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Being on standby: On maintenance work in chronic disease management

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abstract

This paper examines what it means to live with a disease, type 1 diabetes, in tandem with complex technologies. For decades, patients have been tediously replicating the function of an organ on a constant basis, but due to digital developments the materiality of care has changed, with daily treatment now woven into a wide web of digital components. Based on empirical fieldwork, the paper seeks to outline the impact of these transformations on what daily care means. I argue that patients increasingly act as technical maintenance workers who need to be in a constant state of standby in order to be forever ready to re-organise and re-stabilise their disease management. In this, a shift from caring for the body towards caring for technical devices can be observed. The analysis draws from both a sociomaterial perspective and a growing body of work in the field of science and technology that is shifting attention from stability to maintenance and repair. I argue that, against the background of complex technical systems, maintenance as a practice dedicated to restoring order implies a state of vigilance and readiness that I name 'being on standby'. Through the lens of standby, both the fragility of care and the affective tensions of intimate body-technology relations become apparent.

Introduction

Since the proliferation of portable meters and insulin pumps in the 1980s, an intimate relation with battery-powered technologies has been a key feature of living with type 1 diabetes, as poignantly described by a patient on Twitter:

'My pancreas runs on AAA batteries' (DSC Community, 2016). But over the last decade the technologisation of diabetic care has intensified and daily treatment is now woven into a complex web of digital technologies. New smart devices continuously record glucose levels and automatically transmit them to a monitoring device. After more than 40 years of repeated announcements promising to provide automatic insulin delivery systems (Heinemann and Lange 2019: 1), some patients are no longer willing to wait for commercial solutions have started to reprogram their devices to always stay on in order to automate their insulin supply as much as possible. But living with always-on technologies also means living with possible breakdowns or disruptions. The aim of this paper is to explore the facilities, complexities and tensions of living with these technologies on a daily basis, with particular focus on how some patients tinker with technology. Although technology has taken over more of the care workload, I will show that digital improvements do not, in fact, lead to the pairing of passive subjects with active technologies that take over the reins of responsibility. Instead, a shift from caring for the body towards caring for technical devices can be observed: complex and ramified technologies are prone to failure and require maintenance from the persons using them. Once more actors become part of daily care, the potential for disorder spreads. Thus the relations between smart technology and the body are accompanied by 'new kinds of vulnerabilities' (Oudshoorn, 2016: 767) which in turn become a 'matter of care' (Puig de la Bellacasa, 2017).

Based on an analysis of interviews, I argue that in relation to these new vulnerabilities, patients need to be in a constant state of 'standby'. Because maintenance work only intermittently sticks to a schedule, daily care requires a continuous vigilance and readiness to (possibly) re-stabilise and re-organise the heterogeneous care collective. In this regard, the paper draws from a sociomaterial perspective that pays attention to the affordances of materiality and conceptualizes care as a collective doing that unfolds tensions (Mol et al., 2010: 14; Mol, 2008). Furthermore, it contributes to a growing body of work in the field of science and technology studies (STS) that is shifting attention from stability to maintenance and repair. I propose that, in complex human-technology entanglements, maintenance as 'processes dedicated to restoring order' (Denis and Pontille, 2015: 341) implies a state of vigilance and readiness, which can be considered as 'being on standby'. In the course of this argumentation, I will discuss different modes of standby as patients, technologies and bodies become attentive to each other in different ways. However, the analysis given here calls particular attention to a patient-centred mode of being on standby. Patients constantly need to be in a state of readiness in order to repair, replace, recharge or reconnect the devices that help attend to the disease. Thus, a lens of standby puts the fragility of care on view and offers a deeper understanding of what it means to manage a disease together with complex technological systems.

In the following, I will first provide insights into the methodology of the study. Then I will outline an analytical stance on care as an ongoing 'collective doing' and illustrate this by means of the diabetic path to always-on technology. Informed by the work of Dutch philosopher and anthropologist Annemarie Mol, I will demonstrate how care is formed in historically specific sociomaterial constellations and how technical changes have specific effects on daily life. From the materiality of care, I will move on to the care of materiality, and briefly illustrate the connection between care, maintenance and standby. Based on empirical insights, I will then show what it means to be constantly on standby and how the 24/7 attachment and attentiveness to complex technologies generates specific affective tensions. In closing, I provide a conclusion.

Methods

The paper grew out of fieldwork from an earlier ethnographic study. In that study, based on the double context of the quantified-self community and type 1 diabetes, I examined the practice of self-tracking (Wiedemann, 2019). My fieldwork in the context of diabetes involved: 14 semi-structured interviews with persons living with the diagnosis; participant observation of diabetes educational programs, public events and patient meeting groups; and the analysis of personal blogs of patients. Reading the latter became my habit between 2013 and 2017. Within these online journals, patients write, for example, about their daily routines, emotions, wishes for therapeutic changes or experiences with new technologies. As a matter of curiosity, I reanimated my habit in 2019 and a great deal seemed to have changed. The topic of DIY closed-loop systems and artificial pancreas systems (APS) has now seemed to emerge in the German blogger scene, so I resumed my research. Some technically adept patients had started to reverse-engineer their devices in order to partially automate insulin supply.

My previous research on diabetes, examining how digital technologies have changed life with the disease, tried to answer how the possibilities of continuous digital monitoring have strengthened a living by numbers. The paper presented here takes a slightly different approach: its focus is on the vulnerability of digital technologies. The empirical material presented here is primarily based on semi-structured interviews I conducted with two patients who have both managed their disease with a do-it-yourself (DIY) closed-loop system since early 2019. Here, for anonymisation, I have named them Olivia and Tomas. Olivia is 37 years old and was diagnosed with type 1 diabetes at the age of 14; Tomas is 28 years old and received his diagnosis when he was 16. Both have undergone multiple changes with regard to their technological companions. I know both of them because they have each written online blogs for many years. Already on their blogs, both have authored articles on the conflicting and multiple realities created by coexistence with highly complex technologies. My interviews with them focused on daily practices, the impact of technology, programming knowledge, hurdles, disturbances and the increasing need for maintenance work. Both interviews had a length of about 60 minutes. However, I will also refer to some interviews from my previous research. Moreover, the empirical analysis is informed by blog posts focussing on DIY technologies and other online articles on artificial pancreas systems. I have coded the material according to recurring themes and used a sociomaterial perspective during analysis. Based on iterative cycles of analysing the data, the concept being on standby was developed.

It should be noted that 'DIY-looping' does not represent the average way of enacting diabetes: it could be read as an extreme case. On the digital paths of the diabetes online community, one quickly gets the impression that everyone with type 1 diabetes will be wearing an artificial pancreas system by tomorrow (Heinemann 2017: 864). But 'current users', like Olivia and Tomas, 'tend to represent a cohort of "experts" in type 1 diabetes' (Crabtree et al., 2019: 65), who have access to the world of DIY-looping because they are technologically adept patients and have the time to acquire the necessary knowledge to reengineer their devices. There is uneven access to the DIY world, and it is also influenced by legal liability issues, since these homemade medical systems receive no regulatory approval by healthcare providers, medical technology industries or the government. Nonetheless, the circle of patients who entrust part of their disease management to an algorithm is growing, and a Facebook group named ‘Looped’, founded in 2016, now has over 23,000 members.

The path to always-on technology: ‘Doing pancreas’ in specific sociomaterial constellations

Type 1 diabetes is an autoimmune disease in which the body puts its pancreatic islet cells, responsible for producing the hormone insulin, in a shutdown mode. In glucose metabolism, insulin acts as the key to unlock the door to cells. Without it, sugar molecules broken down during food intake cannot be transported from the bloodstream into cells and, as a consequence, the blood glucose level rises continuously. Its symptoms, such as excessive thirst, have been observed since ancient times, and up until 1921, when the surgeon Frederick G. Banting identified the lack of insulin as being responsible for the disease, diabetes was a ruthless killer. With time, diabetes turned from a fatal disease into a chronic one, though survival became possible only with daily injections of insulin.

In the 1980s there was a proliferation of new portable measuring devices that established the current treatment regime. With these devices, patients themselves tediously replicate the function of an organ. In modern technology-dependent treatment, all regulatory processes that a healthy pancreas performs have to be re-enacted by externally balancing measurements, nourishment, physical activity, and insulin intake. The overall goal of self-management is to maintain normal blood sugar levels and consequently to prevent long-term complications. To quote the title of a popular diabetes guide, such self-management requires the patient to ‘think like a pancreas’ (Schreiner, 2004). From an STS-inspired point of view, I suggest speaking of ‘doing pancreas’ (Wiedemann, 2019) because an empirical perspective on the daily life of patients shows that the condition is ‘materialized through a range of activities and practices’ (Danholt et al., 2004: 4).

As illustrated by Annemarie Mol (2002; 2008), caring for a chronic disease is an ongoing endeavour: it never finds closure. There is a widespread set of activities to engage in, thus my interviewee Olivia calls her condition a '24-hour job'.[1] Just as any other medical practice, 'doing pancreas' 'is a collective sociomaterial enactment, not a question solely of an individual's skills' (Fenwick, 2014: 48; see also Mol et al., 2010). Therefore, academic research has already shown that diabetic care activities are constantly negotiated among human and non-human actors (e.g., Bruni and Rizzi, 2013; Danesi et al., 2018; Danholt, 2012; Mol, 2000, 2008, 2009; Mol and Law 2004). Patients, doctors, nurses and others thus find themselves engaging with, for example, AAA batteries, chargers, insulin, smartphone apps, cannula, sensors, charts, smartphones, wires, smart watches, transmitters, receivers or algorithms. However, this enumeration mirrors the digital age in general, and such an assembly should be understood as a historically specific sociomaterial constellation in which the mundane 'doing pancreas' takes place.

Since type 1 diabetes is a silent disease only noticed in cases of high or low blood sugar levels, the objectification of metabolism demands specific strategies that have changed throughout medical history. When diagnostic colours and later numbers materialized the hidden, the development of miniature sensors turned graphs and alarms into another important knowledge category of blood sugar 'control'. Drawing on Mol, I assume that specific realities of 'doing pancreas' are enacted due to the techniques of visualization, and that the difference of material participation affects what diabetic care means.[2] I will illustrate the four different ways of measuring blood sugar levels I encountered during my field work in recent years. The gradual demonstration of a growing closeness to complex technologies leads

1 Because the interviews during my fieldwork were conducted in German, I have translated the passages I quote in this article.

2 In 'The body multiple' (Mol, 2002), Mol's gaze passes through the various departments of a hospital and examines different ways of 'doing arteriosclerosis' in specific sociomaterial configurations. At the centre is the idea that the disease is multiple in its manifestations and the various realities are situated in certain practice settings.

to the central argument of patients needing to be on standby in order to re-organize and re-stabilise the care collective of ‘doing pancreas’.

Diabetes as a colour: syringes, strict schedules and colour charts

Marianna, who at the time of our meeting had been living with diabetes for 40 years, recalls large metal syringes which frequently had to be boiled to sterilize for reuse, and then later, how they were replaced with plastic disposable syringes. During her childhood it was common to manage diabetes through rigid schedules and dietary plans determining the times when she was allowed to eat. For decades, mundane monitoring was dominated by urine tests, though their design evolved over time. In a diabetes podcast, a patient diagnosed in the late 1950s says:

> The only place you could get a blood test was in a hospital and you’d wait a week for the results. So, all we had to test our blood sugar was urine tests […]. It was like a small chemistry kit (Grief, 2019).

This first simplified ‘chemistry kit’ for home tests he speaks about was introduced in the mid-1940s (Clarke and Foster, 2012: 85). Using the so-called Clinitest, patients popped a tablet into a small quantity of urine, which caused the mixture to boil and induced a colour change. The results were interpreted by reading the outcome against a colour chart.

Diabetes as a number: portable meters, pens and pumps

The 1980s paved the way for a growing ‘closeness of technology’ (Pols, 2012) in diabetes treatment. Through the proliferation of portable meters, the clinical practices of blood glucose testing was translated into domestic spaces. The option of self-measurement made it possible to lead a more flexible life, replacing one that been characterized by strict schedules. Additionally, with the development of short-acting insulin, it became possible to avoid sticking to a diet, as food intake became, in turn, a matter of counting carbohydrates and matching the grams of each meal with a corresponding dose of insulin. However, this seeming ‘freedom’ stood in exchange with a huge increase in the responsibilities of the patient and a living by numbers.

When I met with Eva in a café, I could observe how she measures blood sugar. She pricked her finger with a lancing device and squeezed the drop of blood onto a test strip she had already inserted into the measuring instrument. After she read the number on the display, she pulled out an insulin pen and adjusted the unit to be injected. Eva lifted her sweater and injected the calculated dose into her abdomen. This practice is to be repeated before eating, doing sports, driving or sleeping, in case of physical unease, and after eating. Other patients wear an insulin pump, which frees them from self-injections. In that case, a tube is connected to an insulin reservoir in the pump and a thin cannula placed under the skin. Throughout the day, the pump delivers a basal rate of the hormone subcutaneously in small, automatic doses.[3]

But patients still need to do finger pricks and program 'bolus' doses of insulin delivery via buttons on the pump after deciding how much insulin will cover each meal. In both delivery methods, there remains a risk of miscalculating insulin substitution or of a body acting erratically. Insulin is a potentially lethal hormone, and taking an excess amount can lead to serious symptoms such as dizziness, tremors or fainting, thus the fear of hypoglycaemia becomes a constant subject of everyday doings.

Diabetes as a graph and alarm: smartphones, sensors and transmitters

When I met Max, he glimpsed at his smartphone to check his current glucose level. He uses an insulin pump and a system known as a 'continuous glucose monitor' (CGM), which operates with a microneedle-based sensor constantly sitting on his upper arm that measures the glucose concentration in subcutaneous tissue fluid in a nearly continuous manner; a mounted wireless transmitter sends the glucose readings automatically to his smartphone every five minutes. Alternatively, it is possible to use a smart watch or the display on his pump as the receiving device. The chosen display screen presents his glucose results over the last 24 hours in the form of a graph.

Max was enthusiastic about his CGM during our talk as he no longer has to prick his finger and is 'always [able to] counteract immediately.' This

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3 The external pumping machine that the patients have to carry close to the body is nowadays about the size of a small mobile phone.

possibility to 'always' act not only refers to the ability to obtain real-time values at any given moment, it also means the ongoing 'doing pancreas' is accompanied by a variety of new symbols. Besides graphs, dynamic trend arrows provide prospective information on glucose levels. Additionally, in the event of high or low, sharply falling or sinking values, the CGM system acts like an attentive assistant by sending out an alarm that prompts patients to actively regulate their metabolism through additional insulin dosages (via pump or pen) or sugar intake. As the sensor constantly works in the background and the system 'rings' as soon as metabolic or technical problems arise, patients can stay in an on-call mode instead of constantly being alert to physical symptoms of low glucose values and having the fear of (unnoticed) hypoglycaemic events. The removal of this fear was described by a lot of people during my research as a relief.

Connected always-on technology: DIY closed-loop systems

The development of CGM systems is inscribed with the hope to automate disease management. For decades, the medical industry has been promising the development of a 'closed-loop system' consisting of a CGM, insulin pump, and algorithms to allow for complete automation. A milestone on the road to an artificial pancreas was achieved in 2017 when the company Medtronic began marketing the MiniMed 670G insulin pump in the United States (Weaver and Hirsch, 2018: 217). Based on its sensor data, this first commercial 'hybrid closed-loop system' automatically adjusts insulin delivery to a predefined target range every five minutes, and ceases delivery as soon as blood sugar values approach a hypoglycaemia level (Medtronic, 2020). However, numerous regulatory and financial restrictions limit access to the system.

But in the online diabetic community the hashtag '#WeAreNotWaiting' is used to gather patients who are tired of continued delays and obstacles in access to these systems. Moreover, the low customizability of the commercial system is criticized by many patients as well. Members of the community began to disseminate their experiences with 'do-it-yourself artificial pancreas systems', and different open-source algorithms were developed to initiate the practice labelled as 'looping' (e.g., Marshall et al., 2019).[4]

Olivia and Tomas, whose experiences with the 'loop' build the heart of my analysis, decided to begin looping in the beginning of 2019. Both needed to reprogram their existing devices and procure additional ones. Now, pump, sensor and smartphone app interact continuously to regulate their glucose levels day and night. Since these devices are not officially designed or approved to be operated in this looped configuration, Olivia declares: 'one needs to tinker a bit'. Tomas stresses that it is a challenge to get the loop to 'run'. Although he is technically very skilled, he says: 'Well, you actually have to take a holiday to set it [the loop] up.' In addition, 'you have to have a lot of knowledge about your body and your illness before you start looping.' Furthermore, I spoke with Olivia about the fact that she had to buy additional hardware abroad. A so-called 'RileyLink' needs to be kept in close proximity to the other equipment, as it converts Bluetooth signals in order to enable the smartphone and insulin pump to mutually communicate. She also purchased a new computer to compile the looping software, as the smartphone app that harbours the algorithm is not simply downloadable. Before 'the loop can take work off your hands', 'the hurdle' is 'extremely high' at the beginning, as Tomas reports.

But a loop, once initiated, brings many positive changes. Olivia already refers to her CGM system as the 'biggest and best shift' in her treatment because she has been able to read her values 'all the time' without interruptions for testing. The days of 'flying blind', as she calls it, are over. Olivia describes her daily routine as 'irregular'. Although she does sports every day, the intensity can vary. As exercise lowers blood sugar, it is a relief that she is now able to read the glucose levels from her wrist as easily as reading the time of day, and the fear of hypoglycaemia no longer follows. At night, she had years of rising blood sugar levels with symptoms that carried on throughout the day; CGM alarms prompting her to ingest sugar interrupted her sleep, and similarly

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4 In the United States, the so-called OpenAPS movement had already been launched in 2014, and patients and technology enthusiasts made an open source algorithm available that allowed everyone to build their own artificial pancreas system (OpenAPS, 2019).

caused tiredness. By looping, her blood sugar is now kept within a target range and it has become possible to sleep through the night. As Olivia puts it, she no longer has 'this trouble' with 'too high or too low blood sugar values' that often happened before the automatic regulation provided by the loop system. Hence, an overall outcome of the work of these digital devices is an improvement of clinical values and reduction in variability, which leads to her 'being in much better health'. Tomas also told me about better values and improved sleep; however, his approach to looping seemed more playful. He 'likes technology' and learnt to program at a young age. Especially 'new technology helps' him to 'deal' with his disease and he states: 'I think everybody has their own way of finding motivation, because diabetes itself, there is not much to get out of it'. At the same time, Tomas repeatedly refers to the invisibility of digitally connected technologies, as they no longer 'look like diabetes'. For example, when visiting a restaurant, he can now 'just take out his cell phone' and manage insulin injections through the looping app without anyone noticing it.

The effects of technical change

As this paper takes a sociomaterial approach, it is not the intention here to bring technical developments to trial, rather to note that their 'effects are crucial' (Mol, 2010: 255). With the blood glucose meter, a strict schedule was exchanged for flexibility, but then the challenge was to live by numbers, and blood glucose monitoring became tighter. The involvement of smart non-human actors has multiple effects on, for instance, sensory body awareness, ways of knowing the disease in practice, doctor-patient relationships, and the visibility of measurement and daily medical chores (Wiedemann, 2019). Living with always-on technology helps to stabilize glucose levels and thus reduces the risk of long-term complications. But in times of the insulin pen, the switch between off and on was more apparent, an issue I will return to later.

While looping technology takes over therapeutic decisions and a great deal of responsibility in metabolic regulation, it concurrently engenders new responsibilities and vulnerabilities. The latter becomes clear though the words of Tomas: 'Well, with a pen, nothing can go wrong.' In saying this, he wanted to underline his experience that an insulin pen is less troublesome compared to the loop. Complex systems kept in continuous operation might suddenly break or steadily discharge their batteries and thus require time-critical maintenance work, either unplanned or planned. Hence 'a lot is about keeping the technology running, and before that it was about managing the sugar'. Tomas explained. This shift from caring for the body to caring for technology corresponds with a mode of vigilance and readiness I refer to as being on standby. In the following, my paper presents empirical examples of this central effect of smart technologies. Beforehand, it seems worthwhile to concretize the concept of standby in its close relation to maintenance and care.

Holding together – The close relation between maintenance, care and standby

It has become clear how humans and non-humans come together in different sociomaterial constellations, but these constellations also repeatedly fall apart and have to be reassembled in order to keep the process of 'doing pancreas' going. There is a constant necessity of holding the care collective together.

Such an acknowledgment of material vulnerability (Hommels et al., 2014) and fragility is the starting point of maintenance and repair studies. There has been a growing body of work in the field of science and technology studies that has shifted attention away from order, routines, stability and resistance and brought maintenance, repair, mess, instability, fragility and breakdowns to the foreground (e.g. Dant, 2010; Denis and Pontille, 2015; Graham and Thift, 2007; Gregson et al., 2009; Henke, 2000).[5] In his famous essay

[5] Earlier ethnographies have paved the way to this. For example, Lucy Suchman's (1987) analysis of 'situated actions' during the interaction between humans and a photocopier, or Julien E. Orr's (1996) study of the daily work of copier technicians, can be interpreted as a starting point for ethnographies on the subject of maintenance.

'Rethinking repair', Steven Jackson argues for a basic 'broken world thinking' (Jackson 2014: 221) and suggests appreciating 'the ongoing activities by which stability (such as it is) is maintained' (*ibid.*: 222). Considering 'the constant decay of the world' (Graham and Thrift, 2007: 1), maintenance and repair offer a theoretical framework to 'investigate the operations that daily shape and preserve material order' (Denis and Pontille, 2019: 2). Vulnerability and fragility are regarded as 'the primary – "normal" – property of matter. Everything has, in a way or another, to be taken care of' (*ibid.*, 2019: 6). Care in the form of maintenance can thus be given to people, to bodies, to environments or to things. Correspondingly, the STS lens views the never-ending care work as an act of constant maintenance (Denis and Pontille, 2015; Mol, 2008; Jackson, 2014; Puig de la Bellacasa, 2017). Previously, feminist studies have recognized a close connection between care and maintenance, as seen in Berenice Fisher and Joan Tronto's (1990) famous definition of care as: '[E]verything that we do to maintain, continue, and repair "our world" so that we can live in it as well as possible' (*ibid.*: 40).

In her work on 'matters of care', theorist Maria Puig de la Bellacasa (2011, 2017) takes this quote as a pivotal point and includes non-humans 'to probe further into the meanings of care for thinking and living with more than human worlds' (*ibid.*, 2017: 4). Thinking with care has a double significance to her, 'as an everyday labour of maintenance that is also an ethical obligation' in terms of the 'responsibility to take care of the fragile gathering things constitute' (*ibid.*, 2011: 90). Previously, Mol (2008) theorized the logic of care by studying the shared work of human and non-human actors in doing health care. She drew attention to the fact that, no matter what the situation, fragility is a present mode in care practices because 'the logic of care starts out from the fleshiness and fragility of life' (*ibid.*: 11). Notably, bodily, material and technical fragility needs to be taken as a normal part of managing a chronic disease, leading to the necessary of constant tinkering and maintenance work. Care includes 'messy entanglements' (Kaziunas 2018: 92; Shildrick et al., 2018) and thus draws on 'practices for holding together that which does not necessarily hold together' (Law, 2010: 69).

In order to enact temporal stability, the maintenance of chronic disease management calls for tasks such as picking up prescriptions, keeping regular appointments, or submitting copious and comprehensive claims to one's insurance company. Since the 1980s, material oriented maintenance work has been part of diabetic care – e.g. when insulin ampoules have to be replaced or the portable meter asks for new batteries every three months. As pointed out before, an effect of always-on technology is an increasing sociotechnical instability. Because of their constant vulnerability, smart devices strive for re-stabilisation and re-organisation in shorter intervals.

But how does standby take part in this? A continually operating, vulnerable system has enlarged the dependency on technical maintenance, and since 'there is always something' (Olivia) to maintain, more alertness and readiness to intervene at any time is required. If technical systems become more complex or if threats to life are involved – one thinks of intensive care units – stability must somehow be monitored. I consider being on standby as an internal and affective state of coordination, like maintenance and care aimed at holding together. Standby is an operation mode most people know from technical devices: A laptop on standby, for example, receives all operations even though the screen remains black, and it 'wakes up' to become ready for use within seconds. But also clinicians, system administrators or locksmiths often work on standby. For certain professions it is characteristic that some people remain on call, ready to work or intervene on short notice rather than needing to constantly be physically present at the workplace. In these two ontologically different examples of standby, four interwoven characteristics become apparent:

First of all, standby is a constant '*intermediary stage*' (de Laet and Mol, 2000: 240) eroding boundaries between on and off, between work and rest, between being whole and broken, between attendance and waiting. Consequently, it is a state or operation mode that invariably refers to the hybrid. Secondly, and following on from this, it is noticeable that standby is a *state of readiness* without being immediately engaged. Something or someone on standby is soon ready for re-action after receiving an alert, call or note. Thirdly, the state of standby always requires a *certain degree of vigilance and alertness*. Fourthly, being on standby *is not energetically neutral* because intermediary stages demand a certain amount of energy. The in-between is not an empty space. These four characteristics of standby can be identified on different levels in my empirical material, which I will demonstrate in the following. The body, the technology and the patients are all sometimes in a state of standby.

'Something always happens' – Being on standby

Living with a chronic disease always has moments of standby – for instance, we can look back to the wait that was required for clinical results in the medical history before transportable meters. In the 'old' days of the blood glucose meter, patients had to remain on standby in particular awareness of their bodies. As soon as signs of high or low blood glucose were perceived, it became time to actively take measurements. With always-on technologies, sugar levels always remain visible. Tomas tells me he sees them on his smart watch and, while working, in the taskbar on his computer – thus a constant perception of glucose levels can, at least theoretically, dwell in hibernation.[6] Furthermore, one could say that the overall aim of chronic illness management is to keep the body in an intermediate stage between health and symptomatic alarm levels. The disease is never off, but at best, its acute physical symptoms ought to remain silent as long as possible. Accordingly, the glucose graphs of the diabetic CGM system should not slip out of an intermediate stage (target range) between high and low.

To interrogate the technology for a state of being on standby turned out to be more difficult and ambiguous. I have outlined the path to always-on technology above. Both Olivia and Tomas have maintained their loop system for the last year and a half and never intentionally turned it off. In order to recognize moments of standby within complex technical co-operations, one would need to spend a lot of time to study the overlapping technical, metabolic and electrochemical processes in detail. But let me briefly hint at more clearly describable moments of technical standby. In the loop, the pump is, day in and day out, ready to intervene in metabolism as soon as the perpetually measuring sensor notifies it of glucose fluctuations. In addition, the line between technology that is still working and that is broken is constantly blurred. Just-charged battery cells immediately return to a state of discharge again. Moreover, Olivia told me about various devices being part of a backup plan and which always remain ready in her standby bag. Since the

6 The question as to what extent technology intervenes into body awareness cannot be discussed in detail here. However, other studies have already shown that technology in practice is able to train body perception (e.g. Mol and Law, 2004).

practice of looping increases dependency on electrical power sources and draws a lot of energy from her smartphone, it became necessary to 'drag along a power bank'. Sometimes one is simply in places 'where you have no possibility to recharge anything', Olivia points out. It is a common part of her 'doing pancreas' to anticipate technical breakdowns or disruptions. In order to respond to the erratic rhythms of this technology, Olivia told me, she always has replacement units such as additional batteries, emergency insulin syringes, or an alternative meter in her standby bag. Tomas uses two smartphones, with one used for looping; this is both to extend battery charge and to distinguish diabetes-related notifications from other messages or calls. He told me that in his daily life he 'trusts' his loop, but once he leaves his hometown, he makes sure he is accompanied by ready-at-hand spare parts. Even though Tomas and Olivia entrust smart technologies with an important part of their 'doing pancreas', they remain active in the care collective.

The limits of automation

With automated insulin delivery systems it became possible to set up an automated mode for insulin delivery. Since then, Tomas has no longer had alarms at night announcing high or low values that call upon him to spring into action, because the loop 'does it automatically'. In conversation, he explains:

> So what's automated is definitely at night because you don't move, you don't ingest food, you don't actually have any stress unless you have a nightmare, and in those eight hours when you sleep, the loop has full control and can adjust your sugar and I think that's where we have the biggest impact in terms of the loop.

But during the day is not like pushing the autopilot button and having disease management smoothly take over. 'During the day,' Tomas continues,

> I have to look: is the battery fully charged? Is insulin still in [the pump]? Is the Bluetooth connection working? Is everything communicating or am I too far away from my mobile phone?

Moreover, a body that is awake becomes hungry, and it is also confronted with various environmental influences. During our interview, Olivia also repeatedly emphasized the limits of the hope for automation, because the system must be navigated through daily events. She says:

> If I just let this go all through the day, the system doesn't know when I'm eating and what. The system doesn't know when I do sports and when I move. The system doesn't know when I have stress. […] You have more stress, you move, you want to eat something at a different time, and the system has to know that.

Since her everyday life does not always fit the same template, she has to actively feed the system with her doings and feelings. On the one hand the looping app requires user input, especially around meal times, to account for carbohydrates.[7] Tomas told me that he used to estimate how many grams of carbohydrates he ate. But the looping app requires more precise details in order to 'tell' the pump how many insulin needs to be injected. Hence he likes to eat in the same restaurants because he programmed an app that allows him to retrieve stored data on certain dishes; with its help, he quickly tells the loop he is eating a certain dish again. On the other hand, human blood sugar is influenced by many factors which by and large cannot be regulated, such as hormones, seasons of the year, stress, sleep or changes in daily routine. Thus with the loop, to quote Tomas, 'it's never like it is set once and then it runs for a year'. He explains: Although the loop is able to 'smooth out' these manifold influences 'a bit', 'you still have to adjust it again and again, so it's not that easy.' In the case of looping, it becomes clear that despite sophisticated digital technology, disease management cannot be fully automated because living bodies as well as technologies are erratic (Mol, 2009: 1575).

Patients ready for maintenance

Dana M. Lewis, cofounder of the project called Open Source Artificial Pancreas System (OpenAPS), which disseminated the first algorithm for a DIY closed loop, speaks in her book about successful looping and of a required 'maintenance mode' (Lewis, 2019a). Since the technology cannot sustain or repair itself, the loop needs to be maintained by the patient who, in turn, stays in a state of readiness because there is always the potential that something

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7 As the duration of action of insulin is delayed, increases in blood sugar after meals have to be controlled pre-emptively.

needs to be maintained. As Olivia points it out: 'Something always happens'. There are different types of disturbances possible: one may misestimate a value when calculating consumed carbohydrates; the insulin catheter of a pump can bend or be blocked; the body may simply react differently today than it did yesterday; or, for instance, the sensor on the upper arm might accidentally collide with a door frame. Moreover, a part of the care collective can suddenly go belly up with no immediately clear cause. But most notably, digital actors are accompanied by a new variety of technical disruptions.

As Olivia told me during our conversation, the sensors and transmitters of the CGM system can suddenly display error messages that require reaction. This may, for example, be because the sensor is not always able to handle strong metabolic fluctuations, she explains. In that case, its display states 'No readings' or 'Sensor error' and does not display any values for up to three hours. In the meantime, she is only able to measure her blood sugar 'traditionally.' From time to time there are error messages that Olivia isn't familiar with and has to look up online. Additionally, Olivia declares, there are moments of 'transmitter loss', which means that her smartphone does not receive any glucose readings because it is too far away from the transmitter. Or the RileyLink, responsible for communication between the pump and smartphone, is suddenly no longer within range of the other two devices due to movement. It is also possible that the smartphone app coordinating Olivia's loop suddenly crashes and has to be restarted. In the event of such troubles, she receives an immediate warning on her smart watch. But these technical disturbances have no schedule, and they do not happen every day, Olivia explained. Being on standby does not imply that there is sudden maintenance work to do every day; the crucial point is that maintenance work permanently looms in the background, waiting around the corner.

Even on a day when no unscheduled maintenance work occurs, the schedules for planned maintenance need to be kept in mind. Every third day, Olivia has to refill the insulin reservoir of her pump and to secure the device again on a disinfected area of her skin. The software involved in the looping requires occasional updates, but this is not done with a single click of a mouse. Olivia told me that the complicated updates often scare her, but that her husband stands by to assist. The transmitter she uses must be removed and replaced after three months, while other CGM systems require the device to be recharged every few hours. The lifespan of the sensor is even shorter, and should be renewed after 10 days. Every day she needs to recharge her smartphone and her smart watch to be able to read her glucose levels immediately, and the RileyLink, too, needs daily charging. Wiring the mobile devices has become her evening routine and, she explains to me, the devices charge up overnight next to her on a bedside cabinet to be ready for the next day.[8] But even if the time cycles of equipment fatigue are predictable and notifications or battery status bars help to draw attention to them, in practice, the line between planned and unplanned maintenance can quickly dissolve. Every smartphone user is probably familiar with sudden worries about a low battery or a blank screen.

Beeping, humming or buzzing – The affective tensions of being on standby

Care in practice unfolds tensions that need handling (Mol et al., 2010: 14): ‘tensions between different subjectivities and objectivities’ (Law, 2010: 68), bodies and technologies, calculation and the erratic or desires and the metabolism. At this point I would like to highlight the affective tensions becoming apparent through the lens of standby. Always-on technologies reduce the anxieties of strongly fluctuating glucose levels, yet, but constantly discharging batteries, result in temporal ‘range anxiety’ (Müggenburg, 2019) – a term that emerged in the 1990s in the context of electric vehicles and refers to the fear of being stranded: that the battery will run out of power before a charging point can be reached. But devices as well as patients may become temporarily fatigued.

Tying in with this, Tomas spoke about the phenomenon of ‘alarm fatigue’ (Shivers et al., 2013) occurring when one is subjected to frequent alarms as, for example, described earlier in the context of nursing. With an insulin pen, to quote Tomas, ‘if you wanted to ignore’ diabetes you could ‘just put it back in the cupboard’ and ‘then [the] disease was gone – at least in feeling’. When numbers are constantly visible, technical disorders and metabolic fluctuations both cause alarm sounds, or devices invariably need to be kept

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8 Of course Tomas also has to do maintenance work, which due to his different devices, has a partially divergent schedule to what Olivia describes of her system.

close to the body, it becomes a challenging negotiation to temporarily put the disease out of mind. The digital technologies require an attentive body; however, the constant beeping, humming or buzzing of the devices can be 'annoying' and 'burdensome', as Olivia also pointed out. These alarms are for safety and are designed to quickly detect low or high, sharply falling or rising and extremely fluctuating glucose levels, as well as low insulin reservoirs, signal loss or upcoming maintenance. But they create affective tension between feeling safe and annoyed: 'you don't want to hear the sound, but you're glad it's there', states Thomas.

Alarms are part of the trade-off between pricking one's finger to constant visibility and reactivity due to the CGM system. Olivia says: 'You are grateful for these alarms, definitely, because you can intervene and react directly. But it often pulls you away from your doings.' An advantage of DIY systems is that they are more customizable than those available on the market, and alarm thresholds can be customized more to individual preferences. To reduce his alarm fatigue, Thomas adjusted audio settings 'down to a vibration', because the sounds are 'always connected to something negative'. In certain situations, for example, at the movies or in a business meeting, he mutes the alarms and observes his sugar on screen. However, at night, the beeping sound stays activated – as long as he 'didn't forget to turn the phone back on'.

But with looping, there are fewer metabolism alerts, which in turn – as Tomas puts it – benefits his 'diabetes-life balance'. With the CGM system, this balance started to oscillate, he tells me, because 'it was beeping all the time'. Nevertheless, he needs to be on standby because he is attached 24/7 to a technological system which may requires his attention. Unlike professions organized into standby duties, it is not a short on-call period after which another person takes over the shift the following day. The intimate body-technology relation accompanies a lifelong need to be on standby – a state that subtly consumes energy for humans and non-humans alike.

Conclusion

Over the last few years, complex digital technologies have recreated the everydayness of diabetes care; they have facilitated living with the disease and allowed patients to improve their glycaemic levels (Battelino et al., 2012). Due to the vulnerability and unruliness of these technologies, maintenance work has increasingly become more central to the stability of disease management. There is a constant necessity of holding together the care collective, which consists of heterogeneous entities. My paper has argued that the maintenance of complex technical systems requires a constant state of vigilance and readiness, which I have termed being on standby. In this, I consider being on standby as an internal and affective state necessary to re-organize, re-stabilise and coordinate complex and convoluted sociotechnical entanglements. Through the argumentation made here, the paper aims to contribute to the growing field of maintenance and repair studies, and offers the lens of standby as a valuable tool for further enquiries. With standby, an important perspective is added: in the background of complex digital entanglements, the activities of maintaining stability imply a certain degree of being someone or something on standby. I suggest that it is valuable to take this notion of being on standby into account because it is a lens that displays how frequent maintenance work is (affectively) organized. In the context of DIY health technologies, Elizabeth Kaziunas (2018: 165) has already pointed out that there is a great deal of emotional work involved in maintaining and interacting with data and technologies.

Of course, living with a disease always requires attentiveness. In the case of DIY-looping this attention is, to a great extent, directed at battery bars, interfaces, Bluetooth connections, alarms and software error messages. Thus, the state of being on standby is closely related with a shift from caring for the body towards caring for running technologies. An entanglement of sophisticated medical devices is simply more complex than colour charts, portable meters or an insulin pen. However, since the algorithm generally takes good care of metabolism and CGM system alerts as soon as low or high blood glucose values arise, patients do not always have to be vigilant and alerted concerning body signs. Certainly, this is also an analytical ‘exaggeration’, since care for the body is not utterly replaced by care for technologies. Bodies, like technologies, are unruly and vulnerable, and as we have seen, the algorithm must often be navigated by patients.

In this sense, the findings stand in contrasts with public euphoria concerning digital possibilities for the algorithmic automation of disease management.

Instead, we see how the demand of constant readiness and the fragility of care are visualized. Mundane care work is not yet a cybernetic loop, and full control is an illusion (Mol, 2009: 1757). No matter how sophisticated algorithms are, they inevitably contend with unreliable energy cells, erratic bodies or similar. It becomes apparent that the fragility of hardware as well as software must be considered a normal part of everyday life as soon as sophisticated technologies are involved in disease management. Even if algorithms take on a large amount of the workload, they are not able to maintain the delicate balance themselves. Of course, DIY-looping is also an exceptional case and since it is not legal, further complications arise. Nevertheless, on a general level, this paper has shown that the workflows algorithms take on must be vigilantly accompanied as soon as numerous heterogeneous actors are involved and the 'agentic capabilities' of algorithms depend on joint work (Schwennesen 2019: 178).

As has been highlighted by others, maintenance work often takes place behind the scenes (e.g., Denis and Pontille, 2015; Jackson, 2014; Graham and Thift, 2007) and belongs to the field of 'invisible work' (Star and Strauss, 1999). Likewise, behind diabetic maintenance work there are hidden practices that remain mostly invisible to the public or academic view. How digital technology changes the management of chronic disease is a question that has often been addressed over the last decade. With the advent of digital technologies, discourses on the 'digitally engaged patient' (Lupton, 2013), 'healthcare and big data' (Ebeling, 2016), 'datafied health' (Smith and Vonthethoff, 2016) and 'M-health' (Lupton, 2012) have emerged. The effect that smart assistance technology requires a constant 'care of things' (Denis and Pontille, 2015) seems to be barely mentioned.

The question of which daily routines are capable of integrating an ongoing state of standby, or which patients are willing to bear with a constant readiness, remains open for further research. So, too, it can be assumed that not everyone feels comfortable with or is willing to trust a partially automated system that administers a potentially lethal hormone. My interviewees represent a type of patient having the financial resources, the time and the knowledge to tinker with technologies for improvements. Moreover, they have access to the hardware to loop, and the high costs of the systems are reimbursed by their insurance. In this context, it is worth pointing out that

CGM systems and insulin pumps ‘are still not worn by the majority of type 1 patients in North America or Europe’ (Heinemann, 2017: 864). In Germany, for instance, the costs of a CGM system have, theoretically, been covered by health insurance since 2016, but ‘insurance companies try to avoid the high costs associated by establishing additional bureaucratic burdens’ (*ibid.:* 865). In this respect, it is not an old-fashioned way of diabetes management to prick one’s finger and handle syringes.

Although more fundamental power struggles still need to take place, it should be noted: the ‘commercial medical device industry has a huge opportunity to leverage a wide-ranging body of knowledge from the patient community that is using DIY technology’ (Lewis, 2019b: 792). There is ample room for codesign, and designers of the systems should especially consider maintenance work, for instance, by paying particular attention to technical support, the interoperability of devices, and to their battery run times. Likewise, the limits of automation and the background work of care should be publicly discussed more often. Even officially approved systems cannot be switched on and then forgotten. Diabetes, like other chronic diseases, ‘requires’ attention, and ‘that's what it will always be – with or without the loop’, to quote Olivia once more.

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