

Children and young people's experiences and perceptions of self-management of type 1 diabetes: A qualitative meta-synthesis

Health Psychology Open
July-December 2019: 1–24
© The Author(s) 2019
Article reuse guidelines:
sagepub.com/journals-permissions
DOI: 10.1177/2055102919877105
journals.sagepub.com/home/hpo



Ella Tuohy¹, Caroline Rawdon¹, Pamela Gallagher¹,
Michele Glacken², Nuala Murphy³, Veronica Swallow⁴
and Veronica Lambert¹

Abstract

The aim of this review was to conduct a meta-synthesis of the experiences and perceptions of self-management of type 1 diabetes of children and young people living with type 1 diabetes (CYPDs). Six databases were systematically searched for studies with qualitative findings relevant to CYPDs' (aged 8–18 years) experiences of self-management. A thematic synthesis approach was used to combine articles and identify analytical themes. Forty articles met the inclusion criteria. Two analytical themes important to CYPDs' experiences and perceptions of self-management were identified: (1) negotiating independence and (2) feeling in control. The synthesis contributes to knowledge on contextual factors underpinning self-management and what facilitates or impedes transition towards autonomous self-management for CYPDs.

Keywords

meta-synthesis, paediatric, qualitative research, self-management, type 1 diabetes

Introduction

Type 1 diabetes (T1D) is a relatively common chronic illness that frequently has its onset in childhood and adolescence (Mayer-Davis et al., 2018). Management of T1D is onerous and includes frequent blood glucose monitoring, administering insulin and balancing insulin requirements with food and exercise. The unrelenting nature of these tasks is burdensome for children and young people living with type 1 diabetes (CYPDs; Hood et al., 2006). During adolescence, metabolic control tends to deteriorate (Cameron et al., 2018). This deterioration is partly physiological because of pubertal insulin resistance and partially related to reduced adherence to T1D management, engagement with risk taking behaviours (Cameron et al., 2018) and difficulties engaging with self-management (Campbell et al., 2014).

The ability of CYPDs to carry out T1D management is dependent on cognitive, motor and emotional maturity levels, and these levels may determine which T1D management tasks the CYPDs are ready to assume responsibility for and take ownership of (Hanna and Decker, 2010;

Silverstein et al., 2005). Though adolescents may have the necessary motor skills to complete the tasks of T1D management, research indicates that parents maintaining involvement in their children's care lead to better medical outcomes (Markowitz et al., 2015). Self-management of T1D involves sharing responsibilities with others such as parents and healthcare professionals (HCPs), and autonomous decision-making, with the goals of achieving control over health and well-being (Schilling et al., 2002). While parental involvement is important for T1D management, it can impact on parent–adolescent relationships with research

¹Dublin City University, Ireland

²Institute of Technology Sligo, Ireland

³Children's Health Ireland at Temple Street, Ireland

⁴University of Leeds, UK

Corresponding author:

Veronica Lambert, School of Nursing, Psychotherapy and Community Health, Faculty of Science and Health, Dublin City University, Dublin 9, Ireland.

Email: veronica.lambert@dcu.ie



indicating that CYPDs and their parents may experience T1D-related conflict and that parents and CYPDs may not always agree about the level of competence of the CYPDs to carry out T1D management tasks independently (Butner et al., 2009; Hood et al., 2007). Childhood and adolescence is a critical time for children and young people (CYPs) living with a chronic illness to gradually develop autonomy in chronic disease management, with complete autonomy in health-related tasks and decision-making often arriving in late adolescence (Beacham and Deatrick, 2013).

Previous reviews have synthesised CYPDs' experiences of living with T1D (Ellis and Jayarajah, 2016; Spencer et al., 2010) and of managing T1D (Kelo et al., 2011; Marks et al., 2016; Rankin et al., 2017) in specific contexts such as health service provision at paediatric diabetes clinics (Curtis-Tyler et al., 2015) or T1D management in school settings (Kelo et al., 2011; Marks et al., 2016). Of these reviews, none synthesised evidence specifically relating to CYPDs' experiences and perceptions of self-management of T1D. Experiences of younger children (under 12 years) have been recently synthesised (Rankin et al., 2017). Therefore, given the developmental differences that occur across age groups, a synthesis of older children and adolescent experiences of self-management of T1D in day-to-day contexts may contribute to knowledge and allow current qualitative evidence relating to this group to be collated.

As late childhood and adolescence is an important time when CYPDs assume increasing self-management responsibilities and where management difficulties and parental conflict can occur, aggregation and further interpretation of research around CYPDs' experiences of self-management is warranted. This suggests a need for a synthesis of evidence from wider contexts, including studies that focus on experiences in settings beyond schools and also explicitly considering all attributes of self-management which include activities, processes and goals (Schilling et al., 2002). Understanding how CYPDs experience self-management of T1D may inform HCPs and others involved in the care of CYPDs on how best to assist families of CYPDs which in turn may lead to improvements in clinical and psychosocial outcomes. The aim of this review was, therefore, to conduct a meta-synthesis of qualitative studies exploring experiences and perceptions of self-management of CYPDs (age 8–18 years).

Method

This systematic review and qualitative meta-synthesis was conducted and reported in accordance with the Enhancing Transparency in Reporting the Synthesis of Qualitative Research (ENTREQ) statement (Tong et al., 2012).

Search strategy

A search for eligible articles, from database inception up to 26 July 2018, was undertaken across six electronic

databases; PubMed, Medline via Ovid, EMBASE, CINAHL, PsycINFO and Web of Science (Web of Science Core Collection). A search strategy combining controlled vocabulary (e.g. MESH) and free-text words was created and adapted to each database (see example search strategy in Appendix A in the supplementary material). The search strategies reflected the meta-synthesis' focus on CYPDs, T1D, self-management and qualitative methodologies. Searches were limited to articles published in English and studies carried out with human participants. The search in EMBASE was limited to records unique to EMBASE.

Article selection criteria

Articles were selected for inclusion if they (1) were empirical, peer reviewed articles published in English; (2) included CYPDs aged 8–18 years of age (or where data for this group could be clearly disaggregated from other data collected in the article, for example, if parents, individuals aged over 18 years or individuals living with other conditions were also included); (3) included qualitative data pertaining to the experience of self-management of T1D (mixed methods, intervention or quantitative studies with open-ended questions were included if qualitative data were reported separately). Any qualitative studies (1) that explicitly examined self-management of T1D from CYPDs' (8–18 years) perspectives as the primary focus of the study, (2) that examined self-management of T1D from CYPDs' perspectives as a sub-focus of a larger study or (3) where findings pertaining to self-management of T1D from CYPDs' perspectives emerged as a theme or sub-theme, or formed part of a theme or sub-theme were included. Self-management was considered as a range of behaviours, carried out as part of illness management and the promotion of well-being, that have relevance to medical, psychological and social outcomes. Based on the definition used by Panagioti et al. (2014), included studies had to mention actions taken by an individual to lead a healthy lifestyle, care for their condition, meet psychosocial needs and prevent complications or further illness. Table 1 summarises the inclusion and exclusion criteria of the qualitative meta-synthesis.

Screening process

After removing duplicate articles across the databases, a two-stage screening process was undertaken to identify eligible articles that met the inclusion criteria:

1. Two reviewers (E.T., C.R.) independently screened retrieved titles and abstracts;
2. E.T. and C.R. independently read full-texts of retrieved articles. E.T. screened reference lists for potentially eligible articles. Discrepancies were resolved through discussion with two further reviewers V.L. and P.G.

Table 1. Inclusion and exclusion criteria.

	Inclusion criteria	Exclusion criteria
Publication characteristics	Journal articles published in English	Books, book chapters, opinion pieces, editorials, letters, systematic reviews, dissertations/theses, consumer articles, conference abstracts, conference proceedings, guideline documents
Study design	Empirical studies using qualitative methods or mixed methods, intervention or quantitative approaches with a qualitative component	Studies using quantitative methods only, case studies
Population	CYPs aged 8–18 years living with T1D	Studies which focus only on: <ol style="list-style-type: none"> 1. Parent, sibling, peer, health care professional or other views and perspectives 2. Type 2 diabetes, gestational diabetes, monogenic diabetes or where diabetes occurs secondary to another physical condition 3. Other conditions; not T1D or where T1D-specific data cannot be isolated from other data
Study focus	Studies which focus on self-management: <ol style="list-style-type: none"> 1. Taking ownership and responsibility for T1D 2. Actions taken to lead a healthy lifestyle, care for T1D, meet psychosocial needs and prevent complications or further illness 	Studies which focus only on: <ol style="list-style-type: none"> 1. Diagnosis, the use or development of a specific medical device or intervention, one aspect of management, for example, diet only, exercise only 2. Studies which consider outcomes such as quality of life, coping and emotional disorders, transition from paediatric to adult services in isolation

CYPs: children and young people; T1D: type 1 diabetes.

Data extraction

The following information was extracted for each article: author, year, country of origin, aim/objective, recruitment setting, sample, data collection method, analytical approach and findings. Data were extracted by E.T. and cross-checked by C.R.

Methodological quality of included studies

Included articles were independently assessed for methodological quality by E.T. and C.R. using the Critical Appraisal Skills Programme (CASP) (2018) which assesses methodological quality across 10 items. Reviewers indicated whether each checklist item was addressed within the article using *yes*, *no* or *can't tell*. Discrepancies were resolved through discussion and where a decision could not be reached, V.L. and/or P.G. resolved the discrepancy. Quality appraisal aided critical consideration of the methodologies and findings of included articles.

Qualitative meta-synthesis method

In this qualitative meta-synthesis, thematic synthesis (Thomas and Harden, 2008), comprising of three stages, was used to combine primary studies. An inductive thematic synthesis was carried out without an a priori framework for analysis, as described by Thomas and Harden (2008): (1) Line-by-line coding of the available text found in the results

and findings sections of included articles. At least one code was applied to each section of relevant data. Codes were examined, and where necessary an additional level of coding was applied before the final list of codes was generated. (2) Descriptive themes were developed through grouping resulting codes according to similarities, differences and patterns across the codes. Descriptive themes were labelled based on the data which they were describing and remained close to the findings of the primary studies. (3) Analytical themes were developed by 'going beyond' the initial study findings to produce the synthesis product which may indicate new concerns, issues or recommendations in light of the topic under investigation (Barnett-Page and Thomas, 2009). Analytic themes were inferred based on the descriptive themes and the initial review question posed. The results/findings sections of included studies were extracted verbatim and entered into NVivo 11 software for analysis (QSR International Pty Ltd, 2015).

Results

After a systematic search yielding 5341 articles, 40 articles reporting on 34 studies were included (see Figure 1 and Table 2).

Characteristics of included studies

In total, there were 862 participants in the 34 studies (across 40 articles). Of the 34 studies which reported data

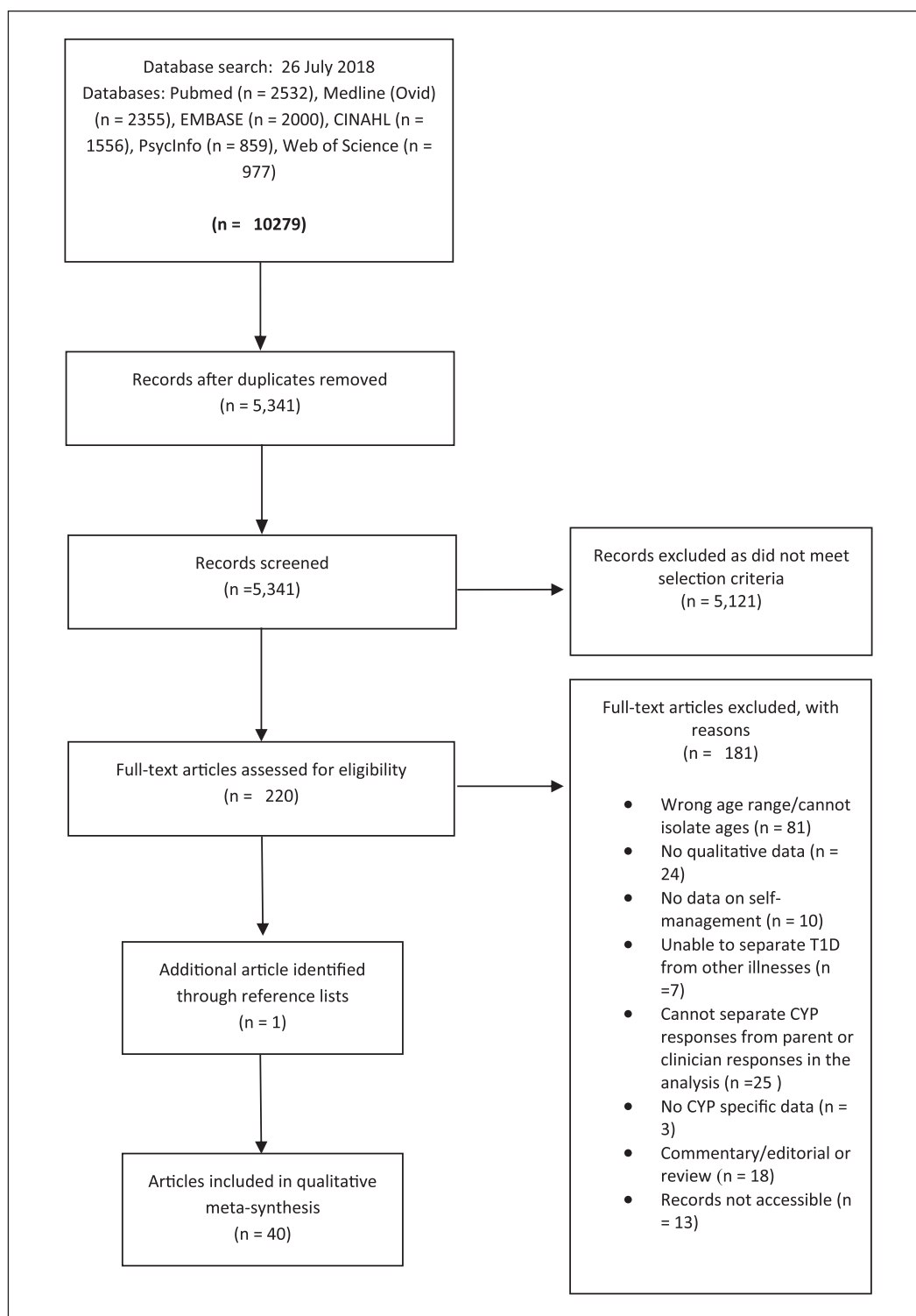


Figure 1. Flow diagram representing flow of article identification and selection process.

on separate participants, 30 provided a breakdown of the gender of participants (50% male and 50% female). Included articles were published between 1987 and 2018. Articles originated from the United States ($n=19$), Sweden ($n=4$), Finland ($n=3$), the United Kingdom ($n=3$), Taiwan

($n=2$), Netherlands ($n=2$), Ireland ($n=1$), Romania ($n=1$), Brazil ($n=2$), Canada ($n=1$), Iran ($n=1$) and Australia ($n=1$). The majority of participants were recruited from doctor's offices, clinics or hospitals ($n=22$). Other recruitment settings were through diabetes camps ($n=6$), not

Table 2. Overview of included articles.

Author (year), country	Aim/objective	Recruitment setting	Sample	Data collection ^a	Analytical approach ^a	Findings related to self-management of T1D ^b
Babler and Strickland (2016) ^c , USA	To gain an understanding of adolescent experiences of living with T1D and to build a theoretical paradigm for future interventions to improve health outcomes for adolescents living with T1D	Clinic	N = 11 (3 males, 8 females), aged 11–15 years (mean, 13.9 years), average HbA1c = 8.2% (range, 7.2%–9.2%; median, 8.4), all Caucasian	Interview	Grounded theory	A theoretical model was created using the concept 'normalising' related to self-management of T1D. The focus of this article was the 'figuring it out' phase (phase 5) of normalising and includes the codes: 1. Learning to accept diabetes 2. Believing it is possible to manage their diabetes 3. Showing responsibility 4. Staying on track A theoretical model was developed about the concept of 'normalizing life with diabetes during adolescence'. The concept of 'normalizing' is defined as the ability of the adolescents to integrate diabetes into the background of their daily life by creating routines to make diabetes 'part of me'. The model includes the following six phases (actions adolescents took to manage their T1D): 1. Recognising life is changing 2. Taking action to prevent a crisis 3. Disclosing to engage support 4. Taking on the burden of care 5. Accepting the 'new normal' 6. Hoping for a normal future The focus of this article was 'moving the journey towards independence' phase (phase 4) of the concept of 'normalizing' related to T1D self-management and codes included: 1. Taking over care 2. Experiencing conflict with parents 3. Realising diabetes is hard
Babler and Strickland (2015a) ^c , USA						
Babler and Strickland (2015b) ^c , USA						
Boman et al. (2015), Sweden	To gain knowledge on the experiences of adolescents from minority ethnic backgrounds of taking care of their T1D and understanding the factors that are important for taking responsibility for self-care	Paediatric hospital	N = 12, aged 13–18 years (all first and second generation immigrants)	Semi-structured interview	Phenomenography	A model based on the informants' statements and Bronfenbrenner's (1979) ecological theory is proposed in this article. Factors influencing ability to take care of T1D were: <i>Micro-level factors</i> Personality, normality, attitude towards the disease, risk, autonomy, forgetfulness, hope <i>Meso-level factors</i> The paediatric diabetes team, school staff, family, friends <i>Macro-level factors</i> The diabetes discourse, school organisation, culture and the youth discourse
Burke and Dowling (2007), Ireland	To gain insight into living with T1D from the perspective of adolescents	Hospital	N = 5 (4 males, 1 female), aged 13–18 years and diagnosed with T1D > 2 years	Unstructured interview	Descriptive phenomenological approach	Themes identified were: 1. Living in the shadow of hypoglycaemia 2. Dietary mismanagement 3. Support (peer, family, school) 4. 'Get used to it'
Carroll and Marrero (2006), USA	To explore adolescents' perceptions of how T1D influences quality of life and relationships with family, peers and others	Physicians' offices	N = 31 (18 males, 13 females), aged 13–18 years (mean, 14.9 years), duration of diabetes = 6 months–14 years (mean = 6.6 years)	Focus group	Thematic analysis	Themes were: personal perceptions of living with diabetes, impact on relationships (parental relationships, peer relationships and physician relationships) and impact on school

(Continued)

Table 2. (Continued)

Author (year), country	Aim/objective	Recruitment setting	Sample	Data collection ^a	Analytical approach ^a	Findings related to self-management of T1D ^b
Chao et al. (2016), USA	To examine general life and T1D-related stressors in adolescents living with T1D	Four diabetes clinical sites Participants were enrolled in a randomised clinical control trial comparing two psychoeducational programmes	N = 205 (120, female, 85 male) aged 11–14 years (mean = 12.28 years), mean HbA1c = 8.26%, mean diabetes duration = 6.32 years Race/ethnicity (%): 63.8 white, 19.1 Hispanic, 7.5 black, 9.4 multi-racial/other	Online questionnaire containing open-ended questions	Content analysis	Themes which emerged relating to general life stressors were: fitting in, having friends, balancing competing demands, living with family and feeling pressure to do well. Themes which emerged as specific to living with T1D were: just having diabetes, dealing with emotions and managing diabetes.
Chilton and Pires-Yfantioua (2015), UK	To gain an understanding of the process of adapting to the self-management of T1D during adolescence	A paediatric diabetes service which runs six diabetes clinics	N = 13 (7 males, 6 females) aged 13–16 years, mean age = 15 years Average HbA1c (over last 12 months) = 9.49% Mean diabetes duration = 6.31 years, range: 1–13 years	Semi-structured interview	Grounded theory approach using constant comparative analysis	A framework for understanding self-management as a continuum was developed. The continuum consists of difficulties with self-management at one end and successful self-management at the other. Transitional phases (which were 'impact of diabetes diagnosis', 'Turning point – time of change', 'Acceptance – coming to terms' and 'Distancing – when diabetes plays a small part in life') and process mechanisms (which were 'Fighting diabetes – trying to be 'normal'', 'Body regulator – using the body to detect diabetes status', 'Trial and error – learning through experience', and 'Self-learning – experiential-based learning') can facilitate adaptation to T1D within the continuum.
Christian et al. (1999), USA	This pilot study aimed to explore and describe adolescent perspectives of living with T1D during adolescence	University paediatric diabetes centre	N = 4 (2 females, 2 males) aged 15–17 years (mean = 15.75 years), diabetes duration > 4 years, all Caucasian	In-depth interview	Grounded theory approach	Three themes related to the process of gaining self-responsibility for T1D management during adolescence. These were: 1. Making it fit 2. Being ready and willing and 3. Having a safety net of friends Four themes were identified: 1. Making sense of diabetes 2. Normalising diabetes 3. Gaining control over diabetes 4. If I take care of diabetes, diabetes takes care of me The two thematic categories which emerged were: 1. Learning of the diagnosis 2. Living with diabetes
Cosma and Baban (2015), Romania	To gain an understanding into how adolescents experience the psychological and behavioural demands of T1D	Paediatric hospital	N = 11, 7 males, 4 females, aged 13–16 years (mean = 14.27 years), mean diabetes duration = 8.18 years, range: 5–11.5 years	Semi-structured interview	Thematic analysis	
Cruz et al. (2018), Brazil	To learn about the experiences of adolescents living with T1D from the perspectives of the Ethics of Alterity	Paediatric outpatient clinic of a university hospital	N = 9, aged 12–17 years, diagnosed > 1 year	Focus groups and semi-structured interviews	Thematic analysis	
Damião and Pinto (2007), Brazil	To understand the experiences of adolescents living with T1D	Diabetes outpatient clinic	N = 7, 4 males, 3 females, aged 12–18 years, Diagnosed > 1 year	Semi-structured interview	Grounded theory	Themes presented are: 1. Receiving the diabetes diagnosis 2. Being transformed by illness 3. Being a 'prickly' life Themes emerged under the following categories: 1. Nature of the condition 2. Personal 3. Care management 4. Relationship 5. Situational 6. Coping behaviours 7. Dilemmas impacting self-care decisions and coping responses
Davidson et al. (2004), USA	To describe stressors and self-care challenges reported by adolescents living with T1D following the initiation of intensive T1D management	Participants had been recruited from a paediatric diabetes clinic for an earlier study evaluating a coping skills training programme, described by Grey et al., 1998; as cited in Davidson et al., 2004)	N = 6, aged 13.0–17.7 years (mean = 14.7 years), 5 males, 1 female, mean diabetes duration = 7.3 years, range: 2.8–10.8 years, mean HbA1c = 9.7%, range: 8.0%–13.6%, 5 Caucasian/white, 1 Hispanic	Transcripts from a coping skills training course	Content analysis	

(Continued)

Table 2. (Continued)

Author (year), country	Aim/objective	Recruitment setting	Sample	Data collection ^a	Analytical approach ^a	Findings related to self-management of T1D ^b
Dickinson and O'Reilly (2004), USA	To gain an understanding of adolescent female experiences of living with T1D	Diabetes camp	N=10 adolescent females, aged 16–17 years, living with T1D for 5–12 years, all Caucasian	Unstructured interview	Phenomenological approach	Themes identified were: 1. Blending in with the adolescent culture 2. Standing out and being watched 3. Weighing the options and making choices 4. Being tethered to the system and to diabetes 5. Struggling with conflicts Themes identified: 1. Restrictions 2. Differentness 3. Negative emotion (chiefly anger) 4. Adaptation Adolescents described the following helpful and non-helpful behaviours in relation to assuming T1D management: <i>Helpful behaviours for assuming T1D management:</i> directive guidance (behaviours to aid performance), non-directive supports and tangible assistance (providing physical assistance) <i>Non-helpful behaviours for assuming T1D management:</i> directive guidance and tangible assistance Adolescents identified the following perceived benefits and barrier to assuming T1D management: <i>Adolescent perceived benefits to diabetes self-management:</i> approval from others <i>Adolescent perceived benefits for parents in adolescents' diabetes self-management:</i> relief from responsibility, stress, and worry <i>Perceived barrier:</i> burden of responsibility, lack of barriers <i>Perceived barriers for parents in adolescents' diabetes self-management:</i> worry, guilt, loss of control and lack of barriers
Faro (1999), USA	This pilot study aimed to assess the impact of T1D on the overall quality of life of adolescents living with T1D and to explore their concerns related to social issues	Diabetes camp	N=23, 12–16 years, 14 males, 9 females, Diabetes duration: <2.0 years: 7 (30%) 2.1–10.0 years: 13 (56%) >10.0 years: 3 (14%)	Semi-structured interview	Qualitative data was analysed for patterns, themes and interconnections between themes	
Hanna and Guthrie (2001), USA	To identify adolescents' perceptions of helpful and non-helpful support in relation to assuming responsibility for management of T1D	Diabetes speciality clinics	N=16, mean age = 14.6 years, 11–18 years, 9 female, 7 male, mean HbA1c = 8.6, mean duration of diagnosis = 6.9 years, range: 1–10 years, 15 Caucasian	Structured face-to-face or telephone interview	Content analysis	
Hanna and Guthrie (2000), USA	To identify adolescents' perceived benefits and barriers to the process of assuming T1D management from parents			Semi-structured interview	Content analysis	
Herrman (2006), USA	To explore the costs and rewards of T1D and its treatment from the perspectives of children and young people	A 1-week diabetes day camp	N=17, 10 females, 7 males, aged 8–15 years (10.8 years), mean diabetes duration = 34 months, range: 6–120 months	Semi-structured interviews	Data analysis using social exchange theory to identify categories and responses	Data were placed in the following categories: 1. Costs of diabetes mellitus 2. Rewards of diabetes mellitus 3. Costs of management of diabetes 4. Rewards of the management of diabetes 5. Costs for family 6. Rewards for family Themes identified were: 1. To be different 2. To be treated differently 3. To live a regular life 4. To know one's body 5. To take care of oneself Themes identified were: 1. Hovering between individual actions and support of others 2. Growth through individual self-reliance 3. Growth through confirmation of others
Huus and Enskar (2007), Sweden	To describe the experiences of adolescents living with T1D	Not reported	N=8, 6 females, 2 males, aged 14–18 years, T1D duration, 3–11 years	Unstructured interview	Phenomenology	
Karlsson et al. (2008), Sweden	To explain the lived experiences of young people living with T1D transitioning towards autonomous self-management of T1D	Diabetes clinic at a children's hospital	N=32 (18 females, 14 males), age 13–17 years (mean = 14.5 years), T1D duration, 1–14 years, mean T1D duration = 6.8 years, mean HbA1c = 7.9%	Semi-structured interview	Phenomenology	

(Continued)

Table 2. (Continued)

Author (year), country	Aim/objective	Recruitment setting	Sample	Data collection ^a	Analytical approach ^a	Findings related to self-management of T1D ^b
Kupper et al. (2018), Netherlands	To explore the contribution of a participatory workshop to understanding the lived experiences of adolescents living with T1D	Treatment centres – through recruitment letters and an online questionnaire.	N = 11 (participated in at least one of two workshops), mean age = 14.09 years, n = 11 (participated in both workshops) Subgroup 1 (younger): 12–14 years Subgroup 2 (older): 15–18 years All participants' HbA1c < 8.5%	Video recordings of workshops where participants explore the lived experience of T1D using the body as an expressive tool	Qualitative data analysis (Miles and Huberman, 1994; as cited in Kupper et al., 2018)	The areas relating to lived experience which the workshops facilitated expression of were: 1. The story of living with diabetes 2. Unravelling the contextual complexity of lived experience 3. Articulating underlying motives: The need to fit in 4. Playful exploration of possible worlds
Kyngas and Barlow (1995) ^c , Finland	To examine the personal meaning and perceived impact of T1D on adolescents living with T1D	Paediatric ward of a university hospital	N = 51 (28 males, 23 females), aged 13–17 years, mean = 15.1 years, mean diabetes duration = 7 years, range: 1–13 years	Interview and illustration task where participants were asked to illustrate the meaning of diabetes in a drawing Interview and observation of participant behaviour during an adaptation course Semi-structured interview	Grounded theory approach	Categories describing the personal meaning of T1D were: a habit, a little devil, a nightmare, stress, prison, death and hell. The main categories which emerged describing the impact of T1D were: threat to physical well-being and threat to psychosocial well-being, the opportunity to live a healthy life
Kyngas and Hentinen (1995) ^c , Finland	To gain an understanding of compliance with self-care for adolescents with T1D			Interview and observation of participant behaviour during an adaptation course Semi-structured interview	Grounded theory	Four categories of behavioural pattern were found: 1. Good compliance 2. Imposed compliance 3. Conscious non-compliance 4. Non-compliance
Kyngas et al. (1998) ^c , Finland	To explore how adolescents perceive the actions of others (clinicians, parents, peers) in relation to compliance with their self-care			Semi-structured interview	Content analysis	Actions under the categories of physicians, nurses, parents and friends were described. Actions of physicians: Motivating, authoritarian, routine, negligent and, routine and negligent Actions of nurses: Motivating, according to physician's instruction and routine Actions of parents: Motivating, acceptance and disciplined control Actions of friends: Domination, silent support, irrelevant (no meaning)
Leach and Erickson (1988), Canada	To examine children's perspectives of and beliefs about T1D and its influence on daily activities	Diabetes camp	N = 76, aged 8–12 years n = 12, completed a follow-up interview	Field notes and audio-recordings from activities during the camp, interview	Interpretive/hermeneutic analysis	Categories which emerged were: 1. Cause of diabetes 2. Experiencing diabetes 3. Physical effects 4. Onset of symptoms 5. Treatment
Leonard et al. (2005), USA	To compare how young people with higher HbA1c viewed parental roles and involvement in T1D management compared with those with lower HbA1c	Paediatric endocrinology service	N = 18 (13 females, 5 males), aged 14–16 years Subgroup 1 (lower HbA1c): n = 7, mean age = 14.7 years, average HbA1c = 7.7% Subgroup 2 (higher HbA1c): n = 11, mean age = 15.1 years, HbA1c = 9.6%, all Caucasian	Semi-structured interviews	Qualitative content analysis	Themes which emerged were: 1. Gaining freedom and responsibility for diabetes management 2. Feeling bothered by parental reminders to manage their diabetes 3. Closeness of family and parental relationships 4. Parental involvement in diabetes management monitoring 5. Parent-teen conflict related to diabetes
Marshall et al. (2018), USA	To explore adolescent perceptions ^d of managing T1D and social support within a community	Open advertisement within a community	N = 2 (female participants living with T1D), aged 15–18 years	Interview	Phenomenology	Themes identified were: 1. Perception of disease 2. Exclusion based on disease 3. Hiding from illness through non-disclosure 4. Sources of support

(Continued)

Table 2. (Continued)

Author (year), country	Aim/objective	Recruitment setting	Sample	Data collection ^a	Analytical approach ^a	Findings related to self-management of T1D ^b
Masiakpak et al. (2010), Iran	To explore the barriers to achieving a good quality of life for Iranian girls living with T1D	A diabetes organisation and city hospitals	N=20 females, aged 13–18 years, diagnosed > 1 year	Semi-structured interview	Content analysis	Two main categories were identified: 1. External world barriers on good quality of life Sub-categories: negative family environment, social wrong perspective about diabetes, problems in school 2. Individual barriers on good quality of life Sub-categories: negative feeling towards treatment and care, negative effects of diabetes, uncertainty about future Three categories and associated themes were identified: 1. Psychosocial (intrapsychic or social themes) Themes: acceptance, view of diabetes, informing others, guilt/blame 2. Developmental (adolescent maturational themes) Themes: independence, peer support, diabetic control 3. Clinical (practical management themes) Themes: difficulties, coping strategies, information sources
Meldman (1987), USA	To explore adolescents' perspectives of their T1D management	Counsellors-in-training at a diabetes youth camp	N=12 (9 females, 3 males), aged 15–18 years, age at diagnosis 7–17 years	Semi-structured interview	Constant comparative analysis – grounded theory	Themes identified were: 1. Impact of diabetes 2. Disclosure 3. Attitude towards support from friends 4. Perceptions of supportive and non-supportive behaviour by friends: Emotional support (normal treatment, interest, fun and distraction, taking the diabetes into account) and instrumental support (offering reminders, providing help)
Peters et al. (2014), Netherlands	The aim of Study 1 ^d (online focus groups with adolescents with T1D) was to investigate perceptions of adolescents with T1D and their friends with respect to the positive social support that friends offer	Four diabetes clinics	N=28 (16 females, 12 males), aged 12–15 years, Female: Mean age=13.1 years Time since diagnosis: <1 year: n=3 1–5 years: n=8 >5 years: n=5 Not reported: n=1 Last HbA1c (%): <7.5: n=2 7.5–9.0: n=3 Not reported: n=1 Male: Mean age=13.7 years Time since diagnosis: <1 year: n=2 1–5 years: n=3 >5 years: n=6 Not reported: n=1 Last HbA1c (%): <7.5: n=3 7.5–9.0: n=1 >9.0: n=1	Online focus groups	Content analysis	Themes which emerged pertaining to self-management were: 1. Insensitive and unsupportive peers 2. Support provided by peers (friends' development of knowledge about diabetes, monitors and prompters, helpers, normalizers) 3. Peer support provided by other children with type 1 diabetes
Rankin et al. (2018), UK	To explore pre-adolescent children's experiences of receiving diabetes support from friends and peers and whether, how and why they found this support helpful	Paediatric diabetes centres	N=24, 11 female, 13 male, mean age=10.3 years, range: 9–12 years, diabetes duration mean=4.3 years, range: 1–10 years	In-depth interviews incorporating optional play-based tasks	Thematic analysis using constant comparative analysis	

(Continued)

Table 2. (Continued)

Author (year), country	Aim/objective	Recruitment setting	Sample	Data collection ^a	Analytical approach ^a	Findings related to self-management of T1D ^b
Ryninks et al. (2015), UK	To examine factors that facilitate or deter engagement with physical activity and to investigate young people's attitudes to, and understanding of, physical activity on glycaemic control, in young people living with T1D	Paediatric diabetes service	N = 12, 8 males, 4 females, 11- to 16-year-olds, mean age = 14.5 years, median HbA1c time 1 = 8.3%, median HbA1c time 2 = 8.1%	Focus group (four focus groups with 11 to 14-year-olds and 15- to 16-year-olds)	Interpretive phenomenological analysis	The four superordinate themes developed were: 1. Benefits of exercise 2. Knowledge and understanding 3. Information and training 4. You can do anything
Serlachius et al. (2012), Australia	To explore stressors related to T1D for adolescents and to obtain feedback on a coping skills programme	Diabetes outpatient clinic at a paediatric hospital	N = 13 (9 males, 4 females), age 13–17 years, mean = 15.4 years, mean time since diagnosis = 5.8 years, mean HbA1c = 8.1%	Four focus groups	Thematic analysis	Key themes which emerged were: 1. Parent/adolescent conflict 2. Balancing self-management and daily concerns 3. Health concerns 4. Benefits of social support 5. Importance of diabetes-specific information and skills
Standiford et al. (1997), USA	To explore personal illness models of T1D of pre-adolescents and adolescents with T1D	Children's hospital	N = 60 (31 females, 29 males), 10–17 years, diagnosed with T1D > 2 years, 58 Caucasian, 2 African American	Structured interview	Content analysis	Themes relating to responses to relevant questions were: <i>What kind of treatment do you think you should get for your diabetes?</i> From health professionals: Help to control blood glucose From family: Direct assistance, support, eat like I do, promote independence From friends: Support, treat me as normal From self: Be responsible <i>What are the most important things you hope this treatment will do for you?</i> Feel better, healthy/improved future, be cured Prevent complications/death Control of blood glucose <i>What are the chief problems diabetes has caused for you?</i> Food restrictions Blood glucose tests/injections Inconvenience of diabetes regimen Symptoms of high or low blood glucose Activity limitations <i>What do you fear most about your diabetes?</i> Complications Insulin reactions
Sullivan-Bolyai et al. (2014), USA	To describe the perspectives of teenagers ^d about self-management knowledge, behaviours (including division of labour associated with T1D management) and resources used to manage T1D	Paediatric diabetes clinic	N = 10, 6 males, 4 females, aged 13–17 years, mean age = 14.9 years, diagnosed > 1 year, mean HbA1c = 8.7, T1D duration, 1–12 years, mean = 6 years, 7 Caucasian, 3 self-identified as culturally diverse	Focus group	Content analysis	Categories which emerged following analysis of the adolescent focus group were: 1. Descriptions of diabetes management and learning about it 2. Clinic: pros and cons 3. Advice for others with T1D

(Continued)

Table 2. (Continued)

Author (year), country	Aim/objective	Recruitment setting	Sample	Data collection ^a	Analytical approach ^a	Findings related to self-management of T1D ^b
Viklund and Wikblad (2009), Sweden	To understand how teenagers living with T1D describe factors affecting decision-making competence in relation to T1D management	Diabetes clinic of a university hospital	N=31 (17 females, 14 males), mean age = 14.2 years; range: 12–17 years; mean T1D duration = 6.8 years; range: 1–15 years	Semi-structured interview	Qualitative content analysis	The five categories which emerged were: 1. Cognitive maturity 2. Personal qualities 3. Experience and development 4. Social network 5. Parent involvement Themes which emerged were: 1. The same yet different 2. Covert and overt 3. Limitations and freedom 4. Independent and dependent 5. Derailing and being on track 6. Disease identity and denial
Wang et al. (2013), ^c Taiwan	To explore the lived experiences of adolescents with T1D in the school setting	Purposive snow-ball sampling at a public high school	N=14 (8 males, 6 females), 14.20 years, mean diabetes duration = 4.64 years, mean self-reported HbA1c = 9.43%	Semi-structured interview	Hermeneutic phenomenological approach	Themes were: 1. Learning to be master of their disease 2. Learning to find ways to feel comfortable 3. Learning to not be different 4. Learning not to let others (especially parents) worry about them
Wang et al. (2010), ^c Taiwan	To gain a preliminary understanding of the school-based lived experiences of adolescents	Purposively recruited at public or junior high school	N=2 (male aged 15, diagnosed for 6 years and female aged 14, diagnosed for 1 year)	Semi-structured interview	Hermeneutic phenomenological approach	Themes were: 1. Learning to be master of their disease 2. Learning to find ways to feel comfortable 3. Learning to not be different 4. Learning not to let others (especially parents) worry about them
Weinger et al. (2001), USA	To increase understanding of adolescent-parent T1D-related conflict and support, and to use the information to develop supports in the management of T1D	Two diabetes summer camps	N=24 (10 males, 14 females), aged 13–15 years, mean = 14.4 years, 97% white	Focus group	Unclear	Sources of T1D-related conflict were: 1. Parental worry and intrusive behaviours 2. Parental lack of understanding and blaming behaviours 3. The parents focus on the future vs the adolescent focus on the present Sources of T1D support were: 1. Parental understanding of the demands of diabetes normative functioning 2. Parental provision of reassurance about their child's illness and
Ye et al. (2017), USA	To describe impacts or consequences of T1D that matter to adolescents living with T1D	Two online diabetes forums (based in the UK and USA)	50 posts written by 36 unique pseudonyms (11 female, 5 male, 20 unknown), median age= 15.5 years, 13–17 years, n = 24, diabetes duration: median = 5 years, range: <2 months–17 years, n = 18	Analysis of posts in an online forum	Content analysis	Themes identified were interactions with peers, emotional well-being, blood glucose management, physical well-being, education and motivation of others, family interactions, academic achievements and interactions with important others such as teachers and health care providers

T1D: type 1 diabetes.

^aAs reported by study authors.

^bMain themes or findings reported by the study authors.

^cArticles reporting on same instance of data collection.

^dArticles reporting multiple studies where only the relevant study findings (pertaining to adolescent responses only) are included.

Table 3. Overview of analytic themes and descriptive themes.

Analytic themes	Descriptive themes
Negotiating independence	Coming to terms with T1D Parental roles and parental involvement in T1D self-management Others' involvement in T1D self-management Becoming independent in T1D self-management
Feeling in control	Structuring self-management into everyday life Ability to self-manage T1D Fitting in or standing out and self-management of T1D Thinking about the future and complications

T1D: type 1 diabetes.

specified ($n=2$), a national diabetes organisation and hospital ($n=1$), open advertisement in community ($n=1$), online forum ($n=1$) or school ($n=1$).

The data reported in each article were collected via interviews ($n=25$), focus groups ($n=5$), open-ended questionnaire ($n=1$), a combination of interview and an illustration task ($n=1$), interviews and focus groups ($n=1$), field notes and audio-recording of diabetes camp activities ($n=1$), interview and observation ($n=1$), interview and play-based task ($n=1$), transcripts from coping skills training meetings ($n=1$), recording of a workshop ($n=1$), online forum posts ($n=1$) and online focus groups ($n=1$). The approaches to analysis reported by the included articles were content analysis ($n=13$), phenomenology ($n=9$), grounded theory analysis ($n=9$), thematic analysis ($n=5$) and other type of analysis or unclear ($n=4$). Characteristics and findings of included studies are summarised in Table 2.

Quality appraisal

The results of the quality appraisal are detailed in Appendix B in the supplementary material. Where articles received *no* or *can't tell* ratings, it was unclear whether the area for appraisal was addressed. This may have been a feature of the reporting within the particular article rather than the methodological quality of the research. For example, it was often not possible to assess the appropriateness of the recruitment strategy or whether the researcher-participant relationship had been adequately considered due to insufficient information reported, and these articles often received *no* or *can't tell* ratings.

Thematic synthesis findings

The synthesis of the findings of the 40 included articles resulted in the identification of two analytic themes associated with CYPDs' experiences of self-management of T1D: 'Negotiating independence' and 'Feeling in control'. The eight descriptive themes that contributed to these analytic themes are outlined in Table 3. The analytic and descriptive themes with example quotations to illustrate how themes were developed are presented in Table 4. The numbers of extracts coded for each descriptive and analytic theme, and

the contribution of each individual article to the development of the descriptive and analytic themes are presented (see Appendix C in the supplementary material).

Negotiating independence. This analytic theme reflects balancing the demands of living with and managing T1D and how this occurs as CYPDs interact with others while moving towards independence in T1D self-management. The analytic theme presents the dynamic nature of the movement towards independence and outlines how internal (in the descriptive theme 'Becoming independent in T1D self-management') and external ('Parental roles and parental involvement in T1D self-management' and 'Others' involvement in T1D self-management') factors may feature within this move towards autonomous self-management. CYPDs gradually accept T1D as a part of their lives, often moving from an initial point of non-acceptance, and how this occurs may influence engagement with self-management for CYPDs as they navigate the process of becoming independent in their self-management ('Coming to terms with T1D'). The demands of self-management may be negotiated with others such as parents or HCPs. The demands of self-management may also be negotiated internally by the CYPDs as they become independent in all aspects of their lives while also becoming independent in T1D self-management.

Coming to terms with T1D. This descriptive theme depicts adapting to the requirements of living with T1D, which is a process that occurs over time. The prospect of lifelong self-management of T1D is introduced at diagnosis and may be marked by feelings of uncertainty, fear, sadness or confusion (Babler and Strickland, 2015a; Cosma and Baban, 2015; Leach and Erickson, 1988). The diagnosis experience may have relevance for current feelings and health beliefs held towards T1D as feelings about diagnosis, time since diagnosis or level of maturity may influence the CYPDs' acceptance of T1D self-management (Chilton and Pires-Yfantouda, 2015; Cosma and Baban, 2015; Damião and Pinto, 2007).

Following initial resistance and questioning in relation to a T1D diagnosis, CYPDs spoke about beginning to accept the lifelong nature of T1D (Chilton and Pires-Yfantouda, 2015). CYPDs contend with living with T1D,

Table 4. Qualitative meta-synthesis: analytic themes, descriptive themes, example codes and illustrative quotations.

Analytic theme	Descriptive theme	Example codes	Illustrative quotations
Negotiating independence	Coming to terms with TID	Accepting TID	'It (diabetes) is there, it will never go, but it is just how much you let it get to you is just the key to it, it never goes away it is always a part of you, until you just accept it, it is always just there'. (Babler and Strickland, 2016: 125) 'It is harder than it looks but gets easier all the time . . . the more you know and the more you work at it . . . the better it gets'. (Herrman, 2006: 218) 'It doesn't bother me that much living with diabetes, I have [had] it a good few years now. It doesn't make any difference really'. (Burke and Dowling, 2007: 92)
		Comparing TID to other illnesses	'. . . you'll realise that you can do things just as, the same as other people but you've just got to take that little bit of care and then, also there's people in the world with much worse stuff than diabetes . . .'. (Chilton and Pires-Yfantouda, 2015: 1497) '(it's) ridiculously hard sometimes because you feel like trapped, then you're just like, well people deal with a lot worse'. (Babler and Strickland, 2016: 125) 'Diabetes is better than many diseases. If diabetes is bad, what about polio and other handicaps? You should be thankful you're diabetic . . .'. (Wang et al., 2013: 239)
		Getting used to TID	'. . . it's just like something that I can deal with'. (Dickinson and O'Reilly, 2004: 102) 'When I was newly diagnosed I was scared to death to go low. Then I went low, and I can identify it now'. (Carroll and Marrero, 2006: 246) 'Diabetes is living hell. I fight against it'. (Meldman, 1987: 438)
		Recognising TID is forever	'I hate having to deal with diabetes management all the time'. (Chao et al., 2016: 139) 'That illness is for life . . . I don't even say it is a disease because, to me, having a disease means you go to the doctor, he tells you what your problem is, you take the medication and you get better. Not diabetes, you don't get better, you control it'. (Damião and Pinto, 2007: 571) 'I hope I will wake up and the diabetes will be gone'. (Kyngas and Barlow, 1995: 943)
		Understanding TID	'Growing up helped me to understand more about diabetes'. (Cosma and Baban, 2015: 238) 'I remember one time I just, erm I was really hungry but my mum was like you've got to do your injection first and this was just a few months after [diagnosis] I think and then erm I was like I'm not doing it, like I don't see why I have to and everything'. (Chilton and Pires-Yfantouda, 2015: 1498)
		Attitude towards TID	'You don't think about it as being extremely hard . . . you start to figure out it's not as hard as people think, once you . . . get used to the motion of it, it becomes just a really simple thing'. (Babler and Strickland, 2016: 125) 'I wouldn't say that erm diabetes has changed anything that I do really, cos I, I still do everything I did before I was diabetic'. (Chilton and Pires-Yfantouda, 2015: 1493)
		Parental roles and parental involvement in TID self-management	Parent roles <i>Checking in with parents</i> <i>Parental reminders</i> <i>Parents help and assist</i> <i>Parents teach</i> <i>Parents motivate</i> <i>Parents reassure</i> <i>Parents step in</i> Conflict, blame and not being in agreement with parents

(Continued)

Table 4. (Continued)

Analytic theme	Descriptive theme	Example codes	Illustrative quotations
		Sharing and negotiating management of parents	<p>'They can get a little too much . . . like letting me . . . a rope to hang yourself . . . both of them [give] too much room I guess. Sometimes if she . . . didn't ask me for a while . . . I'll feel like – oh sluff off on something'. (Hanna and Guthrie, 2001: 218)</p> <p>'They told me that I could do things. They kind of offered a little bit of incentive like "well, you know, we can't let you go over to her house for the whole day if we can't depend on you to check your blood sugar on your own"'. (Hanna and Guthrie, 2001: 218)</p> <p>'My mom would help me. We'd decide together how much I was going to do. Or I'd ask her. Now, she's not even home half the time when I eat'. (Leonard et al., 2005: 409)</p> <p>'They need to trust me more'. (Sullivan-Bolyai et al., 2014: 184)</p> <p>'. . . my parents trust me more, I have freedom to do the things I want. The main thing for me was to start taking care of myself, and I also thank my mother for that'. (Cruz et al., 2018: 133)</p>
	Others' involvement in T1D self-management	Awareness of the impact of T1D on others	<p>'When I was first diagnosed my parents were all worried and stuff, and when I went out with my friends I just got constant texts from mum saying "are you monitoring yourself?" But it's their prerogative, and it's probably quite a good thing that they did that'. (Serlachius et al., 2012: 5)</p> <p>'In house, I'm under pressure; my family has an excessive stress about my health'. (Maslampak et al., 2010: 466)</p>
		Clinic and hospital experiences	<p>'It feels normal when I go there [to the clinic]. I know what will happen: They will weigh me and measure me, and they'll be talking about my diabetes, and then I get to go home again'. (Boman et al., 2015: 10)</p> <p>'So every three months, when I go to the hospital, I always feel nervous because the data from the blood tests don't conceal anything'. (Wang et al., 2010: 262)</p> <p>'I do one thing wrong and the doctor takes a half hour talking about it'. (Sullivan-Bolyai et al., 2014: 185)</p>
		Dealing with school personnel	<p>'They'll [school nurse] want to talk to my parents; they won't talk to me about it or anything, but they'll only talk to them and almost like, "Talk to me about it if you're having a problem with it because I know what my blood sugar was"'. (Dickinson and O'Reilly, 2004: 103)</p> <p>'Our school nurse is great . . . every Wednesday she has a lunch club for kids with diabetes'. (Herrman, 2006: 216)</p> <p>'Sometimes I need to go out of the class, but teachers don't permit me . . . Sometimes I would tell teachers I'm diabetic, but I mean, when you have got five teachers in a day, it wouldn't really matter, because they will forget your problem'. (Maslampak et al., 2010: 467)</p>
		Family and sibling involvement	<p>'I discussed the decision of using an insulin pump with my family. They all agreed that it will be easier for me and I will have more autonomy. It was not an easy decision and I felt relieved when they encouraged me'. (Cosma and Baban, 2015: 241)</p> <p>'I have a sister she helps me with it, like she gives me my injection sometimes if my mum and dad are away she will give it to me or if they are away on holidays she will look after me or whatever, it keeps me going'. (Burke and Dowling, 2007: 92)</p>
		Others' reactions	<p>'I'm tired of everyone saying Are you allowed to eat that? That makes me so mad'. (Chao et al., 2016: 138)</p> <p>'If anyone is nosey and asking what it [the blood glucose monitor] is . . . I just tell them it's a new kind of Palm Pilot'. (Herrman, 2006: 217)</p>
		Relying on and receiving support from others	<p>'My best friend acts like my mom. It gets on my nerves'. (Carroll and Marrero, 2006: 248)</p> <p>'It is comforting to know that someone is there in case that something bad happens with my diabetes'. (Cosma and Baban, 2015: 239)</p> <p>'Like say I just met some random on the street, they wouldn't understand, but I have a few diabetic friends now that I think of it, they can actually understand, like with the whole parent thing as well'. (Serlachius et al., 2012: 5)</p> <p>'sometimes I look like I'm low he asks like, "are you okay with your blood sugars?"' (Rankin et al., 2018: 4)</p>

(Continued)

Table 4. (Continued)

Analytic theme	Descriptive theme	Example codes	Illustrative quotations
Becoming independent in T1D self-management	Talking to HCPs		'My A1C is high and stuff so that's kind of bad. . . . I feel like it's bad because the doctors say it's bad'. (Dickinson and O'Reilly, 2004: 103)
			'It's the same whoever is the patient. The action is always the same. Everything happens according to their own plans and the hospital's needs'. (Kyngas et al., 1998: 764)
	Telling others about T1D		'I don't want to tell any of my boyfriends that I have diabetes because then it makes me feel weird and plus they probably feel weird about the situation themselves'. (Chao et al., 2016: 137)
			'I talk to my friends'. (Herrman, 2006: 216)
	Involvement of friends		'I started in ninth grade last year talking to my friends about diabetes. How, what everything affects it. I wouldn't go into great detail. They don't need to know every single detail that I need to, but I would go into detail about how, if I got low, what they would need to do for me'. (Christian et al., 1999: 6)
			'All of them are considerate. If we are going someplace on a Friday night they usually call me ahead of time and say, "What can you eat so we can get it?" They're real considerate about all of it'. (Standiford et al., 1997: 150)
Making decisions		' . . . at school and at break-time the lads go to the shop to get sweets, sometimes it bothers me and sometimes it doesn't . . . '. (Burke and Dowling, 2007: 91)	
		'They can have suggestions, but I want to feel that it's my body and that I have total control over it and that nobody else decides over it'. (Viklund and Wikblad, 2009: 3265)	
		'I don't know really, but it's that you get to decide, get more freedom to decide how you want things to be and what you think is good and like that'. (Karlsson et al., 2008: 567)	
Figuring out		'I have found that I go high right after I exercise . . . my first reaction is oh, my BS is high and I need to give myself insulin but if you give yourself insulin then you are going to hit the low from the exercise and then you are going to go really low so exercise is like really hard for me'. (Babler and Strickland, 2015a: 654)	
		' . . . it really helps me that I have a lot of information about it and that I learned what works for me and what does not'. (Cosma and Baban, 2015: 238)	
		'We've learned to use sticky notes to remind us of stuff'. (Herrman, 2006: 216)	
Taking on T1D self-management <i>Not feeling ready to take on self-management</i> <i>Assuming responsibility</i>		' . . . it is time to change your site and I'm like I'm not doing it, I'm not doing that nope, like I just started crying and everything and I don't know why . . . I was like 12 or 13 and I was old enough that I didn't need to be crying over that but it still wasn't fun'. (Babler and Strickland, 2015a: 653)	
		'It was getting to the stage where like, all my meters getting too high, high, like off the charts and I was like I cannot carry on like this, and then, I was like I've just got to start looking after it, and it takes a while, but you get there eventually, I'm still doing it'. (Chilton and Pires-Yfantouda, 2015: 1496)	
		'Well, you have to be more responsible. You have to remember your insulin, tester, sugar foods and to count everything you eat'. (Carroll and Marrero, 2006: 246)	
Feeling in control	Structuring self-management into everyday life	Barriers to fitting self-management into life	'I know how to do it; I just am really lazy about that'. (Leonard et al., 2005: 409)
		Routine	"I lost control sometimes, like at parties at school. That climate made me very relaxed. Everyone ate cookies and I ate, too, and my sugar got high". (Wang et al., 2013: 239)
	Lying (avoiding conflict)		'The program I have to follow everyday helps me eat healthier and set right the insulin units. Sometimes, I don't know if it is something helpful or tiresome'. (Cosma and Baban, 2015: 240)
			'I would also just tell my parents that I did my blood sugar and make up a number. And they believed me, but they'd go check and see that I actually didn't'. (Leonard et al., 2005: 409)
Forgetting		'Mostly on like really stressful days when I really have a lot to do sometimes it will like just totally skip my mind and it's just that like a few hours and I'm like, oh no I didn't do my BS . . . '. (Babler and Strickland, 2015a: 652)	

(Continued)

Table 4. (Continued)

Analytic theme	Descriptive theme	Example codes	Illustrative quotations
		Facilitating integration of self-management with daily life	'The insulin pump made it so easy . . . I love my pump'.. (Herrman, 2006: 216) 'The best thing to do is get good with the shots and checks . . . then it's easy'. (Herrman, 2006: 216) 'I have a schedule so like I get up at the same time every day, test at the same times every day, come home test, go to practice, test, eat dinner, test, so the school year it's fairly easy'. (Babler and Strickland, 2015a: 653)
		Choosing to manage or avoid	'when I first turned a teenager it was like, oh erm I just want to be normal so I won't inject or I wouldn't do normal blood tests and like just eat loads of sugar' (Chilton and Pires-Yfantouda, 2015: 1498) ' . . . Sometimes I have crisps and sometimes I have chocolate. Some weeks I might have one bar of chocolate and sometimes I might have four . . .'. (Burke and Dowling, 2007: 91)
		Management activities	'I can't eat all the foods that I would like to eat'. (Faro, 1999: 5) ' . . . I went on a walking weekend with Guides and my blood sugars were really good all the time I was doing that. So that's good for my blood sugars'. (Ryninks et al., 2015: 4) 'When I am home and not feeling well, I will test my sugar without considering anything. If I want to test, I test, but at school I feel some stress . . .'. (Wang et al., 2010: 261)
		Emotional impact of management	'I'm a little scared when it [metabolic glucose level] is high or not good, if my eyes are not good, or my feet are bad. I think of all these things'. (Boman et al., 2015: 9) 'I always have to stop and check . . . you always have to worry about it whether you take care of it or not'. (Herrman, 2006: 214) 'I don't even know what I'm sad about anymore . . .'. (Babler and Strickland, 2015a: 656) 'Sometimes it is kind of hard, you just have those days where like it seems like everything is harder than it really is, when you are young and when you have those days, basically when you have diabetes it's like you just want to give up'. (Babler and Strickland, 2015a: 654)
	Ability to self-manage T1D	Ability to manage	'I mean I can take . . . care of myself and I know how to do that and stay healthy at the same time'. (Hanna and Guthrie, 2000: 169) 'It's kind of rewarding knowing you have calculated everything right and taken the insulin right and you actually end up in your zone . . . it feels nice'. (Herrman, 2006: 215) 'Something came over me and I just wasn't scared anymore, I just overcame my fear and that was the best day of my life actually because I took control'. (Babler and Strickland, 2016: 128) ' . . . Usually, you know whether you are too low or not. Delaying it [the self-management], that is what I would want to do most . . .'. (Kupper et al., 2018: 6)
		Demonstrating management capabilities to others	'Because I don't want to be limited by this disease, I have been working hard to let others know I'm good and I'm doing well'. (Wang et al., 2013: 237) 'Still, I am proud when I correct my mother regarding the optimal insulin level'. (Cosma and Baban, 2015: 239)
		Feeling in control of T1D	'A few months ago it was so hard to stay dedicated to controlling my diabetes. I have a 10.1 A1C right now. So terrifying!' (Ye et al., 2017: 256)
		Overcoming injection fear	'It made me so happy the idea that I could give myself the shots and all, that I'd got over the fear of it too'. (Karlsson et al., 2008: 567)
		Recognising areas for improvement	'You control diabetes rather than it controlling you. So if it controls you then yes it will stop you doing some certain things 'cause you're too unhealthy and you know you're not feeling right'. (Ryninks et al., 2015: 8)
		Meeting targets	'There are always opportunities for improvement'. (Boman et al., 2015: 9)

(Continued)

Table 4. (Continued)

Analytic theme	Descriptive theme	Example codes	Illustrative quotations
	Fitting in or standing out and self-management of T1D	Feeling normal or feeling different	<p>'I find it annoying when I'm different and I'd rather never show it, like by giving myself an injection in the classroom . . .'. (Peters et al., 2014: 3)</p> <p>'All others can live as they want, but I have to adjust to my diabetes, for instance, when I am with my friends and I have to have a sandwich in my pocket'. (Huus and Enskar, 2007: 30)</p> <p>'I know that I am not like others can totally [be] free to eat what they want to eat and to do what they want to do. I need to test my sugar, adjust my insulin, and pay attention to my body carefully'. (Wang et al., 2013: 237)</p> <p>'I mean, I don't really think of it as like – it's a disease, but I'm not like, "Oh, my God, I have a disease", you know. I'm just – it's just like something that I can deal with. I don't consider myself different from anybody'. (Dickinson and O'Reilly, 2004: 102)</p> <p>' . . . It's like, if you're gonna have the food in the house, like, don't treat me like an animal like you're hiding it from me . . .'. (Weinger et al., 2001: 332)</p>
		Fitting in	<p>'I don't care for myself. I live like my friends. I can't care for myself because self-care activities don't fit my friends' life-style. It's very important to me to keep in touch with my friends and to do lots of interesting things with them. If I decide to care for myself well and my friends come and ask me to do other things, I do as my friends want me to'. (Kyngas et al., 1998: 765)</p> <p>'Like not checking your blood, like some days I check my blood like twice I know that is horrible . . . you realize you are different from everyone else and you are trying to fit in . . . if you are going to a movie to eat popcorn . . . you don't want to be hold on I've got to check my blood'. (Babler and Strickland, 2015a: 655)</p> <p>'I just don't realize that . . . The weather is beautiful and everybody is enjoying the sun. I wasn't thinking about it. Whereas normally, I do keep an eye on it' (Kupper et al., 2018: 6)</p>
		Unwanted attention	<p>'So, if I have low blood sugar, for example, I say, "I am hungry". I don't tell them [friends] that I have low blood sugar'. (Boman et al., 2015: 8)</p> <p>'Sometimes, my schoolmates laugh at me and ask me stupid questions about the diabetes'. (Cosma and Baban, 2015: 239)</p>
	Thinking about the future and T1D complications	T1D complications	<p>'Yeah, well even when I first got diagnosed I was thinking in the short-term I won't be able to go, go out with my friends and play football and stuff but then since then I thought about actual adult life and thought well I'm not going to be able to drive, I'm not going to be able to go to university and people are just going to see me as a hindrance, rather than like everyone else and I thought well I'm not going to want to be left out'. (Chilton and Pires-Yfantouda, 2015: 1493)</p> <p>'Ever since I got it, I worry a lot more about death, not because I'm stuck on it or anything. It's just that I'm more realistic now that I have something that can kill me if I don't take care of it'. (Faro, 1999: 7)</p>
		Potential influence on the future	<p>'Like, everyone will have to go through that point, like fighting it [diabetes] at first and then it will just get to that stage when one day you'll be like, ah, I do have it and I do want to have children when I am older'. (Chilton and Pires-Yfantouda, 2015: 1497)</p> <p>'Diabetes is a real stress. What kind of job will I get? What about my schooling and my health? I do not know how I can cope with this. It's too stressful for me diabetes means stress'. (Kyngas and Barlow, 1995: 943)</p> <p>'Only recently only like, about, six months . . . I'm starting to like get my sugars down a lot more. Like, realising that if I don't start looking after it, it is getting to the time now when it is going to affect me when I am older, and I want to like live healthy when I'm older'. (Chilton and Pires-Yfantouda, 2015: 1496)</p> <p>'I want to learn to do things on my own because I know that my mother won't be there all the time'. (Cosma and Baban, 2015: 239)</p> <p>'Now if I take care of myself later on I'll be a lot healthier and so . . . one of my biggest goals is just to maintain my health while I am young . . .'. (Babler and Strickland, 2016: 128)</p>

T1D: type 1 diabetes.

adjusting to diets and insulin pumps and indicate how specific management activities were initially considered challenging (Babler and Strickland, 2016; Cosma and Baban, 2015; Damião and Pinto, 2007; Dickinson and O'Reilly, 2004; Herrman, 2006). This acceptance was evident in descriptions of getting used to T1D as adjustment to a 'new reality' (Cosma and Baban, 2015: 237). Acceptance of T1D involves coming to the realisation that T1D is part of life and is manageable (Babler and Strickland, 2015a, 2015b, 2016; Herrman, 2006; Meldman, 1987). CYPDs may consider management of T1D to be more arduous than the demands posed by other illnesses (Babler and Strickland, 2015a; Carroll and Marrero, 2006; Meldman, 1987; Wang et al., 2013). In contrast, others may frame a diagnosis of T1D positively (Babler and Strickland, 2016; Chilton and Pires-Yfantouda, 2015; Marshall et al., 2018; Meldman, 1987; Wang et al., 2013).

Parental roles and parental involvement in T1D self-management. Parents' involvement in the management of their child's care can range from general assistance with specific tasks such as calculating doses to reminding the CYPDs to do 'everything' (Leonard et al., 2005: 410). Parental involvement may be less tangible, relating to just knowing that parents are 'there' and as a result of this, the CYPDs feel that they do not always have to 'think all the time what I have to do next' (Cosma and Baban, 2015: 239). This can then alleviate the burden posed by self-management. Parents may temporarily take over management, which may be viewed positively by the CYPDs (Viklund and Wikblad, 2009).

Parents can motivate the CYPDs to assume an active role in self-management through incentivising responsibility for independent self-management (Hanna and Guthrie, 2001). As parents hand over responsibility for T1D management, they balance this with the readiness of the CYPDs to assume an active role (Babler and Strickland, 2015a, 2015b, 2016; Carroll and Marrero, 2006; Chao et al., 2016; Cruz et al., 2018; Hanna and Guthrie, 2000, 2001; Huus and Enskar, 2007; Karlsson et al., 2008; Kyngas et al., 1998; Leonard et al., 2005; Meldman, 1987; Sullivan-Bolyai et al., 2014; Viklund and Wikblad, 2009; Wang et al., 2013).

When not restricted to times when the CYPDs need parental assistance with a specific aspect of their management, conflict and frustration can ensue (Leonard et al., 2005); this is evident in situations where parental involvement was perceived as nagging (Babler and Strickland, 2015a, 2015b, 2016; Boman et al., 2015; Carroll and Marrero, 2006; Cosma and Baban, 2015; Davidson et al., 2004; Dickinson and O'Reilly, 2004; Herrman, 2006; Huus and Enskar, 2007; Kyngas et al., 1998). However, parental involvement is valued by CYPDs (Dickinson and O'Reilly, 2004), especially when additional assistance is needed such as during a hypoglycaemic incident (Cruz et al., 2018;

Maslakpak et al., 2010). Therefore, CYPDs' responses to parental input may vary depending on the situation.

Others' involvement in T1D self-management. Self-management of T1D for CYPDs also occurs in the context of others' (in addition to parents) involvement and in the presence of others. Friends (Babler and Strickland, 2016; Boman et al., 2015; Burke and Dowling, 2007; Carroll and Marrero, 2006; Christian et al., 1999; Cosma and Baban, 2015; Damião and Pinto, 2007; Dickinson and O'Reilly, 2004; Herrman, 2006; Huus and Enskar, 2007; Karlsson et al., 2008; Kupper et al., 2018; Kyngas et al., 1998; Kyngas and Hentinen, 1995; Maslakpak et al., 2010; Rankin et al., 2018; Serlachius et al., 2012; Standiford et al., 1997), extended family (Boman et al., 2015; Burke and Dowling, 2007; Christian et al., 1999; Cosma and Baban, 2015; Hanna and Guthrie, 2001; Herrman, 2006; Leonard et al., 2005; Maslakpak et al., 2010; Standiford et al., 1997), teachers (Burke and Dowling, 2007; Carroll and Marrero, 2006; Christian et al., 1999; Cosma and Baban, 2015; Dickinson and O'Reilly, 2004; Herrman, 2006; Maslakpak et al., 2010; Ryninks et al., 2015; Sullivan-Bolyai et al., 2014; Wang et al., 2013) and HCPs (Boman et al., 2015; Carroll and Marrero, 2006; Christian et al., 1999; Dickinson and O'Reilly, 2004; Karlsson et al., 2008; Kyngas and Barlow, 1995; Kyngas et al., 1998; Kyngas and Hentinen, 1995; Meldman, 1987; Standiford et al., 1997; Sullivan-Bolyai et al., 2014; Viklund and Wikblad, 2009; Ye et al., 2017) are also present as CYPDs learn about and carry out self-management. Attending hospital appointments and interacting with HCPs becomes the norm (Boman et al., 2015). CYPDs begin working with HCPs in relation to their T1D management through setting targets, identifying areas for improvement (Sullivan-Bolyai et al., 2014) and beginning to rely on their own judgements and capabilities in their interactions with HCPs (Kyngas and Hentinen, 1995). CYPDs may move towards collaboration with HCPs rather than passively receiving advice (Boman et al., 2015; Karlsson et al., 2008; Kyngas et al., 1998).

Within the family setting, when family members strive towards common goals such as maintaining healthful habits, this contributes to a context that motivates CYPDs' independence in T1D management (Herrman, 2006). T1D presents negative impacts when it causes the family stress or inconvenience (Chao et al., 2016; Herrman, 2006; Maslakpak et al., 2010).

Friends of CYPDs may provide support, reminders or possess knowledge on how to assist the CYPDs such as during a hypoglycaemic incident (Wang et al., 2013). Supportive behaviours of others can contribute to formation of beliefs that self-management is within the CYPDs' capabilities to handle successfully, such as through awareness that friends are available to offer support (Babler and Strickland, 2016; Boman et al., 2015; Carroll and Marrero,

2006; Dickinson and O'Reilly, 2004; Karlsson et al., 2008). Conversely, CYPDs may decide to not involve their peers in their T1D management and may avoid T1D management when in the presence of their friends (Kyngas et al., 1998). CYPDs may struggle to explain T1D to peers who may not have any prior T1D knowledge (Peters et al., 2014). When peers lack knowledge or question the CYPDs, this can contribute to frustration felt towards T1D (Carroll and Marrero, 2006; Leach and Erickson, 1988; Rankin et al., 2018). Therefore, appropriate support and involvement of others may contribute to CYPDs' engagement of self-management through the creation of supportive settings in which self-management can occur.

Becoming independent in self-management. This theme relates to taking ownership of T1D and becoming self-reliant in self-management tasks and decision-making pertaining to care. Making decisions is a feature of gaining independence in T1D management (Christian et al., 1999; Hanna and Guthrie, 2000; Karlsson et al., 2008; Kyngas et al., 1998; Viklund and Wikblad, 2009). CYPDs strive towards independence in self-management as they come to realise that independence is necessary in order to achieve autonomy (Babler and Strickland, 2015a, 2015b, 2016; Carroll and Marrero, 2006; Cosma and Baban, 2015; Dickinson and O'Reilly, 2004; Hanna and Guthrie, 2000; Serlachius et al., 2012; Standiford et al., 1997; Sullivan-Bolyai et al., 2014; Wang et al., 2013). As CYPDs move from childhood into adolescence, a more collaborative approach where the young person is more actively involved in interactions with HCPs is adopted (Karlsson et al., 2008).

As CYPDs become independent in self-management of T1D, they begin to realise that being prepared, through carrying supplies and having plans in place for hypoglycaemic incidents, is their responsibility. For example, CYPDs will ensure that they are aware of their surroundings, such as when away from the home setting, and ensure that it will be possible to carry out required management tasks when needed (Babler and Strickland, 2015a; Damião and Pinto, 2007; Dickinson and O'Reilly, 2004; Herrman, 2006; Karlsson et al., 2008; Kyngas and Hentinen, 1995; Standiford et al., 1997; Sullivan-Bolyai et al., 2014; Viklund and Wikblad, 2009). Engaging with self-management in a positive manner and carrying out tasks as required is described as a source of 'comfort' for CYPDs (Viklund and Wikblad, 2009: 3265).

Feeling in control. This analytic theme relates to the CYPDs' ability and confidence to engage with self-management of T1D. On a daily basis, CYPDs carry out self-management activities which are incorporated into their life in an individualised way, while also contending with situations where it is necessary to resist the temptation to mismanage T1D ('Structuring self-management into everyday life'). Carrying out T1D self-management, while believing that

medical targets are attainable, may be dependent on holding the belief that self-management is compatible with the CYPDs' lifestyle in terms of their school life, home life and hobbies.

There are also situations where control is considered beyond the CYPs' capabilities such as when blood sugar readings fall outside recommended ranges ('Ability to self-manage T1D'). Living with T1D and engagement with its self-management can lead to CYPDs feeling that self-management causes them to stand out among others, which in turn impacts on CYPDs' attitudes towards engagement with self-management and their approach to their self-management ('Fitting in or standing out and self-management of T1D'). Living with T1D may also prompt the CYPDs to consider their future and the potential consequences of not managing T1D in the present ('Thinking about the future and complications'). This can lead to promotion of engagement with self-management or where control over these potential negative consequences or complications is not perceived as possible, it may contribute to disengagement with self-management.

Structuring self-management into everyday life. This theme relates to how CYPDs incorporate self-management into daily life, including managing high and low blood sugars, making adjustments to insulin dosages and carrying medical supplies (Babler and Strickland, 2015a, 2016; Burke and Dowling, 2007; Carroll and Marrero, 2006; Chao et al., 2016; Chilton and Pires-Yfantouda, 2015; Cosma and Baban, 2015; Faro, 1999; Herrman, 2006; Kyngas and Barlow, 1995; Leach and Erickson, 1988; Maslakpak et al., 2010; Meldman, 1987; Peters et al., 2014; Ryninks et al., 2015; Serlachius et al., 2012; Sullivan-Bolyai et al., 2014; Wang et al., 2010, 2013; Weinger et al., 2001). Difficulties associated with food management and eating in social situations were referred to in a number of articles (Babler and Strickland, 2015a; Burke and Dowling, 2007; Chilton and Pires-Yfantouda, 2015; Cosma and Baban, 2015; Faro, 1999; Leach and Erickson, 1988; Meldman, 1987; Rankin et al., 2018; Viklund and Wikblad, 2009; Wang et al., 2013; Weinger et al., 2001). CYPDs who use an insulin pump describe how its use can increase dietary flexibility; however other CYPDs consider insulin pump management to be incompatible with their lifestyles (Boman et al., 2015; Cosma and Baban, 2015) and for others insulin pumps are not readily available (Cruz et al., 2018).

More generally, adopting a routine in relation to carrying out daily management tasks can lead to the formation of the view that T1D is not overly burdensome (Babler and Strickland, 2015a). Positive and negative aspects of the routine nature of self-management are described in a number of articles (Babler and Strickland, 2015a; Cosma and Baban, 2015; Kyngas and Barlow, 1995; Meldman, 1987; Wang et al., 2010). For some, the benefits of routines are outweighed by the unrelenting nature of T1D management

(Babler and Strickland, 2016; Chao et al., 2016; Cosma and Baban, 2015; Davidson et al., 2004; Peters et al., 2014). When the regimen is perceived as restrictive, negative attitudes towards T1D may ensue (Burke and Dowling, 2007; Christian et al., 1999; Cosma and Baban, 2015; Damião and Pinto, 2007; Faro, 1999; Herrman, 2006; Kyngas and Hentinen, 1995; Wang et al., 2013; Weinger et al., 2001). In addition, CYPDs may feel that they do not possess a desirable level of control over the impact of T1D management on their life (Babler and Strickland, 2015b; Davidson et al., 2004).

Successful self-management includes maintaining blood glucose readings within target ranges and becoming familiar with physical symptoms (Herrman, 2006). The physical effects of high or low blood glucose level can limit participation in activities, and this is especially the case when CYPDs have not prepared for their occurrence (Babler and Strickland, 2015a, 2015b, 2016; Burke and Dowling, 2007; Carroll and Marrero, 2006; Chilton and Pires-Yfantouda, 2015; Cosma and Baban, 2015; Faro, 1999; Herrman, 2006; Kyngas and Barlow, 1995; Leach and Erickson, 1988; Maslakpak et al., 2010; Peters et al., 2014; Ryninks et al., 2015; Serlachius et al., 2012; Sullivan-Bolyai et al., 2014; Wang et al., 2010; Weinger et al., 2001).

Inherent with incorporating self-management into daily life is feeling that meeting these daily demands of T1D and other aspects of life is possible. CYPDs may prioritise certain T1D tasks over the demands of social lives and school (Kyngas et al., 1998; Viklund and Wikblad, 2009). This can imply making a conscious decision to stop being 'lazy' and actively complete the tasks of T1D management (Babler and Strickland, 2016: 128). When CYPDs avoid or forget to engage with T1D self-management, they may lie about self-management to others (Babler and Strickland, 2015a; Davidson et al., 2004; Kyngas and Barlow, 1995; Kyngas and Hentinen, 1995; Leonard et al., 2005; Weinger et al., 2001) in order to avoid conflict (Babler and Strickland, 2015a; Kyngas and Barlow, 1995).

Living with T1D can lead to feelings of isolation, anxiety and guilt for CYPDs (Kyngas and Barlow, 1995; Maslakpak et al., 2010). In addition, feelings of worry, frustration, burden and stress may be attributed to the requirements imposed by T1D by the CYPDs (Babler and Strickland, 2015a, 2015b; Chao et al., 2016; Kyngas and Hentinen, 1995). Not meeting targets such as desired blood glucose readings can result in worry about upsetting others such as HCPs (Carroll and Marrero, 2006; Dickinson and O'Reilly, 2004).

Ability to self-manage T1D. Individuals' belief in their ability to self-manage T1D extends beyond the carrying out of management activities to include a more general awareness in terms of one's competency levels: '... just feeling that you can take care of it yourself...' (Hanna and Guthrie, 2000: 169). Gaining confidence in self-man-

agement abilities can contribute to feeling that control over T1D is possible and that CYPDs are capable of integrating its management into daily life (Babler and Strickland, 2016; Christian et al., 1999; Hanna and Guthrie, 2000). This sense of confidence may be preceded by particular barriers, such as injection fear (Karlsson et al., 2008). CYPDs may also demonstrate that they can exert control over T1D by resisting opportunities for mismanagement (Viklund and Wikblad, 2009). CYPDs may encourage themselves to continue with self-management even during times where the desired results are not easily attained, such as when T1D management is perceived as a burden (Babler and Strickland, 2015a) or when glycosylated haemoglobin (HbA1c) targets are considered unattainable (Boman et al., 2015). When blood glucose levels are within normal ranges for the CYPDs, this can contribute to enhanced perceived control over T1D self-management (Karlsson et al., 2008).

CYPDs gradually gain a sense of control over T1D through learning what works for them personally (Cosma and Baban, 2015; Kyngas and Barlow, 1995; Wang et al., 2013). For some CYPDs, awareness of physical symptoms influences engagement with management of T1D through allowing the CYPDs to judge whether management may be temporarily delayed (Kupper et al., 2018).

Fitting in or standing out and self-management of T1D. Living with T1D may highlight differences between the CYPDs and their peers (Babler and Strickland, 2015a; Faro, 1999; Herrman, 2006; Huus and Enskar, 2007; Kyngas and Barlow, 1995; Kyngas and Hentinen, 1995; Peters et al., 2014; Rankin et al., 2018; Wang et al., 2010, 2013). From the CYPDs' perspective, being unable to eat in the same manner as friends can emphasise differences that exist (Huus and Enskar, 2007; Wang et al., 2013). CYPDs choose between either fitting in and being like peers or making adjustments to their daily routines for their T1D. In some cases, T1D management is neglected (Babler and Strickland, 2015a; Herrman, 2006; Kyngas et al., 1998; Wang et al., 2013). Others may feel that it is possible to fit in among healthy peers and also live with T1D (Dickinson and O'Reilly, 2004). The CYPDs may secretly manage T1D or may make the decision to not manage by 'ignoring' T1D (Boman et al., 2015: 8).

The CYPDs may be treated differently through friends asking questions, parents preventing their participation in activities or teachers highlighting differences (Carroll and Marrero, 2006; Chao et al., 2016; Maslakpak et al., 2010; Weinger et al., 2001). Others in the CYPDs' life may not always understand T1D and some feel that sport coaches 'singled them out'. (Dickinson and O'Reilly, 2004: 103). Though the CYPDs may wish to engage fully with teenage life, they may be prevented by parents who they consider overprotective or overinvolved in their care (Carroll and Marrero, 2006). Similarly, differences are perceived through knowing their parents are more worried about them

in comparison to friends' parents (Karlsson et al., 2008). Therefore, the individual CYPDs' approach to self-management may vary depending on their views on perceived differentness resulting from T1D management.

Thinking about the future and complications. In addition to carrying out self-management in the present, CYPDs also may find themselves considering how living with T1D may impact them in the future. CYPDs are aware that their parents will not be available to provide assistance as they get older (Cosma and Baban, 2015). Therefore, it is important that CYPDs feel that independent management of T1D in the future is possible (Babler and Strickland, 2016). The risks posed by not managing and developing complications in the future are sources of uncertainty or may exacerbate worries in relation to living with T1D (Babler and Strickland, 2015a, 2016; Chao et al., 2016; Christian et al., 1999; Dickinson and O'Reilly, 2004; Faro, 1999; Kyngas and Barlow, 1995; Kyngas and Hentinen, 1995; Meldman, 1987; Ye et al., 2017). Awareness of the consequences of not engaging with self-management can prompt CYPDs to strive to achieve control over T1D (Babler and Strickland, 2016; Chilton and Pires-Yfantouda, 2015; Kyngas and Hentinen, 1995; Standiford et al., 1997). Others may feel that preventing complications is beyond their control and this then causes disengagement with self-management of T1D (Viklund and Wikblad, 2009). Some CYPDs choose to avoid envisaging the risk of complications of T1D (Damião and Pinto, 2007; Weinger et al., 2001). This avoidance may be indicative of feeling that T1D self-management and meeting self-management goals is beyond the CYPDs' capabilities.

Discussion

This qualitative meta-synthesis systematically examined the available evidence on the experiences and perceptions of self-management of T1D from the perspectives of CYPDs aged 8–18 years. The meta-synthesis provides insight into the complexity of the experience of self-management of T1D, including the considerable time and emotional demands it can place on CYPDs. Moreover, insight is provided into the experience of gaining independence and increasing responsibility for self-management of T1D for CYPDs. The meta-synthesis also highlights the many common experiences and issues that CYPDs encounter across a range of countries and contexts.

Self-management has previously been described as a process of negotiation of illness management and other areas of life in adults living with chronic illness (Auduly et al., 2009). In our meta-synthesis, CYPDs' descriptions of experiences of negotiating independence have parallels with references to how individuals experience inner conflicts as they encounter barriers to engagement with self-management (Auduly et al., 2009). In the present

meta-synthesis, CYPDs negotiate independence in self-management rather than illness management more generally. This underlines the scope for continued development of models of self-management that are specific to the paediatric setting. Future research may also consider exploring adolescent perceptions of becoming independent in self-management rather than focussing on general experiences of living with T1D. This may add depth to knowledge on issues relating to self-management for CYPDs.

In the current review, there are instances where CYPDs describe the positive impact of friends supporting their self-management. Previous research indicates that parents and peer groups do influence metabolic control and engagement with T1D management (Guo et al., 2011), therefore highlighting the importance of others (parents, peers, HCPs, etc.) in contributing to independent engagement with self-management. However, given that CYPDs may vary in their responses to support, further research addressing the influence of the types of support for different age groups on self-management specifically may be warranted. Increasing the awareness of others such as school staff and peers in line with guidelines on management of T1D in adolescence (Cameron et al., 2018) may contribute to ensuring that CYPDs can feel open towards their self-management and lead to settings where independent self-management is facilitated.

Our second analytic theme 'Feeling in control' supports Spencer et al.'s (2010) review highlighting factors facilitating or impeding engagement with self-management such as the impact of adolescent level of knowledge, self-efficacy, and peer influences. Previous research indicates that higher levels of self-efficacy and confidence in management abilities are associated with better metabolic control and more engagement with T1D management activities (Iannotti et al., 2006), while this analytic theme highlights the importance of perceived control of T1D and self-management. This sheds further light on the relevance of self-efficacy within conceptualisations of CYPDs' self-management. Similar to Spencer et al.'s (2010) review, this meta-synthesis also provides some insight into barriers and facilitators to self-management and how these may impact on perceived levels of control over T1D self-management. More in-depth exploration may be warranted in order to delineate barriers and facilitators to engagement with self-management of T1D during childhood and adolescence, as has been conducted in the context of adult chronic illness (Schulman-Green et al., 2012). This may contribute to the development of a model of CYPDs' self-management of T1D that pays specific attention to the processes of self-management, such as the acquisition of independence and perceived control over T1D, over time.

Our findings indicate that positive experiences and attitudes held by CYPDs towards T1D may contribute to more positive engagement with self-management of T1D that promotes the transitioning of responsibilities for

self-management. Differences in how CYPDs respond to the involvement of others' (parents, peers, school staff, HCPs, etc.) in their self-management indicate the importance that those involved in the CYPDs' care adopt approaches that are individualised to the CYPDs. In addition, the review highlights the importance of the role of others in promoting independence in self-management and also how others' reactions can enhance feelings of perceived control of T1D. Consideration that childhood and adolescence presents a unique set of demands lends to the importance of combining studies which take this developmental period and the unique demands of T1D management into account. This may then eventually contribute to the development of supports that are tailored to CYPDs.

The theme 'Feeling in control' also encompasses the role of perceived normality or difference between the CYPDs and others. In the context of childhood and adolescent chronic illness, adhering to treatment regimens does contribute to feelings of differentness among CYPs living with chronic illness (Lambert and Keogh, 2015). Previous research carried out in the adult context on self-management indicates adults' feelings on normality and stigmatisation as a result of chronic illness can impede engagement with self-management (Auduly et al., 2009). However, in order to understand the impact of increasing responsibilities for self-management during childhood and adolescence, further research which investigates feelings of normality on self-management during this time of transitioning autonomy is required.

When T1D self-management is engaged with positively, the improvements in CYPDs' physical and emotional well-being can enhance feelings of control over T1D. In addition, fostering more long-term goals may contribute to positive engagement with self-management. Fear or powerlessness towards abilities to minimise complications may also be experienced. This indicates that it may be important for others, such as parents and HCPs to be mindful that the CYPDs' perceived control over T1D may contribute to differences in engagement with T1D treatment and is suggestive of a need for individualised approaches.

This qualitative meta-synthesis provides an important contribution to knowledge as it is, to the authors' knowledge, the first qualitative meta-synthesis that aims to combine qualitative evidence on CYPDs' (8–18 years) experiences of self-management of T1D. The scope of this meta-synthesis advances existing reviews by incorporating specific evidence on the self-management experiences of CYPDs aged 8–18 year and captures an influential developmental stage as self-management patterns transition to adolescent dominant (Schilling et al., 2006). However, this meta-synthesis also highlights the difficulties of isolating data across a relatively wide age range. Articles included varied with respect to the amount of contextual data presented, such as methodologies and participant characteristics, and therefore, it was not possible to report on all contextual factors for all studies. Including these characteristics within published reports

minimises the risk of decontextualising findings of primary research during the conduct of the meta-synthesis (Thomas and Harden, 2008). A potential limitation of our search strategy is the lack of a uniform definition of self-management with much divergence in the reporting of definitions employed across studies (Barlow et al., 2002), meaning relevant studies may have been missed. In the current meta-synthesis, a broad search strategy was employed which encompassed several terms that are related to self-management.

In conclusion, our findings provide insight into CYPDs' experiences and perceptions of self-management of T1D. Parents, HCPs and peers may facilitate transition towards independent self-management. Conversely, incidences of non-support from parents, peers, HCPs, and so on, can contribute to feelings of frustration towards T1D and also its self-management. The scope of the studies included in this review highlights a gap in research that explores processes of self-management and suggests that exiting conceptualisations of self-management may be extended to take processes of self-management into consideration. Continued research that aims to understand these interactions from multiple perspectives may contribute to knowledge on how positive engagement with self-management of T1D can be facilitated in settings such as within the home, the clinic and at school and may lead to improved outcomes in terms of self-management engagement.

Acknowledgements

Thank you to our Youth Advisory Group for assisting us with this research.

Declaration of conflicting interests

The author(s) declared no potential conflicts of interest with respect to the research, authorship and/or publication of this article.

Funding

The author(s) disclosed receipt of the following financial support for the research, authorship, and/or publication of this article: This qualitative meta-synthesis forms part of a larger programme of research funded through a project grant (HRA-HSR-2015-1233) awarded by the Health Research Board to Prof. Veronica Lambert (Dublin City University).

Supplemental material

Supplemental material for this article is available online.

References

- Auduly Å, Norbergh KG, Asplund K, et al. (2009) An ongoing process of inner negotiation – A Grounded Theory study of self-management among people living with chronic illness. *Journal of Nursing and Healthcare of Chronic Illness* 1(4): 283–293.
- Babler E and Strickland CJ (2015a) Moving the journey towards independence: Adolescents transitioning to successful diabetes self-management. *Journal of Pediatric Nursing* 30(5): 648–660.

- Babler E and Strickland CJ (2015b) Normalizing: Adolescent experiences living with type 1 diabetes. *The Diabetes Educator* 41(3): 351–360.
- Babler E and Strickland CJ (2016) Helping adolescents with type 1 diabetes ‘figure it out’. *Journal of Pediatric Nursing* 31(2): 123–131.
- Barlow J, Wright C, Sheasby J, et al. (2002) Self-management approaches for people with chronic conditions: A review. *Patient Education and Counseling* 48(2): 177–187.
- Barnett-Page E and Thomas J (2009) Methods for the synthesis of qualitative research: A critical review. *BMC Medical Research Methodology* 9(1): 59.
- Beacham BL and Deatrick JA (2013) Health care autonomy in children with chronic conditions: Implications for self-care and family management. *Nursing Clinics* 48(2): 305–317.
- Boman Å, Bohlin M, Eklöf M, et al. (2015) Conceptions of diabetes and diabetes care in young people with minority backgrounds. *Qualitative Health Research* 25(1): 5–15.
- Bronfenbrenner U (1979) *The Ecology of Human Development: Experiments by Nature and Design*. London: Harvard University Press.
- Burke H and Dowling M (2007) Living with diabetes: Adolescents’ perspectives. *Journal of Diabetes Nursing* 11(3): 90–95.
- Butner J, Berg CA, Osborn P, et al. (2009) Parent-adolescent discrepancies in adolescents’ competence and the balance of adolescent autonomy and adolescent and parent well-being in the context of type 1 diabetes. *Developmental Psychology* 45(3): 835–849.
- Cameron FJ, Garvey K, Hood KK, et al. (2018) ISPAD Clinical Practice Consensus Guidelines 2018: Diabetes in adolescence. *Pediatric Diabetes* 19: 250–261.
- Campbell MS, Schatz DA, Chen V, et al. (2014) A contrast between children and adolescents with excellent and poor control: The T1D Exchange clinic registry experience. *Pediatric Diabetes* 15(2): 110–117.
- Carroll AE and Marrero DG (2006) The role of significant others in adolescent diabetes: A qualitative study. *The Diabetes Educator* 32(2): 243–253.
- Chao AM, Mingos KE, Park C, et al. (2016) General life and diabetes-related stressors in early adolescents with type 1 diabetes. *Journal of Pediatric Health Care* 30(2): 133–142.
- Chilton R and Pires-Yfantouda R (2015) Understanding adolescent type 1 diabetes self-management as an adaptive process: A grounded theory approach. *Psychology & Health* 30(12): 1486–1504.
- Christian BJ, D’Auria JP and Fox LC (1999) Gaining freedom: Self-responsibility in adolescents with diabetes. *Pediatric Nursing* 25(3): 255–255.
- Cosma A and Baban A (2015) Beyond self-care behaviors in diabetes: Learning from adolescents. *Cognition, Brain, Behavior* 19(3): 233–249.
- Critical Appraisal Skills Programme (CASP) (2018) CASP qualitative research checklist. Available at: <https://casp-uk.net/casp-tools-checklists/> (accessed 11 December 2018).
- Cruz DSMD, Silva KDL, Souza JTBD, et al. (2018) Experiences of adolescents with diabetes mellitus from the perspective of the ethics of alterity. *Acta Paulista de Enfermagem* 31(2): 130–136.
- Curtis-Tyler K, Arai L, Stephenson T, et al. (2015) What makes for a ‘good’ or ‘bad’ paediatric diabetes service from the viewpoint of children, young people, carers and clinicians? A synthesis of qualitative findings. *Archives of Disease in Childhood* 100(9): 826–833.
- Damião EBC and Pinto CMM (2007) ‘Being transformed by illness’: Adolescents’ diabetes experience. *Revista Latino-Americana de Enfermagem* 15(4): 568–574.
- Davidson M, Penney ED, Muller B, et al. (2004) Stressors and self-care challenges faced by adolescents living with type 1 diabetes corrected] published erratum appears in APPL NURS RES 2004 Aug;17(3): pp. 221]. *Applied Nursing Research* 17(2): 72–80.
- Dickinson JK and O’Reilly M (2004) The lived experience of adolescent females with type 1 diabetes. *The Diabetes Educator* 30(1): 99–107.
- Ellis M and Jayarajah C (2016) Adolescents’ view and experiences of living with type 1 diabetes. *Nursing Children and Young People* 28(6): 28–34.
- Faro B (1999) The effect of diabetes on adolescents’ quality of life. *Pediatric Nursing* 25(3): 247–253.
- Guo J, Whittemore R and He GP (2011) The relationship between diabetes self-management and metabolic control in youth with type 1 diabetes: An integrative review. *Journal of Advanced Nursing* 67(11): 2294–2310.
- Hanna KM and Decker CL (2010) A concept analysis: Assuming responsibility for self-care among adolescents with type 1 diabetes. *Journal for Specialists in Pediatric Nursing* 15(2): 99–110.
- Hanna KM and Guthrie D (2000) Adolescents’ perceived benefits and barriers related to diabetes self-management – Part 1. *Issues in Comprehensive Pediatric Nursing* 23(3): 165–174.
- Hanna KM and Guthrie D (2001) Parents’ and adolescents’ perceptions of helpful and nonhelpful support for adolescents’ assumption of diabetes management responsibility. *Issues in Comprehensive Pediatric Nursing* 24(4): 209–223.
- Herrman JW (2006) Children’s and young adolescents’ voices: Perceptions of the costs and rewards of diabetes and its treatment. *Journal of Pediatric Nursing* 21(3): 211–221.
- Hood KK, Butler DA, Anderson BJ, et al. (2007) Updated and revised diabetes family conflict scale. *Diabetes Care* 30(7): 1764–1769.
- Hood KK, Huestis S, Maher A, et al. (2006) Depressive symptoms in children and adolescents with type 1 diabetes: Association with diabetes-specific characteristics. *Diabetes Care* 29(6): 1389–1389.
- Huus K and Enskar K (2007) Adolescents’ experience of living with diabetes. *Paediatric Nursing* 19(3): 29–32.
- Iannotti RJ, Schneider S, Nansel TR, et al. (2006) Self-efficacy, outcome expectations, and diabetes self-management in adolescents with type 1 diabetes. *Journal of Developmental & Behavioral Pediatrics* 27(2): 98–105.
- Karlsson A, Arman M and Wikblad K (2008) Teenagers with type 1 diabetes – A phenomenological study of the transition towards autonomy in self-management. *International Journal of Nursing Studies* 45(4): 562–570.
- Kelo M, Martikainen M and Eriksson E (2011) Self-care of school-age children with diabetes: An integrative review. *Journal of Advanced Nursing* 67(10): 2096–2108.
- Kupper F, Peters LWH, Stuijzand SM, et al. (2018) Usefulness of image theater workshops for exploring dilemmas in diabetes

- self-management among adolescents. *Global Qualitative Nursing Research* 5: 2333393618755007.
- Kyngas H and Barlow J (1995) Diabetes: An adolescent's perspective. *Journal of Advanced Nursing* 22(5): 941–947.
- Kyngas H and Hentinen M (1995) Meaning attached to compliance with self-care, and conditions for compliance among young diabetics. *Journal of Advanced Nursing* 21(4): 729–736.
- Kyngas H, Hentinen M and Barlow JH (1998) Adolescents' perceptions of physicians, nurses, parents and friends: Help or hindrance in compliance with diabetes self-care? *Journal of Advanced Nursing* 27(4): 760–769.
- Lambert V and Keogh D (2015) Striving to live a normal life: A review of children and young people's experience of feeling different when living with a long term condition. *Journal of Pediatric Nursing* 30(1): 63–77.
- Leach D and Erickson GL (1988) Children's perspectives on diabetes. *The Journal of School Health* 58(4): 159–161.
- Leonard BJ, Garwick A and Adwan JZ (2005) Adolescents' perceptions of parental roles and involvement in diabetes management. *Journal of Pediatric Nursing* 20(6): 405–414.
- Markowitz JTC, Garvey K and Laffel L (2015) Developmental changes in the roles of patients and families in type 1 diabetes management. *Current Diabetes Reviews* 11(4): 231–238.
- Marks A, Wilkes L, Blythe S, et al. (2016) Intensive insulin therapy in the primary school setting: A meta-ethnographic synthesis. *International Diabetes Nursing* 13(1–3): 2–13.
- Marshall K, Martin H and Siarkowski Amer K (2018) Exploring perceptions about insulin dependent diabetes mellitus in adolescent patients and peers. *Comprehensive Child and Adolescent Nursing* 41(1): 25–41.
- Maslakpak MH, Anoosheh M, Fazlollah A, et al. (2010) Iranian diabetic adolescent girls' quality of life: Perspectives on barriers. *Scandinavian Journal of Caring Sciences* 24(3): 463–471.
- Mayer-Davis EJ, Kahkoska AR, Jefferies C, et al. (2018) ISPAD Clinical Practice Consensus Guidelines 2018: Definition, epidemiology, and classification of diabetes in children and adolescents. *Pediatric Diabetes* 19: 7–19.
- Meldman LS (1987) Diabetes as experienced by adolescents. *Adolescence* 22(86): 433–444.
- Panagioti M, Richardson G, Small N, et al. (2014) Self-management support interventions to reduce health care utilisation without compromising outcomes: A systematic review and meta-analysis. *BMC Health Services Research* 14(1): 356.
- Peters LW, Nawijn L and van Kesteren N (2014) How adolescents with diabetes experience social support from friends: Two qualitative studies. *Scientifica* 2014: 415849.
- QSR International Pty Ltd (2015) *NVivo Qualitative Data Analysis Software*, version 11. Doncaster: QSR International Pty Ltd.
- Rankin D, Harden J, Barnard KD, et al. (2018) Pre-adolescent children's experiences of receiving diabetes-related support from friends and peers: A qualitative study. *Health Expectations* 21(5): 870–877.
- Rankin D, Harden J, Jepson R, et al. (2017) Children's experiences of managing Type 1 diabetes in everyday life: A thematic synthesis of qualitative studies. *Diabetic Medicine* 34(8): 1050–1060.
- Ryninks K, Sutton E, Thomas E, et al. (2015) Attitudes to exercise and diabetes in young people with type 1 diabetes mellitus: A qualitative analysis. *PLoS ONE* 10(10): e0137562.
- Schilling LS, Grey M and Knafl KA (2002) The concept of self-management of type 1 diabetes in children and adolescents: An evolutionary concept analysis. *Journal of Advanced Nursing* 37(1): 87–99.
- Schilling LS, Knafl KA and Grey M (2006) Changing patterns of self-management in youth with type I diabetes. *Journal of Pediatric Nursing* 21(6): 412–424.
- Schulman-Green D, Jaser S, Martin F, et al. (2012) Processes of self-management in chronic illness. *Journal of Nursing Scholarship* 44(2): 136–144.
- Serlachius A, Northam E, Frydenberg E, et al. (2012) Adapting a generic coping skills programme for adolescents with type 1 diabetes: A qualitative study. *Journal of Health Psychology* 17(3): 313–323.
- Silverstein J, Klingensmith G, Copeland K, et al. (2005) Care of children and adolescents with type 1 diabetes: A statement of the American Diabetes Association. *Diabetes Care* 28(1): 186–212.
- Spencer J, Cooper H and Milton B (2010) Qualitative studies of type 1 diabetes in adolescence: A systematic literature review. *Pediatric Diabetes* 11(5): 364–375.
- Standiford DA, Turner AM, Allen SR, et al. (1997) Personal illness models of diabetes: Preadolescents and adolescents. *The Diabetes Educator* 23(2): 147–151.
- Sullivan-Bolyai S, Bova C, Johnson K, et al. (2014) Engaging teens and parents in collaborative practice: Perspectives on diabetes self-management. *The Diabetes Educator* 40(2): 178–190.
- Thomas J and Harden A (2008) Methods for the thematic synthesis of qualitative research in systematic reviews. *BMC Medical Research Methodology* 8(1): 45.
- Tong A, Flemming K, McInnes E, et al. (2012) Enhancing transparency in reporting the synthesis of qualitative research: ENTREQ. *BMC Medical Research Methodology* 12(1): 181.
- Viklund G and Wikblad K (2009) Teenagers' perceptions of factors affecting decision-making competence in the management of type 1 diabetes. *Journal of Clinical Nursing* 18(23): 3262–3270.
- Wang YL, Brown SA and Horner SD (2010) School-based lived experiences of adolescents with type 1 diabetes: A preliminary study. *Journal of Nursing Research* 18(4): 258–265.
- Wang YL, Brown SA and Horner SD (2013) The school-based lived experiences of adolescents with type 1 diabetes. *Journal of Nursing Research* 21(4): 235–243.
- Weinger K, O'Donnell KA and Ritholz MD (2001) Adolescent views of diabetes-related parent conflict and support: A focus group analysis. *Journal of Adolescent Health* 29(5): 330–336.
- Ye CY, Jeppson TC, Kleinmaus EM, et al. (2017) Outcomes that matter to teens with type 1 diabetes. *The Diabetes Educator* 43(3): 251–259.