

Adolescent Perspectives on Negotiating Self-Management Responsibilities for Type 1 Diabetes with their Parents

TUOHY, Ella, GALLAGHER, Pamela <<http://orcid.org/0000-0001-5558-1269>>, RAWDON, Caroline, MURPHY, Nuala, SWALLOW, Veronica <<http://orcid.org/0000-0001-8504-4704>> and LAMBERT, Veronica

Available from Sheffield Hallam University Research Archive (SHURA) at:

<http://shura.shu.ac.uk/31298/>

This document is the author deposited version. You are advised to consult the publisher's version if you wish to cite from it.

Published version

TUOHY, Ella, GALLAGHER, Pamela, RAWDON, Caroline, MURPHY, Nuala, SWALLOW, Veronica and LAMBERT, Veronica (2023). Adolescent Perspectives on Negotiating Self-Management Responsibilities for Type 1 Diabetes with their Parents. *Patient Education and Counseling*, 109: 107629.

Copyright and re-use policy

See <http://shura.shu.ac.uk/information.html>

Potential Journals: Patient Education and Counselling (4000 words maximum)

**Adolescent Perspectives on Negotiating Self-Management Responsibilities for Type 1
Diabetes with Parents**

Ella Tuohy^a, Pamela Gallagher^a, Caroline Rawdon^b, Nuala Murphy^c, Veronica Swallow^d,
Veronica Lambert^b

^aSchool of Psychology, Dublin City University, Ireland

^bSchool of Nursing, Psychotherapy and Community Health, Dublin City University, Ireland

^cDiabetes and Endocrine Unit, Children's Health Ireland at Temple Street, Dublin, Ireland

^dCollege of Health, Wellbeing and Life Sciences, Sheffield Hallam University U.K.

Key words: type 1 diabetes, communication, self-management, adolescence

Word count: 3862

Article type: Research paper

Corresponding author: Prof. Veronica Lambert, School of Nursing, Psychotherapy and
Community Health, Faculty of Science and Health, Dublin City University, Glasnevin
Campus, Dublin D09 V209, Ireland. Email: veronica.lambert@dcu.ie

Abstract

Objective: Adolescents begin to adopt a more collaborative approach to managing type 1 diabetes (T1D) with their parents before becoming independent in self-management. This study aimed to explore adolescent perspectives on communicating with parents about self-management of T1D and negotiating responsibilities for self-management with parents.

Methods: Semi-structured interviews were conducted with 28 adolescents aged 11 to 17 years living with type 1 diabetes. Interviews were audio-recorded, transcribed verbatim and thematically analysed.

Results: Two themes and five sub-themes were identified. The first theme, 'changing levels of involvement in self-management' describes the division of responsibility for self-management within the family and adolescents collaborating and sharing responsibilities with parents for self-management. The second theme, 'talking about self-management with parents' describes changes in patterns of parent-adolescent communication about T1D over time, adolescents' seeking parental feedback and advice and the factors that contribute to the promotion of self-management communication between adolescents and parents.

Conclusion: Overall, this study identified that how adolescents perceive their communication with their parents contributes to the negotiation of responsibilities for self-management during adolescence. The findings provide a nuanced understanding of adolescent perspectives on self-management of T1D and communication with parents about T1D self-management and specifically how parent-adolescent communication can be framed in ways that promote positive adolescent engagement with T1D self-management.

Practice implications: Targeting communication strategies employed by adolescents and their parents may result in more optimal sharing of responsibilities and improved self-management.

1. Introduction

Self-management theories highlight the key role of the family in managing a chronic condition such as T1D [1–3]. This is especially true in the case of children and adolescents who are living with T1D and rely on parents for assistance with carrying out self-management tasks. The trajectory towards becoming independent in self-management is influenced by a myriad of individual, family and clinical factors including adolescent developmental stage, age, clinical characteristics, learning ability and how the family relates to one another [1]. Moreover, assuming ownership of the management of T1D impacts upon multiple facets of an adolescent's life including adolescent quality of life (QOL) and short-term and long-term health [4–6].

The experience of shared management and transfer of responsibility as it relates to gaining independence in managing a long-term condition in childhood and adolescence remains poorly understood [7,8]. Qualitative research conducted with adolescents living with T1D indicates that transferring responsibilities for T1D management in adolescence can be characterised by increased conflict between parents and adolescents in relation to T1D management [9–11]. Conversely, positive aspects of parental involvement are also described with adolescents referring to their parent's role in reminding and educating them on aspects related to T1D [12,13]. While parent-adolescent interactions surrounding management are regularly referred to, there is an absence of qualitative inquiries which specifically seek to investigate the content and context of parent-adolescent communication surrounding T1D self-management during adolescence and the negotiation of responsibilities for self-management of T1D. Moreover, this has not been qualitatively explored from the perspectives of adolescents.

The aim of this study was to explore adolescent experiences of negotiating responsibilities for self-management with parents from the perspectives of adolescents living with T1D.

2. Materials and Method

This qualitative study used semi-structured interviews to explore the perspectives and experiences of adolescents (aged between 11 and 17 years) living with T1D about self-management and communicating with their parents in relation to self-management responsibilities. Ethical approval was obtained from the Research Ethics Committees of the participating hospitals and the University Research Ethics Committee. All adolescents, and their parents, provided written informed assent and consent respectively before participation in the study.

2.1 Sample

Eligible participants were adolescents living with T1D, aged between 11 years and 17 years at the time of interview and diagnosed with T1D for 6 months or longer. Participants were recruited via a national paediatric diabetes and endocrine unit ($n = 21$) and via an adolescent diabetes clinic ($n = 3$) by poster advertisement. Additional participants were recruited through the national diabetes advocacy organisation ($n = 4$). An overview of participants is presented in Table 1 below.

****INSERT TABLE 1****

2.2 Data Collection

Semi-structured interviews were conducted with 28 adolescents living with T1D. Adolescents completed a brief demographic questionnaire prior to the commencement of the interview. Interviews were guided by a topic guide which was developed to elicit information on diagnosis, living with T1D every day, self-management roles and responsibilities, sharing

self-management with parents, communication about self-management, and the psychosocial impacts of self-management and sharing self-management with parents on adolescents.

Most participants opted to be interviewed at their home ($n = 15$). The remainder of interviews were carried out in a room in the university ($n = 13$). All participants chose to be interviewed alone, without a parent or guardian present. Interviews were electronically recorded, with adolescents' permission. The interviews ranged in duration from 28 minutes to 1 hour and 7 minutes.

2.3. Data Analysis

The audio-recorded interview data was transcribed verbatim and transcripts were read and checked for accuracy. Names and any identifiable information were removed from transcripts to protect participants' confidentiality. Data management was aided by NVivo qualitative data management software [14]. Data were analysed using thematic analysis, following Braun and Clarke's [15,16] framework. This approach seeks to identify themes or patterns within the data by becoming familiar with the data, generating initial codes, searching for and reviewing themes, defining and naming themes and producing the final report including the extraction of data quotations.

3. Results

The findings illustrate adolescent experiences of navigating the gradual process of gaining independence in T1D self-management during adolescence, underlined by the following two themes: Changing levels of involvement in self-management and Talking about self-management with parents. The themes and associated subthemes (see Table 2) are presented below.

****INSERT TABLE 2****

3.1. Changing levels of involvement in self-management

Adolescents outlined how responsibilities for management of T1D were divided between them and their parents and how they gradually took over management of T1D through increased collaboration and sharing responsibilities with parents for completion of T1D care. Two subthemes were identified: (1) Division of responsibility for self-management within the family and (2) Collaborating and sharing responsibilities with parents for self-management. See Table 3 for an overview of the subthemes and illustrative quotations.

****INSERT TABLE 3****

3.1.1. Division of responsibility for self-management within the family

Adolescents referred to how parents were initially responsible for many self-management tasks in the aftermath of their diagnosis and when they were younger. Adolescents also described how parents delegated T1D management tasks to other family members such as siblings. Siblings were often instructed by parents to assist with T1D management by reminding adolescents and checking in with them. Over time, adolescents became less reliant on parents for completing management tasks and parental involvement moved to the background.

3.1.2. Collaborating and sharing responsibilities with parents for self-management

Shared and collaborative management was important in supporting adolescents while they experienced ongoing changing levels of parental involvement in care and navigated the move towards more independence in T1D self-management. Being responsible for T1D management was at times considered challenging, and consequently it was necessary for adolescents to continue to collaborate with parents, rather than always self-manage independently.

While parents maintain a level of involvement and responsibilities are still shared, the bulk of responsibilities gradually transitioned to adolescents. Adolescents took over specific self-management tasks from parents. How this came about was related to the self-

management task difficulty and adolescents' readiness to assume responsibility for self-management. For more difficult management tasks, continued parental involvement or a more gradual relinquishment of parental responsibilities was deemed necessary. Sometimes increased responsibility was not balanced with adolescent capability to take charge of self-management. This resulted in adolescents reverting to a reliance on parents for T1D management, following a period of struggle with independent self-management.

Collaborating with parents facilitated gaining independence in T1D self-management tasks and ensured adolescents were supported in the transition to more independent management. Parents supported adolescents by stepping in and relaying appropriate reminders as needed, and by gradually allowing adolescents to make their own decisions related to T1D self-management.

Parents promoted adolescents' independence in self-management by stepping back from involvement, only assisting with management when needed such as when adolescents were unsure about an aspect of T1D management. In this way, adolescents were supported by parents to carry out and learn to manage their T1D more independently through sharing management with parents. Examples of strategies employed by parents to support and motivate adolescents towards more independent management of T1D included reminding adolescents, temporarily taking over T1D management for adolescents or checking in with them. When adolescents felt overwhelmed by the demands of self-management, parents stepped in, took over and completed management tasks. Adolescents stated that it was important that checking in occurred at appropriate times in order to support their engagement with self-management. Parental involvement and collaboration also supported adolescents in managing their health through encouraging healthy choices in relation to management of T1D and overall health.

The presence of parental trust when sharing responsibilities and taking on more responsibilities for self-management was an important factor for adolescents. The presence of trust motivated adolescents to meet blood glucose targets or during times when managing T1D was considered difficult.

3.2. Talking about self-management with parents

How adolescents talked about self-management with parents changed gradually and provided insight into how adolescents became more responsible for self-management. This is reflected in three subthemes: (1) Change in patterns of parent-adolescent communication about T1D over time, (2) Seeking parental feedback and advice; and (3) Promoting self-management communication between adolescents and parents. See Table 4 for an overview of the subthemes and illustrative quotations.

****INSERT TABLE 4****

3.2.1. Change in patterns of parent-adolescent communication about T1D over time

Patterns of communication about T1D management between adolescents and parents changed gradually. This change was illustrated through accounts of changes in the terminology used and how regularly adolescents reported discussing T1D with parents.

The frequency of parent-adolescent conversations held about T1D reduced with time and as adolescents became more knowledgeable. Similarly, as time passes, adolescents described reserving discussions about T1D and consulting with parents for times when they were experiencing an issue with their management.

Adolescents also reported that in comparison to when they were younger, the type of language used when talking about T1D also evolved over time. Adolescents described how they became more familiar and comfortable with the use of technical T1D-related terminology. This familiarity facilitated more effective communication as both adolescents and parents were more familiar with T1D.

3.2.2. Seeking parental feedback and advice

Parent-adolescent conversations frequently revolved around seeking or receiving parental feedback on their performance of self-management tasks and reaching decisions on T1D management.

Communication often revolved around informing parents about blood glucose readings. These conversations presented an opportunity for adolescents and parents to discuss how adolescents should approach T1D management. As adolescents got older, they became more responsible for self-management tasks. However, parental involvement continued, with adolescents keeping parents informed or parents seeking information from adolescents. Some adolescents expressed that there was an expectation between them and their parents, that they would regularly inform their parents about their blood glucose readings. Adolescents indicated that conversations surrounding feedback on their T1D management were frequently initiated by parents. This contrasted with adolescents themselves, who reported that they often reserved discussions for seeking advice on T1D topics of interest to them.

When adolescents were away from home, they often needed to check in with a parent, to ask for advice. Examples included determining the carbohydrate content of foods and calculating insulin doses. Knowing they could check in with parents enabled adolescents to spend time with friends away from home and contributed towards them feeling independent.

Conversations with parents also provided opportunities for adolescents to receive feedback on their engagement with self-management tasks which facilitated their learning and gaining independence in management. Adolescents spoke about talking to parents to seek reassurance or advice about T1D, for example, dispelling worries or concerns related to management. Decisions relating to insulin dosage, carbohydrate content of food and device management were often shared between adolescents and parents. Adolescents also described

reasons for not seeking advice from parents, such as when achieving control over management and blood glucose levels.

3.2.3. Promoting self-management communication between parents and adolescents

Adolescents outlined how positive discussion of self-management with parents was fostered through the presence of openness, closeness and a shared understanding of perspectives within interactions. The presence of these features in interactions facilitated discussion about T1D management and enabled adolescents to assume increased independence in T1D management. Closeness and openness in relationships with parents often corresponded with ease of communication related to T1D and fostered positive experiences of talking to parents about T1D management. Conversely, anticipating a negative interaction following a disclosure about mismanagement of T1D often inhibited communication from occurring. Adolescents highlighted that parents also, at times, avoided conversations about T1D to evade a potential negative parent-adolescent interaction.

Regarding aspects of self-management that were difficult to talk about, blood glucose levels were identified as a challenging aspect of T1D management to discuss and as a result, the struggles of maintaining levels within target ranges was a difficult conversation topic. When adolescents felt that there was an absence of parental understanding for why they were struggling with an aspect of management, this contributed to difficulties interacting with parents. Adolescents described feeling antagonised by parents when they felt parents did not fully understand the challenges of managing T1D while simultaneously navigating other aspects of adolescent life.

When adolescents perceived parental involvement as intrusive, this could lead to frustration and parent-adolescent conflict around management of T1D. Adolescents often reconciled this with the knowledge that parents were trying to help, which could reduce

adolescent frustration towards parents. Adolescents expressed awareness that T1D caused parental worry or concern and led to their reluctance to initiate conversations.

Finding the time to talk about T1D was often presented as a challenge to initiating conversations between adolescents and parents. As a result of other commitments (e.g. after school activities), adolescents relayed not communicating with their parents except for brief encounters related to blood glucose readings and insulin dose requirements. Conversations considered 'awkward' or uncomfortable, such as when management was not going well, were also avoided by adolescents.

The potential for interactions about blood glucose levels or mismanagement of T1D to cause parent-adolescent conflict was highlighted. However, for some adolescents, this conflict served as a reminder of their parent's concern for their wellbeing. As adolescents became more responsible for their T1D management, parental concerns about blood glucose levels remained. Adolescents also recognised that their parents, at times chose to avoid checking in, as they were aware that this could be perceived as nagging or intrusive. This contributed to adolescent beliefs that their parent sometimes avoided talking about T1D.

In contrast, adolescents spoke about how positive interactions with parents were underscored by closeness between parties and a shared understanding of each other's perspectives. Perceived closeness with parents influenced whether adolescents considered their conversations about self-management to be positive. Adolescents described how it was important that they felt understood by their parents as this enabled them to discuss managing T1D and encouraged conversations about issues adolescents encounter with their T1D management.

4. Discussion and Conclusion

For the first time this study provides a nuanced understanding of the intricacies of how levels of parental and adolescent involvement in T1D management change over time

from the perspectives of adolescents living with T1D. Sharing responsibility with parents was a critical factor that enabled adolescents to acquire more independence in self-management. This study presents novel insights into how adolescents perceive communication with their parents surrounding T1D self-management and the role of parent-adolescent communication in assisting adolescents to become increasingly responsible for their T1D self-management.

An emerging trend within research focussing on parental transfer of responsibilities for T1D management considers self-management as a process rather than a transition from one point to another [8]. The findings of this qualitative study indicate that adolescents assume self-management responsibilities in a fluctuating manner, moving between relying on parents and independently managing, thereby supporting the position that the transfer of responsibilities during adolescence should be viewed as a process. Furthermore, the findings clarify that this change in levels of responsibility is characterised by periods of actively taking over from parents, sharing involvement with parents and reverting to parental involvement in management, if needed. The fluidity of navigating the space between independent and shared management of T1D is not often captured in previous studies. Overall, our findings align with the position that adolescence is a time where the roles in management of illness change and shift within the family [1,2], while also identifying specific attributes of parental involvement that contribute to this change in where responsibilities for self-management of T1D lie.

Collaboration and parental involvement in T1D self-management is critical to enabling adolescents to navigate towards independence. This trajectory towards independence can be influenced by the difficulty of the management task, the adolescent's readiness to assume increased responsibility and parental support such as stepping in when needed, providing reminders and presence of trust between adolescents and their parents.

The process of becoming more independent could at times be hindered or influenced by contextual factors and difficulties that adolescents encountered when engaging with T1D self-management. For example, the current findings indicate that parents were relied on to step in and resume management for tasks considered difficult by adolescents, had adolescents assumed too much responsibility or if they were experiencing a decline in blood glucose control. During these times, the importance of parents being flexible and supportive throughout the process of gradually relinquishing control across adolescence was highlighted. Adolescent perceptions of how autonomy supportive their parents are is associated with engagement with self-management [17,18]. Therefore, having parents available to assist adolescents is important to ensure completion of management tasks as well as to support them as they gain independence in self-management.

The findings highlight the importance of assessing adolescent readiness to take on additional management responsibilities and ensuring parents oversee management in a way that is supportive of adolescent's independence through preserving adolescent's confidence and motivation to engage with their self-management. The findings emphasise specific ways parental behaviours can be supportive or non-supportive of adolescents' transition to more independence in T1D self-management. These included parental conveying of trust, offering encouragement and ensuring that reminders were not intrusive. Trust was identified as important and needed to be in place prior to parents relinquishing responsibilities for self-management to adolescents. Parents did not convey trust when they nagged or asked adolescents about blood glucose levels in an accusatory tone. Previous research also identifies the importance of trust between adolescents and parents in collaborating on management tasks but focuses on how the absence of trust can give rise to parent-adolescent conflict and intrusive parental behaviours [19,20]. The findings of this study offer novel perspectives on the positive role of trust in facilitating more optimal sharing of

responsibilities during this period where parent-adolescent involvement in care varies. It may be that the trust referred to within the findings is a feature of or closely related to the warm parenting styles that have been identified within previous research as contributing to better engagement with management tasks and metabolic control [21,22].

This study highlights the specific role of parent-adolescent communication in the journey towards becoming increasingly responsible for self-management. Changes that were identified in parent-adolescent interactions around self-management can be compared to the general changes to parent-adolescent relationships during adolescence. Specifically, a reduction in the frequency of parent-adolescent interactions about T1D was reported as occurring over time. As adolescents got older, they reserved interactions for challenges encountered. Age was another factor that was associated with less communication about T1D self-management. In adolescence, in general, both parents and adolescents reorganise their relationships with one another as they move towards a more egalitarian approach to their interactions [25]. The present findings indicate that this reorganisation is also evident in parent-adolescent communication surrounding T1D self-management during adolescence and reflected in reduced frequency of communication about T1D and self-management. Previous research also presents T1D as a domain where reorganisation of responsibilities for T1D management occurs during adolescence, with adolescent and parental roles for T1D tasks redefined based on the adolescent's developmental stage [26].

The current study unearths the central role of adolescent perceptions of parent-adolescent communication in contributing to adolescent's motivations and confidence in self-management of T1D. In the current study, adolescents mostly outlined the benefits of feedback in the form of parental support, reassurance and encouragement when completing self-management tasks and making decisions relating to their care. However, previous research suggests that the relationship between parental reminders and encouragement to self-

efficacy for adolescents is not straightforward and depends on adolescent's existing levels of perceived competence[27]. Thus, it may be important to be cognisant of how parents frame reminders and assistance with management depending on the individual adolescent.

Furthermore, when adolescents perceive their parents as autonomy supportive, this facilitates shared T1D management, as adolescents complete more self-care tasks independently [17]. Luo et al. recently identified that quality of the parent-adolescent relationship is a factor associated with levels of collaboration with parents for T1D management and adolescent engagement with T1D self-management tasks [28]. The present findings extend Luo et al.'s results through contributing to knowledge on the specific parent-adolescent communication characteristics that can facilitate adolescent engagement with T1D self-management. More specifically, our findings suggest that the benefits of supportive and positive parent-adolescent communication and interactions (characterised by closeness and feeling understood) surrounding T1D may extend to the stimulation of better engagement with self-management, considered more broadly than metabolic control or adherence behaviours.

The findings of this study advances knowledge on some of the motivations behind adolescent avoidance of parent-adolescent communication, such as minimising risk of parental worry and what the content of these interactions might be (e.g. communicating about blood glucose levels, mismanagement or forgotten management). Adolescents referred to avoiding difficult conversations. Adolescents are aware that their T1D is a source of worry for their parents as evidenced in this study and also previously noted by Serlachius et al. [11]. Although previous research suggests an association between less performance of management tasks and parental nagging [29], nagging in this study was not always described as entirely negative and at times, served the important purpose of reminding adolescents or motivating their engagement with a management task. The findings of this study emphasise

the importance of ensuring that interactions motivate positive engagement self-management among adolescents.

Overall, the qualitative approach employed in this research allowed for an in-depth exploration of the salient features of adolescents' experiences of the gradual nature of becoming more responsible for self-management during adolescence. However, this study has limitations that warrant consideration. There were some indicators of homogeneity within the qualitative sample. Though participants were recruited nationally through a national centre for paediatric diabetes and a national diabetes advocacy organisation, participants were predominantly drawn from one urban geographical region. As a result, their experiences may not reflect those of all adolescents living with T1D, attending regional hospitals for treatment and from other geographical regions.

4.1 Conclusion

This research provides a unique understanding into how adolescent perceptions of communication impact upon gaining independence in their self-management of T1D. The findings with respect to the change in levels of involvement between adolescents and parents support that gaining autonomy in self-management is a gradual process. The findings indicate that perceptions of family context (specifically qualities of parent-adolescent communication e.g. openness, warmth and understanding) are an important factor contributing to adolescent engagement with self-management and assumption of increased management responsibilities. Parent-adolescent interactions framed in a way that is supportive of adolescent T1D self-efficacy can contribute to adolescents feeling more capable of engaging with T1D self-management. Moreover, negative communication styles (e.g. nagging) can sometimes have a positive impact on parent-adolescent relations pertaining to the negotiation of levels of involvement in T1D management.

4.2 Practice Implications

HCPs involved in adolescents' T1D care should be cognisant of the factors that contribute to the negotiation of shared responsibilities for T1D management between adolescents and parents. Specifically, they should ensure that adolescents and their parents identify whether there are discrepancies between parties with respect to their views on the adolescent's current self-management capabilities, ensuring both are satisfied with the adolescent's level of responsibility for self-management. Both adolescents and their parents may benefit from training in communication styles and training in how to communicate about adolescent readiness for more independence in self-management. Potential interventions should seek to encourage parents to utilise communication strategies about T1D that are adolescent-centred and are supportive of adolescent's autonomy as these may lead to more optimal negotiation of responsibilities for T1D self-management in adolescence.

Funding

This work was supported by the Health Research Board of Ireland Grant [HRA-HSR-2015-1233].

Acknowledgements

The authors would like to thank the adolescents who participated in this study. We would also like to thank Diabetes Ireland, Youth Work Ireland and the Youth Advisory Group for their contribution to this work.

Competing interests

None to declare.

References

- [1] P. Ryan, K.J. Sawin, The Individual and Family Self-Management Theory: Background and perspectives on context, process, and outcomes, *Nurs. Outlook.* 57 (2009) 217-225.e6. doi:10.1016/j.outlook.2008.10.004.
- [2] M. Grey, D. Schulman-Green, K. Knafl, N.R. Reynolds, A revised Self- and Family Management Framework, *Nurs. Outlook.* 63 (2015) 162–170. doi:10.1016/j.outlook.2014.10.003.
- [3] A.C. Modi, A.L. Pai, K.A. Hommel, K.K. Hood, S. Cortina, M.E. Hilliard, S.M. Guilfoyle, W.N. Gray, D. Drotar, Pediatric Self-management: A Framework for Research, Practice, and Policy, *Pediatrics.* 129 (2012) e473–e485. doi:10.1542/peds.2011-1635.
- [4] M.E. Hilliard, K.A. Mann, J.L. Peugh, K.K. Hood, How poorer quality of life in adolescence predicts subsequent type 1 diabetes management and control., *Patient Educ. Couns.* 91 (2013) 120–5. doi:10.1016/j.pec.2012.10.014.
- [5] M.E. Hilliard, C.S. Holmes, R. Chen, K. Maher, E. Robinson, R. Streisand, Disentangling the Roles of Parental Monitoring and Family Conflict in Adolescents' Management of Type 1 Diabetes, *Health Psychol.* 32 (2013). doi:10.1037/a0027811.
- [6] K.M. Hanna, C.L. Decker, A concept analysis: assuming responsibility for self-care among adolescents with type 1 diabetes, *J. Spec. Pediatr. Nurs. JSPN.* 15 (2010) 99–110. doi:10.1111/j.1744-6155.2009.00218.x.
- [7] R. Nightingale, G. McHugh, S. Kirk, V. Swallow, Supporting children and young people to assume responsibility from their parents for the self-management of their long-term condition: An integrative review, *Child. Care. Health Dev.* 45 (2019) 175–188. doi:10.1111/cch.12645.
- [8] L. Gardener, L. Desha, H. Bourke-Taylor, J. Ziviani, Responsibility sharing for

- adolescents with type 1 diabetes: A scoping review, *Chronic Illn.* (2020) 1742395320959406.
- [9] E. Babler, C.J. Strickland, Moving the Journey Towards Independence: Adolescents Transitioning to Successful Diabetes Self-Management, *J. Pediatr. Nurs.* 30 (2015) 648–660. doi:10.1016/j.pedn.2015.06.005.
- [10] A.M. Chao, K.E. Minges, C. Park, S. Dumser, K.M. Murphy, M. Grey, R. Whittemore, General Life and Diabetes-Related Stressors in Early Adolescents With Type 1 Diabetes, *J. Pediatr. Heal. CARE*. 30 (2016) 133-142}. doi:10.1016/j.pedhc.2015.06.005.
- [11] A. Serlachius, E. Northam, E. Frydenberg, F. Cameron, Adapting a generic coping skills programme for adolescents with type 1 diabetes: a qualitative study, *J. Health Psychol.* 17 (2012) 313–323. doi:10.1177/1359105311415559.
- [12] R. Chilton, R. Pires-Yfantouda, Understanding adolescent type 1 diabetes self-management as an adaptive process: A grounded theory approach, *Psychol. Health.* 30 (2015) 1486–1504.
<http://ovidsp.ovid.com/ovidweb.cgi?T=JS&PAGE=reference&D=medl&NEWS=N&AN=26084198>.
- [13] M. Strand, A. Broström, A. Haugstvedt, Adolescents' perceptions of the transition process from parental management to self-management of type 1 diabetes, *Scand. J. Caring Sci.* 33 (2019) 128–135. doi:10.1111/scs.12611.
- [14] Q S R International Pty Ltd., NVivo qualitative data analysis Software, (2015).
- [15] V. Braun, V. Clarke, Using thematic analysis in psychology, *Qual. Res. Psychol.* 3 (2006) 77–101. doi:10.1191/1478088706qp063oa.
- [16] V. Braun, V. Clarke, Reflecting on reflexive thematic analysis, *Qual. Res. Sport. Exerc. Heal.* 11 (2019) 589–597. doi:10.1080/2159676X.2019.1628806.

- [17] K.M. Hanna, C.J. Dashiff, T.E. Stump, M.T. Weaver, Parent-adolescent dyads: Association of parental autonomy support and parent-adolescent shared diabetes care responsibility, *Child. Care. Health Dev.* 39 (2013) 695–702. doi:10.1111/j.1365-2214.2012.01373.x.
- [18] E.R. Goethals, B. Soenens, M. de Wit, M. Vansteenkiste, L.M. Laffel, K. Casteels, K. Luyckx, “Let’s talk about it” The role of parental communication in adolescents’ motivation to adhere to treatment recommendations for type 1 diabetes, *Pediatr. Diabetes.* 20 (2019) 1025–1034. doi:10.1111/pedi.12901.
- [19] J.B. Ivey, A. Wright, C.J. Dashiff, Finding the Balance: Adolescents With Type 1 Diabetes and Their Parents, *J. Pediatr. Heal. Care.* 23 (2009) 10–18. doi:10.1016/j.pedhc.2007.12.008.
- [20] B.J. Leonard, A. Garwick, J.Z. Adwan, Adolescents’ perceptions of parental roles and involvement in diabetes management, *J. Pediatr. Nurs.* 20 (2005) 405–414. <http://ovidsp.ovid.com/ovidweb.cgi?T=JS&PAGE=reference&D=med5&NEWS=N&AN=16298281>.
- [21] E.R. Goethals, L. Oris, B. Soenens, C.A. Berg, S. Prikken, N. Van Broeck, I. Weets, K. Casteels, K. Luyckx, Parenting and Treatment Adherence in Type 1 Diabetes Throughout Adolescence and Emerging Adulthood, *J. Pediatr. Psychol.* 42 (2017) 922–932. doi:10.1093/jpepsy/jsx053.
- [22] M.S. Faulkner, L.-I. Chang, Family Influence on Self-Care, Quality of Life, and Metabolic Control in School-Age Children and Adolescents with Type 1 Diabetes, *J. Pediatr. Nurs.* 22 (2007) 59–68. doi:10.1016/J.PEDN.2006.02.008.
- [23] A. Main, D.J. Wiebe, K. Van Bogart, S.L. Turner, C. Tucker, J.E. Butner, C.A. Berg, Secrecy from parents and type 1 diabetes management in late adolescence, *J. Pediatr. Psychol.* 40 (2015) 1075–1084. doi:10.1093/jpepsy/jsv060.

- [24] C.A. Berg, T. Queen, J.E. Butner, S.L. Turner, A. Hughes Lansing, A. Main, J.H. Anderson, B.C. Thoma, J.B. Winnick, D.J. Wiebe, Adolescent Disclosure to Parents and Daily Management of Type 1 Diabetes, *J. Pediatr. Psychol.* 42 (2016) jsw056. doi:10.1093/jpepsy/jsw056.
- [25] I.H.A. De Goede, S.J.T. Branje, W.H.J. Meeus, Developmental changes in adolescents' perceptions of relationships with their parents, *J. Youth Adolesc.* 38 (2009) 75–88. doi:10.1007/s10964-008-9286-7.
- [26] J.T. Markowitz, K.C. Garvey, L.M.B. Laffel, Developmental Changes in the Roles of Patients and Families in Type 1 Diabetes Management, *Curr. Diabetes Rev.* 11 (2015) 231–238. <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4826732/>.
- [27] C.A. Berg, J.E. Butner, J.M. Butler, P.S. King, A.E. Hughes, D.J. Wiebe, Parental persuasive strategies in the face of daily problems in adolescent type 1 diabetes management, *Heal. Psychol.* 32 (2013) 719–728. doi:10.1037/a0029427.
- [28] J. Luo, J. Guo, J. Yang, X. Ou, M. Grey, Parent–Child Relationship Quality as a Mediator of the Association between Perceived Stress and Diabetes Self-Management in Adolescents With Type 1 Diabetes, *J. Fam. Nurs.* 27 (2021) 73–82. doi:10.1177/1074840720971584.
- [29] A.M. Delamater, A.M. Patiño-Fernández, K.E. Smith, J. Bubb, Measurement of diabetes stress in older children and adolescents with type 1 diabetes mellitus, *Pediatr. Diabetes.* 14 (2013) 50–56. doi:10.1111/j.1399-5448.2012.00894.x.

Table 1

Overview of participant characteristics

Adolescent characteristics			
Gender	<i>N</i>		
Male	14 (50%)		
Female	14 (50%)		
Age	<i>N</i>		
11-13 years	10		
14-15 years	12		
16-17 years	6		
Age (years) at diagnosis	<i>Mean</i>	<i>SD</i>	<i>Range</i>
11-13 years	5.95	3.37	1.50 - 12
14-15 years	8.31	3.21	1.66 - 12
16-17 years	10.67	3.93	5 - 15
BGM	<i>N</i>		
11-13 years			
<i>Finger prick</i>	7		
<i>Semi-continuous BGM device</i>	3		
14-15 years			
<i>Finger prick</i>	7		
<i>Semi-continuous BGM device</i>	5		
16-17 years			
<i>Finger prick</i>	5		
<i>Semi-continuous BGM device</i>	1		
Insulin administration	<i>N</i>		
11-13 years			
<i>MDI</i>	2		
<i>Insulin pump</i>	8		
14-15 years			
<i>MDI</i>	4		
<i>Insulin pump</i>	8		
16-17 years			
<i>MDI</i>	3		
<i>Insulin pump</i>	3		
Last HbA1c	<i>Mean</i>	<i>SD</i>	<i>Range</i>
11-13 years (<i>n</i> =9)	8.11	0.96	7.10 - 10
14-15 years	7.78	1.01	6.50 - 9.80
16-17 years	7.70	0.54	7.20 - 8.50
Family History of T1D	<i>n</i>		
11-13 years	Yes (5)		
14-15 years	Yes (4)		
16-17 years	Yes (2)		

Table 2*Overview of themes and subthemes*

Themes	Subthemes
(1) Changing levels of involvement in self-management: “I take more responsibility for [this] and ... my mum would do that usually”	(1) Division of responsibility for self-management within the family (2) Collaborating and sharing responsibilities with parents for self-management
(2) Talking about self-management with parents: “I am not just like sitting in on the conversation... I am putting in my own ideas about what to think, what to do”	(1) Change in patterns of parent-adolescent communication about T1D over time (2) Seeking parental feedback and advice (3) Promoting self-management communication between adolescents and parents

Table 3

Overview of subthemes and illustrative quotes: Changing levels of involvement in self-management: “I take more responsibility for [this] and ... my mum would do that usually”

Subthemes	Illustrative Quotes
(1) Division of responsibility for self-management within the family	<p>“I guess my mum because my dad worked more often. My mum wasn’t working yet but like my dad would also help me with the numbers and everything and setting it up and helping me with all these charts and so he’d help me with this. So they both helped me a lot with it.” – P10, Male, 14 years, diagnosed age 6 years</p> <p>“Not unless he [brother] has been instructed to do it but he is good, like he checks up on me and stuff and he helps me.... ‘[P04’s name] you have to do your blood sugars, mum said you have to do that and make sure that you do this at that time’.” – P04, Female, 11 years, diagnosed age 5 years</p> <p>“...Well at the beginning they would, they would help me with my injections but now I pretty much do them myself so no I haven’t really relied on them overly but I have always known they are there to help if I need it.” – P03, Male, 14 years, diagnosed age 11 years</p>
(2) Collaborating and sharing responsibilities with parents for self-management	<p>“But now since I have gotten older I have kind of taken more control over it but my mum still helps me like a lot, I don’t know what I would do without her to be honest.” – P23, Female, 14 years, diagnosed age 6 years</p> <p>“Yeah because they used to do most of the work and now I have kind of I have kind of stepped up and ah-am doing a good bit of the work.” – P27, Male, age 14 years, diagnosed age 1 year</p> <p>“Like I thought I could just manage everything by myself, yeah like just check sugars, do corrections, do everything by myself. But then after a while things were starting to vary a bit so I just went back to my parents, and like not completely but I asked them to like again to help...” – P27, Male, age 14 years, diagnosed age 1 year</p> <p>“But they also give me a chance to think about it as well and they make sure that I have the right basals and everything.” – P04, Female, 11 years, diagnosed age 5 years</p>

“My parents’ role was just to make sure that I know what I was doing at first and then my parents’ role was kind of like they feel they don’t need to be there as much now but they are still there just to help me out like carb counting and stuff like that...” – P17, Female, 15 years, diagnosed age 10 years

“Ehm they would be there like to support me if I don’t want to do it anymore or just don’t feel like doing it. They would help me if I am like that and then they might, if I feel like that they might help a bit more and they would remind me to test often and am my dad would do the insulin and my mam would do the diary, so just to keep me on top of it.” – P24, Female, age 15 years, diagnosed age 11 years

“Yeah in the beginning it was grand. Now it is a pain sometimes, you are sort of going, ‘I did do it, I did do it.’ But it was good because if they don’t say it you will eventually forget once or twice.” – P22, Male, 16 years, diagnosed age 8 years

“Ehm most of the time it is annoying because my mam will be asking me to check all the time and I will say, ‘okay I will do it now.’...” – P24, Female, 15 years, diagnosed age 11 years

“So we might sometimes we [my parents and I] would both be confused about how to use the pump so we will help each other to am learn. Because you are always learning with the pump, there is a lot to it.” – P24, Female, 14 years, diagnosed age 6 years

“Like they [HCPs] would ask a few questions but my mam always has like some questions. She just likes to make sure about things because if my bloods have just been gone mad and she doesn’t know why she would be like- She will show them- We keep a little diary so if we write what food I have and my bloods and she gives it to them and she says, ‘Do you see here? We don’t know what happened there.’ So they will tell us what to do the next time it happens.” – P13, Female, 12 years, diagnosed age 8 years

“If I like if I didn’t have my parents I wouldn’t eat nearly as healthily, I wouldn’t have like the advice I get, they are a big help to me like.” – P11, Male, 16 years, diagnosed age 15 years

“...So that was hard, and also injecting every day was hard for me because am I wasn’t a big fan of injections and it was painful but I got on with it and I wanted to keep my bloods in range because I if I knew if I could do that I could do anything. And I knew that if I had a good trust with my parents then it would be fine...” – P26, Female, 15 years, diagnosed age 12 years

Table 4

Overview of subthemes and illustrative quotes: Talking about self-management with parents:

“I am not just like sitting in on the conversation... I am putting in my own ideas about what to think, what to do”

Subthemes	Illustrative Quote
(1) Change in patterns of parent-adolescent communication about T1D over time	<p data-bbox="660 533 1394 658">“I used to ask them about a lot more things and now I know like a lot more of the stuff so I don’t have to ask them as much.” – P08, Male, 12 years, diagnosed age 5 years</p> <p data-bbox="660 719 1394 1070">“I only if it is a serious low blood sugar, like if I am in the 2s, which I am rarely that, or if I am really, really high and we tell each other I talk to them about it, and if it is a once off time but if it is coming up every time we just talk to each other about it. But it’s it has changed greatly. We only need to tell each other the big the big problems not as well as every single detail like at the start because we were all babies basically.” – P26, Female, 15 years, diagnosed age 12 years</p> <p data-bbox="660 1131 1394 1442">“...They would say to take your bloods at little break if my bloods have been kind of low or high and if I haven’t had a chance to take them at little break they say, ‘well you should have.’ Where if I was younger they would say, ‘okay you know just do it tomorrow.’ So it has kind of gotten, because they know as I get older I will become more kind of like relaxed about it so they want to keep me on top of it.” – P15, Female, 15 years, diagnosed age 11 years</p>
(2) Seeking parental feedback and advice	<p data-bbox="660 1496 1394 1666">“I would say that they explain more to me now about like basal rates and stuff like that. When I was younger, I wouldn’t have known what that meant but now I understand everything” – P16, Female, 14 years, diagnosed age 5 years</p> <p data-bbox="660 1682 1394 1852">“... So I might have got a bit worried that I had to check my blood sugars and give insulin myself but like I usually am having to ring my mam and make sure I was like doing the right stuff.” – P11, Male, 16 years, diagnosed age 15 years, diagnosed age 15 years</p> <p data-bbox="660 1912 1394 1989">“Yeah like yesterday I went with my cousins to bowling and I was texting my mam if I done a blood and what I bolused and stuff to</p>

make sure that everything was okay...” – P02, Female, 13 years, diagnosed age 9 years

“Eh like if I didn’t know what it was they [parents] would find out what it was, tell me and like if I did a bolus wrong, if I did a wrong bolus for what I ate they would tell me what to do...” – P14, Male, 11 years, diagnosed age 3 years

“Well I told them I was nervous about getting it [insulin pump]and then my dad said, ‘sure [P05’s name] I forgot I had it on.’ And they said it wasn’t sore at all so I got it- so then I got it and it was okay.” – P05, Male, 11 years, diagnosed age 9 years

“Yes, we don’t really talk about it otherwise because I have it like fairly under control.” – P16, Female, 14 years, diagnosed age 5 years

“But sometimes it can get a bit difficult with the diabetes because with taking responsibility you want to make your own decisions but if you are stuck you still go to your parents but you are still like, ‘oh I don’t know what to do’.” – P13, Female, 12 years, diagnosed age 8 years

“If I had a question or if I wanted to know about something. You know like when I was quite interested in getting the pump, like I wouldn’t always talk about that I wouldn’t always start the conversation but a lot of the time I would because it was something I wanted. You know.” P25, female, 17 years, diagnosed age 13 years

(3) Promoting self-management communication between adolescents and parents

“...I feel like it is more positive conversations than, more like ‘yeah you did this well done.’ Where the bad conversation is more like ‘what have you done?’ So it is when my bloods are good that I find it easier to talk to them.” – P15, Female, 15 years, diagnosed age 11 years

“Not really, it is just like sometimes it is kind of if like say a school test or I was rushing that day and I didn’t get time to check them at one of the lunches or I forgot to do a bolus, it is kind of it’s frustrating when they are giving out and saying, ‘why didn’t you do this?’ I don’t think they really completely understand like what it is

like to have to have, like every teenager's mind-set and have all those things on your mind plus an added stress." - P16, Female, 14 years, diagnosed age 5 years

"Especially my mam, like she would be a lot more probably a little bit more worried about me but it is good that she is concerned I am staying healthy... Yeah but like sometimes I'd be like, 'Stop at me', but like she is just trying to help out really... Because she wants to just make sure that I am keeping myself healthy." - P11, Male, 16 years, diagnosed age 15 years

"Sometimes it is just easier not to talk to your parents about it. You know because they'll worry less..." - P25, Female, 17 years, diagnosed age 13 years

"We don't really talk about it much, just with the bloods and the boluses, we just talk about that but nothing really overall collectively... because we are always busy, always working, me with the study now and sports and stuff, so not really no." - P18, Male, 15 years, diagnosed age 11 years

"...it might be a little awkward if we were talking about something like the injection or if my pump shuts down or something like that... Usually what I mean by awkward is it is usually hard to find stuff to say [to parents] because you are hoping that it won't actually happen" - P04, Female, 11 years, diagnosed age 5 years

"...I suppose just you are sort of you are afraid they are going to give out to you, but they don't give out to you, they just want to know how you are doing just to make sure that you are all right..." - P22, 16 years, diagnosed age 8 years

"Well sometimes I think she doesn't like asking me in case I am like, 'of course they are fine'." - P25, Female, 17 years, diagnosed age 13 years

"... We are just really, really close the three of us that I can actually talk to them about stuff. We are just really close and I think that's what helps it as well." - P13, Female, 12 years, diagnosed age 8 years

“I usually go [to talk about T1D management or ask a question about T1D management] to my dad first because I feel like, he doesn’t always come to the appointments because he is always in work so I feel like he gets more of an understanding of where I am coming from.” – P15, Female, 15 years, diagnosed age 11 years

“... make sure you have the book done would be one of the main ones, just so that both of us know, we are both looking at the same thing going, ‘okay this is why it went high, this is why he is going okay at the minute’ and all that sort of stuff.” – P22, Male, 16 years, diagnosed age 8 years

“...you can go to them first and it is easier nearly talking to your parents than talking to someone that you don’t really know like a nurse or someone like that.” – P22, Male, 16 years, diagnosed age 8 years

|

Highlights

- Parent-adolescent communication surrounding self-management of T1D plays a critical role in enabling increased uptake of self-management responsibilities.
- Healthcare professionals and parents involved in adolescents' care should be cognisant of the factors that contribute to the negotiation of shared responsibilities for T1D management between adolescents and parents.
- Interventions targeting communication strategies employed by adolescents and their parents may result in more optimal sharing of responsibilities and improved self-management.