

Techno-social reconfigurations in diabetes (self-) care

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Abstract

This article focuses on the ways in which a flash glucose monitoring system, FreeStyle Libre®, is introduced and used by people living with type 1 diabetes, their relatives and healthcare professionals. It draws on a multi-sited ethnography in a variety of clinical and daily situations, and on interviews with caregivers and people living with diabetes. We explore how the users develop knowledge-in-practice, and consider the use of self-management technologies to be largely dependent on locally grounded and situated care acts, and resulting from the relational, pragmatic and creative maneuvering of technology-in-practice. Our findings show that adjustments between users, their bodies and the technology are required, and show the reflexive work and practices of patients and relatives who learn to use the device in a proper way. Moreover, we reveal that practitioners see this technology as a tool that not only improves self-care practices but also clinical practices, and that wearing and using this new medical device may become a moral injunction for self-improvement. Our results illustrate the techno-social reconfigurations at work and the development of new ways of feeling, thinking and acting in diabetes (self-) care.

Keywords

self-management, self-care, type 1 diabetes, flash glucose monitoring, techno-social reconfiguration, multi-sited ethnography

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Introduction

Diabetes self-management is built on four pillars: nutrition, physical activity, monitoring glucose levels and medication (insulin therapy and/or antidiabetic agents). Its goal is to maintain a stable glucose level and to avoid episodes of hypo- or hyperglycemia, liable to lead to hospitalizations and long-term complications. People living with type 1 diabetes (T1D) and undergoing Functional Insulin Treatment have to manage their insulin treatment, ‘this according to the various acts of everyday life, and particularly meals’ (Grimm et al., 2002). In order to inject the right dose of short-acting insulin, they have to monitor their glucose level, calculate the amount of sugar they will consume and take into account the activities they plan for the next hours, or have previously undertaken. In addition, the glycated hemoglobin (HbA1c)¹ and the analysis of the numbers collected during a certain period enable patients who use insulin pens to determine not only the coefficient for dosing short-acting insulin but also the dose of long-acting insulin or the basal rate for those wearing an insulin pump. Self-monitoring glucose levels is thus a fundamental activity in diabetes care (American Diabetes Association, 2017).

Self-monitoring one’s health is an old practice. In the past, self-tracking practices were based on journaling and diary-keeping, whereas nowadays these practices draw on a variety of methods (Lupton, 2014) due to the development of miniaturized and easy-to-use devices (Piras and Miele, 2017), and more recently of digital technologies. More specifically in diabetes healthcare, since the introduction on the market of glucometers and, more recently, of low-cost continuous wearable sensor patches (Swan, 2012), healthcare professionals delegate a series of tasks and measurements to patients and relatives (Danholt, 2013; Hinder and Greenhalgh, 2012; Mol, 2000; Mol and Law, 2004; Schüll, 2016). Therefore, patients become responsible for collecting, assembling and interpreting data about themselves. They are also expected to report details about themselves during the clinical encounter, and to support and share the work of healthcare professionals in the management of their disease (Bruni and Rizzi, 2013; Piras and Miele, 2017). It is not only a matter of enhancing patients’ responsibility for producing and sharing more data on their ‘medical lives’ but also on their ‘everyday actions’ (Schüll, 2016: 319). As Oudshoorn highlights through the concept of the ‘technogeography of care’, these technologies – as well as the request for the patients’ participation in self-care – entail changes in both the ‘landscape of care by connecting previously distinct places, redefining the meaning of these places, and creating new sites of care’, and in the ‘geography of responsibilities by creating interdependencies and distributing responsibilities between people, places, and technical devices, thus reconfiguring who cares’ (Oudshoorn, 2011a: 124). In addition, as has also been underscored in research on

public health genomics (Kerr et al., 2019), responsibilities for preventing and managing health risks are thus delegated, extended to and redistributed between multiple actors; gathering, analyzing and managing these personal, molecular, ‘informatic-behavioral’ (Schüll, 2016: 327) data is at the core of this process. Consequently, changes have occurred in the patient’s and relatives’ work, clinical and research practices, as well as in the relationships between caregivers, patients, and technologies (Baszanger, 1986; Corbin and Strauss, 1985; Oudshoorn, 2011b; Pols, 2012; Schüll, 2016; Williams, 2002).

The patient called ‘2.0’ for his or her cyborgian qualities has been understood ‘as a human actor wired into a network of external health infrastructures and internal miniaturized devices, intermingled with institutions, organizations and social groups ... an agent producing data, information, knowledge, and contents to be shared on a variety of platforms and in different settings’ (Danholt et al., 2013: 5). The ‘digitally engaged patient’ (Lupton, 2013) is the result of the eHealth or Health 2.0 policy. This is frequently portrayed as a forthcoming revolution in contemporary healthcare and public health, which take ‘advantage of new information technology to efficiently redistribute health-care practices outside hospitals and clinics to citizens and their communities’ (Storni, 2015: 1440) and promote a neoliberal political orientation to patient care and preventive health leading to the self-government of autonomous individuals (Rose, 2007; Schüll, 2016). This shift includes the use of digitalized health information systems, telemedicine/telecare, patients’ empowerment through their engagement in self-monitoring and self-care with the use of digital technologies, as well as the possibility for users not only to access and use information but also to produce and share it (Lupton, 2013).

Today, different medical devices can measure the glucose level. Glucometers were first produced in the 1980s and enabled patients to measure their capillary blood glucose (BG) level without having to regularly visit the clinic. Since the beginning of the 21st century, new devices have offered an alternative way of measuring the glucose level. Continuous Glucose Monitoring (CGM) systems² measure the glucose in the interstitial fluid,³ enable continuous real-time glucose readings, and display curves of the glucose profile.

In 2014, the FreeStyle Libre® (FSL), a Flash Glucose Monitoring (FGM) system, was introduced by Abbott Diabetes Care on the European market, and on May 1, 2016 in Switzerland. The company presented the FSL as leading to a ‘revolutionary way’ of monitoring glucose levels, characterized by convenience, and tagged it with the motto ‘why prick when you can scan?’ (Abbott Diabetes Care, 2019). Patients can collect different information regarding their flash glucose (FG) level through a quick and painless scan. The FSL thus allows easier measurement of glucose levels day and night, when driving, swimming or working, etc. FSL’s discretion, since the sensor is small and scanning can be achieved through clothes, its user-friendliness and its possibly even engaging aspects are also advantages.

A socio-material perspective of technology- and knowledge-in-practice

Some definitions of self-management and self-care can be criticized for focusing too heavily on biomedical tasks and skills, and excluding socio-emotional tasks, social and material contexts for self-management, and multiple interacting influences (Hinder and Greenhalgh, 2012). The definitions of self-care by both the WHO (1998) and the Department of Health in the UK (2007) emphasize human action and collaboration between humans, and are thus closely related to knowledge, information and human virtues (Danholt and Langstrup, 2012). However, self-care can be considered a sociotechnical, distributed, and decentered practice, and the 'self' as 'an actor who is thoroughly dependent on, and are [sic] ineluctably interconnected with other actors and entities in infrastructures, to become a self-caring subject' (Danholt and Langstrup, 2012: 514).

Drawing on this assumption, we refer to what Timmermans and Berg (2003) have called 'technology-in-practice', which considers medical technology as located in the practices of designing and/or using it, and the users' agency as co-produced with and by these technologies. This approach contrasts with traditional works of medical sociology that have overestimated (technological determinism) or underestimated (social essentialism) the role of medical technology in society. This approach led us to explore the intertwinement between the material and the social by 'looking at technologies as central mediators in the construction and reproduction of novel worlds ... and how novel medical technologies co-produce novel subjects or bodies' (Timmermans and Berg, 2003: 108). Through this lens, we investigated how the users develop 'knowledge-in-practice' (Mol and Law, 2004) by considering the use of self-management devices as largely dependent 'on locally grounded, situated care acts' (Oudshoorn, 2011a: 121), and as the result of 'relational – often creative – maneuvering of users and technologies in practice' (Nielsen and Langstrup, 2018: 264).

The introduction of a new technology in the management of a chronic condition, such as a new device to continuously monitor interstitial glucose levels, interferes with pre-existing infrastructures (Star, 1999), which afford or impair actions as 'part of the reality that shapes and facilitates human actions and perceptions' (Danholt and Langstrup, 2012: 517). Thus, novel technologies act on the ecology of care that is 'already infrastructured' and where self-care is already at work, open up new assemblages and the opportunity for researchers to investigate reciprocal transformations of the interconnected actors in infrastructures and their work (Danholt and Langstrup, 2012). Technologies prescribe uses because they are 'scripted' (Akrich, 1992) and 'actively co-shape what can be done with them, and address their users in certain ways' (Pols and Willems, 2011: 485). However, they are also 'domesticated' (Oudshoorn and Pinch, 2003), 'de-scribed' (Akrich, 1992), 'tamed', and 'unleashed' (Pols and Willems, 2011) by the users in order to fit them into their daily routines and practices. Therefore, in order to capture 'the complex ecology of healthcare that already facilitates self-care, and already connects the clinic and the home' (Danholt and Langstrup, 2012: 529), we have to consider the materially inscribed and spatially distributed nature of chronic care in the practices of patients, relatives and healthcare professionals.

In her investigation on self-monitoring and data practices, Lupton (2014) makes a useful taxonomy of modes of self-tracking: private, pushed, communal, imposed, and

exploited. The use of a medical device for monitoring glucose levels of people living with T1D is mainly pushed self-tracking, because it is taken up ‘in response to external encouragement or advocating rather than as a wholly self-generated and private initiative’ (Lupton, 2014: 7). This potentially leads to behavior changes and, in the case of people living with chronic diseases, to a reduction of their interactions with practitioners. Not only patients become responsible of self-managing their health risks by producing, consuming, and interpreting data made available by these new devices but also healthcare practitioners have the professional responsibility to maximize data collection through the education of patient to engage with these new devices for research and public health (Kerr et al., 2019). Piras and Miele (2017) call ‘clinical self-tracking’ a form of pushed self-tracking in T1D self-care and observed that while patients at times follow the path prescribed by the provider, at times unexpected self-tracking practices emerge. In her analysis, Schwennesen (2017) underlines that pushed self-tracking in physical rehabilitation is ‘as an ongoing and contingent process through affective and affecting encounters between human ... and nonhuman actors’ (p. 7). These empirical studies and Lupton’s contribution also shed light on the overlapping of the different categories of self-tracking.

Our study explores the incorporation of a Flash Glucose Monitoring (FGM) system in self-care practices of people living with T1D, parents of children and young people living with T1D, and in clinical practices of healthcare professionals. We focus on the reconfigurations of their work and knowledge-in-practice, as well as on the blurring between the different modes of self-tracking. Drawing on a situated approach, we aim to examine how uses are built at the intersection between the world carried by technology and the worlds carried by the different users, both being transformed through the co-construction of realities. Therefore, our analysis focuses on the ‘techno-social reconfigurations’ (Akrich and Méadel, 2004) of the work, experiences and practices of patients, relatives and practitioners, as well as of their interactions triggered by the introduction of a new technology in diabetes care. Our analytical approach pays attention to three main elements: the contexts and conditions of the experimentation and use of this new device (Akrich and Méadel, 2004), users’ ‘tacit’ and ‘subjective’ experiences (Timmermans and Berg, 2003), and the expert, clinical, experiential and practical knowledge that users develop in interaction with this technology and other actors.

A new digital device for monitoring glucose levels: The FreeStyle Libre®

Like other Continuous Glucose Monitoring (CGM) systems, the FSL requires a wearable sensor patch (a thin flexible fiber within the sensor is inserted approximately 5 mm under the skin) connected to a transmitter that sends the data to a receiver (either a remote device or a smartphone) via Bluetooth connection. The FSL measures the glucose concentration in the interstitial fluid and stores eight hours of data. However, in contrast to the CGM systems available in 2016, it is calibrated at the factory and does not require BG tests for calibration. Moreover, it does not have hypo- and hyperglycemia warning alarms and its sensor has a 14-day lifetime, whereas other CGM sensors have to be replaced every 7-10 days (Heinemann and Freckmann, 2015). When the patient scans the

sensor (recommended to be worn on the back of the upper arm), the reader displays the current glucose level, a *curve* of the glucose profile over the previous eight hours, as well as an *arrow* indicating the predictive glucose trend. The data are displayed on the receiver – recently on a smartphone App (LibreLink® App) as well – and can be downloaded on the software Libreview®.

From the first months of FSL's introduction on the Swiss market, both clinicians and patients pointed out a lack of research on its accountability, especially in children and adolescents (Edge et al., 2017; Hansen et al., 2018; Szadkowska et al., 2017). Questions concerned specifically the lack of need for calibration, the delay of interstitial glucose level when compared to capillary value (as with other CGM systems), and the reliability of FG values during the first twenty-four hours after the activation of a new sensor and in extreme values. In these situations and also when patients' symptoms are discordant with sensor readings, medical guidelines recommend measuring the capillary BG level to obtain a tried-and-true value on which patients can rely.

The manufacturer's decision to bypass the traditional distribution channels for medical devices led patients to buy the device directly from the company's website. This raised questions among healthcare professionals about whether patients who received the FSL kit at home and follow the manufacturer's instructions to wear it without going to clinics would receive the necessary information for its use.

Methods

The data were collected by the first two authors through a multi-sited ethnography (Marcus, 1995) in a variety of clinical and daily situations over a period of two years (2016-2018). They are part of a broader research project on knowledge translation mediated by tools in chronic care, and more specifically in diabetes (self-) management.

The first ethnographic observations of this new self-monitoring technology took place at a summer camp for young people living with T1D. Two months after its introduction in Switzerland, the president of the foundation organizing this camp decided to provide all participants (about 30 young people aged between 12 and 17) with the FSL and to give them the opportunity to test it during this seven-day camp. At the same time he carried out a quantitative study on the accuracy, usability of, and satisfaction with this device.

In addition to the medical team (consisting of five doctors, seven nurses and three dietitians), thirteen camp monitors (ages between 19 and 30) took care of the participants. Most of them also were living with T1D and had participated in this camp when they were younger. They were also invited to test the device. All but four tried the FSL for the first time. We focus on the ways in which both the staff and the participants learned how to use this new device and to interpret its data. To achieve this goal, we mixed ethnographic observation with informal and semi-structured interviews carried out with the healthcare professionals, the camp monitors and the participants.

One month after the summer camp, we participated in a workshop about the use of the FSL. Organized by a small team working in a Swiss pediatric diabetes hospital service, it brought together healthcare professionals (one diabetologist and four diabetes nurses), patients and/or relatives. It aimed at enhancing knowledge circulation between these actors in order to achieve the most suitable and beneficial uses of the FSL. We also visited a Swiss pediatric diabetes and endocrinology hospital service for a period of four months, and observed about forty consultations with children and young people living with diabetes and their relatives. We observed consultations in which a diabetologist presented the device to patients and their relatives; a nurse gave the first explanations on how to wear and use it; and the patient discussed his/her first experience of the FSL with the medical team after having tried it over a period of about two weeks. We also observed consultations involving patients who had been using the FSL for several months and had stopped using it. During this period, we attended several public events or training sessions where healthcare professionals presented these new digital technologies (CGM and FGM systems) in diabetes care to other healthcare professionals and/or to patients and relatives.

Another part of the data is made up of in-depth semi-structured interviews carried out with 27 healthcare practitioners (five diabetologists, six diabetes nurses, five home care nurses, three dietitians, three general practitioners and five pharmacists), eleven persons living with T1D and one person living with T2D, aged between 14 and 55, the mother of an 8-year old boy living with T1D, the mother of a 14-year old girl living with T1D, and the mother and father of a 20-year old girl living with T1D. All interviews were audio-recorded and fully transcribed. For this article, the verbatims and field notes have been translated from French to English by the authors.

The data were analyzed according to ethnographic methods. This implied building a composite and transversal picture of the uses of this new device by following and mapping the experiences, practices, discourses, situations, and patterns of interactions involved in its uses by multiple actors. Then, we elaborated 'the descriptions of the elements of organized activities and their interconnections' (Becker, 2002: 304). Our aim was to refine the overall picture to offer 'a consistent representation of its complexity and diversity' (Becker, 2002: 323) and provide a 'thick description' (Geertz, 1973) of the uses in context of this new technology.

Matching body to technology: Trust and sensing through numbers

In order to equip the body with a new device, the technology needs to be adjusted to fit the body ergonomically. Whether it concerns tips on where to place the sensor or how to ensure that it adheres to the skin, interactions between healthcare professionals, patients and relatives foster a common practical knowledge meant to facilitate the material domestication of the technology and the adjustment from theory to practice, from clinical guidelines to 'individualized solutions' (Kingod, 2018: 12).

Testing a new medical device also requires testing its accuracy and relating bodily sensations to single values and trends. The numbers produced by the FSL do not always match sensations and for a few people these values do not match capillary measurements.

So with the FSL I had too many wrong tracks. Wrong data, well wrong values. So, if something is not precise I'm not interested in it. ... Well I have been wearing sensors that displayed values with a difference of 3-4 mmol⁴ during the fourteen days. (interview with John, a 55-year old man living with T1D for almost 40 years)

Because the FSL measures the glucose concentration in the interstitial fluid, its values need to be carefully evaluated. During the workshop on the FSL, Paul, a diabetologist, pointed out that the FSL is not a traditional BG meter, is a 'great tool' but requires 'having a certain feeling', and said:

'You should familiarize yourself with the device'. ... He then explained that the FSL may, for example, display too high a value, while the person might actually already be in hypo. ... According to Paul, the patients should then compare the FG values with the BG values to check possible differences. They should test their 'feeling', their sensations because they [the caregivers] cannot teach them to feel or recognize sensations. He repeated that healthcare professionals 'learn with them how the tool works'. As a conclusion, he advised: 'Always trust your own sensations and symptoms more than the device' (field note)

Denise, a diabetologist working in a medical office, added that people having difficulties in feeling and/or interpreting hypoglycemia sensations can trust the device: 'I tell the patient "when the device tells you that you are in hypo, there are no doubts, you are probably in hypo"'.

Some persons became diabetics when the FSL was already available and started measuring their glucose level with it. Hence, they have no experience of capillary measurements and have learnt to recognize hypoglycemic episodes mainly through use of the FSL. For their part, practitioners have to learn how to manage the diabetes of these patients.

These are patients who use the FSL the most, because they have not known anything else and if they forget to order the sensors once, they are lost and wonder how they're going to do it, they say to themselves that 'six capillary BG measurements per day is not possible!', and these are the patients who most trust the FSL, I think. (interview with Paul, diabetologist)

This practitioner worried because the FG values are not entirely trustworthy for the first twenty-four hours and in extreme values, and because these patients had not developed a sensitivity to their own sensations. Patients are expected to learn to recognize bodily sensations alerting them and their network of hypo- or hyperglycemic episodes. Trustable BG controls help people living with diabetes in developing inner sensitivity because it gives them the possibility to compare numbers with physical sensations (Mol and Law,

2004). Thus the data collection of glucose levels enables the objectification of their bodies through the enhancement of embodied self-awareness.

Changes in the experience of illness transform self-knowledge and lead to a ‘re-discovering of the self’ that results from a ‘re-learning’ process that lies in the development of an experiential and experimental attitude in the patients’ work (Mathieu-Fritz and Guillot, 2017: 663). This attitude involves comparing the data coming from the ‘calculated experience’ with those from the ‘subjective experience’ (Mathieu-Fritz and Guillot, 2017: 667). Not only must technology materially match the body, but both the body and the mind also have to match the technology by wearing and experiencing it in a variety of daily situations. In other words, the body has to act to wear this new technology, to experiment it. Hence, learning to use a new device relies on the one hand on technical gestures made possible through cognitive work and bodily sensations and, on the other hand, on interactions between users and technology aimed at supporting the production and circulation of biomedical, practical and experiential knowledge.

From production to the use of data: Co-interpretation in care work

Patients understand, interpret and make use of data in different ways. For example, Rachel, a 45-year old living with T1D for six years, reported her difficulties in understanding how to read and make sense of the data produced by the device.

I have a type of diabetes that is challenging to manage. I don’t have very bad values but the long-term glycemia is high. ... We don’t know why. ... Yeah, he [the diabetologist] does it (she laughs). He looks on his computer and then he sees 150 points and then he says: ‘We have to do that’ (she laughs). ... Yes, yes, yes, he shows me, but I don’t understand anything, it is so ... there are so many data during one month of treatment. ... These are one-month graphs and then he sees the trends and I don’t see that!
(interview with Rachel)

In another example taken from a consultation, Tania, a diabetologist, warned her 15-year old patient who has lived with T1D for twelve years and wished to try the FSL: ‘There is much information, numbers, thus additional information to interpret to decide the doses.’ Tania indirectly told her patient that wearing this device implied being willing to learn what to do with it and understanding the data produced in order to benefit from wearing it.

Lia explained to us that wearing this device elicits a new apprehension of the glucose values for both patients and practitioners. She also emphasized the importance of teaching this new mode of reasoning to patients in order to take advantage from the use of this device.

It has changed, we no longer work with the result of a moment, we work with a trend, a whole and that’s a big plus because it’s what we try to work with, to transmit to patients, to say ‘stop staring only at the value of a

moment ... it is necessary that when you have the value you have to think what was before, what is going to happen after' ... and there with the arrows and the trends I think that's what's going to be great. ... We'll have a workshop the week before school starts where we invite everyone who ordered it and we have half an hour of really theoretical training for the parents to try to make them change that [she refers to the teaching of what she called the new 'logic'] and, as soon as they use it, they don't use it without considering this change, and then we have an hour and a half where we're going to practice, because I said to myself there's a change that we have to make. (interview with Lia, diabetes nurse)

Delphine, also a diabetes nurse, highlighted that practitioners 'need to support them [patients] in this new therapy' and criticized physicians who do not give explanations on the data produced by the tool. In her view, patients are at risk of not getting the right treatment. Her colleague, Vania, explained how they try to teach patients to read these new data.

Vania: [U]sually we see them twice. The first time we explain how it works and we put the first sensor and then we see them again 15 days later to put the second sensor and then we download [the data] together and we benefit from looking at the curves and talking about them and order the equipment for the next months.

Delphine: ... What will they do with these graphical plots? And then if they do not change anything or if they change and they adjust too much and they have hypos? (interview with Vania and Delphine, diabetes nurses)

Paul also mentioned that his patients faced problems in reading the data produced by the FSL, and underlined the risk that the FSL makes people 'act too much' because 'the information is always available'.

There is an uncertainty in the curves, on the patients' side. On the one hand in relation to a lower precision compared to capillary measurements, and on the other on how to integrate the notion of trends and how to consider the curve preceding the value. ... So this can even introduce uncertainty when the patients' decisions are not the right ones. ... To benefit from the plus of this tool when compared with capillary measurements it is important to know the difference between a high value with an upward trend and a high value with a downward trend, because if not we lose the benefit, and it is here that the teaching is important. ... The difficulty of the curve is the complexity and amount of information, and this can cause problems for a few patients who prefer something simpler. But on our side, it is easier with the curves. ... One of the risks when the information is available, it is that we can also be tempted to act too much. ... We eat at 12 o'clock and at 1 pm we see a high value, we can be tempted to say 'well, the insulin has not worked, we will give it again'. We did not do that before because we did not necessarily check as it was a bother. (interview with Paul, diabetologist)

During the workshop on the FSL, Paul underlined the patients' tendency to measure the glucose concentration when usually they would not. Similarly, Gabriel, a diabetes nurse, warned patients not to act too quickly after a meal. He emphasized the importance of waiting for the insulin to work after the meal: 'Do not act too soon with insulin adjustments, because there are risks of hypoglycemia!'

While acknowledging the practical value of the FSL because of the higher frequency of glucose control it enables, Tania also suspected that it might lead patients to make overcorrections in both insulin injections and sugar consumption. At the summer camp, for example, she witnessed a discussion between two diabetic young women that we also observed.

Marie, who just checked her FG level, turned to Sandrine and showed her the value on the screen: She was hyperglycemic (over 19 mmol). To lower this, Marie, both irritated and amused, quickly injected a dose of insulin using her pen. About five minutes later, she rechecked her FG level: it had not dropped, it had even slightly increased to over 20. Irritated, Marie injected a second dose of insulin, without immediate results. About ten minutes later, her FG level had not yet dropped. Enraged, she decided to go to bed 'and then never mind!' (field note)

The tendency to check the glucose level more often with the risk of making corrections on unreliable values is part of Tania's reservations about the FSL.

During the workshop on the FSL, the nurses organized a few practical tests whose aim was to let the patients share their practices and thoughts, and indicate the most desirable action to undertake in a given situation. They presented a glucose value (e.g., 17 mmol) and the activity that a person was about to undertake (e.g., sport), and asked the patients (mainly adolescents) how they would act in such a situation. The patients' answers were very different.

A diabetic young boy in the room, Michael, declared that he would do sport, without worrying about his glucose level at 17. Another young boy, Philip, said he would take a small dose of insulin. A few parents pointed out that these situations are variable because these are very 'personal' so that it was difficult to answer. (field note)

Such observations led the practitioners to be more aware of the patients' singular experiential knowledge and to realize that the information provided was incomplete and vague. Hence, they added precisions on technical aspects (thus displaying their own expertise), stressed the need to consider the characteristics of each device and prompted the patients to trust their own subjective experience.

After Michael specified that more than 15 with the FSL means 'the patient has to check his/her glucose level with strip', a diabetes nurse said that the 'official recommendation' is to take a capillary BG measurement if, in such situations, the FG value is higher than 15. She added that if the arrow next to value 17 rises, the patient has to inject a small dose of insulin. At this point, Gabriel, another diabetes nurse, specified that depending on the

device, the reasoning might be different: if the person injects insulin with a pen, s/he would not inject insulin again because her/his injection of slow insulin in the morning is still working. However, if the person wears an insulin pump, it would be riskier to not inject insulin because, for example, the catheter may not be properly inserted. In the case of a pump, this nurse would recommend reinjecting a dose of insulin before going to the gym. Monica, the third diabetes nurse, highlighted that, in general, it is always better to rely on one's own feelings, experiences, and symptoms, rather than on the device. (field note)

More than one year after the introduction of the FSL on the market, a diabetologist and a diabetes nurse were invited to present e-technologies that monitor glucose concentration to other healthcare professionals. First, they stressed the importance of using clinical situations in order to determine the kind of advices that should be given to a patient in a given situation. Second, they presented the advantages and disadvantages of using these technologies both for their patients and for their practices and at the same time collected their experiences with patients. They then took the opportunity to underscore the role of the practitioner as a person who has to teach and support the patient in the use of these new technologies by shedding light on critical situations in order to foster clinical knowledge – considered here as a form of practical and experiential knowledge – on the implications of new data in clinical and patients' practices.

Attention and (self-)awareness

New information produced by the tool mobilizes 'attentional resources' (Citton, 2017; Kahneman, 1973). In other words, mental and conscious work is required to complete the tasks that the tool makes its users do in self-care, with the consequence that patients have to combine previous sensation-based information on their glucose level with new data provided by the device.

Thanks to an easier measurement of the glucose level and to the curve showing its fluctuations, a few patients became more aware of their condition, as Fabienne, a 24-year old young woman living with T1D for six years, stressed:

What we can observe with the FSL is that people become aware of their diabetes. What we could not see before, what we could not imagine, we see in front of us with the curve. It is what is great with the curve ... there is awareness at the level of what is going on in our organism. (interview with Fabienne)

Antoine, a 40-year old man living with T2D for five years, is also a doctor who developed an interest and expertise in diabetes digital technologies. According to him, this new type of devices help patients develop self-awareness, as well as to better understand the influence of the treatment, food, and physical activity on the glucose level. He also emphasized why this was not obvious with capillary BG monitoring.

When you prick your fingers, you get BG level at a specific time and then even if we do it four times a day it's only four values over a whole day, so

it's hard to really figure out how our glucose level was during the day but also at night. And then thanks to these tools [CGM and FGM systems] we really have a glycemic profile over twenty-four hours ... and then we can really realize what happens between measurements, between meals, and depending on whether we do a sport activity or not, if we take the treatment or not. We can really understand what is going on and then this is very important for the management because it allows doctors to adjust the treatment. And then for the patient it also makes it possible to understand what happens concretely. ... Whereas if we see on a graph that there is a peak a few minutes after drinking a Coke ... then I see the impact right away. (interview with Antoine)

Lucie, a 14-year old girl living with T1D for ten years, stressed the importance of her identifying hypoglycemic episodes that she might not feel, and knowing when she usually has them. She also underlined that the device enabled her to see if there are regular glycemic fluctuations and to check whether there were glycemic excursions outside the glucose range she set up. Her mother also underlined that the arrow indicated by the FSL (and also by another CGM that Lucie tried) reassured her because she could see the predictive trend of her daughter's glycemia. This additional information enabled her to know if she had to worry about possible hypoglycemic episodes during the night, and consequently whether she should wake up a few hours later to measure FG levels again.

Visualizing trends on the basis of frequent glucose level measurements provides a clearer understanding of the condition and the impact of each activity, food, and treatment. By literally providing an image of their glucose levels, this type of device reconfigures patients' perceptions and understandings of their illnesses, and thus also their actions. Put differently, this device stimulates self-awareness and the development of embodied actions. It enables patients to experience their bodies differently and provides new ways of representing glycemic fluctuations.

Good and bad curves: From self-objectifying to self-regulation

Measuring glucose concentration regularly enables patients not only to develop inner sensitivity but also to become aware of 'decompensated', 'unbalanced' diabetes or 'high' levels of glucose, and to better understand the impacts of what they eat and do. As a result, a few people reported that since wearing the FSL they could 'move again' or 'limit' themselves in their consumption of certain foods, as Delphine, a diabetes nurse, stressed. Sandrine, a 30-year old woman living with T1D for twenty years, started to wear the FSL on the advice of her diabetologist, who told her: 'Definitely, you should wear it, because for you it is the solution really', and because she knew she had a 'very unbalanced diabetes' at that time. Thanks to the tool, she realized that her glucose levels were too high during the night, and that this was so because she did not inject enough insulin during the day, information on which she could act.

Marie, a 23-year old woman with T1D for eight years, tried the FSL for a few weeks. She quickly became aware of the feature of the device that contributed most to improving her diabetes self-management: the visualization of the curve. Specifically, having a ‘nice stable curve’ led her to avoid snacking and to calculate more precisely the dose of short-acting insulin to inject.

For me it is really the visualization of the curve ... there is a psychological effect, it means that in general I have never limited myself for snacking and so on, if I’m hungry, I’m hungry, and then at worst I inject a small dose of insulin ... but it’s true that it is always a bit random With the FSL, if I see a curve that it is on the arrow going up, then I will feel less like eating because I say to myself ‘then it will continue on the arrow going up’ ... so we have a very strong psychological effect with the curve and then when we see that it is stable, there you are incredibly proud and it motivates you to always do well. (interview with Marie)

Marie’s statement echoes those of Antoine and Lucie. Indeed, Antoine highlighted that this device enables him to improve food consumption because of the visualization of his glucose levels. As regards Lucie, she reported that the opportunity to add a pre-fixed range within which the curve should stay helped her make more efforts to succeed in avoiding glycemc excursions.

As it provides 24-hour measurements, the FSL allows for easy adjustments of treatments, by either diabetologists or patients themselves. Remy, a 22-year old man living with T1D for eighteen years, who was wearing a pump, adapted his basal rate thanks to detailed observations of past events. This allowed him to limit hypo- or hyperglycemic episodes in specific situations.

It is much simpler to regulate the basal rate, instead of taking your capillary BG measurements, to print them, to compare your BG values with the doses of insulin you take and so on ... you have the curve under your eyes, you look ‘ah here I did that, it was not enough etc.’, so you can manage your diabetes much more easily. (interview with Remy)

Emile, a 22-year old man living with T1D for ten years and using pens to inject insulin, adapted his long-acting insulin rate after wearing the FSL and having observed the trends of his glucose level.

The second objective was anyway to have it just to see, uh, the curve and then uh typically have an idea of how my glucose level changes during the night because with capillaries you don’t know. ... The right dosage you can surely evaluate by looking at the curve of the night when there is no short-acting insulin action that can influence the result, then I saw that by increasing it, the long-acting insulin, I managed to keep a relatively stable curve. ... It was mainly me and then precisely during the last time I went to see her [his diabetologist], it was two or three weeks ago, and uh I told her that ‘well here I have increased my long-acting insulin’ and then well she looked at the curves of the FSL and she said: ‘Ah! It seems to me that this is in order’. ... And then since then I increased it again, a little bit, by

just a unit. ... But gradually ... with FSL we can play a little. (interview with Emile)

During the workshop on the FSL, the mother of a 9-year old boy reported that she attended all his basketball training sessions to help him manage his glycemia during physical activity. She was actually trying to improve her son's autonomy. Sport activities are difficult to manage, due to the risk of having hypoglycemic episodes during the activity and hyperglycemia after. She wondered if the predictive arrows could help her son to gain autonomy in the management of his regular physical activity.

As regards the information provided by the predictive arrows, Fabienne and Emile insisted that caution was required before acting. Fabienne had a few reservations about the use of all the features of the device.

I find, uh, kinetics compared to FSL, uh, I always use it sparingly. I always analyze parsimoniously because all of a sudden you have the arrow going down suddenly, you say 'but my God but I'm going into hypoglycemia!' when indeed it's not necessarily the case, because insulin is finishing its duration of action. So, it depends on a lot of things. (interview with Fabienne)

As they did not fully trust the arrow, Emile and Fabienne learned to interpret, in relation to specific moments of the day, its direction as data.

By 'playing a little' and experimenting this new technology in their daily lives, Emile, as well as other persons living with diabetes, developed 'tactical decisions about self-care that involve tinkering and puzzling together' (Kingod, 2018: 3) various kinds of knowledge and know-how to maneuver the new tool and integrate it in their daily diabetes self-care.

Temporal adjustments

As Mathieu-Fritz and Guillot (2017) show, the reflexive work of patients living with diabetes is strongly related to a series of concurrent efforts and activities, in particular through the use of a 'quantification system' enabling patients to produce self-knowledge and knowledge on the disease embedded in past experiences. The objective is then to discern patterns to predict and anticipate situations and to inform actions to be taken. They differentiate two registers in this reflexive work: an 'a posteriori' reflexivity that takes a step back on past experiences and events, and the 'in situ' mobilization learnt through the experience of previous situations. According to these authors, it is mainly the second register that is transformed through the use of 'new reflexive technology', which transforms the temporality of the production and processing of information. In our study, we observed that this new reflexive technology transforms the temporality experienced by patients in self-managing their chronic condition because it enables them to view the ongoing activity and to predict the evolution of their health state from recurrent patterns in the fluctuations of the glucose level.

Emile, for example, reported difficulties in measuring the capillary BG level and in his ability to interpret his bodily sensations in specific situations. To avoid a risk of hypoglycemic episodes when he had no opportunity to measure his BG level, Emile always took sugar. It was only when he wore the FSL and could measure his FG levels in many situations that he discovered that sometimes he was not hypoglycemic but had similar sensations for other reasons. He could then avoid ‘unnecessary’ sugar, while at the same time comparing his subjective experience with the objective experience and integrating the latter into the former through a reinterpretation of bodily information and sensations to develop experiential knowledge.

Other examples are taken from Rachel’s and Marie’s experiences during their work or sport activities. Before each work meeting, Rachel systematically ate sweet food in order to avoid hypoglycemic episodes. Since she wears a CGM system, she no longer has to anticipate hypoglycemia by eating sugar. When we met her, she was waiting for the FSL.

When I don’t have it [the CGM system], I’m always asking myself ‘how high is it?’ and then when I have a meeting or an appointment I eat something before because I’m scared to have hypoglycemia but when I have it, I know it’s fine and I leave my food in the bag, but otherwise I eat it because I’m scared, it gives a security even if it’s not always very precise. (interview with Rachel)

Marie always voluntarily ensured that she had hyperglycemia before starting work or sport activities. She stressed that this new self-monitoring system was very important to limit this practice because she knew it was not good in the long run but at the same time, it was the only way to live a normal life.

I do a lot of sports and so I always have to get into ... really high glucose levels for sports and that’s a big problem for me, it’s that ... I have to get up to, depending on what I’m going to do, I have to get up to 18-19 mmol, so I don’t end up hypo after my workout and that’s a problem. (interview with Marie)

Although she thought she ‘cannot do anything about’ the unpredictability of her glucose levels during and after sport activities, she expected the device to enable her to collect data during physical activities over the long run and to provide further analyses likely to help her in her future physical training.

Fabienne described the type of analysis she was doing with the data produced by the FSL.

And then you can also download the data on a computer program and there you really have even more elaborate, even more precise graphics. And in terms of management, we’re ... we can be more efficient because we really know when we should take a little more insulin, for example, I noticed that it was in the early afternoon when I had to ... be a little more careful because I tended to be hyperglycemic for example. (interview with Fabienne)

By considering trends and recurrent patterns during the day, she could adapt her treatment, food consumptions, and physical activity. All these elements with the observation of past situations and experiences help Fabienne anticipate the near future.

The opportunity offered by this tool to treat past and present data, as well as the availability of trends inviting patients to predict the near future reconfigure the temporality of illness experience into a regime which is less based on the present. This transformation of the temporality reconfigures both diabetes self-management and the teaching provided by healthcare professionals.

Pushing self-improvement

Didactic tool

In Antoine's opinion, the FSL provides useful data to help people change their eating habits: 'We struggle in changing eating habits, uh ... it's a very good tool, very practical and then again also very pedagogic to learn to eat, to realize that we overflowed.' According to healthcare professionals, this tool is interesting to teach patients to self-manage their disease and also to teach other practitioners 'what diabetes is'. For example, Edgar, a diabetologist, emphasized that the information collected through this tool is crucial not only for the patients, but also for practitioners who have to learn 'managing the fuzzy logic' surrounding diabetes management.

I: And here they just noted that they ate, that they took insulin, but they didn't actually put the amounts, did they?

E: [t]hat was what I was asking the lady I showed you before [the graph of her glucose curves], there I said: 'I'd like to use that didactically. I wish I could use this to show the assistants what diabetes is.' ... So what I asked Mrs B. there, the pregnant woman, I said: 'You can write down for me how much insulin you take and when you do it. Because I'd like to use that as a teaching tool, not only for patients.' (interview with Edgar, diabetologist)

Denise, another diabetologist, reported her interest for the 'clear framework', which is offered by this tool and enables her to operate as a doctor who can help her patients to gain a better understanding of their glucose levels and to act by themselves.

For the patient, it is a clear framework. When we display it on the computer, he comes here, we sit, we watch together: Have there been upward or downward peaks? Just? A bit? Should we adjust something or should we look at the details of the day he had chemotherapy? Is it the day he vomited all his breakfast? (interview with Denise, diabetologist)

During the workshop on the FSL, Paul underlined that this device has a 'reassuring' and a didactic component, in particular thanks to the arrow displayed with the glycemic value, which, if stable, can reassure and enable a 'finer' diabetes management. He also reported how these features changed and improved his clinical practice, specifically his ability to give advice to patients and help them with self-care.

Well, the emergence of the curves in our daily practice has completely changed the way we follow the patients because we have much more information. Especially with the patients who arrive with very few values, we can really be helpful in consultation by showing them concrete examples. It does not necessarily mean changing the insulin doses but it enables to start the discussion on the topic. ... To see, to adapt insulin doses, to see changes between normal days, the weekend, a sports day or other stuff, and then these are ways to discuss particular things with patients. The reproducibility. (interview with Paul, diabetologist)

Improving as a moral duty

Healthcare professionals pointed out that easier access to the glucose levels and the curves afforded by this technology also help them to better care for their patients. After spending one week with young people wearing the FSL at the summer camp, Tania shared her thoughts on the advantages of this new tool.

The fact that the patients can also see what happened since the last time they measured their glucose level, I think it is ... here [at the summer camp], the first morning we saw what happened during the night ... for me it was like 'Ah! But it's so cool!' It is like lifting the blanket that we couldn't lift until then, of 'what happened at night?' ... For me it was really 'Oh! Finally we know what happened during the damn night!' when there are no measurements of the glucose level for twelve hours and it's a mystery, and we know very well that what happens at night influences what happens during the day. (interview with Tania, diabetologist)

To better care for their patients, physicians eagerly search for data. 'Technophile' diabetologists (as a few of them called themselves) push their patients to wear self-tracking devices and to share their data. The same happens for parents who wish to follow their child's glucose levels at a distance and/or to have the highest number of values for the periods their child spent without them. Thus, these data are expected to help patients and/or relatives but also practitioners who can better understand the diabetes and the factors that, in the life of a specific patient, influence it, to adapt the treatment and provide useful advice.

Nonetheless, a few patients emphasized their difficulties in accepting that wearing this new technology does not solve certain problems and noted that it is not always possible to understand why all their efforts do not lead to an improvement in the HbA1c. Leo, an 8-year old boy living with diabetes for three years, tried the device twice. His mother, Agathe, described the first try as very positive but reported that on the second time she was disappointed.

It was interesting [the first time] and then I felt that I had an improvement in glucose levels, always with the objective of lowering the glycated hemoglobin under 8 as we had failed to do so until then. Dr. B. told me there must be peaks during the night, and we would be able to observe it

and everything. And then the first time I felt it was helping a lot, the second time less. (interview with Agathe)

By using this device with her son, Agathe tried to understand why he had a high HbA1c and wanted to improve the situation. She also expected the physician to find a solution thanks to these new data, and wished to bring him the proof that if the glucose level of her son increased during the night it was not because she did not do enough during the day. As the person primarily responsible for her son's diabetes, she positioned herself as if it were her own disease. 'I did not have bad glucose levels but when we do not manage to go below 8 after three years, we are a little upset, I took it badly!' She felt responsible for not having been able to improve her son's condition, as if this value was as a 'grade' evaluating her performance. Knowing that the explanation of the bad HbA1c of her son could be related to night values would have reassured her, and thus would have helped her feel less guilty and stop 'self-moralizing' (Mol, 2000).

Lucie said, 'the goal is always to improve'. Improvement has different facets, such as better management of physical activities and food intakes, increased autonomy in the self-management of diabetes pillars, and concrete improvements in the HbA1c and/or more stable curves. Of course, some patients felt that in using the device they did not learn more than they already knew through their previous subjective experience and experiential knowledge, or they thought the device was not precise enough to produce reliable data and to enable improve their own analyses which, in their opinion, would be necessary to improve diabetes self-care.

Conclusions

In this article, we have highlighted that engaging with a new technology in diabetes self-care cannot be reduced to a simple gesture, contrary to the suggestion of FSL's manufacturer's advertisement. Its use is a serious matter at two different levels: first, at the level of its incorporation into an ecology of care that is already infrastructured and affords or impairs locally grounded self-care acts (Danholt and Langstrup, 2012); second, at the level of the co-construction of new realities triggered by the intertwinement between the material and the social, opening up reciprocal transformations and new assemblages (Timmermans and Berg, 2003). The 'scanning' of glucose levels at any moment of the day and night and in any situations characterizes the use of the FSL. Moreover, the FSL not only requires new actions for glucose self-monitoring but also brings new and further information on and for the daily situations of people living with diabetes and for care practices of their caregivers. Beyond the technical characteristics of this new tool, our observations showed that multiple actors (including other devices), places, practices, and knowledge participate in the self-care work of patients and their relatives. Hence, what we observe is a distributed work in which the device is only but one actor.

This study provided insights on the development of knowledge-in-practice among patients, relatives and practitioners, and the 'invisible work' (Corbin and Strauss, 1988) required to articulate a new technology in the distributed self-care work and to

accommodate it in their daily and work life. Knowledge-in-practice results from the necessary relational, pragmatic and creative maneuvering of technology-in-practice (Nielsen and Langstrup, 2018), the doing and the tinkering, which characterize the inventive and explorative ways of practicing new technologies in daily diabetes self-care, such as the glucose monitoring activity (Danholt, 2013; Kingod, 2018; Mol and Law, 2004). Moreover, the social and pragmatic 'tinkering reflects a creative practice' (Kingod, 2018: 13) not only in the patients' and relatives' daily life, but also in the daily activities of practitioners who also 'translate biomedical research into something of practical utility' (Kingod, 2018: 2) for their clinical practices.

More specifically, this article suggests that the introduction and use of a new technology may be thought of in terms of the 'adjustment' (Winance, 2000, 2003) and 'attachment' (Hennion, 2004; Latour, 1999) required to fit a new technology in pre-existing infrastructure of care. Indeed, various crucial adjustments between users, their bodies and technology are required to make the latter fit in and match with users' individual physical needs, experiential and bodily knowledge, daily situations, pre-existing 'embodied actions' (Mol and Law, 2004), as well as with pre-existing teaching and learning settings and processes. These adjustments concern both the patients and the professionals and they range from the equipment on the body to the interpretation of the new data through multiple interactions with actors, situations, places, activities, kinds of knowledge and temporalities. The patients develop self-awareness of their disease and its self-management through new attentional resources provided by the tool and by engagement. Through self-objectifying, sensing and reflexive work, the patients put this new knowledge into practice by means of self-regulation acts. It is, however, worth mentioning that adjustments were not always observed, since a few people, the 'non-users' (Weiner and Will, 2016), decided not to wear or to stop wearing the FSL, and did so for different reasons: because it reveals the disease, does not fit the body, is not precise enough, enables surveillance (Danesi et al., 2018) and so on. For the practitioners, this reflexive technology is a resource for healthcare professionals who took the opportunity to use it not only to better understand the disease, their patients and the specific daily situations with which they cope, but also as a didactical tool for patients, relatives, and other practitioners. The incorporation of the tool is thus the result of the process of adjustment, material and emotional, as a collective work in which the technology and the person adapt to each other and the device integrates the physical and social environment of the patient. Moreover, it is this experimental approach that enables the attachment to a new device and the traces it produces, to the own sensations of patients and more broadly, to their knowledge on themselves and their disease.

The FSL articulates and condenses the aspects of a self-sensory prosthesis and the traditional glucose measurement system. Indeed 'these new digital tracking products and apps promise to help fill in the blind spots ... by supplementing the myopic vantage of real-time experience with a continuous, informatic mode of perception' (Schüll, 2016: 325). It produces a new 'visual evidence-based' approach to glucose (self-) monitoring that induces new forms of 'living' (Wahlberg, 2009) and ways of work for its users, a new knowledge based on 'time-series data rather than immediate experience; correlation rather than causation; patterns rather than events' (Schüll, 2016: 325). More specifically, it blurs the boundaries between expert caregivers and lay patient users by individualizing,

more than in the past, the pragmatic and sensory-based management of the disease. In other words, the introduction and use of the FSL, as of other digital self-tracking technologies, opened up new ways of feeling, thinking, learning, teaching and acting. It is not only that models of human behavior shape technologies but also that technologies shape new modes of living (Schüll, 2016: 321). As Ruckenstein (2014) emphasizes, ‘visibility links personal analytics to modern notions of control and governmentality ... (and) by making unknown aspects of bodies and lives detectable, we can gain more control over life processes and entities’ (p. 4). When patients are ‘pushed’ to self-tracking but also when they deliberately choose to engage in ‘personal’ and/or ‘communal’ self-tracking in response to the promise of health improvement or to shift from one self-tracking mode to another (Lupton, 2014), a ‘pushed self-improvement’ emerges as a normative and moral injunction to have better values and well-balanced diabetes, even for the simple visualization of an arrow or a curve that should be ‘nice’, ‘good’, ‘stable’ and so on. Behind the extension and diversification of responsibilities (Kerr et al., 2019) and the prescribed and fostered enhancement of patients’ responsibility to act in the light of the information that are made available to them in order to take care of themselves, self-optimization and self-improvement become a moral duty and the different actors involved have to deal with it (Ruckenstein, 2014).

We can raise a few questions about equipped, engaged and empowered patients who decided or agreed to wear, use and trust this device and also to share the data it produces and to engage with them. Should we say that these patients became more autonomous? Or, in view of the multiple users, actors, technologies, situations, activities and temporalities involved by the use of this new technology, should we rather emphasize their heteronomy? We hope to have shown that such a problematization amounts to neglecting the context in which this new technology is used and the various reconfigurations to which it gives way. If, as its advertisement says, the FSL represents a ‘revolution’ in the way of monitoring the glucose level, this revolution is not to be found in the device itself but in techno-social reconfigurations leading to new assemblages that incorporate existing practices and modify existing ones. In this view, improving self-care management depend not only on a person’s ability to act on their own health, but more broadly on the possibilities for practitioners, persons living with diabetes and their relatives to ‘shape their engagement’ (Nielsen and Langstrup, 2018) and to reconfigure their practices, various types of knowledge, uses of previous devices, etc. It is therefore a situated, collective and invisible work, which cannot be grasped by standardized health protocols and policies.

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Notes

1. The glycated hemoglobin is a test of the average BG level over approximately 90 days.
2. There are different brands and models of CGM systems on the market today, each of them having his own specificities: iPro®, Guardian and Guardian Connect®, Dexcom G4, G5, G6®, and so on.
3. Interstitial glucose values are delayed by about 10-15 minutes when compared to capillary BG values.
4. The target BG levels for the majority of adults with diabetes are the following: between 4.0 and 7.0 mmol/L on an empty stomach or before a meal (fasting glucose); between 5.0 and 10.0 mmol/L 2 hours after mealtime (post-meal or postprandial glucose); hypoglycemia <4.0 mmol/L; hyperglycemia >8.0 mmol/L.

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