

Parents' experiences of parenting an adolescent with Type 1 diabetes

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Abstract

Aim

Parents play a significant role in the management and monitoring of their children's Type 1 diabetes mellitus; however, the experience of parents of adolescents is under-explored. This qualitative study explored parents' experiences of parenting adolescents living with Type 1 diabetes.

Methods

We conducted semi-structured virtual interviews with a sample of ten parents whose adolescent children attended Paediatric Diabetes services at a hospital in Ireland. Interview recordings were transcribed and analysed using inductive thematic analysis.

Results

Our analysis indicates that despite variation in adolescents' ages and duration since diagnosis, parents shared similar emotional experiences. We generated three main themes reflecting parents' experiences: (1) The long shadow of diagnosis: "hard to take and it was hard to digest", (2) Not just parenting but caregiving: "we're trying to do our best every single day" and (3) "There is no emotional support."

Discussion

The findings extend prior research focusing on parents of pre-adolescent children and highlight that although adolescents living with Type 1 diabetes are encouraged to assume more responsibility for diabetes management tasks, parents remain heavily emotionally and

cognitively involved in diabetes management. Parents require psychological support to enable them to support their adolescent in developing independent self-management into adulthood.

Introduction

Type 1 diabetes (T1D) management is a complex process involving blood glucose monitoring, insulin therapy, nutritional knowledge, coping skills, physical activity, numeracy, problem-solving skills, and risk-reduction behaviours¹⁻³. Thus, considerable effort is required to ensure youth living with T1D avoid or delay T1D-related health complications. Unsurprisingly, parents assume much of the management burden, particularly for pre-adolescent children. Knowledge of the adverse health implications of T1D can make caring especially burdensome⁴⁻⁵, and as T1D is not typically visible to others, peer social support may be limited. Importantly, the impact of caregiver burden is not restricted to parents; parental stress predicts a deterioration in their child's HbA1c, while parental diabetes-specific distress predicts an increase in children's depression symptoms⁶. Therefore, understanding the parental experience is important to support parents and for the benefit of youth living with T1D.

To date, however, literature has primarily focused on the experiences of parents of younger children⁷⁻¹⁰, even though adolescence is an important developmental stage and parents remain influential supports into early adulthood¹¹. Although adolescents assume greater responsibility for direct management tasks over time, this transition does not happen overnight¹². Additionally, adolescence is a time when youth are especially susceptible to peer influences and engage in more risky health behaviours like alcohol use that affect diabetes management. In short, despite increasing responsibility on the part of adolescents, parents likely retain significant caring activities during this life stage; however, the experience of parents of adolescents with T1D is underexplored. This qualitative study explored parental experiences of supporting their adolescent's T1D management.

Method

Design

Participants were recruited from one service. Regarding the model of care, the service was understaffed in consultant allocations as well as nursing, dietetics, and clinical psychology, and there is no outpatient medical social work support for this service. Qualitative semi-structured interviews were used. The interview schedule (Table 1) was informed by literature and the priorities of the multi-disciplinary paediatric diabetes team. The research team also included a member with lived experience of T1D during adolescence. The lead author, a

trained counsellor and psychotherapist with no involvement in patient care, conducted virtual interviews in May-June 2022 using Microsoft Teams.

Participants

Study details were provided via email to all 94 parents/guardians of adolescents aged 14-18 years with a diagnosis of T1D attending the Paediatric Diabetes Clinic. 20 eligible parents initially expressed interest in participating; one declined after further discussion. Of the 19 consent forms distributed by the Advanced Nurse Practitioner, 13 were returned and referred on to the interviewer. Ultimately, nine mothers and one father of adolescents aged 15-18 years participated in interviews lasting an average of 45 minutes (31-71 minutes). To preserve confidentiality in a single-site qualitative study, limited descriptive/health information was collated. All parents were White Irish and all bar one resided in two-parent households. Parents had one ($n=9$) or two ($n=1$) children with T1D; number of siblings ranged from none to 4. All bar one adolescent was diagnosed between 7 and 14 years old (the remaining person diagnosed at 3 years). Five used multiple daily injections (for two of these, parents reported that the adolescent did not wish to use a pump) and six used pump technology. Ten interviews were deemed appropriate based on their “information power”¹³ and the project timeline.

Inductive thematic data analysis

The lead author repeatedly listened to the interview recordings, identifying patterns of interest and potential codes. Preliminary codes were discussed with another team member (AMC) who listened to the audio recordings. Themes were reviewed, refined, discussed with the wider research team and again reviewed and defined in collaboration with AMC.

Results

We generated three main themes (see Table 2); and three subthemes for the second theme. Additional quotations are presented in Table 2.

Theme 1 – The long shadow of diagnosis: “hard to take and it was hard to digest”

This theme related to the difficult and emotional time of diagnosis, a significant life-changing event for each parent interviewed. Even when a family relative had T1D, the diagnosis for their child came as a shock.

The diagnosis was described as “devastating” (P8), distressing, and difficult to believe. It was “...so so frightening” (P5), and “horrendous, shocking and very upsetting... it’s a horrible diagnosis” (P2). Only one parent said diagnosis was a relief because “...we finally had our answer” (P1). However, that parent also commented that they were “holding it together” in the hospital at the time of diagnosis, implying that coping with the diagnosis was difficult.

Illustrating the impact on the family, one parent noted:

“It was emotional... it was just unbelievable... the whole world came crashing down around us. We had never experienced it and never dreamt that it would be diabetes... it came ... as a huge blow to us as a family unit” (P7).

A shared experience was how little parents knew about T1D before their child’s diagnosis. “I didn’t have a clue, not a clue. I knew nothing about it” (P11). “...we knew nothing about that so we were in total shock you know” (P12). Parents needed to balance making sense of medical information and terminology while adjusting to or absorbing the news of the diagnosis. That process was “daunting” and “...a minefield” (P10). Parents felt “bombarded with information” (P5) about T1D and how to care for their child.

“... you are given all the information, but it makes no sense to you because you don’t know what DKA is. You don’t know what long acting and short acting and all the different things...” (P5).

One parent observed that often parents “...think we’re fine ... and it’s only when you’re older, and you look back like you’re not fine” (P10). The diagnosis was “...hard to take and it was hard to digest” (P7).

“...I probably cried for about two weeks ... I was very upset about it but ... eventually I realised... it is what it is. It’s here. We have to deal with it. So, get on with it. And that’s what we did” (P11).

Theme 2 – Not just parenting but caregiving: “we’re trying to do our best every single day.”

Regardless of employment status or adolescent age, all parents provided T1D care beyond typical parenting responsibilities. Parents did not necessarily use the terms “carer” or “caregiver” yet all described behaviours more consistent with caregiving than typical parenting.

Mothers usually adopted the primary caregiver role, adapting their working lives to be available for T1D emergencies. Caregivers were continually vigilant, waiting on results, monitoring their child’s mood as an indicator of blood glucose, or calculating insulin readjustments. Parents said it is impossible to explain the extent of all that is involved in T1D management. “... if you don’t have a child with type one diabetes, there’s just no concept of it” (P10). T1D care is “constant, constant, constant...” (P5).

“Every two days is very, very different ... you can make a change today, and it’s not the right change for tomorrow, and that’s very hard to deal with... constant calculating, calculating, calculating, and as right as you can have it, it still mightn’t go to plan....” (P10).

Subtheme 1

The first subtheme captures the essential role of planning in life with diabetes. Meals, medications, and bedtimes are ideally at routine times. T1D is impacted by uncontrollable factors such as friendships, sports, stress or the weather, and controllable factors like diet.

“Now I'd be a bit of a slave to routine myself. Routine wouldn't really bother me, but I think if you weren't like that, it could drive you cracked... it's something that if you try to sit on it and deal with it perfectly, you'd go mad 'cause there's no perfection with it.” (P8)

When T1D is challenging to manage, “... you change whatever you can, and you work with it” (P10). Although planning is necessary, caregivers must be adaptable because T1D runs roughshod over caregivers' best efforts, and planning was sometimes complicated by other factors or comorbidities (e.g., celiac disease).

“I was breaking myself trying to be the best I could be and trying to do the best... I was doing my best, but it just didn't work...” “...you say oh, this is great. I have a hang of it, and the next day, and it could just go to pot again ...” (P10).

Subtheme 2

Because parents were fearful of hypoglycaemia, their sleep had been severely impacted; it was akin to “having a newborn baby” (P2). Some parents accessed glucose readings on a mobile app and regularly checked the app throughout the day and during the night: “every time you turn over [in bed] you're checking, and you got to bed at three o'clock” (P5). One parent commented that on waking every morning, her first thought is her child's numbers; if there is no number on the app, she gets up and goes into him (P1). Although we did not anticipate this degree of sleep disruption, others reported a high level of nighttime T1D management by parents even for children aged over 14 years¹⁴. In short, caregiving responsibilities and being in a high-alert mode throughout the night contributed to significant parental sleep disruption.

Subtheme 3

This subtheme reflected parents' emotional distress since diagnosis. Parents blame themselves for their child's T1D despite reassurances from the hospital. They question whether they did something to cause T1D “...was it our genes ...was it something I ate when I was pregnant” (P9)...

“...there's surely something that I did that caused this ...” (P10)

“...we're blaming ourselves ... even how many years later ... we are still thinking is it our fault that this is something that we done... (P12).

Compounding their distress, parents felt pressure to advocate for school resources or T1D technology because healthcare in Ireland is “... not an even system” (P2).

“...you want them to get the best services, and ... the best ... resources ...why should it be made more difficult...” “... I have to be her advocate all the time” (P2). T1D is a life-changing condition, and parents need an opportunity to “...accept it, to learn to. It's really a journey I think, you know, it takes time...” (P2).

These parents support other familial relationships and advocate for their adolescent while monitoring, checking, and carrying out multifaceted T1D management tasks, differentiating their parenting life from that of parents of young people with no health conditions.

Theme 3 – “There is no emotional support”

This theme reflects psychological support as “the one thing that is seriously missing” (P10) from diabetes healthcare. Parents were grateful for ready phone access to the care team in what they recognised as a resource-constrained context. However, their emotional needs remained unmet. One parent suggested that every T1D patient/parent pair would benefit from meeting with a psychologist at the point of diagnosis:

“...somebody...should visit the patient and just say ‘look, here's my number’ and have a little chat, see where they're sitting ...” (P10).

Peer support on clinic mornings was suggested, when a small group of parents could meet to learn how others deal with T1D. “...it'd be nice to know other people's opinions as well” (P9).

“...if you could talk with another parent within a month of diagnosis ... couldn't you give somebody great solace ... I'd love to have heard at the start that it doesn't have to hold you back, and yeah it's scary as anything but we're going to learn to live with it...” (P5).

Other psychological support mentioned was contact with other parents via Facebook, which was regarded by some as helpful and others as something to avoid. Parents sought reassurance via online forums, however, the quality of the information was variable.

Discussion

Our findings indicate that the significant care burden identified in parents of younger children with T1D persists throughout adolescence. Additionally, the diagnosis remains a significant life event for parents even years after; this, and the on-going care burden suggests that psychological support is warranted for at least some parents. The findings facilitated discussion among diabetes team members around creating psychologically safe environments for parents and adolescents and provide a basis for additional research.

Importantly, the parenting experience was characterized by intensive planning, sleep disruption, and emotional distress beyond that of typical parenting. This aligns with research indicating that while adolescents typically assume more responsibility for T1D management over time, parents continue to share many management tasks (2). Although practical tasks may be transferred to adolescents, the cognitive and emotional burden for parents does not necessarily decrease. Further, some parents might experience additional stress¹⁵ as the process of transferring control of T1D management is itself a stressful experience¹⁶.

Finally, both formal psychological support and peer support were discussed. The evidence base for formal psychological support for parents of adolescents with T1D is limited. However, a recent umbrella review [18] concluded that cognitive behavioural interventions are among those effective in attenuating parenting stress for parents of children living with chronic illness, indicating potential benefit in psychological support to parents. Additionally, enhancing parents' capacity to cope with diabetes-related stressors, may mitigate some psychological outcomes including distress [19] and consequent need for formal support. Importantly, parents also flagged a risk of well-intentioned but inappropriate informational support (i.e., medical advice) from peers, an issue identified elsewhere¹⁷. Therefore, identifying appropriate sources of parental support is required.

Our participants included only one father, reflecting the gender division in primary caregiving observed in population-based studies. Our study reflects the experiences of involved parents of adolescents whose blood glucose readings were relatively well-managed; other parents may need additional psychological support in their caring role. A recent systematic review [20] suggested that hybrid closed-loop systems were associated with better, or comparable, psychological outcomes for youth with T1D and their parents. Therefore, future research exploring parent outcomes in the context of evolving diabetes technologies is warranted.

Declarations of Conflicts of Interest:

None declared.

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References:

1. Hamilton K, Stanton-Fay SH, Chadwick PM, Lorencatto F, de Zoysa N, Gianfrancesco C, et al. Sustained type 1 diabetes self-management: Specifying the behaviours involved and their influences. *Diabet Med*. 2021 May;38(5). doi: 10.1111/dme.14430. Epub 2020 Dec 8. PMID: 33073393.
2. Marker AM, Noser AE, Clements MA, Patton SR. Shared Responsibility for Type 1 Diabetes Care Is Associated With Glycemic Variability and Risk of Glycemic Excursions in Youth. *J Pediatr Psychol*. 2018;43(1):61–71. doi: 10.1093/jpepsy/jsx081.

3. Trudeau S, Madden KM, Mankad S, Stryker A, Courneya J. A developmental milestones map of Type 1 diabetes self-management transition from parents to adolescents. *Diabetes Spectrum*. 2019;32(1):16-23.
4. Balcázar-Hernández L, Huerta-Martínez H, Garrido Magaña E, Nishimura-Meguro E, Jiménez Márquez A, Rivera-Hernández A. Burden in primary informal caregivers of children and adolescents with type 1 diabetes: Is it associated with depression, family dysfunction, and glycemic control?. *Front Endocrinol*. 2023;13:1089160. doi: 10.3389/fendo.2022.1089160.
5. Harrington KR, Boyle CT, Miller KM, Hilliard ME, Anderson BJ, Van Name M, et al. Management and Family Burdens Endorsed by Parents of Youth <7 Years Old With Type 1 Diabetes. *J Diabetes Sci Technol*. 2017;11(5):980–7. doi: 10.1177/1932296817721938.
6. Bassi G, Mancinelli E, Di Riso D, Salcuni S. Parental Stress, Anxiety and Depression Symptoms Associated with Self-Efficacy in Paediatric Type 1 Diabetes: A Literature Review. *Int J Environ Res Public Health*. 2020;18(1):152. doi: 10.3390/ijerph18010152.
7. Chan Sun M, Ramano V, Dowlut TAS. Lived experience of mothers having a child diagnosed with type 1 diabetes in Mauritius: A phenomenological study. *J Pediatr Nurs*. 2021;60. doi: 10.1016/j.pedn.2021.03.030.
8. Commissariat PV, Harrington KR, Whitehouse AL, Miller KM, Hilliard ME, Van Name M, et al. “I’m essentially his pancreas”: Parent perceptions of diabetes burden and opportunities to reduce burden in the care of children <8 years old with type 1 diabetes. *Pediatr Diabetes*. 2019. doi: 10.1111/pedi.12956.
9. Kimbell B, Lawton J, Boughton C, Hovorka R, Rankin D. Parents' experiences of caring for a young child with type 1 diabetes: a systematic review and synthesis of qualitative evidence. *BMC Pediatr*. 2021;21(1):160. doi: 10.1186/s12887-021-02569-4.
10. Rifshana F, Breheny M, Taylor JE, et al. The Parental Experience of Caring for a Child with Type 1 Diabetes. *J Child Fam Stud*. 2017;26:3226–36. doi: 10.1007/s10826-017-0806-5.
11. Habenicht AE, Gallagher S, O’Keeffe MC, Creaven AM. Making the leap and finding your feet: A qualitative study of disclosure and social support in university students with type 1 diabetes. *J Health Psychol*. 2021;26(2):260–9. doi: 10.1177/1359105318810875.
12. Malterud K, Siersma VD, Guassora AD. Sample Size in Qualitative Interview Studies: Guided by Information Power. *Qual Health Res*. 2016;26(13):1753-1760. doi:10.1177/1049732315617444
13. Leocadio P, Kelleher C, Fernández E, Hawkes CP. Adolescents' Experiences of Transition to Self-Management of Type 1 Diabetes: Systematic Review and Future Directions. *Sci Diabetes Self-Manag Care*. 2023;49(6):477–92. doi: 10.1177/26350106231206779.
14. Bazus L, Perge K, Chatelain P, Nicolino M. Objective burden and emotional distress in parents of children with type 1 diabetes. *Horm Res Paediatr*. 2023. doi: 10.1159/000531885.

15. Haegele JA, Holland SK, Hill E. Understanding Parents' Experiences with Children with Type 1 Diabetes: A Qualitative Inquiry. *Int J Environ Res Public Health*. 2022;19(1):554. doi: 10.3390/ijerph19010554.
16. Tomette A, Henderson JN, Hass A, Carson LD, King K. Parental Stress as a Child With Diabetes Transitions From Adolescence to Emerging Adulthood. *J Patient Exp*. 2020;7(3):365–71. doi: 10.1177/2374373519842963.
17. Treadgold BM, Muller I, Teasdale E, Coulson N, Roberts A, Santer M. Parental experiences of eczema advice in online parenting forums: a qualitative interview study. *BJGP Open*. 2023;7(2) doi: 10.3399/BJGPO.2022.0155.
18. Yang J, Gao Y, Wang W, Wang J, Wang Y, & Yuan L. (2024). Interventions to address parenting stress among caregivers of children with chronic diseases: An umbrella review. *Journal of Clinical Nursing*. <https://doi.org/10.1111/jocn.17060>
19. Zhao X, Ai Z, Chen Y, Wang J, Zou S & Zheng S. (2019). The effectiveness of parenting interventions on psychosocial adjustment in parents of children and adolescents with Type 1 diabetes: A meta-analysis. *Worldviews on Evidence-Based Nursing*, 16(5), 351–359. <https://doi.org/10.1111/wvn.12399>
20. Franceschi R, Mozzillo E, Di Candia, F, Maines, E, Leonardi, L, Girardi, M, Fedi, L, Rosanio, FM, Marcovecchio, ML, 2023. A systematic review on the impact of commercially available hybrid closed loop systems on psychological outcomes in youths with type 1 diabetes and their parents. *Diabetic Medicine*, [online] First published 8 April 2023. Available at: <https://doi.org/10.1111/dme.15099>

Table 1: Topic guide designed to support semi-structured interviews with parents of adolescents with T1D

Topics	Example questions
Introduction (family & diagnosis)	Just to get us started, tell me a little about yourself and about your family?
Parent experiences	What is it like for you as a parent to have a child with Type 1 Diabetes?
Parent's role in management	Can you tell me about your current role in the management of your child's diabetes?
Experiences and perceptions of child's own management/independence	Focusing now on your child, when we say that your child has 'good self-management' or 'good self- care of their diabetes' – how would you describe that?
Clinic appointments	How have clinic visits supported you and your child with self-management?

Transition from paediatric to adult services	Regarding your adolescent child and the transition process from child into adult services – what do know about that?
Closing the interview	Is there anything else you would like to say about your experience?

*These questions were used to elicit discussion of parent experiences, with additional follow-up questions and probes used as appropriate.

Table 2: Additional quotations illustrating each theme/subtheme.

Themes	Subthemes	
1. Theme 1: The long shadow of diagnosis: “it was hard to take and hard to digest”		<p>“it was a devastating diagnosis... we've learned to live with it” ... “...it's a horrible illness and ... life-changing but at the end of the day it becomes part of your life and you can control it up to a point you cannot control it 100% by any means” (P8).</p> <p>“we were devastated” ... “...it's not normal... your life is never normal again does that make sense” (P9)</p> <p>“it's shell-shocking I suppose ... and it's so so frightening and even now because you know things change ... it's all-consuming... it's there all of the time ... from when you wake up in the morning until you go to bed...” (P5)</p>
2. Theme 2: Not just parenting but caregiving; “We're trying to do our best every day”		<p>“...I always look at his numbers and I'm always thinking about his numbers...I'm checking, checking and I'm constantly thinking ‘is he ok? is he ok? is he ok?’” (P1)</p> <p>“...as a parent you are always going to be vigilant... this is 24/7 and I don't think that there's a way of eliminating that” (P7)</p> <p>“...you always have to manage it, all the time. It's the intensity of the fact that it's always there 24/7... I think it's going to be ingrained in you forever... it's just a feature of ... the caring role” (P2)</p>
	Planning	<p>“... being prepared ... like the minute you leave the house you have to make sure that you are prepared for every different thing that can happen ... being prepared having all their stuff ready again even in the house ...” (P10)</p> <p>“Oh my God I just find it's just so you have to plan everything ...”(P4)</p> <p>“...I suppose that's what I've been trying to be good at is trying to stay ahead of it” (P5)</p> <p>“...is she going to get a low halfway through the day and it's gonna ruin everything ... it's always forward-thinking with us you know...” P4</p>
	Sleep deprivation	<p>“... we could check his blood three or four times in the night, you know you don't actually go to sleep properly anymore...because we're afraid he'll get a hypo ... and then you'd have to ... wake him up, then we have a Lucozade party” (P12).</p>

		<p><i>"...we haven't known a night's sleep as we used to know it ... It's every night, every night, one hundred per cent...since diagnosis"... "...it is there with you all the time, even at night ... when you wake during the night ... you want to know that she's okay and I need to check" (P7)</i></p> <p><i>"I'll just have the phone next to me in bed...'cause he won't wake up, he's just too in a deep sleep..." (P4)</i></p>
	Emotional distress	<p><i>"... you go in and say ... things will be better tomorrow, things will be better next week, but it... doesn't really change like it's just different every day and I suppose that bit for me it was quite difficult". (P10)</i></p> <p><i>"T1D is challenging... the impact it has on siblings and on you know parents, on your relationship as a parent, and you know all those things you know as a consequence they are also factors. (P2)</i></p> <p><i>"... you just think you're totally alone ...there's no one else around that has it like, but then you cop on after a while" (P12)</i></p> <p><i>"It's a pain in the arse but it's not the end of the world ... it was hard at the beginning it's hard to get the hang of it and get your head around ..." (P11).</i></p>
3. "There is no emotional support"		<p><i>"...there should be an option to see a psychologist maybe every six months ... there's... the diagnosis, then there's just living with it, then there's the burnout... there's lots of different times when you're going to need some support ... at the beginning, middle, end, all the way through...life it's going on, life is going on..." (P2).</i></p> <p><i>"...it was just a gene that he was born with but it still comes back to haunt you ...like six years later nearly and we are still thinking is it our fault..." (P12)</i></p> <p><i>...nobody spoke to us, nobody asked I suppose how were we going to deal with this ourselves ... as a parent whatever happens your children you blame yourself ... psychologically I think ... there's something lacking... in the system..." (P9)</i></p>