

THE UNIVERSITY OF HULL

**An Exploration into Young People with Type 1 Diabetes Perceptions of
Control**

being a Thesis submitted in partial fulfillment
of the requirements for the degree of Doctor of Clinical Psychology

in the University of Hull

by

Cassie Leanne Ward
BSc (Hons.) Psychology

June 2015

Acknowledgements

Firstly I would like to thank the adolescents who took part in my study. My thesis would be nothing without you guys and I am so grateful for you giving me the opportunity to hear about your experiences and to complete this piece of work. Also thank you to the Paediatric Diabetes Teams for your enthusiasm and support for the project.

Secondly I would like to thank my supervisors Dr Dorothy Frizelle and Dr Nikki McCloud for your guidance and support throughout this whole process and for helping me when it all felt too overwhelming.

To the 2012 cohort, thank you for your support and encouragement over the past three years. I also want to give special thanks to Sophie for countless library seshs and helping me to “Just Keep Swimming” and Lauren for always being there for a chat.

I would also like to thank my Mum, Dad and Gemma for always believing in me and being there for me. A special thanks goes to my little niece Abigail, you are my little ray of sunshine and have always made me smile, even on the gloomiest days. Also my fiancé Mark, thank you for always making me laugh when times were hard and keeping me going when I wanted to stick my head in the sand.

Overview

The portfolio thesis has three parts:

Part one is a systematic literature review reviewing the literature on the relationship between parenting style and diabetes management in children and young people with type 1 diabetes. Seven papers were systematically reviewed and the findings and clinical implications are discussed.

Part two is an empirical paper, which explores adolescents with type 1 diabetes perceptions of control. Six adolescents who perceived themselves to have low personal and/or treatment control were interviewed about their experiences. The interviews were analysed using Interpretative Phenomenological Analysis. The findings of the study are discussed along with the clinical implications of the study and areas of future research.

Part three comprises the appendices, which compliment parts one and two of the portfolio. The appendices also includes a reflective statement

Table of Contents

List of Tables	6
----------------------	---

List of Figures	6
-----------------------	---

Part One: Paediatric Diabetes: Parenting Styles and Diabetes Management

Abstract	9
----------------	---

Introduction.....	10
-------------------	----

Method	15
--------------	----

Results.....	20
--------------	----

Discussion	35
------------------	----

Limitations of the Review.....	41
--------------------------------	----

Recommendations and Clinical Implications	42
---	----

Conclusions.....	43
------------------	----

References.....	45
-----------------	----

Part Two: Adolescents with Type 1 Diabetes: An Exploration of Perceptions of Control

Abstract.....	54
---------------	----

Introduction.....	55
-------------------	----

Method	59
--------------	----

Results.....	62
--------------	----

Discussion	74
------------------	----

Helping Adolescents to Feel More in Control: Clinical Implications	79
--	----

Limitations and Future Research	82
---------------------------------------	----

Conclusions.....	83
References.....	85

Part Three: Appendices

Appendix A – Author Guidelines for SLR	91
Appendix B – Excluded Articles	100
Appendix C – Data Extraction Form	102
Appendix D – Quality Checklist.....	104
Appendix E - Data Extracted from Included Articles.....	106
Appendix F – Detailed Quality Ratings for Included Studies	117
Appendix G – Author Guidelines for Empirical Paper.....	118
Appendix H – Ethics Approval Letter	126
Appendix I – Brief Illness Perception Questionnaire (Broadbent et al, 2006)	129
Appendix J – Interview Schedule	130
Appendix K – Participant and Parent/Guardian Information Sheets	131
Appendix L – Consent form for BIPQ and to be contacted for interview.....	139
Appendix M – Consent form for Interview	141
Appendix N – Epistemological Statement.....	143
Appendix O – Worked IPA Example	145
Appendix P – Reflective Statement	148

List of Tables

Part One: Systematic Literature Review

Table 1. Search terms used in the review	16
Table 2. Inclusion Criteria for articles included in the Systematic Literature Review of “What is the impact of parenting style on diabetes management in children and young people with T1DM?”	16
Table 3. Exclusion Criteria for articles excluded from the Systematic Literature Review of “What is the impact of parenting style on diabetes management in children and young people with T1DM?”	17
Table 4. Characteristics of Parenting Style Measures as described by Reviewed Studies	26
Table 5. Characteristics of Diabetes Adherence Measures as described by Reviewed Studies	30
Table 6. Demographic Characteristics of the Interviewed Sample.....	60
Table 7. Super-ordinate and Subordinate Themes Generated from Data Analysis	63

List of Figures

Part One: Systematic Literature Review

Figure 1. Parenting styles in relation to the concepts of demandingness and responsiveness.	14
Figure 2. Flow Diagram of the Article Selection Process	19
Figure 3. Vicious cycle which may decrease adolescents’ diabetes self-efficacy	80

Part One: Systematic Literature Review

Paediatric Diabetes: Parenting Styles and Diabetes Management

Cassie L. Ward^{1*}, Dr Dorothy J. Frizelle² and Dr Nikki McCloud³

^{1,2}Department of Psychological Health and Wellbeing, University of Hull, Hull, United Kingdom, HU6 7RX.

³Rotherham, Doncaster and South Humber NHS Foundation Trust

* Corresponding Author: Telephone Number - 01482 464101

Fax: 01482 464093

Email: C.L.Ward@2012.hull.ac.uk

This paper is written in the format ready for submission to the Clinical Psychology Review.

Please see Appendix A for the Guideline for Authors

Word Count: 10,042 (including abstract, tables, figures and references)

Abstract

Purpose; Helping children and young people (C&YP) with Type 1 Diabetes (T1DM) to manage their diabetes effectively is important as poor management can lead to future complications and early mortality. Parents play an important role in their child's diabetes management. Therefore the review investigated the impact of parenting style (PS) on diabetes management (adherence behaviours and metabolic control) in C&YP with T1DM. **Method;** A systematic literature review was undertaken looking at cross-sectional studies investigating the relationship between PS and diabetes management in C&YP with T1DM. Seven studies were included and were analysed using a narrative synthesis. **Results;** Authoritative parenting was associated with better adherence for C&YP, whereas permissive and authoritarian parenting was associated with poorer adherence. Authoritative parenting was also associated with better metabolic control and permissive and authoritarian parenting was associated with poorer metabolic control. However three studies looking at PS and metabolic control did not find any significant associations. **Conclusions;** Authoritative parenting may be related to better outcomes when solely looking at the relationship between PS and diabetes management. Helping parents to develop authoritative parenting skills/competencies could help to improve diabetes management. Additionally services need to be aware of how parenting affects the C&YP they are working with.

Keywords: Parenting Style, Type 1 Diabetes, Adherence, Metabolic Control, Systematic Literature Review

Type 1 Diabetes

Type 1 Diabetes Mellitus (T1DM) is a life-long autoimmune condition¹ which is usually diagnosed in childhood, (National Health Service, 2014; NHS). In the United Kingdom (UK) 3.2 million people have a diagnosis of diabetes with 10% having a diagnosis of T1DM (Diabetes UK, 2014b). It is estimated that 35,000 children and young people have diabetes and 96% have T1DM (Diabetes UK, 2014b). Diabetes costs the NHS over 1 billion GBP and approximately 80% of this cost is due to addressing treatment complications (Diabetes UK, 2014a).

A T1DM diagnosis can be difficult for families (Rankin et al, 2014) and this is widely recognised (National Institute for Health Care and Excellence, 2004; NICE). Families need to adjust and adapt to the diagnosis; family routines often change (Mellin, Neumark-Sztainer & Patterson, 2004) including mealtime routines, changing eating habits and a loss of spontaneity away from home due to needing to plan for managing the diabetes.

T1DM Management

To effectively manage T1DM, the young person, supported by their parents, has to monitor themselves on a daily basis including dietary intake, sleep, exercise and blood glucose levels (Rubin & Peyrot, 2001). ‘Adherence’ is a term used within the literature to describe the management of diabetes through the behaviours used to maintain normal blood

¹ An individual’s immune system attacks cells in the pancreas (NHS, 2012) leading to individuals not being able to produce the hormone insulin which is responsible for regulating blood glucose levels (Fox & Kilvert, 2008). Individuals with T1DM produce little or no insulin and therefore glucose levels in the blood cannot be regulated, leading to high levels of blood glucose.

glucose levels (Taddeo, Egedy & Frappier, 2008). These ‘behaviours’ are related to agreed recommendations from a health care provider (World Health Organisation, 2003) and therefore the term ‘adherence’ is related to a medical perspective (Johnson, 1992). Adherence can be measured through self-report questionnaires that ask how frequently adherence behaviours are used (Taddeo et al, 2008). However, social desirability affects self-reporting (Van de Mortel, 2008). For example; a young person may say they test their blood glucose levels six times a day when only testing them twice, as they feel that six would be more desirable. Measuring adherence may be a useful way of quantifying diabetes management; however it does not take into consideration biological factors which may impact on diabetes management (Johnson, 1992).

Measuring the young person’s metabolic control is the predominant way services test whether a young person has healthy blood glucose levels and therefore good diabetes management. Metabolic control is assessed through testing an individual’s glycosylated haemoglobin² (HbA1c; Reynolds, Smellie & Twomey, 2006). HbA1c shows an individual’s average blood glucose level over the previous 2 to 3 months, as red blood cells survive for 8-12 weeks (Diabetes.co.uk, 2015a; Holt & Kumar, 2010). Good diabetes management achieves the target HbA1c level of less than 48 mmol/mol (6.5%; NICE, 2015). This is achieved by individuals adhering to the healthcare advice to keep blood glucose levels between 4 and 7 mmol/litre on waking and before meals and between 5–9 mmol/litre after meals (NICE, 2015).

It is important to note however that children and adolescents are constantly developing and although a young person may be adhering to their healthcare regime, biological factors such as the growth hormone and puberty (Tfayli & Arslanian, 2007) can

² Sugar attaches to the haemoglobin within the blood, creating glycosylated haemoglobin (Diabetes.co.uk, 2015a). If an individual has frequently high blood glucose levels then they will have a higher HbA1c.

also impact on an individual's ability to maintain optimal diabetes management. Other studies have also concluded that psychological factors can also be related to metabolic control and adherence. Nardi et al (2008) found that higher HbA1c levels were correlated with poorer quality of life and more psychological problems. Reducing adolescents' stress, supporting them to use healthy coping strategies and helping families to focus on positive communication can help to improve adolescents' diabetes management (Naranjo, Mulvaney, McGrath, Garnero & Hood, 2014).

How Parenting is related to T1DM Management

The complexity of the diabetes adherence regime necessitates parents being involved in the management of their child's diabetes. According to the American Diabetes Association (ADA; Silverstein et al, 2005) the amount of responsibility placed on the parents and the young person for their diabetes management should correlate with the young person's developmental stage. Between the ages of 8 and 11, the ADA state that children are capable of taking on some responsibility, under supervision, for daily tasks of diabetes management such as injecting insulin and checking blood glucose levels.

During adolescence, parental involvement is encouraged as studies have shown that giving total responsibility to adolescents may lead to poorer metabolic control and lower diabetes self-efficacy³ (Helgeson, Reynolds, Siminerio, Escobar & Becker, 2007). Although parental involvement can be beneficial in the management of a young person's diabetes, parental behaviours that are perceived as intrusive by the young person can be a factor which contributes to an increase in family conflict (Weinger, O'Donnell & Ritholz, 2001). Family

³ Diabetes self-efficacy refers to a person's beliefs that they can perform health behaviours which can influence which health behaviours they engage in (Sarkar, Fisher & Schillinger, 2006). Therefore if an adolescent has low diabetes self-efficacy they will have little belief in being able to perform effective self-management for their T1DM and therefore are less likely to engage with self-management.

conflict has been related to poorer diabetes outcomes (Anderson et al, 2002). Anderson (2004) suggests that although parental involvement is helpful throughout childhood, for a young person, it may be the style of parenting that is used that may cause negative effects.

Theories of Parenting Styles

Parenting style (PS) is defined as the context that moderates how a parent behaves towards their child (Darling & Steinberg, 1993). A popular PS theory is Baumrind's typological approach (Baumrind, 1971). Baumrind (2013) suggested that PS is based on two different dimensions; demandingness and responsiveness i.e.:

Responsiveness refers to parents' emotional warmth and supportive actions that are attuned to children's vulnerabilities, cognitions, and inputs and are supportive of children's individual needs and plans. Demandingness has two related components, monitoring and confrontive control, and refers to the claims parents make on their children to become integrated into and contribute to the family unit: monitoring, which provides structure, order, and predictability to the child's life; and control, which shapes the child's behavior and restrains the child's potentially disruptive agentic expressions. (p. 26)

The type of control which a parent uses to shape their child's behaviour can present in different forms; behavioural and psychological control (Barber, 1996). Behavioural control is related to Baumrind's concept of "confrontive control" and is defined as parents' attempts to manage their child's behaviour (Baumrind, 2013). Psychological control is defined as parents' attempts to indirectly control their child's psychological world through their thoughts and feelings (Baumrind, 2013).

Using these concepts, four types of PS have been developed; Authoritarian, Authoritative, Permissive and Neglecting (Baumrind, 2013; (Maccoby and Martin, 1983; see Figure 1).

	High Demandingness	Low Demandingness
High Responsiveness	Authoritative	Permissive
Low Responsiveness	Authoritarian	Rejecting- Neglecting

Figure 1. Parenting styles in relation to the concepts of demandingness and responsiveness.

It is worth acknowledging that although PS encompasses the way in which parents respond and guide their children, it is only one factor out of many which can impact on the development of a young person. Measuring PS for research purposes also has its limitations; one being that PS is usually measured through the use of self-report measures and can therefore be affected by social desirability.

Although it may have its limitations, the role of PS has been investigated in different paediatric conditions including cerebral palsy (Aran, Shalev, Biran & Gross-Tsur, 2007) and cancer (Manne, Jacobsen, Gorfinkle, Gerstein & Redd, 1993). In recent years, PS has begun to be researched in relation to diabetes management, as family has been identified as integral to a child’s diabetes care. However, literature related to the impact of PS on diabetes management has not yet been reviewed. Diabetes causes the NHS financial strain particularly due to medical complications making it vital to find effective ways of helping young people to engage in diabetes management which may beneficially reduce risks of complications in later life (Olsen et al, 2001); consequently reducing the mortality rate related to diabetes and the associated NHS costs. Therefore this systematic literature review aimed to answer the question:

“What is the impact of PS on diabetes management in children and young people with T1DM?”

Method

Design

The review was designed to collate and synthesise cross-sectional studies. Included literature investigated the correlational relationship between PS and diabetes management.

Search Method

A systematic search was conducted in February 2015 using the search terms shown in Table 1. Databases included in the systematic search were Cumulative Index of Nursing and Allied Health Literature (CINAHL) Complete, MEDLINE, PsycINFO and PsycARTICLES using the EBSCOhost platform, to cover both medical and psychological disciplines. Where possible, limiters were set to only include peer reviewed articles. No date limiters were used in order to capture as many relevant articles as possible. Reference lists of studies which met the search criteria were also searched for relevant articles. Studies had to meet the inclusion criteria listed in Table 2. Studies were excluded on basis of criteria listed in Table 3.

Search Terms	Rationale
parent* or matern* or patern* or mother or father	The population and variable under consideration in the review. To include parent, parents, parenting, parental, maternal, maternalistic, paternal and paternalistic.
diabet*	The population under consideration. To include diabetes and diabetic.
adolescen* or child* or juvenile or teen* or you* or p#ediatic	The population under consideration in the review. To include adolescent, adolescents, adolescence, child, children, teen, teenager, teenagers, young, youth, youths, pediatric and paediatric.
style* or strateg* or response* or practice* or authoritarian or authoritative or permissive or neglect*	Variable under consideration in the review. To include style, styles, strategy, strategies, response, responses, practice, practices, neglect and neglectful.

Table 1. Search terms used in the review

Inclusion Criteria	Rationale
Children aged 0-18	Children and adolescents with T1DM were the population under consideration
Published in English	No budget for translating articles
Studies investigating the relationship between parenting styles and diabetes management	The review aimed to investigate the strength and direction of the relationship between PS and diabetes management
Peer reviewed articles	To gain a high level of methodological rigour
Children diagnosed with T1DM	Children with T1DM were the population under consideration
Studies using a correlational/cross-sectional design	The review aimed to investigate the strength and direction of the relationship between PS and diabetes management, rather than individual's experiences

Table 2. Inclusion Criteria for articles included in the Systematic Literature Review of “What is the impact of parenting style on diabetes management in children and young people with T1DM?”

Exclusion Criteria	Rationale
Qualitative methodology & Case Studies	The review aimed to investigate the strength and direction of the relationship between parenting style and diabetes management, rather than individual's experiences
No measure of parenting style	Parenting style is one of the variables being investigated in the review
Not looking at the relationship between parenting style and diabetes management as a primary research aim	The review aimed to look at studies explicitly investigating the impact of parenting style on diabetes management.
Relationship between parenting style and diabetes management based on an outcome of an intervention	The review aimed to look at studies using a cross sectional design, not a prospective design.
Studies validating measures	The review aimed to look at the direct relationship between parenting styles and diabetes management using established reliable and valid measures.
No reference to metabolic control or diabetes adherence	Metabolic control and diabetes adherence are the two concepts which were looked at in the diabetes management variable
Children diagnosed with T2DM	The review aimed to look at children who have T1DM.
Literature Reviews	The review aimed to look at original research articles
Children diagnosed with physical illness related diabetes e.g. cystic fibrosis related diabetes	Having an added physical illness may change the parenting dynamic and adherence behaviours used.
Parents with diabetes	The review is looking at children who have T1DM, not parents.

Table 3. Exclusion Criteria for articles excluded from the Systematic Literature Review of “What is the impact of parenting style on diabetes management in children and young people with T1DM?”

Data Extraction and Quality Assessment

Initial search of the databases, with the peer-review limiter applied, resulted in 2544 articles. After reviewing the articles by title and abstract, 2526 articles were excluded. Full texts of the remaining 18 articles were reviewed and after applying inclusion and exclusion criteria, 11 articles were excluded (see Figure 2 and Appendix B). After the article selection process, key components of the studies were extracted; research aims/hypotheses, research design, participant demographics, measures used, results and conclusions (see Appendix C).

Included studies were assessed for quality using a modified version of Downs and Black's Quality Checklist (Downs & Black, 1998; see Appendix D). The quality checklist was piloted on 3 of the included studies to ensure it was applicable before applying it to all included studies. The quality assessment was not used to exclude studies from the review as there was scant research looking at the direct relationship between PS and diabetes management. However, quality checklist ratings were included in the data extraction process and are reported in Appendix E. An independent reviewer assessed the quality of four randomly selected articles⁴ to assess the reliability of the modified checklist and to reduce bias.

Data Synthesis

A narrative synthesis was utilised as there was diversity between measures and samples used between studies.

⁴ Four papers were randomly selected by allocating each paper a number and picking pieces of paper with the numbers on out of a hat.

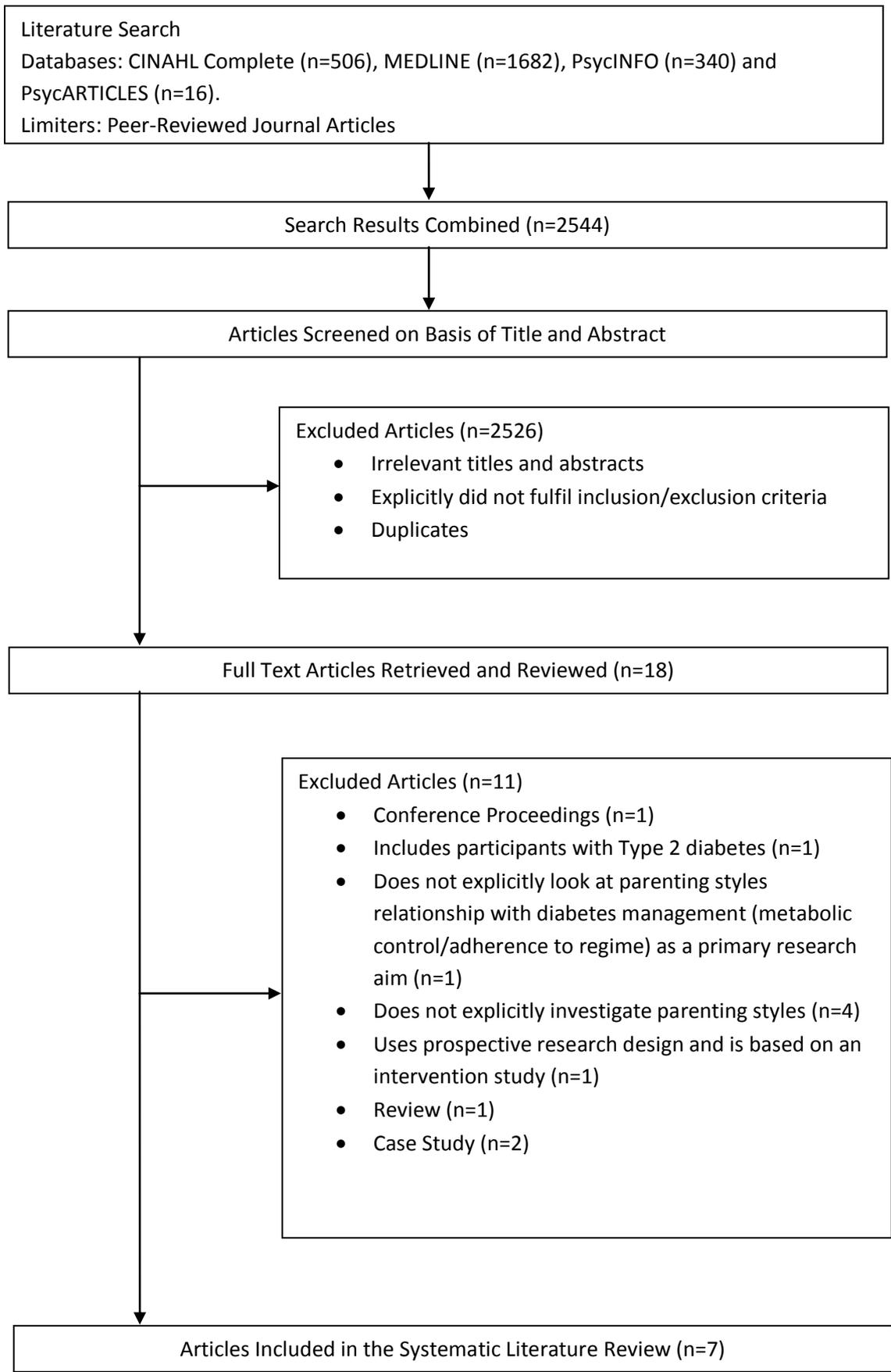


Figure 2. Flow Diagram of the Article Selection Process

Results

Study Characteristics

The characteristics of all included studies are shown in Appendix E. All studies used a cross-sectional design and presented correlational findings except for one which undertook a K-cluster analysis to categorise participants into parenting style groups and a one way ANOVA to assess the difference between PS on adherence and metabolic control (Mlynarczyk, 2013). As well as presenting correlational findings, four studies also undertook regression analyses (Butler et al, 2007; Davies et al, 2001; Greene et al, 2010; Shorer et al, 2011). The majority of studies (n=6) were conducted in the United States of America, with one exception which was conducted in Israel (Shorer et al, 2011).

Four of the studies included both parents and children within their samples (Butler et al, 2007; Greene et al, 2010; Sherifali et al, 2009; Shorer et al, 2011). One study included only adolescents (aged 12-18) within their sample (Mlynarczyk, 2013) and two studies included only parents/primary care givers (Davies et al, 2001; Monaghan et al, 2012). However, although only the parents completed the self-report questionnaires within the study, both studies also included the children's' HbA1c results as a variable.

Largest sample sizes were 216 Parent-Child Dyads (Sherifali et al, 2009) and 142 parents and 100 children (Shorer et al, 2011). Smallest sample sizes were 29 adolescents and at least one of their parents (Greene et al, 2010) and 55 parents (Davies et al, 2001). In the studies which included parents as participants, all studies included mothers. Four studies included fathers but their presence within the sample varied greatly rating from 7.4% (Monaghan et al, 2012) to 44% (Shorer et al, 2011). One study included both parents but did not state the distribution within the sample (Greene et al, 2010). One study also included a grandmother within their sample as one of their inclusion criteria was for participants to

identify themselves as a primary care giver (Monaghan et al, 2012). One study also stated the type of parents that were included in their sample which included 98.1% biological parents, 0.5% step parents, 0.5% adoptive parents and 0.9% other (Sherifali et al, 2009).

The mean (SD) ages of the samples of children with type 1 diabetes ranged from 7.5 years (1.9) to 15 years (1.67). Most of the studies (n=6) included children with type 1 diabetes who had been diagnosed for at least a year; however one study included children who had been diagnosed within the year the study was conducted (Davies et al, 2001). All reviewed studies included both males and females in their samples of children with T1DM.

Most studies investigated the effect of PS on both diabetes adherence and metabolic control (n=5). One study only investigated the effect of PS on metabolic control (Sherifali et al, 2009) and one study only investigated the effect of PS on diabetes adherence (Butler et al, 2007). The majority of studies used Baumrind's (1971) Typological Theory of PS (n=6). Two studies not only used Baumrind's (1971; 1991) theory but also used Maccoby and Martin's⁵ (1983) theory. One study used both Baumrind's (1991) Typological Theory as well as Bean et al's (2006) dimensional approach⁶ for their theoretical underpinning (Butler et al, 2007). One study did not include a theoretical perspective however did include studies investigating parental warmth, coercion and authoritative parenting (Davies et al, 2001).

⁵ Maccoby and Martin's (1983) theory builds on Baumrind's Typological Theory to add the additional parenting style of neglecting (Mlynarczyk, 2013).

⁶ Bean et al's (2006) dimensional approach moved away from the typological approach to parenting styles and looked at parenting styles on the dimensions of psychological control, behavioural control and support. Psychological control is defined as the intrusion and manipulation of a child's psychological world, behavioural control is defined as managing a child's behaviour through regulation and structure and support is defined as a parent's acceptance and warmth.

Four studies assessed the effect of PS on diabetes management but kept PS as typologies (Greene et al, 2010; Mlynarczyk, 2013; Monaghan et al, 2012; Shorer et al, 2011). Two studies assessed PS effect on diabetes management by splitting PS into dimensions; Sherifali et al (2009) split PS into three dimensions; support, control and structure and Davies et al (2001) split PS into warmth, restrictiveness, amount of control and physical punishment. One study assessed the effect of PS on diabetes management in both their typologies and also in dimensions of psychological control, firm control and acceptance (Butler et al, 2007).

Measures of Parenting Styles

Various PS measures were used and Table 4 illustrates these. Only the Parenting Dimensions Inventory (PDI) was used more than once. Most of the studies reported the internal consistency reliability for the utilised PS measure ($n=6$). Most of the subscales were acceptable ($\alpha > 0.70$); however the demandingness subscale on the Parenting Style Index-II had an alpha level of 0.64 for Mlynarczyk's (2013) study sample. One subscale not reaching an acceptable level was the strictness subscale of the PDI in Davies et al's (2001) study sample ($\alpha = 0.49$), therefore the authors split the subscale into its 3 dimensions (Restrictiveness, Amount of Control and Physical Punishment) which improved internal consistencies.

Measures of Adherence

Several measures were used to determine diabetes adherence. Table 5 shows the characteristics of the measures used across all studies. The Self Care Inventory (SCI; La Greca, 2004; La Greca et al, 1990) was the only measure used in multiple studies (Butler et al, 2007; Davies et al, 2001; Monaghan et al, 2012). Five of six studies reported the internal consistency of measures used. Internal consistency values ranged from $\alpha=0.73$ (Butler et al, 2007) to 0.95 (Mlynarczyk, 2013).

Name of Measure	Study included in the Review using Measure	Number of items	Subscales	Internal consistency in studies (Cronbach's alpha (α) unless otherwise stated)	Details of Alterations
Parenting Style Index – II (Darling & Toyakawa, 1997, as cited in Mlynarczyk, 2013)	Mlynarczyk (2013)	15	Three subscales – Responsiveness, Autonomy-Granting and Demandingness. Each subscale contained 5 items	For the study sample: Responsiveness (0.71) Demandingness (0.64) Study also reported Darling & Toyakawa's original alpha levels: Responsiveness (0.74) Demandingness (0.72)	Autonomy-granting subscale was not used in the study.
Child Report of Parent Behaviour Inventory (Schaefer, 1965a, as cited in Butler et al, 2007); Schluderman & Schluderman, 1970, as cited in Butler et al, 2007)	Butler et al (2007)	30	Three domains – Psychological Control, Firm Control and Acceptance.	For the study sample: Psychological Control (0.90) Firm Control (0.81) Acceptance (0.93) Study does not report original studies alpha levels but states that the measure was found to have excellent reliability and validity across cultures.	None reported.
Parent Report of Parent	Butler et al (2007)	30	Three domains –	For the study sample:	None reported.

Behaviour Inventory (Schaefer, 1965b, as cited in Butler et al, 2007)			Psychological Control, Firm Control and Acceptance.	Psychological Control (0.81) Firm Control (0.77) Acceptance (0.90) Study does not report original studies alpha levels but states that the measure was found to have excellent reliability and validity across cultures.	
Parenting Dimensions Inventory (Power, 1993, as cited in Sherifali et al, 2009)	Sherifali et al (2009)	54	Uses 9 uni-dimensional scales (Nurturance, Sensitivity, Non- restrictive Attitude, Type of Control, Amount of Control, Maturity Demands, Involvement, Consistency and Organisation) to create 3 dimensions of Support, Control and Structure.	For the study sample: Internal consistency was cross- validated on a replication sample of 140 parents, with the degree of fit for each scale ranging from 0.97 to 0.99. Study also reported the range of Cronbach's alphas from the original study which was between 0.55 and 0.79.	None Reported.
Parenting Dimension Inventory (Power, 1993, as cited in Davies et al,	Davies et al (2001)	47	Eight parenting dimensions (not stated what these are) which make two scales; warmth and	For the study sample: Warmth (0.85) Strictness (0.49)	Strictness scale split into its 3 dimensions.

2001; Slater & Power,
1987, as cited in Davies
et al, 2001)

strictness.

Due to low internal consistency of
strictness, the three dimensions which
comprise the scale were used instead:
Restrictiveness (0.72)
Amount of Control (0.61)
Physical Punishment (0.85)
Study does not report original studies
alpha levels but states that the
measure's reliability and validity have
been supported by factor analysis and
cross-validation.

Parental Authority
Questionnaire (Buri,
1993, as cited in Shorer
et al, 2011)

Shorer et al (2011)

Does not
state in study

Does not state in study

Does not state in study either for study
sample or the original study.

None reported.

Parent Practices Report
(Robinson et al, 1995, as
cited in Greene et al,
2010)

Greene et al (2010)

62

3 Subscales
Authoritative – 27 items
Authoritarian – 20
Permissive - 15

For the study sample:
For mothers – Authoritative (0.91),
Authoritarian (0.87) and Permissive
(0.75).

None reported.

				For fathers – Authoritative (0.88), Authoritarian (0.86) and Permissive (0.75). Study does not report original study’s internal consistency results.	
Parenting Styles and Dimensions Questionnaire (Robinson et al, 2001, as cited in Monaghan et al, 2012)	Monaghan et al (2012)	32	3 scales – Authoritative Authoritarian Permissive	For the study sample : Authoritative (0.84) Authoritarian (0.70) Permissive (0.74) Study reported that the original study has found that the 3 scales have good to excellent internal consistency reliabilities.	None reported.

Table 4. Characteristics of Parenting Style Measures as described by Reviewed Studies

Measures of Metabolic Control

Six of the studies measured the young persons' HbA1c results. Some studies only used the most recent result HbA1c result (Davies et al, 2001; Sherifali et al, 2009) whereas other studies averaged the HbA1c results across longer time periods (Greene et al, 2010; Mlynarczyk, 2013; Monaghan et al, 2012; Shorer et al, 2011). Most studies took into consideration the “honeymoon” period⁷ that occurs following T1DM diagnosis.

Quality Assessment

All included studies were quality assessed. Inter-rater reliability was assessed and there was 95% agreement in scores between reviewers⁸. An in depth summary of quality rating scores are presented in Appendix F. Quality ratings ranged from seven (Shorer et al, 2011) to nine (Monaghan et al, 2012; Sherifali et al, 2009). The checklist had a maximum score of 11. Mean quality rating score was 8.21 (SD=0.70). Only two studies reported a sample size calculation (Monaghan et al, 2012; Sherifali et al, 2009). Five studies did not report actual probability values and rounded them to 0.05, 0.01 or 0.001, whereas two reported actual values (Davies et al, 2001; Mlynarczyk, 2013). Only one study clearly reported that they had asked subjects to participate that were representative of the entire population from which they were recruited (Sherifali et al, 2009). All included studies reported clear aims and objectives, clearly described the main outcomes to be measured, the characteristics of participants and main findings; all used appropriate statistical tests.

⁷ Honeymoon period refers to a period of time after being newly diagnosed with T1DM, where the pancreas is still able to produce some insulin from the surviving beta cells, however once these remaining cells are attacked by the body's immune system the pancreas will no longer be able to produce sufficient insulin to manage blood glucose levels (Diabetes.co.uk, 2015b)

⁸ When there were disagreements between the reviewers' quality ratings, both reviewers explained their reasons for their ratings and these were taken into consideration. However as there was 95% agreement in scores between reviewers, the original ratings were used for the purpose of the review.

Name of Measure	Study included in the Review using Measure	Number of Items	Subscales	Internal Consistency in Studies (Cronbach's alpha (α) unless stated otherwise)	Details of Alterations
Diabetic Behaviour Rating Scale (Cook, Aikens, Berry & McNabb, 2001, as cited in Mlynarczyk, 2013; McNabb, Quinn, Murphy, Thorp & Cook, 1994, as cited in Mlynarczyk, 2013)	Mlynarczyk (2013)	39	Split into behavioural frequency items and degree of responsibility items	<p>For the study sample: Behavioural Frequency (0.85) Degree of Responsibility (0.95)</p> <p>Original study alpha levels reported in the reviewed study: Behavioural Frequency (0.86) Degree of Responsibility (0.94)</p>	For the study, only the results from the Behavioural Frequency Items were used for diabetes adherence.
Self Care Inventory (La Greca, Follansbee &	Butler et al (2007)	14	None reported	For the study sample (0.73)	None reported

Skyler, 1990, as cited in Butler et al, 2007; La Greca, 2004, as cited in Monaghan et al, 2012)	Davis et al (2001)	For this study, the sample reported using 6 out of 7 items that create an overall adherence score.	None reported.	Study did not report on original alpha levels For the study sample (0.80) Study reported that the Self Care Inventory has been found to have good internal consistency (0.84)	Items looking at “exercising regularly” were excluded as they reduced the internal consistency to 0.76
	Monaghan et al (2012)	14	None reported	For study sample (0.79) Study reported that the Self Care Inventory has been found to have acceptable reliability and validity	None reported
Adherence to Diabetes Treatment Regimen Questionnaire (Tov- Katzav, 2007, as cited in Shorer et al, 2011)	Shorer et al (2011)	Not stated in study	Not stated in study	Not stated in study	Not stated in study

Diabetes Self-Care Instrument (Designed by research team – Greene et al, 2010)	Greene et al (2010)	12	None reported	Research team developed measure and the alpha level for the study sample was 0.79	None reported
--	---------------------	----	---------------	---	---------------

Table 5. Characteristics of Diabetes Adherence Measures as described by Reviewed Studies

Parenting Style

Four studies provided descriptive statistics for the reported PS (Greene et al, 2010; Mlynarczyk, 2013; Monaghan et al, 2012; Sherifali et al, 2009). Three studies used only parental reports of the PS adopted (Greene et al, 2010; Monaghan et al, 2012; Sherifali et al, 2009) and for these studies, the authoritative PS predominated. One study used only adolescents' reports of PS (Mlynarczyk, 2013) and the variance within PS reported was greater, with permissive PS being predominant followed by authoritative PS. Butler et al (2007) measured both mothers and adolescents reports of PS and found moderate correlations between the adolescent and mother reports; psychological control ($r=0.42$, $p<0.01$), firm control ($r=0.41$, $p<0.01$), acceptance ($r=0.32$, $p<0.01$). No descriptive statistics were reported for adolescent and mother reports on these dimensions.

Parenting Style and Adherence

Mlynarczyk (2013) investigated adolescents' (aged 12-18) perceptions of the effect of PS on diabetes adherence. They report authoritative PS had significantly better adherence scores after Post-Hoc Least Significant Difference analysis than the authoritarian ($p=0.024$), permissive ($p=0.013$) and neglectful ($p=0.013$) PS.

Parental reports on the effect of PS on children's (aged 8-11) adherence have also found authoritative PS to be influential. Parents reporting higher levels of authoritative parenting reported better adherence levels compared to parents who report lower levels of authoritative parenting ($F(4,88)=0.35$, $p<0.01$, partial $\eta^2=0.08$) when ethnicity, income and diabetes regime were covariates (Monaghan et al, 2012).

Shorer et al (2011) assessed the parents of 100 adolescents on how both maternal and paternal PS affect adherence. Better adherence was significantly associated with fathers

adopting an authoritative PS ($r=0.24$, $p<0.05$). Poorer adherence was significantly associated with higher levels of permissiveness in mothers ($r=0.25$, $p<0.05$) and when the analysis was limited to just boys, higher levels of maternal authoritarianism, however no statistical data was reported for this.

Greene et al (2010) investigated both the effect of PS on adolescents' diabetes adherence and its effect on individual adherence behaviours. For overall adherence, authoritative mothering was associated with better self-reported adherence ($r=0.639$, $p<0.01$) and neither permissive nor authoritarian parenting for either mother or father were significantly associated with adherence. Authoritative mothering was significantly associated with better self-reported adherence for most of the individual adherence behaviours except for 'low fat diet', 'meals on time' and 'not skipping meals'. Compared to authoritative mothering, authoritative fathering did not have as many significant associations with individual adherence behaviours. Authoritative fathering significantly correlated with 'not skipping meals' ($r=0.375$, $p<0.05$), 'checking blood glucose' ($r=0.396$, $p<0.05$) and 'giving insulin' ($r=0.466$, $p<0.05$). Both permissive and authoritarian mothering were significantly associated with poorer adherence to a low fat diet ($r=-0.0374$, $p<0.05$; $r=-0.0396$, $p<0.05$ respectively), however both permissive and authoritarian fathering were not significantly correlated with any individualised adherence behaviours. Greene et al (2010) also examined associations between PS and adherence when controlling for child age and duration of diabetes and found that authoritative mothering was a significant predictor ($\beta=0.63$, $p<0.001$) and accounted for 36% of the variance. Although these results have been found to be significant, the sample size used for the study was small ($n=29$ Adolescent-Parent dyads) as the study claimed to be a pilot study and did not report a sample size calculation, therefore these results could be different if investigated in a larger sample.

Butler et al (2007) and Davies et al (2001) also assessed the association between PS and adherence; however they split PS into dimensions. Butler et al (2007) investigated maternal PS and found that maternal reports of acceptance was significantly associated with adherence ($r=0.24$, $p<0.05$) but neither psychological control, firm control nor any of the adolescents' reports significantly correlated with adherence. Davies et al (2001) investigated parental reports of PS and its effect on their children's (aged 4-10) diabetes adherence. Davies et al (2001) found that parental warmth significantly correlated with better adherence ($r=0.56$, $p<0.001$) but parental restrictiveness was not associated with poorer adherence. When using regression analysis, parental warmth was the only significant predictor ($\beta=0.32$, $p<0.001$ accounting for 27% of the variance).

Parenting Style and Metabolic Control

Six studies investigated the relationship between PS and metabolic control. Shorer et al (2011) reported that higher levels of authoritativeness in fathers only was significantly associated with better metabolic control ($r=0.35$, $p<0.05$) in adolescents. Authoritarian parenting was reported to have insignificant poor correlations to metabolic control for both mothers and fathers. When Shorer et al (2011) analysed the data with a regression analysis, they found that no PS significantly predicted metabolic control, when controlling for the adolescent's age, sex and treatment method.

Greene et al (2010) concluded that authoritative mothering was significantly associated with better metabolic control ($r=-0.458$, $p<0.05$). They also reported that permissive mothering and fathering were significantly correlated with poorer metabolic control ($r=0.358$, $p<0.05$; $r=0.395$, $p<0.05$, respectively). Authoritarian parenting was not significantly correlated to metabolic control. Greene et al (2010) conducted a regression

analysis resulting in authoritative mothering being the strongest predictor of metabolic control ($\beta=-0.52$, $p<0.01$) accounting for 25% of the variance in HbA1c levels.

Davies et al (2001) found significant effects of PS on metabolic control; however they split PS into the dimensions of warmth, restrictiveness, amount of control and physical punishment. Warmth was not significantly associated with metabolic control ($r=-0.05$, NS). Restrictiveness had a significant association with poorer metabolic control ($r=0.36$, $p<0.05$). Davies et al (2001) also performed a hierarchical regression finding that no parenting variables improved the regression model when predicting metabolic control ($R^2\Delta=0.03$, $p>0.10$).

Three studies did not find significant associations between PS and metabolic control (Mlynarczyk, 2013; Monaghan et al, 2012; Sherifali et al, 2009). Mlynarczyk (2013) used a one-way ANOVA to determine significant differences between authoritative parenting and each of the other PS; authoritarian, permissive and neglectful on metabolic control and found that there were no significant differences. However, Mlynarczyk (2013) did not assess each PS individually with respect as to whether a specific PS may have had a significant effect on metabolic control.

Monaghan et al (2012) also found no significant differences however they only tested if there were a significant difference between high and low levels of authoritative parenting on metabolic control. They too did not investigate the effect of each typology on metabolic control individually. The study also only looked at the difference between levels of authoritativeness, as 97% of the parents in the sample were reported to primarily use this style, and therefore no analyses were performed on the other PS.

Sherifali et al (2009) assessed the association between PS and the children's (aged 5-12) individual metabolic control, however instead of using the typologies as the different

forms of PS; they used the dimensions of support, control and structure. They found no significant correlations between any of the parenting dimensions and metabolic control.

Discussion

This review aimed to investigate the impact of PS on diabetes management in young people with T1DM. The review looked at the impact of PS on two aspects of diabetes management; adherence and metabolic control.

Summary of Key Findings

The review suggests that authoritative parenting may be related to better diabetes adherence in young people with T1DM from both parent and adolescent reports. Adolescents who perceived their parents to use an authoritative PS had significantly better adherence scores than adolescents who perceived their parents to use authoritarian, permissive or neglectful PS (Mylnarczyk, 2013).

Greene et al (2010) found that authoritative mothers were significantly associated with better overall adherence in adolescents, whereas authoritative fathers were not significantly associated with better overall adherence, but were significantly associated to better adherence to the behaviours of ‘not skipping meals’, ‘checking blood glucose’ and ‘giving insulin’. Greene et al (2010) also concluded that authoritative mothers were a significant predictor of better adherence, when controlling for age and duration of diabetes. Although these findings are positive, the sample size for this study was small and did not state the percentage or frequency of the amount of mothers and fathers participating in the study. Fathers are typically under represented within paediatric psychology research (Phares, Lopez, Fields, Kamboukos & Duhig, 2005) and therefore it may be that authoritative fathering did not gain enough power to be significant. Shorer et al (2011) also assessed parental reports of PS individually but their sample of mothers and fathers was made explicit

and was more equally distributed with 79 mothers and 63 fathers. Interestingly in this study authoritative mothering did not reach statistical significance for better adherence in adolescents with T1DM, but authoritative fathering did. One reason for this could be cultural difference; the study sample was from Israel, whereas all of the other study samples were from the USA.

Authoritative parenting was found to have significant associations with better adherence in children aged 8 to 11. Monaghan et al (2012) found parents who used higher levels of authoritativeness reported significantly better adherence scores compared to parents who used lower levels of authoritativeness. The study only investigated authoritative parenting as 97% of the parents were identified as being predominantly authoritative in their PS. Therefore the study compared parents reporting higher levels of authoritative behaviours against parents who utilised less authoritative behaviours. These results need to be viewed cautiously as both the PS measure and the adherence measure were parental self-reports therefore the scores may be influenced by social desirability.

Permissive and authoritarian parenting may lead to poorer adherence. Shorer et al (2011) reported that a higher level of permissiveness in mothers was significantly associated with poorer adherence. They also reported that a higher level of authoritarianism in mothers was significantly associated with poorer adherence, when the analysis was limited to just boys. Greene et al (2010) found that both permissive and authoritarian mothering were significantly associated with poorer adherence to a low fat diet. Interestingly, permissiveness and authoritarianism in fathers, for both of these studies did not reach significance. Perhaps owing to fathers typically not named as the primary care giver (Dashiff, Morrison & Rowe, 2008) and therefore less involved children's diabetes management. However, authoritative fathering may have an impact on a child's diabetes adherence (Greene et al, 2010). Therefore

fathers who are actively involved or are the primary care giver for their child's diabetes management may be most likely to use an authoritative PS.

When PS was conceptualised as dimensions, warmth/acceptance was associated with better adherence using parental reports of PS (Butler et al, 2007; Davies et al, 2001). However, when using adolescent reports, none of the dimensions of acceptance, psychological control or firm control were significantly associated with adherence (Butler et al, 2007). Restrictiveness as reported by parents was also not significantly associated with adherence (Davies et al, 2001). However these results need to be interpreted cautiously as parenting dimensions were measured using self-reports. All of the positive parenting dimensions are significantly correlated with adherence but none of the dimensions that could be perceived as negative, such as restrictiveness and control are. This may again be due to social desirability. However, if self-reporting is accurate, it may be that dimensions such as restrictiveness and control do not significantly correlate with adherence as they have a negative impact. This negative impact may occur due to parents not inspiring their children to improve their diabetes adherence or by reducing their child's belief of how capable they are of managing their own diabetes.

The review suggests that authoritative parenting may also have a significant association with better metabolic control. Shorer et al (2011) found a significant association between higher levels of authoritative fathering and better metabolic control. There was no significant association between authoritative mothering and metabolic control. Greene et al (2010) reported that authoritative mothering was significantly associated with better metabolic control and that authoritative mothering was also the strongest predictor of metabolic control.

The findings of the review suggest that permissive mothering and fathering are significantly associated with poorer metabolic control (Greene et al, 2010) and authoritarian mothering and fathering correlated with poorer metabolic control; however this did not reach significance. Restrictiveness was also found to be significantly associated with poorer metabolic control (Davies et al, 2001).

Three studies looking at the impact of PS on metabolic control did not find any significant associations between any of the PS. Monaghan et al (2012) and Sherifali et al (2009) both investigated the impact of PS for children aged 8-11 and 5-12, respectively. These findings could suggest that the style of parenting may have less impact on young children but have a larger impact during adolescence when the young person is expected to become more autonomous in their diabetes management and when they are more attuned to what their parents are doing. However Mylnarczyk (2013) investigated adolescents with T1DM and found no significant association between PS and metabolic control.

The findings of the review add to the growing literature that using an authoritative PS may be related to better outcomes for children with chronic conditions such as cerebral palsy (Aran, Shalev, Biran & Gross-Tsur, 2007) and cancer (Manne, Jacobsen, Gorfinkle, Gerstein & Redd, 1993). Authoritative parenting may be effective in helping children to successfully manage their diabetes as authoritative parenting is warm and supportive but also has firm and clear boundaries that the child has to follow (Baumrind, 2013). Having firm, clear boundaries allows children to know parents' expectations and because authoritative parents are also warm and supportive, it could be hypothesised that children feel that they can meet parental expectations. This enables greater diabetes self-efficacy which could improve their diabetes management. Qazi (2009) found that authoritative PS was significantly associated with increased generalised self-efficacy in those aged 15-21, whereas permissive and authoritarian PS were not significantly associated with self-efficacy. Tam, Chong, Kadirvelu and Khoo

(2012) also reported similar findings in those aged 16-21. Self-efficacy, both generalised and diabetes specific were also found to be significantly associated with better adherence and metabolic control in adolescents and young adults with insulin dependent diabetes (Griva, Myers & Newman, 2000).

The literature and this review support the trans-theoretical model of health behaviour change (Prochaska & Velicer, 1997) which highlights the importance of motivation, decisional balance (pros and cons of change) and self-efficacy in health behaviour change. This review suggests that authoritative parenting may be related to better diabetes management. This may be linked to authoritative parenting potentially increasing their child's general and diabetes specific self-efficacy which makes it more likely that their child would engage in better diabetes adherence behaviours. Permissive parenting may decrease a child's motivation to change their behaviours as well limiting their child's self-efficacy leading to poorer diabetes management, which would also link to the findings of the review. Authoritarian parenting may decrease a child's self-efficacy and motivation due to the lack of warmth and support and being given orders, which may cause their child to have poorer adherence and potentially a rebellion against their parent's 'orders' and their diabetes.

Although PS appears to impact on diabetes management, the findings of the review suggest that adherence (versus metabolic control) can be influenced more by PS. One hypothesis for this is due to how physiology can impact on metabolic control. During puberty, an adolescent's insulin sensitivity decreases meaning that more insulin is needed to maintain blood glucose levels (Diabetes.co.uk, 2015c). Also hormonal changes such as a large increase in the growth hormone can also impact on an adolescent's blood glucose levels (Tfayli & Arslanian, 2007). Therefore, although a young person may be managing their diabetes well externally, what is happening to their bodies internally can impact on their metabolic levels meaning that PS may have less of an impact on metabolic control. Metabolic

control was measured across studies in a variety of ways which may have impacted on the results of the studies. Some studies only used the most recent HbA1c result and some averaged the young persons' results over a period of time.

Interestingly, when parents were self-reporting on PS most reported a predominantly authoritative PS. However, when adolescents were asked to complete a questionnaire about their parents' PS, authoritative was not the most predominant PS (Mlynarczyk, 2013). Butler et al (2007) assessed both adolescent and maternal reports of PS and found that they were moderately correlated, but the questionnaires were completed at home and posted back to the researchers. Consequently the questionnaires may have been completed together and the adolescent may have answered the questionnaire in a way that would please the mother. Further research should be undertaken into adolescents with T1DM's perceptions of PS and to investigate the similarities and differences between the young person and their parents' reports.

Across the studies, the questionnaires used to measure PS were all different barring two studies (Sherifali et al, 2009; Davies et al, 2001). However, there appear to be discrepancies between the descriptions of the measure. Davis et al (2001) reported that the PDI split into two scales of warmth and strictness which are comprised from 8 dimensions. Sherifali et al (2009) reported that the PDI split into three parenting dimensions of support, control and structure which are comprised from 9 uni-dimensional scales. Although most studies used different measures of PS, the majority of measures had acceptable internal consistency. Differing measures may measure the concept of PS in different ways especially when studies conceptualised PS in different manners e.g. using a dimensional approach over Baumrind's typological approach. Therefore although comparisons can be made between results, the impact of the variety of measures used needs to be kept in mind.

Limitations of the Review

One limitation of this review is that articles were only included if they were peer reviewed and available in the English language. Although this was done to increase methodological rigour, it did stop the review from gaining information from other sources e.g. dissertations and theses. Therefore data may have been missed that could have added to the information derived from included articles.

Only correlational/cross sectional studies were included as the review wanted to look at the direct relationship between PS and diabetes management. This may have limited the amount of information that was available to the review; the review has been able to highlight discrepancies between quantitative studies. Adding qualitative or prospective studies, while being useful for the results, may have complicated the review which aimed to look at the direct impact of PS on diabetes management.

On the contrary, using only correlational data has its own limitations. Although the review has taken the stance of PS impacting on diabetes management, as correlational data cannot distinguish cause and effect, it may be that diabetes management affects the PS used. If a young person is managing their diabetes effectively, parents may be able to take a more authoritative or permissive approach as their child is managing their diabetes and ultimately their health well. Conversely poor management may increase parental anxiety about their child's health. Therefore anxious parents may feel the need to take a more authoritarian approach and take control of their child's diabetes management (Cameron, Young & Wiebe, 2007). Although the review looks at the direct relationship between PS and diabetes management it needs to be acknowledged that other factors including mood, social life, other family dynamics, stress and puberty may also impact on a young person's diabetes management (Borus & Laffel, 2010).

This review is the first to evaluate studies investigating the impact of PS on diabetes management and this in itself leads to its own limitations. Research into this area is in the early stages of development and therefore only a limited amount of research was available. Therefore when assessing the quality of the studies included, no studies were excluded due to the quality of the research. This enabled the review to gather as much information as possible but may have led to a lower level of methodological rigour, meaning that only tentative conclusions can be made. Although only seven articles were reviewed it was interesting that different measures of PS and adherence were used within the studies. This may impact on the validity of the findings of the review as each measure may have been assessing the concepts in a slightly different manner.

The review investigated the impact of parenting styles on both children and adolescents' diabetes management. Four of the studies included adolescents, with mean ages of 14-15 and three of the included studies had samples of children, with mean ages between 7 and 9. Although the review concluded that authoritative parenting may be related to better diabetes management, consideration needs to be made that there are developmental differences between children and adolescents; therefore this review can only make tentative conclusions.

It is also worth commenting on the lack of variability between the studies reviewed. Six out of the seven studies conducted their research in the United States of America and for the majority of the studies mothers were highly represented within the samples and fathers less so, which may also impact on generalising the findings of the review.

Recommendations and Clinical Implications

This review highlights the need to investigate adolescents' and children's perspectives on PS and how this impacts on their diabetes management. Future research

investigating how young person's perspectives compare to their parents and why differences occur would add to existing literature.

Across all measures of PS, adherence and metabolic control there was great variability in how the constructs were measured and conceptualised. Although difficult to achieve due to researchers having differing views on theoretical models and how concepts should be measured, it would be helpful if there was more consistency in future research.

It would be helpful to both services and families if clinicians regularly assessed how parenting may be affecting the young person's diabetes management. The review suggests that PS may impact on both adherence and metabolic control and this is important as helping the young person to manage their diabetes effectively, reduces their chances of complications in the future (Olsen et al, 2000).

In order to help parents to support their child in managing their diabetes, the development of parenting interventions to promote authoritative behaviours would be beneficial. Research investigating the efficacy of such interventions would also be valuable to highlight the importance of involving family in the management of a young person's diabetes.

Conclusions

Due to this review being the first to evaluate the impact of PS on diabetes management, only tentative conclusions can be made. However the review suggests that PS may impact on young person's metabolic control and adherence. Authoritative parenting may be related to better outcomes when solely looking at the relationship between PS and diabetes management. Because of the correlational nature of the studies, it could be that diabetes management may affect what PS parents use with their child. However, it could be argued that such an influence would be on parenting practices versus style, as style goes across

contexts where as practices change depending on context e.g. diabetes management and achievements at school (Darling & Steinberg, 1993).

Future research needs to be more consistent in terms of how PS, adherence and metabolic control are measured as it is clear that they can be measured and conceptualised differently. Future research also needs to investigate young persons' perspectives on PS as only two studies investigated young persons' reports.

In summary, helping parents develop authoritative parenting skills/competencies may help to improve diabetes management. Subsequently this would reduce risk of future complications and ultimately the cost of diabetes management to the NHS. Additionally services need to be aware of how parenting affects the young people they are working with and parenting interventions could be developed to help parents provide evidence-based support to their children with diabetes in the most effective way.

References

(* references included in the systematic literature review)

- Anderson, B. J., Vangsness, L., Connell, A., Butler, D., Goebel-Fabbri, A., & Laffel, L. M. B. (2002). Family conflict, adherence, and glycaemic control in youth with short duration type 1 diabetes. *Diabetic Medicine*, 19(8), 635-642.
- Aran, A., Shalev, R. S., Biran, G., & Gross-Tsur, V. (2007). Parenting style impacts on quality of life in children with cerebral palsy. *The Journal of Pediatrics*, 151(1), 56-60.
- Baumrind, D. (1971). Current patterns of parental authority. *Developmental Psychology Monographs*, 4(1, Pt. 2), 1–103.
- Baumrind, D. (2013). Authoritative parenting revisited: History and current status. In Larzelere, R. E., Morris, A. S. E., & Harrist, A. W. (Eds.), *Authoritative parenting: Synthesizing nurturance and discipline for optimal child development* (pp. 11-34). Washington DC: American Psychological Association.
- Barber, B. K. (1996). Parental psychological control: Revisiting a neglected construct. *Child development*, 67(6), 3296-3319.
- Bean, R. A., Barber, B. K., & Crane, D. R. (2006). Parental Support, Behavioral Control, and Psychological Control Among African American Youth The Relationships to Academic Grades, Delinquency, and Depression. *Journal of Family Issues*, 27(10), 1335-1355.
- Borus, J. S., & Laffel, L. (2010). Adherence challenges in the management of type 1 diabetes in adolescents: prevention and intervention. *Current Opinion in Pediatrics*, 22(4), 405.

- *Butler, J. M., Skinner, M., Gelfand, D., Berg, C. A., & Wiebe, D. J. (2007). Maternal parenting style and adjustment in adolescents with type I diabetes. *Journal of Pediatric Psychology, 32*(10), 1227-1237.
- Cameron, L. D., Young, M. J., & Wiebe, D. J. (2007). Maternal trait anxiety and diabetes control in adolescents with type 1 diabetes. *Journal of Pediatric Psychology, 32*(7), 733-744.
- Darling, N., & Steinberg, L. (1993). Parenting style as context: An integrative model. *Psychological Bulletin, 113*(3), 487.
- Dashiff, C., Morrison, S., & Rowe, J. (2008). Fathers of children and adolescents with diabetes: what do we know?. *Journal of Pediatric Nursing, 23*(2), 101-119.
- *Davis, C. L., Delamater, A. M., Shaw, K. H., La Greca, A. M., Eidson, M. S., Perez-Rodriguez, J. E., & Nemery, R. (2001). Parenting styles, regimen adherence, and glycemic control in 4-to 10-year-old children with diabetes. *Journal of Pediatric Psychology, 26*(2), 123-129.
- Diabetes.co.uk. (2015a). Guide to HbA1c. Retrieved 25 February 2015, from <http://www.diabetes.co.uk/what-is-hba1c.html>.
- Diabetes.co.uk. (2015b).Honeymoon Phase. Retrieved 12 March 2015, from <http://www.diabetes.co.uk/blood-glucose/honeymoon-phase.html>.
- Diabetes.co.uk. (2015c). Insulin Sensitivity. Retrieved 27 April 2015, from <http://www.diabetes.co.uk/insulin/insulin-sensitivity.html>.

Diabetes UK. (2014a). The Cost of Diabetes Report. Retrieved 23 April 2015, from <https://www.diabetes.org.uk/Documents/Diabetes%20UK%20Cost%20of%20Diabetes%20Report.pdf>

Diabetes UK (2014b). Diabetes: Facts and Stats. Retrieved 23 April 2015, from <https://www.diabetes.org.uk/Documents/About%20Us/Statistics/Diabetes-key-stats-guidelines-April2014.pdf>

Downs, S. H., & Black, N. (1998). The feasibility of creating a checklist for the assessment of the methodological quality both of randomised and non-randomised studies of health care interventions. *Journal of Epidemiology and Community Health*, 52(6), 377-384.

Fox, C. & Kilvert, A. (2008). *Type 1 diabetes: Answers at your fingertips*. (6th ed.). UK: Class Publishing.

*Greene, M. S., Mandelco, B., Roper, S. O., Marshall, E. S., & Dyches, T. (2010). Metabolic control, self-care behaviors, and parenting in adolescents with type 1 diabetes a correlational study. *The Diabetes Educator*, 36(2), 326-336.

Griva, K., Myers, L. B., & Newman, S. (2000). Illness perceptions and self efficacy beliefs in adolescents and young adults with insulin dependent diabetes mellitus. *Psychology and Health*, 15(6), 733-750.

Helgeson, V. S., Reynolds, K. A., Siminerio, L., Escobar, O., & Becker, D. (2008). Parent and adolescent distribution of responsibility for diabetes self-care: Links to health outcomes. *Journal of Pediatric Psychology*, 33(5), 497-508.

Holt, T., & Kumar, S. (2010). *ABC of Diabetes*. John Wiley & Sons.

- Johnson, S. B. (1992). Methodological issues in diabetes research: measuring adherence. *Diabetes Care*, *15*(11), 1658-1667.
- Manne, S. L., Jacobsen, P. B., Gorfinkle, K., Gerstein, F., & Redd, W. H. (1993). Treatment adherence difficulties among children with cancer: The role of parenting style. *Journal of Pediatric Psychology*, *18*(1), 47-62.
- Mellin, A. E., Neumark-Sztainer, D., & Patterson, J. M. (2004). Parenting adolescent girls with type 1 diabetes: parents' perspectives. *Journal of Pediatric Psychology*, *29*(3), 221-230.
- *Mlynarczyk, S. M. (2013). Adolescents' perspectives of parental practices influence diabetic adherence and quality of life. *Pediatric Nursing*, *39*(4), 181-189.
- *Monaghan, M., Horn, I. B., Alvarez, V., Cogen, F. R., & Streisand, R. (2012). Authoritative parenting, parenting stress, and self-care in pre-adolescents with type 1 diabetes. *Journal of Clinical psychology in Medical Settings*, *19*(3), 255-261.
- Naranjo, D., Mulvaney, S., McGrath, M., Garner, T., & Hood, K. (2014). Predictors of Self-Management in Pediatric Type 1 Diabetes: Individual, Family, Systemic, and Technologic Influences. *Current diabetes reports*, *14*(11), 1-8.
- Nardi, L., Zucchini, S., D'Alberon, F., Salardi, S., Maltoni, G., Bisacchi, N., ... & Cicognani, A. (2008). Quality of life, psychological adjustment and metabolic control in youths with type 1 diabetes: a study with self-and parent-report questionnaires. *Pediatric Diabetes*, *9*(5), 496-503.
- National Health Service. (2014). Diabetes Type 1. Retrieved 21 February 2015, from <http://www.nhs.uk/Conditions/Diabetes-type1/Pages/Introduction.aspx>.

National Health Service. (2012). Diabetes Type 1. Retrieved 13 April 2015, from

<http://www.nhs.uk/Conditions/Diabetes-type1/Pages/Introduction.aspx>.

National Institute for Health Care and Excellence. (2015). Diabetes (Type 1 and Type 2) in

Children and Young People: Diagnosis and Management. Retrieved 07 December

2015, from [http://www.nice.org.uk/guidance/ng18/resources/diabetes-type-1-and-](http://www.nice.org.uk/guidance/ng18/resources/diabetes-type-1-and-type-2-in-children-and-young-people-diagnosis-and-management-1837278149317)

[type-2-in-children-and-young-people-diagnosis-and-management-1837278149317](http://www.nice.org.uk/guidance/ng18/resources/diabetes-type-1-and-type-2-in-children-and-young-people-diagnosis-and-management-1837278149317).

Olsen, B. S., Sjølie, A. K., Hougaard, P., Johannesen, J., Borch-Johnsen, K., Marinelli, K., ...

& of Diabetes, T. D. S. G. (2000). A 6-year nationwide cohort study of glycaemic

control in young people with type 1 diabetes: risk markers for the development of

retinopathy, nephropathy and neuropathy. *Journal of Diabetes and its*

Complications, 14(6), 295-300.

Phares, V., Lopez, E., Fields, S., Kamboukos, D., & Duhig, A. M. (2005). Are fathers

involved in pediatric psychology research and treatment?. *Journal of Pediatric*

Psychology, 30(8), 631-643.

Prochaska, J. O., & Velicer, W. F. (1997). The transtheoretical model of health behavior

change. *American Journal of Health Promotion*, 12(1), 38-48.

Qazi, T. (2009). Parenting Style, Locus of Control and Self-efficacy: A Correlational Study

Estilos de crianza, locus de control y autoeficacia percibida: Un estudio

correlacional. *Revista Costarricense de Psicología*, 28(41-42), 75-84.

Rankin, D., Harden, J., Waugh, N., Noyes, K., Barnard, K. D., Stephen, J., ... & Lawton, J.

(2014). Pathways to diagnosis: A qualitative study of the experiences and emotional

reactions of parents of children diagnosed with type 1 diabetes. *Pediatric Diabetes*,

15(8), 591-598.

- Reynolds, T. M., Smellie, W. S. A., & Twomey, P. J. (2006). Cases in primary care laboratory medicine: Glycated haemoglobin (HbA1c) monitoring. *BMJ: British Medical Journal*, 333(7568), 586.
- Rubin, R. R., & Peyrot, M. (2001). Psychological issues and treatments for people with diabetes. *Journal of Clinical Psychology*, 57(4), 457-478.
- Sarkar, U., Fisher, L., & Schillinger, D. (2006). Is self-efficacy associated with diabetes self-management across race/ethnicity and health literacy?. *Diabetes Care*, 29(4), 823-829.
- *Sherifali, D., Ciliska, D., & O'Mara, L. (2009). Parenting Children with Diabetes Exploring Parenting Styles on Children Living With Type 1 Diabetes Mellitus. *The Diabetes Educator*, 35(3), 476-483.
- *Shorer, M., David, R., Schoenberg-Taz, M., Levavi-Lavi, I., Phillip, M., & Meyerovitch, J. (2011). Role of parenting style in achieving metabolic control in adolescents with type 1 diabetes. *Diabetes Care*, 34(8), 1735-1737.
- Silverstein, J., Klingensmith, G., Copeland, K., Plotnick, L., Kaufman, F., Laffel, L., ... & Clark, N. (2005). Care of children and adolescents with type 1 diabetes a statement of the American Diabetes Association. *Diabetes Care*, 28(1), 186-212.
- Taddeo, D., Egedy, M., & Frappier, J. Y. (2008). Adherence to treatment in adolescents. *Paediatrics & Child Health*, 13(1), 19.
- Tam, C. L., Chong, A., Kadirvelu, A., & Khoo, Y. T. (2013). Parenting styles and self- of adolescents: Malaysian scenario. *Global Journal of Human-Social Science Research*, 12(14-A), 19-25.

Tfayli, H., & Arslanian, S. (2007). The challenge of adolescence: hormonal changes and sensitivity to insulin. *Diabetes Voice*, 52, 28-30.

Van de Mortel, T. F. (2008). Faking it: social desirability response bias in self-report research. *Australian Journal of Advanced Nursing*, 25(4), 40-48.

Weinger, K., O'Donnell, K. A., & Ritholz, M. D. (2001). Adolescent views of diabetes-related parent conflict and support: a focus group analysis. *Journal of Adolescent Health*, 29(5), 330-336.

World Health Organisation. (2003). Adherence to Long-Term Therapies: Evidence for Action. Retrieved on 08 November 2015, from http://www.who.int/chp/knowledge/publications/adherence_full_report.pdf?ua=1.

Part Two: Empirical Paper

Adolescents with Type 1 Diabetes: An Exploration of Perceptions of Control

Cassie L. Ward^{1*}, Dr Dorothy J. Frizelle² and Dr Nikki McCloud³

^{1,2}Department of Psychological Health and Wellbeing, University of Hull, Hull, United
Kingdom, HU6 7RX.

³Rotherham, Doncaster and South Humber NHS Foundation Trust

* Corresponding Author: Telephone Number - 01482 464101

Fax: 01482 464093

Email: C.L.Ward@2012.hull.ac.uk

This paper is written in the format ready for submission to Qualitative Health Research.

Please see Appendix G for the Guidelines for Authors

Word Count: 9,325 (including abstract, tables, figures and references)

Abstract

Objective: Studies have found that personal and/or treatment control can impact on adolescents with type 1 diabetes (T1DM) management. There is no research investigating the experiences of adolescents with T1DM who have low personal and/or treatment control in relation to their diabetes. **Methods:** Interpretative Phenomenological Analysis (IPA) was used to analyse interviews with six adolescents with T1DM who perceive they have low personal and/or treatment control measured from the Brief Illness Perceptions Questionnaire. **Results:** Two super-ordinate themes and eight subordinate themes emerged from the data: Managing Diabetes – A Numbers Game, Frustration, Impact of Controlling Diabetes and Getting a Balance; Identity – Independence versus Dependence, Being Different, Diabetic Self, and Future Me. **Conclusions:** Services need to emphasise a holistic approach to diabetes management and help adolescents to develop self-compassion around their diabetes management.

Key Words: Type 1 Diabetes; Adolescents; Personal Control; Treatment Control; Interpretative Phenomenological Analysis.

Type 1 Diabetes

Type 1 Diabetes Mellitus (T1DM) is an autoimmune condition where an individual's immune system attacks cells in the pancreas (National Health Service; NHS, 2012a). This leads to an inability to produce the hormone insulin. Insulin is responsible for regulating blood glucose levels (Fox & Kilvert, 2008). Unregulated blood glucose levels can lead to health complications and be fatal if left untreated (not so extreme for diabetes ketoacidosis⁹ to occur).

T1DM is usually diagnosed during adolescence (NHS, 2012a) but it can develop at any age. There are around 400,000 individuals in the United Kingdom (UK) diagnosed with T1DM (NHS, 2012a), the prevalence under the age of 20 being 0.14% (Hall, 2007). Once diagnosed, individuals are dependent on insulin injections, or another form of insulin treatment, for life in order to achieve blood glucose levels at normal or near-normal levels (termed 'metabolic control'; HbA1c)¹⁰. Individuals with T1DM have to monitor many aspects of their life including eating, sleeping, physical activity, blood glucose levels and the amount of insulin needed to maintain a normal blood glucose level (Rubin & Peyrot, 2001). Education is given via health services on the importance of maintaining stable blood glucose levels, to reduce the risk of developing future physical complications, such as nephropathy¹¹ and retinopathy¹² (NHS, 2012b). With such a complicated treatment regime and the need to maintain optimal blood glucose levels, it is unsurprising that many people struggle to manage their diabetes effectively, with only 18.4% of children and young people achieving "excellent

⁹ Diabetes Ketoacidosis – When insulin is not present in the body and sugar cannot be used for energy, fat is broken down to provide the body with fuel but this also produces a by-product known as ketones. High levels of ketones can stop parts of the body working properly and in extreme cases can be fatal (NHS, 2013).

¹⁰ Metabolic control shows an individual's average blood glucose level over the previous 2 to 3 months, as red blood cells survive for 8-12 weeks (Diabetes.co.uk, 2015a)

¹¹ Nephropathy – Small blood vessels in the kidneys become blocked and leaky causing the kidneys not to work as efficiently (NHS, 2012b)

¹² Retinopathy – Blood vessels in the retina of the eye become blocked or leaky or can grow abnormally preventing light from passing fully through the retina, which can damage an individual's vision (NHS, 2012b)

diabetes control” and 23.9% of children and young people having “poor diabetes control” (Royal College of Paediatrics and Child Health, 2014).

Control

How an individual perceives their diagnosis can influence the way it is managed and one model which has examined this is Leventhal’s Self-Regulation Model (Leventhal, Diefenbach, & Leventhal, 1992). Illness representations are comprised of five components; illness identity and associated symptoms, cause, consequences of the illness, duration of the illness and control/cure (Leventhal et al, 1992). However in Moss-Morris’ (2002) paper it was decided that control/cure could be divided into two sub-components; treatment control and personal control. Treatment control is related to an individual’s belief in treatment or recommended advice and personal control is related to how much control an individual believes they have over their illness as well as their self-efficacy beliefs (Moss-Morris et al, 2002). The amount of treatment and/or personal control an adolescent believes they have over their diabetes may impact on how they manage their diabetes and may ultimately impact outcomes.

Adolescents with T1DM and Control

Adolescence can be a difficult time for individuals, without the addition of a diagnosis of T1DM. A relationship has been found between female adolescents’ low perceived levels of personal control and poor metabolic control (Schwartz, Weissberg-Benchell & Perlmutter, 2002). Schwartz et al (2002) defined a sense of personal control as a “measure of a person’s view that they have control, as well as the belief that they could gain control if they wished”.

Personal control may not only be related to metabolic control but also to aspects of the diabetes treatment regime. Griva, Myers and Newman (2000) found an association

between individuals with higher perceived control of their diabetes having greater self-reported adherence to many aspects of the diabetes treatment regime including diet, exercise, taking their insulin and blood glucose monitoring. Griva et al (2000) also found a significant association between individuals' level of perceived control over their illness and their self-efficacy beliefs, with individuals with higher levels of self-efficacy beliefs also having higher levels of perceived control. Hence, having high perceived personal control over diabetes can have a positive impact not only on diabetes management but also on self-efficacy beliefs.

Additionally, treatment control can have an impact on adolescents' diabetes management. Fortenberry et al (2012) found higher perceived treatment control was shown to moderate feelings of negative affect in adolescents dealing with daily problems related to diabetes. Lower perceived treatment control was related to a stronger association between negative affect and number of problems. Therefore, feeling in control of their diabetes helped adolescents to cope with the daily struggles associated with a diagnosis of T1DM.

Personal control can also impact on adolescents psychologically. Schwartz et al (2002) found that having a lower sense of overall personal control (which included need for control, sense of control and bodily control) and a lower sense of control over one's body were both directly related to female adolescents with T1DM having more severe disordered eating symptoms and poorer metabolic control. Disordered eating has also been found to be more prevalent in individuals with T1DM versus non-T1DM individuals (Jones, Lawson, Daneman, Olmsted & Rodin, 2000). Neumark-Sztainer et al (2002) found that 37.9% of females with T1DM and 15.9% of males with T1DM reported using unhealthy weight control practices/disordered eating, which included omitting or restricting their insulin. Research has also shown that adolescents with T1DM are more susceptible to developing psychological difficulty. Blanz, Rensch-Riemann, Fritz-Sigmund and Schmidt (1993) found that adolescents with T1DM were three times more likely to be diagnosed with a psychiatric

disorder versus individuals without T1DM. Anxiety and depression symptoms were also most significant in the T1DM group.

Current Study

There is no known research to date which explores the views of adolescents who may feel lower levels of control in relation to their diabetes; looking into their views as to why they may feel less in control, what impact this has on their lives, what they feel would be beneficial in helping them to gain a greater sense of control over their diabetes and how this would manifest for them. Such research could identify themes to be vigilant to, enabling services to better monitor adolescents' perceptions of control over their diabetes and for those adolescents who appear to be struggling, to guide interventions and initiate conversations around improved diabetes management. Such research could also provide services with adolescents' views of what *they* feel would be helpful to increase feelings of control around their diabetes. Therefore this study aimed to explore the experiences of adolescents with T1DM who have low perceived personal and/or treatment control over their diabetes. The research questions were:

- What are the experiences of adolescents who have low perceived personal and/or treatment control in relation to their diabetes?
 - What do adolescents believe contributes to their feelings of control?
 - What areas of their lives do their feelings of control affect?
 - How do their feelings of control affect them psychologically?
 - How do their feelings of control affect their diabetes management?
 - What do adolescents believe would be helpful for them to gain a greater sense of control over their diabetes?

Method

A qualitative design using semi-structured face to face interviews was used. Ethical approval from the relevant Research and Ethics Committee (see Appendix H) and research governance approval was obtained for each of the NHS trusts from which participants were recruited.

Participants

Participants were adolescents with T1DM between the ages of 14 and 19 who were currently receiving a service from one of four Paediatric Diabetes Teams within the North East of England. This age range was selected as at ages 14 to 19 adolescents with T1DM begin to take more responsibility for their diabetes management which may influence feelings of control around their diabetes. Participants were required to be able to speak English. Participants needed to demonstrate a low score on either of the Brief Illness Perception Questionnaire (BIPQ; Broadbent, Petrie, Main & Weinman, 2006) subscales for personal control and/or treatment control.

Twenty seven adolescents completed the BIPQ and 21 adolescents either did not reach the inclusion criteria (16) or did not want to be interviewed (5). Six participants took part and demographic data are shown in Table 6.

Demographic	Sample Range
Age	15-18 years
Gender	Female 5 Male 1
Current Educational status	Secondary School 3 College 2 Work 1
Duration of Diabetes	6 months – 11 years
Diabetes Treatment Method	Insulin Pump 3 Insulin Injections 3
Parents at Home	Biological Mother & Father 3 Biological Mother & Step Father 2 Foster Parents 1

Table 6. Demographic Characteristics of the Interviewed Sample

Measures

BIPQ – The BIPQ is a valid and reliable nine item measure investigating individuals’ illness perceptions (Broadbent et al, 2006). The BIPQ was used to screen whether participants met the inclusion criteria of low perceived personal and/or treatment control (see Appendix I). Item 3 assesses personal control and item 4 assesses treatment control. A cut off point of 5 or less for each item was used¹³. If a participant scored 5 or less on either item 3 or item 4 of the BIPQ they were invited back for interview.

Semi-Structured Interview - Interview questions were developed from the research questions guiding the study and the clinical and conceptual literature on perceived personal and treatment control in diabetes (see Appendix J for Interview Schedule). The questions

¹³ The researcher contacted one of the authors of the BIPQ to find out if there was a cut-off point to indicate when individuals were feeling low levels of personal and treatment control. The author (Broadbent) responded saying that there were no official cut off points but advised to start with a score of 6 or below.

focused on adolescents' experiences of having diabetes e.g. "Please can you tell me about your experience of being diagnosed with diabetes?" and their experiences around their feelings of control in relation to diabetes e.g. "Please can you tell me about your feelings of control over your diabetes?" The questions included within the schedule were open-ended to allow participants to share their experiences and to express their own perceptions of what "feelings of control" meant to them. Once the interview schedule was developed, service-user and peer feedback was obtained to ensure the questions were clear and understandable. Interviews were recorded so they could be transcribed verbatim for data analysis.

Procedure

Participants were recruited from paediatric diabetes clinics across five NHS sites and three trusts between February and April 2015. Potential participants were approached whilst waiting for clinic appointments. Information and consent forms were provided (see Appendices K and L respectively) and potential participants completed the BIPQ. Participants were told that they would be randomly selected for interview however, to be selected for interview, participants had to obtain a score of 5 or below on the personal and/or treatment subscales of the BIPQ. A degree of deception was necessary to reduce the likelihood of social desirability when participants completed the BIPQ and in order to get a true reflection of their control beliefs. This mitigated against participants putting a higher score to show the researcher that they perceived themselves to be more in control than they actually were.

Prior to interview, the participant was provided a further copy of the information sheet and a consent form to progress with the interview (see Appendix M). Interviews took place in private rooms with only the researcher and participant present and were audio recorded using a digital Dictaphone. On completion of the interview, participants were thanked and asked if

they had any questions. Each participant was sent a summary of the study once data analysis was completed. Contact details for the researcher were also provided so participants could contact them if they had any questions.

Data Analysis Procedures

Interpretative phenomenological analysis (IPA) was used to analyse data (see Appendix N and O for the epistemological statement and worked IPA example, respectively). Once interviews were completed, they were transcribed verbatim. After transcription, data analysis began, following the step by step procedure outlined by Smith, Flowers & Larkin (2009). The first author read and re-read one transcript, highlighting and making notes of text which stood out. These pieces of text were then examined to identify any emerging themes.

The emerging themes were then analysed to look for connections between themes in order to create subordinate themes. Once this process was completed, this process began again with the next transcript. Patterns across transcripts were examined leading to relabeling and reconfiguration of themes. To ensure the first author's interpretations were valid, the super-ordinate and subordinate themes, along with corresponding quotes were discussed with the other authors.

Results

Data analysis generated two super-ordinate themes which encompassed eight subordinate themes as shown in Table 7.

Super-ordinate Themes	Subordinate Themes
Managing Diabetes	<ul style="list-style-type: none"> • A Numbers Game • Frustration • Impact of Controlling Diabetes • Getting a Balance
Identity	<ul style="list-style-type: none"> • Independence versus Dependence • Being Different • Diabetic Self • Future Me

Table 7. Super-ordinate and Subordinate Themes Generated from Data Analysis

Managing Diabetes

A Numbers Game

Among most participants, there was a consensus that feelings of control are related to the “number” which indicates their blood glucose levels or their HbA1c. Feeling in control related to getting blood glucose levels “in range” and if they were too high participants began to feel less in control of their diabetes;

“ ...erm I don’t know sometimes I feel like I’ve got no control at all...erm ‘cause it seems that no matter what I do to try and either bring it down or keep it within that same range, summat cocks up and I feel like I’m completely out of control...” (Participant X, 209-213)

Although most participants related feelings of control to blood glucose levels, one participant recognised that feelings of control may be an internal concept rather than the external concept of blood glucose levels;

“...in terms of control I think I’ve got it under control but it depends how you feel in your mind, it’s not about the numbers” (Participant Y, 66-67)

It seemed that there was a view that being able to manage their diabetes better would improve their blood glucose levels, which would ultimately make them feel more in control of their diabetes. For some of the participants on injections, they were hoping that this would be the case when they transitioned onto the insulin pump¹⁴;

“...if I got a pump, that’d be really good, that’d help ‘cause I think new change in technology, that’s like a new fresh clean slate to start on, try and get that level number...”

(Participant X, 910-912)

Frustration

Among the majority of participants there appeared to be a general consensus that efforts made to manage their diabetes, and get the allusive “numbers”, regularly fell short. Although they felt that they were doing the best they could in their current situation, it appeared that the adolescents would become frustrated with themselves;

“...there are times when I just sit down and think what is it I’m doing wrong I’ve tried everything, why isn’t it working, why won’t it work, will it ever work?”

(Participant U, 290-292)

“...I just thought well I’ve done everything right, I was trying to think of what I’d done wrong and then but I was thinking no I’ve done everything right and that made me really mardy¹⁵...”

‘cause like whatever I do just dint work...’ (Participant N, 533-537)

As well as feeling frustrated with themselves, some of the adolescents felt frustrated when they followed advice from health care professionals and they did not get the results they were looking for;

¹⁴ An insulin pump is a device which delivers insulin into the body around the clock through a tube via a cannula, eliminating the need for insulin injections. (Diabetes UK, 2015)

¹⁵ Slang word for moody

“...I hate going to the clinic because I get told how rubbish my levels are and I’m like I know they’re rubbish but I’m...I am trying and then when I do try it doesn’t work and then when they go rubbish I don’t wanna bother ‘cause it’s just gonna be rubbish anyway”

(Participant V, 865-868)

“...Erm... it’s just difficult when you take advice that you’re given and you follow it to the best of your ability and you do everything that you feel you possibly... could do, it is incredibly frustrating if you don’t get the results you’re looking for...” (Participant U, 218-

223)

Interestingly, it seemed that one participant did not have these feelings of frustration when their blood glucose levels were not what they were expecting;

“...I’m just like oh if it’s high fuck it... have some insulin (laughs)” (Participant B, 329-331)

For some of the participants, there was a frustration with others due to others not understanding why they may be struggling to control their diabetes, what was happening for them personally and how this impacted on how in control they were of their diabetes;

“...they really support me and like they chat to me and stuff but I think when it comes down to the levels and stuff they don’t think about what I’m doing in my life that could affect it, they just think but you’ve eaten that food, this level should be this now... whereas they don’t think about...if I’m eating a little snack, if I just dot in some numbers but that’s because I shouldn’t be doing that... but I’m, you’re not always gonna be perfect and you’re not always gonna do that... but I don’t think they think about if I don’t want to do it or I don’t think they think about things that affect my diabetes personally...” (Participant V, 1147-1161)

For the majority of the adolescents, conflict between the adolescents and their parents, due to their diabetes management caused the adolescents frustration. There was a sense that

the adolescents did not feel their parents understood how their feelings of control affected how well they felt they could manage their diabetes.

“P - ...A few times my Mum said if you don’t then I’m gonna get involved... I’m gonna take over but that’s not actually happened... because I am in control

I – How does it feel when Mum says that then?

P – It annoys me because it’s hard but she doesn’t understand to the extent I do, she doesn’t have to go through it so its kinda like I wish you understood so then you’d know why I’m not as in control of it... then you wouldn’t say that you’d just try to be a bit nicer...”

(Participant Y, 638-649)

Impact of Controlling Diabetes

Unsurprisingly, when the adolescents did not feel as in control of their diabetes participants started to think about reasons why this may be, which, within the interviews, appeared to relate to their own competence in managing their diabetes;

“...Erm, if I’m having a day where my control is just poor... I can feel...very self absorbed... and I’ll start to sort of bully myself maybe, y’know you’re doing this wrong, this is all wrong, this is your fault etc...” (Participant U, 503-508)

“...That’s a, it can play on my mind if it’s not the number I wanted... but I suppose I’ve got that number, that’s what I’ve done... I can’t really blame anyone else...”

(Participant Y, 627-631)

There was recognition across the majority of the participants that diabetes affected them emotionally but it appeared that the adolescents had found strategies to help them to cope with this. One strategy used by participants was avoidance by either avoiding doing

blood glucose tests to stop them from seeing “negative” results, or by avoiding thinking about diabetes and the impact it has at present and in the future;

“...I don’t think about it I just try and brush it under the carpet to be honest”

(Participant V, 722)

“...and then I’ll get to the point where I don’t wanna test because they’re high... so then I don’t wanna face the fact that they’re high...” (Participant X, 751-754)

Some participants found that distracting themselves by engrossing themselves in an activity they enjoyed or being with their friends helped them to put diabetes in the background;

“...sometimes I just want to forget about it, like when I’m with my friends I forget that I’ve got it...” (Participant N, 564-565)

Interestingly, one participant expressed that they did not think about diabetes emotionally and managed their diabetes by ‘just doing it’;

“...I don’t really think of out like that, I just get on with it” (Participant B, 143)

Some acknowledged that their strategies may not be particularly helpful in terms of managing their diabetes most effectively and spoke about a “vicious cycle”;

“...I think when I feel like I’ve had bad levels... it makes me not wanna do tests because then I know it’s gonna be crap and then I’ll feel like rubbish because I’ll do a test and low behold it’s rubbish and then it just makes me not want to do tests because I don’t wanna see that I’m damaging my body... but then it’s just a vicious cycle with me not doing it and then it just gets worse...” (Participant V, 657-665)

Getting a Balance

One struggle for the adolescents was “getting a balance” between managing their diabetes and their life in general. Some participants were stressed about their GCSE examinations and some were struggling to manage their diabetes in social situations. Some were also finding it difficult to manage their diabetes due to work commitments and/or college. Getting a balance seemed to involve weighing up the pros and cons of what was more important to them in the current situation, but the ultimate goal was to manage both their life and their diabetes equally;

“...I think it’s sort of like a seesaw... erm I just want my lifestyle... on one side to be balanced with my diabetes which I would consider like a second life if you like?... There’s my life with my friends and family and which has to be kept level, I want to be happy in that, I want them to be happy and for me to be happy and then there’s my diabetes which I also want to be happy...” (Participant U, 665-674)

Identity

Independence versus Dependence

The interviews highlighted the ambivalence that teenagers can feel between becoming independent and still having a dependency on their parents, this was particularly apparent for their diabetes;

“...I was saying to my boyfriend I just want one day where no one mentions it and just lets me get on with it...” (Participant N, 572-573)

“...it’s not your diabetes. I say that to her and I’m like Mum it’s not your diabetes just give it a like a rest...” (Participant V, 576-577)

There was agreement amongst some participants that their parents' constant questioning affected them emotionally;

"...Erm so when my blood sugars are high... erm my Mum gets on my case... So then that stresses me out a bit more..." (Participant X, 463-467)

"...as soon as I get home Mum's like ohh how's your bloods been and I'm like oh for god sake..." (Participant N, 567-568)

"...Mum err makes me feel bad, like I know she's tryna [SIC] care and make me get on top of my diabetes (coughs) but erm she makes me feel really crap she's like come on let's do this test do this test you should be doing this you should be doing that and I feel like yeah I should be probably but I don't I...I'm gonna do it later I'll do it later and she makes me realise that I'm like slacking and I'm not doing what I'm supposed to be doing..."

(Participant V, 551-556)

Although some of the adolescents were frustrated with their parents for constantly questioning them about their diabetes, they all had an appreciation that this was due to them caring for the adolescent;

"...Well I know she's only doing it because she cares about me..." (Participant N, 556)

"...she's just really caring and I really love her... but sometimes it's like I just need to breathe I need to do it myself Mum..." (Participant V, 571-574)

Although seeking independence, adolescents reported a dependence on their parents' support to manage their diabetes and had concerns about the future when they would be solely responsible for their diabetes;

“...Well my Mum kinda helps me prepare the meal, she prepares the meals, weighs it out for me so she’s controlled that bit and then I have my bit to control...” (Participant Y, 516-518)

There was a sense that the adolescents wanted to be able to put their diabetes in the background but also recognised that their diabetes depends on them;

“...I refer to it as a baby because if you don’t look after it... then it’ll be neglected... and it’ll get worse and worse as time goes on... but if you look after it, then it’s gonna grow into something good and positive hopefully... and not affect your life as much ‘cause when babies get older they get more responsible so that’ll get older and it’ll become more in the background...” (Participant Y, 425-436)

Being Different

The majority of participants expressed a feeling of “being different”. It was apparent that this difference was related to their diabetes and how this made them different from other people;

“...I think more and more now I realise that there is a difference between having diabetes and not having it... and sometimes I would say that can be hard... I’ve had times were just sort of looked at myself and thought you know you are different” (Participant U, 74-81)

“...so I just think oh I’m different to my whole family now... like none of my family is the same as me...” (Participant N, 828-830)

For some participants the difference was more related to how they had to behave now they had diabetes;

“...obviously I have a role to do, I’ve gotta be a bit more grown up than everyone else, I can’t be messing around or being immature and forgetting. So I feel like I’ve had to stop not being normal but stop being my age...” (Participant Y, 473-475)

Other participants noticed a difference due to the physical presence of their insulin pump;

“...erm you care about looks and everything and it’s just... I don’t like having to think about like I can’t put my pump on my stomach today because I want to wear a crop top or... make sure you put it lower down today because I’m wearing high waisted jeans or something like that... So it’s just things like that whereas it would be nice I think to not have to think about that and that’s when I can see myself as being different...” (Participant U, 125-133)

Concerns were expressed around how others would perceive their diabetes and in turn themselves;

“...I dint want people to assume I was taking drugs... and that kind of thing and I just thought y’know for ease I’m just gonna keep it on the low down” (Participant X, 156-159)

“...I can remember I’m not sure if it was necessarily an experience of that but I remember with a pers...a boy I was in a relationship with a few years ago erm... my friend was talking to him about my diabetes... And I thought oh what if it scared him off or what if he thinks of me differently and that is definitely a feeling I still have... especially with the boys...”

(Participant U, 816-827)

Diabetic Self

For some of the participants, diabetes had been integrated into their life and their identity;

“...Obviously it’s always gonna be a massive part of your life maybe for good reasons... in fact that you’ve got control of it and then the negative reasons it’s not really that bad a thing for it to be significant... coz obviously it’s an illness so it’s gotta...it’s gotta be in your life... in some part but if you can push it to the back that’s better because although you remember to check and that, that’s two minutes, two minutes and then going back to normal and pushing it back to the background” (Participant Y, 455-465)

For one participant, integrating diabetes into their identity was something that they actively avoided;

“...what I mean, it’s like I can’t explain it, I know that I have diabetes, I accept that I have diabetes... and everything but then there’s...I don’t incorporate it into my life... or something? I don’t see myself as someone with diabetes...” (Participant V, 806-811)

However, regardless of how well integrated their diabetes is into their lives and identity; sometimes how others related the adolescent to the diabetes caused frustration for the participants;

“...sometimes I think I am human and I am allowed to get upset and get angry and all kind of emotions and it’s not because I’m diabetic it’s because I’m just human... just normal, I’m allowed to have emotions but then obviously my Mum’s going oh go and check your bloods and it’s like it’s not my diabetes, I’m just feeling emotional!... so it, obviously it gets me a bit frustrated...” (Participant X, 433-441)

“...she’s always like, the first thing she says is how is your diabetes, how are your levels, it’s like... can you ask me something else?... Like how’s college, how’s like your friends and everything... instead of how’s your levels...” (Participant V, 1204-1210)

Another relationship that the adolescents had with their diabetes was a sense that although they have diabetes, they would not let it stop them;

“...I came home and the first thing my mum said to me when we were home was... diabetes will change some things but it’s never gonna stop you from doing anything... we won’t let it and I have to say it never has stopped me from doing anything of course it’s... brought challenges in and it, I would say it makes life harder... but if I want to do something I’m not going to let it stop me” (Participant U, 199-207)

Future Me

Most of the participants talked about their futures and how what they do in the present can impact on how they may be in the future;

“...you’ve gotta look after it, if not the possibility is something bad could happen to you later on in your life...” (Participant Y, 419-420)

“...Err I think when I feel like I’ve let myself down like when I have high levels it makes me feel guilty... for future me...” (Participant V, 487-490)

A worry for the future that was predominant for four of the adolescents was how their diabetes may affect having children;

“...Y’know ‘cause I know right now I don’t want children but in later life maybe I do want children and what happens if I can’t have children and I have that choice taken away...”
(Participant X, 853-855)

“...I know I’m really young but that’s like my biggest fear to have like a child with a disability... or have something wrong with them because of my like diabetes...”
(Participant V, 502-505)

Discussion

The study aimed to explore the experiences of adolescents with T1DM who have low perceived personal and/or treatment control. With this knowledge services may be able to provide support to young people with diabetes that helps to improve their perceptions of control and ultimately improve their diabetes management.

What Contributes to Feelings of Control?

Within this study personal control in adolescents with T1DM was related to how they perceived they were managing their diabetes in respect of their blood glucose levels. However, relating personal control to blood glucose levels led to many of the participants feeling frustrated due to diabetes being variable/unpredictable in the way in which the body responds to insulin treatment, especially in the teenage years. It is known that growth hormone and puberty can impact on blood glucose levels as they both decrease insulin sensitivity (Diabetes.co.uk, 2015b; Tfayli & Arslanian, 2007). Participants felt that no matter how hard they tried, they could not control their diabetes to the extent they wanted and this led to frustration when others advice(e.g. health care professionals) also did not help. The adolescents' frustrations appeared to impact on them emotionally and led to the adolescents evaluating their diabetes control as being a product of their perceived inability to manage their diabetes well. A sense of helplessness can develop from feeling that efforts are not good enough, which can be described as poor diabetes self-efficacy¹⁶. Having poor diabetes self-efficacy can lead to feelings of ambivalence towards diabetes, which may lead to diabetes burnout (Fritschi & Quinn, 2010; Hilliard, Harris & Weissberg-Benchell, 2012). Conversely, the one participant who did not have feelings of frustration reported that when they had high blood glucose levels they would just 'get on with it' and not think about the future impact. It is therefore possible that this avoidance strategy served in some way to protect them

¹⁶ i.e.: the belief in one's ability to achieve metabolic control

emotionally from the worry of diabetes complications. Minimisation of the seriousness of high blood glucose levels may be protective in the short term but long term complications are clear.

Although participants felt they were trying their best, there were clear decisions being made between best diabetes management and optimal quality of life. For some participants who were on injections, there was clear hope that being transitioned onto an insulin pump would help them to get a better balance and to feel more in control of their diabetes.

Another theme was the sense of frustration that others did not understand how participants were affected by diabetes and how this impacted on feelings of control. The adolescents spoke about whilst feeling supported by the people around them (whether it be health professionals or family members); there was a sense that at times, others could not understand why they were not controlling their diabetes better, which led to conflict, particularly between the adolescents and their parents. These situations may illustrate a process known as ‘miscarried helping’ in which parents’ actions, whilst being done with the intent to help the child, lead the child to feel blamed and pressured (Harris et al, 2008). Parents believe that their behaviours are in the best interest of the child, without thinking about their child’s wants or needs. When their child is not managing their diabetes effectively, parents can feel that they are failing which is communicated to the child through criticism and blame. This may lead adolescents to feel frustrated that others don’t understand what is happening for them personally as the process of ‘miscarried helping’ is placing a barrier between the adolescent communicating to others what they feel would be helpful to them. These conflicts may impact on their diabetes self-efficacy as adolescents may feel that others do not believe in their ability to manage their diabetes. Services need to be mindful of these processes both within the clinic environment and also between family members, and

help adolescents to express *their* perspectives on why they may not feel in control of their diabetes.

Impact of Feelings of Control

Feelings of control do seem to impact on adolescents with T1DM; emotionally, on relationships and self-esteem. To manage the impact of diabetes and associated feelings of control, adolescents utilised various strategies which could be interpreted as coping strategies. Using strategies that help to minimise distressing emotions are termed ‘emotion focused coping strategies’ (Lazarus & Folkman, 1987). It appeared that the majority of participants used these strategies frequently. One participant appeared to primarily use problem focused coping strategies (Lazarus & Folkman, 1987), and believed in needing to “just get on with it”, following practical strategies to keep their blood glucose levels in range. They also did not think about the future. Coping strategies can sometimes be unhelpful, particularly around times of high stress e.g. examinations. Some participants spoke about a “vicious cycle”, for example an adolescent may use a coping strategy such as avoidance of testing blood glucose levels to manage their emotions, causing poorer blood glucose control, leading to poorer feelings of control and diabetes feeling unmanageable, therefore causing the adolescent to use avoidance again to manage the emotion. Negative thoughts and ineffective coping strategies can be challenged via psychological therapies such as coping skills training (Grey, Boland, Davidson & Tamborlane, 2000) and solution focused therapy (Viner, Taylor & Hey, 2003). It is therefore important that diabetes teams include psychological support into their regular work with adolescents.

Self-blame does not leave space for adolescents to show self-compassion, to believe in themselves and to think that their efforts are ‘good enough’. The adolescents in this study were frequently frustrated with themselves for not having “good” diabetes control and began

to blame themselves for not getting the “allusive” numbers. DePalma, Rollison & Camporese (2011) examined perceptions of self-blame in adults with type 2 diabetes (T2DM) and concluded that self-blame led to poorer diabetes management, through anger and negative social support. Being frustrated and having this sense of negativity/self-blame could lead adolescents to be less motivated to manage their diabetes, perhaps due to increasing feelings of helplessness.

Identity

Feelings of control may also impact on adolescents’ sense of identity. Adolescence is a developmental period in which individuals seek to develop a sense of identity, become autonomous from their parents, accept their body, develop close relationships with peers and prepare for occupational and romantic relationships (Havighurst, 1953). These developmental tasks may be more of a challenge for adolescents with T1DM compared to adolescents without T1DM (Seiffge-Krenke, 1998). The findings of this study elaborate on how adolescents may find these developmental tasks challenging. Participants felt a sense of ambivalence around independence. Whilst wanting to independently manage their diabetes without constant questioning from their parents, there was an appreciation that their parents help them to manage their diabetes. Many were worried about being solely responsible for their diabetes. Perhaps this worry was due to poorer diabetes self-efficacy and therefore a decreased belief that they are able to control their diabetes themselves.

Another developmental task which was discussed in the interviews was how diabetes may affect relationships with others. Participants felt ‘different’ both physically and psychologically. Participants felt they had to be more mature than their peers and wanted to keep their diabetes discreet so that their ‘difference’ to peers would be less noticeable. This may affect adolescents’ feelings of control around their diabetes as they may feel that they

cannot control it as well as they would like to due to the consequences of others becoming aware of their diabetes. This may also have been reflected in adolescents' hopes of their feelings of control increasing when they transitioned onto the pump, making diabetes management more discreet.

There was a sense of frustration for participants when others would associate adolescent expressions of emotions to their diabetes. This may lead to a sense of feeling invalidated by others and a sense that others only relate to them in terms of their diabetes. Participants also spoke about the notion that diabetes will not stop them. This resilience is protective to the sense of self and may serve to help adolescents show others that there is 'more to them than diabetes'. Consequently this may increase an adolescent's internal locus of control towards their diabetes management. Schur, Gamsu and Barley (1999) found that adolescents with T1DM used 'control' as a coping strategy to manage the practical side of diabetes and the anxiety surrounding diabetes. They found that adolescents felt they needed to control their diabetes so that they could put diabetes 'in the background'. The findings of this study may add to and further develop this concept i.e. feelings of control related to diabetes management, managing the impact of diabetes, and having personal control over not letting diabetes interfere with their ability to achieve goals and aspirations.

Conversely, most participants did worry about how their feelings of control may impact on their future selves. One main concern was how their diabetes would affect their ability to have children. One of the developmental tasks of adolescence is preparation for romantic relationships, and ultimately having a family. It appears that diabetes may interfere with this developmental task and cause anxiety. This may increase adolescents' motivation to improve their diabetes management but it may also make the significance of diabetes overwhelming and then too difficult to control. Services can help to alleviate concerns around

diabetes and having children in the future by approaching the topic as part of transition clinic education.

Helping Adolescents to Feel More in Control: Clinical Implications

The findings suggest that feelings of control around diabetes are multifaceted. Participants primarily related feelings of control to how well they could manage their diabetes but they also related it to how much it impacted their quality of life and how much they would let it interfere with achieving their goals and aspirations. The participants had scored themselves low in terms of personal and/or treatment control and therefore may need support to increase feelings of control which could improve their diabetes management. However, it does need to be noted that other factors may also impact on diabetes management as well as feelings of control including stress, hormone changes and puberty (Borus & Laffel, 2010; Tfayli & Arslanian, 2007). From the findings of the study, it appears that the trans-theoretical model of behaviour change (Prochaska & Velicer, 1997) may be a useful model to illustrate why adolescents may feel less in control and what can be done to improve this. The trans-theoretical model explains how motivation to change, self-efficacy and decisional balance influence the likelihood that an individual will change their health behaviours. For the participants it appeared that there was a motivation to improve their diabetes management, however this was difficult to achieve. Adolescents' feelings of control may impact on their diabetes self-efficacy through a vicious cycle, as shown in Figure 3.

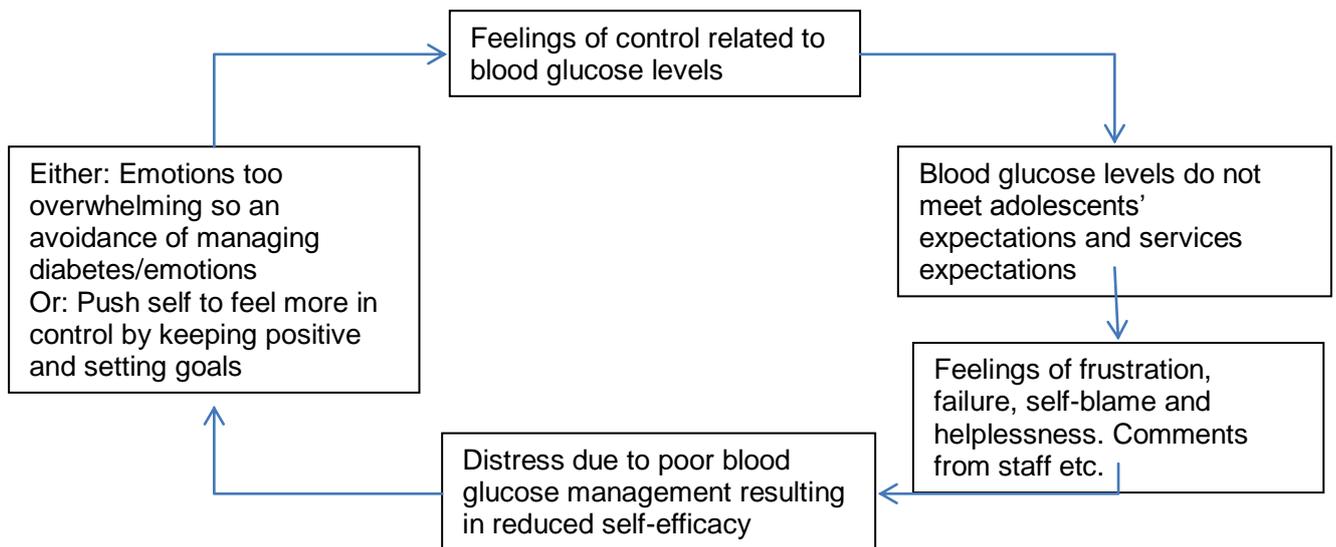


Figure 3. Vicious cycle which may decrease adolescents' diabetes self-efficacy

One participant in this study did not feel a sense of self-blame or helplessness and instead implied that they just 'get on with it', this may either be due to thinking in a more problem focused manner or they may be denying or minimising the emotional impact of diabetes. This may reduce motivation to optimally control their diabetes as they do not experience the anxiety or the guilt for their future self and therefore will 'just do enough' to keep their diabetes in control. This may be the reason that this participant scored themselves as low on personal control as they may relate their feelings of control solely to their blood glucose levels and have awareness that their control could be better.

In order to increase adolescents' diabetes self-efficacy and their feelings of control, services could help adolescents break such vicious cycles. Services could help adolescents reduce their feelings of helplessness and self-blame. This may be achieved through focusing on more than just the medical side of diabetes and helping adolescents to perceive 'good enough' numbers and diabetes management as acceptable, rather than striving for 'perfection'. Although there is an obvious medical need to emphasise good blood glucose levels, this may change how adolescents perceive their control. Adolescents may use their

blood glucose levels as a monitor for their own personal control of their diabetes, which may limit their diabetes self-efficacy and increase feelings of helplessness and self-blame.

Self-compassion¹⁷ has been found to impact on individual's perceived competence (Barnard & Curry, 2011). Lower self-compassion related to individuals perceiving themselves to be less competent than they actually were and failure to be indicative of their competence, whereas individuals high in self-compassion related to better resilience and perceiving their levels of competence more accurately (Barnard & Curry, 2011). Self-compassion has been found to be an important factor in diabetes management. In a sample of adults with T1DM and T2DM, high levels of self-compassion buffered the impact of diabetes distress on metabolic control and lower levels of self-compassion moderated the relationship between diabetes distress and poorer metabolic control (Friis, Johnson, Cutfield & Consedine, 2015). Services could utilise Clinical Psychologists to support adolescents who feel low levels of personal/treatment control in a self-compassionate manner. Techniques from therapies such as Compassionate Mind Training (Gilbert & Proctor, 2006) or Acceptance and Commitment Therapy (Hayes, Luomaa, Bond, Masudaa & Lillisa, 2006) may improve adolescents' self-compassion, their feelings of control and ultimately diabetes management.

The decisional balance section of the Trans-theoretical model was illustrated in the subtheme of 'getting a balance'. Participants struggled to get a balance between optimal diabetes management and quality of life. Sometimes the participants perceived life to be more important than their diabetes and therefore put diabetes management into the background, but ultimately adolescents wanted to be able to treat these equally. Adolescents may feel a sense of ambivalence as services emphasise the need for strict diabetes control to lower the risk of

¹⁷ defined as being kind to oneself in the presence of negative events rather than judgemental or self-critical, understanding failing to be part of the 'human condition' and being mindful of painful feelings rather than avoiding or over-identifying with them (Neff, 2003).

complications for the adolescents in the future, however this may reduce adolescents' quality of life due to diabetes management 'taking up their time'. The World Health Organisation defines health as "...a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity" (World Health Organisation, 2015). Therefore would services be better placed helping adolescents achieve a balance between diabetes management and mental and social well-being? This may be difficult for services which are organised according to a medical model of care where the concern is primarily focused on metabolic control and reduced risk of future complications of diabetes. Perhaps a shift to a more patient-centred, holistic model of care may not only optimise physiological diabetes outcomes but also more positively impact on adolescents' quality of life. Perhaps it is the role of Clinical Psychologists within these services to help services to think about diabetes management and adolescents' struggles with feelings of control in a more holistic manner.

Limitations and Future Research

In order to identify adolescents who may perceive themselves as having lower personal/treatment control, the BIPQ was utilised. Although the BIPQ is a valid and reliable screening measure of illness representations (Broadbent et al, 2006), personal and treatment control are measured using one question for each subscale. It is therefore difficult to ascertain whether the questionnaire captured personal and treatment control effectively. It may have been useful to have used an illness representation questionnaire that had more questions on personal/treatment control. This may have provided more data on how people view their personal/treatment control around their diabetes. However this may have made recruitment difficult due to the questionnaire being more time consuming. Future studies could look into differences between scores on illness representations for personal and treatment control in a sample of adolescents with T1DM.

The sample of participants for the study was skewed in terms of gender as it included five females and one male. For an IPA study, having a skewed sample is acceptable; IPA is concerned with making sense of the perspectives of participants, rather than being representative of the population (Smith, Flowers & Larkin, 2009). Future research could investigate gender differences on the experiences of perceptions of personal/treatment control for adolescents with T1DM, as the study was unable to make inferences as to any gender differences due to the number of males in the study

Future research could also investigate the impact of self-compassion on adolescents with T1DM perceptions of personal and/or treatment control and how this impacts on diabetes management.

Conclusions

Feelings of control for adolescents with T1DM may impact on diabetes management. Feelings of control appear to be predominantly related to blood glucose levels and if blood glucose levels are not 'good enough' then the adolescents feel less in control of their diabetes. Feeling low levels of personal and/or treatment control related to blood glucose levels appears to lead to frustration within the adolescents. This frustration may lead to the adolescents developing a sense of self-blame and helplessness. Adolescents used coping strategies in order to manage the impact of diabetes, including emotion focused coping strategies and problem focused strategies. Diabetes also had an impact on identity and made the developmental tasks of adolescence more challenging.

Services need to provide integrated holistic care which looks at diabetes management from more than the medical perspective. Looking at 'numbers' and adherence behaviours may increase adolescents' feelings of helplessness and decrease diabetes self-efficacy. It may be useful to think about self-compassion for adolescents' who perceive themselves to have

low personal/treatment control, to enable them to aim for 'good enough' diabetes management and understand that it is impossible to get 'perfect' numbers constantly. Being kind to oneself and not judgemental and not ruminating on difficult feelings may help adolescents to gain a better sense of control which may lead to better diabetes management. Services also need to consider health in terms of physical, mental and social well-being and help adolescents to get a good balance between diabetes and quality of life, which may help to improve feelings of control as the adolescent increases their self-efficacy and belief in their own competencies. Clinical Psychology is well placed to facilitate such changes and deliver appropriate interventions when functionally integrated within the diabetes team.

References

- Barnard, L. K., & Curry, J. F. (2011). Self-compassion: Conceptualizations, correlates, & interventions. *Review of General Psychology*, 15(4), 289.
- Blanz, B. J., Rensch-Riemann, B. S., Fritz-Sigmund, D. I., & Schmidt, M. H. (1993). IDDM is a risk factor for adolescent psychiatric disorders. *Diabetes Care*, 16(12), 1579-1587.
- Broadbent, E., Petrie, K. J., Main, J., & Weinman, J. (2006). The brief illness perception questionnaire. *Journal of Psychosomatic Research*, 60(6), 631-637.
- DePalma, M. T., Rollison, J., & Camporese, M. (2011). Psychosocial predictors of diabetes management. *American Journal of Health Behavior*, 35(2), 209-218.
- Diabetes.co.uk. (2015a). Guide to HbA1c. Retrieved 25 February 2015, from <http://www.diabetes.co.uk/what-is-hba1c.html>.
- Diabetes.co.uk. (2015b). Insulin Sensitivity. Retrieved 27 April 2015, from <http://www.diabetes.co.uk/insulin/insulin-sensitivity.html>.
- Diabetes UK. (2015). Pumps. Retrieved 29 May 2015, from <https://www.diabetes.org.uk/teens-pumps>.
- Fortenberry, K. T., Wiebe, D. J., & Berg, C. A. (2012). Perceptions of treatment control moderate the daily association between negative affect and diabetes problems among adolescents with type 1 diabetes. *Psychology & Health*, 27(3), 294-309.
- Fox, C. & Kilvert, A. (2008). *Type 1 diabetes: Answers at your fingertips*. (6th ed.). UK: Class Publishing.

- Friis, A. M., Johnson, M. H., Cutfield, R. G., & Consedine, N. S. (2015). Does kindness matter? Self-compassion buffers the negative impact of diabetes-distress on HbA1c. *Diabetic Medicine*. Advance Online Publication.
- Fritschi, C., & Quinn, L. (2010). Fatigue in patients with diabetes: a review. *Journal of psychosomatic research*, 69(1), 33-41.
- Gilbert, P., & Procter, S. (2006). Compassionate mind training for people with high shame and self-criticism: Overview and pilot study of a group therapy approach. *Clinical Psychology and Psychotherapy*, 13(6), 353.
- Grey, M., Boland, E. A., Davidson, M., Li, J., & Tamborlane, W. V. (2000). Coping skills training for youth with diabetes mellitus has long-lasting effects on metabolic control and quality of life. *The Journal of Pediatrics*, 137(1), 107-113.
- Griva, K., Myers, L. B., & Newman, S. (2000). Illness perceptions and self efficacy beliefs in adolescents and young adults with insulin dependent diabetes mellitus. *Psychology and Health*, 15(6), 733-750.
- Hall, G. (2007). *Providing diabetes care in general practice: A practical guide to integrated care*. (5th ed.). UK: Class Publishing.
- Harris, M. A., Antal, H., Oelbaum, R., Buckloh, L. M., White, N. H., & Wysocki, T. (2008). Good intentions gone awry: Assessing parental "miscarried helping" in diabetes. *Families, Systems, & Health*, 26(4), 393.
- Hayes, S. C., Luoma, J. B., Bond, F. W., Masuda, A., & Lillis, J. (2006). Acceptance and commitment therapy: Model, processes and outcomes. *Behaviour research and therapy*, 44(1), 1-25.

Hilliard, M. E., Harris, M. A., & Weissberg-Benchell, J. (2012). Diabetes resilience: a model of risk and protection in type 1 diabetes. *Current diabetes reports*, 12(6), 739-748.

Jones, J. M., Lawson, M. L., Daneman, D., Olmsted, M. P., & Rodin, G. (2000). Eating disorders in adolescent females with and without type 1 diabetes: cross sectional study. *Bmj*, 320(7249), 1563-1566.

Lazarus, R. S., & Folkman, S. (1987). Transactional theory and research on emotions and coping. *European Journal of Personality*, 1(3), 141-169.

Leventhal, H., Diefenbach, M., & Leventhal, E. A. (1992). Illness cognition: using common sense to understand treatment adherence and affect cognition interactions. *Cognitive therapy and research*, 16(2), 143-163.

Moss-Morris, R., Weinman, J., Petrie, K., Horne, R., Cameron, L., & Buick, D. (2002). The revised illness perception questionnaire (IPQ-R). *Psychology and Health*, 17(1), 1-16.

National Health Service. (2013). Diabetes Ketoacidosis. Retrieved 02 June 2015, from <http://www.nhs.uk/conditions/diabetic-ketoacidosis/Pages/Introduction.aspx>.

National Health Service. (2012a). Diabetes Type 1. Retrieved 09 November 2013, from <http://www.nhs.uk/Conditions/Diabetes-type1/Pages/Introduction.aspx>.

National Health Service (2012b). Diabetes Type 1 – Complications. Retrieved 09 November 2013, from <http://www.nhs.uk/Conditions/Diabetes-type1/Pages/Complications.aspx>.

Neff, K. D. (2003). The development and validation of a scale to measure self-compassion. *Self and Identity*, 2(3), 223-250.

Neumark-Sztainer, D., Patterson, J., Mellin, A., Ackard, D. M., Utter, J., Story, M., & Sockalosky, J. (2002). Weight Control Practices and Disordered Eating Behaviors Among

Adolescent Females and Males With Type 1 Diabetes Associations with sociodemographics, weight concerns, familial factors, and metabolic outcomes. *Diabetes Care*, 25(8), 1289-1296.

Prochaska, J. O., & Velicer, W. F. (1997). The transtheoretical model of health behavior change. *American Journal of Health Promotion*, 12(1), 38-48.

Rubin, R. R., & Peyrot, M. (2001). Psychological issues and treatments for people with diabetes. *Journal of clinical psychology*, 57(4), 457-478.

Royal College of Paediatrics and Child Health (2014). *National paediatric diabetes audit report 2013-14, part 1: Care processes and outcomes*. UK: Royal College of Paediatrics and Child Health.

Schur, H. V., Gamsu, D. S., & Barley, V. M. (1999). The young person's perspective on living and coping with diabetes. *Journal of Health Psychology*, 4(2), 223-236.

Schwartz, S. A., Weissberg-Benchell, J., & Perlmutter, L. C. (2002). Personal control and disordered eating in female adolescents with type 1 diabetes. *Diabetes care*, 25(11), 1987-1991.

Seiffge-Krenke, I. (1998). Chronic disease and perceived developmental progression in adolescence. *Developmental Psychology*, 34(5), 1073.

Smith, J. A., Flowers, P. & Larkin, M. (2009). *Interpretative phenomenological analysis: Theory, method and research*. UK: SAGE Publications.

Viner, R. M., Christie, D., Taylor, V., & Hey, S. (2003). Motivational/solution-focused intervention improves HbA1c in adolescents with Type 1 diabetes: a pilot study. *Diabetic Medicine*, 20(9), 739-742.

Tfayli, H., & Arslanian, S. (2007). The challenge of adolescence: hormonal changes and sensitivity to insulin. *Diabetes Voice*, 52, 28-30.

World Health Organisation (2015). About WHO. Retrieved 30 May 2015, from <http://www.who.int/about/en/>.

Part Three: Appendices

Appendix A – Author Guidelines for SLR



Before You Begin

Ethics in publishing

For information on Ethics in publishing and Ethical guidelines for journal publication see <http://www.elsevier.com/publishingethics> and <http://www.elsevier.com/journal-authors/ethics>.

Conflict of interest

All authors are requested to disclose any actual or potential conflict of interest including any financial, personal or other relationships with other people or organizations within three years of beginning the submitted work that could inappropriately influence, or be perceived to influence, their work. See also <http://www.elsevier.com/conflictsofinterest>. Further information and an example of a Conflict of Interest form can be found at: http://help.elsevier.com/app/answers/detail/a_id/286/p/7923.

Submission declaration and verification

Submission of an article implies that the work described has not been published previously (except in the form of an abstract or as part of a published lecture or academic thesis or as an electronic preprint, see <http://www.elsevier.com/sharingpolicy>), that it is not under consideration for publication elsewhere, that its publication is approved by all authors and tacitly or explicitly by the responsible authorities where the work was carried out, and that, if accepted, it will not be published elsewhere in the same form, in English or in any other language, including electronically without the written consent of the copyright-holder. To verify originality, your article may be checked by the originality detection service CrossCheck <http://www.elsevier.com/editors/plagdetect>.

Changes to authorship

This policy concerns the addition, deletion, or rearrangement of author names in the authorship of accepted manuscripts:

Before the accepted manuscript is published in an online issue: Requests to add or remove an author, or to rearrange the author names, must be sent to the Journal Manager from the corresponding author of the accepted manuscript and must include: (a) the reason the name should be added or removed, or the author names rearranged and (b) written confirmation (e-mail, fax, letter) from all authors that they agree with the addition, removal or rearrangement. In the case of addition or removal of authors, this includes confirmation from the author being added or removed. Requests that are not sent by the corresponding author will be forwarded by the Journal Manager to the corresponding author, who must follow the procedure as described above. Note that: (1) Journal Managers will inform the Journal Editors of any such requests and (2) publication of the accepted manuscript in an online issue is suspended until authorship has been agreed.

After the accepted manuscript is published in an online issue: Any requests to add, delete, or rearrange author names in an article published in an online issue will follow the same policies as noted above and result in a corrigendum.

Author Disclosure Policy

Authors must provide three mandatory and one optional author disclosure statements. These statements should be submitted as one separate document and not included as part of the manuscript. Author disclosures will be automatically incorporated into the PDF builder of the online submission system. They will appear in the journal article if the manuscript is accepted.

The four statements of the author disclosure document are described below. Statements should not be numbered. Headings (i.e., Role of Funding Sources, Contributors, Conflict of Interest, Acknowledgements) should be in bold with no white space between the heading and the text. Font size should be the same as that used for references.

Statement 1: Role of Funding Sources

Authors must identify who provided financial support for the conduct of the research and/or preparation of the manuscript and to briefly describe the role (if any) of the funding sponsor in study design, collection, analysis, or

interpretation of data, writing the manuscript, and the decision to submit the manuscript for publication. If the funding source had no such involvement, the authors should so state.

Example: Funding for this study was provided by NIAAA Grant R01-AA123456. NIAAA had no role in the study design, collection, analysis or interpretation of the data, writing the manuscript, or the decision to submit the paper for publication.

Statement 2: Contributors

Authors must declare their individual contributions to the manuscript. All authors must have materially participated in the research and/or the manuscript preparation. Roles for each author should be described. The disclosure must also clearly state and verify that all authors have approved the final manuscript.

Example: Authors A and B designed the study and wrote the protocol. Author C conducted literature searches and provided summaries of previous research studies. Author D conducted the statistical analysis. Author B wrote the first draft of the manuscript and all authors contributed to and have approved the final manuscript.

Statement 3: Conflict of Interest

All authors must disclose any actual or potential conflict of interest. Conflict of interest is defined as any financial or personal relationships with individuals or organizations, occurring within three (3) years of beginning the submitted work, which could inappropriately influence, or be perceived to have influenced the submitted research manuscript. Potential conflict of interest would include employment, consultancies, stock ownership (except personal investments equal to the lesser of one percent (1%) of total personal investments or USD\$5000), honoraria, paid expert testimony, patent applications, registrations, and grants. If there are no conflicts of interest by any author, it should state that there are none.

Example: Author B is a paid consultant for XYZ pharmaceutical company. All other authors declare that they have no conflicts of interest.

Statement 4: Acknowledgements (optional)

Authors may provide Acknowledgments which will be published in a separate section along with the manuscript. If there are no Acknowledgements, there should be no heading or acknowledgement statement.

Example: The authors wish to thank Ms. A who assisted in the proof-reading of the manuscript.

Copyright

Upon acceptance of an article, authors will be asked to complete a 'Journal Publishing Agreement' (for more information on this and copyright, see <http://www.elsevier.com/copyright>). An e-mail will be sent to the corresponding author confirming receipt of the manuscript together with a 'Journal Publishing Agreement' form or a link to the online version of this agreement.

Subscribers may reproduce tables of contents or prepare lists of articles including abstracts for internal circulation within their institutions. Permission of the Publisher is required for resale or distribution outside the institution and for all other derivative works, including compilations and translations (please consult <http://www.elsevier.com/permissions>). If excerpts from other copyrighted works are included, the author(s) must obtain written permission from the copyright owners and credit the source(s) in the article. Elsevier has preprinted forms for use by authors in these cases: please consult <http://www.elsevier.com/permissions>.

For open access articles: Upon acceptance of an article, authors will be asked to complete an 'Exclusive License Agreement' (for more information see <http://www.elsevier.com/OAauthoragreement>). Permitted third party reuse of open access articles is determined by the author's choice of user license (see <http://www.elsevier.com/openaccesslicenses>).

Author rights

As an author you (or your employer or institution) have certain rights to reuse your work. For more information see <http://www.elsevier.com/copyright>.

Role of the funding source

You are requested to identify who provided financial support for the conduct of the research and/or preparation of the article and to briefly describe the role of the sponsor(s), if any, in study design; in the collection, analysis and

interpretation of data; in the writing of the report; and in the decision to submit the article for publication. If the funding source(s) had no such involvement then this should be stated.

Funding body agreements and policies

Elsevier has established a number of agreements with funding bodies which allow authors to comply with their funder's open access policies. Some authors may also be reimbursed for associated publication fees. To learn more about existing agreements please visit <http://www.elsevier.com/fundingbodies>.

Open access

This journal offers authors a choice in publishing their research:

Open access

- Articles are freely available to both subscribers and the wider public with permitted reuse
- An open access publication fee is payable by authors or on their behalf e.g. by their research funder or institution

Subscription

- Articles are made available to subscribers as well as developing countries and patient groups through our universal access programs (<http://www.elsevier.com/access>).
- No open access publication fee payable by authors.

Regardless of how you choose to publish your article, the journal will apply the same peer review criteria and acceptance standards.

For open access articles, permitted third party (re)use is defined by the following Creative Commons user licenses:

Creative Commons Attribution (CC BY)

Lets others distribute and copy the article, create extracts, abstracts, and other revised versions, adaptations or derivative works of or from an article (such as a translation), include in a collective work (such as an anthology), text or data mine the article, even for commercial purposes, as long as they credit the author(s), do not represent the author as endorsing their adaptation of the article, and do not modify the article in such a way as to damage the author's honor or reputation.

Creative Commons Attribution-NonCommercial-NoDerivs (CC BY-NC-ND)

For non-commercial purposes, lets others distribute and copy the article, and to include in a collective work (such as an anthology), as long as they credit the author(s) and provided they do not alter or modify the article.

The open access publication fee for this journal is **USD 1800**, excluding taxes. Learn more about Elsevier's pricing policy: <http://www.elsevier.com/openaccesspricing>.

Language (usage and editing services)

Please write your text in good English (American or British usage is accepted, but not a mixture of these). Authors who feel their English language manuscript may require editing to eliminate possible grammatical or spelling errors and to conform to correct scientific English may wish to use the English Language Editing service available from Elsevier's WebShop (<http://webshop.elsevier.com/languageediting/>) or visit our customer support site (<http://support.elsevier.com>) for more information.

Submission

Our online submission system guides you stepwise through the process of entering your article details and uploading your files. The system converts your article files to a single PDF file used in the peer-review process. Editable files (e.g., Word, LaTeX) are required to typeset your article for final publication. All correspondence, including notification of the Editor's decision and requests for revision, is sent by e-mail.



Preparation

Use of word processing software

It is important that the file be saved in the native format of the word processor used. The text should be in single-column format. Keep the layout of the text as simple as possible. Most formatting codes will be removed and replaced on processing the article. In particular, do not use the word processor's options to justify text or to hyphenate words. However, do use bold face, italics, subscripts, superscripts etc. When preparing tables, if you are using a table grid, use only one grid for each individual table and not a grid for each row. If no grid is used, use tabs, not spaces, to align columns. The electronic text should be prepared in a way very similar to that of conventional manuscripts (see also the Guide to Publishing with Elsevier: <http://www.elsevier.com/guidepublication>). Note that source files of figures, tables and text graphics will be required whether or not you embed your figures in the text. See also the section on Electronic artwork. To avoid unnecessary errors you are strongly advised to use the 'spell-check' and 'grammar-check' functions of your word processor.

Article structure

Manuscripts should be prepared according to the guidelines set forth in the Publication Manual of the American Psychological Association (6th ed., 2009). Of note, section headings should not be numbered.

Manuscripts should ordinarily not exceed 50 pages, *including* references and tabular material. Exceptions may be made with prior approval of the Editor in Chief. Manuscript length can often be managed through the judicious use of appendices. In general the References section should be limited to citations actually discussed in the text. References to articles solely included in meta-analyses should be included in an appendix, which will appear in the on line version of the paper but not in the print copy. Similarly, extensive Tables describing study characteristics, containing material published elsewhere, or presenting formulas and other technical material should also be included in an appendix. Authors can direct readers to the appendices in appropriate places in the text.

It is authors' responsibility to ensure their reviews are comprehensive and as up to date as possible (at least through the prior calendar year) so the data are still current at the time of publication. Authors are referred to the PRISMA Guidelines (<http://www.prisma-statement.org/statement.htm>) for guidance in conducting reviews and preparing manuscripts. Adherence to the Guidelines is not required, but is recommended to enhance quality of submissions and impact of published papers on the field.

Appendices

If there is more than one appendix, they should be identified as A, B, etc. Formulae and equations in appendices should be given separate numbering: Eq. (A.1), Eq. (A.2), etc.; in a subsequent appendix, Eq. (B.1) and so on. Similarly for tables and figures: Table A.1; Fig. A.1, etc.

Essential title page information

Title. Concise and informative. Titles are often used in information-retrieval systems. Avoid abbreviations and formulae where possible. **Note: The title page should be the first page of the manuscript document indicating the author's names and affiliations and the corresponding author's complete contact information.**

Author names and affiliations. Where the family name may be ambiguous (e.g., a double name), please indicate this clearly. Present the authors' affiliation addresses (where the actual work was done) below the names. Indicate all affiliations with a lower-case superscript letter immediately after the author's name and in front of the appropriate address. Provide the full postal address of each affiliation, including the country name, and, if available, the e-mail address of each author within the cover letter.

Corresponding author. Clearly indicate who is willing to handle correspondence at all stages of refereeing and publication, also post-publication. **Ensure that telephone and fax numbers (with country and area code) are provided in addition to the e-mail address and the complete postal address.**

Present/permanent address. If an author has moved since the work described in the article was done, or was visiting at the time, a "Present address" (or "Permanent address") may be indicated as a footnote to that author's name. The address at which the author actually did the work must be retained as the main, affiliation address. Superscript Arabic numerals are used for such footnotes.

Abstract

A concise and factual abstract is required (not exceeding 200 words). This should be typed on a separate page following the title page. The abstract should state briefly the purpose of the research, the principal results and major conclusions. An abstract is often presented separate from the article, so it must be able to stand alone. References should therefore be avoided, but if essential, they must be cited in full, without reference to the reference list.

Graphical abstract

Although a graphical abstract is optional, its use is encouraged as it draws more attention to the online article. The graphical abstract should summarize the contents of the article in a concise, pictorial form designed to capture the attention of a wide readership. Graphical abstracts should be submitted as a separate file in the online submission system. Image size: Please provide an image with a minimum of 531 × 1328 pixels (h × w) or proportionally more. The image should be readable at a size of 5 × 13 cm using a regular screen resolution of 96 dpi. Preferred file types: TIFF, EPS, PDF or MS Office files. See <http://www.elsevier.com/graphicalabstracts> for examples.

Authors can make use of Elsevier's Illustration and Enhancement service to ensure the best presentation of their images and in accordance with all technical requirements: [Illustration Service](#).

Highlights

Highlights are mandatory for this journal. They consist of a short collection of bullet points that convey the core findings of the article and should be submitted in a separate editable file in the online submission system. Please use 'Highlights' in the file name and include 3 to 5 bullet points (maximum 85 characters, including spaces, per bullet point). See <http://www.elsevier.com/highlights> for examples.

Keywords

Immediately after the abstract, provide a maximum of 6 keywords, using American spelling and avoiding general and plural terms and multiple concepts (avoid, for example, 'and', 'of'). Be sparing with abbreviations: only abbreviations firmly established in the field may be eligible. These keywords will be used for indexing purposes.

Abbreviations

Define abbreviations that are not standard in this field in a footnote to be placed on the first page of the article. Such abbreviations that are unavoidable in the abstract must be defined at their first mention there, as well as in the footnote. Ensure consistency of abbreviations throughout the article.

Acknowledgements

Collate acknowledgements in a separate section at the end of the article before the references and do not, therefore, include them on the title page, as a footnote to the title or otherwise. List here those individuals who provided help during the research (e.g., providing language help, writing assistance or proof reading the article, etc.).

Footnotes

Footnotes should be used sparingly. Number them consecutively throughout the article. Many word processors can build footnotes into the text, and this feature may be used. Otherwise, please indicate the position of footnotes in the text and list the footnotes themselves separately at the end of the article. Do not include footnotes in the Reference list.

Electronic artwork

General points

- Make sure you use uniform lettering and sizing of your original artwork.
- Embed the used fonts if the application provides that option.
- Aim to use the following fonts in your illustrations: Arial, Courier, Times New Roman, Symbol, or use fonts that look similar.

- Number the illustrations according to their sequence in the text.
- Use a logical naming convention for your artwork files.
- Provide captions to illustrations separately.
- Size the illustrations close to the desired dimensions of the published version.
- Submit each illustration as a separate file.

A detailed guide on electronic artwork is available on our website:

<http://www.elsevier.com/artworkinstructions>.

You are urged to visit this site; some excerpts from the detailed information are given here.

Formats

If your electronic artwork is created in a Microsoft Office application (Word, PowerPoint, Excel) then please supply 'as is' in the native document format.

Regardless of the application used other than Microsoft Office, when your electronic artwork is finalized, please 'Save as' or convert the images to one of the following formats (note the resolution requirements for line drawings, halftones, and line/halftone combinations given below):

EPS (or PDF): Vector drawings, embed all used fonts.

TIFF (or JPEG): Color or grayscale photographs (halftones), keep to a minimum of 300 dpi.

TIFF (or JPEG): Bitmapped (pure black & white pixels) line drawings, keep to a minimum of 1000 dpi.

TIFF (or JPEG): Combinations bitmapped line/half-tone (color or grayscale), keep to a minimum of 500 dpi.

Please do not:

- Supply files that are optimized for screen use (e.g., GIF, BMP, PICT, WPG); these typically have a low number of pixels and limited set of colors;
- Supply files that are too low in resolution;
- Submit graphics that are disproportionately large for the content.

Color artwork

Please make sure that artwork files are in an acceptable format (TIFF (or JPEG), EPS (or PDF), or MS Office files) and with the correct resolution. If, together with your accepted article, you submit usable color figures then Elsevier will ensure, at no additional charge, that these figures will appear in color online (e.g., ScienceDirect and other sites) regardless of whether or not these illustrations are reproduced in color in the printed version. **For color reproduction in print, you will receive information regarding the costs from Elsevier after receipt of your accepted article.** Please indicate your preference for color: in print or online only. For further information on the preparation of electronic artwork, please see <http://www.elsevier.com/artworkinstructions>.

Please note: Because of technical complications that can arise by converting color figures to 'gray scale' (for the printed version should you not opt for color in print) please submit in addition usable black and white versions of all the color illustrations.

Figure captions

Ensure that each illustration has a caption. Supply captions separately, not attached to the figure. A caption should comprise a brief title (**not** on the figure itself) and a description of the illustration. Keep text in the illustrations themselves to a minimum but explain all symbols and abbreviations used.

Tables

Please submit tables as editable text and not as images. Tables can be placed either next to the relevant text in the article, or on separate page(s) at the end. Number tables consecutively in accordance with their appearance in the text and place any table notes below the table body. Be sparing in the use of tables and ensure that the data presented in them do not duplicate results described elsewhere in the article. Please avoid using vertical rules.

References

Citations in the text should follow the referencing style used by the American Psychological Association. You are referred to the Publication Manual of the American Psychological Association, Sixth Edition, ISBN 1-4338-0559-6, copies of which may be ordered from <http://books.apa.org/books.cfm?id=4200067> or APA Order Dept., P.O.B. 2710, Hyattsville, MD 20784, USA or APA, 3 Henrietta Street, London, WC3E 8LU, UK. Details concerning this referencing style can also be found at <http://humanities.byu.edu/linguistics/Henrichsen/APA/APA01.html>

Citation in text

Please ensure that every reference cited in the text is also present in the reference list (and vice versa). Any references cited in the abstract must be given in full. Unpublished results and personal communications are not

recommended in the reference list, but may be mentioned in the text. If these references are included in the reference list they should follow the standard reference style of the journal and should include a substitution of the publication date with either 'Unpublished results' or 'Personal communication'. Citation of a reference as 'in press' implies that the item has been accepted for publication.

Web references

As a minimum, the full URL should be given and the date when the reference was last accessed. Any further information, if known (DOI, author names, dates, reference to a source publication, etc.), should also be given. Web references can be listed separately (e.g., after the reference list) under a different heading if desired, or can be included in the reference list.

References in a special issue

Please ensure that the words 'this issue' are added to any references in the list (and any citations in the text) to other articles in the same Special Issue.

Reference management software

Most Elsevier journals have a standard template available in key reference management packages. This covers packages using the Citation Style Language, such as Mendeley (<http://www.mendeley.com/features/reference-manager>) and also others like EndNote (<http://www.endnote.com/support/enstyles.asp>) and Reference Manager (<http://refman.com/support/rmstyles.asp>). Using plug-ins to word processing packages which are available from the above sites, authors only need to select the appropriate journal template when preparing their article and the list of references and citations to these will be formatted according to the journal style as described in this Guide. The process of including templates in these packages is constantly ongoing. If the journal you are looking for does not have a template available yet, please see the list of sample references and citations provided in this Guide to help you format these according to the journal style.

If you manage your research with Mendeley Desktop, you can easily install the reference style for this journal by clicking the link below:

<http://open.mendeley.com/use-citation-style/clinical-psychology-review>

When preparing your manuscript, you will then be able to select this style using the Mendeley plug-ins for Microsoft Word or LibreOffice. For more information about the Citation Style Language, visit <http://citationstyles.org>.

Reference style

References should be arranged first alphabetically and then further sorted chronologically if necessary. More than one reference from the same author(s) in the same year must be identified by the letters "a", "b", "c", etc., placed after the year of publication. **References should be formatted with a hanging indent (i.e., the first line of each reference is flush left while the subsequent lines are indented).**

Examples: Reference to a journal publication: Van der Geer, J., Hanraads, J. A. J., & Lupton R. A. (2000). The art of writing a scientific article. *Journal of Scientific Communications*, 163, 51-59.

Reference to a book: Strunk, W., Jr., & White, E. B. (1979). *The elements of style*. (3rd ed.). New York: Macmillan, (Chapter 4).

Reference to a chapter in an edited book: Mettam, G. R., & Adams, L. B. (1994). How to prepare an electronic version of your article. In B.S. Jones, & R. Z. Smith (Eds.), *Introduction to the electronic age* (pp. 281-304). New York: E-Publishing Inc.

Video data

Elsevier accepts video material and animation sequences to support and enhance your scientific research. Authors who have video or animation files that they wish to submit with their article are strongly encouraged to include links to these within the body of the article. This can be done in the same way as a figure or table by referring to the video or animation content and noting in the body text where it should be placed. All submitted files should be properly labeled so that they directly relate to the video file's content. In order to ensure that your video or animation material is directly usable, please provide the files in one of our recommended file formats with a preferred maximum size of 150 MB. Video and animation files supplied will be published online in the electronic version of your article in Elsevier Web products, including ScienceDirect: <http://www.sciencedirect.com>. Please supply 'stills' with your files: you can choose any frame from the video or animation or make a separate

image. These will be used instead of standard icons and will personalize the link to your video data. For more detailed instructions please visit our video instruction pages at <http://www.elsevier.com/artworkinstructions>. Note: since video and animation cannot be embedded in the print version of the journal, please provide text for both the electronic and the print version for the portions of the article that refer to this content.

AudioSlides

The journal encourages authors to create an AudioSlides presentation with their published article. AudioSlides are brief, webinar-style presentations that are shown next to the online article on ScienceDirect. This gives authors the opportunity to summarize their research in their own words and to help readers understand what the paper is about. More information and examples are available at <http://www.elsevier.com/audioslides>. Authors of this journal will automatically receive an invitation e-mail to create an AudioSlides presentation after acceptance of their paper.

Supplementary material

Elsevier accepts electronic supplementary material to support and enhance your scientific research. Supplementary files offer the author additional possibilities to publish supporting applications, high-resolution images, background datasets, sound clips and more. Supplementary files supplied will be published online alongside the electronic version of your article in Elsevier Web products, including ScienceDirect: <http://www.sciencedirect.com>. In order to ensure that your submitted material is directly usable, please provide the data in one of our recommended file formats. Authors should submit the material in electronic format together with the article and supply a concise and descriptive caption for each file. For more detailed instructions please visit our artwork instruction pages at <http://www.elsevier.com/artworkinstructions>.

3D neuroimaging

You can enrich your online articles by providing 3D neuroimaging data in NIfTI format. This will be visualized for readers using the interactive viewer embedded within your article, and will enable them to: browse through available neuroimaging datasets; zoom, rotate and pan the 3D brain reconstruction; cut through the volume; change opacity and color mapping; switch between 3D and 2D projected views; and download the data. The viewer supports both single (.nii) and dual (.hdr and .img) NIfTI file formats. Recommended size of a single uncompressed dataset is maximum 150 MB. Multiple datasets can be submitted. Each dataset will have to be zipped and uploaded to the online submission system via the '3D neuroimaging data' submission category. Please provide a short informative description for each dataset by filling in the 'Description' field when uploading a dataset. Note: all datasets will be available for downloading from the online article on ScienceDirect. If you have concerns about your data being downloadable, please provide a video instead. For more information see: <http://www.elsevier.com/3DNeuroimaging>.

Submission checklist

The following list will be useful during the final checking of an article prior to sending it to the journal for review. Please consult this Guide for Authors for further details of any item.

Ensure that the following items are present:

One author has been designated as the corresponding author with contact details:

- E-mail address
- Full postal address

All necessary files have been uploaded, and contain:

- Keywords
- All figure captions
- All tables (including title, description, footnotes)

Further considerations

- Manuscript has been 'spell-checked' and 'grammar-checked'
 - References are in the correct format for this journal
 - All references mentioned in the Reference list are cited in the text, and vice versa
 - Permission has been obtained for use of copyrighted material from other sources (including the Internet)
- Printed version of figures (if applicable) in color or black-and-white
- Indicate clearly whether or not color or black-and-white in print is required.
 - For reproduction in black-and-white, please supply black-and-white versions of the figures for printing

purposes.

For any further information please visit our customer support site at <http://support.elsevier.com>.



After Acceptance

Use of the Digital Object Identifier

The Digital Object Identifier (DOI) may be used to cite and link to electronic documents. The DOI consists of a unique alpha-numeric character string which is assigned to a document by the publisher upon the initial electronic publication. The assigned DOI never changes. Therefore, it is an ideal medium for citing a document, particularly 'Articles in press' because they have not yet received their full bibliographic information. Example of a correctly given DOI (in URL format; here an article in the journal *Physics Letters B*):

<http://dx.doi.org/10.1016/j.physletb.2010.09.059>

When you use a DOI to create links to documents on the web, the DOIs are guaranteed never to change.

Online proof correction

Corresponding authors will receive an e-mail with a link to our online proofing system, allowing annotation and correction of proofs online. The environment is similar to MS Word: in addition to editing text, you can also comment on figures/tables and answer questions from the Copy Editor. Web-based proofing provides a faster and less error-prone process by allowing you to directly type your corrections, eliminating the potential introduction of errors.

If preferred, you can still choose to annotate and upload your edits on the PDF version. All instructions for proofing will be given in the e-mail we send to authors, including alternative methods to the online version and PDF.

We will do everything possible to get your article published quickly and accurately. Please use this proof only for checking the typesetting, editing, completeness and correctness of the text, tables and figures. Significant changes to the article as accepted for publication will only be considered at this stage with permission from the Editor. It is important to ensure that all corrections are sent back to us in one communication. Please check carefully before replying, as inclusion of any subsequent corrections cannot be guaranteed. Proofreading is solely your responsibility.

Offprints

The corresponding author, at no cost, will be provided with a personalized link providing 50 days free access to the final published version of the article on [ScienceDirect](http://www.sciencedirect.com). This link can also be used for sharing via email and social networks. For an extra charge, paper offprints can be ordered via the offprint order form which is sent once the article is accepted for publication. Both corresponding and co-authors may order offprints at any time via Elsevier's WebShop (<http://webshop.elsevier.com/myarticleservices/offprints>). Authors requiring printed copies of multiple articles may use Elsevier WebShop's 'Create Your Own Book' service to collate multiple articles within a single cover (<http://webshop.elsevier.com/myarticleservices/booklets>).



Author Inquiries

You can track your submitted article at <http://www.elsevier.com/track-submission>. You can track your accepted article at <http://www.elsevier.com/trackarticle>. You are also welcome to contact Customer Support via <http://support.elsevier.com>.

Appendix B – Excluded Articles

Botello-Harbaum, M., Nansel, T., Haynie, D. L., Iannotti, R. J., & Simons-Morton, B. (2008).

Responsive parenting is associated with improved type 1 diabetes-related quality of life. *Child: Care, Health and Development*, 34(5), 675-681.

Dec, D. (1980). A parent's perspective: It's not child's play. *The Journal of Practical Nursing*, 30(1), 19.

Eckshtain, D., Ellis, D. A., Kolmodin, K., & Naar-King, S. (2010). The effects of parental depression and parenting practices on depressive symptoms and metabolic control in urban youth with insulin dependent diabetes. *Journal of Pediatric Psychology*, 35(4), 426-435.

Geffken, G. R., Lehmkuhl, H., Walker, K. N., Storch, E. A., Heidgerken, A. D., Lewin, A., ... & Silverstein, J. (2008). Family functioning processes and diabetic ketoacidosis in youths with type I diabetes. *Rehabilitation Psychology*, 53(2), 231.

Johnson, G. M., & Johnson, J. B. (1979). Living with diabetic children: A family affair. *Minnesota Medicine*, 62 (1), 51-54.

Jubber, A. P., Olsen Roper, S., Yorgason, J. B., Poulsen, F. O., & Mandleco, B. L. (2013). Individual and family predictors of psychological control in parents raising children with type 1 diabetes. *Families, Systems, & Health*, 31(2), 142.

Klusa, Y., Habbick, B. F., & Abernathy, T. J. (1983). Diabetes in children: Family responses and control. *Psychosomatics*, 24(4), 367-372.

Miller-Johnson, S., Emery, R. E., Marvin, R. S., Clarke, W., Lovinger, R., & Martin, M. (1994). Parent-child relationships and the management of insulin-dependent diabetes mellitus. *Journal of Consulting and Clinical Psychology*, 62(3), 603.

Shiau, S., Chen, Y.C., & Lin, B. J. (1995). Self-management and attributes of juveniles with insulin-dependent diabetes mellitus. *Acta Paediatrica Sinica*, 36(1), 35-40.

Stewart, S. M., Lee, P. W., Low, L. C., Cheng, A., Yeung, W., Huen, K. F., & O'Donnell, D. (2000). Pathways from emotional adjustment to glycemic control in youths with diabetes in Hong Kong. *Journal of Pediatric Psychology*, 25(6), 393-402.

Stoker, M., Mandelco, B., Roper, S. O., Marshall, E. S., & Dyches, T. L. (2008). Adolescents with type 1 diabetes: Self Care, HbA1c, and parenting styles. In Proceedings from Western Institute of Nursing Assembly '08: *The Circle of Nursing Knowledge: Education, Practice and Research*. CA, USA: Western Institute of Nursing.

Appendix C – Data Extraction Form

Author(s)		
Title of Study and Year of Publication		
Research Aims		
Research Design		
Participants	<p>Parents included as participants: Yes/No</p> <p>Type of Parent included (Number of sample - %):</p> <p>Mean Age (SD):</p> <p>Marital Status (Number of sample - %):</p> <p>Ethnicity (Number of sample - %):</p>	<p>Children included as participants: Yes/No</p> <p>Mean Age (SD):</p> <p>Mean Duration of Diabetes (SD):</p> <p>Mean HbA1C (SD):</p> <p>Ethnicity (Number of sample - %):</p> <p>Gender (Number of sample - %):</p>
Sample size	<p>Total:</p> <p>Parent:</p> <p>Child:</p>	
Methodological quality (as assessed by checklist)	Rater 1:	Rater 2:
Theoretical model specified		
Parenting style measure used		

Measure of metabolic control used	
Measure of Diabetic adherence used	
Statistical Analysis	
Main Findings	
Conclusions – Author	
Conclusions – Reviewer	

Appendix D – Quality Checklist

Modified Version of Downs and Black's Quality Checklist

No.	Criteria	Possible Answers	Score
1	Is the hypothesis/aim/objective of the study clearly described?	Yes (1) No (0)	
2	Are the main outcomes to be measured clearly described in the Introduction or Methods section? <i>If the main outcomes are first mentioned in the Results section, the question should be answered no.</i>	Yes (1) No (0)	
3	Are the characteristics of the participants included in the study clearly described? <i>In cohort studies and trials, inclusion and/or exclusion criteria should be given. In case-control studies, a case-definition and the source for controls should be given.</i>	Yes (1) No (0)	
4	Are the main findings of the study clearly described? <i>Simple outcome data (including denominators and numerators) should be reported for all major findings so that the reader can check the major analyses and conclusions. (This question does not cover statistical tests which are considered below)</i>	Yes (1) No (0)	
5	Was a sample size calculation reported?	Yes (1) No (0)	
6	Have actual probability values been reported (e.g.0.035 rather than <0.05) for the main outcomes except where the probability value is less than 0.001?	Yes (1) No (0)	
7	Were the subjects asked to participate in the study representative of the entire population from which they were recruited? <i>The study must identify the source population for patients and describe how the patients were selected. Patients would be representative if they comprised the entire source population, an unselected sample of consecutive patients, or a random sample. Random sampling is only feasible where a list of all members of the relevant population exists. Where a study does not report the proportion of the source population from which the patients are derived, the question should be answered as unable to determine.</i>	Yes (1) No (0) Unable to Determine (UTD; 0)	
8	Were the statistical tests used to assess the main outcomes appropriate? <i>The statistical techniques used must be appropriate to the data. For example non- parametric methods should be used for small sample sizes. Where little statistical analysis has been undertaken but where there is no evidence of bias, the question should be answered yes. If the distribution of the data (normal or not) is not described it must be assumed that the estimates used were appropriate and the question should be answered yes.</i>	Yes (1) No (0) UTD (0)	

9	Were the main outcome measures used accurate (valid and reliable)? <i>For studies where the outcome measures are clearly described, the question should be answered yes. For studies which refer to other work or that demonstrates the outcome measures are accurate, the question should be answered as yes.</i>	Yes (1) No (0) UTD (0)	
10	Was there adequate adjustment for confounding in the analyses from which the main findings were drawn? <i>This question should be answered no for trials if: the main conclusions of the study were based on analyses of treatment rather than intention to treat; the distribution of known confounders in the different treatment groups was not described; or the distribution of known confounders differed between the treatment groups but was not taken into account in the analyses. In non-randomised studies if the effect of the main confounders was not investigated or confounding was demonstrated but no adjustment was made in the final analyses the question should be answered as no.</i>	Yes (1) No (0) UTD (0)	
11	Limitations/Implications of the study are reported	Yes (1) No (0)	

Total Score:

Appendix E - Data Extracted from Included Articles.

Key: PS – Parenting Styles, QR – Quality Rating, ppts – Participants, ANOVA – Analysis of Variance, ANCOVA – Analysis of Covariance

Study (Location)	Key Characteristics of Sample	Theoretical model of PS and measure used	Was PS assessed as typologies or as dimensions	Diabetes management measures used	Findings	QR
Mlynarczyk, 2013 (USA)	Parents included as ppts: No Children included as ppts: Yes Mean Age of Children (SD): 15 (1.67) Average age of child at diagnosis (SD): 7.69 years (3.55) Mean HbA1c (SD): Not stated Ethnicity: 89% Caucasian, 3% African American, 2% Hispanic, 1% Asian American Gender of children: 52 males, 50 females Type of Parent included: Not stated Relationship Status: 68.6% Two	Baumrind Maccoby & Martin Measure Used: Parenting Style Index – II (PSI- II)	Typologies – Authoritative, Authoritarian, Permissive & Neglectful	Diabetes Adherence Measure: Diabetic Behaviour Rating Scale (DBRS) Metabolic Control Measure: Average of last 4 HbA1c values over the last year or since the adolescent came out of the “honeymoon period”	<ul style="list-style-type: none"> Number of Parents grouped into PS by adolescents: Authoritative 37, Authoritarian 16, Permissive 45, Neglectful 4 One way ANOVA showed a significant difference in adherence means between the Authoritative PS group and each of the Authoritarian, Permissive and Neglectful PS groups (p=0.006). The post-hoc Least Significant Difference (LSD) analysis demonstrated a significant difference between the Authoritative PS group and each of the Authoritarian (p=0.024), Permissive (p=0.013) and Neglectful (p=0.013) PS 	8

	Natural Parents, 13.7%				group.
	Single/Divorced Parents, 8.8%				• There we no significant differences between the PS groups in metabolic control.
	Step-Family, Other 8.8%				
	Sample Size: 102 Adolescents				
Butler,	Parents included as ppts: Yes	Baumrind	Assessed in both	Diabetes Adherence	• Child and maternal reports of parenting style moderately correlated;
Skinner,	Children included as ppts: Yes	Main theory - Dimensional	ways.	Measure: 14-item Self	psychological control (r=0.42, p<0.01),
Gelfand, Berg	Mean Age of Children (SD):	approach (Bean, Barber &		Care Inventory –	firm control (r=0.41, p<0.01) and
& Wiebe,	170.53 months (20.21)	Crane, 2006) – Psychological		Adolescents were the	acceptance (r=0.32, p<0.01)
2007 (USA)	Average age of child at diagnosis (SD): not stated	control, Firm control & Acceptance		only participants to complete this measure	• Maternal Acceptance was significantly correlated with Adherence (r=0.24, p<0.05). Adherence was not significantly correlated with maternal psychological control or firm control and
	Mean HbA1c (SD): 8.66% (1.41%)	Measure Used:		Metabolic Control	all 3 of the dimensions from the perceptions of the adolescents.
	Ethnicity: 99% European-American	Adolescents – 30 item Child Report of Parent Behaviour		Measure: None	• Regression Analysis using adolescent reported PS (ARPS), gender and age as predictors in step 1, and interactions between a) ARPS and gender and b) ARPS and age as predictors in step
	Gender of Children: 41 males, 37 females	Inventory (CRPBI)			
	Type of Parent included: Mothers 100%	Mothers – Parental version of same scale (PRPBI)			
	Relationship Status: not stated				
	Sample Size: 78 mother-child dyads				

2. Adolescents reports of psychological control were unrelated to adherence.

Adolescents' reports of firm control were unrelated to adherence.

Adolescents' reports of acceptance were unrelated to adherence.

- Parallel regression analysis conducted using maternal reports of PS. Maternal reports of psychological control and firm control were unrelated to adherence (p 's >0.05). Maternal reports of acceptance interacted with age to predict adherence ($b=-0.24$; $p<0.05$), however the F value for the overall model was marginally significant ($p=0.08$). Higher maternal acceptance was associated with better adherence among younger but not older adolescents.
- Study also assessed the study using a typological approach however no significant results were found.

Sherifali, Ciliska & O'Mara, 2009 (USA)

Parents included as ppts: Yes
 Children included as ppts: Yes
 Mean Age of Children (SD): 9 years (2.3)
 Average age of child at diagnosis (SD): Not stated but had to have had diabetes for at least 1 year
 Mean HbA1c (SD): 8.4 (1.2)
 Ethnicity: 82.9% Canadian, 17.1% Other
 Gender of children: 108 males, 108 females
 Type of Parent included: 81% Mothers, 18.1% Fathers. 98.1% Biological Parents, 0.5% Step Parent, 0.5% Adoptive Parent, 0.9% Other
 Relationship Status: 78.2% married, 13% divorced/separated, 5.1% single/never married, 3.2%

Baumrind
 Measure used: Parenting Dimensions Inventory (PDI)
 Parents completed this measure

Dimensional - Split into support, control and structure, however also calculated the parents PS from the dimensions.
 Diabetes Adherence
 Measure: None
 Metabolic Control
 Measure: HbA1c results from 3-4 months before the date of the study

-
- Mean (SD) results on PDI:
 - Support (nurturance & responsiveness) – 54.65 (7.42)
 - Control (amount of control, maturity demands, physical punishment, material and social consequences, reasoning and scolding) – 34.89 (6.51)
 - Structure (involvement, consistency and organisation) – 51.84 (9.47)
- Most parents in the study were reported to have an Authoritative PS for consistency, nurture and control but a permissive PS for maturity demands.
- Parenting dimensions of support, control and structure did not significantly correlate with metabolic control.

9

common law

Sample Size: 216 Parent-child dyads

Davies,	Parents included as ppts: Yes	Mentions studies looking at	Dimensional -	Diabetes Adherence	<ul style="list-style-type: none">• Warmth was associated with better adherence ($r = 0.56$, $p < 0.001$) and restrictiveness was associated with poorer metabolic control ($r = 0.36$, $p < 0.05$). Warmth was not associated with better metabolic control ($r = -0.05$) and Restrictiveness was not associated with poorer adherence ($r = -0.01$).
Delamater,	Children included as ppts: No	parental warmth and parental	Split into warmth,	Measure: Self-Care	
Shaw, La	Mean Age of Children (SD): 7.5	coercion. Also mentions studies	restrictiveness,	Inventory (SCI)	<ul style="list-style-type: none">• Hierarchical regression:<ul style="list-style-type: none">○ No demographic variables predicted adherence. Warmth, amount of control, restrictiveness and physical punishment were entered into the model, which significantly improved the model ($R^2 = R^2\Delta = 0.33$, $p < 0.001$, adjusted $R^2 = 0.28$, $N = 52$). Warmth was
Greca,	years (1.9)	on authoritative parenting but	amount of control	Metabolic Control	
Eidson,	Average age of child at diagnosis	does not specifically look at	and physical	Measure: Most recent	
Perez-	(SD): 27% diagnosed within the	theories of parenting styles.	punishment.	HbA1c result were	
Rodrigues &	past year Mean duration of	Measure used: Parenting		collected by chart	
Nemery,	diabetes (SD) = 2.7 years (2.0)	Dimensions Inventory (PDI)		review. Six children	
2001 (USA)	Mean HbA1c (SD): 8.7%			lacked a current HbA1c	
	however 43% had HbA1c values			results and 11 newly	
	over 4 SDs above the normal			diagnosed (less than a	
	range.			year) children were also	
	Ethnicity: 58% White Non-			excluded from the	
	Hispanic, 16% Black, 26%			HbA1c analysis due to	
	Hispanic			the 'honeymoon	
	Gender of children: 56% Girls,			period'.	
	44% Boys				
	Type of Parent included: 84%				

8.5

Mothers

Relationship Status: 36% Single

Parent Families

Sample Size: 55 Parents

the only significant predictor

accounting for 27% of the

variability in adherence

ratings. No parenting variables

improved the regression model

when predicting glycaemic

control ($R^2\Delta = 0.03$, $p > 0.10$).

Shorer, David, Schoenberg-Taz, Levavi-Lavi, Phillip & Meyerovitch, 2011 (Israel)	Parents included as ppts: Yes Children included as ppts: Yes Mean Age of Children (SD): 14.37 years (2.67) Average age of child at diagnosis (SD): Not stated but mean duration of diabetes was 4.92 years (3.22) Mean HbA1c (SD): 8.05% (1.27) Ethnicity: Not stated Gender of children: 53 males, 47 females Type of Parent included: 79 Mothers, 63 Fathers	Baumrind Measure Used: Parental Authority Questionnaire— Parents were only participants to complete this	Typologies – Authoritative, Authoritarian and Permissive.	Diabetes Adherence Measure: Adherence to Diabetes Treatment Regimen Questionnaire— Completed by child and 1 parent. Metabolic Control Measure: Average HbA1c value during 2007.	<ul style="list-style-type: none">Higher authoritativeness of fathers but not mothers was associated with better adherence ($r = 0.24$, $p < 0.05$) and better metabolic control ($r = 0.35$, $p < 0.005$). Higher level of permissiveness in mothers was associated with poorer adherence ($r = 0.25$, $p < 0.05$). Authoritarian parenting was not associated with adherence or metabolic control; however when the analysis was just limited to boys, higher levels of authoritarianism in mothers was associated with poorer adherence.Regression models used to assess if
--	---	--	--	--	--

7

Relationship Status: 86.6%
 Married, 11.4% Divorced, 2%
 Single Parents
 Sample Size: 142 Parents, 100
 children

parenting factors predict metabolic control or adherence when controlling for child's age, sex and treatment method and found that none of the parenting styles significantly predicted metabolic control or adherence when regressed with other variables.

Greene, Parents included as ppts: Yes
 Mandleco, Children included as ppts: Yes
 Roper, Mean Age of Children (SD):
 Marshall & 14.04 years (1.98)
 Dyches, 2010 Average age of child at diagnosis
 (USA) (SD): Not stated but mean duration of diabetes was 6.23 years (3.47)
 Mean HbA1c (SD): 8.51 (1.28)
 Ethnicity: 90% White
 Gender of children: 14 males, 15 females
 Type of Parent included: Mothers and Fathers – No percentage

Baumrind
 Maccoby and Martin
 Measure Used: Parenting Practices Report - Completed by mothers and fathers independently

Typologies -
 Authoritative,
 Authoritarian, and
 Permissive.

Diabetes Adherence
 Measure: Diabetes Self-care instrument –
 Developed by the research team and completed by adolescents
 Metabolic Control
 Measure: Last 4 HbA1c results were averaged.
 If researchers could not access 4 consecutive results they performed a

- Mean (SD) scores for PS:
 - Authoritative – Mothers 3.88 (0.25), Fathers 3.76 (0.45)
 - Authoritarian - Mothers 1.70 (0.34), Fathers 1.84 (0.38)
 - Permissive – Mothers 1.81 (0.35), Fathers 1.91 (0.42)
- Authoritative mothering was associated with better metabolic control ($r = -0.458$, $p < 0.05$) and better adherence ($r = 0.639$, $p < 0.01$). Permissive parenting in mothers was associated with poorer metabolic control ($r = 0.358$, $p < 0.05$) and permissive parenting in fathers was also associated

stated

Relationship Status: 86% Two

Parent Households

Sample Size: 29 Adolescents and

at least one of their parents

(number of parents not stated)

statistical analysis based

on the average of the 2

to 3 readings that were

available. Participants

had to have diabetes for

at least 2 years to ensure

there would be no

'honeymoon period'

effects.

with poorer metabolic control ($r=0.395$,

$p<0.05$). Permissive parenting was not

significantly associated with adherence.

Authoritarian parenting was not

significantly associated with either

metabolic control or adherence.

- The study also investigated the associations between PS and individual adherence behaviours. Mothers authoritative PS significantly correlated with eating correct amounts ($r=0.587$, $p<0.01$), right kinds of food ($r=0.387$, $p<0.05$), checking blood glucose ($r=0.436$, $p<0.05$), giving insulin ($r=0.659$, $p<0.01$), testing ketones ($r=0.471$, $p<0.01$), exercising ($r=0.356$, $p<0.05$), adjusting insulin for exercise ($r=0.459$, $p<0.01$) and adjusting insulin for excess food ($r=0.542$, $p<0.01$). Mothers Permissive PS was associated with poorer adherence to a low fat diet ($r=-$

0.374, $p < 0.05$). Mothers Authoritarian PS was also associated with poorer adherence to a low fat diet ($r = -0.0396$, $p < 0.05$). Fathers authoritarian and permissive PS were not significantly associated with any individual adherence behaviour. Fathers authoritative PS was associated with not skipping meals ($r = 0.375$, $p < 0.05$), checking blood glucose ($r = 0.396$, $p < 0.05$) and giving insulin ($r = 0.466$, $p < 0.05$).

- Regression analysis to examine the associations between metabolic control, adherence and PS. After controlling for age and duration of diabetes, authoritative mothering accounted for 25% of the variance in HbA1c values and was the strongest predictor of metabolic control ($\beta = -0.52$, $p < 0.01$). Controlling for the age of the child and duration of diabetes, authoritative

Monaghan, Horn, Alvarez, Cogen & Streisand, 2012 (USA)	Parents included as ppts: Yes Children included as ppts: No Mean Age of Children (SD): 9.33 years (0.87) Average age of child at diagnosis (SD): Not stated but mean duration of diabetes was 3.42 years (2.53) Mean HbA1c (SD): 7.96% (1.04) Ethnicity: 64% Caucasian, 21% African American, 5% Latino, 10% Other Gender of children: 47% Female Type of Parent included: 87 Mothers, 7 Fathers and 1 Grandmother – had to identify as	Baumrind Measure Used: Parenting Styles and Dimensions Questionnaire (PSDQ)	Not split, however most analysis used authoritative PS	Diabetes Adherence Measure: Self Care Inventory (SCI) Metabolic Control Measure: Average of 3 most recent HbA1c results obtained at least 6 months after diagnosis	<p>mothering also predicted adherence ($\beta = 0.63, p < 0.001$) and accounted for 36% of the variance. Also done with permissive PS however it did not predict metabolic control.</p> <ul style="list-style-type: none"> 97% of parents reported behaviours that would indicate they had a primarily authoritative PS. 3% of parents reported behaviours that would indicate they had a primarily permissive PS. Higher use of authoritative PS was correlated with less reported use of authoritarian PS ($r = -0.22, p < 0.05$). Due to high level of sample reporting authoritative PS, the study split the sample into high level of authoritative PS and low level of authoritative PS. ANCOVA were conducted to assess the relationship between authoritative PS, adherence and metabolic control. Ethnicity, income and regimen were
---	--	--	--	---	---

primary care giver

Relationship Status: 83% married

Sample Size: 95 Primary Care

Givers

used as covariates. Parents who used a high level of authoritative parenting reported that their children had better adherence than parents using lower level of authoritative parenting ($F(4,88)= 0.35$, $p<0.01$, partial $\eta^2= 0.08$). No differences in HbA1c were found ($F(4,88)= 0.35$, $p=0.55$) between parents using high and low levels of authoritative PS.

Appendix F – Detailed Quality Ratings for Included Studies

Questions were scored with either a 1 (Yes) or 0 (No or Unable to Determine). Raters also used 0.5 when they felt a paper showed evidence for the questions but not enough to validate a score of 1.

Study	Ratings for each Question – Rater 1 (Rater 2)											Total
	Question 1	Question 2	Question 3	Question 4	Question 5	Question 6	Question 7	Question 8	Question 9	Question 10	Question 11	
Shorer et al (2011)	1 (1)	1 (1)	1 (1)	1 (1)	0 (0)	0 (0)	0 (0)	1 (1)	0 (0)	1 (1)	1 (1)	7 (7)
Butler et al (2007)	1 (1)	1 (1)	1 (1)	1 (1)	0 (0)	0 (0)	0 (0)	1 (1)	1 (0.5)	1 (1)	1 (1)	7 (7.5)
Mlynarczyk (2013)	1 (1)	1 (1)	1 (1)	1 (1)	0 (0)	1 (1)	0 (0)	1 (1)	1 (1)	0 (0)	1 (1)	8 (8)
Davies et al (2001)	1 (1)	1 (1)	1 (1)	1 (1)	0 (0)	1 (0)	0 (0)	1 (1)	1 (1)	1 (1)	0.5 (0.5)	8.5 (7.5)
Greene et al (2010)	1	1	1	1	0	0	0	1	1	1	1	8
Sherifali et al (2009)	1	1	1	1	1	0	1	1	1	0	1	9
Monaghan et al (2012)	1	1	1	1	1	0	0	1	1	1	1	9

Appendix G – Author Guidelines for Empirical Paper

Manuscript Submission Guidelines: Qualitative Health Research (QHR)

Qualitative Health Research (QHR) is an international, interdisciplinary, refereed journal for the enhancement of health care and furthering the development and understanding of qualitative research methods in health care settings. We welcome manuscripts in the following areas: the description and analysis of the illness experience, health and health-seeking behaviors, the experiences of caregivers, the sociocultural organization of health care, health care policy, and related topics. We also consider critical reviews; articles addressing qualitative methods; and commentaries on conceptual, theoretical, methodological, and ethical issues pertaining to qualitative inquiry.

QHR is a member of the Committee on Publication Ethics. This Journal recommends that authors follow the Uniform Requirements for Manuscripts Submitted to Biomedical Journals formulated by the International Committee of Medical Journal Editors (ICMJE)

Please read the guidelines below then visit the Journal's submission site <http://mc.manuscriptcentral.com/qhr> to upload your manuscript. Please note that manuscripts not conforming to these guidelines may be returned. Only manuscripts of sufficient quality that meet the aims and scope of QHR will be reviewed. As part of the submission process you will be required to warrant that you are submitting your original work, that you have the rights in the work, that you are submitting the work for first publication in the Journal and that it is not being considered for publication elsewhere and has not already been published elsewhere, and that you have obtained and can supply all necessary permissions for the reproduction of any copyright works not owned by you.

1. Article types
2. Editorial policies
 - 2.1 Peer review policy
 - 2.2 Authorship
 - 2.3 Acknowledgements
 - 2.4 Funding
 - 2.5 Declaration of conflicting interests
 - 2.6 Research ethics and patient consent
 - 2.7 Clinical trials
 - 2.8 Reporting guidelines
 - 2.9 Data
3. Publishing Policies
 - 3.1 Publication ethics
 - 3.2 Contributor's publishing agreement
 - 3.3 Open access and author archiving
 - 3.4 Permissions
4. Preparing your manuscript
 - 4.1 Word processing formats
 - 4.2 Artwork, figures and other graphics
 - 4.3 Supplementary material

- 4.4 Journal layout
- 4.5 Reference style
- 4.6 English language editing services
- 5. Submitting your manuscript
 - 5.1 How to submit your manuscript
 - 5.2 Title, keywords and abstracts
 - 5.3 Corresponding author contact details
- 6. On acceptance and publication
 - 6.1 SAGE Production
 - 6.2 Access to your published article
 - 6.3 Online First publication
- 7. Further information

1. Article types

Each issue of QHR provides readers with a wealth of information - book reviews, commentaries on conceptual, theoretical, methodological and ethical issues pertaining to qualitative inquiry as well as articles covering research, theory and methods in the following areas:

Description and analysis of the illness experience

Experiences of caregivers

Health and health-seeking behaviors

Health care policy

Sociocultural organization of health care

A Variety of Perspectives

QHR addresses qualitative research from variety of perspectives including: cross-cultural health, family medicine, health psychology, health social work, medical anthropology, medical sociology, nursing, pediatric health, physical education, public health, and rehabilitation.

In-Depth Timely Coverage

Articles in QHR provide an array of timely topics such as: experiencing illness, giving care, institutionalization, substance abuse, food, feeding and nutrition, living with disabilities, milestones and maturation, monitoring health, and children's perspectives on health and illness.

Look Out for These Regular Special Features

Pearls, Pith and Provocation: This section fosters debate about significant issues, enhances communication of methodological advances and encourages the discussion of provocative ideas.

Computer Monitor: These are articles related to computers and qualitative research.

Book Review Section: Qualitative Health Research includes a book review section helping readers determine which publications will be most useful to them in practice, teaching and research.

Mixed Methods: This section includes qualitatively-driven mixed-methods research, and qualitative contributions to quantitative research.

Advancing Qualitative Methods: Here, qualitative inquiry that has used qualitative methods in an innovative way is described.

Evidence of Practice: Theoretical or empirical articles addressing research integration and the translation of qualitatively derived insights into clinical decision-making and health service policy planning.

Ethics: Quandaries or issues that are particular to qualitative inquiry are discussed.

Teaching Matters: Articles that promote and discuss issues related to the teaching of qualitative methods and methodology.

2. Editorial policies

2.1 Peer review policy

QHR strongly endorses the value and importance of peer review in scholarly journals publishing. All papers submitted to the journal will be subject to comment and external review. All manuscripts are reviewed initially by the Editors and only those papers that meet the scientific and editorial standards of the journal, and fit within the aims and scope of the journal, will be sent for outside review.

QHR adheres to a rigorous double-blind reviewing policy in which the identity of both the reviewer and author are always concealed from both parties. Please refer to the editorial on blinding found in the Nov 2014 issue: <http://qhr.sagepub.com/content/24/11/1467.full>.

2.2 Authorship

Papers should only be submitted for consideration once consent is given by all contributing authors. Those submitting papers should carefully check that all those whose work contributed to the paper are acknowledged as contributing authors. The list of authors should include all those who can legitimately claim authorship. This is all those who:

- (i) Made a substantial contribution to the concept and design, acquisition of data or analysis and interpretation of data,
- (ii) Drafted the article or revised it critically for important intellectual content,
- (iii) Approved the version to be published.

Authors should meet the conditions of all of the points above. Each author should have participated sufficiently in the work to take public responsibility for appropriate portions of the content.

When a large, multicentre group has conducted the work, the group should identify the individuals who accept direct responsibility for the manuscript. These individuals should fully meet the criteria for authorship.

Acquisition of funding, collection of data, or general supervision of the research group alone does not constitute authorship, although all contributors who do not meet the criteria for authorship should be listed in the Acknowledgments section. Please refer to the International Committee of Medical Journal Editors (ICMJE) authorship guidelines for more information on authorship.

2.3 Acknowledgements

All contributors who do not meet the criteria for authorship should be listed in an Acknowledgements section. Examples of those who might be acknowledged include a person who provided purely technical help, or a department chair who provided only general support.

2.3.1 Writing assistance Individuals who provided writing assistance, e.g. from a specialist communications company, do not qualify as authors and so should be included in the Acknowledgements section. Authors must disclose any writing assistance – including the individual's name, company and level of input – and identify the entity that paid for this assistance"). It is not

necessary to disclose use of language polishing services. Please supply any personal acknowledgements separately to the main text to facilitate anonymous peer review.

2.4 Funding

QHR requires all authors to acknowledge their funding in a consistent fashion under a separate heading. Please visit the Funding Acknowledgements page on the SAGE Journal Author Gateway to confirm the format of the acknowledgment text in the event of funding, or state that: This research received no specific grant from any funding agency in the public, commercial, or not-for-profit sectors.

2.5 Declaration of conflicting interests

It is the policy of QHR to require a declaration of conflicting interests from all authors enabling a statement to be carried within the paginated pages of all published articles. Please ensure that a 'Declaration of Conflicting Interests' statement is included at the end of your manuscript, after any acknowledgements and prior to the references. If no conflict exists, please state that 'The Author(s) declare(s) that there is no conflict of interest'.

For guidance on conflict of interest statements, please see the ICMJE recommendations here

2.6 Research ethics and patient consent

Medical research involving human subjects must be conducted according to the World Medical Association Declaration of Helsinki.

Submitted manuscripts should conform to the ICMJE Recommendations for the Conduct, Reporting, Editing, and Publication of Scholarly Work in Medical Journals, and all papers reporting animal and/or human studies must state in the methods section that the relevant Ethics Committee or Institutional Review Board provided (or waived) approval. Please ensure that you have provided the full name and institution of the review committee, in addition to the approval number.

For research articles, authors are also required to state in the methods section whether participants provided informed consent and whether the consent was written or verbal.

In terms of patient privacy, authors are required to follow the ICMJE Recommendations for the Protection of Research Participants. Patients have a right to privacy that should not be infringed without informed consent. Identifying information, including patients' names, initials, or hospital numbers, should not be published in written descriptions, photographs, and pedigrees unless the information is essential for scientific purposes and the patient (or parent or guardian) gives written informed consent for publication. Informed consent for this purpose requires that a patient who is identifiable be shown the manuscript to be published. Participant descriptors should not be listed individually. Because qualitative research is descriptive, it is recommended that participant quotations not be linked to identifiers in the manuscript.

2.7 Clinical trials

QHR conforms to the ICMJE requirement that clinical trials are registered in a WHO-approved public trials registry at or before the time of first patient enrolment as a condition of consideration for publication. The trial registry name and URL, and registration number must be included at the end of the abstract.

2.8 Reporting guidelines

The relevant EQUATOR Network reporting guidelines should be followed depending on the type of study. For example, all randomized controlled trials submitted for publication should include a completed Consolidated Standards of Reporting Trials (CONSORT) flow chart as a cited figure, and a completed CONSORT checklist as a supplementary file.

Other resources can be found at NLM's Research Reporting Guidelines and Initiatives.

2.9 Data

SAGE acknowledges the importance of research data availability as an integral part of the research and verification process for academic journal articles.

QHR requests all authors submitting any primary data used in their research articles alongside their article submissions to be published in the online version of the journal, or provide detailed information in their articles on how the data can be obtained. This information should include links to third-party data repositories or detailed contact information for third-party data sources. Data available only on an author-maintained website will need to be loaded onto either the journal's platform or a third-party platform to ensure continuing accessibility. Examples of data types include but are not limited to statistical data files, replication code, text files, audio files, images, videos, appendices, and additional charts and graphs necessary to understand the original research. [The editor(s) may consider limited embargoes on proprietary data.] The editor(s) [can/will] also grant exceptions for data that cannot legally or ethically be released. All data submitted should comply with Institutional or Ethical Review Board requirements and applicable government regulations. For further information, please contact the editorial office at vshannonqhr@gmail.com.

3. Publishing Policies

3.1 Publication ethics

SAGE is committed to upholding the integrity of the academic record. We encourage authors to refer to the Committee on Publication Ethics' International Standards for Authors and view the Publication Ethics page on the SAGE Author Gateway

3.1.1 Plagiarism

QHR and SAGE take issues of copyright infringement, plagiarism or other breaches of best practice in publication very seriously. We seek to protect the rights of our authors and we always investigate claims of plagiarism or misuse of articles published in the journal. Equally, we seek to protect the reputation of the journal against malpractice. Submitted articles may be checked using duplication-checking software. Where an article is found to have plagiarised other work or included

third-party copyright material without permission or with insufficient acknowledgement, or where authorship of the article is contested, we reserve the right to take action including, but not limited to: publishing an erratum or corrigendum (correction); retracting the article (removing it from the journal); taking up the matter with the head of department or dean of the author's institution and/or relevant academic bodies or societies; banning the author from publication in the journal or all SAGE journals, or appropriate legal action.

3.2 Contributor's publishing agreement

Before publication, SAGE requires the author as the rights holder to sign a Journal Contributor's Publishing Agreement. SAGE's Journal Contributor's Publishing Agreement is an exclusive licence agreement which means that the author retains copyright in the work but grants SAGE the sole and exclusive right and licence to publish for the full legal term of copyright. Exceptions may exist where an assignment of copyright is required or preferred by a proprietor other than SAGE. In this case copyright in the work will be assigned from the author to the society. For more information please visit our Frequently Asked Questions on the SAGE Journal Author Gateway.

3.3 Open access and author archiving

QHR offers optional open access publishing via the SAGE Choice programme. For more information please visit the SAGE Choice website. For information on funding body compliance, and depositing your article in repositories, please visit SAGE Publishing Policies on our Journal Author Gateway.

3.4 Permissions

Authors are responsible for obtaining permission from copyright holders for reproducing any illustrations, tables, figures or lengthy quotations previously published elsewhere. For further information including guidance on fair dealing for criticism and review, please visit our Frequently Asked Questions on the SAGE Journal Author Gateway

4. Preparing your manuscript

4.1 Word processing formats

Preferred formats for the text and tables of your manuscript are Word DOC, RTF, XLS. LaTeX files are also accepted. The text should be double-spaced throughout and with a minimum of 3cm for left and right hand margins and 5cm at head and foot. Text should be standard 10 or 12 point. Word and LaTeX templates are available on the Manuscript Submission Guidelines page of our Author Gateway.

4.2 Artwork, figures and other graphics

For guidance on the preparation of illustrations, pictures and graphs in electronic format, please visit SAGE's Manuscript Submission Guidelines. Please refer to clause 4.5 for information on SAGE Language Services.

Figures supplied in color will appear in color online regardless of whether or not these illustrations are reproduced in colour in the printed version. For specifically requested color reproduction in

print, you will receive information regarding the costs from SAGE after receipt of your accepted article.

4.3 Supplementary material

This journal is able to host additional materials online (e.g. datasets, podcasts, videos, images etc) alongside the full-text of the article. These will be subjected to peer-review alongside the article. For more information please refer to our guidelines on submitting supplementary files, which can be found within our Manuscript Submission Guidelines page.

4.4 Journal layout

In general, QHR adheres to the guidelines contained in the Publication Manual of the American Psychological Association [“APA”], 6th edition (ISBN 10:1-4338-0561-8, softcover; ISBN 10:1-4338-0559-6, hardcover; 10:1-4338-0562, spiral bound), with regard to manuscript preparation and formatting. These guidelines are referred to as the APA Publication Manual, or just APA. Additional help may be found online at <http://www.apa.org/>, or search the Internet for “APA format.”

4.5 Reference style

QHR adheres to the APA reference style. Click [here](#) to review the guidelines on APA to ensure your manuscript conforms to this reference style.

4.6 English language editing services

Authors seeking assistance with English language editing, translation, or figure and manuscript formatting to fit the journal’s specifications should consider using SAGE Language Services. Visit SAGE Language Services on our Journal Author Gateway for further information.

5. Submitting your manuscript

5.1 How to submit your manuscript

QHR is hosted on SAGE Track, a web based online submission and peer review system powered by ScholarOne™ Manuscripts. Visit <http://mc.manuscriptcentral.com/qhr> to login and submit your article online.

IMPORTANT: Please check whether you already have an account in the system before trying to create a new one. If you have reviewed or authored for the journal in the past year it is likely that you will have had an account created. For further guidance on submitting your manuscript online please visit ScholarOne.

5.2 Title, keywords and abstracts

Please supply a title, short title, an abstract and keywords to accompany your article. The title, keywords and abstract are key to ensuring readers find your article online through online search engines such as Google. Please refer to the information and guidance on how best to title your

article, write your abstract and select your keywords by visiting the SAGE Journal Author Gateway for guidelines on How to Help Readers Find Your Article Online

5.3 Corresponding author contact details

Provide full contact details for the corresponding author including email, mailing address and telephone numbers. Academic affiliations are required for all co-authors. These details should be presented separately to the main text of the article to facilitate anonymous peer review.

6. On acceptance and publication

6.1 SAGE Production

Your SAGE Production Editor will keep you informed as to your article's progress throughout the production process. Proofs will be sent by PDF to the corresponding author and should be returned promptly.

6.2 Access to your published article

SAGE provides authors with online access to their final article.

6.3 Online First publication

Online First allows final revision articles (completed articles in queue for assignment to an upcoming issue) to be published online prior to their inclusion in a final journal issue which significantly reduces the lead time between submission and publication. For more information please visit our Online First Fact Sheet

7. Further information

Any correspondence, queries or additional requests for information on the manuscript submission process should be sent to the QHR editorial office as follows: Vanessa Shannon, Managing Editor, vshannonqhr@gmail.com.

Appendix H – Ethics Approval Letter

REMOVED FOR HARD BINDING

REMOVED FOR HARD BINDING

REMOVED FOR HARD BINDING

Appendix I – Brief Illness Perception Questionnaire (Broadbent et al, 2006)

REMOVED FOR HARD BINDING

Appendix J – Interview Schedule

- Demographic information including age, age at diagnosis, family at home, current point in education and insulin treatment
- Please can you tell me about your experience of being diagnosed with T1DM?
- Did the diagnosis of T1DM have any impact on yourself or your life?
 - If yes, can you tell me a bit more about that?
- Please can you tell me about your feelings of control over your diabetes?
 - Have you always felt this way about your diabetes?
- What do you feel contributes to how in control you feel about your diabetes?
- What areas of your life do you feel your feelings of control affects?
- How do your feelings of control affect how you feel about yourself?
- Some people with diabetes do not feel they are in control of their body, is this something which you may feel sometimes? (Disordered eating questions may be asked at this point)
- How do you think feelings of control affect your mood?
- (If family have not been mentioned) How do you feel your family may impact on your feelings about your control in relation to your diabetes?
- Do you feel that feelings about control have an impact on diabetes management?
 - If so, how?
- What does diabetes mean to you?
- If you do not feel in control of your diabetes, do you feel that someone else is in control of it?
- How would your life be different if you felt more in control of your diabetes?
- What would need to change in order for you to feel more in control of your diabetes?

Prompts

Can you tell me a bit more about that?

Can you tell me about an experience when that has happened to you?

Appendix K – Participant and Parent/Guardian Information Sheets

Participant Information Sheet

Title of the study: An Exploration of the Experiences of Control in Adolescents with Type 1 Diabetes

We would like to invite you to take part in our research study which is looking at the experience of control in adolescents with Type 1 Diabetes. Before you decide if you want to participate we would like you to understand why this research is being done. We would also like you to understand what it will involve for you if you decide to participate. You can talk to others if you would like before you decide if you want to take part. ***The researcher will answer any questions you may have.***

What is the purpose of the study?

We know very little about adolescents experiences of control in relation to their diabetes and how this may impact on their lives. This study is looking to understand more about adolescents' feelings of control around their diabetes and the impact this has. We hope that this study will help us understand more about these issues which will hopefully help improve support and treatment plans.

Why have I been invited?

This information is given to service-users who attend the clinic, who have type 1 diabetes and are aged between 14 and 19. The researcher or staff member gives this information sheet to people who may fulfil the criteria to take part in the study as they may be interested in participating.

Do I have to take part?

No, participation is completely voluntary. If you decide to take part you will be asked to sign a consent form to indicate that you agree to take part. You are free to withdraw from the study up to the point where the interview is completed and you do not have to give a reason for this. This decision will not affect your medical care or your legal rights.

What will happen if I decide to take part?

If you agree to take part please leave your contact details on the consent form. You will then be asked to complete a brief questionnaire. The researcher then scores the questionnaires away from the clinic and will select individuals to be contacted to ask if they would like to be interviewed. If you are selected and would like to be interviewed, the researcher will arrange a meeting with you at a place and time convenient to you. We will ask you some short questions about you, for example your gender and your age.

Then you will have a conversation with the researcher which will last around 60 minutes. The researcher who is a trainee clinical psychologist will be asking you about your experience of control relating to your diabetes and will audiotape the discussion. There are **no right or wrong** answers and we are only interested in **your opinions, your beliefs and your experience of diabetes and hearing “your story”**. After the interview you will be given the opportunity to ask any questions you may have.

What are the possible disadvantages and risks of taking part?

Participating in the study will require 60 minutes of your time and this may be inconvenient for you. Some people may experience emotional distress when they talk about their experiences of control around their diabetes because it may bring to mind difficult issues for the individual. If this happens to you the researcher will offer support and help you to gain access to further help from your clinical care team, if needed.

What are the possible benefits of taking part?

We cannot promise that you will have any direct benefits from taking part in the study. However, it is hoped that the information you give us will help us to understand more about type 1 diabetes and about the particular issues of adolescents’ experiences of control relating to their diabetes. It may also help to improve relevant treatment plans and support from services. Many people find it beneficial to be able to tell somebody their story.

What will happen if I decide I no longer wish to take part?

You are free to withdraw from the study before the interview is completed, without giving a reason. This will not affect your legal rights or the medical care that you receive in the clinic.

What if there is a problem?

If you have a concern about the study you can contact the researcher or their supervisor who will do their best to answer your questions.

Will my taking part in this study be kept confidential?

Yes, all the personal information that you provide will be kept strictly confidential. Any information that could be used to identify you will not be used in the research. The people who will decide to participate will be given a code to protect their anonymity. After the research is completed all the audio recordings will be destroyed. The only time that information cannot be kept confidential is if you disclose something that suggests that you or someone else is at risk of serious harm. If this happens during the interview the researcher will need to contact appropriate authorities to ensure that you and other

people are safe. It is unlikely that this will happen and the researcher will try to discuss this with you.

What will happen to the results of the study?

After the study is completed if you wish you will be given written feedback about the results of the study. We will also invite you to make comments on the results if you wish but this will be completely voluntary. Then the results will be written-up and submitted for publication in an academic journal. Some direct quotes from your interview may be used in the write-up. Your personal details and any identifiable data **will not** be included in the write-up.

Who is organising and funding the research?

This research is being undertaken as part of a doctoral research project in Clinical Psychology. The research is funded and regulated through the University of Hull. Some relevant sections of data collected during the study which are relevant to taking part in this research may be looked at by responsible individuals from the University of Hull or from regulatory authorities to ensure that appropriate guidance was followed by the researcher.

Who has reviewed the study?

The study is reviewed by an independent organisation which is called a Research Ethics Committee. The Research Ethics Committee protects the interest of people who participate in research.

If you have any further questions, comments or queries, please don't hesitate to contact Cassie Ward. Thank you for taking the time to read this information.

Yours Sincerely,

Cassie Ward
Trainee Clinical Psychologist

Supervised by,

Dr Dorothy Frizelle
Clinical Psychologist

Further information and contact details

Cassie Ward

The Department of Clinical
Psychology
Hertford Building
The University of Hull
Cottingham Road
Hull
HU6 7RX
Tel: 07794689505
E-mail address:
C.L.Ward@2012.hull.ac.uk

Dr Nikki McCloud

Paediatric Diabetes Service
St Nicholas House
Shelford Street
Scunthorpe
DN15 6NU
Tel: 01724 408460

Email address:
Nikki.McCloud@rdash.nhs.uk

Dr Dorothy Frizelle

The Department of Clinical
Psychology
Hertford Building
The University of Hull
Cottingham Road
Hull
HU6 7RX
Tel: 0 1482 464101
Email address:
d.frizelle@hull.ac.uk

Thank you very much for your interest!

Parent/Guardian Information Sheet

Title of the study: An Exploration of the Experiences of Control in Adolescents with Type 1 Diabetes

We would like to invite your child to take part in our research study which is looking at the experience of control in adolescents with Type 1 Diabetes. Before you decide if you would be happy for your child to participate we would like you to understand why this research is being done. We would also like you to understand what it will involve for your child if you are happy for them to participate. You can talk to others if you would like before you decide if your child can take part. ***The researcher will answer any questions you may have.***

What is the purpose of the study?

We know very little about adolescents experiences of control in relation to their diabetes and how this may impact on their lives. This study is looking to understand more about adolescents' feelings of control around their diabetes and the impact this has. We hope that this study will help us understand more about these issues which will hopefully help improve support and treatment plans.

Why has your child been invited?

This information is given to parents/guardians of service-users who attend the clinic, who have type 1 diabetes and are aged between 14 and 19. The researcher or staff member gives this information sheet to the parents/guardians of adolescents who may fulfil the criteria to take part in the study, as they may be interested in participating.

Does your child have to take part?

No, participation is completely voluntary. If you are happy for your child to take part you will be asked to sign a consent form to indicate that you agree for your child to take part. Your child is free to withdraw from the study up to the point where the interview is completed and they do not have to give a reason for this. This decision will not affect their medical care or their legal rights.

What will happen if I agree for my child to take part?

If you agree for your child to take part and they are also happy to take part, please leave your child's contact details on the consent form. Your child will then be asked to complete a brief questionnaire. The researcher then scores the questionnaires away from the clinic and will select individuals to be contacted to ask if they would like to be interviewed. If you child is selected and would like to be interviewed, the researcher will

arrange a meeting with your child at a place and time convenient to them. We will ask your child some short questions about themselves, for example their gender and their age. Then they will have a conversation with the researcher which will last around 60 minutes. The researcher who is a trainee clinical psychologist will be asking them about their experience of control relating to their diabetes and will audiotape the discussion. There are **no right or wrong** answers and we are only interested in **their opinions, their beliefs and their experience of diabetes and hearing “their story”**. After the interview they will be given the opportunity to ask any questions they may have.

What are the possible disadvantages and risks of taking part?

Participating in the study will require 60 minutes of your child’s time and this may be inconvenient for your child or yourself. Some people may experience emotional distress when they talk about their experiences of control around their diabetes because it may bring to mind difficult issues for the individual. If this happens to your child the researcher will offer support and help them to gain access to further help from their clinical care team, if needed.

What are the possible benefits of taking part?

We cannot promise that your child will have any direct benefits from taking part in the study. However, it is hoped that the information your child gives us will help us to understand more about type 1 diabetes and about the particular issues of adolescents’ experiences of control relating to their diabetes. It may also help to improve relevant treatment plans and support from services. Many people find it beneficial to be able to tell somebody their story.

What will happen if your child decides they no longer wish to take part?

Your child is free to withdraw from the study before the interview is completed, without giving a reason. This will not affect their legal rights or the medical care that they receive in the clinic.

What if there is a problem?

If you have a concern about the study you can contact the researcher or their supervisor who will do their best to answer your questions.

Will my child’s taking part in this study be kept confidential?

Yes, all the personal information that your child provide will be kept strictly confidential. Any information that could be used to identify your child will not be used in the research. The people who will decide to participate will be given a code to protect their anonymity. After the research is completed all the audio recordings will be destroyed.

The only time that information cannot be kept confidential is if your child discloses something that suggests that your child or someone else is at risk of serious harm. If this happens during the interview the researcher will need to contact appropriate authorities to ensure that your child and other people are safe. It is unlikely that this will happen and the researcher will try to discuss this with your child.

What will happen to the results of the study?

After the study is completed, if you or your child wishes, you will be given written feedback about the results of the study. We will also invite your child to make comments on the results if your child wishes but this will be completely voluntary. Then the results will be written-up and submitted for publication in an academic journal. Some direct quotes from your child's interview may be used in the write-up. Their personal details and any identifiable data **will not** be included in the write-up.

Who is organising and funding the research?

This research is being undertaken as part of a doctoral research project in Clinical Psychology. The research is funded and regulated through the University of Hull. Some relevant sections of data collected during the study which are relevant to taking part in this research may be looked at by responsible individuals from the University of Hull or from regulatory authorities to ensure that appropriate guidance was followed by the researcher.

Who has reviewed the study?

The study is reviewed by an independent organisation which is called a Research Ethics Committee. The Research Ethics Committee protects the interest of people who participate in research.

If you have any further questions, comments or queries, please don't hesitate to contact Cassie Ward. Thank you for taking the time to read this information.

Yours Sincerely,

Cassie Ward
Trainee Clinical Psychologist

Supervised by,

Dr Dorothy Frizelle
Clinical Psychologist

Further information and contact details

Cassie Ward

The Department of Clinical
Psychology
Hertford Building
The University of Hull
Cottingham Road
Hull
HU6 7RX
Tel: 07794689505
E-mail address:
C.L.Ward@2012.hull.ac.uk

Dr Nikki McCloud

Paediatric Diabetes Service
St Nicholas House
Shelford Street
Scunthorpe
DN15 6NU
Tel: 01724 408460

Email address:
Nikki.McCloud@rdash.nhs.uk

Dr Dorothy Frizelle

The Department of Clinical
Psychology
Hertford Building
The University of Hull
Cottingham Road
Hull
HU6 7RX
Tel: 0 1482 464101
Email address:
d.frizelle@hull.ac.uk

Thank you very much for your interest!

Appendix L – Consent form for BIPQ and to be contacted for interview

CONSENT FORM (Questionnaire and Consent to be contacted for interview)

Title of Project: An Exploration of the Experiences of Control in Adolescents with Type 1 Diabetes

Name of Researcher: Cassie Ward

Please initial boxes

1. I confirm that I have read and understand the information sheet dated 16/1/2015 (Version 2.1) for the above study. I have had the opportunity to consider the information. If I had any questions, they have been answered satisfactorily.

2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason up to the point of completing the interview (if invited back for an interview), without my medical care or legal rights being affected.

3. I understand confidentiality, the limits of confidentiality and the processes which would occur if there was a need to break confidentiality. I have been given the opportunity to ask questions. If I had any questions, they have been answered satisfactorily.

4. I understand that data collected during the study may be looked at by individuals from regulatory authorities or from the NHS Trust, where it is relevant to my taking part in this research. I give permission for these individuals to have access to my records.

5. I agree to complete the Brief Illness Perceptions Questionnaire and to be invited back for an interview exploring my feelings of control relating to my diabetes.

(Please complete contact details on the back of this page)

Yes No

6. If I am not randomly invited back for an interview, I would still like to be given the opportunity to be interviewed about my feelings of control relating to my diabetes.

(Please complete contact details on the back of this page)

Date

Please Turn Over
Signature

Name of Participant

Name of Parent/Legal
Guardian *(if participant is
under 16)*

Date

Signature

Name of person taking
consent

Date

Signature

When completed: 1 for participant; 1 for researcher site file.

Contact Details to be invited back for Interview:

If you are interested to take part in the study please leave your contact details on the space provided below. You will be contacted by the researcher to arrange a meeting at a convenient place and time.

Name:

.....

Address:

.....

.....

.....

.....

Telephone Number:

.....

Mobile Phone Number:

.....

Are there any times of the day that you prefer to be contacted?

.....

Do you have any further comments?

.....

.....

Signature:.....

Date:.....

Appendix M – Consent form for Interview

CONSENT FORM (Consent to be interviewed)

Title of Project: An Exploration of the Experiences of Control in Adolescents with Type 1 Diabetes

Name of Researcher: Cassie Ward

Please initial boxes

1. I confirm that I have read and understand the information sheet dated 16/1/2015 (Version 2.1) for the above study. I have had the opportunity to consider the information. If I had any questions, they have been answered satisfactorily.

2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason up to the point of completing the interview, without my medical care or legal rights being affected.

3. I confirm that direct quotes from the interview may be used in future publications and understand that they will be anonymised.

4. I understand confidentiality, the limits of confidentiality and the processes which would occur if there was a need to break confidentiality. I have been given the opportunity to ask questions. If I had any questions, they have been answered satisfactorily.

5. I understand that data collected during the study may be looked at by individuals from regulatory authorities or from the NHS Trust, where it is relevant to my taking part in this research. I give permission for these individuals to have access to my records.

5. I agree to take part in the interview part of the study and understand that my interview will be audio taped.

Name of Participant	Date	Signature
_____	_____	_____

Name of Parent/Legal Guardian (<i>if participant is under 16</i>)	Date	Signature
_____	_____	_____

Name of person taking consent	Date	Signature
_____	_____	_____

When completed: 1 for participant; 1 for researcher site file.

Appendix N – Epistemological Statement

In order to develop a research question and the procedures that will be taken to conduct a piece of research, one needs to think about their epistemological viewpoint. Epistemology relates to “the nature of knowledge” (Carter & Little, 2007) and the relationship between the researcher and the research participant (Ponterotto, 2005). Positivists, who believe the world to be one true reality that is measurable and quantifiable (Ponterotto, 2005), are likely to take the epistemological viewpoints of dualism and objectivism. Dualism relates to the researcher being independent to the research participants, as well as the research topic and objectivism relates to a belief that the research can be conducted without bias, if stringent and rigorous research protocols are put in place (Ponterotto, 2005). These epistemological viewpoints are normally held by quantitative researchers. Qualitative researchers typically hold the relativist viewpoint that knowledge is made sense of through the relationship between the researcher and the research participant, which captures the lived experiences of reality (Ponterotto, 2005).

A researcher’s epistemological viewpoint influences the research question that is asked and the methodology that is used in order to gain knowledge about the question (Carter & Little, 2007). A relativist stance was taken when approaching the topic of perceptions of control in adolescent’s with type 1 diabetes. Research had previously investigated “control” through quantitative methods and the researcher was interested in the how the adolescents made sense of the concept of personal and treatment control through their lived experiences, therefore the researcher chose to use qualitative methodology.

IPA is a qualitative research approach examining how individuals make sense of major life experiences and the meaning which the individual ascribes to them, which has theoretical underpinnings in phenomenology, hermeneutics and idiography (Smith, Flowers & Larkin, 2009). Phenomenology is the study of lived experience through the meanings and

perspectives developed through a person's relationship to the world (Smith et al, 2009). Hermeneutics relates to the study of interpretation and in order for a researcher to make sense of a person's lived experiences, interpretation is necessary (Smith & Osborn, 2008). As the researcher is interpreting the research participant's interpretations of their experiences, IPA uses what is known as a double hermeneutic (Smith & Osborn, 2008). IPA is also underpinned by idiography, which emphasises a focus on the individual (Smith et al, 2009). IPA was used as the qualitative methodology for the current study as the research question warranted an investigation into the personal lived experiences of the adolescents and to gain a greater understanding of their experiences.

References

- Carter, S. M., & Little, M. (2007). Justifying knowledge, justifying method, taking action: Epistemologies, methodologies, and methods in qualitative research. *Qualitative Health Research*, 17(10), 1316-1328.
- Ponterotto, J. G. (2005). Qualitative research in counseling psychology: A primer on research paradigms and philosophy of science. *Journal of counseling psychology*, 52(2), 126.
- Smith, J. A., Flowers, P., & Larkin, M. (2009). *Interpretative phenomenological analysis: Theory, method and research*. London: Sage Publications Ltd.
- Smith, J.A. & Osborn, M. (2008). Interpretative Phenomenological Analysis. In J.A. Smith (Ed.), *Qualitative psychology: A practical guide to research methods* (53-80). London: Sage Publications.

Appendix O – Worked IPA Example

Excerpt of a transcript showing analysis of making notes and the development of emerging themes

Transcript	Commentary Notes	Emerging Themes
<p>I – Okay, so like you were saying about friends then and that it can impact on, how about family?</p> <p>P – Erm, (sigh – uhh), ooo [SIC] that’s a hard one.</p> <p>I think we all have times when we can be frustrated at our family and I know that from experience... but with diabetes, if I don’t notice the symptoms of a low...</p> <p>I – Mhmm</p> <p>P - ...as an example, erm... it makes me v...<u>very</u> aggravated...</p> <p>I – Mhmm</p> <p>P - ... and I can... not lash out at all but become verbally aggressive</p> <p>I – Yep</p> <p>P – Erm, and obviously that creates tension and it...it’s not a nice atmosphere at that point...</p> <p>I – Mhmm</p> <p>P - ...but I think, my mum especially, has become good at going (name) your low you need to eat</p> <p>I – Mhmm</p>	<p>Difficult to think about impact on family? Defending family – likes to keep positive about family?</p> <p>Family dynamics</p> <p>Diabetes makes frustration with family worse?</p> <p>Less in control when having a hypo?</p> <p>Becomes aggressive when having a hypo – emotions not as controllable?</p> <p>Causes family conflict?</p> <p>Mum supports me to control my diabetes when I am unaware of being low?</p>	<p>Family frustrations</p> <p>Unawareness of hypo</p> <p>Difficult to control emotions</p> <p>Family conflict</p> <p>Mum as a support</p>

<p>P – So I wouldn't say it has a huge effect but obviously it's got... it does cause tension if I, if anyone in the family is angry, I think there's tension and other feelings. Erm not nice feelings are caused so it can add to that definitely...</p>	<p>What other feelings? – Appears there may be more emotions that were not expressed? Family conflict?</p>	<p>Avoidance of negative emotions</p>
<p>I – Mhmm</p>		
<p>P - ... it can make those situations a bit more common</p>	<p>Diabetes causes more tension in the family</p>	<p>Diabetes can add to family conflict</p>
<p>I – Okay, thank you, okay so, so we've talked about how your feelings of control can affect aspects of your life, how do your feelings of control affect how you feel about yourself?</p>		
<p>P – Erm, if I'm having a day where my control is just poor...</p>	<p>Negative about control? Just poor – poor or good, no inbetween?</p>	<p>Poor or good Negativity</p>
<p>I – Mhmm</p>		
<p>P - ...I can feel...very self absorbed...</p>	<p>Diabetes controlling thoughts?</p>	<p>Rumination</p>
<p>I – Uhu</p>	<p>Ruminating?</p>	
<p>P - ...aand [SIC] I'll start to sort of bully myself maybe, y'know your doing this wrong, this is all wrong, this is your fault etc, and as I was saying distractions do help to take that off my mind...</p>	<p>Self criticism and self blame Friends can be a protective factor through distraction</p>	<p>Self-blame Distractions are helpful</p>
<p>I – Uhu</p>		
<p>P - ...but there are times especially if I'm on my own, erm where that <u>can</u></p>	<p>Self criticism and self blame – No self compassion for herself? Being alone</p>	

<p>be a problem I would say...</p> <p>I – Yeah</p> <p>P – There are times when I’ve just felt like... this is all my fault...</p> <p>I – Mhmm</p> <p>P - ...and I’m not the sort of person who thinks why me, why was it me who...</p> <p>I – Mhmm</p> <p>P - ...who has to deal with this... but I would say I blame myself if it does go wrong...</p> <p>I – Mhmm</p> <p>P – ...which it can be hard</p>	<p>makes it harder to distract herself from negative thoughts</p> <p>Self-blame</p> <p>Does not think about why me – protecting self?</p> <p>Self-blame</p> <p>Self-blame makes having diabetes more difficult?</p>	<p>Self-blame</p> <p>Avoid negative thoughts</p> <p>Self-blame</p>
--	---	--

Appendix P – Reflective Statement

Three years, where does the time go? It's amazing to think my thesis journey started such a long time ago. Within this statement I want to share some of my experiences during the research process for both my empirical and SLR papers and I also want to write a separate section on the personal process that I have felt throughout completing this portfolio. The statement then ends with some final reflections.

Choosing a Research Topic

Choosing a research topic began just before the research fair in the 4th year. I knew I had an interest in Eating Disorders (ED) but apart from that I wasn't entirely sure what I would or could possibly do, but I knew I had to pick a topic that would interest me. After the research fair I decided that I wanted to do a piece of research looking at ED, but unfortunately this turned out to not be a feasible option. So I began to look at other directions and when I spoke to my supervisor, she told me that individuals with Type 1 Diabetes (T1DM) can stop taking or reduce the amount of insulin they take in order to lose weight. It felt at this point that I would be able to do a piece of research that involved a topic I was interested in, within the topic of diabetes (which was actually another area of interest due to knowing people who have diabetes). This was when I began to look at doing a piece of research on the perceptions of control in adults with T1DM who also had an eating disorder (ED-T1DM). I contacted a charity called Diabetics with Eating Disorders (DWED), who were very helpful, and began to think about how I would be able to conduct the piece of research. It was in the second year of the course where we began to feel that this was not going to be a feasible research topic either. As well as looking at charities (local and national ED charities, as well as DWED) and local diabetes and ED services it appeared that there was not a great pool of potential participants especially locally, and potential participants from DWED lived in different

locations around the U.K. So it was back to the drawing board, until I met my field supervisor.

My third placement was in a CAMHS service but the Paediatric Diabetes Psychology Service (PDPS) also shared offices with the CAMHS team. During my placement I shadowed some work with the Clinical Psychologist working in the PDPS. Together we spoke about how I wanted to do some research into perceptions of control in individuals with ED-T1DM.

However, within paediatric settings, the prevalence of ED-T1DM was also scarce and therefore my research topic was still not a feasible study. Throughout my third placement I realised that I wanted to work with children when I finished the course and when my Field Supervisor suggested looking at the perceptions of control in adolescents with T1DM we began to formulate a plan and my Field Supervisor came on board.

The Journey to Recruitment

Due to my research evolving and adapting over the first two years of the course, I went to ethics later than my peers, but I wanted a solid idea of what my research would be and this took time and a lot of thought. Going to ethics late was anxiety provoking, not only due to worries about time but also the ethical implications of not telling my participants why they were being invited back for interview. Although I felt this was necessary for the study, I was worried how the ethics board would respond to it. Luckily I got through ethics pretty smoothly and I quickly obtained R&D approval. Now it was time to put the research topic into action!

Recruitment

Recruiting my participants took time, but not longer than I had anticipated thankfully! I was amazed at how willing the adolescents were to complete the questionnaire and the families'

interest in the study. Although I got a good response to the questionnaires, recruiting the participants to be interviewed proved to be more of a challenge, either due to adolescents not meeting the inclusion criteria on the BIPQ (which of course is good for them!) or meeting my inclusion criteria but then not wanting to take part in the interview part of the study. Having said this though, I was able to get my sample and all of my participants were enthusiastic to talk about their experiences.

Interviewing the participants was an interesting experience and made me realise how beneficial it can be for adolescents to talk about how their diabetes affects them, outside of the realms of the medical perspective. More and more psychology is being recognised as an essential resource in paediatric diabetes and I feel that my research adds to the ever growing evidence for this. During the recruitment process, I was also on placement with the PDPS which I felt helped me to recruit due to networking with the diabetes teams and I also gained an even better understanding of diabetes and the impact it has on peoples' lives which helped during analysis and the write up of the study. It also showed me how psychology fits into diabetes care for children and young people and how vital this work is.

Analysis and Write up of Empirical

Analysing the interviews was a difficult task for me. Qualitative research was a new concept to me as my undergraduate research had been quantitative. The interviews were so rich and I was struggling to put names to the themes that were developing. Through using free writing I worked out what seemed pertinent to the adolescents' feelings of control and I hope that I have done them justice! I think my main struggle was wondering was it good enough, this is where supervision was vital to help me to realise that I had done a good job and that I should start writing it up! Writing up my empirical was enjoyable and I really feel like I want to do more qualitative research in the future.

SLR

Creating a question for my SLR was a challenge. I think the hardest thing for me was “marrying” a question and running with it. It took a lot of scoping the literature to find a question and I felt quite disheartened at this point, as I felt like I was getting nowhere and that the task was impossible. When I finally looked at literature around parenting style and diabetes that was when I finally got a flip of excitement in my stomach and it was at that point that I thought this means something... I’m sticking with this! From that point on my SLR felt like a relatively easy process and writing up my SLR was enjoyable. Perhaps I felt quite positive about my SLR and motivated due to it feeling more manageable once I had “married” my question. The SLR has always felt more manageable than my empirical paper and this is what I will now discuss in the next section.

Personal Process

The parallels between myself and the adolescents in my empirical paper astounded me, especially in this last year. In all honesty this thesis has played on all of my emotions and has given me insight into how I cope with uncertain situations. Like the teenagers I struggled, and was amazed when I was asked “why don’t you like your thesis?” that I became tearful as soon as I said the words “because I don’t want to do it”. I was shocked at the emotion that it evoked in me but able to reflect on how it must feel for the adolescents who were diagnosed with diabetes through no fault of their own and had the “choice” from that point to either manage their diabetes and stay healthy or don’t do it and there will likely be serious consequences. For me I also had a choice; complete my thesis and get the doctorate I’ve been dreaming of or give up and don’t achieve my dreams. Of course there wasn’t really a choice, I knew this was all worth it but I was stuck in the mud at that point and couldn’t see a way out. The feelings of not being good enough, helplessness when all felt uncertain, using

avoidance when it was all too much to bear and knowing that wasn't helping anything was overwhelming, but now I can see the clear parallel process that was happening between me and the adolescents.

I began to learn that bottling up my frustration and anger did not help matters, it only made things worse and when I finally started allowing myself to feel the emotions and processing them, my motivation to complete my thesis started to increase. It was amazing how letting the angry tears out made my head so much clearer and how much more I was able to do and I began to feel like I can do this! Obviously there were many hurdles in completing my thesis and each time I could see myself heading towards the unhelpful strategies I had previously used when it was too much. I had to be aware of when I was slipping into this way of thinking and use supervision to talk through what was happening for me at that time.

Final Reflections

Looking back now I feel that I needed to go through this process and yes it has been difficult but actually it has been a memorable and insightful process. I feel like I have a great understanding of what these adolescents go through on a daily basis. There have been times when I've wanted to rebel and say no I don't want to do this. Starting to believe in myself that I am capable of managing this and it will get better was crucial, and without the help of my supervisors and my family I think this would have been an impossible task. Now I can see the light at the end of the tunnel and I have nearly finished writing my thesis, I have such an appreciation for the adolescents I interviewed and have learnt that sometimes you will not feel good enough, you will get upset and angry (that this is ok!), that things are out of your control, but bottling this all up and avoiding it does not help and I think this is one of the main lessons I have learnt along the way.

I am glad that I can finally say I did it! The sense of achievement that I feel is lovely. I hope the personal process part of the statement does not come across as a venting about my thesis, as this was not my intention. From the moment I began to gain insight into how my feelings towards my thesis were alike to the experiences of the adolescents I interviewed, I knew it was something that I wanted to reflect on in this statement as I felt it was an important part of the whole process for me. Although it has taken blood, sweat and tears (plus a lot of sugary snacks!!) my thesis is a piece of work that I am incredibly proud of and will look back on with great fondness in the future.