


## Research Article

# Developing Self-Management of Type 1 Diabetes in the Australian School Setting: Perspectives of Adolescent Involvement in Sharing Responsibility for Diabetes Management

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The International Society for Pediatric and Adolescent Diabetes has identified school as a critical context for adolescents with type 1 diabetes (T1D) who typically hold a fluctuating, though growing, amount of responsibility for diabetes self-management across this time. When parents use frequent autonomy-supportive communication to maintain a mutually agreeable sharing of responsibility for diabetes management with their adolescent, better outcomes are achieved. There is, however, a dearth of research examining the way adolescent responsibility is managed at school. This cross-sectional study investigated adolescents' perspectives of sharing responsibility for T1D management at school and the extent to which these were concordant with parent perceptions. Sixty adolescents (10–19 years) and fifty-five parents completed questionnaires measuring the perceived impact of diabetes on adolescents' school activities and respective involvement in the management of responsibility for school-based diabetes care. Adolescent questionnaires also measured perceptions of autonomy supportiveness (Health Care Climate Questionnaire) and communication quality (frequency, mode, autonomy), in relation to diabetes management. Differences by age and inter-rater agreement between parent and adolescent dyads were examined. Results showed that parents and adolescents did not agree about their relative involvement in setting up diabetes management strategies or the impact of diabetes on school activities. There was no difference in the involvement of older adolescents relative to younger students. Adolescents predominantly communicated about school diabetes care in person, though some reported no communication with school staff (25%) or healthcare workers (36%). Only thirty nine (65%) reported having a diabetes school plan. Nineteen (32%) perceived little or no involvement in setting up diabetes care strategies for the year and most had not attended a school-related meeting. These results suggest more explicit inclusion of adolescents in formal school support strategies may better represent their unique perceptions of responsibility, enabling the consensual sharing of responsibility that is associated with better outcomes.

## 1. Introduction

Although only 11% of the 1.1 million Australians who live with diabetes have type 1 diabetes [1], they bear 29% of diabetes-related hospital admissions [2]. The peak age for type 1 diabetes (T1D) diagnosis is 10–14 years, equating to decades of living with diabetes, wherein 40% will develop a complication such as retinopathy, neuropathy, kidney, and/or cardiovascular disease. The financial cost of caring for those with complications is 5.2 times higher than for

those without [3]. Young people with T1D have more school absences and are more likely to develop depression, with associated social disadvantages of lower employment rates and earnings [3, 4].

Many countries, such as Australia, are facing an increasing prevalence of chronic health conditions, including T1D [5]. This has seen a cultural shift for health care systems that reflect Wagner's seminal Chronic Care Model, moving care from an acute episodic model to one that is "heavily preventative," offering "behaviourally sophisticated support

for the patient as self-manager” (p2) across the multiple contexts in which they live [6]. This approach has been repeatedly referenced in healthcare policies that aim to reduce the burden of chronic health care for the individual and society by promoting self-care as the mainstay of treatment [7, 8].

Proactively supporting adolescents who have T1D to take responsibility for their own diabetes self-management (DSM) is therefore a key principle that underlies health care for this population [9]. This approach sees a loose transition of ownership for diabetes care, within families, such that responsibility is typically apportioned fairly evenly between the adolescent and their parent by the age of thirteen and held in majority by the adolescent by their late teens [10, 11]. Better metabolic rate and quality of life outcomes are achieved when parents maintain a state of shared responsibility for diabetes management with their adolescent [12, 13]. Shared responsibility has been conceptualised as an interdependence that functions to provide flexible, ongoing support for adolescents who must work to constantly meld a burdensome diabetes routine with rapidly changing daily activity patterns [14]. Clinical guidelines recommend that broad support for developing self-management should occur in the context of a collaborative team in which responsibility is shared between healthcare professionals (HCPs), teachers, parents, community groups, and adolescents [15].

To identify the current state of evidence around the practice of responsibility sharing, our research group conducted a scoping review which determined that responsibility sharing primarily occurs through verbal and written communication processes that enable clear, regular delineation, allocation, and enactment of responsibility for diabetes care tasks for all team members [16]. The review found that frequent, explicit communication with adolescents supported effective responsibility sharing by enabling fluctuations in capacity or interest for diabetes care to be recognised and accommodated by caregivers [17, 18]. The use of autonomy-supportive communication to deliver greater choice and control for the adolescent was associated with greater amounts of adolescent responsibility assumption and better metabolic outcomes [19–21]. Families that negotiated responsibilities for diabetes care to a point of agreement achieved better observance of treatment regimens and improved metabolic and quality of life outcomes [16, 22].

As adolescents spend 6–10 hours a day at school and are reported to independently perform a greater number of diabetes care tasks at school compared to home, the school environment is a particularly important context in which support for DSM is required [15, 23]. Older adolescents are reported to hold a larger amount of practical responsibility for the execution of diabetes care tasks compared to younger adolescents and might therefore be expected to have a greater amount of information to contribute towards the determination of optimal school diabetes care processes [24]. Research based within the family home found that shared responsibility was uniquely associated with better metabolic management for older adolescents, and this was

postulated to relate to the increasing burden and complexity of diabetes care for this age group [25]. Outside of the family unit, in health care and school settings, the support needs of older versus younger adolescents on the path to self-management are less clear. An integrative review of familial responsibility transferral for adolescents with chronic kidney disease recommended that the support of HCPs for adolescent self-management should persist into older adolescence, to allow for shifting responsibilities over time [8]. Communication about school, which is responsive to the needs of different age groups, may similarly support developing DSM. While research in this area is lacking, maintaining adolescents’ ongoing involvement in communications about responsibility for diabetes care is seen to be a fundamental aspect of their engagement in diabetes care [4, 26].

For the school context, the use of a school plan to clearly articulate diabetes management responsibilities is considered best practice, yet the contribution of adolescents to plan development and enactment has received scant attention [15]. Qualitative studies report adolescents, teachers, parents, and HCPs best manage shared responsibilities through frequent communication about the performance of diabetes care tasks at school, though these processes are poorly described [27, 28]. While a teamwork approach to diabetes care is broadly endorsed [15, 29], the function of the adolescent within this school-based support team has not been clearly defined or researched to date.

Australian guidelines for managing T1D at school assert overall parental responsibility for the determination of appropriate support strategies with schools, including the provision of the school diabetes management plan that represents the adolescent’s diabetes care requirements. There is a limited role description for student involvement in this process [30]. A key tenet of effective responsibility sharing is the joint involvement of the adolescent and parent in order to clarify discrepancies in responsibility assumption and thereby enable targeted support for gaps in diabetes care [26, 31]. Intrafamily discrepancies about adolescent responsibilities for diabetes care are considered normative, with greater discrepancies associated with poorer outcomes [32]. Better outcomes have been reported when parents and adolescents agree on diabetes responsibilities [33, 34]. Given that adolescents hold a growing majority of the responsibility for their diabetes care during the school day and that autonomy support for their diabetes care is understood to be fundamental to their ongoing development of effective DSM [19, 21], the question of how they are represented in processes that determine school-based diabetes management is an important one. A better understanding of the relative involvement of parents and adolescents in determining responsibility for diabetes management at school is therefore warranted.

This study was developed as the first part of a mixed-method investigation into the way that adolescents who manage T1D at school are involved in the processes of responsibility sharing. Firstly, the study aimed to investigate adolescents’ unique perceptions of participation in the sharing of responsibility for T1D management at secondary

school. Participation is understood to reflect both the frequency and intensity of involvement in formal (e.g., school plans and team meetings) and informal communication processes across this time [35]. Secondly, the paper examined the extent to which parents' report was in agreement with adolescents' report as to the effect of diabetes on their participation in school-related activities and involvement in processes that determine responsibilities for diabetes care at school. The research questions were as follows:

- (1) How do adolescents with T1D perceive their communication about school-based diabetes care (mode, frequency, and autonomy supportiveness), with parents, school staff, and the health care team?
- (2) Do the perceptions of adolescents with T1D differ in relation to their involvement in the management of school-based responsibilities, according to age?
- (3) Do adolescent perceptions of the impact of diabetes on their school activities and their involvement in determining their diabetes care align with parents' perceptions?

## 2. Materials and Methods

This cross-sectional study utilized a paper-based questionnaire with consenting families at diabetes clinics from two study sites as follows: one is the largest children's hospital in Australia (Queensland Children's Hospital) and the other is a private endocrinology practice, both in Brisbane, Australia. The first author collected all data, face to face, in 2018 to 2019 (pre COVID-19 pandemic). Ethical approval was provided by the Children's Health Queensland HREC (LNR/18/QCHQ/46374) and the University of Queensland (#2018002186).

*2.1. Participants and Procedures.* Diabetes educators spoke to all adolescents and their parents on arrival at their usual quarterly outpatient clinic appointment. They were invited to take part in the study if the following inclusion criteria were met: adolescents were aged 10–19 [36], able to speak and read English, diagnosed with T1D for more than one year, attending a mainstream school over the past term, and without any significant concurrent disability that required additional school support. Accompanying parents needed to be proficient in English. Willing parents and adolescents were then approached by the primary researcher (first author) who further explained the study, obtained full consent, and administered separate questionnaires to parents and adolescents.

### 2.2. Measures

*2.2.1. Glycated Haemoglobin (HbA1c % or mmol/mol).* The HbA1c reading provides an indication of the glycated haemoglobin, or level of glucose that has accumulated in the circulating blood, over the previous 2 to 3 months, providing an objective indicator of adolescent glycaemic management. It is standard practice to require HbA1c testing within both

clinics where recruitment took place, and clinic staff, with participants' consent, provided the most recent HbA1c blood test results (%) for each adolescent.

*2.2.2. Involvement in Processes That Handle Responsibility at School.* Due to a lack of instruments that reliably measure responsibility sharing [23], a series of questions were developed for this study to map involvement in processes relevant to responsibility sharing at school (communication mode, communication frequency, and level of stakeholder involvement) [16], and impact of diabetes on school activities. Categorical response sets were used for the mode of communication (email, text, phone, and/or in person) and school plan involvement (e.g., do you have a school plan? 1 = yes; 2 = no). Likert scales were used for frequency of communication (e.g., how many times last term did you communicate with your teacher about diabetes management in the last term? 1 = never to 6 = daily) and perceived level of stakeholder involvement in diabetes care arrangement (e.g., how involved were your parents in setting up your diabetes management at the beginning of the year? 1 = not involved to 5 = totally their job). Questions were mostly replicated in the adolescent and parent questionnaires, with questions rephrased so both parents and adolescents were reporting on their perceptions of the other's actions and their own actions (e.g., adolescent/parent question: how involved were you/was your child in setting up your/their diabetes support at the beginning of the year?). Similarly, replicated questions asked how parents and adolescents perceived that diabetes impacted on adolescent schoolwork, sport, excursions, camps, friendships, and school satisfaction.

*2.2.3. Healthcare Climate Questionnaire (HCCQ).* The HCCQ measures the degree to which people perceive their healthcare providers to be autonomy supportive. The HCCQ short form comprises six items utilizing a Likert scale with seven options from strong disagreement (score = 1) to strong agreement (score = 7). It has good internal reliability (Cronbach  $\alpha = 0.82$ ), has been validated by people with diabetes, and has been used with a high school population with acceptable internal reliability (Cronbach  $\alpha = 0.73$ ). An overall mean score is calculated, with a higher mean interpreted as a higher level of perceived autonomy support from HCPs [37]. Only the adolescent questionnaires contained the HCCQ. The six HCCQ items were repeated three times, with each set of questions relating to the perceived autonomy support for their diabetes management that was provided by their school, parents, or healthcare team.

*2.3. Data Management and Analysis.* Statistical analyses were conducted using the Statistical Package for the Social Sciences (SPSS) Version 28. Descriptive statistics (frequencies, percentages, means, and standard deviations, wherever applicable) were generated for demographic variables. Cohen's weighted kappa (with linear weighting, kw) was calculated for ordinal variables to account for the degree of agreement between parents and adolescents on (a)

perceived level of stakeholder involvement in determining responsibility sharing arrangements and (b) perception of the effect of diabetes on adolescents' involvement in school activities [38]. Wilcoxon signed-rank tests were used to examine directionality of agreement between parent/adolescent-matched responses. The age group differences in processes related to responsibility sharing and HbA1c were analysed using Chi square analysis. Spearman's rank order correlations were used to examine associations between adolescents' perceptions of autonomy supportiveness of parents, school staff, and HCP.

### 3. Results

Questionnaires were completed by sixty adolescents and fifty-five parents, of whom 72% ( $n=40$ ) were mothers. Demographic information is detailed in Table 1. Diabetes-related characteristics are recorded in Table 2. The average HbA1c for the adolescents in this study of 72 mmol/mol (8.7%) is above the recommended target of 53 mmol/mol (7%) for adolescents, which is associated with optimal health outcomes [39].

**3.1. Communication Mode.** Adolescents predominantly reported having in person communication about their diabetes management with parents, HCPs, and relevant school personnel (Table 3).

**3.2. Communication Frequency.** Twenty-five percent of adolescents ( $n=15$ ) reported having no communication with their teachers about their diabetes management over the past school term, and 36% ( $n=21$ ) of adolescents reported no communication with their HCP about school over that time (Table 3). Sixty-seven percent ( $n=39$ ) of adolescents reported they had not been to a meeting in the last full-term to discuss diabetes management (Table 4).

**3.3. Autonomy Support.** Of the 33% ( $n=19$ ) of adolescents who reported they had attended a meeting about their diabetes management, only 21% ( $n=4$ ) described being included in decisions about what was discussed. Thirty-two percent ( $n=19$ ) of adolescents reported that they were either not involved ( $n=9$ , 15%) or a little involved ( $n=10$ , 17%) in setting up their diabetes care at school. Adolescents scored teachers as providing the least support for autonomy (HCCQ) (Table 2). Positive correlations were noted between adolescents' perception of the supportiveness of their parents, teachers, and HCPs; parents and teachers ( $\rho=0.56$ ,  $p<0.001$ ); teachers and HCPs ( $\rho=0.62$ ,  $p<0.001$ ); parents and HCPs ( $\rho=0.65$ ,  $p<0.001$ ).

**3.4. School Plans.** Sixty-five percent ( $n=39$ ) of adolescents reported having a T1D school management plan. Thirty-three percent ( $n=20$ ) reported having helped to develop the plan and 35% ( $n=21$ ) had a copy of the plan. Thirty-three percent ( $n=20$ ) felt they had helped to explain the plan to their teachers. Twenty-two percent ( $n=13$ ) of adolescents

reported that their school plans contained goals for diabetes management. Thirty-one percent ( $n=13$ ) reported that changes were made to their plan in the last year.

While 77% ( $n=46$ ) of adolescents felt school was a place of safety in relation to their diabetes management, fewer affirmed that school was a place where they sometimes (42%) or consistently (22%) learned to better take care of their diabetes.

**3.5. Age Differences.** Two age groups were identified as early (10–14 years;  $n=29$ ) and late (15–19 years;  $n=31$ ) adolescence [13]. Younger adolescents attended their appointment with their parents, while 16% of the older adolescents attended alone. There was no significant difference in the mean HbA1c score between the younger and older adolescents. Chi square analysis showed no significant differences between older and younger adolescent involvement in processes that manage diabetes responsibilities (Table 4).

**3.6. Involvement in Setting Up Diabetes Care and Impact of Diabetes on School Participation.** Almost half of the adolescents perceived little or no involvement from school staff (48%,  $n=29$ ) or HCPs (43%,  $n=26$ ) in the development of their diabetes management strategies for school. Twenty percent ( $n=12$ ) of adolescents believed these decisions were totally their parents' responsibility. Forty-two percent ( $n=25$ ) reported that their parents were very involved in arranging diabetes management strategies for school. Thirty-two percent ( $n=19$ ) of adolescents reported they themselves were only a little involved or not at all.

There was no agreement between parents and adolescents on the level of parental involvement ( $n=50$ ,  $k=0.117$ ,  $p=0.136$ ) or involvement of the HCP ( $n=51$ ,  $k=0.173$ ,  $p=0.007$ ) in setting up diabetes care arrangements for the school year. Parents and adolescents had minimal agreement on the adolescents' level of involvement ( $n=51$ ,  $k=0.248$ ,  $p=0.002$ ) in this process.

Similarly, there were minimal levels of agreement between parents and adolescents in relation to perceptions of the effect diabetes had on excursions ( $n=51$ ,  $kw=0.210$ ,  $p=0.023$ ), sport ( $n=53$ ,  $kw=0.235$ ,  $p=0.010$ ), schoolwork ( $n=52$ ,  $kw=0.288$ ,  $p=0.002$ ), and friendships ( $n=54$ ,  $kw=0.342$ ,  $p<0.001$ ). No agreement was evident for the effect of diabetes on school camps ( $n=49$ ,  $kw=0.166$ ,  $p=0.079$ ). Parents and adolescents also had no agreement on their satisfaction with diabetes management at school ( $n=53$ ,  $k=0.074$ ,  $p=0.326$ ). There was no statistically significant evidence of directionality between parent and adolescent matched responses.

### 4. Discussion

This study explored adolescent perceptions of their participation in processes that handle responsibility for diabetes care at school. In relation to the research questions posed, the findings show that adolescents primarily communicated about their diabetes in person at school though congruent with past research, they were

TABLE 1: Demographics of adolescents ( $N=60$ ) and matched parents ( $N=55$ ).

Adolescent characteristics		Frequency, $N$ (%)
Adolescent age (years) (mean = 14.5, SD = 1.79)	10–14	29 (48)
	15–18	31 (52)
Adolescent school grade (mean = 9.6, SD = 1.69)	7	9 (15)
	8	8 (13)
	9	10 (17)
	10	14 (23)
	11	12 (20)
	$\geq 12^a$	7 (12)
Adolescent gender	Female	19 (32)
	Male	41 (68)
Parent gender	Mother	40 (72)
	Father	15 (18)
School type	Private	29 (45)
	Public	24 (55)
Mothers' level of education	Bachelor	15 (29)
	Advanced certificate	18 (35)
	Year 12	8 (15)
	Year 10	10 (19)
	Less than year 10	1 (2)
Fathers' level of education	Bachelor	15 (29)
	Advanced certificate	12 (23)
	Year 12	11 (21)
	Year 10	11 (21)
	Less than year 10	3 (6)
Family income (\$AUD)	31200–52999	4 (8)
	53000–77999	9 (17)
	78000–103999	13 (25)
	104000 or more	26 (50)

<sup>a</sup>Data for three adolescents collected within three months of finishing final school year, which is "Grade 12" in Australia.

TABLE 2: Adolescent diabetes-related measures.

Adolescent diabetes-related measures	Range	Mean (SD) or median
HbA1c % (mmol/mol) ( $n=59$ )	6.1%–14.0% (42–130 mmol/mol)	8.7% (1.72) (72 mmol/ml)
Effect of diabetes on participation in <sup>a,b</sup>		
School work ( $n=59$ )	1–5	2.00
Exams ( $n=58$ )	1–5	2.00
Sport ( $n=59$ )	1–5	2.00
Camp ( $n=58$ )	1–5	3.00
Friendships ( $n=60$ )	1–5	1.00
Time since diagnosis (years)	1–14	5.5 (3.36)
HCCQ <sup>b</sup> ( $n=58$ )		
Parents' autonomy supportiveness	1.3–7.0	5.67
Teachers' autonomy supportiveness	1.0–7.0	4.83
HCPs' autonomy supportiveness	1.5–7.0	5.67

<sup>a</sup>Likert scale of five where 1 = does not affect and 5 = strongly affects. <sup>b</sup>Adolescent self-report.

underrepresented in team communications that determine school-based diabetes management processes [24]. This level of underrepresentation did not change for adolescents who had reached the later grades of schooling, even though older adolescents are reported to assume comparatively greater responsibility for their own diabetes management by this time [11]. Finally, the lack of agreement between adolescents and their parents about their level of involvement in diabetes care

arrangements and the impact of diabetes on school activities supports the need for more explicit adolescent inclusion in school communication processes.

In line with the overall aim of this study, three main findings will be discussed in relation to the key drivers of effective responsibility sharing; caregiver provision of frequent, autonomy supportive communications about diabetes care; adolescent involvement in the development of management strategies across the adolescent period;

TABLE 3: Adolescent report of frequency and modes of communication about school diabetes management.

Characteristics of communication	Health professional, <i>n</i> (%)	School staff, <i>n</i> (%)	Parents, <i>n</i> (%)
Mode <sup>a</sup>			
In person	28 (72)	38 (82)	38 (65)
Text	—	—	—
Email	1 (3)	—	3 (5)
Combination of text/email/in person	10 (25)	5 (16)	17 (30)
Frequency			
No communication	21 (36)	15 (25)	3 (5)
1–3 per term	32 (55)	23 (39)	13 (22)
7–10 per term	5 (9)	21 (36)	44 (73)

<sup>a</sup>Adolescents indicated as many modes as were relevant.

TABLE 4: Differences by age in adolescents who self-reported no involvement in managing responsibility for diabetes care at school (*N* = 60).

Type of involvement	Young adolescent (11–14 years; <i>n</i> = 29) <i>n</i> (%)	Older adolescent (15–19 years; <i>n</i> = 31) <i>n</i> (%)
Never communicated about school with health care team over last term	10 (34) ( <i>n</i> = 29)	11 (36) ( <i>n</i> = 31)
Never communicated with teachers over last term	5 (17) ( <i>n</i> = 29)	10 (32) ( <i>n</i> = 30)
Never attended meetings about school over last term	16 (55) ( <i>n</i> = 28)	25 (81) ( <i>n</i> = 30)
No involvement in school plan development	11 (50) ( <i>n</i> = 22)	14 (61) ( <i>n</i> = 23)
No changes made to school plan over the year	13 (65) ( <i>n</i> = 20)	16 (73) ( <i>n</i> = 24)
Did not help explain school plan to teachers	11 (50) ( <i>n</i> = 22)	14 (61) ( <i>n</i> = 23)
No involvement in setting up school diabetes care strategies for the year	4 (14) ( <i>n</i> = 29)	5 (17) ( <i>n</i> = 30)

Note. Due to missing data, *n* has been reported for each item.

and parent and adolescent agreement on diabetes management [16].

*4.1. Frequent Autonomy Supportive Communication with Caregivers about School Diabetes Management.* The report of a moderate level of autonomy support that was highly correlated among parents, teachers, and HCPs, together with a predominance of personal communication may reflect a sense of relatedness felt by adolescents for these adults. This has been described as an important condition for adolescent engagement with self-management behaviours [40].

This finding is countered by the report that some adolescents had no individual communications with HCPs (36%) or teachers (25%), and the majority had never attended a team meeting about their diabetes management at school. These gaps in communication may have reflected a lack of initiative by parents, schools, HCPs, or the adolescents themselves. There is a paucity of literature exploring the interpersonal dynamics underlying the relative contribution to this lack of communication. Qualitative studies report adolescents commonly seek privacy around DSM [41], lack confidence, and/or do not prioritise school-based diabetes care [42], which may contribute to this sparse

communication. Alternatively, this may relate to a reduction in the amount of school-based support offered to adolescents compared to children [24]. Frequency of communication about diabetes care is reported to be a key component of effective responsibility sharing that allows responsivity to adolescents' fluctuating needs in order to cover any gaps in performance, mitigate mismatched priorities, and promote skill development [4, 26, 43]. These results suggest that there is opportunity for caregivers to offer a greater amount of personal communication with adolescents, which may enable better sharing of responsibility.

*4.2. Adolescents' Involvement in Development of Strategies for School Diabetes Management.* The finding that one-third of adolescents perceived little or no involvement in setting up their diabetes care strategies for the school year suggests that there is opportunity for greater inclusion in school processes that share responsibilities for diabetes care. Involving students in communication processes that delineate and allocate responsibilities for diabetes has been linked to more effective responsibility sharing by enabling mitigation of any ambiguities and/or disparities of capacity or interest between adolescents and their caregivers [18, 31]. It is also

reported to allow caregivers the opportunity to provide the adolescent with the choice and control over their management that is associated with better observance of diabetes regimens [19]. Hence, the reasons underlying the lack of student inclusion observed in this study are an important area for further investigation.

The reported absence of a school plan for one-third of adolescents in this study aligns with an Irish cross-sectional study that found 74% of adolescents with T1D did not have a school plan and a systematic review of 66 UK-based studies that found more than 50% of students of all ages lacked a school plan for diabetes management [24, 44]. The International Society for Pediatric and Adolescent Diabetes (ISPAD) describes the school plan as an essential part of diabetes care for all students [15]. The school plan functions to delineate school-based responsibilities, while also acting as a means to manage treatment barriers at school that may limit responsibility assumption [29, 45]. Clarity around responsibilities for diabetes care is reported to be a key element of effective shared management [31], and so the lack of broad adolescent inclusion in school plan production and usage also merits further specific consideration.

There was no significant difference between the involvement of younger and older adolescents, with both groups reporting a substantive lack of involvement in processes used to share responsibility for their diabetes management at school (Table 4). These results suggest that older adolescents may not have been routinely afforded a role in the responsibility sharing process that was commensurate with their greater level of responsibility, relative to younger adolescents [11]. Although parents have reported an overall decrease in conversations about diabetes as adolescents mature, they note a greater tendency for older adolescents to seek advice, express opinions, and initiate conversations about diabetes, particularly with respect to management challenges [20, 26, 46]. Providing greater opportunity for involvement in the development of diabetes management strategies may therefore be particularly critical for older adolescents who are learning to self-manage diabetes.

*4.3. Parent and Adolescent Agreement about Managing Diabetes at School.* Parents and adolescents in the current study exhibited low levels of agreement on the level of contribution that they themselves or schools and HCPs made to the processes of responsibility sharing at school or the effect that diabetes has on student participation in school activities. They held no agreement on their general satisfaction with diabetes management at school. Similar parent-adolescent disagreement has been elsewhere reported such that, when compared to adolescent perceptions, parents have reported a greater adolescent burden of diabetes [47] and lower perceived satisfaction with the support their adolescent received at school [48]. It has further been reported that once parents hand over responsibility to schools, they have limited awareness of their child's diabetes management in that environment [49].

The importance of parents' participation in the care team is well-supported with evidence that better outcomes are associated with continued parental involvement in diabetes care across adolescence [4, 26]. Communication about responsibility for diabetes care, between parents and adolescents, is critical for responsibility uptake, with negotiation to the point of agreement associated with better metabolic outcomes [33, 34, 46]. The results of this study highlight the unique views that parents and students have when it comes to responsibility for diabetes care at school—supporting the need for representation of both in negotiation of school-based responsibility allocation.

It is of note that one in six older adolescents attended their health clinic appointment without their parent, despite the findings that sixty-two percent of surveyed adolescents reported that their parents had heavy or complete responsibility for school-based care arrangements. This may represent another loss of opportunity for team communication and agreement about school-related issues. Within the context of regular clinic appointments, physicians have been able to increase parental collaboration with adolescents in order to improve the metabolic management [50]. The reasons for the lack of parental involvement at this appointment therefore warrant further exploration in relation to the management of diabetes for the school context.

Student-centred learning as well as patient-centred care cannot be enacted without the explicit involvement of the central individual, that is, the adolescent living with T1D. This study identifies that greater practical opportunities for adolescent involvement at school (e.g., meetings and school plans) can be offered. More direct involvement of adolescents in responsibility sharing processes may diminish the discrepancies between adolescent and caregiver perceptions of competency and independence for diabetes management, which are known to be related to poorer outcomes [32]. This may also enable greater alignment of priorities between caregivers and adolescents [4].

*4.4. Limitations and Future Research.* This study implemented a survey to gather data to describe the involvement of students in the processes used to share responsibility for T1D at school. There was a lack of reliable, valid measures of responsibility sharing applicable in the school context [23], requiring specific design of a questionnaire for this study. The questions were designed to quantify responsibility sharing processes in schools but were not subjected to psychometric analysis to determine validity and reliability.

The current limited sample involved more families with higher education and income levels and comprised more male adolescents than females. Future studies might involve a larger and more diverse sample. Finally, the cross-sectional nature of the study, small sample size, and lack of psychometrically sound instruments restricted analyses to descriptive and correlational statistics. The current research group is implementing an exploratory mixed methods approach to extend knowledge gained from this study. Further research is needed to develop an understanding of the required responsibilities for the school context, explore the

unique perspective of the adolescent tasked with self-managing their diabetes at school, and measure the effect of purposeful school-based responsibility sharing on the long-term health of adolescents with T1D. Hence, longitudinal studies are vital to identify predictors of better long-term outcomes.

## 5. Conclusion

Overall, these results highlight the unique perspective that adolescents hold in relation to their responsibility for diabetes care and suggests that the student is underrepresented in the team that determines diabetes management at school. Research to date has identified better metabolic and quality of life outcomes in families where positive, warm, and autonomy-supportive communication allows negotiation of responsibility for diabetes care to a position of agreement [16, 51]. The findings in this study suggest that, in the school context, many adolescents with T1D miss the opportunity to participate in these kinds of communications and the accompanying self-management opportunities they afford. The lack of a detailed inclusion process that enables both optimal frequency and intensity of student involvement in school health care may render young people's participation as "no more than passive involvement in a managed process" (p. 238) [52], undermining the sense of autonomy that is widely recognised as critical to adolescent engagement in diabetes self-care [26]. Attainment of more explicit and mutually agreed support strategies to share responsibilities within school processes has the potential to promote better health and educational outcomes for adolescents with T1D.

## Data Availability

No underlying data were collected or produced in this study.

## Conflicts of Interest

The authors declare that they have no conflicts of interest.

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