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Enacting different stories

What does telemonitoring become in chronic ill persons lives?

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Enacting different stories

What does telemonitoring become in chronic ill persons lives?

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Abstract

We scrutinize how people living with diabetes type 2 and co-morbidities enact stories as part of attending telemonitoring services. Although telemonitoring has been attached to a host of promises and diagnoses, we argue, it is pivotal to understand the stories and engagements that care receivers enact about it. This perspective is missing in the literature. We frame our analysis with the notions of 'modes of ordering' and 'justification' to analyze ethnographic interviews, logbooks, and presentations and discussion at a workshop. We conducted sixteen interviews with persons living with diabetes type 2 to scrutiny how they order their lives while, increasingly, care devices enter their private homes. Our analysis leads to four modes of ordering and their justification: (1) telecare as a ritual to gain reassurance, (2) telecare to receive support from nurses, (3) telecare to deal with flexibility and control, and (4) telecare as a signifier of failure to stick to the diabetes regime. The study untangles the contexts of what people aim to achieve, the struggle they undergo, and the transformation of their aims. To get a better understanding of care receivers' engagement, we propose positioning people involved in type 2 diabetes telemonitoring as subjects in need of support to manage their health condition. The research design committed the participants to reflect over self-tracking at home over a period. Also, it gave them an opportunity to demonstrate how they self-track by making a presentation of their everyday self-tracking practice at the workshop. Telemonitoring becomes different things in peoples' lives, and the justifications for participating differ and transform along with the engagement. We conclude that stories about self-tracking is enacted in various ways depending on contexts such as co-morbidity, the support they get and their position at the labor market.

Keywords

Modes of ordering, justification, self-tracking, telemonitoring, diabetes type 2, co-morbidity.

Introduction

We focus on the stories that arise from self-tracking and telemonitoring. Some years ago, the Danish Health Authority set up an expert group to make recommendations for telemonitoring for people living with chronic illnesses. In spite of years of research, the expert group reported that knowledge is lacking about the kinds of self-tracking, monitoring and feedback that is most helpful for this group (Sundhedsstyrelsen, 2017). The report notes that there are indications that self-tracking with telemonitoring and feedback leads to better quality of life. The expert group describe the purpose of self-tracking and telemonitoring in relation to people living with chronic illness as the following:

> "To contribute to potential positive effects of both health and socio-economic character. It is about making the individual citizen with chronic illness act on their own symptoms to achieve increased quality of life, satisfaction, and security and consequently fewer or shorter consultations, admissions, and re-admissions to hospitals" (Sundhedsstyrelsen, 2017) (translated by the authors).

The report provides recommendations relating to ensuring stability to avoid severe incidences. In this report, people living with diabetes type 2 are expected to use an app to send measurements of blood sugar number, blood pressure and weight from home. Subsequently, they will receive feedback from a diabetes nurse sitting at the municipal health center. The report states that the efforts ought to have their outset in the citizens' own resources, their active participation, and support their self-determination and autonomy (Sundhedsstyrelsen, 2017). The trope in this report demonstrates current trends and imaginaries in relation to health service development (Pink, 2022). As such, it stands in opposition to ideas of passive reception of welfare benefits that stand out as unhealthy, life shortening and expensive. The nurses are expected to support coping via continuous and empathic dialogue with people living with chronic illnesses about numbers, data, and wellbeing to prevent worsening of the condition. Not surprisingly, telemonitoring in general has dramatically expanded due to Covid 19 (Lupton, 2022; Nickelsen & Duguid, 2023). While government agencies focus on standards, quality of care and savings, in this paper, we study enacted stories about what telemonitoring becomes in chronic ill persons' homes.

During the empirical work preparing this article, we found inspiration in the discussion about digital health literacy, sometimes referred to as eHealth literacy. It is defined as "the ability to seek, find, understand, and appraise health information from electronic sources and apply the knowledge gained to addressing or solving a health problem" (Estrela, Semedo, Roque, Ferreira, & Herdeiro, 2023). This approach asserts that we can ensure successful use of digital health technology if individuals have the necessary capabilities, which we can measure irrespective of context and improve with education (Greene, 2006).

Our contribution to this literature is a nuanced understanding of care receivers' stories about what telemonitoring entails in private homes; what are the challenges and how it transforms aims. We argue that to develop telemonitoring services, it is crucial to understand more of how people arrange themselves with devices and how they talk about the consequences of moving care from physical meetings to the exchange of data and text messages. In other words, it is pivotal to understand how care receivers often elderly people enact different stories as part of their lives with one or more chronic illnesses and assigned to the telemonitoring services from home. We are interested in how self-monitoring becomes part of personal routines and what people aim to get out of telemonitoring such as a sense of safety or close follow up from nurses. Invariably, we describe our informants as 'persons living with diabetes type 2' and 'people living with co-morbidity' rather than 'patients' or 'citizens'. See table 1 for an overview of our informants. None of our informants are committed to telemonitoring because they must. They are offered to take part in it by the rehabilitation team at the municipal health center. Thus, our informants are in it voluntarily to benefit from it, to self-manage and to improve their health condition. Having this deliberation in mind, we will take a closer look at how people living with diabetes type 2 and co-morbidity, that is people in a bad health condition, enact and talk about their engagement in the telemonitoring services.

While policy agencies propose self-tracking as something that supports peoples' empowerment and independence (Regeringen, KL, & Regioner, 2022), Pols, Willems & Aanestad (2019) argue that digital health technology are involved in people's understanding of the psychology of themselves. We find this interesting to get access to what chronic ill people seek to achieve from telemonitoring, how they adapt, their struggle, the stories they tell, as well as what they get out of it.

Problem, literature and research questions

There is a need to learn more about how care receivers live with diabetes type 2 telemonitoring, not just in terms of certain clinical parameters, but in terms of routines and the ordering of their lives with devices at home. In the following we make a literature review. The academic discussion on telemonitoring is abundant. Many articles indicate the promising potential of eHealth, telehealth, and/or telemedicine solutions in delivering healthcare services as a measure and response to many different diagnoses (Bitar & Alismail, 2021). This took off within science and technology studies (STS) long ago (Mort & Finch, 2005; Mort, May, & Tracy, 2003; Pols, 2012). The discussion of telecare in STS has circled around personal security (López, 2009), new roles and responsibilities (Moser, 2019; Oudshoorn, 2011), and values and ethics (Mort, Roberts, Pols, Domenech, & Moser, 2015; Pols, 2015). Recently, there has been a growing interest in the performative effects of telecare, that is, how the provision of telecare services and smart home technology affect its own outcomes (Stirling & Burgess, 2020, 2021).

Caulfield (2021) for instance discusses drug abuse telecare. He shows that telecare contributes to redefining the experience of familiar places, such as home, into spaces of both care and surveillance, and how the technology presents both affordances and foreclosures to accessing care because the users struggle to conform with its requirements to receive support. In relation to this, Ivanova (2020) calls for fresh thinking about care and place to address the changing nature of care places that we see now. Although much has been written about the organization and management of self-tracking and telemonitoring services, studies about the stories users tell about their own engagement in diabetes type 2 telemonitoring are lacking. Also, there are holes in the literature regarding care receivers justification of their own participation in combination with their ordering of their home as a site containing still more self-tracking and telemonitoring devices and other digital health technology. Service receivers may for instance find themselves excluded due to lack of digital competences or due to emotional issues that do not fit into the services and standards (Lupton, 2019). This is the landscape we explore in this article. Our research question is: How do chronic ill people enact and talk about self-tracking and the telemonitoring services?”

Short outline of the research design

We interviewed eight informants twice either in their private homes, at the municipal health center or by using the digital meeting service, Zoom. We founded the study on chronic ill persons’ stories about their work with self-tracking. We analyzed these data as four modes of ordering. This analysis was discussed at a workshop to get a better understanding of our informants justification for engaging in telemonitoring.

	Pseudonym and gender of informants	**Age**	**Co-morbidities**	**1th Interview**	**2nd Interview**
1	Ole (m)	56	Injured left side of his body in traffic accident	30 min at the health center	60 min interview at the health center
2	Sverre (m)	78	Glaucoma Issues in relation to blood pressure and cholesterol	45 min interview at the health center	3 hours at home incl. walking together to the GP
3	Henning (m)	54	Schizophrenia	45 min interview at the health center	Zoom video recording 30 min
4	Lars (m)	53	Recent heart attack, Sleep apnea, Osteoarthritis	60 min interview at home	Zoom video recording 30 min
5	Nanna (f)	53	Stress, obesity, back pain	Zoom, video recording 30 min	Zoom video recording 30 min
6	Kristina (f)	66	COPD, heart failure	FaceTime 30 min	FaceTime 30 min
7	Line (f)	65	Heart failure	Zoom, video recording 30 min	Zoom video recording 30 min
8	Lone (f)	58	Cancer	Zoom, video recording 30 min	Zoom video recording 30 min

Table 1. Informants’ pseudonyms and gender, age, co-morbidities, time and context of the interviews.

Analytical approach

Modes of ordering

In our work on stories, we have found inspiration in the notion of ‘modes of ordering’ (Law, 1994) originating in Science and Technology Studies (STS). This helps us understand how people living with diabetes type 2 and co-morbidity struggle to adopt the telemonitoring services and seek support from distant nurses to manage their health while their private homes transform into spaces of both privacy and care work.

Modes of ordering constitute recurring patterns produced and reproduced as part of the ordering of relations including technology (Law, 1994). Law developed this notion in opposition to ‘discourse’ in an argument with Foucauldian discourse analysis to scrutinize the means of survival of a large UK laboratory (Daresbury SERC Laboratory) after heavy austerity in the 1980s. Modes of ordering treat social order as a verb rather than a noun and sees social order as an ongoing, precarious, and recursive process. Meanwhile, it stresses the material heterogeneity as well as the multiplicity and complexity of ordering. Switching from ‘discourse’ to ‘modes of ordering’ makes it possible to cut discourse down in size and invites studying how social order enacts itself in various material forms (Law, 1994, p. 95). Modes of ordering signify not just parallel orders, but logics that connect and intermingle. Moser later introduced modes of ordering into the context of care (Moser, 2005). Instead of tracing, for instance, how special education, rehabilitation medicine or welfare policy constitutes disability, modes of ordering inspire to look at performance in practice as the location where different orderings enact, meet and overlap. The crucial question is what normativities and effects various modes of orderings produce and how they connect. Based on this, Moser discusses empirically observed performances of disability (normal, lack, fate and passion), and tries to untangle the interferences among these orderings. This makes a complex and interesting picture available. Although the concept of modes of ordering is not new, several care studies adopt this sensitivity. Näslund et al. for instance studied modes of ordering in relation to visual disability (2017) and Musse, Kroon, Mulder & Pols (2021) studied modes of treatment plans in a community mental health team. Jørgensen & Schou (2020) studied modes of ordering in digitalization of the public sector and Janmyr & Mourad (2018) studied ordering within immigration politics. In addition, Kalff studied project management as a matter of temporal modes of ordering (2022) and Hummel & van der Duim (2016) studied modes of ordering as a tool to analyze development in tourism.

The normativity of self-tracking and telemonitoring

The French pragmatic sociologists Boltanski and Thévenot (2006) have contributed with a theoretical framework of orders of worth. They investigate how actors morally order their social life. Boltanski and Thevenot aim to renew critical sociology by focusing on the critical capacities that actors mobilize in everyday life. Individuals involved in controversies use available normative principles, called orders of worth, to defend their course of action using justification and critique (Blokker, 2011). Justification follows rules of acceptability. While the term ‘orders of worth’ remains vague, it nevertheless helps grasp culturally embedded grammars. We see morals as a term for notions of what is right and wrong, valuable, and reprehensible in social life. All qualities and actions and all social conditions can be assessed as a moral question. Correspondingly, pragmatic sociology comprises a relevant supplement to modes of ordering. It does so by emphasizing the normative dimensions of social life and here engaging in caring with digital technologies (Cloutier, Gond, Leca, & Lounsbury, 2017; Gadinger, 2016). We use pragmatic sociology and the notion of justification here to address questions regarding chronic ill peoples’ normative approach to their own commitment in self-tracking and telemonitoring.

How modes of ordering and justification supplement one another

Our analysis of modes of ordering elucidates that people living with chronic illness and co-morbidities make sense of self-tracking and telemonitoring. They find it useful in managing their own health and they see numbers, apps, and messages as tools they can actively use to improve their bad health. When they tinker (Winance, 2019) with measurements, numbers and apps to adapt to the telemonitoring services, they do so based on different aims and contexts: to get reassurance, to get support, to engage flexibly, to stabilize emotions and one’s health condition. As a supplement, pragmatic sociology helps underpinning the normative dimension of commitment to diabetes type 2 self-tracking and telemonitoring. People justify and defend their commitment to self-tracking (Boltanski & Thévenot, 2006). As such, we apply pragmatic sociology to develop knowledge about how people living with chronic illnesses and co-morbidities not only enact and order, but also tell stories about, argue, explain and morally order and value their participation in diabetes type 2 telemonitoring services.

Methods

Design of the study and research ethics – gaining access to modes of ordering

In order to explore the productive qualities of digitalization, Ruppert, Law, and Savage (2013) propose to scrutinize fields of devices and services as relational spaces and not as epochs or pervasive shifts. They assert that the lively shifts that are brought about by digital technologies should be explored carefully and with due attention to the specificities of the devices. In line with this, we are interested in what people living with diabetes type 2 and co-morbidities do with numbers, graphs and devices and how that affects their routines at home.

The study is part of a research council grant (Independent Research Fund Denmark) called 'The Infrastructure of Telecare - Imaginaries, Standards and Tinkering' (2019-2024). The aim is to contribute to the development of telemonitoring services across hospitals, doctors and municipalities. The middle-sized Danish municipality discussed here entered a collaboration with the researchers with the aim of developing collaboration with doctors and hospitals. The authors were to contribute to a series of workshops aiming at contributing to routines for cross-sector collaboration. It turned out to be difficult to keep all this together, partly due to data security issues, but also because there was political uncertainty about how to organize the telemonitoring service in the municipalities and across various health actors (Nickelsen & Bal, 2021). The first author was project leader and did the fieldwork. Together the authors analyzed the modes of ordering.

Initially, the plan was to visit the informants at home for three hours to observe the use of devices in their private homes and to talk about self-tracking routines. Due to Covid-19, however, we had to change plans. In accordance with the progression of the pandemic, we instead interviewed eight informants twice either in their homes, at the local municipal health center or by using the digital meeting service, Zoom. Thus, the data collection was formed by what considering the pandemic was permissible at a given moment. Correspondingly, our study was founded more on chronic ill persons' stories about their work with self-tracking, than their ordering and enactment of the telemonitoring services. A research assistant verbatim transcribed all interviews. See table 1 for informants' pseudonyms, gender, age, co-morbidity and time and place of the interviews. All informants received an information sheet and signed informed consent. The professionals in the municipality scrutinized and accepted the research procedure and ethics. All names are false to protect informants.

Interviews

We conducted 16 interviews with 8 informants, that is, 2 interviews per informant (see table 1). During the first interviews author 1 (hereafter the researcher) scrutinized the informants' situation, their diabetes type 2 history, and their challenges in relation to managing their blood sugar number. By demonstrating how they do it, the informants helped us to understand how they take medicines, do blood sugar number measurement, navigate the app and communicate with the nurses at the health center (see photos 1, 2, 3). In addition, the researcher encouraged the informants to read aloud some of the text-messages that were exchanged with nurses. It was, however, their own decision whether they chose to do so or not. In some cases, this correspondence was highly illuminating regarding their communication with the health center. The Zoom-interviews were both audio and video recorded. During the second interviews, the researcher asked the informants to elaborate further on aspects of the first interview based on a forwarded full transcript of the first interview. In this context, the researcher was particularly interested in: How informants enact telemonitoring and tell stories about their everyday self-tracking practice in their homes.

Workshop

The aim of the workshop was to elicit what the app and telemonitoring adds in contrast to noting the numbers and data in a book. Prior to the workshop, all the participants were instructed to take notes in a logbook regarding what the app, telephone calls and text messages add in contrast to, for instance, noting the numbers and data in a book at home (as many informants did before). There were 18 participants: eight people living with diabetes type 2, five telemonitoring/diabetes nurses, a GP, an IT manager, two researchers and a research assistant. The workshop was structured as follows: (1) key themes from the interviews were presented as an opening by the researcher, (2) the participants explained one-by-one what they had noted in the logbook, and (3) the following question was discussed in plenary: What do the app, telephone calls and text messages add in contrast to noting the numbers and data in a book at home? In closing, a managing nurse and the researcher summed up the discussion. The workshop lasted three hours, was held at a municipal health center, and was facilitated by the researcher. The research assistant made a detailed summary. Our thorough preparation, communication and conduct about the workshop, we believe, made it clear to our informants what the workshop was all about. This committed our informants to reflect consistently over telemonitoring over a period and gave them the opportunity to demonstrate how they self-track by giving each of them the opportunity to make a presentation of their everyday tasks and struggle with self-tracking in front of the workshop participants.

Procedure of data analysis

As both authors work at universities (in the Netherlands and in Norway), neither of us had a prior deep knowledge about telemonitoring in Danish municipalities. This equipped us with modesty, fresh eyes and many questions. After the workshop, we organized the empirical material in eight narratives about diabetes type 2 self-tracking. First, we highlighter-coded and analyzed the transcribed and video-recorded interviews. Then we analyzed the logbooks as well as the presentations and discussion at the workshop. We soon observed patterns in the material, and eventually we identified four ways of talking about and justifying engagement in the telemonitoring services. By way of emails, the authors discussed the patterns to sort out differences. We elaborated, exchanged and experimented with several versions and titles of the modes of ordering. To ensure a certain level of complexity we decided to name them not just with one word, but with short sentences to embrace movement and process. In the following, we analyse the scope and complexity of justifications and the modes of ordering.

	Modes of ordering: What does telecare become?	**Justifications: What do people living with diabetes type 2 and telemonitoring get out of it?**
1	Telecare as ritual and reassurance	A ritual to create a sense of safety and a firm grounding
2	Telecare to receive support	An activity to obtain support and help from the nurse.
3	Telecare to deal with flexibility and control	An attractive mix of self-chosen and external control
4	Telecare as a signifier of failure to stick to the diabetes regime	A way to strive for a better life and be punished for bad behavior when it is not successful.

Table 2. Modes of ordering – what does telecare become. Justifications – what do people living with diabetes type 2 and telemonitoring get out of it?

The analysis of the empirical material points to four quite different ways of participating in the telemonitoring services. As such, they illustrate a few cases that we argue go beyond the identified individuals and point at certain modes and justifications. In that sense, the mentioned modes of ordering and justifications constitute instances that we also find with other informants, correspondingly, the modes of ordering elucidate the variation and scope we found in the material. The point is not whether one mode of ordering is more typical, correct, useful or relevant than others. They are not pure - rather, they intertwine. We will return to this after analyzing them in more depth.

Analysis

Modes of ordering and justification

In this section, we focus on how our informants' tell stories about and justify their commitment to self-tracking and telemonitoring. We argue that self-tracking practices become part of chronic ill persons' routines, and we are interested in the emotions that arise from self-tracking and telemonitoring. To add an extra layer of complexity to the discussion, we will focus on the connection between self-tracking practices, the numbers (high or low) our informants report and the emotions they express such as sense of control, relief, success and anxiety.

As demonstrated in table 2, we have identified the following modes of ordering: (1) telecare as ritual and reassurance, (2) telecare to receive support, (3) telecare to deal with flexibility and control, and 4) telecare as a signifier of failure to stick to the diabetes regime. The last may appear odd. Why would people commit to telemonitoring if it confronts them with failure? However, we witnessed informants that continually strove to fit into the standards although they did not. This is the situation to which the fourth mode of ordering refers. All quotes below are translated from Danish by the researcher.

Telecare as ritual and reassurance

Kristina is 66 years old and lives with her partner on a farm. Apart from diabetes type 2, she lives with COPD and has problems with her legs and hips and thus walks with a crutch. She also suffers from heart problems and carries a pacemaker. Previously, she worked as a packer in a part-time job at a gasket factory four hours a day for 15 years. Recently, however, she stopped working. She has lived with diabetes type 2 for 5 years. She found herself tired for a period and went to the doctor. Initially, her blood sugar number was 12, 13 or 14 (high). Today, it is half that number and is regarded normal. She attended the diabetes course at the hospital, where she learned about management of the disease. She has been involved in telemonitoring for two years. She got into diabetes telemonitoring through COPD telemonitoring and now engages in both.

She uses a small butterfly needle to prick blood and a FreeStyle device to read the blood sugar number (see photo 1). In addition to noting her blood sugar number in the app (see photos 2 and 3), she notes

Photo 1. Blood sugar measurement device (FreeStyle) with butterfly needle.

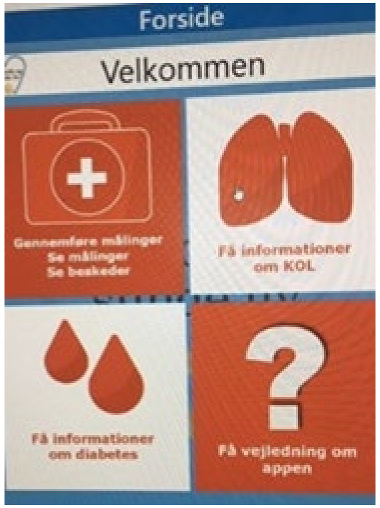

Photo 2. App menu A

Photo 3. App menu B.butterfly needle.

the numbers in a small book. She likes to jot down all the data to keep track of everything. She finds this amusing and a reassuring morning ritual. In her own words:

> “I don't know why I’m involved in telemonitoring. I just am. I think it's kind of fun to see the figures in the app, to follow the graphs and the statistics. I would like to overview it all. But strictly speaking, I didn't have to do this. Perhaps it gives me reassurance.”

Kristina loyally self-tracks and sends the data to the diabetes nurse every morning even in stable periods. She likes to sit with all this in her kitchen at a little table. She uses the devices for self-tracking before breakfast every morning.

> “That's the first thing I do in the morning. I spent 15 minutes there for a little fun. I measure and I take insulin, and then my day begins. I’ll never forget to do it. I do it almost automatically. I could well live without it, but now I’ll keep doing it until they tell me to stop.”

It is quite easy for her to keep the blood sugar numbers down, since she does not eat sweets. Her problem is food with a high fat content. Moreover, an updated app has recently been introduced. This implies a few technical issues. Kristina regrets that the telemonitoring website is often down:

> “It’s annoying when the system is down like it was this weekend. Sitting with all this has become a habit. I check how I ‘felt’ last time. I also check my heart rate occasionally and see if my pacemaker is working properly. I just can’t let go. Is it okay or not? I’m curious”.

In particular, she loves graphs so she can see how the blood sugar

number shifts over a long period. However, this has been removed from the latest version of the app. Kristina regrets that. Nevertheless, she explains she will keep self-tracking until the nurse or doctor tells her to stop. She also points out that although she doesn't need telemonitoring, she never forgets to report the measurement in the app. She will continue to submit numbers because she finds it funny to keep track of all the data.

As mentioned, modes of ordering constitute recurring patterns produced as part of here-and-now ordering of relations including technology. We call this first story ‘telecare as ritual and reassurance.’ Kristina repeats that she will continue self-tracking and report the numbers in the app until somebody asks her to stop, despite contending that she does not need to engage in telemonitoring because her numbers are good. She states that it gives her a sense of security and that she thinks it is amusing. Kristina enjoys having her morning ritual and her own little extra book where she gains a handle on all the data. It has become a part of her life to keep track of everything and to check if all is OK. However, she is annoyed that the graphs have disappeared with the latest updating of the app because here, as she says, she could see “how I ‘felt’ last time.” This is interesting and shows that the blood sugar numbers are integrated in Kristina’s life world. Thus, the data make sense because they bring her in touch with former body sensations and thus helps her to understand actual body sensations.

Telecare to receive support.

Ole is a 56-year-old male. He lives with his wife in a remote town. He was a truck mechanic. While driving home after an 18-hour workday in 2013, his car hit an oncoming car. The accident led to several bones breaking in the left side of his body. He had a steel pipe implanted in his left thighbone, leading to complications. He lost the ability to stand and walk for longer periods. Now, several years later, he experiences swelling in his legs and hands. He recently started a part-time job as a caretaker 15 hours a week. “This is what I can manage”, he explains. The situation implies that he moves less, and, because he eats just as much as he did before, he is gaining weight. Some years ago, by coincidence, he tracked his blood sugar number. It came out to be 22 (very, very high). His GP subsequently diagnosed him with diabetes type 2. He now measures and sends blood sugar numbers in the app on Mondays. Typically, the figure is around eight – "it is almost always in the high end". If the number is above eight, he walks the dog to bring it down. The blood sugar measuring system decided by clinicians requires him to measure and submit the numbers in the app at the same time. This means he must get up early. He finds it annoying that he is not allowed to measure the blood sugar and submit the measurement later with a message about when exactly the measurement was done. When enrolled in telemonitoring, participants are given 150 butterfly needles as part of the service (see photo 1). The participants must purchase the rest themselves. Since they cost 1 Euro each, Ole has decided he will only measure his blood sugar three times on Mondays. Extending over a year, this fits well with the number of needles handed out. In fact, he would like to measure more, but he is firm that he is not willing to take on this expense. On the other hand, he underpins that he feels obliged to self-track seriously. This is because the nurses have been supportive. He now feels an obligation to go all in and self-track conscientiously.

> "The fact that there is somebody reacting is so great. I like that there is somebody at the other end of the app saying 'hey, you are too high, today. Do you know why?"

The feedback from the nurse has a good effect, he explains. For instance, he learned from discussing self-tracking data with one of the nurses that he must take one pill, four times a day. Not two pills, two times a day, as the doctor prescribed. The more spread out the pills, the lower the blood sugar.

In the past, Ole never had time for breakfast. Now he enjoys breakfast every morning. He learned from discussions with nurses that this influences blood sugar number. In addition, Ole and his partner have both changed their diet after Ole received the diabetes type 2 diagnosis. They

always have meat and salad, and they eat no rice, pasta, or potatoes.

> "What's great about self-tracking at home is that you get feedback from a nurse. Somebody follows you and you learn from discussing the data with them. Even when I had gained 2-3 kilograms, the nurse was encouraging. 'It needs to be like that sometimes. Come again', she said. She is always constructive! That is helpful."

However high, Ole's numbers are stable. He listens carefully to the nurse, learns, and uses the data to take precautions. His ambition is to be leaner. He wants to know when the numbers are problematic so he can adjust to his diet and training. The fact that he not only faces the results of his own measurement, but also has contact with nurses seems to give him the strength to continue to improve physically. He self-tracks because he obtains support to lose weight and that helps him to train more.

Whereas the first story of mode of ordering was about gaining reassurance, this one is about staying in contact with the nurse and thus not having to do everything alone. Ole states there would be no point in self-tracking if there was not a nurse at the other end. He justifies his commitment to the telemonitoring services with the feedback he gets from the nurses. We find this point important: Many chronic ill persons justify the use of digital care technologies with contact to care providers. This relates to the literature emphasizing, perhaps paradoxically, that people use technologies to stay in touch with care providers (Benham-Hutchins, Staggers, Mackert, Johnson, & deBronkart, 2017). In this story about mode of ordering, telemonitoring seems to be a way to stay in close contact with the nurse, get support to get leaner, and avoid having to do everything alone.

Telecare to deal with flexibility and control.

Line is a 65-year-old psychiatric nurse. She manages seventy employees in a social-psychiatric institution. Apart from diabetes type 2, she suffers from heart failure. Her blood sugar numbers are always high, however stable. She jots the blood sugar number and fasting weight in the app every morning – mind you at a time that suits her. Although she finds it annoying that the app and website is often down, she praises the flexibility of the telemonitoring services:

> “Self-tracking allows me to take the decisions on when and where to measure my blood sugar. It gives me a sense of freedom. In self-tracking, I am the one that reports and makes contact. I’m in charge. I’m the one being supported. I’m not simply given a time slot that fits into the schedule of the nurse or doctor. I’m in control. I like it like that.”

She decides when to self-track, and she does not need to sit in a waiting room. Line feels the nurses support her in whatever she aims to achieve. She experiences this responsibility positively. Thus, she contends that self-tracking and the telemonitoring services fit well with an active citizen and manager like herself. However, this sense of support and flexibility is contradictory. She also appreciates elements of control:

> “I am being checked, and I can’t just cheat as I would if I was not monitored by a human being. In the evening, I can’t sit on my sofa and eat cakes and candy because it will be revealed the next day when I send my data. That would be embarrassing.”

She self-tracks because it offers a flexible kind of control that makes her accountable. She can self-track and communicate when she wants to, and she is embarrassed if her blood sugar numbers are too high. This keeps her on track, she explains. She uses the nurse to force herself to keep away from cakes and candy. With a twinkle in her eye, she calls herself an ‘exercise economist’: She has long since given up ambitions to train and play sports. But states:

> “I’ve found out that it means a lot to eat evenly throughout the day. I make packed lunches for the whole day. I take several packed lunches with me to work. I have one at 10 am, one at 12 and one at 2. If I don’t have something at 2, I’ll eat something unhealthy that I’ll regret at 4. I weigh too much, but I haven’t gained weight for two years. I probably would have if I hadn’t engaged in the telemonitoring services.”

The third story and ordering is about wanting to be controlled in a way that one can control oneself. The interesting thing about this is the contradiction and precariousness of being controlled and still being accountable and in charge of everything. Line sees herself as accountable for the data she reports because she is being monitored and, if the numbers are high, this may embarrass her. Her ambition is to self-track and send figures flexibly, that is when she has the time and wants to do so. As mentioned, she does already have this option. Self-tracking and telemonitoring helps her to be controlled in a way where she controls everything.

Telecare as a signifier of failure to stick to the diabetes regime.

Henning is 54 years old and retired. He lives alone. For many years, he worked at a glass factory. His blood sugar number constantly fluctuates between too high and too low. He checks his blood sugar number four times a day; however, if it is too high, he will perhaps check as much as eight times a day.

> “When I’m down, I don’t care. I eat too much because I feel bad. Then I stop checking my numbers. The nurse immediately sends messages like, ‘what’s wrong?’ But I’m unable to respond in these periods.”

He takes a blood sugar test during the first interview. The device shows 11 (high) (see photo 1). In the second interview on Zoom, he does it again, and the figure is 15.4 (remarkably high) (see photo 4). He explains:

> "If the figure is high, I must get it down again. Then I walk the dog or go to the gym."

At times, the number can also be exceptionally low. Sometimes he must go into a store when walking his dog to buy some candy to increase the blood sugar level again.

> "Sometimes when I wake up in the morning it's down to 2.7 (very low). Then I get dizzy and may have trouble getting out of bed. I must rush to the fridge to get some apple juice. This raises the blood sugar level immediately."

When Henning is emotionally challenged, he does not report the figures correctly in the app. Nor does he answer messages from the nurses. He sees all this as his own fault. Often it is because he has eaten cake or candy. He feels guilty when he cannot report good data. The higher the number, the harder it is to continue to send data and, suddenly, he drops out. Apart from diabetes type 2, Henning suffers from recurring emotional down periods. He explains that during these periods, he eats for comfort. He lives with the diagnosis 'schizophrenia.'

During both interviews, Henning read messages aloud from the app. In a recent message, the nurse wrote:

> "Hi Henning. I'm afraid I am receiving many empty measurements from you. You need to mark whether you did the measurement before or after a meal. This is important. If you don't, I can't see the numbers you type and send."

At a certain time, he starts to get sloppy with the numbers and ignores all messages. In addition, Henning shows the graph in the app during the first interview. It is immediately clear that he has great difficulties obtaining stable numbers. The graph swings up and down. He really wants to deliver stable numbers and aims to have a good life, he says, however, he struggles not to exclude himself in difficult periods. He justifies comfort eating and subsequent withdrawal from self-tracking with down periods and emotional problems. He can only stay in the telemonitoring service eventually by withdrawing from the app periodically. In these periods, he feels guilty because he cannot report good enough blood sugar data. That is, stable numbers that are not too high.

Photo 4. Henning to the left showing his high blood sugar number on the test device to the computer camera during the second interview (on Zoom). The researcher to the right (anonymized).

The fourth story and mode of ordering 'Telecare as a signifier of failure to stick to the diabetes regime' points to the struggle some chronic ill people have staying in the telemonitoring services. Comfort eating in emotional down periods places the blood sugar level beyond the norms of the telemonitoring services. The fourth story and justification become visible when Henning reports numbers incorrectly, and then stops reporting data in the app. He subsequently withdraws from self-tracking for some time. When he feels better, he starts sending data again. This struggle with identity, standards and numbers relates to what Pols (2019) has called ‘the moralizing working of numbers’. She points out that numbers may induce guilt. This story and mode of ordering concerns the punishment and guilt inducement of the telemonitoring services. Several informants mention that a sense of embarrassment appear when their blood sugar numbers do not match the norms of the telemonitoring services.

Discussion

Telemonitoring as a problematic health promotion standard

The raison d'être of the telemonitoring services is to provide support to make the chronic ill persons care for themselves to avoid referral to hospitals and a worsening of their condition (Sundhedsstyrelsen, 2017). Correspondingly, telemonitoring make care provision accessible to a large group of people needing support to manage their health. The nurses emphasize that they practice a kind of universal health pedagogics. They meet chronic ill people with support, that is, they provide information about the severity of the disease, they monitor data and give feedback (summary from the workshop). This standard and one size fits all logic is interesting, but it stands in opposition with the diversity of the aims of the service receivers, that we have identified. Also, one can discuss whether self-tracking and telemonitoring is a relevant service for Kristina and Henning. She is not sure why she attends, and he periodically doesn't fit into the service.

What does self-tracking and telemonitoring become, and what do the service receivers get out of it?

We see that Kristina’s commitment to self-tracking shapes her mornings. Although it is not completely clear to Kristina why she participates in self-tracking and telemonitoring, she wants to keep track of all the figures. The health data now constitutes something for Kristina to take care of. Thus, self-tracking and the app is involved in transforming Kristina’s aims and needs. Concerning Ole, we see that self-tracking has become an activity focused on getting contact and support to get leaner from the nurse through the app. This is a good example of how self-tracking, apart from providing support, also transforms routines and everyday ambitions of chronic ill people. In relation to Line, we see that telemonitoring has become a particular kind of self-chosen control. She wants to submit to external control if she on the other side is free to send data when she wants to. Thus, Line accepts telemonitoring as a kind of external control of her eating habits. In relation to Henning, we see that telemonitoring becomes a way to be punished for bad behavior. Self-tracking and telemonitoring create failure if people are not able to adapt to standard bodies and minds. Much discussion with our informants circled around the untenable possibility of being revealed to have eaten candy and cakes, and here there are overlaps and intertwinement between the different enacted practices. This guilt inducement may be enough to keep some people living with diabetes type 2 from eating sweets. However, this is not the case for all. Henning’s lack of control of comfort eating makes him withdraw from the telemonitoring services. Thus, the discussion of the guilt inducing figures entails a troubling illustration of failure and punishment as a significant outcome of the telemonitoring services for the persons and bodies that cannot perform standard numbers.

Conclusion and contribution

In this article, we discuss what self-tracking and telemonitoring become for persons living with diabetes type 2, drawing on ethnography and the notions of modes of ordering (Law, 1994; Moser, 2005) and justification (Boltanski & Thévenot, 2006). We discuss different stories and enactments regarding self-tracking and telemonitoring among chronic ill people. What has the analysis delivered and contributed in terms of thinking about self-tracking and telemonitoring and what follows from this discussion and analysis? The contribution to the literature is that the practical use of telemonitoring and the service users' justifications illustrate that even though they are in a bad condition, they make active choices and become consumers of health services. They have intentions and they use the services to satisfy several different wishes and needs. Based on our empirical material, we argue that people involved in the telemonitoring services actively use self-tracking and numbers to manage their health and simultaneously they all appear to gain requested support from the nurses. Our research design committed the informants to reflect over self-tracking at home over a period. Also, it gave them the opportunity to demonstrate how they self-track by making a presentation of their everyday self-tracking routines in front of the workshop participants.

Self-tracking and telemonitoring become different things in peoples' lives, and they aim to get different things out of it. We contribute by identifying four stories and modes of ordering and by positioning people living with diabetes as subjects in need of support to manage their own health condition. This is a generative position from where to start the scrutiny, instead of a priori seeing telemonitoring as for instance a disciplining endeavor, an act of retrenchment or as enactment of instrumental caring. We contribute to the STS literature with insight into the contexts of what people aim to achieve, the struggle they undergo, and the transformations of their aims that they experience due to the app and the self-tracking practice at home. The four stories and modes of ordering illustrate the scope of what self-tracking and telemonitoring become, and that our informants, respectively gain security, support, control, and failure out of it. We conclude that self-tracking in combination with the telemonitoring services is both a way to manage one's own health and to reach out for support. Moreover, self-tracking is practiced differently based on different contexts; it becomes different things in peoples' lives, and the justifications for participating differ and transform along with participation and engagement.

Data availability

The data supporting the conclusions of this study is stored in accordance with legislation using secure storage solutions offered by The University of South-Eastern Norway (USN). Informants could review and supplement interview transcripts, notes, and photos regarding themselves. Due to research ethics and the confidentiality principle, the data cannot be made freely accessible.

Conflicts of interest

There are no conflicts of interests.

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