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Learning to manage diabetes using a flash glucose monitoring device at a summer camp: A collective appropriation process

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ABSTRACT

Self-management of type 1 diabetes (T1D) is a difficult task that involves different actions and decisions and requires various types of knowledge. Nowadays, it can be done partly autonomously, using a mobile digital device that measures the level of blood glucose. The FreeStyle Libre, launched on the Swiss market in 2016, is one such device.

Drawing on Science and Technology Studies and adopting a sociocultural approach to learning, the present study investigated how healthcare professionals and young people living with T1D learned to use this new device during a summer camp. Based on field observations and interviews, results showed that through the mediation of others, an appropriation space was created. Through distributed expertise involving different actors, practices and types of knowledge, the users learned technical and procedural knowledge, and much more besides. In particular, they learned to cope with uncertainty, sidestep obstacles, and trust the device, gaining knowledge about diabetes itself in the process and grasping the potential contribution of the new data provided by this device to therapeutic decisions.

By drawing on an explicit theory of learning that considers learning to be a context-bound activity, the present study will inspire the development of new practices in health education.

1. Introduction

A chronic disease whose prevalence worldwide nearly quadrupled between 1980 and 2014 (de Mestral, Stringhini, Guessous, & Jornayvaz, 2020), diabetes has become a major public health issue in many countries. Characterised by a too high level of glucose in the blood, it takes two main forms: in type 1 diabetes (T1D), an autoimmune disease that occurs mostly in childhood, the pancreas does not produce the insulin required to absorb glucose; in type 2 diabetes, that occurs mostly in adults, the pancreas still produces insulin, but not enough. If not managed adequately, diabetes can result in various diseases, such as cardiovascular, renal, neurological and ocular complications. In Switzerland, the proportion of the population who declared that they have been diagnosed with diabetes varies from 2.1 to 8.6% (Fürst & Probst-Hensch, 2020). Hence, health education should be an absolute priority at different levels: public health policies, diabetes and endocrinology departments in hospitals, diabetologists in private practice, diabetes charities, and schools. Initiatives have been implemented at all these levels, both to prevent diabetes by promoting healthier lifestyles, and to foster

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self-management of diabetes in order to help those living with this disease to gain autonomy.

Managing diabetes involves maintaining a stable blood glucose level and avoiding episodes of hypo- or hyperglycemia and their possible consequences (e.g., fainting or being hospitalised). Persons living with T1D need to monitor their glucose level, calculate the amount of sugar they can eat, by considering the activities they will be carrying out within the next few hours or those they have already carried out, and determine the quantity of slow or quick insulin they have to inject. Insulin is therefore central to the treatment of T1D. Its effect began to be better understood in the '70s, and a decade later, several different types of insulin were launched on the market, leading to a gradual improvement in treatment (dos Santos Mamed, 2020). Since the early '80s, persons living with T1D have been partly able to manage their disease themselves, using various devices that measure the level of blood glucose (e.g., mobile digital self-monitoring devices and apps enabling self-tracking). These devices have allowed them to become increasingly autonomous (Danesi, Pralong, & Pidoux, 2018). One such device is the FreeStyle Libre (FSL) which, at the time of the present study, had only just arrived on the Swiss market. As some diabetes departments were planning to test it, we added the present study to a larger research project on diabetes management. We observed FSL use by young people living with T1D who were attending a summer camp, in order to find out how these young people, the camp counsellors living with T1D and the healthcare practitioners (HCPs) who supervised the camp learned to use this new device, how they dealt with possible obstacles, and how they came up with relevant solutions.

After describing the features of the FSL, we briefly introduce a theoretical framework inspired by sociocultural psychology and Science and Technology Studies (STS). After having reported the methods used to collect and analyse the data, we report and discuss the results.

2. Self-management of diabetes using the FreeStyle Libre

Self-management of T1D is a difficult task that involves different actions and decisions, and requires various types of knowledge. *Knowledge about T1D* is complex, owing to the nature of the relationships between insulin, nutrition, physical activity on the one hand and hypo- or hyperglycaemia on the other hand. Understanding these relationships in turn requires *knowledge about nutrition* and *knowledge about the specificity of one's own T1D*. As there are considerable interpersonal variations, it is important for each person to be able to identify his or her particular bodily sensations associated with a hypo- or hyperglycaemia episode. *Technical and procedural knowledge* is also needed to use technical equipment, which ranges from low-tech printed monitoring tools to digital management systems used for telemedicine. Because of the complexity and variety of all these types of knowledge and techniques, the management of T1D calls for the active participation of persons living with T1D, and relies on close collaboration between patients, HCPs and, notably in the case of children, relatives or caregivers (Danesi, Pralong, Panese, & Burnand, 2021; Danesi, Pralong, Panese, Burnand, & Grossen, 2020).

Continuous glucose monitoring (CGM) devices developed in the 2000s have brought about a major change in the management of T1D. They allow access to the glucose level at any time, and the glucose concentration is measured in the interstitial fluid (i.e., fluid surrounding cells), instead of directly in the capillary vascular system, thus avoiding finger pricks, which can be painful and require more time and equipment. The FSL, a flash¹ glucose monitoring system (FGM) designed by Abbott Diabetes Care, was launched on the Swiss market in 2016. It comprises a wearable biosensor patch, software, and a reader with a logbook function (Illustration 1).

Using the FSL requires (1) *Applying a biosensor patch*. This patch, which the manufacturer recommends wearing on the back of the upper arm, contains a sensor (i.e., thin flexible fibre inserted approximately five millimetres under the skin); (2) *Handling a reader*. The sensor is linked to a transmitter that sends the data to a receiver (smartphone via an app or a reader supplied by the manufacturer) via a Bluetooth connection; (3) *Reading curves and arrows*. When the sensor is scanned, the reader displays the current glucose level, in the form of a curve showing the glucose profile over the previous eight hours, with an arrow indicating the predictive glucose trend. The data can be downloaded to the software; (4) *Recording data in the digital logbook* (i.e., date, carbohydrates, units of insulin per meal). Using the digital logbook is not compulsory, but enhances the follow-up of a person living with T1D.

The FSL has many ergonomic advantages: For a start, the sensor is small and in principle painless, it can be scanned easily and discretely, through clothing. Moreover, the graphic design of the curves is attractive, there are no hypo- or hyperglycemia alarms,² and the sensor has a 14-day lifetime, in contrast to other CGM sensors that have to be replaced every 7-10 days (Heinemann & Freckmann, 2015). Taken together, these features have won over increasing numbers of persons (over one million in the world) to use it.

Several studies involving the FSL have been carried out. Some have focused on the medical aspects, showing the positive outcomes of wearing CGM or FGM systems (Battelino et al., 2011; Lal & Maahs, 2017). They have also demonstrated the accuracy of FSL in adults and paediatric patients, and provided recommendations on the exact times at which flash glucose measurements should be checked, together with blood glucose measurements (Bailey, Bode, Christiansen, Klaff, & Alva, 2015; Hansen et al., 2018). Other studies have focused on FSL use, showing that its characteristics (e.g., no daily calibration, no alerts) enable users to overcome some of the barriers inherent to the use of other CGM systems (Pearson & Ajjan, 2017; Rodbard, 2016). Multiple obstacles to the effective use and success of CGM and FGM systems have also been reported, such as psychosocial factors modulating their uptake, effectiveness, clinical outcomes, and quality of life (Kubiak, Mann, Barnard, & Heinemann, 2016; Lal & Maahs, 2017; Rodbard, 2016), as well as difficulties in their clinical implementation (e.g., discomfort, interface usability and issues, negative feelings when expectations are not met, lack of recommendations for the optimum use of this technology) (Kubiak et al., 2016; Lawton et al., 2018; Rodbard, 2016).

These now numerous studies provide a large overview of the advantages and obstacles that may be encountered in the use of the

¹ The term *flash* refers to the fact that the user has simply to scan the patch to obtain the values.

² Since the launch of the FSL in 2016, a new version of this FGM has been developed to enable users to program alarms.



Illustration 1. FreeStyle Libre biosensor patch and reader (https://jdrf.org.uk/wp-content/uploads/2017/10/MG_JDRF_Products_34-1.jpg).

FSL. However, they do not account for the processes through which persons living with T1D actually learn to use this device, what concrete difficulties they face, and what solutions they develop to overcome them. Instead, they provide a general and decontextualised picture of these uses, thus failing to identify actual practices that are relevant in their context of use, but which may differ from the designers' expectations. They also tend to neglect the collaborative work required from persons living with T1D, their relatives, HCPs and, in the case of children, school representatives (teachers, youth workers, school nurses, etc.) (Pralong, *in progress*).

To understand how people learn to use the FSL, we need to draw on a theoretical framework that (a) focuses on actual and context-bound practices; (b) considers the context in which learning occurs, including all the persons involved in the management of T1D with their different types of experience and expertise; (c) takes into account the constraints and opportunities offered by the technological features of the device, and (d) adopts a comprehensive outlook to capture the relations between specific users, the device's technological features, and other people (in particular, relatives, HCPs, and other users).

3. A transdisciplinary framework

For the purpose of the present study, we drew on a transdisciplinary theoretical framework that brings together aspects of both sociocultural psychology and STS, thus yielding particularly fruitful results.

Research in the field of sociocultural psychology has mainly focused on the *sociocognitive processes of knowledge co-construction* in various situations, more specifically at school (e.g., Mercer, Wegerif, & Major, 2019) and in the workplace (e.g., Kloetzer, Clot, & Quillerou-Grivot, 2015; Ludvigsen, Lund, Rasmussen, & Säljö, 2010; Mäkitalo, 2012; Ros & Grossen, 2020). To put it briefly, it has generated four major results that are relevant to our present study. First, in everyday situations, adult guidance and peer interactions play a central role in learning and development (e.g., Arcidiacono, 2013; Rogoff, 2003). Studies carried out in school have focused both on situations in which teachers are in an expert position and on situations in which teachers and students collaborate to solve an open-ended problem (e.g., Kumpulainen, Kajamaa, & Rajala, 2019; Tooth & Renshaw, 2012). By so doing, they have shown that learning is favoured by the quality of the interactions and talk (e.g., Mercer et al., 2019; Muller Mirza & Perret-Clermont, 2009). Second, a given learning situation may be interpreted differently by different participants (typically in classroom interactions), leading to *sociocognitive misunderstandings* (Bonnéry, 2015). Third, learning cannot be reduced to information processing, and requires the construction of an “appropriation space” (Grossen, Zittoun, & Ros, 2012) or a “thinking space” (Perret-Clermont, 2015), that is, a teaching-learning setting that creates the conditions for thinking and in which learners can lend a personal meaning (Zittoun & Glaveanu, 2018) to the knowledge or skill to be learned. Fourth and last, assuming that human activity is mediated by tools and signs that work as *psychological instruments* (Vygotsky, 1934/2012), research in this field has paid particular attention to the systems of signs and tools that people use to regulate their own thinking and activity. This implies considering human development and societal change as being closely interwoven or, as Säljö put it, capturing the “interactive and dynamic co-evolution of societal practices and people's adaptations and engagements in these” (Säljö, 2020, p. 5). According to Säljö, the mind “is neither a closed universe of cognitive processes, nor a stand-alone device” (p. 5). Rather, it is a “hybrid mind”, in that the material and symbolic artefacts provided by an ever-changing environment are inherent to the development of human cognitive capacity. As a consequence, “our mind and capacities for thinking co-evolve with societal, intellectual and technological developments” (p. 5). Hence, studying the human mind implies adopting a unit of analysis (Damsa & Jornet, 2020) that considers both the person, his or her activities in concrete contexts, and the various technical and symbolic artefacts that he or she uses. According to this view, a person is always engaged in present or distant dialogues with others (Grossen & Muller Mirza, 2020).

Like sociocultural psychology, STS emphasises the importance of technical artefacts in human thinking and activities. In this field, Actor-Network Theory (ANT) has been very influential, showing that objects and technological artefacts are “deliberately designed to both replace human action and constrain and shape the actions of other humans” (Latour, 1992, p. 151). They are “non-human actors because they contribute to and are fully part of our transformative activities and their related meaning-making. As such, nonhuman agency can be decoupled from traditional human intentionality and subjectivity, insofar as it concretely orients and frames human actions and situations (Latour, 2007). As technological devices are used in a complex network made up of human and nonhuman

actors, and are part of practices developed within certain communities or groups, using them is not about learning technical skills, but about making sense of them and adapting their use to specific situations. Put differently, they are “technology-in-practice” (Timmermans & Berg, 2003). Users integrate certain bodies of knowledge and adapt them to specific contexts, goals and practices (e.g., Akrich, Callon, & Latour, 2006; Callon, 1986; Chiapperino, Graber, & Panese, 2021). They also interpret technologies and incorporate them into their everyday lives in multiple and creative ways (Oudshoorn & Pinch, 2003). Therefore, using any technology entails a process of “translation” (Callon, 1984), that is, an adaptation of its use to a specific context, or even a transformation of its intended use. *Translation* is a dynamic process involving multiple interactions between human and nonhuman actors who strive to construct local and shared definitions and meanings of technological devices. As a result, the *actual* use of a technological device can never be fully predicted. At stake here is the link between the material and semiotic dimensions of devices, as well as the understanding of the relations between things and humans, tools and concepts, practices and meanings.

Within this field, several studies have concerned self-care management devices and, more generally, medical technology. These have shown that, compared with other technological devices, self-care management devices have five features of particular importance. First, like other devices, they follow sociotechnical rationalities that may differ from the designers’ original intentions and thus prompt the latter to make changes or adaptations (Oudshoorn & Pinch, 2003). In this light, the use of a self-care management device can be viewed as a *co-construction* emerging from both the designers’ and the users’ practices. They result from a “relational – often creative – maneuvering of users and technologies in practice” (Nielsen & Langstrup, 2018, p. 264) and go together with technosocial reconfigurations (Akrich, 1997). Second, self-tracking devices, such as the FSL, position users as “digitally engaged patients” (Lupton, 2013; see also Danholt, Piras, Storni, & Zanetti, 2013, Oudshoorn, 2011), giving them an opportunity not only to access and use information, but also to produce and share it (Lupton, 2013). Third, as self-tracking devices, they aim to regulate the person’s behaviour towards his or her own body (Piras & Miele, 2017). These devices require users to make sense of these bodily sensations and create “embodied action” (Mol & Law, 2004). Fourth, they deal with *medical knowledge* (i.e., scientific type of knowledge that gives rise to scientific vulgarisation and meets everyday knowledge). Hence, medical knowledge consists of dynamic and polysemous content that is liable to be understood and interpreted differently by the various actors involved (Mol, 2008). Constructed within local situations and practices (Nielsen & Langstrup, 2018), knowledge can thus be termed “knowledge-in-practice” (Mol & Law, 2004) or “practical knowing in action” (Pols, 2014). Fifth, as self-tracking devices dealing with chronic diseases that require the collaboration of many HCPs and of other people in the person’s entourage (relatives, friends, teachers, etc.), they can be seen as “boundary objects”, that is, “objects, which not only inhabit several intersecting social worlds, but also satisfy the informational requirements of each of them” (Star & Griesemer, 1989, p. 393). Also present in sociocultural psychology (e.g., Akkerman & Bakker, 2011; Edwards, 2011; Ramsten & Säljö, 2012), this notion accounts for the observation that collaboration between actors with different types of expertise, practices and goals, can coexist despite differences and tensions between their own specific interpretations of a shared project or object. Hence, we can assume that self-tracking devices act as boundary objects in the collaboration between various “communities of practice” (i.e., formal or informal groups engaged in shared practices) (Wenger, 1998).

In brief, this transdisciplinary framework suggests that T1D self-management should be regarded as part of a complex network that relies on a triple mediation: self-tracking devices as nonhuman actors, the body of the person living with T1D and its specific sensations, and the social network in which the persons compare their experience, practices and knowledge. We can thus hypothesise that this complex network is a potential appropriation space where persons living with T1D, HCPs, and other persons concerned can learn from each other, leading to technosocial reconfigurations.

4. Presentation of the study

The study took place in the French-speaking part of Switzerland just after the canton of Vaud had launched a prevention programme aimed at fostering (self-)care management and reducing acute medical situations (Courvoisier, Bize, Dubois-Arber, & Peytremann-Bridevaux, 2015). It was carried out within a larger research project concerning the production and use of self-management tools in diabetes (I-Knot project), but was not initially intended to be part of it. The launch of the FSL on the Swiss market a few months after the start of our project, and the organisation in 2016 of a summer camp where children and adolescents living with T1D could try this device, prompted us to seize this opportunity and observe how persons living with T1D and HCPs learned to use this new self-tracking device.

To obtain permission to carry out the study, the first two authors (GD and MP) presented the study’s aim and methodology to the board of the foundation that was organising the camp. After receiving permission, they met some of the staff members of the camp, who also gave their permission. The study itself was conducted after ethics committee approval.

4.1. The summer camp

The summer camp was intended to offer children and young people living with T1D a safe, outdoor holiday, a space for talking about living with T1D with the support of a professional team, and education to improve their autonomy, as well as give their parents some respite. It took place in a village in a French-speaking canton.

A multidisciplinary team composed of paediatric diabetologists, nurses and dieticians was responsible for diabetes management. Daily activities were carried out and/or supervised by camp counsellors who were, so to speak, peers, as many of them lived with T1D and had also participated in the same camp when they were younger. Many of the participants had already heard of the FSL, but only four had already used it: one young boy who had recently been diagnosed, two HCPs, and one counsellor.

The daily organisation of the camp followed a routine that alternated T1D workshops, leisure activities, and up to five daily meals.

At each meal, the children and young people visited five stands with their personal paper-based weekly logbook. At the first stand, manned by dieticians, they calculated the amount of carbohydrates (CH) they would eat; at the second, manned by nurses, they measured their blood and flash glucose levels; at the third, manned by diabetologists, the quantity of insulin to inject was jointly decided; at the fourth, they again scanned the flash glucose level and entered the amount of CH they would eat and the insulin for the meal in their logbook; and at the fifth, other nurses assisted in insulin administration, if needed. At each stand, several HCPs wrote down information in the weekly logbook (amount of CH, blood and flash glucose levels, and insulin doses). There was also a permanent stand manned by several nurses where the participants could measure their glucose level at any time of the day and take CH or add insulin, according to the standard procedure set out in a plan for hypo- and hyperglycaemia episodes (Hansen et al., 2018). An infirmary where the nurses could change equipment (e.g., sensors, catheters), provide insulin refills, and deliver personalised care if necessary, was also provided.

The camp lasted two weeks. The first week was reserved for children aged 6-12 years, and the second for young people aged 12-17 years. The present study covered only the second week.

4.2. Research questions

In line with our theoretical framework, we examined how the persons living with T1D and the HCPs learned to use the FSL, how they made sense of its use and of the various types of knowledge required to use it, the obstacles they faced in their actual use, and the opportunities for learning that emerged from these obstacles.

4.3. Participants

4.3.1. Summer camp (week 2)

The HCP staff ($N = 15$) included five doctors (including three medical students), seven nurses (including four student nurses), and three dieticians. Many of the HCPs belonged to teams attached to two hospital diabetes units. Two of them lived with T1D.

The camp counsellors ($N = 13$) were, as already mentioned, mostly former camp participants. Four of them were not living with T1D and participated because they were a counsellor's friend. Each counsellor was the referent of three or four young people. Many of them had no experience of any type of CGM devices.

The young people (aged 12-17 years) were 17 girls and 15 boys. One of the girls decided not to participate in the study, and one boy did not participate because he was already equipped with another CGM device. Some of these young people were the patients of HCPs participating in the camp.

The researchers' participation was not limited to collecting data, but also included informal interactions with the participants, and they gave a helping hand when required.

The participants were fully informed of the aim of the study and signed a consent form. Hereafter, the term participants refers to all those who attended the camp, including those who did not live with T1D.

4.4. Data and method

The data were collected in four different settings: (1) in a meeting held two months before the camp between foundation board members, HCP staff, and counsellors; (2) during the second week of the camp attended by young people living with T1D; (3) in a training session for children and young people living with T1D and their relatives that took place one month after the camp, at one of the paediatric diabetes and endocrinology units involved in the camp. It was organised by four diabetes nurses and two diabetologists. One diabetologist and one nurse had participated in the summer camp for children (week 1). It was attended by about twenty persons (children and young people living with T1D and their relatives). (4) in interviews conducted after the camp (post-camp interviews) with HCPs and camp counsellors who could not be interviewed during the camp owing to a lack of time, as well as with HCPs who had taken part in the camp with children (week 1). These were included because they had extensive experience of the camp and were more acquainted with the FSL. An adolescent who had taken part in the camp and her mother were also included.

Data were collected through ethnographic observations and interviews: (1) observations were made in the meeting that took place before the camp, during the camp, and in the training session that took place after the camp. The first two authors (GD and MP) took individual or joint fieldnotes, recording details of the contexts, interactions, types of knowledge, and practices surrounding FSL use. They either did it on the spot or, when this was not possible, as soon as they could afterwards. These notes, which were regularly written up, also included quick transcripts of informal interviews with the participants; (2) interviews were semi-structured. The interview guides (one for HCPs and one for the counsellors living with T1D and the young people) were based on a literature review, comments and feedback by the clinicians, and previous interviews. The post-camp interviews were revised according to observations made during the camp. The interviewees were asked to talk about their knowledge of T1D, and their experience with and use of the FSL. They were invited to provide concrete examples, in order to favour references to their personal experience. The interviews lasted 45-120 min. In total, 12 interviews were conducted: six with HCPs (three diabetologists, two diabetes nurses and one dietician, including two HCPs who had attended the summer camp for children (week 1), five with counsellors living with T1D (three young women and two young men), and one with an adolescent and her mother. The semi-structured interviews were integrally transcribed with minimal transcription conventions, and anonymised. Informal interviews resulted in transcripts taken on the spot and completed post hoc.

4.5. Data analysis

The analysis of the data consisted of a recursive process that started at the very beginning of the observations. Through repeated readings of all the data, adopting a comprehensive and inductive approach that interprets data in the light of contextual information (Atkinson, Coffey, Delamont, Lofland, & Lofland, 2001), we were able to identify recurrent practices in FSL use. We systematically noted the obstacles to the use of the FSL, the actions carried out to sidestep or solve them, and the creative uses and outcomes of these actions. Comments about the use of the FSL, as well as dialogues in which participants discussed certain features of the FSL or tried to overcome an obstacle, were also systematically considered and analysed.

Finally, in a bottom-up procedure, we divided our observations into six broad categories that described the various types of learning required to use the FSL and the obstacles that were encountered: (1) learning to apply and wear the FSL's biosensor; (2) learning to handle the logbook and the reader; (3) learning to appreciate the benefits of scanning; (4) learning to trust flash glucose values; (5) learning to read the curves and arrows; and (6) learning to integrate this new technology into the clinical practice.

5. Results

The results are presented according to these six categories, and are illustrated by excerpts taken from both interviews and fieldnotes.

5.1. Learning to apply and wear the biosensor

Generally, the nurses who presented the FSL to the users at the camp and applied the sensor to their arms could draw on previous experience and practice with other CGM systems and sensor-patch pumps to apply the sensors properly and connect them to the reader. Meanwhile, participants could observe the nurses and be indirectly introduced to the procedure. However, achieving what seemed at first sight to be easy, namely applying a biosensor to the upper arm, proved to be less simple in practice, and required the users to complete two steps: deciding to wear the sensor, and learning how to apply it.

Deciding to wear the sensor. On the first day of the camp, some participants were reluctant to wear such a visible device. Wearing a sensor on the body might not only be physically uncomfortable, but also involve wearing a visible device, which might attract questions from others. Those who already knew each other discussed whether they should try it, and whether, after all, they should withdraw from the study. Marie told us:

[1] Marie, a counsellor living with T1D (post-camp interview)

First, when I heard about the FSL I was not interested, I was like "A patch on me, no way!" and it's the fact of having tried it with the others at the camp [...] that was a breakthrough.

Discussing with peers and confronting diverging perspectives proved to be important for those who hesitated to try the FSL and to experience what it feels like to wear a sensor on one's arm.

Learning how to apply the sensor concerned both the HCPs and the persons living with T1D. Users were confronted with technical obstacles related to either the sensor or the reader. They worried because the device did not always stick to their arms. Shortly after application, some users lost their sensor and had to replace it in the infirmary. They shared this problem with their friends and compared their experiences. Lucie noticed that the sensor stuck very well on her, compared with her peers:

[2] Lucie, 14 years old (post-camp interview)

I tried it [the FSL] first at the camp, and I loved it, besides that, it stuck to me very well, and the values were precise enough.

Technical problems (e.g., how to change the sensor and how to make it stick) were daily addressed with the HCPs, especially the nurses. Lia, a diabetes nurse, reported that it was during the camp that she and her colleagues realised that the sensor did not stick very well on children with thin arms:

[3] Lia, member of the nursing staff in the children's camp (post-camp interview)

To apply the sensors to the children, we struggled a lot [...] not because of the adhesive part of the sensor as we thought, but because their arms are actually so small that the sensor couldn't entirely stick to the skin.

The HCPs tried to find solutions, first by using bandages and then by applying tapes to fix the sensors on the youngest children's tiny arms or older male adolescents' muscled arms. The camp also enabled the HCPs to observe how the FSL worked in various situations and to note, for example, that the sensor could become detached if it came into contact with water (swimming pool or sweat) or when a user took off his or her sweater. Lia also reported that in the last days of the camp, a few children complained that the sensor itched. She experienced it herself when she tried the device for 14 days.

In other words, the HCPs directly witnessed several technical problems that, in their usual workplace, they would only have heard about indirectly, during consultations or phone calls. This gave them an opportunity to anticipate obstacles and provide some solutions. In this sense, the camp provided a space of experimentation for all the actors involved.

5.2. Learning to handle the logbook and the reader

Mastering how to handle the FSL reader and enter the data in the logbook was a source of difficulty that was tackled through discussions and with guidance from the HCPs:

[4] Emile, a member of the medical staff for both camps who lives with T1D (fieldnotes)

On the first day of the camp, Emile explained the procedure for switching the logbook on and entering the amounts of CH and the insulin doses. He then let the participants do it themselves and answered any questions they had. At every meal, he supervised and checked what the participants did and whether they did it properly.

One of the difficulties encountered in the initial handling of the logbook was that it did not allow half doses of insulin to be entered. In such cases, some users wondered what value to enter. Other users did not enter any data at all, maybe because they struggled to do so, did not want to ask for help, or were discouraged or bored by the length of time needed to do it. Entering the grams of CH involved pressing a button on the logbook for each gram. This was very time-consuming for the young people, who were getting hungry and still had to inject insulin. Therefore, Emile sometimes entered the data for them, as he did for a boy who used to eat very large amounts of CH at each meal. Emile was also asked technical questions about the reader, such as the absence of a display of the curve and of LO or HI values (i.e., symbols indicating when scanned results are beyond the reportable range), and to give advice on specific functions, such as curves, arrows, diary function, and range.

While all these obstacles enabled the participants to solve technical problems, they also showed that handling the reader and using the logbook require more than just technical know-how, as users have to understand the relevance and purpose of certain measures. These obstacles therefore gave them opportunities to learn more about T1D and its management. They also led the HCPs to discover elements that were not included in the instructions for use, witness the users' actual use, and hence adopt their perspective and gain a better insight into the young people' understanding of T1D.

5.3. Learning to appreciate the benefits of scanning

Scanning the values with the reader is a feature of the FSL that the participants discovered. The more they used it, the more convenient they found it. For example, Myriam (a diabetes nurse and member of the nursing staff in the young people's camp) noticed that at night, measuring flash glucose values was more appropriate than measuring blood glucose values, as it saved a lot of time. She pointed out that the young people did not have to be woken up, contrary to what happens with a finger prick. She underlined that not disturbing their sleep has a very positive impact on the children's and young people's quality of life, not to mention that of their parents (or relatives), who have to wake up regularly at night to measure their children's blood glucose levels.

Emile observed that some participants living with T1D regularly visited the nurses' stand because they wished to check the flash glucose value. He also noted, as we did, the enthusiasm of the counsellors living with T1D about wearing this device - an enthusiasm they shared in the meeting held every evening before bedtime. Moreover, as they discussed the number of scans they did per day, a few counsellors living with T1D realised that they did it very frequently, and discussed this with their colleagues. Clémence reported:

[5] Clémence, a camp counsellor living with T1D (fieldnotes)

"I can't stop scanning, I really dig it!" Like other colleagues, she scanned the values just for the pleasure of seeing them displayed whenever she wanted.

In the post-camp interview, Clémence told us that she usually wore another CGM system, but did not like it because even if she just wanted to read the time on her pump, she would still see the glucose values. She greatly appreciated the possibility of checking her flash glucose level only when she wanted, as well as the absence of a disturbing alarm.

The counsellors also talked about the values, typically the lowest versus highest value of the day, or the duration of severe hyper- or hypoglycaemia episodes that occurred at night and went unnoticed. They also discussed flash glucose values taken at times of the day (e.g., after-dinner values) when they would not normally have pricked their fingers.

These observations showed that, beyond the fact that scanning the values is simple, and even fun, the users came to learn temporal and metabolic aspects of their own T1D that they previously ignored, owing to the fact that finger prick measurements were not taken at certain times of the day or night because they were too complex and time-consuming.

5.4. Learning to trust flash glucose values

The easy access to glucose values is, however, only one aspect of measurement. The users who had experience of other self-tracking devices were not only concerned with obtaining the right glucose values, but also with understanding the meaning of these values and assessing their reliability. The comparison between flash and blood glucose values therefore prompted frequent discussions between the users and the HCPs. For example, Marie (a camp counsellor living with T1D) observed a discrepancy of 2 mmol/L between the flash glucose and blood glucose values, but did not worry because, on Fabienne's advice (an HCP living with diabetes who had used the FSL for longer), she took this difference into account when managing her insulin and CH intakes.

As using the FSL does not eliminate the necessity of doing capillary blood tests, the advantages of the FSL were discussed right up to

the very last day of the camp, when a few participants asked why they should use the FSL if they still had to do capillary blood tests. They compared the FSL values with other values. They related them to what they had just eaten and to their physical activity. Through this active meaning-making process, they gained knowledge about the device and its accuracy, and learned when and how to trust it, as Paul, a diabetologist, highlighted:

[6] Paul, a diabetologist, member of the medical staff during the children's camp (post-camp interview)

We observed the device in a large number of children, and every day we had several examples of “can it be trusted, no it can't, why yes and why no”. In this way, I came to trust the tool more and more and it was on the basis of the decisions made at the camp that we subsequently developed recommendations here in our unit. [...] the level of the thresholds above which it is necessary to check with capillary measurements, examples of situations where you have to be careful with the device, all this comes from the experiences we had at the camp. There were not many publications on the FSL in paediatric care when we introduced it.

Informal discussions also provided opportunities to discuss the conditions in which the values can be trusted:

[7] Marie and Sandrine, counsellors living with T1D (fieldnotes)

One evening, Marie discussed with Sandrine, another counsellor living with T1D, the fact that her flash glucose level was too high. She kept monitoring her flash glucose level every 5 to 10 minutes and, as it did not fall, kept injecting little doses of insulin. She eventually decided to go to bed and to rely on her night curve to check if her flash glucose level had decreased. Tania, a diabetologist, joined in as Marie and Sandrine were relating Marie's flash glucose values to the chocolate milk she had drunk earlier in the evening. Tania advised Marie to stop injecting insulin too quickly and to wait for it to take effect. She recommended trusting the device only partially, and paying attention to bodily symptoms.

As Tania told us later on, she recognised the advantage of frequent glucose checks, but feared that users might be prompted to overcorrect both insulin injections and CH consumption, instead of waiting for the insulin to take effect. Taken together, these observations showed that the users actively tried to make sense of the values displayed by the FSL. To evaluate the reliability of these values, they drew on both their own previous experience and knowledge, and that of others. They compared their glucose values and discussed possible discrepancies between flash glucose levels and capillary blood tests. Through these comparisons of experiences, the HCPs who were initially concerned by the uncertainty of flash glucose values and feared that accessing them constantly would lead users to make the wrong decisions, came to trust the accuracy of the FSL and to understand which periods are critical. For them, the camp gave them practical training and helped them not only to trust the device, but also to be cautious and, hence, to manage certain obstacles to its use.

5.5. Learning to read the curves and arrows

The FSL also provides curves and arrows indicating whether the level of glucose is rising or falling. The users rarely discussed the interpretation of these curves and the consequent insulin adjustment with the HCPs. This was mainly because the insulin treatment was supervised by a diabetologist, and also because the users had access to the FSL readers only at mealtimes or at the nurses' stand. However, for the persons living with T1D, as well as the diabetologists, observing the night curves proved insightful to reveal night-time hypo- and hyperglycaemia episodes, as Tania stressed:

[8] Tania, a diabetologist (interview during the camp)

The first morning we saw what had happened during the night [...] for me it was like “Oh! But it's so cool!” It was like lifting a veil we hadn't been able to lift until then, on “what happened during the night?” [...] Finally, we know what happened during this damn night! [...] as we know perfectly well that what happens at night influences what happens during the day.

The arrows, and more specifically the curves, displayed on the screen prompted discussion between the young people on various occasions, such as when they were queuing to get their insulin dose before meals. Here again, some of them compared their curves and showed them when they were “nice” ones (as they said), that is, when the curves were flat with no extreme values during the day or night. Put briefly, by providing immediate and visual feedback on the body's responses, these curves seemed to work as a psychological tool that guided the users' and HCPs' actions and decisions. They gave them new opportunities for understanding T1D and its individual specificity, and for adapting its management accordingly.

5.6. Learning to integrate the device into clinical practice

In the post-camp interviews, some members of the HCP staff emphasised that the experiences they gained during the camp had major consequences for their work in the hospital. Some teams drew up guidelines and new procedures to be used within their unit, and set up formal and informal training for their colleagues, together with patients and their relatives. The region's paediatric diabetes units also received several requests for FSLs, so their teams started to think about standardizing its presentation and a method of teaching its use. For example, Paul (diabetologist) reported that after the camp, his team worked together to ensure that they always

delivered the same information to patients. They did this mainly by reading publications on the characteristics of the device and by sharing experiences gained during the camp. His team wrote guidelines and organised a workshop for patients who were about to receive the FSL kit and their relatives. His team also planned to implement health education within the unit and to integrate this tool, more specifically the graphic representation of glucose levels and profiles, within other diabetes (self-)management devices.

According to Lia (diabetes nurse), using the FSL led both the patients and the HCPs to take trends in glucose fluctuations into account, and gave them a new understanding of glucose values and diabetes:

[9] Lia, a diabetes nurse and member of the nursing staff at the children's camp (post-camp interview)

We no longer work with the result of a specific timepoint, we work with a trend, a whole and that's a big plus because it's what we try to work with, to pass on to patients, to say 'stop looking only at the value of just one moment' (...) and this is what's going to be great with the arrows and trends.

Lia emphasised the importance of teaching this new mode of reasoning, in order to take advantage of this device in the daily management of T1D. In brief, the camp provided an opportunity to develop and experience a collective learning whose outcome could then be used in the course of the HCPs' daily work, in particular by considering glucose fluctuations over time and developing new modalities of health education.

6. Discussion

Drawing on observations made in the everyday life of a summer camp and on formal and informal interviews, the results of this study provide an in-depth understanding of how persons living with T1D and HCPs learned to use the FSL and what obstacles they met in its actual use. In the course of this learning process, guided participation (Rogoff, 1990) played an important role, and was achieved through the participants' active involvement in hands-on activities in the use of the FSL and in the interpretation of its data. Even though the HCPs' guidance (scaffolded by the camp setting) predominated, the occurrence of various obstacles, together with the fact that the HCPs were themselves partly novices when it came to using the FSL, led participants to collaborate in order to find adequate explanations and solutions. The young people shared their impressions, fears and difficulties. They discussed whether they would use the FSL and wear a visible biosensor, compared their glucose values and curves, and discussed their decision to inject insulin. Even though we did not systematically study the characteristics of these discussions, we observed that they often involved sociocognitive conflicts, argumentation (Muller Mirza & Perret-Clermont, 2009), and exploratory talk (Hennessy et al., 2016; Mercer et al., 2019) - conditions that have been shown in previous research to foster learning.

Learning mainly concerned technical and procedural knowledge: how to wear a biosensor on the arm, handle the FSL reader, and grasp what 24-h glucose values implied. As many of the young people and the counsellors had no experience of other CGM devices, the camp was also an introduction to the graphic and numerical display of glucose fluctuations and profiles (curves), and to predictive information (arrows). Hence, they also learned to deal with the availability of these values over a 24-h period. By observing how persons living with T1D used this new device in their daily lives, and sometimes by trying it themselves, the HCPs learned how the FSL works in concrete situations and how to solve technical problems.

As we showed, learning was not limited to procedural knowledge. By facing and overcoming technical obstacles, participants developed knowledge and skills about T1D and its interindividual variations. The immediate feedback provided by the device, and more specifically by the display of curves and arrows, enabled them to track features of the disease that are not usually accessible, such as glucose fluctuations at night. Put differently, curves and arrows worked like nonhuman actors (according to Latour's concept) or psychological instruments (according to sociocultural psychology), enabling the persons living with T1D to regulate their activities, and thus to self-manage their diabetes. They also opened up new opportunities for the HCPs to regulate the disease. HCPs learned how these new data could inform therapeutic decisions, as well as health education, so as to foster patients' and relatives' ability to use these new data. Through their interactions, the young people and the HCPs gradually constructed a partially, if not fully, shared understanding of the functioning of this device, the metrics and the relevance of these metrics. They became more sensitive to interindividual variability and, through critical values and situations, learned to trust the values, which required them to consider the circumstances and contexts in which these values were produced.

The immersion of all the participants in a daily situation was the source of another type of knowledge: how to regulate their emotions in the face of uncertainty. Even though the camp, contrary to everyday life at home, was a highly controlled situation, using a new device (i.e., FSL) involved coping with uncertainty and dealing with mistakes. Hence, using the FSL involved overcoming a range of emotional states, including impatience, fear, and even anger. Interacting and discussing with others appeared to be a way of making sense of these emotions and being able to regulate them.

To sum up, by actually handling the FSL and encountering different types and levels of expertise and experiences, participants learned how to use the FSL and to sidestep some of the obstacles inherent to use-in-context. Through the mediation of others (either other persons living with T1D or HCPs), they learned to regulate their emotions and to trust the device, from which we can infer that trusting the FSL is jointly trusting others.

7. Conclusions

Four main conclusions can be drawn from our findings. First, introducing a new device is a matter not only of whether the

technology works or not, but also of whether it fits the actual situations in which the potential users find themselves, and the ways in which they learn to use it and deal with its resources and limitations. In other words, using a new technology always involves a network of actors, knowledge and practices. Thus, what can be called “adequate” use is not “adequate” in general, but for a given user in a given situation.

Second, a group situation, such as the summer camp observed in this study, seems to be a setting which is particularly favourable to collective learning. The complex network in which the device was used was characterised by intensive social interactions between participants with different types and levels of knowledge and expertise. This particular situation created an appropriation space in which both the persons living with T1D and the HCPs could establish a continuity between knowledge and experiences past and present, thereby making sense of the device, lending it a personal meaning (Lawrence & Valsiner, 2003; Zittoun & Glaveanu, 2018), and learning new knowledge.

Third, in this situation of distributed expertise (Edwards, 2010), the appropriation space not only enabled the HCPs to identify advantages and obstacles to the use of the FSL, but also created an opportunity to develop *relational agency*, that is:

a capacity [...] which involves: (i) working together to expand ‘the object of activity’ or task being working on by recognising the motives and resources that others bring as to bear as they too interpret; (ii) aligning one's own responses to the newly enhanced interpretations, with the responses being made by the other professionals as they act on the expanded object (Edwards, 2010, p. 64).

In other words, this appropriation space not only fostered individual skills, but also contributed more generally to the development of *work* itself, that is, new professional gestures that can be shared and used within a given professional arena.

Fourth, these results are also relevant to the field of health education in general. By demonstrating the advantages of a collective setting designed to promote interactions and the sharing of experiences, feelings and understandings, this study highlighted the relevance of having an explicit theory of learning and articulating it with a theory of technology use. It is clearly important to pay close attention to the features of the settings in which health education is delivered and to base them on explicit expectations that concrete experiences may either confirm or undermine (dos Santos Mamed, 2020). The case of the summer camp observed in this study urges us to think about other similar settings that might favour interactions, dialogue, and appropriation.

This study also had several limitations. One of them is that our observations were restricted to the duration of the summer camp, whereas it would have been interesting (but beyond our scope) to follow these same young people after the camp, in order to understand how they integrated the FSL and used their new knowledge in their daily lives. This would have been all the more interesting as the organisation of the camp provided a high degree of guidance and control.

Nevertheless, our results show that the development of new devices would benefit from considering the diversity of situations and experiential registers involved (material, bodily, cognitive, and emotional) in using a new technology and overcoming unexpected obstacles. Therapeutics related to technology would benefit from considering the specific contexts in which a new device is used and the opportunities that are provided for users and HCPs to share their expertise, discuss the obstacles they encounter and, more broadly, talk about their daily situations, difficulties, and emotions.

Statement of ethical approval

The design was approved by the Ethics Committee of the Canton of Vaud (no. 439/15) and by the board of the non-profit organisation that held the summer camp.

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Credit authorship contribution statement

Giada Danesi and Mélody Pralong carried out the fieldwork and analysed the data, under the supervision of Francesco Panese, Michèle Grossen and Bernard Burnand. The paper itself was written by Giada Danesi, Mélody Pralong and Michèle Grossen, and revised by Francesco Panese and Michael Hauschild.

Declaration of competing interest

None.

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