

Caring through Data: Attending to the Social and Emotional Experiences of Health Datafication

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ABSTRACT

Designing systems to support the social context of personal data is a topic of importance in CSCW, particularly in the area of health and wellness. The relational complexities and psychological consequences of living with health data, however, are still emerging. Drawing on a 12+ month ethnography and corroborating survey data, we detail the experiences of parents using Nightscout—an open source, DIY system for remotely monitoring blood glucose data—with their children who have type one diabetes. Managing diabetes with Nightscout is a deeply relational and (at times) contested activity for parent-caregivers, whose practices reveal the tensions and vulnerabilities of caregiving work enacted through data. As engagement with personal data becomes an increasingly powerful way people experience life, our findings call for alternative data narratives that reflect a multiplicity of emotional concerns and social arrangements. We propose the analytic lens of *caring-through-data* as a way forward.

Author Keywords

Caregiving; diabetes; chronic illness management; personal data; self-tracking; personal health informatics; remote monitoring; health and wellness; healthcare technology; emotion work; DIY health.

ACM Classification Keywords

J.3 Life and Medical Sciences, Health, Medical Information Systems; H.5.2 User Interfaces, User-centered design; H.5.3 Group and organization Interfaces, Computer Supported Cooperative Work

INTRODUCTION

Recently, there has been a growing interest in how personal data can support a wide range of health and wellness goals. As low cost mobile sensing technologies become more accurate and popular, healthcare providers, insurance

companies, and medical device manufacturers have begun to examine the potential benefits, risks, and costs of remotely monitoring patient data. While CSCW and HCI have largely celebrated personal data as a means to improve individual health outcomes, researchers have also articulated a need to better understand the social context of personal health and wellness data. Studies, for instance, have investigated self-tracking communities like the Quantified Self [10], data-tracking anxieties [50], and sought new collaborative design directions for health and wellness informatics [6, 17]. Since the everyday health experiences are increasingly being mediated through shared data, it is important to consider how this trend affects the practices and meanings of care itself, as well as to reconsider the emotional impact of data beyond the individual in the design of healthcare technologies.

Within this unfolding story of what we call ‘health datafication,’ we hone in on the use of personal data in the collaborative management of chronic illness. Specifically, we draw from ethnographic research of people involved in the creation and use of an open source, DIY (do-it-yourself) biofeedback system to manage type 1 diabetes (or T1D). In 2013, a small group of professional engineers and software programmers whose children were diagnosed with T1D hacked a continuous glucose monitor, a commercial medical device used to manage blood glucose levels, with the goal of liberating personal health data and uploading it to the cloud. Sharing code on social media, they were quickly joined by others—both parents and adults with T1D—who, as one developer explained, “*knew what they were doing*” with code. Their design work was guided by a common interest in developing better tools to visualize and interpret blood glucose data, a facility with technology, and a shared ethos of DIY and open sharing. No longer fated to be a mystery, diabetes was approached as a ‘puzzle’ in which one could use data to figure out and solve the practical, everyday problems of diabetes management.

Eventually, these ad-hoc efforts coalesced into Nightscout, an open source system that allows people to remotely monitor and track blood glucose levels in real time via software that runs on a range of mobile displays. Quickly gaining attention in the wider online diabetes community, the system was later adopted by many non-technical parents who desired a way to track their children’s blood glucose

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levels from home or work while their children were at school or daycare. In the hands of non-engineering T1D parents, data took on new import, whereas solving the puzzle of diabetes through software and data hacks became the means to care for loved ones.

Nightscout parents are the focus of this paper. We chose highlight parents, rather than young children, teenagers, or adults with T1D and their partners, because we want to unpack the psychosocial facets of collaboratively managing health through data. The role of parenthood, embodied in the everyday acts of protecting and nurturing those dependent and vulnerable, makes visible the complex and often subtle ways in which people experience the impact—both positive and negative—of datafication in everyday life. Nightscout enabled parents to care for their children using data in ways that were often personally conflicting and not well understood by their social worlds or the wider healthcare industry. That the caregiving practices of Nightscout parents were often viewed as extreme and/or controversial [19] suggests a need to better understand the why along with the what and how of caregiving as it is performed through personal data.

Bringing together several domains of research, including health and wellness, DIY making cultures, and personal informatics, Nightscout exemplifies how the broader sociotechnical processes of “datafication” has begun to reshape the responsibilities and meanings of managing health and illness. Healthcare is dramatically shifting through increased access to biomedical data, the rise of social media, and DIY “self” care technologies [11, 25]. Popular narratives in the media often celebrate personal data tracking as a new paradigm of patient-centered health [42]; however, a straightforward data story of personal empowerment and control does not fully capture the nuanced experiences of Nightscout parents’ caregiving work.

As others have noted, relying on tropes like “big data” can limit how we conceptualize life with data [1, 4, 24]. Our study of Nightscout parents highlights that there are many unexpected and deeply human narratives about data still emerging and that these stories offer an alternative way of living with data. We offer the CSCW community, then, a story of the practices (and politics) of personal health data at a watershed moment when the narratives of “data society” are being institutionalized through design. In this paper, we take pause to consider: What is care and what types of care are important in a world of data-driven health? In doing so we propose an analytical approach—*caring-through-data*—that reveals the multiplicities of care work and offers considerations for design concerned with navigating social boundaries, engaging tensions, and negotiating human dependencies.

Given the complexity of the medical, information, and emotion work involved for parent-caregivers, we start off by giving an account of both T1D management and the

Nightscout system. We then situate our analytic approach in relation to literature on informal care work, focusing on CSCW studies that discuss the social and emotional facets of caregiving. Next, we describe our field site and present findings from an ethnographic study of Nightscout, detailing how diabetes data is experienced in the everyday lives of parents, as well as the emotional complexities and social tensions that have arisen for families in its adoption and use. Finally, we present considerations of our work for the CSCW community, unpacking how Nightscout can help illuminate what might be at stake in a life increasingly mediated by data.

Motivation for DIY Diabetes Data Tracking

Managing T1D Before Nightscout

T1D is an autoimmune disease in which a person’s pancreas stops producing insulin, a hormone necessary for using sugar (glucose) from the carbohydrates that one eats. Currently, T1D can neither be prevented or cured. Caring for T1D therefore requires careful and routine monitoring of blood glucose levels and injection of manufactured insulin, a process that can be both physically and emotionally challenging for both child and parent alike. Blood-glucose levels are typically checked throughout the day and night. Drops of blood are drawn through a special needle (e.g. “finger pricks”) and then measured with a blood glucose meter. Insulin doses must be precisely balanced—by multiple daily injections or a continuous infusion through an insulin pump—with everyday activities like eating, exercise, and sleeping.

Even with vigilant monitoring, people with T1D are constantly at risk for dangerously high or low blood-glucose levels, both of which can be life threatening. Uncontrolled blood glucose levels for people with T1D can lead to serious health problems and even death. Parents of young children with T1D, especially those who do not feel their “lows” when their blood glucose levels drop rapidly, are particularly vulnerable. Sam’s first encounter with T1D, for instance, happened unexpectedly after bringing her infant daughter home only to find her becoming increasingly ill. Returning to the hospital, her daughter was diagnosed with T1D and the early days of being a parent became an education in learning the difficulties of managing blood glucose levels: *“We’re at the emergency room and her blood sugars were over 500 at the time. In the hospital they stabilized her within 24 hours, but they keep her [daughter] for about three days while they teach you how to keep her alive. And that was a process in and of itself, because everything we were discussing for three days is hyper blood sugar and then three hours before they discharge, they talk about hypo [e.g. low blood glucose]. We really had no idea. That’s the part that just terrified me.”*

Given the complex and critical information needed to manage the unruly blood sugar levels of her daughter, Sam researched technological solutions and was relieved when

her family got a CGM. Continuous glucose monitoring systems (or CGM), are FDA-approved medical devices that replace the finger pricks and can measure and display real time blood glucose readings, allowing people to view and track fluctuations in their glucose levels. Even with the use of a CGM and insulin pump to give them some data, however, Sam and her family struggled with their daughter’s blood glucose levels. “You’ve got a 12-month old infant, this little teeny body that you are having to balance insulin and with a little quarter unit,” Sam explained and added, “It’s horrifically difficult to keep her stable on an ongoing basis.” She and her husband took turns each night watching over their daughter, always anxious that she might not wake up from her sleep, a phenomenon in T1D known as ‘dead in bed syndrome.’

Parent-as-caregiver experiences such as Sam’s are important in that they highlight dimensions of care work that extend beyond medical expertise and knowledge of the body. Parents of both young children and teenagers with T1D often engage in types of care work that is deeply emotional and relational. “Being a T1D mom,” explained a parent of a 16-year-old son, “there’s an underlying fear that you can never shake. While I strive to constantly motivate [my child] to believe that this disease doesn’t define him and to inspire him to continue dreaming big—deep inside I’m scared to death.”

Nightscout as a Data-centric Solution

The anxiety and exhaustion of managing T1D has driven many parents to seek alternative care solutions that provided increased insight into their child’s health status. Nightscout became favored as a technological work-around for frustrated caregivers because it provides access to blood glucose data typically locked down by proprietary commercial CGM software. (Until relatively recently, commercial options to remotely display real-time blood glucose data were unavailable to purchase.). Offered as a free download, Nightscout was an affordable and customizable care option for parents who wanted blood glucose data displayed according to their personal preferences.

While several versions of code and configurations of devices exist (i.e. xDrip, a DIY/open source hardware and a software application connected to Nightscout), most participants in our study used the ‘community build’ for monitoring blood sugars. This Nightscout system consisted of a “rig,” i.e. the combination of a smartphone + Dexcom Continuous Glucose Monitor (CGM), a small wearable device that tracks blood glucose levels through the use of a sensor embedded under the skin. An Android application transfers data from the CGM to the cloud and a web application displays the blood glucose (BG) values stored by the CGM. These values can then be displayed on a mobile or wearable device, such as a smart watch for displaying data.

Upon learning about Nightscout while researching diabetes technology online or through social media, many parents were determined to try out an unregulated, DIY medical system even though they are not ‘techie.’ One father, for instance, described to us the experience of learning to code as sleep-deprived caregiver: “It was very technical. You have to do a lot of work yourself because the developers wanted to make sure that you were aware that this was DIY. You literally were compiling code...And the whole community comes into this sleep deprived. You are not coming into this well-rested, having had a good meal, and the only thing you have to do today is set up Nightscout. You are literally having to add this to the crushing burden of what you are currently going through.”

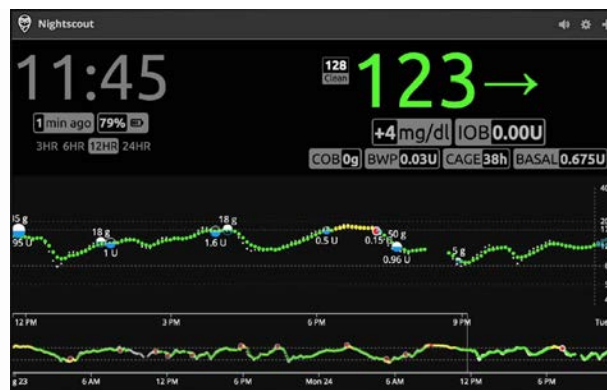


Figure 1. The top image shows how Nightscout can track and display blood glucose levels in real-time. The bottom image shows that, by uploading their children’s blood glucose data to the cloud, it enables the remote monitoring of CGM data through mobile devices like Pebble Watches. Image courtesy Amy Stieglitz Kirk.

To address such barriers, Nightscout users developed a range of digital tools, social support, and organizational resources, including: websites, instructional YouTube videos, an associated 501(c) 3 foundation, community certificates and awards, diabetes conference presentations, ‘install parties,’ and a thriving Facebook group called

‘CGM in the Cloud’ with over 18,000+ members and a dedicated 24/7 technical support team.

THEORIZING CARE WORK IN CSCW

An underlying goal of this paper is to offer evidence of the social and emotional impact of data monitoring technologies that extends beyond what is found in the current literature on pediatric caregiving [47] or the self-tracking of health and wellness data [10], as well as contribute to CSCW theories of care work. To this end, our field site allows us to examine several unique dimensions of care, including: 1) Personal health data that is deeply social and in constant use among families, providing insights into how data technologies impact relationships over time; 2) Costs and unintended consequences of health datafication revealed by the critical, often life and death nature of managing T1D; 3) How people engage with data monitoring technologies when they are not constrained by the designs of commercial software and devices.

Numerous studies have explored the everyday challenges of managing health and wellness in CSCW-related literature, particularly in relation to chronic illnesses like diabetes [16]. For instance, Mamykina et al., [30] has discussed the varied needs of those living with T1D in terms of medical self-care strategies while O’Kane et al. [38] investigated people’s relationships to their T1D devices. Storni [43] and Grönvall and Verdezoto [18] have both examined the impact of self-monitoring in chronic illness management on people’s daily lives. Others have examined the role of informal care networks, such as online support groups, in helping those with chronic illness [21]. Our work adds to this literature by focusing on the inmate setting of family life in using shared data to manage chronic illness.

Three strands of CSCW literature are relevant here. Recently, there has been a growing interest in better understanding the practices and social roles of caregivers in a wide range of health contexts, from taking care of depressed family members at home [51] to supporting families during hospital stays [23, 31], to the everyday lives of parents with teenagers with chronic illnesses [20] or high-risk infants [28]. Understanding the personal needs of caregivers has also been of growing concern [37] as their work is often invisible [8, 43] and unsupported [41]. To date, there has been little examination of the experiences of parent-caregivers whose activities extend beyond procedures in inpatient and clinic settings and what is typically found in online patient forums or support groups. Our ethnography of Nightscout adds to the growing corpus of CSCW caregiving research with an examination of an open source community of both T1D patients and caregivers, by detailing their lived experience of data.

Second, studies of the chronic illness experience have found that people often require help managing medical activities and health-related information as well as good deal of emotional support [7, 22]. In much of the CSCW literature and the medical literature, however, “care” has

been primarily conceptualized as various types of collaborative work between the patient and their care team of nurses, physicians, and family and friends (e.g., Chen et al. 2014). Drawing on ethnographic insights from hospital settings, Strauss et al., for instance, described several types of micro-activities related to care, such as the ‘information work’ required to manage a patient’s chart [48] or the ‘sentimental work’ nurses’ might perform in soothing an anxious patient about to have their blood drawn [45]. New types of care-related work are also just beginning to be explored in a range of healthcare contexts, such as DIY/making cultures [36, 37]. We see our study as adding to these ongoing efforts to better understand care as it is lived.

As care has been studied in CSCW mainly from the perspective of professional medical contexts: the theoretical framings of “work” so often used to describe collaborative caregiving practices are rooted in activities found in the hospital, doctor’s office, and clinic. The notion of “care partnerships,” for instance, evokes the type of collaboration between patient, clinician, and family that is needed to meet various clinical health outcomes. We see our study as providing additional insight into the informal practices and meanings of care among families and friends that are of increasing interest to the CSCW community [41, 48].

Our study highlights the conflicting social and emotional experiences of care work in the everyday lives of families. Care goes beyond collaboration to include ways of being with someone in and through illness. Neither the sentimental work or information work of clinicians fully describes the complex anxious-togetherness of Nightscout parents and their children. In our analysis of Nightscout we therefore draw inspiration from conceptualizations of ‘care’ in the humanities to articulate the nuanced socio-emotional dimensions of care work we observed in the Nightscout community. We highlight the multiplicity of (often conflicting) meanings that care work embodies—the burden of control and the anxiety of freedom—in the practices around providing for the welfare of another. As Nunes et al. [35] argued, more studies of non-medicalized care work are needed, perhaps leading to a CSCW re-conceptualization of “care work” from the majority of medical literature.

Third, we also engage with feminist STS (science and technology studies) scholars like Mol [32, 33] who have theorized chronic illness in terms of its sociomaterial practices. The experience of care is multiple (and often messy), dependent on the shifting relations between policies and people, knowledge and technologies, and diseased bodies. Importantly, practices both shape (and are shaped by) varying care logics that have both political power and moral weight. Mol’s work argues for understanding the relationship between established and emerging care logics enacted through the practices around DIY data technologies; as well as the importance of proposing theories of care that provide a necessary counter-balance to

the predominant view of data-tracking as inherently beneficial to people's health and wellness.

METHODS

Data Collection and Participants

Our data include 21 semi-structured interviews with members of the Nightscout community. These data were also informed by over 12 months of ethnographic observations of Nightscout presentations at diabetes conferences and technology workshop as well as informal planning conversations held by core developers and foundation board members by the first, second, and third authors. Observational data were recorded as field notes and later transcribed and added to our understanding of the Nightscout project. Additionally, over the course of 9 months, an ongoing analysis of Nightscout-related websites [34], personal patient blogs, code repositories (e.g. GitHub), various technical documentation, news articles, and a wide range of social media, including Twitter feeds, Instagram accounts, YouTube videos, and Facebook posts added to our understanding of people's experience using Nightscout. In particular, we coded 664 distinct posts from the "CGM in the Cloud," a popular Facebook group among Nightscout users to triangulate our interview and observational data.

The data reported in this paper are a part of larger research project aimed at understanding the patient-centered technology design and the use of technology to manage T1D. Our understanding of Nightscout was also informed by a survey of the CGM in the Cloud Facebook group Nightscout users completed by 727 respondents (led by the fourth author). IRB approval for data collection was obtained along with participant consent.

The 21 interviews were conducted with 20 individual participants (some participants were interviewed more than once) in the Nightscout community. Although participants had varying levels of technical expertise, experience with T1D, and participation in the community, all were currently using the Nightscout technology either personally or with a family member in daily management of diabetes. Interviews were approximately 1 hour and were recorded and transcribed; children were recorded with permission from their parents. These semi-structured interviews took place both face-to-face at various diabetes conferences and also electronically via Skype.

Interviews focused on exploring (1) types of involvement in the Nightscout project and related communities, (2) everyday practices around diabetes management using Nightscout and related technologies, (3) impact of Nightscout on family life and clinical care, and (4) broader views on the ethos and motivation of those who participate in the project and community.

Interview participants were selected to represent a wide range of experiences with Nightscout and included 10 parents with children who have T1D (specifically, 3 mothers and 7 fathers) along with 7 adults and 1 teenager

all living with T1D. Additional interview participants were heavily involved with the Nightscout community, and include: core developers (9), Nightscout Foundation board members (7), and active members of the technical support group (2); furthermore, all 20 interview participants were active members of the "CGM in the Cloud" Facebook group. (These categories are not mutually exclusive and several participants had multiple roles within the Nightscout community.)

Participants came from a wide range of ages as well as technical and educational backgrounds, although the majority of participants had advanced degrees. We also note that the core developers we spoke with all had previous training in computer science or work experience as software engineers or in the broader tech industry.

Limitations

It is noteworthy that Nightscout users represent a small, self-selected population of patients and caregivers. Since only 11% of people with T1D currently use a continuous glucose monitor, the basic device used in Nightscout, our field site can best be understood as a population of early adopters that embrace technology in diabetes management [40]. The experiences of Nightscout caregivers may also represent a self-selected group of parents who are prone to anxiety and intervention, since many people have successfully managed T1D without remote monitoring. We were careful to look for extremes in the population, using them to cast the nuances of data monitoring into high relief and make visible the social/emotional dynamics around data.

Additionally, while parental caregivers are the main focus of this paper, we acknowledge a child's experience living with Nightscout and diabetes is a study unto itself, as too are adults managing their own T1D with Nightscout. It is important, however, to highlight that the parents we interviewed commonly spoke about their Nightscout experience using collective language such as "we" and "our family." Furthermore, almost all of our participants—caregivers and adults with T1D alike—articulated common challenges faced by families living with diabetes and referred often to the broader "the Type 1 community." This observation points to the social impact of chronic illnesses like T1D that intimately involve family in patients' everyday care practices and the shared experience of T1D.

Data Analysis

We followed the situational analysis approach to grounded theory as articulated by Adele Clarke [12] in that iterative cycles of data collection and analysis informed one another. After a set of initial interviews were transcribed, the first three authors analyzed the data using an open coding method to identify significant themes. Coded interviews were then discussed among the entire research team during data analysis sessions. New codes were generated collectively as important concepts were identified, compared, and revised. These subsequent codes were later

used as probes in future interviews. The second stage of data analysis with new transcribed interview data resulted in consistent themes and confirmed our findings.

Fieldnotes and Facebook posts were read, coded, and analyzed in a similar manner during data analysis sessions. Furthermore, utilizing Clarke's situational analysis mapping methods, we generated an array of situational, discourse, and social worlds/arena maps and analytical memos. These map artifacts and memos were discussed among the group as theoretical insights emerged from the ongoing data collection and analysis.

All data presented here has been anonymized. Some minor edits to quotations have been made for clarity.

FINDINGS

Overwhelmingly, we heard two responses from almost every parent we spoke with: 1) using Nightscout helped give their child and family back their "freedom" to live life more fully, and 2) Nightscout provided parents with greater "peace of mind." Indeed, the people we worked with repeatedly described their family's experience with Nightscout as "life changing." Taking this claim seriously, in the following sections we explicate the shifting dynamics around caregiving and family life in relation to the use of DIY diabetes technologies to highlight the opportunities for care that a remote data tracking system like Nightscout makes visible.

Despite their evident appreciation of Nightscout, for instance, over the course of our study, parents often reflected about their struggles of fixating on numbers, anxieties on making dosing decisions based on data, and difficulties in taking on the burdens of data tracking—all the while teaching their children to learn how to independently manage their own diabetes. In the next section, we examine the varied experiences of Nightscout parents, noting how data tracking has brought with it new emotional complexities and social tensions to family life.

Peace of Mind through Data: Going to Sleep

The mundane act of putting one's child to bed is a cause of anxiety and stress for parents whose children have T1D. While Nightscout was adopted by many parents so they could finally sleep through the night; in fact, the system often kept parents up at night as they felt compelled to examine and use the data 24 hours a day.

Managing T1D prior to Nightscout often involved multiple "night checks" to measure a child's blood glucose levels with finger pricks, depending on how strictly parents attempted to keep their child's glucose levels steady. Parents compared those blood glucose (BG) values to the CGM readings (which may be inaccurate), in order to make an insulin correction. Parents might make multiple corrections a night if a child were sick or going through a major growth spurt, as a number of environmental and physiological factors can affect BG levels.

Many parents describe their lives prior to Nightscout as one of sleep deprivation and desperation. As one mother explained, "*I think it's almost innate that you just don't sleep anymore.*" One participant, a father of a teenage boy, noted that he and his wife have not slept a full night since his son was diagnosed. "*I just want to sleep! We have been tired for 4 years.*" As a system designed for the remote monitoring of BG data, Nightscout allowed parents to create customizable alarms and push notifications to alert them if their child's glucose levels slipped outside of a prescribed range. This feature was particularly useful at night as it allowed parents to get out of bed for fewer checks during the night. As one father remarked, "*It changes your life as a diabetes parent.*"

For a number of parents, however, Nightscout also gave them the ability to carefully monitor and control their child's BG levels to minimize highs or lows. As one father, a software engineer, explained that his family now monitors and tracks his 8 year-old-son's BG data in order to devise care strategies for keeping it within normal range as he sleeps: "*We can basically micro-correct with insulin or glucose... We'll break glucose tabs into quarters and give it to him just to keep him really smooth... He'll eat glucose tabs in his sleep.*"

These efforts to tinker and tweak based on real-time blood glucose data during the night often lead to a constant state of sleep deprivation for parents. A number of our participants described feeling more secure with Nightscout's alarms and push notifications, but also acknowledged that for them, the routines of night checks have become "*what we do*" as T1D parents. One mother explained to us that she now looks at her Pebble watch at her child's BG numbers instead of sleeping: "*We don't sleep through the night... maybe 2 or 3 nights out of a month the numbers are flat and stable all the time and you do sleep through the night. If that happens, that's great, but it doesn't mean I'm not still tapping my watch... and looking at it. I'll wake up, just because that's what we do. We're used to it... I won't say we sleep through the night, but we certainly have a better idea of what's going on in the night because of Nightscout.*"

In summary, while Nightscout provided parents more accurate data and a greater sense of control in managing their child's T1D, it did not necessarily always bring a sounder sleep or eliminate the stress of care work. While DIY data monitoring devices were designed to keep children safe and help parent sleep, many parents in our study found that the increased access to diabetes data kept them awake long into the night, actively engaged in trying to control diabetes better. Achieving peace of mind through data often remained an elusive goal for parent-caregivers.

Freedom through Data: School and Sleepovers

Along with sleep, mundane childhood activities like going to school, playing at a friend's house or participating in

athletic events can be a challenging event for families managing T1D. Parents worry about their children receiving proper care if they are not around to catch and treat dangerous highs and lows. One Nightscout user described how school became at times a dangerous place, especially for young children who were not yet able to care for themselves: *“For parents, they lack this peace of mind because they are sending their kids to school with an insulin pump filled with a lethal hormone. And they could kill themselves at any moment. Like there is enough insulin in that pump to kill their kid 30 different times, and that kid has total control of the buttons: like that is ridiculous! And until Nightscout there was no way for a parent to see if your kid’s blood sugar was crashing.”*

Nightscout changed this, allowing parents to view their children’s blood glucose data while they sat at a desk in a classroom or played during recess. Parents developed plans with schools to coordinate care based on real-time data, sometimes calling the school nurse to alert them when their child was in danger.

While we found that most people were successful in finding ways to collaborate with teachers and administrators in providing care for their children using the remote monitoring of data, some parents said that they and other families they knew have received pushback from school districts over their use of Nightscout. Schools, for instance, have argued that the responsibilities of monitoring real-time data were a distraction for teachers in the classroom and led to the over-involvement of parents. Discussions on the CGM in the Cloud Facebook group often discussed strategies for educating wary school administrators, and at times parents must take legal measures to ensure their children are able to use Nightscout.

Despite such misconceptions of ‘helicopter parenting,’ we found Nightscout parents deeply reflective about how data figured into the different social and emotional aspects of caregiving—seeing their role as both enabling their children to be free from the fear, responsibilities, and daily grind of diabetes management, as well as finding ways of training their children to use data to effectively so as to take care of diabetes themselves.

Being able to remotely monitor blood glucose data was often a liberating experience for both parents and children. One mother described how Nightscout gave her 8-year-old son freedom to experience the joys of childhood, *“It’s been beyond a lifesaver for us, just beyond...just the freedom to let him be a child, to go on play dates, to basically—just be—without an adult all the time.”* Another parent told us she loved Nightscout because it made her feel comfortable to put her infant son with T1D into daycare and go back to work after maternity leave: *“We get peace of mind and we get comfort to know that we can still see what’s going on. And he can be a kid and the caregivers can be there and present with him and not be so worried.”* Being present—living together and experiencing the world with and through

data—changed the nature of caregiving work from something that was burdensome to potentially empowering.

Growing Up Through Data: Teaching and Letting Go

In general, while many parents noted their children with T1D are incredibly self-reliant and have managed their care from a young age, many others expressed exasperation or fear that their children would be unable to manage their health very well. Parents with older children and teenagers acknowledged that Nightscout impacted the parent-child relationship in stressful ways. The feelings of freedom through data experienced were often tempered by worry about teaching their children how to understand and use diabetes data independently. We heard stories of how parents tracked their high school children’s glucose levels as they ran cross-county meets or texted treatment plans to teenagers while at a sleep-over.

Martin, the father of a high school senior with T1D, had given careful consideration to the newly gained freedom his son, Jonah, will shortly experience when he starts college. Martin told us he is actively working on preparing Jonah to take on greater ownership of his diabetes data. *“He’s going to go to college. He is going to get drunk at a party. I get that, I was at college, it happens. When he goes to sleep at night...I will not be there and mom will not be there to deal with the alarms and what’s going on.”* Such situations are a cause of concern for Martin and his wife who at times feel frustrated at their son’s lack of independence. *“[Jonah] sort of chastised me, ‘How come you temp basal me [an insulin treatment] instead of giving me a juice box?’”* And I said, *“Well you’re welcome to take over that role anytime you want. You can either chastise me or you can do it yourself. I am happy to let you!”* As a Nightscout developer, Martin explained that the knowledge that Jonah will be leaving home had motivated him to work with his son to customize new alarms specific for college life.

Other parents were less prepared and described being at a loss for how they would manage diabetes data as their children mature. *“It terrifies me because I know that someday I’m going to have to hand this over and I don’t know how it’s going to go,”* admitted one mother a 2-year-old with T1D. *“I’m hoping by that time there will be something even better than what we have now.”*

While Nightscout enabled people to experience short-term freedom from the daily grind of diabetes through the remote data monitoring, long-term use of the system led to concerns about how this freedom would be used. As children matured, care work for parents shifted to learning how to let go of their child’s data. This was a difficult task. Many parents expressed a need for guidance and support in anticipating an uncertain future when their children would increasingly need to take control over their own data and diabetes management.

Empathy through Data: Monitoring Bodies

A number of parents tried out Nightscout on themselves. Most parents we spoke with wore the CGM sensor and smart watch for a few days to monitor their own blood sugar levels; however, some even went so far as to inject themselves with saline using an insulin pump. They did this for a number of practical reasons, including learning how the system functioned, but also to discover what the experience was like for their children both physically and emotionally. On taking the step to insert the CGM sensor into their arm, a father explained, *“I really wanted to experience what [my son] did—if it hurt.”* He acknowledged ruefully, *“I am much more careful about where I place sensor since trying it myself.”*

Another T1D father, also a software designer of diabetes data applications, explained his reasoning for using the Nightscout for a few months in a blog post: *“I wear a Dexcom [CGM] so I can always demo the technology, and for a while I was also using an insulin pump and injecting myself with saline. The first time I did it though was to better understand what it really meant to manage Type 1. I did it for nine months and did everything my daughter did (except of course, I never went low or high). She was 12 at the time, and she’d ask me, ‘Where are your low supplies, Dad?’ [referring to checking current levels of insulin stored in pump]. And a lot of times I’d have to say, ‘I know, I blew it.’ It really established this camaraderie between us” [3].*

Another parent noted that she decided to wear her daughters’ CGM when her child decided to *“take a break”* from the system. In doing so she learned better how the pancreases functioned in response to eating particular foods, but also enlightened her on the intimacy of living with the data. *“I figured I would take the opportunity to feel what she experiences in some small way. It’s been good for her too! She likes to keep the [Nightscout] receiver and check the phone! [the phone displays real time BG data] She likes to tell me when I’m going up or how what I have eaten is affecting me. It’s given her a way to voice her feelings in a way I wasn’t able to hear prior to wearing it.”*

This intimate sharing of biometric data between parents and their children can bring them together in the experience of diabetes—allowing them gain a different care perspective. At the same time, however, the experience of data tracking also becomes a source of uneasiness. After using Nightscout herself, a mother reflected, *“I think it has given me the realization that it is strange to have people have access to seeing what your body is doing.”*

Having your body monitored, sometimes 24/7 is a strange (and often unsettling) experience for many children, especially teenagers. Parents, for instance, described how their children told them Nightscout sometimes felt *“invasive”* and like *“being under a microscope.”* Fluctuations in stress and hormones, for instance, can impact blood glucose numbers and lead to an awkward

over-sharing between parent and child through data. One father explained how he could see his 16-year-old son’s blood glucose numbers fluctuate during a school dance, a time of socializing with peers as well as adolescent romance. His father admitted feeling he unintentionally invaded his son’s privacy with Nightscout at such times.

Another parent on CGM in the Cloud explained that emotional boundaries between parent/child and caregiver/patient are in constant negotiation in such data-centric care work: *“For our T1 kids, every sip, every morsel eaten can be seen. We see when their site [the CGM sensor embedded in the child’s body] is petering out, when they played on the trampoline, when they study for a big test or play video games. I know so much from seeing the Dexcom [type of CGM] data. My son complains that no one else in the family is under that kind of scrutiny and it makes him feel defensive, like he has to explain even the ordinary.”* He noted that using Nightscout himself gave him empathy for his son’s diabetes experience. Despite anxieties about glucose levels, together their family had a conversation and agreed that better care—in this case their son’s mental and emotional wellbeing—demanded they limit data tracking activities to night and only lows that could get dangerous.

Tensions through Data: Being More than a Number

In providing parents with an endless stream of data—Nightscout assuages the panic of the unknown, but also demands the constant attention of caregivers. For many parents the ability to take action upon data through insulin corrections can make it easy to fixate on the numbers. Parents articulated constantly trying to find the right balance between doing too much or too little in regards to their child’s blood glucose levels. *“This is such an emotional disease,”* explained a mother whose daughter had been diagnosed at 3 years of age, *“It’s like so personal, you almost take it personal when some things go wrong with [her child] because we’re responsible for the settings.”*

As managing and interpreting data became central to care, many parents felt inadequate to protect their child’s body and wellbeing. A developer noted, *“We see people looking at their kid’s data and we have this widget that shows what percent of the day you were above range, in range, and below range. And these kids are above range 85% of the day. And you look at their mother’s face or their father’s face, they just feel like failures. They’re like, ‘I’m f-cking this up. I’m destroying my child.’”*

Data-induced guilt brought on by remote monitoring led some parents to try *“beating the disease”* through data. Sharing his observations of Nightscout parents, a developer noted: *“I know some people who are overdoing things. They’ve got 15 basal patterns [instructions for dispensing types of insulin treatments via the insulin pump] set up and they’re jiggering them every night.”* One father admitted he and his wife struggle with the temptation to constantly tweak his 13-year-old daughter’s corrections: *“We’re on her like a hawk. We measure every piece of food she*

eats...We change basal rates and bolus rates [used in insulin treatments] and sensitivities. We try to do the best we can.” While steady glucose levels can lead to improved long-term health outcomes, the pursuit of ‘good numbers’ can sometimes conflict with ‘good care.’ Later in the same interview, this father wryly acknowledged to us that his teenage daughter “*didn’t love*” her parent’s obsession with her data: “*We were checking her too much...And she wants to shoot me sometimes, and my wife as well sometimes, because we are always on her about her diabetes...I’ve got to watch that, because I’m on her too much...There’s definitely a quality of life thing to this...I know I don’t have the right mix.*”



Figure 2. A text message exchange [5] between mother and daughter on managing dropping blood glucose with real-time data using Nightscout. “Catching” low blood glucose levels involved parental emotional care work that attends to the person, not just the number.

Finding the balance of caring through data can take time. Jamie shared an experience of when she first began using Nightscout with her son to manage T1D diabetes, explaining that it was easy at times to lose perspective—and one’s humanity—in the stream of data. “*When I first started monitoring him using a spare receiver, I was forever worrying about meal spikes and asking what he ate and if he bolused.*” Jamie explained that in her impatience to see immediate changes in the data, she would nag her son even though he was taking care of his insulin treatments. Insulin, however, takes time to impact the human body and her son felt judged by her attention to the data. “*We just want the best care and outcome for our kids,*” reflected Jamie, “*but sometimes their spirit suffers the more we concentrate on the numbers.*”

Providing good care for diabetes has always been a difficult undertaking and counter to the aforementioned narratives of freedom and empowerment having access to an endless stream of blood glucose data does not necessarily make it less challenging. Data tracking can bring about a radical empathy between parent and child, but control is often elusive and the abstraction of diabetes through numbers can at times obscure the person altogether. Stories of data as individual empowerment and problem solver warrant

critical reflection by the CSCW community. In the following section, we discuss how the datafication of diabetes is shifting the idea of care itself as well as the emotional and social consequences this has for designing collaborative systems to support health and wellness.

DISCUSSION: CARING THROUGH DATA

The experiences of Nightscout parents demonstrate the varied ways care can be enacted through data. Everyday caregiving in our study was full of tensions: fear and freedom, peace of mind and never-ending vigilance, an enigmatic mystery and a puzzle to be solved like an engineering problem, alienation and familial togetherness. In lived experience, care work can hold some or all of these meanings simultaneously.

Our findings, therefore draw on, but do not line up neatly with, straightforward narratives of personal data as carrying the means of empowerment, leading to freedom or greater control often found in the popular media and even CSCW. In what follows, we offer a way to make visible the unintended consequences of taking an overly simplified approach to supporting care work through data-tracking and remote data monitoring systems. Drawing inspiration from the fields of medical ethics and philosophy as well as feminist scholars in STS (science and technology studies), we propose the sensitizing concept of *caring-through-data*, as an alternative to *data-as-care*. Using a critical lens to analyze the types of care work we observed among Nightscout parents highlights the varied social and emotional dimensions of care work that have the potential to enrich CSCW, both in theory and design.

Engaging a Multiplicity of Care Experiences

In our study we saw Nightscout parents managing care through remote data-monitoring. This was often done with the best of intentions (from love and a desire to protect one’s child with T1D from harm), and many people we spoke with described situations when they believed access to real-time diabetes data saved the life of their child from an extreme low or high. Along with ‘peace of mind’ and ‘freedom,’ however, Nightscout also resulted in a sense of extreme monitoring and a sense of loss of control. Our study provides evidence of the unintended social and emotional consequences of a design focused on finding technological solution to chronic illness, including data-induced guilt among parents who felt a heightened-sense of responsibility to make sense of and use data in all manner of care decisions for their child, be they big or small. Parents also expressed that their fixation on the display of blood glucose values at times led to distance in the parent-child relationship as children felt the parent was more concerned about getting a ‘good number’ than addressing their emotional needs. We do not see these outcomes as a failure of DIY design, but rather illustrating a more complex, nuanced dimension of care work as mediated through data that we in CSCW need to better understand.

Good care is often associated with technical competence and expertise in modern medical practices. However, as a historical practice and philosophical idea, care has long embodied multiple meanings. In the field of medical ethics, Reich [39] has discussed the conceptualization of care from Socrates to Heidegger, noting that ‘care’ has long had two fundamental, but at times conflicting meanings: to live with the worries, troubles, and anxieties of being human, but also to actively provide for the welfare of another person. “The struggle between opposing meanings of care,” Reich argues regarding the experience of lament/hope, “is part of the radical importance of care to being human” [p.6].

More recently, in the field of STS (science and technology studies), Annemarie Mol has pointed to the ways in which health care—as an assemblage of practices and people, data and discourses—is not just dualistic in nature, but inherently experienced as multiple [32, 33]. Our findings suggest that we should aim to support a greater multiplicity of care experiences in the design of data-centric technologies. For Nightscout parents, being attentive to the needs of their T1D children encompasses navigating many fundamental tensions—care is (and has always been) many things simultaneously: a human struggle between control and freedom; of seeking peace of mind and giving into anxiety; and of empowerment and taking on the burden of another.

From “data-as-care” to “caring-through-data”

This paper has accounted for a fairly unique approach towards care. We have shown how a group of parents, many of whom have a background in engineering and software development, ‘coded’ care as a problem that can be solved by data granularity and management. This approach of *data-as-care*, i.e. care as experienced and managed through data, has already become a powerful intervention. Members of Nightscout, for instance, have engaged political and regulatory bodies like the FDA to legalize (at least parts of) the system, all the while Dexcom (a medical device manufacturer) has released its own version of a remote data monitoring app for the Apple Watch. The kind of *data-as-care* we reported in this paper, then, is already partially legitimized and institutionalized.

Given the impact of datafication upon health and wellness in our society [11], we believe that much can be gained from a designerly intervention [2] that shapes how the underlying approach of *data-as-care* proliferates beyond this immediate case. Nightscout in its current implementation codifies care through an engineering ethos that motivates much of contemporary IT culture from large software companies like Google all the way to DIY maker culture: the ideal that technology can lead to individual empowerment and help people (re)gain control over various aspects of their lives [13, 26].

In the case of Nightscout, this ethos of empowerment and self-actualization is applied to chronic illness, whereas diabetes is rendered as a puzzle that can be solved through the right kind of technology. This approach promises to turn anxiety, pain, and suffering into freedom, control, and empowerment. In this paper, we have shown how these aspirations break down on numerous occasions, and how one form of suffering is often replaced with yet another. For example, parents adopting data monitoring to calm fears that their child may not wake up one morning find monitoring brings with it the emotional weight and responsibility of paying attention to every data point. Research in CSCW and STS has long shown the limitations of any such technologically deterministic view. And yet, technosolutionism, i.e. the idea that technologies provide solutions to complex societal problems like health and wellness, still drives contemporary system design and implementation [26].

What we propose here is an intervention into this trope of technosolutionism. What this requires is acknowledging that care is both a set of practices and narratives (e.g. ideas about what constitutes ‘good’ care and how data help make care better). Recognizing that this narrative of Nightscout represents only one of many possible types of care allows us envision alternatives and how it can still be otherwise [46]. Moving away from *data-as-care*, we start instead from an approach of *caring-through-data*, where the relationship between care and data is multiple, and both care and data can mean many different things depending on the particulars of family, social contexts, life stages, etc.

With *caring-through-data* we attempt to shift the lens from the technosolutionism of data, as enticing as it may be, back to the practices of caregiving. In doing so, we found glimpses of people maneuvering data in ways to promote empathy, relational intimacy, and compassion. Parents wearing a continuous glucose monitor in solidarity with their T1D children points to unexpected ways in which people are using data technologies to share the experiences of chronic illness together as an intimate ‘we.’ *Caring-through-data* is a narrative that engages a wider range of human experiences between people, data, and technologies. Our conception of care in the age of datafication should be flexible enough to make space for new ways of being with/in/through data, such as this kind of radical empathy that seeks to be present with others through data-sharing.

To give one concrete example of what we have in mind, this paper discussed how families experienced Nightscout simultaneously as sites of gaining and losing control through data. And yet, parents and children had little control over control, i.e. the system, designed to monitor and display data, did not afford ways for parents to quickly relinquish control when needed (e.g. when teenagers felt surveilled at school). We could design, instead, for a different type of control—one that allowed for a variety of care options, e.g. to pull closer to a friend or family member

when there was an urgent need for physical help or emotional support, and to maintain important social and emotional boundaries.

As CSCW increasingly designs systems that use personal data, we need to scrutinize not only how data impacts the ‘self’—how and why people maneuver data-tracking tools to mitigate feelings like guilt, obsession, friction, alienation—but also the collective ‘us’. Examining the ways in which interacting with data impacts the most intimate of human experiences—how people care for one another—we in CSCW can design for a wider range of interactions with data. If we continue to draw only from *data-as-care* narratives (whereas data becomes the technical solution to diseases of the body) without understanding or addressing *caring-through-data* (whereas data is a means of fostering empathy and togetherness), we impoverish not only the design of health technologies, but care itself. As a way of enriching our understanding of the possibilities data can play in everyday life, we need to create counter narratives that account for *caring-through-data*. Our paper is one such effort to open up the conception of ‘personal data’ towards this multiplicity.

CONCLUSION

The exciting possibilities of data in health and wellness have begun to shift the arrangements of care in ways that makes it easier than ever to reduce the experiences of chronic illness or wellness to number or the configuration of a device. As an ethnographic study of Nightscout caregivers, this paper offers the CSCW community evidence of a more nuanced health datafication narrative that impacts computer-supported system design writ large. We suggest *caring-through-data* as new theoretical framing for opening up the various meanings of care.

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