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PSYCHOSOCIAL ASPECTS (SS JASER, SECTION EDITOR)

School-Based Management of Pediatric Type 1 Diabetes: Recommendations, Advances, and Gaps in Knowledge

Laura B. Smith[1] · **Amanda Terry**[1] · **Sureka Bollepalli**[1] · **Kaitlyn Rechenberg**[2]

Abstract

Purpose of Review Children and adolescents with type 1 diabetes (T1D) spend much of their waking time in the school environment. However, there is limited empirical understanding of the challenges youth face in managing their T1D at school. There is even less literature focused on potential interventions to improve health or psychological outcomes in youth with T1D in this milieu. This review seeks to summarize the recent literature on diabetes T1D management in the school setting, including recommendations for care, barriers, and targets for intervention.

Recent Findings T1D organizations recommend strong collaboration amongst families, school personnel, and health care providers to enable successful T1D management in schools. While challenges remain according to parent, child, and teacher reports, perceptions of school-based management of T1D show signs of improvement. The few existing school-based intervention studies have generally focused on educational or structural interventions to improve diabetes care.

Summary The management of T1D within the school setting is critical for overall diabetes management. While barriers to effective T1D care have been examined, a greater understanding of the impact of new diabetes technologies and well-characterized interventions is lacking in this area.

Keywords Type 1 diabetes · School health · School nurse · Pediatrics

Introduction

Successful management of type 1 diabetes (T1D) requires daily balancing of insulin administration, blood glucose (BG) monitoring, dietary tracking, and exercise with the goal of achieving BG levels as near normal as possible [1]. Unfortunately, most individuals, particularly children and adolescents, with T1D do not meet the goals for glycemic control, which are important targets in helping to avoid diabetes-related complications [2]. For children, the school environment is a critical component of their daily routine and a milieu in which they spend much of their waking time during the school year. Consequently, successful management of diabetes at school promotes good overall diabetes control [3].

Despite the importance of the school environment in the care for children with T1D, there is a surprising paucity of research focusing on this setting. Historical reviews in this area identified that improvements were needed in communication and the education of school staff [4]. Families and advocacy organizations, such as the American Diabetes Association (ADA), responded to these identified challenges and over the past several decades, advocacy efforts have allowed for more self-determination as well as appropriate accommodations for children with T1D in managing their condition at school (e.g., [5, 6]. However, despite these gains, it is clear that many barriers and challenges still exist for children with this condition in the school setting. In this review, we examine the recent literature in the areas of (1) the impact

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✉ Laura B. Smith
lsmith5@health.usf.edu

Amanda Terry
aterry1@health.usf.edu

Sureka Bollepalli
sbollepa@health.usf.edu

Kaitlyn Rechenberg
krechenberg@health.usf.edu

[1] Department of Pediatrics, Health Informatics Institute, Morsani College of Medicine, University of South Florida, 13330 USF Laurel Dr. MDC 62, Tampa, FL 33612, USA

[2] College of Nursing, University of South Florida, Tampa, FL, USA

of diabetes on school functioning, (2) expert recommendations on T1D management in schools, (3) perceptions of diabetes care in school, and (4) school-based diabetes interventions. We also identify gaps in the literature and potential next steps in this area of research.

Expert Recommendations for T1D Management in School

In recent years, US organizations focusing on T1D clinical care and research (e.g., ADA, American Association of Diabetes Educators—AADE) have published updated position statements or recommendations for the care of children with T1D while at school [1, 7]. Other organizations, such as the National Association of School Nurses (NASN), have adopted these recommendations and presented examples of application in specific settings (e.g., Colorado [8]). In general, the themes of these recommendations are consistent across organizations and include the following:

- The requirement for a written plan for diabetes care within the school setting developed by the child's diabetes health care provider and the family. The Diabetes Medical Management Plan is the most commonly recommended plan, but other examples of school documents that may include diabetes-related plans are Individual Health Plans, 504 Accommodation Plans, and Individualized Education Plans.
- The importance of ongoing and individually tailored training of school staff, including nursing, teaching, coaching, and administrative staff, to support the child with diabetes in their daily diabetes care tasks.
- The recognition that legal requirements for the provision of diabetes care in schools may differ somewhat between institutions (e.g., public versus private), and within the USA, between states.
- The need to promote a gradual transition to the child's diabetes self-management in the school setting that is both developmentally appropriate and individually tailored.
- The value of communication and close collaboration between the child with diabetes and all stakeholders including the school nurse, other trained school staff members, the diabetes health care provider, and the child's family.

One area of ongoing challenge within the school setting is the recommendation for training other individuals, outside of school nursing staff, in managing diabetes-related tasks. While all diabetes organizations state that a nurse should be the primary diabetes caregiver at school, most also advocate that additional school staff be trained to conduct or supervise diabetes-related tasks in the event that nursing staff are not readily available.

Perceptions of T1D Management in Schools

One of the primary topical categories represented in the recent literature on school-based T1D care includes parent, child, and teacher perceptions of the adequacy of T1D management in school and daycare settings. Parents have been the focus of the majority of this research. Driscoll and colleagues [9] used questionnaire responses to compare parent perceptions of diabetes care at school in permissive states (i.e., that allow non-nursing staff to provide diabetes care) with that of parents in non-permissive states (i.e., that require nursing staff provide diabetes care). In the USA, on a state-by-state basis, the ADA has worked along with families of children with T1D on the Safe at Schools campaign, which promotes legislation to allow non-nursing staff to provide diabetes care and/or supervision (i.e., permissive T1D care). As this legislation has been implemented at the state (rather than federal) level, there has been interest in whether the school-based experiences of children with T1D are different in permissive versus non-permissive states. Parents in permissive states perceived their children to be as safe as children in non-permissive states, and further, parents in non-permissive states indicated a desire to have non-nursing staff trained to provide diabetes care in school. Parents cited the inadequate number of nursing staff as the primary reason for their desire to have additional staff trained, as the current system requires students independently manage diabetes when nursing staff are unavailable, which may limit children's opportunities to take part in field trips or other extracurricular activities [9]. Fear of hypoglycemia in school settings is commonly reported by parents and may impact parent perceptions of school-based diabetes care. To further elucidate this issue, Herbert and colleagues [10] assessed this and related factors in134 parents using both diabetes specific and more general psychological questionnaires (e.g., fear of hypoglycemia, general and diabetes-specific quality of life). Their findings suggested that parents of younger children and those on intensive insulin regimens had less confidence that school staff could appropriately care for their child's T1D. Further, parents of children with a history of serious hypoglycemic events reported poorer quality of life in the school domain. Taken together, these findings suggest that certain child factors and diabetes treatment factors are related to parent perceptions about school-based diabetes care as well as their children's school-related functioning.

Although they are often the focus of study, it is not only parents that perceive challenges in diabetes care at school. For example, a small qualitative study ($n = 19$) of children with T1D described barriers to care in school that included not only a perceived lack of school staff training but also psychosocial concerns related to how peers will perceive them due to their condition [11]. College students also express challenges related to diabetes management; a large survey of young adults in the UK found that 63% of college students with T1D noted that diabetes was more challenging to manage in college than while attending secondary school [12]. However, it is unclear if these challenges were solely related to the college environment per se or whether the broader transition to independent care that occurs for young adults may have contributed to this finding. Teacher perceptions, too, have highlighted significant barriers to T1D care in school. A large study of over 700 participants in Spain focused on teachers' attitudes and perceptions about training received to assist students with T1D in public schools [13]. Although 43% of teachers reported having had a T1D student, only 0.8% reported they received specific training on diabetes. Further, half of teachers stated the belief that their school, as a whole, was not prepared to deal with T1D emergencies. Overall, these findings indicate that all stakeholders perceive ongoing barriers and gaps in the care of children with T1D at school.

Despite identified challenges, some evidence supports that caregiver perceptions of diabetes care in school have improved over time with the implementation of legislative changes or the increased use of diabetes technology. In a 2014 report from Sweden that surveyed parents via diabetes clinics, initial findings from a 2008 study demonstrated deficiencies in diabetes care support at schools, including 40% of children without a written action plan for hypoglycemia, over half without an assigned primary staff member to provide diabetes support, and 21% of parents reporting giving less insulin than needed at breakfast due to fear of hypoglycemia at school [14]. Following the implementation of new legislation requiring a written care plan and school staff training, a 7-year follow-up survey was conducted in 2015 utilizing the same recruitment procedures. While the participants were not the same as those from the prior survey, the study samples were similar, differing only on A1c levels and frequency of insulin pump usage (average A1c was lower and frequency of insulin pump usage was higher in the 2015 sample). Study results showed that staff support had increased and parents were more satisfied with school T1D management, due to the greater coordination between health care providers, school teachers, and families [15•]. A recent qualitative study conducted with 33 parents and 17 school caregivers also found that the use of continuous glucose monitoring by daytime caregivers, including school nurses, led to collaborative diabetes care with parents and less worry about their child's diabetes care [16]. Thus, while the data is sparse, the limited literature suggests that legislative initiatives and technological advances can lead to positive improvements in school-based diabetes management.

Overall, parent, child, and teacher perceptions of T1D management in schools demonstrated several common findings across articles. First, significant parental fear of hypoglycemia in school persists, despite legislative requirements for staff resources and training to manage children with T1D. Further, students, parents, and even teachers perceive that school staff are not adequately trained to assist students with T1D management. Many parents also report the belief that they are obligated to attend their child's extracurricular activities, regardless of whether requirements exist for the school to provide medical coverage during all school activities. Another common theme expressed in this area was that there are too few school nurses available to ensure medical coverage at all times, even in locales where T1D management is required to be completed or overseen by school nursing staff (e.g., nurses are "shared" across schools in the district). And finally, given the dearth of school nurses, most parents and children would prefer non-nursing school staff to be trained in T1D management, with a preference towards all teachers and coaches receiving training.

Within the literature focusing on perceptions of school-based T1D management, several limitations should be noted. Parent participants in these studies disproportionately represented mothers, leaving a paucity of information regarding fathers' perceptions of T1D management in schools. There was also little diversity in the study samples with the majority of participants across studies middle to upper class, White families. Importantly, parents of non-White children reported more positive school perceptions than their White counterparts [10] indicating there may be important socioeconomic and racial differences in perceptions and experiences of T1D care in schools that should be further explored. Finally, to better understand how legislation regarding T1D management in schools is implemented, we must include all stakeholder groups and assess not only perceptions but actual diabetes behaviors and diabetes health-related outcomes to determine next steps in improving school management.

School-Based T1D Interventions

Despite consistency in the perceptions of all stakeholders—parents, teachers, and children—that school-based T1D care has critical gaps and needs improvement, there have been surprisingly few interventions targeting care in this setting. A 2014 systemic review of school-based interventions by Edwards and colleagues highlighted only 11 intervention studies (3 randomized controlled trials; RCTs) in the 15 years prior focusing on this population [17]. A further systematic review by Pansier and Schulz in 2015 [18] identified 15 intervention studies, although some of these focused on type 2 diabetes. Interventions tested in these studies included case management services, a telehealth intervention, and the application of the Healthy Learner Model for Chronic Conditions [19], which included access to a diabetes nurse specialist for school nurses [20]. Of the studies identified that intervened upon the child/student with T1D, quality of life improved in two studies [21, 22] and glycemic control improved in the 2 out of 3 studies in which it was measured [21, 23], with the other study evidencing no change [24]. The remaining 6 studies targeted school personnel (teachers, nurses) using real-time or computerized educational programming. Results of these studies targeting school personnel suggested that the educational interventions improved diabetes knowledge [25–27], increased teacher confidence in managing a hypothetical child with T1D [28, 29], and increased nurse perceived competence [27, 28, 30] while one study evidenced no change in diabetes knowledge following the intervention [28]. Overall, these earlier studies of school-based interventions suggest that there is some, limited, evidence for improving glycemic control and quality of life outcomes of children with T1D with school-based interventions. Educational interventions targeting school personnel do appear to have some mixed benefit on outcomes surrounding knowledge and related constructs; however, examination of how this impacted children with T1D cared for by these school personnel was not conducted. One more recent intervention conducted in Brazil provided an educational pamphlet to school personnel about T1D and T2D and, similar to past studies, found that staff knowledge and confidence in diabetes care improved [31•]. All intervention studies described here were limited by small sample size and few were randomized study designs, limiting the conclusions that can be drawn.

Gaps in the Literature and Next Steps

In addition to the limitations of existing descriptive and interventional studies noted above, the extant literature has several important gaps worth noting. The authors' anecdotal clinical experiences suggest that alternative school settings (e.g., homeschool, hospital home-bound school, virtual school) are at times pursued by families of children with diabetes for a variety of reasons. These reasons can include frequent school absences related to BG levels and/or medical appointments, family perceptions of challenges in managing T1D at school, and teasing/bullying experienced by children with T1D. However, there are currently no examinations of this phenomenon in the literature and thus we do not have estimates of the frequency with which families make these choices or the reasons behind them. Perhaps just as importantly, we also have little understanding of the impact such alternative school choices have on diabetes care or associated psychological, social, and educational outcomes. In the literature to date, there is also a lack of attention to additional consequences that school-based T1D management may have on families. For example, parents who have little confidence and perceived support for diabetes care in the school setting may choose not to work, may seek only part-time work, or may seek employment at their child's school in order to be available to assist with their child's T1D management on a daily basis. While this phenomenon has not been studied in the literature, it likely has an impact on parent quality of life in addition to financial consequences.

The impact of technologies such as insulin pumps and continuous glucose monitors on diabetes care in general also requires further study in relation to school management. Only one small study has examined the role diabetes technology plays in the collaboration between parents and daytime caregivers, including school personnel [19], and further work needs to examine the way in which the use of technology may mitigate or exacerbate challenges in managing diabetes in school. While early evidence suggests that parents and school caregivers appreciate the use of technology in schools, we do not know how these technologies impact school-age children—does the use of these devices contribute to unwanted social attention? Or might device alarms cause yet further disruptions in a child's educational functioning? Are school nurses comfortable with new technology? Further work is needed to answer these important questions and to address any school-based barriers to technology that exist, such as technology limitations (e.g., connectivity challenges) and school personnel with limited education about the devices. Finally, the literature in the area of school-based diabetes management has traditionally focused on secondary school settings. We know much less about how diabetes is managed at the extremes of the educational continuum, that is, in preschool and college settings. Yet these populations, due to their young age or their newly acquired independence, may be at heightened risk of encountering barriers and challenges in effective diabetes management in educational settings.

Conclusion

The school environment is clearly relevant for the safe and effective management of T1D in children. Limited evidence supports that stakeholder (teacher, parent) perceptions of T1D management at school is improving in certain ways, namely, following legislative mandates or the use of diabetes technologies such as continuous glucose monitoring. Markedly less is known about the perceptions of students' perceptions of diabetes management. Further, the preponderance of literature continues to suggest that ongoing barriers to school-based management of T1D exist including deficits in school staff education, less than adequate structural support for diabetes management at school, and parental fear of hypoglycemia. Despite this, there have been remarkably few school-based intervention studies and those that do exist were generally conducted more than 5 years ago, although they do evidence early promise in improving the knowledge base of school personnel and in child outcomes such as glycemic control and quality of life. The dearth of T1D-focused interventional studies in schools likely highlights the difficulty of conducting research in this setting. For example, it can be challenging for researchers to find large enough samples to appropriately test interventions when there are only a small number of children with T1D attending each school. Further, school-based research requires navigating complex organizations (e.g., city and county school boards) for approvals and researchers must obtain support from a variety of stakeholders (e.g., families, diabetes clinics, school educational staff, school nursing staff, school leadership) with differing needs and concerns (e.g., student instruction time and academic impact, medical management of T1D, cost-effectiveness and sustainability of the interventions being tested). Creative approaches are necessary to successfully conduct research in this setting, such as by providing continuing education credits for teachers or nurses participating in educational interventions and the use of simple, cost-effective interventions that are easily sustainable, such as the education pamphlet developed by Chinnici and colleagues [31•]. Overall, it is clear that the literature in this area has notable gaps including the absence of recent, well-characterized interventions, investigations of educational settings relevant for very young children and young adults, and the consideration of additional factors such as newer diabetes technologies and non-traditional educational settings such as home school. There is a clear need for additional research to further our understanding of the barriers to school-based management of T1D and develop and test strategies to overcome these challenges.

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Compliance with Ethical Standards

Conflict of Interest The authors declare that they have no conflict of interest.

Human and Animal Rights and Informed Consent This article does not contain any studies with human or animal subjects performed by any of the authors.

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31.• Chinnici D, Middlehurst A, Tandon N, Arora M, Belton A, Reis Franco D, et al. Improving the school experience of children with diabetes: evaluation of the KiDS project. J Clin Transll Endocrinol. 2019;15:70–5 **This qualitative study highlights a low-cost, low-intensity intervention consisting of a T1D-focused education pamphlet targeting school staff developed in collaboration with the International Diabetes Federation. Emerging themes suggested that the intervention improved school staff knowledge and confidence in T1D management and also improved their relationship with students with T1D**.