Adolescent Perspectives on Communication and Negotiation of Self-Management Responsibilities for Type 1 Diabetes with Parents: A Mixed Methods Study

A thesis presented to Dublin City University for the Degree of Doctor of Philosophy (PhD)
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Declaration

I hereby certify that this material, which I now submit for assessment on the programme of study leading to the award of Doctor of Philosophy (PhD) entirely my own work, and that I have exercised reasonable care to ensure that the work is original, and does not to the best of my knowledge breach any law of copyright, and has not been taken from the work of others save and to the extent that such work has been cited and acknowledged within the text of my work.

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LIST OF ABBREVIATIONS

BGM	Blood Glucose Monitoring
CASP	Critical Appraisal Skills Programme
CHI at TS	Children’s Health Ireland at Temple Street
CYP	Child and/or Young Person
CYPD	Child and/or Young Person living with Type 1 Diabetes
DCU	Dublin City University
DFCS-R	Diabetes Family Conflict Scale Revised
DFRQ	Diabetes Family Responsibility Scale
DQOLY-SF	Diabetes Quality of Life in Youth Short Form
ENTREQ	Enhancing Transparency in Reporting the Synthesis of Qualitative Research
HbA1c	Glycosylated Haemoglobin
HCP	Healthcare Professional
HSE	Health Service Executive
HMR	Hierarchical Multiple Regression
IDF	International Diabetes Federation
IFSMT	Individual and Family Self-Management Theory
ISPAD	International Society for Pediatric and Adolescent Diabetes
M	Mean
MDI	Multiple Daily Injections
MeSH	Medical Subject Headings
MMUH	Mater Misericordiae University Hospital
PACS	Parent-Adolescent Communication Scale
PAM	Patient Activation Measure

PPI	Patient and Public Involvement
PSMF	Pediatric Self-Management: A Framework for Research, Practice, and Policy
QUAL	Qualitative
QUAN	Quantitative
SCT	Social Cognitive Theory
SD	Standard Deviation
SDT	Self-Determination Theory
SEDM	Self-Efficacy for Diabetes Management
SMODA	Self-Management of Diabetes in Adolescence
SMODA-I	Self-Management of Diabetes in Adolescence – Ireland Version
SNA	Special Needs Assistant
TSCUH	Temple Street Children’s University Hospital
T1D	Type 1 Diabetes
WHO	World Health Organisation
QOL	Quality of Life
YWI	Youth Work Ireland

ABSTRACT

Adolescent Perspectives on Communication and Negotiation of Self-Management Responsibilities for Type 1 Diabetes with Parents: A Mixed Methods Study

Isabella Claire Tuohy

Adolescents living with type 1 diabetes (T1D) begin to adopt a more collaborative approach to managing T1D with their parents before becoming independent in self-management. However, adolescents can encounter difficulties with T1D management and ambiguity in relation to the division of responsibilities for T1D management with their parents. This study aimed to explore: (1) how adolescents living with T1D experience self-management of T1D and share self-management responsibilities with parents and (2) the relationship between adolescent communication with parents about T1D self-management and demographic, clinical and psychosocial variables. A meta-synthesis of qualitative literature on child and adolescent experiences of self-management of T1D was conducted. The findings of the meta-synthesis indicated that balancing the demands of self-management with other aspects of life and sense of control over T1D are important for self-management of T1D. Following this a mixed methods study involving two phases was conducted; semi-structured interviews with adolescents aged 11 to 17 years (*n* = 28) and a cross-sectional survey with adolescents aged 11 to 17 years (*n* = 113). In interviews, adolescents highlighted their experiences of gaining independence in self-management in the overarching theme 'Navigating increasing responsibility for self-management during adolescence: "it changed gradually… and I am almost fully doing it [self-managing] now". The following themes contributed to the overarching theme: (1) Changing levels of involvement in self-management, (2) Talking about self-management with parents, (3) Taking ownership of self-management and (4) Environmental and contextual influences affecting self-management. The findings from the quantitative phase of this study indicated that parent-adolescent communication and T1D-specific family conflict are associated with T1D self-efficacy, division of family responsibility for T1D management, activation and self-management of T1D. However, the findings also indicated that T1D-specific family conflict and parent-adolescent communication are differentially related to distinct aspects of self-management and QOL. Overall, this study identified that parent-adolescent communication and family context characteristics relate to and contribute to self-management and T1D-specific QOL in adolescents living with T1D. This research identified what factors contribute to helping or hindering adolescent engagement with self-management of T1D and specifically that adolescents' perceptions of their communication with their parents about T1D management are important. For the first time, the findings provide a nuanced understanding of adolescent perspectives on self-management of T1D and communication with parents about T1D self-management. Promoting self-efficacy through targeting communication strategies employed by adolescents and their parents may result in more optimal sharing of responsibilities, improved self-management and better QOL for adolescents living with T1D.

Chapter 1: Introduction

1.1 Introduction

This research explores adolescent perspectives on self-management of type 1 diabetes (T1D), communicating about T1D self-management and negotiating responsibilities for T1D self-management with their parents. In this chapter, background information on T1D, conceptualisations of self-management and self-management as it applies to T1D will be introduced. The importance of communication between adolescents and parents for adolescents living with T1D will also be outlined. Finally, an overview of the current study and an outline of the thesis will be presented.

1.2 Type 1 Diabetes: Definitions, Epidemiology and Consequences

T1D is a chronic autoimmune condition characterised by a reduction or cessation of insulin secretion, resulting in chronic hyperglycaemia (Mayer-Davis et al., 2018). T1D frequently has its onset in childhood, and worldwide, an estimated 1,110,100 children and adolescents under 19 years live with T1D (International Diabetes Federation, 2019). The peak age of onset of T1D is between 10 and 15 years (Levy, 2011). Incidence of T1D varies regionally and the estimated incidence rate per 100,000 of the population aged 0 to 14 years, for the Republic of Ireland is 27.5 (ranked 9th globally and 5th in Europe) (International Diabetes Federation, 2019). The absence of a clinical register of individuals living with T1D in Ireland makes it difficult to estimate total numbers living with T1D within Ireland. However, the Irish Childhood Diabetes National Register, which monitors the incidence of T1D in individuals under 15 years of age nationally, indicates that the incidence rate in Ireland is highest amongst 10 to 14 year olds (Roche et al., 2016). More recent estimates in 2016 of prevalence of T1D in those under 18 living in Ireland is 0.22% (Gajewska et al., 2020).

Management of T1D is complex, consisting of multiple components including regular monitoring of blood glucose levels, insulin administration, and exercise and diet modification, undertaken to regulate blood glucose levels. Failure to maintain glycaemic control is associated with short and long-term health implications for individuals living with T1D (DiMeglio et al., 2018). The clinical marker for blood glucose control is glycosylated haemoglobin (HbA1c). HbA1c identifies the concentration of glucose in the blood over a period of eight to 12 weeks, with higher values indicating less control of blood glucose levels (Nathan et al., 2007). A target level of HbA1c, recommended by the International Society for Pediatric and Adolescent Diabetes (ISPAD), for children, adolescents and young adults living with T1D, with access to comprehensive care is 7.0% (<53 mmol/mol) and under (DiMeglio et al., 2018). There are some contexts (e.g. history of hypoglycaemia or lack of access to T1D technologies), however, where a target of 7.5% (<58 mmol/mol) may be recommended (DiMeglio et al., 2018). Maintaining metabolic control is necessary to reduce the risk of T1D-related complications e.g. neuropathy, retinopathy, nephropathy and macrovascular diseases such as stroke and heart disease, and to improve physical health in the long-term (The Diabetes Control and Complications Trial Research Group et al., 1993). Based on the data reported from an audit of 14 paediatric diabetes centres in Ireland, average HbA1c for adolescents included in the audit aged 12 to 16 years ranged from 8.1% - 9.6% and averages for 16 to 18 year olds ranged from 8.2% - 10.2% (Hawkes & Murphy, 2014). In other countries including Austria, Denmark, England, Germany, Norway, Sweden, the United States, and Wales, average HbA1c for children and adolescents ranged from 7.6% - 8.8% (Anderzén et al., 2020). Furthermore, HbA1c increased by close to 0.7% in the aforementioned countries between childhood and late adolescence (Anderzén et al., 2020). It is concerning that these figures are higher than the recommended HbA1c levels and that there is an increase in HbA1c observed from childhood to adolescence.

Declines in metabolic control during adolescence are frequently observed (Cameron et al., 2018; Helgeson et al., 2009; Pinhas-Hamiel et al., 2014). Difficulties maintaining optimal metabolic control during adolescence can be attributed to a number of factors including increased insulin resistance due to hormonal factors, non-adherence to treatment regimens, engagement with risk taking behaviours and changes to adolescents' daily routines (Cameron et al., 2018). Family conflict is one factor that is associated with poorer glycaemic control (Snyder et al., 2019). Adolescents who live with T1D experience T1D-specific stress in addition to general life stress and these stressors contribute to poorer engagement with T1D management behaviours, lower quality of life (QOL) and higher HbA1c levels (Rechenberg et al., 2017). Therefore, the daily management of T1D can be perceived as burdensome and places considerable demands on children and adolescents living with T1D.

1.3 Self-Management of T1D in Childhood and Adolescence

Adolescence is a developmental period that describes the transition between childhood and adulthood (Feldman & Elliott, 1990). Specifically, in adolescence biological (e.g. related to puberty), psychological (e.g. development of higher order cognitive processing skills) and social role changes (e.g. becoming independent of parents) present (Feldman & Elliott, 1990). This development occurs in the context of the adolescent's environment (Bronfenbrenner, 1994). Adolescence can also set the scene for the formation of habits related to management of a chronic illness, in addition to the establishment of general health-related behaviours (Holmbeck, 2002). Given that adolescence presents the unique developmental landscape of acquiring additional autonomy in all aspects of life, as well as for responsibilities relating to health, it is vital that research specifically addresses this developmental context (Holmbeck, 2002).

Self-management of a chronic illness generally refers to the ability of an individual “to manage the symptoms, treatment, lifestyle changes and physical and psychosocial consequences inherent in living with a chronic condition” (Barlow et al., 2002, p. 178). The context and content of self-management is dependent on the specific chronic illness (Lorig & Holman, 2003). Interventions which aim to support self-management do so through the promotion of the empowerment of the individual living with a chronic illness to manage their own care and meet health-related goals and targets (McCorkle et al., 2011). Therefore, promotion of self-management encourages individuals to assume an active role in their treatment and in decision making relating to healthcare and chronic illness management. Self-management is a complex and multi-faceted term, extending beyond related terms such as self-efficacy, adherence or compliance (Bodenheimer et al., 2002). This complexity is captured in Panagioti et al.’s (2014) account of self-management as including the engagement in behaviours or actions to promote health, manage a condition, meet psychosocial needs and prevent complications.

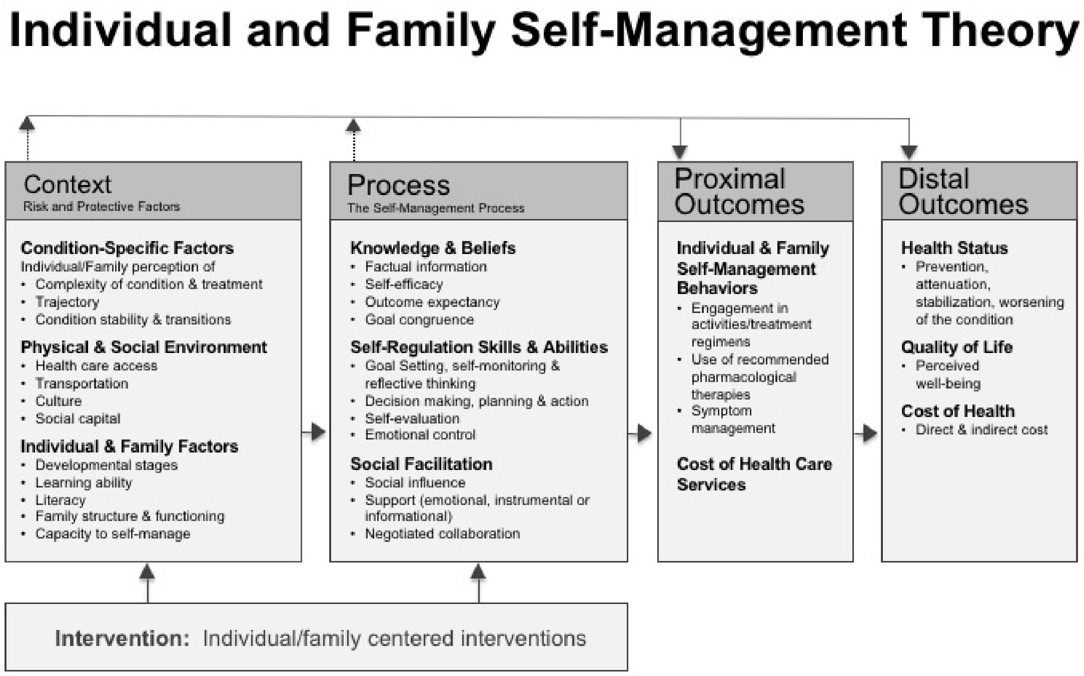
In the paediatric setting, the content and context of self-management differs in comparison with adult settings, with young people requiring distinct supports in order to engage with self-management (Sattoe et al., 2015). Childhood and adolescence presents a unique developmental context in which autonomy in illness management comes about (Modi et al., 2012). Within the Pediatric Self-Management Framework (PSMF) for research, practice, and policy, the family context is described as very pertinent to the experience of illness management, especially in adolescence (Modi et al., 2012). Literature on paediatric self-management of chronic conditions emphasises the importance of the role of families in self-management and describes how families may influence an individual's approach to chronic condition management and engagement with health-related behaviours (Grey et al., 2006, 2015). Children and adolescents living with long term conditions, such as T1D, generally rely on parents for support with many or all aspects of condition management initially, but as they mature, they become less reliant on parental assistance (King et al., 2014).

Given that self-management is condition and context specific, definitions developed for self-management of T1D in children and adolescents warrant consideration. A concept analysis of self-management of T1D in children and adolescents identified three attributes of self-management of T1D during childhood and adolescence: process, activities and goals, and defines self-management of T1D as "…an active, daily and flexible process in which youth and their parents share responsibility and decision-making for achieving disease control, health and well-being through a wide range of illness activities" (Schilling et al., 2002, p. 92). This definition emphasises the role of parents in T1D management.

Definitions and frameworks describing self-management vary with respect to their consideration or emphasis placed upon self-management processes (Schulman-Green et al., 2012). Individual and Family Self-Management Theory (IFSMT) is a theory which addresses individual and family experiences of self-management related to health behaviours (Ryan & Sawin, 2009). Within IFSMT, self-management is defined as:

"a process by which individuals and families use knowledge and beliefs, self-regulation skills and abilities, and social facilitation to achieve health-related outcomes. Self-management takes place in the context of risk and protective factors specific to the condition, physical and social environment, and individual and family. Proximal outcomes are self-management behaviours and cost of health care services; distal outcomes are health status, quality of life and cost of health. Self-management is applicable to chronic conditions as well as health promotion” (UWM Self-Management Science Center Working Group, 2011, para. 2).

Under this conceptualisation of self-management, self-management is composed of three attributes: context, processes and outcomes. Context is also referred to as risk or protective factors and includes condition specific factors (e.g. complexity of the management and treatment), physical and social environment (e.g. access to healthcare) and individual and family factors (e.g. family structure and functioning). In IFSMT, Ryan and Sawin (2009) define processes of self-management as encompassing knowledge and beliefs, regulation of skills and abilities, decision making and emotional control. IFSMT places responsibility for engaging with health behaviours with the individual and/or their family. Proximal outcomes describe engagement with adherence behaviours, while distal outcomes refer to health status and QOL. IFSMT emphasises the processes of self-management within their representation of self-management. Furthermore, IFSMT broadly delineates the outcomes of self-management as related to the management of overall health in addition to the specific management of a long-term condition. Ryan and Sawin (2009, 2014), propose that contextual (e.g. age, gender, medical regimen, etc.) and self-management process variables (e.g. beliefs, knowledge, self-regulation) contribute to proximal and distal outcomes of self-management including self-management and QOL (Ryan & Sawin, 2009; Verchota & Sawin, 2016). IFSMT considers self-management from both the individual lens and the family lens (Ryan & Sawin, 2009). For example, IFSMT refers to the family factors, including family characteristics, cohesion and family knowledge, which can impact on self-management. Therefore, it allows for a comprehensive perspective on self-management that considers family, friendship network, and other relationships as they relate to health. As such, IFSMT was used as a guiding framework throughout this study. IFSMT is depicted in Figure 1.1.



Ryan, P. A., & Sawin, K. J. (2014). Individual and Family Self-Management Theory [Revised Figure]. Retrieved from http://www4.uwm.edu/nursing/about/centers-institutes/self-management/theory.cfm

Figure 1.1. Model of the Individual and Family Self-Management Theory

IFSMT provides a useful framework for understanding the involvement of families in long-term condition self-management (Ryan & Sawin, 2009). In IFSMT, family is considered as a contextual factor (e.g. specific family characteristics) and a process (relating to how the family interacts with the individual living with a chronic illness) (Sawin, 2017). This integration of individual and family perspectives, within the one theory, allows for enhanced understanding of how shifts in levels of reliance between individuals and others for the completion of self-management impacts upon health-related outcomes. Furthermore, IFSMT adopts a broader approach to self-management in comparison to other frameworks in its consideration of how the specific processes of self-management result in health-related outcomes (Ryan & Sawin, 2009). This can be contrasted with the PSMF, which considers self-management a factor that contributes to adherence and health (Modi et al., 2012). The IFSMT has been used previously as a framework for understanding self-management of T1D in adolescents (Verchota & Sawin, 2016). Self-management is considered a proximal outcome within IFSMT, which can be contrasted with other frameworks where the processes of self-management are not clearly defined (Moore et al., 2016). IFSMT is a suitable framework or scaffold for conducting research seeking to understand process mechanisms on self-management and related outcomes such as health status and health related QOL.

Research indicates that when parents maintain involvement in their adolescent children's care, this leads to better physical and psychological health for adolescents living with T1D (Gruhn et al., 2016; Helgeson et al., 2008). However, parents and adolescents frequently struggle with the negotiation of self-management responsibilities for T1D and this is reflected in reported levels of T1D-related family conflict and discrepancies reported in relation to the division of family responsibility for T1D management tasks (Anderson et al., 1990; Hood et al., 2007; Law et al., 2013).

Research also identifies self-efficacy (the beliefs held by the adolescent in relation to controlling and managing their illness) as an important component in assuming self-management responsibilities for adolescents living with chronic illness (Lansing & Berg, 2014). Previous research has also found associations between adolescent perceptions of self-efficacy and parental behaviours, including parenting behaviours perceived as non-supportive. For example, supportive or non-supportive parental feedback can promote or undermine adolescent T1D self-efficacy during adolescence (Goethals et al., 2019; Ott et al., 2000). Therefore, this suggests that parent-adolescent interactions and communication may influence, either positively or negatively, both T1D self-efficacy and self-management for adolescents living with T1D.

While the complexity of assuming increased responsibility for self-management of long-term conditions including T1D, during childhood and adolescence is acknowledged, (Nightingale et al., 2019), there is a dearth of research that seeks to specifically explore adolescent perspectives on the process of responsibility transfer for self-management. Therefore, research is needed to investigate how readiness to assume responsibilities for aspects of T1D management transpires and is negotiated between adolescents and their parents. Furthermore, considering that increases in parent-adolescent conflict are associated with this period of transitioning self-management responsibilities, in-depth exploration of the content of this conflict may contribute to knowledge on how the negotiation of self-management occurs between adolescents and their parents.

1.4 Parent-Adolescent Communication and Self-Management of T1D

Family functioning refers to the specific characteristics and properties of a family environment and includes family interactions and relationships, particularly levels of conflict, cohesion, adaptability, organisation and quality of communication (Alderfer et al., 2008). The presence of a chronic illness within a family system has specific consequences for all members of that family system (Kazak, 1989). Family communication refers to how “each member of the family engages in communicative behavior and exchanges verbal and nonverbal messages and information with other family members. Through this communication the unique individuals of the family engage in interaction and create and maintain relationships with one another" (Stamp et al., 2004, p. 18-19). Family communication may be of key importance during adolescence as during this time adolescents negotiate increasing responsibility and changes in roles in a variety of domains (Barnes & Olson, 1985). The Circumplex Model of Family Systems comprises two dimensions: cohesion (the emotional bonding between family members) and adaptability (the ability of the family to reorganise during times of stress), with optimal functioning characterised by balance across the two dimensions (Barnes & Olson, 1985; Olson, 2000). According to this model, positive communication promotes adaptability while negative communication has an adverse impact on adaptability and cohesion (Barnes & Olson, 1985). Alternatively, communication between family members has also been described as more nuanced than positive or negative (Koerner & Fitzpatrick, 2006). Family Communication Patterns Theory conceptualises that communication is composed of conversation orientation (relating to how freely family members participate in interactions) and conformity orientation (relating to the presence of shared values, attitudes and beliefs within the family), and whether these interactions are adaptive depends on the individual family (Koerner & Fitzpatrick, 2002). Family communication is often considered in terms of the degree of warmth (e.g. positive communication, acceptance and positive involvement) and control (e.g. whether communication is intrusive, hostile or withdrawn) that it evokes (Murphy et al., 2017). As communication may influence how responsibilities are negotiated for T1D management in adolescence, it is important to establish how and if communication influences adolescent experiences of self-management of T1D.

A review of literature on adults living with chronic illness found that family functioning does influence engagement with long-term condition self-management behaviours (Rosland et al., 2012). In terms of children living with chronic illness, interactions which promote family cohesiveness and not conflict between parents and children lead to increased adherence with treatment (DiMatteo, 2004). It is also evident within IFSMT that understanding specific aspects of family functioning, like communication characteristics, may also lead to improvements in the proximal and distal outcomes of IFSMT, including metabolic control, QOL and general health status (Ryan & Sawin, 2009). However, there is a need to determine what specific aspects of family functioning relate to T1D management in adolescence. In IFSMT, family function can be either a contextual factor or a process related to self-management (Ryan & Sawin, 2009). Furthermore, increased consideration within research, into how attributes of family functioning including parent-adolescent communication relate to self-management processes in adolescence rather than to metabolic control or adherence behaviours only, should also contribute to knowledge on self-management.

Adolescents living with a chronic illness contend with the negotiation of roles with parents as they begin to become responsible for their health management and in other domains of life (Beacham & Deatrick, 2013). Older children and adolescents living with chronic illness can experience lower levels of family functioning, including family communication, in comparison to younger peers (Herzer et al., 2010). This further underlies the relevance of specifically considering how family functioning and communication are related to T1D self-management in adolescence. Research with parents and adolescents living with T1D indicates that disclosure about management is important for T1D outcomes (Berg et al., 2016; Main et al., 2015) but the context of and properties of these interactions remains poorly understood.

During adolescence, adolescents begin to take on more management responsibilities for T1D. Adolescents also assume more responsibilities and independence in other aspects of their lives through reorganisation of their relationship with their parents in a process referred to as separation-individuation (Blos, 1967; Koepke & Denissen, 2012). Separation-individuation is a process in which adolescents move towards autonomy and reduced dependence on parents (Alonso-Stuyck et al., 2017). Parent-adolescent interactions characterised by warmth, support and collaborative parental involvement are associated with increased adherence when compared to those that are characterised by negative affect, conflict and parental control (Dashiff et al., 2008). Moreover, positive communication styles are associated with better adherence and glycaemic control (Iskander et al., 2015). Parents and adolescents living with T1D can differ in their perceptions of who takes responsibility for T1D management and in perceptions of the ability and self-efficacy of the adolescent for the carrying out of T1D management tasks (Law et al., 2013). These discrepancies in relation to perceived division of responsibility and perceived ability are suggestive of a need to investigate the role of parent-adolescent communication while patterns of self-management change during adolescence. Furthermore, the quantitative designs of the aforementioned studies make it difficult to identify adolescent specific perspectives in relation to their T1D management and the assumption of increased responsibilities for self-management during adolescence.

In comparison to parents and healthcare professionals (HCPs), adolescents living with T1D identify more barriers to carrying out T1D management and are more likely to consider internal factors such as their proficiency in the self-management task as impacting on engagement with T1D self-care (Palladino & Helgeson, 2013). This highlights that discrepancies exist between parent and adolescent perceptions of T1D self-management, which could be of relevance to family functioning. Differences across parent, HCP and adolescent accounts indicate the importance of ascertaining adolescent perspectives pertaining to influences on their T1D management. Research also highlights the benefit of young people identifying goals with their parents that are mutually exclusive for autonomy in health care and in the transition towards adulthood (Ersig et al., 2016). Therefore, understanding what contributes to better parent-adolescent communication in relation to goals and abilities specific to T1D self-management may lead to improvements in adolescent self-management through its impact on overall family functioning. Thus, it is important to ascertain adolescent perspectives on engaging with self-management and how interactions with their parents feature within this reorganisation of responsibilities for self-management during adolescence.

1.5 The Present Study

Considering that research indicates that adolescents struggle with the negotiation of the demands of balancing self-management responsibilities with parental involvement, research seeking to understand how the process of becoming independent in T1D self-management occurs for adolescents is required. Furthermore, although research has highlighted that parent-adolescent interactions are relevant to T1D outcomes during adolescence, few studies have specifically explored parent-adolescent communication as it relates to self-management of T1D in adolescence; this warrants further exploration. Moreover, no previous studies explore adolescent perspectives on the specific content and characteristics of parent-adolescent communication and how these relate to self-management. The present study sets out to address these gaps. It will also examine the relationships between how adolescents talk about T1D self-management, how adolescents assume responsibilities for T1D self-management, and adolescent wellbeing. Examining the content and context of adolescent dialogue with parents and identification of barriers and facilitators to assuming self-management responsibilities may lead to the development of informed supports that may assist families as they talk about self-management and negotiate the transfer of self-management responsibilities from parents to adolescents living with T1D and support adolescents living with T1D.

1.6 Thesis Conspectus

This thesis consists of 11 chapters. Following this introductory chapter, Chapter 2 presents a qualitative meta-synthesis of children and young people's (aged 8 to 18 years) experiences and perceptions of T1D self-management. The methodology employed in this two-phased mixed methods study is outlined in Chapter 3. Within Chapter 4 the qualitative methods for the first phase of the study are detailed. The qualitative findings are presented within Chapter 5 and critically discussed in Chapter 6. In Chapter 7, the quantitative methods for phase two of the study are described. In Chapter 8, the quantitative results are presented, and these are discussed in Chapter 9. In Chapter 10, the integration of the findings from the qualitative and quantitative phases are presented and critically discussed. Finally, in Chapter 11, the concluding chapter, the original contribution, strengths and limitations, and implications of this mixed methods study are advanced.

Chapter 2: Qualitative Meta-Synthesis

2.1 Introduction to Qualitative Meta-Synthesis

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 T1D (CYPDs) (Hood et al., 2006). As mentioned in the previous chapter, metabolic control tends to deteriorate during adolescence. 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 the tasks of self-management (Campbell et al., 2014).

The ability of a CYPD to carry out T1D management is dependent on cognitive, motor and emotional maturity levels and these levels may determine which T1D management tasks the CYPD is ready to assume responsibility for and take ownership of (Hanna & Decker, 2010; Silverstein et al., 2005). Though adolescents may have the necessary motor skills to complete the tasks of T1D management, research indicates that parental involvement in their children’s care leads 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 wellbeing (Schilling et al., 2002). While parental involvement is important for T1D management, it can impact on parent-adolescent relationships with research indicating that CYPDs and their parents can experience T1D-related conflict and that parents and CYPDs do not always agree about the level of competence of the CYPD to carry out T1D management tasks independently (Butner et al., 2009; Hood et al., 2007). Childhood and adolescence are critical times for CYPs living with a chronic illness to gradually develop autonomy in chronic illness management, with complete autonomy in health-related tasks and decision making often arriving in late adolescence (Beacham & Deatrick, 2013).

Previous reviews have synthesised CYPD experiences of living with T1D (Ellis & 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 CYPD 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 CYPD 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 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 CYPDs and 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 T1D self-management of CYPD (aged 8-18 years).

2.2 Method

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

2.2.1 Search strategy

A search for eligible articles up to 26th July 2018 was undertaken across six electronic databases; PubMed (1940s-July 2018), Medline via Ovid (1946-July 2018), EMBASE (1947-July 2018), CINAHL (1937-July 2018), PsycINFO (1597-July 2018) and Web of Science (Web of Science Core Collection) (1900-July 2018). A search strategy combining controlled vocabulary (e.g. MESH) and free-text words was created and adapted to each database. The search strategies reflected the qualitative meta-synthesis' focus on T1D, CYP, self-management and qualitative methodologies. An example of the search strategy for PubMed is presented in Table 2.1. The search strategies for Medline, EMBASE, CINAHL, PsycINFO and Web of Science are available in Appendix A. The search strategy was supplemented by searching the reference lists of included articles for additional relevant studies for inclusion. Searches were limited to English language and humans. The search results in EMBASE were limited to results from EMBASE, therefore excluding Medline citations indexed in EMBASE.

Table 2.1

Search terms and strategy (PubMed)

Key Search Terms	Search Strategy
Child and Young Person	child OR child* OR adolescent OR adolesc* OR juvenile* OR pediatric OR pediatric* OR paediatric* OR teen* OR youth* OR young* OR girl* OR boy OR boys
	AND
Type 1 Diabetes	type 1 diabetes OR iddm OR t1dm OR t1d OR "type 1 diabetic" OR "juvenile onset diabetes" OR “juvenile diabetes” OR "early onset diabetes" OR "autoimmune diabetes" OR “auto immune diabetes” OR insulin depend* OR insulindepend* OR absolute insulin deficien* OR “paediatric diabetes” OR “pediatric diabetes” OR “childhood diabetes” OR type i diabetes OR “type one diabetes”
	AND
Self-Management	"Self Care"[Mesh] OR "Self Efficacy"[Mesh] OR self manag* OR self care OR self efficac* OR self treat* OR self direct* OR self help* OR self monitor* OR "Consumer Participation"[Mesh] OR "Personal Autonomy"[Mesh] OR "Decision Making"[Mesh] OR decision mak* OR patient participat* OR autonomy OR autonomous OR responsibilit* OR "Health Behavior"[Mesh] OR adherence OR "Life Change Events"[Mesh] OR "Adaptation, Psychological"[Mesh] OR empower* OR "Power (Psychology)"[Mesh] OR "Attitude to Health"[Mesh] OR "Emotional Adjustment"[Mesh] OR health attitude* OR patient involv* OR psychological adaptation* OR psychological adjust* OR behavioural adaptation* OR behavioral adaptation* OR behavioural adjust* OR behavioral adjust*
	AND
Qualitative	"Qualitative Research"[Mesh] OR "Nursing Methodology Research"[Mesh] OR "Interviews as Topic"[Mesh] OR qualitative OR interview* OR theme* OR thematic OR grounded theor* OR phenomenol* OR ethnograph* OR ethnolog* OR emic OR etic) OR hermeneutic* OR heuristic* OR semiotic* OR data saturat* OR participant observ* OR experienc* OR purposive sampl* OR cluster sampl* OR "Focus Groups"[Mesh] OR focus group* OR observational method* OR content analys* OR constant compar* OR key informant* OR theoretical sampl* OR theoretical saturat* OR discourse analys* OR discursive* OR discuss* OR narrativ* OR narration* OR ethnomethodolog* OR mixed method* OR mixed model* OR mixed design* OR multiple method* OR multimethod* OR conversation analys* OR triangulat* OR "Attitude"[Mesh]) OR attitud* OR opinion* OR perspectiv* OR experiential

2.2.2 Article selection criteria

Articles were selected for inclusion if they were (1) 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 (a) that explicitly examined self-management of T1D from CYPD (8-18 years) perspectives as the primary focus of the study, (b) that examined self-management of T1D from CYPD perspectives as a sub-focus of a larger study or (c) where findings pertaining to self-management of T1D from CYPD 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 wellbeing, 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 the condition, meet psychosocial needs and prevent complications or further illness. For the purpose of this qualitative meta-synthesis, self-management of T1D was also considered an active and flexible process, with youth and their parents sharing responsibility and decision-making to achieve T1D management (Schilling et al., 2002). Table 2.2 summarises the inclusion and exclusion criteria of the qualitative meta-synthesis.

Table 2.2

Meta-synthesis 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, case studies
Population	CYP aged 8-18 years living with T1D	Studies which focus only on: parent, sibling, peer, health care professional or other views and perspectives type 2 diabetes, gestational diabetes, monogenic diabetes or where diabetes occurs secondary to another physical condition other conditions; not T1D or where T1D specific data cannot be isolated from other data
Study focus	Studies which focus on: taking ownership and responsibility for T1D actions taken to lead a healthy lifestyle, care for TID, meet psychosocial needs and prevent complications or further illness	Studies which focus only on diagnosis, the use or development of a specific medical device or intervention, one aspect of management e.g. diet only, exercise only studies which consider outcomes such as quality of life, coping and emotional disorders, transition from paediatric to adult services in isolation

2.2.3 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: (i) Two reviewers independently screened retrieved titles and abstracts for eligibility;

(ii) Two reviewers independently read full texts of retrieved articles. One reviewer screened reference lists for potentially eligible articles. Reasons for exclusion were recorded by the reviewers and are noted in Figure 2.1. Discrepancies were resolved through discussion with two further reviewers.

2.2.4 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 one reviewer and cross-checked by another reviewer with any discrepancies resolved through discussion.

2.2.5 Methodological quality of included studies

Included articles were independently assessed for methodological quality by two reviewers using the Critical Appraisal Skills Programme (CASP Qualitative Research Checklist, 2018) which assesses methodological quality across ten items (aims, methodology, research design, recruitment, data collection, data analysis, consideration of researcher/participant relationship, ethical issues, clarity of statement of findings and value of the research). 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, a third reviewer resolved the discrepancy. Quality appraisal aided critical consideration of the methodologies and findings of included articles.

2.2.6 Qualitative meta-synthesis

Meta-synthesis of qualitative literature involves combining primary research studies to gain insights and conceptual knowledge that extends beyond the findings of each individual study and therefore adopts an interpretive rather than aggregative approach to combining studies (Campbell et al., 2003). In this qualitative meta-synthesis, thematic synthesis comprising three stages, was used to combine primary studies (Thomas & Harden, 2008).

The thematic synthesis approach was chosen as it allows for the synthesis of heterogeneous studies, and studies which may vary in terms of the level of depth of findings presented in their published reports (Gough et al., 2012) and the research methodologies employed (Barnett-Page & Thomas, 2009). Also, the outputs of a thematic synthesis seek to inform policy and provide practical implications, informing practice in the domain where the synthesis is undertaken (Barnett-Page & Thomas, 2009).

Strengths of thematic synthesis include the clarity of the description of the methods it employs and its structured approach to analysis. Thomas and Harden (2008) provide a detailed and transparent account of the approach to searching for studies, the analytic process and guidelines on how computer software can be used to aid the synthesis of findings from primary studies. Thematic synthesis lends itself well to the synthesis of primary studies containing ‘thin’ accounts of findings (Gough et al., 2012). This feature further contributes to its flexibility as an approach to qualitative meta-synthesis.

An inductive thematic synthesis was carried out without an a priori framework for analysis, as described by Thomas and Harden (2008): (i) 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 (see Appendix B for example coded data in NVivo). Codes were examined, and where necessary an additional level of coding was applied before the final list of codes was generated, (ii) 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, (iii) 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 & Thomas, 2009). Analytic themes were inferred based on the descriptive themes and the aim of the review. The analytic themes may indicate new concerns, issues or recommendations considering the topic under investigation. The results/findings sections of included studies were extracted verbatim and entered into NVivo 12 software for analysis (QSR International Pty Ltd., 2015).

2.3 Qualitative Meta-Synthesis Findings

The initial search yielded 10279 articles for screening. After removing duplicates, 5341 articles were screened at title and abstract level. Following the screening of titles and abstracts, 220 articles were deemed potentially eligible for inclusion in the review. Following the stage two screening of full texts, 181 papers were removed. Reasons for exclusion at this point are summarised in Figure 2.1 One additional paper was included following manual screening of reference lists of: (i) articles deemed eligible for inclusion; and (ii) relevant review articles. A total of 40 articles, reporting on 34 studies, were identified as eligible for inclusion in the review (see Figure 2.1 below).

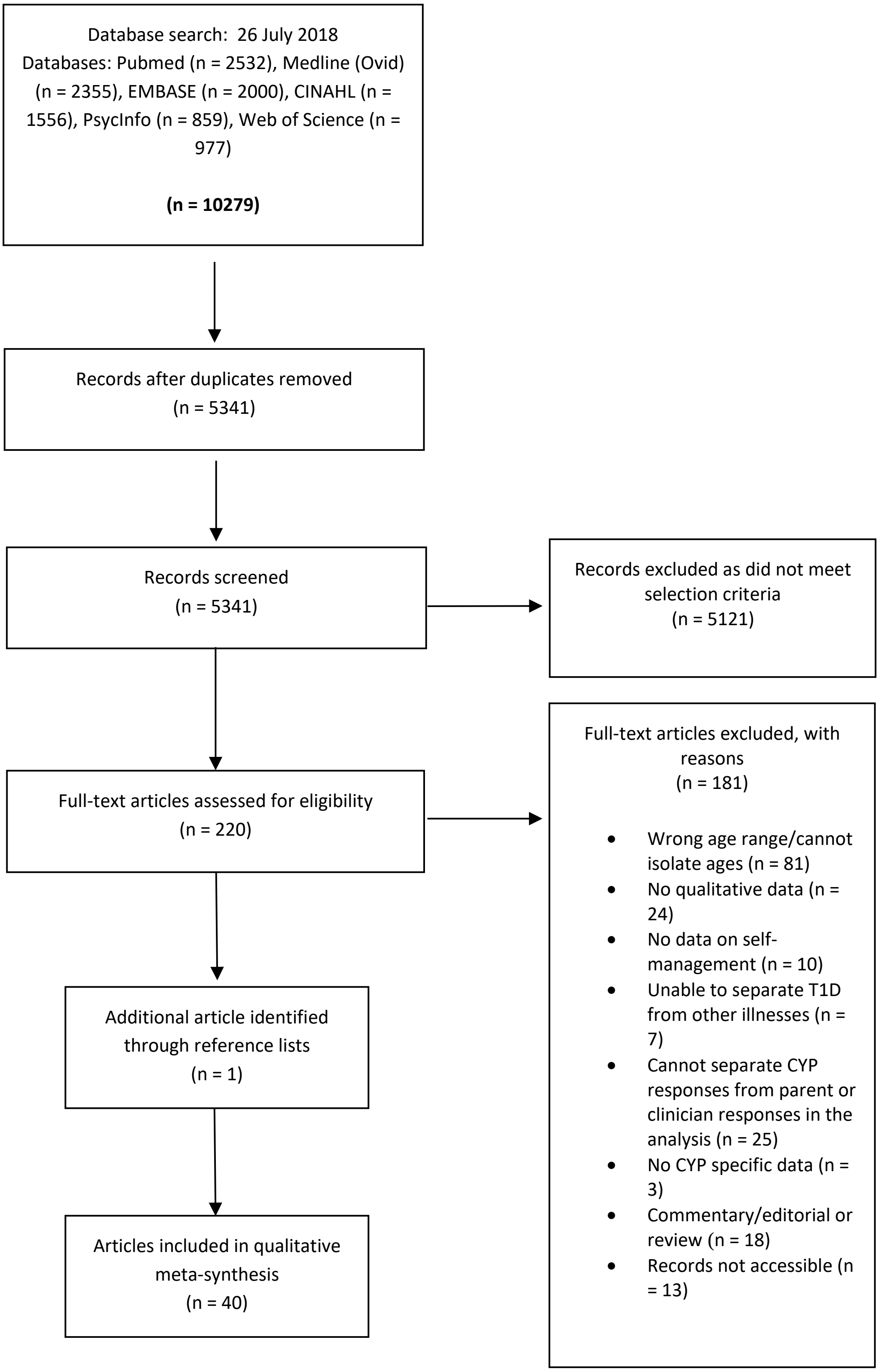


Figure 2.1. Flow diagram representing flow of article identification and selection process

2.3.1 Characteristics of Included Studies

In total there were 862 participants in the 34 studies (across 40 articles). Of the 34 studies which reported data 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 USA (*n* = 19), Sweden (*n* = 4), Finland (*n* = 3), UK (*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). Most participants were recruited from doctor's offices, clinics or hospitals (*n* = 22). Other recruitment settings were through diabetes camps (*n* = 6), not 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 types of analysis or unclear (*n* = 4). Characteristics and findings of included studies and their findings are summarised in Table 2.3.

Table 2.3

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 & Strickland (2016)†, 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 “normalizing” related to self-management of T1D. The focus of this article was the “figuring it out” phase (phase 5) of normalizing and includes the codes: 1. Learning to accept diabetes 2. Believing it’s possible to manage their diabetes 3. Showing responsibility 4. Staying on track
Babler & Strickland (2015a)†, USA						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. Recognizing 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

Author (year), country	Aim/ objective	Recruitment setting	Sample	Data collection[a]	Analytical approach [a]	Findings related to self-management of T1D[b]
Babler & Strickland (2015b)†, USA						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
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; as cited in Boman et al., 2015) ecological theory is proposed in this article. Factors influencing ability to take care of T1D were: *Micro level factors:* Personality, normality, attitude toward the disease, risk, autonomy, forgetfulness, hope *Meso level factors:* The paediatric diabetes team, school staff, family, friends *Macro level factors:* The diabetes discourse, school organisation, culture and the youth discourse
Burke & 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”

Author (year), country	Aim/ objective	Recruitment setting	Sample	Data collection[a]	Analytical approach [a]	Findings related to self-management of T1D[b]
Carroll & 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 identified were: personal perceptions of living with diabetes, impact on relationships (parental relationships, peer relationships and physician relationships) and impact on school
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 randomized clinical control trial comparing two psychoeducational programs	*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 withT1D were: just having diabetes, dealing with emotions and managing diabetes

Author (year), country	Aim/ objective	Recruitment setting	Sample	Data collection[a]	Analytical approach [a]	Findings related to self-management of T1D[b]
Chilton & Pires-Yfantouda (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
Cosma & Baban (2015), Romania	To gain an understanding into how adolescents experience the	Paediatric hospital	*N*=11, 7 males, 4 females, aged 13-16 years	Semi-structured interview	Thematic analysis	Four themes were identified: 1. Making sense of diabetes 2. Normalizing diabetes 3. Gaining control over diabetes

Author (year), country	Aim/ objective	Recruitment setting	Sample	Data collection[a]	Analytical approach [a]	Findings related to self-management of T1D[b]
	psychological and behavioural demands of T1D		(mean=14.27 years), diabetes duration mean diabetes duration = 8.18 years, range 5-11.5 years)			4. If I take care of diabetes, diabetes takes care of me
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	The two thematic categories which emerged were: 1. Learning of the diagnosis 2. Living with diabetes
Damaio & 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 identified were: 1. Receiving the diabetes diagnosis 2. Being transformed by illness 3. Being a “prickly” life
Davidson et al. (2004), USA	To describe stressors and self-care challenges reported by adolescents living with T1D following the	Participants had been recruited from a paediatric diabetes clinic for an earlier study evaluating a coping skills training programme,	*N*=6, aged 13.0-17.7 years (mean 14.7 years), 5 males, 1 female, mean diabetes	Transcripts from a coping skills training course	Content analysis	Themes emerged under the following categories: 1. Nature of the condition 2. Personal 3. Care management 4. Relationship 5. Situational 6. Coping behaviours

Author (year), country	Aim/ objective	Recruitment setting	Sample	Data collection[a]	Analytical approach [a]	Findings related to self-management of T1D[b]
	initiation of intensive T1D management	described by Grey et al. (Grey et al.,1998; as cited in Davidson et al., 2004)	duration = 7.3 years, range, 2.8. to 10.8 years, mean HbA1c = 9.7%, range of 8.0% to 13.6%, 5 Caucasian, 1 Hispanic			7. Dilemmas impacting self-care decisions and coping responses
Dickinson & 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
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%)	Semi-structured interview	Qualitative data was analysed for patterns, themes and interconnections between themes	Themes identified: 1. Restrictions 2. Differentness 3. Negative emotion (chiefly anger) 4. Adaptation

Author (year), country	Aim/ objective	Recruitment setting	Sample	Data collection[a]	Analytical approach [a]	Findings related to self-management of T1D[b]
			>10.0 years 3 (14%)			
Hanna & 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	Adolescents described the following helpful and non-helpful behaviours in relation to assuming T1D management: *Helpful behaviours for assuming T1D management:* directive guidance (behaviours to aid performance), non-directive supports and tangible assistance (providing physical assistance) *Non-helpful behaviours for assuming T1D management:* directive guidance and tangible assistance
Hanna & Guthrie (2000)‡, USA	To identify adolescents' perceived benefits and barriers to the process of assuming T1D management from parents			Semi-structured interview	Content analysis	Adolescents identified the following perceived benefits and barrier to assuming T1D management: *Adolescent perceived benefits to diabetes self-management:* knowledge/confidence in self-management abilities, freedom and approval from others *Adolescent perceived benefits for parents in adolescents' diabetes self-management* relief from responsibility, stress, and worry *Perceived barrier:* burden of responsibility, lack of barriers *Perceived barriers for parents in adolescents' diabetes self-management* Worry, guilt, loss of control and lack of barriers

Author (year), country	Aim/ objective	Recruitment setting	Sample	Data collection[a]	Analytical approach [a]	Findings related to self-management of T1D[b]
Herrman (2006), USA	To explore the costs and rewards of T1D and its treatment from the perspectives of children and young people	A one-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 were coded and placed in categories	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
Huus & 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	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
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	Themes identified were: 1. Hovering between individual actions and support of others 2. Growth through individual self-reliance 3. Growth through confirmation of others

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 & 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 & Barlow (1995) §, 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	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 wellbeing and threat to psychosocial wellbeing, the opportunity to live a healthy life

Author (year), country	Aim/ objective	Recruitment setting	Sample	Data collection^{a}	Analytical approach ^{a}	Findings related to self-management of T1D^{b}
			mean 7.0 years			
Kyngas & Hentinen (1995)§, Finland	To gain an understanding of compliance with self-care for adolescents with T1D			Interview and observation of participant behaviour during an adaptation course	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) §, 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 & 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	Paediatric endocrinology service	*N*=18, (13 females, 5 males), aged 14-16 years, <u>*Subgroup 1*</u>	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

Author (year), country	Aim/ objective	Recruitment setting	Sample	Data collection[a]	Analytical approach [a]	Findings related to self-management of T1D[b]
	in T1D management compared with those with lower HbA1c		*(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			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[c] of managing T1D and social support	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
Maslakpak 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 to good quality of life *Sub-categories:* negative feeling toward treatment and care, negative effects of diabetes, uncertainty about future

Author (year), country	Aim/ objective	Recruitment setting	Sample	Data collection[a]	Analytical approach [a]	Findings related to self-management of T1D[b]
Meldman (1987), USA	To explore adolescents' perspectives on 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	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
Peters et al. (2014), Netherlands	The aim of Study 1[c] (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 (%)	Online focus groups	Content analysis	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)

Author (year), country	Aim/ objective	Recruitment setting	Sample	Data collection[a]	Analytical approach [a]	Findings related to self-management of T1D[b]
			<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			
Rankin et al. (2018), UK	To explore pre-adolescent children's experiences of receiving diabetes support from friends and	Paediatric diabetes centres	*N*=24, 11 female, 13 male, mean age = 10.3 years, range 9-12 years, diabetes duration	In-depth interviews incorporating optional play-based tasks	Thematic analysis using constant comparative 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)

Author (year), country	Aim/ objective	Recruitment setting	Sample	Data collection[a]	Analytical approach [a]	Findings related to self-management of T1D[b]
	peers and whether, how and why they found this support helpful		mean=4.3 years, range 1 -10 years			3. Peer support provided by other children with type 1 diabetes
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, 11-16 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 11-14 year olds and 15-16 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	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

Author (year), country	Aim/ objective	Recruitment setting	Sample	Data collection[a]	Analytical approach [a]	Findings related to self-management of T1D[b]
			HbA1c = 8.1%			
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: *What kind of treatment do you think you should get for your diabetes?* *What kind of treatment do you think you should get for your diabetes?* Help to control blood glucose (from health professionals) Direct assistance, support, eat like I do, promote independence (from family) Support, treat me as normal (from friends) Be responsible (from self) *What are the most important things you hope this treatment will do for you?* Feel better, healthy/improved future, be cured Prevent complications/death Control of blood glucose *What are the chief problems diabetes has caused for you?* Food restrictions Blood glucose tests/injections Inconvenience of diabetes regimen Symptoms of high or low blood glucose Activity limitations *What do you fear most about your diabetes?* Complications Insulin reactions

Author (year), country	Aim/ objective	Recruitment setting	Sample	Data collection[a]	Analytical approach [a]	Findings related to self-management of T1D[b]
Sullivan-Bolyai et al. (2014), USA	To describe the perspectives of teenagers[c] 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
Viklund & 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

Author (year), country	Aim/ objective	Recruitment setting	Sample	Data collection[a]	Analytical approach [a]	Findings related to self-management of T1D[b]
Wang et al. (2013)¶, 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 T1D duration 4.64 years, mean self-reported HbA1c, 9.43%	Semi-structured interview	Hermeneutic phenomenological approach	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. (2010)¶, 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 2. Parental provision of reassurance about their child's illness and normative functioning

Author (year), country	Aim/ objective	Recruitment setting	Sample	Data collection[a]	Analytical approach [a]	Findings related to self-management of T1D[b]
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 wellbeing, blood glucose management, physical wellbeing, education and motivation of others, family interactions, academic achievements and interactions with important others such as teachers and health care providers

†Articles reporting on same instance of data collection

‡Articles reporting on same instance of data collection

§Articles reporting on same instance of data collection

¶Articles reporting on same instance of data collection

[a] As reported by study authors

[b] Main themes or findings reported by the study authors

[c] Articles reporting multiple studies where only the relevant study findings (pertaining to adolescent responses only) are included

2.3.2 Quality appraisal

The results of the quality appraisal are detailed in Table 2.4. Where articles received no or can’t tell ratings, it was usually unclear whether the area for appraisal was addressed. This may have been a feature of the reporting within the individual 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.

Table 2.4

Quality appraisal of included articles

Author (year)	Clear statement of aims	Qualitative methodology appropriate	Appropriate research design	Appropriate recruitment strategy	Appropriate data collection method	Researcher and participant relationship considered	Consideration of ethical issues	Rigorous data analysis	Clear statement of findings	Valuable research
Babler & Strickland (2016)	Yes	Yes	Yes	Can't tell	Yes	No	Yes	Yes	Yes	Yes
Babler & Strickland (2015a)	Yes	Yes	Yes	Can't tell	Yes	No	Yes	Yes	Yes	Yes
Babler & Strickland (2015b)	Yes	Yes	Yes	Can't tell	Yes	No	Yes	Yes	Yes	Yes
Boman et al. (2015)	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Burke & Dowling (2007)	Yes	Yes	Yes	Can't tell	Yes	Can't tell	Yes	Can't tell	Yes	Yes
Carroll & Marrero (2006)	Yes	Yes	Yes	Can't tell	Can't tell	Can't tell	Yes	Can't tell	Can't tell	Can't tell
Chao et al. (2016)	Yes	No	Can't tell	Can't tell	Can't tell	Can't tell	Can't tell	Yes	Yes	Yes
Chilton & Pires-	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes

Author (year)	Clear statement of aims	Qualitative methodology appropriate	Appropriate research design	Appropriate recruitment strategy	Appropriate data collection method	Researcher and participant relationship considered	Consideration of ethical issues	Rigorous data analysis	Clear statement of findings	Valuable research
Yfantouda (2015)										
Christian et al. (1999)	Yes	Yes	Can't tell	Can’t tell	Yes	No	Can't tell	Yes	Yes	Can't tell
Cosma & Baban (2015)	Yes	Yes	Can't tell	Can’t tell	Yes	Can't tell	Can't tell	Can't tell	Yes	Yes
Cruz et al. (2018)	Yes	Yes	Can’t tell	Can’t tell	Yes	No	Can’t tell	Can’t tell	Yes	Yes
Damaio & Pinto (2007)	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes	Yes
Davidson et al. (2004)	Yes	Yes	Can’t tell	Can’t tell	Can’t tell	No	Can’t tell	Yes	Yes	Yes
Dickinson & O’Reilly (2004)	Yes	Yes	Yes	Can’t tell	Can't tell	Can't tell	Yes	Yes	Yes	Yes
Faro (1999)	Yes	Yes	Yes	Yes	Yes	No	Can't tell	Yes	Can't tell	Yes
Hanna & Guthrie (2001)	Yes	Yes	Can't tell	Yes	Yes	Can't tell	Yes	Yes	Yes	Yes
Hanna & Guthrie (2000)	Yes	Yes	Yes	Yes	Yes	Can't tell	Yes	Can't tell	Can't tell	Yes

Author (year)	Clear statement of aims	Qualitative methodology appropriate	Appropriate research design	Appropriate recruitment strategy	Appropriate data collection method	Researcher and participant relationship considered	Consideration of ethical issues	Rigorous data analysis	Clear statement of findings	Valuable research
Hermann (2006)	Yes	Yes	Yes	Yes	Yes	Can't tell	Yes	Yes	Yes	Yes
Huus & Enskar (2007)	Yes	Yes	Yes	Can’t tell	Yes	No	Can't tell	Can't tell	Yes	Can't tell
Karlsson et al. (2008)	Yes	Yes	Yes	Can’t tell	Yes	Yes	Yes	Yes	Yes	Yes
Kupper et al., 2018	Yes	Yes	Yes	Can’t tell	Yes	Can’t tell	Yes	Yes	Yes	Yes
Kyngas & Barlow (1995)	Yes	Yes	Yes	Can’t tell	Yes	No	Yes	Yes	Yes	Yes
Kyngas & Hentinen (1995)	Yes	Yes	Yes	Can’t tell	Can't tell	Yes	Yes	Can't tell	Yes	Yes
Kyngas et al. (1998)	Yes	Yes	Can't tell	Can’t tell	Can't tell	Can't tell	Yes	No	Yes	Yes
Leach & Erickson (1988)	No	Can't tell	Can't tell	Can’t tell	Yes	No	No	Can't tell	Can't tell	Can't tell
Leonard et al. (2005)	Yes	Can't tell	Can't tell	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Marshall et al. (2018)	Yes	Yes	Yes	Can’t tell	Yes	Can’t tell	Can’t tell	Can’t tell	Yes	Yes

Author (year)	Clear statement of aims	Qualitative methodology appropriate	Appropriate research design	Appropriate recruitment strategy	Appropriate data collection method	Researcher and participant relationship considered	Consideration of ethical issues	Rigorous data analysis	Clear statement of findings	Valuable research
Maslakpak et al. (2010)	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes	Yes
Meldman (1987)	Can't tell	Yes	Yes	Can't tell	Yes	Can't tell	Can't tell	Yes	Yes	Yes
Peters et al. (2014)	Yes	Yes	Yes	Can’t tell	Yes	No	Yes	Yes	Yes	Yes
Rankin et al. (2018)	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Ryninks et al. (2015)	Yes	No	Can't tell	Yes	Can't tell	Yes	Yes	Yes	Yes	Yes
Serlachius et al. (2012)	Yes	Yes	Yes	Yes	Yes	No	Yes	Can't tell	Yes	Yes
Standiford et al. (1997)	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Can't tell	Yes	Yes
Sullivan-Bolyai et al. (2014)	Yes	Yes	Yes	Can’t tell	Can't tell	Yes	Yes	Can't tell	Yes	Yes
Viklund & Wikblad (2009)	Yes	Yes	Yes	Yes	Can't tell	Can't tell	Yes	Yes	Yes	Yes
Wang et al. (2013)	Yes	Yes	Yes	Yes	Yes	Can't tell	Yes	Yes	Yes	Yes

Author (year)	Clear statement of aims	Qualitative methodology appropriate	Appropriate research design	Appropriate recruitment strategy	Appropriate data collection method	Researcher and participant relationship considered	Consideration of ethical issues	Rigorous data analysis	Clear statement of findings	Valuable research
Wang et al. (2010)	Yes	Yes	Yes	Can’t tell	Yes	Can't tell	Yes	Can't tell	Yes	Yes
Weinger et al. (2001)	Yes	Yes	Yes	Can’t tell	Yes	Can’t tell	Yes	Can’t tell	Yes	Yes
Ye et al. (2017)	Yes	Yes	Yes	Yes	Yes	Can’t tell	Yes	Yes	Yes	Yes

2.3.3 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 2.5. The analytic and descriptive themes, with example quotations to illustrate how themes were developed are presented in Table 2.6. 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 in Appendix C.

Table 2.5

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

Table 2.6

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 T1D	Accepting T1D	"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 & Strickland, 2016, p. 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, p. 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 & Dowling, 2007, p. 92)
		Comparing T1D 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 & Pires-Yfantouda, 2015, p. 1497) "(it's) ridiculously hard sometimes because you feel like trapped, then you're just like, well people deal with a lot worse" (Babler & Strickland, 2016, p. 125)

Analytic theme	Descriptive theme	Example codes	Illustrative quotations
			“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, p. 239)
		Getting used to T1D	“… it’s just like something that I can deal with” (Dickinson & O’Reilly, 2004, p. 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 & Marrero, 2006, p. 246)
			“Diabetes is living hell. I fight against it.” (Meldman, 1987, p. 438)
		Recognising T1D is forever	‘‘I hate having to deal with diabetes management all the time.’’ (Chao et al., 2016, p. 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 & Pinto, 2007, p. 571)
			“I hope I will wake up and the diabetes will be gone.” (Kyngas & Barlow, 1995, p. 943)
		Understanding T1D	“Growing up helped me to understand more about diabetes” (Cosma & Baban, 2015, p. 238)

Analytic theme	Descriptive theme	Example codes	Illustrative quotations
			“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 & Pires-Yfantouda, 2015, p. 1498)
		Attitude towards T1D	“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 & Strickland, 2016, p. 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 & Pires-Yfantouda, 2015, p. 1493)
	Parental roles and parental involvement in T1D self-management	Parent roles *Checking in with parents* *Parental reminders* *Parents help and assist* *Parents teach* *Parents motivate* *Parents reassure*	“They let me go out and do things by myself and everything, but they always ask me what my blood sugars have been every day.” (Leonard et al., 2005, p. 409) “They don’t bug me about food and that stuff but they will bug me about testing.” (Carroll & Marrero, 2006, p. 247) “I didn’t know anything about diabetes, I’d never heard of it, so I just had to have like a lot of help from my mum but, I wasn’t really worried cos I didn’t understand what it really meant.” (Chilton & Pires-Yfantouda, 2015, p. 1496) “When I’m alone it works well, but I think that when I’m at home I can relax, I automatically put more responsibility on my mother and in this situation it works

Analytic theme	Descriptive theme	Example codes	Illustrative quotations
		Parents step in	better when she does the thinking. If I'm alone at home it works well, but if she's there I relax or maybe I care less." (Viklund & Wikblad, 2009, p. 3267)
		Conflict, blame and not being in agreement with parents	"That I sometimes get yelled at for having high blood sugars and it gets stressful." (Chao et al., 2016, p. 137) "She yells at me all the time. 'You're supposed to do your shots.' 'Oh, yeah. I know but I'm tired.' 'You're supposed to test your blood'." (Leonard et al., 2005, p. 411)
		Sharing and negotiating management of parents	"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 & Guthrie, 2001, p. 218) "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 & Guthrie, 2001, p. 218) "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, p. 409)

Analytic theme	Descriptive theme	Example codes	Illustrative quotations
			“They need to trust me more.” (Sullivan-Bolyai et al., 2014, p. 184)
			“… 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, p. 133)
	Others’ involvement in T1D self-management	Awareness of the impact of T1D on others	“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, p. 5)
			“In house, I’m under pressure; my family has an excessive stress about my health.” (Maslakpak et al., 2010, p. 466)
		Clinic and hospital experiences	“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, p. 10)
			“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, p. 262)
			“I do one thing wrong and the doctor takes a half hour talking about it.” (Sullivan-Bolyai et al., 2014, p. 185)

Analytic theme	Descriptive theme	Example codes	Illustrative quotations
		Dealing with school personnel	“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 & O’Reilly, 2004, p. 103) “Our school nurse is great. . .every Wednesday she has a lunch club for kids with diabetes.” (Herrman, 2006, p. 216) “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.” (Maslakpak et al., 2010, p. 467)
		Family and sibling involvement	“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 & Baban, 2015, p. 241) “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 & Dowling, 2007, p. 92)

Analytic theme	Descriptive theme	Example codes	Illustrative quotations
		Others’ reactions	“I’m tired of everyone saying ‘Are you allowed to eat that?’ That makes me so mad.” (Chao et al., 2016, p. 138)
			“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, p. 217)
		Relying on and receiving support from others	“My best friend acts like my mom. It gets on my nerves.” (Carroll & Marrero, 2006, p. 248)
			“It is comforting to know that someone is there in case that something bad happens with my diabetes.” (Cosma & Baban, 2015, p. 239)
			“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, p. 5)
			“sometimes I look like I’m low he asks like, ‘are you okay with your blood sugars?’” (Rankin et al., 2018, p. 4)
		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 & O’Reilly, 2004, p. 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, p. 764)

Analytic theme	Descriptive theme	Example codes	Illustrative quotations
		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, p. 137)
			“I talk to my friends.” (Herrman, 2006, p. 216)
			“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, p. 6)
		Involvement of friends	“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, p. 150)
			“…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 & Dowling, 2007, p. 91)
	Becoming independent in T1D self-management	Making decisions	“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 & Wikblad, 2009, p. 3265)

Analytic theme	Descriptive theme	Example codes	Illustrative quotations
			"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, p. 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 & Strickland, 2015a, p. 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 & Baban, 2015, p. 238) "We've learned to use sticky notes to remind us of stuff." (Herrman, 2006, p. 216)
		Taking on T1D self-management *Not feeling ready to take on self-management* *Assuming responsibility*	"…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 & Strickland, 2015a, p. 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 & Pires-Yfantouda, 2015, p. 1496)

Analytic theme	Descriptive theme	Example codes	Illustrative quotations
			“Well, you have to be more responsible. You have to remember your insulin, tester, sugar foods and to count everything you eat.” (Carroll & Marrero, 2006, p. 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, p. 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, p. 239)
			“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 & Baban, 2015, p. 240)
		Lying (avoiding conflict)	“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., 2015, p. 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 & Strickland, 2015a, p. 652)
			“The insulin pump made it so easy...I love my pump..” (Herrman, 2006, p. 216)

Analytic theme	Descriptive theme	Example codes	Illustrative quotations
			“The best thing to do is get good with the shots and checks. . .then it’s easy.” (Herrman, 2006, p. 216)
		Facilitating integration of self-management with daily life	“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 & Strickland, 2015a, p. 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 & Pires-Yfantouda, 2015, p. 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 & Dowling, 2007, p. 91)
		Management activities	“I can't eat all the foods that I would like to eat.” (Faro, 1999, p. 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, p. 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, p. 261)

Analytic theme	Descriptive theme	Example codes	Illustrative quotations
		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, p. 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, p. 214) “I don’t even know what I’m sad about anymore…” (Babler & Strickland, 2015a, p. 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 & Strickland, 2015a, p. 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 & Guthrie, 2000, p. 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, p. 215)

Analytic theme	Descriptive theme	Example codes	Illustrative quotations
			“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 & Strickland, 2016, p. 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, p. 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, p. 237) “Still, I am proud when I correct my mother regarding the optimal insulin level.” (Cosma & Baban, 2015, p. 239)
		Feeling in control of T1D *Overcoming injection fear* *Recognising areas for improvement* *Meeting targets*	“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, p. 256) “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, p. 567) “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, p. 8) “There are always opportunities for improvement.” (Boman et al., 2015, p. 9)

Analytic theme	Descriptive theme	Example codes	Illustrative quotations
	Fitting in or standing out and self-management of T1D	Feeling normal or feeling different	“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, p. 3)
			“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 & Enskar, 2007, p. 30)
			“I know that I am not like others can totally [be] free to eat what they want to eat and to do want they want to do. I need to test my sugar, adjust my insulin, and pay attention to my body carefully.” (Wang et al., 2013, p. 237)
			“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 & O’Reilly, 2004, p. 102)
			“…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, p. 332)
		Fitting in	“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, p. 765)

Analytic theme	Descriptive theme	Example codes	Illustrative quotations
			“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 & Strickland, 2015a, p. 655)
			“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, p. 6)
		Unwanted attention	“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, p. 8)
			“Sometimes, my schoolmates laugh at me and ask me stupid questions about the diabetes.” (Cosma & Baban, 2015, p. 239)
	Thinking about the future and T1D complications	T1D complications	“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 & Pires-Yfantouda, 2015, p. 1493)

Analytic theme	Descriptive theme	Example codes	Illustrative quotations
			“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, p. 7)
		Potential influence on the future	“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 & Pires-Yfantouda, 2015, p. 1497)
			“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 & Barlow, 1995, p. 943)
			“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 & Pires-Yfantouda, 2015, p. 1496)
			“I want to learn to do things on my own because I know that my mother won’t be there all the time.” (Cosma & Baban, 2015, p. 239)
			“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 & Strickland, 2016, p. 128)

2.3.3.1 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 can 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 can 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 CYPD 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 & Strickland, 2015b; Cosma & Baban, 2015; Leach & Erickson, 1988). The diagnosis experience may have relevance for current feelings and beliefs held towards T1D as feelings about diagnosis, time since diagnosis or level of maturity may influence the CYPD's acceptance of T1D self-management (Chilton & Pires-Yfantouda, 2015; Cosma & Baban, 2015; Damião & 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 & Pires-Yfantouda, 2015). CYPDs contend with living with T1D, adjusting to diets and insulin pumps and indicate how specific management activities were initially considered challenging (Babler & Strickland, 2016; Cosma & Baban, 2015; Damião & Pinto, 2007; Dickinson & O'Reilly, 2004; Herrman, 2006). This acceptance was evident in descriptions of getting used to T1D as adjustment to a 'new reality' (Cosma & Baban, 2015, p. 237). Acceptance of T1D involves coming to the realisation that T1D is part of life and is manageable (Babler & Strickland, 2015a, 2015b, 2016; Herrman, 2006; Meldman, 1987). Some CYPDs consider management of T1D to be more arduous than the demands posed by other illnesses (Babler & Strickland, 2015a; Carroll & Marrero, 2006; Meldman, 1987; Wang et al., 2013). In contrast, others choose to frame a diagnosis of T1D positively (Babler & Strickland, 2016; Chilton & 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 CYPD to do 'everything' (Leonard et al., 2005, p. 410). Parental involvement may be less tangible, relating to just knowing that parents are 'there' and as a result of this, the CYPD feels that they do not always have to 'think all the time what I have to do next' (Cosma & Baban, 2015, p. 239). This can then alleviate the burden posed by self-management. Parents may temporarily take over management (Viklund & Wikblad, 2009).

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

When not restricted to times when the CYPD needs 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 & Strickland, 2015a, 2015b, 2016; Boman et al., 2015; Carroll & Marrero, 2006; Cosma & Baban, 2015; Davidson et al., 2004; Dickinson & O'Reilly, 2004; Herrman, 2006; Huus & Enskar, 2007; Kyngas et al., 1998). However, parental involvement is valued by CYPDs (Dickinson & 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 & Strickland, 2016; Boman et al., 2015; Burke & Dowling, 2007; Carroll & Marrero, 2006; Christian et al., 1999; Cosma & Baban, 2015; Damião & Pinto, 2007; Dickinson & O'Reilly, 2004; Herrman, 2006; Huus & Enskar, 2007; Karlsson et al., 2008; Kupper et al., 2018; Kyngas et al., 1998; Kyngas & Barlow, 1995; Maslakpak et al., 2010; Rankin et al., 2018; Serlachius et al., 2012; Standiford et al., 1997) extended family, (Boman et al., 2015; Burke & Dowling, 2007; Carroll & Marrero, 2006; Christian et al., 1999; Cosma & Baban, 2015; Hanna & Guthrie, 2001; Herrman, 2006; Leonard et al., 2005; Maslakpak et al., 2010; Standiford et al., 1997) teachers (Burke & Dowling, 2007; Carroll & Marrero, 2006; Christian et al., 1999; Cosma & Baban, 2015; Dickinson & O'Reilly, 2004; Herrman, 2006; Maslakpak et al., 2010; Ryninks et al., 2015; Sullivan-Bolyai et al., 2014; Wang et al., 2013, 2010) and HCPs (Boman et al., 2015; Carroll & Marrero, 2006; Christian et al., 1999; Dickinson & O'Reilly, 2004; Karlsson et al., 2008; Kyngas et al., 1998; Kyngas & Barlow, 1995; Kyngas & Hentinen, 1995; Meldman, 1987; Standiford et al., 1997; Sullivan-Bolyai et al., 2014; Viklund & 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 & Hentinen, 1995). CYPDs can then 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 CYPD 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 CYPD such as during a hypoglycaemia incident (Wang et al., 2013). Supportive behaviours of others can contribute to formation of beliefs that self-management is within the CYPD's capabilities to handle successfully, such as through awareness that friends are available to offer support (Babler & Strickland, 2016; Boman et al., 2015; Carroll & Marrero, 2006; Dickinson & O'Reilly, 2004; Karlsson et al., 2008). Conversely, CYPDs may decide to not involve their peers in their T1D management and avoid T1D management when in the presence of their friends (Kyngas et al., 1998). CYPDs can 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 CYPD, this can contribute to frustration felt towards T1D (Carroll & Marrero, 2006; Leach & Erickson, 1988; Rankin et al., 2018). Therefore, appropriate support and involvement of others may contribute to CYPD's 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 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 & Guthrie, 2001; Karlsson et al., 2008; Kyngas et al., 1998; Viklund & Wikblad, 2009). CYPDs strive towards independence in self-management as they come to realise that independence is necessary in order to achieve autonomy (Babler & Strickland, 2015a, 2015b, 2016; Carroll & Marrero, 2006; Cosma & Baban, 2015; Dickinson & O'Reilly, 2004; Hanna & 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 & Strickland, 2015b; Damião & Pinto, 2007; Dickinson & O'Reilly, 2004; Herrman, 2006; Karlsson et al., 2008; Kyngas & Hentinen, 1995; Standiford et al., 1997; Sullivan-Bolyai et al., 2014; Viklund & 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 & Wikblad, 2009, p. 3265).

2.3.3.2 Feeling in control. This analytic theme relates to the CYPD's ability and confidence to engage with self-management of T1D. Daily, 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 CYPD's lifestyle in terms of their school life, home life and hobbies.

There are also situations where control is considered beyond the CYPD's 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 CYPD's 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 CYPD 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 & Strickland, 2015a, 2016; Burke & Dowling, 2007; Carroll & Marrero, 2006; Chao et al., 2016; Chilton & Pires-Yfantouda, 2015; Cosma & Baban, 2015; Faro, 1999; Herrman, 2006; Kyngas & Barlow, 1995; Leach & Erickson, 1988; Maslakpak et al., 2010; Meldman, 1987; Peters et al., 2014; Ryninks et al., 2015; 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 & Strickland, 2015b; Burke & Dowling, 2007; Chilton & Pires-Yfantouda, 2015; Cosma & Baban, 2015; Faro, 1999; Leach & Erickson, 1988; Meldman, 1987; Rankin et al., 2018; Viklund & 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 & Baban, 2015) and for others insulin pumps are not readily available (Cruz et al., 2018).

More generally, adopting a routine with respect to carrying out daily management tasks can lead to the formation of the view that T1D is not overly burdensome (Babler & Strickland, 2015a). Positive and negative aspects of the routine nature of self-management are described in a number of articles (Babler & Strickland, 2015a; Cosma & Baban, 2015; Kyngas & Barlow, 1995; Meldman, 1987; Wang et al., 2010). For some, the benefits of routines are outweighed by the unrelenting nature of T1D management (Babler & Strickland, 2016; Chao et al., 2016; Cosma & Baban, 2015; Davidson et al., 2004; Peters et al., 2014). When the regimen is perceived as restrictive, negative attitudes towards T1D may ensue (Burke & Dowling, 2007; Christian et al., 1999; Cosma & Baban, 2015; Damião & Pinto, 2007; Faro, 1999; Herrman, 2006; Kyngas & Hentinen, 1995; Wang et al., 2013; Weinger et al., 2001). Additionally, CYPDs may feel that they do not possess a desirable level of control over the impact of T1D management on their life (Babler & Strickland, 2015a; 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 & Strickland, 2015a, 2015b, 2016; Burke & Dowling, 2007; Carroll & Marrero, 2006; Chilton & Pires-Yfantouda, 2015; Cosma & Baban, 2015; Faro, 1999; Herrman, 2006; Kyngas & Barlow, 1995; Leach & 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 & Wikblad, 2009). This can imply making a conscious decision to stop being ‘lazy’ and actively complete the tasks of T1D management (Babler & Strickland, 2016, p. 128). When CYPDs avoid or forget to engage with T1D self-management, they may lie about self-management to others (Babler & Strickland, 2015a; Davidson et al., 2004; Kyngas & Barlow, 1995; Kyngas & Hentinen, 1995; Leonard et al., 2005;

Weinger et al., 2001) in order to avoid conflict (Babler & Strickland, 2015a; Kyngas & Barlow, 1995).

Living with T1D can lead to feelings of isolation, anxiety and guilt for CYPDs (Kyngas & Barlow, 1995; Maslakpak et al., 2010). Additionally, feelings of worry, frustration, burden and stress may be attributed to the requirements imposed by T1D by the CYPD (Babler & Strickland, 2015a, 2015b; Chao et al., 2016; Kyngas & Hentinen, 1995). Not meeting targets such as desired blood glucose readings can result in worry about upsetting others such as HCPs (Carroll & Marrero, 2006; Dickinson & 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 & Guthrie, 2001, p. 169). Gaining confidence in self-management abilities can contribute to feeling that control over T1D is possible and that CYPDs are capable of integrating its management into daily life (Babler & Strickland, 2016; Christian et al., 1999; Hanna & Guthrie, 2000). This sense of confidence can be preceded by barriers, such as injection fear (Karlsson et al., 2008). CYPDs also demonstrate that they can exert control over T1D by resisting opportunities for mismanagement (Viklund & 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 & Strickland, 2015b) or when glycosylated haemoglobin (HbA1c) targets are considered unattainable (Boman et al., 2015). When blood glucose levels are within normal ranges for the CYPD, this can contribute to enhanced perceptions of 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 & Baban, 2015; Kyngas & Barlow, 1995; Wang et al., 2013). For some CYPDs, awareness of physical symptoms influences engagement with management of T1D through allowing the CYPD 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 can highlight differences between CYPDs and their peers (Babler & Strickland, 2015a; Faro, 1999; Herrman, 2006; Huus & Enskar, 2007; Kyngas & Barlow, 1995; Kyngas & Hentinen, 1995; Peters et al., 2014; Rankin et al., 2018; Wang et al., 2010, 2013). From the CYPD’s perspective, being unable to eat in the same manner as friends can emphasise differences that exist (Huus & Enskar, 2007; Wang et al., 2013). CYPDs choose between either fitting in and being like peers or adjusting their daily routines for their T1D management. In some cases, T1D management is neglected (Babler & Strickland, 2015a; Herrman, 2006; Kyngas et al., 1998; Wang et al., 2010, 2013). Others feel that it is possible to fit in among peers without T1D and also live with T1D (Dickinson & O’Reilly, 2004). The CYPD may secretly manage T1D or may make the decision to not manage by ‘ignoring’ T1D (Boman et al., 2015, p. 8).

CYPDs can be treated differently through friends asking questions, parents preventing their participation in activities or teachers highlighting differences (Carroll & Marrero, 2006; Chao et al., 2016; Maslakpak et al., 2010; Weinger et al., 2001). Others in the CYPD’s life may not always understand T1D and some feel that sport coaches ‘singled them out.’ (Dickinson & O’Reilly, 2004, p. 103). Though the CYPD may wish to engage fully with teenage life, they may be prevented by parents who they consider overprotective or overinvolved in their care (Carroll & 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 CYPD's approach to self-management can 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 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 & Baban, 2015). Therefore, it is important that CYPDs feel that independent management of T1D in the future is possible (Babler & Strickland, 2016). The risks posed by not managing and developing complications in the future are sources of uncertainty and can exacerbate worries in relation to living with T1D (Babler & Strickland, 2015a, 2016; Chao et al., 2016; Christian et al., 1999; Dickinson & O'Reilly, 2004; Faro, 1999; Kyngas & Barlow, 1995; Kyngas & 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 & Strickland, 2016; Chilton & Pires-Yfantouda, 2015; Kyngas & Hentinen, 1995; Standiford et al., 1997). Others can feel that preventing complications is beyond their control and this then causes disengagement with self-management of T1D (Viklund & Wikblad, 2009). Some CYPDs choose to avoid envisaging the risk of complications of T1D (Damião & 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 CYPD's capabilities.

2.4 Discussion

This qualitative meta-synthesis systematically examined the available evidence on experiences and perceptions of self-management of T1D from the perspectives of CYPDs aged 8 to 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 (Audulv et al., 2009). In the present meta-synthesis, CYPDs' descriptions of experiences of negotiating independence, has parallels with references to how individuals experience inner conflicts as they encounter barriers to engagement with self-management (Audulv 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 and 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.

The 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, peer influences, etc. 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 emphasises the relevance of self-efficacy within conceptualisations of self-management in childhood and adolescence. 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 CYPD 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.

These 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 CYPD's care adopt approaches that are individualised to the CYPD. 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 over 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 CYPD 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 & Keogh, 2015). Previous research carried out in an adult context on self-management indicates adults' feelings on normality and stigmatisation as a result of chronic illness can impede engagement with self-management (Audulv 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 wellbeing can enhance feelings of control over T1D. Additionally, 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 CYPD's 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 CYPD (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 between 8 and 18 year olds and captures an important developmental stage as self-management patterns transition to adolescent dominant, with adolescents performing more T1D tasks than their parents (Schilling et al., 2006). The period between late childhood and adolescence is characterised by physiological and psychosocial development that can be difficult to capture in systematic reviews and literature syntheses conducted in the paediatric setting (Farid-Kapadia et al., 2017). This meta-synthesis also highlights the difficulties of isolating data across a relatively wide age range. Within the current review, it was not possible to further stratify findings according to specific age subgroups. Nonetheless, the present review's findings that adolescence is characterised by increased responsibility for self-management aligns with Schilling et al.'s (2006) finding that patterns of self-management are transitional by 11 years of age.

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 decontextualizing findings of primary research during the conduct of the meta-synthesis (Thomas & Harden, 2008). A potential limitation of the present search strategy is the lack of a uniform definition of self-management. There has been much divergence in the reporting of definitions employed across studies, meaning relevant studies may have been missed. Previous reviews in the area of self-management have described the difficulty of identifying relevant articles when self-management as a definition and term is used variably across studies and contexts (Barlow et al., 2002). In the current meta-synthesis, a broad search strategy was employed which encompassed several terms that are related to self-management, in order to mitigate the possibility of excluding relevant articles.

2.5 Conclusion and Implications for Thesis

The findings of the current qualitative meta-synthesis provide insight into CYPD 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 and HCPs can contribute to feelings of frustration towards T1D and its self-management. The scope of the studies included in this review highlight a gap in research that explores processes of self-management. Furthermore, there is a need to determine how these processes relate to the proximal and distal outcomes of self-management according to the IFSMT (Ryan & Sawin, 2006). The findings from the review and meta-synthesis highlight that further understanding into how adolescents perceive their interactions with others should 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. More specifically there is scope for research that seeks to explore and identify the features of these interactions. The findings of the meta-synthesis indicate that much change occurs in how independent adolescents are in T1D management during adolescence. Further research is needed to capture the context of how adolescents specifically assume responsibility for, and increase independence, in self-management, and their perspectives on negotiating parental involvement in T1D management. In depth accounts of what can contribute to optimal negotiation and sharing of management responsibilities should lead to better understanding of how CYPDs can be supported in their transition towards self-management.

In conclusion, this chapter provided a meta-synthesis of qualitative literature on the experiences of self-management of T1D of CYPDs. The findings of the qualitative meta-synthesis indicate several different contextual factors and processes underpinning the transition towards independence in T1D self-management and assumption of self-management responsibilities. Parents adopt a key role in this transition from parent-dominant to adolescent dominant patterns of self-management of T1D. While this review identifies the key role of parents in CYPD experiences of self-management, there is a need for an in-depth exploration into CYPD perspectives on the nature of parental involvement in their T1D care and specifically how involvement changes as they mature. The meta-synthesis suggests the need for an in-depth investigation into the communication that occurs between adolescents and their parents in relation to self-management of T1D from the perspectives of adolescents. There are no studies that specifically focus on adolescent-specific perspectives on communicating and interacting with parents with respect to negotiating involvement in their care. The proceeding chapters will elucidate the mixed method study seeking to explicate adolescent perspectives on negotiating self-management responsibilities with their parents.

Chapter 3: Methodology

3.1 Introduction

In this chapter, the methodology of the present study will be outlined. The aims and objectives for this mixed methods study, the study design and approach will be presented**.**

3.2 Study Aims and Objectives

The aims of this mixed methods study are to:

- Explore how adolescents living with T1D experience self-management of T1D and share self-management responsibilities with parents
- Elucidate the relationship between adolescent communication with parents about T1D, self-management and a number of demographic, clinical and psychosocial variables

The objectives of phase one are to:

- Explore the process of sharing self-management responsibilities for T1D with parents, from the perspectives of adolescents
- Understand the context and content of parent-adolescent communication about self-management and shared self-management responsibilities from the perspectives of adolescents
- Identify enablers and challenges to assuming self-management responsibilities for T1D for adolescents living with T1D
- Explore consequences of sharing and shifting responsibilities for self-management for adolescents living with T1D
- Identify constructs related to parent-adolescent communication and self-management that warrant follow up quantitatively in phase two

The objectives of phase two are to:

- Investigate the relationship between parent-adolescent communication and, demographic and clinical variables including age, time since diagnosis and self-reported metabolic control (last HbA1c result)
- Examine the relationship between adolescent communication with parents and self-management of T1D in adolescents
- Examine the relationship between parent-adolescent communication and psychosocial variables relating to T1D including T1D-specific family conflict, T1D self-efficacy, patient activation, division of T1D-related responsibilities between parents and adolescents, T1D self-management and health-related quality of life (QOL)

In addressing the study aims and objectives, the following mixed methods research questions will be answered:

- What helps or hinders adolescent engagement with self-management of T1D?
- How does parent-adolescent communication contribute to negotiation and sharing of responsibilities for self-management for adolescents?
- How does negotiating self-management responsibilities impact on adolescent life?

3.3 Mixed Methods Research

In the present study, a mixed methods research design is employed to address the aims of this study. Mixed-method approaches to data collection and analysis continue to gain popularity and are used within a variety of disciplines including in health related research (Johnson et al., 2019). Mixed methods allow for an increased depth of understanding of complex or under-researched phenomena (Doyle et al., 2009, 2016). Varying definitions for mixed methods research have been proposed (Tashakkori & Teddlie, 2003). Based on consideration of a number of descriptions of mixed methods research, Johnson et al. defined mixed methods research as “the type of research in which a researcher or team of researchers combines elements of qualitative and quantitative research approaches (e.g., use of qualitative and quantitative viewpoints, data collection, analysis, inference techniques) for the broad purposes of breadth and depth of understanding and corroboration” (2007, p. 123). Therefore, mixed methods studies draw from both qualitative and quantitative approaches. Qualitative research seeks to explore the experiences, views and contexts of participants (Mason, 2018). In doing so, it seeks to gain an in-depth understanding of the phenomena or concept that is under investigation. Quantitative research differs from qualitative research in that it focuses on the objective and adoption of closed-ended questions and pre-defined hypotheses (Creswell, 2009). Therefore, mixed methods research attempts to use these different standpoints to best understand the research problem of interest.

3.3.1 Philosophical foundations

The current study is underpinned by pragmatism. Pragmatism proposes that research should be approached in such a way that best answers the research question (Johnson & Onwuegbuzie, 2004). Therefore, in addition to placing primary importance on the specific research question, this worldview also allows for the combining or compatibility of qualitative and quantitative research.

Pragmatism is concerned with the consequences or the practical applications of the research and its outputs (Cherryholmes, 1992; Creswell & Clark, 2017). This approach places value on both objective and subjective knowledge, and balancing these during the research process (Creswell & Clark, 2017; Shannon-Baker, 2016). A subjective approach is generally adopted by qualitative research while the objective stance is generally assumed in quantitative research.

The pragmatic approach is “intersubjectivity”, which places value on the objective and subjective, and does not force the acceptance of one of those aforementioned dichotomies (Morgan, 2007). Research in applied or practical settings is often underpinned by pragmatism as it supports the use of the research method considered most appropriate to answer the research question, independent of the worldview or epistemological standpoint of the approach (Tashakkori & Teddlie, 2003).

Pragmatism relies on abductive reasoning which is an approach that moves between data-driven induction and theory-driven deduction in order to explore and explain the phenomena that is under investigation (Morgan, 2007). In the current study, an abductive approach is employed, as the researcher engages with the inductive qualitative phase of data collection and analysis which subsequently informs the quantitative or deductive phase of the research. Through the adoption of a pragmatist worldview, the researcher may draw upon qualitative and quantitative data in order to answer the research question. Within the present study, the research seeks to understand adolescent self-management of T1D and the interplay of parent-adolescent communication with assuming responsibilities for T1D self-management. Therefore, a combination of qualitative and quantitative approaches is required to address the objectives of this study, outlined at the beginning of this chapter.

3.3.2 Rationale for Mixed Methods Approach

Mixed methods allow for the presentation of wide and divergent viewpoints across data, provide stronger insights into findings (offering confirmatory insights across qualitative and quantitative) and answer distinct research questions (mixed methods allow for researchers to answer exploratory and confirmatory questions within the same study) (Tashakkori & Teddlie, 2003).

There are several justifications for the use of mixed methods research which include triangulation, expansion, exploration, completeness, offsetting of weaknesses, answering different research questions and illustration of findings (Doyle et al., 2009). Firstly, through triangulation the results from qualitative and quantitative phases may be corroborated through comparison. As an approach, it allows for the expansion or explanation of findings from an initial phase. Advantages of the adoption of a mixed methods approach include that it allows for the incorporation of the respective strengths of qualitative and quantitative research (Creswell & Clark, 2017). Mixed methods research allows for the identification of additional phenomena or hypotheses that require testing and allows for a more complete account of the area that is under investigation and can minimise weaknesses of individual methods. Finally, the adoption of mixed methods allows for quantitative and qualitative research questions to be answered within a study.

However, mixed methods research also presents inherent practical and philosophical challenges. The philosophical underpinnings and challenges of mixed methods research are described previously in 3.3.1. Practical challenges in carrying out mixed methods research include ensuring that researchers are skilled with respect to each method within the mixed method framework and encountering issues with the integration of divergent findings (Farquhar et al., 2011). The challenges of maintaining transparency and credibility in mixed methods research can be mitigated through following a specific technique for integration (O’Cathain et al., 2010). Furthermore, a systematic approach to interpretation and integration of discrepant findings can enhance the overall conclusions of the mixed methods study (Moffatt et al., 2006).

3.4 Design of the Present Study

The current study employs a two-phased sequential-exploratory mixed-methods design. This method is characterised by an initial qualitative data collection and analysis phase followed by a quantitative data collection and analysis phase (Tashakkori & Teddlie, 2003). The intent of this design is that the qualitative data collection and analysis informs the quantitative phase. Therefore, the quantitative phase is grounded within the experiences and viewpoints of participants (Creswell & Clark, 2017). In the present study, the first phase is qualitative and involves the collection of data through semi-structured interviews with adolescents living with T1D. This design was employed as parent-adolescent communication as it specifically relates to self-management and the negotiation of levels of responsibility for self-management in adolescents has not been previously investigated. Therefore, the qualitative phase gathers in-depth accounts of adolescent experiences relating to their perspectives on communication with parents about self-management and changing levels of involvement for self-management of T1D. The exploratory interviews identified and confirmed constructs that warranted follow up quantitatively. Within the quantitative phase, data was gathered through a cross-sectional survey carried out with adolescents living with T1D. Integration is the combining of quantitative and qualitative research within a mixed methods inquiry (Tashakkori & Teddlie, 2003). In mixed methods studies, points of integration are evident where qualitative and quantitative research are brought together (Moseholm & Fetters, 2017). In the present study, there were several points of integration. Points of integration are evident in the study methods (where qualitative findings suggested a construct for follow up in the subsequent quantitative phase) and analysis level (through matching findings from each phase and drawing interpretations based on this). Measures for the quantitative survey, conducted in phase two, were selected based on consideration of the initial findings of the analysis of the qualitative data from phase one of the study. The findings from each of these two phases were analysed and interpreted separately before undergoing integration (see Figure 3.1 below for visual representation of study design). The overall interpretation of the integrated findings was guided by IFSMT (Ryan & Sawin, 2009).

When selecting a design type, one factor considered is the weighting of each phase of the study, which refers to the priority afforded to each individual phase within the overall inquiry (Creswell & Clark, 2017). In the current mixed methods study, both phases are weighted equally, as the qualitative and quantitative phases address different aspects of the mixed methods research questions. In addressing the objectives of the qualitative phase, the subsequent quantitative strand is informed. Therefore, the interpretations of the qualitative and quantitative phases are equal in their contribution to the overarching findings of the present mixed methods study. Furthermore, both phases have the ability to elicit information on distinct aspects of self-management of T1D and perspectives on adolescent communication with parents surrounding self-management of T1D.

In the present mixed methods study, data from each phase were analysed separately before integration occurs through the consideration of each phase. Inferences are the specific conclusions that are drawn based on the findings of the individual phases (Tashakkori & Teddlie, 2003). For integration, findings across phases can be considered in terms of the ‘fit’ across results, which refers to coherence (Fetters et al., 2013). Confirmation, expansion and discordance are specific dimensions of fit (Fetters et al., 2013; Moseholm & Fetters, 2017). In the present study, instances of confirmation, expansion and discordance were explicitly identified (see 10.3 for more information on how these dimensions were applied in the present study).

A joint display was developed to facilitate integration of findings across phases (see Chapter 10, Table 10.1). The purpose of the joint display was to develop meta-inferences which are new insights or findings gained through the combination of results or findings from distinct phases of research (Fetters et al., 2013; Moseholm & Fetters, 2017). Presenting qualitative and quantitative data visually within a joint display is one approach to merge findings in mixed methods research and has been used within various mixed methods designs including sequential exploratory (Guetterman et al., 2015). Merging is defined as “using tables or figures that combine and display both quantitative and qualitative data together” (Johnson et al., 2019, p. 301). The joint display approach to integration was chosen as it has been previously used to integrate data in sequential exploratory designs conducted on patient perspectives (Haggerty et al., 2012) and as it provides a clearly defined approach to integration. Furthermore, this approach addresses some of the issues regarding lack of transparency with respect to how integration occurs within mixed methods studies through representing the integration visually (Guetterman et al., 2015).

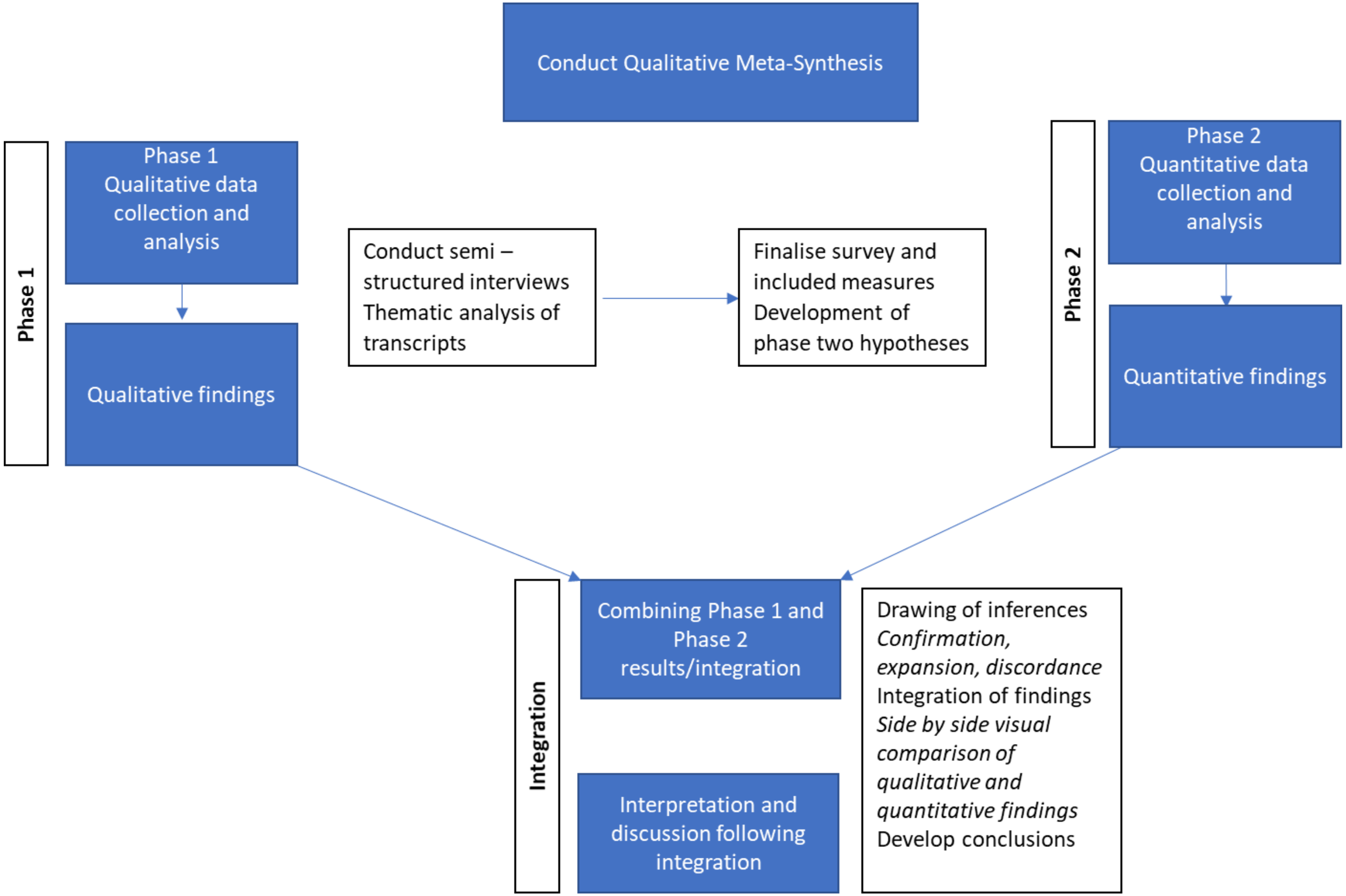


Figure 3.1. Visual diagram of study design

3.5 Patient and Public Involvement in the Research: Youth Advisory Group

Adolescents living with T1D were recruited to join a Youth Advisory Group and provide input and feedback on the research and interpretation of findings of the current mixed methods study. The Youth Advisory Group meetings took the form of workshops which are summarised below (see Appendix D for a detailed overview of the meetings of the Youth Advisory Group). Adolescents were invited to join the youth advisory group via an open advertisement hosted on the Diabetes Ireland website and social media pages (see Appendix E). Parents of interested adolescents contacted the researcher, seeking further information about participation in the group or to outline their adolescent child’s interest in participating.

A group of nine adolescents ranging in age between 11 to 17 years participated in at least one of three workshops that were held. The involvement of the Youth Advisory Group involved providing input and feedback on the research methods and findings of the study. Within the first meeting of the group, the adolescent advisors provided feedback on the data collection methods of the qualitative phase of this study. Within the second workshop adolescents provided feedback and suggestions for the methods of the quantitative phase. The adolescent advisors also provided feedback on the emergent findings of the qualitative phase. The final workshop centred on discussions and activities surrounding how to disseminate findings and the potential implications of the present study.

3.6 Conclusion

This chapter presented an overview of the methodology employed in the present mixed methods study. The detailed methods used within the qualitative and quantitative phases of the study will be described in Chapter 4 and Chapter 7.

Chapter 4: Phase One: Background and Qualitative Method

4.1 Introduction

Self-management theories highlight the key role of the family in managing a chronic condition such as T1D (Grey et al., 2015; Modi et al., 2012; Ryan & Sawin, 2009). This is especially true in the case of children and adolescents who are living with T1D and rely on parents for assistance with carrying out self-management tasks. The trajectory towards becoming independent in self-management is influenced by a myriad of individual, family and clinical factors including adolescent developmental stage, age, clinical characteristics learning ability and how the family relates to one another (Ryan & Sawin, 2009).

The far-reaching impacts of T1D management and assuming ownership of the management of T1D on multiple facets of the adolescent's life have also been delineated within the literature, with reference made to the impact of T1D management on QOL and short-term and long-term health in adolescence (Hanna & Decker, 2010; Hilliard, Holmes, et al., 2013; Hilliard, Mann, et al., 2013). Specific precursors to assuming more responsibility such as possession of appropriate knowledge to carry out self-management and the ability to take ownership of mistakes in self-management are crucial components of self-management of T1D in adolescence (Strand et al., 2019).

The experience of shared management and transfer of responsibility as it relates to gaining independence in managing a long-term condition in childhood and adolescence is poorly understood (Gardener et al., 2020; Nightingale et al., 2019). Qualitative research conducted with adolescents living with T1D indicates that transferring responsibilities for T1D management in adolescence can be characterised by increased conflict between parents and adolescents in relation to T1D management (Babler & Strickland, 2015a; Chao et al., 2016; Serlachius et al., 2012). Conversely, positive aspects of parental involvement are also described with adolescents referring to their parent’s role in reminding and educating them on aspects related to T1D (Chilton & Pires-Yfantouda, 2015; Strand et al., 2019). While parent-adolescent interactions surrounding management are regularly referred to, there is an absence of qualitative inquiries which specifically seek to probe the content and context of parent-adolescent communication surrounding T1D self-management during adolescence and the negotiation of responsibilities for self-management of T1D. Moreover, this has not been qualitatively explored from the perspectives of adolescents.

Furthermore, whilst there is some quantitative research that has examined the association between ineffective communication characterised by parent-adolescent disagreement and T1D outcomes including metabolic control and QOL (Law et al., 2013), there is no research that sets out to disentangle the perspectives of adolescents on self-management of T1D and negotiating responsibilities for self-management of T1D with their parents and the wider implications of this on adolescent life. The aim of this phase of the mixed methods study was to explore adolescent experiences of self-management, negotiating responsibilities for self-management with parents and the impact of self-management on daily adolescent life from the perspectives of adolescents living with T1D.

The objectives of this phase were to:

- Explore the process of sharing self-management responsibilities for T1D with parents, from the perspectives of adolescents
- Understand the context and content of parent-adolescent communication about self-management and shared self-management responsibilities from the perspectives of adolescents

- Identify enablers and challenges to assuming self-management responsibilities for T1D for adolescents living with T1D
- Explore consequences of sharing and shifting responsibilities for self-management for adolescents living with T1D
- Inform constructs related to parent-adolescent communication and self-management that warrant follow up quantitatively in phase two

4.2 Qualitative Phase Design

This phase utilised a qualitative exploratory design. Semi-structured interviews were conducted with adolescents (aged 11-17 years) living with TID to explore their experiences of self-management and communication with their parents in relation to self-management responsibilities.

4.3 Phase One Sample

Eligible participants were adolescents living with T1D who met pre-defined selection criteria.

4.3.1 Inclusion and exclusion criteria

The inclusion criteria for phase one of this mixed methods study were as follows:

- Adolescents aged between 11 years and 17 years at the time of interview
- Adolescents diagnosed with T1D for 6 months or longer

The age range of 11 to 17 years was selected as this is reflective of the timing during which patterns of self-management change from parent-dominant to adolescent dominant. Transitional patterns of self-management of T1D are observed in early (11 to 15 years) and mid-adolescence (15 to 17 years) (Schilling et al., 2006). Prior to this management is primarily parent-dominant and by late-adolescence management is adolescent–led. Parents may handover responsibilities for aspects of management while adolescents simultaneously seek increasing independence and responsibilities T1D management (Carroll & Marrero, 2006). However, during this time increased conflict relating to T1D management can occur between parents and adolescents (Babler & Strickland, 2016; Karlsson et al., 2008; Kyngas & Barlow, 1995; Serlachius et al., 2012).

Diagnosis of longer than six months was to ensure that the adolescent had adequate time to engage with and experience management of T1D and adequate time had passed for some discussion about T1D self-management to have been established between adolescents and their parents.

The exclusion criteria were:

- Adolescents presenting with an intellectual disability or developmental delay
- Adolescents presenting with any significant medical condition in addition to T1D

The exclusion criteria were chosen to minimise the possibility of findings being influenced by factors such as the presence of additional concerns that are not a result of or related to T1D management.

4.4 Recruitment

Participants were recruited via the Diabetes and Endocrine Unit at Children's Health Ireland at Temple Street (CHI at TS), formerly Temple Street Children's University Hospital (TSCUH) (*n* = 21) and via an adolescent diabetes clinic at Mater Misericordiae University Hospital (MMUH) (*n* = 3) by poster advertisement (see Appendix F). Additional participants were recruited through the national advocacy organisation, Diabetes Ireland (*n* = 4).

4.4.1 Recruitment Route 1: Diabetes and Endocrine Unit at TSCUH and Adolescent Diabetes Clinic at MMUH

Parents and adolescents attending outpatient clinic appointments at TSCUH and MMUH were approached by the researcher and informed verbally about the study and given a poster containing written information about the study. The researcher then returned to the parent and adolescent, once both had read through and considered the materials provided and answered any queries the parent or adolescent had in relation to participation in the research. If families were interested in the study, parents provided contact details and were followed up with at a later date to discuss forwarding study materials (information sheets, assent/consent forms) and to schedule an interview with the adolescent. Some families who provided contact details opted out of participating in interviews when contacted to schedule an interview but agreed that their contact details could be used in relation to recruitment for phase two. Other reasons for non-participation in interviews included not meeting the inclusion criteria of greater than 6 months since diagnosis.

4.4.2 Recruitment Route 2: Diabetes Ireland

Additional participants recruited through Diabetes Ireland volunteered to participate in semi-structured interviews by responding to an open advertisement on Diabetes Ireland's website and social media (See Appendix F). Parents contacted the researcher via telephone or email to express interest in participating. If families wished to participate, information packs including study information sheets and informed consent/assent forms were sent via post or email. Parents of eligible and interested adolescents were then followed up with at a later date, and if adolescents still wished to take part, an interview was arranged at their preferred time and location by the parent on the behalf of the adolescent.

4.5 Participant Profile

A total of 28 adolescents with TID participated in the qualitative phase, ranging in age from 11 to 17 years (mean = 14.07 years; *SD* = 1.76). A more detailed profile of participants is presented in Appendix M. Ten participants were aged 11 to 13 years, twelve were aged 14 to 15 years and six were aged 16 to 17 years. 50% of participants were female (*n* = 14). Participants recruited for semi-structured interviews were from seven counties across Ireland (see Figure 4.1 for geographic distribution of participants and for the number of participants recruited per county).

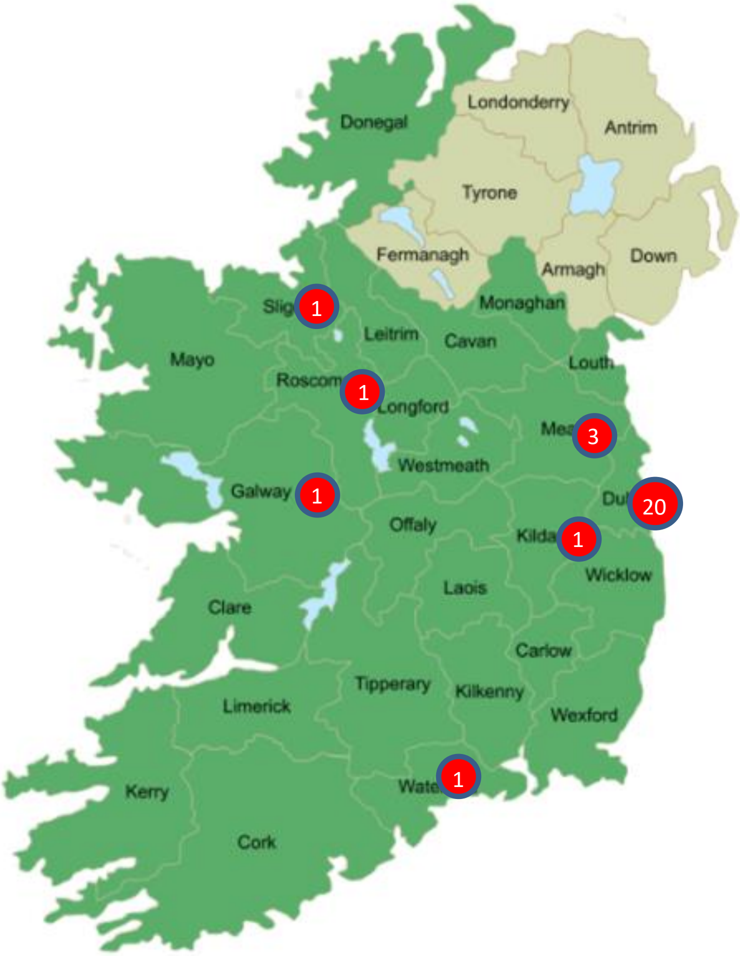


Figure 4.1. Geographic distribution of interview participants

Eighteen percent of participants were attending primary school and 82% were attending secondary school, at the time of interview. School years ranged from fifth class in primary school to fifth year in secondary school. Adolescent age at diagnosis ranged from 1.5 years to 15 years (mean = 7.97 years; SD = 3.74). Participant's HbA1c ranged from 6.5 to 10% (mean = 7.87%, SD = 0.89; *n* = 27). The most frequent method of blood glucose monitoring (BGM) was the finger prick method (*n* = 19), while nine interview participants used a semi-continuous device such as the FreeStyle Libre to monitor blood glucose levels. Nineteen interview participants used an insulin pump to administer insulin and the remainder of participants relied on multiple daily injections (MDI). Data describing T1D management characteristics of participants are presented in Table 4.1 below.

Table 4.1

Interview participant characteristics

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

4.6 Data Collection

Semi-structured interviews were conducted with 28 adolescents living with T1D. Adolescents also completed a brief demographic questionnaire prior to the commencement of the interview (see Appendix K).

4.6.1 Interview guide

Interviews were guided by a topic guide developed through consideration of the study aims and objectives (see Appendix L for topic guide). The interview guide was developed to elicit information on diagnosis, living with T1D every day, self-management roles and responsibilities, sharing self-management with parents, communication about self-management, barriers and facilitators to management and the psychosocial impacts of self-management and sharing self-management with parents on the adolescent. Seven key questions addressed these areas, with additional prompts also asked as needed. The interview schedule was piloted with one participant and no changes were made to the schedule based on this pilot. However, the pilot interview provided an opportunity for the researcher to reflect on interviewing techniques employed such as building rapport and effective use of questioning to elicit information.

4.6.2 Interview procedures

Interviews were conducted at a time and location convenient for the participant. Most participants were interviewed at their home (*n* = 15). The remainder of interviews were carried out in a room in the university (*n* = 13). All participants chose to be interviewed alone, without their parent(s) present. Interviews were electronically recorded with adolescents' permission. Interview duration ranged from 28 minutes to 1 hour and 7 minutes. Interviews carried out with younger adolescents tended to be shorter. More probing questions were asked in the interviews with younger adolescents also as answers were frequently short and not in-depth especially in relation to questions pertaining to communication with parents about T1D self-management and sharing responsibilities with parents. Strategies used with adolescents during the interview process were in part informed by the advice of the youth advisory group described in Chapter 3, section 3.7.

4.7 Ethical Considerations

Ethical approval was obtained from the research ethics committees at Dublin City University (DCU), Temple Street Children's University Hospital (TSCUH) and the Mater Misericordiae University Hospital (MMUH) (See Appendix J). Ethical considerations in this study were guided by the core ethical principles and concepts outlined in the 'Guidance for developing ethical research projects involving children' document (Department of Children and Youth Affairs Working Group on Ethics, 2012). The ethical considerations were guided by the United Nations Convention on the Rights of the Child (United Nations, 1989), the Data Protection Acts (1988, 2003) and the Children First: National Guidance for the Protection and Welfare of Children (Department of Children and Youth Affairs, 2017). Prospective participants in the semi-structured interviews, and their parents, were informed that while the findings may not be of direct benefit to them, other adolescents living with T1D may benefit from the findings in the future.

4.7.1 Minimising risk of harm

Protocols were developed to outline the actions that would be taken should (1) an adolescent become distressed during data collection and (2) an adolescent become unwell including signs of hypo/hyperglycaemic episode (See Appendix G). At the beginning of, and during each semi-structured interview adolescents were advised that they could pause the interview or withdraw from the interview at any time if they wished or needed to do so.

4.7.2 Informed consent and assent

Written informed consent and written informed assent was obtained from parents and adolescents respectively, prior to interviews. Written informed consent was obtained from parents for their adolescent children's participation in the research (see Appendix H). Adolescents were provided with age appropriate information sheets outlining the nature of the study (see Appendix H1-H3). As adolescent participants were aged 17 and under, assent was sought via age-appropriate assent forms (See Appendix I1-I3). Two adolescents living with T1D (not participants in the research) aged 11 years and 15 years reported on the readability of the study information sheet and assent form. Adolescents were encouraged to read through the study information provided with their parents. If an adolescent chose to withdraw their participation at any stage, the interview would be ceased regardless of whether parental consent was still present.

4.7.3 Confidentiality and anonymity

Confidentiality was afforded to participants by inviting the young person to interview on their own at a venue chosen by the adolescent and their parent(s). Parents and adolescents were informed that confidentiality could not be guaranteed in the event of the disclosure of a child protection issue (see 4.7.4 below). Adolescents and parents were assured that their identity and involvement in the research would not be revealed to anyone outside of the research team. Anonymity was also assured through the anonymising of interview transcripts through the removal of any identifiable data.

4.7.4 Child protection and wellbeing

In order to ensure the protection of adolescents and their wellbeing, the researcher was Garda vetted prior to the commencement of recruitment. The researcher also completed the Children First E-Learning Programme which covers identifying and reporting concerns relating to child welfare (Department of Children and Youth Affairs, 2017). At the outset of the study, it was stressed to adolescents and their parents that confidentiality could not be guaranteed in the event of a child protection issue being disclosed. Adolescents and parents were informed that should an adolescent disclose information suggesting that they or another child were at risk, the researcher was obliged to ensure the welfare of the child was protected in accordance with the Children First: National Guidance for the Protection and Welfare of Children (Department of Children and Youth Affairs, 2017). A protocol outlining the actions to be taken in the event of a child protection or child welfare issue being raised is available in Appendix G.

Adolescents were given the choice of having their parent(s) present as they completed the interview. The parent of the adolescent was present in a nearby room where interviews were conducted in participants' homes. Where interviews were conducted in the university, parents remained in the same building as the adolescent in a room adjacent to or nearby to the room where the adolescent interview was conducted. Interviews at the university were conducted in university classrooms located adjacent to busy hallways. Adolescents were reminded that they could pause or withdraw their participation in the research study at any point during the interview.

4.8 Data Analysis

The audio-recorded interview data was transcribed verbatim and transcripts were read and checked for accuracy. Data were analysed using thematic analysis, following the framework outlined by Braun and Clarke (2006, 2019). This approach to analysis seeks to identify themes or patterns within the data. Data management was aided by NVivo qualitative data management software (Q S R International Pty Ltd., 2015).

The first phase of thematic analysis involved the researcher listening to the audio file and checking each transcript against the corresponding audio file for accuracy. Subsequent to this, each transcript was read/re-read before each transcript was imported into the qualitative data management software. During the reading of transcripts, repeated reading and initial noting of points and patterns within the data relating to the objectives within interviews aided familiarisation with the data. The second phase involved the generation of initial codes by systematically applying at least one code to each line of the transcript. This process was applied across the entire dataset. An example of a coded interview extract is presented in Appendix N. Next, all codes were collated, and the analysis became focused on organising codes into themes or organising structures. These were developed following the consideration of the relationships that exist between each code. Once themes had been identified these were reviewed by the research team. Themes were then named and defined. The final stage of the process resulted in the production of a written report where the researcher presents the findings and analysis using extracts. The research questions were addressed and pre-existing literature on the topic area is referred to. An overview of the stages and process involved in thematic analysis as described by Braun and Clarke (2006) is presented in Table 4.2.

Table 4.2

Analytic process

Phases of thematic analysis (Braun & Clarke, 2006)	Description	Application in NVivo	Objective of analytic process
Familiarising with data	Verbatim transcription and re-reading of transcripts	Data management	Descriptive accounts
Generating initial codes	Applying codes to interesting data excerpts	Open coding	
Searching for themes	Collating and categorising codes into potential or candidate themes	Maintaining analytic memos, using ‘annotate’ function on transcripts to record descriptive accounts	↓
Reviewing themes	Checking if themes work across each coded excerpt and across the entire dataset	Reviewing of emergent themes using ‘map’ function on NVivo	
Defining and naming themes	Refining, naming and developing definitions of themes	Development of more detailed analytic memos	
Producing a report	Producing a report of the analysis, comparing findings to the initial research objectives	Generating themes and concepts in a final report	Interpretation

4.9 Conclusion

This chapter outlined the qualitative method employed for phase one of this mixed methods study. The next chapter will present the findings from phase one.

Chapter 5: Phase One: Qualitative Findings

5.1 Introduction

This chapter outlines Phase 1 findings from the qualitative analysis of the semi-structured interviews carried out with adolescents aged between 11 and 17 years and living with T1D for six months or longer. Interviews sought to explore adolescent experiences of self-management, negotiating responsibilities for self-management with parents and the impact of self-management on daily adolescent life. The overarching theme developed is Navigating increasing responsibility for self-management during adolescence: “it changed gradually… and I am almost fully doing it [self-managing] now”. An overview of the themes and subthemes generated is presented in Table 5.1.

Table 5.1

Overview of overarching theme, themes and subthemes

Overarching theme: Navigating increasing responsibility for self-management during adolescence: “it changed gradually… and I am almost fully doing it [self-managing] now”

Themes	Subthemes
(1) Changing levels of involvement in self-management: “I take more responsibility for [this] and … my mum would do that usually”	(1) Division of responsibility for self-management within the family
	(2) Collaborating and sharing responsibilities with parents for self-management
(2) Talking about self-management with parents: “I am not just like sitting in on the conversation… I am putting in my own ideas about what to think, what to do”	(1) Change in patterns of parent-adolescent communication about T1D over time
	(2) Seeking parental feedback and advice
	(3) Promoting self-management communication between adolescents and parents
(3) Taking ownership of self-management: “It’s my responsibility”	(1) T1D and self-management becomes a “part of daily life”
	(2) Learning about self-management and understanding T1D
	(3) Gaining confidence and mastery in self-management
	(4) Catalysts or prompts to assuming more management
(4) Environmental and contextual influences affecting self-management: “Even though I know what to do, it’s just that support really helps”	(1) Setting and/or devices can influence engaging with self-management
	(2) Family involvement in self-management
	(3) Involving friends and peers in self-management
	(4) Collaborating with HCPs while gaining independence in self-management

5.2 Navigating increasing responsibility for self-management during adolescence: "it changed gradually… and I am almost fully doing it [self-managing] now"

This overarching theme describes how adolescents experience moving towards increased independence in self-management of T1D and the various features and contexts that contribute to this. It describes how responsibilities for self-management of T1D are shared between adolescents and their parents, and the changes in where these responsibilities for managing T1D lie. Adolescents relayed how patterns of management change gradually, with this change characterised by increasing collaboration with parents to achieve self-management. This overarching theme describes how adolescents engage in shared management with their parents as they work towards goals of more independent management. The accounts of adolescents indicated that how they and their parents relate and communicate with one another is implicated in adolescent experiences in moving towards more independently managing T1D. Adolescents gradually take ownership of their responsibilities for self-management, while learning to live with and integrate self-management into their daily lives and through gaining confidence in their self-management. Taking on increased responsibilities was facilitated or supported by the setting in which self-management was carried out in, the presence of support or involvement of others and contextual factors such as approaches to treatment. The following themes were generated:

(1) Changing levels of involvement in self-management: "I take more responsibility for [this] and … my mum would do that usually"

(2) Talking about self-management with parents: "I am not just like sitting in on the conversation… I am putting in my own ideas about what to think, what to do"

(3) Taking ownership of self-management: "It's my responsibility"

(4) Environmental and contextual influences affecting self-management: "Even though I know what to do, it's just that support really helps"

5.2.1 Changing levels of involvement in self-management: "I take more responsibility for [this] and … my mum would do that usually"

This theme encompasses the change in responsibility for carrying out management that occurs during adolescence. Adolescents outlined how responsibilities for management of T1D were divided between them and their parents. Instances where either adolescents or parents took the lead with management tasks and where carrying out management tasks was shared between adolescents and parents were illustrated. It describes how adolescents experience division and delegation of self-management tasks between them and their parents, and their experiences of parents delegating T1D tasks within the family unit. Furthermore, it describes how adolescents gradually take over management of T1D from their parents through increased collaboration and sharing responsibilities with parents for completion of T1D care. The following two subthemes were identified to reflect the above: (1) Division of responsibility for self-management within the family and (2) Collaborating and sharing responsibilities with parents for self-management.

5.2.1.1 Division of responsibility for self-management within the family. Adolescents described how responsibilities for management tasks were distributed between them and their parents and within their families. Within the family unit, parents assumed differing levels of responsibility for adolescent's management with some parents assuming a more active role in management. Adolescents highlighted that a change in the division of responsibility for self-management comes about over time and is reflected in the specific management tasks that adolescents complete and how much parental input is required.

Adolescents frequently described how one parent was relied on more for support and assistance with self-management relative to their other parent. The division of involvement between parents appeared to be dependent on which parent was at home most.

> *"I guess my mum because my dad worked more often. My mum wasn't working yet but like my dad would also help me with the numbers and everything and setting it up and helping me with all these charts and so he'd help me with this. So they both helped me a lot with it."* – P10, Male, 14 years, diagnosed age 6 years

The parent who attends hospital appointments was often described as being more involved in the adolescent's care or having more knowledge on management. For this reason, this parent was relied upon more frequently.

> *"And my mom would kind of like understand more if there was like, if I wasn't coming down more… Cause my mam goes to all the clinics with me."* – P01, Female, 13 years, diagnosed age 3 years

Adolescents described how parents delegated T1D management tasks to other family members such as siblings. Examples were provided of instances where siblings were instructed by parents to assist with T1D management by reminding adolescents and checking in with them.

> *"Not unless he [brother] has been instructed to do it but he is good, like he checks up on me and stuff and he helps me…. '[P04's name] you have to do your blood sugars, mum said you have to do that and make sure that you do this at that time'."* – P04, Female, 11 years, diagnosed age 5 years

Adolescents referred to how their parents were initially responsible for many of the tasks of self-management in the aftermath of their diagnosis and when they were younger. Over time, the division of responsibilities between adolescents and parents changed and adolescents became more responsible for tasks including, administering insulin, managing their insulin pump, keeping track of blood glucose levels and their medical supplies. Adolescents became less reliant on their parents for completing these tasks with their parent's involvement moving more to the background.

> *"…Well at the beginning they would, they would help me with my injections but now I pretty much do them myself so no I haven't really relied on them overly but I have always known they are there to help if I need it."* – P03, Male, 14 years, diagnosed age 11 years

Adolescent accounts of keeping track of their T1D medical supplies provided a discernible example of how division of responsibility for managing T1D is approached. Many adolescents mentioned that keeping track of T1D supplies was something parents still assumed full responsibility for, even in cases where adolescents had lived with T1D for a long time. For others, while parents may still be relied upon for collecting medications or supplies, the adolescent was now responsible for keeping track of supplies and informing their parents that they needed supplies, indicating how levels of involvement for managing supplies and equipment changes.

> *"Like my mum will still go to the pharmacy for me and get me all my stuff, which is really helpful, but sometimes I have to tell her now like when I am running out of things which whereas I wouldn't have really before."* – P25, Female, 17 years, diagnosed age 13 years

5.2.1.2 Collaborating and sharing responsibilities with parents for self-management. Shared and collaborative management was important in supporting adolescents while they experienced ongoing changing levels of parental involvement in care and navigated the move towards more independence in self-management of T1D.

Being responsible for T1D management could at times be considered challenging, and as a result it was necessary for adolescents to continue to collaborate with their parents, rather than self-manage independently at all times. As adolescents gained more responsibility, they also acknowledged that there were times when they needed to rely on parental assistance such as when they felt they needed a break from their self-management. In sharing responsibility with adolescents, parents supported adolescent's engagement with self-management tasks through stepping in and stepping back from T1D management as needed, use of reminders, providing and supporting learning opportunities, promoting healthy habits and trusting adolescents in their self-management.

Adolescents conveyed how they strive towards becoming more responsible for self-management however, assuming increased responsibilities was often influenced by the difficulty of the management task. In this case, continued parental involvement or a more gradual relinquishment of parental responsibilities was sometimes necessitated.

> *"But now since I have gotten older I have kind of taken more control over it but my mum still helps me like a lot, I don't know what I would do without her to be honest."* – P23, Female, 14 years, diagnosed age 6 years
>
> *"As I have gotten older I have kind of tried to manage it more but then it hasn't really worked out because there is a lot of working out with the carbs that I have had to eat so I nearly let the carbs and the working out of the insulin up to my parents and the doing my bloods in school and taking the injections is more down to me."* – P15, Female, 15 years, diagnosed age 11 years

While parents maintain a level of involvement and responsibilities are still shared, the bulk of responsibilities gradually transitioned to adolescents. Adolescents took over specific self-management tasks from parents. The following extract reflects stepping up and assuming more responsibility for all aspects of T1D management.

> *"Yeah because they used to do most of the work and now I have kind of I have kind of stepped up and ah-am doing a good bit of the work."* – P27, Male, age 14 years, diagnosed age 1 year

Additionally, adolescents, at times, found that the amount of independent responsibility they took on is not balanced with their capabilities at a particular time point. This resulted in the adolescent reverting to a reliance on their parents for T1D management.

> *"Like I thought I could just manage everything by myself, yeah like just check sugars, do corrections, do everything by myself. But then after a while things were starting to vary a bit so I just went back to my parents, and like not completely but I asked them to like again to help…"* – P27, Male, age 14 years, diagnosed age 1 year

Adolescents outlined how their parents collaborated with them on their T1D management by overseeing and allowing adolescents to complete management tasks such as calculating insulin doses, making decisions related to diet, approaching management of out of range blood glucose levels. This facilitated their gaining of independence in these tasks and ensured that they were supported in the transition to more independent management. Other ways of supporting adolescents included stepping in and relaying appropriate reminders as needed. In the following example, the adolescent describes how her parents supported her increasing independence in management by gradually allowing her to make decisions more independently.

> *"But they also give me a chance to think about it as well and they make sure that I have the right basals and everything."* – P04, Female, 11 years, diagnosed age 5 years

Parents were described as encouraging more independence in management by stepping back from involvement, only assisting with management when needed such as when the adolescent was unsure about an aspect of their T1D management. In this way, the adolescent was supported by their parents to carry out and learn to manage their T1D more independently.

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

Through sharing management with their parents, adolescents were supported and encouraged to engage with their management tasks. Examples of strategies employed by parents to support and motivate adolescents towards more independent management of T1D included reminding adolescents, temporarily taking over T1D management for adolescents or checking in with them. In such situations, parents stepped in, took over and completed management tasks when adolescents felt overwhelmed by self-management.

> *"Ehm they would be there like to support me if I don't want to do it anymore or just don't feel like doing it. They would help me if I am like that and then they might, if I feel like that they might help a bit more and they would remind me to test often and am my dad would do the insulin and my mam would do the diary, so just to keep me on top of it."* – P24, Female, age 15 years, diagnosed age 11 years
>
> *"And she just makes sure that I am injecting for the right amount and I'm doing my bloods or to make sure I do my bloods again after I have a low."* – P06, Male, age 15 years, diagnosed age 11 years

Adolescents stated that it was important that checking in occurred at appropriate times in order to support their engagement with their management. While checking in could be considered intrusive, there were also times where it was deemed necessary, as adolescents would have forgotten to carry out the task if their parents had not reminded them. Adolescent awareness of this contributed to the realisation that reminders served the important function of supporting their engagement with management.

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

When reminders were considered excessive or not warranted, they were likened to nagging. Nagging could result in conflict with parents or adolescent frustration.

> *"Ehm most of the time it is annoying because my mam will be asking me to check all the time and I will say, 'okay I will do it now.'..."* – P24, Female, 15 years, diagnosed age 11 years
>
> *"... I know that it is helpful and it is for my own good but it does get kind of tiring, especially if I have done it and she is saying, 'did you check your bloods?' 'Yeah like I know how to do it.' So sometimes you would wish that she would get off your back, but like sometimes you do need the nagging so it does help."* – P16, Female, 14 years, diagnosed age 5 years

Becoming more responsible for self-management was often facilitated by adolescent perceptions of parents as knowledgeable and willing to learn about T1D management together with the adolescent. Adolescents were supported in becoming more independent by learning alongside their parents.

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

Adolescents described how their parent's attendance at clinic appointments and the contribution of their parents to the clinic appointment supported their learning. For example, at hospital appointments adolescents outlined how parents ensure that all T1D queries are addressed within the consultation, ensuring that adolescents and their parents are best placed to understand and manage T1D.

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

Another example of how parental involvement and collaboration supported adolescents in managing their health was through encouraging adolescents to make healthy choices in relation to T1D and overall health. Adolescents acknowledged the importance of the continued involvement of their parents in supporting them to engage in positive health behaviours and thereby aiding their engagement with their T1D self-management behaviours.

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

Adolescents mentioned the importance of the presence of trust between adolescents and parents, when sharing responsibilities and taking on more responsibilities for management. It was particularly important that the adolescents felt trusted by their parents to self-manage. The presence of trust supported adolescents in maintaining their motivation to meet blood glucose targets or during times when managing T1D was considered difficult.

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

5.2.2 Talking about self-management with parents: "I am not just like sitting in on the conversation… I am putting in my own ideas about what to think, what to do"

In this theme, adolescents indicated that parent-adolescent interactions relating to T1D and the management of T1D changed overtime. Navigating increasing independence in management was reflected in how adolescents experienced interacting with their parents about T1D management. Furthermore, experiences of communicating with parents provided insight into how adolescents became more responsible for their self-management. The ways in which conversations changed over time, as adolescents became more familiar with T1D through having lived with T1D for longer were described. Adolescents outlined how parent-adolescent interactions supported them to become more active in their self-management. The various ways parents and adolescents related to each other such as through reassuring, supporting and teaching as adolescents carried out self-management were identified by adolescents within interviews. What can contribute to more positive parent-adolescent communication around self-management was also described. Finally, some of the ways discussing T1D management with parents can pose difficulties were illustrated. The following subthemes were identified to reflect the above: (1) Change in patterns of parent-adolescent communication about T1D over time, (2) Seeking parental feedback and advice and (3) Promoting self-management communication between adolescents and parents.

5.2.2.1 Change in patterns of parent-adolescent communication about T1D over time. Over time, patterns of communication about T1D management between adolescents and their parents changed. These changing patterns reflected the change in parent-adolescent division of responsibility for management that occurred during adolescence. The evolving nature of how T1D is discussed was illustrated through accounts of changes in the terminology used and the approach of parents and adolescents to conversations including how regularly adolescents reported discussing T1D with their parents. Changes to conversation characteristics over time were attributed to getting older, gaining proficiency in self-management and increased understanding of T1D.

Over time, the frequency of parent-adolescent conversations held about T1D reduced. For example, as adolescents became more knowledgeable, they mentioned communicating and consulting with parents less.

> *"I used to ask them about a lot more things and now I know like a lot more of the stuff so I don't have to ask them as much."* – P08, Male, 12 years, diagnosed age 5 years

Similarly, as time passes, adolescents described reserving discussions about T1D and consulting with parents for times when they were experiencing an issue with their management. Previously, adolescents would have needed to discuss smaller issues relating to T1D with their parents.

> *"I only if it is a serious low blood sugar, like if I am in the 2s, which I am rarely that, or if I am really, really high and we tell each other I talk to them about it, and if it is a once off time but if it is coming up every time we just talk to each other about it. But it's it has changed greatly. We only need to tell each other the big the big problems not as well as every single detail like at the start because we were all babies basically."* – P26, Female, 15 years, diagnosed age 12 years

Adolescents described how parents began to change their approach to communicating with them. Adolescents reported that in comparison to when they were younger, their parents held them more accountable for their management. For example, parents were described as less forgiving of adolescent mismanagement of T1D.

> *"…They would say to take your bloods at little break if my bloods have been kind of low or high and if I haven't had a chance to take them at little break they say, 'well you should have.' Where if I was younger they would say, 'okay you know just do it tomorrow.' So it has kind of gotten, because they know as I get older I will become more kind of like relaxed about it so they want to keep me on top of it."* – P15, Female, 15 years, diagnosed age 11 years

The type of language used when talking about T1D was described as changing over time. Adolescents described how they became more familiar and comfortable with the use of technical T1D–related terminology. This familiarity facilitated more effective communication as both adolescents and parents were more familiar with T1D.

> *"I would say that they explain more to me now about like basal rates and stuff like that. When I was younger, I wouldn't have known what that meant but now I understand everything"* – P16, Female, 14 years, diagnosed age 5 years
>
> *"Cause at the start I was like using like different words. I didn't really know how to explain it and then now that we have learnt more words about the diabetes and we have all copped on to what they mean we just sort of use them to like explain it."* – P13, Female, 12 years, diagnosed age 8 years

5.2.2.2 Seeking parental feedback and advice. Within this subtheme, adolescents stated reasons for parent-adolescent conversations around T1D and management of T1D, outlining what prompted these conversations. Frequently, parent-adolescent conversations revolved around seeking or receiving parental feedback on their performance of self-management activities or tasks. Adolescents also consulted with parents for advice on reaching decisions, to check in with them about T1D management or seek advice on T1D-related topics that they were interested in.

In terms of prompts for parent-adolescent conversations around management of T1D, communication often involved informing parents about blood glucose readings. These conversations presented an opportunity for adolescents and their parents to discuss how the adolescent should approach their T1D management. As adolescents got older, they became more responsible for the tasks of self-management. However, parents continued to be involved, with adolescents keeping parents informed or parents seeking information from the adolescent. Some adolescents mentioned that there was an expectation between them and their parents, that they would keep their parents regularly informed about their blood glucose readings. This was often expressed alongside the knowledge that when parents were informed, they stepped in or assisted with T1D management when needed.

"… So I might have got a bit worried that I had to check my blood sugars and give insulin myself but like I usually am having to ring my mam and make sure I was like doing the right stuff." – P11, Male, 16 years, diagnosed age 15 years, diagnosed age 15 years

"… so I usually just ring my mam and she knows when I'm going to ring so she always has her phone with her and I ring my mam and tell her like 'I'm this level, I'm going to take this much, is that okay?' And she will be like, 'yeah'." – P13, Female, 12 years, diagnosed age 8 years

Needing to check with parents about an aspect of management served as a prompt for discussions about self-management. Below the adolescent checks with the parent to see how they should approach managing high blood glucose.

"…if I am high I just kind of need to ask my mum if I'm like should I do the injection but then I can do that by myself if I have to." – P07, Male, 11 years

, diagnosed age 4 years

When adolescents were away from home, they often needed to check in with a parent, to ask for advice such as in relation to the carbohydrate content of food. Knowing that they could check in with their parents enabled adolescents to spend time with friends away from home and contributed towards feeling independent.

"Yeah like yesterday I went with my cousins to bowling and I was texting my mam if I done a blood and what I bolused and stuff to make sure that everything was okay…" – P02, Female, 13 years, diagnosed age 9 years

Conversations with parents also provided opportunities for adolescents to receive feedback on their management especially for management tasks they were unsure of or were unable to carry out independently. In this way, conversations facilitated increased learning and independence in management.

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

Adolescents spoke about needing to talk to parents in order to seek reassurance or advice about T1D, for example, dispelling their specific worries or concerns related to management. Changing to insulin administration via an insulin pump is an example of a change to management regimen adolescents contended with.

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

Adolescents described reasons for not seeking advice from parents. Achieving control over management and blood glucose levels, often negated the need to consult with their parents, as illustrated in the following interview excerpts.

> *"Not really, I haven't asked questions often like so not really… Because like I didn't really need to know anything because I know most of the things about the pump already."* – P14, Male, 11 years, diagnosed age 3 years

> *"Yes, we don't really talk about it otherwise because I have it like fairly under control."* – P16, Female, 14 years, diagnosed age 5 years

Management and decisions relating to T1D care were often carried out by adolescents with input from their parents. Decisions relating to insulin dosage, carbohydrate content of food and device management were often shared between adolescents and their parents. Though adolescents might want to manage more independently, it was sometimes necessary to seek advice from parents on how to approach an aspect of management.

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

Adolescents indicated that conversations surrounding feedback on their management performance were also frequently driven by their parents. Parents were described as initiating conversations about how the adolescent was managing their T1D, while the adolescent might reserve discussions for seeking advice on T1D topics of interest to them.

> *"Am normally mum, she would be like, 'P23's name where is your blood test book? Have you written it up? Let's look back and see.' It would be mostly like driven by her."* – P23, Female, 14 years, diagnosed age 6 years
>
> *"If I had a question or if I wanted to know about something. You know like when I was quite interested in getting the pump, like I wouldn't always talk about that I wouldn't always start the conversation but a lot of the time I would because it was something I wanted. You know."* P25, female, 17 years, diagnosed age 13 years

5.2.2.3 Promoting self-management communication between parents and adolescents. Adolescents described encountering challenging aspects of talking about T1D self-management with parents. Adolescents reported experiences of conversations that were difficult or situations where conversations with parents about T1D management were avoided. In situations, such as when the adolescent anticipated a negative interaction following a disclosure, this inhibited communication from occurring. Similarly, adolescents highlighted that parents also, at times, avoided conversations about T1D to evade negative interactions with them. Conversely, adolescents outlined how positive discussion of self-management with parents was fostered through the presence of openness, closeness and a shared understanding of perspectives within interactions. The presence of these features in interactions facilitated discussion about T1D management and enabled adolescents to assume increased independence in T1D management. Adolescents described that when conversations with parents were not considered difficult, such as when adolescents felt comfortable discussing self-management with a parent; this lent itself to more positive adolescent perceptions of communication around self-management. Having a good relationship with parents in general often corresponded with ease of communication related to T1D also. Closeness and openness in relationships fostered positive experiences of talking to parents about T1D management.

Regarding aspects of self-management that were difficult to talk about, blood glucose levels were identified as a challenging aspect of T1D management to discuss and as a result, the struggles of maintaining levels within target ranges was a difficult conversation topic. Adolescents mentioned that interactions about high blood glucose levels could elicit a negative reaction from parents.

> *"You feel nervous saying to my ma that my bloods are like that in case she starts giving out to me about it."* – P06, Male, 15 years, diagnosed age 11 years

Adolescents described how it was often more difficult to talk about T1D when experiencing a period of poorer blood glucose control or following an instance where they forgot to carry out a management task. Adolescents temporarily delayed interactions with a parent about T1D management until they were back to managing well.

> *"...I feel like it is more positive conversations than, more like 'yeah you did this well done.' Where the bad conversation is more like 'what have you done?' So*

> *it is when my bloods are good that I find it easier to talk to them."* – P15, Female, 15 years, diagnosed age 11 years
>
> *"I kind of find it easy all the time like I don't really unless I forgot to take my insulin, I would be a bit resistant to talk about it…."* – P23, Female, 14 years, diagnosed age 6 years

When adolescents felt that there was an absence of parental understanding for why they might be struggling with an aspect of management, this contributed to difficulties interacting with parents. Adolescents described feeling antagonised by parents when they felt parents did not fully understand the challenges of managing T1D and navigating other aspects of adolescent life.

> *"Not really, it is just like sometimes it is kind of if like say a school test or I was rushing that day and I didn't get time to check them at one of the lunches or I forgot to do a bolus, it is kind of it's frustrating when they are giving out and saying, 'why didn't you do this?' I don't think they really completely understand like what it is like to have to have, like every teenager's mind-set and have all those things on your mind plus an added stress."* - P16, Female, 14 years, diagnosed age 5 years

When adolescents perceived their parent's involvement as intrusive, this often posed a challenge to communicating effectively. Adolescents relayed how these intrusive interactions could lead to frustration and parent-adolescent conflict around management of T1D. However, adolescents often reconciled this with the knowledge that their parents were trying to help them, which could reduce adolescent frustration towards their parents.

> *"Especially my mam, like she would be a lot more probably a little bit more worried about me but it is good that she is concerned I am staying healthy…*

> *Yeah but like sometimes I'd be like, 'Stop at me', but like she is just trying to help out really… Because she wants to just make sure that I am keeping myself healthy."* – P11, Male, 16 years, diagnosed age 15 years

Adolescents expressed awareness that T1D caused parental worry or concern and led to their reluctance to initiate conversations. In the following example, the anticipation of causing parental concern acted as a barrier to discussing T1D and management of T1D with a parent.

> *"Maybe the way I am feeling. So like if I am feeling upset about it and really down about it I don't really want to like come down and start crying and saying I don't want this anymore because I don't really want to get them upset, because I have seen them upset before when I was first diagnosed and I just felt like it was my fault they were getting upset. So I try to keep all that, not to myself but like I try work it out myself.."* – P15, Female, 15 years, diagnosed age 11 years
>
> *"Sometimes it is just easier not to talk to your parents about it. You know because they'll worry less…"* - P25, Female, 17 years, diagnosed age 13 years

Finding the time to talk about T1D was often presented as a challenge to initiating conversations between adolescents and parents. As a result of other commitments (e.g. when adolescents were busy with activities after school), adolescents mentioned not communicating with their parents apart from short conversations in relation to blood sugar readings and confirming insulin doses.

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

Conversations considered ‘awkward’ by adolescents were also similarly avoided by adolescents. Adolescents described how communicating with a parent about their T1D management can be uncomfortable or embarrassing and this subsequently contributed to avoidance of conversation and reduced openness. Adolescents mentioned that they felt awkward and struggled to start conversations when management was not going well.

> *“…it might be a little awkward if we were talking about something like the injection or if my pump shuts down or something like that… Usually what I mean by awkward is it is usually hard to find stuff to say [to parents] because you are hoping that it won’t actually happen”* - P04, Female, 11 years, diagnosed age 5 years
>
> *“Usually if they bring it up, I kind of feel a bit awkward bringing it up, even though they are my parents I do feel awkward and embarrassed bringing it up. So if they bring it up I am fine, like I don’t get awful embarrassed talking about it, it is kind of how to bring it into a conversation so they know I don’t bring it up like they usually start the conversation.”* - P15, Female, 15 years, diagnosed age 11 years

The potential for interactions about blood glucose levels or mismanagement of T1D to cause conflict was highlighted. However, for some adolescents, this conflict served as a reminder of their parent’s concern for their wellbeing. As adolescents became more active and responsible for their T1D management, parental concerns about blood glucose levels remained.

> *“…I suppose just you are sort of you are afraid they are going to give out to you, but they don’t give out to you, they just want to know how you are doing*

> *just to make sure that you are all right..."* – P22, 16 years, diagnosed age 8 years
>
> *"...And she would always be like really worried about seeing if my blood sugars are okay, like even now she wants to know if they are like fine."* – P11, Male, 16 years, diagnosed age 15 years

Adolescents also recognised that their parents, at times chose not to ask the adolescent, as they were aware that checking in could be perceived as nagging or intrusive. This contributed to adolescent beliefs that their parent sometimes avoided talking about T1D.

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

In contrast to the parent-adolescent interactions described that inhibited communication, adolescents spoke about how positive interactions with parents were underlined with closeness between parties and a shared understanding of each other's perspectives. Perceived closeness with parents influenced whether adolescents considered their conversations about self-management to be positive.

> *"... We are just really, really close the three of us that I can actually talk to them about stuff. We are just really close and I think that's what helps it as well."* – P13, Female, 12 years, diagnosed age 8 years
>
> *"Yeah it is grand. My parents are both really easy to talk to, like I never hesitate talking to them about anything. Like it is grand. And especially because there is a lot not a lot but there is a bit of diabetes in my mum's family, she already understands a lot about it. My dad is supportive and they are easy to talk to and I wouldn't hesitate over asking them for help."* – P25, Female, 17 years, diagnosed age 10 years

Adolescents described how it was important that they felt understood by their parent. This enabled adolescents to discuss managing T1D and more specifically facilitated conversations about issues adolescents encounter with their T1D management.

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

Similarly, it was also important that both the adolescent and their parents agreed on expectations for completion of self-management tasks such as monitoring blood glucose levels. When this was ensured, positive shared management was fostered, making it easier for adolescents and parents to find solutions to issues with respect to T1D management.

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

The familiarity of parents also contributed to positive adolescent-parent interactions in relation to management of T1D. Seeking advice from parents was also considered easier than seeking advice from others such as HCPs. When adolescents felt that regular communication occurred within the family about T1D management, this lent itself to a family environment characterised by openness in communication.

> *"Everything is really easy to talk to them about."* – P18, Male, 15 years, diagnosed age 11 years

> *"...you can go to them first and it is easier nearly talking to your parents than talking to someone that you don't really know like a nurse or someone like that."* – P22, Male, 16 years, diagnosed age 8 years
>
> *"Talking to them a lot really, because I would talk to them often so that does make it easier that I am used to talking to them about it and they are used to me talking to them."* – P09, Male, 13 years, diagnosed age 1 year

5.2.3 Taking ownership of self-management: "It's my responsibility"

Adolescents increasingly took charge of self-management over the course of adolescence and became predominantly responsible for ensuring T1D was managed. Over time, adolescents began to see self-management as an integral part of their daily lives. The importance of being able to self-manage independently was recognised by adolescents. Indeed, the integration of self-management within daily life was evident as they moved towards completing self-management upon their own volition rather than because they were instructed by others or their parents. Furthermore, the feeling of being restricted attributable to the necessity of managing T1D dissipated over time for adolescents as they gradually learnt to live with T1D. An increased understanding and knowledge contributed to adolescents feeling capable of taking more ownership of their T1D management. Adolescents described intrinsic factors that motivated them to engage with self-management, including their perceived capabilities and confidence in their own ability to carry out self-management. In addition to being intrinsically motivated to assume more ownership over self-management, adolescents were also prompted to become more responsible by external prompts that they encountered within their life, such as moving to secondary school or wanting to spend a night away from home. The following subthemes were identified: to reflect the above (1) T1D and self-management becomes a "part of daily life", (2) Learning about self-management and understanding T1D, (3) Gaining confidence and mastery in self-management and (4) Catalysts or prompts to assuming more management.

5.2.3.1 T1D and self-management becomes a "part of daily life". This subtheme encompasses how adolescents continually adjusted and made adaptations to daily life in order to carry out T1D self-management. Adolescents described how T1D and its self-management had an impact on their day-to-day life and relayed the need to increasingly incorporate T1D as a part of their daily life through assuming increased ownership of their responsibilities for self-management. Adolescents provided examples of how they minimised the impact of management or how restrictive it was considered. This allowed for management of T1D to be integrated more seamlessly within their lives.

Adolescents described integrating self-management routines with their daily activities. Adolescents got used to various management activities such as administering insulin and living with T1D more generally. They learnt how to carry out self-management in different situations and contexts. Over time, adolescents became more comfortable with T1D management, illustrated through adolescents' references to "getting used" to T1D. This ensured that adolescents maintained their blood glucose readings within target ranges and ensured that T1D was not perceived to be overly intrusive to their lifestyle. Getting used to the requirements of living with T1D contributed to adolescent's positive engagement with management tasks such as frequent monitoring of blood glucose levels.

> *"Nothing's really changed that much but it is just I have got more used to it so I don't mind it as much."* – P07, Male, 12 years, diagnosed age 4 years

"It's just you get used to something like…Yeah… I think if I like sat down and like didn't take my numbers or something I'd kind of be wondering like what's going on." P01, Female, 13 years, diagnosed age 3 years

Adolescents also mentioned that getting used to T1D involved getting used to the management of physical symptoms and the consequences of engagement with management.

"Sometimes it is still sore, I thought I would have got used to it. But you do get used to it but it is sometimes still sore, but it is grand yeah." - P21, Male, 17 years, diagnosed age 14 years

The constant nature of managing T1D was frequently referred to. Adolescents relayed how T1D required continual engagement with management tasks and thinking about T1D.

"Am. It is a bit of a burden because you have to test regularly and it is kind of always on the back of your mind, ehm yeah it is not the best." – P24, Female, 15 years, diagnosed age 11 years

Making the time for self-management and ensuring that it was carried out reduced the impact of T1D on adolescent life. Maintaining blood glucose levels within target ranges enabled adolescents to participate fully in sports and activities, which they might otherwise not have been able to or permitted to do.

"The sports because usually during the summer I would be out all day doing sport, so I'd be doing like ten hours a day and I would have to make sure that my bloods wouldn't go low and I would have to have my dinner and it is kind of hard managing it with all the sport but then I don't want to let it get in the way of me loving sport." – P15, Female, 15 years, diagnosed age 11 years

> *"Am yeah sure yeah, like I am not going to be, like as I said if you are running high and you are not feeling the best, you're not going to get like you'd be playing sport, you are not going to get the best out of what you are doing because you are high the whole time and you are not enjoying it, you wouldn't be happy, you'd be in a bad mood sort of when you are high."* – P22, Male, 16 years, diagnosed age 8 years

Positive impacts of managing T1D well prompted adolescents to make changes to their lifestyle or to pay more attention to their overall health. These positive changes helped with the integration of T1D with daily life and taking ownership of T1D management. Through attending regular appointments with HCPs, adolescents felt that they had access to more health information and were more knowledgeable about their health than others. T1D sometimes prompted adolescents to take up exercise and some referred to the benefits of being active and the positive impacts of this for them in terms of overall health. This increased knowledge and improved physical health enabled successful integration of management with daily life.

> *"It has probably made me healthier because I have started training a lot more so I would be fitter so my exercise regime has gone up."* P02, Female, 13 years, diagnosed age 9 years
>
> *"And then my diet has been much healthier, I eat a lot less fast food because I don't know what is in it carbs wise. It has definitely helped and I also cook a lot more where I would never have cooked before. I find it easier to cook my own meals because I know exactly what is in it as well and that makes me feel comfortable."* P11, Male, 16 years, diagnosed age 15 years

Adolescents described how T1D influenced their experiences of activities. For example, their parents could be required to supervise or attend school trips. This then influenced how adolescents perceived their level of independence in T1D self-management.

> *"Well most of the time it doesn't really affect how you kind of live but then say for instance the Gaeltacht, my mum has to come up with me on that because say if like my site fails or anything, I can't do anything about that."* – P07, Male, 12 years, diagnosed age 4 years

Beliefs about how difficult management of T1D is gradually changed as adolescents learnt to increasingly integrate T1D management with their daily lives. Adolescents also mentioned the importance of hobbies and interests and not allowing T1D to interfere with these.

> *"My attitude towards it because I used to think it was the worst thing in the world, that I couldn't do anything. I was like, I couldn't do anything… I can't go out with my friends any more, I can't eat chocolate anymore but then as soon I started getting into it I was like, I can eat chocolate, I can go out with my friends, I can still do this"* – P13, Female, 12 years, diagnosed age 8 years

Adolescents described balancing conflicting feelings towards management. They overcame initial resistance and incorporated T1D and management of T1D as an integral part of their routine. Adolescents gradually became less overwhelmed by the demands of T1D. Adolescents referred to how living with T1D for many years meant T1D was now considered normal for them. For some, they could not remember their lives prior to their diagnosis.

> *"You just kind of like forget about it, you don't really realise, because it is just part of your day like, you just go about it and just do whatever you need to do."* – P21, Male, 17 years, diagnosed age 14 years

> *"Cause I had never done it before and then I'd have to do this monitoring four times a day and that was a big change so I found that really annoying but since I had been doing it for a few months it is totally like normal and I don't find like it annoying at all."* – P11, Male, 16 years, diagnosed age 15 years

Through living with T1D, adolescents became more knowledgeable and accepting of T1D and the specific requirements of T1D management.

> *"I had to be on a diet, eat certain foods, not eat certain foods and to learn about diabetes is just a lot of experience, you can't learn about diabetes if you don't have it. You can only learn about it from books and stuff but it is mostly life experience of it that you can really learn about diabetes."* – P17, Female, 15 years, diagnosed age 10 years

Over time, adolescents became more comfortable with T1D and its management. Adolescents described how living with T1D gradually became integral to their own identities. T1D became an additional aspect of the adolescent's life that must be managed and was not considered an inconvenience.

> *"Sometimes I do wish I hadn't got it but other times I think it is part of who you are so you wouldn't want to get rid of it"* – P04, Female, 11 years, diagnosed age 5 years

> *"... And that diabetes shouldn't own you, you should own diabetes, it shouldn't change the person you are or how you feel. You just kind of have to move on and just deal with it I guess."* – P23, Female, 14 years, diagnosed age 6 years

Over time, adolescents adjusted to their diagnosis. However, there were still times when adolescents experienced T1D as overwhelming and this influenced how difficult the adolescent considered engaging with management. Therefore, while adolescents mostly indicated that as time passes, T1D became more integrated with life, the experience of challenges often co-existed alongside this. These experiences of challenge were part of living with T1D.

> *"In the last couple of months it has been a bit more stressful and I am finding it a lot harder than when I was first diagnosed. But I think because I am getting older and I just don't want it at this stage."* – P15, Female, 15 years, diagnosed age 11 years

Living with T1D and having to complete T1D management at times contributed to adolescents feeling different to their peers. This posed a difficulty for taking ownership of their T1D through issues with the integration of self-management with their daily lives and routines. Adolescents living with T1D contended with constant management while their peers without T1D do not. Their awareness of differences between them and peers also heightened as they got older which made integrating T1D with daily life more difficult.

> *"…and then with my friends if I ever go out with my friends, I don't like to say I have to eat, I just suggest the idea so I kind of keep it subtle about the diabetes."* – P15, Female, 15 years, diagnosed age 11 years

> *"When I was younger I didn't really care, I just thought it was just something everyone around you dealt with, I didn't realise it was something that very few people- Like when I was growing up I knew one other girl in primary school, but then again she was so many years older than me it was kind of impossible, and that was the only and then she left so it was only me in the school. So there wasn't really anyone else around me…"* – P20, Female, 16 years, diagnosed age 5 years

> *"And at the end of the day I am really exhausted because I am just testing my bloods 24/7, taking insulin and doing things that other kids my age don't do so at the end I am really tired."* – P17, Female, 15 years, diagnosed age 10 years

5.2.3.2 Learning about self-management and understanding T1D.

Adolescents reported that taking on increased self-management responsibilities required that they learn about and understand T1D. Furthermore, learning about self-management also allowed adolescents to take ownership of their T1D and enabled them to maintain their health. Adolescents learnt to manage the medical aspects of T1D, how to carry out management in different settings and the risks of not managing their T1D. They also learnt about specific tasks of management i.e. managing food and maintaining blood glucose levels. Learning about self-management was a gradual process that occurred over time for adolescents as they increasingly found themselves managing more independently and away from home.

In terms of the specific daily self-management tasks that adolescents gained proficiency in, these included calculating insulin doses, carbohydrate counting, giving injections, learning how to use an insulin pump and managing in different situations. The engagement of adolescents with continued learning allowed them to take more control of their self-management.

> *"Am just again about the cannulas, the cartridges, you learn how to do it with time, you learn how to manage it with regards to sport, in regards to like being given more freedom, you learn how to take control of it a lot more yourself."* - P16, Female, 14 years, diagnosed age 5 years

Food management was also frequently referred to by adolescents as an important feature of the management tasks that were carried out. Adolescents described learning how to balance food with insulin requirements, plan meals and interpret carbohydrate content. Being familiar with the content of food allowed for more control over blood glucose levels.

> *"No it hasn't been too recent, I have kind of gotten used to how much to do for the stuff I have been eating."* – P09, Male, 13 years, diagnosed aged 1 year
>
> *"…What you do. How you eat. Or if you are eating- If you are eating very really high things and not bolusing enough it's a way of really high carbs. When you are over bolusing you can go low..."* – P10, Male, 14 years, diagnosed age 6 years

Adolescents also described becoming aware of the risk of not managing their T1D and experiencing long-term complications. Learning more about the impacts of not managing encouraged adolescents to engage with T1D self-management and minimise the risk of longer-term complications occurring.

> *"I read one of the booklets and my ma started telling me that if I don't look after it I could go blind or it gets worse and I'd get glasses… Yeah that sometimes makes you want to manage, I have to start pulling up my socks and start taking more responsibility."* -P06, Male, age 15 years, diagnosed age 11 years
>
> *"I felt like - Probably at the start I didn't really want to hear any of that because I wasn't used to it but like it was good that my ma made sure that I felt like responsible for myself, otherwise I could be like could end up really unhealthy like in the future."* - P11, Male, 16 years, diagnosed age 15 years

Indeed, through regular and repeated carrying out of daily tasks and activities of self-management and living with T1D, adolescents learnt to recognise symptoms of and how to manage and treat hypoglycaemia and hyperglycaemia when it occurs.

> *"So sometimes I would be asleep and I would feel low, so I have kind of picked up that if I am low during the night I would wake up and I can't get back to*

> *sleep or if I am low during the day that I would kind of have shaky legs or I would get very hot. Or if I am high I wouldn't be able to sit still and my legs would be shaking."* - P15, Female, age 15 years, diagnosed age 11 years
>
> *"And lows are a lot more just, not painful, but more tiring and the sort of not, really not wanting to feel that makes me want to make sure that everything is okay constantly because you don't want to feel like that again."* - P20, Female, 16 years, diagnosed age 5 years

Over time, adolescents described becoming more knowledgeable about their own blood glucose patterns and learning what approaches to managing their T1D work for them.

> *"Just like treating highs and lows and like sometimes depending on the time it might be like the wrong time to do a correction but I would do a correction and then I would go low, yeah."* – P19, Female, 15 years, diagnosed age 8 years
>
> *"Just doing the blood sugars and noticing if there's anything that's out of order or with the insulin, bolusing myself."* – P20, Female, 16 years, diagnosed age 5 years

Furthermore, by managing T1D when participating in activities, adolescents learnt to manage their T1D in different contexts. Adolescents described how various types of physical activity require a distinct approach, with some activities affecting their blood glucose levels differently. Learning to manage independently when participating in sports was an additional aspect of management with which adolescents gradually became familiar.

> *"No sport would be just the one now that I haven't sort of gotten my head around yet so you are still trial and error with it. Because you know every sport is different… That is why sport is so hard to get to know what to do."*- P22, Male, 16 years, diagnosed age 8 years

5.2.3.3 Gaining confidence and mastery in self-management. Feeling capable and confident in their T1D self-management was integral in encouraging and motivating adolescents to engage with and take ownership of self-management tasks. Adolescents described assuming an active role in their T1D management and seeking out more responsibilities for their management as they get older. Adolescents described becoming gradually more assured about their capabilities to independently manage their T1D and becoming more familiar with self-management tasks and with what works for them. Instances where adolescents did not believe they were capable of carrying out an aspect of their self-management and how this belief impacted on engagement with self-management were also illustrated. An absence of perceived competence and capability to manage T1D at times gave rise to feelings of frustration towards T1D.

Gaining mastery in self-management tasks and figuring out what works for them as individuals resulted in pride in adolescents' own management capabilities and increased their engagement with self-management behaviours. Where adolescents felt capable of carrying out a management task, they described carrying out the task independently of their parents.

> *"I will tell my parents if I can do the pump myself, I wouldn't be lazy letting them do it themselves when I can"* – P05, Male, 11 years, diagnosed age 9 years

Similarly, when adolescents did not believe they were capable of independently completing an aspect of self-management, this resulted in relying on a parent. For tasks adolescents did not yet feel fully competent or capable of carrying out, parental assistance was required in order to support them to develop competencies in those tasks.

> *"Well there are things like basals and stuff that I don't really know about so I can work my way around the pump on my own but they would tell me what to do and then I would do it."* – P04, Female, 11 years, diagnosed age 5 years

Furthermore, there seemed to be a multiplying effect of feeling competent and gaining mastery in that as competence increased, so too did mastery in self-management of T1D. On realising that their parent's assistance was not needed, adolescents described how they actively sought more responsibility or an increase in their existing responsibilities from their parents. Adolescents mentioned how over time their confidence and competence related to T1D increased. As they got older, adolescents reported feeling more capable and able to manage their T1D.

> *"They [parents] were on board with it [becoming more responsible for T1D management]. I said it before we went into the hospital, the next appointment that we had and they said it to the doctors and they said 'sure we'll give it a go and see what happens."* – P18, Male, 15 years, diagnosed age 11 years

> *"I am able to ask more questions about it. I've been able to tell them to kind of give me more advice that I can understand better now because I'm older. I guess taking the information in you couldn't really take it in because you were just- You were kind of young."* – P10, Male, 14 years, diagnosed age 6 years

Adolescents became more confident in completing management tasks over time. For example, some adolescents described the transition from being initially unsure about management using an insulin pump to gradually becoming more confident.

> *"I'm more in the hang of it. Like I know more how to use it and I'm not as cautious of it anymore because at the start I was afraid that I would give the wrong units but now I'm just way sure…"* – P13, Female, 12 years, diagnosed age 8 years

Adolescents described how improving their management skills over time was fundamental to feeling capable of successfully and independently completing self-management. When adolescents felt they understood and were familiar with their own body this led to enhanced feelings of management capabilities for adolescents.

> *"…I now know the way my body feels highs and feels lows, she doesn't have to check on me all the time…"*– P25, Female, 17 years, diagnosed age 13 years
>
> *"…I understand my body more obviously than other people do so my bloods have been better than ever…"* -P26, Female, 15 years, diagnosed age 12 years

Where the cause of outside of range blood glucose levels was attributed to something outside of the adolescent's control, adolescents felt relieved that they were not to blame. Being able to attribute the blame for mismanagement to something that they considered outside their control contributed to relief for the adolescent.

> *"Yeah, I was just like okay, thank God because I thought that I did something wrong and I was like, oh this can't be my fault. Like I don't remember doing anything wrong. So when we came to, it was definitely the line I was like, thank God."* – P13, Female, 12 years, diagnosed age 8 years

Some adolescents described not having mastery and not feeling in control over T1D as they were not getting desired management outcomes. Adolescents described feeling frustration towards T1D when management was forgotten about or where blood glucose readings were outside of the ranges that they would have hoped for or expected.

> *"I feel kind of disappointed that I have forgotten because I have had it for so long and I should be used to it."* - P02, Female, 13 years, diagnosed age 9 years
>
> *"If I give in and start eating during meals and my blood is high or not giving enough insulin and all, it is my fault, I can't turn around and say it was my ma's fault."* – P06, Male, age 15 years, diagnosed age 11 years
>
> *"It just- Or when you know you have been doing everything right but then you are high or you are really low and you don't understand what you have done*

wrong. That can be really frustrating." – P24, Female, 15 years, diagnosed age 11 years

Managing T1D well was acknowledged as being difficult. Keeping on track of management was acknowledged as deserving of pride and feelings of accomplishment.

> *"I think you just need to grit your teeth and completely just shove it out, you need to wear your pump when you can, just be proud, and especially if you try and keep your bloods in a tight range and you feel as if you can manage it, that is something to be proud of because it is a lot of hard work…"* – P26, Female, 15 years, diagnosed age 12 years

5.2.3.4 Catalysts or prompts to assuming more management. Catalysts or prompts to taking on more self-management responsibilities included moving from primary to secondary school, the transition from paediatric to adult care, or a change to the management regimen. A desire to spend more time away from home also prompted adolescents to take on more self-management responsibilities. These events or experiences often necessitated adolescents becoming more responsible for their self-management or encouraged them to take more ownership of their T1D management.

An impending transition to secondary school prompted adolescents and their parents to consider their current management capabilities. Reasons for this included the longer school day that required adolescents to carry out more management while away from home. Adolescents mentioned less support with management was available in secondary school, with some adolescents describing no longer having a special needs assistant. Secondary school teachers were described as treating adolescents as more mature, in comparison to primary school teachers. Secondary school also presented more opportunities to go on school trips and spend more time away from home, thereby prompting more independent self-management.

> *"Yeah the even without diabetes in primary school you are more minded, kind of the teachers are always there helping you and all the kids because you are younger and when you go to secondary school you are more independent and responsible for yourself. So like since I have been in secondary school I haven't been asked any questions about my diabetes by any teachers. Ehm I am sure they know I have it but unless I am unwell, and even at that they wouldn't really, because I am able to do it myself if I'm low or whatever I know how to deal with it."* – P24, Female, 15 years, diagnosed age 11 years
>
> *"Yes. Eh when I was smaller it was between me, my mam and my dad but as I was getting older because of all the needles and all the injection sites and stuff like that it was really only between me and my mam. And then over the past two years I have sort of taken more control over the insulin pump because when I was in primary school the teacher always had to confirm that what I was bolusing myself was the right amount, just in case I ate too much or too little. But now I am sort of in charge of the pump now."* – P20, Female, 16 years, diagnosed age 5 years

Some older adolescents described how the transition to an adult or adolescent diabetes service prompted changes in their self-management and encouraged them to continue moving towards independence in self-management. Examples of this included adolescents attending their clinic appointments alone, rather than with a parent. HCPs in adult or adolescent services were described as relating to the adolescent differently, in comparison to their paediatric consultations. This was reflected in HCPs considering adolescents to be more responsible. Moreover, topics discussed with HCPs advanced to topics more relevant to older adolescents such as alcohol or learning to drive.

> *"Cause I just I kind of went straight from being treated like a kid to being treated like someone that needs to know their business now. Where I am in now is the in between stage but they are still going from being like a kid to having to know your stuff really well." – P20, Female, 16 years, diagnosed age 5 years*

Aspiring to become independent of parents also served as a prompt for more adolescent-led self-management. Adolescents described their desire to spend more time away from home, such as to attend parties, sleepovers, school trips or no longer wishing to rely on a parent's assistance with their T1D management.

> *"… I kind of wanted to start changing them myself because I wanted to be able to like sleep over in friend's houses and you know gain a bit of independence."*
>
> – P16, Female, 14 years, diagnosed age 5 years

A change to insulin regimen, usually moving from MDI to an insulin pump, in conjunction with getting older was also relayed as a starting point for assuming more responsibilities for T1D management.

> *"So again when I first sort of had the pump that is when it started [becoming responsible], I suppose that's when I – I don't know what age I was when I got the pump but I was getting older so I had more responsibility."* – P22, Male, 16 years, diagnosed age 8 years

The impending transition into adulthood also encouraged adolescents to adopt the belief that self-management was now their responsibility.

> *"I think that diabetes is my responsibility now… I am 15, nearly 16, I am going into adulthood soon enough in a couple of years and I feel as if I need to take on board everything and that if I learn how to do it fully now that when I am an adult I can just flourish and it will just get better…"* – P26, Female, 15 years, diagnosed age 12 years

Conversely, not perceiving themselves as mature impeded adolescents from believing they could take on more responsibilities for their management.

> *"I would say they help me a lot because I feel like a like I haven't really matured like I still take it like a child, I still give out when I have to take my bloods and have the injection, I still feel it hasn't really become a part of my life yet, I am still trying to fight it off. I am thinking if I fight I won't have to do it. I still feel like a child in that sense."* – P15, Female, 15 years, diagnosed age 11 years

5.2.4 Environmental and contextual influences affecting self-management: "Even though I know what to do, it's just that support really helps"

In this theme adolescents described negotiating many different environments and contexts whilst living with and self-managing T1D. These different environments and contexts including family, school, social networks and the type of medical devices used, contributed to and influenced the ways in which adolescents engaged with self-management. Self-management was influenced by the involvement and reactions of others around the adolescent. Others such as the family unit, friends and HCPs supported adolescents to engage with self-management. Adolescents referred to how self-management occurs in the context of their family life. Family members exchanged knowledge that they had gained on T1D and supported adolescents in their management through assisting with specific management tasks. Adolescents felt supported in their engagement with self-management tasks with this type of family involvement. Adolescents spoke about choosing to talk to friends about management and about T1D in general. Talking to friends was a source of support, as adolescents can tell friends about their worries and concerns related to T1D and self-management of T1D. They also described relying on friends for support with carrying out T1D self-management tasks. Adolescents also identified the potential for HCPs to support them as they become more independent in their self-management. The following subthemes were identified to reflect the above: (1) Setting and/or devices can influence engaging with self-management, (2) Family involvement in self-management, (3) Involving friends and peers in self-management and (4) Collaborating with HCPs while gaining independence in self-management.

5.2.4.1 Setting and/or devices can influence engaging with self-management. The context of self-management which includes the setting management is carried out within and the specific medical devices that the adolescent uses and has access to, can facilitate carrying out self-management for adolescents. Self-management tasks can be less effortful depending on the management related devices used by the adolescent, for example if the devices facilitate discreet engagement with self-management or provided access to comprehensive information regarding blood glucose levels and patterns within these. Encountering difficulties with management often resulted in disengagement or temporary delay of self-management for adolescents. Settings that were supportive of the adolescent's self-management often contributed to environments where completing self-management was not considered difficult. For example, the routine and structure of school was often perceived as supporting the engagement of adolescents with self-management. Adolescents also mentioned encountering difficulties with carrying out management and times where they were prevented from carrying out self-management. These included when management was considered intrusive or when adolescents forgot to complete a self-management task. Some of the situations which gave rise to difficulties mentioned were school, social situations, snacking, or simply forgetting to manage.

Devices such as blood glucose monitors, insulin pumps and functions associated with these devices, for example comprehensive information on blood glucose levels made management less effortful. Adolescents described specific benefits of certain devices, which included allowing increased dietary flexibility, being more discrete, allowing for more frequent monitoring, and allowing them to become more familiar with their blood glucose readings and observe patterns.

> *"The FreeStyle Libre because it has the graph, what your blood sugar has been, whereas when you had the finger pricking you only had that precise moment whereas with the FreeStyle Libre it has a graph of how you have been the entire time and that has been a real help..."* – P20, Female, 16 years, diagnosed age 5 years

The discreteness of management devices facilitated engagement with self-management ensuring management was considered less effortful and completed more promptly. Some adolescents relayed that they chose to be open with others about their management while others chose to be discreet, and management devices allowed adolescents additional freedom in choosing how open they wished to be with others about their T1D management. For some adolescents, this discreetness enabled their engagement with self-management.

> *"If I was on the bus I wouldn't be too bad checking if it was with the Libre because it is kind of more, like people can't see it as much. In school checking is not that bad either no because again with the Libre it is quite confidential like. But if I had to check with blood people would be sometimes over asking."* – P09, Male, 13 years, diagnosed age 1 year

> *"Well it was hard when I had the other needles but now I have the scanner and the pump and it is way easier to manage."* – P05, Male, 11 years, diagnosed age 9 years

Like T1D management devices, the setting management was carried out within could facilitate or impede engagement with management. One of the most frequently described settings for adolescents was school. Some schools set aside a space for adolescents to check their blood glucose or to store their medical supplies. Additionally, some schools provided a staff member who assisted the adolescent with their management. Having teachers who were knowledgeable about T1D also contributed to a supportive environment for adolescents to engage with their self-management. These contexts were considered supportive of managing T1D by adolescents.

> *"At school normally at small break and big break we have lunch so they are kind of the only times I check my BM and take insulin with my food. Or during classes if I feel low or anything. And in school I have there is like an office, and the other girl with diabetes, she has like a box with Lucozade and so do I, so if we ever get low in school and we have run out of our own Lucozade there is spare ones there."* – P23, Female, 14 years, diagnosed age 6 years
>
> *Am like well I have three different SNAs, so I would have to check my sugars, fill in my book, eat and then do my bolus and then I can go and play in the yard... Like earlier on when I was younger they would have to do it all but like really now all they do is go over and tell me if it is right or wrong and then do it."* – P14, Male, 11 years, diagnosed age 3 years
>
> *"And the like the teachers, before I started secondary school we went in and met the teachers to like tell them about diabetes, that if I am high I always need to go to the bathroom. So just in case I do need to do that that they don't think I*

> *am like going mitching class or anything, that they understand that I do need to go to the bathroom. Or if I am low to go to the office or anything."* – P23, Female, 14 years, diagnosed age 6 years

For the most part, the routine of school was described as facilitating the carrying out of management of T1D. The structure of the school day promoted remembering tasks and helped with the scheduling of meals.

> *"Am at school it is fine, it is much easier in school than when I am on summer because there is a routine, you have your snack at 11, you have your lunch at 1, it's very like you know what you are doing. Like classes don't- they might bring down your sugars a bit because it is using a bit of brain power but that is it, it doesn't you know what it is going to do to your sugar."* – P25, Female, 17 years, diagnosed age 13 years

For others, school posed a challenge to remembering to engage with management. Examples of this included the transition to secondary school or school exam periods. Moving to secondary school required the adolescent to assume more responsibility and it was sometimes difficult to ensure that management was carried out as adolescents were often less supported by others to manage their T1D in secondary school.

> *"I forget more often than I would have during primary school so a little bit more difficult*." – P09, Male, 13 years, diagnosed age 1 year

> *"…But obviously breaks at different times and you are not anticipating when your lunch is going to be, depending on what exams you have on that day and your bloods can tend to be a bit more unstable."* - P26, Female, 15 years, diagnosed age 12 years

Adhering to a food regimen was more difficult for adolescents when they were presented with the opportunity to snack. Adolescents struggled with avoiding snacking, especially when away from home and spending time with their friends.

> *"I have been a tiny bit disappointed but I know myself that I have only myself really to blame because it's myself to take care of these numbers, I'm the one snacking that- It's my responsibility to do this stuff."* – P10, Male, 14 years, diagnosed age 6 years
>
> *"When I am snacking, she [parent] can't stop that, obviously I won't eat in front of her because she won't let me but sometimes she can't help that because she is not around when I am doing it."* – P06, Male, 15 years, diagnosed age 11 years

Forgetting to carry out an aspect of care led to delaying management until it was either remembered, the adolescent was reminded, or was not carried out. Reasons for forgetting included the presence of competing interests and distractions.

> *"Yeah. Because I didn't take my injection but not on purpose. I just forgot. I walked away from the table and didn't take it [I: Oh OK] And am and then I checked my numbers like an hour later and they were like 19.2 so then I remembered not taking my injection… I had it like winded up and everything. I just like- something distracted me."* P01, Female, 13 years, diagnosed age 3 years

Management of T1D posed an inconvenience to adolescents when it necessitated interrupting time with friends when adolescents were away from home or attending social events. For these reasons, adolescents may not want to carry out self-management tasks in these contexts.

> *"Sometimes it can just be annoying because- but usually it is the last thing you want to do when you are out with your friends to just like do a test. And the pump can be a bit noticeable."* – P19, Female, 15 years, diagnosed age 8 years

As adolescents got older, they described encountering more distractions to engaging with T1D management. If adolescents were out with friends, felt rushed or were experiencing stress, they chose to delay or not carry out the management task.

> *"Sometimes, even like my ma says it, I am getting worse. Like I am not very, very bad but just simple things that I just don't do that should be easy for me like coming in on time for my injection, it should be easy."* – P06, Male, 15 years, diagnosed age 11 years

5.2.4.2 Family involvement in self-management. Adolescents described being supported in their self-management by family members (parents, siblings and extended family) who ensured that adolescents had time and space to carry out management. Family members contributed to self-management in several ways. Adolescents described how their family must live with the adolescent's T1D, taking steps to integrate T1D within the family life and family activities. Family members assisted adolescents with carrying out management tasks. The family learnt about T1D with the adolescent and this contributed to the adolescent feeling supported in their self-management. Some of the benefits of living with T1D included prompting the family to become healthier to accommodate the adolescent's T1D management. Finally, the family's adoption of behaviours that were supportive of the adolescent's self-management contributed to adolescents feeling less restricted by T1D.

Adolescents described how their family context supported their T1D management. Over time, adolescents together with their family moved towards managing T1D and ensured its management was not considered overwhelming.

> *"It [T1D] is there and we [family] have to deal with it but it is not something we are ashamed of or something we are frightened of, we deal with it, diabetes is just there."* – P26, Female, 15 years, diagnosed age 12 years

The family experience of a T1D diagnosis and their subsequent approach to its management was described as dependent on the family's prior knowledge of T1D. In the case of some families, when there was another family member living with T1D, prior to the adolescent's diagnosis, this contributed to a more positive response by adolescents and their family to the diagnosis and subsequent living with T1D.

> *"…I think it was easier on my family because like kind of even though it is not hereditary we were kind of seeing who would get it and because my brother and sister were getting older and I was showing more signs. It kind of just happened, it wasn't a big huge shock and we like we knew what to do and stuff so it was easier."* – P02, Female, 13 years, diagnosed age 9 years

Siblings, especially older siblings were required to learn about T1D, and to assist adolescents in their engagement with the tasks of self-management.

> *"If my parents were gone away or something it is easier now if my brother knows like how to help me with like carb bolus and stuff like that."* – P02, Female, 13 years, diagnosed age 9 years

Some adolescents described positive aspects of living with T1D for the family. For example, some adolescents described how together with their families, they had adopted healthier habits. Examples of this included through incorporating healthier eating into their lifestyles, which supported the adolescent to manage T1D well.

> *"I think it was such a shock at first, you know new lives, new beginnings but then it just became a part of me and it was actually a good thing because we are now on diets, there is no really sweetie things in the house anymore and it was*

> *like a good change but a bad change at the same time because it's a new lifestyle…"* – P17, Female, 15 years, diagnosed age 10 years

Family members supported adolescents by passing on advice and knowledge about T1D. Specific ways family members supported adolescents included when family members did not treat the adolescent differently, through making accommodations for the adolescent and helping them with management.

> *"Like growing up with the whole sugar thing like with cakes and all that stuff, it is hard to explain, even with my friends or my family at home, my brothers and my sister, they didn't eat any sugar in front of me. They didn't make me feel like I was missing out on anything."* - P20, Female, 16 years, diagnosed age 5 years

5.2.4.3 Involving friends and peers in self-management. Adolescents described the ways in which their friends and peers were involved in their self-management. Friends and peers were often a source of support for adolescents as they engaged with their self-management. When others were knowledgeable about T1D, they were able to provide support to adolescents by assisting them, making accommodations for them and listening to their concerns. The advantages of knowing others living with T1D were described. Specifically, knowing others meant that adolescents could share their experiences and learn from other's lived experiences of T1D. This subtheme also speaks to the ways that adolescents deal with others' misconceptions about T1D, including its seriousness and what management entails. Moreover, dealing with others' misconceptions at times contributed to adolescent feelings of differentness between them and their peers.

Talking to friends was described as a source of support by adolescents as it provided a forum within which adolescents could share worries or concerns relating to T1D with another person. Adolescents referred to how the perceived negative emotional impact or burden associated with living with and managing T1D dissipated through being open with friends.

> *"Do talk to friends because it does help, even though I try to avoid it, I do talk to some of my friends who I have known for years about it and knowing that they care just makes you feel so much better."* - P15, Female, 15 years, diagnosed age 11 years

When friends were knowledgeable, adolescents expressed that their friends could assist with their T1D management, if needed, such as during hypoglycaemia. Adolescents relayed that it was also helpful when friends recognised the signs of low blood glucose levels and were able to remind the adolescent to carry out a management task. Friends were described as supporting management when they accompanied adolescents with T1D when they experienced hypoglycaemia or paused with the adolescent to carry out a T1D management task.

> *"Yeah sort of because you'd be thinking your friends wouldn't really understand what it is, whereas now it doesn't- like they sort of all realise that when you are high you mightn't be feeling the best, or when you are low that you need sugar. It is grand now because if I felt low walking down the street with some of my friends now I can say, 'oh lads I don't feel the best.' They'd be like, 'oh what can we do?' And they would go in and get you maybe a Lucozade or maybe some biscuits or something, just to make sure you are all right. So it is great that way."* – P22, Male, 16 years, diagnosed age 8 years

Adolescents described positive interactions and receipt of support from others such as friends, classmates, teachers and sports coaches, etc. Examples of the support to engage with self-management given by others included sports coaches accommodating adolescents when they needed breaks, and friends or family members offering to wait with them while they treated a low or carried out a management task. Feeling that others were understanding of this contributed to adolescents feeling supported in their carrying out of self-management. Moreover, this contributed to a setting that enabled adolescents to independently manage their T1D.

> *"And they just support me by letting me do what I need to do and being who I really am and they know that sometimes my moods depends on my sugars so they try to understand that."* – P17, Female, 15 years, diagnosed age 10 years

Adolescents spoke of the benefits of having friends who live with T1D. These relationships were described as particularly supportive by adolescents due to others also living with T1D being able to share their own personal insights and T1D experiences. Adolescents described how they received support or help from friends who were also living with T1D. Adolescents mentioned how it was helpful to learn from others' experiences of self-management and of living with T1D more generally. This could be at school, during activities or on social media.

> *"It's just nice to know that you are friends with someone who understands and gets what you have and she's a lovely person. I met her while I was getting my pump and we just talked about diabetes so it was fun."* – P13, Female, 12 years, diagnosed age 8 years

> *"Ehm I found out that there was three or four other people in the actual school who had diabetes so I didn't feel like I was the only one with it and I was like on my own doing it, I kind of felt they were there with me doing it."* – P23, Female, 14 years, diagnosed age 6 years

> *"…but am no social media was big for me because on Instagram I-we could post pictures and even if you are feeling down, people or if you had any problems whatsoever they'd say look there is a website, this is where I get this*

> *type of stuff from… And the problem would be solved..."* - P26, Female, 15 years, diagnosed age 12 years

Some adolescents also demonstrated how they tried to enable others who have T1D to manage their T1D well. Adolescents demonstrated their ability and knowledge relating to T1D management when they described their willingness and desire to contribute to settings that were supportive for others living with T1D to engage with self-management.

> *"Just see how he is getting on with it, like because he is new to it and I know how tough it is to start going, especially when you are older I suppose it would be tougher because you are not as used to it, you have lived a lot longer without it so it is sort of new to you".* – P22, Male, 16 years, diagnosed age 8 years

In contrast to the supportive experiences with others, adolescents also experienced instances where they were met with a lack of understanding or misconceptions about T1D from others in the environment where they were engaging with self-management tasks in. Adolescents mentioned that often others at school or acquaintances may not distinguish or understand the difference between T1D and T2D and that this could lead to frustration for some adolescents. Similarly, peers or friends frequently expressed shock and disbelief at the level of management required by T1D.

> *"'Cause like the people would relate that with being really unhealthy or really fat because people like with type 2 diabetes, they think oh that is what I have but like they don't know the difference, like because they don't know about it they can take it like they think it is something else and like they could like possibly slag you over it or like just say like stupid stuff like."* – P11, Male, 16 years, diagnosed age 15 years

> *"It is just people just misunderstood – don't understand it because most people think that diabetes, oh check your sugars, you can't eat sugar but they don't know the long term effect, they don't know the ketones and what they do to you, what it does to your system…"* – P17, Female, 15 years, diagnosed age 10 years

Adolescents described their experiences of responding to queries from others about T1D. For some this was viewed positively, as it gave them a chance to inform others about T1D. However, sometimes dealing with lack of understanding about T1D from others frustrated adolescents when they were carrying out management tasks.

> *"They are completely fine. They will ask me kind of basic questions of what type you are... They are kind of fascinated by it to be honest and ask curious questions like when your friends have this kind of patch thing and you don't really know what it is and you kind of ask questions what it is and you describe it to them and like, okay."* – P10, Male, 14 years, diagnosed age 6 years

> *"I don't like really mind but just like sometimes in class when I don't really know people in different classes it is sort of a bit like weird in case like they keep looking at me and like wondering what I am doing and I just don't want to explain it to them."* – P12, Female, 13 years, diagnosed age 12 years

5.2.4.4 Collaborating with HCPs while gaining independence in self-management. This subtheme describes HCP's involvement in adolescents' experiences of self-management and gaining independence in the management of T1D. This was through offering advice and overseeing self-management at appointments. Adolescents indicated how they learnt from HCPs about their T1D management through their exchanges with them at appointments. Adolescents described how over time, the way HCPs interacted with them changed as they got older and assumed increasing responsibility for their self-management. Adolescents described being held more accountable for their self-management by HCPs. HCPs also offered support through identifying and suggesting when an adolescent might need more parental support with their self-management.

Adolescents mentioned learning tips and strategies for self-management from HCPs that assisted them in becoming more involved in their self-management. Attending clinic appointments was a structured way to obtain advice and to receive feedback from HCPs in relation to their self-management.

> *"… we'd be brought into a room and an intern I think of [doctor's name] would come in and ask us about how we are doing and look at my diary and the scores and why this happened, why didn't this happen or whatever, and how to improve it. And then [doctor name] would come in and am ask how I am doing, how to change things and improve."* – P24, Female, 15 years, diagnosed age 11 years

Adolescents described negatively anticipating their interactions with HCPs during periods where they believed their blood glucose control had worsened. Relations with clinic staff were described as good when HbA1c was within their target range, had improved or when blood glucose levels had been within range in the time leading up to their appointment.

> *"I get a bit nervous because if I ever have high sugars I feel like I will get into trouble because I wouldn't know why I would get them and I am nervous going there."* – P12, Female, 13 years, diagnosed age 12 years

Adolescents recognised that their increasing independence was reflected in how their HCPs interacted with them. This served as encouragement for adolescents in their striving towards more independent self-management. This change in how HCPs interacted with them also highlighted to adolescents that they were expected to take on more responsibility for their self-management.

> *"Yeah everything they explain to my mum they'd explain to me just so I know what is going on and clued in because like at this age you need to kind of start taking control of it yourself."* – P16, Female, 14 years, diagnosed age 5 years

Adolescents also described how the presence of trust between them and HCPs led to adolescents taking on more self-management responsibilities. When adolescents were managing well, HCPs considered them capable of looking after an aspect of their care independently. Adolescents also referred to how HCPs interacted with their parents by asking them to step back and transfer additional responsibility for T1D management to adolescents. HCPs also recognised times when adolescents needed more parental assistance following the relinquishment of some parental control for T1D management. These interactions increased adolescent involvement in shared self-management and shared management related decision making.

> *"Well when I took more independence the HbA1c went up a little bit because that would have been my first time doing it so the doctors asked my mam to step in a little bit more. But mainly it is me doing most of the stuff."* – P18, 15 years, diagnosed age 7 years
>
> *"... but taking my insulin, I do that on my own because I have been trusted, the doctors trusted me that I am in charge enough to do the stuff that my mum and dad used to do for me."* – P17, Female, 15 years, diagnosed age 10 years

5.3 Summary of Qualitative Findings

The aim of the qualitative phase was to explore adolescent experiences of self-management, negotiating responsibilities for self-management with parents and the impact of self-management on daily adolescent life from the perspectives of adolescents living with T1D. In this chapter, key findings relating to adolescent experiences of self-management of T1D and of sharing responsibilities for management with their parents were presented. The findings of this phase illustrate adolescent perspectives on becoming more responsible for self-management of T1D. How involved parents and adolescents are in the completion of management tasks was elucidated within interview accounts. The negotiation of levels of responsibility for self-management was characterised by gradual changes in the level of parental involvement. Adolescent accounts of communicating with their parents about T1D management were also presented. Characteristics of communication that contributed to positive and negative parent-adolescent interactions relating to the negotiation of self-management responsibilities were referred to. The contribution of parent-adolescent interactions to adolescents' experiences of gaining responsibility for more independently managing their T1D were also referred to. Adolescents outlined features of parent-adolescent interaction that facilitate conversations with parents including openness, feeling that parents were understanding of their perspectives and feeling generally close to their parents. This enabled consultation with parents about T1D management and reduced the risk of conflict surrounding T1D interactions occurring. The specific experiences of taking more ownership of management responsibilities were also described and the factors that contribute to this include learning, confidence and encountering specific prompts or catalysts necessitating a change in the level of responsibility of adolescents. The situation and context of self-management play a role in adolescents' individual journeys towards more independent management of T1D. These specific situations and environments where adolescents navigate changing levels of responsibility for self-management of T1D included the family context, school setting, social and healthcare setting. The qualitative findings will be discussed further in the following chapter.

Chapter 6: Phase One: Discussion of Qualitative Findings

6.1 Introduction

The aim of the qualitative phase of this mixed method study was to explore adolescent (aged 11-17 years) experiences of self-management, negotiating responsibilities for self-management with parents and the impact of self-management on daily adolescent life from the perspectives of adolescents living with T1D. Within this chapter, the overarching theme (Navigating becoming increasingly responsible for self-management during adolescence: "it changed gradually… and I am almost fully doing it [self-managing] now") will be discussed. Next the subthemes will be discussed in the following order: (1) Changing levels of involvement in self-management, (2) Talking about self-management with parents, (3) Taking ownership of self-management and (4) Environmental and contextual influences affecting self-management. Strengths and limitations of this phase of the research will then be outlined. Finally, how these findings informed the quantitative phase of this mixed methods study will be outlined.

6.2 Navigating becoming increasingly responsible for self-management during adolescence

For the first time, the findings of this qualitative phase identified how adolescents navigate becoming increasingly responsible for the self-management of T1D. The overarching theme outlines how sharing and reorganisation of responsibilities occurs between adolescents and their parents, from the perspectives of adolescents. Moreover, the trajectory from being reliant on their parents for completing self-management of T1D to becoming more responsible for self-management of T1D is explicated. Navigating becoming more independent in and increasingly responsible for self-management of T1D involves key areas which will be discussed. These key areas include contending with changing levels of parental involvement in T1D management tasks and a gradual reduction in reliance on parents for completion of T1D self-management, acquiring the ability and skills to self-manage T1D, and the contextual factors (e.g. the setting T1D management is carried out within, family characteristics, T1D characteristics) that are related to becoming independent.

Firstly, parental involvement was a key issue related to how adolescents become more responsible for T1D management. Adolescents expressed awareness that parents maintain varying degrees of involvement in their care, often completing tasks the adolescent was not yet competent in completing, advising the adolescent, or overseeing the management that was carried out. For the most part, this was welcomed by adolescents, and it facilitated their taking on increased responsibility for T1D management. However, this navigation towards independence in self-management, was not always a smooth transition due to the risk of parent-adolescent conflict occurring e.g. as a result of mismanagement by the adolescent. This research identifies specific characteristics of parent-adolescent interactions (e.g. facilitating adolescent learning, being open and reassuring adolescents) that contribute to becoming increasingly responsible for self-management of T1D. This research addresses a gap in research that considers how adolescent perceptions of parental involvement contribute to gaining independence in self-management of T1D. The role of families, including parents is referred to within previous models explaining self-management of long-term conditions, and family environment is considered an important contextual factor contributing to self-management (e.g. Grey et al., 2015; Ryan & Sawin, 2009). Moreover, specific content and characteristics of the parent-adolescent relations involved in transferring ownership of and responsibility for the tasks of T1D management were previously not well defined (Gardener et al., 2020). Therefore, while previous models and research have identified the role of families as a contextual factor contributing to self-management, their specific contribution remained poorly understood and findings from the present phase address this gap.

The current research emphasises the non-linear nature of sharing management responsibilities and how certain internal and environmental factors can facilitate or impede the transition to more independence in self-management. The overarching theme emphasises a more encompassing view of self-management that is concerned with experiences surrounding assuming self-management responsibilities, rather than engagement with specific behaviours relating to adherence. This research highlights that adolescent perceptions of collaboration with their parents are associated with their experiences of gaining autonomy in their T1D management and the formation of good habits in relation to engagement with positive self-management behaviours. Other studies similarly found that parents assist adolescents with T1D decision making and T1D management tasks (Karlsson et al., 2008; Sullivan-Bolyai et al., 2014). Previous research identifies that parental involvement is associated with better metabolic control and treatment adherence among adolescents (Young et al., 2014).

Navigating increased responsibility involves moving between being independent, sharing responsibilities with parents and being reliant on parents. This qualitative phase confirms that it is not easy to categorise levels of adolescent involvement in their self-management. Furthermore, it is also difficult to determine where the distribution of responsibility for self-management of T1D lies, as it exists in a fluctuating manner. Patterns of self-management and transitioning responsibilities are previously referred to in studies conducted with adolescents living with T1D (Karlsson et al., 2008; Schilling et al., 2006). Furthermore, there is an emerging trend within research focussing on parental transfer of responsibilities for T1D management that considers self-management as a process rather than a transition from one point to another (Gardener et al., 2020). The present qualitative phase describes the process of assuming increased responsibilities for self-management i.e. this process occurs in a manner where adolescents assume some self-management responsibilities in a fluctuating manner moving between relying on parents and independently managing.

Another key issue that featured within this overarching theme is the role of adolescent perceptions of their beliefs in relation to taking on more responsibilities and acquiring the skills to engage in self-management. Adolescent-held beliefs with respect to their capabilities and competence to engage in self-management evolved as adolescents moved towards increased independence in self-management of T1D. Specifically, experiences of pride and confidence towards management occurred when adolescents were successfully engaging with their T1D management and maintaining their blood glucose levels within recommended parameters. Adolescent beliefs pertaining to their competence and confidence in their abilities to engage with self-management indicated that this facilitated adolescent integration of their management with their daily activities. Furthermore, the current findings emphasise the way that parental involvement in T1D management is entwined with self-management through supporting adolescents as they engage with self-management in a more autonomous way. This is also comparable with Babler and Strickland’s theme ‘Believing it’s possible to manage’ which describes how gaining confidence in their ability to successfully manage T1D allows adolescents to reach the goal of maintaining health and general aspirations towards living independent lives (2016, p. 127). Furthermore, according to IFSMT, possessing the illness related knowledge and self-efficacy facilitates engagement with self-management (Ryan & Sawin, 2009; Verchota & Sawin, 2016). The findings with respect to the role of parent-adolescent interactions in enabling adolescents to engage with their management in a way that is more autonomous highlights that parenting styles are deserving of consideration in the context of T1D. Recent research identifies the importance of parent-adolescent communication patterns that are supportive of adolescents without being controlling (Goethals et al., 2019).

The overarching theme provides new understanding into the context and processes of self-management that are identified within the IFSMT (Ryan & Sawin, 2009) through highlighting the interrelatedness across family context, adolescent beliefs held with respect to self-management and subsequent engagement with self-management. The findings of the present phase do this by emphasising that contextual factors (e.g. adolescent age and management characteristics) can facilitate or impede the process of transitioning to more independence in self-management and the non-linear nature of sharing management responsibilities. To the author's knowledge, this is the first study which specifically addresses the gap in knowledge surrounding how adolescents across an age range that spans early to mid/late adolescence experience taking on increased responsibilities for self-management of T1D. Few studies specifically examine adolescent perceptions surrounding becoming responsible for self-management (Strand et al., 2019).

Furthermore, gradual progression or navigation towards ownership of management responsibilities was influenced by adolescent confidence and beliefs about their self-management, and the wider context in which self-management takes place. Adolescents share management with parents and assume responsibility in a fluctuating manner that is influenced by a myriad of factors including the various contexts of their adolescent lives, including family life, school life and their time with their friends. Furthermore, the phase's findings agree with both the PSMF (Modi et al., 2012) and IFSMT (Ryan & Sawin, 2009), that specific modifiable and non-modifiable factors influence adolescent engagement with self-management. For example, in the present phase, management technologies (insulin administration methods, BGM devices) were highlighted across adolescent accounts as important to T1D management. These non-modifiable factors influenced the adolescent trajectory towards independent management in that management approaches were described as facilitating adolescent engagement with management, through contributing to adolescent understanding of blood glucose reading and flexibility in completing management tasks.

Finally, the overarching theme 'Navigating becoming increasingly responsible for self-management during adolescence' considers what contributes to adolescent experiences of becoming more responsible for self-management of T1D. In the following sections, the four themes embedded within the overarching theme are discussed.

6.2.1 Changing levels of involvement in self-management

For the first time, the findings of this qualitative phase provide a nuanced understanding of the intricacies of how levels of parental and adolescent involvement in T1D management change over time, from the perspective of adolescents living with T1D. Sharing responsibility with parents was identified as a critical factor by adolescents that enabled them to acquire more independence in self-management. The present findings explain that specific areas where responsibilities for T1D management transition, such as making independent decisions relating to management while they are at school or away from home, form key parts of the experience of gaining independence. Adolescents recounted that parents oversee self-management and step in if required.

The current findings present qualitative evidence on how the process of becoming independent in management occurs and is experienced by adolescents.

Furthermore, knowledge on how adolescents become independent provides clarification that this change in responsibility is characterised by periods of actively taking over from parents, sharing involvement with parents and reverting to parental involvement in management, if needed. The fluidity of navigating the space between independent and shared management of T1D is not often captured in previous studies. It has been previously acknowledged that adolescents move between self-reliance and support from others as they gain independence in self-management (Karlsson et al., 2008), however while this period of transition between self-reliance and reliance on others is identified, it has not been explored in depth. How the transfer of self-management responsibilities for T1D self-management occurs between adolescents and their parents and what contributes to optimal negotiation of self-management responsibilities has not been sufficiently explored. This research makes strides in unearthing how changes in the distribution of responsibility for self-management of T1D coincide with changes in parent-adolescent interactions and changes in adolescent perception of their capabilities to independently manage their T1D. Specifically, among the current adolescent respondents, the opportunity to share decisions and learning experiences with parents was considered positively in terms of learning to engage with their self-management. Previous research has identified that gaining independence is gradual and focuses on moving towards full independence or self-reliance for completion of management tasks (Babler & Strickland, 2015a; Spencer et al., 2013). Overall, these findings align with the position that adolescence is a time where the roles in management of illness change and shift within the family (Grey et al., 2015; Ryan & Sawin, 2009), but for the first time this research identifies specific attributes contributing to this change in where responsibilities for self-management of T1D lie.

The current findings from the qualitative phase of this study indicated that adolescents considered that sharing self-management with their parents supported them to complete management tasks and enabled them to take on more self-management responsibilities. However, this was not a straightforward transfer of responsibilities for care between adolescents and their parents, in that levels of responsibility for T1D self-management were influenced by contextual factors and difficulties that adolescents encountered when engaging with T1D self-management. For example, the current findings indicate that parents were relied on to step in and resume management for difficult tasks (e.g. infusion site changes, calculating boluses, carbohydrate counting), had the adolescent assumed too much responsibility or if they were experiencing a decline in blood glucose control. Moreover, the findings highlight the importance of being flexible throughout the process of gradually relinquishing control across adolescence. The present findings add to understanding what factors contribute to difficulties with self-management and specifically with changes in self-management. Finding self-management difficult often made it challenging to carry out the required management and in turn assume more responsibility for management. Parents stepped in and ensured that management was completed, when the adolescent found completing their management difficult, such as remembering tasks, determining carbohydrate content of foods, completing insulin infusion set changes, etc. This is supported by previous qualitative research which found that adolescents rely on parents for T1D decisions and tasks considered difficult (Karlsson et al., 2008; Schilling et al., 2006). It is important that these parental interactions where parents temporarily take over care are framed in a way that is supportive of the adolescent’s autonomy. Adolescent perceptions of how autonomy supportive their parents are is associated with engagement with self-management (Goethals et al., 2019; Hanna et al., 2013).

Therefore, having parents available to assist adolescents is important to ensure completion of management tasks as well as supporting them as they gain independence in self-management.

As mentioned previously, assuming independence in self-management for adolescents is a gradual process (Babler & Strickland, 2015a). The realisation of the adolescent that they need their parents to oversee some T1D tasks, even though they may possess the ability to complete the task independently has been acknowledged (Schilling et al., 2006). The current qualitative findings extend this knowledge through providing suggestions that there may be ways to discern how much responsibility and when responsibility should be taken by adolescents. For example, adolescents within the current phase of this study, outlined how they held discussions with HCPs and parents prior to taking on more management. Furthermore, reverting to more parental involvement following independence suggests a need for adolescents and parents to be mindful of the gradual process of assuming increased independence. HCPs and parents should ensure that adolescents are aware that they may need to rely on their parent again, even though they may consider themselves capable of independently managing.

Additionally, the present findings highlight the importance of assessing adolescent readiness to take on additional management responsibilities and ensuring parents oversee management in a way that is supportive of the adolescent’s independence through preserving the adolescent’s confidence and motivation to continue to engage with their self-management. The current findings emphasise specific ways parental behaviours can be supportive or non-supportive of an adolescent’s transition to more independence in self-management of T1D. These included parental conveying of trust, through the offering encouragement and ensuring that reminders were not intrusive. Within this phase, trust was identified as important and needed to be in place prior to parents relinquishing responsibilities for self-management to the adolescent. Parents did not convey trust when they nagged or asked the adolescent about blood glucose levels in an accusatory tone. Previous research also identifies the importance of trust between adolescents and parents in collaborating on management tasks but focuses on how the absence of trust can give rise to parent-adolescent conflict and intrusive parental behaviours (Ivey et al., 2009; Leonard et al., 2005). The current findings offer novel perspectives on the positive role of trust in facilitating more optimal sharing of responsibilities during this period where parent-adolescent involvement in care varies. It may be that the trust referred to within the current phase is a feature of or closely related to the warm parenting styles that have been identified within previous research as contributing to better engagement with management tasks and metabolic control (Faulkner & Chang, 2007; Goethals et al., 2017). However, continued research is warranted to understand how best to harness and promote trust between adolescents and parents while levels of involvement and collaboration for self-management change.

The current findings also identify that collaborating on learning about T1D with parents was a key feature of sharing management with parents. Learning both from and with parents allowed adolescents to manage their T1D and to become familiar with new management devices or technologies such as their insulin pump, promoting positive shared management experiences. Frequently, parents provide management education and teach self-management skills to adolescents (Strand et al., 2019; Sullivan-Bolyai et al., 2012), which is important given that general collaboration with parents is associated with better metabolic control (Helgeson et al., 2008). Collectively, the current and previous evidence suggests that these learning experiences should be constructed in a way that promotes positive experiences around learning about T1D and becoming more responsible for T1D decisions.

6.2.2 Talking about self-management with parents

The qualitative phase of the current study presents novel insights into how adolescents perceive communication with their parents surrounding self-management of T1D and the role of parent-adolescent communication in their journey towards becoming increasingly responsible for their self-management. Findings pertaining to how communication changes over time, how communication can influence engagement with self-management and aspects of parent-adolescent communication that adolescents consider to be helpful or challenging as they relate to T1D management will be discussed.

For the first time, how adolescents discuss T1D management with their parents and reasons behind communicating with their parents about T1D management (e.g. receiving advice on how to proceed with their management, supporting their learning about managing T1D, making decisions) were identified. How illness management roles are negotiated and how parent-adolescent communication features within this reorganisation emerged as important to the negotiation of levels of responsibility for self-management between adolescents and parents, from the perspectives of adolescents living with T1D. As adolescents become more proficient in their management, they consult with their parents less. This differs in comparison to when they were younger and more unsure about completing T1D management tasks. Furthermore, the current findings highlight that adolescents consider their parents hold them more accountable for instances of T1D mismanagement. These changes identified in parent-adolescent interactions around self-management can be compared to the general changes to parent-adolescent relationships during adolescence. In adolescence, in general, both parents and adolescents reorganise their relationships with one another as they move towards a more egalitarian approach to their interactions (De Goede et al., 2009). The present findings indicate that this reorganisation is also evident in parent-adolescent communication surrounding T1D self-management during adolescence. Previous research presents T1D as an additional domain where reorganisation of responsibilities for T1D management occurs, with adolescent and parental roles for T1D tasks redefined based on the adolescent's developmental stage (Markowitz et al., 2015). Adolescents move towards increased autonomy in all aspects of life, including in their T1D management during adolescence. In the context of the current study, adolescents described actively asking for more responsibility for T1D management which contributed to independence from the parent. The findings indicate that how adolescents describe parent-adolescent communication patterns can illustrate how roles are reorganised for T1D management between adolescents and their parents. The current T1D-specific role reorganisation and move towards becoming more independent of parents during adolescence may in part be explained by the process of separation-individuation during adolescence (Blos, 1967; Koepke & Denissen, 2012). Within this process, adolescents gain autonomy, reduce ties to parents and become increasingly responsible for their own actions (Alonso-Stuyck et al., 2017; Blum, 2004).

The present findings unearth the central role of adolescent perceptions of parent-adolescent communication in contributing to adolescent's motivations and confidence in self-management of T1D. Adolescents described how receiving feedback from parents can be an important means through which they develop self-management skills and gain confidence in their ability to problem-solve and make decisions about T1D management. This was particularly evident in accounts of parents providing reassurance and encouragement contributing to adolescent beliefs in their competence to engage with their management independently. The beneficial impact of parental feedback on adolescent performance of T1D self-management can be understood in the context of contributing to the development of the self-management processes outlined in IFSMT (e.g. self-efficacy, self-regulation) (Ryan & Sawin, 2009). Furthermore, social cognitive theory (SCT) posits that feedback on performance contributes to enhanced feelings of confidence and self-efficacy (Bandura, 1993; Ott et al., 2000). In the current phase, adolescents mostly outlined the benefits of feedback in the form of parental support, reassurance and encouragement when completing self-management tasks and making decisions relating to their care. However, previous research suggests that the relationship between parental reminders and encouragement to self-efficacy for adolescents is not straightforward and depends on adolescent's existing levels of perceived competence (Berg et al., 2013). Thus, it may be important to be cognisant of how parents frame reminders and assistance with management depending on the individual adolescent. Additionally, parent-adolescent communication styles, considered controlling, have been linked with reduced adolescent motivation levels to engage with T1D self-management (Goethals et al., 2019). Though adolescents in the present phase of this study did not explicitly refer to finding their parents controlling, they did refer to instances where parental reminders were intrusive and could give rise to parent-adolescent conflict. These findings emphasise the importance of considering the relationship of parent-adolescent communication to self-management and distribution of responsibility for self-management through promotion of self-efficacy.

In the current study, adolescents described the role of their parents in the process of assuming more responsibilities for self-management and outlined how parents support them to make informed decisions relating to T1D, without being overbearing. Previous research identifies that it is important that support and closeness are still present within parent-adolescent relationships in all aspects of adolescent life (De Goede et al., 2009). The current phase's identification of parents-adolescent interactions and perceptions of their self-management is comparable with previous studies focusing on parent-adolescent interactions and adherence and QOL. For example, ensuring that parents avoid interactions considered intrusive is important for T1D outcomes such as metabolic control and QOL (Whittemore et al., 2014). Furthermore, when adolescents perceive their parents as autonomy supportive, this facilitates shared T1D management, as adolescents complete more self-care tasks independently (Hanna et al., 2013). The findings of this qualitative phase suggest that the benefits of supportive and positive parent-adolescent interactions (characterised by closeness and feeling understood) surrounding T1D may extend to the stimulation of better engagement with self-management, considered more broadly than metabolic control or adherence behaviours.

The qualitative current phase also identified features of parent-adolescent communication that contributed to adolescents maintaining positive perspectives around self-management. For example, when adolescents considered that their communication (general and T1D-specific) with their parents was easy, occurred frequently, and was characterised by openness, this contributed to perceptions that all interactions including T1D related interactions were positive. Indeed, this supports previous findings on the relationship between better parenting styles and less withholding of information about T1D management (Main et al., 2015). Disclosure about T1D management to parents is also associated with less forgetting and better treatment adherence (Berg et al., 2016). These benefits of openness in discussions about self-management identified in this current phase include ensuring adolescents feel able to seek support and T1D advice from parents. The benefits of openness are important findings in their addition to the body of literature on related constructs such as disclosure and secrecy in parent-adolescent communication about T1D self-management. Previous research has indicated that increased disclosure about T1D management with parents is associated with improved T1D outcomes including adherence and metabolic control (Berg et al., 2016). Similarly, the drawbacks of not being open or of being secretive with parents about T1D management are documented as associated with lower adherence, poor metabolic control (Main et al., 2015) and greater adolescent endorsement of depressive symptoms (Osborn et al., 2013). The current qualitative phase expands upon these findings relating to openness surrounding disclosure of mismanagement to consider openness as it relates to parent-adolescent interactions surrounding self-management more generally. In this qualitative phase the role of openness, beyond simply disclosing mismanagement about T1D with parents is elucidated. In this qualitative phase, openness was present when both adolescents and parents were informed about the adolescent's management, when honesty was maintained and when adolescents felt comfortable in parent-adolescent discussions about self-management. When adolescents and parents are open with each other, this provides opportunities for the adolescent to receive input from a parent or support for their T1D management. The present findings suggest that further research may follow up quantitatively on the relationship between more general openness in communication to T1D outcomes including self-management.

The present findings add clarification to adolescent perspectives on the nature of challenging aspects of communication with parents about self-management. In contrast to the features of parent-adolescent communication about self-management identified as positive, adolescents in this phase also referred to some challenging aspects of talking about T1D with their parents. Challenges surrounding negotiating responsibilities for self-management are well documented among adolescents and their parents and are reflected in parent-adolescent discrepancies in management distribution and parent-adolescent conflict related to management (Anderson et al., 2009; Babler & Strickland, 2015a; Ingerski et al., 2010; Vaid et al., 2018). However, some of the specific reasons for conflict identified in the present study can be contrasted with quantitative research where no relationship was observed between how frequently adolescents and parents communicate about T1D and metabolic control (DeBoer et al., 2017).

The current phase indicates that adolescents find conversations about forgetting to manage or out of range blood glucose levels difficult. T1D was sometimes a difficult topic to broach for the adolescent as it could elicit or exacerbate negative feelings towards T1D and its management. For this reason, more in-depth discussions about T1D management with parents were sometimes avoided and in turn an opportunity to receive support from their parents could be missed. Avoiding conversations was also a strategy employed by adolescents to avoid conflict or avoid causing parental worry. Adolescents are aware that their T1D is a source of worry for their parents as evidenced in the present study and also by Serlachius et al. (2012). The present phase of this study advances knowledge on some of the motivations behind adolescent avoidance of parent-adolescent communication, such as minimising risk of parental worry and what the content of these interactions might be (e.g. communicating about blood glucose levels, mismanagement or forgotten management).

The present findings emphasise the potential relevance of perceptions of communication to impact upon gaining independence in self-management during adolescence. Adolescents in the current study presented some novel perspectives on how adolescents rationalise the benefits of parental nagging including recognising parents nagged in order to ensure adolescents remained healthy. Although previous research suggests an association between less performance of management tasks and parental nagging (Delamater et al., 2013) and lower motivation to engage with self-management tasks (Kyngas et al., 1998), nagging in this phase was not always described as entirely negative and at times, served the important purpose of reminding the adolescent or motivating their engagement with a management task. Therefore, this research offers a more nuanced perspective on the role of nagging behaviours as adolescents become more independent in self-management. The current findings indicate that parents engage in intrusive parental behaviours such as nagging as a result of their concern for the health and wellbeing of the adolescent. However, it remains that even with the knowledge that parental nagging is for the adolescent’s benefit, nagging can be a source of annoyance to the adolescent. Previous research suggests that intrusive parental behaviours can lead to adolescents disengaging with their management (Chilton & Pires-Yfantouda, 2015) or withholding information about their T1D management from parents (Weinger et al., 2001). In the current phase of this study, nagging was viewed negatively by adolescents while reminders that were considered appropriate and encouraging were positively viewed. This has been referred to in earlier studies (Karlsson et al., 2008; Viklund & Wikblad, 2009). These various accounts of parental nagging and T1D emphasise the importance of framing reminders in a way that the adolescent considers helpful to facilitate better engagement with and motivation to self-management among adolescents. Excessive nagging can also have a detrimental impact on adolescent motivation to carry out the tasks of T1D self-management (Chilton & Pires-Yfantouda, 2015). This phase provides a unique understanding into how adolescent perceptions of communication impact upon gaining independence in their self-management of T1D.

6.2.3 Taking ownership of self-management

This phase offers new perspectives on adolescent experiences of taking ownership of their self-management responsibilities for T1D. Adolescents take ownership of their self-management through integrating its management tasks and requirements with their everyday lives. This increased ownership of responsibilities was also characterised by reduced perception of restrictions associated with T1D. Feeling that responsibilities for T1D management lie with adolescents rather than with their parents involved adolescents feeling motivated to manage more independently and forming positive beliefs surrounding their T1D self-management capabilities.

This phase identified adolescent internalisation of the importance of self-management and motivation towards engaging with self-management as facilitating taking ownership of T1D management responsibilities. Adolescents gradually gained confidence in self-managing T1D through continued carrying out of T1D management tasks and specific prompts necessitating the adolescent to engage more in their self-management. As adolescents took more control over and got used to living with T1D, T1D had less of an impact on their lives and participation in activities. Adolescents frequently described the importance of feeling capable of controlling their blood glucose levels and of carrying out management tasks when required. When adolescents feel a sense of control over T1D, this is associated with increased engagement with self-management behaviours for adolescents (Lee et al., 2020; Rising Holmström et al., 2017; Schulman-Green et al., 2016). Similarly, an absence of perceived control over T1D has been identified as a stressor among adolescents in prior studies (Ersig et al., 2016; Souris et al., 2019) and can lead to a disengagement with management (Huston & Houk, 2011). Within the current findings, not feeling a sense of control meant that adolescents felt frustration at the encroachment of T1D on their activities or general inconvenience. Similarly, when adolescents felt they possessed a sense of control over their T1D, they described not feeling restricted by T1D.

The present findings revealed that when adolescents felt supported, this promoted their confidence in their ability to engage with and carry out their T1D self-management more independently. More specifically, when adolescents prioritised their management by delaying other activities such as when spending time with friends, this resulted in their feeling pride at their ability to successfully self-manage. This pride also motivated adolescents to maintain their successful engagement with self-management. This is consistent with self-determination theory (SDT), in that higher levels of internalisation of the importance of engaging in a behaviour lead to more motivation to engage in that behaviour (Ryan & Deci, 2000). Furthermore, it is consistent with research reporting on adolescent’s internalised feelings and beliefs towards illness management as facilitating increased self-management in older adolescents (Lee et al., 2020).

The findings of this phase also identified that assuming increased ownership was characterised by admitting blame for mismanagement (e.g. snacking or choosing to skip a management task) or forgetting management. Adolescents described self-blame and feeling disappointed following instances where they may have not carried out a self-management task, indicating assumption of responsibility for mismanagement. Becoming more responsible in management also means that the adolescent begins to admit and accept responsibility for mistakes made and is a feature of becoming less reliant on parents and others for T1D management (Spencer et al., 2013; Strand et al., 2019). The findings of the current phase are congruent with this but also indicate that there is a potential for these instances where responsibility for mismanagement is assumed to have a negative emotional impact on the adolescent. Therefore, while assuming responsibility for instances or consequences of mismanagement may be a key feature and attribute of taking ownership of their T1D responsibilities, additional support may be warranted to mitigate some of the emotional impacts of becoming responsible for self-management.

6.2.4 Environmental and contextual influences affecting self-management

The current findings indicate that adolescents encountered various contextual factors that acted as enablers or challenges to engaging with self-management including medical devices, whether others were supportive and the presence of supports within the environments where adolescents engaged in self-management. Furthermore, perceptions of these influences as supportive aided adolescents' transition towards taking on more responsibilities for their self-management.

The adolescent perspectives uncovered in the present phase add to understanding how environmental and contextual factors can contribute to meeting the goals related to managing more independently. The present research identified a number of factors that were particularly salient for adolescents living with T1D. For instance, engagement with self-management processes (goal setting, perceptions of capability to manage T1D) was facilitated by medical devices which allowed adolescents to complete their management in a more discreet way and enabled direct access to increased information about their blood glucose levels. Furthermore, specific settings and environments (e.g. school, participation in activities) were described as having the potential to be either supportive or not supportive to adolescent engagement with self-management tasks. Conversely, certain situations such as spending time with friends contributed to difficulties with adhering to a dietary regimen among adolescent participants. This supports the intertwining influence of individual and community factors in maintaining engagement with self-management tasks (Modi et al., 2012; Peters et al., 2014). Indeed, while previous research does document the influence of the wider environment on engaging with self-management, considering these in terms of relevant self-management processes (beliefs held relating to self-management capabilities, transitioning parent-adolescent responsibilities and setting goals related to managing independently) should increase understanding into how to best facilitate adolescents' transition towards independent management and also how they assume more responsibility for aspects of self-management.

In support of previous research that investigated challenging aspects of T1D management during adolescence (Babler & Strickland, 2015a; Berg et al., 2013), adolescents in this present study also revealed challenges to engaging with self-management including maintaining blood glucose levels within target ranges, forgetting to manage and managing in settings where distractions might be present. However, these insights gained advance previous research by identifying strategies and ways that these influences could be minimised, including fostering supportive family environments and autonomy supportive interactions with their HCPs. Moreover, this suggests that HCPs can be key figures in supporting adolescents and parents through facilitating adolescent learning and ensuring adolescents are equipped with knowledge and skills to overcome any obstacles or challenges to engagement with self-management.

School was frequently mentioned by adolescents in this current qualitative phase as an important factor influencing their ability to engage with self-management. This was attributable to how supportive to engaging with self-management adolescents considered their individual school settings, with several adolescents describing less supportive secondary school experiences in comparison to their experiences at primary school. The transition to secondary school, including the longer school day and less informed teachers, presented specific challenges to managing T1D within this setting. These findings support previous research indicating that adolescents have to adapt to managing T1D in secondary school (Newbould et al., 2007). Research conducted with Irish children and adolescents found that levels of support available decline markedly from primary to secondary school (McCollum & O'Grady, 2020). This, together with the accounts of adolescents in the current phase, suggests a need to ensure that supports are in place for adolescents in secondary school, in order to bridge the gap between primary and secondary school, ensuring they can complete their self-management and assume responsibility for T1D management in the school setting.

The current phase identified some of the specific ways a family's approach to T1D can aid its integration within the family's life and the adolescent's life (e.g. not buying unhealthy foods, pausing with the adolescent when they are experiencing hypoglycaemia, offering reminders). Adolescents described how this integration of self-management is aided when their family is knowledgeable about T1D e.g. when another family member with T1D being present within the family. Research highlights the positive impact of support from family members living with T1D on adolescent's general adaptation to receiving a diagnosis (Souris et al., 2019). Based on the current findings, these benefits may also extend to aiding adolescent's transition towards independent engagement with self-management in the longer term. This could also be attributable to the benefits of learning from others, particularly those living with T1D, which was identified as helpful for carrying out and learning about self-management by adolescents in the current study. The benefits of having a parent who lives with T1D (Strand et al., 2019) and friends who live with T1D (Spencer et al., 2013) for the adolescent's learning about self-management were echoed within the current phase. This was also the case for friends with the unique support that discussing T1D with another adolescent living with T1D offers, evident within the current phase. This extends findings that peer support from adolescents also living with T1D is advantageous for support and learning about T1D management (Barone et al., 2016) with the present study highlighting the advantages of having informal, regular contact with others living with T1D either face-to-face or online, on feeling capable of more independent engagement with self-management.

Adolescents also identified friends, including those not living with T1D, as having a key role in their T1D self-management and their transition to becoming increasingly independent. Friends played a positive role when they were understanding and when they helped the adolescent to engage with their management. At school, telling peers was identified as a feature of living with T1D. Having informed friends and classmates can make self-management easier for the adolescent, in that they do not feel awkward carrying out self-management and they feel that friends are positioned to support the adolescent's self-management. The opportunity to teach school peers and teachers about T1D was referred to as helpful in the current interviews by adolescents, who had this experience. However, other research has found that this can be a negative experience for some as it can lead to unwanted attention (Rankin et al., 2018).

Adolescents in the current phase also contended with other's perceptions of and at times, lack of knowledge about T1D. Some adolescents reported feelings of differentness, often exacerbated by this lack of awareness of others about T1D. Previous research also highlights that living with T1D can contribute to feelings of differentness in adolescents and young people living with T1D (Babler & Strickland, 2015a; Karlsson et al., 2008; Souris et al., 2019) and that when the adolescent is made to feel different, this causes stress and impacts upon how adolescents engage with T1D management (Chao et al., 2016). The findings indicate that these various social and contextual factors feature in adolescent's transition to becoming independent in their self-management.

6.3 Strengths and Limitations of the Qualitative Phase

The first phase of this mixed methods study makes a significant contribution to knowledge of adolescent perspectives on self-management, negotiating responsibilities for self-management and gaining independence in self-management, and communicating about self-management responsibilities with their parents. The current findings address gaps in the literature on understanding adolescent perspectives on collaborating with parents for self-management and the nature of their perspectives on and experiences of communicating with parents about self-management. The qualitative approach allowed for an in-depth exploration of the salient features of adolescents' experiences of the gradual nature of becoming more responsible for self-management during adolescence.

In addition to these strengths, the first phase also has some limitations that need to be considered. There were some indicators of homogeneity within the qualitative sample. Though participants were recruited nationally through a national centre for paediatric diabetes (TSCUH) and Diabetes Ireland, most participants were largely drawn from one urban geographical region (the Dublin region). As a result, their experiences may not reflect those of all adolescents living with T1D, attending regional hospitals for treatment and from geographical regions across Ireland.

A high proportion of the participants reported having access to medical technologies such as an insulin pump (68%) and/or a flash glucose monitor (32%). This is higher than the 19.1% - 38% rate of uptake in children and young people aged 0-24 years in 2016 in Ireland (Gajewska et al., 2020). It has been suggested that access to and uptake of medical technologies is dependent on specific resources available within healthcare services (Shulman et al., 2012). This may be a tentative suggestion of disparities between the current participants and other Irish adolescents living with T1D.

Both in Ireland (Gajewska et al., 2020) and internationally (Bruttomesso et al., 2015; Royal College of Paediatrics and Child Health, 2019), uptake and insulin pump use vary according to geographic locations. This increased uptake could also be a consequence of increasing trends towards use and availability of technologies among patients. Notwithstanding this, a detailed description of participant characteristics, as suggested by Thomas and Magilvy (2011) to enable determination of the applicability of the findings to wider contexts, is provided in Appendix M.

Volunteer bias is documented in research situations where those who volunteer for research tend to differ in comparison to those who do not volunteer (Thompson, 1999). Most adolescents reported many positive accounts of living with T1D and that their negotiations of self-management with parents could for the most part be characterised as positive with little conflict. It is possible that adolescents who were not experiencing challenges with T1D management were more likely to volunteer for participation.

6.4 Implications of the Qualitative Phase for the Quantitative Phase

In this two-phased mixed methods study, one of the objectives of the qualitative phase was to inform the quantitative phase and specifically to identify constructs related to parent-adolescent communication and self-management that warrant follow up (section 3.2). This qualitative phase highlighted the evolving nature of self-management and how adolescents negotiated becoming increasingly responsible for self-management of T1D. Parent-adolescent communication, adolescent T1D self-efficacy, adolescent perspectives on division of responsibility and collaboration with parents emerged as worthy of further consideration in the subsequent quantitative phase. The findings from this qualitative phase highlighted the importance of adolescent perceptions on parent-adolescent communication when discussing T1D. However, it remains to be seen whether these findings have a discernible impact on adolescent engagement with self-management.

The experiences of successfully integrating and encountering difficulties with daily T1D management into daily life was also a feature of adolescent experiences in the current phase. Adolescents demonstrated awareness that parents experience worries, and concerns related to the adolescent's T1D management and that this impacted upon how they communicated with their parents. In response to these findings T1D-specific family conflict and aspects of QOL such as impact of parent issues and impact of activities on QOL will be examined further in the quantitative phase. The quantitative phase will examine to what extent these constructs relate to self-management. Adolescent beliefs about their competence and ability to complete self-management heavily featured in adolescent accounts in this first qualitative phase. Furthermore, within some adolescent's accounts, it was highlighted that parents often reinforced and promoted these beliefs by communicating with adolescents in ways that support and encourage independence in self-management of T1D. The qualitative phase informed the selection of instruments to follow up on constructs and potential relationships warranting further examination, including the relationship between specific aspects of parent-adolescent communication (e.g. openness in parent-adolescent communication) to self-management outcomes in adolescents (specifically self-management and QOL). Furthermore, the potential relationship between self-management and QOL will be examined. Instruments measuring parent-adolescent communication, T1D specific family conflict, division of family responsibility for management of T1D, self-management, T1D self-efficacy and T1D-specific QOL will be included in the quantitative phase.

6.5 Conclusion of Discussion of Qualitative Findings

The qualitative phase of this mixed methods study explored adolescent experiences of self-management, negotiating responsibilities for self-management with parents and adolescent perspectives on the impact of self-management of T1D on daily adolescent life. The qualitative phase highlights how adolescents living with T1D experience negotiating responsibilities for T1D self-management with their parents. The findings support that context and process variables specified in IFSMT (Ryan & Sawin, 2009) feature in the transition towards more independent management experienced by adolescents. Further research is required that explores self-management and characteristics of parent-adolescent communication surrounding changing levels of responsibilities for T1D self-management in adolescence. The findings indicate that perceptions of family context (specifically qualities of parent-adolescent communication e.g. openness, warmth and understanding) are an important factor contributing to adolescent engagement with self-management and assumption of increased management responsibilities. The findings also indicate that family context, self-management and health related QOL might be related, however this requires further investigation within the quantitative phase of this mixed methods study in order to determine whether a relationship exists between these constructs. The next phase of this study will address these gaps through specific investigation of these constructs of interest.

Chapter 7: Phase Two: Background and Quantitative Design

7.1 Introduction

For adolescents living with T1D, self-management includes collaboration with parents, performance of T1D care activities, problem solving related to T1D, communication about T1D and possession of T1D-related goals (Schilling et al., 2009). Moreover, becoming responsible for the management of T1D and the carrying out of T1D management can influence multiple facets of the adolescent’s life such as QOL and the short-term and long-term health of the adolescent (Hanna & Decker, 2010). Little is known about how adolescents experience self-management and how they negotiate assuming greater responsibility for self-management. Phase one has identified that key components for adolescents navigating increasing responsibility for self-management involve the changing levels of involvement, talking about self-management with parents, taking ownership of self-management and the environmental and contextual influences affecting self-management.

Within IFSMT, the context of self-management is influenced by factors, including family factors, which can be risk or protective in their influence on proximal, (e.g. engagement with self-management tasks) and distal health outcomes (e.g. HbA1c and QOL) (Ryan & Sawin, 2009). Previous research has found that supportive parent-adolescent interactions can enable older adolescents to become more independent in their T1D management (Strand et al., 2019) and has highlighted the association between parent-adolescent interactions and T1D management outcomes (Goethals et al., 2019; Hilliard, Wu, et al., 2013). Family factors such as division of family responsibility and family conflict specific to T1D have been linked to both metabolic control, meeting metabolic control targets, and to health-related QOL in adolescents living with T1D (Hilliard, Holmes, et al., 2013; Ingerski et al., 2010). Adolescents’ perceptions of how autonomy supportive their parents are is also related to treatment adherence and metabolic control (Goethals et al., 2019). However, the qualitative phase of the current mixed method study identified parent-adolescent communication, adolescent possession of appropriate knowledge to carry out self-management and the ability of adolescents to take ownership of their T1D self-management as pertinent factors in assuming self-management responsibilities.

The link between T1D-specific parent-adolescent conflict with metabolic outcomes and treatment adherence suggest that negative communication about T1D between parents and adolescents may be important in terms of T1D outcomes during adolescence, and although parent-adolescent communication emerged as a key consideration in assuming greater responsibility for self-management, the relationship between parent-adolescent communication and T1D self-management has not been explored. The relationship between specific parent-adolescent communication characteristics and self-management warrants investigation to clarify if particular parent-adolescent interactions are associated with more optimal outcomes for adolescents living with T1D. Openness and problems in communication are important for promoting bonding between family members, adaptability in times of stress and overall more optimal family functioning (Barnes & Olson, 1985; Long & Marsland, 2011). To date, there is no research examining the relationship between openness and the extent of problems in parent-adolescent communication to adolescent self-management of T1D. Furthermore, previous research, described above on adolescent T1D management, predominantly focuses on distal outcomes e.g. QOL and HbA1c, rather than proximal outcomes such as engagement with self-management behaviours.

Within IFSMT, self-management processes (e.g. self-efficacy, self-regulation, beliefs) are important factors in determining both proximal and distal health outcomes

(Ryan & Sawin, 2009). Self-efficacy (the beliefs held by the adolescent in relation to controlling and managing their illness) is an important component in assuming self-management responsibilities for adolescents living with chronic illness (Lansing & Berg, 2014). Supportive or non-supportive parental feedback can promote or undermine self-efficacy in self-management of T1D during adolescence (Ott et al., 2000). Therefore, this suggests that parent-adolescent interactions and communication may influence both management self-efficacy and self-management for adolescents living with T1D. However, previous studies conclude that there is a need to examine how contextual factors such as the family environment and process variables such as self-efficacy are implicated in self-management outcomes for adolescents living with T1D (Verchota & Sawin, 2016).

Activation is associated with self-efficacy and self-management, and is concerned with knowledge, skills and confidence for carrying out self-management (Hibbard et al., 2007). Activation has been associated with increased engagement with positive health behaviours, with highly activated individuals taking a more active role in the management of their health (Lazaroff et al., 2019). However, activation remains an understudied construct among adolescents (Bravo et al., 2020). Therefore, it remains to be seen whether family interactions contribute to adolescent activation in T1D management.

There is a dearth of research examining the interplay between self-management context, self-management processes and self-management in adolescents. Furthermore, there is a need to examine self-management and the relevant behaviours that make up self-management, given that much research looks at adherence, specific management tasks or metabolic control. While research has advanced our understanding into the importance of family factors for adolescent self-management of T1D and being cognisant of IFSMT, there is little known about the role of specific family context characteristics (specifically parent-adolescent communication and T1D-specific family conflict) and self-management processes and their interrelationships to relevant T1D outcomes.

The overall aim of phase two was to assess the inter-relationships between parent-adolescent communication, T1D-specific family conflict, T1D self-efficacy, self-management, family division of responsibility for T1D management, patient activation, T1D-specific QOL and a number of demographic (age, gender), and clinical (age at diagnosis, T1D duration, insulin administration method, BGM method, self-reported last recorded HbA1c result).

The objectives of this phase were to investigate:

- The relationship between parent-adolescent communication and, demographic and clinical variables
- The relationship between adolescent communication with parents and self-management of T1D in adolescents
- The relationship between adolescent communication with parents and T1D-specific family conflict, T1D self-efficacy, self-management, patient activation, division of T1D-related responsibilities between adolescents and parents and QOL

In this chapter the method for the second phase of this mixed method study is outlined. Recruitment, participants, data collection, ethical considerations and the analysis outline for the quantitative phase of the study are detailed.

7.2 Phase Two Research Design

The second phase of this sequential exploratory mixed methods study was a quantitative, cross-sectional survey of adolescents (aged 11-17 years) living with T1D.

7.3 Phase Two Sample

Eligible participants were adolescents living with T1D who met pre-defined selection criteria**.**

7.3.1 Inclusion and exclusion criteria. Adolescents aged between 11 years and 17 years and who had a diagnosis of T1D for 6 months or more were eligible for participation in this phase. Adolescents presenting with an intellectual disability or developmental delay were excluded. The justification for these inclusion and exclusion criteria were provided previously (see section 4.3.1).

7.3.2 Recruitment. Participants were recruited via the Diabetes and Endocrine Unit at CHI at TS, (formerly TSCUH) and through the national diabetes advocacy organisation, Diabetes Ireland.

7.3.2.1 Route 1: Recruitment through the Diabetes and Endocrine Unit at TSCUH. Potential participants who met the inclusion criteria for phase two of the study were identified through liaison with TSCUH administrative staff. A survey pack (i.e. cover letter, parent and adolescent information sheets, adolescent questionnaire, and adolescent resource sheet), sent from the TSCUH consultant, was distributed by post to adolescents living with T1D and their parents following their identification as eligible participants though the diabetes and endocrine clinic database. See Appendix P for a copy of the cover letter and Appendix Q for information sheets. In addition, posters containing details of the survey were displayed in the waiting area at the Diabetes and Endocrine Outpatient Clinic at TSCUH (see Appendix R for recruitment poster). Nursing staff and healthcare assistants were provided with information about the surveys and were asked to distribute flyers relating to the research to adolescents, who met the inclusion criteria for phase two, and their parents as they attended their routine outpatient clinic appointments during the data collection period (see Appendix S for recruitment flyer). These flyers ensured that adolescents and parents were aware that they would receive a survey pack posted to their home address. TSCUH staff advised interested parents and adolescents to contact the researchers if they required more information on the survey.

If adolescents with T1D and their parents decided to participate in the study, they were offered the option of completing paper copies of the questionnaires at home and returning them directly to the researcher in the stamped addressed envelope provided or of completing the questionnaire online. It was explained to potential participants that the return of a questionnaire implied parental consent and adolescent assent for adolescent's participation in the survey. If they chose to complete the questionnaires online, they were provided with a link to a Diabetes Ireland web page hosting the survey and the accompanying information sheets and resource sheets. In addition, adolescents with T1D and their parents who participated in the qualitative phase of this research study and gave permission to be contacted and provided contact details (postal addresses, email addresses, and/or phone numbers) were invited to participate in the quantitative phase of this research via telephone calls. A number of these participants attended TSCUH.

7.3.2.2 Route 2: Recruitment through Diabetes Ireland. Adolescents living with T1D and their parents were recruited via advertisements on the Diabetes Ireland website. Links to this web page advertisement were posted on Diabetes Ireland's social media sites (Facebook and Twitter) (see Appendix R). Participants were provided with information regarding the study and were offered the opportunity to either: (1) complete the questionnaire online via a Qualtrics survey link provided on the Diabetes Ireland website; or (2) request a hard copy via email or phone contact with the researcher. Two reminder letters were sent to all potential participants after their initial invitation to participate in the research.

7.4 Questionnaires

The questionnaire for adolescents (see Appendix T) was developed from an amalgamation of existing valid and reliable age appropriate instruments (outlined below). These instruments were selected to establish a profile of adolescents' perspectives on parent-adolescent communication, and T1D-specific family conflict. In addition, adolescent self-management of T1D, division of family responsibility for T1D management tasks, patient activation, and T1D self-efficacy were measured. T1D-specific QOL was also measured. Alongside these instruments, the following demographic details were recorded by adolescents in Section A of the questionnaire (see Appendix T, Section A): age, gender, ethnicity, county of residence, school year and family structure. The following clinical details were also recorded: adolescent's other diagnosed medical conditions, T1D duration, age at diagnosis, mode of insulin administration, blood glucose monitoring methods and metabolic control (i.e. most recent HbA1c result).

All measures, except for the Patient Activation Measure have been successfully implemented with adolescents previously and have been validated with the adolescent age ranges in the current study (i.e. adolescents aged 11 to 17 years). The instruments are listed below. Cronbach's alpha coefficients for the current sample are presented in Appendix U. All instruments achieved adequate reliability in the current sample ($\alpha =$ >.7) with the exception of two subscales which are referred to below.

7.4.1 Parent-Adolescent Communication Scale (PACS) (Section C, Appendix T) – PACS adolescent version (Barnes & Olson, 1985; Huizinga et al., 2005)**.**The PACS is a 20-item scale which assesses the degree of openness of communication and the extent of problems in parent-adolescent communication. In the current study, adolescents filled the form in once for one or both parents. Each subscale contains 10 items. The alpha coefficient for openness of communication is 0.87 and for problems in communication is 0.78 (Barnes & Olson, 1985). Items are responded to on a five-point Likert type scale ranging from “strongly disagree” to “strongly agree.” Higher scores on the openness subscale are indicative of more openness in parent-adolescent communication (more free flowing of information, perceived understanding and satisfaction within interactions). Higher scores on the problems in parent-adolescent communication subscale indicate low problems in parent-adolescent communication (negative aspects of communication and interaction, hesitancy to share, selectivity and caution surrounding interactions). Higher scores for total communication indicate better parent-adolescent communication.

7.4.2 Diabetes Family Conflict Scale–Revised (Section E, Appendix T) – DFCS-R (Hood et al., 2007; Sand et al., 2013)**.** The DFCS-R measures the level of T1D-specific conflict in families around direct management tasks including checking blood glucose, taking insulin, meals and snacks, telling others about diabetes, logging blood glucose results, etc. The measure has been validated with children and adolescents aged 8 to 18 years. It measures T1D-specific conflict around direct management tasks (e.g. checking bloods, administering insulin) and T1D-specific conflict around indirect management tasks (e.g. telling friends, telling relatives, school absences) with alpha coefficients of 0.85 and 0.88 respectively (Hood et al., 2007). A higher total score indicates more T1D specific conflict within the family. Responses are: “almost never”, “sometimes” and “almost always”.

7.4.3 Self-management of Type 1 Diabetes in Adolescents (Section B, Appendix T) – SMODA (Schilling et al., 2009)**.** The SMODA contains 52 items and consists of five subscales: collaboration with parents (range of scores 0-39), diabetes care activities (range of 0-45), diabetes problem solving (range 0-21), diabetes communication (range 0-30) and goals (range 0-21). Higher scores are indicative of better performance in the aforementioned areas. The measure has been validated with adolescents aged 13-21 years with alpha coefficients for each subscale ranging from 0.71 to 0.85 (Schilling et al., 2009). The SMODA has been used previously with adolescents aged 11-14 years (Jaser et al., 2012). Responses are on a 4-point Likert type scale ranging from “never” to “always” and for the goals subscale ranging from “never a goal for me” to “always a goal for me”. In discussion with the scale authors, minor edits (the phrase ‘figure’ was amended to read ‘figure out’ in Item 35, a footnote explaining HbA1c was added and a definition clarifying the meaning of ‘goal’ in the instructions for the second section of the SMODA was included) were made to items and the layout of the survey based on feedback from youth advisors and to reflect linguistic differences in Ireland. As a result of these edits, the scale authors requested that in the current study the measure referred to as Self-Management of Type 1 Diabetes in Adolescents – Ireland version (SMODA-Ireland) to reflect these changes.

7.4.4 Diabetes Family Responsibility Questionnaire (Section D, Appendix T) – DFRQ (Anderson et al., 1990; Kaugars et al., 2011). The DFRQ is a 17-item scale, measuring adolescents’ perceptions of who takes responsibility for T1D-related tasks across three domains of regimen tasks, general health monitoring and social presentation of diabetes. It has been validated for use with children and adolescents aged 6 to 21 years. The alpha coefficient for the total scale is 0.84 (Anderson et al., 1990). Adolescents choose from three responses: “I take responsibility for this almost all of the time”, “My parent(s) and I share responsibility for this about equally” and

“My parent(s) take responsibility for this almost all of the time”. Higher scores are indicative of more parental involvement in management tasks.

7.4.5 Patient Activation Measure (Section H, Appendix T) – PAM (Hibbard et al., 2004, 2005)**.** The PAM-10 UK comprises 10 items, responded to on a 5-point scale. Hibbard et al. (2004) define patient activation as the belief (held by a patient) that the patient plays an important role in the self-management of their own care and maintenance of their health, including collaboration with health care providers. Patients who are activated have the knowledge and skills to manage their condition and to maintain health, collaborate with health care providers, and seek out appropriate care. The measure has not been validated for use with adolescents within this age range. The PAM has been used in one previous study with children and adolescents (age 8-17 years) and Cronbach’s alpha for this sample was 0.73 (Bravo et al., 2020). To the author’s knowledge, the measure has not been used specifically with adolescents living with T1D. Unpublished Rasch analysis conducted by the scale authors, using the data from the sample in this phase of the mixed methods study indicated the validity of the PAM 10-UK within the current sample.

7.4.6 Self-efficacy for Diabetes Management (Section F, Appendix T) – SEDM (Iannotti et al., 2006)**.** The SEDM comprises ten items responded to on a 10-point scale ranging from “not sure at all” to “completely sure”. The SEDM measures self-efficacy for areas of T1D management. The measure has been validated with children and adolescents aged 10 to16 years. Cronbach’s alpha for the scale is 0.90 (Iannotti et al., 2006). A higher score indicates more T1D self-efficacy.

7.4.7 Diabetes Quality of Life for Youth–Short Form (Section G, Appendix T) – DQOLY-SF (Skinner et al., 2006)**.** The DQOLY-SF measures impact of symptoms relating to T1D, impact of treatment, impact on activities, parent issues, worries about diabetes and health perception. Lower scores are indicative of a poorer QOL. Respondents answer on a 5-point scale ranging from “never” to “all of the time”. The final question on health perception is responded to on a 4-point scale. The measure has been tested for construct validity in several countries including Ireland with children and adolescents aged between 10 and 18 years (Skinner et al., 2006). Internal consistency values for Ireland were as follows: impact scales combined ($\alpha = 0.64$), parent issues ($\alpha = 0.76$) and worry ($\alpha = 0.70$) (Skinner et al., 2006). In the current sample, Cronbach’s alpha for two subscales was below the recommended .7 (Impact of symptoms subscale, $\alpha = .66$ and impact of treatment subscale, $\alpha = .50$). However, lower alpha levels in subscales containing a low number of items are considered adequate (Bowling, 2014; Schmitt, 1996). Given the low item numbers (three items) of these subscales, the decision was undertaken to proceed with the use of these subscales in the subsequent analysis undertaken.

7.5 Pilot of Surveys

The employment of several psychometric instruments, with many items for completion, has been previously successfully implemented with adolescent samples such as by Goethals et al. (2020). The final compiled questionnaires were reviewed by the project team, T1D experts and the youth advisory group. The questionnaires were piloted with three adolescents living with T1D, aged 11 years, 13 years and 15 years. The youth advisory group (see Chapter 3, section 3.7) provided feedback on the overall survey including all instruments and provided suggestions in relation to the order of each of the instruments included within the survey. This established clarity of instructions, question readability and understanding, and the length of time taken to complete the survey. Following the pilot, the instruction preceding the PACS (see

Section C, Appendix T) was reformatted so "about your type 1 diabetes" was underlined to emphasise the focus of this scale on T1D.

7.6 Ethical Considerations

Ethical approval was obtained from the research ethics committees at DCU and TSCUH (See Appendix O). Informed consent/assent, confidentiality and data protection were taken into consideration. Survey packs distributed to the parents of eligible participants contained a cover letter asking parents to invite their adolescent child to participate in the survey, adolescent and parent information sheets, adolescent resource sheets and a stamped and addressed envelope for questionnaire returns. Participants were also given the option to fill out the survey online via Qualtrics platform. Participant assent was obtained via a series of 'yes' or 'no' formatted questions at the beginning of the questionnaire. Participants were made aware, via the information sheet attached to the questionnaire, that once their questionnaire was submitted (posted or submitted online) they were no longer able to withdraw from the study. In order to respect adolescents' right to confidentiality, the decision about whether the adolescent wished for a parent to be present during completion of their questionnaire remained at the prospective participant's discretion. Similar to Dyson et al.'s (2010) strategy, participants were asked to provide information regarding whether a parent assisted them with completion of the questionnaire (i.e. yes or no).

7.7 Data Analysis

Data analysis was carried out within SPSS version 25 (IBM Corp, 2019). Descriptive statistics (total scores, ranges, mean scores standard deviations and frequencies, where appropriate) were generated for all outcome measures. Reliability analyses, referred to in section 7.4 previously and available in Appendix U, were conducted using Cronbach's alpha, to evaluate internal consistency of total scales and subscales. Prior to performing statistical analyses, the data were checked for normality through inspection of the skewness and kurtosis values and visual inspection of the normality probability plots generated from the SPSS output. Skewness values falling outside of the range of +1 and -1 are indicative of a skewed distribution and may warrant further investigation (Hair et al., 2019). Within the range of +2 or -2 have also been proposed as adequate (Hoyle, 1995). See Appendix V for skewness and kurtosis values. Where data did not meet the assumptions for parametric statistics, non-parametric statistics were utilised. Some scales indicated a slight skew but based on visual inspection of the plots, which suggested distributions were approximately normal, and considering the sample size, the data were deemed suitable for parametric analysis. In the instance of the DFCS-R, where there was a tendency towards a skewed distribution (DFCS-R skew value = 2.31), both parametric and non-parametric statistics were used in univariate analyses including this measure. There were no differences between the results of parametric and non-parametric tests in the DFCS-R, with the exception of the test for gender differences (see section 8.4).

An overview of the demographic and clinical characteristics of participants was generated. Differences according to clinical and demographic variables were examined using t-tests, ANOVA and correlations. Next, the associations between clinical, demographic, parent-adolescent communication, family conflict, T1D self-efficacy, self-management, division of responsibility for management, patient activation and T1D-specific QOL were examined using correlations. Given the lack of published consistent evidence to form a-priori assumptions, two-tailed correlations were computed. In cases where responses were missing, pairwise deletion was employed (analysis was conducted for cases there was data available for each variable).

A hierarchical logistic regression was carried out to test the ability of parent-adolescent communication, family conflict and T1D self-efficacy to predict high or low HbA1c (low was categorised as up to/including 7.5% and high was categorised as 7.6% or above). Preliminary analyses were conducted to test for the assumptions of normality, linearity, homoscedasticity, independence of residuals and presence of influential cases.

Finally, hierarchical multiple regression analyses were conducted, examining predictive associations between parent-adolescent communication and T1D-specific family conflict to (1) self-management, activation and division of responsibility and (2) T1D-specific QOL. For multiple regression analyses listwise deletion was employed to handle missing data (a case was excluded where any value was missing). Preliminary analyses ensured the assumptions of normality, linearity, homoscedasticity and independence of residuals were met. The data set was also checked for influential cases. It is advised that influential cases be identified through evaluation of multiple methods (Hair et al., 2019). In the current analysis, standardized residuals, standardized DFBeta values and leverage points measured using Mahalanobis distance were consulted. Cook's distance was also assessed to evaluate the impact of an observation on overall model fit. Based on inspection of these values, two cases were identified as influential in the model predicting the DFRQ and the self-management problem solving subscale of the SMODA-I (case 23 and case 67). These cases were excluded from these analyses.

7.8 Conclusion

This chapter described the background to, and method employed in phase two of this study. The next chapter will present the results of the quantitative phase.

Chapter 8: Phase Two: Quantitative Results

8.1 Introduction

In this chapter, results from the quantitative phase of this mixed methods study will be presented. The measures administered are described in section 7.4 of Chapter 7. The aim of this phase was to assess the inter-relationships between parent-adolescent communication (PACS), T1D-specific family conflict (DFCS-R), demographic variables (age, gender), clinical variables (age at diagnosis, insulin administration method, blood glucose monitoring method, T1D duration, self-reported last recorded HbA1c result), T1D self-efficacy (SEDM), self-management (SMODA-I), family division of responsibility for T1D management (DFRQ), patient activation (PAM-10 UK) and T1D-specific QOL (DQOLY-SF).

More specifically, this research sought to examine whether specific family context variables i.e. parent-adolescent communication characteristics (namely perceived openness or problems in parent-adolescent communication and T1D-specific family conflict) contribute to adolescent T1D self-efficacy and in turn adolescent self-management, activation, levels of family responsibility and HbA1c. The research also investigated the relationship between these parent-adolescent communication characteristics and adolescent T1D-specific QOL. Next, the relationship between self-management, patient activation and division of responsibility for T1D management to T1D-specific QOL was examined. The relationship between HbA1c and self-efficacy to self-management and QOL was also investigated. Finally, the ability of parent-adolescent communication and T1D-specific family conflict, self-management and T1D self-efficacy to predict adolescent QOL was examined. The hypotheses of phase two were:

1. More open parent-adolescent communication, fewer problems in parent-adolescent communication and less T1D-specific family conflict will be associated with higher T1D self-efficacy (see section 8.5)
2. More open parent-adolescent communication, fewer problems in parent-adolescent communication, less T1D-specific family conflict and higher T1D self-efficacy, will be associated with more adolescent T1D self-management, higher levels of activation, higher adolescent T1D-related responsibility, and lower HbA1c (see section 8.6)
3. More open parent-adolescent communication, fewer problems in parent-adolescent communication, less T1D-specific family conflict and higher T1D self-efficacy, will be associated with better T1D-specific QOL (see section 8.7)
4. Higher T1D self-efficacy and lower HbA1c, will be associated with better T1D-specific QOL (see section 8.7)
5. Higher T1D self-efficacy, more adolescent T1D self-management, higher levels of activation, and higher adolescent T1D-related responsibility, will be associated with better T1D-specific QOL (see section 8.7)
6. More open parent-adolescent communication, fewer problems in parent-adolescent communication, less T1D-specific family conflict, higher T1D self-efficacy, and more adolescent self-management will be associated with better T1D-specific QOL (see section 8.8)

First, an overview of the demographic and clinical characteristics of participants will be presented. Next, the associations between demographic, clinical, parent-adolescent communication, T1D-specific family conflict, T1D self-efficacy, self-management, division of responsibility for management, patient activation and T1D-specific QOL are examined using correlations. Finally, hierarchical multiple regressions are presented, which examine predictors of (1) self-management, activation and division of responsibility, HbA1C and (2) T1D-specific QOL.

8.2 Sample Description

A total of 166 invitations to participate and hardcopy questionnaires were posted to parents of eligible adolescent patients of two paediatric endocrinologists at CHI at TS (formerly TSCUH) in April and November 2018 (see Chapter 7 for procedure employed). Parents of adolescents who participated in the qualitative interviews, as part of the larger study were informed about the survey of adolescents and were given the opportunity to request a paper copy of the questionnaire or were provided with a link to the online version of the survey. The survey was also advertised to potentially eligible participants online via Diabetes Ireland. The returned questionnaires were filled in on hardcopy paper format (n = 101) and online (n = 12).

Adolescents who completed the survey were aged between 11 and 17 years (M = 13.85 years, SD = 1.78 years). Where their last recorded HbA1c was known or reported (n = 101), the majority of adolescents (81%) reported HbA1c higher than the blood glucose control targets set by ISPAD, for children, adolescents and young adults (< 7%) (DiMeglio et al., 2018). Most adolescents administered insulin via an insulin pump (66%) with the remainder reliant on multiple daily injections (MDI). Sixty-three percent of participants used a flash glucose monitoring system and finger prick test to monitor blood glucose levels, 26% relied only on a finger prick test and 11% reported that they used a continuous glucose monitoring device (CGM) and finger prick test. Five percent of respondents reported having a parent living with T1D and 13% reported a sibling living with T1D. A breakdown of the demographic and clinical characteristics of participants is presented below in Table 8.1.

Table 8.1

Demographic and clinical characteristics of adolescents

Adolescent characteristics	
Gender	*N* (%)
Male	58 (51%)
Female	55 (49%)
Age	*N* (%)
11-13 years	55 (49%)
14-15 years	27 (24%)
16-17 years	31 (27%)
Mean	13.85 years
SD	1.78 years
Range	11-17 years
Age (years) at diagnosis	
Mean	8.19 years
SD	3.37 years
Range	1-16 years
BGM	*N* (%)
Finger prick test only	30 (26%)
Flash glucose monitoring system and finger prick test	71 (63%)
Continuous glucose monitoring system and finger prick test	12 (11%)
Insulin administration	*N* (%)
MDI	39 (34.5%)
Insulin pump	74 (65.5%)
Last HbA1c result	*N* (%)
Less than 6.5% (Less than 48 mmol/mol)	7 (6.2%)
6.6 – 7.0% (49 – 53 mmol/mol)	12 (10.6%)
7.1 – 7.5% (54 – 58 mmol/mol)	20 (17.7%)
7.6 – 8.0% (60 – 64 mmol/mol)	23 (20.4%)
8.1 – 8.5% (65 – 69 mmol/mol)	25 (22.1%)
8.6 – 9.0% (70 – 75 mmol/mol)	6 (5.3%)
9.1 – 9.5% (76 – 80 mmol/mol)	3 (2.7%)
More than 9.5% (More than 80 mmol/mol)	5 (4.4%)
Unknown	9 (8.0%)
Missing	3 (2.7%)
Family history of T1D (Parent with T1D)	*N* (%)
Yes	6 (5.3%)
No	107 (94.7%)

Adolescent characteristics	
Family history of T1D (Sibling with T1D)	
Yes	15 (13.3%)
No	98 (86.7%)

8.3 Descriptive data on parent-adolescent communication, T1D-specific family conflict, self-management and related constructs, and T1D-specific QOL

Descriptive information including means, standard deviations and ranges for total scale and subscale scores of instruments measuring, parent-adolescent communication, T1D-specific family conflict, self-management, division of responsibility for management tasks, T1D self-efficacy, activation and T1D-specific QOL are presented in Table 8.2. Inspection of mean values in Table 8.2 suggested that participants scored highly for openness in parent-adolescent communication (PACS), collaboration with parents (SMODA-I), performance of T1D care activities (SMODA-I), T1D self-efficacy (SEDM) and had low scores for T1D-specific family conflict (DFCS-R) and worries related to T1D (DQOLY-SF).

Table 8.2

Descriptive information for parent-adolescent communication, T1D specific family conflict, self-management, division of responsibility, T1D self-efficacy, activation and QOL measures

Scale/subscale	*M*	*SD*	Range (possible range)	*N*
PACS (parent-adolescent communication)				
Openness in parent-adolescent communication	41.35	7.32	16-50 (10-50)	113
Problems in parent-adolescent communication	33.87	7.69	16-50 (10-50)	113
Total communication	75.21	13.36	34-97 (20-100)	113
DFCS-R (T1D-specific family conflict)	25.44	6.29	19-54 (19-57)	112
SMODA-I (self-management of T1D)				
Collaboration with Parents	21.41	7.86	4-39 (0-39)	113
Care activities	32.98	5.26	20-43 (0-45)	113
Problem solving	15.07	4.54	2-21 (0-21)	113
Communication	18.00	4.94	6-28 (0-30)	113

Scale/subscale	*M*	*SD*	Range (possible range)	*N*
Goals	15.83	3.13	7-21(0-21)	113
DFRQ (division of family responsibility)	31.22	4.91	21-43 (17-51)	112
SEDM (T1D self-efficacy)	72.21	16.28	36-100 (10-100)	112
PAM-10 UK (activation)	63.97	14.52	39-100 (0-100)	113
Frequency of PAM activation levels				113
1: Disengaged and overwhelmed	8 (7.1%)			
2: Becoming aware, but still struggling	31(27.4%)			
3: Taking action	45 (39.8%)			
4: Maintaining behaviours and pushing further	24 (25.7%)			
DQOL-Y SF (T1D-specific quality of life)				
Impact of symptoms	4.14	2.16	0-11 (0-12)	112
Impact of treatment	3.84	2.38	0-11(0-12)	112
Impact on activities	4.92	3.56	0-14 (0-20)	113
Parent issues	5.45	3.21	0-12 (0-12)	113
Worries about diabetes	6.14	5.21	0-25 (0-28)	113
Frequency DQOL-Y Health perception				109
Excellent	42 (38.5%)			
Good	54 (49.5%)			
Fair	12 (11%)			
Poor	1 (0.9%)			

Prior to performing statistical analyses, the data were checked for normality (see section 7.7 for an account of this).

8.4 Testing for differences and associations in outcome variables by demographic and clinical variables

A series of t-tests were conducted to examine differences between adolescent males and females in parent adolescent communication (PACS), T1D-specific family conflict (DFCS-R), self-management (SMODA-I) and related constructs (PAM, SEDM, DFRQ), and T1D-specific QOL (DQOLY-SF). Pearson product moment correlations were used to examine associations between parent adolescent communication, T1D-specific family conflict, self-management and related constructs, and T1D-specific QOL and each of age, age at diagnosis and T1D duration. Spearman's rho was used to test for significant associations with self-reported, last recorded HbA1c, as HbA1c was measured on an ordinal scale. Finally, t-tests and one-way ANOVA tests were used to test for differences in parent adolescent communication, T1D-specific family conflict, self-management and related constructs, and T1D-specific QOL depending on insulin mode of administration and BGM method.

Gender differences are reported in Table 8.3. Significant differences were observed between adolescent males and females for scores on T1D specific family conflict (DFCS-R) and the Worries subscale of the DQOLY-SF. Males reported significantly more family conflict than females; t (112) = 2.29, p = .02. A non-parametric Mann-Whitney U test did not detect a significant difference at p <.05 (p = .08) while the parametric equivalent t-test yielded a significant difference (p = .02) in mean scores on the DFCS-R. Females reported more worries related to T1D than males; t (112) = -2.62, p = .01. There were no other significant differences observed between adolescent males and females.

Table 8.3

Summary of the results of differences in scores on outcome measures by gender

Scale/subscale	*N*	*M (SD)*	*t/U*	*p*
PACS (Openness)				
Male	58	41.19 (7.13)	-.23	.82
Female	55	41.51 (7.58)		
PACS (Problems)				
Male	58	34.12 (7.08)	.36	.72
Female	55	33.60 (8.35)		
PACS (Total Communication)				
Male	58	75.31 (12.46)	.08	.94
Female	55	75.12 (14.36)		
DFCS-R			1265.5 (*U*) /2.29* (*t*)	.08/.02
Male	57	26.74 (7.58)		
Female	55	24.09 (4.25)		
SMODA-I (Collaboration with Parents)				
Male	58	21.84 (8.35)	.61	.55
Female	55	20.95 (7.36)		
SMODA-I (Care Activities)				
Male	58.	33.07 (5.59)	18	.86
Female	55	32.89 (4.95)		
SMODA-I (Problem solving)				
Male	58	14.71 (4.77)	-.88	.38
Female	55	15.45 (4.29)		
SMODA-I (Communication)				
Male	58	18.10 (5.23)	.23	.82
Female	55	17.89 (4.65)		
SMODA-I (Goals)				
Male	58	15.72 (3.12)	-.37	.71
Female	55	15.95 (3.18)		
DFRQ				
Male	57	31.56 (5.16)	.74	.46
Female	55	30.87 (4.66)		
SEDM			1.18	.24
Male	58	73.95 (16.00)		
Female	54	70.33 (16.52)		
PAM-10 UK			.30	.77
Male	58	64.37 (16.44)		
Female	55	63.55 (12.32)		
DQOLY-SF (Impact of symptoms)			-1.42	.16
Male	58	3.86 (1.73)		
Female	54	4.44 (2.52)		
DQOLY-SF (Impact of treatment)			.03	.98
Male	58	3.84 (2.59)		

Scale/subscale	*N*	*M (SD)*	*t/U*	*p*
Female	54	3.83 (2.15)		
DQOLY-SF (Impact on activities)			.51	.61
Male	58	5.09 (3.67)		
Female	55	4.75 (3.47)		
DQOLY-SF (Parent issues)			.11	.92
Male	58	5.48 (3.02)		
Female	55	5.42 (3.43)		
DQOLY-SF (Diabetes worries)			-2.62*	.01
Male	58	4.91 (4.05)		
Female	55	7.44 (6.00)		

**p* < .05. ***p* < .01.

Significant correlations were observed for adolescent age, and collaboration with parents (SMODA-I), problem solving (SMODA-I), goals (SMODA-I), family responsibility (DFRQ), impact on activities (DQOLY-SF) and worries (DQOLY-SF). Older age was significantly associated with less collaboration with parents (*r* = -.49, *p* = <.001), more problem solving (*r* = .34, *p* = <.001), more self-management goals (*r* = .24, *p* = <.01) and less parental involvement in management (*r* = -.64, *p* = <.001). Older age was also associated with less impact on activities (*r* = -.19, *p* = <.05) and more worries (*r* = .23, *p* = <.01). There were no other significant correlations observed (see Table 8.4 below for full results).

Table 8.4

Relationship between outcome variables and age

Scale/subscale	*N*	*r*	*p*
PACS (Openness)	113	-.14	.15
PACS (Problems)	113	-.12	.19
PACS (Total Communication)	113	-.15	.12
DFCS-R	112	.08	.32
SMODA-I (Collaboration with Parents)	113	-.49**	<.001
SMODA-I (Care Activities)	113	-.04	.67
SMODA-I (Problem solving)	113	.34**	<.001
SMODA-I (Communication)	113	.05	.59
SMODA-I (Goals)	113	.24*	.01
DFRQ	112	-.64**	<.001
SEDM	112	.03	.74
PAM-10 UK	113	.28**	.003
DQOLY-SF (Impact of symptoms)	112	.17	.07
DQOLY-SF (Impact of treatment)	112	-.08	.44
DQOLY-SF (Impact on activities)	113	-.19*	.05
DQOLY-SF (Parent issues)	113	-.08	.38
DQOLY-SF (Worries about diabetes)	113	.23*	.01

**p* < .05. ***p* < .01.

Age at diagnosis significantly correlated with levels of responsibility for management (DFRQ). Older age at diagnosis was associated with less parental involvement (*r* = -.23, *p* = .02). No other significant correlations were observed for age at diagnosis (see Table 8.5 for full results of correlations with age at diagnosis).

Table 8.5

Relationship between outcome variables and age at diagnosis

Scale/subscale	*N*	*r*	*p*
PACS (Openness)	113	-.05	.63
PACS (Problems)	113	-.04	.71
PACS (Total Communication)	113	-.05	.64
DFCS-R	112	.01	.997
SMODA-I (Collaboration with Parents)	113	-.18	.06
SMODA-I (Care Activities)	113	.08	.40
SMODA-I (Problem solving)	113	-.08	.39
SMODA-I (Communication)	113	-.03	.76
SMODA-I (Goals)	113	.11	.24
DFRQ	112	-.23*	.02
SEDM	112	.13	.18
PAM-10 UK	113	.13	.17
DQOLY-SF (Impact of symptoms)	112	-.06	.53
DQOLY-SF (Impact of treatment)	112	.02	.85
DQOLY-SF (Impact on activities)	113	-.12	.22
DQOLY-SF (Parent issues)	113	-.17	.08
DQOLY-SF (Worries about diabetes)	113	.03	.79

**p* < .05. ***p* < .01.

T1D duration significantly correlated with problem solving (SMODA-I) (*r* = .27, *p* = .003). Longer duration was associated with more problem solving. No other significant correlations were observed for the duration of T1D (see Table 8.6 for correlations with T1D duration).

Table 8.6

Relationship between outcome variables and T1D duration

Scale/subscale	*N*	*r*	*p*
PACS (Openness)	113	-.03	.77
PACS (Problems)	113	-.03	.74
PACS (Total Communication)	113	-.03	.72
DFCS-R	112	.03	.81
SMODA-I (Collaboration with Parents)	113	-.09	.36
SMODA-I (Care Activities)	113	-.11	.26
SMODA-I (Problem solving)	113	.27**	.003
SMODA-I (Communication)	113	.06	.53
SMODA-I (Goals)	113	.02	.86
DFRQ	112	-.11	.23
SEDM	112	-.12	.23
PAM-10 UK	113	.02	.85
DQOLY-SF (Impact of symptoms)	112	.16	.09
DQOLY-SF (Impact of treatment)	112	-.06	.53
DQOLY-SF (Impact on activities)	113	.02	.87
DQOLY-SF (Parent issues)	113	.13	.17
DQOLY-SF (Worries about diabetes)	113	.10	.29

**p* < .05. ***p* < .01.

Regarding the BGM method, there were no significant differences observed for any outcome measure (see Table 8.7 below).

Table 8.7

Differences in outcome measures by blood glucose monitoring method

Scale/subscale	*N*	*M (SD)*	*F*	*p*
PACS (Openness)			1.03	.36
Finger prick test	30	39.70 (8.59)		
Flash glucose monitoring	71	41.93 (6.50)		
Continuous glucose monitoring system (CGM)	12	42.00 (8.47)		
PACS (Problems)			1.70	.19
Finger prick test	30	32.20 (8.39)		
Flash glucose monitoring	71	34.89 (6.97)		
CGM	12	32.00 (9.45)		
PACS (Total Communication)			1.50	.19
Finger prick test	30	71.90 (14.70)		
Flash glucose monitoring	71	76.82 (12.30)		
CGM	12	74.00 (15.38)		
DFCS-R			.66	.52
Finger prick test	30	26.57 (7.77)		
Flash glucose monitoring	69	25.00 (5.80)		
CGM	11	25.17 (4.91)		
SMODA-I (Collaboration with Parents)			.99	.38
Finger prick test	30	19.70 (7.23)		
Flash glucose monitoring system	71	22.10 (8.09)		
CGM	12	21.58 (7.98)		
SMODA-I (Care Activities)			.05	.95
Finger prick test	30	32.83 (4.74)		
Flash glucose monitoring	71	32.97 (5.89)		
CGM	12	33.42 (4.89)		
SMODA-I (Problem solving)			.96	.39
Finger prick test	30	15.23 (4.39)		
Flash glucose monitoring	71	14.73 (4.83)		
CGM	12	16.67 (2.57)		
SMODA-I (Communication)			1.72	.42
Finger prick test	30	17.07 (5.11)		
Flash glucose monitoring	71	18.30 (5.04)		
CGM	12	18.58 (3.80)		
SMODA-I (Goals)			1.21	.30
Finger prick test	30	16.20 (2.94)		
Flash glucose monitoring	71	15.51 (3.29)		
CGM	12	16.83 (2.48)		
DFRQ			.97	.65
Finger prick test	30	30.23 (4.92)		
Flash glucose monitoring	71	31.54 (5.10)		
CGM	11	31.91 (3.30)		
SEDM			.25	.78
Finger prick test	30	71.77 (16.87)		
Flash glucose monitoring	71	71.86 (16.24)		
CGM	12	75.33 (16.08)		
PAM-10 UK			.38	.69
Finger prick test	30	64.82 (14.84)		
Flash glucose monitoring	71	63.14 (14.44)		
CGM	12	66.73 (15.01)		
DQOLY-SF (Impact of symptoms)			.46	.63

Scale/subscale	*N*	*M (SD)*	*F*	*p*
Finger prick test	30	3.83 (2.28)		
Flash glucose monitoring	70	4.29 (2.20)		
CGM	12	4.08 (1.56)		
DQOLY-SF (Impact of treatment)			.08	.92
Finger prick test	30	3.70 (2.12)		
Flash glucose monitoring	70	3.87 (2.44)		
CGM	12	4.00 (2.83)		
DQOLY-SF (Impact on activities)			2.16	.12
Finger prick test	30	4.63 (3.68)		
Flash glucose monitoring	71	4.70 (3.57)		
CGM	12	6.92 (2.75)		
DQOLY-SF (Parent issues)			.47	.63
Finger prick test	30	5.93 (3.11)		
Flash glucose monitoring	71	5.35 (3.13)		
CGM	12	5.42 (4.01)		
DQOLY-SF (Worries about diabetes)			.26	.77
Finger prick test	30	6.07 (5.00)		
Flash glucose monitoring	69	6.34 (5.46)		
CGM	12	5.17 (4.37)		

$^{*}p < .05$. $^{**}p < .01$.

T-tests were carried out to examine differences between MDI mode of insulin administration and insulin pump. Differences were identified between MDI and insulin pump users for collaboration with parents (SMODA-I), problem solving (SMODA-I), goals (SMODA-I), family responsibility (DFRQ), T1D self-efficacy (SEDM), impact of treatment (DQOLY-SF) and parent issues (DQOLY-SF). MDI users reported significantly more collaboration with parents (t (112) = 3.20, p = .002) and significantly less problem solving than adolescents using an insulin pump (t (112) = -4.76, p = <.001). Adolescents using MDI reported significantly less self-management goals (t (112) = -3.33, p = .001), more parent responsibility for management tasks (t (111) = 2.28, p = .03) and lower T1D self-efficacy (t (111) = -2.69, p = .01) than adolescents who used an insulin pump. MDI users reported greater perceived impact of treatment on QOL; t (111) = 3.52, p = .001. MDI users reported more perceived impact of issues with parents on QOL; t (112) = 2.56, p = .01. The results of all t-tests for differences in insulin mode of administration are reported in Table 8.8.

Table 8.8

Group differences on measures according to insulin mode of administration

Scale/subscale	*N*	*M (SD)*	*t*	*p*
PACS (Openness)			.20	.84
Insulin pump	74	41.24 (7.46)		
MDI	39	41.54 (7.14)		
PACS (Problems)			-.53	.59
Insulin pump	74	34.15 (7.24)		
MDI	39	33.33 (8.55)		
PACS (Total Communication)			-.20	.85
Insulin pump	74	75.39 (12.68)		
MDI	39	74.87 (14.73)		
DFCS-R			1.69	.10
Insulin pump	73	24.63 (5.33)		
MDI	39	26.95 (7.62)		
SMODA-I (Collaboration with Parents)			3.20**	.002
Insulin pump	74	19.76 (7.41)		
MDI	39	24.54 (7.82)		
SMODA-I (Care Activities)			-1.63	.11
Insulin pump	74	33.62 (4.57)		
MDI	39	31.77 (6.26)		
SMODA-I (Problem Solving)			-4.76**	<.001
Insulin pump	74	16.58 (3.27)		
MDI	39	12.21 (5.22)		
SMODA-I (Communication)			.20	.84
Insulin pump	74	17.93 (4.66)		
MDI	39	18.13 (5.49)		
SMODA-I (Goals)			-3.33**	.001
Insulin pump	74	16.51 (2.85)		
MDI	39	14.54 (3.28)		
DFRQ			2.28*	.03
Insulin pump	73	30.47 (4.56)		
MDI	39	32.64 (5.28)		
SEDM			-2.69**	.01
Insulin pump	73	75.15 (15.03)		
MDI	39	66.69 (17.28)		
PAM-10 UK			-1.36	.18
Insulin pump	74	65.31 (13.84)		
MDI	39	61.42 (15.60)		
DQOLY-SF (Impact of symptoms)			-.05	.96
Insulin pump	73	4.15 (1.91)		
MDI	39	4.13 (2.59)		
DQOLY-SF (Impact of treatment)			3.52**	.001
Insulin pump	73	3.29 (2.12)		
MDI	39	4.87 (2.53)		
DQOLY-SF (Impact on activities)			1.80	.07
Insulin pump	74	4.49 (3.35)		
MDI	39	5.74 (3.84)		
DQOLY-SF (Parent issues)			2.56**	.01
Insulin pump	74	4.91 (2.87)		

Scale/subscale	*N*	*M (SD)*	*t*	*p*
MDI	39	6.49 (3.59)		
DQOLY-SF (Worries about diabetes)			.85	.40
Insulin pump	74	5.84 (4.86)		
MDI	39	6.72 (5.83)		

$^*p < .05$. $^{**}p < .01$.

Spearman's rho was used to test for associations between self-reported, last recorded HbA1c and outcomes measured (see Table 8.9). Higher HbA1c was significantly associated with less performance of T1D care activities ($r_s = -.20$, $p = .04$), less problem solving ($r_s = -.21$, $p = .04$), less self-management goals ($r_s = -.40$, $p = <.001$) and lower T1D self-efficacy ($r_s = -.24$, $p = .02$).

Table 8.9

Relationship between outcome variables and HbA1c

Scale/subscale	*N*	r_s	*p*
PACS (Openness)	101	-.09	.39
PACS (Problems)	101	.01	.93
PACS (Total Communication)	101	-.02	.82
DFCS-R	100	.16	.10
SMODA-I (Collaboration with Parents)	101	.14	.17
SMODA-I (Care Activities)	101	-.20*	.04
SMODA-I (Problem Solving)	101	-.21*	.04
SMODA-I (Communication)	101	-.12	.23
SMODA-I (Goals)	101	-.40**	<.001
DFRQ	100	.08	.43
SEDM	100	-.24*	.02
PAM-10 UK	101	-.13	.20
DQOLY-SF (Impact of symptoms)	100	.14	.17
DQOLY-SF (Impact of treatment)	100	.18	.07
DQOLY-SF (Impact on activities)	101	-.10	.31
DQOLY-SF (Parent issues)	101	.07	.47
DQOLY-SF (Worries about diabetes)	101	.10	.32

$^*p < .05$. $^{**}p < .01$.

8.5 Correlations between parent adolescent communication, T1D-specific family conflict, self-management and related constructs, and T1D-specific QOL

Pearson product-moment correlations were conducted to examine the following relationships:

1. Between self-management, division of family responsibility for T1D management, T1D self-efficacy and patient activation
2. Between parent-adolescent communication (openness, problems and total communication) and T1D-specific family conflict
3. Between parent-adolescent communication and T1D-specific family conflict and self-management, division of family responsibility, T1D self-efficacy and patient activation
4. Between parent-adolescent communication, T1D-specific family conflict and T1D-specific QOL
5. Between self-management, division of family responsibility, T1D self-efficacy and activation to T1D-specific QOL

Significant ($p < .05$) bivariate correlations are reported in the text below. All bivariate correlations between variables measured are reported in Table 8.10 below.

8.5.1 Self-management, division of family responsibility, T1D self-efficacy and patient activation

Significant correlations were observed between division of family responsibility (DFRQ) and three subscales of the self-management measure, the SMODA-I. Higher scores on the DFRQ, indicating more parent responsibility for management tasks, were associated with more collaboration with parents (SMODA-I; $r = .71$), less adolescent problem solving (SMODA-I; $r = -.52$), and less self-management goals (SMODA-I; $r = -.46$). More parent responsibility for management tasks was also associated with lower T1D self-efficacy (SEDM; $r = -.27$) and lower patient activation (PAM; $r = -.42$). Higher T1D self-efficacy was associated with more performance of T1D care activities (SMODA-I; $r = .58$), more problem solving (SMODA-I; $r = .41$), more T1D communication (SMODA-I; $r = .45$), more self-management goals (SMODA-I; $r = .49$)

and higher activation (PAM; *r* = .65). Higher activation was also associated with less collaboration with parents (SMODA-I; *r* = -.24), more performance of T1D care activities (SMODA-I; *r* = .37), more problem solving (SMODA-I; *r* = .40), more T1D communication (SMODA-I; *r* = .47) and more self-management goals (SMODA-I; *r* = .55).

8.5.2 Parent-adolescent communication (openness, problems and total communication) and T1D-specific family conflict

Family conflict specific to T1D (DFCS-R) was significantly correlated with problems in parent-adolescent communication and total parent-adolescent communication (the openness and problems subscale of the PACS combined). More problems in communication was significantly associated with less T1D-specific family conflict (*r* = -.23). Better total parent-adolescent communication was also significantly associated with less T1D-specific family conflict (*r* = -.22). There was no significant relationship observed between openness in parent-adolescent communication and T1D-specific family conflict.

8.5.3 Parent-adolescent communication, T1D-specific family conflict, to self-management, division of family responsibility, patient activation and T1D self-efficacy

Significant relationships between self-management and related measures and the measures of communication and T1D-specific family conflict (DFCS-R) were observed. More openness in parent-adolescent communication (PACS) was significantly correlated with more collaboration with parents (SMODA-I; *r* = .23), more performance of T1D care activities (SMODA-I; *r* = .26), more T1D communication (SMODA-I; *r* = .33) and self-management goals (SMODA-I; *r* = .24). More openness was also associated with higher T1D self-efficacy (SEDM; *r* = .28) and higher activation (PAM; *r* = .31).

Fewer problems in parent-adolescent communication was significantly correlated with more collaboration with parents (SMODA-I; *r* = .30), more performance of T1D care activities (SMODA-I; *r* = .28) and higher T1D self-efficacy (SEDM; *r* = .24).

Better total parent-adolescent communication was significantly correlated with more collaboration with parents (SMODA-I; *r* = .30), more T1D care activities (SMODA-I; *r* = .31), more self-management problem solving (SMODA-I; *r* = .31), higher T1D self-efficacy (SEDM; *r* = .30) and higher activation (PAM; *r* = .28).

Higher levels of reported T1D-specific family conflict (DFCS-R) was significantly correlated with less performance of T1D care activities (SMODA-I; *r* = -.32), less T1D communication (SMODA-I; *r* = -.22), less self-management goals (SMDOA-I; *r* = -.21) and lower T1D self-efficacy (SEDM; *r* = -.28). There were no significant correlations identified between division of family responsibility and openness in parent-adolescent communication, problems in parent-adolescent communication, total parent-adolescent communication or T1D-specific family conflict.

8.5.4 Parent-adolescent communication, T1D-specific family conflict and T1D-specific QOL

Significant correlations were identified between QOL (DQOLY-SF) subscales and parent-adolescent communication (PACS) and T1D-specific family conflict (DFCS-R). More openness in parent-adolescent communication (PACS) was associated with less impact of T1D on activities (*r* = -.22), less parent issues (*r* = -.46) and less worries related to T1D (*r* = -.23). Fewer problems in parent-adolescent communication (PACS) was significantly associated with less perceived impact of treatment (*r* = -.23), less impact on activities (*r* = -.24), less parent issues (*r* = -.51) and less T1D related worries (*r* = -.31). Better perceived total parent-adolescent communication (PACS) was associated with less perceived impact of treatment (*r* = -.20), less perceived impact on activities (*r* = -.26), less parent issues (*r* = -.54) and less T1D worries (*r* = -.31). More T1D-specific family conflict (DFCS-R) was associated with more perceived impact of symptoms (*r* = .25), impact of treatment (*r* = .27) and parent issues (*r* = -.38).

8.5.5 Self-management, division of family responsibility, activation and T1D self-efficacy to T1D-specific QOL

A significant correlation was observed between more collaboration with parents (SMODA-I) and more perceived impact of treatment (*r* = .23). More performance of T1D care activities (SMODA-I) was associated with less perceived impact of treatment (*r* = -.20) and less parent issues (*r* = -.30). More T1D communication (SMODA-I) was associated with less parent issues (*r* = -.21). More self-management goals (SMODA-I) was associated with less perceived impact of treatment (*r* = -.22) and less parent issues (*r* = -.21). More perceived parental involvement in T1D care was associated with more perceived impact of treatment (*r* = .19) and less worries related to T1D (*r* = -.26). Higher T1D self-efficacy (SEDM) was associated with lower scores for perceived impact of treatment (*r* = -.31), lower perceived parent issues (*r* = -.27) and lower worries (*r* = -.28). Higher patient activation (PAM) was associated with less perceived impact of treatment (*r* = -.30), impact on activities (*r* = -.26) and less perceived parent issues (*r* = -.19).

Table 8.10

Pearson product-moment correlations between parent-adolescent communication, T1D-specific conflict, self-management and related constructs and T1D-specific QOL

Scale	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17
1 PACS (Openness)		.58**	.88**	-.16	.23*	.26**	.01	.33**	.24*	.13	.28**	.31**	-.14	-.12	-.22*	-.46**	-.23*
2 PACS (Problems)			.90**	-.23*	.30**	.28**	-.04	.10	-.02	.18	.24**	.18	-.16	-.23*	-.24**	-.51**	-.31**
3 PACS (Total Communication)				-.22*	.30**	.31**	-.01	.24*	.12	.18	.30**	.28**	-.17	-.20*	-.26**	-.54**	-.31**
4 DFCS-R (T1D family conflict)					.06	-.32**	-.04	-.22*	-.21*	.06	-.28**	-.06	.25**	.27**	.08	.38**	.10
5 SMODA-I (Collaboration with parents)						0.12	-.41**	.07	-.30**	.71**	-.11	-.24**	-.10	.23*	.15	.01	-.18
6 SMODA-I (Care Activities)							.30**	.43**	.42**	-.11	.58**	.37**	-.16	-.20*	-.05	-.30**	-.12
7 SMODA-I (Problem Solving)								.35**	.47**	-.52**	.41**	.40**	.15	-.18	-.07	.003	.16
8 SMODA-I (Communication)									.45**	-.17	.45**	.47**	.03	-.04	.02	-.21*	.02

Scale	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17
9 SMODA-I (Goals)										-.46**	.49**	.55**	-.03	-.22*	-.17	-.21*	.04
10 DFRQ (family responsibility)											-.27**	-.42**	-.12	.19*	.13	.02	-.26**
11 SEDM (T1D self-efficacy)												.65**	-.13	-.31**	-.10	-.27**	-.28**
12 PAM (activation)													-.16	-.30**	-.26**	-.19*	-.13
13 DQOLY-SF (Impact of symptoms)														.45**	.32**	.23*	.47**
14 DQOLY-SF (Impact of treatment)															.60**	.44**	.38**
15 DQOLY-SF (Impact on activities)																.37**	.14
16 DQOLY-SF (Parent issues)																	.28**
17 DQOLY-SF (Worries)																	

**p* < .05. ***p* < .01.

8.6 Predicting T1D self-management, division of family responsibility, activation and HbA1c

Hierarchical multiple regression was used to examine the association between three blocks of predictor variables: (1) demographic and clinical, (2) openness in communication and problems in communication (subscales of the PACS) and T1D-specific family conflict (DFCS-R), (3) T1D self-efficacy (SEDM), with self-management of T1D (subscales of the SMODA-I), patient activation (PAM) and division of family responsibility for T1D management tasks (DFRQ). In hierarchical multiple regression analysis, predictor variables are entered individually or in blocks and are assessed in terms of the contribution they make to explain the specified outcome variable (Tabachnick & Fidell, 2013). The ability of the three blocks of predictor variables to predict HbA1c was examined using hierarchical binary logistic regression.

Independent variables were entered based on the hypotheses of this phase of this study and Individual and Family Self-Management Theory (IFSMT), described previously, which outlines how contextual (e.g. age, gender, medical regimen, family context, etc.) and process variables (e.g. beliefs, knowledge, self-regulation, self-efficacy) contribute to self-management (Ryan & Sawin, 2009; Verchota & Sawin, 2016). IFSMT outcomes include self-management, health status and QOL (Ryan & Sawin, 2009). The analysis sought to gain clarity on how context and process variables are related to self-management and QOL outcomes. Demographic and clinical variables (age, gender, duration of T1D and mode of insulin administration) identified by previous research as important influences of T1D outcomes for adolescents were grouped together as context variables. Previous research and IFSMT informed the selection of these variables for inclusion. Research has identified gender as associated with adherence to self-care in adolescents living with T1D (Almeida et al., 2019; Austin et al., 2011; Naar-King et al., 2006). Gender has also been identified as a correlate to health-related QOL for adolescents (Lawrence et al., 2012). Regimen complexity, specifically use of insulin pump devices over MDI, has been previously associated with self-management behaviours and QOL for adolescents living with T1D (Hilliard, Wu, et al., 2013; Modi et al., 2012; Verchota & Sawin, 2016). Only T1D duration was included due to the presence of high tolerance values, indicative of multicollinearity, in preliminary models, which included both T1D duration and age at diagnosis.

The preliminary analyses ensuring the assumptions of normality, linearity, homoscedasticity and independence of residuals were met and influential cases were identified are described in Chapter 7, 7.7.

The results of the hierarchical regression analyses are presented in Table 8.11. The analysis sought to determine what variables make the most unique contribution to self-management of T1D, division of family responsibility for management tasks and activation. Clinical and demographic variables were entered at step 1 (gender, age, T1D duration and mode of insulin administration). Parent-adolescent communication and family conflict variables were entered at step 2 (openness in parent-adolescent communication, extent of problems in parent-adolescent communication and T1D-specific family conflict). Finally, T1D self-efficacy was entered at step 3.

For the collaboration with parents (SMODA-I subscale) model, the demographic and clinical variables (gender, age, T1D duration, insulin mode) in step 1 accounted for 34% of the variance in collaboration with parents scores and was significant. After entering openness in communication, problems in communication and family conflict variables at step 2, a further 7% of the variance was accounted for, which was significant. The addition of T1D self-efficacy at step 3 of the model did not contribute to a significant amount of additional explained variance (<1% additional variance explained). In the final model, younger age, use of MDI and fewer problems in parent-adolescent communication remained significantly associated with more collaboration with parents. Overall, the final model explained 41% of the variance in collaboration with parents (*F* (8, 102) = 8.99, *p* < .001).

In the model predicting TID care activities (SMODA-I subscale), blocks 2 and 3 were significant contributors to the model. The demographic and clinical variables entered at step 1 did not make a significant contribution and explained 6% of the variance. After entering openness in parent-adolescent communication, problems in parent-adolescent communication and family conflict at step 2, an additional 13% of the variance in T1D care activities was explained, which was significant. Step 3 explained an additional and significant 18% of the variance in T1D care activities. In the final model, only T1D self-efficacy made a significant contribution to the model with higher T1D self-efficacy associated with more performance of T1D care activities. The final model explained 37% of the variance in T1D care activities (*F* (8, 102) = 7.48, *p* < .001).

In the model predicting problem solving (SMODA-I), the demographic and clinical variables entered at step 1 explained 34% of the variance in problem solving, which was significant. The addition of parent-adolescent communication and conflict at step 2 did not make a significant contribution to the model and explained an additional 1% of the variance in problem solving. The addition of T1D self-efficacy at step 3 made a significant contribution explaining an additional 11% of the variance in problem solving. In the final model, older age, insulin pump use and higher T1D self-efficacy was associated with more problem solving. Overall, the final model explained 46% of the variance in self-management problem solving (*F* (8, 100) = 10.53, *p* < .001).

In the model predicting T1D communication (SMODA-I subscale), the demographic and clinical variables entered at step 1 did not make a significant contribution to the model, explaining 1% of the variance. After entering parent-adolescent communication variables and T1D-specific family conflict at step 2, an additional 18% of variance was explained which was significant. At step 3, an additional 14% of variance was explained. In the final model, mode of insulin administration, openness in communication and T1D self-efficacy were significantly associated with T1D communication. Use of MDI, more openness in communication and more T1D self-efficacy was associated with more T1D communication. The final model explained 33% of the variance in T1D communication (F (8, 102) = 6.29, $p < .001$).

In the self-management goals (SMODA-I subscale) model, the demographic and clinical variables entered at step 1 explained 17% of the variance, which was significant. After entering open communication, problems in communication and family conflict variables at step 2, an additional 14% of the variance in goals was explained, which was significant. The addition of T1D self-efficacy at step 3 was significant and contributed to an additional 11% of variance in self-management goals. In the final model, older age, use of an insulin pump, more openness, more problems in parent-adolescent and more T1D self-efficacy were associated with self-management goals. The final model explained 42% of the variance in self-management goals (F (8, 102) = 9.37, $p < .001$).

In the model predicting division of responsibility for T1D management (DFRQ), the demographic and clinical variables entered at step 1 explained a significant 46% of the variance in scores on the DFRQ. At step 2, the addition of open communication, problems in communication and family conflict contributed significantly to an additional 5% of variance explained in family responsibility for T1D management. At step 3, the addition of T1D self-efficacy explained an additional 3% of the variance, which was significant. In the final model, younger age and lower T1D self-efficacy were associated with more parent involvement in management. The final model explained 53% of the variance in family responsibility for management (*F* (8, 99) = 13.87, *p* < .001).

In the patient activation (PAM) model, the demographic and clinical variables entered at step 1 explained 10% of the variance, which was significant. In step 2, the addition of open communication, problems in communication and family conflict explained an additional 13% of the variance in patient activation, which was significant. At step 3, an additional 31% of variance was explained when T1D self-efficacy was included in the model, which was significant. In the final model, more openness and more T1D self-efficacy were significantly associated with more activation. The final model explained 54% of the variance in activation (*F* (8, 102) = 15.04, *p* < .001).

Table 8.11

Hierarchical multiple regression analyses predicting self-management (subscales of the SMODA-I), division of family responsibility (DFRQ) and activation (PAM)

	Collaboration with parents (SMODA-I)		Care activities (SMODA-I)		Problem solving (SMODA-I)		Communication (SMODA-I)		Goals (SMODA-I)		Division of Family Responsibility (DFRQ)		Patient Activation (PAM)	
Predictor	ΔR^2	β	ΔR^2	β	ΔR^2	β	ΔR^2	β	ΔR^2	β	ΔR^2	β	ΔR^2	β
Step1:	.34**		.06		.34**		.01		.17**		.46**		.10*	
Gender		-.08		-.02		.07		-.02		.06		-.10		-.03
Age		-.51**		-.03		.32**		.05		.27**		-.66**		.29**
T1D duration		.15		-.18		.03		.07		-.18		.13		-.07
Insulin mode		-.33**		.23*		.46**		-.04		.36**		-.23**		.16
Step 2:	.07**		.13**		.01		.18**		.14**		.05*		.13**	
Gender		-.04		-.07		.06		-.09		-.002		-.06		-.04
Age		-.48**		.02		.32**		.10		.30**		-.65**		.34**
T1D duration		.14		-.14		.03		.10		-.16		.12		-.07
Insulin mode		-.33**		.18		.46**		-.08		.35**		-.19*		.16
Openness in communication (PACS)		.01		.16		.09		.42**		.43**		-.03		.36**
Problems in communication (PACS)		.27**		.09		-.09		-.16		-.29**		.20*		.001

	Collaboration with parents (SMODA-I)		Care activities (SMODA-I)		Problem solving (SMODA-I)		Communication (SMODA-I)		Goals (SMODA-I)		Division of Family Responsibility (DFRQ)		Patient Activation (PAM)	
Family Conflict (DFCS-R)		.09		-.25*		-.03		-.24*		-.16		.19*		-.01
Step 3:	.003		.18**		.11**		.14**		.11**		.03*		.31**	
Gender		-.05		-.003		.12		-.03		.05		-.08		.05
Age		-.47**		-.04		.26**		.05		.25**		-.62**		.26
T1D duration		.13		-.05		.12		.18		-.09		.08		.06
Insulin mode		-.31**		.03		.35**		-.21*		.24**		-.14		-.03
Openness in communication (PACS)		.03		.04		-.01		.31**		.33**		.02		.20*
Problems in communication (PACS)		.27**		.08		-.07		-.18		-.30**		.19		-.02
Family Conflict (DFCS-R)		.08		-.15		.16		-.15		-.08		.10		.13
T1D Self-efficacy (SEDM)		-.06		.49**		.43**		.43**		.38**		-.20*		.65**
Total R^2	.41		.37		.46		.33		.42		.53		.54	
n	111		111		109		111		111		108		111	

ΔR^2 = R squared change, **p*<.05. ***p*<.01.

A hierarchical logistic regression was carried out to test the ability of parent-adolescent communication, T1D-specific family conflict and T1D self-efficacy to predict high or low HbA1c (low was categorised as up to/including 7.5% and high was categorised as 7.6% or above). Hierarchical logistic regression was used to examine the association between three blocks of predictor variables: (1) demographic and clinical, (2) openness in communication and problems in communication (subscales of the PACS) and T1D-specific family conflict (DFCS-R) and (3) T1D self-efficacy (SEDM) in predicting high or low HbA1c. The model containing all predictors did not reach statistical significance, chi-square (8, *n* = 101) = 10.79, *p* = .21, indicating the model was unable to distinguish between high HbA1c and lower HbA1c. The addition of variables at blocks 1, 2 or 3 did not contribute to a significant improvement. No independent variable made a significant contribution at steps 1, 2 or 3. See Table 8.12 for results of hierarchical logistic regression.

Table 8.12

Logistic regression predicting HbA1c (up to/including 7.5% or 7.6% or above)

Predictor	*B*	*SE*	Wald	*p*	Odds Ratio	95% C.I. for Odds Ratio
Block 0: Constant	.43	.21	4.34	.04	1.54	
Block 1:						
Gender	.24	.43	.31	.58	1.27	.55 – 2.92
Age	.06	.12	.27	.60	1.06	.84 – 1.34
T1D duration	.08	.08	1.00	.30	1.08	.93 – 1.26
Insulin mode	.51	.49	1.07	.30	1.66	.64 – 4.32
Constant	-1.15	1.66	.48	.49	.32	
Block 2:						
Gender	-.001	.44	<.001	.998	1.00	.42 – 2.39
Age	.05	.12	.19	.66	1.06	.83 – 1.34
T1D duration	.06	.08	.57	.45	1.06	.91 – 1.24
Insulin mode	.34	.52	.43	.51	1.41	.51 – 3.88
Openness in communication (PACS)	-.02	.04	.44	.51	0.98	.91 – 1.05
Problems in communication	.03	.03	.83	.36	1.03	.97 – 1.10

Predictor	*B*	*SE*	Wald	*p*	Odds Ratio	95% C.I. for Odds Ratio
(PACS)						
Family Conflict (DFCS-R)	.09	.05	3.10	.08	1.09	.99 – 1.21
Constant	-3.08	2.76	1.24	.27	.05	
Block 3:						
Gender	.13	.46	.07	.79	1.13	.46 – 2.79
Age	.10	.13	.62	.43	1.11	.86 – 1.42
T1D duration	.03	.08	.12	.73	1.03	.88 – 1.21
Insulin mode	.12	.54	.05	.82	1.13	.39 – 3.25
Openness in communication (PACS)	-.01	.04	.02	.90	1.00	.93 – 1.07
Problems in communication (PACS)	.03	.04	.88	.35	1.03	.97 – 1.11
Family Conflict (DFCS-R)	.06	.05	1.67	.20	1.06	.97 – 1.16
T1D Self-efficacy (SEDM)	-.03	.02	3.61	.06	.97	.94 – 1.00
Constant	-.1.33	2.82	.22	.64	.27	

8.7 Predicting T1D-specific QOL

Hierarchical multiple regressions were conducted to investigate associations between openness in parent-adolescent communication, problems in parent-adolescent communication, T1D-specific family conflict, T1D self-efficacy, self-management of T1D, patient activation, HbA1c and T1D-specific QOL. Preliminary analyses ensured the assumptions of normality, linearity, homoscedasticity and independence of residuals were met. There were also no influential cases identified. Again, drawing on the hypotheses of this phase of this study and IFSMT, described previously, context variables were controlled for at step 1 for each analysis (gender, age, T1D duration and mode of insulin administration). Variables were entered in blocks according to whether they were considered clinical or demographic, family contextual, or proximal or distal outcomes related to self-management (Ryan & Sawin, 2009). Considering the sample size and the appropriate number of predictors, separate hierarchical multiple regression analyses were undertaken, rather than the incorporation of all independent variables within one model. For example, the associations between different categories of predictor variables (e.g. self-management and activation as a proximal outcome, HbA1c as a distal outcome) to T1D-specific QOL were investigated in separate regressions. Furthermore, self-efficacy as a self-management process was investigated separately and with different self-management outcomes as a predictor variable to T1D-specific QOL in separate regressions.

In this section, in the first instance, hierarchical multiple regression was used to examine the association between three blocks of predictor variables: (1) demographic and clinical, (2) openness in communication and problems in communication (subscales of the PACS) and T1D-specific family conflict (DFCS-R), (3) T1D self-efficacy (SEDM), with adolescent QOL (the subscales of the DQOLY-SF). Parent-adolescent communication and family conflict, which were considered family context variables, were entered at step 2. T1D self-efficacy as a T1D process variable was entered at step 3.

The next set of analyses used hierarchical multiple regression to examine the association between three blocks of predictor variables: (1) demographic and clinical, (2) T1D self-efficacy (SEDM), and (3) self-management (subscales of the SMODA-I) and activation (PAM) with adolescent QOL (the subscales of the DQOLY-SF). T1D self-efficacy was entered in a separate block to self-management in the hierarchical multiple regression analyses predicting T1D-specific QOL. T1D self-efficacy was entered separately to reflect its distinctness from self-management as a self-management process variable and in order to determine its individual contribution to explaining the variance in T1D-specific QOL. The DFRQ was not included in these analyses in block 3 along with other self-management constructs due to being highly correlated (*r* > .7) with collaboration with parents (subscale of the SMODA-I).

The final set of analyses in this section examine the predictive associations between T1D self-efficacy and last recorded HbA1c (up to/including 7.5% and 7.6% and above) and adolescent QOL (the subscales of the DQOL-SF). Demographic and clinical variables were entered at step 1. T1D self-efficacy was entered at step 2. HbA1c was considered a distal outcome and entered at step 3.

For the first set of analyses in this section, hierarchical multiple regressions were conducted to investigate the role of parent-adolescent communication (openness and extent of problems in communication) and T1D-specific family conflict, and T1D self-efficacy in predicting T1D-specific QOL (subscales of the DQOLY-SF; impact of symptoms, impact of treatment, impact on activities, parent issues and worries related to T1D) having controlled for demographic and clinical variables (See Table 8.13). Gender, age, T1D duration and mode of insulin administration were entered at step 1. At step 2, openness in parent-adolescent communication, problems in parent-adolescent communication and family conflict were entered. At step 3, T1D self-efficacy was entered.

For the impact of symptoms (DQOLY-SF) model, the demographic and clinical variables (gender, age, T1D duration, insulin mode) in step 1 accounted for 7% of the variance in impact of symptoms, which was non-significant. Openness, problems in parent-adolescent communication and family conflict were added at step 2 and accounted for an additional 7% of variance explained, which reached significance. Adding T1D self-efficacy at step 3 of the model did not contribute to a significant amount of additional variance (<1%). In the final model, family conflict remained significantly associated with impact of symptoms. The final model explained 14% of the variance in impact of symptoms (*F* (8, 102) = 2.02, *p* < .05).

Where impact of treatment (DQOLY-SF) was the dependent variable, step 1 accounted for 8% of the variance explained and reached significance. At step 2, an additional and significant 8% of variance was explained. Following the addition of T1D self-efficacy, non-significant 2% additional variance was explained. In step 3, only insulin mode of administration remained significantly associated with impact of treatment. The final model explained 18% of the variance in impact of treatment (*F* (8, 102), = 3.45, *p* < .001).

In the analysis where impact on activities (DQOLY-SF) was entered as the dependent variable, step 1 explained 8% of the variance and did not reach significance. At step 2, an additional 8% of variance was explained, which reached significance. The addition of T1D self-efficacy at step 3 explained a non-significant <1% additional variance. In step 3, only younger age and use of MDI was significantly associated with more impact on activities. The final model explained 17% of the variance in impact on activities (*F* (8, 102) = 2.55, *p* < .01).

For the parent issues subscale (DQOLY-SF) model, the demographic and clinical variables entered in step 1 explained 7% of the variance, which was non-significant. The addition of openness in parent-adolescent communication, problems in parent-adolescent communication and family conflict at step 2 explained an additional and significant 35% of variance explained. The addition of T1D self-efficacy explained <1% additional variance and was not significant. Less openness, more problems and more family conflict remained significantly associated with more perceived parent issues at this step. The final model explained 41% of the variance in parent issues (*F* (8, 102) = 9.00, *p* <.001).

For the worries (DQOLY-SF) model, the demographic and clinical variables entered at step 1 explained a significant 13% of the variance in worries scores. At step 2, an additional and significant 8% of variance in worries was explained, following the addition of openness in parent-adolescent communication, problems in parent-adolescent communication and family conflict. At step 3, the addition of T1D self-efficacy explained an additional, non-significant 3% of the variance in worries. Female gender and older age were significantly associated with more worries at step 3. The final model explained 23% of the variance in worries (*F* (8, 102) = 3.84, *p* < .001).

Table 8.13

Openness in parent-adolescent communication, problems in parent adolescent communication, family conflict and T1D self-efficacy predicting QOL

	Impact of symptoms (DQOLY-SF)		Impact of treatment (DQOLY-SF)		Impact on activities (DQOLY-SF)		Parent issues (DQOLY-SF)		Worries (DQOLY-SF)	
Predictor	ΔR^2	β	ΔR^2	β	ΔR^2	β	ΔR^2	β	ΔR^2	β
Step1:	.07		.08*		.08		.07		.13**	
Gender		.11		-.004		-.06		.01		.24*
Age		.15		-.08		-.21*		.10		.22*
T1D duration		.14		.08		.14		-.07		.07
Insulin mode		-.05		-.35**		-.21*		-.21*		-.12
Step 2:	.07*		.08*		.08*		.35**		.08*	
Gender		.16		.03		-.07		.05		.24*
Age		.12		-.12		-.26**		.01		.18
T1D duration		.11		.05		.14		-.11		.06
Insulin mode		.01		-.30*		-.21*		-.14		-.09
Openness in communication (PACS)		-.05		-.01		-.16		-.25**		-.08
Problems in communication (PACS)		-.04		-.18		-.18		-.30**		-.22

	Impact of symptoms (DQOLY-SF)	Impact of treatment (DQOLY-SF)	Impact on activities (DQOLY-SF)	Parent issues (DQOLY-SF)	Worries (DQOLY-SF)
Family Conflict (DFCS-R)	.25*	.19*	-.03	.26**	.05
Step 3:	<.001	.02	.004	.001	.03
Gender	.16	.01	-.06	.05	.21*
Age	.12	-.10	-.27**	.01	.20*
T1D duration	.10	.02	.15	-.12	.02
Insulin mode	.01	.25*	-.24*	-.13	-.04
Openness in communication (PACS)	-.05	.03	-.18	-.24*	-.03
Problems in communication (PACS)	-.04	-.17	-.18	-.30**	-.21
Family Conflict (DFCS-R)	.24*	.16	-.01	.25**	.01
T1D Self-efficacy (SEDM)	-.02	-.16	.08	-.04	-.19
Total R^2	.14	.18	.17	.41	.23
n	111	111	111	111	111

ΔR^2 = R squared change, *p<.05. **p<.01.

Next, hierarchical regression analysis was used to examine associations between T1D self-efficacy (SEDM), self-management (SMODA-I) and activation (PAM) and T1D-specific QOL (each of the subscales of the DQOLY-SF; impact of symptoms, impact of treatment, impact on activities, parent issues and worries related to T1D). The results of these analyses are presented in Table 8.14. Again, clinical and demographic variables (gender, age, T1D duration and insulin mode) were entered at step 1. T1D self-efficacy was entered at step 2. Self-management (subscales of the SMODA-I) and activation (PAM) were entered in the final step. Again, the DFRQ was not included in these analyses in block 3 along with other due to being highly correlated ($r > .7$) with the collaboration with parents, subscale of the SMODA-I.

In the model predicting impact of symptoms, step 1 explained a non-significant 6% of the variance in impact of symptoms. The addition of T1D self-efficacy at step 2 explained an additional and non-significant 1% additional variance in impact of symptoms. The addition of self-management and activation at step 3 explained <1% additional variance, which was also non-significant. Less activation was significantly associated with more impact of symptoms at step 3. The final model explained 15% of the variance in impact of symptoms (F (11, 100) = 1.63, p = .10).

Where impact of treatment (DQOLY-SF) was the dependent variable, step 1 accounted for 11% of the variance explained and reached significance. At step 2, an additional and significant 5% of variance was explained. Following the addition of self-management (subscales of the SMODA-I) and activation (PAM), 5% additional variance was explained not reaching significance. At this step, only insulin mode of administration remained significantly associated with impact of treatment. The final model explained 21% of the variance in impact of treatment (F (11, 100), = 2.48, p < .01).

In the model predicting impact on activities (DQOLY-SF), step 1 explained a non-significant 8% of the variance in impact on activities. The addition of the T1D self-efficacy at step 2 explained a non-significant <1% additional variance. Following the addition of the self-management subscales (SMODA-I) and activation (PAM), a non-significant 7% additional variance was explained. At this step, MDI and lower activation were significantly associated with more impact on activities. The final model explained 15% of the variance in impact on activities (*F* (11, 100), = 1.64, *p* = .10).

In the model predicting parent issues (DQOLY-SF), step 1 explained a non-significant 7% of the variance in parent issues. The addition of the T1D self-efficacy (SEDM) at step 2 explained a significant, additional 6% variance. Following the addition of self-management and activation (SMODA-I and PAM), an additional and significant 12% variance was explained. At this step, only more self-management problem solving was associated with more parent issues. The final model explained 25% of the variance in parent issues (*F* (11, 100), = 2.95, *p* < .01).

In the model predicting worries (DQOLY-SF), step 1 explained 13% of the variance in worries, which was significant. The addition of T1D self-efficacy (SEDM) at step 2 explained an additional and significant 6% variance. Following the addition of self-management and activation (SMODA-I and PAM), an additional and significant 8% variance was explained. At this step, female gender and lower self-efficacy were significantly associated with more worries. The final model explained 26% of the variance in worries (*F* (11, 100), = 3.25, *p* < .01).

Table 8.14

T1D Self-efficacy, T1D self-management and activation predicting QOL

	Impact of symptoms (DQOLY-SF)		Impact of Treatment (DQOLY-SF)		Impact on activities (DQOLY-SF)		Parent issues (DQOLY-SF)		Worries (DQOLY-SF)	
Predictor	ΔR^2	β	ΔR^2	β	ΔR^2	β	ΔR^2	β	ΔR^2	β
Step1:	.06		.11*		.08		.07		.13**	
Gender		.12		-.01		-.06		.01		.24*
Age		.15		-.09		-.21*		.10		.22*
T1D duration		.13		.08		.15		-.07		.07
Insulin mode		-.05		-.35**		-.22*		-.21*		-.12
Step 2:	.01		.05*		.001		.06**		.06**	
Gender		.11		-.03		-.06		-.01		.22*
Age		.16		-.07		-.21*		.12		.24**
T1D duration		.11		.03		.14		-.14		.004
Insulin mode		-.01		-.27**		-.21		-.12		-.03
T1D Self-efficacy (SEDM)		-.11		-.24*		-.03		-.26**		-.26**
Step 3:	.08		.05		.07		.12*		.08	
Gender		.11		-.02		-.06		-.02		.18*
Age		.17		.02		-.17		.07		.13
T1D duration		.06		-.03		.13		-.19		-.01
Insulin mode		-.06		-.25*		-.26*		-.22		-.15

	Impact of symptoms (DQOLY-SF)	Impact of Treatment (DQOLY-SF)	Impact on activities (DQOLY-SF)	Parent issues (DQOLY-SF)	Worries (DQOLY-SF)
T1D Self-efficacy (SEDM)	.05	-.13	.14	-.15	-.36*
Collaboration with parents (SMODA-I)	.02	.16	-.04	.13	-.12
Care activities (SMODA-I)	-.16	-.13	-.01	-.23	.04
Problem solving (SMODA-I)	.20	.13	.13	.40*	.23
Communication (SMODA-I)	.13	.11	.10	-.16	.11
Goals (SMODA-I)	<.001	.02	-.03	-.06	.09
Activation (PAM)	-.30*	-.21	-.36*	-.01	-.14
Total R^2	.15	.21	.15	.25	.26
n	112	112	112	112	112

ΔR^2 = R squared change, *p<.05. **p<.01.

The relationship between T1D self-efficacy and HbA1c to QOL was also examined using hierarchical multiple regression. The results of these analyses are summarised in Table 8.15. Demographic variables were added in step 1. T1D self-efficacy (SEDM) was entered at step 2 and HbA1c (up to/including 7.5% or 7.6% and above) was added at step 3.

In the model predicting impact of symptoms (DQOLY-SF), step 1 explained a significant 10% of the variance in impact of symptoms. The addition of T1D self-efficacy explained an additional and non-significant 1% in variance in impact of symptoms. HbA1c was added in step 3 and explained a non-significant, <1% additional variance. There were no significant associations observed between any independent variables and impact of symptoms at steps 1, 2 or 3. The final model explained 11% of the variance in impact of symptoms (*F* (6, 93) = 1.95, *p* = 0.08).

In the model predicting impact of treatment (DQOLY-SF), step 1 explained a significant 14% of the variance in impact of treatment. The addition of T1D self-efficacy at step 2, explained a significant, additional 6% of the variance in impact of symptoms. At step 3, following the addition of HbA1c additional, non-significant <1% of the variance in impact of treatment was explained. Use of MDI and lower self-efficacy was significantly associated with more impact of treatment. The final model explained 20% of the variance in impact of treatment (*F* (6, 93) = 3.91, *p* < .01).

In the model predicting impact on activities (DQOLY-SF), step 1 explained a non-significant 6% of the variance in impact on activities. The addition of T1D self-efficacy at step 2 explained an additional and non-significant <1% of variance. At step 3, the addition of HbA1c contributed to an additional and non-significant 1% variance explained. There were no significant associates with impact on activities observed in the final step. The final model explained 7% of the variance in impact on activities (*F* (6, 93) = 1.14, *p* = .35).

In the model predicting parent issues (DQOLY-SF), step 1 explained a significant 10% of the variance in parent issues. The addition of T1D self-efficacy at step 2 explained a significant 9% additional variance in parent issues. At step 3, the addition of HbA1c explained an additional, non-significant, 1% of the variance in parent issues. At step 3, only lower T1D self-efficacy was associated with more parent issues. The final model explained 20% of the variance in parent issues (*F* (6, 93) = 3.87, *p* < .01).

In the model predicting worries (DQOLY-SF), step 1 explained a significant 11% of the variance in worries. The addition of T1D self-efficacy explained a significant additional 5% of the variance in worries. The addition of HbA1c at step 3 explained a non-significant <1% additional variance in worries. Again, at step 3, female gender, older age and lower self-efficacy were significantly associated with more worries. The final model explained 17% of the variance in worries (*F* (6, 93) = 3.17, *p* < .01).

Table 8.15

Self-efficacy and HbA1c predicting QOL

Predictor	Impact of symptoms (DQOLY-SF)		Impact of treatment (DQOLY-SF)		Impact on activities (DQOLY-SF)		Parent issues (DQOLY-SF)		Worries (DQOLY-SF)	
	ΔR^2	β	ΔR^2	β	ΔR^2	β	ΔR^2	β	ΔR^2	β
Step1:	.10*		.14**		.06		.10*		.11*	
Gender		.17		.02		-.01		.03		.22*
Age		.19		-.10		-.13		.13		.21*
T1D duration		.13		.16		.18		-.08		.08
Insulin mode		-.08		-.38**		-.21*		-.26*		-.10
Step 2:	.01		.06**		.001		.09**		.05*	
Gender		.17		.004		-.02		.02		.21*
Age		.20		-.08		-.13		.15		.23*
T1D duration		.10		.09		.17		-.16		.02
Insulin mode		-.05		-.31**		-.20		-.17		-.03
T1D self-efficacy (SEDM)		-.12		-.27**		-.04		-.32**		-.24*
Step 3:	.004		.003		.01		.01		.004	
Gender		.17		.01		-.02		.01		.21*
Age		.19		-.08		-.12		.16		.24*
T1D duration		.10		.09		.18		-.15		.03
Insulin mode		-.05		-.30**		-.20		-.17		-.03

	Impact of symptoms (DQOLY-SF)	Impact of treatment (DQOLY-SF)	Impact on activities (DQOLY-SF)	Parent issues (DQOLY-SF)	Worries (DQOLY-SF)
T1D Self-efficacy (SEDM)	-.10	-.25*	-.06	-.35**	-.26*
HbA1c	.07	.05	-.08	-.12	-.07
Total R^2	.11	.20	.07	.20	.17
n	100	100	100	100	100

ΔR^2 = R squared change, *p<.05. **p<.01.

8.8 Parent-adolescent communication, T1D-specific family conflict, T1D self-efficacy, self-management, and activation predicting aspects of QOL

Based on the results of the previous analyses predicting QOL using (1) parent-adolescent communication, T1D specific family conflict and (2) T1D self-efficacy, self-management and activation, a model incorporating context (demographic and clinical), family context (parent-adolescent communication, problems in parent-adolescent communication, T1D specific family conflict), self-management process variables (T1D self-efficacy) and self-management variables that were significantly associated was tested (activation and self-management problem solving). Significance was indicated by standardized beta coefficients that reached statistical significance in the preceding hierarchical multiple regression analyses (see section 8.7). Self-management and self-management process variables were selected based on consideration of the sample size and the employment of a parsimonious set of variables relating to parent-adolescent communication, T1D specific family conflict, self-management and self-management processes. Parsimony encompasses explaining the maximum amount of variance using the least number of explanatory constructs (Hair et al., 2019).

Step 1 in each model included the clinical and demographic variables (gender, age, T1D duration, insulin mode). Step 2 included openness in parent-adolescent communication, problems in parent-adolescent communication, T1D-specific family conflict variables that were significantly associated in the previous analyses. Step 3 included T1D self-efficacy. At step 4, self-management problem solving and activation were included. These were identified based on standardized beta coefficients that reached statistical significance in the preceding hierarchical multiple regression analyses (section 8.7). See Table 8.16 for full results of this analysis.

In the first hierarchical multiple regression predicting impact of symptoms, when entering context variables at step 1 (gender, age, T1D duration, insulin mode), a non-significant 7% of the variance in impact of symptoms was accounted for. After openness in parent-adolescent communication, problems in parent-adolescent communication and family conflict were added at step 2, a further 7% of the variance was accounted for, which was a significant contribution. The addition of T1D self-efficacy at step 3 of the model contributed to an additional < 1% explained variance and was not significant. At step 4, the addition of self-management problem solving and activation explained an additional 6% variance and was significant. In the final model, conflict and activation were significantly associated with impact of symptoms. More family conflict and less activation were associated with more perceived impact of T1D symptoms. Overall, the final model explained 20% of the variance in impact of symptoms (F (10, 100) = 2.46, p = .01).

In the model predicting impact of treatment, the context variables entered at step 1 explained 11% of the variance in impact of treatment, which was a statistically significant contribution. At step 2, an additional and significant 8% of the variance in impact of treatment was explained, following the addition of openness in parent-adolescent communication, problems in parent-adolescent communication and family conflict. The addition of T1D self-efficacy, at step 3 of the model contributed to an additional 2% explained variance and was not significant. At step 4, the addition of self-management problem solving and activation contributed to an additional 3% variance explained and was not significant. In the final model, use of MDI was associated with more impact of treatment on QOL. Overall, the final model explained 24% of the variance in impact of treatment (F (10, 110) = 3.13, p < .01).

In the model predicting impact on activities, the context variables entered at step 1 explained 8% of the variance in impact of treatment, which was not statistically significant. At step 2, an additional and significant 8% of variance in worries was explained, following the addition of openness in parent-adolescent communication, problems in parent-adolescent communication and family conflict. The addition of T1D self-efficacy at step 3 of the model contributed to an additional < 1% explained variance and was not significant. The addition of self-management problem solving and activation at step 4 explained an additional 4% variance, which was not significant. In the final model, younger age, use of MDI and less activation were associated with more perceived impact on activities. Overall, the final model explained 21% of the variance in impact on activities (F (10, 110) = 2.60, $p < .01$).

In the model predicting parent issues, the context variables entered at step 1 explained 7% of the variance in impact of treatment, which was not statistically significant. At step 2, an additional and significant 35% of variance in worries was explained, following the addition of openness in parent-adolescent communication, problems in parent-adolescent communication and family conflict. The addition of T1D self-efficacy at step 3 of the model contributed to an additional < 1% explained variance and was not significant. The addition of self-management problem solving and activation at step 4 explained an additional 2% variance and was not significant. In the final model, use of MDI, less openness in parent-adolescent communication, more problems in parent-adolescent communication and more conflict were associated with more perceived parent issues. Overall, the final model explained 43% of the variance in parent issues (F (10, 110) = 7.60, $p < .001$).

In the model predicting worries, the context variables entered at step 1 explained 13% of the variance in impact of treatment, which was statistically significant. At step

2, an additional and significant 8% of variance in worries was explained, following the addition of openness in parent-adolescent communication, problems in parent-adolescent communication and family conflict. The addition of T1D self-efficacy at step 3 contributed to an additional 3% explained variance, which was significant. The addition of self-management problem solving and activation at step 4 explained an additional 4% and was not significant. In the final model, lower T1D self-efficacy and more self-management problem solving were significantly associated with more perceived worries. Overall, the final model explained 28% of the variance in worries (*F* (10, 110) = 3.80, $p < .001$).

Table 8.16

Hierarchical multiple regression analyses: parent-adolescent communication, family conflict, self-management, T1D self-efficacy and activation predicting T1D-specific QOL

	Impact of symptoms (DQOLY-SF)		Impact of treatment (DQOLY-SF)		Impact on activities (DQOLY-SF)		Parent issues (DQOLY-SF)		Worries (DQOLY-SF)	
Predictor	ΔR^2	β	ΔR^2	β	ΔR^2	β	ΔR^2	β	ΔR^2	β
Step1:	.07		.11*		.08		.07		.13**	
Gender		.11		-.004		-.06		.01		.24*
Age		.15		-.08		-.21*		.10		.22*
T1D duration		.14		.08		.14		-.07		.07
Insulin mode		-.05		-.35**		-.21*		-.21*		-.12
Step 2:	.07*		.08*		.08*		.35**		.08*	
Gender		.16		.03		-.07		.05		.24*
Age		.12		-.12		-.26**		.01		.18
T1D duration		.11		.05		.14		-.11		.06
Insulin mode		.01		-.30**		-.21*		-.14		-.09
Openness in communication (PACS)		-.05		-.01		-.16		-.25**		-.08
Problems in communication (PACS)		-.04		-.18		-.18		-.30**		-.22

	Impact of symptoms (DQOLY-SF)		Impact of treatment (DQOLY-SF)		Impact on activities (DQOLY-SF)		Parent issues (DQOLY-SF)		Worries (DQOLY-SF)	
Predictor	ΔR^2	β	ΔR^2	β	ΔR^2	β	ΔR^2	β	ΔR^2	β
Family Conflict (DFCS-R)		.25*		.19*		-.03		.26**		.05
Step 3:	<.001		.02		.004		.001		.03	
Gender		.16		.01		-.06		.05		.21*
Age		.12		-.10		-.27**		.01		.20*
T1D duration		.10		.02		.15		-.12		.02
Insulin mode		.01		-.25*		-.24*		-.13		-.04
Openness in communication (PACS)		-.05		.03		-.18		-.24*		-.03
Problems in communication (PACS)		-.04		-.17		-.18		-.30**		-.21
Family Conflict (DFCS-R)		.24*		.16		-.01		.25**		.01
T1D Self-efficacy (SEDM)		-.02		-.16		.08		-.04		-.19
Step 4:	.06*		.03		.04		.02		.04	
Gender		.16		.01		-.06		.03		.18
Age		.16		-.06		-.22*		-.03		.13
T1D duration		.10		.02		.15		-.14		-.01
Insulin mode		-.06		-.28*		-.28*		-.19*		-.13

	Impact of symptoms (DQOLY-SF)		Impact of treatment (DQOLY-SF)		Impact on activities (DQOLY-SF)		Parent issues (DQOLY-SF)		Worries (DQOLY-SF)	
Predictor	ΔR^2	β	ΔR^2	β	ΔR^2	β	ΔR^2	β	ΔR^2	β
Openness in communication (PACS)		.02		.07		-.12		-.24*		-.03
Problems in communication (PACS)		-.03		-.17		-.18		-.29**		-.18
Family Conflict (DFCS-R)		.27*		.18		.01		.23*		-.02
T1D Self-efficacy (SEDM)		.12		-.04		.21		-.10		-.28*
Problem solving (SMODA-I)		.17		.07		.11		.18		.28*
Activation (PAM)		-.33*		-.23		-.28*		-.02		-.03
Total R^2	.20		.24		.21		.43		.28	
n	111		111		111		111		111	

ΔR^2 = R squared change, **p*<.05. ***p*<.01

8.9 Summary of Phase 2 Findings

The present chapter outlined findings pertaining to the quantitative investigation of family context variables (openness in parent-adolescent communication, extent of problems in parent-adolescent communication and T1D-specific family conflict), T1D self-efficacy, self-management of T1D, patient activation, division of family responsibility, and T1D-specific QOL.

The following significant differences and associations between clinical and demographic characteristics to outcomes measures were observed:

- Females reported significantly more worries (DQOLY-SF) than males.
- Older adolescent age was significantly associated with less collaboration with parents (SMODA-I), more problem solving (SMODA-I), more goals (SMODA-I), less parental involvement (DFRQ), less impact on activities (DQOLY-SF) and more worries (DQOLY-SF).
- Older age at diagnosis was significantly associated with less parental involvement (DFRQ) in care.
- Longer T1D duration was significantly associated with more problem solving (SMODA-I).
- Use of an insulin pump was associated with less collaboration with parents (SMODA-I), more problem solving (SMODA-I), more goals (SMODA-I), less parent involvement (DFRQ), higher T1D self-efficacy (SEDM) and less parent issues (DQOLY-SF).
- Higher HbA1c was significantly associated with less performance of T1D care activities (SMODA-I), less problem solving (SMODA-I), less goals (SMODA-I) and lower T1D self-efficacy (SEDM).

Table 8.17 summarises the results of the analyses carried out, with the findings mapped onto the relevant hypotheses (see 8.1) in Table 8.17. Statistically significant ($p < .05$) associations identified are referred to. Within Table 8.17, summaries of the following analyses are presented:

- Bivariate associations between parent-adolescent communication, T1D-specific family conflict, T1D self-efficacy, self-management, division of family responsibility and activation
- Bivariate correlations between parent-adolescent communication and T1D-specific family conflict and QOL
- Bivariate correlations between QOL, T1D self-efficacy, self-management, family responsibility and activation
- Regressions predicting T1D self-management, family responsibility, activation and HbA1c
- Regressions predicting QOL

Table 8.17

Hypotheses mapped onto summary of findings

Hypothesis	Finding
More open parent-adolescent communication, fewer problems in parent-adolescent communication and less T1D-specific family conflict will be associated with higher T1D self-efficacy	Higher T1D self-efficacy was significantly correlated with more openness in parent-adolescent communication, fewer problems in parent-adolescent communication and less T1D-specific family conflict
More open parent-adolescent communication, fewer problems in parent-adolescent communication, less T1D-specific family conflict and higher T1D self-efficacy, will be associated with more adolescent T1D self-management, higher levels of activation, higher adolescent T1D-related responsibility, and lower HbA1c	More openness in parent-adolescent communication (PACS) was significantly correlated with: • more collaboration with parents (SMODA-I) • more performance of T1D care activities (SMODA-I) • more T1D communication (SMODA-I) • more goals (SMODA-I) • higher T1D self-efficacy (SEDM) • higher activation (PAM) No significant relationships observed between: Problem solving (SMODA-I), DFRQ

Fewer problems in parent-adolescent communication (PACS) was significantly correlated with:

- more collaboration with parents (SMODA-I)
- more performance of T1D care activities (SMODA-I)
- higher T1D self-efficacy (SEDM)

No significant relationships observed between: problem solving (SMODA-I), T1D communication (SMODA-I), goals (SMODA-I), Family responsibility (DFRQ), and higher activation (PAM)

More T1D-specific family conflict (DFCS-R) was significantly correlated with:

- less performance of T1D care activities (SMODA-I)
- less T1D communication (SMODA-I)
- less self-management goals (SMODA-I)
- lower T1D self-efficacy (SEDM)

No significant relationships were observed for collaboration with parents (SMODA-I), problem solving (SMODA-I), activation (PAM)
Hierarchical binary logistic regression was used to examine associations between these variables to HbA1c. No significant association observed with HbA1c

Hierarchical multiple regression was used to examine associations between predictor variables (clinical/demographic factors, parent-adolescent communication, family conflict, T1D self-efficacy) and self-management (SMODA-I), division of responsibility (DFRQ) and activation (PAM).

In the final model predicting collaboration with parents (SMODA-I), age, insulin administration via MDI and fewer problems in parent-adolescent communication were significantly associated with more collaboration with parents. Overall, the final model was significant and explained 41% (7% of this explained by parent-adolescent communication, family conflict and T1D self-efficacy) of variance in collaboration with parents.

In the final model predicting T1D care activities (SMODA-I), only more T1D self-efficacy was associated with more performance of T1D care activities. The final model was significant and explained 37% of the variance.

In the final model predicting self-management problem solving (SMODA-I), older age, use of insulin pump and more T1D self-efficacy was associated with more problem solving. Overall, the final model was significant and explained 46% of the variance.

In the final model predicting T1D communication (SMODA-I), insulin pump use, more openness in communication and higher T1D self-efficacy were significantly associated with more T1D communication.

	Use of MDI, more openness in communication and more T1D self-efficacy was associated with more T1D communication. The final model was significant and explained 33% of the variance. In the final model predicting goals (SMODA-I), older age, use of an insulin pump, more openness, more problems in parent-adolescent and higher T1D self-efficacy were associated with more self-management goals. The final model was significant and explained 42% of the variance in self-management goals. In the final model predicting division of family responsibility for management tasks (DFRQ), younger age and lower T1D self-efficacy were associated with more parent involvement in management. The final model explained 53% of the variance in family responsibility for management and was significant. In the final model predicting activation (PAM), more openness and more T1D self-efficacy were significantly associated with more activation. The final model explained 54% of the variance in activation and was significant. There were no significant predictors of membership of the up to/including 7.5% HbA1c or 7.6% or above categories.
More open parent-adolescent communication, fewer problems in parent-adolescent communication, less T1D-specific family conflict and higher T1D self-efficacy, will be associated with better T1D-specific QOL	Significant bivariate correlations between parent-adolescent communication and T1D-specific family conflict and QOL: • More openness in parent-adolescent communication was associated with less impact of T1D on activities (DQOLY-SF), less parent issues (DQOLY-SF) and less worries related to T1D (DQOLY-SF). • Fewer problems in parent-adolescent communication was significantly associated with less perceived impact of treatment (DQOLY-SF), less impact on activities (SMODA-I), less parent issues (DQOLY-SF) and less T1D related worries (DQOLY-SF). • Better perceived total parent-adolescent communication was associated with less perceived impact of treatment (DQOLY-SF), less perceived impact on activities (SMODA-I), less parent issues (DQOLY-SF) and less T1D worries (DQOLY-SF). • More T1D-specific family conflict was associated with more perceived impact of symptoms (DQOLY-SF), impact of treatment (DQOLY-SF) and parent issues (DQOLY-SF). Hierarchical multiple regression was used to examine associations between predictor variables (clinical/demographic factors, parent-adolescent communication, family conflict, T1D self-efficacy) and T1D-specific QOL

	In the final model, predicting impact of symptoms (DQOLY-SF) only family conflict (DFCS-R) was significantly associated with impact of symptoms. The final model explained 14% of the variance in impact of symptoms and did not reach statistical significance. In the final model, predicting impact of treatment (DQOLY-SF), only insulin mode of administration was significantly associated with impact of treatment. The final model explained 18% of the variance in impact of treatment and was significant. In the final model predicting impact on activities (DQOLY-SF), younger age and use of MDI were significantly associated with more impact on activities. The final model explained 17% of the variance in impact on activities and reached statistical significance. In the final model predicting parent issues (DQOLY-SF), less openness (PACS), more problems (PACS) and more family conflict (DFCS-R) were significantly associated with more perceived parent issues. The final model explained 41% of the variance in parent issues and was statistically significant. In the final model predicting worries (DQOLY-SF), female gender and older age were significantly associated with more worries. The final model explained 23% of the variance in worries and reached significance.
Higher T1D self-efficacy, more adolescent T1D self-management, higher levels of activation, and higher adolescent T1D-related responsibility, will be associated with better T1D-specific QOL	Bivariate correlations between QOL, T1D self-efficacy, self-management, family responsibility and activation: • More impact of treatment (DQOLY-SF) was significantly associated with more collaboration with parents (SMODA-I), more performance of care activities (SMODA-I), less goals (SMODA-I), more parental involvement (DFRQ), lower T1D self-efficacy (SEDM) and lower activation (PAM). • More impact on activities was significantly associated with lower activation (PAM). • More parent issues (DQOLY-SF) was significantly associated with less care activities (SMODA-I), less communication (SMODA-I) and less goals (SMODA-I). • More worries were associated with more parental involvement (DFRQ) and lower T1D self-efficacy (SEDM). Associations between T1D self-efficacy (SEDM), self-management (subscales of the SMODA-I), activation (PAM) to QOL (DQOLY-SF) using hierarchical multiple regression were investigated. Clinical and demographic variables (gender, age, T1D duration and insulin mode) were entered at step 1. T1D self-efficacy was entered at step 2. Self-management (subscales of the SMODA-I) and activation (PAM) were entered in the final step.

	In the final model predicting impact of symptoms (DQOLY-SF), less activation (PAM) was significantly associated with more impact of symptoms. The final model did not reach statistical significance and explained 15% of the variance in impact of symptoms. In the final model, predicting impact of treatment (DQOLY-SF), only use of MDI remained significantly associated with more impact of treatment. The final model explained 21% of the variance in impact of treatment and reached statistical significance. In the model predicting impact on activities (DQOLY-SF), MDI and lower activation (PAM) were significantly associated with more impact on activities. The final model explained 15% of the variance in impact on activities and was not significant. In the final model predicting parent issues (DQOLY-SF), more self-management problem solving (SMODA-I) was associated with more parent issues. The final model explained 25% of the variance in impact on activities and was significant. In the final model predicting worries (DQOLY-SF), female gender and lower self-efficacy (SEDM) were significantly associated with more worries. The final model explained 26% of the variance in impact on activities and was significant.
Higher T1D self-efficacy and lower HbA1c, will be associated with better T1D-specific QOL	Associations between T1D self-efficacy (SEDM), and HbA1c to QOL (DQOLY-SF) were investigated using hierarchical multiple regression. In the final model predicting impact of symptoms (DQOLY-SF), no significant associations were observed between any independent variables and impact of symptoms at steps 1, 2 or 3. The final model explained 11% of the variance in impact of symptoms and did not reach statistical significance. In the final model predicting impact of treatment (DQOLY-SF), use of MDI and lower self-efficacy (SEDM) were significantly associated with more impact of treatment. The final model explained 20% of the variance in impact of treatment and reached statistical significance. In the final model predicting impact on activities, there were no significant associates with impact on activities observed. The final model explained 7% of the variance in impact on activities and was not significant. In the final model predicting parent issues (DQOLY-SF), only lower T1D self-efficacy was associated with more parent issues. The final model explained 20% of the variance in parent issues and was significant.

	In the final model, predicting worries (DQOLY-SF), female gender, older age and lower self-efficacy were significantly associated with more worries. The final model explained 17% of the variance in worries and was significant. HbA1c was not a significant predictor for any model
More open parent-adolescent communication, fewer problems in parent-adolescent communication, less T1D-specific family conflict, higher T1D self-efficacy, and more adolescent self-management will be associated with better T1D-specific QOL	Hierarchical multiple regression was used to examine associations between predictor variables clinical/demographic factors entered at step 1, parent-adolescent communication and family conflict, entered at step 2, T1D self-efficacy entered at step 3 and self-management problem solving (SMODA-I) and activation (PAM) entered at step 4, predicting QOL (subscales of the DQOLY-SF). In the final model predicting impact of symptoms (DQOLY-SF), more family conflict and higher activation were significantly associated with more impact of symptoms. The final model explained 20% of the variance in impact of symptoms and reached statistical significance. In the final model predicting impact of treatment (DQOLY-SF), use of MDI was significantly associated with more impact of treatment. The final model explained 24% of the variance in impact of treatment and reached statistical significance. In the final model predicting impact on activities (DQOLY-SF), younger age, use of MDI and lower activation were significantly associated with more perceived impact on activities. The final model explained 21% of the variance in impact on activities and was significant. In the final model predicting parent issues (DQOLY-SF), use of MDI, less openness, more problems and more family conflict were associated with more parent issues. The final model explained 43% of the variance in parent issues and was significant. In the final model, predicting worries (DQOLY-SF), female gender, older age and lower self-efficacy and higher scores for self-management problem solving were significantly associated with more worries. The final model explained 28% of the variance in worries and was significant.

8.10 Conclusion

This chapter has outlined the results of the quantitative phase of this mixed methods study. The quantitative findings will be discussed in further detail in the next chapter.

Chapter 9: Phase Two: Discussion of Quantitative Results

9.1 Introduction

In this chapter the findings from the quantitative phase of this mixed methods study will be discussed. Phase Two was informed by IFSMT (Ryan & Sawin, 2009) which posits that contextual variables (e.g. gender, age, clinical characteristics, family context or functioning characteristics) and process variables (e.g. self-efficacy, self-regulation) are associated with health-related outcomes including self-management behaviours, QOL and overall health status.

The aim of phase two of this mixed methods study was to examine the relationship between specific family context characteristics (namely openness and extent of problems in parent-adolescent communication and T1D-specific family conflict) to adolescent T1D self-efficacy, self-management (self-management, activation and division of family responsibility for management), HbA1c and T1D-specific QOL. This research represents the first time that the association of family context variables such as adolescent perceptions of openness and extent of problems in parent-adolescent communication, and T1D-specific family conflict and self-efficacy to adolescent self-management and T1D-specific QOL has been investigated.

The findings of this phase of the research contribute to knowledge on how family context characteristics and self-efficacy are relevant to health-related outcomes for adolescents living with T1D. The findings offer new insights into what features of family characteristics and functioning are related to some of the key proximal (self-management) and distal (HbA1c and QOL) health outcomes that are referred to within IFSMT (Ryan & Sawin, 2009). Overall, the findings of this study support that parent-adolescent communication, T1D-specific family conflict are important features of the context of adolescent self-management and contribute to some proximal and distal outcomes. The findings from this phase of the study indicate that parent-adolescent communication, T1D-specific family conflict and T1D self-efficacy are relevant to T1D in adolescence. Specifically, this phase contributes to previous observations that family environment and self-management processes are central to engagement with self-management (Grey et al., 2015; Martire & Helgeson, 2017; Ryan & Sawin, 2009). The family domain is considered an important factor in adolescent management of T1D (Modi et al., 2012) and the current findings expand upon this to highlight that different aspects of parent-adolescent communication contribute to distinct T1D outcomes in adolescence. This research adds to understanding into how family context (parent-adolescent communication and T1D-specific family conflict in the current study) relates to T1D management through specifying novel dimensions of parent-adolescent communication and investigating their association to self-management and QOL. Parent-adolescent communication and T1D self-efficacy contributed to the proximal outcome self-management. The findings were less clear with respect to the distal outcomes measured (QOL and HbA1c). T1D self-efficacy was only associated with one aspect of QOL measured (parent issues). Higher self-efficacy demonstrated a bivariate association with lower HbA1c, an association between T1D self-efficacy and HbA1c was not evident in a logistic regression model incorporating clinical and demographic factors, family context characteristics and T1D self-efficacy.

The research also identifies T1D self-efficacy as an important process variable as related to adolescent perceptions of parent-adolescent communication, engagement with some aspects of self-management and perceptions of the impact of T1D on some aspects of adolescent QOL. First, the relationships between clinical and demographic variables are discussed. How parent-adolescent communication and T1D-specific family conflict are related to T1D self-efficacy and self-management will then be considered. Next, the relationships between parent-adolescent communication, T1D-specific family conflict, self-management, division of family responsibility, activation and self-efficacy to QOL will be considered. Finally, strengths and limitations of the current phase will be discussed.

9.2 Context (demographic and clinical) associations to parent-adolescent communication, T1D-specific family conflict, T1D self-efficacy and self-management

The present phase examined how demographic (age, gender) and clinical (age at diagnosis, insulin administration method, blood glucose monitoring method, T1D duration, self-reported last recorded HbA1c result) factors relate to parent-adolescent communication, T1D-specific family conflict, T1D self-efficacy, self-management, activation, division of family responsibility for T1D management tasks and QOL (see section 9.5 for discussion of findings pertaining to QOL). Gender was the only clinical or demographic variable associated with T1D-specific family conflict. Males reported higher T1D-specific family conflict than females. However, age, duration of T1D and insulin administration method demonstrated associations to self-efficacy and some self-management variables. There were no significant associations between age at diagnosis, blood glucose monitoring method and self-reported last recorded HbA1c and any of parent-adolescent communication and T1D-specific family conflict.

The findings with respect to older age and less perceived parental involvement in care, more self-management problem solving, more self-management goals and higher activation, are expected given that developmental literature characterises adolescence as a time of increasing independence and a time where competencies in higher order cognitive processes such as problem solving are honed (Steinberg, 2005). The association of longer T1D duration to better self-management problem-solving ability could be in part explained by adolescents becoming more comfortable with T1D management over time. There were no other associations observed between T1D duration and self-management. Moreover, there were no associations between T1D duration evident within multivariate analyses. This is in contrast with findings of previous research investigating T1D duration and T1D outcomes in adolescence, and with the assumption of IFSMT regarding the influence of contextual variables identified on self-management. IFSMT posits that illness duration can be either a risk or protective contextual factor for engagement with self-management behaviours and distal health outcomes (Ryan & Sawin, 2009). Furthermore, previous research reports that adolescents with longer T1D duration report less engagement with self-management behaviours, but do not differ with respect to problem solving (Chao et al., 2014). Furthermore, research also finds longer duration is associated with more difficulties with dietary adherence during adolescence (Austin et al., 2011). Conversely, it has also been observed that longer T1D duration is associated with more positive attitudes towards T1D (Amer, 2008). The absence of significant associations between T1D duration and self-management outcomes (with the exception of problem solving) in the current study together with the mixed results from previous research suggests a need for further research to discern the factors contributing to becoming competent in self-management.

The findings, with respect to insulin administration method (insulin pump use was associated with less collaboration with parents, more problem solving, more self-management goals and higher T1D self-efficacy) may, in part, be attributable to the need for adolescents and/or their parents to attend education and training prior to commencing insulin pump treatment. Attendance at T1D education, including insulin pump education by adolescents and their parents is associated with beneficial effects on metabolic and psychosocial outcomes for adolescents living with T1D (Lange et al., 2014). Less collaboration with parents may indicate that use of an insulin pump allows the adolescent more freedom to manage independently, and therefore require less collaboration with parents. Although this increased independence following commencement of insulin pump therapy has also been referred to in qualitative accounts on T1D self-management in adolescence (Babler & Strickland, 2015a). Insulin pump use was associated with more collaboration with parents in previous quantitative research (Gruhn et al., 2016). This is indicative of a need to follow up with adolescents at various time points to understand how commencement of insulin pump therapy corresponds to gaining independence in self-management. Previous research finds that insulin administration via insulin pump is associated with improved HbA1c, T1D self-efficacy (Hilliard, Wu, et al., 2013; McMahon et al., 2005) and some subscales of the self-management measure (SMODA; self-management activities, problem solving, communication and goals) (Verchota & Sawin, 2016). The absence of a finding in the current study with respect to insulin pump use and improved HbA1c is unexpected given the benefits of insulin pumps reported in previous research. However, a review of paediatric use of insulin pumps suggests that some improvements observed in terms of metabolic control and performance of management behaviours following initiation of insulin pump treatment are not always sustained over time (Shulman et al., 2012). Therefore, the association of insulin regimen to self-management may need to be followed up at several timepoints in order to determine its association to adolescent self-management. This may partially explain the absence of some associations of outcome variables to insulin administration method.

9.3 Family context variables (parent-adolescent communication, T1D-specific family conflict), T1D self-efficacy and T1D self-management, division of family responsibility and activation

This phase of the study investigates, for the first time, the inter-relationships between family context variables (parent-adolescent communication, T1D-specific family conflict), T1D self-efficacy and self-management (self-management of T1D, division of responsibility for T1D management, activation). The hypothesised relationships between openness in parent-adolescent communication, problems in parent-adolescent communication, T1D-specific family conflict to self-management and T1D self-efficacy were, for the most part, confirmed following bivariate analyses. More openness in parent-adolescent communication was associated with higher T1D self-efficacy, all aspects of self-management (apart from problem solving) and higher activation. Fewer problems in parent-adolescent communication was associated with more collaboration with parents, more performance of T1D care activities and higher T1D self-efficacy. No relationship was evident between the family context variables and division of family responsibility for T1D management tasks. More family conflict was associated with less performance of T1D care activities, less communication about self-management and less self-management goals and less T1D self-efficacy. In hierarchical multiple regression analysis, context variables (gender, age, duration of T1D and mode of insulin administration) were entered at step 1, family context variables at step 2 and T1D self-efficacy at step 3. Context variables, as a block, were significant predictors of adolescent T1D self-management (except for T1D care activities and communication), activation and parent-adolescent division of responsibility for management tasks, as evidenced by significant contributions following their addition at step 1 of the models. More specifically, age and mode of insulin administration were significant predictors in the final models for collaboration with parents, problem solving and self-management goals. The family context variables (T1D-specific family conflict, openness in parent-adolescent communication and extent of problems in parent-adolescent communication) when entered as a block at step 2, made a significant contribution to explaining division of responsibility, activation and all aspects of self-management measured, apart from self-management problem solving. In the final model, more openness in parent-adolescent communication was associated with more self-management communication and higher activation. More openness and more problems in communication was associated with more self-management goals. Fewer problems in parent-adolescent communication was associated with more collaboration with parents for self-management of T1D. T1D-specific family conflict was non-significant in the final models. In the final models, higher T1D self-efficacy was associated with higher scores for all aspects of self-management (apart from collaboration with parents).

The findings that family context and more specifically, parent-adolescent communication and family conflict are related to self-management provide unique insights into these specific aspects of family functioning and their relationship to T1D outcomes. Whilst previous research has found that family behaviours and family functioning are related to T1D management during adolescence (Cameron et al., 2008; DeBoer et al., 2017; Hanna et al., 2003; Lewin et al., 2006), the present phase of this study considers, for the first time, parent-adolescent communication specifically and its relationship to self-management more broadly, rather than adherence to a specific management behaviour or metabolic control. That different aspects of parent-adolescent communication were related with distinct aspects of self-management reinforces the need for continued research to consider the precise nature of parent-adolescent interactions that are relevant to T1D outcomes in adolescence and self-management in particular.

The association identified in the current phase between more problems in parent-adolescent communication and greater adolescent self-management goals was unexpected, given that previous studies highlight the links between positive parental interactions with more optimal self-management and engagement with T1D management behaviours (King et al., 2014; Mackey et al., 2011). Furthermore, more problems in parent-adolescent communication was also associated with less collaboration with parents. It may be that the presence of problems in communication may act as a driving factor, encouraging increased adolescent autonomy or may be a feature of adolescents striving for more independence in their management. Adolescence is characterised as a period for increasingly separating from their parent's influence, explained in part by a process referred to as separation-individuation (Blos, 1967). Separation-individuation can introduce conflict into parent-adolescent interactions and relationships (Alonso-Stuyck et al., 2017). As adolescents are gaining autonomy in all aspects of life, this can present specific conflict and problems in communication with parents (Riesch et al., 2003). Previous research suggests that more family conflict may be reported as adolescents become more self-reliant in their T1D management (Karlsson et al., 2008). It is possible that this period of striving towards the goals of independent management is characterised by more problems in communication with parents. However, given the data is cross-sectional, this limits the conclusions that can be drawn and additional longitudinal investigation into the role and nature of problems in parent-adolescent communication and gaining independence in self-management is necessary.

Additionally, the findings from the hierarchical multiple regression analysis highlight that adolescent perceived openness in parent-adolescent communication is important for T1D goals, communication about T1D and greater activation. This research on openness in parent-adolescent communication adds to existing research which has found that more disclosure and honesty in parent-adolescent interactions has been associated with improved adherence and better T1D management (Berg et al., 2016; Osborn et al., 2013). When adolescents perceive parental behaviours as warm and caring, this contributes to more adolescent participation in self-care behaviours (Faulkner & Chang, 2007). Honesty, warmth and interactions with high levels of disclosure could be considered to share some of the characteristics of openness in communication. However, this is the first study to measure openness in parent-adolescent communication in adolescents living with T1D. The current findings suggest the presence of openness in parent-adolescent interactions might contribute to better self-management outcomes in adolescents. T1D-specific family conflict was not significant in final models but demonstrated some associations in some models prior to the addition of T1D self-efficacy. The present findings, that dimensions of parent-adolescent communication impact differentially upon aspects of self-management, suggest openness and problems in parent-adolescent communication as they relate to specific aspects of self-management of T1D in adolescence warrant further investigation.

The findings of this phase confirm the strong links between self-efficacy and engagement with self-management behaviours (except for collaboration with parents). Investigating both the role of parent-adolescent communication, T1D-specific family conflict and T1D self-efficacy and self-management is novel. Following the addition of self-efficacy to the final model, family conflict was no longer significantly associated with performance of T1D care activities, self-management communication and division of responsibility for management tasks. The inter-relationship between these constructs to self-management warrants further investigation. The findings for family conflict contrast with previous research which found that more family conflict and less self-efficacy was related to lower engagement with self-management behaviours and poorer metabolic control (Noser et al., 2017). Considering that parent-adolescent communication remained significantly associated while T1D-specific family conflict did not in the final models, might suggest these constructs were more important among the current adolescent respondents. Conversely, the overall mean score for conflict among current respondents was indicative of low conflict in the current sample. The results pertaining to the association of conflict to self-management may differ among adolescents reporting a higher level of family conflict related to T1D.

The finding that parent-adolescent communication and self-efficacy are associated with T1D self-management is supported by theories of self-efficacy. Receiving feedback on performance can enhance self-efficacy and perceptions of competence in the carrying out of a specific task (Bandura, 1993). Within the context of T1D, it may be important that parents are aware of how best to support adolescent's self-efficacy in T1D management. IFSMT posits that self-efficacy increases engagement with self-management behaviours (Ryan & Sawin, 2009). Improving T1D self-efficacy may contribute to improved T1D outcomes during adolescence, as research on self-management has already indicated the role of self-efficacy in positive engagement with T1D self-management behaviours (Iannotti et al., 2006; Noser et al., 2017).

The current findings that more openness in communication and higher self-efficacy contribute to more self-management communication, self-management goals and activation add to knowledge on what constitutes helpful parent-adolescent interactions that promote adolescent engagement with self-management. When parents are perceived as supportive towards the adolescent's T1D management, this can reinforce engagement with positive management behaviours and increase perceptions of self-efficacy for carrying out T1D management (Ott et al., 2000). Furthermore, when adolescents are clear on their parents' expectations and feel respected by parents, this contributes to motivation to engage with adherence behaviours of their own volition (Goethals et al., 2019). The present research extends these findings to suggest that parent-adolescent communication is a specific domain of family function that could be targeted along with self-efficacy to improve engagement with and motivation towards self-management.

This present research also investigated, for the first time, associations between T1D self-efficacy, parent-adolescent communication and T1D-specific conflict to levels of patient activation. Activation is important given its focus on how engaged individuals are in the management of their care. Furthermore, activation has been associated with improved health outcomes in adults (Kinney et al., 2015). The present phase of this study, for the first time, measures activation in adolescents living with T1D. It is also the first study to examine the relationship of any aspect of family functioning to activation. Openness in parent-adolescent communication was associated with activation even when T1D self-efficacy was also accounted for. This suggests that promoting open communication between parents and adolescents may lead to increases in activation. Changes in activation have been linked with performance of self-management behaviours in adults with chronic illness (Hibbard et al., 2005). The present findings are also comparable with the strong correlations previously observed for self-efficacy and activation in a small sample of children and adolescents living with a chronic illness or a complex health care need that required hospitalisation (Bravo et al., 2020). However, the measure of activation (PAM) has not been widely used within paediatric settings and thus, there is a need for continued research that evaluates activation in adolescent chronic illness, including T1D (Bomba et al., 2018; Bravo et al., 2020). These findings indicate that activation is a construct that should be considered in conjunction with self-management in adolescents living with T1D.

9.4 Family context variables (parent-adolescent communication, T1D-specific conflict), T1D self-efficacy, self-management and HbA1c

Significant bivariate relationships were observed between higher HbA1c and lower T1D self-efficacy and some of the domains of self-management (less performance of care activities, less problem solving and less goals). Parent-adolescent communication, T1D-specific family conflict and T1D self-efficacy were not significant statistical predictors of adolescent self-reported HbA1c. These results contradict the hypothesis pertaining to HbA1c, stating that parent-adolescent communication and family conflict would be related to HbA1c. HbA1c can be considered an indicator of adolescent management of T1D and health status and a distal outcome within the IFSMT framework (Ryan & Sawin, 2009). Therefore, according to IFSMT, context variables, including family characteristics and self-management processes should be associated with HbA1c.

Though there were no associations observed for parent-adolescent communication, T1D-specific conflict and T1D self-efficacy to HbA1c in the current study, previous research suggests that self-efficacy and family functioning would be related to indicators of metabolic control. For example, more family conflict is associated with a deterioration in adolescent HbA1c (Ingerski et al., 2010). Family conflict and family distress have also been associated with adolescent metabolic control

(Hilliard, Holmes, et al., 2013; Moore et al., 2013). Parent-adolescent involvement in T1D (relationship quality and monitoring) is also associated with adherence and metabolic control through self-efficacy (Berg et al., 2011). Therefore, the findings highlight the importance that HbA1c is considered with attributes of self-management, and not in isolation in order to comprehensively ascertain how adolescents are engaging with T1D management. Therefore, the findings highlight that HbA1c can be considered as one indicator among others that warrant attention when considering T1D management status in adolescence. The absence of a clear relationship in the present findings suggests that other factors related to difficulties adolescents encounter with maintaining metabolic control e.g. biological and social factors (Cameron et al., 2018) are likely to be more pertinent influences on metabolic control of T1D during adolescence. Furthermore, metabolic control can vary following attendance at appointments with HCPs due to receiving support or advice on their management (Nuti et al., 2015). This suggests that HbA1c may need to be followed up over a period of time.

9.5 Demographic and clinical characteristics related to QOL

In terms of associations between T1D-specific QOL and adolescent demographic and clinical characteristics, differences on QOL scores with respect to gender, age and mode of insulin administration were observed. Males and females only differed with respect to worries related to T1D, with females reporting more worries. This finding is consistent with previous research that found that females report lower QOL compared to males (Hilliard, Mann, et al., 2013; Kalyva et al., 2011; Lukács et al., 2018). Furthermore, older age was associated with less perceived impact of T1D on activities and more T1D worries in this phase. Whilst a number of studies have identified links between lower self-reported QOL and older adolescent age (Kalyva et al., 2011; Skinner et al., 2006; Wagner et al., 2005), the link between older age and lower QOL is not always found (Lukács et al., 2018). The findings from this phase themselves are also contradictory in that older age is associated with less perceived impact of T1D on activities but more T1D worries. Aspects of QOL may be differentially impacted upon depending on adolescent age and further research is required to tease this out further in the context of T1D specifically. Finally, associations between mode of insulin administration and impact of T1D on QOL were observed, with insulin pump use associated with lower perceived impact of T1D treatment on QOL and lower impact of parent issues on QOL. There is some evidence indicating that QOL is improved in children and adolescents using an insulin pump compared to those on other insulin regimens (Lukács et al., 2018; McMahon et al., 2005). Qualitative accounts of parents suggest that parents experience less stress and find sharing management with their children is easier following the initiation of insulin pump therapy (Alsaleh et al., 2012). Therefore, the current findings and previous research suggest that insulin pump use might lead to reduced adolescent perceptions of parental stress surrounding the adolescent's T1D management.

9.6 Family context variables (parent-adolescent communication, T1D-specific conflict), T1D self-efficacy, self-management and T1D-specific QOL

Demographic/clinical, family context, self-management process and self-management variables were assessed in terms of their ability to predict T1D-specific QOL. This was investigated through hierarchical multiple regression analysis, testing the ability of blocks of variables to predict adolescent T1D-specific QOL. Variables were entered in blocks based on the type of variable i.e. type of context variable, process variable or proximal or distal outcome (IFSMT; Ryan & Sawin, 2009). The findings will be discussed in the following order. Firstly, the findings from models using clinical and demographic context variables, family context variables and T1D self-efficacy to predict T1D-specific QOL will be discussed. Next, the findings from models using clinical and demographic context variables, self-efficacy and activation and self-management to predict T1D-specific QOL will be discussed. Finally, the findings from models using clinical and demographic context variables, T1D self-efficacy and HbA1c to predict T1D-specific QOL will be discussed.

9.6.1 Parent-adolescent communication, T1D-specific family conflict, T1D self-efficacy and T1D-specific QOL

For the first time, how parent-adolescent communication, T1D-specific family conflict, and T1D self-efficacy relate to T1D-specific QOL was examined in this research. The findings contribute to our understanding of how specific domains of family function impact on QOL in adolescents living with T1D, through distinguishing parent-adolescent communication from general family functioning.

The hypothesised relationships between openness in parent-adolescent communication, problems in parent-adolescent communication, T1D-specific family conflict and QOL were partially supported following bivariate analyses. More openness and less problems in parent-adolescent communication was associated with fewer parental issues, and fewer worries related to T1D. Additionally, fewer problems in parent-adolescent communication were associated with less perceived impact of T1D treatment on QOL. Higher T1D specific family conflict was also associated with more impact of symptoms and more parental issues. The relationships observed between positive parent-adolescent communication and less T1D-specific family conflict to better QOL are similar to those previously observed for positive family behaviours. For example, warm, supportive and caring family behaviours are associated with better QOL for children and adolescents living with T1D (Botello-Harbaum et al., 2008;

Faulkner & Chang, 2007). Furthermore, family behaviours and characteristics, such as the presence of family cohesion and low levels of family conflict, contribute to improved metabolic control and QOL (Anderson et al., 2017; Hilliard, Mann, et al., 2013; Pereira et al., 2008; Rybak et al., 2016). Adolescent perceptions of general family functioning, which includes family problem solving, family communication and family roles, has been found to be significantly associated with health-related QOL in adolescents living with T1D (Firat & Tuncay, 2020). The current research identifies for the first time the potential importance and relevance of parent-adolescent communication for the QOL of adolescents living with T1D.

Following their incorporation into hierarchical multiple regression analysis, some associations previously identified in the bivariate analysis were no longer significant. In the hierarchical multiple regression analysis, context variables (gender, age, duration of T1D and mode of insulin administration) were entered at step 1, family context variables at step 2 (openness in parent-adolescent communication, problems in parent-adolescent communication, T1D-specific family conflict) and T1D self-efficacy at step 3. Family context variables were significant in final models predicting parent issues and perceived impact of symptoms. In the hierarchical multiple regression analysis, context variables (gender, age, duration of T1D and mode of insulin administration) were entered at step 1, family context variables at step 2 (openness in parent-adolescent communication, problems in parent-adolescent communication, T1D-specific family conflict) and T1D self-efficacy at step 3. More specifically, in the final model for parent issues, which measures how worried or concerned the adolescent perceives their parent is about their T1D, more openness in parent-adolescent communication, less problems in parent-adolescent communication and low T1D family specific conflict were significantly associated with lower perceived parent issues. In the final model for impact of symptoms, lower T1D-specific family conflict was significantly associated with lower perceived impact of symptoms. These findings suggest that targeting parent-adolescent communication strategies around the management of T1D and reducing family conflict may, in turn, reduce how worried and concerned adolescents perceive their parents to be. Parental worry and concerns about T1D management can be a source of conflict among adolescents living with T1D (Weinger et al., 2001). Clear definition of roles is also important for ensuring adolescent T1D-specific QOL (Firat & Tuncay, 2020). The current findings suggest that improving parent-adolescent communication strategies and reducing T1D-specific family conflict could be one way to ensure clearly defined parent-adolescent roles and reduce issues with parents that impact on adolescent QOL. Previous research indicates that adolescent disclosure about management of T1D and about T1D more generally is linked with adolescent psychosocial wellbeing and associated with engagement with T1D management behaviours (Berg et al., 2016). Fostering environments where the adolescent can be open about their T1D management and that reduce how worried and concerned adolescents perceive their parents to be is important for adolescent QOL.

T1D self-efficacy did not emerge as a significant predictor of QOL in any of the final models incorporating context variables, family context variables and self-efficacy. This is in contrast to previous research which has found associations between self-efficacy and QOL. Given that parents are frequently relied upon for encouragement with management tasks (Strand et al., 2019) and parenting behaviours considered supportive are associated with better self-efficacy (Berg et al., 2013; Ott et al., 2000), the absence of this relationship in the final models was unexpected. The current findings, especially the absence of a relationship between self-efficacy and QOL, after accounting for the family context variables, suggest this may warrant further investigation, in order to clarify the presence of relationships between self-efficacy, parent-adolescent communication, T1D-specific family conflict and QOL. It is also possible that features of the family context such as parent-adolescent communication and T1D-specific family conflict are more dominant factor in determining QOL than T1D self-efficacy, however repeated testing with a larger group of adolescents is warranted. The findings also highlight that it is important to consider all potential factors that play a role in the relationship between T1D self-efficacy and QOL in adolescents living with T1D.

9.6.2 T1D self-efficacy, self-management, activation and QOL

The current phase of research identified links between T1D self-management and activation to QOL. Several associations were observed indicating that self-efficacy and self-management are related to QOL.

In hierarchical multiple regression analysis, context variables (gender, age, duration of T1D and mode of insulin administration) were entered at step 1, T1D self-efficacy at step 2 and T1D self-management and activation at step 3. The only final model where a significant association of T1D self-efficacy was observed was the worries subscale where lower T1D self-efficacy was significantly associated with more worries. Previous research finds that lower self-efficacy is linked with lower QOL for adolescents living with T1D (Abolfotouh et al., 2011; Cramm, Strating, Roebroeck, et al., 2013). T1D self-efficacy has also been associated with T1D distress in adolescents (Law et al., 2013). The current findings suggest that increasing perceptions of competence for completing management tasks could alleviate adolescent worries about T1D.

To date, the relationship between patient activation and QOL has not been examined previously in adolescents with T1D. This research importantly addressed this gap and found that in the regression analyses, significant associations were observed in the final model, with less activation associated with more impact of symptoms and impact on activities. To date, activation (measured using the PAM) has only been measured in a small sample of children and adolescents with either chronic illness or complex medical needs, and was significantly associated with health-related QOL (Bravo et al., 2020). However, as mentioned previously, there is a paucity of research investigating patient activation among adolescents generally and none focusing on adolescents with T1D specifically. These findings suggest that activation may be an important construct related to QOL for adolescents living with T1D.

T1D self-management was only a significant predictor in one final hierarchical multiple regression model. The significant association observed between more self-management problem-solving ability and more perceived parent issues was somewhat unexpected. It may be possible that more problem-solving ability is associated with more adolescent-led management. For example, as adolescents become more responsible for their T1D management, they also become less reliant on parents for assistance (Babler & Strickland, 2016). The change in roles, between adolescents and parents, reflected in adolescents making more T1D related decisions might introduce conflict. Changing parent-adolescent roles can introduce conflict into family interactions (Alonso-Stuyck et al., 2017). Parents may also report more worries as a result of being less involved in their child’s T1D management in adolescence (Whittemore et al., 2012). As the parent is less actively involved in the adolescent’s care, disagreements between adolescents and parents can arise about carrying out management tasks and where self-management responsibilities lie (Law et al., 2013; Miller & Drotar, 2003). Therefore, this may offer some explanation for the current association observed between problem solving and parent issues among the current sample, however further research is needed to determine this.

9.6.3 T1D self-efficacy, HbA1c and QOL

HbA1c did not emerge as a significant predictor in any of the final hierarchical multiple regression models for T1D-specific QOL. Context variables (gender, age, duration of T1D and mode of insulin administration) were entered at step 1, T1D self-efficacy at step 2 and HbA1c at step 3. Only lower T1D self-efficacy was significantly associated with greater impact of treatment, more parent issues and more worries. These findings are inconsistent with findings where lower HbA1c is associated with better adolescent QOL (Kalyva et al., 2011) and lower distress related to T1D in adolescents (Law et al., 2013). Research, using the DQOLY-SF, also identified significant associations between HbA1c and impact of symptoms, parent issues and worries (Keller et al., 2017). The authors comment that the lack of associations between some QOL domains and HbA1c may, in part, be attributable to the content of the scale items and that they may not be fully inclusive of issues that are salient in terms of engaging with management and in turn HbA1c (Keller et al., 2017). Previous longitudinal research finds that when adolescents report impaired QOL, the impact of this on metabolic control may take time to manifest (Stahl-Pehe et al., 2017). It may take time before reduced QOL impacts on adolescent engagement with self-management behaviours and subsequent metabolic control however it is not possible to draw conclusions based on the current cross-sectional data. This may also account for an absence of association between HbA1c and QOL. Longitudinal follow up may allow for the identification of more conclusive findings with respect to links between HbA1c and QOL.

9.6.4 Parent-adolescent communication, family conflict, self-management, T1D self-efficacy and activation predicting T1D-specific QOL

In the hierarchical multiple regression models predicting T1D-specific QOL, demographic and clinical variables were entered at step 1, family context variables (openness in parent-adolescent communication, problems in parent-adolescent communication, T1D-specific family conflict) were entered at step 2, T1D self-efficacy at step 3 and self-management (problem solving and activation) at step 4. In the final models, more T1D-specific family conflict and less activation were associated with more perceived impact of T1D symptoms; younger age, use of MDI and less activation were associated with more perceived impact on activities; use of MDI, less openness in parent-adolescent communication, more problems in parent-adolescent communication and more T1D specific family conflict were associated with more perceived parent issues; and lower T1D self-efficacy and more self-management problem solving were significantly associated with more perceived worries.

The findings emphasise the complexity of the relationship between the context of self-management, T1D self-efficacy, activation and self-management problem solving and QOL. This was evident in findings that family contexts and T1D self-efficacy, activation and self-management problem solving impact upon different aspects of QOL. The differential associations observed between the predictor variables and the domains of QOL indicate that multiple factors should be considered for their impact on specific areas of QOL in adolescents living with T1D. Overall, this research highlights the importance of considering the distinction between components of self-management for their impact on T1D outcomes including QOL. Previous research finds that engagement with specific self-management behaviours (e.g. monitoring BGLs is associated with level of burden relating to treatment perceived) are associated with distinct aspects of health related QOL (Anderson et al., 2017).

More self-management problem-solving ability was associated with more worries in the final model. This was unexpected but the cross-sectional design limits the conclusions that can be drawn relating to the directionality of the relationship. It is possible that the relationship is attributable to the content of the items on the scale and the impact of problem solving depends on the content of the worries or concerns. Previous research finds that adolescent responses to worries related to T1D vary with respect to whether these are long-term or short-term worries or consequences of T1D (e.g. experiencing dietary restriction when with friends vs. experiencing a health complication in the future) (King et al., 2017). Self-efficacy and problem-solving abilities related to illness management have an established link in children and adolescents living with a chronic illness (Cramm, Strating, Sonneveld, et al., 2013).

The findings identify that specific aspects of self-management relate to distinct areas of QOL. As a result, it expands current understanding of QOL as a distal outcome as it is described in IFSMT (Ryan & Sawin, 2009). However, further research is needed to clarify which factors contribute to optimal adolescent QOL.

9.7 Strengths and Limitations

A key strength of this phase is it investigates, for the first time, the inter-relationships between parent-adolescent communication, T1D-specific family conflict, T1D self-efficacy, self-management, division of family responsibility for T1D management, patient activation and T1D-specific QOL from the perspective of adolescents. The current phase of this study builds on previous studies that have been carried out investigating family functioning and management of T1D in adolescence (Cameron et al., 2008; DeBoer et al., 2017; Hanna et al., 2003; Lewin et al., 2006). The specific focus on parent-adolescent communication offers a new perspective, not previously captured, in that studies to date have predominantly considered the relationships of family conflict and general family functioning to T1D management. This research also builds on studies that have been carried out, which consider adolescent QOL (Hilliard et al., 2013; Kalyva et al., 2011; Lukács et al., 2018). More specifically, the IFSMT provided a useful guiding framework to examine the role of family context variables and self-management processes and their relationship with proximal (self-management) and distal outcomes (T1D-specific QOL). The research conducted in this phase is also the first time that activation has been investigated in adolescents living with T1D.

Relatedly, this phase adds to the current body of literature on adolescent T1D management, through its focus on psychosocial aspects of self-management as outcomes. Numerous studies on T1D management have recorded adherence behaviours, carrying out T1D management tasks or focused on blood glucose control and readings as outcomes of interest. In addition to engagement with self-management behaviours, this research considers self-management processes such as collaborating with parents, problem solving, goal setting and communicating about T1D. A particular strength of the research is its investigation of the relationship of family context variables (more specifically parent-adolescent communication and T1D-specific family conflict) with specific aspects of self-management, as outlined above.

The limitations of cross-sectional design apply to this phase of research and therefore the relationships identified do not imply causality. Future research should consider incorporating a longitudinal component and follow up with adolescents during this period of transitioning responsibilities for the self-management of T1D. Longitudinal research may garner an increased understanding of the relationships between parent-adolescent communication, self-management and QOL over time. Further research is also needed to investigate whether there is an association between parent-adolescent communication, T1D-specific family conflict and T1D self-efficacy to metabolic control over time.

A further possible limitation is that this phase measures only two dimensions of parent-adolescent communication. Given the complex nature of parent-adolescent communication, future research might quantitatively assess other dimensions of family function and communication (e.g. affective involvement, perceptions of control), in addition to openness, extent of problems in parent-adolescent communication and family conflict related to T1D, and their impact on self-management and T1D-specific QOL. In terms of measures, it is also important to note that the internal consistency for the impact of treatment subscale of the DQOLY-SF was low ($\alpha = .50$). Therefore, the findings associated with this subscale should be interpreted cautiously. The research is also limited by the sample size which did not allow for the investigation of interrelationships between all variables of interest within one hierarchical multiple regression model. Only self-management variables that were significant predictors of T1D-specific QOL in section 8.7 were subsequently incorporated into one model investigating interrelationships between parent-adolescent communication, T1D-specific family conflict, T1D self-efficacy, self-management and T1D-specific QOL (see section 8.8), rather than all included within one model.

Another limitation of research of this nature was the potential bias of adolescents self-selecting to participate in the survey. As mentioned previously, this sample reported low levels of family conflict. Furthermore, although recruitment took place through a national centre, it is not possible to know if the sample is representative of adolescents with T1D who are living in Ireland. The results indicate that most adolescents included in the current phase had access to management technologies such as insulin pumps and flash glucose monitors or CGM for T1D management. In Ireland, insulin pump uptake among individuals under 18 years of age is estimated to be around 34.7% (Gajewska et al., 2020). 65.5% of respondents in the current phase reported using an insulin pump. However, in the absence of a national register, a clinical database or population-based data, it is difficult to estimate how these values reflect adolescents with T1D who are living in Ireland.

9.8 Conclusion

The findings from the quantitative phase of this mixed methods study indicate, for the first time, that parent-adolescent communication and T1D-specific family conflict are associated with T1D self-efficacy, activation and self-management of T1D. Furthermore, the findings also indicate that T1D-specific family conflict and parent-adolescent communication are differentially related to distinct aspects of self-management. This phase has also contributed important knowledge on the relationship of parent-adolescent communication, T1D-specific family conflict and the psychosocial aspects of T1D management with adolescent QOL. These findings provide novel insights into how parent-adolescent communication characteristics relate to self-management and adolescent perceptions of QOL. Supporting adolescents and parents to employ communication strategies that are open will ensure that both adolescents and parents have clear expectations with respect to their involvement and roles in managing T1D. Understanding how communication potentially features in the negotiation and navigation of management responsibilities during adolescence is critical, especially given the difficulties with management of T1D that occur over the course of adolescence. The research also provides a point of departure for further inquiry into how parent-adolescent communication, T1D-specific family conflict, self-management and QOL may be associated. For example, longitudinal research examining additional dimensions of family function in addition to parent-adolescent communication to determine whether individual dimensions of family function demonstrate a differential relationship to T1D self-management and QOL. The results indicate that targeting parent-adolescent communication and reducing conflict may lead to improved T1D outcomes and facilitate the transition towards independent self-management of T1D, thereby also improving adolescent QOL.

Chapter 10: Integrative Findings and Discussion

10.1 Introduction

This chapter will present the integration of the findings from the qualitative and quantitative phases to address this mixed methods study's research questions (see Section 3.2): What helps or hinders adolescent engagement with self-management of T1D?; How does parent-adolescent communication contribute to negotiation and sharing of responsibilities for self-management for adolescents?; How does negotiating self-management responsibilities impact on adolescent life? An account of how the findings were integrated (a more detailed description is provided in 3.4) will be presented first. Next, the integrated findings will be detailed. Finally, key findings of this mixed methods study will be discussed.

10.2 Integrating the findings from phase one and phase two

Qualitative and quantitative findings from each phase were incorporated within a joint display (see Tables 10.1-10.3). The use of a joint display to integrate and present qualitative and quantitative findings facilitates the direct evaluation and identification of points of comparison across results from qualitative and quantitative phases of research (Creswell & Clark, 2017). This approach has been previously adopted with various mixed methods designs including sequential exploratory mixed methods studies (e.g. Haggerty et al., 2012). The outputs of conducting integration are the identification of meta-inferences which will be discussed below in section 10.3.

10.3 Meta-inferences: Confirmation, expansion and discordance

The purpose of integrating findings from phase one and phase two is to develop meta-inferences, which are new insights that are gained through the merging/joint display of qualitative and quantitative findings (Guetterman et al., 2015; Tashakkori & Teddlie, 2003). Firstly, the qualitative themes and subthemes were mapped onto scales and subscales administered in the quantitative phase, that were conceptually similar to the qualitative themes/subthemes (see Appendix W). Qualitative findings (themes, subthemes, illustrative quotations from phase one) and quantitative evidence (statistics generated using the data gathered from the cross-sectional surveys in phase two) were mapped onto the joint display in Tables 10.1-10.3 and examined side by side for fit or coherence (Fetters et al., 2013). The particular dimensions of fit that the data were examined for were instances of confirmation, expansion or discordance (Fetters et al., 2013). Where *confirmation* was noted, agreement was present across the findings from each phase. Where confirmation was evident, this strengthened the findings from each individual study phase, in highlighting the specific factors that are relevant to adolescent experiences of negotiating involvement in their T1D self-management. *Expansion* was noted where findings from each phase, when considered together, provided additional or complementary insights to the mixed methods research question it related to. Where expansion was evident, this contributed to further elaboration of the specific contexts that adolescent's experiences of self-management occurred within and adolescent experiences surrounding negotiation of responsibilities for self-management in adolescence. Finally, *discordance* occurred where qualitative and quantitative findings were inconsistent or contradictory. Once identified, these meta-inferences were mapped, together with the corresponding qualitative and quantitative evidence, within the joint displays (see Tables 10.1-10.3). The meta-inferences or outputs of the side by side comparison of qualitative and quantitative findings, were then matched to the overarching mixed methods research question with which they were associated. The tables map onto the mixed methods questions posed at the outset of this mixed methods study.

10.3.1 What helps or hinders adolescent engagement with self-management of T1D?

Following the integration of qualitative and quantitative findings, key areas which help or hinder adolescent engagement with self-management of T1D were identified. Integration involved comparing the qualitative and quantitative findings for instances of confirmation, expansion and discordance. Key areas identified, which help or hinder adolescent engagement with self-management, were: demographic and clinical factors (including age, time since diagnosis, use of technologies), parental involvement (including parent-adolescent communication and family characteristics) and the role of T1D self-efficacy and perceptions of ability to engage with T1D self-management. Table 10.1 below presents a joint display of the related qualitative and quantitative findings side-by-side, and the associated mixed methods meta-inferences generated.

Specific non-modifiable or context (e.g. adolescent age, T1D management characteristics) factors identified as important in the qualitative findings were *confirmed* within the quantitative findings. Across both phases, older adolescent age was associated with less parental involvement in care and increased adolescent responsibility for self-management tasks. Furthermore, the qualitative findings *confirmed* and emphasised that parent-adolescent negotiation of responsibilities for self-management was prompted by an increase in adolescent age. The integrated findings *expanded* knowledge on how taking on more responsibilities for self-management was facilitated by certain specific contextual factors (mode of insulin administration, being supported by others e.g. friends and HCPs) of self-management. Within qualitative accounts the benefits of insulin pumps as a mode of insulin administration that helped with self-management engagement was highlighted. These findings were *expanded* upon within the quantitative findings where use of MDI was associated with less problem solving and less goals related to T1D self-management. However, there was also some *discordance* across the integrated findings regarding the role of management technologies as factors that help adolescents to carry out their T1D self-management tasks. For instance, while the qualitative findings suggest that certain management devices (e.g. insulin pumps and BGM monitors) facilitated some adolescents' engagement with their self-management, this was not observed in quantitative differences in performance of the tasks of self-management according to BGM method and mode of administration.

Across the qualitative and quantitative phases, family context and specifically perceptions of interactions with parents contributed to increased engagement with self-management and increased knowledge and skills to engage with self-management among adolescents. Therefore, the integration *confirmed* that aspects of self-management were impacted upon by specific family context factors such as parent-adolescent communication characteristics. The findings across both phases *confirmed* that collaboration with parents could help adolescents to engage with T1D self-management. The integrated findings *expanded* on the characteristics of family context and parent-adolescent communication (adolescent perceptions of openness, understanding and T1D-specific family conflict in interactions) that differentially impact upon areas of self-management. As mentioned above, adolescent involvement in their T1D management increased from the point of diagnosis and with their increasing age. The qualitative findings *expanded* upon this through highlighting how this change comes about in a gradual and nuanced way, influenced by features of the family context (e.g. how much time parents devote to collaborating with the adolescent on their self-management and perceptions of closeness within the parent-adolescent relationship). Across findings there was *discordance* evident in the relationship between parent-adolescent communication and adolescent perceptions of their self-management problem-solving abilities. This quantitative finding was *discordant* with the qualitative data which highlighted that being able to consult with parents in an unrestricted and open way helped adolescents to figure out how to approach their self-management. There was also *discordance* across the phases with respect to parental involvement in adolescent T1D management and the impact of this on metabolic control of T1D and perceptions of the impact of completing the tasks of self-management. The potential for parental involvement in T1D management to alleviate subjective burden of T1D referred to within the qualitative findings was not identified in the quantitative data. Similarly, taking on more responsibility was described as having the consequence of a decline in metabolic control by adolescents in the qualitative findings. No quantitative associations between collaboration with parents and division of parent-adolescent responsibility for T1D management to either HbA1c or the impact of treatment were observed.

Finally, the integrated findings *confirmed* the important role of the beliefs and competencies of adolescents as facilitators of adolescent engagement with self-management of T1D. Both phases *confirmed* that when adolescents felt competent and able to carry out management, this contributed to improved problem-solving ability and their assuming of a more active role in T1D self-management. The integrated findings indicated that the relationship between T1D self-efficacy and T1D self-management was associated with openness about self-management with others such as HCPs. In qualitative accounts, being open with others facilitated the carrying out of self-management of T1D as required. The quantitative findings *expanded* upon this qualitative finding through demonstrating that being open with others about T1D management was associated with perceptions of self-efficacy. Finally, there was some *discordance* across findings relating to adolescent age and adolescent perceptions of their T1D self-efficacy. Age was not associated with increased T1D self-efficacy, however qualitative accounts suggested that adolescents consider themselves more capable of independently engaging with self-management as they get older.

Table 10.1

Joint display of qualitative findings, quantitative findings and mixed methods meta-inferences for the research question: What helps or hinders adolescent engagement with self-management of T1D?

Theme/Subtheme	Example Quotations	Quantitative finding/statistic	Meta-inferences: Confirmation, expansion, discordance
Changing levels of involvement in self-management: "I take more responsibility for [this] and … my mum would do that usually" (1) Division of responsibility for self-management within the family	*"Well it - she [parent] used to help me 90% of the time because I didn't know what to do a lot of the time but it has changed… I am just starting to like kind of remember to do a lot more things than I used to do and it probably changed three years ago when I turned around 8 or 9."* – P07, Male, 11 years, diagnosed age 4 years	Older age significantly associated with less parent involvement in management tasks (r = -.64), less collaboration with parents (r = -.49) and higher activation (r = .28)	Confirmation – both QUAL and QUAN findings suggest older age coincides with reducing parental involvement in care
(2) Collaborating and sharing responsibilities with parents for self-management	"*I have to do more stuff myself. My ma used always do everything for me... So it is like you have to take more on yourself the more you go on.*" – P06, Male, 15 years, diagnosed age 11 years *"I guess like when I started off doing the cartridges, started off doing the cannulas, when I started taking responsibility, they would always watch or I would watch them do the cartridges before I would try it, just share*	**Results of HMR analysis** **DV:** Activation (PAM) **IVs:** demographic and clinical characteristics, parent-adolescent communication (PACS) and T1D-specific family conflict (DFCS-R), T1D self-efficacy (SEDM) **Key finding:** Addition of PACS and DFCS-R explained an additional 13% of variance (p < .01). the addition of SEDM explained an additional 31% variance (p < .01). In final model, more openness in parent-adolescent	Confirmation – how adolescents perceive parent-adolescent interactions is relevant to taking on additional responsibility and beliefs relating to activation

Theme/Subtheme	Example Quotations	Quantitative finding/statistic	Meta-inferences: Confirmation, expansion, discordance
	responsibility in the sense that I am taking control but I don't have the full trust yet." – P16, Female, 14 years, diagnosed age 5 years	communication and higher scores for T1D self-efficacy was associated with more activation.	
(3) Gaining confidence and mastery in self-management	*"Like earlier on when I was younger they would have to do it all but like really now all they do is go over and tell me if it is right or wrong and then do it."* – P14, Male, 11 years, diagnosed age 3 years	More activation (PAM) was significantly associated with more performance of T1D care activities (SMODA-I) (r = .37**), more problem (SMODA-I) solving (SMODA-I) (r = .40**) and more goals (SMODA-I) (r = .55**)	Confirmation – when adolescents feel activated and competent to engage with management, this contributes to more optimal engagement with the tasks of management and promotes more independence in self-management.
	"*I am all right about it, like I wouldn't be too scared of it. I can't think of the word but I wouldn't mind it, like I am all right about having to do it myself*." – P09, Male, 13 years, diagnosed age 1 year *"… especially if you try and keep your bloods in a tight range and you feel as if you can manage it, that is something to be proud of because it is a lot of hard work…"* – P26, Female, 15 years, diagnosed age 12 years	**DV:** Activation (PAM) **IVs:** demographic and clinical characteristics, parent-adolescent communication (PACS) and T1D-specific family conflict (DFCS-R), T1D self-efficacy (SEDM) **Key finding:** The addition of SEDM explained 31% of the variance (p < .01). In the final model, only more openness in parent-adolescent communication and higher SEDM were significantly associated with more adolescent activation.	Confirmation – findings from both phases emphasise the links between activation and T1D self-efficacy
(4) Catalysts or prompts to assuming more management	*"Before my mam would probably do all of the site change or my dad*	**DV:** Goals (SMODA-I)	Confirmation – adolescent perceptions of their beliefs and

Theme/Subtheme	Example Quotations	Quantitative finding/statistic	Meta-inferences: Confirmation, expansion, discordance
	would have everything ready for me but then I was able to do that because I needed to, like say I was asked on a sleepover I would need to do it, so I was able to do it then." – P24, Female, 15 years, diagnosed age 11 years	**IVs:** demographic and clinical characteristics, parent-adolescent communication (PACS) and T1D-specific family conflict (DFCS-R), T1D self-efficacy (SEDM) **Key finding:** The addition of SEDM explained 11% of the variance (*p* < .01). In the final model, older age, use of insulin pump, more openness in parent-adolescent communication, more problems in parent adolescent communication and higher SEDM were significantly associated with more self-management goals.	competencies are important for formation of goals of managing T1D more independently. Specific situations can prompt this such as the desire to spend time away from home, referred to in qualitative interviews.
Changing levels of involvement in self-management: "I take more responsibility for [this] and … my mum would do that usually" (1) Division of responsibility for self-management within the family	*"I would say like-I am pretty involved because like I am the one who has diabetes but I feel like my mum is the one who like kind of stands up and like takes like control I guess. Yeah."* – P23, Female, 14 years, diagnosed age 6 years *"Yeah my mam is a lot more involved, my dad like doesn't really do much."* – P11, Male, 16 years, diagnosed age 15 years	Collaboration with Parents (SMODA-I) (*M* = 21.41, *SD* = 7.86, range = 4-39, possible range = 0-39) DFRQ (*M* = 31.22, *SD* = 4.91, range = 21-43, possible range = 17-51)	Expansion – QUAN findings indicate that across adolescents how involved they believe themselves to be in their care varies. QUAL findings indicate that this change comes about over time and how this division of responsibility appears varies across individual families
	"…Well at the beginning they would, they would help me with my		Expansion – QUAN findings suggest that the age of the

Theme/Subtheme	Example Quotations	Quantitative finding/statistic	Meta-inferences: Confirmation, expansion, discordance
	injections but now I pretty much do them myself so no I haven't really relied on them overly but I have always known they are there to help if I need it." – P03, Male, 14 years, diagnosed age 11 years	Older age at diagnosis significantly associated with less parental involvement in T1D tasks (*r* = -.23)	adolescent at diagnosis might also be a factor that influences gaining independence
	"Like my mum will still go to the pharmacy for me and get me all my stuff, which is really helpful, but sometimes I have to tell her now like when I am running out of things which whereas I wouldn't have really before." – P25, Female, 17 years, diagnosed age 13 years	**Results of HMR analysis** **DV:** Division of family responsibility (DFRQ) **IVs:** demographic and clinical characteristics, parent-adolescent communication (PACS) and T1D-specific family conflict (DFCS-R), T1D self-efficacy (SEDM) **Key finding:** Addition of PACS and DFCS-R explained an additional 5% of variance (*p* < .05). the addition of SEDM explained an additional 3% variance (*p* < .05). In final model, older age and lower scores for T1D self-efficacy predicted more parent involvement in T1D management tasks.	Expansion – QUAN findings demonstrate that parent-adolescent communication, T1D-specific family conflict and T1D self-efficacy can play a role in the change that comes about for responsibility for tasks of self-management
(2) Collaborating and sharing responsibilities with parents for self-management	*"My mam and dad, they watch everything I would say, they just like they always know what is going on but I would probably be doing most*	Higher activation (PAM) was significantly correlated with less parental involvement in care	Expansion – QUAN data identifies associations between perceived parental involvement in care and adolescent activation. QUAL data

Theme/Subtheme	Example Quotations	Quantitative finding/statistic	Meta-inferences: Confirmation, expansion, discordance
	of it. If you know what I mean." – P03, Male, 14 years, diagnosed age 11 years	(DFRQ) (r = -.42**) and less collaboration with parents (SMODA-I) (r = -.24**)	indicates that as adolescents become more involved and activated, they are aware that their parents still oversee their management
	"No it was kind of like well I was like I can do this [manage T1D without help from parents], I just rushed into it and it was very silly… I was just like I can do this now, I don't need any help and da da da and I can I can do it without any help but then just realised I couldn't." – P27, Male, age 14 years, diagnosed age 1 year		Expansion – QUAL findings expand upon QUAN through providing examples of how responsibilities for management can shift between adolescents and parents in a dynamic manner
	"As I have gotten older I have kind of tried to manage it more but then it hasn't really worked out because there is a lot of working out with the carbs that I have had to eat so I nearly let the carbs and the working out of the insulin up to my parents and the doing my bloods in school and taking the injections is more down to me." – P15, Female, 15 years, diagnosed age 11 years		Expansion – QUAL accounts contribute to understanding the nature of the difficulties that adolescents encounter with assuming more responsibility for self-management
(2) Seeking parental feedback and advice	*"If I was just having problems in or if I had a question about it they*	More T1D self-efficacy (SEDM) was significantly related to more	Expansion – the QUAL and QUAN findings, suggest that openness with

Theme/Subtheme	Example Quotations	Quantitative finding/statistic	Meta-inferences: Confirmation, expansion, discordance
	[parents] would sit down and listen and give the answer to it. I would take it in and learn from the next thing." - P18, Male, 15 years, diagnosed age 7 years *"They have generally been grand with that, they wouldn't really give out to me, they'd kind of just try and see how we can prevent it from happening again and to deal with it."* – P03, Male, 14 years, diagnosed age 11 years	openness (*r* = .28**) and fewer problems in parent-adolescent communication (PACS) (*r* = .24**), and less conflict (DFCS-R) (*r* = -.28**)	parents may lead to improvements in T1D management through receiving parental advice on how to approach management when it is proving difficult. When parents are available to provide this support, it can promote feelings of adolescent self-efficacy. The QUAL findings also suggest that this can be extended from T1D self-efficacy to perceptions of independence
(2) Learning about self-management and understanding T1D	*"Just like treating highs and lows and like sometimes depending on the time it might be like the wrong time to do a correction but I would do a correction and then I would go low, yeah."* – P19, Female, 15 years, diagnosed age 8 years *"I read one of the booklets and my ma started telling me that if I don't look after it I could go blind or it gets worse and I'd get glasses… Yeah that sometimes makes you want to manage, I have to start pulling up my socks and start taking more responsibility."* -P06, Male, age 15 years, diagnosed age 11 years	Less performance of T1D care activities was associated with greater perceived impact of treatment (*r* = -.20*)	Expansion – QUAN found that less performance of T1D care activities was associated with more perceived impact of treatment. The QUAL data illustrates how knowing what to do in a specific situation facilitates management

Theme/Subtheme	Example Quotations	Quantitative finding/statistic	Meta-inferences: Confirmation, expansion, discordance
	"So like I have learnt to control it in regards to sport. I also have to take my pump off because it is a contact sport that I play so it can often lead to spikes, or ehm if I am running around a lot then it can lead to lows. So you kind of you have to find a balance.."- P16, Female, 14 years, diagnosed age 5 years		
(3) Gaining confidence and mastery in self-management	*"I am able to ask more questions about it. I've been able to tell them to kind of give me more advice that I can understand better now because I'm older. I guess taking the information in you couldn't really take it in because you were just- You were kind of young."* – P10, Male, 14 years, diagnosed age 6 years	Age was significantly associated with more activation (r = .28**) and more self-management problem solving (r = .34**) T1D duration was not significantly associated with management self-efficacy or activation. Longer T1D duration was significantly associated with more problem solving (r = .27**)	Expansion – age is associated with more activation and problem solving in QUAN indicating that demographic factors impact on different attributes of self-management
	"*Well for me, I know that when I am older it is going to be me doing it myself so I always knew that I was going to take more control over it as I got older*." – P03, Male, 14 years, diagnosed age 11 years *"I was so happy with myself because I felt like I was really*	**Results of HMR analysis** **DV:** Problem solving (SMODA-I) **IVs:** demographic and clinical characteristics, parent-adolescent communication (PACS) and T1D-specific family conflict (DFCS-R), T1D self-efficacy (SEDM) **Key finding:** The addition of SEDM explained 11% of the	Expansion – QUAL findings indicate how adolescent feelings of self-efficacy can develop over time and how confidence and pride can contribute to this, leading to better engagement with self-management

Theme/Subtheme	Example Quotations	Quantitative finding/statistic	Meta-inferences: Confirmation, expansion, discordance
	getting like a grip of it [T1D management] and I knew what to do then." – P13, Female, 12 years, diagnosed age 8 years	variance (p < .01). In the final model, only older age, insulin administration via pump and higher SEDM were significantly associated with more self-management problem-solving ability.	
(4) Catalysts or prompts to assuming more management	*"… I really want to take it on myself now because I feel I need to grow up and take charge of it.…"* – P20, Female, 16 years, diagnosed age 5 years *"I would deal with it with my parents but as they are busy I will have to try and do it myself so it's kind of being kind of forced upon me. I have to start taking more responsibility and I guess yeah that's another factor I'd start taking"* - P10, Male, 14 years, diagnosed age 6 years *"When I was younger it was a lot more they would talk to my mum but now like they talk to me like. Sometimes I don't let my mum come in [to appointments] anymore. Just cause it's not like*-I *still live at home obviously and she is still my mum*	Older age was significantly associated with less collaboration with parents (SMODA-I) (r = -.49**), more problem solving (r = .34**), more self-management goals (SMODA-I) (r = .24**) and less parental involvement in management (DFRQ) (r = -.64**).	Expansion – QUAL gives some indication of situations (e.g. interactions with HCPs, feeling mature, secondary school) that can prompt the adolescent to become more responsible self-managing T1D

Theme/Subtheme	Example Quotations	Quantitative finding/statistic	Meta-inferences: Confirmation, expansion, discordance
	and I am only 17 but I sometimes like being independent about it because it is my disease and I am the one that controls it and stuff like that..." – P25, Female, 17 years, diagnosed age 13 years		
	"I would say they help me a lot because I feel like a like I haven't really matured like I still take it like a child, I still give out when I have to take my bloods and have the injection, I still feel it hasn't really become a part of my life yet, I am still trying to fight it off. I am thinking if I fight I won't have to do it. I still feel like a child in that sense." – P15, Female, 15 years, diagnosed age 11 years	**Results from HMR analysis** **DV:** T1D care activities (SMODA-I) **IVs:** demographic and clinical characteristics, parent-adolescent communication (PACS) and T1D-specific family conflict (DFCS-R), T1D self-efficacy (SEDM) **Key finding:** The addition of SEDM explained 18% of the variance ($p < .01$). In the final model, only higher SEDM was significantly associated with more performance of T1D care activities.	Expansion -the QUAL findings indicate that adolescents encounter difficulties with engaging with management tasks and viewing management of T1D as solely their responsibility
Environmental and contextual influences affecting self-management: "Even though I know what to do, it's just that support really helps" (1) Setting and/or devices can influence engaging with self-management	*"I suppose like the Libre is kind of like it's easier to take my numbers cos like finger-pricking [I: Yeah] and it doesn't hurt my fingers as much every time I take my numbers. [I: OK] So It's a lot easier so I'm more likely to do it then when it's easier."* – P01, Female, 13 years, diagnosed age 3 years	MDI users reported significantly more collaboration with parents (t (112) = 3.20, p = .002), less problem solving (t (112) = -4.76, p = <.001), less self-management goals (t (112) = -3.33, p = .001), more parent responsibility for management tasks (t (111) = 2.28, p = .03) and lower T1D self-efficacy	Expansion – the QUAN provides more specificity towards the identification of situations and areas of T1D management that use of an insulin pump can enable engagement with self-management

Theme/Subtheme	Example Quotations	Quantitative finding/statistic	Meta-inferences: Confirmation, expansion, discordance
		(t (111) = -2.69, p = .01). No significant differences observed for mode of insulin administration and performance of self-management tasks, activation and impact on activities.	
	"Sometimes it can just be annoying because- but usually it is the last thing you want to do when you are out with your friends to just like do a test. And the pump can be a bit noticeable." – P19, Female, 15 years, diagnosed age 8 years *"When I was in school last week I just kept getting high sugars all the time and I didn't really know why and like I couldn't do anything about it because I was in school and you are not really allowed walk around or get food or get a drink so I couldn't so anything so I had to just keep them high all day and like I didn't know what to do with them."* – P12, Female, 13 years, diagnosed age 12 years	**Results of HMR analysis** **DV:** Impact of Symptoms (DQOLY-SF) **IVs:** demographic and clinical characteristics, T1D Self-efficacy (SEDM), Collaboration with parents (SMODA-I), Care activities (SMODA-I), Problem solving (SMODA-I), Communication (SMODA-I), Goals (SMODA-I), Activation (PAM) **Key finding:** Addition of SEDM explained an additional 1% of variance (p = ns). The addition of the SMODA-I subscales and PAM explained 8% of the variance (p = ns). In final model, only higher activation was significantly associated with more impact of symptoms	Expansion –The QUAL adds depth to the experiences of adolescents of encountering distractions and situations that can make engaging in activities to minimise the impact of T1D-related symptoms on life.
	"Am at school it is fine, it is much easier in school than when I am on summer because there is a routine,		Expansion – the findings from both phases indicate that some aspects of self-management together with

Theme/Subtheme	Example Quotations	Quantitative finding/statistic	Meta-inferences: Confirmation, expansion, discordance
	you have your snack at 11, you have your lunch at 1, it's very like you know what you are doing..." – P25, Female, 17 years, diagnosed age 13 years		context can make it easier to engage with treatment
(3) Involving friends and peers in self-management	*"But also having friends that like are aware is helpful as well, if you are ever in a bad situation they can help you out."* – P11, Male, 16 years, diagnosed age 15 years	More communication about T1D self-management was significantly related to higher management self-efficacy (*r* = .45**)	Expansion – being open with others may be associated with higher self-efficacy as the adolescent feels supported to engage with their management by those around them
	"… And sometimes my friends, they don't mean it in a mean way, they say sometimes, 'don't you know how to have fun?' I'm like "no because I had to grow up" and they say it is pretty sad that you don't know how to have fun and it is like yes because I had to grow up with diabetes." - P17, Female, 15 years, diagnosed age 10 years		Expansion – Based on QUAL findings, sometimes adolescents' friends can remind adolescents of some of the drawbacks of living with T1D, which can be considered non-supportive adolescents with T1D
	"Well uhm am I find social media is absolutely huge at the moment and I have talked to many diabetics online and I have made actually a few friends online … and they help me, we all keep in touch and they let me know about different diabetes	**Results of HMR analysis** **DV:** T1D communication (SMODA-I) **IVs:** demographic and clinical characteristics, parent-adolescent communication (PACS) and T1D-	Expansion – when adolescents are open with communication with parents, this can also lead to them being more open in their interactions with others about T1D. The QUAL findings also indicate the different setting that adolescents

Theme/Subtheme	Example Quotations	Quantitative finding/statistic	Meta-inferences: Confirmation, expansion, discordance
	products out there and different things I could eat and low carb snacks....” - P26, Female, 15 years, diagnosed age 12 years “*Because most people when they think of diabetes they think of the type 2, and there is nothing wrong with type 2 diabetes, but just it is just very different from type 1 and sort of the word is associated with a lot of shame I think.*” – P20, Female, 16 years, diagnosed age 5 years	specific family conflict (DFCS-R), T1D self-efficacy (SEDM) **Key finding:** Addition of PACS and DFCS-R explained an additional 18% of variance ($p < .01$). The addition of SEDM explained 14% of the variance ($p < .01$). In final model, only mode of insulin administration, openness and SEDM were significant	are open with others about their T1D management. The QUAL findings also demonstrate how these interactions with friends can vary from positive to more negative (especially when friends are perceived as not understanding T1D)
(4) Collaborating with HCPs while gaining independence in self-management	*“By the doctors, they showed my parents and me and so they just showed like how to use the injection, how to use the monitor, the different types of monitors, different ways to inject insulin… And then they just at the start they let my parents do it but as time went on they allowed me to do my own injection and test my own bloods and going out and stuff like that.”* – P17, Female, 15 years, diagnosed age 10 years *“Yeah everything they explain to my mum they’d explain to me just so*	Higher self-efficacy (SEDM) was significantly associated with more activation (PAM) ($r = .47^{**}$)	Expansion – QUAL findings indicate that HCPs are involved in adolescents’ experiences of gaining independence in self-management. More self-management communication was associated with more activation

Theme/Subtheme	Example Quotations	Quantitative finding/statistic	Meta-inferences: Confirmation, expansion, discordance
	I know what is going on and clued in because like at this age you need to kind of start taking control of it yourself." – P16, Female, 14 years, diagnosed age 5 years		
(2) Collaborating and sharing responsibilities with parents for self-management	*"I think it is really good [to share management responsibilities with parents] because if I was left to do it myself I would say I would forget it half of the time. I could be awful sort of clumsy some ways and it is just good to have someone there as well. And even when you think you are doing everything right is always good to have someone else there just to have another look at things to just see how you could improve just a little bit more."* - P22, 16 years, diagnosed age 8 years	More perceived impact of treatment was significantly associated with more collaboration with parents (SMODA-I) (r = .23*) and more parental involvement (DFRQ) (r = .19*)	Discordance – some QUAN evidence suggests that when parents are more involved in T1D management this can contribute to more perceived impact of T1D management
(3) Gaining confidence and mastery in self-management	*"I am able to ask more questions about it. I've been able to tell them to kind of give me more advice that I can understand better now because I'm older. I guess taking the information in you couldn't really take it in because you were just- You were kind of young."* – P10, Male, 14 years, diagnosed age 6 years	Age not significantly associated with management self-efficacy.	Discordance – age was not associated with increased T1D self-efficacy in QUAN data though in QUAL, adolescents described feeling more capable in comparison to when they were younger

Theme/Subtheme	Example Quotations	Quantitative finding/statistic	Meta-inferences: Confirmation, expansion, discordance
(4) Catalysts or prompts to assuming more management	*"I suppose once I got comfortable enough with the pump into secondary school, that is when I started more responsibility, just to because when you do get to secondary school you are treated like more of an adult than when you are in primary school...."* – P22, Male, 16 years, diagnosed age 8 years	No significant difference observed for mode of insulin administration and performance of T1D care activities (SMODA-I). However, there was a significant difference observed for collaboration with parents (SMODA-I) and the DFRQ, indicating that adolescents who use MDI report more collaboration with parents (t (112) = 3.20, p = .002) and significantly more parent responsibility for management tasks (t (111) = 2.28, p = .03)	Discordance – QUAL data suggests that there might be a link between modes of management and performance of T1D care activities, however no significant associations were evident for BGM method. MDI users report more collaboration with parents in QUAN results
Environmental and contextual influences affecting self-management: "Even though I know what to do, it's just that support really helps" (1) Setting and/or devices can influence engaging with self-management	*"I suppose like the Libre is kind of like it's easier to take my numbers cos like finger-pricking [I: Yeah] and it doesn't hurt my fingers as much every time I take my numbers. [I: OK] So It's a lot easier so I'm more likely to do it then when it's easier."* – P01, Female, 13 years, diagnosed age 3 years	No significant differences observed for BGM method on the impact subscales of the DQOLY-SF	Discordance – QUAL accounts indicate BGM method can facilitate more frequent checks but no associations were observed with any of the measures of self-management and BGM method in QUAN data
	"Sometimes it can just be annoying because- but usually it is the last thing you want to do when you are out with your friends to just like do a test. And the pump can be a bit	No significant relationship was observed for performance of T1D care activities to either impact of symptoms or impact on activities.	Discordance – between the associations mentioned about management in the social setting in QUAL findings, and the QUAN based on the activities included in the DQOLY-SF

Theme/Subtheme	Example Quotations	Quantitative finding/statistic	Meta-inferences: Confirmation, expansion, discordance
	noticeable.” – P19, Female, 15 years, diagnosed age 8 years		
	“When I was in school last week I just kept getting high sugars all the time and I didn’t really know why and like I couldn’t do anything about it because I was in school and you are not really allowed walk around or get food or get a drink so I couldn't so anything so I had to just keep them high all day and like I didn't know what to do with them.” – P12, Female, 13 years, diagnosed age 12 years	**DV:** Impact of Treatment (DQOLY-SF) **IVs:** demographic and clinical characteristics, T1D Self-efficacy (SEDM), Collaboration with parents (SMODA-I), Care activities (SMODA-I), Problem solving (SMODA-I), Communication (SMODA-I), Goals (SMODA-I), Activation (PAM) **Key finding:** Addition of SEDM explained an additional 5% of variance ($p < .05$). The addition of the SMODA-I subscales and PAM explained 5% of the variance (p = ns). In final model, only mode of insulin administration was significantly associated with more impact of treatment	Discordance – only mode of insulin administration was associated with impact of treatment in the final model. QUAL findings suggest that the responsibility of engaging with management can contribute to negative feelings such as blame
(4) Collaborating with HCPs while gaining independence in self-management	*“Well when I took more independence the HbA1c went up a little bit because that would have been my first time doing it so the doctors asked my mam to step in a little bit more. But mainly it is me doing most of the stuff.”* – P18,	Higher HbA1c was associated with less performance of T1D care activities (SMODA-I) (r_s = -.20*), less problem solving (SMODA-I) (r_s = -.21*), less goals (SMODA-I) (r_s = -.40**) and less T1D self-efficacy (SEDM) (r_s = -.24*)	Discordance – The QUAL findings suggest higher HbA1c may be associated with adolescents taking on more responsibility for management, and increased independence is associated with higher HbA1c.

Theme/Subtheme	Example Quotations	Quantitative finding/statistic	Meta-inferences: Confirmation, expansion, discordance
	Male, 15 years, diagnosed age 7 years	No relationship with DFRQ or collaboration with parents (SMODA-I)	
(2) Collaborating and sharing responsibilities with parents for self-management	*"They both just encourage me. If they say, 'Do this' I would be like, 'no I think this is what we should do-' They would be like, 'okay you do that if you think that's right you go and do it.' They are not like, 'no we will do it our way!' They just encourage me to do if I want to do it a certain way. They would be like, 'okay, we will see what happens.' They allow me to make decisions on my own."* – P13, Female, 12 years, diagnosed age 8 years	**Results of HMR analysis** **DV:** Problem solving (SMODA-I) **IVs:** demographic and clinical characteristics, parent-adolescent communication (PACS) and T1D-specific family conflict (DFCS-R), T1D self-efficacy (SEDM) **Key finding:** Addition of PACS and DFCS-R explained an additional 1% of variance (*p* = ns). the addition of SEDM explained an additional 11% variance ($p < .01$). In final model, older age, use of an insulin pump and higher scores for T1D self-efficacy predicted more self-management problem solving.	Discordance – HMR analysis indicated that parent-adolescent communication and T1D-specific family conflict were not associated with problem solving, while QUAL data suggests that positive interactions support the adolescent in their self-management problem solving and decision making about T1D

Note. HMR = hierarchical multiple regression, QUAL = qualitative phase, QUAN = quantitative phase

10.3.2 How does parent-adolescent communication contribute to negotiation and sharing of responsibilities for self-management for adolescents?

The integration of findings allowed for the identification of ways in which adolescent perceptions of parent-adolescent communication can contribute to negotiation and sharing of responsibilities for self-management. Again, findings across both study phases were compared for confirmation, expansion and discordance (see Table 10.2) relating to the mixed methods research question: How does parent-adolescent communication contribute to negotiation and sharing of responsibilities for self-management for adolescents? The key areas identified included the contribution of specific aspects of parent-adolescent communication to negotiation and sharing of T1D self-management responsibilities and the relationship between parent-adolescent communication, perceptions of competence and engagement with self-management of T1D. These key areas are outlined below.

Regarding the contribution of specific aspects of parent-adolescent communication to the negotiation and sharing of T1D self-management responsibilities self-management, across both phases, the relationship between T1D-specific family conflict and openness in parent-adolescent communication on adolescent engagement with tasks of self-management was *confirmed*. However, the integrated findings pertaining to parent-adolescent communication and HbA1c were *discordant*. The qualitative findings suggested that poorly controlled blood glucose levels were frequently associated with parent-adolescent conflict, which can occur while adolescents negotiate their levels of independent involvement in self-management with their parents. This was not evident within the quantitative data with no relationship evident between HbA1c and T1D-specific family conflict or characteristics of parent-adolescent communication.

The findings from the quantitative phase *expanded* upon the qualitative finding regarding positive experiences of parent-adolescent communication contributing to more optimal sharing of self-management responsibilities with parents. Specifically, fewer problems in parent-adolescent communication was associated with more collaboration with parents for self-management in the quantitative phase. Moreover, openness in parent-adolescent communication was also *confirmed* as associated with performance of T1D management tasks. However, there was *discordance* evident in the findings relating to how characteristics of parent-adolescent communication contribute to self-management problem-solving. In the quantitative phase, parent-adolescent communication characteristics were not associated with self-management problem-solving, whereas, qualitative accounts highlighted that perceptions of positive communication contributed to helping adolescents to figure out the aspects of their self-management that they were learning.

Both phases provided *expansion* of understanding on how openness in parent-adolescent communication can alleviate adolescent worries related to T1D management. The qualitative findings *expanded* upon the influence of openness in parent-adolescent communication with examples of how discussing problems and worries with their parents can lead to positive experiences of negotiating sharing management with their parents, while also alleviating the perceived burden of engaging with T1D management.

The integrated findings *confirmed* that how adolescents view parent-adolescent communication contributes to how responsibilities for self-management are shared between adolescents and their parents. Specifically, the integrated findings highlighted associations between parent-adolescent communication, adolescent perceptions of their competence in their self-management and their transition towards more independent engagement with the tasks of self-management. More perceived openness in parent-adolescent communication was *confirmed* across phases, as a factor contributing to increased adolescent knowledge and skills to manage their T1D care and increased perceptions of their competence and ability to engage with T1D management. The qualitative findings *expanded* upon this finding with adolescents outlining that openness with their parents about T1D, can lead to increased access to advice and opportunities to learn, that facilitate optimal sharing and motivate adolescent’s transition to more independence in T1D self-management.

Table 10.2

Joint display of qualitative findings, quantitative findings and mixed methods meta-inferences for the research question: How does parent-adolescent communication contribute to negotiation and sharing of responsibilities for self-management for adolescents?

Theme/Subtheme	Example Quotations	Quantitative finding/statistic	Meta-inferences: Confirmation, expansion, discordance
Talking about self-management with parents: "I am not just like sitting in on the conversation… I am putting in my own ideas about what to think, what to do" (1) Change in patterns of parent-adolescent communication about T1D over time	*"I would say that they explain more to me now about like basal rates and stuff like that. When I was younger I wouldn't have known what that meant but now I understand everything"* – P16, Female, 14 years, diagnosed age 5 years	Higher levels of T1D self-efficacy (SEDM) was significantly correlated with openness in parent adolescent communication (PACS) (r = .28**)	Confirmation - As how knowledgeable the adolescent perceives them self to be changes, so too might their communication with their parent, as suggested by the QUAN association
	"… I feel like I am not just like sitting in on the conversation, I am actually getting involved and talking in it. I don't just feel like I am just nodding along saying, 'yeah change this, yeah do whatever you think.' I am putting in my own ideas about what to think what do." – P23, Female, 14 years, diagnosed age 6 years	More openness in parent-adolescent communication (PACS) significantly correlated with activation (PAM) (r = .31**). More self-management communication (SMODA-I) was significantly correlated with more activation (PAM) also (r = .47**)	Confirmation – both findings suggest a relationship between adolescents' openness to talk about T1D with others, including parents and their active involvement in their T1D management
(3) Promoting self-management communication between adolescents and parents	*"I find it find it fine talking to my parents because they are open to conversation about it."* – P11, Male, 16 years, diagnosed age 15 years	Openness in parent-adolescent communication scores, subscale of the PACS suggest high openness: M = 41.35, SD = 7.32, range = 16-50 (possible range = 10-50)	Confirmation – QUAN indicates that for the most part communicating with parents was presented as a mostly positive experience (high openness, low problems) which was also

Theme/Subtheme	Example Quotations	Quantitative finding/statistic	Meta-inferences: Confirmation, expansion, discordance
	"…you can go to them first and it is easier nearly talking to your parents than talking to someone that you don't really know like a nurse or someone like that." – P22, Male, 16 years, diagnosed age 8 years *"If I'm like struggling with one of the cartridges, if the bubbles can't come out I am fine with going to my mum and saying 'listen can you help me with this?'"* – P16, Female, 14 years, diagnosed age 5 years *"Sometimes it is just easier not to talk to your parents about it. You know because they'll worry less…"* - P25, Female, 17 years, diagnosed age 13 years	Problems in parent-adolescent communication scores: $M = 33.87$, $SD = 7.69$, range = 16-50 (possible range = 10-50)	suggested in the QUAL accounts, along with perceived closeness
	"… We are just really, really close the three of us that I can actually talk to them about stuff. We are just really close and I think that's what helps it as well." – P13, Female, 12 years, diagnosed age 8 years	**DV:** Parent Issues (DQOLY-SF) **IVs:** demographic and clinical characteristics, parent-adolescent communication (PACS) and T1D-specific family conflict (DFCS-R), T1D self-efficacy (SEDM) **Key finding:** Addition of PACS and DFCS-R explained an additional 35% of variance ($p < .01$). In final model, the addition of SEDM explained < 1% additional variance ($p < .01$). Less openness, more	Confirmation – Communication and conflict with parents are linked with adolescent perceptions of how they and their parents relate to one another about T1D

Theme/Subtheme	Example Quotations	Quantitative finding/statistic	Meta-inferences: Confirmation, expansion, discordance
		problems and more conflict were significantly associated with more parent issues (SEDM was non-significant)	
	“I kind of find it easy all the time like I don’t really unless I forgot to take my insulin, I would be a bit resistant to talk about it….” – P23, Female, 14 years, diagnosed age 6 years	Significant correlations were observed for more performance of T1D care activities and less parent issues (DQOLY-SF) (r = -.30**), less T1D-specific family conflict (DFCS-R) (r = -.32**), more openness in communication (r = .26**) and fewer problems in communication (PACS) (r = .26**)	Confirmation – findings from both phases suggest a relationship between family context (presence of conflict and parent-adolescent communication and interaction characteristics) and performance of T1D care activities
	“Well sometimes I think she doesn’t like asking me in case I am like, ‘of course they are fine’.” – P25, Female, 17 years, diagnosed age 13 years	Parent issues (DQOLY-SF) was significantly correlated with openness (r = -.22*) and problems (r = -.24**) in parent-adolescent communication (PACS).	Confirmation – perceptions of parent worry and concern demonstrates an association with parent-adolescent communication in both phases
	“Sometimes when I am out it is better for me, for comfort for my mum to ring her to say ‘this and this and this so how many units of insulin should I take?’”’ - P17, Female, 15 years, diagnosed age 10 years	**Results of HMR analysis** **DV:** Parent Issues (DQOLY-SF) **IVs:** demographic and clinical characteristics, openness in communication (PACS), problems in communication (PACS), family conflict (DFCS-R), T1D self-efficacy (SEDM), problem solving (SMODA-I), activation (PAM)	Confirmation – QUAL findings suggest that even when adolescents feel they possess the capability to manage their T1D, parental worry and concern can remain, with QUAN suggesting that parent-adolescent communication might mitigate the impact of this

Theme/Subtheme	Example Quotations	Quantitative finding/statistic	Meta-inferences: Confirmation, expansion, discordance
		Key finding: Addition of PACS and DFCS-R explained an additional 35% of variance (*p* < .01). The addition of SEDM explained <1% of the variance (*p* = ns). The addition of problem solving (SMODA-I) and PAM explained an additional 2% of the variance (*p* = ns). In final model, mode of insulin administration, less openness, more problems, more conflict were significantly associated with more parent issues.	
Talking about self-management with parents: "I am not just like sitting in on the conversation… I am putting in my own ideas about what to think, what to do" (1) Change in patterns of parent-adolescent communication about T1D over time	*"Cause at the start I was like using like different words. I didn't really know how to explain it and then now that we have learnt more words about the diabetes and we have all copped on to what they mean we just sort of use them to like explain it."* – P13, Female, 12 years, diagnosed age 8 years	Higher levels of T1D self-efficacy (SEDM) was significantly correlated with general adolescent self-management communication (SMODA-I) (*r* = .45**)	Expansion – The QUAN findings complement the QUAL findings suggesting that there is a relationship between perceived knowledge and competence and communicating about T1D with parents, peers and HCPs
(2) Seeking parental feedback and advice	*"Well I told them I was nervous about getting it [insulin pump]and then my dad said, 'sure [P05's name] I forgot I had it on.' And they said it wasn't sore at all so I got it- so then I got it and it was okay."* –	Openness in parent-adolescent communication (PACS) is significantly correlated with fewer worries related to T1D (*r* = -.23*)	Expansion – findings from both phases suggest that when parents and adolescents openly seek advice and express concerns, this can alleviate some of adolescent worries

Theme/Subtheme	Example Quotations	Quantitative finding/statistic	Meta-inferences: Confirmation, expansion, discordance
	P05, Male, 11 years, diagnosed age 9 years		
	“Yes, we don’t really talk about it otherwise because I have it like fairly under control.” – P16, Female, 14 years, diagnosed age 5 years *“If I had a question or if I wanted to know about something. You know like when I was quite interested in getting the pump, like I wouldn’t always talk about that I wouldn’t always start the conversation but a lot of the time I would because it was something I wanted. You know.”* - P25, female, 17 years, diagnosed age 13 years	**Results of HMR analysis** **DV:** Collaboration with parents (SMODA-I) **IVs:** demographic and clinical characteristics, parent-adolescent communication (PACS) and T1D-specific family conflict (DFCS-R), T1D self-efficacy (SEDM) **Key finding:** Addition of PACS and DFCS-R explained an additional 7% of variance (p < .01). In final model, only more problems in communication was associated with less collaboration with parents (openness, conflict and T1D self-efficacy were non-significant)	Expansion – QUAN suggests that the association between adolescent perceptions of their competencies and the context of their relationship with parents influences engagement with self-management tasks. QUAL findings also identify some of the motivations of adolescents for talking about T1D management related topics with parents
(3) Promoting self-management communication between adolescents and parents	*“Ehm if I haven’t tested if I just haven’t been doing well and I just don't feel like it at all [talking to parents]”* – P24, Female, 15 years, diagnosed age 11 years	Fewer problems in parent-adolescent communication (PACS) was significantly associated with more collaboration with parents (SMODA-I) (r = .30**)	Expansion - Fewer problems in communication were associated with more collaboration with parents, indicating that adolescents are more likely to rely on parents when they consider parent-adolescent interactions will be predominantly positive
	“I have more responsibility but I think my ma makes sure she does her responsibilities, like sometimes I	Less performance of T1D care activities (SMODA-I) was significantly associated with more	Expansion – the QUAN findings suggest the relationship between metabolic control and parent

Theme/Subtheme	Example Quotations	Quantitative finding/statistic	Meta-inferences: Confirmation, expansion, discordance
	forget to do stuff but my ma never forgets the stuff she has to do but sometimes I do. So it is more me bringing people down." - P06, Male, age 15 years, diagnosed age 11 years	parent issues (DQOLY-SF) (*r* = -.30**) Higher HbA1c was significantly correlated with more performance of T1D care activities (SMODA-I) (r_s = -.20*) HbA1c was not significantly correlated with parent issues (DQOLY-SF)	issues might be influenced by performance of care activities as there was no relationship between the QUAN metric for metabolic control (HbA1c) and parent issues.
Talking about self-management with parents: "I am not just like sitting in on the conversation… I am putting in my own ideas about what to think, what to do" (1) Change in patterns of parent-adolescent communication about T1D over time	*"It has kind of minimised [talking with parents about T1D management]so I have more independence now, because I have- we have gained a lot more experience so and because we are dealing with it better it is am it is less frequent we need to communicate with each other."* – P26, Female, 15 years, diagnosed age 12 years *"I used to ask them about a lot more things and now I know like a lot more of the stuff so I don't have to ask them as much."* – P08, Male, 11 years	No significant correlations observed between age, age at diagnosis and T1D duration to openness (PACS), problems (PACS), conflict (DFCS-R), T1D communication (SMODA-I) and T1D self-efficacy (SEDM)	Discordance – No relationship observed between parent-adolescent communication and age, age at diagnosis and T1D age, age at diagnosis and T1D duration, though QUAL data suggested that these might be linked.
	"I only if it is a serious low blood sugar, like if I am in the 2s, which I	No significant correlations observed between HbA1c and parent-	Discordance – QUAL suggests there would be a relationship

Theme/Subtheme	Example Quotations	Quantitative finding/statistic	Meta-inferences: Confirmation, expansion, discordance
	am rarely that, or if I am really, really high and we tell each other I talk to them about it, and if it is a once off time but if it is coming up every time we just talk to each other about it. But it's it has changed greatly. We only need to tell each other the big the big problems not as well as every single detail like at the start because we were all babies basically." – P26, Female, 15 years, diagnosed age 12 years	adolescent communication, T1D-specific family conflict HbA1c was not significantly correlated with parent issues (DQOLY-SF) **Results of logistic regression:** **DV:** HbA1c Finding: openness in communication, problems in communication (PACS) and conflict (DFCS-R) did not distinguish between high or low HbA1c.	between HbA1c, however this was not observed in the QUAN findings
	"…They would say to take your bloods at little break if my bloods have been kind of low or high and if I haven't had a chance to take them at little break they say, 'well you should have.' Where if I was younger they would say, 'okay you know just do it tomorrow.' So it has kind of gotten, because they know as I get older I will become more kind of like relaxed about it so they want to keep me on top of it." – P15, Female, 15 years, diagnosed age 11 years	No significant correlations observed between division of responsibility (DFRQ) for T1D management tasks and parent-adolescent communication (PACS) and conflict (DFCS-R) variables	Discordance – The QUAL suggests that perceived shifts in responsibility would be related to communication. However, this was not evident in the QUAN data
(2) Seeking parental feedback and advice	*"But sometimes it can get a bit difficult with the diabetes because*	No significant correlations observed between problem solving (SMODA-	Discordance– the QUAL findings provide additional context for

Theme/Subtheme	Example Quotations	Quantitative finding/statistic	Meta-inferences: Confirmation, expansion, discordance
	with taking responsibility you want to make your own decisions but if you are stuck you still go to your parents but you are still like, 'oh I don't know what to do'." – P13, Female, 12 years, diagnosed age 8 years	I) and openness, problems (PACS) or T1D family conflict (DFCS-R)	adolescent experiences of collaborating with parents on T1D management decisions. However, there was no significant relationship present between problem solving and parent-adolescent communication
		DV: Problem solving (SMODA-I) **IVs:** demographic and clinical characteristics, parent-adolescent communication (PACS) and T1D-specific family conflict (DFCS-R), T1D self-efficacy (SEDM) **Key finding:** Addition of PACS and DFCS-R explained an additional 1% of variance (p = ns). In final model, the addition of SEDM explained 11% additional variance ($p < .01$). Only higher scores for SEDM was significantly associated with more self-management problem solving (problems, openness, and conflict were non-significant)	Discordance – QUAL findings were suggestive that a predictive significant association might be present between parent-adolescent communication and self-management problem solving. However, an association was only identified between T1D self-efficacy
	"Not really, I haven't asked questions often like so not really… Because like I didn't really need to know anything because I know most of the things about the pump	No significant relationship observed for management self-efficacy (SEDM) and collaboration with parents (SMODA-I)	Discordance – there was no QUAN relationship observed between perceptions of self-efficacy and the amount of collaboration with parents. Some

Theme/Subtheme	Example Quotations	Quantitative finding/statistic	Meta-inferences: Confirmation, expansion, discordance
	already." – P14, Male, 11 years, diagnosed age 3 years		of the QUAL data appears to suggest that as adolescent competence in completing tasks increases, the amount they collaborate with parents on management tasks would decline
(3) Promoting self-management communication between adolescents and parents	*"Let's say I have snacked in between, I have ate a bar of chocolate and my bloods are high so it is my fault and I know it is my fault so I don't really want to say."* – P06, Male, age 15 years, diagnosed age 11 years	No significant correlations were observed for HbA1c with openness, problems (PACS) or family conflict (DFCS-R)	Discordance – QUAL accounts indicate that when management is going well, it is easier to talk with parents, however, this was not reflected in the QUAN data on HbA1c and its association to measures of parent-adolescent communication and T1D-specific family conflict
	"It's just frustrating because you know like all the things on your mind and like again parents not really understanding that or maybe they do, they just don't show it." - P16, Female, 14 years, diagnosed age 5 years	There was no significant correlation observed between collaboration with parents (SMODA-I) and T1D family conflict (DFCS-R)	Discordance – no QUAN relationship between collaboration with parents and conflict. QUAL suggests adolescents feel that parents do not understand their perspectives and reasons for mismanagement of T1D
	"When my bloods are high, I feel nervous saying it because I know she is gonna say that again she is gonna feel she has been let down." – P06,	**Results of HMR analysis** **DV:** Parent Issues (DQOLY-SF) **IVs:** demographic and clinical characteristics, T1D Self-efficacy (SEDM), Collaboration with parents	Discordance – there was an absence of explicit examples in the QUAL data of more adolescent self-management

Theme/Subtheme	Example Quotations	Quantitative finding/statistic	Meta-inferences: Confirmation, expansion, discordance
	Male, age 15 years, diagnosed age 11 years	(SMODA-I), Care activities (SMODA-I), Problem solving (SMODA-I), Communication (SMODA-I), Goals (SMODA-I), Activation (PAM) **Key finding:** Addition of SEDM explained an additional 6% of variance (*p* < .01). The addition of self-management and activation explained 12% of the variance (*p* < .05). In final model, only more self-management problem solving was significantly associated with more parent issues.	problem solving coinciding with more parental issues and worries.

10.3.3 How does negotiating self-management responsibilities impact adolescent life?

The integration of findings identified the ways that negotiating T1D self-management responsibilities impacted adolescent life. Findings across both study phases were compared for confirmation, expansion and discordance (see Table 10.3) relating to the mixed methods research question: How does negotiating self-management responsibilities impact adolescent life? The integrated findings highlighted that negotiating levels of independent involvement in self-management of T1D during adolescence impacted key areas of adolescent life including adolescents' interpersonal contexts (e.g. school life, family life) and their overall physical health.

The integrated findings *confirmed* that contending with and negotiating a change in their level of independence in self-management of T1D during adolescence impacts on adolescents' participation in social contexts, e.g. playing sports or spending time with their friends. Across both phases, more active adolescent involvement with self-management was associated with adolescent perceptions of the impact of T1D management on participating in activities. The qualitative findings *expanded* upon quantitative findings relating to the levels of perceived impact of management of T1D on adolescent QOL. The qualitative phase indicated that as adolescents become more independent in their self-management, families play a role in facilitating increased adolescent independence in T1D self-management. Examples of this included through minimising how restrictive T1D is considered by pausing activities, reminding adolescents to complete T1D management tasks and ensuring adolescents do not feel restricted by their diet.

The integrated findings indicated that as adolescents negotiate becoming increasingly independent in their self-management, this can lead to a change in their level of reliance on others including friends and family members. The qualitative findings *expand* upon this through highlighting that low perceived impact of engaging with self-management can be attributed to the involvement of others. The integrated findings *expanded* understanding of how the contexts adolescents engage in self-management within can promote perceptions of their competence and ability to successfully manage their T1D. Adolescents revealed that family members and friends support their engagement with their management, often through adapting or making adjustments to their activities.

There was *discordance* present across the findings with respect to whether sharing responsibilities for management with parents contributes to a reduction in the perceived burden of engaging with T1D self-management. In the qualitative findings, collaborating with parents on self-management meant that adolescents were able to participate in activities, however, this relationship was not evident within the quantitative findings.

Table 10.3

Joint display of qualitative findings, quantitative findings and mixed methods meta-inferences for the research question: How does negotiating self-management responsibilities impact adolescent life?

Theme/Subtheme	Example Quotations	Quantitative finding/statistic	Meta-inferences: Confirmation, expansion, discordance
Environmental and contextual influences affecting self-management: "Even though I know what to do, it's just that support really helps" (3) Involving friends and peers in self-management	*"Ehm I found out that there was three or four other people in the actual school who had diabetes so I didn't feel like I was the only one with it and I was like on my own doing it, I kind of felt they were there with me doing it."* – P23, Female, 14 years, diagnosed age 6 years	Less performance of T1D care activities was significantly associated with more impact of treatment ($r = -.20^*$)	Confirmation – both findings indicate an association between less perceived impact of engaging with T1D management and engagement with self-management tasks
(2) Family involvement in self-management	*"…I think it was easier on my family because like kind of even though it is not hereditary we were kind of seeing who would get it and because my brother and sister were getting older and I was showing more signs. It kind of just happened, it wasn't a big huge shock and we like we knew what to do and stuff so it was easier."* – P02, Female, 13 years, diagnosed age 9 years *"Like we are all just used to it and my dad and my brother know the*	Parent with T1D: Yes: 6 (5.3%) No: 107 (94.7%) Sibling with T1D Yes: 15 (13.3%) No: 98 (86.7%)	Expansion – QUAL findings suggest that prior family experience of T1D can make the adolescent and family more prepared for T1D self-management, which can in turn reduce the perceived impact of becoming more independent in self-management on adolescent life

Theme/Subtheme	Example Quotations	Quantitative finding/statistic	Meta-inferences: Confirmation, expansion, discordance
	signs for a low or a high and it doesn't really affect me when I'm at home. But they-It is just normal." – P23, Female, 14 years, diagnosed age 6 years		
	"I think it was such a shock at first, you know new lives, new beginnings but then it just became a part of me and it was actually a good thing because we are now on diets, there is no really sweetie things in the house anymore and it was like a good change but a bad change at the same time because it's a new lifestyle…" – P17, Female, 15 years, diagnosed age 10 years	Impact of treatment: $M = 3.84$, $SD = 2.38$, range = 0-11(possible range = 0-12) Impact on activities: $M = 4.92$, $SD = 3.56$, range = 0-14, (possible range = 0-20)	Expansion – QUAL data provides examples of ways that families can minimise how restrictive T1D is considered in terms of engagement with treatment and its impact on engaging with activities
(3) Involving friends and peers in self-management	*"Or if it is a new friend and let's say I am just going into town with them or something I feel like I always have to tell someone if it is just me and them together in case something happened."* – P25, Female, 17 years, diagnosed age 13 years	More communication about T1D self-management was significantly related to higher management self-efficacy ($r = .45$**)	Expansion - Adolescents may choose not to tell others which might be related to their perceived capability for carrying out self-management
	"… and I just got support from my friends and stuff like that and I knew that they would support me		

Theme/Subtheme	Example Quotations	Quantitative finding/statistic	Meta-inferences: Confirmation, expansion, discordance
	through and through.” – P17, Female, 15 years, diagnosed age 10 years		
Taking ownership of self-management: “It’s my responsibility” (1) T1D and self-management becomes a “part of daily life”	*“It is kind of second nature now, you just do it and it doesn’t really, it’s not really different or anything.”* – P04, Female, 11 years, diagnosed age 5 years *“Yeah definitely improved my diet because I have like a lot less takeaways, I make my own food and make sure I have like a balanced diet.”* – P11, Male, 16 years, diagnosed age 15 years	Impact of symptoms: *M* = 4.14, *SD* = 2.16, range = 0-11 (possible range = 0-12) Impact of treatment: *M* = 3.84, *SD* = 2.38, range = 0-11 (possible range = 0-12)	Expansion - Participants in both QUAL and QUAN samples indicated that the impact of T1D on their lives was mostly low. The QUAL also indicates the ways that the impact of management of T1D can be reduced through getting used to T1D and the changes inherent to living with T1D
	“It has probably made me healthier because I have started training a lot more so I would be fitter so my exercise regime has gone up.” - P02, Female, 13 years, diagnosed age 9 years	Health perception item – 88% reported ‘Good’ or ‘Excellent’ health	Expansion – The QUAL findings expand upon QUAN by indicating the ways that the impacts of T1D on daily life can be minimised and how T1D can contribute to improved health
	“The sports because usually during the summer I would be out all day doing sport, so I’d be doing like ten hours a day and I would have to make sure that my bloods wouldn’t go low and I would have to have my dinner and it is kind of hard	Impact on activities: *M* = 4.92, *SD* = 3.56, range = 0-14 (possible range = 0-20)	Expansion – Participants in the QUAL phase acknowledged how T1D management could impact on their daily activities but mean scores in the QUAN data, indicate the overall impact on activities was

Theme/Subtheme	Example Quotations	Quantitative finding/statistic	Meta-inferences: Confirmation, expansion, discordance
	managing it with all the sport but then I don't want to let it get in the way of me loving sport." – P15, Female, 15 years, diagnosed age 11 years		considered low among the QUAN respondents
	"*I would be kind of a shy person anyway so I wouldn't want to be someone to stand out and like say 'let's go to eat' or 'I am going to go and eat now'. So I try to be shy and subtle about it so I wouldn't have to stand out*." – P15, Female, 15 years, diagnosed age 11 years		Expansion – QUAL provides contextual information on the ways engaging with T1D treatment can impact on adolescent life, especially interactions with their friends
	"Am. It is a bit of a burden because you have to test regularly and it is kind of always on the back of your mind, ehm yeah it is not the best." – P24, Female, 15 years, diagnosed age 11 years	More performance of T1D care activities was not associated with more perceived impact of symptoms or impact on activities. More performance of T1D care activities was significantly associated with less perceived impact of treatment (r = -.20*)	Expansion – QUAL and QUAN together indicate that as adolescents gets used to completing the tasks of self-management and these are not perceived as burdensome, some of the impact of T1D on QOL is reduced
		A significant correlation observed between T1D self-efficacy (SEDM) and impact of treatment (DQOLY-SF) (r = -.31**).	
	"The pump has been a big difference in my life. It's making	Use of an insulin pump (M = 3.29) was associated with less perceived	

Theme/Subtheme	Example Quotations	Quantitative finding/statistic	Meta-inferences: Confirmation, expansion, discordance
	me do more sports more often, it has enabled me to eat more stuff more freely if that's the word. It's just made my life much easier.” – P10, Male, 14 years, diagnosed age 6 years	impact of treatment than use of MDI (*M* = 4.87), *t* (111) = 3.52, *p* < .01	Expansion – use of an insulin pump was associated with perceived impact of treatment, with QUAL indicating how an insulin pump can introduce more flexibility into daily life and participation in activities
Taking ownership of self-management: “It’s my responsibility” (1) T1D and self-management becomes a “part of daily life”	*“I had to be on a diet, eat certain foods, not eat certain foods and to learn about diabetes is just a lot of experience, you can’t learn about diabetes if you don’t have it. You can only learn about it from books and stuff but it is mostly life experience of it that you can really learn about diabetes.”* – P17, Female, 15 years, diagnosed age 10 years	**HMR analysis** **DVs:** Impact on activities DQOLY-SF) **IVs:** demographic and clinical characteristics, Openness in communication (PACS), Problems in communication (PACS), Family Conflict (DFCS-R), T1D Self-efficacy (SEDM), Problem solving (SMODA-I), Activation (PAM) **Key finding:** In the final model predicting impact on activities, use of MDI and lower activation (PAM) were significantly associated with more perceived impact of symptoms.	Discordance – In the QUAN data, there was an absence of a clear link between independence in management tasks and perceived impact of T1D on QOL. Adolescents in QUAL accounts indicate that they need their parents for certain tasks that can impact on other aspects of their lives, and activities they participate in
Environmental and contextual influences affecting self-management: “Even though I know what to do, it’s just that support really helps”	*“Do talk to friends because it does help, even though I try to avoid it, I do talk to some of my friends who I have known for years about it and knowing that they care just makes you feel so much better.”* - P15,	Scores for T1D Communication: *M* = 18.00, *SD* = 4.94, range = 6-28 (possible range = 0-30) Scores for T1D Worries: *M* = 6.14, *SD* = 5.21, range = 0-25 (possible range 0-28)	Discordance – no relationship between T1D worries (more long-term worries included in scale) and being open with others in QUAN data while this was alluded to in the QUAL data.

Theme/Subtheme	Example Quotations	Quantitative finding/statistic	Meta-inferences: Confirmation, expansion, discordance
(3) Involving friends and peers in self-management	Female, 15 years, diagnosed age 11 years	No significant correlation observed for T1D communication and worries related to T1D	

10.4 Discussion of Key Integrative Findings from the Present Study

The findings from the two phases of this mixed methods study have been discussed separately in previous chapters (see Chapter 6 and Chapter 9). Within this section, the integrative findings across both study phases will be discussed with respect to the three research questions of this mixed methods study (section 3.2). Prior to this mixed methods study, there has been limited evidence on adolescent perspectives of assuming responsibilities for self-management of T1D. Furthermore, to the author’s knowledge no previous research has focused on how adolescent perceptions of parent-adolescent communication feature in the negotiation of self-management responsibilities for T1D between adolescents with T1D and their parents. Recent systematic reviews highlight that a lack of clarity exists on the transfer of responsibility between parents and adolescents for the management of long-term conditions including T1D (Gardener et al., 2020; Nightingale et al., 2019). Previous research and theoretical models have described self-management of chronic illnesses in paediatric settings and its components (Hanna & Decker, 2010; Modi et al., 2012; Ryan & Sawin, 2009; Schilling et al., 2002). However, a lack of knowledge existed pertaining to what factors specifically contribute to gaining independence in self-management of T1D in adolescence. The current study exposes the complexity of the process of gaining independence in self-management of T1D in adolescence and adolescent perspectives on their parents’ involvement and the role of parent-adolescent communication within this.

10.4.1 What helps or hinders adolescent engagement with self-management of T1D?

This mixed methods research identified what factors contribute to helping or hindering adolescent engagement with self-management of T1D. IFSMT (Ryan & Sawin, 2009), suggests that contextual factors, which can also be considered as risk or protective factors contribute to proximal outcomes including self-management behaviours and distal outcomes such as QOL. The integrative findings add to our understanding of what these contextual factors are and how they contribute to T1D outcomes. An example of this is through the identification of the interplay between adolescent beliefs about their self-management abilities and engagement with self-management of T1D. Demographic/clinical characteristics of adolescents, parental involvement and adolescent perceptions of their self-management capabilities were key factors that helped or hindered adolescent engagement with self-management. Of key interest is the finding that adolescent perceptions of parental involvement in their T1D management can be an important factor within the association between self-efficacy and adolescent engagement with self-management and assumption of increased responsibility for T1D self-management.

The present study highlights the importance of considering the helpful or hindering factors that contribute to an individual adolescent's T1D self-management trajectory. Adolescence is a key developmental period with its own unique developmental tasks and challenges (Holmbeck et al., 2002). However, the unique nature of adolescence is often not specifically reflected within models and theories that seek to explain self-management. Key contextual factors related to self-management outcomes identified within this study included the age of the adolescent and clinical characteristics such as mode of insulin administration. The findings indicate that contextual factors such as age and clinical characteristics are important factors in self-management. This is in line with IFSMT, and research which has evaluated its application, that have found clinical factors contribute to self-management and related outcomes including health status and QOL (Verchota & Sawin, 2016).

Within IFSMT, self-management is described as dynamic (Ryan & Sawin, 2009). Whilst it is recognised that the trajectory from the point of diagnosis to successful integration of illness management with daily life for adults is not straightforward (Schulman-Green et al., 2012), it is also important to recognise the non-linear nature of engaging with self-management for adolescents. This was particularly evident in the qualitative phase where a period of increased independence often occurred as a result of an adolescent's wish to become more responsible for their T1D or as a result of an external event such as a school transition. This mixed methods study clarifies the particular contexts and factors that feature within adolescents' transition towards more independence in self-management. This highlights the need for ongoing access to support that is tailored to each individual adolescent's own self-management trajectory.

Adolescence presents a complex period where higher order cognitive processes are honed including problem solving and adolescent's social environments begin to change (Steinberg, 2005). This myriad of developmental changes that adolescents encounter are of paramount importance for their engagement with self-management. Within the present study adolescents' qualitative accounts of learning to complete specific tasks of self-management illustrate how their development influences their ability to engage with T1D management, through increased understanding and their capability to retain what they were learning about T1D management from parents. Furthermore, quantitative findings indicate that factors such as age and T1D duration are relevant for adolescent engagement with some aspects of T1D self-management. Increased age helped adolescents to assume additional responsibility as it coincided with increased adolescent ability and relinquishment of parental responsibility for T1D management. Adolescents were more likely to report more attendance at sleepovers and activities away from their parents as they got older, which prompted increased adolescent engagement with T1D self-management. This research emphasises the importance of considering adolescent progression towards independence in management from a developmental standpoint in terms of the developmental milestones that adolescents have reached and their duration of T1D, rather than chronological age. It is crucial that clinicians and parents are cognisant of the developmental readiness of the adolescent, adolescent age and age at diagnosis, when opportunities to change or negotiate involvement in care arise.

The current research emphasises the importance of adolescent perceptions of how competent they are to engage with their self-management. It also highlights the subtle nuances in the different aspects of self-management with adolescent independence varying based on individual management tasks and for different components of self-management (e.g. responsibility for a task, making decisions related to their care, deciding to take on more management, choosing to change to an alternative insulin administration method, or problem solving related to blood glucose levels). Feeling confident in their capabilities contributed to positive feelings surrounding T1D self-management. Furthermore, this was mirrored with respect to findings on how adolescent accounts in the qualitative phase demonstrated that T1D self-management becomes integral to their own values. Similarly, when adolescents did not believe that they possessed these capabilities, this impeded their engagement with independent T1D management. According to IFSMT, the knowledge and beliefs of an individual impact self-efficacy for health behaviours and health-related goals (Ryan & Sawin, 2009) which in turn impact upon proximal (self-management) and distal outcomes (QOL). The integrated findings of the present mixed methods study identified that parental involvement and perceptions of knowledge and beliefs held with respect to

T1D self-management can help adolescents to engage with their self-management. Previous research with adolescents emphasises the links between how adolescents perceive their self-efficacy as important for T1D related outcomes such as management and metabolic control (Noser et al., 2017; Ott et al., 2000). This research considers how these beliefs and competencies contribute to self-management, from a more nuanced perspective i.e. extending beyond metabolic control or specific self-management behaviours. In doing so, the relevance of the contribution of adolescent beliefs relating to competencies to specific attributes or components of management (e.g. problem solving, goal setting, engagement with management tasks) is highlighted.

Of specific interest in the current study was the relationship between family context factors including parent-adolescent communication and T1D-specific family conflict from the perspective of adolescents themselves. In the context of the present study, these findings could be both risk or protective factors contributing to self-management processes and self-management outcomes. Adolescent experiences of their family environment are important in leading to increased activation and engagement with attributes of self-management. This research also highlights that extended families can play a role in adolescent self-management of T1D. The integrated findings emphasised that extended family members, including siblings, can facilitate adolescent engagement with their self-management. Research already advocates for the inclusion of key family members in family focused interventions that target T1D outcomes in childhood and adolescence (Pals et al., 2020). Future research may consider quantitatively assessing family involvement in the negotiation of self-management responsibilities, extending beyond parental involvement such as that of siblings and other family members and considering this using a larger sample.

10.4.2 How does parent-adolescent communication contribute to negotiation and sharing of responsibilities for self-management for adolescents?

For the first time, this mixed methods study conducts an in-depth exploration of adolescent perceptions of communication about T1D management with their parents. The integrated findings identified that parent-adolescent communication has a differential contribution to the negotiation of responsibilities for self-management of T1D based on its characteristics. The integrated findings identified the contribution of parent-adolescent communication characteristics to negotiation of levels of responsibilities for self-management with parents. Furthermore, the integrated findings highlighted the associations between parent-adolescent communication and adolescent perceptions of competence in T1D self-management and in turn, the level of adolescent involvement in the completion of self-management tasks.

Theories of adolescent development state that adolescents break away from dependency on parents to assume more autonomy in their daily activities (Blos, 1967; Blum, 2004). The mixed methods findings of this study highlight that this also occurs in the context of T1D self-management, but it does not adopt a linear trajectory and adolescents can find themselves oscillating between being increasingly self-reliant and being reliant on their parents for their self-management. This is reflected in communication patterns and the present study indicates that communication characteristics are factors which feature within this negotiation of responsibilities for T1D self-management. Specifically, patterns of communication characterised as open were identified as important for some aspects of self-management. Moreover, closeness and openness in parent-adolescent interactions contributed to an environment where adolescents were able to freely request more involvement in their T1D self-management. Becoming independent in self-management during adolescence has been linked to hovering between independence and support of others (Karlsson et al., 2008). For the first time, parent-adolescent communication and interactions have been situated explicitly within the nuanced trajectory that adolescents embark upon, in their journey towards independence in self-management.

Parents are perceived as able to alleviate adolescent worries with respect to their T1D and offer advice when the adolescent encounters specific difficulties or is unsure how to approach a difficult management task. The findings highlight the nuanced nature of parent-adolescent communication in how the qualities of communication vary based on adolescent knowledge. This indicates that parent-adolescent communication as it relates to self-management of T1D needs to be interpreted through a lens that does not assume that any specific characteristic of communication is inherently ‘functional’ or ‘dysfunctional’ (Koerner & Fitzpatrick, 2006). For example, with respect to conflict and nagging relating to completing T1D care, the present study highlights that these sometimes served an adaptive function and were considered helpful by adolescents. In the present study, nagging often reminded the adolescent to complete a task, reinforced the importance of ensuring that they engaged with their management or encouraged them to acknowledge T1D as their responsibility. Research also suggests that adolescents may differ in their appraisal of nagging with some categorising nagging as supportive communication (Ersig et al., 2016).

Openness in parent-adolescent communication was associated with better self-management outcomes and improved perceptions surrounding self-management. Openness was presented as adaptive or functional as it ensured adolescents had access to feedback and support on their engagement with T1D self-management. When adolescents considered their parent-adolescent interactions to be open, this also contributed to their openness about their T1D with others and openness about engagement with self-management. Furthermore, this enabled open discussion between parents and adolescents regarding seeking out increased responsibilities for self-management. Therefore, parent-adolescent interactions should be considered in terms of their ability to impact upon the wider structures of adolescent's environment e.g. school, the social setting.

Within the Circumplex Model of Family Functioning the most adaptive family communication is characterised by high openness and low problems (Barnes & Olson, 1985; Olson, 2000). However, in the current study, the findings relating to problems in parent-adolescent communication were less straightforward. For instance, it seemed increased problems in parent-adolescent communication was a feature of more adolescent goals relating to independent engagement with self-management. Within the quantitative phase, problems in parent-adolescent communication demonstrated less associations to attributes of self-management in comparison to openness. The integrated findings suggested that this could be attributable to some of the situations that give rise to conflict as responsibilities for self-management are negotiated. An increase in adolescent involvement in self-management can introduce more parental reminders for completion of T1D management tasks which can in turn contribute to adolescent frustration.

Making decisions pertaining to health is a key component of self-management of T1D in adolescence (Schilling et al., 2009). In this context, the circumplex model of family functioning which characterises adaptive family communication in one way is insufficient to fully explain the findings of this study. Consequently, it might be more useful to consider the perspective of Family Communication Patterns Theory (Koerner & Fitzpatrick, 2006; Koerner & Schrodt, 2014; Saphir & Chaffee, 2002), which states family behaviours should be considered in terms of the context in which the particular family behaviour or communication style occurs within. In the context of T1D self-management, it is possible that some problems in communication may be a feature of this developmental period of striving towards independence and formation of increased goals pertaining to independent self-management during adolescence. This may also in part be explained by separation individuation theory applied to adolescents as it was postulated by Blos (1979). According to this theory, adolescents gradually unsubscribe from their parent's authority and this parent-adolescent role reorganisation can contribute to fractious parent-adolescent interactions (Alonso-Stuyck et al., 2017). Furthermore, adolescence is a period where increased conflict occurs between adolescents and parents more generally, so can be considered a typical feature of adolescent development (Arnett, 1999; Montemayor, 1986). Therefore, some problems in interactions may be inevitable and potentially 'adaptive' as adolescents become more responsible for T1D management. However, longitudinal research may be better placed to clarify the relationship between problems in parent-adolescent communication and self-management and to specifically tease out how role reorganisation applies to the negotiation of responsibilities for T1D management.

From the adolescent perspective, parental interactions that considered adolescent autonomy and were understanding of the adolescent's perspective contributed to more perceptions of optimal negotiation of responsibilities for self-management of T1D. Specifically, the complementary findings across the study phases indicate that it is important that parent-adolescent interactions are framed in a way that promotes motivation to engage with self-management, especially during times where adolescents consider management difficult or frustrating. Feeling frustration contributed to less optimal negotiation of self-management responsibilities as adolescents reported feeling that they were not understood by parents or that the positives of their engagement with their self-management was not recognised by their parents. Positive interactions contributed to encouraging experiences regarding the change in distribution of responsibilities for management during adolescence. Ensuring adolescents feel capable of managing their T1D, contributes to positive experiences surrounding T1D including pride, increased adolescent activation and less perceived impact of T1D on QOL. The present study highlights the importance that supportive parent-adolescent communication is relied upon as responsibilities for self-management are negotiated between adolescents and their parents. When parental communication is supportive of the adolescent's autonomy, increased motivation of adolescents to engage with self-management tasks is also evident (Goethals et al., 2019). The present mixed methods research offers a more in-depth understanding of what contributes to more optimal parent-adolescent negotiation of responsibility for self-management from adolescents' perspectives, through highlighting how it applies to the individual attributes of self-management including problem-solving, goal setting in addition to performance of self-care tasks.

10.4.3 How does negotiating self-management responsibilities impact on adolescent life?

The present study presents new perspectives on how negotiating self-management responsibilities impacts on several areas of adolescent life. Key interpersonal contexts for adolescent development include family, social, peer and school contexts (Holmbeck, 2002). Adolescents described how negotiating the demands of increased independence in T1D self-management impacted upon these domains of their lives. Indeed, the systematic review presented in Chapter 2 highlighted that adolescents experience T1D in a range of settings but there is an absence of in-depth exploration into how changing levels of responsibility impacts on these areas of adolescent life.

Contending with assuming increased responsibility for self-management can impact on adolescents' social environments. As adolescents become more independent in their management of T1D, this places new demands on their social lives. It was important that friends of the adolescent were supportive of the adolescent and that adolescents were able to be open about their management with their friends. As a result of assuming increased responsibility for management, adolescents become more reliant on their friends for this support to ensure their engagement with their self-management. This can place new demands on the adolescent's social relationships that may not have been present when the adolescent was more reliant on their parents for completion of T1D management. The perceived supportiveness of the social environment can be recognised as a specific protective factor within IFSMT. Adolescence is a period where young people, begin to attribute increased importance to relationships with friends (Smetana & Asquith, 1994). Previous research indicates that children and adolescents living with T1D differ with respect to the importance they attribute to peer relationships for T1D outcomes (Sullivan-Bolyai et al., 2014; Rankin et al., 2018). Therefore, the impact of self-management on the adolescent's social life is dependent on the importance that the individual adolescent attributes to their friends' involvement in their T1D management.

The integrated findings indicated that negotiating self-management responsibilities and becoming more independent in their self-management impacted on adolescents' lives through their physical health. As adolescents become more responsible for their T1D management this also allows them to exert more control over their health through adolescent engagement in positive health behaviours (e.g. exercise, being conscious of nutrition). These findings highlight the importance that adolescents are encouraged to consider the benefits of gaining independence in their self-management. Although previous research has frequently focused on barriers to achieving QOL (Maslakpak et al., 2010), and challenges posed by living with T1D (Freeborn et al., 2013) and gaining independence in self-management (Castensøe-Seidenfaden et al., 2017), the integrated findings from this study are in keeping with the findings that some individuals identify benefits of living with a chronic illness following a period of adjustment, referred to as benefit finding (Rassart et al., 2017). Therefore, harnessing the perceived benefits of living with and managing more independently can ensure a more seamless transition to increased independence and self-reliance for engaging with self-management.

The present research suggests that processes related to self-management might be important factors that are present in the interplay between assuming increased responsibilities for the self-management of T1D and the impact this has on aspects of adolescent life such as adolescent QOL. The integrated findings of this study identified that processes of self-management such as self-efficacy are relevant to QOL for adolescents living with T1D. The links between self-efficacy and activation and adolescent perceptions of the impact of T1D in their lives, suggest that targeting some of the self-management processes that contribute to T1D management will reduce negative perceptions surrounding the impact of T1D on adolescent life. Moreover, ensuring that these self-management processes are honed by adolescents should mitigate perceptions of the negatives of assuming increased responsibility for self-management.

10.5 Conclusions of Key Integrative Findings

The integration of both phases of this mixed methods study has highlighted key findings relating to adolescent experiences of self-management of T1D. This study marks the first time that adolescent perspectives on parent-adolescent communication in the context of negotiating responsibilities for T1D self-management, have been explored in depth. The findings highlight that negotiating responsibilities for management is a key feature of transition towards independence in T1D self-management for adolescents. Self-management process variables, specifically T1D self-efficacy, were identified as key factors contributing to self-management outcomes. How adolescents and parents relate to one another in turn has the potential to influence how these self-management processes contribute to self-management and adolescent perspectives of the impact of negotiating changing levels of involvement in self-management on various aspects of adolescent life. The final conclusions and implications of the current study will be presented in the next chapter.

Chapter 11: Conclusions

11.1 Introduction

The aims of the present mixed methods study were to (1) explore how adolescents living with T1D experience self-management of T1D and share self-management responsibilities with parents and to (2) elucidate the relationship between adolescent communication with parents about T1D self-management and a number of demographic, clinical and psychosocial variables. In this chapter, the original contribution of the present study will be outlined. Next, the overall strengths and limitations of this mixed methods research will be presented. Finally, the implications and concluding points of this thesis will be presented.

11.2 Original Contribution of the Present Study

This is the first study to provide an original contribution to understanding how adolescents living with T1D experience self-management and what contributes to their experience of self-management. For the first time, adolescent perspectives on negotiating and communicating about responsibilities for T1D self-management with their parents is examined. The findings of the meta-synthesis identified a need for in-depth exploration of adolescent perspectives on negotiating levels of responsibility for T1D management with their parents. These areas were subsequently explored in depth within the qualitative and quantitative phases of the mixed methods study.

For the first time, this mixed methods study demonstrates that parent-adolescent communication contributes to how adolescents living with T1D experience negotiating responsibilities for self-management. Specific characteristics of parent-adolescent communication (e.g. presence of openness and understanding) support adolescent learning and uptake of more responsibility for T1D self-management during adolescence. This thesis contributes to understanding how adolescent perspectives on parent-adolescent communication interplays with other environmental and contextual factors contributing to the negotiation of responsibilities for self-management of T1D. External events (e.g. a school trip, going to a friend's house) and settings outside the home (e.g. at school or at healthcare appointments) could prompt or bring about a change in existing levels of parental involvement in T1D self-management. Parent-adolescent interactions contribute to self-management processes such as T1D self-efficacy, that in turn are related to self-management outcomes. Parent-adolescent interactions framed in a way that is supportive of adolescent T1D self-efficacy can contribute to adolescents feeling more capable of engaging with T1D self-management. The findings suggest areas that can be targeted in order to ensure optimal engagement with self-management of T1D during adolescence.

This thesis provides support for IFSMT (Ryan & Sawin, 2009), which seeks to explain self-management. This research adds to existing research which has applied IFSMT to adolescents living with T1D (Totka et al., 2021; Verchota & Sawin, 2016), through exploring the relationships between specific self-management context and process variables. The interrelationships between family context (i.e. parent-adolescent communication), self-efficacy and attributes of self-management, observed in this study, support IFSMT which proposes that context and process variables contribute to self-management and health related outcomes including T1D-specific QOL. Moreover, this study advances knowledge on how specific family context characteristics (specifically parent-adolescent communication and T1D-specific family conflict) in the current study contribute to self-management and QOL in adolescents living with T1D.

This thesis further extends theoretical knowledge on theories of family communication including Family Communication Patterns Theory (Koerner & Fitzpatrick, 2006). The study findings support this theory in that negative communication styles can sometimes have a positive impact on parent-adolescent relations pertaining to the negotiation of levels of involvement in T1D management. For instance, in this thesis parental nagging, or problems in communication sometimes elicited increased adolescent self-management goals and often motivated adolescent's engagement with T1D self-management. The study also provides support for the Circumplex Model of Family Communication (Barnes & Olson, 1985; Olson, 2000) which describes family functioning. The study also extends these theories through the identification of specific elements (e.g. understanding what constitutes effective communication strategies for adolescents living with T1D and their parents) that are relevant to adolescents living with T1D.

The findings of this study support that high openness in parent-adolescent communication is an adaptive characteristic in the negotiation of T1D management responsibilities. Across both phases of this study, the benefits of openness in parent-adolescent interactions were highlighted. The findings with respect to the change in levels of involvement between adolescents and parents support theories of adolescent development that describe adolescent's separation from their parents in order to become autonomous individuals (Blos, 1967; Koepke & Denissen, 2012). Separation-individuation theory in adolescence (Blos, 1967) also posits that this shifting of parent-adolescent roles can introduce conflict and there was evidence of this in relation to sharing responsibilities for self-management within the current study. While the present study supports the importance of openness in communication, it also indicates the utility of considering the purpose of any negative communication between adolescents and their parents and whether it has an 'adaptive' function in relation to changing levels of parental involvement in T1D management.

The current findings on parent-adolescent communication and negotiation of responsibilities for self-management of T1D add to previous research that reports that family functioning constructs are related to T1D outcomes (Gruhn et al., 2016; Helgeson et al., 2009; Main et al., 2015). Much of the research to date focuses on parent-adolescent conflict. This research identifies other aspects of parent-adolescent communication (e.g. parent-adolescent interactions characterised by high openness and low problems in communication) that are relevant to T1D self-management. This thesis presents novel perspectives through the identification of parent-adolescent interactions and parent-adolescent communication as related to T1D self-management and T1D outcomes. Furthermore, this research for the first time identifies associations between parent-adolescent communication and health-related QOL in adolescents living with T1D. This research contributes to knowledge on how adolescent perceptions of parent-adolescent communication contribute to gaining independence in self-management and assuming self-management responsibilities during adolescence.

11.3 Strengths and Limitations of the Present Study

To the author's knowledge, there is no previous research that investigates negotiating self-management responsibilities of T1D in adolescents using mixed methods. The use of a mixed methods approach in this thesis allowed for a comprehensive exploration into adolescent perspectives on self-management and communicating about self-management responsibilities with their parents, for the first time. Furthermore, this study presents unique perspectives on parent-adolescent communication as it relates to self-management of T1D during adolescence, an important developmental timepoint.

Despite the strengths of the present study, some limitations were also noted. Although participants were predominantly drawn from a national centre for paediatric

T1D care, across both phases of the study, most participants resided in the Dublin region. Most participants in the current study also reported access to management technologies such as insulin pumps and semi-continuous BGM devices. Consequently, the sample may not be representative of the adolescent population within Ireland. Overall, the cross-sectional nature of the data across both phases limits the conclusions which can be drawn with respect to the results. Therefore, it was not possible to determine the direction of the associations observed within the present study. For example, the associations between characteristics of parent-adolescent communication and T1D self-management could also be bidirectional, with better self-management leading to more openness in parent-adolescent communication.

11.4 Study Implications

The implications of the present study will be highlighted below with respect to informing practice, policy, education and research.

11.4.1 Practice Implications

The practice implications of the present study are of relevance to those who work with adolescents living with T1D and their parents, including HCPs and diabetes advocacy organisations.

- HCPs involved in adolescents' T1D care should be cognisant of the challenges that adolescents encounter when discussing T1D management and negotiating shared responsibilities for T1D management with their parents. Specifically, they should ensure that adolescents and their parents identify whether there are discrepancies between parties with respect to their views on the adolescent's current self-management capabilities, ensuring both are satisfied with the adolescent's level of responsibility for self-management.

- HCPs should encourage adolescents and parents to employ communication strategies that are open to ensure that both adolescents and parents have clear expectations with respect to their involvement and roles in managing T1D. Employing open communication strategies should also reduce secrecy surrounding T1D mismanagement and contribute to the formation of an environment where the adolescent openly shares information about their T1D management with their parents.
- Interventions should seek to encourage parents to utilise communication strategies about T1D that are adolescent-centred and are supportive of adolescent's autonomy as these may lead to more optimal negotiation of responsibilities for T1D self-management in adolescence.
- HCPs should regularly check in with adolescents and their parents in relation to the level of parental involvement that is needed in the adolescent's T1D care. As adolescent levels of responsibility for their T1D care fluctuates, it is necessary that parents and HCPs observe for periods where additional parental assistance is required.

11.4.2 Policy Implications

The findings of the present study identify policy implications that may contribute to facilitating improved self-management for adolescents and improvements in communication surrounding self-management responsibilities between adolescents and their parents.

- The findings inform ISPAD guidelines surrounding psychological care for adolescents living with T1D (Delamater et al., 2018). The guidelines recommend that communication is assessed when determining levels of family functioning within adolescent's families. The present study identifies specific attributes of communication that could be assessed, in particular the presence of open communication styles.

- The findings contribute to the objectives of the Health Service Executive (HSE) Model of Care for All Children and Young People with Type 1 Diabetes in Ireland (HSE, 2015). One of the key objectives of this model of care is to provide a pathway to improved health-related QOL of young people and their families living with T1D, and to reduce complications of T1D. The present findings suggest that targeting self-management through family functioning should contribute to improvements in engagement with T1D management and in turn, reduced risk of complications.
- The ISPAD guidelines for T1D management at school state that all children and adolescents regardless of age should receive support and supervision when managing T1D at school, by school staff (Bratina et al., 2018). The findings of this study relating to the contexts adolescents engage in self-management in suggest that some adolescents in Ireland should benefit from increased supports specific to T1D management at school, such as ensuring the adolescent has access to a quiet space where they can manage their T1D and where school staff members are knowledgeable about T1D. Education for school staff and individualised support for school-going students should improve glycaemic control and similarly contribute to an environment that is supportive of increased independence in T1D management and engagement with self-management tasks. Furthermore, this study specifically highlighted the need for the provision of additional supports for adolescent living with T1D as they transition from primary to secondary schools.

- The findings of this study highlight the importance of delivering interventions that promote self-efficacy and foster patient empowerment among adolescents living with T1D. This corresponds with the recommendations within the HSE’s ‘Framework for Self-management Support’ which recommends that younger patients have access to self-management support and self-management education (Chronic Conditions Working Group, 2017).

11.4.3 Education Implications

Regarding education, the following implications are recommended:

- The provision of training to parents and adolescents in communication styles and how to frame interactions in ways that are supportive of adolescent’s autonomy should enable parents to promote adolescents’ T1D self-efficacy.
- HCPs should benefit from education on how to assess whether adolescents have assumed an appropriate amount of responsibility for self-management of T1D. Furthermore, this could allow HCPs to encourage dialogue between adolescents and parents in relation to negotiating responsibilities for self-management of T1D.
- Both adolescents and their parents should benefit from training in how to promote openness in interactions and ensure adolescents and parents convey trust and understanding of each other’s perspectives around self-management. Parents should also be trained in how to tailor their communication to the adolescent’s current self-management abilities and developmental stage.
- Adolescents could benefit from the opportunity to meet with peers living with T1D. This could contribute to a social environment that is more supportive of adolescent’s T1D management. Interactions with others who are also becoming independent in their T1D self-management may lead to opportunities to discuss

their experiences with others. Diabetes advocacy organisations may play a role in facilitating this.

- There is a need for increased awareness surrounding T1D and T1D management in the public domain. Within school settings both teachers and students should receive information on T1D and its management, in order to address lack of awareness and reduce insensitive reactions of others towards adolescents living with T1D. This should contribute to environments that are more supportive of more independent adolescent involvement in self-management.
- Adolescents should benefit from support in managing independently that is specific to the life events and activities that they are involved in. Guidance on how to navigate these life events may assist adolescents to cope with situations in which self-management and living with T1D are considered difficult, including dealing with stressful situations e.g. self-management during school exams.
- Adolescents should benefit from education in how to identify benefits from living with T1D. Having positive perceptions surrounding their T1D (e.g. positive impact on diet and maintaining overall health) and T1D management can contribute to reduced perception of burden and perceived negative impact of T1D on QOL.

11.4.4 Research Implications

Future research is necessary to address several areas that have been indicated as potentially important in the current study.

- Longitudinal research is required to ascertain whether adolescent and parent interactions change over time with respect to communicating about self-management and changing levels of self-management responsibilities. This future research could provide clarification on how the characteristics and content of communication used by adolescents and their parents change as adolescents get older and more proficient in their self-management. Longitudinal research would also allow for the evaluation of how communication patterns may vary according to changes in individual or clinical characteristics (e.g. developmental stage, T1D duration).

- Longitudinal-type research is needed on how adolescents assess their readiness for taking on more management responsibilities and how adolescents seek out additional self-management responsibilities from their parents.
- Future research should seek to further explore the relationships between parent-adolescent communication, T1D self-efficacy and specific aspects of T1D self-management and determine whether causal mechanisms exist between these variables.
- Additional research is needed to determine the relationship between family characteristics such as parent-adolescent communication and QOL in adolescents living with T1D. Specifically, more research is needed that considers how varied, specific attributes of parent-adolescent communication are related to QOL for adolescents living with T1D.

11.5 Concluding Comments

This thesis presents the first in-depth investigation into adolescent perspectives on self-management of T1D and on communicating about self-management responsibilities with their parents. The study provides a novel contribution to the literature through its focus on how specific characteristics of parent-adolescent communication and family context relate to and contribute to self-management and T1D-specific QOL in adolescents living with T1D. Moreover, it contributes to a limited body of literature that considers the processes of self-management as they relate to adolescents. These findings are important as they suggest key areas that could be targeted within parent-adolescent based interventions focusing on self-management and handover of responsibilities for self-management during adolescence. These findings are of relevance to individuals working with adolescents living with T1D, such as HCPs. Through promoting positive communication strategies surrounding self-management, adolescents should be able to experience more optimal negotiation of self-management responsibilities with parents which should be reflected in better QOL and engagement with T1D self-management.

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Appendix A: Search strategies for systematic review

A1 Medline (OVID)

1. exp Child/
2. exp Adolescent/
3. exp Pediatrics/
4. (child* or adolesc* or juvenile* or p?ediatric* or youth* or teen* or young* or girl* or boy*).tw.
5. 1 or 2 or 3 or 4
6. exp Diabetes Mellitus, Type 1/
7. (IDDM or T1DM or T1D).tw.
8. ((diabet* or dm) adj5 ((typ? adj (one or '1' or I)) or typ?1 or typ?I)).tw.
9. ((earl* or juvenil$ or child$ or p?ediatric) adj3 (diabet* or dm)).tw.
10. (insulin depend* or insulindepend* or insulin-depend*).tw.
11. (insulin* defic* adj3 absolut*).tw.
12. ((auto-immun* or autoimmun* or sudden*) adj3 (diabet* or dm)).tw.
13. 6 or 7 or 8 or 9 or 10 or 11 or 12
14. exp Self Care/
15. exp Self Efficacy/
16. exp Consumer Participation/
17. exp Personal Autonomy/
18. exp Decision Making/
19. exp Health Behavior/
20. exp Life Change Events/
21. exp Adaptation, Psychological/
22. exp "Power (Psychology)"/
23. exp Attitude to Health/
24. (selfcare or selfhelp* or selfmanag* or selfdirect* or selfmonitor* or selfefficac* or selftreat*).tw.
25. ((psychologic* or behavio?r*) adj (adjust* or adapt*)).tw.
26. decision mak*.tw.
27. (patient adj (participat* or involv*)).tw.
28. (autonomy or autonomous or responsibilit*).tw.
29. Health adj2 attitude*.tw.
30. adherence.tw.
31. empower*.tw.
32. (self adj1 (care or help* or manag* or direct* or monitor* or treat* or efficac*)).tw.

33. 14 or 15 or 16 or 17 or 18 or 19 or 20 or 21 or 22 or 23 or 24 or 25 or 26 or 27 or 28 or 29 or 30 or 31 or 32
34. exp Qualitative Research/
35. exp Nursing Methodology Research/
36. exp Interviews as Topic/
37. exp Focus Groups/
38. exp Attitude/

39. qualitative.tw.
40. theme*.tw.
41. thematic.tw.
42. ethnograph*.tw.
43. grounded theor*.tw.
44. phenomenol*.tw.
45. ethnolog*.tw.
46. emic.tw.
47. etic.tw.
48. hermeneutic*.tw.
49. heuristic*.tw.
50. interview*.tw.
51. semiotic*.tw.
52. (data adj3 saturat*).tw.
53. (participant adj3 observ*).tw.
54. experienc*.tw.
55. ((purposive or cluster) adj3 sampl*).tw.
56. focus group*.tw.
57. (observational adj3 method*).tw.
58. (constant adj3 compar*).tw.
59. key informant*.tw.
60. (theoretical adj3 (sampl* or saturat*)).tw.
61. discourse*.tw.
62. discursive*.tw.
63. discuss*.tw.
64. narrative*.tw.
65. narration*.tw.
66. (mixed adj1 (method* or model* or design*)).tw.
67. ethnomethodolog*.tw.
68. multiple method*.tw.
69. mulitmethod*.tw.
70. conversation analys#s.tw.
71. triangulat*.tw.
72. experien*.tw.
73. attitud*.tw.
74. opinion*.tw.
75. perspectiv*.tw.
76. 34 or 35 or 36 or 37 or 38 or 39 or 40 or 41 or 42 or 43 or 44 or 45 or 46 or 47 or 48 or 49 or 50 or 51 or 52 or 53 or 54 or 55 or 56 or 57 or 58 or 59 or 60 or 61 or 62 or 63 or 64 or 65 or 66 or 67 or 68 or 69 or 70 or 71 or 72 or 73 or 74 or 75
77. 5 and 13 and 33 and 7

A2 EMBASE search strategy

1. 'child'/exp
2. OR 'adolescent'/exp
3. OR child*
4. OR adolesc*
5. OR juvenile*
6. OR pediatric*
7. OR paediatric*
8. OR youth*
9. OR teen*
10. OR young*
11. OR boy*
12. OR girl*
13. #1 OR #2 OR #3 OR #4 OR #5 OR #6 OR #7 OR #8 OR #9 OR #10 OR #11 OR #12
14. 'insulin dependent diabetes mellitus'/exp
15. iddm OR t1dm OR t1d
16. (diabet* OR dm) NEAR/5 type NEXT/1 (one OR '1' OR i)
17. (earl* OR juvenil* OR child* OR pediatric OR paediatric) NEAR/3 (diabet* OR dm)
18. insulindepend*
19. insulin NEXT/1 depend*
20. absolut* NEAR/3 'insulin* defic*'
21. ('auto immun*' OR autoimmun* OR sudden*) NEAR/3 (diabet* OR dm)
22. #14 OR #15 OR #16 OR #17 OR #18 OR #19 OR #20 OR #21
23. 'self care'/exp
24. 'self concept'/de
25. 'patient participation'/exp
26. 'personal autonomy'/exp
27. 'psychological adjustment'/exp
28. 'patient decision making'/exp
29. 'patient compliance'/exp
30. 'empowerment'/exp
31. 'attitude to health'/exp
32. selfcare OR selfhelp* OR selfmanag* OR selfdirect* OR selfmonitor* OR selfefficac* OR selftreat*
33. self NEXT/1 (care OR help* OR manag* OR direct* OR monitor* OR treat* OR efficac*)
34. (psychologic* OR behavior* OR behaviour*) NEXT/1 (adjust* OR adapt*)
35. decision NEAR/1 mak*
36. patient NEAR/1 (participat* OR involv*)
37. autonomy OR autonomous OR responsibilit*
38. health NEAR/2 attitude*
39. adherence
40. empower*
41. #23 OR #24 OR #25 OR #26 OR #27 OR #28 OR #29 OR #30 OR #31 OR #32 OR #33 OR #34 OR #35 OR #36 OR #37 OR #38 OR #39 OR #40
42. 'qualitative research'/exp
43. 'nursing methodology research'/exp
44. 'interview'/exp
45. qualitative

46. theme*
47. thematic
48. ethnograph*
49. grounded NEAR/1 theor*
50. phenomenol*
51. ethnolog*
52. emic
53. etic
54. hermeneutic*
55. heuristic*
56. interview*
57. semiotic*
58. data NEAR/3 saturat*
59. participant NEAR/3 observ*
60. (purposive OR cluster) NEAR/3 sampl*
61. focus NEXT/1 group*
62. observational NEAR/3 method*
63. constant NEAR/3 compar*
64. key NEXT/1 informant*
65. theoretical NEAR/3 (sampl* OR saturat*)
66. discourse*
67. discursive*
68. discuss*
69. narrative*
70. narration*
71. mixed NEAR/1 (method* OR model* OR design*)
72. ethnomethodolog*
73. multiple NEXT/1 method*
74. mulitmethod*
75. conversation NEXT/1 (analysis OR analyses)
76. triangulat*
77. experien*
78. attitud*
79. opinion*
80. perspectiv*
81. #42 OR #43 OR #44 OR #45 OR #46 OR #47 OR #48 OR #49 OR #50 OR #51 OR #52 OR #53 OR #54 OR #55 OR #56 OR #57 OR #58 OR #59OR #60 OR #61 OR #62 OR #63 OR #64 OR #65 OR #66 OR #67 OR #68 OR #69 OR #70 OR #71 OR #72 OR #73 OR #74 OR #75 OR #76 OR#77 OR #78 OR #79 OR #80
82. #13 AND #22 AND #41 AND #81

A3 CINAHL search strategy

1. (MH "Child+")
2. (MH "Adolescence+")
3. child* OR adolesc* OR juveline* OR youth* OR teen* OR young* OR boy* OR girl* OR pediatric* OR paediatric*
4. 1 or 2 or 3
5. (MH "Diabetes Mellitus, Type 1+")
6. Iddm OR t1dm OR t1d
7. (diabet* OR dm) N5 ((typ# W1 (one OR '1' OR one)) OR typ#1 OR typ#i)
8. (early* OR juvenil* OR child* OR p#ediatric OR sudden*) N3 (diabet* OR dm) ((juvenil* OR child*) N3 (diabet*or dm))
9. insulin depend* OR insulindepend* OR insulin-depend* (insulin* N1 depend*) N3 (diabet*OR dm)
10. (auto immun* OR autoimmun* OR auto-immun*) N3 (diabet* OR dm)
11. absolut* N3 (insulin* W1 defic*)
12. 5 OR 6 OR 7 OR 8 OR 9 OR 10 OR 11
13. (MH "Self Care+")
14. (MH "Self-Efficacy")
15. (MH "Consumer Participation")
16. (MH "Autonomy+")
17. (MH "Decision Making+")
18. (MH "Health Behavior+")
19. (MH "Life Change Events+")
20. (MH "Adaptation, Psychological+")
21. (MH "Empowerment")
22. (MH "Attitude to Health+")
23. self N1 (care OR manag* OR efficac* OR treat* OR direct* OR help* OR monitor*)
24. selfcare OR selfmanag* OR selfefficac* OR selftreat* OR selfdirect* OR selfhelp* OR selfmonitor*
25. self-care OR self-manag* OR self-efficac* OR self-treat* OR self-direct* OR self-help* OR self-monitor*
26. decision N1 mak*
27. patient N1 (participat* OR involv*)
28. autonomy OR autonomous OR responsibilit* OR adherence OR empower*
29. (psychologic* OR behaviour* OR behavior*) N1 (adjust* OR adapt*)
30. 13 OR 14 OR 15 OR 16 OR 17 OR 18 OR 19 OR 20 OR 21 OR 22 OR 23 OR 24 OR 25 OR 26 OR 26 OR 27 OR 28 OR 29
31. (MH "Qualitative Studies+")
32. (MH "Interviews+")
33. (MH "Focus Groups")
34. (MH "Attitude+")
35. (MH "Multimethod Studies")
36. qualitative OR theme* OR thematic OR ethnograph* OR ethnolog* OR emic OR etic OR hermeneutic* OR heuristic* OR interview* OR semiotic* OR experienc*

37. discourse* OR discursive* OR discuss* OR narrative* OR narration* OR ethnomethdolog* OR multimethod* OR triangulat* OR experiential OR attitud* OR opinion* OR perspectiv*
38. grounded N1 theor*
39. data N3 saturat*
40. participant N3 observ*
41. (purposive OR cluster) N3 sampl*
42. focus W1 group*
43. observational N3 method*
44. constant N3 compar*
45. key W1 informant*
46. theoretical N3 (saturat* OR sampl*)
47. mixed N1 (method* OR model* OR design*)
48. multiple W1 method*
49. (cooperative OR cooperative) W1 inquir*
50. conversation N1 analys?s
51. 31 OR 32 OR 33 OR 34 OR 35 OR 36 OR 37 OR 38 OR 39 OR 40 OR 41 OR 42 OR 43 OR 44 OR 45 OR 46 OR 47 OR 48 OR 49 OR 50
52. 4 AND 12 AND 30 AND 51

A4 PsycINFO search strategy

1. child* OR adolesc* OR juveline* OR youth* OR teen* OR young* OR boy* OR girl* OR p#ediatric

2. Iddm OR t1dm OR t1d
3. (typ? one OR typ? 1 OR typ? i) N5 (diabet* OR dm)
4. (auto-immun* OR autoimmun* OR autoimmun* OR sudden* OR early* OR p#ediatric) N3 diabet*
5. (juvenil* OR child*) N3 diabet*
6. (insulin* N1 defic*) N3 absolut*
7. 2 OR 3 OR 4 OR 5 OR 6

8. DE "Self-Management"
9. DE "Self-Monitoring"
10. DE "Self-Care Skills"
11. DE "Client Participation"
12. DE "Self-Efficacy"
13. DE "Adjustment" OR DE "Emotional Adjustment"
14. DE "Independence (Personality)" OR DE "Empowerment"
15. DE "Decision Making" OR DE "Choice Behavior" OR DE "Autonomy"
16. DE "Life Changes" OR DE "Developmental Stages"
17. DE "Health Attitudes"
18. self care OR self manag* OR self efficac* OR self treat* OR self direct* OR self help* OR self monitor*
19. selfcare OR selfmanag* OR selfefficac* OR selftreat* OR selfdirect* OR selfhelp* OR selfmonitor*
20. self-care OR self-manag* OR self-efficac* OR self-treat* OR self-direct* OR self-help* OR self-monitor*
21. decision N1 mak*
22. patient N1 participat*
23. autonomy OR autonomous OR responsibilit* OR adherence OR empower*
24. 8 OR 9 OR 10 OR 11 OR 12 OR 13 OR 14 OR 15 OR 16 OR 17 OR 18 OR 19 OR 20 OR 21 OR 22 OR 23

25. DE "Qualitative Research"
26. DE "Interviews"
27. Qualitative OR theme* OR thematic OR ethnograph* OR ethnolog* OR emic OR etic OR hermeneutic* OR heuristic* OR interview* OR semiotic* OR experienc* OR discourse* OR discursive* OR discuss* OR narrative* OR narration* ethnomethodolog* OR multimethod* OR triangulat* OR experiential OR attitud* OR opinion* OR perspectiv*

28. grounded N1 theor*
29. data N3 saturat*
30. participant N3 observ*
31. (purposive OR cluster) N3 sampl*
32. focus W1 group*
33. observational N3 method*
34. constant N3 compar*
35. key W1 informant*
36. theoretical N3 (saturat* OR sampl*)
37. mixed N1 (method* OR model* OR design*)
38. multiple W1 method*
39. (cooperative OR cooperative) W1 inquir*
40. conversation N1 analys?s
41. 25 OR 26 OR 27 OR 28 OR 29 OR 30 OR 31 OR 32 OR 33 OR 34 OR 35 OR 36 OR 37 OR 38 OR 39 OR 40
42. 1 AND 7 AND 24 AND 41

A5 Web of Science search strategy

TOPIC: (child*) OR (adolesc*) OR (juvenile*) OR (p$ediatric*) OR (youth*) OR (teen*) OR (young*) OR (boy*) OR (girl*)

AND

TS=((insulin* NEAR/1 depend*) OR (((type NEAR/1 (1 OR one OR i)) NEAR/5 diabet*)) OR (“type i diabet*”) OR ((p$ediatric* OR child*) NEAR/3 (diabet* or dm)) OR ((absolut* NEAR/1 insulin*) NEAR/3 defic*) OR (("auto-immune" OR "autoimmune” OR "auto immune") NEAR/3 (diabet* OR dm)) OR ((juvenile* NEAR/3 (diabet* OR dm)) OR (("juvenile onset”) NEAR/3 (diabet* OR dm)) OR ("juvenile-onset” NEAR/3 (diabet* or dm))) OR ((early* NEAR/3 (diabet* OR dm)) OR ("early-onset” NEAR/3 (diabet* OR dm)) OR ("early onset”) NEAR/3 (diabet* OR dm)) OR early* NEAR/3 (diabetes OR dm) OR (IDDM OR T1DM OR T1D) OR ("type 1 diabet*") OR (((type NEAR/1 (1 OR one OR i)) NEAR/5 dm)))

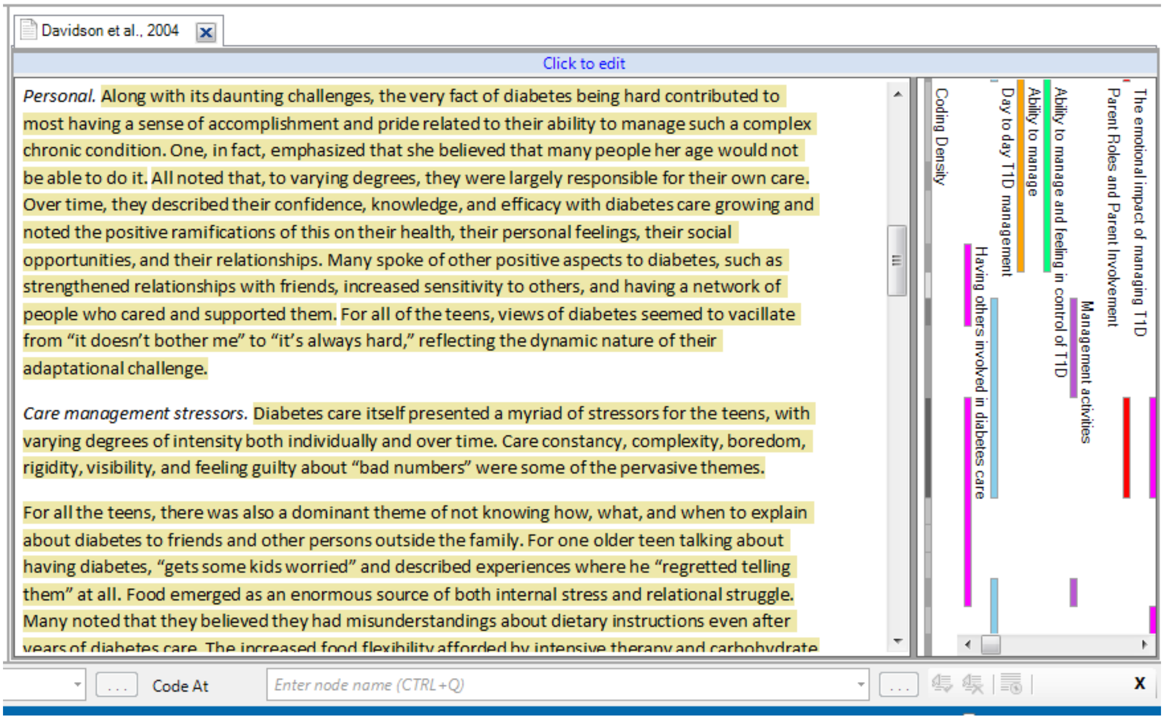
AND

TOPIC: (autonomy OR autonomous OR responsibilit* OR adherence OR empower*) OR (health NEAR/3 attitude*) OR (behavio$r* NEAR/3 adapt*) OR (behavio$r* NEAR/3 adjust*) OR (psychologic* NEAR/3 adapt*) OR (psychologic* NEAR/3 adjust*) OR (decision NEAR/1 mak*) OR (patient NEAR/1 participat*) OR (patient NEAR/1 involv*) OR ("self care" or "self help*" or "self manag*" or "self direct*" or "self monitor*" or "self efficac*" or “self treat*” or "self-care" or "self-help*" or "self-manag*" or "self-direct*" or "self-monitor*" or "self-efficac*" or “self-treat*” or selfcare or selfhelp* or selfmanag* or selfdirect* or selfmonitor* or selfefficac* or selftreat*)

AND

(conversation NEAR/1 analys?s) OR ((cooperative OR cooperative) NEAR/1 inquir*) OR (multiple NEAR/1 method*) OR (mixed NEAR/1 (method* OR model* OR design*)) OR (theoretical NEAR/3 (saturat* OR sampl*)) OR (key NEAR/1 informant*) OR (constant NEAR/3 compar*) OR (observational NEAR/3 method*) OR (“focus group*”) OR ((purposive OR cluster) NEAR/3 sampl*) OR ((purposive OR cluster) NEAR/3 sampl*) OR (participant NEAR/3 observ*) OR (data NEAR/3 saturat*) OR (“grounded theor*”) OR qualitative OR theme* OR thematic OR ethnograph* OR ethnolog* OR emic OR etic OR hermeneutic* OR heuristic* OR interview* OR semiotic* OR experienc* OR discourse* OR discursive* OR discuss* OR narrative* OR narration* ethnomethodolog* OR multimethod* OR triangulat* OR experiential OR attitud* OR opinion* OR perspectiv*

Appendix B: Example coded extract from NVivo (thematic synthesis)



Personal. Along with its daunting challenges, the very fact of diabetes being hard contributed to most having a sense of accomplishment and pride related to their ability to manage such a complex chronic condition. One, in fact, emphasized that she believed that many people her age would not be able to do it. All noted that, to varying degrees, they were largely responsible for their own care. Over time, they described their confidence, knowledge, and efficacy with diabetes care growing and noted the positive ramifications of this on their health, their personal feelings, their social opportunities, and their relationships. Many spoke of other positive aspects to diabetes, such as strengthened relationships with friends, increased sensitivity to others, and having a network of people who cared and supported them. For all of the teens, views of diabetes seemed to vacillate from “it doesn’t bother me” to “it’s always hard,” reflecting the dynamic nature of their adaptational challenge.

Care management stressors. Diabetes care itself presented a myriad of stressors for the teens, with varying degrees of intensity both individually and over time. Care constancy, complexity, boredom, rigidity, visibility, and feeling guilty about “bad numbers” were some of the pervasive themes.

For all the teens, there was also a dominant theme of not knowing how, what, and when to explain about diabetes to friends and other persons outside the family. For one older teen talking about having diabetes, “gets some kids worried” and described experiences where he “regretted telling them” at all. Food emerged as an enormous source of both internal stress and relational struggle. Many noted that they believed they had misunderstandings about dietary instructions even after years of diabetes care. The increased food flexibility afforded by intensive therapy and carbohydrate

Appendix C: Themes identified in each article by number of extracts coded

Analytic themes	Negotiating independence				Feeling in control				
Descriptive themes (Number of articles descriptive theme is present in)	Coming to terms with T1D (32)	Parental roles and parent involvement in T1D self-management (33)	Others' involvement in T1D self-management (40)	Becoming independent in T1D self-management (31)	Structuring self-management into everyday life (39)	Ability to self-manage T1D (24)	Fitting in or standing out and self-management of T1D (34)	Thinking about the future and T1D complications (25)	Total number of extracts coded for descriptive theme
Babler & Strickland, 2016	42	6	7	11	37	24	1	3	131
Babler & Strickland, 2015a	11	4	4	10	12	3	3	4	51
Babler & Strickland, 2015b	5	42	5	28	50	4	4	2	140
Boman et al., 2015	5	10	48	7	24	8	5	4	111
Burke & Dowling, 2007	6	0	16	0	13	0	0	0	35
Carroll & Marrero, 2006	8	39	29	6	32	3	1	3	121
Chao et al, 2016	1	5	11	1	18	1	1	4	42
Chilton & Pires-Yfantouda, 2015	26	6	13	13	31	6	1	6	102
Christian et al., 1999	1	10	18	15	13	5	2	1	65

Analytic themes	Negotiating independence				Feeling in control				
Descriptive themes (Number of articles descriptive theme is present in)	Coming to terms with T1D (32)	Parental roles and parent involvement in T1D self-management (33)	Others' involvement in T1D self-management (40)	Becoming independent in T1D self-management (31)	Structuring self-management into everyday life (39)	Ability to self-manage T1D (24)	Fitting in or standing out and self-management of T1D (34)	Thinking about the future and T1D complications (25)	Total number of extracts coded for descriptive theme
Cosma & Baban, 2015	16	7	18	5	28	3	7	4	88
Cruz et al., 2018	1	6	4	1	8	0	1	3	24
Damaio & Pinto, 2007	14	0	8	4	15	0	1	2	44
Davidson et al., 2004	3	5	12	5	12	6	1	0	44
Dickinson & O'Reilly, 2004	2	9	30	6	23	2	5	8	85
Faro, 1999	3	0	4	0	25	0	6	4	42
Hanna & Guthrie, 2001	0	8	2	0	0	0	0	0	10
Hanna & Guthrie, 2000	0	1	2	5	3	3	0	0	14
Hermann, 2006	12	9	24	4	52	6	6	3	116
Huus & Enskar, 2007	0	5	6	1	6	1	2	0	21
Karlsson et al., 2008	2	21	10	10	12	8	1	0	64
Kupper et al., 2018	0	1	6	2	7	0	5	0	21
Kyngas & Barlow, 1995	5	3	10	0	18	0	5	12	53

Analytic themes	Negotiating independence				Feeling in control				
Descriptive themes (Number of articles descriptive theme is present in)	Coming to terms with T1D (32)	Parental roles and parent involvement in T1D self-management (33)	Others' involvement in T1D self-management (40)	Becoming independent in T1D self-management (31)	Structuring self-management into everyday life (39)	Ability to self-manage T1D (24)	Fitting in or standing out and self-management of T1D (34)	Thinking about the future and T1D complications (25)	Total number of extracts coded for descriptive theme
Kyngas & Hentinen, 1995	2	7	10	5	37	3	2	15	81
Kyngas et al., 1998	2	18	33	1	7	0	2	0	63
Leach & Erickson, 1988	4	1	3	0	11	1	1	2	23
Leonard et al., 2005	1	44	14	2	4	0	0	4	69
Marshall et al., 2018	3	0	9	0	3	0	3	0	18
Maslakpak et al., 2010	1	4	24	1	18	0	1	7	56
Meldman 1987	13	2	15	3	12	3	1	3	52
Peters et al., 2014	2	0	28	0	3	0	7	0	40
Rankin et al., 2018	0	0	39	1	10	0	10	0	60
Ryninks et al., 2015	3	2	12	0	6	1	1	0	25
Serlachius et al., 2012	0	7	8	9	16	0	1	6	47
Standiford et al., 1997	1	5	18	3	5	0	2	2	36

Analytic themes	Negotiating independence				Feeling in control				
Descriptive themes (Number of articles descriptive theme is present in)	Coming to terms with T1D (32)	Parental roles and parent involvement in T1D self-management (33)	Others' involvement in T1D self-management (40)	Becoming independent in T1D self-management (31)	Structuring self-management into everyday life (39)	Ability to self-manage T1D (24)	Fitting in or standing out and self-management of T1D (34)	Thinking about the future and T1D complications (25)	Total number of extracts coded for descriptive theme
Sullivan-Bolyai et al., 2014	2	15	15	4	7	1	0	0	44
Viklund & Wikblad, 2009	1	26	3	21	8	4	0	2	65
Wang et al., 2013	3	5	15	4	29	2	10	1	69
Wang et al., 2010	1	10	17	5	8	2	5	0	48
Weinger et al., 2001	0	28	6	0	6	0	2	2	44
Ye et al., 2017	1	0	15	4	15	1	4	3	43
Total number of codes per descriptive theme	203	371	571	197	644	101	110	110	

Appendix D: Overview of Youth Advisory Group Workshops

The three youth advisory group workshops were held in a large room in the Youth Work Ireland (YWI) building in Dublin City Centre, outside of school term time. The workshops were participatory and used art-based activities. The workshops were facilitated by up to two members of YWI staff and two DCU staff working on the research project, including the PhD student.

Workshop 1

Workshop 1 was held in April 2017. Nine adolescents (aged 11-15 years; $n = 7$ females and $n = 2$ males) participated in the first workshop. The workshop was facilitated by two YWI staff and two DCU researchers.

The first workshop served an introductory purpose and to inform the adolescent advisors on the purpose of the group and the format of subsequent workshops. The goal of the first workshop was to elicit feedback on data collection for phase one of the research study. Following initial introductions, all group members and facilitators participated in icebreaker games. The icebreaker game, ‘Human Bingo’ involved players mixing with other group members to find those who matched the traits on a bingo type card. Staff participated and this helped staff to open a discussion in relation to research and asking questions. The conversation led to establishing the point that if we want to learn things, we need to make sure we have the right questions. This led to establishing the purpose of the youth advisory group which is to both help to ensure that we have good questions and to make sure we understand the answers for the research project.

After a short break, staff spoke about the research project and the work to be carried out over the next two years, and the involvement of the youth advisory group. Two youth members provided feedback that self-management and learning can differ depending on the time of diagnosis. They felt that young people who are diagnosed earlier (e.g. 3 years old) might pick up bad habits from their parents when learning to self-manage but young people diagnosed later (e.g. 10 years old) might learn directly from medical staff.

This led to a discussion about group members motivations for attending these workshops. YWI staff introduced the idea of a group contract and invited the adolescents to set their own rules and terms for the group. All group members agreed to the rules that were suggested.

Following lunch, adolescents completed a timeline activity. The purpose of the timeline activity exercise was to inform the researchers how best to capture all aspects of adolescent's T1D management and communication with parents. Each adolescent was provided with a set of cards. Each adolescent then completed cards for each self-care event that usually takes place in a 24-hour period – staff encouraged them to be creative, fun, and include all the dimensions of their lives, draw, write, or create a diagram on the cards.

Adolescents were specifically asked to include when they talk to their parents on the cards but upon completion of their timelines, this was notably lacking. It was also noted by YWI staff that the activity was for a 24-hour period but the nighttime was missing on all timelines. YWI adapted the task to include a follow-on activity. As part of this activity, adolescents were asked to add red stickers to their timelines to indicate when they speak to their parents about T1D management. These stickers focused the conversation and pinpointed key conversation times.

While adolescents were initially slow to volunteer information, following some prompting, adolescents reflected that lots of conversation seems to be happening with parents. Following this activity, the group discussed the activity. Adolescents discussed potential issues surrounding communication with parents about T1D. The issues identified included key difficult T1D management conversations (e.g. pre-clinic, post-clinic, when bloods are high for a few readings in a row, and how mood can be affected by lows and this affects their conversations with parents). Avoiding some conversations with parents was referred to. In the context of the research interviews, it was commented that if we want adolescents to talk about their conversations with their parents about T1D management they need to be asked very direct questions on this.

Workshop 2

Workshop 2 was held in November 2017. Seven adolescents (aged 12-16 years; *n* = 5 females; *n* = 2 males) participated in Workshop 2. The workshop was facilitated by one YWI staff and two DCU researchers. The workshop aimed to elicit feedback on emergent findings related to division of parent-adolescent responsibility for T1D management tasks.

On arrival the group appeared comfortable and talked to each other, while they made name badges. Icebreakers were used throughout the day to introduce and break up activities.

Next the group completed an activity on self-management responsibilities, followed by a discussion. Adolescents broke into three groups and completed the activity based on how they believed responsibilities should be divided for self-management at the following ages: 11-13 years (*n* = 3), 14-15 years (*n* = 2), and 16-17 years (*n* = 2). The activity involved pinning activities to a flip chart to indicate who takes responsibility for each activity at each age group.

The 11-13 year old group pinned monitoring and tracking blood glucose levels and keeping blood glucose levels within range as being carried out by both adolescents and parents at this age. For talking to others about diabetes, this group noted that adolescents at this age talk to their friends. They mentioned that parents manage blood glucose levels when 11-13 year olds are sick and at night time. The group said that their parents listen in the clinic and that they remember the advice given as the adolescent might forget what the doctors say.

The 14-15 year old group put monitoring blood glucose levels at night as parent’s responsibility. For monitoring and tracking BG levels they stated responsibility lies with both the parent and the adolescent, as parents might manage their blood glucose levels on sick days and parents might help with monitoring and tracking blood glucose levels at times.

The 16-17 year old group mentioned that at this age, adolescents take responsibility for their food intake, as they spend more time apart from their parents. They mentioned that parents are better at noticing patterns in blood glucose readings. They also mentioned that overall health incorporated more than diabetes (meals, exercise etc.). The older group also stated that they needed support from parents when talking to doctors.

The group then paused before completing the second part of the activity where adolescents were asked to think about how adolescents talk to their parents about seeking assistance for completing a self-management task. The group were asked to think about diabetes management responsibilities and to think about the following questions: “What do adolescents need help with?” and “Do parents help automatically or do you ask for help?”

The following points were raised:

For 11-15 year olds, both groups said that whether or not parental help is automatic depends on who remembers the task first, e.g. site changes, running low on syringes/supplies. Age at diagnosis was referred to as a factor that had the potential to influence how adolescents engaged with their self-management. It was suggested that two adolescents could have contrasting experiences depending on whether they are diagnosed in young childhood versus in adolescence, e.g. an older adolescent could self-manage independently for themselves from the start. The group seemed to agree that parents stepped in when necessary. It was mentioned that parents and adolescents mainly talk about diabetes when it is a problem and some parents and adolescents argue more than talk where T1D management is concerned.

The next activity involved reviewing the measures proposed for inclusion in the cross-sectional survey for phase two. Two groups were formed and each adolescent was given a copy of each survey tool. Adolescents were asked to read through these and note any instances that were difficult to understand or where they believed an adolescent would find the survey difficult to understand or complete. Upon completion of this activity, this resulted in some feedback that they felt that some items should be taken out. For example, they highlighted that some of the items on the PAM were difficult to understand. They also suggested changing some wording slightly to improve the clarity of some items. They also discussed their preference for completing a survey on paper rather than online and this was attributed to the novelty of receiving post.

Workshop 3

Workshop 3 was held in November 2018. Eight adolescents (aged 13-17 years; *n*=8 females) participated in Workshop 3. The workshop was facilitated by one YWI staff and two DCU researchers.

Icebreakers were used throughout the day to introduce and break up activities. Adolescents were updated on the surveys and reminded of the work carried out in interviews. The first activity surrounded the interview codes (on parent-adolescent communication about self-management) and was followed with a discussion. The entire group read a list of interview codes individually. Next, the group was split into two groups. The groups were asked to discuss what might help to break the barriers adolescents and parents encounter when talking about T1D management.

The discussion from Group 1 focussed on the development of an app. Some key features of the design of the app included both young people and parents having access to T1D management information, e.g. blood glucose readings and tasks carried out, e.g. insulin administration and in which changes could be set. The key message was that parents could check independently and could track the adolescent’s T1D management without having to check in with them. This group also mentioned that after clinic appointments families are often on top of their management in relation to T1D management and an app might help to maintain this performance over time. They mentioned that the training for such an app would be best facilitated through an in-person event with the nursing staff. The group also spoke about how each manufacturer of insulin pumps/semi-continuous blood glucose monitors etc. have their own apps and it is not easy to integrate information across different devices and that an app which could integrate information across devices would be very beneficial. There was a suggestion that parents could set reminders via this app but that reminders could also be disabled to allow for individualised settings according to age/stage/level of independence. Visual representation of information would also be important in such an app if it were developed. If parents could see T1D management activity this may lead to more focussed discussions and reduce attribution of blame.

It was also mentioned that adolescents might benefit from the opportunity to attend ‘refresher’ courses, especially if they had been diagnosed at a young age. The main reason for this being that while the adolescent might be capable of managing independently, they may not know all the specific T1D terminology or understand its mechanisms as they learnt from experience. Conversely for adolescents diagnosed at an older age, the experience was the opposite of this. In this case it might be helpful for a parent to receive some additional training. The group mentioned that this typically only happens with pump training.

Group 2 discussed activity trips for young people with T1D as a way to help adolescents with T1D self-management. The group mentioned that there seemed to be fewer activities available for teenagers than for younger children. They mentioned that structured and social activities should be tailored to the specific needs of adolescents living with T1D. Some members of the group stated they would have appreciated more time to talk about T1D experiences at an activity camp that they attended for children with medical needs. The group mentioned that they were never taught about long term implications until things were bad, i.e. bad blood results. The group identified the importance of keeping conversations open and agreed with the code relating to understanding that sometimes arguments may be due to parents seeking to help. The group also identified the need for events for parents on how to manage when things are going wrong.

After lunch, the group began the next activity which related to dissemination. First, a short video was played, explaining this research project and some of the emergent findings. The group was then split into two groups again and asked to consider the best ways to tell people about the findings from the research.

The first group focused on social media, and in particular Instagram, Snapchat and Facebook. They mentioned that information from Facebook is provided via their parents. For social media posts a good infographic or video is useful.

These adolescents also suggested that a written piece in the Diabetes Ireland Magazine published quarterly by Diabetes Ireland and leaflets available in hospital waiting areas which may be seen by adolescents as they wait for clinic appointments, along with posters in the clinic area. They specified that leaflets need to be colourful and need a catchy title and a question if possible and should include a QR code.

The second group suggested that Snapchat and the Diabetes Ireland Magazine as ways to disseminate findings to adolescents. They mentioned that focused talks such as those held at conferences for people would also be suitable settings for reaching adolescents as they had attended similar conferences/talks previously. They suggested that videos on hospital monitors possibly with no sound would have to include information that could be understood visually.

The full group completed a drawing exercise at the end of the workshop where they traced the outline of their hand and each other member of the group wrote a message on the hand. The workshop ended with the presentation of certificates of attendance and a voucher for each group member.

How the workshops informed the research process

How Workshop 1 informed the research process:

- The initial interviews that had been conducted to date echoed some of the points made by the adolescents in the Youth Advisory Group.
- Getting adolescents to reflect on their experiences of parent-adolescent communication can be difficult. The workshops emphasised that at times it might be necessary to ask all the interview prompt questions on the interview topic guide to ensure adolescents are asked directly about parent-adolescent communication surrounding self-management. The workshops highlighted that adolescents at times, would need to be asked about parent-adolescent communication several times before getting to the root of their experiences of

- negotiation and communication surrounding sharing self-management with their parents.

How Workshop 2 informed the research process:

- The first activity elucidated the nuanced nature of sharing management tasks with parents. It confirmed the importance of better understanding how responsibilities are negotiated and whether adolescent age and adolescent age at diagnosis impact upon the parent-adolescent division of responsibility for management tasks. This highlighted the importance of being mindful of contextual characteristics when interpreting the qualitative data on experiences of negotiating parental involvement in self-management.
- Some slight changes were made to some of the measures (see Chapter 7, 7.6.1). These slight changes were requested with the original authors of the scales.

How Workshop 3 informed the research process:

- The discussions informed some of the conclusions and implications that this research can suggest. Furthermore, it suggests ways to ensure that the findings of the research can be made meaningful for adolescents through ensuring they are relevant and that they meet their target audience.

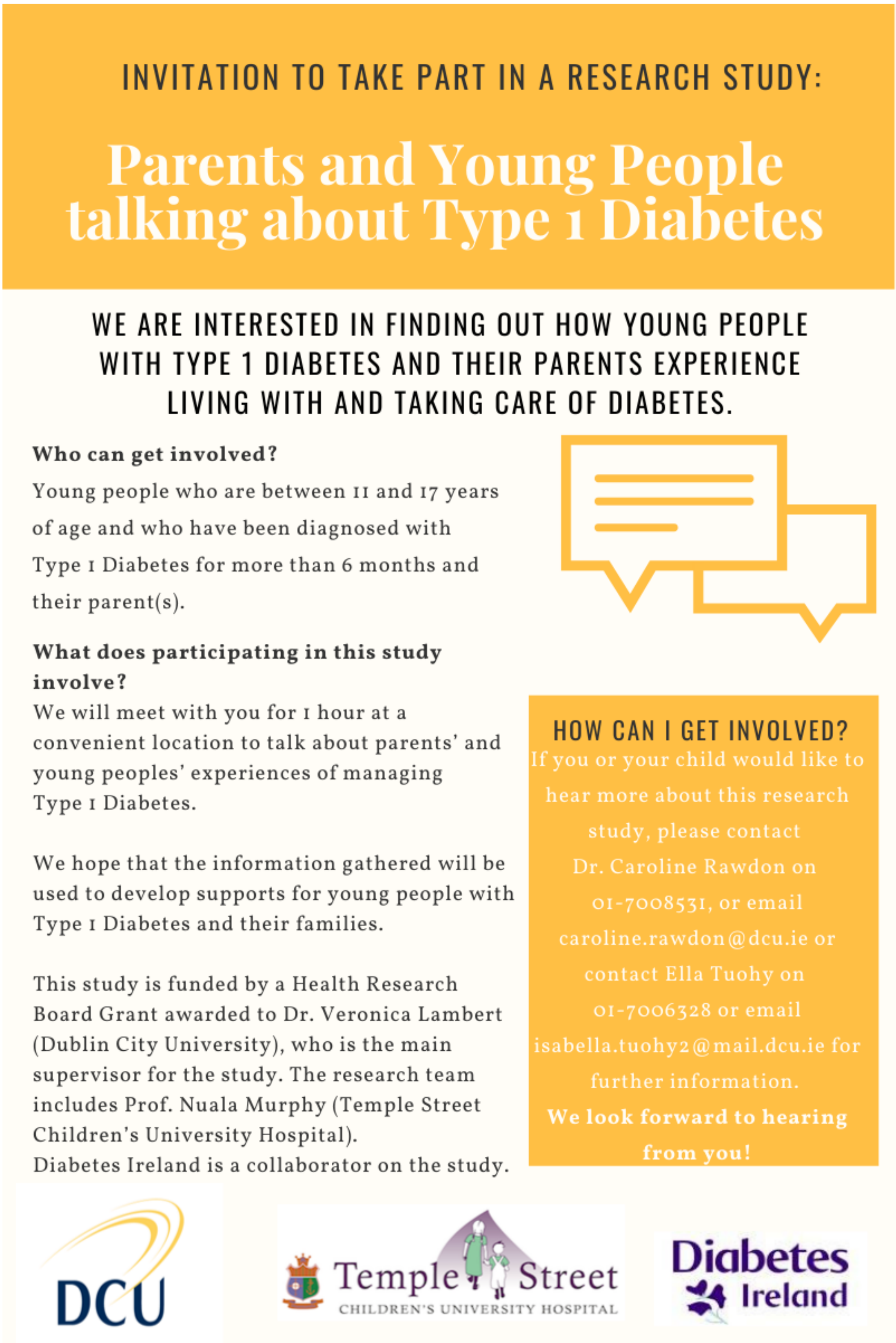
Appendix E: Youth Advisory Group Recruitment Post

RESEARCHERS AT DUBLIN CITY UNIVERSITY ARE RECRUITING A YOUTH ADVISORY GROUP

If you are between 11 and 17 years old with type 1 diabetes and are interested in getting involved
follow the link for more information
https://www.diabetes.ie/get-involved-type-1-youth-advisory-group/

Appendix F: Recruitment Materials (Phase One)

Appendix F1: Recruitment Poster (Phase One)



INVITATION TO TAKE PART IN A RESEARCH STUDY:

Parents and Young People talking about Type 1 Diabetes

WE ARE INTERESTED IN FINDING OUT HOW YOUNG PEOPLE WITH TYPE 1 DIABETES AND THEIR PARENTS EXPERIENCE LIVING WITH AND TAKING CARE OF DIABETES.

Who can get involved?

Young people who are between 11 and 17 years of age and who have been diagnosed with Type 1 Diabetes for more than 6 months and their parent(s).

What does participating in this study involve?

We will meet with you for 1 hour at a convenient location to talk about parents' and young peoples' experiences of managing Type 1 Diabetes.

We hope that the information gathered will be used to develop supports for young people with Type 1 Diabetes and their families.

This study is funded by a Health Research Board Grant awarded to Dr. Veronica Lambert (Dublin City University), who is the main supervisor for the study. The research team includes Prof. Nuala Murphy (Temple Street Children's University Hospital).
Diabetes Ireland is a collaborator on the study.

HOW CAN I GET INVOLVED?

If you or your child would like to hear more about this research study, please contact Dr. Caroline Rawdon on 01-7008531, or email caroline.rawdon@dcu.ie or contact Ella Tuohy on 01-7006328 or email isabella.tuohy2@mail.dcu.ie for further information.

We look forward to hearing from you!

DCU

Temple Street
CHILDREN'S UNIVERSITY HOSPITAL

Diabetes Ireland

Appendix F2: Social Media Post

ARE YOU 11-17 YEARS OLD WITH TYPE 1 DIABETES?

OR

ARE YOU THE PARENT OF AN 11-17 YEAR OLD WITH TYPE 1 DIABETES?

Would you like to take part in a research study exploring how young people and their parent/s experience life with type 1 diabetes?

Follow the link for more information

Appendix G: Safety Protocols

Although this study is exploratory and low risk there is a chance that a participant may become distressed or fatigued during data collection. As the young people who participate in this research will have a diagnosis of T1D, there is also a possibility that they may experience a hypo/hyperglycaemic episode during data collection. Protocols are outlined below to address these issues. At the beginning of each semi-structured interview parents and adolescents will be advised that they can take a break at any time if they need to do so.

Protocol if a participant becomes distressed during data collection

Researchers will remain alert for both verbal and non-verbal signals of distress during data collection. Should a participant (adolescent with T1D or their parent(s)) become distressed, the researcher (Dr. Caroline Rawdon or Ms. Ella Tuohy) will adopt the following protocol:

- Respond sensitively to the participant by stopping any conversation relating to the study to check in with the participant.

- Acknowledge the participant's distress, empathise where appropriate (within the boundaries of the researcher role), and allow the participant time to deal with their distressed reaction accordingly.

- Remind participants that they are free to stop participation or to withdraw from the study at any time.

- Where appropriate refer to the child protection protocol outlined in Section C4.9.

Participants will be provided with a debriefing sheet including a list of relevant support services (see Appendix H).

Protocol if adolescent becomes unwell including signs of hypo/hyperglycaemic episode

Due to the chronic nature of T1D the prospective adolescent may become unwell during a semi-structured qualitative interview. A kit containing suitable refreshments (Lucozade and digestive biscuits) will be available on-site at DCU when semi-structured interviews take place at this location. Parents will be advised to stay on-site during semi-structured interview data collection in case an emergency situation arises. Parents will be advised of both researchers' qualifications (Dr. Caroline Rawdon and Ms. Ella Tuohy) and that both researchers are not medical professionals with expertise in in the management of Type 1 Diabetes. Participants will be advised that they can take a break at any time during the interview if necessary. Should such a situation arise the following protocol will be implemented:

- The interview will be immediately halted and if the parent of the adolescent has not stayed in the room during the interview they will be called in straight away.

- The researcher (Dr. Rawdon or Ms. Tuohy) will stay with the adolescent and make sure that s/he is ok until the parent comes into the room. The procedure the family would normally follow in this situation will be undertaken.

- The researcher will ensure that the parent and adolescent are ok before leaving.

- If the adolescent/parent still wishes to participate at a later date the researcher will call the family to reschedule.

- If the adolescent/parent does not wish to participate thereafter, the researcher will thank them for their time.

Child Protection Protocol

It will be stressed at the outset of the study to parents, adolescents and participating multidisciplinary healthcare professionals that absolute confidentiality cannot be guaranteed, i.e. if a child protection issues arise. This will be made explicitly clear in writing on information sheets provided to parents, adolescents and healthcare professionals prior to their participation in observational fieldwork, semi-structured interviews and audio-diaries, and verbally at the beginning of semi-structured interviews with adolescents and their parents.

If an adolescent discloses any information that indicates that s/he or anyone else is at risk (i.e. child abuse or if a young person discloses that they are at risk of harming themselves or another person) during observational fieldwork, the researcher responsible for data collection (Dr Caroline Rawdon) and act in accordance with reporting procedures outlined by the hospital in line with the Department of Children and Youth Affairs Children First document (2011).

If an adolescent discloses any information that indicates that s/he or anyone else is at risk (i.e. child abuse or if a young person discloses that they are at risk of harming themselves or another person) during a semi-structured interview, the researcher carrying out the data collection (Dr. Caroline Rawdon or Ms. Ella Tuohy) will gently end the interview, ensuring the adolescent is not distressed or will allow her/him time to recover if s/he is distressed. Any child protection issues which arise during semi-structured interview data collection will be reported to Dr. Veronica Lambert as soon as is possible (preferably immediately). The research team (Dr. Rawdon, Ms. Tuohy and Dr. Lambert) who will act in accordance with the Department of Children and Youth Affairs Children First document (2011) if a child protection issue arises. Information related to the disclosure of child protection concerns will not be discussed with a third party without informing the young person first.

If an adolescent discloses any information that indicates that s/he or anyone else is at risk (i.e. child abuse or if a young person discloses that they are at risk of harming themselves or another person) in an audio-diary recording, the researcher carrying out the data analysis (Dr. Caroline Rawdon or Ms. Ella Tuohy) will inform Dr. Veronica Lambert who will act in accordance with the Department of Children and Youth Affairs Children First document (2011).

Information will be accurately recorded using templates from the National Guidelines for reporting such allegations. Both Dr. Rawdon and Ms. Tuohy have received Garda vetting in April 2016 via DCU.

Following the occurrence of any adverse event during the interview process, the researcher will document the details in full, as soon as is possible following the incident. This document will include details on the incident and action taken by those present at the time. This information will be stored safely in a locked filing cabinet in DCU to which only the principal investigator (Dr. Veronica Lambert) and post-doctoral researcher will have access.

Appendix H: Participant Information Sheets (Parent and Adolescent) and Debriefing sheets

Appendix H1 Adolescent Information Sheet (11-14 years)

Invitation to participate in research

Young people and parents talking about type 1 diabetes

We are Caroline and Ella, and we are doing a project on what it is like to talk to your family about Type 1 Diabetes.

Caroline will be talking to parents and Ella is especially interested in what experiences young people feel when talking to parents about looking after their Type 1 Diabetes. ....

My name is Ella and I would like to talk to you about what it is like having Type 1 Diabetes and how your family help you...

What will you do in the project?

Voice recorder/
Audio-diary

I will record our conversations and might take some notes. I will chat with you about what it is like to decide with your parents how to look after Type 1 Diabetes and how you and your parents talk about taking care of Type 1 Diabetes.

After the interview, families may be asked if they would like to keep an audio-diary. This is a spoken diary, recorded using a voice recorder. If you would like to keep a diary, I will ask you to take about 20 minutes each evening (or whenever suits you) to talk about taking care of your diabetes for 2 weeks.

Where will we meet?

Caroline and I will come to your house to chat to you, or wherever you and your parents choose.

How long will it take?

Not too long. It depends on how much you have to say but the interview will probably take about 30-45 minutes.

Why do we want your help?

Caroline and I are interested in finding out about parents' and young peoples' experiences of living with and looking after of Type 1 Diabetes. Information collected may be used as part of research articles and presentations.

Caroline and I hope that what you tell us will help with developing supports for young people with Type 1 Diabetes and their families.

What will happen to your answers?

With your permission I will take notes and will also audio-record our conversations.

I will be writing a project about what you tell me in the interview and also in your audio-diary (if you choose to take part) but I won't mention your name in the project.

I will keep our conversations as private as possible but if you tell me or mention that you or another young person might be in danger, I will have to tell someone about this.

What about your safety and wellbeing?

Your parents can stay with you while we chat, if you like. If you become upset during our conversations, I will ask you if you want to stop, take a break or if you would like to have your parent sit with you to make you feel more comfortable.

I will ask that you keep your audio-diary in a safe place where only you will have access to it. This is to ensure that only you and the researchers have access to your diary entries.

What if you don't want to take part or want to leave the study at any stage?

You can stop talking at any time and if you don't want to take part that is fine.

My name is Ella Tuohy and I am a student at Dublin City University…

My phone number is (01)7006328 and my email address is isabella.tuohy2@mail.dcu.ie

My name is Caroline Rawdon and I am a researcher at Dublin City University…

My phone number is (01)7008531 and my email address is caroline.rawdon@dcu.ie

If you have any questions, just ask your parents if you can contact one of us –

We are very happy to answer any questions you might have.

Appendix H2 Participant Information Sheet (15-17 years)

Invitation to Participate in Research: Young People and Parents Talking about Type 1 Diabetes

We are Dr. Caroline Rawdon and Ella Tuohy, and we are doing a project on what it is like to talk to your family about Type 1 Diabetes.
Caroline will be talking to parents and Ella is especially interested in the experiences young people feel when talking to parents about looking after their Type 1 Diabetes.

What will you be asked to do?

- We would like to have the opportunity to speak with young people about living with type 1 diabetes and what it is like to decide with your parents how to manage and look after type 1 diabetes.
- The conversation will be recorded and Ella (the interviewer) may take some notes.
- Some families may also be asked if they would like to keep an audio-diary after the interview for 2 weeks. This is a spoken diary, recorded using a voice recorder which we will show you how to use.

Where will we meet?

- We will come to your house or wherever is most convenient for you and your parents.

How long will it take?

- It depends on how much you have to say, but the interview will probably take about 30-45 minutes.
- If you decide to complete an audio-diary after the interview, we will ask you to take about 20 minutes each evening (or whenever suits you) to talk about how you take care of your diabetes each day and your feelings about this.

Why do we want your help?

We are interested in finding out about parents’ and young peoples’ experiences of living with and taking care of type 1 diabetes.

Information collected may be used as part of research articles and presentations and what you tell us will help to design a support for young people with Type 1 Diabetes and their families.

What will happen to your answers?

With your permission we will take notes and will also audio record the conversations.

All data will be stored in password protected, computer files and your name or any identifying information will not be included in any articles or presentations.

What about your safety and wellbeing?

Your parents can stay with you while we chat, if you like. If you become upset during our conversations, we will ask you if you want to stop, take a break or if you would like to have your parent sit with you to make you feel more comfortable.

The conversation will be kept as private as possible but if you tell us or mention that you or another young person might be in danger, we will have to tell someone about this.

If you decide to keep an audio-diary, we ask that you keep your audio-diary in a safe place where only you will have access to it. This is

What if you don't want to take part or change your mind and want to leave the study at any stage?

It is your decision to take part in this project. You can choose not to take part and you do not have to give a reason.

If you decide to take part and change your mind at any point, there will be no repercussions for changing your mind.

If you have any questions, wish to know more about this project, or would like information about the outcomes of the study, please do not hesitate to contact Ella or Caroline (see details below).

We would be delighted to answer any questions you may have.

Ella Tuohy (PhD student at Dublin City University) Ph: (01) 7006328 E-mail: isabella.tuohy2@mail.dcu.ie	Caroline Rawdon (Post-doctoral researcher at Dublin City University) Ph: (01) 7008531 E-mail: caroline.rawdon@dcu.ie

pendix H3: Adolescent Debriefing Sheet (11-14 years)

Young People and Parents Talking about Type 1 Diabetes

Thank you for taking the time to participate in our research study. We really appreciate it and we hope that you enjoyed talking to us.

If you have been affected by any of the issues that you have talked about with Ella or Caroline, or if you need any further information or help with managing your Type 1 Diabetes, it is important that you talk to an adult about it. This could be your parent, your Consultant Endocrinologist or a member of their team, or your General Practitioner. You can also access resources available from Diabetes Ireland.

Diabetes Ireland:

Website – https://www.diabetes.ie/

Helpline -1850 909 909

Appendix H4: Adolescent Debriefing Sheet (15-17 years)

Young People and Parents Talking about Type 1 Diabetes

Thank you for taking the time to participate in our research study. We really appreciate it and we hope that you enjoyed talking to us.

If you have been affected by any of the issues that you have talked about with Ella or Caroline, or if you need any further information or help with managing your Type 1 Diabetes, it is important that you talk to an adult about it. This could be your parent, your Consultant Endocrinologist or a member of their team, or your General Practitioner. You can also access resources available from Diabetes Ireland.

Diabetes Ireland:

Website – https://www.diabetes.ie/

https://www.diabetes.ie/living-with-diabetes/living-type-1/young-adult/

Helpline -1850 909 909

Appendix H5: Parent Information Sheet

Young People and Parents Talking about Type 1 Diabetes

Parent/Guardian Information Sheet – Interviews and Audio-diaries

Dear parent/guardian,

We would like to invite you and your child to take part in a research study to help us to understand how young people (aged 11-17 years) learn to manage their Type 1 Diabetes. This research study is being carried out by a team of researchers from the School of Nursing and Human Sciences at Dublin City University in collaboration with Prof. Nuala Murphy and her team at Temple Street Children's University Hospital and the Mater Misericordiae University Hospital and Diabetes Ireland. This research study is funded by the Health Research Board.

What is this research study about and who can take part?

We are carrying out this research study to find out more about how young people learn to manage their Type 1 Diabetes and how families communicate about Type 1 Diabetes management.

- We would like to have an opportunity to speak with you and/or your child with Type 1 Diabetes if they are **between 11 and 17 years of age** and **have been diagnosed with Type 1 Diabetes for more than 6 months**.

- If you give consent for your child to take part, we will remind them that this does not mean they *have* to take part, just that if they want to take part, you have confirmed that it is OK for them to do so.

- Your child will also receive an information sheet. It will be a simple, age appropriate version of this information sheet. We would encourage you to discuss the information sheet with your child.

What does participation in this research study involve?

- If you decide to take part in this research study, a member of the research team (Dr. Caroline Rawdon or Ms. Ella Tuohy) will call you in the coming weeks to arrange a time and place that suit you and/or your child with Type 1 Diabetes to take part in the interview.

- The interviews with you and your child with Type 1 Diabetes will be carried out separately but at the same time where possible. One member of the research team will talk to you while another member of the research team will speak to your child.
- If both parents/guardians from a family wish to participate in the research study that's ok, but we would like to interview each parent/guardian separately if possible.

- Some families will be invited to complete audio-diaries following their participation in interviews (young person with Type 1 Diabetes and/or one parent). You can choose to take part in the interview only and there is no obligation to complete an audio-diary after your family's interview(s). If you or another family member chooses to complete an audio-diary, you will be asked to record daily events relating to Type 1 Diabetes management over a two-week period. We will only need one parent from each family to complete the audio-diary. Should you or your child wish to participate and complete an audio-diary, we will provide you with more information after your family's interview(s).

How long will the process take?

The interview should take no longer than 45-60 minutes for each parent/guardian to complete and may take a little less time for your child to complete (30-45 minutes) depending on how much you and/or your child wish to speak to us about your experiences.

Where will the interview take place?

Ella and Caroline can arrange to call to your home to complete the interviews with you and your family. Alternatively, if you would prefer to come to Dublin City University to complete your interviews Ella and Caroline can meet you there. If you decide to come to Dublin City University your travel expenses will be reimbursed (bus ticket/petrol, car parking fee).

What type of questions will me and my child be asked?

- You and your child will be asked questions e.g. how you/they manage their Type 1 Diabetes healthcare and how you communicate about their condition as a family. This interview will be audio-recorded, with your and your child's permission.

- Your child will be given the option of having a parent/guardian with them at the time of interview or of being interviewed alone (if you do not wish to be present during the interview please let us know in advance). This will allow your child to personally voice their views on what it is like to have Type 1 Diabetes and how they manage their healthcare and communicate about their condition.

- You will also be asked to fill out a brief demographic questionnaire about you and your child.

How will this research study be of benefit to me and my child?

While there may be no immediate benefits to you and/or your child from taking part in this research study, the research team hope that studies such as this one can be used to identify the needs of young people living with Type 1 Diabetes and their families. We hope that the findings of this study will help to inform current practices and develop new services to support young people living with Type 1 Diabetes and their families, such as an intervention or educational material to support parent-adolescent communication as adolescents take on the responsibility of managing their Type 1 Diabetes themselves. It is an opportunity for you and/or your child to share your experience with others.

Are there any risks involved in taking part in this research?

It is not expected that participation in this research will be distressing for you or your child. However, there is a chance that while you or your child talk about your experiences, you or your child may feel upset. If you or your child become upset when talking to us, we will ask you/your child if you want to stop, take a break or, for child interviews, if they would like to have a parent/guardian sit with them to make them feel more comfortable. We will let you know if your child becomes upset at any stage. After the study, if you feel it might help to talk to somebody about any of the issues that came up, we can put you in touch with appropriate services (e.g. Diabetes Ireland) who can advise you on next steps.

How will my family's privacy be protected?

- Only the research team will have access to the audio-recorded interviews and these will be treated in the strictest of confidence at all times.

- Recorded interviews will be transcribed and made anonymous (i.e. the written version of the interviews will not have your or your child's name on it, but will be numbered so that we can identify it later). All information from the study (i.e. audio recordings, consent forms and demographic questionnaires) will be destroyed after the research project is complete/results are published.

- Any personal details recorded during the interview process pertaining to you and/or your child such as demographic information or signed consent forms will be stored in a separate file to the audio-recorded interviews.

- All information will be stored in locked filing cabinets and/or on encrypted, password-protected computers in the School of Nursing and Human Sciences at Dublin City University.

- The information we collect from all of the families who take part will be used to write a report on the findings of this research study. The Health Research Board who is funding the project will receive annual reports and the findings from this research study may be published in journals whereby direct quotes from the interviews may be used and published. Data gathered from interviews and audio-diaries with young people will also be published in a PhD thesis completed by Ms. Ella Tuohy and submitted to the School of Nursing and Human Sciences at Dublin City University. However, no information that might identify you or your family will be used.

- Anything you and/or your child say to us will be kept private between the research team and your family. We will only break this privacy if there is a concern for a child's safety. In this situation, we are obliged to bring this to the attention of the relevant authorities. We will also make your child aware that if they make a disclosure during the study that suggests they are at risk of harming themselves or others, the researcher (Caroline or Ella) also has an obligation to report this to

- the relevant authorities. You and your child will be made aware of this need should the situation arise.

- Participant confidentiality will be protected to the extent permitted by laws & regulations such as those described under Data Protection (Amendment) Act 2003.

How long will data arising from this study be kept for?

Data arising from this research study (audio recordings, consent forms and demographic questionnaires) will be held at the School of Nursing and Human Sciences at Dublin City University until the results of the study are published. We anticipate that the results will be published within 5 years.

What happens if my child or I no longer wish to participate?

If you and/or your child agree to take part but later change your mind, all you have to do is let the research team know by phone call or email. You do not have to give a reason for withdrawing your participation and withdrawing from the study will in *no way* affect your child's hospital treatment, nor will it prevent you from being a part of any support groups/activities/services organised by Diabetes Ireland in the future.

What if we decide not to take part?

We understand that not all families will have the time to take part in our study, and some families may not be interested. If you choose not to take part in the study, this will in *no way* affect your child's hospital treatment, nor will it prevent you from being a part of any support groups/activities/services organised by Diabetes Ireland in the future.

Is there anything else I need to know?

If you would like to talk informally with a member of the research team and discuss any questions or queries you may have in relation to this research we would be happy to speak with you, our contact details are provided below.

Dr. Caroline Rawdon
Post-doctoral Researcher
School of Nursing and Human Sciences
Sciences
Phone: (01) 7008531
E-mail: caroline.rawdon@dcu.ie
isabella.tuohy2@mail.dcu.ie

Ms. Ella Tuohy
PhD Student
School of Nursing and Human

Phone: (01) 7006328
E-mail:

Additionally, you can contact the Principal Investigator, Dr. Veronica Lambert, at veronica.lambert@dcu.ie

Thank you for taking the time to consider participating in this research study. Please keep this information sheet for your records.

Appendix I: Informed consent/assent forms

Appendix I1: Adolescent Assent Form (11-14 years)

YOUNG PERSON ASSENT FORM
Young people and parents talking about Type 1 Diabetes

- I, ______________________________, have agreed to take part in this project to help others to find out what it is like to have Type 1 Diabetes and to talk about Type 1 Diabetes at home. ☐
- I understand that Caroline or Ella is going to talk to me about my Type 1 Diabetes and that there is no right or wrong things to say. Caroline and Ella are just interested in knowing my story. ☐
- I know this project might help other young people living with Type 1 Diabetes in the future. ☐
- I have read the Information Sheet and I understand the information provided. ☐
- I have had an opportunity to ask questions and discuss this study. ☐
- I have received satisfactory answers to all my questions. ☐
- I am aware that my interview will be audiotaped. ☐
- I understand that my participation is entirely voluntary and that there will be no repercussions if I decide not to participate. ☐
- I have been promised that anything I tell Caroline or Ella will be kept as confidential as possible but if I tell Caroline or Ella that I or another young person might be in danger they will have to tell someone about this. ☐
- I understand that the recordings of the interviews will be transferred to a computer and stored in a password protected encrypted electronic file. ☐
- I understand that all data will be stored securely and will be anonymised. ☐

- I understand that the information collected may be presented and/or published in articles and at conferences, but that no individual young person or family will be identifiable from the information. ☐
- I know that I can ask Caroline or Ella questions at any time, now or later. ☐

By signing below you are confirming that you have read and understand the above statements and that you agree to take part in this research:

Young Person Signature: ______________________________________
Date: ________________________
Researcher Signature: ______________________________________
Date: ________________________

Appendix I2: Adolescent Assent Form (15-17 years)

Young People and Parents talking about Type 1 Diabetes

Young Person (aged 15-17) – Assent Form

- I understand that Caroline or Ella is going to talk to me about my Type 1 Diabetes and that there are no right or wrong things to say. Caroline and Ella are just interested in knowing my story. ☐
- I know this project might help other young people living with Type 1 Diabetes in the future. ☐
- I have read the Information Sheet (or had it read to me). ☐
- I understand the information provided. ☐
- I have had an opportunity to ask questions and discuss this study. ☐
- I have received satisfactory answers to all my questions. ☐
- I am aware that my interview will be audiotaped. ☐
- I understand that my participation is entirely voluntary and that there will be no repercussions if I decide not to participate. ☐
- I have been promised that anything I tell Caroline or Ella will be kept as confidential as possible but if I tell Caroline or Ella that I or another young person might be in danger they will have to tell someone about this. ☐
- I understand that the recordings of the interviews will be transferred to a computer and stored in a password protected encrypted electronic file. ☐
- I understand that all data will be stored securely and will be anonymised. ☐
- I understand that the information collected may be presented and/or published in articles and at conferences, but that no individual young person or family will be identifiable from the information. ☐
- I know that I can ask Ella or Caroline questions at any time, now or later. ☐

I have read and understood the information in this form. My questions and concerns have been answered by the researchers, and I have a copy of this assent form. Therefore, I assent to take part in this research project.

Participant Signature: ____________________________________

Name in Block Capitals: ____________________________________

Witness: ____________________________________

Date: ____________

Appendix I3: Parent Consent Form

Parent/Guardian Consent Form – Semi-structured Interview

Young People and Parents Talking about Type 1 Diabetes

Parent/Guardian Informed Consent Form – Interviews

Purpose of the research study

The purpose of this research study is to find out more about how young people (11-17 years) learn to manage their Type 1 Diabetes and how young people and their parent(s)/guardian(s) communicate about Type 1 Diabetes management. This will be achieved through interviewing young people and their parent(s)/guardian(s).

Research study team

This research study is being conducted by a team, led by Dr. Caroline Rawdon (Email: caroline.rawdon@dcu.ie; Tel: 01-7008531) at the School of Nursing and Human Sciences, Dublin City University. Other members of the Dublin City University research study team include; Dr. Veronica Lambert, Prof. Pamela Gallagher and Ms. Ella Tuohy. This research study is being carried out in collaboration with Prof. Nuala Murphy (Temple Street Children's University Hospital/ Mater Misericordiae University Hospital) and Diabetes Ireland. This research study has received ethical approval from the Research Ethics Committee at Dublin City University and the appropriate local research ethics committee (i.e. Temple Street Children's University Hospital/ Mater Misericordiae University Hospital).

Involvement in the research study

By signing this consent form I understand that I am agreeing to participate in an interview with a member of the research team (Dr. Caroline Rawdon or Ms. Ella Tuohy).

I understand that, if I decide to participate in this research study, Dr. Rawdon or Ms. Tuohy will also invite my child to participate by completing a separate interview.

I am aware that the interviews will be audio-recorded (with my permission) for transcription purposes to aid recall and will last approximately 45-60 minutes in duration. Interviews with adolescents may be shorter, approximately 30-45 minutes.

I have been assured that access to audio recordings will be restricted (to the research team), storage will be secure (i.e. locked in cabinet in the lead researcher's (Dr. Rawdon) office and data will be destroyed once the research study is complete/results are published.

I am aware that in reporting the outcomes of the research study, no names will be recorded on any final reports; rather information will be generically tabulated and collectively presented.

I am aware that the results may be presented at academic conferences or submitted to peer-reviewed academic journals for publication and results will be presented in report format to the Health Research Board who fund this research and other organisations such as Diabetes Ireland.

Data gathered from interviews with young people will also be published in a PhD thesis completed by Ms. Ella Tuohy and submitted to the School of Nursing and Human Sciences at Dublin City University.

Voluntary participation
I have had time to consider whether I would like to take part in this research study. ☐

I am aware that my participation is voluntary and I can withdraw at any time without reason. ☐

I am aware that my decision to withdraw from the study will in *no way* affect my child's hospital treatment. ☐

Consent to participate
For the research study I understand that I will be asked to give my written consent at the outset of the interview. I will be asked to answer the following;

I have read the Parent/Guardian Information Sheet (or had it read to me) ☐
I understand the information provided ☐
I have had an opportunity to ask questions and discuss this study ☐
I have received satisfactory answers to all my questions ☐
I am aware that my interview will be audio-recorded ☐

Signature:
I confirm that I have read and understood the parent/guardian information sheet for the proposed research study and have received an explanation of the nature, purpose, duration of the study, what my involvement will be and any possible risks/benefits to taking part in this research study.

I have the contact details of the research team. My questions and concerns have been answered by the research team, and I have a copy of this consent form.

☐ **I consent to take part in this research study.**

☐ **I consent for my child to be invited to take part in this research study.**

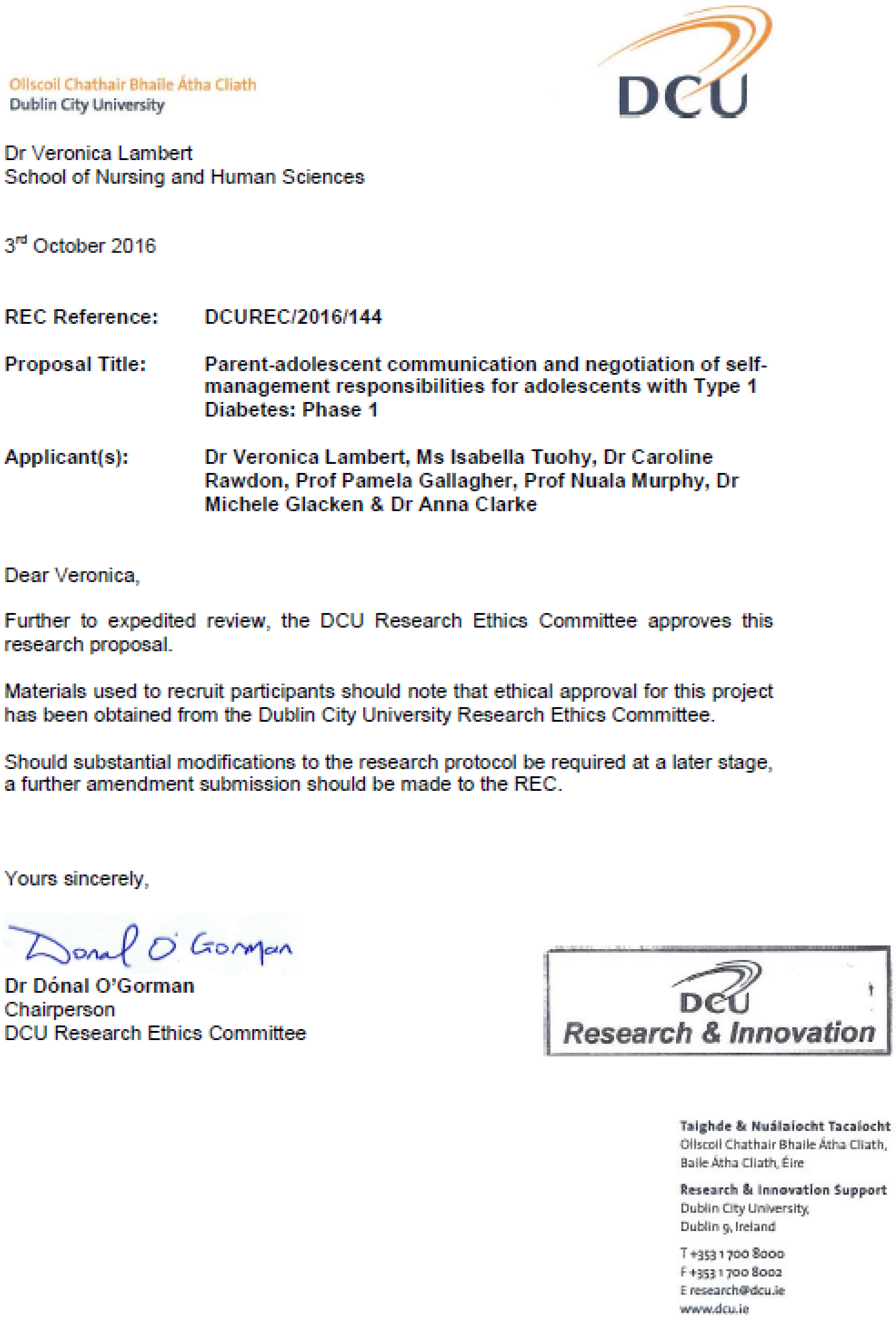
Participant's Signature: ________________________________

Name in Block Capitals: ________________________________

Witness: ________________________________
Name in Block Capitals: ________________________________

Date: __________________________

Appendix J Ethical Approval Phase One



Ollscoil Chathair Bhaile Átha Cliath
Dublin City University

DCU

Dr Veronica Lambert
School of Nursing and Human Sciences

3rd October 2016

REC Reference: **DCUREC/2016/144**

Proposal Title: **Parent-adolescent communication and negotiation of self-management responsibilities for adolescents with Type 1 Diabetes: Phase 1**

Applicant(s): **Dr Veronica Lambert, Ms Isabella Tuohy, Dr Caroline Rawdon, Prof Pamela Gallagher, Prof Nuala Murphy, Dr Michele Glacken & Dr Anna Clarke**

Dear Veronica,

Further to expedited review, the DCU Research Ethics Committee approves this research proposal.

Materials used to recruit participants should note that ethical approval for this project has been obtained from the Dublin City University Research Ethics Committee.

Should substantial modifications to the research protocol be required at a later stage, a further amendment submission should be made to the REC.

Yours sincerely,

Donal O Gorman

Dr Dónal O'Gorman
Chairperson
DCU Research Ethics Committee

DCU
Research & Innovation

Taighde & Nuálaíocht Tacaíocht
Ollscoil Chathair Bhaile Átha Cliath,
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Tel: +353 1 892 1787
Email: research@cuh.ie Web: www.cuh.ie

Dr Caroline Rawdon
Post-doctoral researcher
School of Nursing and Human Sciences
Dublin City University
Glasnevin
Dublin 9

18th July 2016

Re: 16.056. Parent-adolescent communication and negotiation of self-management responsabilitites for adolescents with Type 1 Diabetes: Phase 1

Dear Dr Rawdon,

We thank you and Dr Lambert for attending the Ethics Research Committee meeting held on Tuesday 12th July 2016 and for providing further clarification on the concerns raised.

The Committee recognizes the excellent quality of your piece of research. No concerns were raised and the Committee is happy to grant approval for your project.

We wish you every success with your research. The Research Office would like to receive a report on completion.

Yours sincerely,

Michael Riordan
checked and signed electronically

Dr Michael Riordan
Medical Secretary Ethics Research Committee
MCRN: 281464

c.c. Department of Research

Mater Misericordiae
University Hospital
Sisters of Mercy
Eccles Street, Dublin 7, Ireland

Ospidéal Ollscoile
Mater Misericordiae
Siúracha na Trócaire
Sráid Ecles, Baile Átha Cliath 7, Éire

Tel: +353 1 8032000 Fax: +353 1 8032404 Email: mmh@mater.ie Web: www.mater.ie

Not for prescription purposes
Professor Nuala Murphy
Consultant Paediatric Endocrinology
Diabetes/Endocrinology Department
Mater Misericordiae University Hospital
Eccles Street
Dublin 7

30th January 2017 Our Ref: 1/378/1850

RE: **Parent-adolescent communication and negotiation of self-management responsibilities for adolescents with Type 1 Diabetes: Phase 1**
Research Proposal
Recruitment Poster for Observational Fieldwork, Version 1 July 2016
Parent/Guardian Information Sheet - Observational Fieldwork, Version 2 November 2016 (Appendix 7)
Parent/Guardian Consent Form - Observational Fieldwork, Version 2 November 2016 (Appendix 8)
Parent/Guardian Information Sheet – Semi-structured Interviews and Audio-diaries, Version 2 November 2016 (Appendix 16)
Parent/Guardian Informed Consent Form – Semi-structured Interview, Version 2 November 2016 (Appendix 20)
Parent/Guardian Information Sheet on Use and Safe Storage of Audio-diary, Version 2 November 2016 (Appendix 23)
Parent/Guardian Informed Consent Form - Audio-diary, Version 2 November 2016 (Appendix 25)
Healthcare Professional Information Sheet - Observational Fieldwork, Version 2 November 2016 (Appendix 13)
Healthcare Professional Consent Form - Observational Fieldwork, Version 2 November 2016 (Appendix 14)
Adolescent 16 – 17 years Information Sheet - Observational Fieldwork, Version 2 November 2016 (Appendix 11)
Adolescent 16 – 17 years Assent Form - Observational Fieldwork, Version 2 November 2016 (Appendix 12)
Adolescent 16 – 17 years Information Sheet - Semi-structured Interview and Audio-diary, Version 2 November 2016 (Appendix 18)
Adolescent 16 – 17 years Information Sheet on Use and Safe Storage of Audio-diary, Version 2 November 2016 (Appendix 24)
Adolescent 16 – 17 years Assent Form - Semi-structured Interview, Version 2 November 2016 (Appendix 22)
Adolescent 16 – 17 years Assent Form - Audio-diary, Version 2 November 2016 (Appendix 26)

Dear Prof Murphy

I acknowledge receipt of your correspondence dated 16th November 2015 enclosing a completed Application for Supernumerary Appointment form and correspondence dated 19 January 2017 in respect of Ms Caroline Rawdon's involvement, revised documents and addressing points of clarification for the above research study to be carried out at the Mater Misericordiae University Hospital (MMUH) as requested by the Mater Misericordiae University Hospital and Mater Private Hospital Institutional Review Board (IRB).

These correspondences have been noted and the revised documents have been approved. Approval to proceed with this research study at the MMUH is granted; this approval is valid until 26th October 2018.

It is your responsibility to adhere to the approved study protocol and ensure that all researchers involved with the research only use the approved documents without deviation (unless they have been approved by the

IRB), to submit annual reports setting out the progress of the research (giving details of the number of participants who have been recruited, the number who have completed the study and details of any adverse events etc.) and to notify the IRB when the research is concluded.

The Mater Misericordiae University Hospital and Mater Private Hospital IRB would like to remind all investigators involved in research of their legal obligations under the law on Data Protection.

Yours sincerely

Prof Malcolm Kell
Chairman
Institutional Review Board

c.c. Dr Veronica Lambert, Senior Lecturer in Children's Nursing and Deputy Head, DCU
Ms Caroline Rawdon, Postdoctoral Researcher, School of Nursing and Human Sciences, DCU

Appendix K: Adolescent Demographic Questionnaire (Phase One)

Demographic Information – Adolescent Questionnaire

Name: ____

Please tick or fill in your responses to each question below

Which gender do you identify as?

____

Were you born in Ireland?

○ Yes

○ No

If no, please specify where you were born

____

In terms of your ethnic or cultural background, are you:

White ○ Black ○ Asian ○ Irish Traveller ○

Other ○ If other, please specify ________________________________

Date of Birth (dd/mm/yy): ______________ **Age:** _________

What school are you in?

Primary School ○ Secondary School ○

What school year are you in?

○ 4th Class (Primary School)
○ 5th Class (Primary School)
○ 6th Class (Primary School)
○ 1st Year (Secondary School)
○ 2nd Year (Secondary School)
○ 3rd Year (Secondary School)
○ 4th Year (Secondary School)
○ 5th Year (Secondary School)
○ 6th Year (Secondary School)

If you are in 5th Year in secondary school did you do Transition Year?

○ Yes
○ No

What age were you when you were diagnosed with Type 1 Diabetes?

____

Do you have any other diagnosed medical conditions?

____

How do you monitor your blood glucose?

Continuous Glucose Monitoring Device ○ Finger Prick Test ○ Other Method ○

If other method, please specify: ___________________________________

How do you administer your insulin?

Insulin Pen ○ Insulin Pump ○ Syringe ○ Other Method ○

If other method, please specify: ________________________________

What was your last HbA1c result?

____

Thank you very much for taking the time to fill out this questionnaire

Appendix L: Qualitative Semi-structured Interview Topic Guide for Adolescents

1) **Can you tell me about your experience of being diagnosed with diabetes?**

   Additional Prompts:

   a. *When, where and how were you diagnosed?*
   b. *How did you feel about it then?*
   c. *Who supported you? (parents, other family members, peers/friends, clinicians, health services, other)*
   d. *Did you find information about diabetes easy to obtain?*
   e. *Are there any particular people/things that helped you to learn about diabetes?*
   f. *How do you feel about having diabetes now?*

2) **Can you tell me about what it is like for you to live with diabetes every day?**

   Additional Prompts:

   a. *Diet/food management*
   b. *Metabolic control:*
      Blood glucose monitoring (frequency, who, when, where, how, feelings)
      Insulin regime/administration (frequency, who, when, where, how, feelings)
   c. *Exercise*
   d. *Going to school*
   e. *Meeting friends and participating in activities/events*
   f. *Attending hospital/clinic appointments*
   g. *Has your role in managing your diabetes changed over time? (when, how, what happened)*

3) **Can you tell me about your role in managing your diabetes?**

   Additional Prompts:

   a. *What do you do on your own?*
   b. *What parts of your diabetes care do you see as your responsibility?*
   c. *How do you feel about managing your own diabetes care?*

4) **Can you tell me about your parents' role in helping you to manage your diabetes?**

   Additional Prompts:

   a. *Who is more involved in your care (you or one/both of your parents), and in what ways?*
   b. *What do your parents do to help you manage your diabetes?*
   c. *How much/often do your parents help you with your diabetes care?*
   d. *How do you feel about your parents helping you to manage your diabetes?*
   e. *When it comes to managing your diabetes, what do feel you need your parents to help you with?*

f. *Has how your parents help you to manage your diabetes changed since you were first diagnosed? (when, how, what happened)*
g. *When did your parents start to give you more responsibility for managing your diabetes?*
h. *How did you know that you were ready to look after your diabetes care/this part of your diabetes care yourself?*

5) **Can you tell me about what it is like for you to talk to your parents about your diabetes care and management?**

Additional Prompts:
a. *Why, how, when do you talk to them about your diabetes?*
b. *Do you find it difficult/easy to talk to your parents about managing your diabetes?*
c. *Can you tell me about a time when you found it difficult to talk to your parents about your diabetes care?*
d. *Can you tell me about a time when you found it easy to talk to your parents about your diabetes care?*
e. *What do you find difficult/easy to talk about?*
f. *What things stop you from talking to your parents about you diabetes?*
g. *What things help you to talk to your parents about your diabetes?*
h. *Has this changed as you have gotten older?*

6) **What kinds of things affect how you manage your diabetes?**

Additional Prompts:
a. *Facilitating – What helps you to manage your diabetes?*
b. *Hindering – What makes it difficult for you to manage your diabetes?*
c. *What helps/hinders the sharing of responsibility for your diabetes care between you and your parents?*

7) **What is it like for you as a young person with diabetes?**

Additional Prompts:
a. *How does sharing the responsibility for your diabetes care with your parents have an impact on your health and wellbeing?*
b. *How does your parents' involvement in your diabetes care affect you and your activities/what you can/cannot do?*
c. *How does living with diabetes impact on your life at home with your family, i.e. daily life and activities?*

Appendix M: Interview Participant Characteristics

Participant number	Gender	Age (years)	Class in school	Age at diagnosis (years)	Last HbA1c (%)	Insulin administration	Blood glucose monitoring (BGM)	Family history of T1D
1	Female	13	2nd Year	3	9.10	MDI	Finger Prick Test	No
2	Female	13	2nd Year	9	10	Insulin Pump	Finger Prick Test	Yes
3	Male	14	2nd Year	11	7.10	MDI	Finger Prick Test	No
4	Female	11	5th Class	5	7.80	Insulin Pump	Finger Prick Test	Yes
5	Male	11	6th Class	9	8.50	Insulin Pump	FreeStyle Libre (Semi-continuous BGM)	No
6	Male	15	3rd Year	11	9.80	MDI	Finger Prick Test	Yes
7	Male	12	6th Class	4	7.30	Insulin Pump	Finger Prick Test	Yes
8	Male	12	6th Class	5	7.20	Insulin Pump	Finger Prick Test	Yes

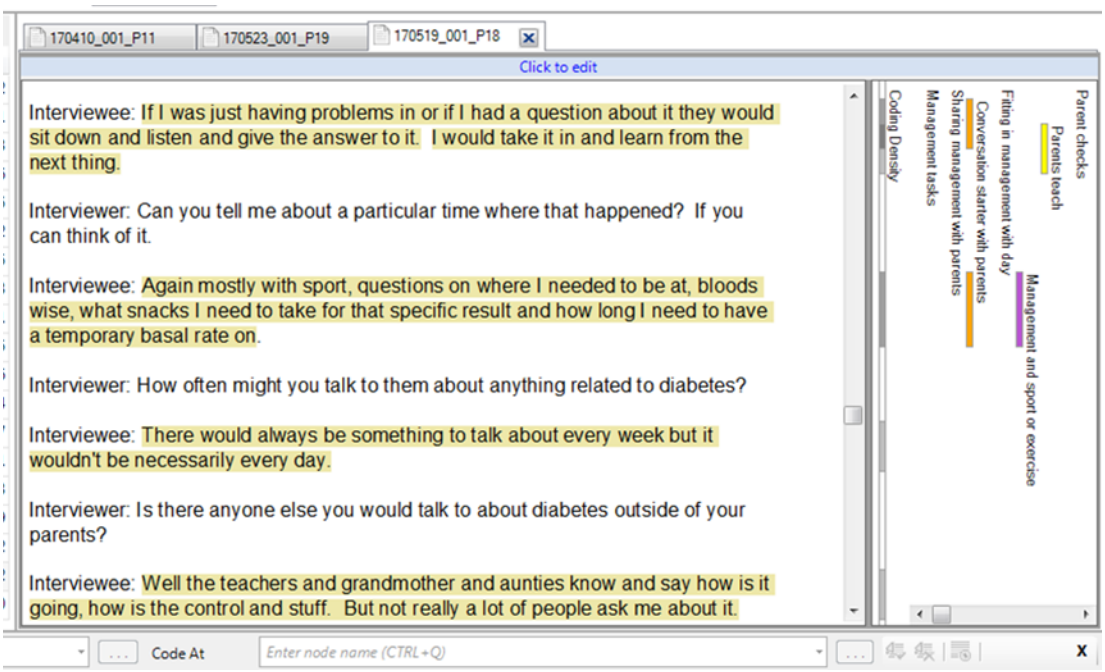
Participant number	Gender	Age (years)	Class in school	Age at diagnosis (years)	Last HbA1c (%)	Insulin administration	Blood glucose monitoring (BGM)	Family history of T1D
9	Male	13	1st Year	2	7.10	Insulin Pump	Continuous Glucose Monitoring Device	No
10	Male	14	1st Year	6	8.50	Insulin Pump	Continuous Glucose Monitoring Device	No
11	Male	16	4th Year	15	8.50	MDI	Finger Prick Test	No
12	Female	13	1st Year	12	Not known	MDI	Finger Prick Test	Yes
13	Female	12	1st Year	8	7.80	Insulin Pump	FreeStyle Libre (Semi-continuous BGM)	No
14	Male	11	5th Class	3	8.20	Insulin Pump	Finger Prick Test	No
15	Female	15	3rd Year	11	7.60	MDI	Finger Prick Test	No

Participant number	Gender	Age (years)	Class in school	Age at diagnosis (years)	Last HbA1c (%)	Insulin administration	Blood glucose monitoring (BGM)	Family history of T1D
16	Female	14	2nd Year	5	7.20	Insulin Pump	Continuous Glucose Monitoring Device	No
17	Female	15	3rd Year	10	9.20	MDI	Finger Prick Test	Yes
18	Male	15	3rd Year	7	6.80	Insulin Pump	Finger Prick Test	No
19	Female	15	3rd Year	8	6.80	Insulin Pump	FreeStyle Libre (Semi-continuous BGM)	Yes
20	Female	16	5th Year	5	8.00	Insulin Pump	FreeStyle Libre (Semi-continuous BGM)	No
21	Male	17	5th Year	14	7.20	MDI	Finger Prick Test	Yes
22	Male	16	4th Year	8	8.00	Insulin Pump	Finger Prick Test	No
23	Female	14	3rd Year	6	8.10	Insulin Pump	Finger Prick Test	Yes

M3

Participant number	Gender	Age (years)	Class in school	Age at diagnosis (years)	Last HbA1c (%)	Insulin administration	Blood glucose monitoring (BGM)	Family history of T1D
24	Female	15	4th Year	11	7.90	Insulin Pump	Finger Prick Test	No
25	Female	17	5th Year	13	7.20	MDI	Finger Prick Test	Yes
26	Female	15	3rd Year	12	6.50	Insulin Pump	FreeStyle Libre (Semi-continuous BGM)	No
27	Male	14	2nd Year	2	7.80	Insulin Pump	FreeStyle Libre (Semi-continuous BGM)	No
28	Male	16	4th Year	9	7.30	Insulin Pump	Finger Prick Test	No

Appendix N: Example coded extract from NVivo (Interviews)



Interviewee: If I was just having problems in or if I had a question about it they would sit down and listen and give the answer to it. I would take it in and learn from the next thing.

Interviewer: Can you tell me about a particular time where that happened? If you can think of it.

Interviewee: Again mostly with sport, questions on where I needed to be at, bloods wise, what snacks I need to take for that specific result and how long I need to have a temporary basal rate on.

Interviewer: How often might you talk to them about anything related to diabetes?

Interviewee: There would always be something to talk about every week but it wouldn't be necessarily every day.

Interviewer: Is there anyone else you would talk to about diabetes outside of your parents?

Interviewee: Well the teachers and grandmother and aunties know and say how is it going, how is the control and stuff. But not really a lot of people ask me about it.

Appendix O: Ethical Approval Phase Two

Ollscoil Chathair Bhaile Átha Cliath
Dublin City University

DCU

Dr Veronica Lambert

School of Nursing and Human Sciences

6 February 2018

REC Reference: **DCUREC/2018/012**

Proposal Title: **Parent-adolescent communication and negotiation of selfmanagement responsibilities for adolescents with type 1 diabetes: Phase 2**

Applicant(s): **Dr Veronica Lambert**

Dear Veronica,

Further to expedited review, the DCU Research Ethics Committee approves this research proposal.

Materials used to recruit participants should note that ethical approval for this project has been obtained from the Dublin City University Research Ethics Committee.

Should substantial modifications to the research protocol be required at a later stage, a further amendment submission should be made to the REC.

Yours sincerely,

Donal O Gorman

Dr Dónal O'Gorman
Chairperson
DCU Research Ethics Committee

DCU
Research & Innovation

Taighde & Nuálaíocht Tacaíocht
Ollscoil Chathair Bhaile Átha Cliath,
Baile Átha Cliath, Éire

Research & Innovation Support
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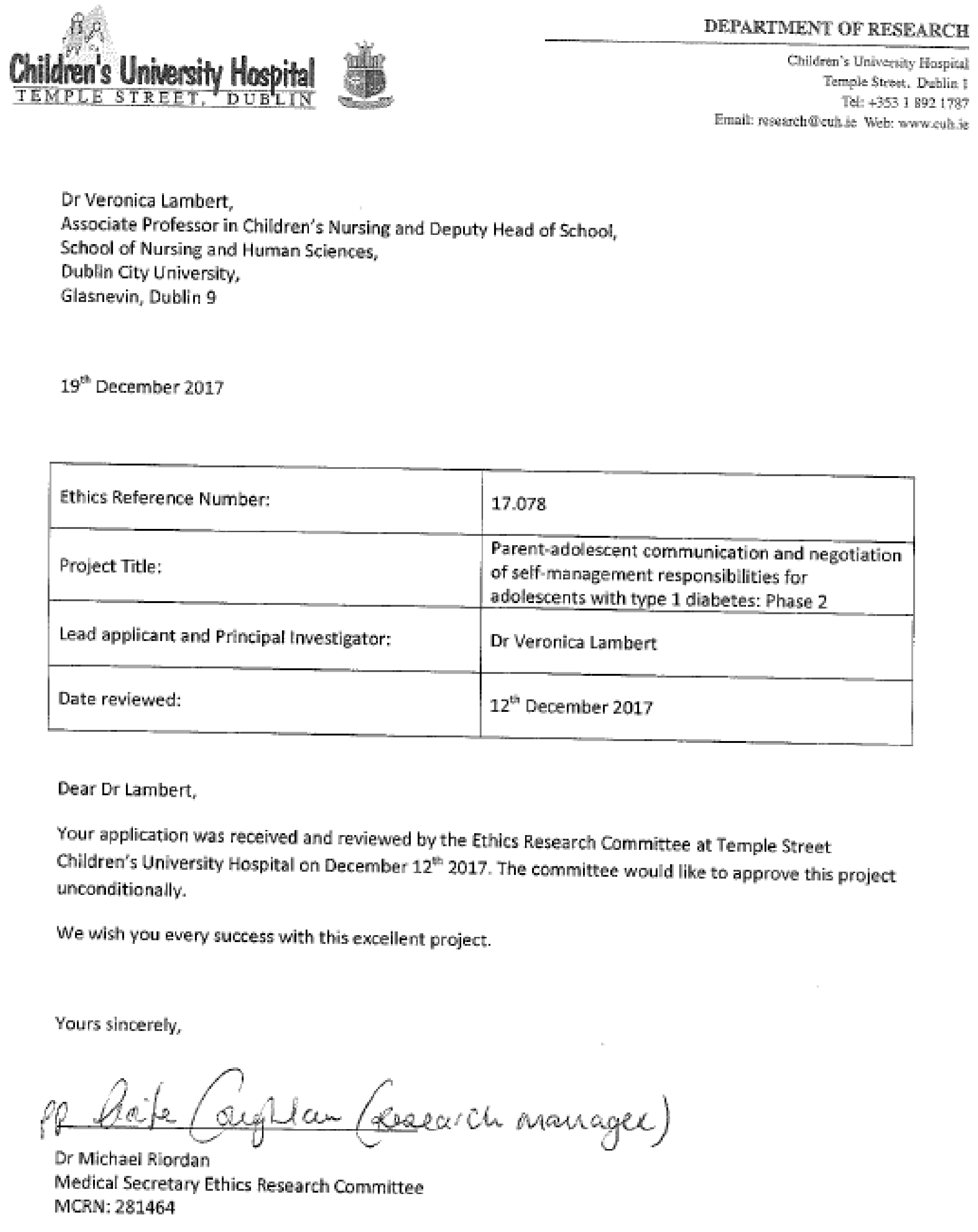


Children's University Hospital
TEMPLE STREET, DUBLIN

DEPARTMENT OF RESEARCH
Children's University Hospital
Temple Street, Dublin 1
Tel: +353 1 892 1787
Email: research@cuh.ie Web: www.cuh.ie

Dr Veronica Lambert,
Associate Professor in Children's Nursing and Deputy Head of School,
School of Nursing and Human Sciences,
Dublin City University,
Glasnevin, Dublin 9

19th December 2017

Ethics Reference Number:	17.078
Project Title:	Parent-adolescent communication and negotiation of self-management responsibilities for adolescents with type 1 diabetes: Phase 2
Lead applicant and Principal Investigator:	Dr Veronica Lambert
Date reviewed:	12th December 2017

Dear Dr Lambert,

Your application was received and reviewed by the Ethics Research Committee at Temple Street Children's University Hospital on December 12th 2017. The committee would like to approve this project unconditionally.

We wish you every success with this excellent project.

Yours sincerely,

pp Aoife Coughlan (Research manager)

Dr Michael Riordan
Medical Secretary Ethics Research Committee
MCRN: 281464

Appendix P: Letter of Invitation to Participate from TSCUH Consultant

Temple Street
CHILDREN'S UNIVERSITY HOSPITAL

Dear Parent/Guardian,

I am writing to tell you about a research study we are undertaking and to invite you and/or your child to take part. The study is looking at how adolescents learn to manage their type 1 diabetes and how parents and adolescents talk about the responsibilities involved in type 1 diabetes management. The study is being carried out by Temple Street Children's University Hospital together with researchers at the School of Nursing and Human Sciences at Dublin City University.

It is up to you to decide to take part or not in this study and you are under no obligation. Please read the enclosed parent/guardian information sheet carefully before you make the decision. You must be a parent of a child 11-17 years old diagnosed with type 1 diabetes for 6 months or longer. If you decide to take part it will involve filling in the enclosed parent questionnaire. You will not be identified by name in any way on the questionnaire. Return your completed parent questionnaire to the researchers in the stamped addressed envelope provided.

I am also inviting your child to take part, and have enclosed an adolescent information sheet for them to read carefully before making a decision to take part. They can take part if they are 11-17 years old and have a diagnosis of type 1 diabetes for 6 months or longer. If your child decides to take part it will involve them filling in the enclosed adolescent questionnaire. Your child can return their completed questionnaire to the researchers in the second stamped addressed envelope provided.

If you have any questions about the study or if you would like more information please do not hesitate to contact the researchers at Dublin City University at 01-7008531/ caroline.rawdon@dcu.ie or 01-7006328/isabella.tuohy2@mail.dcu.ie

You can also contact the researchers if you wish to request additional copies of the parent or adolescent questionnaires, i.e. if both parents wish to take part or if you have more than one child with type 1 diabetes aged 11 to 17 years and they also would like to take part.

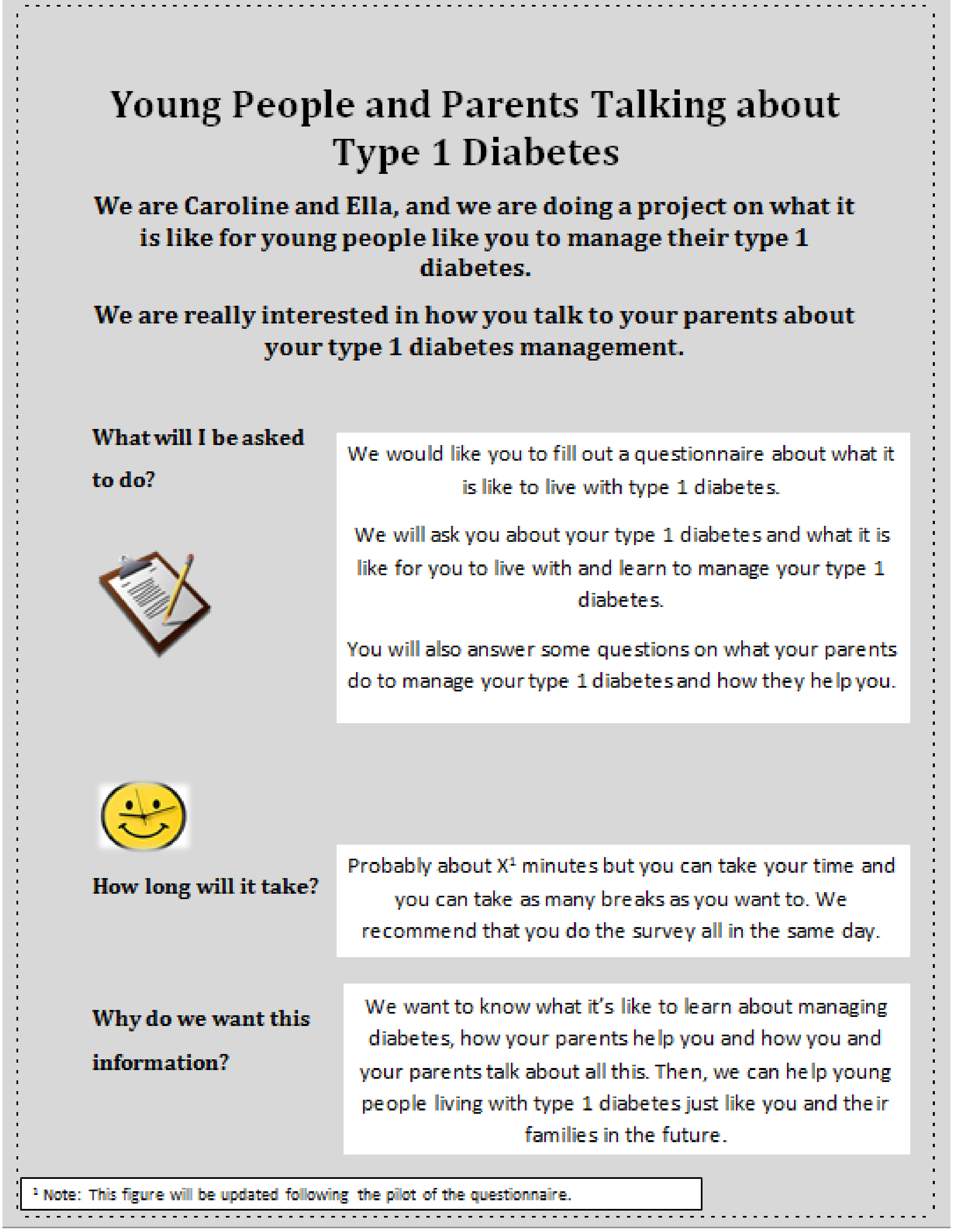
I would like to thank you for taking the time to consider taking part in this research study. It is hoped that the findings of this research study will be used to inform future health service delivery for families living with type 1 diabetes.

Yours sincerely,

____

Prof. Nuala Murphy, MD FRCPI DCH
Consultant Paediatric Endocrinologist

Appendix Q: Participant Information Sheets (Phase Two)
Appendix Q1: Adolescent Information Sheets



Young People and Parents Talking about Type 1 Diabetes

We are Caroline and Ella, and we are doing a project on what it is like for young people like you to manage their type 1 diabetes.

We are really interested in how you talk to your parents about your type 1 diabetes management.

What will I be asked to do?	We would like you to fill out a questionnaire about what it is like to live with type 1 diabetes. We will ask you about your type 1 diabetes and what it is like for you to live with and learn to manage your type 1 diabetes. You will also answer some questions on what your parents do to manage your type 1 diabetes and how they help you.
How long will it take?	Probably about X[1] minutes but you can take your time and you can take as many breaks as you want to. We recommend that you do the survey all in the same day.
Why do we want this information?	We want to know what it's like to learn about managing diabetes, how your parents help you and how you and your parents talk about all this. Then, we can help young people living with type 1 diabetes just like you and their families in the future.

[1] Note: This figure will be updated following the pilot of the questionnaire.

What will happen to my answers? 🔒🔒🔒🔒🔒	You will not be writing your name anywhere on the questionnaire so no one will know what you have answered. Your answers will be kept locked up safely so that no one else can see them. We will be writing a project about what you tell us but we will not mention your name in the project. There are no right or wrong answers; we are just really interested about what it is like to have type 1 diabetes.
Can one of my parents stay with me while I fill in my answers?	Yes, of course, but if you want to you can also fill in your answers by yourself.
What should I do if I do not want to take part?	That is fine. We will respect your wishes. We won't mind at all.

If you have any questions you want to ask us before you fill in your answers, you can ask your parents if it would be ok for you to contact us. We would be very happy to answer any questions you have.

Our contact details are:

Ella , phone: (01) 7006328, e-mail: isabella.tuohy2@mail.dcu.ie

or

Caroline, phone: (01) 7008531, e-mail: caroline.rawdon@dcu.ie

Funded by:

Appendix Q2: Parent Information Sheet (Survey)

Young People and Parents Talking about Type 1 Diabetes

Parent/Guardian Information Sheet – Survey

What is this research about?

We are doing this research to find out more about you and your child's experiences of living with type 1 diabetes. We are interested in how adolescents (aged 11-17 years) learn to manage their type 1 diabetes and how parents and adolescents talk about and negotiate responsibilities for type 1 diabetes management.

Who is conducting this research?

Led by Dr. Veronica Lambert, this research is being carried out by a team of researchers from the School of Nursing and Human Sciences at Dublin City University (DCU) in collaboration with Prof. Nuala Murphy and her team at Temple Street Children's University Hospital (TSCUH) and Diabetes Ireland. Two researchers at DCU are working on this research project. Caroline Rawdon is a post-doctoral researcher and Ella Tuohy is a PhD student. This research project is funded by the Health Research Board.

If I give consent to take part what will my child and I be asked to do?

- The team of researchers has created two questionnaires, one for adolescents (11-17 years) living with type 1 diabetes and one for their parents to complete. We would like you to complete the parent questionnaire, either online or in paper form, about being the parent or guardian of an adolescent living with type 1 diabetes.
- You will also have received an information sheet for your child and an adolescent questionnaire for your child to complete about their type 1 diabetes. The adolescent information sheet will contain all of the information your child needs to complete their questionnaire. We would encourage you to discuss the information sheet with your child.
- If you complete the parent questionnaire in hard copy form, we would ask you to kindly return the questionnaire using the enclosed stamped addressed envelope. We have provided two envelopes so that your child can return their questionnaire separately.

How long will the process take?

The questionnaire should take no longer than X[1] minutes to complete.

What if my child and I decide not to take part?

We understand that not all families will have the time to take part in our research, and some families may not be interested. If you choose not to take part in the survey, this will in *no way* affect your child's treatment in TSCUH, nor will it prevent you from being a part of any support groups/ activities organised by Diabetes Ireland in the future.

What will be done with the information collected from my child and I?

---

[1] This figure will be updated following the pilot of the questionnaire.

All the information you and your child provides will be anonymous (i.e. no one will be able to tell what you specifically answered).

- As we will not be able to identify your data, once you have submitted the questionnaires (by post *or* online) you will not be able to withdraw from the research as we will not be able to identify which questionnaire is yours.
- Only the research team and possibly the examiners of the PhD thesis will have access to the anonymised data and these will be treated in the strictest of confidence at all times.
- All information will be stored in locked filing cabinets and/or on password-protected computers in DCU.
- The information we collect from all the completed questionnaires will be used to write a report on the findings The Health Research Board who are funding this project will receive annual reports and the findings from this research may be published in journals.
- Data gathered from the survey with adolescents will also be published in a PhD thesis completed by Ms. Ella Tuohy and submitted to the School of Nursing and Human Sciences at DCU.

How will this study be of benefit to me and my child?

While there may be no immediate benefits to you and your child from taking part in the study, the researchers hope that the findings of this study will help to inform current practices and develop new services to support adolescents living with type 1 diabetes and their parents, such as an intervention or educational material to support parent-adolescent communication as adolescents take on the responsibility of managing their type 1 diabetes themselves.

Are there any risks or downsides to taking part?

There should be no risks involved in taking part, however if you feel it might help to talk to somebody about any of the issues that came up, we can put you in touch with someone (e.g. your Diabetes Ireland representative) who can advise you on next steps. We have included an additional sheet in your survey pack with the contact details of some useful services should you need additional support.

Is there anything else I need to know?

If you would like to talk informally with a member of the research team and discuss any questions or queries you may have in relation to this research we would be happy to speak with you, our contact details are provided below.

Dr. Caroline Rawdon
Post-doctoral Researcher
School of Nursing and Human Sciences
Phone: (01) 7008531
E-mail: caroline.rawdon@dcu.ie

Ms. Ella Tuohy
PhD Student
School of Nursing and Human Sciences
Phone: (01) 7006328
E-mail: isabella.tuohy2@mail.dcu.ie

Additionally, you can contact the Principal Investigator, Dr. Veronica Lambert, at veronica.lambert@dcu.ie

If participants have concerns about this study and wish to contact an independent person,
please contact: The Secretary, Dublin City University Research Ethics Committee, c/o Research and Innovation Support, Dublin City University, Dublin 9. Tel 01-7008000, e-mail **rec@dcu.ie**

Thank you for taking an interest in this research and completing this questionnaire!

Funded by: Health Research Board

Appendix R: Recruitment Poster (Phase Two)

Invitation to Participate in a Research Study

We are interested in finding out about how young people with type 1 diabetes and their parents experience living with and taking care of diabetes.

Who can get involved?

Young people (11 and 17 years) who have been diagnosed with type 1 diabetes for more than 6 months ***and their parent(s)***.

What does participating in this study involve?

We would like you to complete a survey. You can complete the survey questionnaire online by visiting the following website [insert website details] or we can send you a survey pack in the post.

We hope that the information gathered will be used to develop supports for young people living with type 1 diabetes and their families.

This study is funded by the Health Research Board

If you would like to find out more about this research study or request a survey pack please contact us:

Caroline Rawdon: 01-7008531/caroline.rawdon@dcu.ie

Ella Tuohy: 01-7006328/isabella.tuohy2@mail.dcu.ie

Appendix S: Recruitment Flyer (Phase Two)

Have you heard about our research study?

Young People and Parents Talking about Type 1 Diabetes

DCU

Temple Street
CHILDREN'S UNIVERSITY HOSPITAL

Diabetes Ireland

We are interested in finding out about how young people with type 1 diabetes and their parents experience living with and taking care of diabetes.

We are inviting all patients aged 11 to 17 years living with type 1 diabetes for more than 6 months and their parents to take part in this research study. We will be sending survey packs in the post. The survey questionnaire can also be completed online at [insert website details].

You can contact Caroline or Ella to find out more about this research or to request a survey pack:

Caroline Rawdon: 01-7008531/caroline.rawdon@dcu.ie
Ella Tuohy: 01-7006328/isabella.tuohy2@mail.dcu.ie

HRB Health Research Board

Appendix T: Adolescent Survey

Young People and Parents Talking about Type 1 Diabetes

Adolescent Questionnaire

If you have a brother or sister who is also diagnosed with type 1 diabetes they can take part too but we would like each family member to complete their own questionnaire. If you need more paper copies of the questionnaire you can contact Caroline 01 7008531/caroline.rawdon@dcu.ie or Ella 01 7006328/isabella.tuohy2@mail.dcu.ie and they will send them to you by post.

If you prefer, you can fill in the questionnaire online at [insert website details]

Remember: To take part in this research you must be aged 11-17 years old and diagnosed with type 1 diabetes for six months or longer.

Once you have completed the questionnaire you can return it to the research team in the stamped addressed envelope we have included in your survey pack.

IF YOU WANT TO TAKE PART IN THIS RESEARCH PLEASE FILL IN THE ANSWERS BELOW, OTHERWISE THANK YOU FOR YOUR TIME.

Please tick yes/no;

• I am 11–17 years old and have been living with type 1 diabetes for 6 months or longer	☐ Yes ☐ No
• I have read the information sheet about the project	☐ Yes ☐ No
• I agree to take part in the project	☐ Yes ☐ No
• I am aware that I do not have to take part	☐ Yes ☐ No
• I am aware that I can stop taking part as long as I stop before sending back the questionnaire	☐ Yes ☐ No
• I am aware that the researchers may talk about the findings of the project or write about them, but nobody will know what I have answered	☐ Yes ☐ No

By answering these questions and sending back the questionnaire, you are giving your permission to take part in our project.

In order to help us to link your and your parent's answers (if they are taking part), please list the following letters/numbers:

____ ____	____ ____	____ ____
Please enter the first two letters of your first name here	*Please enter your age here*	*Please enter the last two letters of your last name here*

For example, if your name was Susan Smith and you were 13 years old, you would enter:

__S__ __U__	__1__ __3__	__T__ __H__

Section A

In this section, we would like to ask you a few questions about your life.

Please tick ☑ or fill in your responses to each question below. Please answer all of the questions in Section A.

1. Which gender do you identify as?

○ Male
○ Female
○ Other

2. What age are you (in years)? _________

3. Were you born in Ireland?

○ Yes
○ No

If no, please tell us the country you were born in

____

4. What county in Ireland do you live in?

____

5. In terms of your ethnic or cultural background, are you?

○ White Irish
○ Irish Traveller
○ Any Other White Background
○ Black Irish or Black African
○ Any Other Black Background
○ Chinese
○ Any Other Asian Background
○ Other

If other, please specify

____

6. What school are you in?

○ Primary School
○ Secondary School

7. What school year are you in?

○ 3rd Class (Primary School)
○ 4th Class (Primary School)
○ 5th Class (Primary School)
○ 6th Class (Primary School)
○ 1st Year (Secondary School)
○ 2nd Year (Secondary School)
○ 3rd Year (Secondary School)
○ 4th Year (Secondary School)
○ 5th Year (Secondary School)
○ 6th Year (Secondary School)
○ 1st Year (3rd Level Education)
○ I do not attend school

If you are in 5th or 6th Year in secondary school did you do Transition Year?

○ Yes
○ No

8. What age were you when you were diagnosed with type 1 diabetes?

____

9. Have you been diagnosed with Coeliac Disease?

○ Yes
○ No
○ I don't know

10. Have you been diagnosed with Under-active Thyroid (Hypothyroidism)?

○ Yes
○ No
○ I don't know

11. Have you been diagnosed with Over-active Thyroid (Hyperthyroidism)?

○ Yes
○ No
○ I don't know

12. Do you have any other diagnosed medical conditions?

○ Yes
○ No

If yes, please tell us about these additional medical conditions

____

13. Do you take any other medication (other than insulin)?

○ Yes

○ No

If yes, please tell us about the other medications you take

____

14. Do you have a parent who has type 1 diabetes?

○ Yes

○ No

○ I don’t know

15. Do you have a brother or sister who has type 1 diabetes?

○ Yes

○ No

○ I don’t know

16. Who lives at home with you (tick all of the people that live with you)?

Mother	○	
Father	○	
Step-mother	○	
Step-father	○	
Sister(s)	○	How many sisters? __________________________
Brother(s)	○	How many brothers? _______________________
Other	○	**If other, please specify** _______________________

17. How do you monitor your blood glucose (please tick one answer only)?

○ Finger Prick Test Only

○ Flash Glucose Monitoring System (i.e. Freestyle Libre) and Finger Prick Test

○ Continuous Glucose Monitoring Device and Finger Prick Test

○ Other Method

If other method, please specify ________________________________

18. How do you administer your insulin (please tick one answer only)?

○ Multiple Daily Injections (Insulin Pen or Syringe)

○ Insulin Pump

○ Other Method

If other method, please specify _____________________________

19. What was your last HbA1c result?
Remember: Your doctor will usually tell you what your HbA1c is at your outpatient clinic appointment. Your doctor or nurse will do a finger prick test to find out your HbA1c. It is usually a percentage and tells you what your blood glucose control has been like in the 3 to 4 months between appointments.

○ Less than 6.5% (Less than 48 mmol/mol)

○ 6.6 – 7.0% (49 – 53 mmol/mol)

○ 7.1 – 7.5% (54 – 58 mmol/mol)

○ 7.6 – 8.0% (60 – 64 mmol/mol)

○ 8.1 – 8.5% (65 – 69 mmol/mol)

○ 8.6 – 9.0% (70 – 75 mmol/mol)

○ 9.1 – 9.5% (76 – 80 mmol/mol)

○ More than 9.5% (More than 80 mmol/mol)

○ I don’t know

20. Which hospital do you attend?

- ○ Temple Street Children's University Hospital
- ○ Another Children's Hospital in Dublin

  (i.e. Our Lady's Children's Hospital,

  Crumlin or The National Children's Hospital, Tallaght)
- ○ An Adolescent/Adult Clinic in a Dublin Hospital
- ○ Another Hospital outside of Dublin

End of Section A

Section B

In this section, we would like to ask you some questions about what young people (adolescents) and their parents do to take care of type 1 diabetes.

Section B, Part 1:

The statements below describe different things adolescents may do in taking care of their type 1 diabetes. Tick the box ☑ that indicates how frequently you do each thing.

Statements	**Never**	**Sometimes**	**Most of the time**	**Always**
1. I consult my parents when I'm not sure what to do to manage my diabetes.				
2. I adjust my insulin dose by myself.				
3. I handle my high blood sugars myself.				
4. My parents talk to me about what to eat or not to eat.				
5. My parents help me decide my insulin dose.				
6. My parents count carbohydrates with me.				
7. I ask my parents what to do when my blood sugar is out of range.				
8. My parents and I look together at the record of my blood sugar readings to make adjustments.				

Statements	**Never**	**Sometimes**	**Most of the time**	**Always**
9. My parents check to see if I’ve taken my insulin.				
10. My parents check my meter to see if I’ve tested my blood sugar.				
11. I ask my parents how many carbohydrates are in some foods.				
12. My parents tell me how much insulin to take.				
13. I tell my parents when my blood sugar is out of range.				
14. I follow my meal plan or count carbohydrates.				
15. I check my blood sugar before eating.				
16. I eat without first checking my blood sugar.				
17. If my blood sugar is high, I check it again in 1 to 2 hours.				
18. I carry glucose tabs (sweets) or some quick-acting sugars.				
19. I test for ketones if my blood sugar is high.				

Statements	**Never**	**Sometimes**	**Most of the time**	**Always**
20. If my blood sugar is too low, I treat and then check later if I still feel low.				
21. I need to be reminded to take my insulin.				
22. I skip insulin injections or boluses.				
23. My parents and I argue about when I should test my blood sugar.				
24. I carry something with me that says I have diabetes.				
25. I go out without my diabetes supplies.				
26. I don’t like it when someone reminds me to check my blood sugar.				
27. I check my blood sugar without being reminded.				
28. I keep my own record of blood sugar numbers.				
29. When I exercise I change how I eat or how much insulin I take.				
30. I decide how much insulin to take.				
31. I adjust my dose of insulin based on my blood sugar numbers.				

Statements	**Never**	**Sometimes**	**Most of the time**	**Always**
32. If my blood sugar is high, and it's not mealtime, I give myself insulin.				
33. I remember what my HbA1c (A1c)[2] number is from my last clinic visit.				
34. I know what my HbA1c (A1c) number should be.				
35. To figure out my insulin dose, I consider my blood sugar and what I will eat.				
36. When my diabetes bothers me, I talk to my nurse or doctor about it.				
37. I try to change my diabetes routine if my nurse or doctor asks me to.				
38. If my parents have a problem with how I manage my diabetes, we talk about it.				
39. Before clinic visits I think about what I want to say to my nurse or doctor.				

---

[2] **Remember:** Your doctor will usually tell you what your HbA1c is at your outpatient clinic appointment. Your doctor or nurse will do a finger prick test to find out your HbA1c. It is usually a percentage and tells you what your blood glucose control has been like in the 3 to 4 months between appointments.

Statements	**Never**	**Sometimes**	**Most of the time**	**Always**
40. I stay informed about what's new in diabetes.				
41. I review my blood sugar records with my nurse or doctor.				
42. During clinic visits, I spend some time alone with my nurse or doctor.				
43. I tell my friends that I have diabetes.				
44. If something is bothering me about the way things are going with my diabetes, I talk to my parents about it.				
45. I contact my nurse or doctor when I can't get my blood sugars back into range.				

Section B, Part 2

The statements below describe different goals adolescents may have in taking care of their type 1 diabetes. Tick the box ☑ that indicates if – and how frequently – each is a goal for you (what you want and try to do), or whether it is a goal that you have already met (you do this).

Statements	**Never a goal for me**	**Sometimes a goal for me**	**Definitely a goal for me**	**I've met this goal**
1. One of my goals is to take care of my diabetes more on my own.				
2. I take care of my diabetes to try to not have problems in the future.				
3. I take care of my diabetes to feel good.				
4. I take care of my diabetes so I'm able to do things with my friends.				
5. One of my goals is to be able to stay away from home overnight.				
6. One of my goals is to be in charge of taking care of my diabetes.				
7. I want to understand why sometimes my blood sugar numbers are too high or too low.				

End of Section B

Section C

In this section, we would like to ask you about what it is like for you to talk to your parent(s) about your type 1 diabetes.

Tick the box ☑ to indicate how much you agree or disagree with each statement.

	Strongly Disagree	Moderately Disagree	Neither Agree nor Disagree	Moderately Agree	Strongly Agree
1. I can discuss my beliefs with my parents without feeling restrained or embarrassed.					
2. Sometimes I have trouble believing everything my parents tell me.					
3. My parents are always good listeners.					
4. I am sometimes afraid to ask my parents for what I want.					
5. My parents have a tendency to say things to me which would be better left unsaid.					

6. My parents can tell how I’m feeling without asking.					
7. I am very satisfied with how my parents and I talk together.					
8. If I were in trouble, I could tell my parents.					
9. I openly show affection to my parents.					
10. When we are having a problem, I often give my parents the silent treatment.					
11. I am careful about what I say to my parents.					
12. When talking to my parents, I have a tendency to say things that would be better left unsaid.					

13. When I ask questions, I get honest answers.					
14. My parents try to understand my point of view.					
15. There are topics I avoid discussing with my parents.					
16. I find it easy to discuss problems with my parents.					
17. It is very easy for me to express all my true feelings to my parents.					
18. My parents nag/bother me.					
19. My parents insult me when they are angry with me.					
20. I don't think I can tell my parents how I really feel about some things.					

End of Section C

Section D

In this section, we would like to ask you about who takes responsibility for different parts of type 1 diabetes management in your family.

For each of the following parts of diabetes care, choose the answer ☑ that best describes the way you handled things at home during the PAST MONTH.

	I take responsibility for this almost all of the time	**My parent(s) and I share responsibility for this about equally**	**My parent(s) take responsibility for this almost all of the time**
1. Remembering day of clinic appointment.			
2. Telling teachers about diabetes.			
3. Remembering to take morning or evening injection or boluses (pump).			
4. Making appointments with dentists and other doctors.			
5. Telling relatives about diabetes.			
6. Taking more or less insulin according to results of blood sugar monitoring.			
7. Noticing differences in health, such as weight changes or signs of an infection.			

8. Deciding what to eat at meals or snacks.			
9. Telling friends about diabetes.			
10. Noticing the early signs of a low blood sugar.			
11. Giving insulin injections or boluses (pump).			
12. Deciding what should be eaten when family has meals out (restaurants, friends' homes).			
13. Carrying some form of sugar in case of a low blood sugar.			
14. Explaining absences from school to teachers or other school personnel.			
15. Rotating injection sites or infusion set-ups (pump).			
16. Remembering times when blood sugar should be checked.			
17. Checking expiration dates on medical supplies.			

End of Section D

Section E

In this section, we would like to ask you about things you may have argued with your parent(s) about and how often these arguments might have happened.

For each of the following parts of diabetes care, choose the answer ☑ that best describes how much your family argues about it.

During the <u>PAST MONTH</u>, I have argued with my parent(s) about…	**Almost never**	**Sometimes**	**Almost always**
1. Remembering to give shots or to bolus (pump)			
2. Taking more or less insulin depending on results			
3. Remembering to check blood sugars			
4. Remembering clinic appointments			
5. Giving shots or boluses (pump)			
6. Meals and snacks			
7. Results of blood sugar monitoring			
8. The early signs of low blood sugar			
9. What to eat when away from home			
10. Making appointments with dentists and doctors			
11. Telling teachers about diabetes			
12. Telling friends about diabetes			
13. Carrying sugar/carbs for low blood sugars			
14. School absences			
15. Supplies			
16. Telling relatives about diabetes			
17. Rotating injection sites or infusion sets (pump)			
18. Changes in health (like weight or infections)			
19. Logging blood sugar results			

End of Section E

Section F

Please read the following questions about taking care of your type 1 diabetes. Please select the number ☑ that best describes how you feel about the following statements, from *not sure at all* to *completely sure*.

How sure are you that you can do each of the following, almost all of the time?

	Not sure at all	←							→	Completely sure
	1	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	**10**
1. Adjust your insulin correctly when you eat more or less than usual?										
2. Choose healthful foods when you go out to eat?										
3. Exercise even when you don't really feel like it?										
4. Adjust your insulin or food accurately based on how much exercise you get?										
5. Talk to your doctor or nurse about any problems you're having with taking care of your diabetes?										

How sure are you that you can do each of the following, almost all of the time?

	Not sure at all	←						→	Completely sure
	1	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	**10**
6. Do your blood sugar checks even when you are really busy?										
7. Manage your diabetes the way your health care team wants you to?										
8. Manage your diabetes even when you feel overwhelmed?										
9. Find ways to deal with feeling frustrated about your diabetes?										
10. Identify things that could get in the way of managing your diabetes?										

End of Section F

Section G

The following questions are about how you see your life with type 1 diabetes. Select ☑ the best answer for you. Please provide an answer for each question.

	Never	**Very Seldom**	**Sometimes**	**Often**	**All the time**
1. How often do you feel physically ill?					
2. How often do you have a bad night's sleep?					
3. How often do you miss school because of your diabetes?					
4. How often do you feel pain associated with the treatment?					
5. How often does diabetes interfere with your family life?					
6. How often do you feel restricted by your diet?					
7. How often does diabetes limit your social relationships and friendships?					
8. How often does diabetes keep you from cycling a bicycle or using a machine (For example a computer)?					

9. How often does diabetes interfere with you exercising?					
10. How often does diabetes interrupt your leisure time activities?					
11. How often does diabetes prevent you from doing activities at school?					
12. How often do you feel that your parents are too protective of you?					
13. How often do you feel that your parents worry too much about your diabetes?					
14. How often do you feel that your parents act like diabetes is their disease, not yours?					
15. How often do you worry about whether you will get married?					
16. How often do you worry about whether you will have children?					

17. How often do you worry about whether you will not get a job you like?					
18. How often do you worry about whether you will faint or pass out?					
19. How often do you worry about whether you will be able to complete your education?					
20. How often do you worry about whether your body looks different because of diabetes?					
21. How often do you worry about whether you will get complications?					

Compared with others your age, would you say your health is?

Excellent	○
Good	○
Fair	○
Poor	○

End of Section G

Section H

Below are some statements that people sometimes make when they talk about their health. Please indicate how much you agree or disagree with each statement as it applies to you personally by ticking ☑ your answer. If the statement does not apply to you, tick N/A.

	Disagree Strongly	**Disagree**	**Agree**	**Agree Strongly**	**N/A**
1. I am the person who is responsible for taking care of my health.					
2. Taking an active role in my own healthcare is the most important thing that affects my health.					
3. I know what each of my prescribed medications do.					
4. I am confident that I can tell whether I need to go to the doctor or whether I can take care of a health problem myself.					
5. I am confident that I can tell a doctor or nurse concerns I have even when he or she does not ask.					
6. I am confident that I can carry out medical treatments I may need to do at home.					
7. I have been able to maintain lifestyle changes, like healthy eating or exercising.					
8. I know how to prevent problems with my health.					

	Disagree Strongly	Disagree	Agree	Agree Strongly	N/A
9. I am confident I can work out solutions when new problems arise with my health.					
10. I am confident that I can maintain lifestyle changes, like healthy eating and exercising, even during times of stress.					

Did your parent help you to complete this questionnaire?

○ Yes
○ No

End of Section H

Section I

We would like you to complete section I if you are 15 years of age or older. These questions are about moving to an adult diabetes service (i.e. outpatient care in an adult hospital) for your type 1 diabetes care. Please tick ☑ or fill in your answers to the questions below.

1. Do you know what age you will transition to an adult diabetes service at?

○ Yes
○ No

If yes, please tell us what age you will be when you transition to an adult diabetes service

____

2. Do you know what hospital you will transition to?

○ Yes
○ No

3. How ready are you to transition to an adult diabetes service?

○ I am ready to transition to an adult diabetes service
○ I am almost ready to transition to an adult diabetes service
○ I am not sure if I am ready to transition to an adult diabetes service
○ I am not ready to transition to an adult diabetes service

4. How do you feel about moving to an adult diabetes service?

____

____

____

5. To what extent are you worried about moving to an adult diabetes service?

○ A great deal
○ A lot
○ Somewhat
○ A little
○ Not at all

6. What age do you think young people living with type 1 diabetes should be when they transition to an adult diabetes service?

____

7. Have you discussed moving to adult diabetes services with your health care team?

○ Yes
○ No

If yes, please tell us what you talked about

____

____

____

End of Section I

END OF QUESTIONNAIRE

Please check that you have answered all of the questions in the questionnaire

Thank you for filling out the questionnaire. We have included a resource sheet in your survey pack which has the details of useful services you might like to contact if you need some help.

Please return the completed questionnaire to the research team in the stamped addressed envelope we have included in your survey pack.

Appendix U: Cronbach's alpha for measures with the present sample

Measure	α
PACS	
Openness	0.91
Problems	0.76
T1D-specific family conflict (DFCS-R)	0.91
SMODA-I	
Collaboration with Parents	0.87
Diabetes Care Activities	0.69
Problem Solving	0.78
Communication	0.73
Goals	0.75
DFRQ	0.81
SEDM	0.86
PAM-10 UK	0.76
DQOLY-SF	
Impact of Symptoms	0.66
Impact of Treatment	0.50
Impact on Activities	0.78
Parent Issues	0.83
Worries about Diabetes	0.83

Appendix V: Normality, skewness and kurtosis tests

Outcome Variable	Skew statistic	Skew Std. Error	Kurtosis statistic	Kurtosis Std. Error
SMODA-I (Collaboration with Parents)	.148	.227	-.397	.451
SMODA-I (Diabetes Care Activities)	-.399	.227	-.382	.451
SMODA-I (Diabetes Problem-solving	-.958	.227	.259	.451
SMODA-I (Diabetes Communication)	-.282	.227	-.505	.451
SMODA-I (Goals)	-.325	.227	-.309	.451
DFRQ	.133	.228	-.431	.453
DFCS-R	2.307	.228	7.233	.453
SEDM	-.281	.228	-.698	.453
DQOLY-SF (Impact of symptoms)	.449	.228	.578	.453
DQOLY-SF (Impact of Treatment)	.386	.228	-.049	.453
DQOLY-SF (Impact on Activities)	.419	.227	-.697	.451
DQOLY-SF (Parent Issues)	.311	.227	-.635	.451
DQOLY-SF (Worries)	1.174	.227	1.789	.451
PAM-10 UK	.597	.227	-.229	.451
PACS (Openness)	-1.207	.227	1.354	.451
PACS (Problems)	-.179	.227	-.458	.451
PACS (Total Communication)	-.557	.227	-.097	.451

Appendix W: Overview of overarching themes, themes and subthemes and corresponding or similar quantitative measures

Theme	Subtheme	Corresponding/similar quantitative measures	Approach to QUAN analysis
(1) Changing levels of involvement in self-management: “I take more responsibility for [this] and … my mum would do that usually”	(1) Division of responsibility for self-management within the family	Age, Family Responsibility (DFRQ), Collaboration with parents (SMODA-I), Impact of treatment (DQOLY-SF), T1D care activities (SMODA-I)	Mean scores each measure/subscale, correlations between (i) DFRQ and (ii) Collaboration with parents to age, T1D care activities HMR analysis DV: DFRQ IVs: demographic and clinical characteristics Openness (PACS), Problems (PACS), family conflict (DFCS-R), T1D self-efficacy (SEDM) HMR analysis DV: T1D Care Activities (SMODA-I) IVs: demographic and clinical characteristics Openness (PACS), Problems (PACS), family conflict (DFCS-R), T1D self-efficacy (SEDM)
	(2) Collaboration and sharing responsibilities with parents for self-management	Family responsibility (DFRQ), Collaboration with parents (SMODA-I), problem solving (SMODA-I), activation (PAM), Impact of Treatment (DQOLY-SF)	Mean scores, correlations between (i) DFRQ and (ii) Collaboration with parents to problem solving, activation HMR analysis: DV: T1D Problem Solving (SMODA-I) IV: demographic and clinical characteristics Openness (PACS), Problems (PACS), family conflict (DFCS-R), T1D self-efficacy (SEDM) HMR analysis:

Theme	Subtheme	Corresponding/similar quantitative measures	Approach to QUAN analysis
			DV: Activation (PAM) IV: demographic and clinical characteristics Openness (PACS), Problems (PACS), family conflict (DFCS-R), T1D self-efficacy (SEDM)
(2) Talking about self-management with parents: “I am not just like sitting in on the conversation… I am putting in my own ideas about what to think, what to do”	(1) Change in patterns of parent-adolescent communication about T1D over time	Age, age at diagnosis, T1D duration, parent-adolescent communication (PACS), T1D-specific family conflict (DFCS-R) and T1D self-efficacy (SEDM), T1D communication (SMODA-I)	Correlations between (i) age, (ii) T1D duration to parent-adolescent communication (PACS), T1D specific family conflict (DFCS-R), T1D self-efficacy (SEDM), T1D communication (SMODA-I) Correlations between HbA1c and parent-adolescent communication, T1D-specific family conflict Correlation between DFRQ and parent-adolescent communication (PACS) and conflict (DFCS-R) Correlations between T1D self-efficacy and T1D communication and parent-adolescent communication (PACS) Correlations between parent-adolescent communication, T1D communication and activation
	(2) Seeking parental feedback and advice	Parent-adolescent communication (PACS), Collaboration with parents (SMODA-I), T1D communication (SMODA-I) T1D self-efficacy (SEDM)	Correlations between T1D self-efficacy to openness in communication and T1D communication (PACS), problems in parent-adolescent communication (PACS) and conflict (DFCS-R)

Theme	Subtheme	Corresponding/similar quantitative measures	Approach to QUAN analysis
			Correlations between problem solving (SMODA-I) and openness, problems (PACS) or T1D family conflict (DFCS-R) Correlation between openness (PACS) and adolescent worries (DQOLY-SF) Correlation between T1D self-efficacy (SEDM) and collaboration with parents (SMODA-I) (1) HMR analyses DV: Collaboration with parents (SMODA-I), T1D communication (SMODA-I) IVs: demographic and clinical characteristics, PACS and T1D-specific family conflict, T1D self-efficacy (SEDM)
	(3) Promoting self-management communication between adolescents and parents	Parent issues (DQOLY-SF), openness (PACS), problems (PACS), family conflict (DFCS-R)	Mean scores, outcome variables demonstrating a relationship to parent-adolescent communication (PACS) and T1D specific family conflict (DFCS-R) HMR analysis DV: Parent Issues (DQOY-SF) IVs: demographic and clinical characteristics, PACS and T1D-specific family conflict, T1D self-efficacy (SEDM) Correlations between PACS and DFCS-R to (i) HbA1c, (ii) T1D care activities and (iii) parent issues (DQOLY-SF)

Theme	Subtheme	Corresponding/similar quantitative measures	Approach to QUAN analysis
			HMR analysis DV: T1D care activities (SMODA-I), parent issues (DQOLY-SF) IV: demographic and clinical characteristics Openness (PACS), Problems (PACS), DFCS-R, T1D self-efficacy (SEDM)
(3) Taking ownership of self-management: "It's my responsibility"	(1) T1D and self-management becomes a "part of daily life"	Impact of symptoms (DQOLY-SF), Impact of treatment (DQOLY-SF), Impact on activities DQOLY-SF), Worries (DQOLY-SF), Health perception item (DQOLY-SF), HbA1c	Mean scores and ranges of DQOLY-SF subscales, frequency of health perception Correlations between HbA1c and impact of symptoms (DQOLY-SF), impact of treatment (DQOLY-SF), impact on activities DQOLY-SF) HMR analyses DV: Impact of treatment, Impact on activities, Parent Issues, Worries IV: demographic and clinical characteristics Openness (PACS), Problems (PACS), DFCS-R, T1D self-efficacy (SEDM), Problem solving (SMODA-I), Activation (PAM)
	(2) Learning about self-management and understanding T1D	Insulin mode, T1D care activities (SMODA-I), Impact of treatment (DQOLY-SF), T1D self-efficacy (SEDM)	Differences in T1D care activities (SMODA-I) based on T1D management characteristics
	(3) Gaining confidence and mastery in self-management	T1D self-efficacy (SEDM), activation (PAM), problem solving (SMODA-I), age, T1D duration	HMR analysis DV: activation (PAM) IV: demographic and clinical characteristics Openness (PACS), Problems (PACS), family conflict (DFCS-R), T1D self-efficacy (SEDM) HMR analysis

Theme	Subtheme	Corresponding/similar quantitative measures	Approach to QUAN analysis
			DV: Problem solving (SMODA-I), activation (PAM), role of T1D self-efficacy (SEDM) in these IV: demographic and clinical characteristics Openness (PACS), Problems (PACS), family conflict (DFCS-R), T1D self-efficacy (SEDM)
	(4) Catalysts or prompts to assuming more management	Age, T1D duration and insulin mode, T1D care activities (SMODA-I), goals (SMODA-I)	Differences according to management characteristics and T1D care activities (SMODA-I) and goals (SMODA-I)
(4) Environmental and contextual influences affecting self-management: “Even though I know what to do, it’s just that support really helps”	(1) Setting and/or devices can influence engaging with self-management	Activation (PAM), T1D self-efficacy (SEDM), T1D care activities (SMODA-I), Problem solving (SMODA-I),	Differences for T1D self-efficacy, T1D care activities and impact on activities according to T1D management characteristics
		Insulin mode, BGM method, family responsibility (DFRQ), Collaboration with parents (SMODA-I), T1D care activities (SMODA-I), Goals (SMODA-I), Impact of treatment (DQOLY-SF), Impact on activities (DQOLY-SF)	(1) HMR analyses DV: Impact of Symptoms, Impact of Treatment, Impact on Activities (DQOLY-SF) IV: demographic and clinical characteristics parent-adolescent communication (PACS) self-management and self-management process variables
	(2) Family involvement in self-management	Family history of T1D	Frequency, scores for impact on activities (DQOLY-SF)
		Impact of treatment (DQOLY-SF), Impact on activities (DQOLY-SF)	
	(3) Involving friends and peers in self-management	T1D communication (SMODA-I), Worries (DQOLY-SF)	Correlations between T1D self-efficacy and self-management communication
			HMR analysis

Theme	Subtheme	Corresponding/similar quantitative measures	Approach to QUAN analysis
		T1D activities (SMODA-I), Impact of symptoms (DQOLY-SF), Impact of treatment (DQOLY-SF), Impact on activities (DQOLY-SF), T1D self-efficacy (SEDM)	DV: T1D Communication (SMODA-I) IV: demographic and clinical characteristics, Openness (PACS), Problems (PACS), family conflict (DFCS-R), T1D self-efficacy (SEDM)
		T1D communication (SMODA-I), Impact on treatment (DQOLY-SF), Impact on activities (DQOLY-SF)	DV: Impact of symptoms (DQOLY-SF), Impact of treatment (DQOLY-SF), Impact on activities (DQOLY-SF) IV: demographic and clinical characteristics, T1D Self-efficacy (SEDM), Collaboration with parents (SMODA-I), Care activities (SMODA-I), Problem solving (SMODA-I), Communication (SMODA-I), Goals (SMODA-I), Activation (PAM)
	(4) Collaborating with HCPs while gaining independence in self-management	Family responsibility (DFRQ), Goals (SMODA-I), HbA1c	Correlations between family responsibility, T1D goals, activation and HbA1c

Appendix X: Research Dissemination

Conference Proceedings

- Tuohy, E., Gallagher P., Rawdon, C., Glacken, M., Murphy, N. & Swallow, V. & Lambert, V. *Examining the relationship between adolescent type 1 diabetes-specific quality of life and parent-adolescent communication.* 43rd Annual International Society for Pediatric and Adolescent Diabetes. Boston, USA October 30 - November 2, 2019 (Poster Presentation).
- Tuohy, E., Gallagher P., Rawdon, C., Glacken, M., Murphy, N. & Swallow, V. & Lambert, V. *Investigating the relationship between adolescents self-managing their type 1 diabetes and diabetes-specific conflict with parents.* 33rd Annual Conference of European Health Psychological Society. Dubrovnik, Croatia September 3-7, 2019 (Oral Presentation).
- Tuohy, E., Gallagher P., Rawdon, C., Glacken, M., Murphy, N. & Swallow, V. & Lambert, V. *Investigating the relationship between adolescent self-management of type 1 diabetes and open parent-adolescent communication.* British Psychological Society Health Psychology Annual Conference. Manchester, UK, July 10-11, 2019 (Poster Presentation).
- Tuohy, E., Gallagher P., Rawdon, C., Glacken, M., Murphy, N. & Swallow, V. & Lambert, V. *Adolescent experiences of assuming increasing self-management responsibilities for Type 1 diabetes.* Psychology, Health, and Medicine Conference. Maynooth, Ireland, March 22, 2019 (Oral Presentation).
- Tuohy, E., Gallagher P., Rawdon, C., Glacken, M., Murphy, N. & Swallow, V. & Lambert, V. *Adolescent Perspectives on Talking to Parents about Type 1 Diabetes Self-Management.* Irish Postgraduate Research Conference, Dublin, Ireland, November 8-9, 2018 (Poster Presentation).
- Tuohy, E., Lambert, V., Gallagher P., Rawdon, C., Glacken, M., Murphy, N. & Swallow, V. *Barriers and Facilitators to Talking about Type 1 Diabetes Self-Management: Adolescent Perspectives.* 16th International Conference on Communication in Healthcare. Porto, Portugal, September 1-4, 2018 (Oral Presentation).
- Tuohy, E., Lambert, V., Gallagher P., Rawdon, C., Glacken, M., Murphy, N. & Swallow, V. *Children and young people's experiences of self-management of type 1 diabetes: A qualitative meta-synthesis.* 32nd Annual Conference of the

European Health Psychology Society. Galway, Ireland, August 21-25, 2018 (Oral Presentation).

- Tuohy, E., Lambert, V., Gallagher, P., Rawdon, C., Glacken, M. & Murphy, N. *Process of Negotiating Self-Management Responsibilities for Type 1 Diabetes and Psychosocial Wellbeing from the Perspective of Adolescents.* 43rd Annual Conference of the International Society for Pediatric and Adolescent Diabetes, Innsbruck, Austria, October 18-21, 2017 (Poster Presentation).
- Tuohy E., Lambert, V., Gallagher, P., Rawdon, C., Glacken, M. & Murphy, N. *Adolescents' Experiences of Communicating and Negotiating Type 1 Diabetes Self-Management.* International Conference on Communication in Healthcare and Health Literacy Annual Research Conference, American Academy on Communication in Healthcare, Baltimore, Maryland, USA, October 8-11, 2017 (Oral Presentation).
- Tuohy, E., Lambert, V. & Gallagher, P. *Young people with type 1 diabetes negotiating self-management responsibilities.* Children's Research Network (CRN) PhD Symposium, National University of Ireland Maynooth, Ireland, September 2016 (Oral Presentation).

Publication

- Tuohy, E., Rawdon, C., Gallagher, P., Glacken, M., Murphy, N., Swallow, V., & Lambert, V. (2019). *Children and young people's experiences and perceptions of self-management of type 1 diabetes: A qualitative meta-synthesis.* Health psychology open, 6(2).