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Type 1 Diabetes & Schools: Parents’ Experiences

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Abstract

The purpose of this study was to explore the experiences, and meaning ascribed to those experiences of parents of children with type 1 diabetes (T1D) in U.S. school settings. Twenty-nine parents (19 mothers and 10 fathers) participated, and four sources of data were collected for this interpretivist, phenomenological study; a demographic questionnaire, written prompt, semi-structured focus group interviews, and reflective interview notes. Three themes were constructed: (a) I’m fighting for my child, (b) nurses are central to experiences, and (c) physical education problems. The findings highlighted parents’ frustrations with resistant schools and the need to be advocates for their child’s needs while also emphasizing the importance of an available, and T1D-competent, nursing staff in reducing fear and anxiety associated with in-school care. Uniquely, parents discussed contextual experiences and how experiences changed throughout the day with particular emphasis on the problematic and negative experiences associated with physical education.

Keywords: School nurses, physical education, parent advocates, school-parent relationship

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Introduction

Recent data suggests that an estimated 149,500 children and adolescents younger than 20 years old were newly diagnosed globally in 2021, which represents a considerable increase from 128,900 just two years earlier (Ogle et al., 2022). This trend is reflected in the US, where according to the Centers for Disease Control and Prevention (2024), approximately 304,000 children and adolescents younger than age 20 had diagnosed T1D in 2021. Given these epidemiological trends, it is of no surprise that the number of children and adolescents with T1D in schools continues to rise (Bratina et al., 2018; Kaufman, 2002). Schools are a critical context for children with T1D, as they generally spend approximately 1/3 of their day in schools with few professionals who have specific training related to diabetes management (Amillategui et al., 2007). In addition, children are growing physically at a rapid pace during each academic year, requiring frequent changes to their personal and individualized treatment and management plan (Schwartz et al., 2010). Here, we echo Kaufman (2002), who noted that "children with diabetes spend an enormous amount of time in school and must be able to achieve the same level of diabetes management in school that they do during the rest of the day" (p. 63). This translates to families needing to develop relationships with school to ensure that children can independently monitor blood glucose levels, meal plan, and potentially administer insulin injections at school (Gutzweiler et al., 2020; Kaufman, 2002), all while also participating fully and safely in all school activities (Amillategui et al., 2007).

Parents of students with T1D can face a plethora of challenges in navigating the educational system, of which ensuring a safe and equitable learning experience are primary concerns (Wilt, 2022). For example, parents in the US have reported a number of institutional barriers that impede their children's diabetes self-management, such as restricted access to blood glucose monitoring supplies, limited daily access to well-trained nurses or school staff, and participation restrictions in extracurricular (e.g., sport, after-school activities) and enrichment (e.g., field trips) activities (Commissariat et al., 2020; Kaufman, 2002, Skelley et al., 2013; Wilt, 2022). In addition, parents have expressed a lack of support from teachers and administrators who are uncomfortable with injections (Nurmi & Stieber-Roger, 2012), and that students with T1D tend to spend excessive time out of the classroom to travel to and from the nurse's office, as most students are not permitted to test their glucose levels or take insulin in the classroom, regardless of their independence (Schwartz et al., 2010). Concerns expressed by parents in the United States are well-aligned with research internationally (Alaqeel, 2019; Amillategui et al., 2007). For example, in a cross-sectional analysis of 499 mothers and fathers of children with T1D in Spain, approximately 25% of parents reported that their children hid their condition in schools because of a desire not to be different than their peers (Amillategui et al., 2007). This finding is in line with assertions by Schwartz and colleagues (2010), who note that children with T1D tend to believe that they are treated differently by teachers and peers once they are aware of their condition. Complicating issues, parents have also recalled experiencing negative reactions from schools when they informed the school of their child's diabetes, including experiencing forms of discrimination or being forced to find other, more accommodating schools for their children (Amillategui et al., 2007).

Despite the existence of research examining the experiences of parents with children with T1D within school settings, this area of inquiry neglects to explore the sense of meaning and understanding, as shaped through interactions with school personnel and contexts, that parents make with regard to experiences with schools. That is, many studies conducted in this area of inquiry utilize cross-sectional survey designs and are conducted in international contexts, therefore limiting the depth of our understanding of particularities of how parents experience issues and everyday challenges related to schools for their children in the US. More work is needed to continue to understand what is happening in schools, and how parents understand their experiences with schools, to continue to improve experiences for children with T1D and their families. As such, this article reports findings from a recent qualitative study that investigated the experiences of parents of children with T1D in schools. Qualitative research is an ideal approach to understand the unique challenges of vulnerable groups, such as parents of children with T1D (Commissariat et al., 2020; Iversen et al., 2018), and to excavate the meaning ascribed to particularities of these experiences. By situating this study in a qualitative paradigm, we were able to explore the meaning participants ascribed to their experiences and describe salient features of experiences that contributed to that meaning (Haegele & Sutherland, 2015). As such, the purpose of this study was to explore the experiences, and the meaning ascribed to those experiences, of parents of children with T1D with schools. A better understanding of issues associated with schools can help promote positive approaches to developing successful relationships between parents and the schools in which their children with T1D attend.

Methods

This study was underpinned by an interpretivist research paradigm, with an emphasis on understanding the participants and their interpretations of the world around them (Kivunja & Kuyini, 2017). More specifically, in this study, the researchers attempted to make sense of the participants' interpretations of their lived experiences with schools as parents of children with T1D. The interpretivist research paradigm assumes a relativist ontology, which acknowledges that the situation under study has multiple realities that can be explored, and a subjective epistemology, where meaning making occurs by the researchers through their own thinking and cognitive processes informed by interactions with the participants (Goodwin, 2020). Aligned with the interpretivist research paradigm, we adopted a phenomenological approach. Phenomenological studies focus on exploring how individuals make sense of the world around them from their own perspectives, and aim to provide insight into a person's lived, embodied experiences (Goodwin, 2020). This methodology was selected as it allowed for a deep exploration of the participants' experiences and the meaning they ascribed to those experiences in an open and systematic way (Goodwin, 2020).

Participants

A convenience sample of parents of children with T1D were recruited to participate in this study at a one-day recreational day program for youth with T1D in the Hampton Roads area. To be eligible to participate in this program, youth must have been between the ages of 6 and 16 years and be diagnosed with T1D. Parents were initially informed about the opportunity to participate in this study, as well as the study's purpose, time commitment, and data collection procedures, via email after enrolling their child in the program. The morning of the program, parents were then reminded of the particularities of the study and were asked if they had any questions about participation. Those who were interested in participating were asked to take and complete an informed consent document. Parents who agreed to participate in the study and completed and signed the informed consent document were enrolled in the study.

In total, 29 parents of children with T1D, including 19 mothers and 10 fathers, participated in this study. Each parent reported having just one child with T1D, with an average of 2.58 children total (range, 1-4 children). Of the 29 parents, 10 were part of parenting dyads who shared their children. As such, the 29 participants parented a total of 24 children with T1D. Among those 24 children, ages ranged from 6 to 15 years (M_{age} = 10.5 years), and 13 were girls and 11 were boys. Parent reported that 17 children were White, four were Hispanic, two were Black, and one was White and Hispanic. Parents were asked to report how many years their child had a T1D diagnosis, and responses ranged from three months to seven years (M_{years} = 3.015 years). In addition, parents were asked their child's last known hemoglobin A1c (HbA1c) test result, and responses ranged from 5.9% to >15%, with three parents not recalling.

Data Collection

All data collection took place on the same day and at the same location as the one-day recreational day program. The Institutional Review Board at Old Dominion University reviewed and approved of the study protocols prior to data collection. After parents completed and signed the informed consent document, they were randomly assigned to one of four groups with specific times to meet the interviewer for data collection. Groups were determined by the one-day recreational day program staff to ensure that data collection did not interrupt activities of the program. Data collection took place in a private location at the location, that was separated from the children and staff participating in the day program. When parents arrived for data collection, the interviewer welcomed each participant and introduced himself and his background to expose his positionality. More specifically, he identified that he was a parent himself, as well as a researcher who is interested in understanding how persons with disabilities and chronic health conditions experience educational contexts. The interviewer exposed that despite his interest in understanding and improving educational experiences for children, he had limited prior background or experience with T1D and invited the participants to help construct his understanding of this topic.

Four sources of data were collected for this study: a demographic questionnaire, a brief written prompt, semi-structured focus group interviews, and reflective interview notes. First, when arriving at the data collection session, each participant was asked to complete an eight-item survey that asked parents to report (a) how many children they had, (b) how many of those children have T1D, (c) what their role in the family was (e.g., mother, father), (d) how old their child with T1D was, (e) how many years it had been since their child was diagnosed, (f) their child's last known HbA1c test result, (g) their child's gender, and (h) their child's race/ethnicity. All responses were open ended, allowing the participants to interpret for themselves what best represented their family and children.

The second source of data for this study was brief written prompts. After completing the demographic survey, participants were asked to respond to a written prompt that included the following question "In the space below, can you describe in your own words what it's like to be a parent of a child with diabetes and send them to schools?" Participants were instructed to write as much or as little as they would like to answer the question about their experiences. The written prompt was intended to provide the participants with an opportunity to privately reflect on their experiences as parents of children with T1D, and to stimulate thinking for what they might want to share with the group during the focus group interviews. This strategy can be useful in contexts where you need and want participants to reflect and share as openly as possible when only a single interview opportunity is available (Teachman & Gibson, 2013). Some researchers refer to this type of data collection as part of the 'pre-interview' process in which you give participants time to think and reflect and, as in our case, ask them to come to the interview prepared (Nardon et al., 2021). Participants were asked to keep their written prompt responses during the focus group interviews and were encouraged to continue to add to the prompt form throughout the focus group interviews at times when they wanted to record data to share with the interviewer but did not want to voice those opinions to the group.

The third, and primary, source of data for this study were focus group interviews. After the completion of the demographic questionnaire and short written prompt, the 29 participants were involved in one of four audio-recorded focus group discussions. The first focus group included seven parents and was 63 minutes in length, the second included nine parents and lasted 50 minutes, the third included three parents and lasted 49 minutes, and the final group included ten parents and lasted 67 minutes. Groups were constructed by the day-camp staff to fit within the program without disrupting activities, and therefore the research team had no control on group size or composition. All interviews were facilitated by the first author. A semi-structured interview guide that was inspired by the research focus and phenomenological research approach was used during each of the interview sessions. The interview guide was used as a checklist, ensuring that similar lines of inquiry were followed across groups, while allowing conversations to drive the order and magnitude of topics (Smith & Sparkes, 2017). The guide was initially developed by the first author and was reviewed by each member of the research team to ensure relevancy and validity. Questions were purposely open and expansive, to encourage participants to talk at length about topics. Examples of questions included: (a) in general, can you tell me about what it's like to be a parent of a child who has T1D?; (b) can you describe any considerations you have when you send your child to school?; (c) can you tell me about any interactions you've had with your child's teachers about diabetes?

The final data source in this study were reflective interview notes, which were recorded during and immediately following each focus group interview. These notes included the interviewer's reflections on what the participants said, initial feelings about the conversation, and items that appeared to be exceptionally meaningful during the conversations (Smith & Sparkes, 2017). This note taking process allowed for the interviewer to critically reflect on himself and record potential biases that may have affected the interview or interpretations of the interview (Walker et al., 2013).

Data Analysis

Following the completion of the data collection process, audio files from the focus group interviews were transcribed verbatim to obtain a semantic, written record of the interviews. One research team member acted as the analyst (the first author), who thematically analyzed the written prompt responses and transcriptions using a three-step analytical process that was both iterative and interpretive in nature. The first step involved data immersion, where the analyst read and re-read each of the written prompt responses, focus group interviews, and reflective interview notes multiple times to gain a deep and intimate understanding of the data. At this time, the analyst noted descriptive and exploratory commentary associated with meaningful pieces of data (Howard et al., 2019). Following, the analyst constructed initial codes from the data (i.e., written prompt responses, focus group interview transcriptions, reflective interview notes) as well as descriptive and exploratory comments that were central to the focused topic of the study. At this stage, the analyst drew on the second author as a critical friend to check and challenge the initial codes and to deepen the analyst's understanding of the knowledge he was generating (Tracy, 2017). Following, constructed codes were analyzed and combined into overarching themes. These themes were subsequently reviewed by the first and second authors to ensure that they reflected the participants' narratives as a whole (Braun & Clarke, 2006). The themes that were considered to align with the study purpose were subsequently summarized and presented as findings.

To support trustworthiness, detailed notes in the form of an audit trail were maintained on each step of the data analysis process. It is also important to note that the analysis was conducted by one research team member, as it is recognized that the background knowledge and experience of the analyst inescapably influences data coding and interpretation. As noted, a second research team member was employed as a critical friend, to help challenge the meaning making that was driven by the analyst. The research team was also mindful to include an abundance of verbatim quotes from the written prompt responses and transcriptions to ensure that participants' voices were central to meaning construction, and to allow readers to check interpretations and safeguard against themes simply echoing existing findings. Finally, transparency and coherence were supported throughout the research process by thoroughly describing critical elements of the research process, including data collection and analysis procedures.

Findings

Results are presented as three independent yet interrelated themes that depict the meaning that participants ascribed to their experiences with schools as parents of children with T1D: (a) I'm fighting for my child, (b) nurses are central to experiences, and (c) physical education (PE) problems.

I'm Fighting for My Child

"The first word that pops into my head is *frustrating*." The preceding quote was the response from a parent from Focus Group 3 when asked to reflect on their feelings about their experiences with schools. This feeling appeared to be salient across participants, who in addition to several reporting being frustrated, noted "constant worrying" and "always being alert", schools "definitely being a challenge" and "can be scary", and experiences being "difficult, stressful, constant, sleepless, and fearful" when reflecting what it's like to be a parent of a child with T1D and sending them to schools in the written prompts. These feelings were associated with a variety of challenging experiences that parents recalled when discussing interactions with schools, ranging from their children missing significant amounts of instructional time to teachers and administrators misunderstanding the rights of children with T1D. Further, parents expressed concern regarding their children's teachers understanding and comfort with teaching students with T1D, reflecting that teachers "don't understand what or how individualized T1D is" [Focus Group 3] and that "teachers that are scared" [Focus Group 2] of teaching students with T1D. In addition, bullying and marginalization were highlighted specifically in a number of verbatim quotes, including one parent reporting that "it's devasting, it's horrible, that my 11-year-old son is being ostracized and kind of bullied" [Focus Group 1] in schools. Instances like this were perpetuated by school's personnel themselves at times. For example, one parent recalled that a teacher told her child that:

> *Well, we can't go on a field trip because of you Charlotte [pseudonym]. You're responsible, because the principal couldn't provide what you need, every one of us can't go. [Focus Group 1]*

Feelings of frustration appeared to escalate for parents when schools resisted to provide accommodations that were legally mandated for their children. Parents recalled that, for example, administrators would say "while she's eligible, she doesn't seem to need [accommodations] at this point" [Focus Group 4], or would "try to deny things, like field trips, even though they're required to do so [Focus Group 1]." These instances led parents to reflect that perhaps their most important function with regard to their child's schooling was to "fight" or act as an advocate to help unlock provisions for their child. For example, participants noted that:

> *The biggest thing I tell all T1D parents is, you're going to have to be your kid's biggest advocate. Especially when it came to my son getting his 504 plan, they tried rejecting it, but I wasn't having that [Focus Group 1]*

And

> *It's a tough one, because when you come in and advocate, they [school personnel] feel like you're asking for something special. And, yes, I am, because it's an individualized disease. I feel like I do more than just fight. [Focus Group 3]*

The need to advocate for their child took on a number of different forms, where parents reported "bringing handouts" to teachers [Focus Group 3], or that "one of the first conversations we have, every single teacher, is to let them know that she [child] has diabetes" [Focus Group 3]. In addition to advocating themselves, though, the parents also reflected on the importance of supporting their children in advocating for themselves. That is, a number of parents expressed pride in their child when they would "stand up and [speak] to the class for a couple of minutes" about T1D [Focus Group 3] or "help put a PowerPoint together about T1D and shared it with the class" [Focus Group 3]. Parents noted that these were important instances that helped explain privileges or behaviors that their children had, such as using their phone to check glucose levels or leaving for the nurse's office without asking. Parents were vigilant in ensuring that their children understood their rights and focused on the importance of empowering them in difficult situations. Two primary examples of this included one parent encouraging her daughter to protect her personal space by "threatening a boy to punch him in the face" [Focus Group 2] who tried to touch her glucose monitor on her hip, whereas another recalled telling her son that:

> *I don't give a shit if you get in trouble. If you don't feel good, and they're telling you that you can't go to the nurse or asking why you're looking at your phone, just walk out. You tell me, then I'll go talk to your teacher.*

Nurses are Central to Experiences

The second theme constructed from the data analysis focuses on the parents' reflections about the central role that nurses play in their experiences with schools. While participants described a number of challenges throughout their interactions with their child's schools, they noted that many of the concerns they had with schools could be ameliorated with qualified and thoughtful nurses. In this sense, the 'fighting' described in theme 1 was reduced when qualified nurses were on hand and supported their children. That is, and fortunately, many of the parents noted that their school's nurse was amazing (*n*=12), and that nurses are "a key ally" [Focus Group 3], "we have a lot of trust in her [nurse]" [Written Response], "sort of like my lifeline at school" [Focus Group 4] and was "like her [my daughter's] advocate in the school" [Focus Group 4].

Participants reported a variety of different factors that influenced positive experiences with nurses, many of which centered around nurses helping parents feel comfortable and reduce tension between the parents and schools (Theme 1), with their child being away from home. For example, one Focus Group 3 parent noted that "it [having a good nurse] makes you feel comfortable, especially if you have to work and you're leaving your children in the care of, you know, strangers." Another parent reported that the close attention the nurse pays to her son made her feel more comfortable with him being in school, noting that

> *she [nurse] checks at the end of the day before he leaves. She'll say 'oh, you're at 54, you're not getting on the bus, go get some juice.' It's just good to know she is there and in charge" [Focus Group 4].*

In many instances, parents related their comfort to the active communication that they had with their nurse, noting that "we have an amazing nurse at his middle school. She calls my wife twice a day and tells us what it is. Then we make adjustments when needed" [Focus Group 1] and "she [my wife] sends cards to the school nurse every day, and she's very receptive. She is absolutely amazing, and our son can walk in there any time of day and there's never a question".

While positive experiences with supportive and comforting nurses influenced parents to have positive experiences with schools, negative experiences with nurses, often because they were perceived to be stubborn or unprepared, contributed to tense relationships with schools. For example, one parent from Focus Group 3 recalled struggling with her daughter's nurse, because "the nurse wanted her to come back [to the nurse's office] for everything, even though she was independent and could test and stuff in class." Similarly, a parent from Focus Group 2 recalled challenging experiences she had with an overprotective nurse, recalling that:

> *We had this nurse the first two years who had experience with a diabetic child before, and I don't know what happened with that prior experience, but she did not like for my son to be below 70. So, she'd give him a snack, and put him on the bus, and he'd*

> *come home at 300. So, he suffered with school, because he was always at 300. She was a barrier to me, for me to control his sugars, because she was so afraid he'd go low. Honestly, it was crazy.*

Despite these experiences, the majority of parents reported that their schools' full-time nurses were capable and supportive. This perspective did change, however, when discussing substitute nurses, who were reported to be "a big issue" because they "would come in and be like, 'Oh, you have to do this and read exactly from this thing' and I would have to leave work to come to school because they would refuse to give her insulin" [Focus Group 2 parent]. Experiences like this, where parents were clearly frustrated and even "fearful" [Written Responses] of the stubbornness or unpreparedness of substitute nurses, appeared to make parents more likely to confront schools (theme 1), feel grateful for their full-time nurse, as well as apprehensive about changes in nurses in their child's life.

Physical Education Problems

The final theme depicts the challenges that participants recalled, and the meaning associated with those challenges, with physical education (PE) classes and teachers. Across each of the four focus group interviews, PE classes and teachers were directly and specifically identified by parents as the most challenging aspect of their experiences with their child's education. Highlighting this, when discussing what it's like to deal with schools as a parent of a child with T1D, participants noted that "[the hardest part] for me is going to be PE, that's the one" [Focus Group 4] and that "[I'm in] a constant battle with PE" [Written Prompt Response]. For these parents, PE was viewed as a space within the schools where 'fighting for my child' (Theme 1) took on a central role.

Chief among the concerns about PE classes was that parents perceived physical educators specifically to have a lack of understanding of T1D and the needs of their children. Several parents noted that their child's PE teacher didn't understand how to manage physical activity and exercise for their child and didn't believe their child when they said they were not feeling well during class. For example, during the final focus group, one parent noted that their son's physical educator "just thought that he was just doing it [saying he didn't feel well] to get out of class", whereas during the first focus group, a parent recalled that:

> *The PE teacher doesn't understand that my son doesn't feel well. He thinks it's fake. But if he doesn't feel well, he needs to sit down. This seems to just like, go right over the PE teacher's head. He seems to think 'you [child] don't want to run. Oh, stop being lazy,*

> *hey pick up the pace.' But he literally isn't feeling well, and this seems to be a constant battle.*

While one participant admitted that her child "knew how to get out of PE" and would "just tell them [physical educator] that I don't feel good so I could go to the nurse and check my blood" [Focus Group 3], to escape PE and go to the safe haven at school, the nurse (Theme 2). However, this was largely not the case with the parents. Rather, parents felt that their child wanted to participate fully, but safely, and that their PE teachers did not understand what that meant regarding diabetes. A few participants explicitly noted that they felt a responsibility to help educate their child's physical educators to enhance their child's experience, but to no avail. Highlighting this, one parent reflected that she "had to reach out to PE a couple of times to kind of, educate her. She was a bit too intense" to attempt to enhance her child's experiences.

Despite the parents' efforts, however, they reflected that understanding diabetes and the implications of diabetes appeared to "just go over these professionals' heads" [Focus Group 1]. With that, their physical educators' lack of understanding of diabetes manifested in challenging experiences that reverberated throughout their child's school day. According to the parents, this took the form of being yelled at or bullied by their PE teacher. For example, one parent recalled a conversation with her son about PE where their son came home in a bad mood:

> *Son: Oh, I got yelled at in PE class because I didn't run to first base in kickball.*
> *Parent: Was everything alright?*
> *Son: Yeah, I just didn't feel well. [Focus Group 1]*

Like this parent, a participant during the third focus group recalled her child coming home and reflecting about her physical educator belittling him during class, asking

> *'why are you so slow, pick up the pace, you can do better, you can do faster', and sometimes he [son] can, but sometimes, physically, he just cannot".*

Experiences like these were recalled with pain and frustration during the interviews [reflective interview notes] and made the children "feel even worse and more isolated" [Focus Group 1] during the school day. Perhaps the most frustrating experience with PE was depicted by a parent in focus group 2, who recalled that:

> *So it's been super frustrating for us talking about PE teachers. My child had a PE teacher this year fresh out of college. He literally, during virtual learning, was like calling her out and embarrassing her in front of her classmates for not participating. She was like*

> *'mom, I tried to text it in the chat, but I'm not feeling good, and he's not reading me'. But she has had a really hard time with the whole COVID virtual thing and PE.*

The parent continued by talking about one specific instance where her frustration with her daughter's physical educator escalated, recalling that:

> *One time, they [physical educator and class] were talking about candy or something, and some kid said 'yeah, like if you eat a lot of candy, you're going to become a diabetic', and he [physical educator] laughed and said 'yeah, you're right.' She [daughter] was pissed, and so was I.*

As evidenced here, teachers' behaviors and comments also influenced the way in which peers interacted with the participants' children. This was supported by some comments shared by a parent in the first focus group, who noted that "kids in his class, they don't bully, but pick on him. Say things like 'you're so slow'. Maybe this is something the PE teacher can control, maybe by not having stuff that is as intense everyday".

Discussion

The purpose of this study was to explore the experiences, and the meaning ascribed to those experiences, of parents of children with T1D in schools. Utilizing a phenomenological approach, three themes were constructed that depict central experiences, feelings, and reflections of parents' experiences with schools. In the first theme, parents reflected about the frustrations that they experienced with schools, who they viewed as being largely resistant to providing legally mandated provisions for their child. These findings appear to be consistent with, and provide additional depth to, findings in prior research depicting institutional barriers to meaningful experiences of children with T1D in schools (Commissariat et al., 2020; Kaufman, 2002; Skelley et al., 2013; Wilt, 2022). Because of these challenges, the parents in this study, as well as their children, took on the role of advocates to help enhance their educational experiences. This finding appears to be unique to the literature, which generally focuses on the roles of nurses, teachers, or diabetes educators acting as advocates on behalf of parents and children within schools (American Association of Diabetes Educators, 2018; Bobo et al., 2011). Future research should consider further exploring the roles of parent-advocates and student-advocates, and how success and failures within these roles can influence experiences within school settings.

The importance of nurses in schools has emerged as a central topic in the extant literature (Commissariat et al., 2020; Kaufman, 2002; Schwartz et al., 2010; Skelley et al., 2013; Wilt, 2022). For example, an integrative review by Tolbert (2009) noted several studies that highlighted the need for daily availability of nurses within schools to ensure a safe environment for children with T1D to learn. This sentiment is echoed throughout this study, where parents noted that the availability of nurses strongly influenced their and their child's experiences with schools. It is important to note, though, that the simple availability of nurses on staff was not enough for parents to feel comfortable and confident in the care their children received at schools. Rather, parents reported the need for collaborative and communicative nurses, who would work with parents to provide care for their child that aligned with the parents and family's viewpoints. This is an important extension beyond much of the existing research, that generally advocates for the need for daily availability of nurses (Amillategui et al., 2007; Cangelosi et al., 2024; Tolbert, 2009) but does not consider the nature of the available nurses. With that, we would suggest that our findings support the need for targeted training for nurses, that focuses specifically on instructing nurses on developing collaborative strategies with parents to co-construct health plans for children with T1D in schools.

The final theme constructed for this study depicts parents' experiences with one specific problematic aspect of their child's schooling; PE. In this study, parents reflected about the physical educators' lack of understanding of T1D and preparedness to teach children with T1D, and deleterious outcomes associated with these shortcomings. This finding is somewhat unique to the literature, where prior studies examining parents' views toward school have not considered this unique educational context. Perhaps, however, the findings here are unsurprising, as what little research does exist examining T1D and PE generally demonstrates that physical educators tend to have little, if any, knowledge of T1D (Halpern & Agwu, 2009; MacMillan et al., 2015). For example, in a study by Halphon and Agwu (2009), just 3 of 156 (2%) secondary school PE teachers demonstrated effective knowledge levels of T1D. This is of concern, as it appears that little training is being conducted for HPE teachers to understand and be able to effectively teach children with T1D (MacMillan et al., 2015), which can influence instances of bullying and ostracization in classes. To combat these issues, MacMillan and colleagues (2015) suggest, and we agree, that improved and consistent diabetes management training and better communication with teachers, parents, and youth with T1D are critical for HPE teachers to enhance their practices to ensure meaningful HPE experiences for this group.

Conclusions

Given the amount of time children spend in the care of others during the school day, understanding the experiences of parents and children with T1D in school settings is an important consideration. This study sought to add to the growing body of literature related to parents' experiences navigating school-based care, which, to this point, has largely examined broad, institutional-level barriers and concerns through cross-sectional survey methodology. In adopting an interpretive, phenomenological approach, this study identified nuanced and detailed concerns of parents and the ways in which certain contexts within the school environment (i.e., PE) can create more concern and anxiety than others. Noteworthy findings included the role of parents and students as advocates and self-advocates respectively, which provides a unique contrast to literature that positions school personnel as advocates for the child and family. Further, parents described the importance of having T1D knowledgeable nurses accessible to their child in reducing their anxiety and fear, which provides more nuance and detail than extant literature that simply advocates for the daily availability of nurses. Finally, and perhaps most unique, parents described how experiences and feelings related to school change as their student navigates various environments within the school. Specifically, parents expressed fear, worry, and frustration with PE and physical educators. These findings highlight the need to further examine the experiences of parents and children with T1D as they relate to school, and specific school contexts, to ensure student's individualized needs are met and considered. That is, future research that explores issues affecting school-parent relationships and parental involvement in schools among parents with children with T1D, as well as studies examine the influence of socio-economic and cultural factors on the experience of parents and their children with T1D in schools, would add considerable to the literature. Further, research exploring how to construct positive relationships between critical school stakeholders, such as nurses or PE teachers identified within this study, can help identify mechanisms for improving school experiences for children with T1D and their families.

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