or losing consciousness. As Mol (2008) states in her study on diabetes, there is the preferred silent civil body and then there is the body in the consulting room. The body in the consulting room should be able to properly express itself verbally to be taken seriously.

Kira tries to predict her next long-term result by mentally calculating the range of low and high blood glucose levels during the previous month. This task seems impossible, given the huge number of measurements she must consider. The process is about both predicting a number and forecasting the impact of various activities of daily life that might influence her blood glucose:

I do so much and still I feel that it is not enough. I am not good enough. And the numbers speak their own language, and then I get this feeling that I am NOT doing a good enough job. But when you look at my printouts and how much I act, you know I take data from my insulin pump, then you can see that I actually boost myself with insulin about 10-15 times in a row. And then I DO act!

The quote illustrates how Kira is besieged with self-judging feelings of not being a good enough patient. Even though she receives support from her healthcare professional and assurance that she is taking enough action on deviant blood glucose numbers, she fears the negative effect these numbers might have on her body.

Oxlund (2012) attends to a numerical ontology of living in his ethnographic study among older adults in a provincial area in Denmark. With two cases of elderly women, he describes and situates a conflict between the daily self-care practices of elderly people with technological measurements and the abstracted numerical standards used to categorize normal and pathological states. The normativity of measurements and the “normal” numerical values of a preferred blood glucose level, which have been defined in a laboratory, can also be found in Mol’s 2008 study. She states that a normal blood glucose level relies on facts. At the clinic, informants are told that they should strive to be within the lines of normality. Lines of normality are depicted on an insulin pump display by two horizontal red lines, and the number revealed by the glucometer should fall between them. It is normative fact. As Canguilhem (1989:228) writes in his historical account of biological normativity, “There is no life whatsoever without norms of life, and the morbid state is always a certain mode of living.” I will state that living with type 1 diabetes is a certain “kind of living” (Wahlberg 2009). However, as we shall see later, the knowledge of how to live with illness is derived through day-to-day practices where self-care is carried out, experimented with, and pieced together to fit individual bodies and living circumstances.
In relation to self-care for type 1 diabetes, the informants were constantly aware of how to keep their blood glucose level within the normal range of 4-6 mmol/L. Thus, feelings of failure related to the inability to control untamable blood glucose levels is something they all shared. Many struggled with feelings of doing an inadequate job of self-care and constantly searched for information and support beyond biomedical information. They did so because bodies are unpredictable and at times untamable (Mol 2008). Even though the whole chronic care team does its best, Kira’s blood glucose still fluctuates into both the low and high ranges displayed on her insulin pump. This is one of several elements of unpredictability and doubt about self-care that motivates informants to seek guidance from peers on Facebook.

Mol highlights the need for support in the consulting room. However, although emotional support is crucial, it is not enough. What people with diabetes seek is support in “disentangling practicalities” (Mol 2008:60). Mol describes the case of Mr. Zoomer and how he tends to forget how to measure his blood glucose. She reflects on how this might happen because he is newly diagnosed and lacks training. Mol observes how a nurse guides him through repeated practice to enhance his measuring skills. Mol also describes how Mr. Zoomer needs knowledge about how to live with diabetes and that acquiring it will take a great deal of both his time and practical and emotional energy.

During the observations of processes and practices of seeking and sharing knowledge within the Facebook communities, the practice of blood glucose measuring was rarely discussed. As a practice, it was considered elementary and easily routinized because it occurred several times a day. Practices that were considered difficult to routinize were based on four overlapping domains of how to place the self-care technology to the body and how to continuously adjust it to the body and lifestyle (e.g. physical activity and diet).

![Figure 7: Four overlapping areas of doubt in daily self-care where tinkering often was performed](image-url)
These are practices that are both difficult to routinize and therefore difficult to directly emulate as a one-size-fits-all solution. It is within these overlapping areas that peers would guide each other on Facebook about how to tinker with their self-care.

**Individual Individuals and Unique Daily Lives**

I really hope that this month mountaineering comes to an end. It is so challenging with ovulation! Totally dropped (referring to blood glucose level) last night and ‘stop before low’ (function in an insulin pump) could not at all follow. I ended up in the kitchen and ate too much and had a BS (blood glucose) of 18 when I woke up. My level was fine this afternoon and then a new mountain on 18, followed by a total drop. I really hope for a reasonable night!

(Post by Marie, with type 1 diabetes for almost half of her life)

Marie, a study informant, posted this comment in a more recently established Facebook community. It demonstrates that type 1 diabetes manifests through blood glucose fluctuations in ways that depend on both biology and lifestyle (Wahlberg 2009). Lifestyle reflects the unique ways people arrange their lives that involve disparate levels of activity and varying routines that influence blood glucose. The lives of individuals are as distinct as they are, and physical components, such as hormonal levels, of a body are as distinct as fingerprints. That is why the impact of blood glucose varies between persons. Although peer advice on Facebook was greatly appreciated, informants knew that one person’s advice could not be simply transferred to another person’s life with the same result. They would all have to tinker to attune it to own daily lives.

Marie’s concern is about unpredictable blood glucose fluctuations appearing monthly during ovulation. She joined a specific community on Facebook to receive peer advice from like-minded women. Mazanderani, Locock, and Powel (2012) explore the mechanisms of how peer-to-peer (which they call by a slightly different name) experiences are turned into a source of knowledge and support. They argue that the degree to which people provide emotional or practical support is dependent on the ability of others to identify with them, and a shared illness diagnosis is a sufficient foundation for this identification. However, during the PhD study presented here, this was not observed to be the case. Identification tended to be based on highly individual practices of doing self-care defined by gender, being a woman with type 1 diabetes, use of specific digitalized self-care brands, and lifestyle, with a focus on specific foods and exercise. Identification was a much more complicated and nuanced process than simply sharing a diagnosis; the type of disease does not determine care (Pols 2012:76). Different communities supported different ways of living with type 1 diabetes and, even within specialized Facebook communities, the individuality of living with the illness was recognized.
Knowing

The epistemic validity of other people’s experiences as a source of knowledge in the context of peer support is premised, crucially, on managing the simultaneously embodied and empathetic dimensions of experiential knowledge. Indeed, others’ experiences would not be considered knowledge if they were not deemed, in some way, as an empathetic (shared) embodiment of a particular condition.

(Mazanderani, Locock, and Powell 2012: 551)

While carrying out fieldwork online and offline, it became apparent that one of the primary activities that took place was the sharing of patient knowledge. Doing and knowing occurred in an iterative flux instead of being in a fixed relationship with one another.

In the second article, I outline how adults with type 1 diabetes co-construct knowledge on Facebook. However, the various digitalized devices used for self-care are also involved in co-shaping knowledge because the informants never care for themselves in isolation. Self-care always involves relationships with devices, healthcare professionals, peers, and relatives in various configurations (Pols 2012:64). It is knowledge generated bottom-up.

The idea of contrasting the knowledge of patients and healthcare professionals can be traced back to Georges Canguilhem, who distinguished between scientific knowledge as derived through laboratory work when defining and separating enzymes from anatomy and genes from epidemiology and clinical knowledge. Whereas scientific practice aims to generate knowledge about the way bodies behave in certain conditions, clinical practice aims at accumulating knowledge to improve the daily life of patients (Pols 2012). It is in this setting that Mol has conducted her research on how healthcare professionals tinker. However, the concept of patient knowledge is missing from this two-dimensional description. Patient knowledge can be described as experiential knowledge created when people extract facts from the mountain of information accumulated in daily life and put them on trial (Rabeharisoa 2017). This trial is what Pols (2012) defines as tinkering within her concept of patient knowledge, and it can be compared to notions of bricolage.

In the late 20th century, a shift occurred within healthcare toward increased sensitivity to patient viewpoints (Prior 2003). This shift is clearly reflected within policy formulations of western governments. A focus on patient knowledge and viewpoints incorporates various terms, such as lay (expert) knowledge, patient (or, more recently, person) knowledge, and experiential knowledge (Greenhalgh 2009). People with illness become what many researchers refer to as well-informed lay experts through their years-long practices of handling and living with illness (Blume 2017). These lay experts often develop their knowledge through research in the wild, whereas medical experts develop knowledge in laboratories and through controlled scientific methods.

In this section we will look further at Pols concept of patient knowledge derived from a knowing-by-doing and including embodied knowledge and experiential knowledge.
Knowing-by-Doing

We know as we go, not before we go.

(Ingold 2000:230)

Knowing-by-doing involves know-how derived from action in the now. This was reflected in posts on Facebook in which members posted a question about a practical concern they were occupied with now with the goal of receiving instant replies with self-care support and guidance. The problem often encountered by informants was how to adapt, translate, and tinker with the general information they received from healthcare professionals. Informants often experienced this knowledge as challenging to adapt to their bodies and daily lives. In the second article, Mia provides an example as she tinkered with the technology inspired by peers within an insulin pump community on Facebook. Mia’s concern was how to apply her continuous glucose monitor to her body; she did not gain the knowledge she needed from healthcare professionals. This happened because the knowledge supplied by healthcare professionals at the clinic was based on directions from Medtronic, the device supplier. It clearly did not rely on knowledge-by-doing based on how to live with the illness in various situations of daily life. Mia was told that the device should be attached to the skin on her abdomen; this repeatedly failed, so she searched for knowledge derived from practical hands-on-experiments in real-life situations with the device.

Figure 8: Self-care pictures of tinkering with a continuous glucose monitor posted on Facebook
In an insulin pump community on Facebook, she finally arrived at a solution when she was inspired to apply the monitor to her upper arm. She also experimented with different ways to ensure a more solid and durable attachment. After a period of extensive tinkering and experimenting, she finally arrived at a solution that worked for her. She uploaded a photo of her experiment to Facebook; the first picture is her failed experiment and the second is her successful tinkering (Figure 8). The last is a photo of the medical adhesive she found that worked. Her knowledge derived from doing could then provide a source of inspiration for her peers. Facebook shapes and addresses a fluid mixture of physical, social, emotional, and, not least, practical problems and solutions (Pols 2012). Peers help peers learn how to practice self-care and live a tolerable life with illness. Uploaded photographs of self-care experiments were almost as embodied online as offline. Facebook helped turn experiments and experience into useful knowledge.

**Embodied Knowledge**

Every technology serves the body in one way or other…Mobile phones and other digitalized devices link our bodies to a world of knowledge and communication, on the move, day and night…Technologies extend what a body can do literally. (Fox 2012:181)

A long science of embodiment exists, particularly in the field of phenomenology, with a focus on how we have access to our senses. Within this dissertation, I position a notion of embodiment beside scholars such as Jeannette Pols, Nick Fox, and Griet Scheldeman that emphasizes a human-technology embodiment and with a focus on performativity and socio-material practice.

In Pols’ ambition to develop on a concept of patient knowledge, she touches on embodiment in her 2011 article in the section on ‘embodied subject positions’ defining the ill body as a source of knowledge. Pols brings forth another notion of a ‘shared body’ when the body becomes part of a community that shares embodied experiences of skills and practices. She moves from earlier descriptions of the singular autonomous expert lay to lays in a plural sense that share experiences, make collectives, and create bonds in their efforts to support each other and themselves: “helpful positions were found when a shared body was enacted; a body which was part of a community that shared embodied experiences” (Pols 2011:202). Pols defines a concept of co-constructed ‘embodied empowerment’ based on her observations of shared knowledge of self-help groups. The shared embodied concept is interesting to consider and can be applied to the processes and practices of support I observed in both the online and offline fields. Although bodies were shared in the way that people would support and comment on each other’s self-care experiments and experiences, the knowledge generated could not be used as a one-size-fits-all model, as previously stated.

Fox (2012) states that to embody knowledge, one must first embody technologies because technologies have become a basic and cultural product, created by bodies to serve bodies. Fox (2010:184) tends to view embodiment as a
development of how bodies and technologies have become more intimately associated to improve and enhance a body as well as to treat a body from the inside. He describes embodiment with the use of a Haraway notion of ‘cyborg technologies,’ which includes a mention of various assistive technologies for sensory impairments of vision, speech and hearing. Although his lists do not include an insulin pump, Scheldeman (2010) makes comparisons to the pump as a cyborg technology. In a study on ‘technokids’ (young people’s use of insulin pumps), her objective is to explore the impact of a technological device on modalities of embodiment. She does this by observing how insulin pumps are linked to bodies of young people, inspired by a science and technology literature. She relies on a rather broad term of embodiment: “the way we live our life ‘embodied’: with and through our bodies.” She further describes embodiment as ‘technology-in-practice’ where people and technologies are actively involved in the performance. As she states, “a technological device can enable us or disable us” (Scheldeman 2010:157).

The way I refer to embodied knowledge within this dissertation is that the experiential is always related to what adults with type 1 diabetes do in daily self-care through the use of various technologies and devices. Knowledge is not simply of the mind but highly embedded in embodied (and often shared) practices that cannot be entirely expressed in spoken words, rendering observation essential. In this PhD dissertation, I have strived to show the embodiment of various human-technology interactions, negotiations, and relations. I will further strengthen my argument with a field excerpt of the embodiment of knowledge I observed.

As I have outlined, embodiment relies on both a phenomenological tradition and a theoretical focus on practice. Within the latter, embodied knowledge is created through the making and doing of bodies and often through technological artefacts, wherein the body becomes a site of experience. I will argue that in relation to the illness type 1 diabetes learning self-care is related to embodied knowledge. In practical terms, people with type 1 diabetes move through several practices outside the clinic, constantly finding new situations they must address (Pols 2012). They must live the practices and, through this practical living, they eventually become experts in embodied knowledge reflected in, for example, skill at using a specific self-care device. Pols expanded on know-how when she described people with illness is using know-now when they interpret new situations to establish what the problem is and how they should act. Transferred to this PhD dissertation, know-now comprises skills that are tacitly and automatically applied. It is a type of embodied knowledge developed through years of self-care involving ongoing processes and practices of decision-making, prediction, and controlling blood glucose levels. Know-now is derived from a knowing in action.

As the informant Mia (32 years old and diagnosed at the age of 6) said to me during a conversation in her home, “Look, today is a tricky day as I had to make several temporary basals. My blood glucose just kept crashing. I don’t know why!” This is “pump language” in its most literal sense. An insulin pump must be programmed to fit the life and routines of its user. It can be compared to setting up a personal cellular phone, including more advanced options; however, a first-time user of an insulin pump may have no earlier reference point or know-how for guidance. When one changes smartphones, some embodied skills apply, making the new operation easier regardless of the brand because there is a common logic to the setup. Learning to operate an insulin pump is a skill that must be developed through continuous trials and practice as changes in the rhythms of bodies and daily lives require similar adjustments in insulin patterns and intervals.
Mia told me that she received her pump three years ago, and it is obvious that she now handles it with quick and graceful movements. By using both of her thumbs she could quickly turn off an alarm indicating a low number: “Just a second, I just have to get a sip of a Coke,” she said to me before disappearing into the kitchen. I heard the noise of a soda can opening. Within a short time, Mia returned from the kitchen with an apple in her hand. She first silenced and then made a temporary basal adjustment to her pump, which had stopped the infusion of insulin for a half hour to allow her blood glucose to rise above the safe line on the graph of her pump display. This is a repairing practice for a low blood glucose level that she has already embodied. It has become know-now. She knows exactly what she needs to do to reverse her blood glucose. Too many carbohydrates will make it sky-high within half an hour. Just a tiny sip of her Coke and an apple will hopefully be sufficient to return it to a normal state. The sip is important as liquid carbohydrates work faster on her blood glucose than non-liquid. However, she also measured her blood glucose with the glucometer to verify the exact level. She always pricks the same finger because she does not want to risk damaging her other fingers. This was something she learned from a peer on Facebook. Her glucometer revealed a level of 3.1 mmol/L. This was too low, and Mia again handled her insulin pump, so it would accept the number being transferred by Bluetooth from her glucometer. After accepting this external information, her pump could automatically calculate and adjust her active level of insulin. When Mia’s blood glucose eventually increased, she had to calculate the carbohydrates in her sip of Coke and apple and then type it into her insulin pump, so it could infuse insulin to ensure that her blood glucose level would not rise above the upper line of normality on the pump display. Mia revealed how challenging the continuous adjustment of the insulin pump is and about her fear about tinkering with unfamiliar patterns and intervals. Thus, Facebook has helped her feel more secure about handling her insulin pump. By reading how other people with type 1 diabetes who have the same brand of insulin pump tinker, adjust, and situate it to their bodies and daily lives, she has become more courageous about experimenting with adjustments she has never tried before. These adjustments are typically related to basal intervals that adjust insulin dosing over a defined time frame. Through the experiential peer support from Facebook, she has become more motivated to control her blood glucose level.

**Experiential Patient Knowledge**

While developing the first article, a qualitative systematic review of the literature on health-related online peer-to-peer communities, I stumbled upon the expression “experiential knowledge,” describing a type of knowledge that was sometimes placed in opposition to medical knowledge or a special type of knowledge used to gain recognition of an illness with an indistinct diagnostic profile (Kingod et al. 2017).

Thomasina Borkman was one of the first researchers to define the concept of experiential knowledge. Through extensive fieldwork in various self-help groups, she concluded that the people she studied created a special type of knowledge that in many ways can be placed in opposition to professional knowledge. Borkman defines experiential knowledge as both pragmatic and holistic in that it emphasizes obtaining concrete observable results in “work,” as subjectively perceived by the individual who is going through an experience. It is oriented towards here-and-now action rather than the long-term development within a biomedical context (Borkman 1976). This action-orientedness is also something professionals share, but their time perspective is usually longer. Whereas Borkman makes clear distinctions
between lay knowledge and professional knowledge, others strive to acknowledge these two positions as overlapping and interdependent.

Both Pols (2012) and Rabeharisoa (2017) stress the importance of avoiding romanticizing the experiential knowledge of patients as more real than medical knowledge. Throughout this PhD dissertation, it has not been my intention to imply that experiential knowledge is inherently more valuable than biomedical knowledge. As Pols (2012: 80) writes, “medical knowledge is everywhere in the form of devices, medications, lifestyle rules and so on.” Even though it may not always fit an individual’s situation, biomedical knowledge is always a part of informants’ experiences. Both experiential knowledge, derived through years of tinkering with self-care, and biomedical knowledge were equally important in the lives of the informants but at different levels.

Guell’s (2012) analysis of migrants with diabetes in Berlin reveals that they value experiential knowledge from self-help groups because they find it challenging to adapt self-care advice from healthcare professionals to their specific needs. She exemplifies this with a description of informants guiding each other in counting carbohydrates. The charts they received at the clinic did not cover all types of food. Guell documented how members of the group collaboratively made a more exhaustive chart. Furthermore, she noted how informants had to “tap into another set of knowledge and skills” to make recommendations work in their everyday lives (Guell 2012:525). She described how they began experimenting with food and ingredients and strived to name this experiential work with reference to Nettleton (1995) and Mol et al. (2010). She preferred the term tactics, inspired by de Certeau (1984), and concluded that tactics does not imply that patients resist adherence. Migrants with diabetes developed tactics as a crucial practice to make sense of the “complexity and messiness” of their everyday lives (Guell 2012: 526). Her work echoes the processes and practices of informants in this study. Although Guell’s study took place in an offline context, her findings are applicable to the online-offline peer support I observed. Food is just one area of support and experimentation within the online-offline peer communities and meetings, particularly in relation to a low carbohydrate diet or how to count carbohydrate values and measure insulin dispersions.

I will further describe how the informants valued experiential patient knowledge. Mary is a 47-year-old woman who was diagnosed with type 1 diabetes at the age of eight. She is an active member of several Danish and international Facebook communities. However, she prefers the Danish communities because of differences across countries between numeric values for blood glucose measurements. She describes her life as a teenager as challenging, especially in terms of controlling her blood glucose. When she became independent and moved away from home, she experimented with her diet in relation to reduced carbohydrates and increased dietary fiber. Nevertheless, she still found it difficult to control her blood glucose. However, on Facebook, she read about a woman who had great success with a low carbohydrate diet program developed by an American doctor with personal experience of type 1 diabetes. She used Google searches to learn more about the doctor and his diet institute and was directed to several YouTube videos. She assessed this doctor as trustworthy because he was diagnosed with type 1 diabetes and had spent many years experimenting with a low carbohydrate/high fat diet, using his own body as a living laboratory. Mary explains that this very strict diet worked quite well for her. She reduced her long-term blood glucose level and finally got pregnant. She explains that her diabetes doctor (endocrinologist) was unhappy about her low intake of carbohydrates even though her numbers were better than ever, and she felt great. This made her particularly aware of the vast resources online.
communities provide and that she should not listen only to what her doctor says: “The online communities have made me aware that there is another type of knowledge that I can use. I should not always listen to the doctor’s advice. At least I should discuss it.”

Mary’s case is one example of many that illustrates different approaches to knowledge. The knowledge that informants produce in their daily lives with illness is a different type of knowledge based on tinkering with self-care in various situations of daily life. The informants searched for peers and healthcare professionals who had hands-on knowledge based on a knowing-by-doing with the illness and self-care. Within the Facebook communities, people recommended the “good” doctors, the ones who knew what it was like to live with type 1 diabetes and could reflect on this throughout the consultation in a way that encouraged a listening atmosphere. For many informants, this knowledge should be lived and not something solely learned through a medical book.

I asked about these patient-doctor experiences, and there was a tendency for informants to remember the situations where they experienced not being listened to or taken seriously. I had to deliberately probe for positive experiences, which were generally descriptions of healthcare professionals who listened to patients reporting tinkering through Facebook instead of immediately patronizing them.

**Attuning**

Attuning everything to everything else, one way or the other. What to fiddle with and what to keep fixed, is rarely obvious. What you try to do, may not work out. Try something else. Keep on tinkering.

(Mol 2009:1757)

In this section I will first trace how attunement has been described within related fields in the literature. Thereafter, I will further exemplify areas of attunement as derived through fieldwork and analysis.

In a 2009 ethnographic study, Mol shows the real lives of people with diabetes and how they care for themselves and are cared for by others. In an exploration of the logic of care and the logic of choice, she distinguished attunement from practices of calculation. Attunement is a process of adjusting, of “attuning everything to everything else” (Mol 2009:1757). This is done through collaborations between healthcare professionals and patients at the clinic. The patients in Mol’s study are given choices about care but must make personal decisions about how to apply their choices in their daily lives. Some guidance can be given, but she compares deciding with calculating but with results that might not turn out as anticipated in daily life. Mol argues that the world is only adaptable and adjustable to a point. This is particularly
the case with diabetes, in which variables tend to be diverse and fluid, rendering self-care challenging. Mol applies a model of balance, drawing on accountancy to describe the advantages and disadvantages of various courses of action. Mol’s account of attunement is based on the calculations and goal-setting practices in diabetes management without really engaging in the unpredictable areas of self-care. Whereas Mol offers a pragmatic approach to attunement derived from a practice theoretical understanding, other scholars view attunement as derived from habitus and phenomenological traditions.

In Vigh’s 2008 study on crisis and chronicity, he describes attunement as the constant practice of deliberate and unconscious skill of attuning to the environment. His ethnographic account and theoretical development of attunement is built upon inspiration from Bourdieu’s praxis and understanding of how people move within a social environment and how this environment moves people. Through fieldwork among youth in Bissau, Vigh shows how they navigate an uncertain terrain with skills that are tacitly developed over time. The environment of chronic instability or crisis that they are born into has enhanced their attention towards the environment, defining attunement as a heightened attention and imagination (or forecasting) of environmental mood shifts.

In fact, in many areas of the world that are characterised by conflict and war, the social world seems so fluid that it is experienced as having lost its course; as being in perpetual but ‘progressless’ motion: not as field or structure but as moving environment in which one constantly has to adjust one’s trajectory and praxis to the shifting terrain. Predictability is minimised as one constantly needs to be attentive toward — and act in relation to — the shifts of social forces.

(Vigh 2008)

Whereas Mol and Vigh attend to attunement as a process of navigating unpredictable numbers and environments in which attunement becomes a process of reversing this unpredictability, Throop’s (2017) conception of attunement is of emotional response and sensibility in relation to routinized practices. In his argument, culture shapes the individual. In what Throop (2017) calls “mooded attunements”, he illustrates how a Yapese woman named Thiil with type 2 diabetes continuously attunes to worldly conditions that define an increasingly diminished range of possibility for her and her family: “Arising from, and disclosing, ongoing attunements to our everyday dealings, distinctive moods thus structure particular modes of access and orientation to the world” (Throop 2017:202-203). With a concept of attunement as a special type of engagement with and entanglement in diverse relationships that enable different ways of living, he draws on earlier work by Heidegger and Zigon. Through a historical depiction of how traditional food culture has been placed with a western Coca Cola-consuming culture, he describes the despair Thiil experiences from the loss of traditional ways of being with an entanglement of context, morality, and food. Although Throop is less interested in emotional contagion or how moods like despair spread through sharing in a system, he touches upon attunement as a “corporal resonance” arising from ongoing attunements to everyday dealings.
Having traced three relevant approaches to the concept of attunement, I will now bring these understandings into a dialogue in relation to my own data and analysis. When looking at the attunement concept in relation to my own data, Mol’s practical attention to attunement cannot be fully incorporated and applied to the analysis because it omits the interaction between patient knowledge and pragmatic tinkering. What I have strived to bring forth in the previous sections are the negotiations with bodies, technologies and daily lives. Experiential patient knowledge derives through ongoing bodily interaction and socio-materiality. In relation to Vigh’s study, it is not the terrain that the informants cannot control but their bodies. Similarly recalling Throop, they do not negotiate in dialogue but in practice. The chronic crisis I observed among the informants and in Facebook communities is internal from a failed pancreas, where tinkering is a practice of getting to know the body as well as the technologies used for self-care. It is something that is rehearsed and practiced over years. It is through tinkering as an aspect of attunement that adults with type 1 diabetes gain experience of the many self-care practices used for managing the illness, thus realizing that they will never truly be able to control it. In similar vein as the informants in Vigh’s study can never truly count on the environment, this same unpredictability is applicable to uncontrollable blood glucose and a body ‘going wild’. However, within this dissertation, attunement comprises a certain state of fine-tuning information that calls for various practices in daily self-care of type 1 diabetes to sense and know the body and technologies used for regulating blood glucose, as well as knowing how to find the right support and address data overload arising from bodies, self-care technologies, and Facebook. At all levels, there is reason for doubt. The knowledge-enhancing process derives through tinkering. The purpose of tinkering was to reduce an unwanted and augmented focus on the illness and to finally make sense of daily self-care and balance life with illness. Tinkering is both explicit and implicit.

As I began analyzing my empirical data, it became apparent that my informants were constantly moving back and forth between acquiring knowledge and trying things out and that attunement emerged from this observation and analysis. Fine-tuning information is continuously at play in daily self-care and involves being able to tinker. Tinkering never ends, and there is no blueprint for it, due to all the variables of life with type 1 diabetes. It is a full-time practice. In the introduction, I described how I had to attune to my daughter, like the way in which informants attune to a life with illness. This included attunement to specific self-care technologies, a skill that is developed over time through continuous processes and practices of tinkering and negotiations with the body and the various technologies to situate them to daily life circumstances. Simultaneously, I have discussed how the informants applied various practices to attune to a life with type 1 diabetes, which included handling different technologies and learning how to listen to bodies and situate digitalized devices to the body and daily life. In the second article, I described these processes and practices of negotiations and tinkering and the crucial part that Facebook plays in facilitating the co-construction of useful experiential patient knowledge, which is a certain knowledge-by-doing and living with illness. There was a fine balance required in self-care in terms of when and how much to tinker and sort through posts on Facebook. Dysappearance occurred when informants spent too much time on the illness and when the illness, the bodies, and the technologies went “wild.” Although the concepts of tinkering, noise, and dysappearance are introduced in the second and third articles, I will further elaborate on strategies informants used to avoid an unwanted and augmented focus on the illness.

Scheldeman (2010) draws on Leder’s tacit body when analyzing the body-machine experience of doing diabetes through insulin pumps. She illustrates how the body resides in the background when all works well, when devices work, and how they then become more or less taken for granted. “When the pump works well, it functions in a tacit mode.
Accordingly, diabetes can recede into the background” (Scheldeman 2010:153). Scheldeman is primarily concerned with how the insulin pump works because it modifies how young people embody illness and less concerned with the many adjustment and fine-tuning practices young adults apply to live well with machines and the illness. She states that eventually doing type 1 diabetes will be an incorporated skill that is no longer thought about; consequently, both pump and illness reside entirely in the background. My analysis does not share a similar view of an illness that disappears. There are simply too many variables that continually force it to the foreground of daily life. Attunement as fine-tuning and adjusting covers the many practices that informants in this dissertation developed and tried out in their daily life to be able to tip the scale. The main practice observed is that of tinkering defined as ongoing negotiations between bodies, technologies, and daily lives. Attunement occurs at several levels: a bodily or embodied level, a technological level, and an online social level. It represents what are primarily referred to in the literature as technological adjustments and sorting out data originating in bodies, technologies, and online interactions. In this section I will elaborate on two crucial adjustment practices – tinkering and training the senses, which also has to do with fine-tuning and sorting out information.

**Tinkerability**

Patients tinkered with various logics of care for themselves. Piecing them together using different strategies for particular problems. You could say the telecare devices tinkered with the patients too, since the devices permitted several ways of using them and had their restraints as well.

(Pols 2012:76).

Whereas tinkering can be defined as an activity, tinkerability is an approach, which is nearly permanent. Tinkering can be interpreted as handling or experimenting. In the literature, tinkering and bricolage have often been connected to how knowledge is shaped and reshaped by laypeople as a “science of the concrete” (Hester 2005; Lévi-Strauss 1968; Prior 2003; Broom 2009). In his classic book, *The Savage Mind*, the French anthropologist and structuralist Claude Lévi-Strauss introduced and conceptualized bricolage as one of two ways of acquiring knowledge (Lévi-Strauss 1968). He described bricolage as a kind of “do-it-yourself” practice performed by a handyman. This concept has been borrowed, expanded, and reconceptualized by others. In a study of systematic and creative research processes involved in the act of metasynthesizing, Kinn *et al.* (2013) use bricolage to help define a practice of combining or puzzling together techniques, methods, and materials to work on any number of tasks and creations. Bricolage has been applied to describe modes of use characterized by tinkering and improvisation, focusing in particular on creative and unexpected outcomes arising from these practices (Ciborra 2002; Gabriel 2002). Hester (2005) used bricolage as a metaphor to
illustrate how women put together disparate pieces of information about oral contraceptives. Inspired by the work of Hester, Broom (2009) used bricolage to describe individual engagement with a multiplicity of therapeutic options.

Tinkering is one aspect of the many attunement practices that informants carried out in daily life. As I have shown previously, self-care for type 1 diabetes is highly technological, and tinkering was necessary to adapt the technology to the body and situate it to daily living circumstances. Pols states that patients need to translate medical knowledge and tinker with it to make it fit the particular situation at hand. Inspired by studies by Pols, I argue that when the informants in this study experimented and tinkered with their self-care, they created experiential patient knowledge. Thus, the process of creating experiential knowledge aims at making sense of people’s experiences and gives rise to issues that are not necessarily on the agenda at scientific institutions (Rabeharisoa 2017). This does not mean that people with type 1 diabetes do not need face-to-face consultations with their healthcare professionals. Online peer support through Facebook can supplement quarterly visits; it is not “colder” because of its online interface.

Pols’ (2012) study on telecare in everyday life with COPD challenges previous assumptions of technology as providing cold care in opposition to warm human interactions. She states that it is naive to think of digitalized devices or online communities as “cold” or “warm” care. Technology has become a crucial part of daily life. I often observed a special relationship between informants and their technologies, particularly insulin pumps. The informants expressed appreciation for the technological advancement in treating the illness represented by frequent releases of new and ever smarter devices that act on their behalf. Digital self-care devices, such as an insulin pump, seemed to almost come alive when informants talked to them and, for example, tried to silence them, calling their pump an impudent companion. I observed this question raised occasionally within the Facebook communities as people sought to understand the special relationship they felt with an insulin pump that was both a lifesaver and an intrusive companion. Such posts garnered several responses as peers acknowledged how they both appreciated the insulin pump as a lifesaving and loving companion and found it very complicated to live with. Talking was a way of relating to the device, to personalize and embody it. It was also a way to attune to it at a cognitive and practical level. On the pragmatic level, informants had to continually tinker with the insulin pump as patterns and intervals of insulin dispensing would change with variations in the routines and activities of daily life. Facebook contained many posts on insulin pump adjustments and setting activities.

Peter received an insulin pump because he found it difficult to stabilize his blood glucose. He has had long periods during which he tended to neglect his illness and forget to take his insulin. In retrospect, he described this as a strategy to ignore his diagnosis and diminish the space it occupied in his daily life:

I felt at peace when not speculating about the illness and my blood glucose was just up and down and through longer periods extremely high. It was a stupid solution, but I had peace in my mind. I just didn’t think about it and there could go months without measuring my blood glucose. It is not smart, really not!
Peter finally received an insulin pump, and he describes it as keeping him “alert.” He can no longer ignore his illness because his pump alarms whenever it senses a blood glucose fluctuation. When he received an insulin pump, he found his way into the type 1 diabetes Facebook communities because the pump needed to be handled more carefully than an insulin pen. It was more complicated, and he wanted the insulin pump connected to a continuous glucose monitor to keep it from “screaming for action.” Facebook has made him more aware of carbohydrates and how they impact his blood glucose. It motivated him to see that he was not alone with his concerns and that there was help online. At times, he has sent personal messages to some of the more experienced peers (or super users) on Facebook, the individuals everyone knows by name and relies on. On Facebook, he immediately received guidance and answers that were more suited to his daily life than the advice from healthcare professionals: for example, how to understand the ISIG number on his continuous glucose monitor and how to write a convincing letter to get a new medical device when the old one malfunctioned. He appreciated posts that could inspire and support his self-care with an insulin pump because he found it challenging to adjust the pump to his body and lifestyle. A setting may work fine one day and need to be changed the next because something unidentifiable has occurred inside the body. He reasoned that this could be an emerging virus that his body was fighting, a malfunctioning insulin pump, or a failed attachment of the pump cord to his body. Or perhaps the continuous glucose monitor loses its signal for unknown reasons and reveals an inaccurate ISIG number with the consequence of an unreliable blood glucose number. On Facebook he could reason about these concerns with peers. The continuous glucose monitor measures the blood glucose from the tissue and not directly through a drop of blood like a glucometer. Had it been calibrated too many times in a row or attached to the body in a way that impinged on its Bluetooth connection to the insulin pump? Or perhaps the batteries in the charger were dead. These are all examples of the doubt Peter struggled with daily that required him to tinker in one way or another. Facebook acted as a life preserver when he was still trying to understand how to use and individualize his insulin pump. Whereas other informants felt that they were drowning in online information at times, what I have called online social noise, Peter adroitly surfed on the surface of a huge amount of data to find the precise information he needed. He was adept with technology and taught me about functions in Facebook that I did not know existed. He always used his computer in the evening because he found it easier to get an overview of the many communities on the larger screen and he always used the search function. He never just scrolled through the online sea of posts.

**Training the Senses**

As discussed in the third article, Andy worked on developing his ability to sense blood glucose fluctuations as a strategy for self-care and balance in a life with illness. However, others preferred to rely entirely on self-care technology because they would find that Andy’s method made the illness more present in daily life. In the third article, I looked at the relationship between self-care practices and sensory experience of an embodied illness in the development of the concept of illness-associated noise as dysappearance.

Digitalized self-care equipment makes people with type 1 diabetes less dependent on sensing blood glucose fluctuations and more reliant on a visual reading of the number revealed by the technology. A reason for receiving an insulin pump is a hypoglycemia unawareness effect that affects about 25% of people with type 1 diabetes (Lawton *et al.* 2014). This effect occurs when people no longer experience symptoms that warn them of a low blood glucose level, and the
proportion of affected individuals rises to 50% among those diagnosed for more than twenty years. The hypoglycemia unawareness affect is a term used when the internal sensation of the symptoms of the illness decreases.

Within the literature, there has often been a focus on the visual sense in modern western cultures and other senses as more pertinent in other cultures (Ingold 2000). I strived to understand the reliance on the skill of sensing blood glucose fluctuations and how it was experienced and practiced differently according to illness stage and self-care technologies. Informants often talked in terms of how they had to “sense their bodies” and “the illness inside” in order to take appropriate action before it was too late. On Facebook I also saw a course developed by a peer on learning techniques derived from eastern philosophical traditions (such as meditation and qi gong) to regain bodily awareness with the aim of better sensing their blood glucose numbers. Although training the senses is simply a part of some people’s self-care of type 1 diabetes, the notion of embodied, technological, and online social noise makes it important to understand the relationship between categories of sensory experience and practice in daily life with illness. I strived to untangle the relationship between sensory meaning and self-care practices in the third article, although it was not a straightforward exercise. Informants experienced blood glucose fluctuations differently in terms of both the levels at which they sensed them (i.e. how low or high) and the sensory experiences of very low or very high fluctuations. Some would start sweating, tremble internally and externally, or talk nonsense, symptoms that were visible to others, and others would be confused, lose the sense of hearing, or just feel dizzy, which were invisible. The trick is to identify the individualized embodied signs before they turned into severe bodily alarms. Although informants often described the need to “listen” to signs from within, it seemed that the senses were not separate entities that could be directly translated. They were both tightly interwoven and diffuse.

My interest in the sensory perception and experience of blood glucose fluctuation appeared when the informant Andy showed me the table he used as a tool to train his senses (Figure 9).

<table>
<thead>
<tr>
<th>Tid</th>
<th>Blodsukker</th>
<th>Oplevet</th>
<th>Motion</th>
<th>Bemærkning</th>
</tr>
</thead>
<tbody>
<tr>
<td>7:24</td>
<td>7,3</td>
<td>3</td>
<td></td>
<td></td>
</tr>
<tr>
<td>9:30</td>
<td>5</td>
<td>Højt</td>
<td>1 time, slow</td>
<td>Drake cider juice og sprit en muskel</td>
</tr>
<tr>
<td>11:20</td>
<td>2,4</td>
<td>LAV!</td>
<td></td>
<td>Drake en vand og sprit og muskel</td>
</tr>
</tbody>
</table>
| 14:15| 7          | Normal, 6 |                 | tag vidt og rislul |)
| 16:10| 13         | Normal, AV |                 | Tag 4 enkoker, rislul |)

Figure 9: Andy’s schedule to train his skills of sensing blood glucose fluctuations (in Danish)
Several Facebook communities display columns where uploaded files, documents, and pictures are stored. Andy found a table that he uses to train his senses. On a daily basis, he practices his skill at sensing blood glucose fluctuations and compared his sensations to a measured number. He pays attention to his embodied and biological sensory perception. Informants practiced this focus on the senses differently because it involved individual experiences and agency. This was not knowledge conveyed by healthcare professionals; it was experiential patient knowledge developed as a tool by peers and shared on Facebook.

**Attunement - a constant state of filtering and adjusting**

I will now elaborate on another strategy to avoid online social noise. Coincidentally, I meet Anna on the bus, and we choose a seat where we could converse informally. Anna has been one of my key informants; in the initial stages of the design of this PhD study, she directed me to some of the existing communities on Facebook for adults with type 1 diabetes. A few weeks earlier, we had both attended the same offline peer meeting, and I had since been troubled by the format of that meeting. Several of the other meetings I had attended had used a loosely structured format that emphasized time for peer-to-peer interaction. At this particular meeting, three guest speakers were invited, and little time was dedicated to informal discussion and sharing. I ask Anna why there was so little time for peer-to-peer informal conversation at this meeting. She replies that this was due to an ongoing conversation among the founders of this network (which exists both online and offline) to maintain an empowering focus on the illness. Karen says: “It is like, in my own case, I am in a period where I fear late complications a lot.” I ask why her fear has arisen, and she reveals that it is due to a focus on the negative aspects of illness that often occurs at more loosely structured peer meetings and because she senses her body in a different way now. She explains that, during earlier peer group meetings, she became aware of the limited help from the Danish system for late complications of type 1 diabetes. She explains how she finds peer meetings both empowering and disempowering; the latter has created an augmented focus on her illness where it tended to be too much in the foreground. Her recent strategy is to silence the illness, to disappear dysappearance, by ignoring and avoiding any exposure to unwanted information. To restore a positive attitude about her illness, she only attended meetings with invited guest speakers:

I think about the illness all the time. I can never take a vacation from it. It is always there in the back of my head, and that is why I need to be aware about how I need positive input and not something that creates too much fear.

Anna’s strategy to avoid a negative awareness of her illness was to only attend peer meetings with a clear agenda and limited time dedicated to peer-to-peer interactions. In the first article I reviewed, some of the included studies reported that online interaction could sometimes create fear due to a focus on unwanted aspects of the illness. In studies by Sandaunet (2008a, 2008b), the focus is on online communities and how disempowering information sometimes circulates, creating fear and distress. A coping strategy of members within these communities was to momentarily or
entirely withdraw or to create a humorous atmosphere. While Throop merely touches on how Thiil’s mood of despair was attuned to something communicable, Gron’s (2017) study (although she does not rely on the literal term of attunement) focuses exactly on the dynamics that characterize the spread, not of moods inflicted by illness, but of the systemic spread of obesity. Her focus is based on both an inspiration and a critique of the study by Christakis and Fowler (2007) on how a non-communicable illness becomes communicable and obesity spreads from person to person. Introducing three analytical concepts where the two are of social contagion and contamination she shifts from a contextual to a systemic analytical level to explore the dynamics of how obesity “runs in the family.” Although I have relied on praxiography in addition to phenomenology, I will return to an attunement strategy to avoid fear and noise as dysappearance that tended to circulate in groups and communities, and it becomes relevant to return to Throop and Gron. Particularly in considering the concept of noise (embodied, technological, and online social), we must acknowledge the entanglement of the body and mind in practice; a singular focus on mechanical practices with no connection to cognitive influences would stray from the aim of this PhD study. As Mol states, the mind cannot be separated from the body and vice versa (2008).

In Gron’s study on obesity, one of her concepts is social contagion as a “process where actors catch something from the surrounding or environment” (Gron 2017:24). On introducing the concept of configuration, she argues that a dynamic interplay of social contagion and contamination and other biosocial and material processes occurs over time. Replicated to this PhD dissertation Anna fears that her mood will be affected when exposed to disturbing information from peers. Emotional information is easily spread through sharing of posts on Facebook. If you hang out in a community with people with negative posts, then you can easily adopt this negative attitude about your illness. On the other hand, if people are positive and hopeful and express a humorous side of the illness, Anna might be better off. Her strategy is to withdraw from some of the communities and be more selective in what types of communities she participates in. They must promote empowerment and focus on practical aspects of living with the illness and avoid too much emotional content. She has rejected the communities where peers tend to share pictures of late complications, such as foot wounds. This is not helpful for her as she becomes easily affected by other people’s “mooded” interaction. This type of social noise has been described in the third article: it can be contagious and infect an already distressed mind.

When observing Facebook, it was clear how much the communities differed in terms of both the overall focus (insulin pump, brands, food, or exercise) and the community netiquette, which was often revealed in community-specific introductory statements. I want to compare two of these. The first one is from the “Type 1 Lodge – Only for Women” community with 148 members:

Introductory note: Here we can share our thoughts and worries. Subjects do not necessarily have to be about a problem which demands a solution. It is accepted to express all feelings surrounding your life with diabetes. You are allowed to express feelings of a bad day, without being called a pessimist. And posts that are not directly type 1 diabetes relevant are also welcome. I wish to make a loving and kind network, where we can seek support and guidance, but also just tomfoolery, if you want it. Maybe there is no need. Let’s see. If not, then I will just close it again. In advance, thank you for your support.
Within this community, there is more focus on the hardships of living with type 1 diabetes than in some of the other communities. However, this community also demonstrates gender-specific aspects of living with type 1 diabetes reflected in both an emotional need to express the illness in a certain way and in self-care practices. One informant joined this community to seek practical guidance on how to hide her insulin pump when she carried it close to her body. She was tired of having to hide her insulin pump in her bra and needed inspiration.

In contrast, here is the introductory note to an exercise community for people with type 1 diabetes with 680 members:

Exercise and diabetes type 1 & 1.5 is a group for people with type 1 diabetes and type 1 ½ diabetes who wish to share knowledge and experiences on exercise. It is a group for people with type 1 and type 1 ½ who have a plentiful and active life. Our diabetes takes up much space – but not all of it. We are and can so much more than our diabetes, and our resources should be used on supporting others, if we can.

The netiquette guiding this community differs by virtue of its heightened focus on practicalities of daily life and decreased emphasis on emotional struggles. Whereas some informants permanently settled in the communities they found most relevant to their daily self-care, others relied on a nomadic practice of temporarily settling in communities to avoid an augmented focus on the illness.

**Summing Up Chapter 2**

In this chapter, I have proposed a conceptual framework to understand how people with type 1 diabetes engage with online media in their daily efforts of self-care of doing, knowing, and attuning.

Through (auto-)praxiographic excerpts, combined with analytical and theoretical perspectives deriving from praxiography and concepts of doing, knowing, and attuning, I outlined the online-offline entanglement in daily life and self-care of type 1 diabetes. I sketched the many strategies that adults with type 1 diabetes use to attune to a life with illness, which involve online searching and sharing and offline tinkering with self-care based on ongoing negotiations between bodies, technologies, and daily lives. Thus, attunement was also a constant practice of processing data from bodies, self-care technologies, and Facebook. Without processing skills, noise as dysappearance was evident. The challenge was to balance focus on the illness and self-care with ensuring that the illness would not take up too much space in daily life.

In the doing section, I explored how informants practice self-care and how it involves handling various self-care devices and applying processes and practices of decision-making, prediction, and control. In the knowing section, I elaborated
on how different types of self-care and use of devices involve different kinds of knowledge. I have showed how new skills are co-created when one receives an insulin pump, for example, and social media is the means by which complicated, and highly technological practices of self-care become codified and explained. Thus, I often grappled with following questions throughout fieldwork and analysis: Exactly what is it that people with type 1 diabetes know through their years of living with illness and how has this knowledge been derived? How can Facebook support the development and use of this knowledge? I will answer these questions in the concluding chapter of this PhD dissertation. Facebook contains a wealth of information about how to carry out self-care in various areas of daily life and with new devices come new communities. The practices of self-care evolve with advances in technologies used for treating the illness. In the attuning section, I have described the various strategies that informants applied to balance life with illness, such as tinkering to fit technologies to bodies and daily lives and sorting out information to reduce noise as dysappearance.

Attunement is a state of fine-tuning information to balance life and self-care with type 1 diabetes, which includes several conscious and unconscious skills and strategies. It is tinkering as negotiations between bodies, technologies, and daily life and the ability to filter out an overload of information from bodies, technologies, and social relations on Facebook. It is a process of finding your way in an immense self-care regime of living with type 1 diabetes.

Turning to the methodological considerations of this PhD dissertation, questions arose about how to engage in fieldwork among networked individuals. How does one carry out ethnography on Facebook and what counts as observation on social media?
CHAPTER 3: METHODOLOGY

In this chapter, I will describe how I chose to conduct an intertwined online-offline (auto-)praxiography and what it encompassed in terms of data collection. I will define in detail the methods used, such as online observations within type 1 diabetes communities on Facebook, offline interviews including follow-up methods, participant observations at offline peer meetings, and focus group discussions. Furthermore, I will argue how the “auto” part has abled me to keep a unique reflexivity due to entanglement with the illness applied to all phases of this PhD dissertation.

Data such as interviews and focus group discussions have been transcribed verbatim. Notes taken during fieldwork were rewritten and uploaded to Nvivo. When all data had been converted into text, I first read all the transcripts several times and then started a coding process using NVivo10 and later 11. I coded all data according to the overall research aim of looking at self-care practices. Themes connected to the coding included self-care 24/7, sharing, online posting, online-offline relatedness, support on Facebook, downside to Facebook, and experiential knowledge. I looked for patterns in and explanatory models for the interconnectedness of online-offline connecting, including micro-practices of self-care inspired by Facebook and processes and practices of the doing-knowing cycle and how people co-constructed knowledge.
Introducing Praxiography and Tracing Self-Care Practices Online and Offline

Praxiography (also referred to as ‘praxiology’ or ‘praxeology’) is a special approach to ethnography that places the myriad of micro-practices in the foreground. Hine states that ethnography in virtual settings differs from classical ethnography in that it does not require the unrelenting immersion of the researcher in the field (Hine 2000). Although there might be some truth to this statement, I will later argue that diffuse fieldwork boundaries in the online setting can be troublesome. On the positive side, data were already available, stored permanently, and I could enter and leave the virtual realm at will and download extensive amounts of data consisting of posts, documents, and pictures. However, this PhD dissertation is also an (auto-)praxiographic voyage on which I have sought not only to give voice to the practices of the informants enrolled in peer communities on Facebook but also reflected on these through my own surrogate self-care experiences with type 1 diabetes. This brings forth issues of boundaries and disconnectedness, which I will return to within this chapter. By placing in the foreground the self-care practices of those who choose to participate online, including myself at some points, I have sought to foster a deeper understanding of the complexities that arise in everyday situations with self-care.

Buerger (2014) states that every praxiographer will have to make personal choices in the conduct of research and the context of the practices studied. Furthermore, a praxiographical study must be tailored to the problems and practices at hand, which often requires the use of multiple existing strategies and the invention of new ones in response to the material studied. In this way, praxiography can be defined as a research approach that calls for multiple methods to understand practices of various human and non-human actors within a given field consisting of an online space or offline setting. It is the field that defines the praxiographical approach and which methods will be applied (Law 2004). Multiple methods under an umbrella of praxiography are what Trowler (2008) calls hybrid methods of praxiography such as the online observation on Facebook, offline practice-near interviews and human-technology observations, participant observations at offline peer meetings, focus group discussions, and follow-up conversations that I will outline in this chapter.

Hine (2015) states that the classical “field site” in social science with fixed boundaries is becoming ever more defragmented through modern technologies. The notion of a field is stretched with the introduction of the Internet. My initial interest spanned both online and offline contexts, but I was agnostic about precisely how to research online and offline activities. Facebook provided a means to recruit informants, a source of data on their self-care practices, and a space of observation on its own. Hine argues that the Internet and social media extend a field in time and space beyond a notion of a specific online and offline site.

When I began observing the interactions in the 16 identified Facebook communities, it became evident that every life with type 1 diabetes is composed of complicated practices of handling self-care technologies throughout the day. There was no fixed time for Facebook use; informants entered and left communities, often several times a day, to read notifications from peers and post replies. I wanted to both capture and explore the doings that were shared online. This involved a focus that was not on written content per se but reflected self-care practices. This focus was made possible...
by virtue of including uploaded photos and videos on self-care practices within the type 1 diabetes community on Facebook, as well as conducting a combined offline-online fieldwork.

**Online Fieldwork**

My first fieldwork involved a pilot interview with a woman with type 1 diabetes that I knew was an active member within a larger type 1 diabetes community on Facebook. She told me about three other communities, and, fortuitously, co-administrated one community and knew the administrators of the others. She was helpful in posting an announcement about my research study within the five initially identified Facebook communities. However, she also advised me to observe unobtrusively because many investigations target people with type 1 diabetes and they are very selective about the types of research they want to take part in. Furthermore, community introductory statements and netiquettes often indicated that the communities are only for peers. With this information, I was happy about her kind offer to post a short announcement within several communities because her reputation and acknowledgement of my PhD project might generate more positive interest. The posted announcement had three aims: to reveal my lurking status, inform members about the purpose of the PhD project, and invite them to contact me to arrange individual interviews.

The Facebook communities are closed to ensure a secure environment for members, and gaining access required demonstrating familiarity with type 1 diabetes; several other administrators of Facebook communities requested that I observe unobtrusively so as not to interfere with the natural environment and inadvertently cause members to withdraw from the community. Unobtrusive observations have been identified as a method of data collection and analysis that enables the researcher to gather data across perspectives and time and in the natural setting of online social interaction without interfering in it (Patton 2002; Nørskov and Rask 2011). I only used posts from informants with whom I had established contact and who had agreed to my direct use of their posts.

**Identifying Type 1 Diabetes Communities and Getting a Sense of the Landscape**

To locate the various type 1 diabetes communities for adults, I typed different combinations of words that included type 1 diabetes, Denmark (Danmark), and Danish (Dansk) into the search field. Some communities were easy to locate in this way; I found others when informants mentioned them in interviews or when they were recommended within the communities I had already joined. I developed an experiential sense of the type 1 community landscape through my ongoing processes of identification, mapping, and observing and understanding how communities related to one another. Hine (2015) states that it is possible to get a sense of the web as a landscape. This perspective prompted exploration of the structures, routes, introductory statements, and connections between the communities and how the landscape continuously changes as new communities are established and membership increases or decreases.

During my year of fieldwork, the online field grew from five to 16 communities because the membership of existing communities increased, and new ones arose. This made it extremely difficult to follow all ongoing interactions through
continuous notification of activities on my smartphone and computer. I had to choose communities to follow more closely. I chose the top five communities that informants had ranked during face-to-face interviews as those they were most likely to use. They included two larger general communities for people type 1 diabetes, a larger community for people using insulin pumps, a community focused on exercise, and a community focused on food. I repeatedly mapped and categorized the communities (Figure 3 and 4) to understand the social processes and mechanisms of support and how they related to self-care topics I learned about through other methods. I took notes (similar to conducting offline fieldwork) and downloaded data from the communities to support my understanding of how sharing knowledge online was integrated into daily life with illness. During the interviews, informants told me about any posts they could remember having made, and I received informed consent to use them as direct quotes within articles and the dissertation.

Several online researchers have stated that online ethnography reduces time and costs, increases convenience, can be conducted in any physical setting with Internet or Wi-Fi access, allows for more sampling diversity, the potential for a large amount of data to be quickly accumulated, and more thoughtful follow-up observations and questions. It requires a single step, avoids interfering with informants, and poses no danger or discomfort for the researcher. However, pitfalls of conducting an online-only study include its criticism as a form of armchair anthropology, lacking a deeper foundation and understanding of its integration in daily life. This was another argument for a combined online-offline design.

After the introductory advertisement was posted in the five identified communities, I received many positive responses from people with type 1 diabetes who wanted to participate in the study. I experienced Facebook as a good tool for recruiting informants. I wanted to recruit people who varied in terms of insulin pump and pen use, gender, geography, age and years of living with illness, and I asked those who expressed interest in participating to share their knowledge of the research with others with the purpose of attracting more participants. This snowball recruiting method ensured a good mix of informants who were all Facebook users to varying degrees. Therefore, they represent a special group and not the entire community of people with type 1 diabetes, which also includes many children without Facebook accounts. It is difficult to obtain a clear understanding of the exact number of adults with type 1 diabetes on Facebook because many communities are open to relatives, parents of children with type 1 diabetes, and researchers lurking in the background. Furthermore, I did not focus on people who did not use Facebook in this dissertation. During some of the peer meetings, I spoke to individuals who did not use Facebook, but I will not reflect here on the reasons that they did not do so.
Struggling to Disconnect

I have never been a super user of Facebook. In 2008, I created my own personal profile on Facebook, with the purpose of staying connected to friends and to stop being pestered by relatives wanting an update when I was living abroad. By having a personal Facebook account, I became part of a group of all users whose privacy settings allow you to view their information (Brügger 2015). I could then choose from a list of people identified by name and profile pictures with whom I wanted to personally connect with by making a friend request. I carefully chose to invite family members to my personal wall to avoid any strains on biological relationships, and over the years my list of Facebook friends has steadily grown. Since I joined Facebook, the social media platform has undergone dramatic changes, expansions, and modifications that I will not detail here.

I was neither a poster nor a lurker. I did not follow the updates and activities from friends and families that, to my annoyance, spammed my Gmail account inbox. My intentional Facebook navigation began when I was inspired to go online in 2013. I carefully followed notifications of the community for parents of children with type 1 diabetes to learn all I possibly could about my daughter’s condition. At that time, I did not feel overwhelmed by the number of posts, and I entered and withdrew from the community without much reflection as I got caught up in other areas of daily life. It was not an issue or challenge to disconnect.

During fieldwork, Facebook changed from an occasional activity to an “always on” condition in my life. After I was accepted as a member of a community, I could lurk, observe ongoing interactions in shared posts, photos, and videos. Through hours of Facebook engagement, I learned that all communities have a space for uploaded files and documents, photos, and notifications of events related to the community. I also learned that these are not always visible when using a smartphone. I therefore initially chose to use my computer for viewing Facebook. Notifications about new posts within communities continually appeared on my computer and smartphone. I grew accustomed to the loud chirping noise and vibrating sensation from my purse announcing new notifications within the communities. In retrospect, I can see that I feared missing out on important interactions. With 16 communities to follow, a lot of noise and many interruptions occurred throughout the day. My increasing reliance on my smartphone changed my fieldwork to a continuous and tiresome practice of logging in and out throughout the day. The final thing I would do in the evening when lying in bed was to scroll through the various type 1 diabetes communities on Facebook, and the first thing I would do in the morning when arriving at work was to copy and paste the Facebook walls of chosen communities into a secure space for later analysis.

After I logged in, I felt that the Facebook news feed that makes up the center of the homepage served as my personal observation tower, informing me, for instance, about new posts in the insulin pump community by a woman I didn’t know. At times when I logged in, there were more than 50 new notifications within just one of the Facebook communities I followed. I felt overwhelmed, and I often considered whether I had somehow become incapable of disconnecting and if my immersion in Facebook would have negative consequences for my health. After withdrawing from the field, I still receive notifications. But they appear less and less frequently as more time passes between log-ins. I have often thought about closing my personal account because I am unwilling to spend time on activities within my personal network. However, I would not miss out on the opportunity to learn more about type 1 diabetes. As the informants often said, learning about the illness never stops.
**Understanding the Type 1 Diabetes Landscape on Facebook**

I asked for membership in other type 1 diabetes communities, primarily originating in the U.S., because I wanted to explore why Danish people with type 1 diabetes interacted only in Danish communities. When applying for membership, the U.S. administrator informed me that blood glucose values in the US are given in mg/dl, whereas Danish blood glucose values are provided in mmol/L (Figure 11). Recently, a new target value for HbA1c had been issued for long-term blood glucose measurement at quarterly clinic visits, creating much confusion within the Danish Facebook communities because it had to be translated to the common value of mmol/L. The differences between countries in numerical expressions of HbA1c levels were primary reason why Danish adults were reluctant to enroll in communities outside Denmark. Another preference for the Danish Facebook communities was the idea of a “neighborhood.” Many posts that circulated within the communities reflected a Danish context of recommending healthcare professionals, discussing and comparing municipalities in terms of financial support options, arranging meetings and offline networks, and physically sharing equipment.

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**Figure 11**: US values in mg/dl versus Danish values in mmol/L.

I was interested in understanding the uniqueness of the type 1 diabetes landscape with its many specialized communities; I therefore became a member of a Danish community for people suffering from thyroid problems. Hypothyreose or hypothyroidism is another metabolic disorder in which the thyroid gland produces insufficient levels of hormones. The Facebook community to support people with thyroid conditions has more than 17,000 members and is growing in membership numbers at the same pace as the Danish type 1 diabetes communities.

However, I experienced the landscapes of thyroid conditions and type 1 diabetes communities on Facebook as quite different. Whereas I identified 16 type 1 diabetes communities representing the nature and complexity of self-care for
this illness by specializing in self-care technologies and ways of living with the illness, this was not the case for the thyroid community. I could only identify three larger communities on Facebook for people with thyroid conditions, although the number of individuals affected with a thyroid condition is higher than the number of people affected with type 1 diabetes. Hypothyroidism is treated with an oral tablet taken once or twice a day, and no self-care technological monitoring or measuring equipment is required, compared to the many measuring, scanning, and monitoring devices used daily for people with type 1 diabetes.

Discussions within the two larger communities (I was not allowed to join a third community of people treated with “natural thyroid hormones”) generally pertained to how to understand medical records; people posted records supplied by the clinic to receive help understanding the significance of their levels and whether they should ask for supplementary blood tests. Discussions also centered on types of medicine and positive and negative effects experienced by others. People shared names and address of doctors who were willing to prescribe a thyroid medicine developed from dried thyroid glands of pigs providing both T4 and T3, compared to the “chemically produced” T3 products primarily distributed at clinics.

There was a spirit of activism within these communities, represented primarily by women who tried to convince doctors and politicians of the negative side effects of chemically produced tablets and the positive effects of the naturally produced thyroid tablets. I observed reported experiences of doctors who wouldn’t listen to individuals who were living in pain despite normal lab values, forcing women to travel to clinics outside Denmark where they received a more thorough evaluation of their condition. However, the areas of support provided in these communities did not appear as technologically focused as the areas of support provided by the type 1 diabetes communities. The complexity of living with a thyroid condition differed from the complexity of living with type 1 diabetes, and this was clearly reflected in the many established type 1 diabetes communities on brands of self-care technologies.

**Offline Fieldwork**

I interviewed a total of twelve people with type 1 diabetes. Interviews are very different from online surveys and questionnaires because they are in-depth, semi-structured, open-ended, and multi-phased and generally allow for give and take between researcher and informants (Chayko 2008). There are several modes of conducting online research, each with strengths and weaknesses. Electronic interviewing, as has been conducted in the phenomenological Chayko study, aimed at examining people’s state of mind and feelings regarding online and mobile connectedness would not have yielded insights into the pragmatic side of daily self-care. I was also concerned about the lack of visual cues in an interview conducted by Internet-based messaging, even though feelings are often expressed through emoticons. I feared that this lack might hinder understanding. Some people also prefer to share information face-to-face. I thus chose to conduct all interviews offline, and I asked informants to show me their self-care technological devices as well as how they would navigate within the preferred communities on Facebook.
**Practice-near Interviews**

The interviews took place at locations that were relevant to informants’ use of Facebook. I initially thought that the interviews, including observations of Facebook use, would take place in informants’ homes; however, it was quickly apparent that this use happens at all times of the day. Because I also wanted to understand how informants approach, enter, and navigate Facebook in their offline lives, I asked them to choose a location that was relevant to its use. Interviews were conducted in homes, at offices, on public transport, and at cafes. I called the interviews “practice-near” because I wanted to be as physically near as possible to natural instances of Facebook use. The interviews usually lasted 60 to 90 minutes. I first asked informants about their daily lives with type 1 diabetes, and they would often bring up difficult and doubt-ridden aspects of self-care. This was often followed by probing to prompt further elaboration on practices about which informants felt doubt and how they dealt with it. I asked about their use of Facebook, such as when they joined, how they found the various communities, and in what situations they would seek or share knowledge online. I also asked them about their posting behavior and how they perceived the online environment within the communities. All informants had created posts, but they did so with varying frequency. Finally, I asked informants to identify all the Facebook communities they had joined and conducted a small mapping exercise to understand how they related to each other. I then asked informants to enter one of their preferred communities while I observed. Inspired by a “think-aloud” method, I asked them to verbalize their actions when navigating online and, especially, when seeking and sharing practices (Patton, 2002; Van Someren *et al*., 1994). I will exemplify this with a small excerpt from an interview with Peter in his home, after I asked him to verbalize his actions as he completed them:

Peter: Look here…I often go to this site to download documents. Here is one with a memo when travelling.

Researcher: I didn’t get it. What did you do?

Peter: You just have to go into ‘files’. (He points to the ‘file’ function on the right side at the top of the menu within the community). And here you can upload documents, if you want. Here is one about ISIG number. This is made by Medtronic and uploaded by this woman.

(Peter now enters another community on Facebook where he is looking for a notification of an offline activity)

Peter: It is just showing the same on this page…now it is just troublesome. (He has difficulty finding his way around within the community.) Why is it not in chronological order? I just wanted to show you this advertisement. What is this now popping up…Arrrgh…look at this notification. That is just so annoying…what is this? (He reads aloud a post that just appeared as a notification at the bottom of his iPad screen, accompanied by a beeping sound that almost made him jump in his chair. When he inadvertently presses on the notification, the screen shows the new post and he loses track of where he was on the site.) Something about a mother and her trouble regulating her child’s blood sugar during exercise (he is still reading aloud the post)…looking for any suggestions…Well this is so not relevant for me!
Observing informants use and navigate within the communities with a think-aloud method enabled me to understand Facebook navigation. I was able to observe challenges they experienced in finding the right support and to understand how Facebook functions differed across devices (computer, iPad/smartphone). Informants often did not recognize the variation across devices, which caused unwanted noise.

I had several follow-up meetings with informants through email, during coffee breaks at offline peer meetings, and in their home environments. 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. Gammeltoft (2003) notes the importance of intimacy and relationships between researcher and informant as more important than the ability to distance oneself from overly entangled relationships. It was impossible to relate to the informants through my online lurking status, I used the additional follow-up methods noted above on several occasions to both clarify issues discussed previously and as a tool for further networking.

**Participating at Peer Meetings**

Participating at offline peer meetings was another method to understand self-care practices and online and offline support. I wanted to understand boundaries to online-offline interacting, levels of connectedness or relatedness, and what type of support were raised offline versus online.

I participated in six peer meetings throughout Denmark, three of which took place in the same location. They were usually announced every second month, but participation varied, as noted in the introduction. All meetings were announced through Facebook and sometimes through the Danish Diabetes Association; they usually lasted two to four hours. I used a small notebook to note down areas of support that were discussed, and I recorded all experiences in writing immediately after the meetings, allowing for an opening of all senses related to participating. On two occasions, I could record the meetings with a digital voice recorder. I was able to observe on several occasions how there was a divide in insulin pump users and insulin pen users. It was usually an opening conversation around tables: “Hi, are you on pen or pump?” which determined self-care practices and technological languages. One of the peer meetings I followed was initially for pen users and people on insulin pumps would be directed to their own groups – this occurred online as well as offline. I observed an overrepresentation of women in all peer meetings, which is more difficult to identify online. At the peer meetings, conversations tended to be on other areas as well as focused on diabetes. However, I observed how this would at times make meeting participants impatient when, for instance, conversations in smaller groups tended to include small talk such as the bad Danish weather. I also observed how conversations would turn to very intimate and personal areas such as sex, marriage, divorce and relationships in relation to type 1 diabetes that were rarely touched upon within the online communities.

Meeting informants in other ways than during interviews gave me time to both reflect and to further build rapport. Throughout the course of the fieldwork and analysis, I formulated new questions from time to time and directed them to the informants through email. I worked rather creatively even though I had a fieldwork plan and an interview guide. However, I did not strictly follow the guide because I paid attention to new questions arising during interviews and to
peer meeting discussions of issues and concerns about which I had been previously unaware. The interview guide was revised and updated frequently, and I sent follow-up questions to informants, sometimes months after the initial interview or peer meeting, to further clarify issues.

**Focus Group Discussions**

The identification of issues described in the previous section required additional data collection, and I chose to conduct two focus group discussions in a rather late stage of my fieldwork period. My aim with the focus group was to obtain more insight into the intertwined nature of online-offline support.

The focus groups were conducted at two different locations in Denmark and supplied me with a different type of data because I included exercises before and during the meetings. I used selective sampling, striving for eight participants in each focus group and an equal distribution of gender, insulin pump versus insulin pen, age range, and years of living with the illness. Thus, it turned out to be more challenging to recruit for the focus groups than the interviews. One of the focus groups was located at a peer meeting and, even though I had help in recruiting for this focus group from the administrators of the peer meeting, it was difficult to keep track of the recruitment process. I was told that there were eight people attending who represented a good selection in terms of the above-mentioned criteria; however, when we started two more people appeared who had not signed up. They thought that it was a regular peer meeting and that they could just show up before signing up for the focus group discussion. One walked out again because he did not like the format. I was concerned about the possible intrusiveness of conducting a focus group at a peer meeting, but the remaining participants assured me that it was not an issue for them and that they had been looking forward to a more structured “meeting”. The other focus group meeting took place at Steno; although I recruited eight participants, three called in sick that day. Before the discussions, I asked informants to use a camera to visually represent situations in their daily self-care in which they would use Facebook for support, as well as the resulting outcome. I realized that this homework task was rather difficult and revised it to allow for any illustration that they found relevant in relation to their self-care. Before the focus groups, participants sent me photos with a brief text note. Not all focus group participants completed the exercise, but I used these depictions as an initial probing tool during discussions to further explore real-life situations of concern to informants. I analyzed the photos collaboratively with the focus group participants and later mapped them in a photo collage as an analytic visual tool (Figure 12).
I also conducted a mapping exercise with focus group participants to understand the relationships between the different Facebook communities and how they would rate them using their own labels, such as “too general”, “only insulin pumps”, “low carb diet”, “exercise”, and “hacking”. Another exercise was a twenty-four-hour time line on which they were supposed to highlight the times of Facebook use throughout the day. This was an almost impossible task for them to carry out because Facebook was viewed several times a day from a smartphone and was not something that many restricted to specific hours during the day. I relied on the work by Wibeck, Dahlgren, and Öberg (2007) in the analysis process after transcribing both focus groups. I looked for disagreements, levels of involvement, reactions to certain expressions, commonality of experiences, and consensus of themes. I scheduled half an hour of free peer talk in the middle of the discussion, which allowed participants to share their contact information with each other. The informants expressed gratitude for the opportunity to meet with like-minded through this facilitated peer meeting space camouflaged in the format of a focus group.
“How is it to be in your shoes?” On Stretching, Empathy and Mutuality

Although we cannot feel what the other is feeling, we can use our own feelings to put us in the other’s situation and imagine how experiences such as happiness, want, longing, and pain emerge in her life.

(Gammeltoft 2003:285 – translated from Danish to English)

To conduct an interview on a warm summer day with someone who came to be one of my main informants, I bike to a café in a fancy suburban area. I had arranged to meet there with Lisa, a woman in her forties who had lived with type 1 diabetes for most of her life; in addition to the work of her daily self-care, she is a self-employed businesswoman. Her schedule is full, and she has asked to meet near her office over lunch. We choose to sit outside because the modern, minimalist décor of the café interior amplifies the small sounds made by glasses and plates into loud noises that make it difficult to hear one another. I fear that my digital recorder would miss important words and sentences. We are the only ones sitting outside, which makes it the perfect spot for conducting an interview. I know that Lisa has a great deal of useful knowledge arising from her many years of self-care practice and her insight into several Facebook communities and offline peer meetings; she is an expert patient, as described in the previous chapter.

During my usual introduction to my PhD and the aim of the interview, I notice that Lisa looks at her watch several times as if she is supposed to be somewhere else or is wondering how soon she can leave. She tells me about a peer meeting, and I ask her if I may participate at this particular meeting. Lisa replies that adults with type 1 diabetes are heavily investigated and that many are now quite reluctant to meet with researchers. As a result, she and her peers had talked about not inviting researchers to peer meetings because they should be “a free space to talk openly about the illness.” With this reply in mind, I begin to question how fruitful this interview will be. Then Lisa suddenly stops the conversation to take out an insulin pump that had been hanging from the waistband of her pants, perfectly hidden under her shirt. When she looks at the pump display to check her blood glucose number, I notice that it is the new Medtronic 640g. I ask her if it is as smart as everyone on Facebook says it is and if it is easier to calibrate than the old one. The Medtronic 640g is an insulin pump that is an upgrade of the now-old Medtronic Minimed 530g, and I have read quite a bit about it within the Facebook communities. This insulin pump has just come on the Danish market, and I am not surprised that Lisa has one. Being a fortunate owner of this device would require having a good reason for swapping it with the old one – or at least being good at coming up with a reason to swap it. Its functions are even smarter than the last one, with technology that acts intelligently on behalf of the user in new ways. What makes the 640g even more ingenious is an upgraded “Alert before Low” function. When blood glucose levels are predicted to be low in the next 30 minutes, the insulin pump will alert its user through an alarm and suspend insulin infusion. When sensing an “about to be high” number, it will begin infusing insulin again. When I first read about this device through a Facebook community, it was easy to understand the huge interest in swapping the old Medtronic device for this one, and it was also the genesis of a new community targeting only this device. Within this community, people with type 1 diabetes share advice and experience about how to get the device and support each other in convincing hospitals to distribute it.
Surprised by my technological know-how about her new device, Lisa looks up from her pump and squints at me; the sun behind me is very bright on this summer day. It is as if she suddenly remembers that, in a side remark during some telephone conversation months earlier, I told her about having a daughter with type 1 diabetes. She asks me with renewed interest what it is like to have a daughter with type 1 diabetes because she wants to understand “how it is to be in your shoes.” She apologizes for asking me the same question that she has been answering for the last decade for family, friends, and researchers. For the next thirty minutes, I explain in detail the many practices and emotional ups and downs of being a mum and a main caregiver for an illness that is outside me but deeply entangled with my life. Lisa is mesmerized as I talk, and my revealing my story creates a reciprocity that makes her more eager to reveal her own.

This interview turned out to be one of the longest I conducted. We talked for 2 1/2 hours, and it took twice as long to transcribe as any other interview. Even though my surrogate self-care is for an illness that I do not sense directly, I still share many similar practices with Lisa. I am a guardian of the life of my daughter, and Lisa is a guardian of her own life. We speak the same diabetes language; we share the same technological brands of insulin, glucometer, and insulin pump. We are both women and mothers. It is as if a special bond of mutuality was created between us as I “stretched” my position as a praxiographer.

The concept of stretching within the ethnographic encounter has been brought up by Grønseth (2010) in an ethnographic introduction on mutuality and empathy. A desired attribute of the ethnographer is stretching toward the other, without actually becoming the other. I did not intend to show Lisa that I was like her and could easily understand her condition. During the interviews, I was aware of an undesired consequence of ethnography “going native,” which has been described in earlier studies, particularly within the genre of autobiography, in which the researcher is so immersed that it becomes difficult to relate to the other and distinguish between “me” and “them” (Okely and Callaway 1992).

Grønseth (2010) state that making sense of the other is a process of analogy in which self and other are not alike but hold something similar in common that can be compared. This ability to put oneself in another’s shoes is a human attribute of empathy. The empathetic recognition and understanding of the other as like oneself requires practical and bodily engagement in others’ day-to-day living and personal interpretations and meanings of these activities and experiences. For this reason, I started this (auto-)praxiographic section with a description of my nightly blood glucose control practices as a self-care surrogate.

Through my embodied understanding and story, I did not attempt to make my own life and situation the ethnographic interest; instead, I used my personal experiences of self-care as a heightened reflexive and empathetic tool. In contrast, not revealing a part of my personal involvement with type 1 diabetes would likely have led to a closed door to the peer meeting and a very brief interview. In retrospect, I don’t consider this a formal interview, in which I carefully went through all the questions in my interview guide. It was more of a mutual sharing of life worlds. The process of stretching emphasizes a “negotiated and reciprocal common humanity across and beyond differences” (Grønseth 2010:15). The encounter with Lisa became an exploration of specific similarities connected to self-care for type 1 diabetes. Our shared experiences and practices of self-care created a mutual understanding that should not be taken for

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granted or confused with a single-minded identification on my part of Lisa’s story as identical to my own. Grønseth argues that her personal entanglement with an informant in her field worked to embody, emphasize, and create insights that made her sense her informant’s complex social and emotional processes (Grønseth 2010:151). My experiences of self-care for my daughter were not the same as Lisa’s experiences, but they allowed me to imagine what it is like to be, in her words, “in her shoes.” Learning about the other demands respect. This respect is born out of deep engagement and immersion in one’s own and the other’s world to compare and recognize distinctions and commonalities (Grønseth 2010:18). My own story of type 1 diabetes opened a magic door to a deeper level of conversation about the illness and self-care practices and about doubt, frustration, sorrow, and the hope and friendship bonds of Facebook and peer networks. The sharing of self-care practices connected to living with illness created reciprocal empathy that was possible because I had a specific kind of knowledge about the other attained through my personal practices and bodily sensations. Our lives are different, but the practices of self-care create many commonalities. At the end of the interview, Lisa invited me to the peer meeting. I am sure that the personal history and mutuality created in a process of mirroring and exploring became my ticket to this meeting.

(Auto)-Praxiography

Even though the aspect of (auto-)praxiography is not explicitly expressed in the research articles, it has been an important reflexive tool throughout this PhD dissertation. In this dissertation I have chosen to mobilize auto-praxiography as a methodological tool while carrying out studies of online-offline interactions as well as during my reading of interview transcripts, focus groups and social media postings. The research articles that follow are build up around the before mentioned online-offline approach to studying the use of self-care among adults with type 1 diabetes and at the same time auto-praxiography has played an important role in the design and analysis process.

This section moves my self and self-care surrogate practices from the backstage to the frontstage. I use (auto-)praxiography in a vein like that of auto-ethnography and other types of autobiographical writings that connect the personal with the cultural, practical, and social (Ellis and Bochner 2000). This is possible because my own practices of self-care are not unique; they hold something generalizable (Reed-Danahay 1997). Through fieldwork excerpts I will show how I relied on my own embodied knowledge as an analytical and reflexive tool.
“You don’t know how it truly feels!”

I have already described how my personal experiences of self-caring type 1 diabetes worked to open doors in the field and as an iterative reflexive tool. In this section, I will focus on how I also needed to be cautious about revealing my own story as the wife and mother of a husband and a child with type 1 diabetes.

In general, being the parent and spouse of a loved one with type 1 diabetes is obviously distinct from having the illness inside one’s body, no matter how similar the practices of self-care are. I usually emphasized this difference to informants because I know that I could never truly understand how it feels to sense fluctuating numbers or experience a state of insulin shock (hypoglycemia) or, conversely, ketoacidosis (hyperglycemia). I merely related briefly that I had a child and husband with type 1 diabetes and that I was thus aware of many of the practices related to self-care. A common reply from the informants was a positive acknowledgement along the lines of “then we share the same language.” This acknowledgement of a specific language covers the many self-care practices and vocabularies that are unique to digitalized self-care devices. However, sharing a common language of self-care practices is not the same as understanding how it truly is to live with an illness, and this was apparent while observing interactions within Facebook communities, at offline peer meetings, and even when conversing with informants.

There was an inside/outside dichotomy within the overall landscape of type 1 diabetes, illustrated by the many varied Facebook communities targeting people with type 1 diabetes that were subdivided into ways of providing self-care and living with the illness. On Facebook, parents of children with type 1 diabetes were often guided into their own communities; informants reflected on this during interviews, conversations, and peer meetings. In general, there was a perception that parents of children with type 1 diabetes are overly worried and at times exert too much control over their child. Similarly, relatives of a person with type 1 diabetes, such as a wife or husband, would never truly understand what it is like to have type-1 diabetes and should not act as a “teacher” or “diabetes police.” Concerned about being labeled as an overly concerned and controlling mother and wife, I de-emphasized my personal experiences and kept any mention of it to a brief statement or a “by the way” aside to the effect that I had practical knowledge, a different kind of embodied knowledge that a researcher or healthcare professional cannot achieve without being personally affected by the illness. The brief remark was an act of honesty that also had the purpose of creating mutual trust and empathy arising from a shared self-care language; in a few instances, I was asked to tell my personal story in depth. Nevertheless, I often struggled with feelings of being neither an insider nor an outsider in terms of this illness. Rather, I was something “in between” that I had difficulty defining. I will reflect more on this experience, using an excerpt from a participant observation at a peer meeting.

I participated in a large peer meeting that was open to people with type 1 diabetes and their relatives. There were many adults with type 1 diabetes, a few parents of children with type 1 diabetes, and a handful of relatives who appeared to have been dragged along and seemed to be silently observing. The meeting had been organized by healthcare professionals and a representative for Medtronic, which is the largest insulin pump brand in Denmark. The focus of the meeting was exercise, insulin, and carbohydrates, a combination that is often considered very difficult to handle in daily life with type 1 diabetes. There were several presentations by adults with type 1 diabetes addressing how to “crack the code” of blood glucose fluctuations before, during, and especially after exercise. The meeting lasted four hours, and there were about 50 participants, of whom only about 10 were men. Participants ranged in age from approximately 20 to
70 years and represented a mix of insulin pen users and insulin pump users. We were seated at four elongated tables, and people engaged in small talk about the difficulties of controlling blood glucose levels in relation to exercise. Many participants knew each other from network meetings and summer camps, and there was an atmosphere of positive reunion. A common conversational opener among people who were not acquainted was “Are you on a pump or a pen?” because each has a different language and practices of self-care. A group of people lined up in front of the Medtronic stand, where brochures and machines were neatly arranged on the table along with two jars containing small gifts bearing a Medtronic logo. I overheard the conversation, noting the extremely humble attitude of the Medtronic representative, who apologized for not understanding the illness “from the inside” and only being able to give technical advice related to insulin pump use. During the break, I went up to the Medtronic stand to check out the new insulin pumps. There were two demo pumps that people could try out. I was handling a demo, navigating within its many functions, when Tove, one of my main informants, came over to greet me. We talked about the ingenious new Medtronic 640g and were reflecting on how much easier self-care would be with this device when we were suddenly interrupted by a woman who pointed to the pump with a hesitant gesture. “Hey, your pump is broken. Where is your cord?” she asked, indicating that the plastic tubing that attached it to the body to infuse life-saving insulin was missing. If I had been diagnosed with type 1 diabetes and was using an insulin pump that I was manipulating to adjust an insulin dose, it would have been very inconvenient if the end of the plastic tubing connecting it to my body had somehow fallen out. Her action would have provided a very useful notification for me. However, before I had the chance to reply, Tove shouted to her, “No, Marie, she is not a type 1. She is not like us!” Marie had a confused look on her face, and Tove started laughing. I heard myself provide a longer justification of why I was handling the demo pump and then continue with an even more awkward apology about not having type 1 diabetes but being able to operate an insulin pump because I provide self-care for my daughter with the illness. At that moment, I realized that I was something in between. I was not fully accepted within the type 1 diabetes community, but, at the same time, I was not an outsider like the Medtronic representative who repeatedly excused himself for not truly understanding the illness when demonstrating the new insulin pump.

Fieldwork at (My Own) Home

An annoying sound calls me in the distance. It is pitch black in the bedroom, telling me that the beeping noise that brutally tore me away from my sleep could not have been the alarm on my smartphone. Disoriented and lying in my bed trying to adjust my eyes to the darkness, I use my right hand to find the power switch on my night lamp. The noise sounds again: beep beep beep beep....beep beep beep beep. I am suddenly completely awake as the noise sends a signal to my brain and my body reacts with a jolt of adrenalin. Quick thoughts run through my head: What if I am too late? How long has it been alarming? It is these thoughts that occasionally occupy my mind, causing fear and distress and putting a strain on my life as a mother. I know this sound very well. It is the alarm on the insulin pump belonging to my 5-year-old daughter Olivia, a digitalized life-saving machine with the purpose of replicating the function of a pancreas of a healthy person by continuously infusing small amounts of insulin. However, the pump is not without problems; it must be operated, handled, adjusted, and, finally, silenced. These nurse-like practices cannot be carried out by a child of her age. All are serious tasks that could destroy the natural innocence and unworried mind of a child, and even worse, as
we often feared in the beginning, lead to an incident of insulin shock. This was a great fear among the informants as well, which they referred to in interviews and at peer meetings and brought up within several Facebook communities as an ultimate experience of loss of control of the body and self-care. Olivia’s diabetes psychologist once told us that we should first teach her to operate the insulin pump when she is ten years old. Until then, she is completely reliant on support and guidance from machines and from my husband and me in our dual roles as her parents and her primary caregivers, replicating several practices similar to the work of a nurse. We only consult with healthcare professionals about four times a year, which is the same limited frequency reported by the study informants; we, Olivia’s parents, are her primary nurses and caregivers.

I jump out of bed and stumble out into the hallway to my daughter’s bedroom door, just across from my own and left wide open at night to allow us to hear any alarms. In the dim light from her night lamp, I can see the contours of my daughter lying peacefully in her bed. As I carefully drag her duvet away to reach the small belt bag that holds her insulin pump, I notice the specific smell of insulin. This smell clings to her insulin pump after injecting vials of insulin into small plastic reservoirs and fitting them into her insulin pump, a self-care task we carry out twice a week. The smell that meets me in the night reminds me of the difficulty of comparing it to something more familiar. I remember posts within Facebook type 1 diabetes communities drawing comparisons to Band-Aids, alcohol, or a dental clinic. However, for me, it creates the same strong sensations in my nostrils that a permanent marker does. And, just like a permanent marker, the smell is difficult to wash off if I get it on my hands or clothes. The smell gets stronger in the heat from her duvet and body temperature. After she first received the insulin pump, I often carefully checked it for any damage that might cause insulin to leak and create the distinctive odor, but I now know the smell is unavoidable.

I find the Velcro opening to the homemade belt bag and notice that it’s getting too tight; I soon have to sew new ones. We regularly have to make new ones as she grows. This is a necessary accessory that accompanies her illness and the technology used for treating it. Even though the technology has been designed to be as handy as possible to be carried around all day, an insulin pump is still a rather large and clumsy device, especially on a girl who is just 46 inches (120 cm) tall. This device is the exact model and size of the one many study informants have, except for the small glittery stickers we attached to appeal to her when she is distressed or frustrated. At times, the illness takes up too much space in her life, and she occasionally wants to destroy both the insulin pump and the “stupid illness.” When, in an overwhelming moment of despair due to the illness taking up augmented space in her daily life or in an utterly understandable moment of childish fury, she stands with the insulin pump in one hand and threatens to hurl it onto the floor, we can talk about the pretty glittery stickers on the pump. My aim is to distract and calm her down before she impulsively destroys the machine; the consequence would be going back on the insulin pen while her pump is repaired or replaced, a turn of events that would indubitably cause the illness to be ever more present.

I open the Velcro on the belt bag, purple with small flowers, her own choice some six months ago in a fabric store. I remember she wished for a “cute, princess-like” belt bag, and it almost crushed my heart experiencing her pure joy at getting this “gift bag” for her lifesaving machine. This illness was an unwanted “gift,” that she received just before her second birthday. It is a gift she did not ask for and that will be her unpredictable companion for the rest of her life.
I press the bottom of the pump to open it; simultaneously, the four-beep alarm sounds again. I silence it and open the lock on the bottom of the pump by pressing two buttons at the same time. It opens, and I see a downward arrow and a number telling me that her blood glucose is low. A text message on the insulin pump reads, “I have diabetes. Get emergency aid,” illustrating the seriousness of a low blood glucose level. When I was a beginner at stabilizing her blood glucose and prone to self-doubt, this message provoked fear and frustration. Now, years after her diagnosis, I have learned to ignore it because my experience tells me that her blood glucose can easily be fixed; liquid carbohydrates will eventually turn the downward arrows into upward ones. However, I must acknowledge this message by pressing a button repeatedly until revealing the main display where I am a step closer to functions that can stop insulin infusions, raise or decrease insulin dosages, and adjust intervals and patterns. In addition to her blood glucose number, the insulin pump display contains a graph with the green line of her number going up and down like it is climbing up and sliding down hills, the time, and how much insulin remains in the plastic container. This container is hidden inside the pump and connects the machine to her body by a plastic needle and a strip of adhesive holding it in place. I notice at the top of the pump display that it is 3.40 in the morning. Just 50 minutes before, I had checked her blood glucose and poured half a deciliter of apple juice into her, using a straw to spare her teeth from the acid in the juice. Sometimes she talks nonsense, a symptom of a low number, when I gently put her in an upright position to wake her enough to sip the liquid carbohydrates. Luckily, she always falls asleep again immediately afterward.

With such a low number detected by the continuous glucose monitor sending the signals to her insulin pump, I also need to prick her finger or toe. The continuous glucose monitor detects the blood glucose in her tissue, which can sometimes be inaccurate, so I need to check the level in her blood. My anxiety is that the number might be a lot lower than the 3.2 mmol/L displayed on her insulin pump, which requires immediate action. I find her feet underneath the duvet and reach for the foot I did not prick last time, the one that still wears a pink size 28 sock. I take off the sock to be able to puncture one of her little toes. Inserting a small lancet into her glucometer turns the device on so it’s ready to work with me. With a single push on a small button on the side of her finger-pricking device, I swap the old needle with a new one and adjust the size of the needle to ‘a toe’, with 1.5 indicating the length of the needle that is the smallest I can use to obtain a successful result. If I make the needle too long, I risk damaging the tissue in her fingertips or toes, which could cause loss of feeling. If the needle is too short, I have to prick her more times. That is another reason why I switch between her fingers and her toes. Her toes require a longer needle than her fingers to create a puncture that can squeeze out a large enough drop of blood. I will also have to carefully prick the side of her toe because the middle part is more sensitive. It takes some time to calculate where to prick her toe in the dim light; I must measure where I should place the small hole for the needle before I can press on the top of the device to create a perfect puncture. I press the top button and hear a clicking sound that tells me that the needle pricked her toe. Then I silently count to 10. The delay allows more blood to flow so that I can use the smallest size needle, a trick I learned in a type 1 diabetes community on Facebook. I effortlessly press out a drop of blood that is large enough to be sucked up by the small lancet going into the glucometer. The device makes a small beeping noise, indicating that there is enough blood to measure her blood glucose level. The meter counts down and reveals a number of 3 mmol/L, just slightly different from the number revealed by the continuous glucose monitor. But this number is still too low, and I fear that it will continue to fall, and I will have to make sure that her continuous insulin infusion is put on hold. She must be above 4 mmol/L, at least, and I am more confident if her number stays between 6 and 8 mmol/L. I run down the stairs to the kitchen and open a new
box of juice, measuring out a deciliter this time. Her blood sugar needs to go up, so we can have some peaceful hours of sleep before we are awakened by another alarm, this time from the clock on my smartphone ….

(Auto-praxiographic excerpt, August 2015)

Figure 13: A practice of calibrating a blood glucose number in my daughter’s insulin pump
(Auto-)Praxiographic Reflections

This (auto-)praxiographic section was recorded in my personal diary during the period in which I also conducted fieldwork. It resembles many of the practices of the informants in terms of self-care, decision-making, predictions, and many nurse-like practices. However, it also shares similarities with the identity work associated with reconstructing and negotiating feelings such as fear and anxiety and times when the presence of the illness tends to negatively influence daily life. When illness tended to dominate daily life, informants sought out strategies to make self-care easier and reduce an unwanted focus on the illness.

Controlling nightly blood glucose fluctuations is a common practice that was eagerly discussed online. It was also a concern that informants repeatedly raised during interviews, on Facebook, and at offline peer meetings. The greatest asset of an “auto” approach is that it offers a tool to research themes or practices that are difficult or impossible to study (Uotinen 2011). I was unable to observe this nightly practice in the homes of informants, where Facebook becomes a lifeline for some, but (auto-)praxiography allowed me to reflect on my own nightly practices and compare them to the practices informants described in interviews, at peer meetings, and online in the Facebook communities. In the study by Scheldeman (2010) on young people’s use of insulin pumps, she describes how she used a method (similar to auto-praxiography even though she does not label it as such) of wearing an insulin pump herself as an “embodied experiment” because she could not follow her informants and observe pump use in action. She used her own reflections of wearing a pump as an opening topic when discussing self-care issues with informants.

The (auto-)praxiographic journey adds another layer to my data, because it is used as a reflexive tool to create in-depth understanding of embodied self-care practices described by informants. Coffey (1999) argues that fieldwork is an embodied practice and that the researcher’s body matters regardless of the research method employed. Similarly, Ellingson recommends writing autoethnographically about the research process, relying on all senses. She refers to a call from Ellis and Bochner for more studies in which researchers expose a vulnerable self by revealing how they are moved by and move through emotional and difficult times in the field (Ellingson 2006; Ellis and Bochner 2000). Even though the (auto-)praxiographic excerpt reveals a difficult nightly practice, it is not the emotional aspects that I wanted to shed light on. Rather, my aim is to highlight its commonality at a highly practical level with rich descriptions of comprehensive practices and negotiations with technologies provided by informants. The term embodied does not imply that I am a carrier of this illness in a biological sense; it relates to experiential and entangled practices of ongoing negotiations between bodies, technologies, and daily lives for which peer support on Facebook becomes a medium and a facilitator of knowledge-enriching processes.

Through ongoing practices in my own home in my role as my daughter’s surrogate self-care practitioner and with her being my most intimate as well as most challenging informant, I was both an insider and an outsider. The self-care practices with which I am involved on a daily basis have given me an extended opportunity for ongoing reflections and embodied experiences that have generated further examination of informants’ experiences. They gave me fuel to more closely examine self-care practices I experienced online and offline, which were often related to technology used in daily care. When taking notes during online observations or offline interviews and participant observations, I made brief notes about differences and similarities and areas that I needed to further explore.
Several times I used my own experiences to retrospectively discuss issues with informants, an experience that my entanglement with the field made possible. Michael Moffat (1992) states that ethnographers who are studying people similar to themselves may be more attuned to cultural nuances than far-from-home anthropologists and more capable of drawing on experiential understanding. They can often “blend-in more completely – verbally, behaviorally, physically - possibly making for better rapport.” (Moffat 1992:2006).

In practical terms, my (auto-)praxiographic and embodied fieldwork began when my daughter was diagnosed with type 1 diabetes in 2013, just two months after I started this PhD study. This fieldwork was elevated to the level of analysis when I began interviewing informants in June 2015. I decided to carefully record experiences, thoughts, and feelings in my personal diary that might parallel the practices of adults with type 1 diabetes; my dissertation supervisors encouraged this approach. Initially, I was afraid that my personal embeddedness in the field would somehow keep me from an objective stance. While writing this section, I repeatedly reflected on what actually constitutes a field for “real” research. This reflection leads to a new question: what is knowledge? The question of knowledge has influenced this PhD work on more than one level. My self-reflections are intimately related to the overall question of what comprises patient knowledge and to what extent individuals with chronic illness go about constructing a particular kind of practical knowledge about how to live with illness. In acknowledging that all knowledge is co-constructed, why should my own practices not also count as a special type of reflexive “data”?

The shift to “auto” represented extended reflexive fieldwork in my own home and added another dimension to the online and offline data gathering I conducted when following informants. What defines the results of the (auto-)praxiography as a special type of reflexive data are my praxiographic diary and the analytical reflections throughout fieldwork that explored how my experiences and practices were different from and similar to the practices of the adults diagnosed with type 1 diabetes who were the focus of this study. This position—of analyzing the practices of self and others—demanded a high level of consideration, and I used my personal diary as a tool for extensive reflection. In the process of transcribing interviews, peer meetings, and focus group discussions, I retrospectively reflected on my own experiences, which often raised new questions about self-care.

The term “fieldwork at home” originally pertained to fieldwork in one’s own country, typically defined by shared language, culture, and norms; sometimes, it correlates with autoethnography as an inner study within one’s own context (Denshire 2014). Autoethnography has been defined as a highly personal account that draws upon the experience of the author/researcher (Denshire 2014); it creates a “space of resistance between the individual (auto) and the collective (ethno) where the writing (graphy) cannot be foreclosed” (Lionnett 1990: 391). (Auto-)praxiography is less interested in the ethno and can be defined as the continuous practice of participant observation that took place simultaneously in my home and while following informants outside of it. The fieldwork was never on hold, not even on weekends or vacations or during other natural retreats from the field. In a less structured way, it will continue from dusk to dawn after this PhD is finished.

I became inspired to follow in the footsteps of distinguished anthropologists, such as Danilyn Rutherford, Faye Ginsburg, and Rayna Rapp, drawing on personal experiences of being mothers and providing self-care for disabled children. In the essay, “How Structuralism Matters,” Rutherford reveals her auto-ethnographic endeavor halfway
through the text. She reflects on her own situation with Millie, her sixteen-year-old severely disabled daughter (Rutherford 2016). Through her experience as a mother to a disabled child, she raises her embodied knowledge of a life with a disabled child to an analytical level to highlight important points of “examining matter out of place” (ibid: 62). In an article on entangled ethnography, Ginsburg and Rapp draw on embodied experiences of being mothers to children with a rare genetic disorder (Ginsburg and Rapp 2013). “Entangled ethnography” articulates the way they brought both insider and outsider perspectives into a productive dialogue on learning disability.

My extensive fieldwork in my home gave me the opportunity to draw on my expertise about life with type 1 diabetes, including daily self-care practices and terminology that are difficult for outsiders to grasp. Practices related to self-care involve learning a practical language that must be mastered over time. Participant observation has always stressed that the ethnographer should learn the “natives’ language” (Grønseth 2010b:8). This often requires extended fieldwork, which is an impossible luxury for many ethnographers. Therefore, ethnographers often rely on a gatekeeper who also works as an interpreter in the field. I experienced the ability to speak the same self-care language as informants as providing many advantages, which are discussed in the following section.

**Ethical Considerations and Limitations**

Informed consent, privacy, and confidentiality are basic ethical tenets of research involving people. I have followed the seven considerations for researchers before, during, and after studying an internet community proposed by Eysenbach and Till (2001). The considerations are intrusiveness, perceived privacy, vulnerability, potential harm, informed consent, confidentiality, and intellectual property rights. I will now discuss some of these in detail.

My first concern has been to protect the informants from potential harm associated with disclosing their identities. This is a concern that all qualitative researchers must consider before, during, and after fieldwork. This consideration becomes more critical when researching small, connected communities, particularly on the social media site Facebook because posts are linked to the account of the individual who created them (Damianakis and Woodford 2012). Achieving informed consent is pivotal. Even though the informants in this PhD study allowed the use of direct quotes and posts on Facebook, my concern was whether this would be sufficient ethically. When conducting research in small communities, there is an increased risk of unintentionally disclosing the identities of study informants. I had to carefully consider how to make sure that the identities of the informants would remain unknown even though some allowed me to disclose their identities. Although I asked informants about demographic information such as gender, age, geographical location, names of Facebook communities used, occupation, years of living with type 1 diabetes, use of self-care technology (pen versus insulin pumps, continuous glucose monitor, and brands), I have chosen not to disclose geographical location and their real names in order to conceal their identities. Morse (1998) raised issues related to using raw data even when it is anonymized through the use of pseudonyms. I protect the confidentiality of informants by applying a method of mixing pseudonyms, which means I have changed the names of individual informants throughout to obscure any identification. Although I used direct quotes in some instances, I strived to report all
information about the informants in general terms, altering nonessential details and omitting any potentially harmful details about occupation and lifestyle. In addition, I protect the privacy of the communities on Facebook that I observed that were also mentioned by informants, describing them only generally. Even though informants have given me their consent to use their posts from Facebook in this dissertation, I have included only a few. Eysenbach and Till (2001) advise researchers who conduct research within online communities to retrospectively request written permission from each person whose posts will be used, giving them the opportunity to decline the opportunity for inclusion in the analysis. I ensured that I received specific written consent through email that included the direct quote (posts) I wanted to use. This gave informants time to reflect about whether they would allow me to use their post as is or if they wanted to modify or add to it. I have not directly connected individual informants to the community where the post is located by disclosing the name of the community. I have provided only the topic of the community, such as general type 1 diabetes, exercise, or insulin pumps.

My lurking status must also be addressed. Eysenbach and Till (2001) report increasing evidence that researchers who post or lurk may be perceived as intruders damaging the natural environment of online communities. They state that the researcher must take into consideration whether the community is public or private. As stated earlier, I observed in the non-obtrusive way advised by the community administrators. However, my lurking status was revealed in a short post about my research. Eysenbach and Till define a private community as one in which membership access requires some form of registration. I find this definition difficult to compare to the communities for people with type 1 diabetes on Facebook; although they are closed communities, which are comparable to a private status, they rarely required any rationale when applying for access. Initially, I wrote to the administrators of the communities I had identified, disclosing my research aim and desired lurking status. According to Eysenbach and Till, this is ethically insufficient because the administrators are unlikely to be able to speak on behalf of all community members. Therefore, I also provided an additional description of my research aim that was posted within the communities. Another issue related to my status as an online lurker is whether it truly represents ethnography because I did not directly participate in posting activities. Hine (2015) recommends that the ethnographer actively participate online as one would do in a real field site, but she acknowledges the different forms and online constructions of social media and that a lurking status is more common with online discussion groups. Online lurking can be supplemented by a strategy of following members into offline meetings in which it is easier for the researcher to participate:

Mutual visibility for ethnographic purposes may not, therefore, have to happen solely through the medium of the online discussion group itself, and can be achieved through direct email contact, through participation in face-to-face meetings, through blogging, or in whatever additional means are deemed sensible and appropriate by that group.

(Hine 2015:3)
I adhered to this recommendation by following informants to offline peer meetings, which allowed me to participate more fully than I could in online discussions. I supplemented this method with additional interviews, focus group discussions, and several informal conversations. As many new communities were established, I chose to apply without first revealing my status to the administrators, who were often either founders of the new communities or co-administrators. I simply applied for membership with a single press of a button, and I was allowed access to these communities without providing any additional details. However, these communities are used in this PhD dissertation only as background information. The question remains of how to define and assess the public or private status of online communities. Eysenbach and Till also noted that the size of the community dictates whether it should be regarded as public or private. A membership of less than 10 defines a private community; more than 100 members indicate a public one. The communities I investigated had 100 to 4000 members and so could be considered public by these criteria. Finally, the welcome or introductory page to the specific communities that detailed its norms, codes of behavior, target audience, and aim did not prohibit researchers from applying for membership and lurking. I carefully read all community introductory or welcome statements to ensure I did not violate any specified rules. The only restriction typically mentioned was on marketing or sales or services or products, and the consequence of violating it was expulsion from the community.

More members of Facebook communities for people with type 1 diabetes lurk than post. I anticipated that members who more actively posted in the Facebook communities might be more likely than non-posters to respond to appeals for interviews (Hine 2015). Therefore, I had to consider the representativeness of these informants, e.g., whether they belonged to a smaller segment of super users. To recruit less active informants, I used a snowball method in which I asked informants I had already interviewed to help identify additional informants who were both active and less active posters. I wanted to talk to very active posters within the communities who did not respond to the appeal in my introductory post; I contacted some of these individuals directly through a messenger text or asked informants who were acquainted with them to assist me in establishing contact. A potential limitation to this study is very few interactions with non-users of Facebook. However, the aim of this PhD has been to understand self-care practices facilitated through Facebook, and data from non-users would not have helped me achieve it.

There are several reasons why I have bracketed the ‘auto’ in front of praxiography. First, this methodological reasoning was not mentioned in the second and third research articles (the first article is built on analysis of secondary data). This was a matter of choice, style, and strategy. My primary goal was to describe the practices of adults with type 1 diabetes that I followed online; word limits precluded an adequate description of my personal praxiography. Furthermore, I realized that the field of auto-ethnography is energetically discussed and criticized; revealing my (auto-)praxiographic approach, which is understudied within the literature, calls for a separate research article specific to the topic. A reflexive attention to the choices being made by the ethnographer is key, such as considering the nature of the circumstances under which a particular account was produced and exploring how it could have been otherwise (Hine 2015). In terms of “going (auto-)praxiographic,” I was well aware of the universal criticisms related to self-indulgence, narcissism, or going native. Sparkes provides a more nuanced perspective, declaring that writing about the self always involves writing about relationships and contexts (Sparkes 2013). Hine states that the ethnographer as auto-ethnographer can attend to generalized terms and common discourses that inform actions and shape expectations,
thinking about where pressures to conform come from and how they are mediated (Hine 2015: 29). An ethnography will always be to some extent auto-ethnographic (or praxiographic, depending on the overall objective and lenses for analyzing the data) because individuals can never truly detach from processes or avoid psychological mirroring or relating to embodied know-how. However, this can comprise a highly self-reflexive tool. Particularly in relationship to media dissemination in which I translate my academic writing and analysis into text for public consumption, I rely on Low and Merry (2010) who state that, in practice, academic and activist endeavors are never autonomous, despite any analytical assumptions of disconnectedness.

Anthropology in particular has a tradition of conducting extensive fieldwork, after which the ethnographer returns from the field with a quantifiable amount raw data that need to be analyzed. For the articles and this PhD framework I have only used a part of my data, excluding that which I considered highly sensitive and potentially harmful to informants if revealed. In my ongoing reflection and self-critique during this PhD process, I also reached out to researchers in a number of disciplines who conduct studies on the Internet and asked them to elaborate on areas of their work that raised ethical aspects related to research on the Internet and in social media spaces. Furthermore, I conducted an extensive review of the literature pertaining to ethical conduct in qualitative research and, more specifically, in research on the Internet.

**Summing Up Chapter 3**

With a focus on doing and knowing, methodological inspiration for designing the fieldwork was found within praxiography. Combining online and offline fieldwork while at the same time mobilizing (auto-)praxiography has contributed exhaustive insights into the comprehensive practices of self-care for type 1 diabetes and how social media has become an extensive part of daily life for an increasing number of people. I have shown how I used my embodied knowledge as a self-care surrogate to both build rapport and as a reflexive tool in the analysis to understand complex human-technological practices of self-care. Using field excerpts, I discuss how I felt like an insider, an outsider, and something in between due to my lack of sensed physicality of living with type 1 diabetes. I could relate to the many practices surrounding self-care but I would never be able to grasp how it really is to experience blood glucose fluctuations.

Remaining questions include: How does a study of living with type 1 diabetes in the twenty-first century become pertinent? What do social media and interactive communities on Facebook signify for the daily struggle of living with type 1 diabetes? I address these in the final chapter of this dissertation.
CHAPTER 4: CONCLUSION, RECOMMENDATIONS AND FUTURE PERSPECTIVES

The Tinkering M-Patient Attuning to a Life with Type 1 Diabetes

This chapter concludes this PhD dissertation by highlighting the main finding of a conceptual definition of a tinkering M-patient attuning to a life with type 1 diabetes, which combines the major findings of the three research articles.

With a recent transition from E-Health to M-Health, support and guidance on how to self-care and live with an illness have become available through a single click on a smartphone (Horst and Miller 2012). As Hine (2015) states, the Internet, including social media platforms used in daily life by people with and without chronic illness, are now ever more embedded and embodied in daily life. Facebook can be defined as a space of online biosociality that facilitates a community of self-care practice (Rabinow 1996; Wenger 1991). The themes circulating within the type 1 diabetes communities on Facebook were based on what peers know about through their bodies and sharing this knowledge so others can tinker with it (Pols 2012: 86).

Facebook becomes pertinent by providing knowledge shared and co-created by people with illness that is highly specific to individual daily living circumstances. However, the importance of social media for support in daily life with a chronic illness such as type 1 diabetes is not always fully recognized (Fergie, Hunt and Hilton 2016). Acknowledging the ways in which seeking information online has changed by including social media that explores people’s practices through peer-to-peer connections could offer new insights into contemporary engagement with and use of online information and knowledge for health-related purposes.

As discussed in this PhD dissertation, social media is not only a space to interact; it is also a space for collective learning about self-care at a pragmatic level. Type 1 diabetes communities are spaces to post questions, supply answers, and express thoughts and feelings about how to attune to self-care and a life with illness. They are used as a space for freedom and for frustration, an experiential space, and a knowing-by-doing encyclopedia. Facebook has outperformed other types of social media, taking the lead in online social interaction among Danish adults with type 1 diabetes; we can only anticipate that it is here to stay. It is time to acknowledge the importance of Facebook searching and sharing in the daily life of people with type 1 diabetes and how Facebook peer-to-peer interaction turns patients into persons again. This view is in contrast to the many stories of clinical visits with impersonal routines that dismissed and even demeaned informants’ personal attunement strategies. Informants perceived these interactions as dehumanizing and felt treated as though they were not fully capable of making their own self-care decisions.

Facebook communities for adults with type 1 diabetes are important for the transmission of self-care knowledge. A wealth of knowledge exists on how to carry out self-care practices in situated areas of daily life using specific technologies. The communities become interactive sources of inspiration with rich troves of uploaded pictures and step-by-step descriptions. Facebook highlights the nature of helpful knowledge, and, over a year, I outlined and categorized the support it provided that included emotional and practical advice on how to self-care and live with illness. What I
observed was a very practical type of knowledge derived through continuous embodiment of the illness and self-care technologies for treating it and knowing-by-doing. Facebook was especially used as a melting pot for experiential knowledge; member-reported experiments would be recreated and co-constructed into new experiments by other members.

My analytical interest is in processes and sharing of experiential patient knowledge that inspired offline tinkering with self-care and how informants use various attunement strategies to balance life with illness. Indeed, Facebook played a pivotal role in both translating and transforming knowledge from the clinic to the home through processes and practices of co-construction among peers. Biomedical knowledge was questioned; experiments were conducted through practices of tinkering based on ongoing negotiations between bodies, technologies, and daily lives. These situated experiments were then shared within the various communities, often accompanied by uploaded visual material that inspired new rounds of situated offline tinkering. In comparison to Pols study on webcams she describes how the sharing of peer experiences created a messy type of knowledge, as a patient-practiced research in the wild. The sociality and interactive element of connecting through technology helped turn experience into knowledge (Pols 2012: 76). In relation to this PhD dissertation this type of knowledge was crucial for informants to make sense of self-care in various situations of daily life.

I have defined the informants in this PhD dissertation as active tinkering M-patients with unlimited access through portable devices such as smartphones, tablets, and iPads to knowledge and groups of people with whom they can share experiences through communities on Facebook. As Pols states in her 2012 study self-care and management becomes interdependent through the technology and therefore “together-management” is a better term (Pols 2012: 76). The platform allows for extensive peer-to-peer connections and for building communities that were generally seen as useful and rewarding. However, these communities differed, encompassing varying types of knowledge based on how adults with type 1 diabetes practiced and organized self-care.

M-health opens new opportunities in daily self-care of people with type 1 diabetes and other chronic illnesses. I observed the ease of accessing various health-related communities on Facebook and the speed with which support came in the form of replies and answers to posted concerns. Adults with type 1 diabetes would scroll through various posts on Facebook at their own pace and learn about self-care concerns that they struggled with or ask questions about concerns that they did not yet grapple with. Facebook has a potential to supplement four yearly clinic visits because it is both approachable from and embedded in everyday life. Facebook has become both an online manual and a virtual pat on the shoulder. Nevertheless, I observed that it was sometimes difficult for informants to find their way into the right community for their specific self-care and lifestyle situation. This difficulty created online social noise and, in this way, Facebook was viewed as another item to handle in daily life, in addition to an illness that created embodied noise and self-care technologies that required handling and adjustment to avoid excess noise from alarms.

Learning how to use the various Facebook functions and being able to process the huge amount of data from bodies, technologies, and Facebook can be a substantial contribution to daily self-care. However, in situations where the illness and the technologies created too much noise, there was a risk of dysappearance, defined as an augmented focus on the illness that caused fear and distress and tipped the scale away from a balanced life with illness.
In this PhD dissertation, I have relied on several concepts and metaphors (emic and etic) that emerged through analysis. The concept of a tinkering M-patient supplies a factually accurate concept of a growing societal tendency among laypeople to search for and share health-related information on and through social media by use of wearable technologies such as smartphones. Facebook has become a center for online biosociality, allowing people to group together in a sense of shared embodiment of an illness condition that requires extensive self-care.

Metaphors for illnesses can be used to enhance communication between doctors and patients. Illness-related metaphors, such as walking on a hillside to refer to daily struggles with fluctuating blood glucoses, are tools used by people with type 1 diabetes to express experiences of their daily self-care (Sontag 1978). The metaphor of excess noise as dysappearance of the chronic illness of type 1 diabetes reflects life with illness amidst 21st century advances in medical and digitalized technologies.
Recommendations

An industrial PhD supported by the Innovation Fund calls for a section that highlights recommendations for Health Prevention at Steno Diabetes Center Copenhagen where this PhD was situated.

Much evidence indicates that Facebook is here to stay because of the way it has already outpaced other social media platforms and healthcare-driven patient portals and become fundamentally integrated into daily life. Facebook provides fast and easy access to peer support that can supplement quarterly clinic visits. I will now outline pragmatic suggestions targeting healthcare professionals and people with type 1 diabetes.

Facebook as an area of dialogue

I recommend that healthcare professionals devote consultation time to discuss Facebook support whenever it comes up naturally. Use of both online and offline peer support should be a topic of interest and not suspicion. Turning one’s back on Facebook or dismissing the experiential patient support it facilitates does not enhance dynamics and dialogue between healthcare professionals and patients. When an open dialogue around Facebook is created, healthcare professionals can help persons distinguish between valuable information and misinformation. Similarly, I suggest that people with type 1 diabetes reveal their knowledge-sharing activities to their healthcare professionals. In this way, they can receive necessary support and guidance in relation to these activities, which might create dialogue about emerging modes of support related to recent research findings or other people’s successful tinkering about which the healthcare professional might be aware.

Facebook as a valuable source of experiential patient knowledge

Healthcare professionals could consider joining Facebook because it represents an opportunity to engage with patients in new person-centered ways and obtain access to the experiential patient knowledge that is eagerly shared online. Facebook offers a tool to better understand patients’ current concerns and needs related to self-care. People with type 1 diabetes should consider letting healthcare professionals “lurk” as background observers because it creates opportunities for them to gain insight into important areas of concern and doubt in self-care. This insight can augment and enhance traditional care delivery and patient-provider communication.

An overview of the good communities

The different Facebook communities contained distinct types of information and knowledge: personal stories, tips, emotional disclosures met with many likes and emoticons, reviews of healthcare practitioners with and without personal experience with the illness, and announcements of offline peer meetings. Facebook was both an online manual on how to self-care and an online encyclopedia about how to live with illness that could be made more accessible to healthcare professionals. An international example of a well-established platform is PatientsLikeMe. It is a free online community platform
for patients with life-changing conditions to monitor and share the course of their disease. While patients interact to help improve their outcomes, the data they provide helps researchers, healthcare professionals, and industry learn how these diseases act in the real world. Recommending the right community to people with type 1 diabetes can support them in their daily living with illness and use of particular self-care technologies. Furthermore, people with type 1 diabetes should identify the good communities and those targeting specific areas of support for healthcare professionals.

Experiential Patient Knowledge

Healthcare professionals should both consider the scope of their knowledge and be open to a concept of “experiential patient knowledge.” This PhD reveals that the experiential patient knowledge co-created by people with type 1 diabetes through Facebook is pragmatic knowledge developed in daily life situations with the illness. Tinkering with self-care is crucial to living a good life with illness and should be both acknowledged and encouraged.

Moderate use of Facebook

Although Facebook use in general was seen to be supportive, it is important to recognize that appropriate levels of engagement are very individual. For some individuals too much time spent on Facebook can lead to a negative, augmented focus on the illness. This was particularly the case when informants had difficulties finding their way into the right community or lacked skills for navigating the platform. Searching in an overload of information can be time-consuming and increase the awareness of the illness. Furthermore, healthcare professionals could supply patients with knowledge about how to critically appraise information provided on Facebook.

A knowledge database intervention

People with type 1 diabetes, social scientists, nursing scientists, and healthcare professionals could collaboratively create a database of the types of experiential patient knowledge valued by people with type 1 diabetes and recognized by healthcare professionals, thus increasing its availability and acceptability to patients, researchers, and healthcare professionals.
Areas for Future Research

Developing the research articles raised questions calling for future research. One area of future research is examining the effect on the healthcare professional/patient relationship when people with type 1 diabetes disclose their experiential knowledge mediated through Facebook peer interaction in the consultation room. This PhD dissertation merely touched on this question, which requires a broad focus that includes the perception and experiences of healthcare professionals.

Oxlund (2012) argues that the development of the “Patient 2.0” and new technologies empower patients and may also contribute to undermining the traditional authority of healthcare professionals, who are regularly presented with print-outs of information from the Internet during clinic visits.

I observed that people with type 1 diabetes came to understand more about their illness than their healthcare professionals did, in terms of living with the illness. People with type 1 diabetes have only one specialization to keep up with and plenty of time and motivation to research all aspects of their illness (Pols 2012). The experiential patient knowledge peers co-create through Facebook was far more attuned to their bodies and daily lives than the knowledge distributed by healthcare professionals. This stimulated peer discussions on Facebook about how to find a healthcare professional with experiential knowledge of the illness. A diagnosis of type 1 diabetes enables membership in peer communities on Facebook, and little research has been done on how the processes and practices observed and analyzed within this PhD dissertation change the symmetry of patient-healthcare professional interactions.

Pols (2012:81) states that equipping patients with the right technology will help them provide better self-care, including management of bodies, illness, and daily lives. However, online communities on Facebook might not have been a part of this plan. The knowledge shared within these communities is often beyond the reach and influence of healthcare professionals, and national discussions in healthcare are currently taking place on how to control the flow of health-related information. When visiting clinic waiting rooms, I never encountered a notice or informational flyer about the many Facebook communities for adults with type 1 diabetes. The informants had to find their own ways into online communities because healthcare professionals neither suggested nor recommended them. Conversely, informants were reluctant to disclose their use of the peer communities as a result of previous experiences of negative responses from healthcare professionals that included annoyance when informants negotiated with them about the best ways to provide self-care. Peer-to-peer knowledge sharing on social media is uncontrollable, but patient experience is generally treated as authoritative and worthy of being characterized as knowledge only to the extent that it seems compatible with biomedical knowledge and assumptions. An informant who sets off down a radically different path, relying, for example, on peer advice from a Facebook community on tinkering with self-care technologies is a subject that needs further research. Informants frequently saw healthcare professionals as an obstacle to informed choice, rather than an impartial source of advice and information.
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This PhD dissertation will explore how adults with type 1 diabetes engage in social media as they go about their daily self-care. The overall research aim guiding this dissertation is how practices and knowledge about how to self-care and live with illness become co-constructed through processes of online searching and sharing and offline tinkering with self-care.

I conducted a year of (auto-)praxiography with a method of following informants into online and offline social spaces where knowledge about self-care is shared and co-constructed. Data collection includes online observations, offline practice-near interviews, participant observations of offline peer meetings and focus group discussions. (Auto-)praxiography signifies how I, as a self-care surrogate to a child with type 1 diabetes, have drawn on my embodied knowledge and experiences of diabetes self-care as a reflexive methodological tool.

I propose a conceptual framework of doing, knowing, and attuning to understand how people with type 1 diabetes engage with social media in their daily efforts of self-care. The concept of attuning was developed during analysis when it became apparent that attunement worked as a bridge between doing and knowing. Attunement is a state of fine-tuning and adjusting. It involves practices of filtering information as well as tinkering with and negotiating knowledge from bodies and technologies to fit daily lives. It is a constant balancing process. Thus, the analysis also reveals how living with a chronic illness in the twenty-first century is demanding because people must process enormous amounts of data from their bodies, self-care technologies, and social media to avoid noise as dysappearance, defined as an augmented focus on the illness. The analysis further reveals that daily life with type 1 diabetes comprises many daily decision-making, prediction, and calibration practices focused on quotidian fluctuations in blood glucose. The inherent complexity of these practices is such that informants were often left in doubt about how to perform self-care. With a few limited interactions a year with healthcare professionals, patients turn online and offline to peers for guidance and support. The analysis indicates that processes and practices of online searching and sharing and offline tinkering with self-care create experiential patient knowledge on how to live with illness. This practical patient knowledge is generated through a dialogue between doing and knowing in which attunement as a state of fine-tuning information evolved.

Attuning to self-care and a life with type 1 diabetes involves practices of tinkering and negotiations between bodies, technologies and daily lives. While Facebook has become a valuable space for self-care support, as illustrated by 16 communities on this platform for adults with type 1 diabetes in Denmark alone, it was often also surrounded by noise. Noise is dysappearance, used as a metaphor for an overload of information from bodies, self-care technologies, and Facebook that creates an unwanted focus on the body and illness. To reduce levels of experienced noise, informants must develop strategies of attuning to a life with illness that includes listening to bodies, adjusting self-care technologies, and sorting through posts on Facebook.

Finally, I conclude that people living with type 1 diabetes are carriers of practical knowledge through their comprehensive endeavors in daily self-care. Facebook is a valued medium for sharing knowledge about self-care that, through peer-to-peer interactions, becomes co-constructed to fit individual bodies, technologies, and daily lives.
**Dansk**

**DANSK RESUMÉ**

Denne Ph.d. afdækker, hvordan voksne med type 1 diabetes bruger og integrerer Facebook i hverdagslivet og egen-behandlingen af type 1 diabetes. Det overordnede forskningsobjekt i afhandlingen viser, hvordan praksis og viden om egen-behandling og liv med type 1 diabetes understøttes af processer af online søgning og deling samt offline eksperimenter med egen-behandling.

Jeg har udført et års (auto-)praksiografi, hvor jeg har fulgt informanter på online og offline fællesskaber, hvor viden om egen-behandling deles og udvikles. Dataindsamlingen inkluderede online observationer, deltagende observationer ved offline peer møder, interviews og fokus grupper. (Auto-)prakiografi indebærer, at jeg som mor til et barn med type 1 diabetes varetager barnets egen-behandling og dermed trækker på egen viden og erfaring om behandlingen som et reflektivt metodisk redskab.


Afhandlingen konkluderer, at personer med type 1 diabetes ophyber praktisk viden gennem omfattende egen-behandlings bestrebelser. Facebook er et værdifuldt medie til at dele viden om egen-behandling, der via interaktioner med ligestillede udvikles, så krop, teknologi og dagligdag i højere grad spiller tilfredsstillende sammen.
PART TWO

The Articles

*Online peer-to-peer communities in the daily lives of people with chronic illness: A qualitative systematic review*


Authors: Natasja Kingod, Bryan Cleal, Ayo Wahlberg, and Gitte Husted

Abstract

This qualitative systematic review investigated how individuals with chronic illness experience online peer-to-peer support and how their experiences influence daily life with illness. Selected studies were appraised by quality criteria focused upon; research questions and study design, participant selection, methods of data collection and methods of analysis. Four themes were identified: 1) illness-associated identity work; 2) social support and connectivity; 3) experiential knowledge sharing; and 4) collective voice and mobilization. Findings indicate that online peer-to-peer communities provide a supportive space for daily self-care related to chronic illness. Online communities provided a valued space to strengthen social ties and exchange knowledge that supported offline ties and patient-doctor relationships. Individuals used online communities to exchange experiential knowledge about everyday life with illness. This type of knowledge was perceived as extending far beyond medical care. Online communities were also used to mobilize and raise collective awareness about illness-specific concerns.

Keywords: chronic illness & disease; internet, social support, thematic analysis, systematic review
Introduction

People with chronic illness increasingly use online environments to support daily self-management (Barak, Boniel-Nissim, & Suler, 2008). Studies indicate that people with chronic conditions go online when looking for insights on health-related problems, symptoms, and treatments and to connect with others who share the same illness (Barak et al., 2008). Nevertheless, more knowledge is needed about how online communities intersect with and influence living with a chronic illness on a daily basis.

Online searches for illness-related information date back to early stages in the existence of the Internet, with many health care professionals raising safety concerns about the quality of much of the available information (Jadad & Gagliardi, 1998). More recently, with the emergence of Web 2.0, platforms offering peer-to-peer features have attained global popularity among people with chronic health conditions (Van der Eijk et al., 2013; Eysenbach & Till, 2001). Interactive social media platforms such as Facebook and Twitter, as well as patient portals for people with specific chronic illnesses, provide ways for peers to communicate about health and illness and to share experiences and mutual support (Miller, 2011). Daily support in a variety of forms is crucial because living with a chronic illness such as cancer, diabetes, chronic low back pain, and other conditions often requires a combination of behavioral practices (Mattingly, Grønn, & Meinert, 2011). These practices, which can be viewed as daily ‘homework’ tasks, often require technological skills and know-how and include taking medication, monitoring blood-sugar levels, engaging in physical activity, and managing diet and weight (Mattingly et al., 2011). Self-management of chronic illness has traditionally been supported by regular ambulatory clinic visits in combination with patient education (Nielsen & Grønn, 2012). Great efforts have been made to meet individual needs in, for instance, traditional group-based patient education.

Nevertheless, traditional forms of support are not always a sufficient means of providing individuals with the skills required to navigate the challenges of daily life with chronic illness (Nielsen & Grønn, 2012; Corbin & Strauss, 1987; Bury, 1982; Strauss & Glaser, 1975). Although there is an increased focus on establishing a person-centered approach in one-to-one consultations and group-based patient education, it is still difficult to meet needs that arise in individuals’ home settings (Nielsen and Grønn, 2012).

In the context of chronic illness self-management, peer-to-peer support is defined as linking people with the same illness and similar characteristics to enable them to share knowledge and experience (Gilbert, Dodson, Gill, & McKenzie, 2012; Dennis, 2003; Eysenbach, Powell, Englesakis, Rizo, & Stern, 2004.) Recently, offline peer-to-peer support has been highlighted as a process that can complement patient education programs and interventions led by health care professionals (Carol, 2011). A recent systematic review of offline peer-to-peer support interventions concluded that peer-to-peer support is effective in promoting health behavior changes across a variety of diseases and settings (Fisher et al., 2012). Peer-to-peer support is now used by a number of health care professionals in combination with existing patient education programs to address the fact that chronic illness management requires various forms of support in daily life (Kristiansen, Antoft, Primdahl, & Petersen, 2015).

Peer-to-peer support can be delivered in many forms. A few studies have focused on the ways in which online peer-to-peer support can augment face-to-face consultations (Van der Eijk et al., 2013; Hordern, Georgiou, Whetton, & Prgomet, 2011). With the rise and influence of information and communication technologies, interest is increasing in
the potential for health-related online peer-to-peer support (Eysenbach et al., 2004; Armstrong & Powell, 2009; Greene, Choudhry, Kilabuk, & Shrank, 2011). In a systematic review, Eysenbach et al. (2004) concluded that online peer-to-peer support is harmless, but it also lacks any significant empowering effect. In a similar vein, Dedding, van Doorn, Winkler, and Reis (2011) identified contradictory conclusions within the e-health literature concerning potential harm or benefits of online communities. Conversely, Demiris (2006) and Barak et al. (2008) concluded that online communities have the capability to empower individuals.

Other studies have shown that online peer-to-peer support is highly valued among people with a chronic illness as an expedient means to receive information about how to manage their illness (Lian & Nettleton, 2005; Greene et al., 2011). Some identified advantages of online peer-to-peer support, in contrast to offline peer support, include instant information exchange, easy access, the self-paced nature of interaction and lack of restrictions regarding time and location (Horst & Miller, 2012; Brown & Duguid, 2000; Chung, 2013).

Even though previous studies have pointed to the potential empowering effect of online peer-to-peer support, it is still not evident how peer-to-peer support through online communities supports individuals in daily life with chronic illness. The aim of this review is to examine findings across qualitative studies to understand how individuals with chronic illness experience online peer-to-peer communities (which include both forums and interactive groups) and how these experiences influence daily life with illness.

Methods

Systematic Qualitative Review

To address the question of how people with chronic illness experience online peer-to-peer communities and the influence that this has on their daily lives we determined to undertake a systematic review of qualitative literature pertinent to this. The systematic review has, of course, a long and well-established place within medical research of a quantitative orientation. More recently, however, systematic reviews have been adapted to qualitative studies (Eager, Davey Smith, & Phillips, 1997). The impetus for this can be found in the need to pose research questions which involve complex concepts that resist easy quantification. As this implies, however, systematic qualitative reviews have a different purpose to systematic reviews in which the aim is to achieve a formal aggregation of the selected material. In looking systematically at the literature relating to the topics identified, our aim is to critically reflect on the material and thereby capture some of the complexity that inheres in the question of apprehending people’s experiences. Adopting this approach it is necessary to acknowledge the important and ongoing debates that have followed in the wake of the method’s migration from the quantitative to the qualitative. In these debates researchers have been compelled to focus on elements in the construction of a review (Lloyd Jones, 2004); methods for searching for qualitative research (Eakin & Mykhalovskiy, 2003); and appraisal of qualitative research as well as methods for synthesis (Dixon-Woods et al. 2006; Dixon-Woods, Agarwal, & Jones, 2005). For this review we have combined elements from the existing literature on how to synthesize qualitative studies such as the appraisal tool for assessing qualitative studies developed by Carroll, Booth, and Lloyd-Jones (2012) and a systematic approach to searching the literature guided by Dixon-Woods et al.
As such, what follows is a qualitative systematic review of research findings that shed light on how people with a chronic illness experience online peer-to-peer support.

**Search strategy and inclusion criteria**

Our original aim was to identify qualitative studies of online peer-to-peer support communities for adults with type 1 diabetes. However, our initial literature search revealed a single qualitative study of adults with type 1 diabetes and online peer-to-peer support, and we subsequently broadened our aim to include other somatic chronic illnesses. The research question has been used as a compass to guide the search field, however with the flexibility of being modified in the process as our original focus changed (Dixon-Woods et al., 2006; Eakin, & Mykhalovskiy, 2003). We conducted systematic and comprehensive searches in the autumn (September-October) of 2015 in six electronic databases: PubMed (1426), Scopus (184), Web of Science (86), and PsychINFO and Cinahl via the EBSCO database (164). We used database filters to select peer-reviewed and qualitative studies in English that pertained only to adults. (Insert table 1)

Identifying social science and qualitative studies through systematic database searches is challenging, so we also manually searched five qualitative journals online: *Qualitative Health Research* (198), *Sociology of Health and Illness* (120), *Health* (87), *Anthropology and Medicine* (0), and *Medical Anthropology Quarterly* (0). The search process resulted in a total of 2,265 articles. We eliminated duplicates and reviewed titles and abstracts of studies, excluding those that did not address: 1) interactive patient-to-patient web-based solutions; 2) social support for adults with chronic illness; and 3) peer-to-peer interactive online groups, forums, or communities. For example, studies that addressed Internet searches, doctor-patient communication through email or text messaging, and blogs with one-way posting and little peer interaction were excluded. Disagreement or uncertainty about articles was resolved by discussion within the research team.

Thirteen articles met our criteria. They were published in *Qualitative Health Research* (5), *Sociology of Health and Illness* (3), *Health* (1), *Patient Education and Counselling* (1), *Societies* (1), *Journal of Health and Social Behavior* (1) and *Journal of Health Psychology* (1).

**Quality assessment**

We assessed the quality of the 13 articles, including only those with an explicit and rigorous qualitative methodology and theoretical analytical research frame (Carroll et al., 2012). Even though the quality assessment checklist was originally designed for studies in offline settings, we found it was adaptable and suitable for the included studies which addressed online settings. Qualitative research methods used in the selected articles frequently included observations of
interactions (posts) in online communities. These were sometimes combined with more traditional qualitative methods, such as semi-structured interviews or focus groups.

The checklist focuses on the quality of reporting in terms of: 1) research questions and study design; 2) participant selection; 3) methods of data collection; and 4) methods of analysis. Following Carroll et al. (2012), studies that were assigned a clear yes in at least three criteria were included in the analysis. We found no methodological weaknesses disqualifying any of the 13 studies from the review.

(Insert Table 2)

Data analysis and categorization

We grouped findings by themes to identify and analyze patterns within data related to the research aim (Braun & Clarke, 2006). Thematic analysis is a flexible and useful research tool that provides a rich, detailed, and complex account of data (Braun & Clarke, 2006). It has been referred to as an independent and reliable qualitative approach to analysis that is unmistakably undervalued (Vaismoradi, Turunen, & Bondas, 2013). Thematic analysis involves searching for and identifying common themes across material (DeSantis & Ugarriza, 2000). It is used in cases where there are no previous studies dealing with the phenomenon; therefore, the coded categories are derived directly from the text data (Hsieh & Shannon, 2005). It can also be referred to as a descriptive approach of identifying, analyzing, and reporting themes within the data. A theme is defined as a coherent integration of disparate pieces of data that constitute the findings (Sandilowski & Leeman, 2012). The importance of a theme is not necessarily dependent on quantifiable measures, but rather on whether it captures something important in relation to the research aim (Braun & Clarke, 2006).

We followed the six analytical phases defined by Braun and Clarke (2006): 1) familiarizing oneself with the data, 2) generating initial codes, 3) searching for themes among codes, 4) reviewing themes, 5) defining and naming themes, and 6) producing the final report. The familiarization process yielded a broad understanding of the selected articles. We read the 13 articles several times and grouped them using preliminary codes to identify sub-themes across articles. The sub-themes consisted of descriptive content within the data and can be seen as an expression of the manifest sub-themes of the text (Graneheim & Lundman, 2004). This semantic approach to sub-themes was based on explicit meaning, rather than on interpretation.

After the familiarization process, we systematically generated initial codes for sub-themes of interest across all papers. Even though our overall aim guided the analysis, the initial sub-themes were data-driven; we did not attempt to fit sub-themes into a pre-existing thematic framework. We carefully discussed sub-themes emerging from the data and began to arrange them into overall themes. All themes were analyzed in a recursive process in which we constantly moved back and forth between the studies and the identified themes (Braun & Clarke, 2006). As the process of developing themes progressed, we conducted comprehensive latent analysis by examining underlying sub-thematic concepts and meaning, which provided further definition and iteratively refined theme names. We also reviewed the themes several times to verify that they comprehensively and exclusively represented coded semantic extracts of the data set. We then
summarized findings from each sub-theme within the four overall themes, describing them as closely as possible to the source article, using direct quotations whenever appropriate.

Table 3 shows the variability of manifest sub-themes and the grouping into final overall latent themes. Thematic analysis research requires considerations of both manifest and latent content before proceeding to the next stage of data analysis (Braun & Clarke, 2006).

(Insert table 3).

Results

Overall, four themes were identified: illness associated identity work; social support and connectivity; experiential knowledge; and collective voice and mobilization.

Illness associated identity work

This theme refers to the kind of emotional work people with a chronic illness undertake in order to renegotiate and normalise their identities in the wake of an illness diagnosis. A number of studies showed how identity work was carried out online in reciprocal ways among peers in order to reshape a fragmented identity caused by the diagnosis of an illness. Online interaction among peers with the same condition was also a resource for self-expression in the wake of illness onset. Identity work was articulated through online narratives and even though these autobiographical stories were rather short, they often drew on profound psychological experiences and expressed emotionally difficult topics in the context of daily life with chronic illness. Peers supported each other emotionally with replies of solidarity as a way to validate illness stories and provide emotional relief. This identity work was done in a reciprocal way; it often encouraged both posting one’s own illness stories and replying in a supportive and acknowledging way to those of other community participants. Illness-specific issues were common, such as moral and ethical discussions surrounding the disclosure of HIV/AIDS and uncertainty in the challenges of obtaining a definitive diagnosis for symptoms of low back pain, arthritis and fibromyalgia. However, many findings related to this theme were consistent across all illness groups. Online communities became a space where users dealt reciprocally with difficult emotions. Sub-themes most evident across studies were fear, hope, and uncertainty. The heavy emotional burden that accompanied a chronic illness included fear of an uncertain future. In the study by Saundanet (2008) in some instances fear seemed to involve withdrawal from the community. However in other studies, one way that study participants dealt with this fear was to turn it into something positive. In the case of women with breast cancer, identity work aimed at reaching a state of hope and emotional relief as a way to address emotional fear. In the study by Sandaunet (2008a), 40 Norwegian women with breast cancer used an online community as a tool for reframing negative and painful emotions into something positive. Reciprocal illness stories generated hope when they emphasized opportunities instead of challenges.
To turn the illness into something positive creates meaning and the awareness that I can influence my own life – during serious illness as well. (Woman with breast cancer [Sandaunet, 2008a, p. 6]).

In this way, breast cancer sufferers strived to establish meaning in relation to their illness that supported a positive account of their integrity as agents. Humor was also used as a strategy to re-frame a negative illness identity into a positive one (van Uden-Kraan et al., 2008; Høybye, Johansen, & Tjørnhøj-Thomsen, 2005). For example, Høybye et al. (2005) highlight jocular exchanges among women with breast cancer, referring to ‘shampoo for bald-headed people’ or ‘chemo-brains’ when experiencing forgetfulness.

Another sub-theme within this theme was peers encouraging each other to fight the emotional effects of illness. Shared stories of encouragement were seen to provide strength to cope with the uncertainty raised by illness (Høybye et al. 2005; Armstrong, Koteyko, & Powell, 2012; Rier, 2007; Bar-lev, 2008). Sharing stories became an important survival tool for some users, just as writing about their illness became a work of self-actualization when dealing with a disrupted identity caused by a new illness.

Social support and connectivity

This theme treats how people with chronic illnesses connects with and support each other online and, in so doing, how they also attempt to manage social relations in their daily lives. Thus, another reason for consulting peers with the same illness was to alleviate strains on relationships with family and friends. Users created a social network in which it was socially acceptable to have a very explicit focus on disease and illness, in contrast to other social networks. The study by van Uden-Kraan et al. (2008) illustrates how chronically ill people found online peer-to-peer support communities an ideal space to share experiences. They did not want to bore, annoy, or worry people in their surroundings, although they still needed to talk about their situation.

Several studies identified the potential of online communities to rebuild a social network lost due to feelings of isolation and loneliness (Høybye et al., 2005). The importance of initiating new friendships through participation in online communities was further highlighted in Mazzoni and Cicognani (2014, p. 4), as they showed how people with lupus joined online communities with the aim of connecting with others with the same illness:

In those moments I felt that I was missing someone for sharing my feelings, my fears, my discouragement. My family is close to me, but it is not the same. Please feel free to contact me, if you want to listen to my story and to tell me yours. (Female, 24, with systemic lupus erythematosus).
Similarly, in van Uden-Kraan et al. (2008), a woman with fibromyalgia explained that she lost offline relationships due to the illness and intentionally used the online community to strengthen her social ties. Another area of social support concerned the strengthening of relationships with health care professionals. Through exchanges in online communities, peers equipped one another with the critical skills required to experience more rewarding interactions in their consultations with health care professionals. This was related to the fact that people with chronic illnesses often found it difficult to address their concerns and formulate them in terms that physicians would understand and accept.

Furthermore, people expressed frustration due to their lack of understanding of medical terms. In online communities, peers supplied each other with information given in language that was closer to real-life situations (van Uden-Kraan et al., 2008). This prepared participants in online communities for their interactions with doctors as they became more adept at expressing their concerns in illness-specific vocabularies that made it easier to discuss treatment choices with their doctors as showed in Caiata, Zufferey and Schulz (2009, p. 3):

_I have had the chance to clarify some things concerning the problem and thus be able to discuss it better with my doctor._ (Person with low back pain).

**Experiential knowledge sharing**

This theme shows how people with chronic illnesses share knowledge online on how to live with chronic illness. Online communities were often used to share experiential knowledge tailored to specific needs and illnesses. The urge to seek out knowledge from people who have gone through similar experiences is illustrated in Armstrong et al. (2012, p. 10):

_...I’ve got so many questions and I just need anyone who has either gone through it, or knows any words of wisdom to put my little mind at rest._ (Woman with type 1 diabetes).

Peers exchanged knowledge that emerged from their own experiences of living with illness. This knowledge was not something that could be generated by health care professionals because it arose from real-life experiences and situations. Reciprocal exchange of experiential knowledge gave people a feeling of embodied control that supported them in daily illness self-management. Høybye et al. (2005) demonstrated how women with breast cancer felt empowered by the exchange of experiential knowledge. In many of the studies, it was evident that a form of peer mentoring took place in which individuals with more lived experience of a particular condition shared the knowledge they had acquired with individuals who were less familiar with the chronic illness experience (van Uden-Kraan et al., 2008; Gillett, 2003). Knowledge about how to overcome specific difficult situations had a particularly empowering effect, in part because it helped restore some of the sense of control that was threatened by chronic illness. This corresponds to Caiata Zufferey and Schultz (2009), in which the process of reading and acknowledging online testimonies had a supporting and empowering effect among people with low back pain.
Collective voice and mobilization

This theme illustrates how individual voices congregate online with the explicit aim of collective mobilization and the promotion of perspectives and discourses relevant to their situation and condition. Several studies illustrated how online peer-to-peer communities were used to promote collective agendas, such as advocating for changes in health care services addressing the condition of interest (van Uden-Kraan et al., 2008; Radin, 2006; Gillet, 2003).

Even though online communities were used to express individual illness stories, they were also used to articulate a strong united voice through which participants sought to address issues of a more structural nature. Lian and Nettleton (2015) defined this shared collective voice articulated through online peer-to-peer communities as a tool to obtain political awareness for myalgic encephalomyelitis, for example through an online announcement on a Facebook community aiming to raise awareness about the illness and attract more members. The same method of raising awareness about a chronic illness was evident in studies of people with fibromyalgia (van Uden-Kraan et al., 2008; Barker, 2008). Online communities explicitly addressed the political domain, as a means of promoting patient-centered biomedical research and clinical guidelines. In another study, an online community for people with breast cancer worked as a social movement in the way it encouraged people with the same illness to interact and work cooperatively (Radin, 2006). Similarly, van Uden-Kraan et al. (2008) reported that people with breast cancer collectively decided to ask for a different type of medical examination. In regard to type 1 diabetes, an online community was used to question and contradict medical advice, creating a movement of expert ‘patient-hood’ (Armstrong et al. 2012). Interactions in online communities were seen to legitimize lay knowledge, challenging the notion that expertise in this area is solely synonymous with biomedical expertise (Gillett, 2003).

Discussion

In the course of our systematic qualitative review, we found that online peer-to-peer communities are used in various ways in the daily ‘homework’ of people diagnosed with chronic illnesses (Mattingly et al, 2011). Through their online interactions, individuals with chronic illness animated illness associated identities, sought and provided social support and connectivity, shared experiential knowledge only available from those living with particular chronic illnesses, while also mobilizing collective voices for the purposes of promoting otherwise neglected perspectives concerning life with chronic illness.

A key finding is that the longing for mutual solidarity and emotional support in relation to the day-to-day management of illness motivates people with a chronic illness to seek advice and inspiration among peers with the same condition. Identity work in the wake of a chronic illness is not a new phenomenon and has been described in several studies across different illness groups. The study by Mathieson and Stam (1995) details how people with cancer are involved with collaborative identity work including processes of ‘fitting’ disrupted feelings. The identity work carried out is aimed to renegotiate identities and attribute meaning to illness within the contexts of various social relationships. Nevertheless, with the availability of online communities’ new ways of renegotiating identity is evident. The collaborative identity work in the form of sharing of feelings and experiences is an online phenomenon. Across illness groups in online
environments the sharing of autobiographical stories seemed to help them through processes of self-realization, providing a kind of emotional relief and enabling identity work. Kaufman and Whitehead (2016) describe this process as ‘reciprocal empathic practices’ in a study investigating how people with chronic illness use shared feelings and experiences as a resource for producing empathy. They argue that the reciprocal activity of sharing empathy has a strong supportive effect in daily illness associated identity work (Kaufman & Whitehead, 2016). Other studies have demonstrated that people with a chronic illness recover and obtain a sense of normalcy by mirroring each other’s illness stories (Chung, 2013; Lowe, Powell, Griffiths, Thorogood, & Locock, 2009). It was evident in our review that online peer-to-peer communities strengthen the process of attaining a ‘normal identity’ through shared emotional identity work. Online communities were a means to offer rapid responses of emotional support which, in contrast to offline peer-to-peer emotional support, seemed to be more adapted to a situational and individual day-to-day need.

Our review identified different ways that social support took place. Online communities were a valued space to seek out new friendships. This was important for the chronically ill because illness-related thoughts could not always be shared with family and friends without putting a strain on these relationships. Online social support provided a forum for articulating thoughts and feelings that might be deemed burdensome for family members. This had the effect of alleviating any strain that was experienced in relation to existing offline ties and was seen to actually strengthen offline relationships. Chung (2013) supports this view of online social support in a study on preference for online interaction over offline interaction; in particular, people who lack sufficient support from offline networks regard online interaction as supportive (Chung, 2013).

Another type of social support we identified was the translation of information from medical terms to patient knowledge and experiences and vice versa. This seemed to enhance patient-doctor understanding and cooperation and reduce feelings of stress and despair, particularly for individuals who had chronic illnesses with diffuse and ambiguous diagnostic profiles. In our review, this type of support was mostly perceived as strengthening patient-doctor relationships.

However, Conrad and Stults (2010) suggest another view of the effect of this type of online support; the Internet empowers patients who occasionally challenge the expertise of health care professionals, which might negatively impact doctor-patient relationships. Although this may certainly be the case in some instances, potentially negative impacts on doctor-patient relations were not apparent in the studies we reviewed, at least from the point of view of people with chronic illness. The benefit we identified in the thematic analysis was that people became experts in their illness and symptoms, which empowered them to take control. This view is also supported by Bartlett and Coulson (2011).

The findings in our review regarding experiential knowledge sharing were related to how peers used online communities to share day-to-day self-care experiences. The online communities provided a space to search for and to supply more practical and situated knowledge on how to live with illness on a daily basis. Participants in online communities accelerated the acquisition of knowledge adapted to daily life that supplemented the more formal information provided by health care professionals. This type of knowledge has been termed ‘patient knowledge’ by the sociologist and anthropologist Jeannette Pols (2013, 2014). She explicates how patients use this knowledge to transform
medical and technical knowledge into something useful. She further states that patients develop knowledge and techniques to interpret, appreciate, and shape their daily lives with a chronic disease in a good way (Pols, 2014). In the studies we reviewed, people with a chronic illness used knowledge generated from daily experiences with the illness to navigate life in various situated ways on a day-to-day basis.

In terms of collective voice and mobilization, although online communities elicited individual stories, they also worked as a space to mobilize collective action and solicit individual and illness-specific issues at a societal level. In the political sphere, online peer support communities for people with chronic illnesses are increasingly used to challenge the paradigms of biomedical knowledge. Conrad, Bandini, and Vasquez (2016) argue that patients are increasingly active consumers of their own medical care and health-related knowledge. Nielsen and Grøn (2012) also suggest that peer-to-peer communities represent a contemporary expression of what people with chronic illnesses require, both with respect to influence and in relation to active participation in care and treatment. Active patient mobilization is represented in several studies included in this review, reflected in online groups being used to raise awareness about specific illnesses and to generate a collective identity.

We sought to understand what participation in online communities provides people living with chronic illness. Our findings are centered on acute needs that revolve around rebuilding life, reassembling a fragmented identity, and acquiring skills that support the process of coping with the challenges inherent in daily life with a chronic illness (Conrad et al., 2016). Online peer-to-peer communities supported the ability of individuals to meet these needs. Nielsen and Grøn (2012) view the growth of online peer-to-peer communities as a consequence of the growing trend of encouraging people with chronic illness to become active participants in managing their health and further legitimize the use of online peer-to-peer communities by highlighting that some offline chronic illness management programs are not designed to give space to illness narratives and identity work. We believe that online peer-to-peer communities offer a platform for sharing feelings and knowledge relevant to people with chronic illness and should be further investigated for their potential as an important resource in the daily business of chronic illness homework.

This study has implications for advocates and health care practitioners who want to improve social support systems for individuals with chronic illness. However, a limitation of this review is the overrepresentation of some chronic illnesses and underrepresentation of others, even though they share commonalities in relation to the four overall themes. We recommend further studies on individual chronic illnesses, especially those that are underrepresented in this review, to fully understand how online peer-to-peer communities are experienced and might influence daily life with specific illnesses. Another limitation is that most of the selected studies focused on online communities and not on the realities of participants’ daily experiences offline. Consequently, it was difficult to fully grasp the essence of their daily lives aside from the areas mentioned in the results. We expect that peer-to-peer interaction might influence areas of life other than those discussed here. The reviewed articles demonstrate a tendency to conduct studies on online groups, forums, and communities in a disembodied and disintegrated way with limited interface into the physical and mundane dimensions of daily life with a chronic illness. More studies are needed that use methods combining online and offline ethnography with an integrated time and space dimension to fully understand how interlinked and overlapping online and offline dimensions construct, reshape, and constitute daily life with chronic illness. Furthermore, we acknowledge
that people, ill or not, may not actively use social media platforms or may use them to varying degrees, which further emphasizes the need for online and offline methods of inquiry.

**Conclusion**

Online peer-to-peer communities for people with chronic illnesses have generated a public space in which issues and concerns relevant to their daily lives can be articulated and exchanged. Generally speaking, online peer-to-peer interaction supports people with a chronic illness emotionally, socially, practically, and politically, as represented in the four overall themes. Online communities can be seen as a unique space for peer-to-peer interaction in daily life with the potential for producing rich, embodied, and situated knowledge for people with chronicity who engages in them. Reciprocal emotional and social support was found to be especially empowering at an individual, social, practical and collective level. Further studies are needed to ensure a better understanding of boundaries of online and offline social dimensions and the relevance and influence of peer-to-peer online communities in the daily self-care ‘homework’ of people with chronic illnesses.

**References**


Carolan, M. (2011). In individuals with poorly controlled diabetes, a reciprocal peer support programme gives greater 6-month improvement in HbA1c than does nurse care management. Evidence Based Nursing, 14, 49-50. doi:10.1136/ebn.14.2.49.


Table 1. Example of a search string in Scopus.

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### Table 2. Quality assessment of studies

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<th>Methods of data collection Description</th>
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<td>Understanding the theoretical nature and content of peer-to-peer exchanges</td>
<td>11 patients with type 1 diabetes using an online self-management clinic with peer-to-peer chat</td>
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<td>Thematic content analysis and coding in NVivo</td>
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<td>Capisa-Zufferey &amp; Schuler (2009)</td>
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<td>1 online community for people with HIV/AIDS</td>
<td>Online observation</td>
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<td>Gillett (2003)</td>
<td>Examining self-management attitudes and behaviours</td>
<td>16 chronic back pain sufferers in an online community</td>
<td>In-depth interviews</td>
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<td>Hoybye, Johnson &amp; Thomsen-Yeomans (2005)</td>
<td>Study of media practices</td>
<td>23 online sites including chat rooms for people with HIV/AIDS</td>
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<td>Online observations, online interviews, and semi-structured face-to-face interviews</td>
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<td>Mazisri &amp; Ciompi (2014)</td>
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* ✓ reflects passing the assessment category; × reflects not meeting assessment criteria.*
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- Expert patients
- Dissidents
- Illness recognition
- Mobilisation
- Collective voice
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

Status: Submitted and re-submitted to Health: An Interdisciplinary Journal for the Social Study of Health, Illness, and Medicine

Author: Natasja Kingod

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 emergent space for biosociality through which knowledge about how to self-care become co-constructed by peers based on their pragmatic experiences of self-care on a daily and ongoing basis.

Keywords

Type 1 diabetes, Facebook, online biosociality, 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 mathematical 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 glucose levels. 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 from Tanja cited above 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.

Ethnographic studies have a long tradition of accentuating the relational complexities between patients and healers, with accounts of how people with chronic illness try to navigate health systems both as patients and customers (Kleinman 1981, Good 1994; Mattingly 1998). Recent studies have focused on how people with chronic illness are prepared, in various settings, to try out unconventional therapeutic itineraries in order to seek health-related support when biomedical guidelines do not offer relief in daily life (Mogensen 2005). Whyte’s (2005) concept of ‘subjunctivity’ illustrates how people in Bunyole try out ideas and negotiates uncertainty in pragmatic and creative ways when living with illness, while at the same time adhering to biomedical tests and pharmaceuticals. Although there are rich ethnographic accounts from offline contexts of people’s creativity in face of the frustration generated when biomedical knowledge is not directly transferable to everyday lives, studies on the actual ways in which people with a chronic illness such as type 1 diabetes co-construct and integrate experiential knowledge through recent social media are lacking.

Whereas the first-generation Web 1.0 allowed patients to search the Internet for information about health and illness, the Web 2.0 has made it possible for people to connect and interact with others through online platforms (Barak et al., 2008; Farmer et al. 2009; Greene et al., 2010). Facebook was established in 2004 as a Harvard-specific social networking site and by 2008 it was declared the most popular social networking platform in the world. With the launch of “Community Pages” in 2010 it was possible for people to group around a topic of interest such as an illness (Brügger, 2015). One consequence of this connectivity and interactivity is that new information is continually being
generated in response to specific social interactions among people with similar interests and concerns about their health. Studies have shown that an increasing number of people seek health information and support in online communities, rather than from traditional sources, despite being unable to verify the reliability of the information and clinical evidence available online (Jones et al., 2013; Wikgren, 2001). Other studies have attended to how online connections expand possibilities for social interaction and communication outside a handful of annual scheduled face-to-face consultations with healthcare professionals (Bjoernes et al., 2012). Opportunities to seek and share self-care knowledge in daily life with type 1 diabetes is especially important as 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 a complex management regime of handling needles, changing insulin vials for insulin pumps, checking blood glucose number by use of glucometers and scanning devices and counting and calculating. Although these practices are often classified under the cover-all concept of self-management, I will attend to self-care in a wider context of doing and knowing e.g., know-how relating to the navigation of complex self-care technologies and know-how about how best to situate devices to bodies and daily life, a type of knowledge that is often developed through practices of 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 specific 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, patients with type 1 diabetes are drawn in large numbers into a form of biosociality (Rabinow, 1996) in which social media interactions are key to the development of illness understanding and adaptive self-care practices; concomitant with these changes is an increase in the complexity of the knowledge and skills required for self-care.

The time-consuming nature of self-care for type 1 diabetes has 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). So while it is the case that self-care activities for type 1 diabetes have always involved some form of technological intervention since treatment first became possible in the 1920s, 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 (Mol, 2008; Mol and Law, 2004).

Due to complicated and technological self-care practices that require skills equivalent to those of a nurse and a technician, Tanja, as previously illustrated in her own words, turns to peers on Facebook to obtain guidance and
knowledge. This situated self-care requires the social and pragmatic tinkering that is the focus of this article. The knowledge required to adequately perform self-care on a daily basis cannot be extracted in full and complete form from biomedical knowledge or clinical guidelines. It must be generated through a continual and complex interplay between devices, bodies, and specific daily situations. As will be shown within this article, knowledge creation related to self-care is both an individual as well as a social process, a process which, for many, is increasingly facilitated through biosociality via Facebook.

Previous studies on the social processes and knowledge creation in daily life that accompany life with chronic illness have adopted varied approaches. Paul Rabinow (1996) has, for example, coined the term biosociality in relation to how social identities are being formed on the basis of some biological criteria, which in the current case has the label type 1 diabetes. This article will not attend to identity formations online, but the relation between doing and knowing when people with type 1 diabetes tinker with self-care to co-construct situated patient knowledge. This practical knowledge is what the social scientist Jeannette Pols defines as patient knowledge, a knowledge which patients create and relate to 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 arise 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 clinics and home where patients independently find own solutions to problems that arise on a daily basis (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 as a new form of online biosociality (Chayko, 2008; Kingod et al., 2017). This reflects a trend in healthcare from e-health to m-health, 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). With an installed Facebook app on her smartphone, self-care support is just a click away.

In this article, I explore how Facebook transforms the ways in which patients can tinker with their self-care and discuss the nature of what is at issue when people attend to their self-care on their own. In adopting this focus my intention is to illuminate the wider consequences for both patients and healthcare providers when Facebook becomes a key resource through which people can articulate general concerns and specific problems relating to their health and, at the same time, have an expectation that viable responses will be obtained.

**Praxiography: Following practices on- and offline**

A praxiographic design was applied in which I followed informants 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 the myriad of micro-practices that constitute everyday life (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 distinct and separate social dimensions. Several recent studies stress the inadequacy of this approach, highlighting the need for studies which follow people through online and offline settings (Kingod et al., 2017) without assuming an a priori distinction between the two (Miller, 2016; Hine, 2000). Indeed to the extent that such a distinction is meaningful at all, it is through the ways in which it can be actively utilized by people to account for particular actions and behaviour or, for that matter, the absence of the same. 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 with particularly focus on the relation between doing and knowing. 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 online. 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 how 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 600 to 4000 individuals.

According to Dalgas (2016), long-term ethnographic fieldwork involves engagement and investment in the lives of study participants, and thus informal conversations and observations are of equal importance to structured interviews. I had ongoing conversations with my 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 log 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 glucose under control. She highlights the daily routines of sleeping, staying awake, being
physically active, and eating that all have an impact on her blood glucose in one way or the other. She believes that the consequences of these routines on her body and blood glucose 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 glucose she must control. This is exemplified by the 24-hour display on her insulin pump with a graph of her blood glucose 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 glucose 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 glucose that she needs to figure out, which often leaves her in doubt. Lisa addresses the difficulties in keeping her blood glucose 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.

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 glucose 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 Peter 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 (60 years old and 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 repeats how he lacks a situated 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 glucose levels experienced by informants required a type of knowledge, information and experience other than that supplied at the clinic. Yet as Whyte (2005) states, 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 self-care in various situations of daily life 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 remedial practices to apply in the face of a fluctuating blood glucose, as described by the informants of this study, can only be derived continual self-care experiments.

The interviews began as predominantly verbal stories of daily experiences of living with type 1 diabetes and 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 glucose before, during, and after various kinds of sport. She rejects the larger communities due to the large amount of irrelevant information that also circulates. She wants information to be as tailored to her needs as much as possible and consequently she only posts within specific communities related to exercise or to specific insulin pump brands. Adjustment and calibration of technology, in combination with carbohydrate calculations and levels of exercise, established doubt. A doubt that could be best addressed by people with comparable experiences. 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 glucose 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 blood glucose was 18.2 (mmol/l) after two hours of yoga class without sweat but with a BS (blood glucose) 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)

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 to two of the people who had provided replies, requesting further clarification.

The metaphor of running blindfolded in a labyrinth used by Lise in her post illustrates the doubt she experiences 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_

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 glucose 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 illustrated 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 glucose levels. Some insulin pumps are interoperable with a continuous glucose monitor, also attached to the body, which measures blood glucose 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 episodes of low blood glucose, 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 glucose. 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 glucose. 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, indicating to her that remedial action, such as consuming a sugary drink, is required. She has, however, experienced extreme frustration as a result of the fact that her monitor tends to fall 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 glucose 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 glucose 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 glucose 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 in order to adapt it 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 glucose 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 all my interaction with informants indicated, 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 often doubted how to self-care; which guided them into various illness-related communities on Facebook. I observed how Facebook offered a space where peers would co-create knowledge on how to self-care that went beyond biomedical knowledge.

The tinkering m-patient is a product of Web 2.0 technologies offering a form of sociality less bound by the constraints of space and time, which provides patients with access to a very particular kind of knowledge that enables them to tailor and situate self-care collectively and individually (Lupton, 2012). My informants were already on Facebook, with personal profiles through which they entered the communities several times a day and seen in this light it is easy to understand how Facebook has become embedded, embodied, and everyday and an emergent space for biosociality (Hine, 2015; Rabinow 1992).

Informants use Facebook as an online manual for self-care through written posts, with uploaded photos and documents, which 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. 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 the fact that it is a practice which can have unforeseen and potentially dangerous outcomes. 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. This seriousness is reflected within the type 1 diabetes communities on Facebook that do now allow for the extended circulation of inaccurate or erroneous information.

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 online engagement, my informants,
as tinkering m-patients, were drawn in by a certain form of biosociality configured around type 1 diabetes, a biosociality which they were also actively contributing towards 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’. Shaw and Baker 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 the 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 chronically 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. My informants were still following medical advice given during quarterly clinic visits, based on a long-term blood glucose test that indicates appropriate adjustments of insulin levels. However, numeric values and the advice of the medical care team are insufficient in and of themselves to support people with type 1 diabetes in how to live with the illness. What they generate is 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.

**Limitation**

A limitation to this study is its singular focus on m-patients using Facebook. Informants were highly active both in terms of their online behaviour on Facebook and in their attention to daily self-care. As a result, they do 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, those who withdraw or reject Facebook. Likewise, a further and, as yet, scarcely addressed topic is the perspective of healthcare professionals. Little research has thus far been conducted on the implications for the relationship between healthcare professionals and patients when patients turn to health-related communities on Facebook and how it might create asymmetrical relations both between patients and healers as well as patients and Facebook. With regards to the latter, there is an obvious concern of surveillance in relation to how patients feel controlled and concerned about who owns the data on Facebook. At present there is a good deal of concern and skepticism amongst healthcare professionals with respect to what patients do and do not do on social media. Greater understanding of these concerns and how they might be overcome is also an issue worthy of greater study. Given that the online biosocial practices that I have outlined here are likely to become more widespread in the future, this would appear to be an important point upon which to conduct further research.
Conclusion

Adults with type 1 diabetes often live in 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 peer communities on Facebook to seek guidance and support on how to tailor 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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**Noise as dysappearance: Attuning to a life with type 1 diabetes**

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**Abstract**

In this article, we use noise as a metaphor for the overload of information - embodied, technological, and online social - that characterizes life with type 1 diabetes. Noise, as an emic and etic term, illustrates embodied sensations of fluctuating blood glucose, measurement problems and alarms from digital self-care devices, and irrelevant or emotionally disturbing posts on Facebook. Attunement is crucial to the quality of self-care achieved by individuals and comprises: 1) developing skills to receive clear signals from the body, 2) adjusting and individualizing self-care technologies to bodies and daily lives, and 3) discerning appropriate distracting and unhelpful self-care information. Ideally, life with type 1 diabetes is balanced, with clear messages from bodies, technologies and Facebook that enable better self-care.

**Keywords:** Type 1 diabetes, Noise, Dysappearance, Attunement, Facebook
Introduction

On a spring evening in 2016, the first author attended a peer meeting, held once every two months, for adults with type 1 diabetes in a large Danish city. Three men and six women had gathered to discuss issues about their illness; some were participating for the first time, others were already acquainted through Facebook or previous meetings. The meeting had been announced through a Facebook community run entirely by adults with type 1 diabetes. With no predetermined theme, the dialogue among participants drifted between topics related to life with diabetes with which they were currently concerned. In the midst of this calm and relatively quiet environment, Mia, a woman in her 50s, introduced the topic of noise. “Noise, noise, noise,” she proclaimed before continuing, “It is not only the illness that causes noise, it is also Facebook. I just think that there’s a lot of noise, and it’s infuriating.” Mia had an insulin pump and its alarm had just triggered. Mia’s outburst about noise came moments after John, another meeting participant, had to deal with the alarm on his insulin pump. This is noise in its most literal sense, to which one must be attuned in a life with type 1 diabetes. In truth, Mia’s alarm was somewhat redundant because she had already recognized the symptoms of low blood glucose and taken action, drinking half a carton of apple juice to raise her blood glucose. Hence, she could turn off the alarm on her insulin pump without further thought. In contrast, John’s insulin pump had been triggered by the fact that his blood glucose was too high, a situation that could not be immediately resolved with a sugary drink. John’s alarm had already been triggered three times during the meeting, and its insistent noise was clearly making him agitated. He suddenly stood up, trying to extract the pump from the pocket of his tight-fitting jeans as the shrill alarm continued. He shouted at it to ‘shut it’, as he turned it off with exaggerated movements. At that point, it was hard not to concur with Mia’s assertion that life with diabetes is a life filled with noise. As we shall emphasize, however, one inevitably encounters various types of noise when living with type 1 diabetes. Although some noises can be muted with an off switch, others do not provide that luxury. Individuals must learn to attune to these noises.

As seen in our initial ethnographic vignette, the idea that life with diabetes is characterized by noise is not merely an analytical conceit; people with diabetes also evoke the concept of noise as a way of characterizing their daily experiences. Susan Sontag (1978) originally highlighted the pervasive nature of metaphor in discussions about illness and disease and her point about metaphor capturing feelings of bemusement and anger is brought to mind in the way people with diabetes talk about noise. The metaphor of noise encapsulates the struggles people with type 1 diabetes experience when practicing self-care at a daily level, a metaphor all the more persuasive for its capacity to seamlessly capture diverse aspects of life with diabetes in Denmark in the 21st century. In our analytical focus on noise in the context of life with type 1 diabetes, we propose a distinction between three types: embodied noise, technological noise, and online social noise. For all three, noise evokes the frequently unpleasant experience of managing information of indeterminate relevance from diverse sources, including bodies, self-care technologies, and Facebook.

The concept of noise has emerged in various guises in many disciplines (Novak and Sakakeeny 2015). Although the concept of noise, generally understood as unsolicited sound, may be evaluated neutrally, it is often associated with negative connotations. For example, noise can be defined as a pollutant, with the notion of environmental noise pollution serving as a powerful metaphor for the auditory bombardment to which people are exposed in technology-saturated environments. Studies have found that exposure to noise pollution can lead to symptoms of poor physical and
psychological health (Stansfeld and Matheson 2003; Gan et al. 2012). More recently, Rice (2013) applied the concept of noise to extensive fieldwork on the practice of auscultation based in a London hospital, describing different kinds of noise stemming from diverse medical devices, such as monitors, and embodied practices in which augmented listening to bodily sounds, such as heart rate, is an integral aspect of diagnostic practice.

Throughout this article, we attend to aspects of life with type 1 diabetes that are associated with noise, defined here as an overload of unprocessed information that can include embodied noise, technological noise, and the noise of social relations on Facebook. We explore how people with type 1 diabetes develop strategies to differentiate between various daily information inputs, paying particular attention to the practice of diabetes self-care; in other words, we explore how people attune themselves to the noise of type 1 diabetes. Attunement to life with type 1 diabetes requires a range of knowledge, skills, and strategies, which are developed through years of living with the illness (Pols 2010; Mattingly, Grøn, and Meinert 2011; Nielsen and Grøn 2012).

**Background: Contextualizing self-caring type 1 diabetes in Denmark**

Type 1 and type 2 diabetes pose an alarming public health problem calling for a multifaceted approach to care (Barry et al. 2017). Type 1 diabetes is an autoimmune illness in which beta cells in the human pancreas, the body’s sole generators of insulin, are attacked and destroyed by the immune system. The body becomes incapable of generating insulin, without which it cannot metabolize its energy intake. Treatment requires daily injections of insulin and vigilant blood glucose monitoring (American Diabetes Association 2013). No cure exists. The chronic, high-maintenance nature of the illness results in a blurred distinction between treatment and life with type 1 diabetes (Mol 2008; Guell 2011). In Denmark, with a total population of around 5.7 million people, approximately 30,000 people are diagnosed with type 1 diabetes. Receiving a diagnosis of a chronic illness such as type 1 diabetes is a major event shaping and reconfiguring all areas of daily life. Funnell and Anderson (2004) claim that the self-care regime for type 1 diabetes is one of the most complicated of all chronic illnesses, due to the highly specialized practices involved in daily management. Self-care involves daily insulin injections by insulin pen or insulin pump, blood glucose measurements, carbohydrate intake calculations, and changing vials and needles (Coyle, Francis, and Chapman 2013). Patients conduct these practices alone, without direct support from healthcare professionals. After diagnosis, patients must gradually learn and assume responsibility for these practices, a process requiring the development of some degree of mastery over the complex interactions between bodies, biologies, and technologies occurring in the context and course of daily life (Danholt 2013; Mol and Law 2004).

The sheer amount of time required has been stressed in some studies focusing on the demands of diabetes self-care regimes and the use of digital self-care devices (Mol and Law 2004; Mol 2008; Danholt 2013; Guell 2011; Guell 2012; Hernandez 1996). Patient education is offered in a group-based format in Denmark, but it can fail to meet individual needs that arise during the daily practice of self-care (Nielsen and Grøn 2012; Bury 1982). For some patients, the resulting uncertainty about their condition and what is required to achieve and maintain effective self-care leads them to seek out peers in online communities including on social media platforms (Kingod et al. 2017).
The emergence of internet technology and social media have facilitated a significant shift in both access to health-related information and the ways in which health information is communicated. Part of this shift is characterized by the spread of horizontal health communication in which patients, peers, and laymen gather and disseminate knowledge without recourse to the expertise of a healthcare professional. Previous studies examining these developments have focused on the empowering effect, or lack thereof, of health-related online communities (Eysenbach et al. 2004; Dedding et al. 2011; Demiris 2006; Barak, Boniel-Nissim, and Suler 2008). Other studies have focused more narrowly on possible components of empowerment (Sandaunet 2008; Høybye, Johansen, and Tjørnhøj-Thompsen 2005; Mazzoni and Cicognani 2014; Armstrong, Koteyko, and Powell 2012). A few studies have included people with diabetes, their interaction in online communities, and how the latter are used as a space for reporting personal experiences, asking questions, and receiving direct feedback from peers (Greene et al. 2011). To the best of our knowledge, however, no reports focus on the experience of illness-associated noise in daily life with type 1 diabetes.

Methodology
This study is inspired by praxiography, defined as ethnography with a primary focus on practices (Mol 2002). A practice focus examines how people practice self-care, including the interplay between bodies and technologies used for treating the condition (Shove, Pantzar, and Watson 2012). The practices we observed primarily relate to how adults with type 1 diabetes made sense of daily self-care and their strategies for dealing with noise. As a praxiographic study calls for multiple methods adapted to the research design, our aim was to approach online and offline social dimensions as complementary, rather than as distinct and essentially at odds with one another (Bueger 2014; Mol 2002). Any distinction between the two fails to capture the way they are seamlessly incorporated into the daily self-care of adults with type 1 diabetes. Several studies highlight the fact that Web 2.0 and social media apps on smartphones have become embedded, embodied, and everyday technologies (Hine 2015; Miller et al. 2016, Kingod et al. 2017; Chayko 2008).

Fieldwork was conducted between June 2015 and June 2016. It included a year of observations of interactions within 16 Facebook communities for adults with type 1 diabetes, 12 in-depth interviews, and 6 participant observations at offline peer meetings announced through Facebook. In Denmark, the use of Facebook is widespread among people with type 1 diabetes. Recognizing the extensive amount of activity within Facebook communities, individuals were asked during interviews to list the ones they participated in most. Three type 1 diabetes communities on Facebook with different foci (a larger general community on type 1 diabetes, a community on insulin pumps, and a community on exercise) were selected for in-depth study on a daily basis, and thirteen other communities were observed more occasionally.

Access to the communities on Facebook for adults with type 1 diabetes was gained during a pilot interview with one of the administrators, who was a founding member of a few online and offline peer communities and meetings. She assisted with identifying other existing communities and was kind enough to upload a post revealing the research aim and the researcher’s requested lurking status so as to avoid interfering with the natural online environment (Patton 2002; van Someren et al. 1994). The post also served to recruit people for individual interviews, which were conducted to understand how adults with type 1 diabetes integrated Facebook into their daily lives and self-care.
Observations were not restricted to interactions in Facebook communities. They also took place during interviews with individuals who navigated between online and offline domains with a smartphone and well-developed digital dexterity. The aim of individual interviews was to illuminate the integration of online and offline sociality. Interviews were structured to understand daily self-care practices with type 1 diabetes and the use of Facebook for peer support and to provide data on individuals’ experiences of using Facebook throughout the day and on how online practices and shared content within communities interfered with daily self-care practices. Interviews were augmented by several informal conversations during and after offline peer meetings, e-mail contact, and phone calls with the same individuals to obtain a deeper understanding of daily life with type 1 diabetes (Dalgas 2016).

Following people with diabetes as they moved seamlessly between online and offline contexts was made somewhat easier by the fact that some participants in the online Facebook groups actively sought to integrate the two. Thus, six participant observations of offline peer meetings also contributed to the data used in our analyses. These meetings were all announced through the Facebook communities, although they appealed only to people living in relatively close proximity to the meeting location. All interviews and participant observations were anonymized and transcribed verbatim.

Embodied noise

Daily life with type 1 diabetes comprises various noises. While their origins and nature may be diverse, a universal attribute is that they cannot be ignored; these noises demand the attention of the person who is exposed to them. Embodied noise can be exemplified as an experience of an unregulated blood glucose level that requires action on the individual’s part for stabilization.

Embodied noise relates to internal signals caused by a faulty pancreas; if this noise goes unnoticed, it intensifies. Untreated, a body that is unable to generate its own insulin will fail to obtain energy from food and begin to metabolize available fat cells. Left unchecked it results in a potentially fatal condition known as ketoacidosis. At the other extreme, treatment with insulin brings its own risks, including hypoglycemia, in which levels of glucose in the blood reach critically low levels and body functions begin to shut down. In its most extreme form, hypoglycemia can lead to coma and death. The nature of these risks means that managing blood glucose is a continuous and critical endeavor for people with type 1 diabetes. High blood glucose over a prolonged period is a proven risk factor for the onset of diabetes complications, whereas repeated instances of hypoglycemia can reduce an individual’s awareness of symptoms (Lawton et al. 2014). Although the immediate consequences of blood glucose outside the normal range are less obvious than the consequences of the extremes of ketoacidosis and severe hypoglycemia, the uncertain nature of the threat is one of the factors that make living with diabetes a challenge that requires constant vigilance.

Andy exemplifies this vigilance. Despite being 60 years old, Andy was new to life with type 1 diabetes, having been diagnosed little more than a year before. He monitored his blood glucose with a blood glucometer and took insulin on a daily basis, which he injected with a purpose-designed insulin pen. Andy used his glucometer less frequently than
recommended by health professionals, in part because he was concerned that the constant pricking of his fingers would cause permanent nerve damage. He was acutely aware of the danger of infrequent blood glucose measurements and explained his strategy as based on developing a sense for the signs of fluctuating blood glucose. Far from neglecting his diabetes, Andy’s strategy was one that demanded continual attention to his body. His strategy also required him to be able to identify the symptoms as diabetes-related, which was not always immediately obvious because physical symptoms of low blood glucose, such as fatigue or irritability, are easily conflated with life in general. During a conversation in his home, Andy laid out on the table all the equipment he used for regulating his blood glucose:

If I am on the wrong side of 8 (blood glucose number in mmol/L) then I become tired and drowsy. That means that I am aware of my bodily sensation. I measure before I take a run. I take carbohydrates if I am too low, and I always carry an energy bar in my pocket, when I feel that I can use it.

This quote illustrates Andy’s need to rely both on his senses and a blood glucose level measured by a device. As he in particular finds it challenging to control his blood glucose level during and after exercise, he measures more often in these instances. How to crack the code of fluctuating blood glucose during and after exercise was a topic that was often brought up and discussed within type 1 diabetes communities on Facebook. Andy’s way of ‘listening to’ or sensing his body is evocative of points highlighted in the study by Rice (2013) on auto-auscultation. In a hospital-based ethnographic study, Rice describes both patients and healthcare professionals as embodied listeners, a skill mastered over time and through practice. Focusing on patients with heart disease who practice listening to the sound of their hearts, Rice identifies rapid transitions between different types of listening, such as inner listening to a heart rhythm and outer listening to heart rates and intervals detected by technological devices. As with the experiences of people with heart disease recounted by Rice, the case of Andy highlights a potential tension between the full-blown sensory experience of illness and the more restricted, primarily visual, markers of disease status used by healthcare professionals. This potential tension can, in part, be located in what Duden calls ‘medicine’s visual command performance’ (Duden 1993:21), and the fact that visual data are generally valued as more reliable than data derived from other senses. In Rice’s ethnography this tension is something which impacts on both patients and healthcare professionals, especially when information acquired from other senses is effectively rendered as either redundant or invalid. Andy is resistant to a self-management strategy that negates his embodied experience of diabetes. This is an approach which requires more vigilance, since it demands a continuous attention to the various signs of fluctuating blood glucose. At the same time, Andy is cognizant of the fact that he can only operate with the self-management strategy he prefers if he is also vigilant with regard to the objective markers of his diabetes status. He is, in other words, continuously striving to achieve harmony between the two.

Embodied noise is exemplified when Andy’s blood glucose fluctuated, which he defined as small sounds that would turn into severe alarms without action. Problems arose when it became difficult for him to register the fluctuations. Throughout the day, Andy needed to process data from his body and from numbers, displayed by his self-care technology, because he relied on the technology when his senses failed him. He hoped he could become less reliant on measuring with more practice of attuning to his body. He explained that this was not easy but could be mastered by practicing attention, which was a strategy for him to understand his body and reduce the levels of experienced noise. He
had developed a table, inspired by his peers in Facebook communities, in which he noted the hour of the day, his measured blood glucose level, which he compared with his sensed one, carbohydrates, and exercise. He used this table as a tool to train attunement to his physical condition. Ingold (2011; 1993) describes attunement as knowledge and skills developed by a practice of bodily fine-tuning and attention. It requires strengthening the senses of watching, listening, and feeling (Ingold 1993). Andy ‘listened’ to inner signs of fluctuating blood glucose, which were quiet noises from an out-of-balance body that could easily be confused with less ominous physiological noises arising from hunger, thirst, and fatigue. He had to sort all data from his body to take timely action on a fluctuating blood glucose level.

The sensory experience of blood glucose fluctuation varied among informants. Some could sense a fluctuation close to normal levels (defined by blood glucose levels of 4-8 mmol); others first sensed fluctuations when several bodily alarming sensations such as inner restlessness or agitation indicated a number that was too low or too high. At times, these fluctuations were visible to outsiders through physiological reactions such as sweating, shaking, or talking nonsense, which could only be reversed by consuming carbohydrates to raise blood glucose levels. It was not uncommon for inner alarms to go off several times a week or even many times a day. This had a potentially stigmatizing effect, as individuals with type 1 diabetes were required to momentarily withdraw from their social lives to undertake self-care practices to either raise or lower levels. Tanja 41-year-old, who as diagnosed with type 1 diabetes at the age of 21 provided an example of this:

At times I am forced to take a break, in order to ‘pull out the plug’. This could be a situation where I have to get some sugar, because I suddenly sense that I am rambling. Even though I know that there are people nearby to assist me if necessary, I always carry some sugar around.

Listening to herself rambling, Tanja experiences what Leder (1990) defined as bodily dysappearance, referring to an unwanted consciousness of the body or aspect of the body that occurs during times of disease, distress, or dysfunction. The dysappearance of inner embodied noise worked as a useful alarm about the need to address blood glucose levels simultaneously making illness more present in daily life. The study by Maynard (2010) on disability and dysappearance when living with cystic fibrosis also describes an unwanted consciousness of the body, which required practices of bodily interpretation.

When Andy practiced listening to or sensing his body, it gave him a sense of control over what happened inside him, which is also why he preferred using an insulin pen, rather than an insulin pump. An insulin pump is attached to the body and provides continuous small amounts of insulin, replicating the actions of a healthy pancreas. With an insulin pump, Andy feared that he might get lazy and lose the skill of listening to his body. The bodily signs, when processed correctly, guided him in regulating his blood glucose.
Technological noise

Using an insulin pen requires a continuous attunement to the body cross-referenced with visual comparisons to the number revealed by the glucometer. Whereas using an insulin pump in combination with a continuous glucose monitor calls for an attunement to the technology because the pump has to be continuously adapted and adjusted to the body it must serve (Winance 2010). Here noise becomes extended from the body to the technology and therefore the strategies of attunement from using a pen to a pump differ.

Newly diagnosed individuals are often more sensitive to fluctuations, whereas a potential side effect of the illness over time is a decreased ability to sense low blood glucose levels, a risk, in other words, that the body is silenced (DeVries, Snoek, and Heine 2004). This distinction was evident within Facebook communities, in which individuals with long-standing type 1 diabetes searched for ways to regain sensitivity towards the signs of hypoglycemia. When sensitivity to blood glucose levels deteriorates, which in biomedical terms is referred to as ‘hypoglycemia unawareness’, an insulin pump becomes potentially advantageous (Lawton et al. 2014). Lisa had been living with type 1 diabetes for more than forty years, diagnosed at the age of 8. She had difficulty sensing her blood glucose levels, so the visible number and alarms on her insulin pump acted as a compass, steering her self-care in the right direction. She downloaded the data on her insulin pump and analyzed it in conjunction with her healthcare practitioner, which allowed her to adjust her insulin pump to her particular needs. Her pump became what Koksvik (2016) has defined as a communicator on behalf of the patient. Koksvik describes fluid relationships between human (patients) and nonhuman (lifesaving machines) actors in which the machine communicates for the patient and the patient also communicates through the machine. Even though Lisa appreciated the machine, she often felt that it was not properly adjusted to her body. In a 2008 study, Mol describes how technologies, daily habits, and people’s skills require mutual adjustment and that the human and the technology have to be attuned to one another (Mol 2008).

Lisa was very interested in finding out how to ‘hack’ and reconfigure her device to make self-care easier, including changing the pump’s annoying alarm to a sound from her smartphone. Changing technology to fit individual needs and lifestyles has been stressed in several studies, from self-tracking technologies (Lupton 2016; Fox 2015) to negotiating and fitting technologies to bodies and daily lives (Winance 2010; Pols 2012). Lisa reflected on how receiving an alarm from her smart phone rather than her insulin pump was less ‘noisy’ because she found the alarm on the pump very disturbing:

The pump has an interface that just makes me want to kill it all the time, because I am tired of needing to press on the bottom so many times to silence it! If I hack the pump I can use a remote function that is more user-friendly and less disturbing for me.

She had recently considered joining a newly established community on Facebook for practical guidance and information about how to hack her insulin pump and connect it with a smart phone. Membership of this community was growing, and it offered offline meetings with unauthorized tutorials on how to change the technology. However, hacking her insulin pump would only succeed if the accompanying continuous glucose monitor maintained its signal to her insulin pump. Lisa had many examples of how the insulin pump misguided her when the continuous glucose
monitor measured her blood glucose level incorrectly, resulting in loud false alarms throughout the day. This technological noise was common among the observed individuals, due to difficulty attaching the monitor properly to the body. Lisa explained how these alarms could sound at all times of day, sometimes in very inconvenient situations.

It is so frustrating when the alarm goes off several times, and I have to get it from underneath my shirt. And it just keeps going off. Stupid pump!!

Rice (2013) describes technological sounds as offering patients a way to ‘hear’ or imagine what is taking place inside their bodies. Even though Lisa appreciated the assessment of her blood glucose level, the insulin pump with its noisy alarms often also made her illness too present. The noise of the alarm was not congruent with the state it was indicating, or at least with Lisa’s subjective experience of this state. Confronted with a quieted body, people with diabetes become more reliant on technological surrogates, yet these surrogates tend to be relatively crude communicators. This was particularly evident when the technology malfunctioned, or the insulin pump was not properly adjusted to the body it was intended to serve. As a pump user, it is necessary to make continuous adjustments of insulin doses in order to respond to internal and external factors affecting blood glucose. Too many false reminders from malfunctioning technology are counterproductive, creating a negative awareness of illness as more present than usual. In a study on telecare, Pols (2012) reports that a device reminding someone of their illness is beneficial, but it should not make the illness take up too much space. Despite her frustration with the pump, Lisa noted that it was sometimes even worse when the pump did not sound an alarm and she recognized that relying on sensory input from her own body was no longer an option, since by the time she could sense these signs it was generally too late, with symptoms, such as shaking hands, sweating, dizziness, and speaking nonsense also visually apparent to others.

Even though Lisa had been living most of her life with type 1 diabetes and Andy had been diagnosed just the year before, they both regularly felt lost about how to self-care in specific situations. In general, adults with type 1 diabetes have approximately four annual visits with healthcare professionals, primarily dedicated to numbers-based routinized biomedical practices (measuring blood glucose and blood pressure, weight, vitamin and mineral levels, and eyesight). These visits rarely provide knowledge about how to manage type 1 diabetes in various situations that occur in daily life. The need for comprehensive daily self-care practices drove informants to Facebook to find guidance and support about how to silence unwanted illness-associated noise.

**Online social noise**

The informants in this study were members of several Facebook communities and interacted in them to varying degrees. Enrolling in Facebook communities was a strategy to solicit guidance and support, to address doubt and decrease an unwanted focus on the illness. The amount of data from these communities was, however, often overwhelming, causing the opposite effect. When this occurred, Facebook became another device to operate and another source of noise.

When confronted with instances of the embodied and technological noise described here, informants often approached peers on Facebook with questions. However, noise also appeared online. An overload of irrelevant or emotionally
disturbing information could occur, especially among people not used to navigating Facebook, who lacked familiarity with the search functions provided by the platform. Selecting particular communities targeting specific aspects of individual self-care was a strategy to reduce the noise caused by information overload.

To use this strategy, individuals first had to find the right communities for their specific self-care needs and regimens; e.g., insulin pump users posted most actively in communities targeting their specific brand of insulin pump. The multiplicity of communities reflected various methods of self-caring for type 1 diabetes. Conversely, even though the observed individuals were selective about the communities in which they participated, they still often felt flooded with information. Continual smart phone notifications about community activity increased the focus on illness to the point where informants felt a great deal of time was required to sort out wheat from chaff in terms of their individual information needs.

Although they experienced Facebook as a quick and easy way to receive essential experiential knowledge on how to live with illness, study informants needed to understand the site’s platform, options and communities’ netiquette before Facebook could be truly supportive. Observations of their interactions with the technology revealed that the informants both created and received noise. This was evident when information and questions were posted in the wrong communities or when individuals did not understand platform functions. For example, when questions about insulin pens were posted in the insulin pump communities, members of those communities directed these posts to the larger and more general communities. Irrelevant information sometimes resulted when individuals were unaware of Facebook functions or how to use them within the communities. For example, they often created a post about a question or concern without either using the search function or scrolling through previous content to see if others had already raised the issue. This type of online navigation generated unnecessary confusion and frustration and caused an unwanted awareness on the illness, here exemplified by the informant Susan:

> It is the proportion. It is like you get the same question 10,000 times. It is usually something like, ‘I am high in the morning’ …then some of the old ones writes back, ‘try to use the search field.’
> (Susan, living with type 1 diabetes for 24 years)

The noise generated by many similar posts throughout the day caused people to withdraw from the larger general communities into newly established communities, which were more specialized. Even though there was often an introductory guideline explaining how to interact within a community, people tended to neglect it. Often, experienced members would post within communities about appropriate netiquette:

> ...The fact that the same information is posted all the time makes the threads unnecessarily long. There is the risk that concrete and useful information is drowned out. I have often looked for answers that I almost couldn’t find because of all the ‘noise’. I wish that people would just browse through the information…I just wish for shorter and clearer threads. (A woman who created a post that received 57 replies)
This post illustrates the problem of noise. This issue was developed further during a conversation with Anna in which she addressed the noise of irrelevant replies to her question:

A thread tends to develop, and then so much irrelevant information is posted. You know, just to give an example, of a community on food and type 1 diabetes. I am vegan and there are not a lot of vegans. Then I ask, is this also a vegan group? And then I get 7000 replies (exaggerating). The first replies are typically a ‘yes’ or a ‘no’ and then it develops into ‘I don’t like this’ or ‘I eat this and this’…In this way there is suddenly so much information about something completely different. And it was not what I asked about initially. And then I just sit there, and I am tempted to scream out: ‘JUST READ MY QUESTION!’ (Anna 36 years old, and living with type 1 diabetes since she was 14-year-old)

Anna joined the Facebook communities to find solutions to specific concerns that would make her self-care easier and make her illness stay in the shadows instead of being in the foreground all the time. However, she often felt that she received irrelevant replies to her questions, which tended to develop into other topics; she then felt more lost than when she initially posted the question. Rice and Katz (2001) note that online information-searching skills must be learned. Every online platform requires an understanding of how to navigate within it. It was evident that not all informants were equally skilled in sorting out the information within the Facebook communities. Another informant, Susan who was diagnosed just three years ago at the age of 50, elaborated on how she had to filter the posts online:

It is all about being able to sort out, so you won’t drown. If you have to relate to everything, then you get stressed. In some groups, however not these ones, you can only like the content, and then you have to search for your information. But in our groups, we share everything and then you have to be able to filter/sort out the posts.

Susan used the strong metaphor of drowning to illustrate the massive amounts of information circulating within the communities. However, she would have rather filtered the information than not receive any. She described how, over time, she learned to navigate within the communities to find specific information, which included using Facebook functions such as the search option and knowing whom to contact for the right peer advice. For some informants, managing noise required filtering information and finding the right peer community - and also periodically withdrawing from the community:

It is like…if I have a period in my life where the illness takes up too much space, then I ignore it…then I don’t read it. And when I am on top of it or think that I can handle my illness or when I feel that I can overcome it or just need it. It also differs when I feel that I need it. It is not the same for me. I can need it in periods where I either feel it is difficult to control or when I feel on top of it. It can take up too much space in periods. (Anna)

Another area identified with online social noise related to posts with an emotionally disturbing effect. These posts primarily included information about late complications such as nerve damage, retinopathy, kidney disease, or foot
problems as side effects of high blood glucose over time (Steffens and Anderson 2013). This finding is consistent with a study among women with breast cancer who withdrew from an online community to avoid painful and anxiety-provoking information (Sandaunet 2008). Studies have shown a tendency for participants to manage noise by seeking affirming information online, fostering hope instead of fear (Kaufman and Whitehead 2016; van Uden-Kraan et al. 2008; Radin 2006). The Facebook communities observed in this study often identified desirable content in introductory comments about community netiquette on the welcome page. Some communities emphasized strong emotional support and free sharing of difficult stories about illness; others aimed to empower individuals through a decreased focus on the negative aspects of the illness and an increased focus on empowering messages, borrowing from positive psychology. Lisa explained how she established a more empowering community in response to a general community in which she was exposed to stories of late complications, often combined with uploaded photos of foot wounds. This made it more difficult for her to cope with her illness:

I think that most people with type 1 diabetes want it to take up as little space as possible. It is like now when we talk, I don’t want to only sit in a diabetes energy. Because it is very difficult to talk about all the time, I can tell you. I would break down. It becomes too much diabetes…I like to have access to information, but not to the posts that are disempowering. (Lisa)

Noise, related to what Lisa defined as disempowering information, caused the illness to stay in the foreground. “Too much diabetes”, with a focus on the many severe and negative side effects, strained her ability to cope with her illness.

**Conclusion**

*Attuning to a life with illness*

In this article, we have shown that adults with type 1 diabetes use different strategies when attuning to illness-associated noise that causes an unwanted augmentation of the focus on illness. Dampening noise in one area of life may create more noise in others, underlining the pervasive nature of noise as a metaphor to organize understanding of life with diabetes. We developed a conceptual definition of embodied, technological, and online social noise; each type of noise requires distinct strategies that share a common focus on attunement that enable individuals to filter out information that is neither relevant nor helpful. For individuals who live with type 1 diabetes, noise is unavoidable, and the study informants tried a variety of practices to fine-tune themselves to a life with type 1 diabetes including sensing bodies, adjusting technologies and filtering social media data.

The metaphor of noise is pervasive and certainly captures something of the mystical or dangerous aspects of diabetes as an illness (cf. Sontag 1978). Yet while the noise may be said to have generally negative connotations, it is not something which can be ignored and in certain respects people with diabetes appear drawn towards the noises that they encounter. Living with a body that has been muted, people with type 1 diabetes are drawn towards devices that replace subtle embodied signals with crude alarms. Thus, the concept of noise poses a paradox, because it is both desirable and unwanted. The informants expressed a desire for information, but exposure to information overload could lead to the
unwanted consequence of dysappearance bringing the illness to the foreground of daily life. Nevertheless, when informants could process data from bodies, technologies, and Facebook to receive a clear signal, noise changed into useful information. This paradox also highlights the fact that type 1 diabetes causes unwanted noise, but the noise can also contribute to self-management when individuals can ‘tune in’ what is taking place inside the body and then apply correct practical knowledge to deal with it. The process of attunement was adapted to bodies, technologies and Facebook, which required continuous development of skills and effective practices. Even though processes and practices of attunement were seen to be individualized and situated they had generalizable elements that could be shared among peers on Facebook.
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PART THREE

Media Dissemination

There is an expectation that anthropological work be scientific, objective, and neutral rather than humanistic and personal. This often means presenting work in theoretical terms, sometimes with heavy use of jargon. Anthropologists who are interested in activism and critique are deterred from presenting their knowledge in forms that are readily accessible to the media and make a strong advocacy statement.

(Low and Merry 2010: 213)

From the very beginning it was my aim to make the anthropological work important to Steno Diabetes Center Copenhagen where this industrial PhD dissertation resides. I view this media dissemination as my contribution to the type 1 diabetes field as something relevant to people with type 1 diabetes. It can be considered a branch of applied, engaged anthropology or stakeholder relevant anthropology. Although this dissemination contribution is placed in a separate part at the end of this PhD dissertation, I will argue that it represents an anthropological contribution in itself, especially when placed within the above-mentioned fields. The way I have brought academia out of the university and into the public has validated my research in the sense that I received public response to the three small articles from the people concerned. In the history books of anthropology, there has been a tendency to sail away from the field, detaching from any understanding of impact or influence of the research. This has not been an option for me. My research was based in Denmark, and I will never entirely withdraw from the field due to my personal entanglement with type 1 diabetes. I am still very much a part of online biosociality.

When viewing this media dissemination from within engaged anthropology with its long history of making research public, it has been influenced by early pioneers such as Margaret Mead, who in 1942 actively wrote and spoke publicly about people in the contemporary world. She brought to the public a critique of problems she encountered in the field, particularly related to urban development, race, and pollution.

Several researchers point to the fact that anthropology is at the threshold of a new era in which anthropological expertise, activism, theory, and knowledge are being disseminated widely and freely through new technologies, as well as news media, journal publications, and institution-sponsored reports (Low ad Merry 2010).

My intention with the media dissemination was to bridge my work to the world, acknowledging the justified critique of and profound ambivalence related to muting scientific language and detailed descriptions of research methods and theories. Low and Merry call for more anthropological engagement in the public, thus pointing to the difficulties of conducting media-friendly anthropology that might challenge academic credibility and even threaten career paths:
To be persuasive to the general public, narratives need to be straightforward and emotionally engaging. To be persuasive to an academic audience, they require nuance and intricacy. Outrage and moral judgments must be muted.

(Low and Merry 2010:211)

Anthropology has a long tradition of speaking about crucial issues in contemporary society and, as a discipline; anthropology has pursued many paths toward public engagement on social issues. With the op-ed, my intention was both to insert my knowledge based on extensive fieldwork and analysis into the center of the public debate about social media and to contribute another “face” of Facebook as a scientific and highly personal strike in an ongoing debate about and criticism of the many dangers of social media.

Despite Facebook’s positive attributes in terms of connecting people with illness-specific peer support, it is also a very controversial medium due to an abundance of uncontrolled and uncontrollable information. Within the Danish media, recent discussions have occurred on the many dangers of the fake news and half-truths that appear on Facebook. This contributes to a perception that Facebook supports and enables inaccurate information, and study informants described healthcare professionals as often distrusting their ability to distinguish truth from half-truth on Facebook. Consequently, they were reluctant to disclose their use of Facebook and the tinkering with self-care that it inspired. Through an op-ed that was published in a well-known Danish newspaper, I challenged this view and discussed the other face of Facebook, in which many emerging health-related peer communities provide vital support for people living with illness.

After the op-ed was published in Politiken, I received several replies and acknowledgements from people with various chronic illnesses and researchers in related fields. The op-ed was posted and shared within several Facebook peer communities, other social media channels, as well as on patient association websites. Hundreds of likes and replies included statements of gratitude for listening to and acting on concerns arising from problematic patient-doctor relationships. On Facebook, peer-to-peer recommendations were made to print out the op-ed and bring it to consultations in the hope of creating more supportive relationships with healthcare professionals.
Drop kritikken af sociale medier i sundhedssektoren: Det er en myte, at det er skadeligt at mødes om sygdom på Facebook og andre sociale medier


Author: Natasja Kingod

Kronisk syge udveksler erfaringer på sociale medier som aldrig før

Det er en myte, at det er skadeligt at mødes omkring sygdom på Facebook og andre sociale medier

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Dette samstemmer med indlæg fra kronisk syge, der peger på et behov for individualiseret viden, som oftest ikke kan imødekommes af de sundhedsprofessionelle. Og det fremgik med al tydelighed af en kronik i Politiken den 19. februar.


Samme måned kunne man i Diabetessbladet læse, hvordan 42-årige Jesper med type 1 diabetes føler sig umyndiggjort af de sundhedsprofessionelle. Artiklen var et opråb til de sundhedsprofessionelle om at anerkende, at personer med
krisk sygdom ofte er ekspert og deres egen sygdom. Med type 1 diabetes, hvor 95 procent af behandlingen er helt op til patienten selv, kan Facebook supplere de fire årlige konsultationer på hospitalen.

Behovet for at søge information om egen sygdom har altid eksisteret, men brug af sociale medier er et nyt fænomen. Med mit igangværende antropologiske ph.d.-studie har jeg igennem et år fulgt en gruppe personer online og offline for at kortlægge, hvordan sociale medier som fx Facebook benyttes i hverdagen med sygdom. Mit studie af Facebook grupperne viser, at det er en myte, at det er skadeligt for kronisk syge at dele og finde oplysninger om deres sygdom på sociale medier. Jeg har konstateret, at misinformation straks bliver korrigeret af andre patienter. Baggrunden for projektet er min egen deltagelse i et online netværk på Facebook for forældre til børn med type 1 diabetes. For fire år siden, da min ældste datter var to år, fik hun konstateret type 1 diabetes. I min kamp for at forstå den omfattende daglige praksis med at håndtere sygdommen som min datters primære behandler deltog jeg i et af de første netværk på Facebook for type 1 diabetikere.

Det blev en øjenåbner for mulighederne på Facebook. Nat efter nat sad jeg ved min datters sengekant og stak nålen i hendes små tær (for at skåne fingerspidserne, der blev stukket dagen igennem) for at måle et stadigt faldende blodsukker. Fortvivlet måtte jeg konstater, at blodsukkeret ikke var steget, til trods for at jeg havde postet flere deciliter juice i hende. Men heldigvis var der hjælp online. Mens jeg ventede på virkningen af juicen, så jeg igen kunne stikke og måle hendes blodsukker, søgte jeg svar på Facebook. Og det svigtede aldrig. Om klokken så var 23 eller 03 var der altid trøst, en ligesindet med samme problem eller et råd. Som oftest en der tilkendegav en viden om, at det ikke var unormalt, og at blodsukkeret nok skulle stabiliseres. Pyha, som mor til en ny, lille kronisk syg med, hvad der føltes – og reelt også er – en livstruende sygdom, gav det mod til at fortsætte behandlingen af det ustabile blodsukker og komme igennem natten, og det gav håb for fremtiden for min lille datter. Hun var ikke alene med sin sygdom. Der var mange andre, og de var derude – et klik væk.

Det gav interessen for forskningsstudiet af voksne med type 1 diabetes og deres brug af Facebook. Da jeg startede var der få grupper på Facebook, og i dag har jeg identificeret 16. Tendensen er, at grupperne bliver mere og mere individualiserede.

Til sammenligning med type 1 diabeteslandskabet på Facebook, meldte jeg mig ind i en anden sygdomsspecific gruppe, målrettet personer med stofskiftelidelser. Da TV1’s Sundhedsmagasinet belyste stofskiftelidelser, fulgte jeg interesseret med. Dette indslag bekræftede timers samtaler med personer med type 1 diabetes, der føler, at lægerne ikke lytter til dem og ej heller anerkender deres egne eksperimenter med at leve godt med sygdommen. Programmet fulgte en kvinde, som havde lavt stofskifte og ønskede en nyere kombinationsbehandling med T3 medicin i stedet for den alment kendte T4 medicin. Udsendelsen belyste hendes tilstand og fulgte hendes bøn til endokrinologen om at få den kombinationsbehandling, som hun selv mente kunne bedre hendes dårlige tilstand. Et ønske lægen afviste.

Programmet benævnete T3 medicin som ”grisetabletter” (en kedelig betegnelse, som stofskiftpatienter aldrig ville benytte om T3, som de selv kalder fx naturligt stofskifte hormon eller Armour, ERFA thyroid). Endokrinologen fortalte, at problemet med T3 er, at det er svært at regulere og let at overdosere.
Da programmet sluttede, gik jeg på Facebook for at observere reaktionerne. 12.000 personer med stofskiftesygdom følger denne Facebook gruppe, som i stigende grad benyttes til både at oversætte uforklarlige skemaer fra lægene til hverdagssprog samt til at erfaringsudveksle om de ”gode læger”, dem der lytter og tager patientens symptomer seriøst og tør tilbyde andre medicintyper end T4. Der udveksles også adresser på kliniker i udlandet, som jeg ser benyttes i stigende grad, hvor T3 tabletterne har større anerkendelse. Mange i denne gruppe oplever, at lægene ikke lytter til deres beretninger om, at de stadig, trods fine tal, føler sig i ubalance.

Reaktionerne på tv programm var en klar afstandtagen fra betegnelsen ”grisetabletter” og forundring over det ensidige fokus på negative konsekvenser af kombinationsbehandling eller ren T3 medicin. Programmet formåede ikke at skildre det store antal patienter, der selv betaler og behandler sig med T3 medicin, og bruger Facebookgruppen til at dele slæende før og efter billeder med beretninger om stærkt øget livskvalitet. Der var udelatt sympati for kvinden, som fik afvist sit ønske om en ny behandling.


Min analyse af Facebook grupperne for voksne med type 1 diabetes understreger kronisk syges behov for at blive hørt som unikke personer. Analysen viser stor variation og individualitet i måder at leve med sygdommen på. Type 1 diabetes vurderes som en af de vanskeligste kroniske sygdomme at egenbehandle på grund af komplicerede selvbehandlingsteknologier.

Blandt andet derfor er Facebook en unik vej for personer med denne sygdom til kontakt med andre i samme båd, når de er i tvivl om, hvordan de skal tackle et problem. Tvivl om selvbehandling er yderst aktuel i min forskning og forekommer på alle timer af døgnet, fx når et blodsukkerniveau pludselig løber løbsk og enten bliver for højt eller for lavt, eller når den blodsukkerregulerende teknologi fejler. Når diabetesklinikken er lukket, kan man støtte sig til andre kronikere på Facebook. Når ens slægtninge eller venner sover, er der altid en vågen person i ens online netværk, parat med en løsning på ens problem, en hjælpsom bemærkning eller blot et venligt ”like”. Facebook er blevet et online skulderklap, der virker motiverende på egenbehandling.

Facebook er et medie til deling, hvor udveksling af sygehistorier opleves som stærk følelsesmæssig støtte. Nogle omtaler netværket som en familie med fælles diabetesprogr og, da det er nemt at identificere sig med folk med lignende livshistorier og oplevelser. Netværkene faciliterer oftest også møder offline. Nogle personer bruger Facebook som en flygtvej fra ”diabetespolitiet”, som kan være familie, venner eller kolleger, der kan føles alt for omklamrende i forhold til livsstilvalg - især i forbindelse med mad og motion.


Grupperne er et forum for patientcenteret viden. Det er grupper, som deler viden om dagligdagen, om samspillret mellem hverdagsliv, krop og teknologier, om mad og motion, og om at være en unik person med et særligt behov. Og på Facebook er alle individuelle, og der er altid en anden individuel person, som er lydhør.

Ja, det kan selvfølgelig være skræmmende for den "etablerede" viden, at der findes en individuel viden, formidlet af mennesker uden lægefaglig baggrund. Og ja, den viden kunne måske have uheldige konsekvenser. Men min forskning tyder ikke på, at det er tilfældet.

De sociale netværk er kommet for at blive, uanset om sundhedsprofessionelle anerkender patients online navigation og sygdomsudvekslinger. Min forskning peger på, at de sociale medier rummer en uvurderlig viden om sygdom og sygdomsforløb. En viden, generet af mennesker med førstehåndskendskab. Interviews med personer med type 1 diabetes understreger den berøringsangst for patientens egen viden, sundhedspersonale udviser. Konsekvensen er, at patienterne fravælger at fortælle sundhedsprofessionelle om deres brug af Facebook. Lad os nu få en mere konstruktiv debat om de sociale medier, som i stigende grad benyttes af patienter, og finde ud af, hvordan disse medier måske kan bygge bro imellem patient og behandler og i stedet åbne op for en debat om forskellige tilgange til viden. Mit studie viser, at patienter også er medskabere af viden. En viden, der er situeret, og når ud i alle hverdagslivets krinkelkroge.
Do social media really help people with diabetes?


Author: Natasja Kingod

How do people with Type 1 diabetes use and apply social media in their everyday life? This theme is studied in a PhD project at the Steno Diabetes Center Copenhagen, Denmark and the Department of Anthropology at the University of Copenhagen. The PhD student and anthropologist Natasja Kingod explains:

The starting point for my PhD was my own involvement in an online community on Facebook for parents of children with Type 1 diabetes. Four years ago, when my eldest daughter was two years old, she was diagnosed with Type 1 diabetes. In my own struggle to understand this illness, I joined one of the first communities on Facebook for people with diabetes. Since then many more communities targeting both people with Type 1 diabetes and their relatives have been established on the platform.

My PhD is about how adults with Type 1 diabetes manage daily life with the help of online and offline peer support. I have followed adults with Type 1 diabetes into online and offline social spaces, including communities on Facebook. As well as observing what is going on, I’ve interviewed and had informal conversations with people about their experiences as well as going to offline meetings of people with diabetes.

Anytime, anyplace, anywhere

The appeal of Facebook is that it can be engaged with anytime and anywhere through your smartphone.

When the diabetes clinic is closed you can turn to peers on Facebook. When your relatives or best friends are asleep there is always someone within your online Facebook community who has a solution to offer to your problem, a helpful remark or just a supporting ‘like’ to your post.

Many of the communities are entirely peer initiated and peer facilitated. Health care professionals and even relatives are often not welcomed into these communities or have to observe silently in the background.
Practical help

Within the Type 1 diabetes community, Facebook is a convenient way to connect with peers when in doubt about how to self-care. This doubt is very apparent in my research and appears at all times of the day: when a blood sugar level suddenly becomes too high or low; when there is a malfunction of the technology used for regulating blood sugar; or when a combination of food and exercise requires complicated changes to insulin pump settings.

Part of my research emphasizes how people with type 1 diabetes use the online communities as a source of inspiration on how to ‘tinker’ with their self-care. People want individualized knowledge on how to live with their illness. This type of knowledge is highly experiential and based on various ways of tinkering with one’s body, and with self-care technologies in their daily lives. It is not the type of knowledge that you get from a doctor or a nurse.

There is no manual on how to live with type 1 diabetes, which is why people turn to peers online. However, people with diabetes have experience that is valuable for themselves as well as others. It should be acknowledged more within evidence-based medicine.

Sharing stories

Facebook is a medium of sharing – and people with Type 1 diabetes share their stories about diabetes. This can be a real emotional support for others in the community. Some people refer to the communities as “a family with a common diabetes language”. The communities are also used as a get-away from the ‘diabetes police’, which could be relatives, friends or colleagues who might be considered overly concerned when it comes to lifestyle choices particularly about food and exercise.

More personalized new communities keep being created in order to target all facets of care. It is not enough to be a member of a general community on type 1 diabetes. Communities are now targeting insulin pumps, insulin pens, glucose monitor brands as well as food and exercise.

These many communities strive to reduce the noise of irrelevant information and increase personalized care and knowledge. It’s not just about technology – there are also communities for women with Type 1 diabetes.

Helping people get the right information

I have seen a tendency among healthcare professionals to disregard, object to or fear online peer to peer interaction on Facebook. This fear emanates from a belief that there is a lot of misinformation circulating online – and perhaps that there usually is ONE solution to challenges. Of course wrong information may sometimes occur. Nevertheless through 12 months observing these communities I have experienced again and again how misinformation is immediately corrected by several peers within the community.
I think that it is a myth and a prejudice that it is harmful to interact in communities on Facebook with other people with type 1 diabetes. In fact I have witnessed cases where information received from health care practitioners was built on miscommunications or failure to translate the medical language into an everyday language, which has resulted in potentially harmful practices over extensive periods. This could perhaps have been avoided or even prevented if people had accessed peer expertise and support from networks on Facebook in their specific area of concern or doubt.

My research has found really positive news. I know from personal experience how difficult it is to manage diabetes and online communities are filling gaps that could never be met offline. People with diabetes and their families are helping to share the load and give specialized support at all times of day and night.

Sometimes the help is very practical. And sometimes it is a motivating and recognizing online pat on your shoulder from people who know just how you feel.
Facebook som vidensbank


By William Meyer

Som medarbejder har du måske oplevet, at en borger henvender sig til dig med ny viden, som vedkommende har fået på Facebook. Men hvad gør man i sådan en situation? Få fem gode råd fra antropolog Natasja Kingod, der er i gang med at forsk i emnet.

I Facebook-grupper foregår der en flittig videndeling blandt borgere om, hvordan man f.eks. håndterer sygdomme, eller det at være pårørende til en syg. Det giver borgerne mulighed for hurtigt at få støtte og brugbar viden, men det kan også skabe udfordringer i mødet med de fagprofessionelle.

Det har antropolog Natasja Kingod erfaret. Hun er i gang med at skrive en ph.d. om netop dette emne.

- Når borgerne fortæller, hvad de har lært på Facebook, bliver de ofte mødt med stor skepsis fra de fagprofessionelles side. Og det er ikke hensigtsmæssigt, siger hun.

Hun har i sin undersøgelse fundet ud af, at borgerne har stor glæde af den nemme adgang til viden, de får på Facebook. Desuden er fejlinformation en sjældenhed og bliver typisk fjernet eller korrigeret af de mere erfarne borgere.


Her kan du læse fire andre råd til, hvordan man ifølge Natasja Kingod i stedet kan agere.

Kend de gode grupper

Det andet gode råd er, at man som fagprofessionel kan skabe sig et overblik over, hvilke grupper der findes inden for ens område.

- Så kan man fortælle borgerne, at her er der et sted, hvor de kan gå hen med deres specifikke problemstilling og få relevant viden.

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Hun giver et eksempel fra det område, hun forsker i, diabetespatienter med type 1 diabetes og pårørendes brug af Facebook:

- Der er et væld af forskellige selvbehandlings-apparater til diabetespatienter. Hvis man har undersøgt Facebookgrupperne i forvejen, kan man give borgerne en henvisning til de grupper, hvor der er andre, som har erfaring med de samme apparater, som de bruger.

**Brug selv grupperne**

Natasja Kingod understreger, at uanset hvad man synes om Facebook, så er mediet kommet for at blive. Derfor kan man lige så godt gøre brug af den viden, der er på mediet. Det er det tredje råd:

- Som fagperson kan man for eksempel få et indblik i, hvordan borgerne taler med hinanden om deres sygdom, og hvilke emner der optager dem, hvis man melder sig ind i de samme Facebook-grupper som dem, fortæller hun.

Her er det dog ikke nødvendigvis en god idé at være alt for aktiv i borgernes interne diskussioner, mener hun.

- Nogle borgere foretrækker, at deres Facebook-grupper er et rum, hvor de professionelle ikke blander sig. Derudover kan det være tidskrævende at deltage i diskussionerne. En idé kan derfor være, at man i stedet nøjes med at uploade dokumenter og artikler med nyttig viden, som borgerne selv kan læse og tage stilling til, hvis man gerne vil bidrage til grupperne.

**Skab grupper**

Hvis man som fagprofessionel mener, at der mangler et sted at diskutere viden inden for ens område, anbefaler hun som fjerde råd, at man ganske enkelt opretter en Facebook-gruppe.

- Borgerne er allerede på Facebook, og derfor er det nemt at få fat på dem der. Erfaringer fra udlandet viser, at det ikke kan betale sig for eksempelvis organisationer at skabe deres egne platforme, for de bliver lynhurtigt overhalet indenom af Facebook, forklarer hun.

**Anbefal mådehold**

Som sit femte råd anbefaler Natasja Kingod, at man på ét punkt råder borgerne til forsigtighed med Facebooks grupper: Der bør være mådehold i, hvor jævnligt borgerne læser i grupperne.
- Grupperne kan hurtigt blive et stressende element i hverdagen, som får sygdommen til at fylde mere, end den bør. En god idé er derfor at anbefale, at borgerne ikke melder sig ind i for mange grupper ad gangen, og at de slår notifikationerne fra, så de ikke konstant bliver mindet om dem, siger hun.

Desuden pointerer hun, at man kan rådgive borgerne i at sortere i viden og være kildekritiske.

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