

The Coded Pancreas: Motivations for Implementing and Using a Do-It-Yourself Medical Technology in Type 1 Diabetes Self-Care

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Abstract

Type 1 diabetes (T1D) is a severe chronic disease with potentially serious acute and long-term consequences. A technology that adequately replaces pancreatic function is not yet available. Committed people with T1D no longer want to wait for the approval of a commercial system and develop their own systems: Do-it-yourself Artificial Pancreas Systems (DIY APS) automatically adjust insulin delivery through the insulin pump to keep blood glucose levels in a safe range. The question arises why a steadily increasing number of people with T1D relies on a technology that strongly influences their health, but which is not approved by an official body and therefore no-one can be held responsible in case of faultiness. In this article we are drawing upon empirical findings to better understand the motivation behind using a DIY technology for self-care in chronic disease management. We describe the multifaceted motivations of people with T1D engaging in the implementation and usage of DIY APS and how they integrate the new system into their daily practices. Empirically, the article is based on two still ongoing qualitative studies on the lived experiences of people implementing and using DIY APS. We can trace a strong emphasis on community aspects, trust in both the community and the technology, frustration with currently commercially available technical aids as well as actors of the established healthcare systems, and a vigorous dedication from both the users and the developers.

Keywords: Do-It-Yourself Artificial Pancreas System, Type 1 Diabetes, Community, Closed Loop System, Health Technology

1 Introduction

Diabetes mellitus is a disorder of the blood glucose metabolism in the body with permanently elevated blood glucose levels. In Germany, an estimated 8 million people suffer from diabetes, 3000.000 of them from type 1 diabetes (T1D) (related to 2016) (Bundesgesundheitsministerium 2019), which is the most common metabolic disease in children and adolescents (Diabetesinformationsdienst 2019). Unlike type 2 diabetes, T1D has no association with lifestyle choices, but rather develops as a consequence of an individual's auto-immune system destroying the insulin-producing cells in the pancreas (Atkinson et al. 2014). Because of its increasing prevalence, T1D is described to be of particular public policy significance (Harries et al. 2019). If not properly managed, the chronic health condition might cause severe long-term effects, such as vision loss and peripheral neuropathy (Harries et al. 2019). So far, the condition is incurable. The disease has serious effects on the entire body, as well as determines the daily lives of those affected. Thus, the task of people with T1D is not only to follow medical instructions for recovery. They have to manage an irreversible condition, which means self-observation and monitoring of symptoms become constant tasks (Bruni/Rizzi 2013). This involves affected people "doing a pancreas" (Wiedemann 2016), for simulating the functions of the organ. T1D requires constant monitoring and recording of i.a. recent and anticipated food intake and activities (e.g. sports) for patients or caretakers of an individual with T1D. Additionally, they have to constantly monitor their blood glucose levels and administer appropriate amounts of manufactured insulin doses via infusion or injection in order to keep blood glucose levels within a required range. This has to be done by patients themselves, after consultation with their physician. Corbin and Strauss (1988) describe this demand for constant care in chronic illnesses, as *work*, which is not reserved to medically trained professionals. This increasing focus on self-responsibility in managing one's own health is a widely researched phenomenon in social sciences, leading to concepts such as "expert patient" (Fox et al. 2005), "active patient" (Rabeharisoa et al. 2014), and, in light of the increasing importance of digitalization in self-care, "digitally engaged patient" (Lupton 2013). These concepts entail the notion that patients can no longer be understood as solely "passive recipients of care" (Lewis/Leibrand 2016), which leads to challenges of traditional hierarchies in healthcare (Kingod 2018).

Besides the high level of self-responsibility, T1D is characterized by the fact that the subjective perception of the disease only occurs when the blood sugar level is very high or very low. This means there are no other clinical symptoms that manifest themselves externally, this is referred to as “absence of symptoms” (Hess 2018). Especially while sleeping, this ‘absence of symptoms’ is problematic, and can cause insecurities for affected individuals. T1D technologies, such as insulin pumps, injection pens or blood glucose monitoring devices aid patients in their everyday life practices to manage their chronic illness and to make the bodily processes more visible, which is why T1D can be described as a highly technologized disease (Hess 2018).

1.1 Technologies for self-care in T1D management

These technological aids for the self-care in T1D therapy have advanced significantly over the last years. While until a few years ago the measuring process was usually carried out by pricking a finger to perform a blood glucose test, it is now possible to measure the interstitial glucose concentration through continuously glucose measuring sensors (CGM). These CGMs are placed on the skin with a sensor filament reaching under the skin and can be worn over a prolonged time on the body (Freestyle Libre 2019, Dexcom 2019, Medtronic 2019a, Wiedemann 2016). These sensors also enable constant monitoring of the glucose level (cf. Fig. 24). Thurm and Gehr (2013) compare the difference between traditional blood-based and sensor-based glucose measurements to that of image and film (Thurm/Gehr 2013): while the measurement with blood only shows a single point value and there is no information about the blood sugar progression, sensor-based measurement devices continuously display glucose levels.



Fig. 24: Freestyle Libre sensor and reading device displaying tissue glucose of the past eight hours.
Source: SW

CGM devices constitute a first step towards an autonomous adjustment of the insulin rate. The technological vision, of combining a blood sugar measuring device and an insulin pump in a closed loop system, which is also referred to as Artificial Pancreas System (APS), is not a new idea; it has been subject to research since 1973 (Home 2017). However, at the moment, full closed loop systems are not available at all. There is only one commercially available APS (cf. Barnard et al. 2018): Medtronic MiniMed 670G (Medtronic 2019b, cf. Messer et al. 2018, Cordero et al. 2017), a hybrid closed loop system, which means that insulin for carbohydrate intake still has to be administered manually. So, it is still far from actually simulating the functions of the pancreas. Medtronic MiniMed 670G was FDA approved (for the US market, FDA 2019) in February 2018 and CE licensed (for the EU market, Medtronic 2019c) in June 2018. CE license does not mean that the system is available in all EU countries (Medtronic 2019c); and also, not for any person with T1D even in the countries in which the system is available.

1.2 Vision of an artificial pancreas system and DIY realization

A closed loop system in T1D therapy would connect a CGM and an insulin pump in order for them to communicate with each other, enabling an algorithm-controlled automated delivery of insulin doses adapted to current glucose values (cf. Fig. 25).

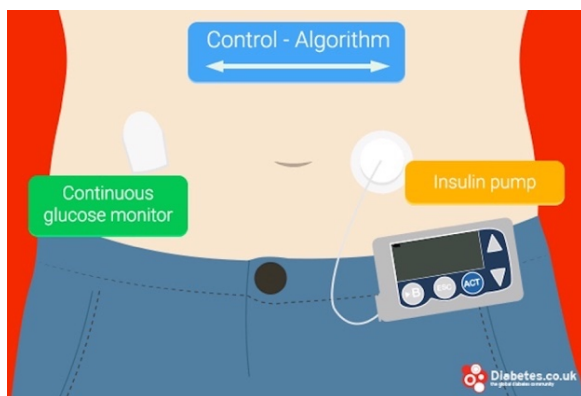


Fig. 25: An APS linking the data of the CGM and the insulin delivery of the insulin pump.
Source: Diabetes.co.uk

When the sensor reports a low or decreasing glucose level, the pump reacts by delivering less or no insulin. When the sensor reports a high or increasing glucose level, the pump delivers more insulin. As mentioned before, so far only one hybrid closed-loop system (Medtronic MiniMed 670G) worldwide has gained approval from regulatory bodies. As the development of commercial systems progresses slowly, a group of dedicated affected

people and their relatives have joined forces and developed DIY versions of an APS in a collaborative effort and made the instructions and source-codes online available for everyone to recreate and further develop (OpenAPS 2019, AndroidAPS 2019, Loop 2019). Users refer to the software as ‘the loop’, as what the algorithm does is closing the loop between CGM and the insulin pump via a smartphone app. The different DIY systems all have in common that they combine commercially available CGM devices¹ and commercially available insulin pumps with a smartphone app that was developed as a collective endeavor in the DIY community. That part of the community consists of software developers, engineers, as well as medically trained professionals. Previously programming knowledge was needed to use the system, but today with the support of the community and very well documented instructions, programming skills are not a requirement for using a DIY APS, but caution and patience are needed (Braune/Wolf 2019).

These DIY systems are supposed to be precise. Dana Lewis and Scott Leibrand, developers of the first open source DIY APS, OpenAPS, describe it as “far safer than standard pump” therapy and argue that it leads to “remarkable improvements in quality of life due to increased time in range, uninterrupted sleep, and peace of mind” (Lewis/Leibrand 2016). Currently, at least 1303 people worldwide use DIY APS (OpenAPS Outcomes 2019).

Most of our participants report an increase of quality of life and improvement of their glucose levels, especially more time in range (TIR, the time in which blood glucose is in the target range of 70-180 mg/dl, Danne et al. 2018) and an improvement of HbA1c (mean value of blood glucose over a longer period of time, usually three months, Danne et al. 2018) (cf. Fig. 26). Also, the majority of the interviewed diabetologists and diabetes advisors report improvement of glucose levels of patients using the system.

1. It should be noted that Abbott’s Freestyle Libre sensor (Freestyle Libre 2019) has to be enhanced with a transmitter (e.g. BluCon 2019, Miaomiao 2019) in order to function as a CGM.

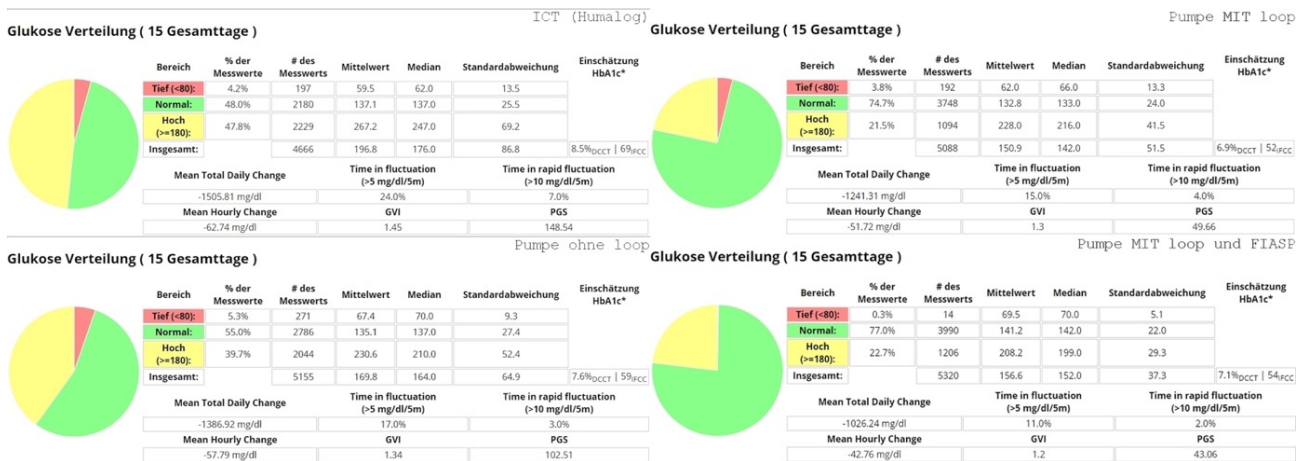


Fig. 26: Gradual improvements of TIR, depicted by a user: 1) “ICT” (therapy with insulin pens), 2) “Pumpe ohne loop” (therapy with insulin pump without DIY APS), 3) “Pumpe MIT loop” (therapy with insulin pump and DIY APS (AndroidAPS), 4) “Pumpe MIT loop und FIASP” (therapy with insulin pump, DIY APS and a fast-acting insulin). Green area: blood glucose in range; yellow area: blood glucose too high; red area: blood glucose too low. Source: zehn.BE

This technology comes with many promises, but also changes the self-care for people using the system vastly as they operate in a legal grey area and cannot easily draw upon the advice of medical professionals. Thus, they mostly rely on the help of other users and the information they find online, in the DIY online community. Therefore, the question arises why more and more people with T1D are engaging in the DIY APS and actively advocating the DIY systems, despite the technological obstacle and the lack of approval from a regulatory body. What are the motivations of people with T1D to put a lot of effort and their time in developing, implementing and using a health technology that is situated outside of the sphere of medical development and research?

To better understand the motivation behind using a DIY technology for self-care in chronic disease management, this article describes the multifaceted motivations of people with T1D engaging in the implementation and usage of DIY APS and how they integrate the new system into their daily practices. We explore how patients are using and modifying commercially available technology in innovative ways to improve their daily lives with T1D.

2 Methodology

In light of the anticipated complexity of the study subject, our empirical approach consisted in combining a sociological and a technology assessment perspective to better capture the researched phenomenon. Empirically, the article is based on two ongoing qualitative

studies on the lived experiences of people developing and using DIY APS. Bianca Jansky's PhD is mainly focused on aspects of expertise shifts, knowledge production and health and patient activism in the context of DIYAPS; Silvia Woll's PhD examines current technologies for handling T1D with a vision assessment (2.2) approach.

For this article we are combining the data sets gathered parallel by the two authors. For the analysis, both samples were combined and interpreted in light of the mutual research question.

2.1 Situational Analysis

To better empirically understand the complex and dynamic phenomenon that is DIY APS, from a sociological point of view the analysis is oriented at a Situational Analysis (SA) approach as suggested by Adele Clarke (2005, 2015). This constitutes a new conceptualization of grounded theory methodology, inspired by Anselm Strauss' theoretical social worlds and arenas concept, as well as Michel Foucault's emphasis on discourses as analytical framework. With the perception that "[t]here is no such thing as 'context'" (Clarke 2015), the different elements of the researched phenomenon are seen as *constitutive parts* of it, and not as mere surroundings, which makes it possible to situate our analysis deeper on individual, collective, material and discursive levels. This form of empirical approach to our material allowed us to get a deeper understanding of the phenomenon in question, as we can obtain a dense description of both the motivations of people engaging with DIYAPS and at the same time other elements that outline the researched situation.

2.2 Technology Assessment – Vision Assessment

While a SA approach can give us a deeper understanding of the researched phenomenon, with a Technology Assessment (TA) approach, we can examine the benefits and risks of the technology in question, and analyze and judge "trends in science and technology as well as their societal aspects, contributing to the formation of public and political opinion on these aspects" (Ferrari/Lösch 2017). New and emerging technologies (NEST) in many cases come with a visionary character, with a semblance of a potential to change current state of the arts and to improve current unsatisfactory situations. Such technologies' underlying "(guiding) visions have been a research topic at least since the 1980s, when the idea caught on that imaginations about the future, i.e. about future socio-technical

constellations, are extremely relevant in the context of socio-technical innovation processes [a]nd that the analysis and assessment of these (guiding) visions might help to better understand the dynamics of innovation processes” (Böhle/Bopp 2014). In 2000, Grin, Grunwald and others developed Vision Assessment (Grin/Grunwald 2000) “as a tool to analyse, to assess and to shape the use of such visions in debates and controversies” (Ferrari/Lösch 2017).

Visions have the potential to “motivate and fuel public debate because of the impact these visions have on everyday life and on the future of areas of society” (Grunwald 2013). On the one hand, positive visions can be seen as drivers for a longing for (societal) change and sometimes also for the use of technologies. On the other hand, “[n]egative visions and dystopias could mobilise resistance to specific technologies” (Grunwald 2013).

In context with our research phenomenon (positive) visions can already be found in the motto of the movement: People are meeting like-minded people under the hashtag “#WeAreNotWaiting” on social media platforms such as Twitter to exchange experiences and knowledge living with the system (OpenAPS 2019, Twitter #WeAreNotWaiting 2019). As mentioned above, the developers of OpenAPS describe their system as safe and leading to improvements in quality of life (Lewis/Leibrand 2016). With such promises, a vision of a less complicated, less exhausting and healthier life emerges. OpenAPS is described as “advanced but easily understandable” (OpenAPS Reference Design 2019) - however, challenges and obstacles of setting up such a system on one’s own should also be considered. Combining a SA and a TA approach can, thus, help to both better understand the researched phenomenon on a deeper individual, collective, material and discursive level, and at the same time keep in sight the challenges and obstacles people that are engaging in this innovative new technology have to face when developing, implementing and using the system.

Data

Altogether, the sample consists of 32 in-depth interviews with users and developers of DIY APS systems, caretakers, friends, family members of people with T1D who support them, as well as diabetologists and diabetes advisors. The interviews, lasting from 20 to 120 minutes, were conducted mostly via telephone or Skype and took place from June 2018 to April 2019. In addition to our interview-based material, our sample also consists of

fieldnotes from participatory observations, in the context of DIY APS. We joined regular meetings, as well as going to hackathons and larger events.

For maximizing confidentiality, pseudonyms were used where necessary, and all data was anonymized. Interviews were audio-recorded and later transcribed verbatim. Interviews conducted in German were translated for the article.

3 Findings

In what follows, we will trace the main motivations for using and developing a DIY APS that we obtained from the empirical material. We can show a strong emphasis on communal aspect, trust in both the community and the technology, frustration with currently available technical aids as well as actors of the established healthcare systems, and a vigorous dedication from both the users as well as the developers.

3.1 Community - DIY APS as collective endeavor

One of the main findings is that the observed DIY practices can be described as collective endeavors; even though there is an emphasis on *yourself*, our participants all refer in one way or another to the community. The community refers to everyone involved in the DIY APS, including users and developers, and those supportive of or interested in the technology. The community comes together in multiple ways either via social media platforms, such as Facebook or Gitter, or face-to-face on one of the many regular meetups or bigger events. Markus, who is very actively involved in the DIY APS community, describes the division of labor in the community as follows:

“The community is just people who get involved. There are people who can't program, who can't do anything, but they can speak a language for example that means they can help with translating or supporting newer members, so the developers and the more experienced members don't have to answer the standard questions.”

In the community it is not about being professionally trained in medical technology development, but rather everyone there has a specific skill that they can contribute to the development of the community. At first glance, it would seem that programming would be most needed in the community, but other skills such as the knowledge of multiple languages or even of having a bit more experience in using the system can help. It seems that, as everyone finds their place within the community, everyone can contribute in some

form. Without everyone having professional medical or technical knowledge, the division of labor becomes crucial. This observed solidarity in the community can even be the reason to start 'looping' in the first place, as Christian states:

“This community, it's the reason I started looping. I have never experienced so much solidarity, so much support and so much willingness to selflessly give something to others, to do something good, to support other people. I have a problem today and tomorrow I have three answers [...]. That's completely different than when I compare it with any problems I have commercially, I often get answers – from I have no idea, but they are well packaged, and that's what the community really is. So, that's why I did that, because I realized nothing can happen to you because you will never be left out in the rain.”

Christian's statement can again illustrate the different forms of work, that people in the community take on (in their spare time, without monetary compensation). Christian states that the community IT-support is more reliable than the one he is used to from commercial technology providers, and because of this strong and fast acting community support, he has no fear using the system.

3.2 Trust

Christian's statement also illustrates the trust in the community and the shared work of the community. In our empirical material we do not only trace the trust in the immediate support of the community, but also the trust in the collectively developed technology: the 'loop', the algorithm that connects the sensor and insulin pump.

One issue raised by regulatory bodies, such as the Food and Drug Administration (FDA) is that DIY approaches are unauthorized and could result “in inaccurate blood glucose (sugar) measurements or unsafe insulin dosing, which can lead to injury requiring medical intervention or even death” (FDA 2019a). Especially in the case of insulin treatment, the accurate dosage of insulin is crucial as a wrong dosage can cause severe acute health adverse events, such as hypoglycemia and ketoacidosis. But the FDA statement does not consider that also with conventional pump therapy, “errors of insulin infusion can occur due to pump failure, insulin infusion set [...] blockage, infusion site problems, insulin stability issues, or a combination of these” and “[u]sers are therefore exposed to significant and potentially fatal hazards” as severe hyperglycemia and hypoglycemia (Heinemann et

al. 2015). Also, an insulin treatment with pens is associated with risk as a too large as well as too small amount of insulin will always lead to glucose levels out of range. Another issue is “that useful information held by the manufacturing companies is not currently shared in a sufficiently transparent manner” (Heinemann 2015). Developers of DIY APS address this aspect by providing the coding open source, so all is publicly accessible.

As mentioned before, the self-responsibility in T1D, is very noticeable and gives people with T1D in-depth understanding of their disease, in which their knowledge gained in everyday practice is intertwined with medical knowledge. In their everyday life living with the chronic disease, they have been trained to avoid the causes and to recognize the symptoms of the potential adverse events. People with T1D are well-equipped to judge the safety of monitoring systems, considering that these systems’ outcomes are people’s own glucose levels. When regulatory bodies such as the FDA issue warnings against the usage of the DIY system, the question arises: how is trust built in this context? Our empirical findings show that trust in DIY APS emerges from the experience that using the ‘loop’ leads to more TIR and to better glucose levels - but also from the knowledge that developers are coding the system for their own children, as Marie states:

“And most of all, these developers, they have their kids on it. So, if someone like them doesn't work and check carefully, then who does?”

Developing a system and using it on one’s own children shows for Marie the trustworthiness of the system. Especially when one’s children are involved; she assumes developers would control their designed technology especially careful under these circumstances.

This trust does not only lead to a feeling of safety, but also to more relief of users. This is especially the case when it comes to sleep. One of the main issues for those affected by T1D is the quality of sleep due to fear of too high or especially too low blood glucose levels. Strongly decreasing or increasing glucose levels are problematic especially during the night as it is likely that people with T1D do not notice them. Recent CGM systems with alert functions help the situation, but the quality of sleep still suffers. As reported by its users, looping has an effect on the quality of sleep due to stabilizing glucose levels during the night:

“This was the first time after almost 30 years of diabetes the prospect of sharing a part of this 24-hour task [...] with something [...] which, for example, guards me for the night. [...] For me it was also really a safety thought. Something is watching over me and [...] takes some of this 24-hour job away from me.”

Self-care in chronic illness is, as Strauss and Corbin (1988) put it, work for the affected. Marie describes the workload as a 24-hour task, as she cannot just have time off from managing her T1D. With using the 'loop' she feels as if she is not alone, but that “something is watching over [her]”. This shared workload also leads to a feeling of safety during the night for her, as the technology takes some parts of her 24-hour job “away” from her. Similarly, Tim explains his trust in the system and his feeling at ease with the DIY technology:

“So, when I see the glucose rising, I realize it. I know, the loop, it takes care of it. So, it will take a while. But it'll get it down again.”

Usually, when the blood sugar drops or rises, which can happen several times a day, often unexpectedly and also independent from food intake or exercise, people with T1D have to take care of it by administering insulin or carbohydrates, or by decreasing the amount of administered insulin. With using the DIY APS, Tim can just realize what is happening and does not have to intervene as he knows that the 'loop' will bring his glucose level back in the desired range.

As already mentioned above, safety issues and subsequent fears and concerns are broadly discussed issues concerning the DIY APS, as it is not an authorized and officially regulated health technology. Tim also refers to those safety issues:

“I see the advantage of this system. It's just much bigger than what might happen. So, the situation you're afraid of with the loop. That doesn't happen because of the loop.”

Regulatory agencies and other actors of the established healthcare system see a danger in shifting some responsibility from the individuals to the 'loop'. However, it is this exact shift in responsibility which allows individuals with T1D to feel less in danger. Their trust in the technology allows for a greater sense of safety living with T1D.

3.3 Frustration with traditional self-care in T1D management

The warning issued by the FDA can be interpreted as an example of the tension between patients, who want to take their health into their own hands and do not want to wait for actors of established healthcare systems to come up with solutions, and regulatory bodies in the public health context. The warning was issued as a reaction to a patient who required hospitalization while using the DIY system - something that could have also happened while using FDA approved commercial devices - but since a DIY system was involved, there was greater public scrutiny. Looking at the media coverage and the public discourse surrounding the DIY APS, two of the main questions are: why are people relying on a DIY system and why is there only one commercially available technology, so far? As we mentioned before, recently, the first commercially developed systems have become available in some countries, but development of a medical device in traditional research and development context is a time consuming and highly regulated practice. This leads to frustration among the affected.

This frustration with pharmaceutical concerns and other actors of the established healthcare system, can also be traced by the use of the hashtag #WeAreNotWaiting. As previously mentioned, affected people did not want to wait for a commercial actor to finally take up the development of a closed loop system, but started to take matters into their own hands, and developed the system open source. Jacob, a father to a six-year-old boy with T1D, explains his frustration:

"As a computer scientist I was frustrated by the amount of manual management required for diabetes, how many simple calculations you have to make every day and how high the probability of errors is when you have to make these calculations yourself on paper. [...] and we were somewhat frustrated as to why we have to do this ourselves – the data is all there, the pump has the data, the sensor has the data."

In T1D self-care, the focus on self-responsibility of one's health has traditionally been very noticeable: The treatment of the chronic disease requires a demanding regime of self-care for patients, including consistency in diet, as well as blood sugar level monitoring and insulin injections. These practices have to be repeated throughout the day. Referring to his background as a computer scientist, Jacob expressed "frustration" with the lack of automatization in the care of his young child and he turned towards a DIY solution; for him the manual calculations are as much or even more prone to failure than an open source

algorithm, as the 'loop'. With this newly gained confidence of people with T1D through their DIY approaches, the traditional hierarchies in healthcare are being challenged. This is especially visible looking at the role of physicians in the context of DIY APS:

“So, there are doctors, [...] who are diabetes patients themselves, who are also endocrinologists, who are totally active in this field. And then, I also had several doctors who don't know their way around. If I tell them about artificial pancreas, they don't know what that is, it is as if I would talk to them in a foreign language.”

Marc describes how boundaries of previously defined social roles are blurred by DIY strategies. The healthcare professionals are not seen as omniscient amongst members of this DIY community, but rather, they are perceived either as a member of the community or as or as outsiders without the specific community knowledge.

3.4 Commitment

Our empirical material shows that, using DIY APS seems to come along with a lot of improvements regarding quality of life and glucose levels, compared to the currently very limited commercial alternatives. But on the flip side of the DIY technology is that even with the great solidarity in the community, some things have to be done by every user themselves, for example compiling the app to connect sensor and insulin pump, which is reported to be quite difficult by some of the participants. Marie states:

“Well, that was difficult with me. But what was even more difficult for me to figure out before that, [...] what do I need at all? Well, [...] I didn't even know I needed a transmitter. I didn't even know that the thing I needed was called a transmitter. Well, I'd gotten a few words knocked around my ears, like BluCon and an XDrip and Nightscout and APS, okay. But now, what was in charge now, I didn't know. I had to puzzle it out first. Then somehow, I had this Nightscout, I thought: What do I do with it? That this is just a database for uploading [...] my values, which I still need somehow, for what I have not yet understood why it is absolutely necessary, an AAPS [...]. But it won't work without it. Those were the sticking points where I had a hard time. This linking of apps, [...] of XDrip and then XDrip has to communicate with AAPS and Nightscout has to communicate with AAPS to get those links done, that was difficult for me.”

Setting up a DIY APS can be a challenge without being tech-savvy, so additional to their already very high medical knowledge regarding T1D, users have to acquire some understanding of connecting the respective devices and compiling the app. But since the alternative would be to not use the system at all, people are dedicated to understanding how to do all that.

Achieving to setting up the DIY APS, leads to outcomes beyond improved glucose levels. A feeling that is reported is pride, as Marie expresses:

“Of course, I'm proud of it. Yes, I am proud of it. Now I'm thinking, why? Yes, because as a mum and housewife I managed to do that. Yes, it also makes me a bit proud. [...] That's the way it is. I had to do something for it.”

The commitment of engaging in the setting up of a DIY APS even leads to remarkable outcomes regarding the way parents perceive their diabetic child since using DIY APS. Clara, a mother of a child with T1D, states:

“I mean for us Sarah is a healthy child, I say. Because we invest so much effort that she has these good blood values.”

Children affected by T1D usually are not considered to be healthy. Their parents' care includes much more effort than the care of parents of healthy children. Therefore, it is astonishing that Clara considers her daughter a “healthy child” due to effort she takes for her wellbeing. Without DIY APS, this effort might be less (but still much more compared to non-diabetic children) but would never lead to perceiving Sarah as healthy. Engaging in the implementation and usage of a DIY technology for T1D self-care, does lead to some new forms of patients work (Corbin/Strauss 1988) but at the same time takes work away from patients and caretakers and can lead to new notions of what is considered healthy and ill.

4 Conclusion

Motivations for people with T1D to use and implement a DIY APS in their T1D self-care are multifaceted. We can show that a lot of the motivation to engage in the DIY APS context is related to the closely knitted community, and the help people receive through this community. This solidarity throughout the community can in some cases even be the reason for starting using the DIY system. The setting outside of clinical and commercial

context also leads to change in the traditional division of labor in medical contexts, where patients follow instructions from physicians. In the context of DIY APS this hierarchy in expertise is no longer stable. Physicians are either part of the community or outsiders, without the community's specific knowledge. People in the community take on new forms of work, that even surpass the notion of patient work of Corbin and Strauss (1988). We can also show that both the community and the collectively developed technology gain much trust from the users and help them in their everyday life. Not only report almost all of our participants better glucose levels using the system but also more trust is put into the (IT) support of the community than in that from commercial actors. We can see this also in relation to the close personal involvement of the developer in the DIY system, as one participant described that her trust derives from the fact that a lot of the developers use the DIY APS on their own children. We can also show that the OpenAPS developers' promise of improvement of sleep quality is confirmed from our participants, they also report a feeling of ease and less fear during the night. Our empirical material shows the frustration of T1D with pharmaceutical concerns and other actors of the established healthcare system, and their dedication to improve their daily lives without waiting for a commercial actor to step in. Our findings show a shift in the conceptualization of 'expertise': they illustrate, how informed patients are successfully engaging in the development process of a medical technology, that improves not only their blood glucose values but also their quality of life. This shows that people living with a chronic illness are experts of their disease and should be included more in the development and research of health technologies and other approaches of treatment.

So far there is little empirical research on the lived experiences of people using and engaging with a DIY system to manage their health condition. We therefore argue for more research on the subject, and we emphasize the importance to engage and involve people with T1D in the research to better understand their experiences and practices using a DIY system for their self-care, as they can be considered experts of their disease.

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Figures

Figure 24: SW

Figure 25: Diabetes.co.uk. APS how it works <https://www.diabetes.co.uk/artificial-pancreas.html>

Figure 26: zehn.BE

Overview over cited Interviews

Pseudonym	Description	Interview date
Clara	Mother who uses DIY APS on her diabetic daughter	07.03.2019
Christian	DIY APS user	17.04.2019
Jakob	Father of a child with T1D, uses the system for the child	02.05.2019
Marie	DIY APS user	20.03.2019
Marc	At the time of the interview no user of DIY APS, but actively involved in the community	12.07.2018
Markus	DIY APS user/developer and actively involved in the community	19.07.2018
Tim	DIY APS user	29.03.2019

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