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Original Research

Living with Sensor-Augmented Pump Therapy in Type 1 Diabetes: Adolescents' and Parents' Search for Harmony



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ABSTRACT

Objective: Adolescents have difficulty successfully sustaining use of continuous glucose monitoring even when it is introduced to experienced pump users. However, little is known about how adolescents and parents perceive and manage sensor-augmented pump therapy (SAPT) in daily life. The purpose of this study was to explore adolescents' and parents' daily experience of living with SAPT.

Methods: We used an interpretive phenomenological study design. We conducted in-depth, digitally recorded interviews with 7 adolescents and 9 parents recruited through 1 Canadian pediatric diabetes program. Adolescents who participated were 13 to 17 years of age with type 1 diabetes mellitus and had experience (current or past) living with SAPT. Transcripts of the interviews were subjected to a thematic analysis guided by the procedure outlined by Colaizzi.

Results: The overarching theme, seeking harmony, reflected adolescents' and parents' daily struggles with balancing multiple tensions that arose from managing SAPT and harmonizing seemingly opposing choices that were brought to the fore, while also struggling to live with both wellness and chronic illness. Four themes constituted the struggle to find harmony living with diabetes managed with SAPT: struggling with hopes and expectations for SAPT, being ready for SAPT, living the burdens of continuous glucose monitoring and creating partnerships.

Conclusions: Healthcare providers can facilitate adolescent and parental decision-making about the optimal timing for SAPT introduction. Success with SAPT requires exploration of adolescent and parental expectations for SAPT as well as the degree to which parents have previously fostered their adolescent's involvement in and responsibility for diabetes management.

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R É S U M É

Objectif : Les adolescents éprouvent de la difficulté à utiliser efficacement un système de surveillance de la glycémie en continu même lorsqu'il est proposé à des utilisateurs expérimentés de pompe. Cependant, on en connaît peu sur la manière dont les adolescents et les parents perçoivent et prennent en charge le traitement par pompe reliée à un capteur (SAPT : *sensor-augmented pump therapy*) dans la vie quotidienne. Le but de cette étude était d'examiner le vécu quotidien des adolescents et des parents sur le plan du SAPT. **Méthodes :** Notre plan d'étude consistait en une analyse interprétative phénoménologique. Nous avons mené des entrevues en profondeur enregistrées sous forme numérique auprès de 7 adolescents et 9 parents recrutés dans 1 programme canadien sur le diabète pédiatrique. Les adolescents participants qui avaient de 13 à 17 ans et souffraient de diabète sucré de type 1 expérimentaient ou avaient expérimenté un SAPT. Les transcriptions des entrevues ont été soumises à une analyse thématique selon la procédure de Colaizzi.

Résultats : Le thème principal, soit l'atteinte de l'harmonie, reflétait les luttes quotidiennes des adolescents et des parents pour trouver l'équilibre entre les multiples tensions qui résultaient de la prise en charge du SAPT et l'harmonisation des choix apparemment opposés qui avaient été mis en évidence, tout en vivant difficilement l'alternance entre les périodes de bien-être et de maladie chronique. Les quatre

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(4) thèmes étaient fondés sur la lutte pour trouver l'harmonie lors d'un diabète pris en charge par le SAPT : la lutte remplie d'espoirs et d'attentes concernant le SAPT, la capacité à suivre le SAPT, le vécu du fardeau de la surveillance de la glycémie en continu et la création de partenariats.

Conclusions : Les prestataires de soins peuvent faciliter la prise de décision des adolescents et des parents concernant le moment optimal pour entreprendre le SAPT. La réussite du SAPT exige l'exploration des attentes de l'adolescent et des parents à propos du SAPT, et du degré auquel les parents ont su encourager leur adolescent à s'engager et à se responsabiliser quant à la prise en charge de leur diabète.

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Introduction

Insulin pump therapy combined with real-time continuous glucose monitoring (CGM), known as sensor-augmented pump therapy (SAPT), has been shown to improve metabolic control and reduce rates of hypoglycemia in adults with type 1 diabetes mellitus compared to multiple daily injections or standard pump therapy (1–4). However, most pediatric trials of SAPT have demonstrated modest or no improvements in glycated hemoglobin (A1C) levels, although more frequent sensor use is associated with a greater reduction in A1C, mean glucose and rates of hypoglycemia (2,5,6). These same studies have demonstrated that adolescents, including experienced pump users, have difficulty sustaining SAPT—defined as using CGM at least 6 days a week (2,5). Adolescents have reported—using a survey being tested for its psychometric properties—that alarms, body image issues, loss of freedom and pain with sensor insertion were a few barriers to the use of a previously available CGM device, the GlucoWatch G2 Biographer (7). Parents, reporting on the same tool, said that they considered glucose trend data and the opportunity to detect hypoglycemia and self-correct out-of-range glucose levels to be benefits of SAPT, while recognizing barriers such as physical discomfort and technical glitches (8).

Undoubtedly there are both costs and benefits to using SAPT but it is unclear how these relate to SAPT sustainability in adolescents. No studies have explored the lived experience of using SAPT from the adolescents' or parents' perspectives and its relationship to sustainability of SAPT, and only 1 qualitative study has examined parents' perspectives on pump therapy use in their children, all of whom were less than 12 years of age (9). Both clinicians and patients struggle to determine the optimal use of SAPT in the adolescent age group. It has been suggested that the most important factor for successful CGM use is good selection of potential candidates (10). Given that parental involvement in diabetes management often fluctuates during adolescence and is a key predictor of diabetes outcome (11), we chose to explore adolescents' and parents' daily experience of living with SAPT to better assist them in determining when or if SAPT is an appropriate choice for them.

Methods

We used an interpretive phenomenological study design because this methodology enables the researcher to conduct a detailed examination of each person's perception or account of living with SAPT. That requires understanding both the cognitive, subjective perspective of the person who has the experience and the effect that perspective has on the lived experience or behaviour of that person (9). Our intent in using this methodology was not to develop a predictive and prescriptive theory, but to explore the nature of this experience so as to influence a thoughtful, reflective, attentive practice through the revealing of some meanings of this experience.

Participants and recruitment procedures

We employed criterion-based sampling (12). We were interested in exploring the perceptions of adolescents and their parents while living with SAPT and, therefore, included persons in the study who met the following criteria: adolescents aged 12 to 17 years with type 1 diabetes, who had past or current SAPT use for at least 4 weeks to ensure they had some lived experience with the technology before its rejection, and who resided at home at the time of SAPT. Parents (mothers and fathers) of eligible adolescents were also invited to participate. The sample size was not predetermined, as is consistent with interpretive phenomenology, although 3 to 10 participants are often sufficient for this type of study design (12). We stopped recruitment when we deemed the data to be information rich and complex. Seven English-speaking adolescents and 7 mothers and 2 fathers (i.e. 7 adolescent-parent dyads) volunteered. The adolescents' characteristics are described in the Table.

Once approval was obtained from the institution's Research Ethics Board, we recruited participants from a single regional diabetes program in Ontario, Canada. We placed recruitment posters in the program's clinic, and the program's healthcare team distributed recruitment letters at clinic appointments and mailed them to eligible participants. Interested participants contacted the research nurse directly. We obtained written informed consent at the time of the interview from parents and all adolescents aged 14 years and older and written informed assent from those younger than 14 years.

Data collection

Adolescents and parents engaged in an in-depth interview using a flexible interview guide with open-ended questions. All adolescents and parents were asked to describe their experience of making the decision to implement SAPT. Desired outcomes for SAPT, accounts of satisfaction and dissatisfaction with the

Table

Characteristics of adolescent participants

Female/male, n	4/3
Age, years, median (range)	15 (13–17) [†]
Diabetes duration, years, median (range)	11 (3–14)
Age at diabetes onset, years, median (range)	4 (1.5–10)
Duration of pump use, years, median (range)	4 (0–7)
Duration of CGM use,* months, median (range)	18 (1.5–24)
Introduction to CGM	3 simultaneous pump+CGM 4 delayed: pump, then CGM [‡]

* Two adolescents used sensor-augmented pump therapy (SAPT) for a 6- to 8-week period and then chose to abandon the continuous glucose monitoring (CGM) component. One of these adolescents retried SAPT 1 year later and had been using it for 18 months when enrolled in the study, the last 6 months of which had been nearly continuous usage. The other 5 adolescents were using SAPT on an intermittent basis; all but 1 of the 5 planned to continue this form of diabetes management, whereas the 1 participant who had been struggling with SAPT for 18 months remained undecided.

[†] All ages represented.

[‡] Median, 5 years after pump initiation (range, 1–10).

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