

Transitioning from Childhood to Adulthood with Type 1 Diabetes

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The transition from childhood to adulthood is generally considered a challenging process. However, it is particularly difficult for adolescents with type 1 diabetes (T1D) (International Diabetes Federation, 2021). As they become more independent, the needs and practices around adolescents' T1D technologies are gradually transformed. This transformation involves a shift from care by others to self-care. In my PhD project I explore deeply situated design as a means of designing care technologies in general and for this demographic in particular (Vallgård, 2024). As I am still in the early stages of my research, I have just begun to explore the role of data and interactive technologies in this context. However, there are clear signs that current data monitoring practices may become problematic over time. Below, I elaborate on my findings so far.

T1D is a life-threatening chronic condition in which the pancreas fails to produce adequate insulin, that is, the hormone that regulates blood glucose levels. Care management of T1D includes close monitoring and daily insulin injections to maintain blood glucose levels within an appropriate range. In the capitol region of Denmark, where I am conducting my research, most children and adolescents use a continuous glucose monitor (CGM) to track glucose data and a wearable insulin pump to administer insulin based on algorithmic predictions. Although these T1D technologies significantly improve blood glucose regulation (Benkhadra et al., 2017; Dos Santos et al., 2021; Nuboer et al., 2008), T1D management remains challenging for affected families (Diabetes Foreningen, 2020; Kaziunas et al., 2017; Kjærulff et al., 2024). When a child is diagnosed with T1D, in Denmark, the family is kept at the hospital for a few days to stabilize the child's blood glucose levels while parents are taught how to “keep their child alive” through monitoring and regulating glucose levels (Kaziunas et al., 2017). After the child is discharged, the responsibility of coordinating the daily care management of the child's T1D falls on the parents. Since they cannot be vigilant 24 hours a day, a follow-function enables parents to use their smartphones to monitor their children's glucose fluctuations remotely.

Last month I attended an event for parents of children living with T1D that featured a talk by a chief physician from the local diabetes center. Her presentation included an interactive element that required parents to scan a QR code. “Do you all have your phones on you?” she asked, prompting the crowd of around 60 parents to burst into spontaneous laughter. “Always!” one parent responded loudly. After the presentation, I spoke with one of the mothers who explained that the laughter was not just about the general ubiquity of smartphones; it was about the reality that for this group of parents it is unthinkable to go anywhere without their phones. “I don’t even go for a run without my phone” she shared, emphasizing how she constantly checks her teenage daughter’s glucose levels – even while jogging. This example illustrates that parents might be equally affected by their children's transition to self-care, as they will be required to relinquish control of their child's care-management, and it also hints at possible tensions between parental monitoring and the changes that occur during adolescence.

Various factors influence blood-glucose levels, including physical activity, diet, and hormonal fluctuations during puberty, such as increases in estrogen, testosterone, and stress hormones like cortisol (International Diabetes Federation, 2021). Consequently, bodily sensations like excitement and arousal also become part of the glucose data reviewed by parents and medical staff. I had the opportunity to observe several doctor-patient consultations with adolescents at the local diabetes center. During these sessions, the patient’s data is displayed on a large screen in various graphs. The doctor reviews the charts, pointing out the highs and lows, and asking, “What happened here?” Needless to say, not all the patients seemed comfortable answering these questions. To them this process might feel like a form of interrogation or judgment, further straining their already delicate sense of autonomy. Adolescents often struggle with a strong desire for independence, and their quest for normalcy can conflict with their need for strict adherence to treatment regimens. As noted by Kjærulff et al. (2024), this can lead to deviations from prescribed treatment, exacerbating the complexities of their care. Additionally, the way data is shared with healthcare providers and parents may contribute to feelings of being constantly monitored and scrutinized, leading some adolescents to disengage from their treatment. For example, as shared by a young woman at the diabetes event, her decision to stop using an insulin pump was motivated both by a desire to feel “normal” and to escape the feeling of being under constant surveillance, a common sentiment among adolescents who yearn for autonomy but feel constrained by the demands of their condition.

These initial observations prompt important questions about data-sharing practices, the evolving roles within the care collective, and how these dynamics affect and are affected by the transition from childhood to adulthood. As I move forward in my research, I aim to explore how we might design T1D technologies that effectively support both adolescents and their parents during this transition, while ensuring effective care management.

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