Review Article

Qualitative studies of type 1 diabetes in adolescence: a systematic literature review

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Background

T1D is the third most common chronic illness in childhood following asthma and cerebral palsy (1), affecting 237 000 people in the UK, 20 000 of whom are under the age of 15 (2). Diabetes management is lifelong and unpredictable (3). It changes throughout childhood and adolescence alongside age, psychological development, physiology and maturity (4). It may impact on identity development and psychological well-being, and increase risk of depression (5) and eating disorders (6).

Multiple complications are present in almost one fifth of patients with diabetes (7) as a result of maintained high blood glucose levels in the younger years (8). Effective blood glucose control can considerably reduce the risks of developing micro-vascular complications (9). There is global evidence to suggest that metabolic control deteriorates during the period of adolescence (10–12) and only 15% of under-fifteens with diabetes in the UK are currently achieving recommended blood glucose levels (as defined by glycated haemoglobin/HbA1c) of 7.5% (13). This has provoked a wealth of research into factors affecting adolescent metabolic control with findings suggesting many individual, cultural and societal influences. These include gender (14), developmental level (15), illness perceptions (16), school support (17), peers (18) and the family (19).

A literature review of T1D in adolescence was conducted to explore the causal factors of deteriorating metabolic control in adolescents with T1D. Recent systematic reviews have highlighted that continuous subcutaneous glucose monitoring is no more effective in reducing HbA1c than finger-stick monitoring in both adults (20) and children (21), implying a need to explore wider psychosocial factors as determinants of poor control. This identified a need for qualitative research to explore adolescents' experiences of living with T1D, but no existing systematic reviews were found. This systematic review fills this gap, identifies areas for future research and has informed empirical qualitative research exploring the experiences of adolescents with T1D and their parents (22).

Search methods

Electronic databases were searched using all combinations of the terms 'Type 1 diabetes', 'adolescence', 'teenager', 'parents', 'family' and 'qualitative'

for the period 1988–2008. Databases included Medline, Web of Science, British Nursing Index, CINHAL, PsychInfo, Science Direct, and Scopus. Grey literature was searched using the National Research Register, FADE and Proquest Dissertations and Theses. Qualitative studies of adolescents aged 13–16 years and their parents, published in English since 1988, were included. Quantitative studies, qualitative studies of adolescents and/or parents with T1D younger than 13 or older than 16, published in languages other than English and before 1988 were excluded. Mixed methods studies were included only if qualitative methods were prioritized.

Our searches identified 73 studies, including duplicates. After screening titles and abstracts for relevance, 38 full papers were obtained. The full text of these papers was then examined again against the inclusion/exclusion criteria. A total of 28 papers remained, relating to 20 individual studies (23–48). A second researcher was consulted when decisions regarding inclusion/exclusion were unclear.

Quality appraisal

All studies were systematically evaluated using Attree and Milton's checklist (49) (Appendix 1), chosen because of its balance between providing a comprehensive list of quality markers, whilst remaining meaningful and simple to administer. Two studies were excluded based on poor quality.

Data extraction and synthesis of evidence

A qualitative research integration approach aimed to provide a description, comparison and critique of current research and identify areas for further research (50). Data were extracted from computer-based forms developed for the review, and synthesized. The quality appraisal revealed varied methodological approaches, numbers of participants, reporting of participant characteristics, theoretical foundations, and settings. Epistemological grounding was not explicit in the majority of papers; therefore, a meta-synthesis was not attempted as findings were not transferable. The studies were grouped into 'sets' in relation to aims and content, and findings were compared, contrasted and discussed with reference to methodological issues emerging from the quality appraisal. Table 1 provides a detailed summary of each study.

Results: quality appraisal

Epistemology and theoretical framework

Epistemological grounding and theoretical basis are essential in qualitative research to facilitate methodological rigour. Data collection and analysis are grounded within a validated theoretical approach, thus improving the transparency and validity of the findings. Only six studies explicitly stated an epistemological viewpoint (24, 28–30, 36, 44, 47) and only three reported applying a theoretical framework (30, 35, 40–42). One study stated an ethnographic approach, but no evidence of ethnographic methods (i.e., observation) was described (30).

Sampling and population

The sample sizes of all studies, apart from Christian and D'Auria (44) and Davidson and colleagues (35) (four and six, respectively), ranged from 10 to 59. Most of the studies clearly described and justified their sampling strategy, aside from Carroll and colleagues (25–27). All of the studies implemented a purposive strategy, recruiting participants of a certain age and duration of diabetes from diabetes clinics. Authors applied a range of strategies within this approach including convenience (24, 28–30, 32, 33, 35, 36, 43, 46, 47), self-selecting (31, 33, 48), theoretical (23) and maximum variation (45) sampling. Olsen and Sutton described employing a stratified sampling technique in order to facilitate age-banding within their focus groups. Adolescents then self-selected from the stratified groups (48). Mellin and colleagues (37–39) recruited participants from a larger study, although it was not clear how these adolescents were selected, or how the sample was originally recruited. Two of the studies involved a secondary analysis of previously collected data: Ivey and colleagues (23) selected interaction transcripts based on HbA1c classifications; Davidson and colleagues (35) took a convenience approach to the selection of transcripts from coping skills training workshops.

Methods

Interviews were the primary method of data collection reported in 19 of the studies, including semi-structured in grounded theory and studies defined as 'qualitative' (30–32, 37, 39–42, 46, 47), and unstructured in phenomenological studies (24, 28, 29, 36). Other methods of data collection included focus groups (25–27, 34, 43, 48), drawings (47), and accessing the transcripts of coping skills training sessions (35).

Only three of the studies incorporated triangulation into their methodology in the form of multiple methods (39, 47, 48), thus reducing interpretation bias (60). Eight studies utilized multiple groups of participants (i.e., adolescents, parents, and siblings) (23, 25–29, 31, 33, 34, 37–39, 40–42) and one (28, 29) investigated family experiences by interviewing both adolescents and parents and analysing the data in terms of family narratives. Three studies explored family perspectives

Table 1. Studies included in the review

Study	Primary Focus	Epistemology	Theoretical Framework	Sampling Method and Population	Methods	Data Analysis	Integration Sets
Ivey et al. (23) USA	Parent/teen communication in relation to diabetes management	Not stated	Not stated	*Theoretical: metabolic control/* Adolescents aged 11–15 (n = 28) and their parents (n = 28)	Secondary content analysis of interaction transcripts	Content analysis	3
Karlsson et al. (24) Sweden	Lived experiences of teenagers, focussing on the transition towards autonomy in diabetes self-management	Descriptive phenomenology	Not stated	*Convenience* Adolescents aged 13–17 (n = 32)	In-depth interviews	Halldorsdittir (51)	1, 4
(i) Carroll et al. (25); (ii) Carroll and Marrero (26); (ii) (27) USA	(i) Mobile monitoring technology for self-management assistance and adolescent–parent conflict (ii) Adolescents' perceptions of diabetes influence on quality of life and relationships with others (iii) Parents' perceptions of their child's well-being, parent–child relations, peer influence and school on their child's diabetes management	Not stated	Not stated	*Not clear* Adolescents aged 13–18 (n = 31) and their parents (n = 28)	Focus groups: adolescents and parents	(i) Five step analysis process (52); 3 researcher team	1, 2, 3, 4
Wennick and Hallstrom (i) (28); (ii) (29) Sweden	Families' lived experiences at diagnosis and one year after	Hermeneutic phenomenology	Not stated	*Convenience* Children/ adolescents aged 9–14 (n = 11), their parents (n = 21) and siblings (n = 6)	In-depth interviews	van Manen (53); family narratives compared	1, 2, 3
Herman (30) USA	Costs and rewards of living with diabetes	Ethnography	Social exchange theory	*Convenience* Children/ adolescents aged 8–15 (n = 17)	Semi-structured interviews	Thematic analysis underpinned by social exchange theory	1, 2, 3
Schilling et al. (31) USA	Differences in self-management responsibility across adolescent developmental stages	Not stated	Not stated	*Self-selecting* Children/ adolescents aged 8–19 (n = 22) and their parents (n = 22)	Semi-structured interviews	Content analysis	1, 3

Table 1. Continued

Study	Aim	Theoretical framework	Sampling / participants	Data collection	Analysis	Themes
Leonard et al. (32) USA	Teens' views of their parents' involvement in diabetes management	Not stated	*Convenience* Adolescents aged 14–16 (n = 18)	Semi-structured interviews	Content analysis	1, 3
Low et al. (33) USA	Experience of insulin pump use	Not stated	*Convenience/self-selecting* Adolescents aged 11–18 (n = 18) and their parents (n = 21)	Semi-structured interviews	Content analysis	1, 3
Waller et al. (34) UK	Perceived acceptability of the Dose Adjustment For Normal Eating (DAFNE) programme (64) for adolescents and parents	Not stated	*Self-selecting* Adolescents aged 11–16 (n = 24) and their parents (n = 29)	Focus groups	Specific focus group analysis method (54)	4
Davidson et al. (35) USA	Stressors and self-care challenges reported by adolescents undergoing initiation of intensive management	Hymovich and Hagopian's stress-adaptation model (55)	*Convenience* Adolescents aged 12–20 (n = 34)	Coping skills training sessions	Content analysis	1, 2, 4
Dickinson and O'Reilly (36) USA	Lived experiences of females	Hermeneutic phenomenology	*Convenience* Adolescents aged 16–17 (n = 10)	In-depth interviews	van Manen (53)	1, 2, 4
(i) Hayes-Bohn et al. (37); (ii) Mellin and Neumark-Sztainer (38); (iii) Mellin et al. (39) USA	(i) Diabetes care at school (ii) Experiences of parenting (iii) Familial interactions regarding food and eating patterns	Not stated	*Purposive* Adolescent females/young adults aged 13–20 (n = 30) and their parents	(i) and (ii) Semi-structured interviews (iii) Disordered eating questionnaire; semi-structured interviews	Content analysis	3, 4
Hanna and Guthrie (i) (40); (ii) (41); (iii) (42) USA	(i) Dimensions of support related to assumption of T1D management responsibility (ii) Influences on the assumption of diabetes management from parents (iii) Parents' perceived benefits and barriers to transferring diabetes management to adolescents	(i) Barrera and Ainlay's social support dimensions (56) (ii) and (iii) Janis and Mann's decisional balance sheet (57)	*Purposive* Adolescents aged 11–18 (n = 16) and their parents (n = 17)	Semi-structured interviews	Content analysis	1
Weinger et al. (43) USA	Sources of diabetes-related conflict and support within families	Not stated	*Convenience* Adolescents aged 13–15 (n = 24)	Focus groups	Focus group analysis	3

Table 1. Continued

Study	Primary Focus	Epistemology	Theoretical Framework	Sampling Method and Population	Methods	Data Analysis	Integration Sets
Christian and D'Auria (44) USA	The experience of living with T1D in relation to taking on responsibility for care	Grounded theory	Not stated	*Purposive* Adolescents aged 15–17 (n = 4)	In-depth interviews	Constant comparative method (58)	1
Williams (45) UK	Impact of gender on the meanings and management of diabetes	Not stated	Not stated	*Maximum variation* Adolescents aged 15–18 (n = 20)	In-depth interviews	Open coding (59)	1
(i) Kyngas et al. (46); (ii) Kyngas & Barlow (47) Finland	(i) Adolescents' perceptions of the actions of physicians, nurses, parents and friends and their relationship to compliance (ii) Personal meaning and perceived impact of diabetes	(i) Not stated (ii) Grounded theory	Not stated	*Convenience* Adolescents aged 13–17 (n = 51)	(i) Semi-structured interviews (ii) Semi-structured interviews and drawings	(i) Content analysis (ii) Constant comparative method (58)	1, 2, 3, 4
Olsen and Sutton (48) UK	Family relationships and interactions with formal routine health care	Not stated	Not stated	*Stratified/ self-selecting* Adolescents aged 14–17 (n = 21)	In-depth interviews and focus groups	Framework analysis	1, 4

but published the findings from parents and adolescents as separate papers (26, 27, 38, 39, 41, 42).

Data analysis

Of the studies which did not state an epistemological stance, eight described a content analysis approach (23, 31–33, 35, 37–42, 46). This is the most basic type of qualitative analysis. The content of the data is analysed in order to categorize the recurrent or common themes (61), and thus it has been described as 'quantitative' description of qualitative material (62). Content analysis can be applied in a deductive manner which introduces a degree of bias. Interpretation and new meaning are minimal, as the findings provide a description of the data close to the form in which it was given (63). This was apparent in Shilling and colleagues' study (31), in which themes were predefined from the research questions. In an attempt to improve rigour, Low and colleagues (33) utilized a content analysis approach combined with the constant comparison method usually utilized in grounded theory studies, with a function of *"testing provisional hypotheses as additional cases were reviewed"* (33, p. 24). Three of the focus group studies applied specific authors' frameworks to their data analysis (25–27, 34, 43, 48). Carroll and Marrero (25–27) applied a basic thematic approach to analysis, but the validity of this study was improved as the analysis was collaborative, thus reducing interpretation bias. Bias was also reduced through member checking in one study (48).

The phenomenological studies utilized two different approaches to data analysis, grounded in the phenomenological tradition. Karlsson and colleagues (24) described an eight-step descriptive method based on Halldorsdottir's (51) approach and both of the interpretive phenomenological studies (28, 29, 36) utilized van Manen's (53) approach. The two grounded theory studies (44, 47) utilized open coding (59) and constant comparison (58).

The studies which utilized a content analysis approach were generally descriptive in their presentation of the findings. The validated approaches to analysis in the epistemologically-grounded studies moved the findings beyond pure description towards an interpretation of the meaning of the phenomena. This allowed for the inductive transformation of the data from its original form, towards a 'new' interpretation of the phenomena (63). Subjective meaning was privileged (49) and thus improved the transparency and validity of the findings.

Synthesis of findings

Four sets emerged from the integration of studies and each set was divided into sub-sets. Some studies'

findings covered more than one set, as detailed in Table 1. The total number of studies in each set are as follows:

(i) Independence and autonomy for diabetes management (n = 14);
(ii) Living with T1D (n = 5);
(iii) Family relationships (n = 10);
(iv) Diabetes care (n = 8).

Set 1: Independence and autonomy for diabetes management

Psychological and emotional maturity

Becoming emotionally ready to take responsibility for diabetes management was a complex process underpinned by gaining factual, experiential knowledge and problem-solving skills. Diabetes camps and school trips provided safe environments to gain such experience away from home (24, 44). Self-esteem increased as a by-product of successful self-management, suggesting that confidence may facilitate independence (24, 30, 32); however, being away from home also caused stress for some (35).

Adolescent girls incorporated diabetes into their identities more than boys, for whom mothers took on most of the responsibility for their care (45). Girls described T1D forcing them to be more independent and responsible than their peers (36). This suggests that gender differences in developmental level may relate to cognitive capacity for independence.

Parental input as a barrier to autonomy

Parents took an administrative role in adolescents' diabetes management, including monitoring medication, organizing clinic appointments and liaising with health professionals (25). Unnecessary parental input often resulted in conflict between parent and child (31) and adolescents felt mistrusted as a consequence (46). Parents were aware that their reminders were annoying, but found it difficult to step back from assistance (25). Teenagers with poor control had a more negative view of parental reminders and tended to ignore them rather than utilizing the support. There was also a higher instance of parent–adolescent conflict in these young people compared to those with better control (32).

Parental facilitation of autonomy

Parental involvement gradually decreased as adolescents grew older (31). Parental trust in adolescents' ability to manage their diabetes reduced anxiety about the consequences of poor management and enabled parents to give their child more freedom (24). Allowing adolescents to build the confidence to manage their

diabetes independently whilst giving background support (40, 44, 46) was the ideal scenario. The process of gaining autonomy for diabetes management was characterized by *'hovering'* between individual actions and the support of parents (24).

Peer facilitation of autonomy

The demands of living with diabetes became greater as socialization needs increased with age, leading to feelings of frustration and restriction (44). Adolescents felt that they had to take on more responsibilities than their peers (26). Feeling comfortable and not different from peers was key to integration of diabetes into daily life (24) and independence (24, 44). It was important for adolescents to disclose their diabetes to friends (26, 44, 48) as they felt *'safe'* in the knowledge that their friends could cope in an emergency. This enabled them to *'forget'* about their diabetes when with their peers (24). Peer support was generally valued, but too much interest from friends was also seen as intrusive and patronizing (26, 48).

Biomedical facilitation of autonomy

Encouragement for independent decision-making by health professionals was beneficial for autonomy. Basal bolus insulin regimes (44) and insulin pumps (33) benefited autonomy, lifestyle freedom and independence for some adolescents.

Implications of autonomy for adolescents and parents

Many parents took personal responsibility for their child's diabetes, and interpreted the HbA1c check at clinic appointments as confirmation of how they had discharged their parental responsibilities (28). Transferring responsibility over to their child was therefore often difficult. Parents felt that they had lost control, and had to deal with negative consequences of reducing their input, such as increased blood glucose fluctuations. Parents and adolescents worried about the burden of increased responsibility for adolescents. Adolescents recognized that their parents felt guilty and worried as they took on more responsibility (41, 42).

Adolescent autonomy positively relieved the burden of responsibility for parents, whilst adolescents enjoyed increased knowledge and confidence in their own abilities, more freedom and the approval of others (41, 42). Successful self-management had the benefit of reducing worry for parents and adolescents and increasing freedom (30). Parents and adolescents described confidence and pride in adolescents' abilities to manage independently (41, 42).

Set 2: Living with T1D

Managing conflict

Living with diabetes meant having to make decisions and manage conflicts (37), including whether to follow their management plan (35, 36), be truthful about self-care action (35), tell others about their diabetes (35, 36), and ask for help (35). Adolescents also reported emotional conflicts: being healthy yet invisibly ill, feeling acceptance yet frustration, independent yet supervised, and confident yet insecure (28).

Facilitators of self-management

Successful management of diabetes was related to knowledge and experience, adherence, exercise and parental support (30). Confidence, knowledge, and self-efficacy had a positive effect on health, emotions, social opportunities, and relationships (35).

Adolescents and parents felt that an implantable testing device which automatically tested blood glucose and administered insulin, and a blood glucose tester incorporated into a mobile telephone or personal digital assistant (PDA) would be beneficial to self-management. Desired functions were calculation of insulin dose based on blood glucose levels, storage of data, automatic upload onto a website which could be accessed by parents and health professionals, and alarmed reminders for blood glucose testing (25).

Barriers to self-management

Some adolescents saw T1D as a threat to their physical and psychosocial well-being (47). Adolescents were aware of the potential health costs of not taking care of their diabetes (30); however, self-monitoring was inconvenient and disruptive, and negatively influenced by increase in age, school and peer influences and social stigma (25). They were concerned with fitting in with the adolescent culture (36) and some received unwanted attention when injecting or testing in public. Not taking care of diabetes had the perceived benefit of enabling some adolescents to fit in with their peers more adequately; however, poor adherence also led to blood glucose fluctuations (30) and feelings of guilt (35, 36).

Restrictions, stressors, and coping

Diabetes was perceived as a difficult and demanding condition (35) with inconvenient dietary restrictions and interruptions to daily life (30), but also as potentially manageable (35). Some adolescents felt controlled by school staff, sports coaches and health care providers. Anxiety was caused by the threat of complications and poor HbA1c results (36). Coping mechanisms included implementing routines for diabetes management, carrying supplies in preparation for potential blood glucose fluctuations, asking parents for help and thinking ahead regarding the possible implications of non-compliance (35).

Set 3: Family relationships

Family adaptation and learning

Adapting to T1D was an on-going learning process for families which occurred in two stages. (i) *'Learning about the inevitable':* acknowledgement of the symptoms of the child's diabetes prediagnosis, followed by feeling overwhelmed and powerless. Confidence emerged once they had experienced managing the child's diabetes at home. (ii) *'Learning about the extent':* learning about the effect of the child's diabetes on family relationships, the restrictions imposed on family life, and anxiety about blood glucose fluctuations (28).

Parents created new family routines following diagnosis (29) and changed their lifestyle (e.g., reducing working hours), to cope with the demands of the diabetes regime (38). Adhering to routines reduced feelings of parental anxiety (29, 38) but caused inconvenience for some siblings (28). Some adolescents perceived changes to family life as a *'cost'*, as conflicts and inconvenience were introduced (30). T1D also had positive effects for some families, including improved diet (30, 38), increased exercise, smoking cessation (38), improved sibling relationships, and a sense of the family *'working together'* (30). Negative family meal time behaviour was thought to influence disordered eating in adolescents, whereas maintaining structure for meals and focussing on positive eating behaviours served as a protective function (39).

Parent–child relationships

Adolescents felt supported by parents who reassured them about complications and blood glucose fluctuations (43), and felt motivated by positive parental feedback (46). Parent–adolescent conflict occurred as a result of non-adherence to the diabetes regimen and resulting parental anxiety (31, 32, 38, 43). Although such disagreement was common (43), some parents felt close to their adolescent daughters and rarely experienced conflict (38). Relationships between adolescent daughters and mothers were perceived as positive when daughters displayed 'responsible' behaviour including being reliable and trustworthy in other areas of life as well as with diabetes (38). When daughters achieved good control of diabetes, relationships with mothers improved as parents reported experiencing less stress (32).

Parental anxiety

Parents were likely to perceive their child's diabetes as more serious than the child (27). Diabetes brought

parents increased anxiety about complications, management away from home, quality of management and hypoglycaemia (23, 38). Parents reported increased stress in the initial adjustment period when their child began using an insulin pump (33). Parents coped with anxiety by maintaining a positive outlook and providing practical support (38).

Intrusive behaviours precipitated by parental anxiety (43) and a lack of confidence in the adolescent's ability to manage their diabetes led to negative adolescent–parent communications, and left adolescents feeling mistrusted (47) and as if they had failed their parents (28, 43). This affected self-esteem, confidence, autonomous functioning and ultimately diabetes control, as adolescents sometimes compromised their self-management behaviour in order to avoid potential conflict and negative feedback from parents (25, 26, 43). Parents described changing their own behaviours and expectations of *'perfect'* management, in order to reduce conflict (38).

Set 4: Diabetes care

Clinical care

Adolescents valued health professionals who had a *'friendly'* manner and spoke to them about other things aside from their diabetes (26, 34). They felt supported when health professionals made suggestions about insulin doses or food choices (36) and when care was planned collaboratively with them (47). Professional advice often did not conform to their real-life situation (24) and some felt they were treated as a *'disease'* rather than a person (26). Some adolescents did not understand the information that health professionals gave them, and allowed their parents to interpret it for them (34). Others felt that some physicians worked to a specific, immutable model of care regardless of communication between the adolescent and physician (47). Older adolescents wanted communication in consultations to be directed towards them rather than their parents (26).

Teenagers did not completely trust the care plans issued to them by health professionals and wanted more input into their care decisions (35). Clinic attendance tended to decline as adolescents get older and transition to adult service occurred. Efforts to engage adolescents at transition age should be made to prevent them losing contact at this complex time in their lives (48).

Education

Group education was beneficial, as it facilitated a support network. Adolescents disliked *'refresher sessions'* which covered the basics of diabetes management, as they did not learn anything *'new'*. They preferred education away from the hospital, presented in a simple

manner without the pressure of tests and assessments, and enjoyed the incorporation of *'fun'* activities. Parents felt that practical exercises rather than didactic teaching were beneficial for adolescent learning and that the use of technology would encourage participation (34).

Diabetes care in schools

Lack of understanding about T1D from teachers in school was common. Adolescents were often questioned by teachers during blood testing and eating (36, 37). Food choices conducive to 'healthy' diabetes management were poor in school canteens and adolescents sometimes struggled to meet school rules, which they felt were insensitive to their needs. Transitions to new school settings caused stress, with new challenges and care resources in an unfamiliar situation (37).

Discussion

Twenty quality-assessed studies of adolescent diabetes were reviewed in this research integration exercise. Findings, centred around four sets, are summarized as follows:

- Developing autonomy for diabetes management is a complex process influenced by many psychosocial factors including psychological and emotional maturity and gender. It was inhibited by intrusive parental input and facilitated by parents finding a balance between holding back on input and providing background support. Adolescents felt safe in the company of peers who had diabetes knowledge but who also gave them space. Encouragement of autonomy by health professionals was beneficial, and basal bolus and pump regimes had a positive influence. Increased autonomy relieved a burden for some parents and improved confidence and knowledge for adolescents, although the process caused anxiety for parents and adolescents as they adjusted to decreased/increased responsibility.
- Living with T1D involved conflict resolution on a daily basis regarding decision-making and emotions. Knowledge, experience, and parental support facilitated effective self-management and adherence; not fitting in with peers was a barrier. Poor adherence led to blood glucose fluctuations and guilt. Some felt controlled, anxious and restricted by T1D.
- Living with adolescent T1D was an on-going learning process for all family members. Routine and positive parental support improved adolescent adherence and blood glucose control, whereas negative adolescent–parent communication negatively influenced self-efficacy, confidence, autonomy, and control. Adolescent–parent conflict was common; parental

anxiety was reduced when blood glucose control was good.
- Adolescents valued individualized care and involvement in care planning. Group education incorporating activities was an effective way for adolescents to learn. Clinic attendance declined with increasing age; transition services were important to avoid losing contact. Schools did not always provide an environment conducive to diabetes management.

Research gaps and methodological limitations

These findings must be viewed alongside the following limitations: (i) there were considerable inconsistencies between the research settings and methodologies of the studies; (ii) the reviewer's secondary interpretation of the included papers meant that the findings were subjective; (iii) limiting the search to studies published in English meant that studies in different cultural contexts were not included.

The quality appraisal highlighted a number of methodological issues, which have served to identify the following research gaps. However, it must be noted that the appraisal was based solely on the methods reported in papers and therefore may not accurately reflect the actual research process. Word-length limits in peer-reviewed publications can lead to poor quality in the reporting of research methods, although some papers provided more detail than others. Authors were not contacted for clarification of the methodology employed when epistemological approach and methods were unclear.

(i) The majority of papers described studies conducted in the USA (n = 18). These findings are not transferable to adolescents in other counties/settings where health care provision, education, and culture differ. Only one qualitative study was conducted in the UK in the past 10 years (34) and this focussed on an evaluation of a DAFNE-style (64) programme rather than adolescents' lived experiences. There is therefore a need for qualitative research exploring the lived experiences of adolescents with T1D in other countries/settings.

(ii) The findings suggest that significant others within the family, school, and clinic are paramount to managing the demands of living with diabetes in adolescence alongside the development of personal autonomy. Eight studies reported adolescents' and parents' perceptions of diabetes (23, 25–29, 31, 33, 34, 37–42), and one combined adolescents', parents' and siblings' perceptions (28, 29). The importance of parent–child beliefs and interactions in relation to adolescent diabetes

management and autonomy was apparent. Family perspectives in future research are therefore needed.

(iii) Measures should be taken to improve the validity of qualitative research in this area. Researcher reflexivity was under-reported in the majority of studies and only three incorporated triangulation in the form of multiple methods (39, 47, 48). The study of adolescent diabetes requires a combination of qualitative methods to give greater diversity. Although analysis was checked by other researchers in some studies (24, 30, 46), there is also a need for member checking in order to reduce interpretation bias.

(iv) Qualitative research in this area should be grounded in epistemological traditions and underpinned by theory. Only six studies explicitly stated an epistemological viewpoint (24, 28–30, 36, 44, 45, 47) and only three of the studies applied a theoretical framework (30, 35, 40). Findings from high-quality, trustworthy studies can lead to a better understanding of the factors that inhibit good blood glucose control in the adolescent age group, and the potential impact on care provision.

Conclusion

This systematic review met the aim of integrating the research findings in reports of qualitative studies of T1D and adolescence in order to define the content of the literature to date and identify research gaps. In light of previous systematic reviews which found that subcutaneous glucose monitoring is no more effective than finger-stick testing (20, 21), the findings indicate that social relationships are a key factor in the management of T1D. Adolescents face juggling the different demands of their diabetes within the social spheres of the family, school, peers and clinic. Teenagers' abilities to be independent in diabetes management are embedded within relationships with parents, peers, health professionals and teachers. This warrants further investigation in the UK and other settings, using rigorous qualitative research methodologies underpinned by epistemological tradition and novel theoretical frameworks. This will enable a better understanding and new perspectives of what it is like for adolescents and their significant others to live with T1D and the complex social interactions surrounding self-management in this age group, with the ultimate aim of improving blood glucose control and future health outcomes.

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Appendix 1. Quality Appraisal Checklist (49)

Checklist for the quality appraisal of qualitative research

Quality scoring system:

A: No flaws;

B: Some flaws;

C: Considerable flaws, study still of some value;

D: Significant flaws that threaten the validity of the whole study.

Methodological Area	Key Criteria	Yes	No	Quality Score
Background of research	Source of funding (relationship to findings?).........................			
	Name of study...			
	Is the connection of the research to an existing body of knowledge or theory clear?			
Aims and objectives	Is there a clear statement of the aims of the research?			
	Are the research questions clear?			
Context	Is the context or setting adequately described?			
Appropriateness of design	Are qualitative methods appropriate?			
	Is the research design appropriate to address the research aims? Is it 'fit for purpose'?			
Sampling	Sampling strategy...			
	Is the sampling strategy appropriate to address the research aims?			
	Criteria used to select the sample....................................			
	Does the sample include an adequate range of possible cases or settings?			
	Sample size..			
	Is the sample size justified? (Data saturation)			
	Did any participants choose not to take part in the study?			
	If so, why?..			
Data collection	How were data collected, and by whom?			
	Is the form of data clear (e.g., tape recordings, fieldnotes etc.)?			
	Were any methods modified during the research process?			
	If so, why?..			
	Does data collection involve triangulation (of multiple methods or data sources)?			
	Is there evidence that data collection was systematic (e.g., an audit trail)?			
Data analysis and findings	How was the analysis carried out?...................................			
	Are sufficient data presented to support the findings?			
	How were data selected for inclusion in the report?..			
	Are data annotated with demographic details of contributors?			
	Do the findings directly address the research question?			
	Does the research privilege subjective meaning?			
	What steps are taken to demonstrate the trustworthiness of the findings (e.g., negative cases, respondent validation)?........................			
	Have the limitations of the study and their impact on the findings been taken into account?			
Reflexivity	Has the relationship between researchers and participants been adequately considered?			
	Do the researchers reflect on their personal viewpoints and experience that they bring to the research setting?			
How valuable or useful is the research?	Does the research add to knowledge, or increase the confidence with which existing knowledge is regarded?			
	Is there a discussion of how findings relate to wider theory; consideration of rival explanations?			
	What are the implications for policy and practice–how is it 'fit for purpose'?...			
Ethics	How have ethical issues been taken into consideration (e.g., consent, confidentiality, anonymity, distress to participants)?....................			

OVERALL STUDY SCORE