

Varied & Bespoke Needs of Caregivers: Organizing and Communicating Diabetes Care for Children in Era of DIY

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ABSTRACT

Type 1 diabetes in children is a complex chronic condition that requires high levels of coordination among a range of caregivers in order to communicate and organize care for best health outcomes. We examined three types of care, at home, at school, and at the clinic, to explore the communication needs of a range of caregivers. Not only were there differences between types of caregiver, but there were also varied personal preferences for communication, different levels of knowledge regarding caregiving that required different forms of communication, and changes in child health leading to different care needs and communication styles. We frame these findings within the new trend of diabetes technologies that allow for cloud connected communication in order to show the need to respect varied and individual communication practices. Technologies that link current health data over the cloud may not have a one-size-fits-all solution for all caregivers, however, open-source DIY health trends may be a way towards supporting personalized communication needs.

CCS Concepts

H.5.m. [Information Interfaces and Presentation (e.g. HCI)]: Miscellaneous.

Keywords

Type 1 diabetes; caregivers of children; communication; ICT; cloud; IOT; healthcare; DIY health; chronic care.

1. INTRODUCTION

People with Type 1 diabetes (T1D) cannot generate sufficient amounts of the hormone insulin to use glucose (sugar) in their blood for energy. In the short term, the lack of control of blood glucose (BG) levels can lead to hyper- or hypoglycemia, which can have immediate and serious ill effects on a child. Over time, it may lead to serious complications such as kidney, eye and cardiovascular diseases [17]. To control the condition, people with Type 1 diabetes have to calculate the amount of insulin to inject. This is a complicated process that can be difficult for an adult, let alone a child, to navigate.

Difficulties calculating the correct dosage of insulin is exacerbated when children with T1D are going through puberty [5]. Their bodies are changing rapidly so the medication,

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primarily the insulin dosage, needs to be adjusted from time to time. As a result, the parents of these children have to constantly engage in a trial and error process with the clinical care providers (CCPs) to find a new formula to calculate dosage. For the CCPs to make an informed decision, the parents and school nurses need to supply the recent blood glucose levels of the child to the clinic. After the decision is made, the updated insulin dosage needs to go down the pipeline so that everyone involved in the child’s care learns about the change.

The choice of technologies for the management of T1D has never been greater, and new systems and devices are being released not only by research groups and manufacturers, but also from grass-roots open-source movements. These new technologies are still being slowly adopted around the world, however, much can be learned about designing future open-source tools by studying the way caregivers of children with T1D currently communicate with each other.

Communication of care is important throughout the child with diabetes’ life and becomes potentially more problematic when children are pre-pubescent and adolescents. Individuals with T1D between 10-20 years were found to have the worst adherence rate when compared to the other age groups [10]. Besides physiological changes, psychological states of adolescents are in flux and these changes can cause insulin adherence issues. The reasons for not taking insulin are primarily psychological, such as deliberate failure as a part of a weight-loss strategy or simple fatigue. In order for the child with Type 1 diabetes to meet their management goals, their caregivers (e.g., parents, clinicians and school staff) must synchronize care through communication [2]. If there is a break down in this communication network, the children can be negatively impacted.

We investigated these current communication practices by conducting exploratory qualitative interviews with 13 parents, school caregivers and CCPs who care for children with Type 1 diabetes. Through this exploration, the varied and bespoke needs to communicate and organize care arose, beyond the separation of caregiver roles that point to the demand for personalized communication systems that take into account individual and situational differences. We discuss these findings in relation to the open-source DIY health maker movement and the possibility of developing personalized T1D communication devices.

2. BACKGROUND

There have been a number of studies in the health psychology and HCI domains related to the communication of care needs for Type 1 diabetes for both adults and children. In HCI literature, Mamykina et al. investigated the daily management tasks of adult with diabetes [8,9], developing a tool that automatically logs blood glucose and connects users with their CCPs through a web-

based blog. Other studies investigated how allowing CCPs to remotely provide timely feedback to the people about their blood glucose levels on mobile phones can help them improve their condition [6,11]. Pena et al. examined how mobile phones can support the caregiving process and found the biggest concern of the parents is to have sufficient access to the CCPs [14]. Rami et al. designed a system for adolescents to send their blood glucose readings through text messages to their CCPs and receive feedback [15], and the system designed by Carroll et al. also allows sharing BG levels with CCPs [4]. However, beyond sharing BG levels, there is considerable communication with the CCPs that is still handled by the parents, including at school.

The caregivers at school should establish and follow a written care plan that defines when to communicate with the other caregivers to take care of a child with diabetes [1]. However, an earlier study found 45% of children do not have a written care plan at school [16]. This oversight significantly influences the ability for the caregivers at school to determine when communication with the other caregivers needs to take place. Nabor et al. studied the challenges of school nurses in supporting children with diabetes [12]. They found that communication is one of the key challenges in the school nurses' work, specifically, communicating with other caregivers to establish, update, and carry out care plans to overcome barriers to successful diabetes management.

The literature has explored the role that communication plays in T1D, but has largely treated the caregivers in silos. In this study we bridge the gap in the literature by extending the understanding of communication needs among the various caregivers. We then present our findings and suggest an opportunity to leverage DIY technologies to interlace the ecosystem of parents, CCPs, and school caregivers in personalized ways, regardless of their role.

3. METHODOLOGY

We conducted 13 semi-structured interviews with caregivers of children with T1D at home, at school, and at the clinic, with each interview taking around 30 minutes. Six parents each with a child with diabetes ranging in age between 10 and 16 years of age (P1-P6), four diabetes specialist CCPs with experience ranging from 2.5 to 12 years (C1-C4), and three grade school caregivers with experience ranging from 1 to 9 years (S1-S3) participated in the study. Most of these caregivers worked with 10-12 year-old children who still rely on their parents to manage their condition while going through the early stages of puberty.

The CCPs were recruited through word of mouth from a diabetes clinic in Atlanta, GA, USA. The roles of these CCPs included diabetes specialist nurse practitioners and diabetes educators who support patient education and clinic administration. For the caregivers at school, we recruited teachers and school nurses from local public schools through word of mouth that were caring for approximately one student with diabetes per year. For the caregivers at home, we recruited parents of children with diabetes from the clinic during their regularly scheduled visits and they were either interviewed over the phone or at the clinic.

Questions were open-ended, but focused on the caregivers' roles in helping the children manage their diabetes and the contents and patterns of communication with the other two groups of caregivers. As remote communication is most difficult and could benefit most from digital assistance, we explicitly inquired about this type of communication in our study. Interviews were audio recorded, transcribed, and open-coded. Building on these codes, themes emerged from the data and were further analyzed using latent Thematic Analysis [3]. These codes and themes were

validated with coding comparisons with an additional two independent researchers and discrepancies were resolved through discussions. The participants were not compensated and all data was collected via an IRB approved protocol.

4. FINDINGS

The different caregivers work together while negotiating their needs to accomplish their mutual high-level goal: keeping the children healthy. However, their individual needs and priorities are very different with regards to preferred type of communication, caregiving knowledge, and dealing with changing health needs.

4.1 Preferred Communication Mediums Vary

The frequency of communication is the number of times a caregiver initiates a remote communication (phone call, email, etc.) with another caregiver. As expected, parents are the most proactive party in reaching out to the other caregivers whereas the CCPs at the clinic primarily take a reactive role in supporting the other caregivers. Moreover, the communication between home and school is much more frequent than those to and from the clinic. This volume of communication is necessary because parents frequently communicate with the school to care for their child with diabetes on a day-to-day basis. However, independent of their particular role, the frequency can vary significantly from case to case. We learned that parents reached out to the school as frequent as three times a week or as little as once a year, with one school nurse describing a parent preferring daily reports: "*(The parent) wanted me to call her everyday at lunch... I will call her on her cell, tell her and she would agree or disagree with what number I come up with*" (S3).

As expected, the phone is the dominant communication medium. However, there are many cases when the parents cannot receive or answer a phone call based on availability or signal issues. In these cases, the school nurses who are trying to contact the parents become extremely frustrated. As a result, at times the school nurses will choose to send notes home with the child to document these communication efforts, but they are certainly not timely. Another issue with the phone is that there is no documentation of what is communicated. Therefore, when a large amount of data transfer (blood glucose logs) or documentation (authorization) is required, faxes and emails are used. A solution using texting also has limitations, based on people's varied preferences: "*I am a texter so I don't have a problem with texting, but like I said, in an emergency situation, I would prefer to do it either face to face or by phone call so I can know that everything is ok...*" (P2).

When there is a need for closer observation of BG levels, parents and the school nurses have to put in a lot of work to provide all the numbers (4+ readings per day with 28+ numbers a week) in the proper format and communicate them to the clinic. Parents and school caregivers find it very tedious to record and send the readings: "*it really is a hassle to write down every blood sugar, every day, all the time and then email it or fax it, that is like so tedious*" (P1). There are many electronic tools available that can help record these numbers but the output format varies, so some CCPs insist the use of the standard form provided. Other CCPs try to make communicating this information easier by allowing multiple communication media (phone, fax, email) to send the blood glucose data to the clinic. However, data coming in through multiple channels can cause issues for the CCPs: "*[It] can be a little bit confusing and you currently thinking to yourself, when did I last check email, when did I last check the faxes, when did I last check the blood sugar line?*" (C3).

4.2 T1D Care and Knowledge Can Differ

The CCPs primarily provide educational information and medical advice to the parents who use the information to make requests to the caregivers at school. The school nurse is the primary point of contact for all health-related issues, however, their experience can vary and sometimes they have to supplement this knowledge. If they do not know the solution to a certain issue, the participants of our study indicated they have a 'chat group' that is implemented as an email list for all the school nurses in the area to find peer support on these issues.

In addition, the CCPs can directly communicate with the school nurses for educational purposes when they feel that the school nurses may not be taking care of the child appropriately. The message of instruction to the school nurses could be carried over by the parents, but it is much stronger coming directly from the clinic: *"I will communicate with the (school) nurse if I feel like they are doing something potentially dangerous, like giving too much insulin or completely inaccurately dosing the patient."* (C4). Nevertheless, the school nurses are still the primary source of education in health-related issues at school. They have the responsibility of not only learning how to take care of individual students with special needs, but also educating the rest of the staff how to take actions, in case they are not around in an emergency.

The parents are the secondary source of education on diabetes after learning the materials directly from the CCPs during their regularly scheduled visits. They are responsible for making sure that others around their children also know how to handle the condition. That group normally includes family, friends and caregivers at school, with one parent even educating their child's friends to look for signs of problems: *"We always brought the diabetes books to school and educated the children in his classrooms. The kids are really good. The kids pick up on his eyes look dark, his sugar must be low."* (P5).

Parents can vary in their personal knowledge of the condition and what care is needed, with some requiring special support from other caregivers. One CCP communicates directly with parents when they feel that they are not properly supporting their children, as it can have a large impact on quality of care: *"[Children] need that family support and parental involvement if we are going to be successful in the overall management and there are very few kids that independently manage their diabetes well. The ones that do the best are the ones with parental involvement and family support"* (C4). The CCPs will ask some parents to take concrete steps to help keep the children in line with the medication regimen and in a special case, a CCP even asked a school nurse to help administer additional medications when a child was not doing well at home: *"she was struggling and couldn't get it together at home, so I spoke with the school nurse and we arranged that during the school week she would go to the school nurse first thing in the morning so she would get her oral medications and morning insulin."* (C1).

4.3 Strategies Vary for Dealing with Changing Health Needs

In the U.S., the 504 Plan is the care plan that any school, private or public, receiving federal funding should establish that specifies these standard procedures [1]. At the beginning of the school year, schools create these care plans for children with chronic conditions with collaboration from the parents. However, health needs change and medication adjustment is often necessary for a child whose body is changing as they grow. This process requires

a great deal of communication between the caregivers to make sure everyone has up to date information, which often varies.

The current practice requires the parents to be the intermediaries who communicate these changes. Unfortunately, a phone call or a written note from the parents to the school about the change is often not sufficient. The schools prefer to obtain a written authorization directly from the CCP in order to administer the updated medication: *"[for] anything that is administered in the school setting we have to have [an authorization], and I am talking even the over-the counter stuff, we have to have a doctor's notes with a doctor's signature on an authorization form."* (S3). Therefore, the school nurses will need to contact the CCPs to fax a copy of the authorization over before they can apply the change. If any of the aforementioned communication is delayed, the insulin dosage administered at school may not be updated in time, potentially causing problems for the child.

In the clinic, there are diabetes educators dedicated to educating the other caregivers on diabetes-related topics, but as the condition changes as the child grows, the education corresponding to the medication has to change accordingly. A CCP considered the task of keeping all the caregivers up to speed with education the most difficult part of the job: *"...the most difficult part is the fact that they are children, so they have more than one adult in charge of them or take care of them, so having to educate multiple adults while engaging the child... Getting everyone on the same page."* (C2).

CCPs also need to manage the psychological state of the children and their families, and issues are often unique and complex. Medication adherence has been linked to poor glycemic control and unfortunately the population included in our investigation is the worst in following their treatment plans [10]. CCPs need to help families deal with the mental health issues that may arise such as stress, depression or phobia, and these needs can change over time: *"The additional stress, sometimes we are dealing more with the parents, sometimes we are dealing more with the patients, depending on the age, sometimes it's both."* (C4).

5. DISCUSSION AND CONCLUSIONS

Type 1 diabetes is a complex chronic condition that has been commonly investigated from a single caregiver's perspective. In this paper we brought together the major stakeholder caregivers of children with T1D: parents, teachers, school nurses and CCPs. Our qualitative exploratory research provides an insight into the communication practices of this caregiving ecosystem. We found that the communication mediums vary but are fundamentally situated in pre-smartphone capacities (texting, calls). Despite the small sample size, we also found that the knowledge and care practices can vary drastically and that they must be continually updated to accommodate changing needs of growing children.

Although our study only investigated caregivers of children with Type 1 diabetes, we see many communication issues also prevalent in other pediatric chronic conditions, such as asthma. Jeong et al. investigated the challenges and design opportunities of pediatric asthma care revealing similar communication challenges such as keeping all the caregivers up to date with the treatment plan, permission seeking in medication administration, and the ineffectiveness of phone calls [7].

Our findings show that communication is needed for special support, for medication adjustment, and as a channel for education. However, the financial burden of deploying a communication system as well as the required technical training

are both costs that will bring challenges in the early phases of adoption. Moreover, if the new system is not properly designed, it could increase the stress level of the caregivers [4]. In addition, the introduction of such a system requires significant changes in the information technology infrastructure and workflow of the caregivers. Moreover, there are large differences between communication preferences and practices of the different types of caregivers, and amongst the caregivers as individuals themselves. It is clear a one-size-fits-all solution would not suit all caregivers and other individuals supporting children with chronic conditions.

We look to the advances that the DIY diabetes community is making in developing bespoke diabetes technologies as one potential way forward. There is room for person specific technologies that add to the current infrastructure rather than replacing any part of it, allowing for customization. Previously, it was only possible to get insulin readings from worn continuous glucose monitors by Bluetooth, which had distance limitations. A group of dedicated hackers have taken these readings and sent them to the cloud so that they can be broadcast to devices outside the reach of Bluetooth, with massive implications to the way that T1D is managed for children [13]. This system, Nightscout, is a technology for sharing blood glucose (BG) data over the cloud. Its open-source nature can allow caregivers to make choices about the interfaces that they interact with and even the types of devices that they use for this communication. Data can be shared seamlessly between caregivers leveraging their personal preferences for technologies, including worn smartwatches, mobile phones, and desktop computers. This can allow parents to get alarms on their smartwatch if something has gone wrong at school. It can allow teachers to use their mobile phone to see in real time if their student's BG levels are going up or down at a rate that requires their intervention. Likewise, it can allow school nurses to see the blood glucose levels of the various children in their care on their school desktop. Although exemplar case does not solve all of the communication issues that have been uncovered through this research and indeed there are many other concerns that the healthcare HCI domain are only starting to uncover [13], it does show the potential of the open-source community to provide possible solutions to these problems from the bottom-up and support personal choice in healthcare communication technology for caregivers of children with T1D.

Our findings show that caregivers often require support from other caregivers to accomplish their common goal of keeping children with T1D healthy. However, despite this common goal, there are specific preferences and needs for this communication. Future systems should support the caregivers' communication and organization needs by building on the knowledge presented here on current practices and leveraging new advances in personalized cloud connected and DIY health technologies.

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