

THE UNIVERSITY OF HULL

Anxiety, Illness Beliefs and Management of Child Type 1 Diabetes

**being a Thesis submitted for the Degree of
Doctor of Clinical Psychology
in the University of Hull**

by

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Overview

This portfolio thesis is comprised of three parts; a systematic literature review, an empirical study and a set of appendices.

Part One is a systematic literature review of empirical papers examining parent and child illness beliefs in child Type 1 Diabetes.

Part Two is an empirical paper examining parent and child trait anxiety and illness beliefs in children aged six to eleven years with a diagnosis of Type 1 Diabetes. These factors are then examined as predictors of parent and child responsibility for managing the illness and the child's metabolic control.

Part Three comprises the appendices (including all additional information relevant to the thesis papers) and a reflective statement.

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Word Counts:

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PART 1

Illness Beliefs in Child Type 1 Diabetes: A Systematic Review

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Illness Beliefs in Child Type 1 Diabetes: A Systematic Review

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This paper is written in the format ready for submission to the Journal of Pediatric Psychology. Please see Appendix 3 for the Guidelines for Authors.

¹ American spelling

Abstract

Aim: A systematic review was undertaken to investigate the role of child and parent illness beliefs in child Type 1 Diabetes.

Method: Five electronic databases (PsycINFO, Science Direct, Scopus, Cochrane Library, CINAHL) were searched for studies fitting inclusion criteria. Key information was extracted and analysed for themes. Studies were subject to a quality control check.

Results: Nine studies were included which examined illness beliefs using parent and adolescent samples. Illness beliefs were examined in relation to well-being, self efficacy, support, management and metabolic control.

Conclusion: Parent and child illness beliefs play a mediating role in child T1D conceptualised within two key models. Further research in to illness beliefs is required in school age children and within dyads.

Keywords: diabetes; child; adolescent; parent; illness beliefs.

Type 1 Diabetes (T1D) is a potentially fatal illness characterised by a lack of insulin and unstable blood sugar levels, first occurring in childhood (Snoek & Skinner, 2005). To manage T1D, a strict routine is required involving adherence to an insulin regimen and controlled diet with ongoing health care providing routine assessment at diabetes clinics (National Institute of Clinical Excellence (NICE), 2004). Parents take varying degrees of responsibility for their child's T1D, dependent on child need and age, amongst other factors (Anderson, Auslander, Jung, Miller & Skyler, 2003). The transition of responsibility over to the child usually occurs gradually and across adolescence, which is often a time of non-adherence (Snoek & Skinner, 2005).

Type 1 Diabetes is an important illness to understand due to its increasing prevalence, poor control in the UK and the cost of poor management to the healthcare system (Making Every Young Person with Diabetes Matter, 2007). Further understanding of this illness is necessary due to its complex nature, which involve interlinking of biological, psychosocial and familial factors (Delameter, 2009). A growing area of interest in illness literature including T1D, are illness beliefs or representations. Illness beliefs stem from cognitive and schema theory and are thought to be created through experience and information from the environment to give illness a personal meaning (Kaptein & Weinman, 2004). A number of models have been proposed, to measure and structure illness beliefs and to relate them to health related behaviour. Two main models have been proposed.

The Health Belief Model (HBM; Rosenstock, 1974) was originally developed to examine why people sought health care but has since been used in a wide range of studies and contexts. It proposes that an individual will have perceptions about their own (or other's) susceptibility to an illness and illness severity and describes the likelihood of positive health behaviour being influenced by whether the individual perceives there to be benefit from action and whether they perceive any barriers to their

efforts. Beliefs and behaviours are moderated by ‘cues to action’ such as comments from others and media influence. The HBM acknowledges that further variables (e.g. individual differences such as culture, age and education) also moderate health related behaviour. A strength of this model is its recognition of the influence of other people in ‘cues to action’ and so recognition that health related behaviour can be viewed from a systemic perspective. Its focus on risk and self efficacy is clear but it is limited in that it doesn’t examine the specific meaning of the illness, such as how it is recognised or understood.

The Common Sense Model (CSM; Leventhal, Meyer & Lorenz, 1984) focuses on illness beliefs as factors uniting perception and behaviour. An illness representation is a set of organised beliefs about the meaning of illness developed through experience and external sources. These are categorised as follows: *identity*, how a person recognises the illness through symptoms; the *cause* of the illness; *timeline* or duration of the illness, referring to how long it will last; *time cycle*, the illness variability and predictability; *consequences* of the illness and the impact that it has on their and others, selves and lives; *coherence* which is the understanding the person has of the illness; *controllability/ curability* referring to both personal ability to control their illness, as well as treatment ability to control/ cure. Finally, a representation was added of *emotional response*, addressing the fact that illness can evoke distress through anger, fear and upset, which add meaning and run parallel with the beliefs. Correlations exist between the various beliefs that comprise the full representation such as worse consequences and more distress (Kaptein & Weinman, 2004).

Models of illness beliefs are useful in order to help structure an understanding of how people perceive and give meaning to illness and how they manage it through health related behaviours. Models can help predict the influence of illness beliefs, therefore

informing professionals who aim to develop interventions. Within T1D this may include improving regimen adherence, dietary behaviour and controlling blood glucose. Existing research has examined T1D in relation to a number of psychosocial variables, such as self efficacy, social support and anxiety, often with well-being or illness management as an outcome (Cameron, Young & Wiebe, 2007; Faulkner & Chang, 2007; Streisand, 2005). Illness beliefs have been explored in relation to these areas across the lifespan and cultures, suggesting that illness beliefs as a concept may be universal and thus strengthening theory (Kaptein & Weinman, 2004).

The role that parents play has lent itself to research examining familial factors and illness beliefs in parents, though the latter area is currently limited (Urquhart-Law, 2002). Understanding factors that impact on T1D can be used to develop health care services and promote child health and well-being. Professionals and families strive to improve well-being, adjustment, understanding, control and management of this complex illness. Unlike illnesses that develop later in life, the opportunity to achieve good holistic health care in T1D is increased as it is developed in childhood, allowing good routines and adjustment to occur at an early stage in life and illness.

When research is diffuse across many areas, systematic reviews can be useful in assessing the existing research and looking for themes, which may be otherwise missed by professionals in their searches. This can guide future research, theory and practice. Therefore this review aims to examine the role of illness beliefs in T1D. Due to the nature of the illness a systemic perspective will be taken where both parental and child beliefs will be examined. The aim of the review is to explore and assimilate existing findings on parent and child illness beliefs in child T1D and to establish a more thorough understanding of their role within the illness.

Method

A systematic electronic search was completed using the databases PsycINFO, Science Direct, Scopus, Cochrane Library and CINAHL (Cumulative Index to Nursing and Allied Health Literature). These were chosen to provide cover of a wide range of disciplines.

Search terms used were: *parent**, *mother**, *father**, *maternal*, *paternal*, *care**, *dad**, *mum* AND/ OR *child**, *school age*, *paediatric*, *adolescent*, *daughter*, *son*, *girl*, *boy* AND *belief*, *representation*, *schema*, *cognition*, *model* AND *diabet**, *type 1 diabet**, *diabetes mellitus*.

The full body of text for each article was searched to capture all related research.

Inclusion criteria

To be included in the review the study had to:

1) Include a child/ adolescent (age 19 years or below) and/or parent sample, in which the young person had a diagnosis of Type 1 Diabetes. 2) Be from a peer reviewed journal (to provide a baseline of quality) and be published before May 2010. No start date was chosen. It was anticipated that studies would exist from 1970 onwards based on research relating to illness belief models. 3) Include a measure of illness beliefs.

Exclusion criteria

Studies were excluded for the following reasons:

1) Papers reviewing the psychometric properties of illness belief questionnaires (due to purpose). 2) Individual case studies (due to inability to generalise findings). 3) Papers including a lifespan approach, in which the child sample results could not be separated from the adult sample. 4) Studies published in a language other than English.

Selection Process and Data Extraction

The titles (and abstracts when required) of all articles meeting inclusion criteria were scanned to check suitability. From the selected studies the full text was read to confirm suitability for inclusion. Finally, the references were checked manually for further suitable articles. Information was extracted from each study and analysed for themes. [See Appendix 4 for Data Extraction table and Appendix 5 for List of Studies not included.]

Quality

Quality checks were undertaken for each article to ensure valid and reliable conclusions could be made. A quality control checklist was created based on a number already in existence. These were Downs & Black (1998), CONSORT statement (Moher, Schulz & Altman, 2001) and the TREND statement (Des Jarlais, Lyles & Crepaz, 2004). Pre-existing checklists are mainly designed to measure quality of experimental and random controlled trials. Due to the cross-sectional non-experimental nature of the studies included in this review, a specifically designed checklist was required. Each study was rated by two researchers and discrepancies discussed. [See Appendix 6 for Quality Checklist and Appendix 7 for Quality Scores.]

Results

Selection Process

Of the 2460 articles identified from the review process 2433 were eliminated after screening titles and abstracts. Twenty seven were included for full review, two of which were requested from the authors as they were not available freely. Seventeen articles were excluded due to not meeting criteria. From the ten articles left, one was not obtained freely or after contacting the author. Nine were included (see Figure 1). Four articles were written from two samples as will be discussed, leaving nine articles from

seven samples. All results can be found in the Data Summary tables (See Table 1).

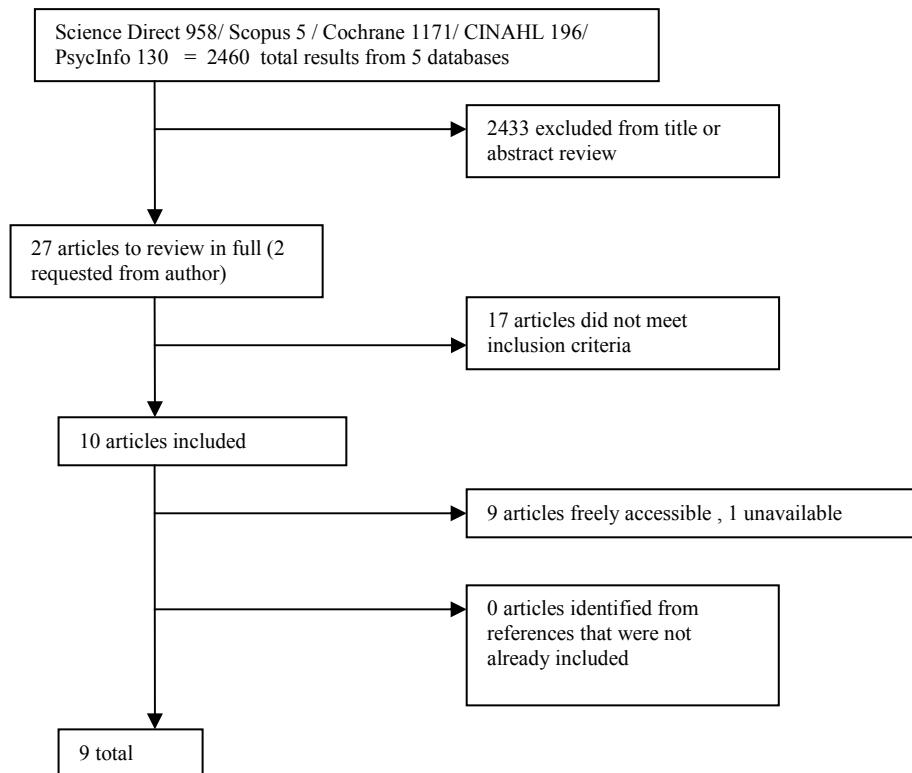


Figure 1. Illustration of the article selection process.

Quality

All studies were found to be of good quality using the bespoke assessment tool scoring between 10 and 13 out of 14, suggesting that study findings have reliability and validity. Inter-rater reliability was strong, when analysed using a Pearson correlation ($r=.088$, $p=.002$).

Participants

Two studies included both an adolescent and parent sample in their studies, both of which were mothers only. Urquhart-Law (2002) included 26 mothers and Olsen, Berg and Wiebe (2008) included 84. Bond, Aiken and Somerville (1992) included the parent most involved in their adolescent's care ($N=56$) and required them to complete a telephone based interview as part of the study. The other six studies were comprised of adolescent and young adult samples. Urquhart Law (2002) and Urquhart-Law, Kelly,

Huey and Summerbell (2002) used the same sample as did Skinner, John and Hampson (2000) and Skinner and Hampson (2000).

Age

Mothers in the sample had a mean age of 42.7 years (Urquhart- Law, 2002) and 48.6 years (Olsen et al., 2008). Remaining studies all used an adolescent sample which in one paper was grouped 15 to 19 and 19 to 25 years ($M= 20.6$ years) (Griva, Myers & Newman, 2000). Two papers included a sample age 10-19 years with mean ages of 13.6 years and 14.4 years respectively (Bond et al., 1992; Patino, Sanchez, Eidson & Delameter, 2005). Two studies from one sample aged 12 to 18 years, had a mean age of 15.2 years (Skinner & Hampson, 2001; Skinner et al., 2000). Urquhart-Law (2002) and Urquhart-Law et al., (2002) included 13 to 19 year olds with a mean age of 15.5 years. Olsen et al. (2008) used a sample aged 11.5 to 17.5 years ($M= 14.16$ years). No selected studies recruited children below ten years.

Gender

All studies included both male and female adolescents. The smallest sample size of 30 included 16 males and 14 females (Urquhart-Law, 2002; Urquhart-Law et al., 2002). The largest sample size of 84 adolescents (Olsen et al., 2008) included 44 males and 40 females). Generally, all papers included an almost equal number of each gender ($m=52\%$ male and 48% female, range = 43- 60% male).

Time since diagnosis

Studies ranged in how long participants had been diagnosed, based on age of the sample and cut off points that were used, if any. Two studies did not include a cut off for minimum time since diagnosis (Griva et al., 2000; Urquhart- Law, 2002). Articles by Patino et al. (2005) and Edgar and Skinner (2003) included adolescents diagnosed at least six months ago, the mean durations being 4.7 years and 5.4 years for males with slightly shorter 4.5 years for females. Skinner et al., (2000) included adolescent

Author/ Pub date/ country	Response rate	Participant age/ gender / sample size	Diabetes duration	Measures included	Aim of study	Findings	Qual score (14)
Bond, Aiken & Somerville (1992) USA Cross- sectional	56/60 consented. Two excluded and two declined.	43% m/ 57% f 10- 19 years (m= 14.2 yrs) N=56	T1D > 1 yr (m= 5.8 yrs).	Adol: Child Self Administered Questionnaire comprised of Diabetes Health Belief Scale (Harris & Linn, 1985), Barriers to Adherence Questionnaire (Glasgow, 1986), Diabetes Health Belief Questionnaire (Brownlee-Duffeck, 1987), Diabetes Regimen Compliance Questionnaire and Diabetes Self Care Activities Schedule (Brownlee-Duffeck, 1987) and 3x Child Compliance Telephone Interview (Johnson et al., 1986). HbA1c. Parent: Parent compliance Telephone Interview.	To test the predictive ability of the Health Belief Model in adherence to a complex and ongoing medical regimen, as an extension of Brownlee-Duffeck's study. To examine this in relation to age, illness duration, health beliefs, self reported adherence and metabolic control.	Threat interacted with cues to predict metabolic control. Higher threat and cues were associated with poorer metabolic control. Greatest compliance occurred with low perceived threat and high perceived cues and benefits.	12/11
Edgar & Skinner (2003) UK Cross- sectional	70/126 (56%) responded	40m/ 30 f 11- 18 years Male mean age= 14.1 yrs/ Female mean age= 14.1 yrs. N=70	T1D > 6 months. Male mean duration= 5.4 yrs/ female mean duration= 4.5 yrs	Well-Being Questionnaire (Bradley, 1994) Diabetes Illness Representation Questionnaire (Skinner et al, 2003). The Kidscope (Spirito, Stark & Williams, 1988)	To examine whether coping acts to mediate the relationship between illness beliefs and emotional well-being.	Higher anxiety experienced when higher perceived impact and more symptoms. No relationship between illness beliefs and emotional well-being- maybe due to cognitive restructuring.	11/11
Griva, Myers & Newman (2000) UK Cross- sectional	64/ 83 responded. Adolescents and young adults.	31m/ 33f (N=64) 15- 19 years (m= 20.6yrs) Data split into 15-19 years/ 20- 25 years. N=26 adolescents.	T1D 1- 17 years (m= 7.7 years). No cut off.	Illness Perception Questionnaire (Weinman, Petrie, Moss- Morris & Home, 1996). Generalised Self Efficacy Scale (Jersulam & Schwarzer, 1992). Self Efficacy for Diabetes Scale (Croassman, Brink & Hauser (1987). Self Report Adherence Scale (Constructed for study) HbA1c level	To examine the role of illness perceptions and self efficacy in diabetic regimen adherence and metabolic control.	Beliefs of control, identity and consequence were associated with self reported adherence. 38% variance on glucose control was due to diabetes self efficacy, consequences and identity. Self efficacy is thought to mediate the relationship between illness beliefs, intention and action in adherence.	13/13

Author/ Pub date/ country	Response rate	Participant age/ gender	Diabetes duration	Measures included	Aim of study	Findings	Qual Score (14)
Olsen, Berg & Wiebe (2008) USA	66% response rate.	Adolescent: 53% m/ 47 % f 11.5 – 17.5 yrs (M= 14.1 yrs).	T1D > 1 year (m= 4 yrs).	<u>Adol</u> : Child Depression Inventory (Kovacs, 1985). <u>Diabetes</u> Quality of Life Scale (Ingersoll & Marrero, 1991) <u>Adol/ Mother</u> : Positive and Negative Affect Scale (Watson et al, 1988). Illness Perception Questionnaire (Moss-Morris, 2002) Mother: Center of Epidemiological Studies of Depression Scale (Radloff, 1977)	To explore how two measures of mother and adolescent dissimilarity in illness representations related to emotional adjustment.	Adolescents viewed illness as less chronic, containing fewer negative emotional representations and that mother had less control over the illness than mothers did. Mothers and adolescents illness representations dissimilarity were not associated with negative adjustment.	10/11
Patino, Sanchez, Eidson & Delameter (2005) UK	74/ 88 responded	38m/ 36f 10- 19 yrs (m= 13.6yrs) Data split in to 10-12yrs/ 13-15 yrs/ 16-19yrs. N=74	T1D > 6 months (m= 4.7 yrs)	Diabetes Health Belief Questionnaire (Brownlee- Duffeck et al, 1987). Diabetes-Related Health Problems (constructed for study). Self- Care Inventory (La Greca, Swales, Klemp & Madigan, 1988) HbA1c level	Examine the appraisal of short and long term diabetes health risk and adherence and determine whether risk predicts adherence in a minority group.	Health beliefs didn't predict adherence or HbA1c levels. Perceived short term risks were greater than long term risks.	11/11
Skinner & Hampson (2001) UK	74/ 130 consented and 54 remained until follow up.	42 m/ 32f 12- 18 years (m= 15.2 yrs). N=54	T1D > 1 year.	Well-being Questionnaire (Bradley, 1994) Summary of Diabetes Self Care Schedule (Toobert & Glasgow, 1994). Personal Models of Diabetes Questionnaire (Copp, Skinner & Hampson, 1998)	To see if personal models of diabetes predict well-being, self care from a cross sectional and prospective view point.	Girls experienced higher anxiety, depression perceived diabetes as more serious, having more impact and had poorer glucose control than boys. The more belief adolescents have that the treatment will control diabetes, the better their self management. Short term beliefs in perceived impact of diabetes and effectiveness of treatment predicted management but not long term beliefs such as prevention of complications.	13/13
Cross- sectional							

Author/ Pub date/ country	Response rate	Participant age/ gender	Diabetes duration	Measures included	Aim of study	Findings	Qual Score (14)
Skinner, John & Hampson (2000) UK	52/74 who consented completed the 6 month follow.	28m/24 f 12- 18 years (m= 15.2 yrs). N=52	T1D > 9 months (m= 5.3yrs)	Well-being Questionnaire (Bradley, 1994) Diabetes Self Care Schedule (Toobert & Glasgow, 1994). Perceived Social Support from Family and Friends Questionnaires (Procidano & Heller, 1983). Diabetes Inventory of Peer Support (constructed for study). Personal Models of Diabetes Questionnaire (Hampson et al, 1990)	To examine whether peer support and illness representations mediate the link between family support, self management and well- being.	Greater impact of diabetes associated with poorer well-being. Dietary behaviour predicted by perceived seriousness and efficacy of treatment. Family warmth mediates dietary behaviour but this is mediated by illness beliefs. Personal models don't predict insulin injections but do mediate between support and dietary behaviour.	13/13
Urquhart- Law (2002) UK	30/100 consented. Adol-escents had already completed previous study.	Adol: 16 m/ 14f 13-19 yrs (m=15.5yrs) Mothers: M= 42.7 yrs. N=30 adolescents, N=26 mothers	No cut off. Mean duration = 4.9 years (range 0.3 – 13.9 yrs)	Well-being Questionnaire (Bradley, 1994) Illness Perception Questionnaire Revised (Weinman, 1996; Moss-Morris, in press)	Compare illness representations between mothers and adolescents. Examine if incongruence influences adolescent psychological adjustment.	Some similarity in beliefs. Mothers believed illness to be significantly more serious, puzzling and emotionally distressing than adolescents. Mothers and adolescents perceived emotional impact were positively correlated.	12/12
Urquhart- Law, Kelly, Huey & Summerbell (2002) Cross- sectional	Not allowed by ethics to collect on those who declined.	16 m/ 14 f 13- 19 years (m= 15.5yrs). N=30.	T1D m=4.9 years	Well-being Questionnaire (Bradley, 1994) Illness Perception Questionnaire Revised (Moss-Morris, 2002). Summary of Diabetes Care Schedule (Toobert & Glasgow, 1994). HbA1c	To investigate the applicability of the Self Regulatory (Common Sense Model) to adolescents with T1D. Examine the relationship between illness beliefs, behaviours, well- being and glucose control.	Illness beliefs were not related to self management behaviours but both were contributors to well-being.	12/12

Table 1. Data Summary Table

diagnosed for at least nine months ago ($M= 5.3$ years). The remaining articles included adolescents diagnosed for at least one year (Bond et al., 1992, $M= 14.2$ years; Olsen et al., 2008, $M= 4$ years; Skinner & Hampson, 2001, $M= 15.2$ years). No studies gave explicit reasons for the decision to include a cut off and only Griva et al. (2000) controlled for this variable in relation to illness beliefs. Time since diagnosis was not examined in relation to illness beliefs in any included study.

Models

The studies used two main models of illness beliefs on which to structure theory and research. Leventhal's Common Sense Model (CSM; 2001) was used in seven studies (Edgar & Skinner, 2003; Griva et al., 2000; Olsen et al., 2008; Skinner & Hampson, 2001; Skinner et al., 2000; Urquhart-Law, 2002; Urquhart-Law et al., 2002).

The Health Belief Model (HBM; Rosenstock, 1974) was used in two studies (Bond et al., 1992; Patino et al., 2005). Patino et al. (2005) described the HBM accounting for 52% of the variance in self reported adherence as the reason for its inclusion (Brownlee-Duffeck et al, 1987).

Skinner and Hampson (2001) and Skinner et al. (2000) described a Personal Model of Diabetes (PMD) which is constructed by the individual's from five of the main constructs in the CSM (identity, cause, consequence, timeline and control/ cure). They explained that in a sample of 2000 participants, this model was a better predictor of self management and treatment effectiveness than either perceived seriousness or barriers to adherence, as found in the HBM (Glasgow, Strycker, Hampson & Ruggiero, 1997)

Illness Beliefs Measures

The Illness Perception Questionnaire Revised, (IPQ-R; Moss-Morris, 2002) was used by Griva et al. (2000), Olsen et al. (2008), Urquhart-Law (2002) and Urquhart-Law et al. (2002) to measure adolescent illness representations from Leventhal's CSM. The

IPQ-R has a Flesch Reading Ease of 65.9² and a Flesch Kincaid Grade Level³ of 9.0 years. Forty-four items are rated on a 5 point scale according to the strength of their agreement. The Cronbach's alpha values for the scales range from 0.73 to 0.82. The questionnaire was reworded for use with mothers to reflect the illness relationship (e.g. 'my diabetes' was exchanged for 'my child's diabetes', in Urquhart-Law,2002)..

The Diabetes Health Belief Questionnaire, (DHBQ; Brownlee-Duffeck et al., 1987) was used to examine illness beliefs within the context of the HBM. This is a 27 item measure designed to assess perceived severity, susceptibility, benefits and costs and cues to adherence. It comprises a five point scale on which individuals rate the severity of the illness, the chance of it impacting upon them, effect/ helpfulness of any action and observation of cues. Cronbach's alpha estimates reliability ranging between 0.66 to 0.78 (Bond et al., 1992; Patino et al., 2005). Bond et al. (1992) included the DHBQ along with a range of other questionnaires; however, the paper stated that items were excluded if not suitable for an adolescent population or seeming too complex to be understood. The excluded items were not listed.

Personal Models of Diabetes Questionnaire, (PMD; Hampson et al., 1990) was developed from the Adult Personal Models of Diabetes Interview. It is a brief eight item measure, examining the four constructs of perceived treatment effectiveness to control, perceived treatment effectiveness to prevent, perceived seriousness and perceived impact of diabetes. These are rated on five point scales across helpfulness, likelihood, seriousness and importance. Spearman's ρ^4 showed internal consistency ranging from $r= 0.54$ to $r= 0.68$. Skinner and Hampson (2001) and Skinner et al. (2000) used the PMD.

² Flesch Reading Ease is a measure of ease of reading of a text. Scores of 60-70 are suitable for 13 to 15 years (100 easy- 0 difficult)

³ Flesch Kincaid Grade Level is a measure of reading age based on reading ability in U.S school grades.

⁴ Spearman's Rank Order Correlation Coefficient is a non-parametric correlation.

The Diabetes Illness Representation Questionnaire, (DIPQ; Skinner et al., 2003) was developed from the Personal Models of Diabetes Interview (Hampson et al., 1990). It examines the five dimensions of the CSM; identity, cause, timeline, consequence and perceived impact of diabetes. In addition, there is an open ended question to explore the individual's understanding of potential complications in diabetes. Constructs are rated on a five point scale measuring their agreement. Internal consistency ranged from 0.67 to 0.94 with an American reading grade of 7.

The Diabetes Health Belief Scale, (DHBS; Harris and Linn, 1985) was included as part of a questionnaire set by Bond et al. (1992). The measure examines the aspects of the HBM as does the DHMQ (Brownlee-Duffeck et al., 1987). In addition to perceived susceptibility, severity, benefits, costs and cues, it also examines general health motivation unrelated to diabetes.

Illness Beliefs

Urquhart- Law et al. (2002) explicitly stated the outcomes of the illness beliefs measures for the sample. Adolescents reported their diabetes to be chronic and as having high levels of personal control over it. Treatment control was scored moderately and the timeline reported to be variable (cyclic). Moderate consequences of the diabetes on life were reported. Diabetes was not reported as confusing (high coherence) or emotionally distressing. It was recognised by thirst and shakiness and believed to be developed due to bad luck (40%), altered immunity (40%) and heredity (37%). Other studies described and discussed illness beliefs within their relationship with other variables and did not describe or discuss the illness beliefs individually.

Dissimilarity in dyads

Urquhart- Law (2002) examined dissimilarity of illness beliefs between adolescents and their mothers and the influence on psychological adjustment. It was found that mothers believed T1D to be more serious, puzzling and emotionally distressing than did

adolescents. These differences did not impact on well-being. The emotional impact that mothers and adolescents perceived was positively correlated. Olsen et al. (2008) also examined dissimilarity between adolescents and mothers illness representations and emotional adjustment. Similarly for Urquhart-Law (2002), dissimilarities were found within the dyad, this time having an impact on adjustment. Adolescents perceived T1D to be less chronic and less emotionally distressing than did mothers. The differences between these beliefs did not predict adolescent emotional adjustment, but the existence of difference when taken into account with the adolescents' own beliefs, was predictive of negative emotional adjustment. Mothers represented the illness as more serious and distressing than their adolescent did. As the adolescent aged the difference in perceived seriousness reduced and became more similar to their mothers. This suggests that a developmental aspect may play a part in the representation of illness and risk perception.

Perceived control also differed between adolescents and mothers, with adolescents reporting mothers to have more control than mothers perceived (Olsen et al., 2008). This may lead to mothers adjusting their behaviours to accommodate for this perceived control possibly leading to conflict and poor management. Both studies highlight the need to assess both adolescent and maternal illness representations.

Self Efficacy

Griva et al. (2000) examined the role of illness beliefs and self efficacy in diabetes adherence and metabolic control. Together self efficacy, perceived consequences of the diabetes and identity (recognising symptoms) accounted for 38% of the variance regimen adherence. Researchers suggest that self efficacy mediates the relationship between intention to act (due to illness representation of the consequence of inaction) and actual behaviour. Past research suggested that self efficacy may positively correlate with illness control (Griva et al., 2000) which was supported by this study. In addition,

40.6% of the variance in HbA1c levels (metabolic control) was due to diabetes specific and generalised self efficacy combined with illness representations of consequence and identity. Again, this study acknowledges that due to the cross sectional design it can not attribute cause or effect.

Emotional Well-being

Six studies (Edgar & Skinner, 2003; Olsen et al., 2008; Skinner & Hampson, Skinner et al., 2000); 2001; Urquhart-Law, 2002; Urquhart-Law et al., 2002) examined psychological and emotional well-being in relation to illness beliefs and T1D. Five of the studies measured well-being using the Well-Being Questionnaire (Bradley, 1994). Well-being was conceptualised on this measure as energy, depression, anxiety and positive well-being. Personal models were found to be important in well-being with perceived impact of diabetes positively correlating with anxiety and depression (Skinner et al., 2000). Supporting this, in Edgar and Skinner's study (2003), perceived impact of diabetes was positively correlated with depression and anxiety. Similarly, illness beliefs accounted for around 52% of the variance in anxiety and positive well-being (Urquhart-Law et al., 2002). Urquhart-Law (2002) examined dissimilarity in adolescents and mothers illness beliefs finding no relationship between the perception of T1D and the adolescent's emotional well-being. In contrast to this, Olsen et al. (2008) in their examination of both mothers and adolescents found that dissimilarity in their illness perceptions was associated with poorer adolescent well-being and adjustment. This study, however, used the Positive and Negative Affect Scale (Watson, 1988) to measure well-being in adolescents and mothers as opposed to the Well-being Questionnaire so may lack comparability. Skinner and Hampson (2001) reported that short term beliefs about diabetes such as immediate impact were more predictive of adolescent well-being than longer term consequences.

Support

Skinner et al. (2000) examined peer support and illness beliefs as mediators between family support, self management and well-being using a Personal Models framework. The findings were that social support, specifically acceptance and emotional support from peers, predicted dietary self care behaviour. This adds evidence to the systemic nature of diabetes care. This relationship was further found to be mediated by the adolescent's personal illness model (perceived treatment efficacy and seriousness) which were more important than the support. The study acknowledges that in adult samples, perceived seriousness often leads to better self care, however the opposite was found in this study (Hampson et al., 1990. Cited in Skinner et al, 2000). One possible conclusion was that adolescents who manage their diabetes well and who have support perceive the illness to be less serious. It also suggests that illness beliefs may be influenced by conflict that arises from helpful or unhelpful support. Neither support nor personal models predicted insulin injecting or blood glucose control. Personal Models mediated support and dietary behaviour.

Self Management/ Self Care⁵

The following five studies examined self care or adherence to the diabetes regime in relation to illness beliefs. Significant results were found with beliefs of control, identity and consequences of diabetes accounting for 38% of the variance in adolescents' self reported regimen adherence (Griva et al., 2000). Similarly, beliefs in treatment control predicted better management. Short term beliefs, around immediate severity and consequences were more predictive of good self care than long term beliefs linked to preventing complications (Skinner & Hampson, 2001). Interestingly Skinner et al. (2000) found that personal models of diabetes (perceived seriousness and treatment control) predicted good dietary behaviour, as part of the diabetes regimen but did not

⁵ The World Health Organization defines self care as "activities individuals, families, and communities undertake with the intention of enhancing health, preventing disease, limiting illness, and restoring health".

predict adolescents' compliance with insulin injections. Finally and in some contrast, greatest regimen compliance was found to occur when least threat was perceived but also more perceived cues to action and benefits (Bond et al., 1992). Patino et al. (2005) reported no significant relationship between illness beliefs and adherence.

Metabolic/ Blood Glucose Control (HbA1c)

Metabolic control although a main outcome of successful diabetes care, was not measured in all of the studies. The following four studies included a measure of metabolic control. Higher HbA1c levels were positively correlated with perceived short term illness risk, which is suggested to be a logical evaluation by the adolescents as HbA1c levels are a three monthly outcome (Patino et al., 2005). Griva et al. (2000) reported results of 40.6% variance of HbA1c levels being accounted for by beliefs around perceived ability to manage diabetes, perceived consequences and identity. Neither Urquhart-Law et al. (2002) nor Bond et al. (1992) found any link between illness beliefs and metabolic control. Bond et al. (1992) accounted for this result by hypothesising that illness beliefs and management are of less direct influence on metabolic control than stress and hormones or other biological factors.

Discussion

This systematic literature review examining illness beliefs in child T1D has identified key findings which will be discussed.

Age: A surprising point is that the included articles did not include school age children below 10 years and so appear to be an understudied population in terms of assessing and understanding their illness beliefs. This may be due to perceived difficulty in recruiting younger children or a view that they will not be able to recognise and report their beliefs. Further more, a suitable measure for younger children may either not exist or be validated for the models described. The measures used that specify age are suitable for adolescent populations. Younger children are an important population as diabetes

beliefs at this age are newly developing with aspects of self management. Strategies which may prevent later complication could be implemented if understood in this younger age group.

Models: It is common within literature for a variety of frameworks to exist to conceptualise theory, aid understanding and allow measurement. The two models in the review were the Health Belief Model (Rosenstock, 1974) and the Common Sense Model (Leventhal et al., 1984). Although a further model was described, Personal Model of Diabetes (Skinner et al., 2000), for the purpose of this review it has been termed under the CSM category. Whilst the HBM focuses more on risk and health behaviour, the CSM offers a deeper understanding of the illness itself, referred to in whole as an ‘illness representation’; however both models offer an understanding of the perception and meaning of illness and related behaviour.

The inclusion of studies using a range of models reduces the comparable nature of the studies and complicates the theory. Whilst specific models could have been picked for this review, this would have reduced the diversity of articles and narrowed the exploratory purpose of the review. Findings on the role of illness beliefs appear to interlink the CSM and HBM. Results imply that illness beliefs, self efficacy and anxiety may be related. These fit with the risk perception, severity and barriers concepts of the HBM and also the identity, consequence and personal control concepts in the CMS. The similarity of the role of beliefs across models means more weight can be given to both the conceptualisations of beliefs in these ways. The model chosen within each study was dependent on the area to be explored, although this choice was not always explained explicitly, rather through the process of reading, the reader was led to the conclusion that the model was suitable for the research question.

Measures: The use of different measures also adds complication to interpreting the research findings, making it difficult to compare and contrast studies in order to gain a

confident understanding of illness beliefs. To access and understand beliefs they must be measured and in clinical practice and research, measures play a vital part in the assessment process. Four illness belief measures had good internal consistency but one measure was not reported. The use of statistically strong measures is a strength of the studies, however without further information it is not known how widely used the measures are. Bond et al. (1992) adapted the Diabetes Health Belief Questionnaire by excluding items but did not report which ones. Though this does not necessarily affect the findings or conclusions, it weakens the study overall through missing information and difficulty in replication.

Terminology: The variation in terminology in measures and models in referring to illness beliefs could be confusing for professionals reviewing the area in attempting to extract theory or apply findings to clinical practice. Terms such as illness representations and cognitions are used interchangeably when referring to illness beliefs, adding confusion to a currently varied and mixed literature base.

Well-Being: Six studies examined the relationship between illness beliefs and emotional well-being with mixed findings (using predominantly the Well-Being Questionnaire, Bradley, 1994). Urquhart-Law (2002) queried whether this was a sensitive measure for adolescents as it is officially recommended for 15 years and over and so may lead to unreliable findings. The importance of looking at emotional well-being as an outcome is important to retain a holistic focus on diabetes healthcare. Whilst studies have found that illness beliefs such as consequence, severity and control are predictive of anxiety and positive well-being in adolescents (in the HBM and CSM) the interplay seems more complex than this. Specifically, well-being seems more associated with short term consequences, whilst long term consequences have less impact (Urquhart-Law, 2002). This is likely to be due to young people's cognitive development and focus on the present, whilst parents think about the future. This may be emphasised by the three

monthly HbA1c checks. Anxiety, beliefs and well-being are likely to be dynamic in nature, influencing each other. Literature would suggest that external factors such as complications, hospital admissions and T1D in the media would also impact on these factors (Kaptein & Weinman, 2004; Leventhal, 1984).

Illness Management: Within diabetes care teams, the focus is often on increasing health related behaviour and within the illness belief models, health related behaviour is conceptualised as an outcome of beliefs. Illness beliefs, in the CSM, were found to predict adolescents' regimen adherence and metabolic control. Specifically, perceiving the illness as serious and recognisable, appeared to predict health related behaviour (Griva et al., 2000). These factors may serve to prioritise T1D to the individual, activating thoughts of management though to achieve the behaviour, other skills may be required. Self efficacy was found to mediate the relationship between illness beliefs and behaviour in adolescents (Griva et al., 2000), showing that illness beliefs influence the intention to act but this is further mediated by adolescents' beliefs about their ability to complete the behaviour. Interestingly, some parts of the diabetes regimen (dietary care) were found to be predicted by illness beliefs whilst others were not (insulin injections) (Skinner et al., 2000). Regimen tasks vary in the effort they require, their intrusiveness and threat. Here, beliefs and management are possibly mediated by self efficacy and anxiety; each task requiring different amounts of confidence and motivation to achieve them. If so, anxiety and self efficacy may influence beliefs to make aspects of an illness more severe or controllable and so influencing health behaviour. Achieving the desired outcome in illness is suggested in the CSM to be appraised and assimilation of new information in to beliefs.

Metabolic Control: Medically, metabolic control is the most important outcome in diabetes care, although only four of the reviewed studies included this. The role of illness beliefs in metabolic control (HbA1c levels) was variable across studies with

varied findings (Law et al., 2002; Patino et al., 2005) Metabolic control is seen to be the final outcome within the diabetes regimen, following the process of recognising and managing the symptoms. Due to its biological nature it has many other influencing variables acting upon it, which could account for wide variability in findings. Short term perceived risk and perceived consequences were predictive of better metabolic control. Better adherence may occur when consequences are palpable, if it is perceived that action would be of benefit. Although there is evidence for the role of illness beliefs and behaviour in metabolic control, there are also many biological factors within the body which also influence metabolic control.

Systems: Adolescents as influenced by their parents who share illness responsibility and whose illness beliefs are also of value. Findings in this area are brief and limited.

Whilst adolescents generally perceived diabetes to be less severe than their parent, there were links between the dyads beliefs. It is important to note here that the perception of the illness was not more important in one member of the dyad than the other.

Individuals' perceptions, whilst differing, are equally valid and relevant to that person.

The positively correlated aspects of illness beliefs between parent and adolescent suggest a shared illness representation, for example altering the distress in one, may affect the other. This could have implication for clinical formulation and intervention when working both individually and systemically. If findings transfer in to younger children, it may be possible to work with parents rather than the child, to affect change and gain understanding. Although the difference between beliefs within the dyad did not predict self management it did predict poorer well-being and adjustment and differing perceptions of control between the dyad led to conflict, as have been discussed. Illness beliefs appear to play an integral role between the dyad as well as in the individual and it seems that congruent beliefs of a helpful nature can be protective. Continuing on the systemic theme, illness beliefs in the HBM were thought by Skinner

et al. (2000) to mediate the relationship between peer support and diabetes self care. Skinner et al (2000) concluded that illness beliefs of lesser severity were an outcome of good support and illness management. Diabetes beliefs can be affected by surrounding influences, therefore parents and peer input and beliefs may be areas worth further research. Clinically, it is worth remembering that social support is a protective factor to be assessed but to hold in mind the impact that the presence or absence of this may also have on the meaning of T1D and the ability to manage the illness. Although not included in the studies, school maybe a system worth further research and the role of illness beliefs in larger systems and culture.

Summary Roles: Illness beliefs would appear to play variety of important roles within T1D. They appear to be both predictive of related outcomes, e.g. adherence. They may be mediated by other psychosocial factors, e.g. anxiety. They can also be an outcome through the process of appraisal and assimilation, e.g. when behaviour alters the meaning of illness. A dynamic relationship exists between aspects of illness beliefs, health behaviour and related variables e.g. self efficacy and anxiety. Furthermore, illness beliefs also play a role systemically when individual's with varying beliefs are united. As parental factors were not studied in the majority of these studies, it is possible that the interplay seen in Urquhart-Law (2002) and Olsen et al. (2008) studies is important and needs further investigation.

Studies Limitations: The majority of cross sectional designs creates difficulty in forming any generalised or concrete judgement of the findings. Variation in measures and models used also creates difficulty in summarising findings. Weaknesses were also in the lack of theoretical explanation of control for variables such as time since diagnosis and few comparison or control groups. Each study has a relatively small sample which further limits their generalisability and can impact on the strength of statistically significant results. This may be an issue in diabetes research due to the nature of

chronic illness meaning that populations remain stable and so young people may be recruited for multiple studies. Recruiting from clinics seems the most logical way to access participants, however participating in research may not be a priority at that time. The lack of information on younger children is a gap in the wider literature base.

Studies Strengths: The studies have a number of strengths in aim, design and discussion. The quality of the papers reviewed was good overall, with identifiable aims and research questions, reporting clear findings and concise discussions. Each study acknowledged its weaknesses in design, sample size and generalisability making these limitations explicit. They also acknowledge that they were reviewing new areas of theory and as such need to be interpreted with caution, as little support is available to build hypotheses upon. Within each study, proportionate numbers of males and females were recruited, limiting bias, though gender was not a variable discussed specifically in the research. Though the research is limited in some areas of T1D, it became clear in reviewing the articles and references that the authors had made full use of existing literature. This is encouraging for the diabetes literature as a firm research base can be developed and expanded.

Quality: As a suitable quality control checklist was not in existence, one was created for purpose. It has therefore not been tested for its psychometric properties, although efforts were made to check for face validity and to structure it on tools already validated, this may have implications for the review. To remedy this, the tool was created using yes/ no criteria to reduce subjectivity. Strong consistency in inter-rater reliability supports the strength of the studies and validity of the checklist.

Review Limitations: Unfortunately, one study may have been suitable for review but was not accessible; this is unlikely to have significantly changed the overall findings but may have provided further information on illness beliefs in specific areas of T1D or added more support to overall conclusions. As in many reviews, dissertations were not

included nor were non-English articles or those requiring purchase due to limited financial resources. The review is also limited by the nature of studies chosen for publication and held on databases. With more time and resources, it may have been possible to investigate whether unpublished research meeting the inclusion criteria exists.

Review Strengths: The review does hold a significant number of strengths. It pulls together and summarises existing research related to illness beliefs and the role they play in T1D. It highlights gaps in the existing research, including illness beliefs in children under ten years old and also illness beliefs within dyads or related to anxiety and self efficacy. Reviewing a research field at regular intervals identifies the point at which the research in this area may be. In circumstances where a literature base is growing, the focus is often on new research rather than understanding what has already been found. The literature base around illness beliefs in child T1D appears to be mixed and varied as it develops and broadens across a range of factors related to T1D that illness beliefs may be part of. With the illness belief models already in use, these factors could be integrated as suitable. This may allow illness beliefs to be understood within a framework combined with health related behaviour and psychosocial and systemic factors as appropriate.

A number of clinical implications have also arisen from the review, including the importance of illness meaning within and between individuals and in highlighting issues to be considered in the assessment and formulation of T1D. Further to this, the findings of the study interlinking illness beliefs and behaviour lend support to a cognitive behavioural approach to intervening in illness, as well as considering systemic and indirect working. As well as biological and practical issues, professionals in clinics may hold in mind the importance of illness beliefs and psychosocial factors in diabetes

care. Illness beliefs in all family members, schools and the wider society and culture may warrant further consideration when assessing and formulation diabetes care.

Conclusion

This review is the first systematic synthesis of data relating to illness beliefs in child T1D. It has highlighted gaps in the current varied and developing research, including the focus on adolescence rather than school age children and an individualistic rather than systemic investigation of illness beliefs. When examined alongside psychosocial factors and health related behaviour across the HBM and CSM, illness beliefs are highlighted as playing significant roles as mediating factors, predictors and outcomes. They have shown themselves to be associated with support, behaviour, self efficacy and well-being and the review has highlighted likely areas such as anxiety that they may also relate to when thinking about the meaning of illness and aspects of diabetes care in young people.

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PART TWO

Trait Anxiety, Illness Beliefs and Management of Child Type 1 Diabetes

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Anxiety, Illness Beliefs and Management of Child Type 1 Diabetes

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This paper is written in the format ready for submission to the Journal of Pediatric Psychology. See Appendix 3 for Guidelines for Authors.

Abstract

Objective: To examine parent and child trait anxiety and illness beliefs in child Type 1 Diabetes and investigate these as predictors of diabetes management and metabolic control.

Method: Children (age 6-11 years) and their parents ($N=52$) completed measures of trait anxiety, illness beliefs and diabetes responsibility. Children's HbA1c levels were recorded at their clinic appointment.

Results: Pearson's correlations highlighted significant relationships between parent and child illness beliefs and trait anxiety. Parent and child regimen responsibility was best predicted by age, trait anxiety, coherence and time cycle when controlling for age and time since diagnosis using multiple regression. An independent t-test showed older children held more responsibility for their regimen.

Conclusions: Parent and child trait anxiety and illness beliefs interplay within the dyad creating a shared emotional and cognitive representation and influencing a shared responsibility for diabetes. These are important factors for healthcare professionals to consider in diabetes care.

Keywords: type 1 diabetes; parent; child; anxiety; illness beliefs; responsibility; management.

Type 1 Diabetes (T1D) is one of the most common childhood chronic illnesses, characterised by the body producing little or no insulin which if poorly managed leads to severe short and long term health consequences and financial costs to healthcare providers (NICE Guidelines for Type 1 Diabetes (NICE), 2004). Aims of diabetes care are to maintain metabolic control⁶ and good child physical health and well-being, through a regimen of insulin injections, diet control and monitoring of blood glucose levels (Delemeter, 2009; NICE, 2004).

Parents are heavily involved in their child's care, taking the majority of responsibility when children are young or newly diagnosed due to children's cognitive development and skill (Anderson & Brackett, 2005). Too much or too little age appropriate responsibility is associated with family disagreement, child anxiety and poor metabolic control (Wysocki, 2002). The transition of responsibility over to the child as they develop is an important part of the path to self management and ideally occurs gradually across development with adult supervision (Beveridge, Berg, Wiebe & Palmer, 2006; La Greca, Follansbee & Skyler, 1990). Adolescence is often a time of non-adherence and as such, adolescent research has often taken prominence over school age children (Butler, Skinner, Gelfand, Berg & Wiebe, 2007; Edgar & Skinner, 2003; Greening, Stoppelbein & Reeves, 2006; Urquhart-Law, 2002; Snoek & Skinner, 2005, p. 28).

Despite medical focus on physical health, psychosocial factors are of great importance in T1D. A recent review stated that 'psychosocial factors are the most important influences affecting the care and management of diabetes' (ISPAD Guidelines, 2009, p. 175). A diagnosis of T1D can occur at any point in childhood or adolescence and evoke anxiety in families due to the threat that it poses to health and well-being and the emotional and lifestyle adjustments required (Delameter, 2009).

⁶ As measured by HbA1c levels, referring to the percentage of glycated haemoglobin in the blood stream. Levels between 4 and 7.5% are deemed well controlled (NICE, 2004).

Reduced anxiety and improved adherence in children and families have been found to occur one to three years post diagnosis but to fluctuate thereafter, suggesting that factors influencing T1D are changeable (Grey, Cameron, Lipman & Thurber, 1995. In Snoek & Skinner, 2005. p. 9; Kovacs et al., 1989). Family warmth and cohesion have a protective nature, associated with better diabetes care and metabolic control (Faulkner & Chang, 2007; Lewin et al., 2006; Miller-Johnson et al., 1994). It is generally accepted that anxiety and family and psychosocial factors play a role but the interaction between them is less clear. These will be examined further.

Trait anxiety is defined as ‘a relatively stable, individual difference in anxiety proneness’ (Spielberger, 1973, pp. 17). Through both disposition and shared environment, parent and child trait anxiety have been found to positively correlate (Beidel & Turner, 1997; Povey, Hallas, White, Clark & Samuel, 2005). Anxiety increases an individual’s vigilance to threat perception (Sanders & Willis, 2003. pp. 23) which in illness can be observed as vigilance to symptoms and illness threat and links to changes in illness behaviour.

Considerable research has examined trait anxiety within T1D. Mothers high in trait anxiety perceived more symptoms and threat from T1D and increased responsibility for child’s diabetes management (Cameron, Young & Wiebe, 2007). Adolescents reported perceiving anxious mothers as intrusive (Cameron, Young & Wiebe, 2007; Leonard, Garwick & Adwan, 2005; Weinger, O’Donnell & Ritholz, 2001). Parental trait anxiety may be inferred by young people as meaning that T1D is unmanageable or threatening and be associated with increased anxiety or low self efficacy⁷. These may be barriers to management and require parents to take responsibility if young people feel unable to. Some findings show higher parent trait anxiety to be related to better child metabolic control through increased parental input

⁷ Self efficacy is a person’s perception of their ability or capability.

but this may be dependent on the parent's perception of the illness and their self efficacy (Stallwood, 2005; Streisand, 2005). As a parent, one's role is to guide their child and as such they have an influential role on their child's emotional and cognitive states and behaviour (Carr, 2006. p. 55-57).

Perceptions of illness can be understood using the Common Sense Model (CSM; Leventhal, Meyer & Lorenz, 1984) in which illness beliefs are induced by triggers associated with the illness, leading to management behaviour. Illness beliefs are thought to evolve with time and experience, therefore beliefs at diagnosis may differ to a later point. Within a systemically managed illness, the interplay between parent and child anxiety, illness beliefs and management could be evaluated within this model with anxiety and vigilance playing an influencing role. This model is widely used in health literature and T1D (Kaptein & Wiseman, 2004, pp. 56).

Within the CSM illness beliefs are represented along the following dimensions; identity (perception of associated symptoms), timeline (perceived illness duration/ chronicity), consequences (perceived implications psychosocially, financially, medically and emotionally), cause (perception of original cause of illness), personal control (perception of personal control over the illness), treatment control (perception of the efficacy of the illness treatment), coherence (perception of the illness as understandable and making sense), time cycle (perception of the illness as varied, unpredictable and cyclical in nature) and emotional distress (perceived emotional impact of the illness, such as causing worry, upset, anger).

Literature examining illness beliefs is developing and as such has mixed findings across a broad area. Parental and child trait anxiety have been found to positively correlate with perceiving more symptoms, severe consequences and having an external locus of control⁸ (Edgar & Skinner, 2003; Wheatcroft & Creswell, 2007).

⁸ An external locus of control is the belief that events are outside of one's own control.

Dissimilarities between parent and child illness beliefs can exist, with parents leaning towards perceiving T1D as generally more severe than their child and thinking long term (Edgar & Skinner, 2003; Urquhart-Law., 2002). This may be a normal reaction in parents who have responsibility for their child's well-being and see illness as a bigger picture whilst children focus on the present. Illness beliefs of identity, treatment efficacy and consequence have been associated with adherence (Griva, Myers & Newman, 2000; Skinner & Hampson, 2001) whilst other studies have found no association (Patino, Sanchez, Eidson & Delameter, 2005). Urquhart-Law (2002) using the CSM found that beliefs did not predict diabetes management in adolescents but did predict well-being.

This study aims to extend findings from existing research; to examine both parent and child trait anxiety and illness beliefs in T1D within the dyad. These factors lend themselves to conceptualisation within the CSM; a well established illness belief model. This study will look at school age children (6-11 years), an overlooked population, with a view to exploring these factors at earlier points in development when self management begins and interventions can be put in place. To develop our understanding of these factors across the age range, it is important to explore differences between younger and older children. Diabetes management responsibility will be examined along with metabolic control (HbA1c levels) as important outcomes. The overall aim is to examine relationships between parent and child trait anxiety and illness beliefs as predictors of diabetes management responsibility and metabolic control in children age 6 to 11.

This study aims to answer the following questions; i) Is there a relationship between parent and child trait anxiety? ii) Are there relationships between parent and child illness beliefs? iii) Are there relationships between parent and child trait anxiety and illness beliefs? iv) Do the variables differ between age groups? v) Do parent and

child trait anxiety and illness beliefs predict responsibility for management of diabetes?

vi) Do parent and child trait anxiety and illness beliefs predict HbA1c levels?

It is hypothesised that parent and child trait anxiety will positively correlate and that increased trait anxiety will be associated with increased severity of illness beliefs. Parents and children are likely to have a shared representation of the illness shown by positive correlations. Trait anxiety and beliefs of increased personal control may be predictive of taking responsibility for managing diabetes (shown through significance in multiple regression) but parents are likely to take more responsibility for younger children (shown in significant difference in t-tests). It is unclear from past findings, whether these factors are likely to influence HbA1c levels due to the impact of both biological and psychosocial factors.

Method

Participants

Participants were recruited at routine clinic visits from Paediatric Diabetes Outpatient Clinics across three sites in the North of England over an 11 month period. Children with a medical diagnosis of T1D between 6 and 11 years were included with their parent who provided diabetes care. Children with a comorbid illness such as celiac⁹ were excluded, as were those with a sibling with T1D in the same age range¹⁰. Non-English speakers were excluded due to questionnaires only being validated in the English language. Children or parents who could not give informed consent or complete the measures alone or with support were excluded.

Of the 81 dyads approached, 78 consented, two parents declined due to time and one child did not consent. A questionnaire completion rate of 52 was achieved (67%). A total of 32 girls (62%) and 20 boys (38%) completed the measures. Child's average age

⁹ Having a comorbid illness may alter beliefs about one illness specifically which could bias results. Celiac is an illness which requires diet control and so may impact directly on diabetes regimens.

¹⁰ Having a sibling with diabetes may impact on a person's beliefs about the illness and how it is managed. Parents would be required to complete two sets of measures which may bias results as it may be difficult to separate out the individual beliefs towards each child's illness.

was 9.1 years (*range*= 6 years -11.9 years; *SD*= 1.6 years). Parents completing the measures were comprised of 44 mothers (85%) and 8 fathers (15%). Only two of 52 of the parents had a diagnosis of T1D themselves and 33 children had a relative with T1D. Dyads were white British (*n*=47), Indian (*n*=3) and Polish (*n*=2). Information on household income and education were not obtained nor reason for non-completion (due to ethics).

Procedure

Ethical approval was obtained from the East Riding Ethics Committee¹¹. Potential participants were identified by the diabetes team two weeks before their routine appointment. Those meeting the criteria were sent age appropriate research information via post [see Appendix 10 & 11 for Research Information]. On attending clinic, parents within each dyad gave written informed consent for themselves and child to participate (children completed their own form to show evidence of their assent). Dyads in which both members did not give informed consent were excluded [see Appendix 12 & 13 for Consent Forms]. Those who consented either stayed to complete the measures in a quiet space with the researcher or completed them at home, with advice that children may require support. Dyads who had not returned the measures in two weeks were contacted via telephone by a member of the care team as a reminder and to check if support was required. Child HbA1c levels were recorded from their clinic appointment. No payment was given to participants; however they were given the option of requesting a summary of overall study findings. [See Appendix 14 for Procedure Flowchart.]

Measures

Packs were developed for both parents and children containing instructions, background data collection forms and three measures.

¹¹ Ethical approval and related documentation originally included in Appendix 8 and 9.

Trait Anxiety Inventory (Spielberger, 1973; Spielberger, Gorsuch, & Lushene, 1974).

Child: The 20 item child version uses a 3 point scale to measure the frequency of experience of statements (1= hardly ever, 2= sometimes, 3= often), total score of 60.

This is a widely established measure used in research and clinical settings, with high test retest validity 0.65 to 0.71 and internal consistency with Cronbach's alpha reported as between 0.78 and 0.81 in other studies and $\alpha=0.86$ in this sample.

Adult: The 20 item adult (parent) version uses a 4 point scale to measure frequency of experience of statements (1=hardly ever, 2= sometimes, 3= often, 4= almost always), total score of 80. This is widely used and established measure with Cronbach's alpha of $\alpha=0.86$ reported elsewhere and $\alpha=0.94$ for this sample.

Illness Perceptions Questionnaire- Revised (IPQ-R; Moss- Morris et al., 2002).

This 72 item measure assesses illness beliefs across seven domains on nine subscales as in Leventhal's et al. CSM (1984). These are: identity (15 items), timeline (6 items), time cycle (4 items), cause (16 items), personal control (6 items), treatment control (5 items), consequence (6 items), coherence (5 items) and emotional distress (6 items).

Statements are rated by participants on a five-point scale by how much they agree with them (1=disagree a lot/ 5= agree a lot). Higher scores on identity, timeline,

consequence, time cycle and emotional distress are negative, showing diabetes as being perceived to have more symptoms, be chronic, severe, variable and distressing. High

scores on personal control, treatment control and coherence are positive, showing

diabetes to be perceived as curable/controllable and understandable. Five symptoms

congruent with T1D (wheeziness, weight gain, thirst, sore throat, loss of strength) were

added to the original symptom list, in line with Urquhart-Law et al. (2002) and two

items (smoking/ drinking) were removed due to unsuitability for age range.

Parent: The Parent's version of the IPQ-R was reworded to the perspective of the parent as directed by Moss-Morris et al. (2002). The Parent IPQ had the following internal

consistency (timeline $\alpha=0.041$, consequence $\alpha=0.7$, personal control $\alpha=0.54$, treatment control $\alpha=0.57$, coherence $\alpha=0.87$, time cycle $\alpha=0.64$, emotional distress $\alpha=0.82$) for this sample. In other populations Cronbach alpha's of 0.73- 0.82 and as low as 0.5 on treatment control, have been reported (Urquhart-Law et al., 2002).

Child: The IPQ-R was reworded for children¹² by the researcher to use language suitable for the participant age range. This was checked for face validity and suitability by two independent Clinical Psychologists working within diabetes care and a Primary School English Teacher. Indices of reading level give a Flesch Reading Ease¹³ of 80 and Flesch Kincaid Reading Grade level¹⁴ of 4.7. Five children recompleted the reworded IPQ-R after 2 weeks to examine test- retest reliability, however due to the small sample size, analysis could not be performed. Scores remained largely consistent when checked for face validity. The Child IPQ-R has moderate to good internal consistency (timeline $\alpha=0.8$, consequence $\alpha=0.6$, personal control $\alpha=0.37$, treatment control $\alpha=0.28$, coherence $\alpha=0.87$, time cycle $\alpha=0.63$, emotional distress $\alpha=0.85$) for this sample.

Diabetes Family Responsibility Questionnaire (Anderson, Auslander, Jung, Miller & Santiago, 1990).

This questionnaire measures diabetes responsibility as shared between child and parent on three subscales (regimen: diabetes regimen tasks such as giving injections, social presentation: social tasks such as telling school about diabetes, general health: tasks related to general health such as noticing ill health). Lower totals or scale items show more child responsibility (1=child, 2= equal, 3= parent).

To adapt the scale for a younger age range two additional items were added to the general health scale, based on expected child responsibility for this age range, as

¹² See Appendix 15 for Child IPQ-R.

¹³ Flesch Reading Ease is a measure of ease of reading of a text. Scores of 80-89 are termed easy (100 very easy- 0 very confusing).

¹⁴ Flesch Kincaid Grade Level is a measure of reading age based on reading ability in U.S school grades. Grade 4 and 5 include children age 7 to 11 years.

suggested by experienced nursing staff within one of the diabetes clinics. These were: ‘Asking questions in clinic about diabetes such as diet or injections’ and ‘Remembering to take things to clinic such as diabetes diary’. The Child’s DFRQ has moderate to good internal consistency (General Health $\alpha= 0.6$, Diabetes Regimen $\alpha=0.69$, Social Aspects $\alpha=0.44$) for this sample¹⁵. The Parent’s DFRQ also showed moderate to good internal consistency (General Health $\alpha=0.69$, Diabetes Regimen $\alpha= 0.69$, Social Aspects $\alpha=0.41$) for this sample.

Metabolic Control measured by HbA1c level (glycosylated haemoglobin)

This is a measure of metabolic diabetes control and is an indication of the average blood glucose level over approximately a 12 week period. Low or high HbA1c levels suggest poorer blood glucose control and increased risk of health problems. Levels between 4 and 7.5% are medically judged to be ‘well controlled’ (NICE, 2004).

Data Analysis

All data was analysed using SPSS 17.0. Pearson’s correlations were conducted to examine relationships between anxiety and beliefs. Independent t-tests examined differences between age groups. Stepwise hierarchical regressions examined anxiety and beliefs as predictors of responsibility and HbA1c level.¹⁶

Results

Table 1 shows the descriptive statistics for parents and children ($N=52$ dyads). Each subscale of parent and child anxiety, beliefs and responsibility, shows the mean item score along with the total scale mean and standard deviation. From examining these descriptive values it can be seen that parents perceived T1D as overall more severe than their child but making more sense and having more personal control. The child’s data was then grouped in to age ranges six to eight years ($n= 15$; $M= 6.9$ years) and nine to eleven years ($n= 37$; $M=10.3$ years). The mean length of time since diagnosis was 3.9

¹⁵ See Appendix 16 for Child DFRQ.

¹⁶ See Appendix 17 for Explanation of Analyses.

years (range= 1-10 years; $SD= 2.5$). This was shorter in the younger group ($M=2.9$; $SD=.32$) than the older group ($M=4.3$; $SD=.46$), $t(50)=2.9$, $p=.016$. The IPQ-R's 'cause' subscale was excluded from analysis as it requires a sample of > 80 , as was 'timeline' due to poor internal consistency and perceived illness chronicity. Parent and child total responsibility was correlated ($r=.452$, $p=.001$).

Variables	Parent Item M (Total M / SD)	Child Item M (Total M / SD)
Trait Anxiety	2.0 (40, 10.9)	1.6 (32, 6.9)
Identity	1-15 (5.9, 3.2)	0-10 (4.7, 2.6)
Timeline	4.7 (28, 1.8)	4.0 (24, 5)
Consequence	3.9 (24, 3.9)	3.3 (20, 4.8)
Coherence	4.0 (19.9, 4.9)	3.4 (17.3, 4.9)
Personal Control	4.3 (25.5, 3.3)	3.5 (21.2, 3.7)
Treatment Control	3.6 (18, 3.2)	3.5 (17.7, 3.3)
TimeCycle	3.3 (13.2, 3.4)	3.5 (14.1, 3.3)
Emotional Distress	3.3 (19.7, 4.7)	2.9 (17.4, 6.6)
DFRQ Regimen	2.1 (12.7, 2.4)	1.9 (11.5, 2.8)
DFRQ General	2.6 (23.3, 2.3)	2.4 (21.3, 2.6)
DFRQ Social	2.4 (9.8, 1.2)	2.1 (8.7, 1.5)
DFRQ Total	2.3 (43.8, 4.3)	2.1 (41.5, 4.8)

Table 1. Parent and child *Item M*, *Total M* and *SD* across measures.

Parent and Child Trait Anxiety

Parent and child trait anxiety were not significantly correlated $r= .233$, ($N=52$), $p= .097$.

Parent Illness Beliefs

Parents who perceived diabetes to be variable in nature also perceived the illness to have more symptoms and more severe consequences. Perceiving more symptoms was associated with experiencing the illness as more distressing. When parents perceived diabetes as making more sense they perceived it to be less severe and more controllable (personal and treatment). See Table 2 for parent illness belief subscale correlations.

Correlations between subscales of parent beliefs (N=52)							
	Identity	Consequence	Time Cycle	Personal Control	Treatment Control	Coherence	Emotional Distress
Identity	-	.273	.436**	-.023	.002	.103	.490**
Consequence		-	.315*	-.161	-.200	-.349*	.158
Time Cycle			-	-.178	-.255	-.330*	.189
Personal Control				-	.338*	.388*	-.277*
Treatment Control					-	.481*	-.267
Coherence						-	.253
Emotional Distress							-

Table 2. * $p < 0.05$, ** $p < 0.01$

Child Illness Beliefs

Children who perceived diabetes as having more symptoms also experienced the illness as more distressing and more variable. Those who perceived greater personal and treatment control over the illness also tended to think it made sense. Child personal and treatment control were moderately correlated.

Correlations between subscales of child beliefs (N=52)							
	Identity	Consequence	Time Cycle	Personal Control	Treatment Control	Coherence	Emotional Distress
Identity	-	.242	.146	-.059	.002	-.259	.323*
Consequence		-	-.019	.244	.020	-.290*	.257
Time Cycle			-	-.232	-.018	-.346*	.341*
Personal Control				-	.557**	.364*	-.276*
Treatment Control					-	.204	-.306
Coherence						-	-.507**
Emotional Distress							-

Table 3. * $p < 0.05$, ** $p < 0.01$

Like parents, children tended to see diabetes as less severe when it made more sense and they also experienced more emotional distress when they perceived having less personal control. See Table 3 for correlations between child illness belief subscales.

Parent and Child Illness Beliefs

The relationships between parent and child illness beliefs are documented in Table 4. Children perceived more personal control when parents perceived the treatment to offer control. Parent and child treatment control were positively correlated. Children also perceived having more personal control when parents perceived the diabetes as more coherent. Similarly when parents perceived having more personal control their children reported diabetes as more coherent. Parent and child coherence was positively correlated. Parents who perceived diabetes as distressing had children who saw it to be less coherent.

<i>Parent</i>	Identity	Conseq	Time	Personal	Treat	Cohe-	Emotional
<i>Child</i>		uence	Cycle	Control	Control	rence	Distress
Identity	.131	.090	-.007	-.243	-.102	.019	.068
Consequence	-.031	.204	-.132	-.310*	.084	.017	-.004
Time Cycle	.306*	-.124	.375**	.035	-.082	-.074	.345*
Personal Control	-.057	-.144	-.332*	.114	.339*	.324*	-.273
Treat Control	.104	.036	.088	.183	.312*	.156	-.198
Emotional Distress	.108	.138	.219	-.479**	-.162	-.173	.525**

Table 4. Correlations between parent and child illness beliefs, * $p < 0.05$, ** $p < 0.01$

Parent and child perceptions of the variable nature of diabetes were positively correlated. Parent’s perception of diabetes having many symptoms and causing distress, was associated with children perceiving the illness as more variable. A moderate positive correlation was found to be evidenced between child and parental emotional distress.

Children perceived diabetes as having more severe consequences when parents perceived less personal control. When parents rated diabetes as being cyclical this was associated with children feeling less personal control. Children who perceived the illness as making less sense, tended to have parents who perceived the illness as more variable. Parents who did not perceive having personal control over the diabetes tended to have children who perceived the illness as emotionally distressing.

Parent and Child Anxiety and Illness Beliefs

Both parents and children’s increased anxiety was associated with them perceiving diabetes as having more symptoms (identity) and severe consequences, being more cyclical and emotionally distressed and making less sense (coherence) (See Table 5 and 6). No other correlations were significant.

	Parent	Identity	Consequences	Time Cycle	Coherence	Emotional Distress
Parent Trait Anxiety		.376**	.410**	.326*	-.383**	.506**

Table 5. Correlations between parent anxiety and beliefs, * $p < 0.05$, ** $p < 0.01$

	Child	Identity	Consequences	Time Cycle	Coherence	Emotional Distress
Child Trait Anxiety		.430**	.301*	.348*	-.431**	.695**

Table 6. Correlations between child anxiety and beliefs, * $p < 0.05$, ** $p < 0.01$

Further Pearson’s correlations were performed to examine the relationship between child anxiety and parent beliefs and parental anxiety and child beliefs. Children were more anxious when parents perceived less personal control over T1D, $r(52) = -.329, p = .017$ and parents perceived more emotional distress, $r(52) = .340, p = .014$. Children perceived the illness as more variable when parents were more anxious $r(52) = .367, p = .007$. No other correlations were evidenced as being significant.

Age

Using a series of independent samples t-tests, no differences were found between the age groups in either child or parent trait anxiety or illness beliefs. When responsibility was examined across ages, there was a significant difference between scores in younger ($M=12.8$, $SD= 2$ and older children ($M= 11$, $SD= 2.2$) in responsibility for managing their diabetes regimen, $t(50)= 2.74$, $p=.009$, with older children taking more responsibility. There was also a significant difference between scores in younger ($M=9.5$, $SD= 1.6$) and older children ($M=8.4$, $SD= 1.4$) in responsibility for managing the social aspects of their diabetes, $t(50)= 2.33$, $p= .024$, with older children taking more responsibility. A significant difference was found in parents' responsibility for their child's diabetes regimen between age groups, $t(50)= 4.12$, $p< .001$. They reported less responsibility for regimen management with older children ($M=12$, $SD=2.4$) than younger children ($M= 14.5$, $SD=1$). No differences were found between HbA1c levels across age groups when using an independent samples t-test, $t(50)= -1.1$, $p= 0.263$

Parent and Child Anxiety, Illness Beliefs and Management

A series of hierarchical regression analyses were conducted to examine predictors of parent and child responsibility for aspects of diabetes management (regimen, social, general). Tabachnick and Fidell (2001) suggest a minimum sample size of $50 +8y$ (y = number of independent variables), however 5 to 10 participants per variable is also suggested for power calculations. In view of the current study sample size, attempts were made to reduce the number of IV's to minimise problems of overfitting. Duration of illness was controlled for due to variation between age groups and literature suggesting this may impact on anxiety, beliefs and management. Child's age was also controlled for due to differences in responsibility between age groups. Parent and child trait anxiety, coherence, personal control and time cycle were included due to clinical relevance. Identity, consequence, treatment control and emotional distress were

excluded due to being more highly correlated with other included variables and/or having lower internal reliability. Standardised coefficients were reported (Tabachnick & Fidell, 2001).

Hierarchical multiple regression analyses were conducted using the Enter method. Time since diagnosis was controlled for by being entered in to Block 1 and child's age was controlled for in Block 2. In Block 3 Parental trait anxiety, coherence, personal control and time cycle were entered as predictors of responsibility. These were not given order as no variable was assumed to be of greater importance than another.

Altogether, these factors accounted for 57% (Illness duration; $R^2=.006$, $p=.594$. Age; $R^2\text{change}=.29$, $p<.001$) of the overall variance in Parent Regimen Responsibility $F(6,45)=10.1$, $p<.001$). Age ($\beta =-.501$, $t=-4.73$, $p<.001$), parent anxiety ($\beta=.352$, $t=3.15$, $p=.003$) and time cycle ($\beta=.259$, $t=2.4$, $p=.021$) contributed significantly. Following the same sequence for Child Regimen Responsibility there was 52% (Illness duration; $R^2=.016$, $p=.373$. Age; $R^2\text{change}=.26$, $p<.001$) of the overall variance accounted for by these factors $F(6,45)=8.1$, $p<.000$). Age ($\beta =-.441$, $t=-3.92$, $p<.000$), illness duration ($\beta =.339$, $t=2.93$, $p=.005$) and coherence ($\beta =-.317$, $t=-2.4$, $p=.019$) contributed significantly. No other aspects of responsibility were predicted by these variables.

Following the same procedure, child independent variables were examined as predictors of responsibility. Child trait anxiety, coherence, personal control and time cycle were entered in to Block 3 (Block 1 & 2 as before). These accounted for 31% of Child Regimen Responsibility (Illness duration; $R^2=.016$, $p=.373$. Age; $R^2\text{change}=.26$, $p<.001$) but only age was a significant contributor to this ($\beta =-.510$, $t=-3.75$, $p=.001$) accounting for 26% of the variance ($F(6,45)=3.39$, $p=.008$). Finally, 44% (Illness duration; $R^2=.006$, $p=.59$. Age; $R^2\text{change}=.29$, $p<.001$) of the variance in Parent Regimen Responsibility $F(6,45)=5.8$, $p<.001$) was accounted for most significantly by age ($\beta =-.513$, $t=-4.2$, $p<.001$) and time cycle ($\beta=.394$, $t=3.15$, $p=.003$). No other child

predictors were found for other aspects of responsibility. No other aspects of child or parent responsibility were predicted by child anxiety or beliefs.

Using Pearson's correlation, no relationships were found between HbA1c levels and other variables. Using hierarchical multiple regression as described, parent and child anxiety and beliefs did not account for significant variance in HbA1c levels.

Discussion

This study aimed to examine parent and child illness beliefs and T1D management across the age range. The findings from this study reveal many interesting relationships. Perhaps surprisingly and inconsistent with the hypothesis, parent and child trait anxiety were not significantly positively correlated. This differs from findings in previous studies (Beidel & Turner, 1997; Last, Hersen, Kazdin, Francis & Grubb, 1987) which found more anxious parents had significantly more anxious children, supposedly due to a combination of disposition and shared environment. Few individuals with extremely high or low anxiety appear to have completed the study possibly due to having more pressing priorities. Trait anxiety was associated with beliefs and responsibility of diabetes.

It is not possible to establish cause and effect from the correlations but the results can be interpreted based on theory and clinical relevance. The findings relating to illness beliefs show a complicated interplay in the dynamics between parents and children. Illness beliefs intertwine to create the individual's representation of the illness as well as between the dyad, supporting previous findings (Law et al., 2002 Olsen et al., 2008). Diabetes seeming controllable and making sense was associated with perceiving less severe consequences, fewer symptoms and feeling less distressing. The variability of the diabetes may warrant further research due to the up and down nature of the illness. Examining the diabetes profile (high/low glucose levels) may be useful to give clearer insight as to whether anxiety and perception create the belief of variability or

whether it is a practical issue for the dyad. The specific diabetes regimen may be considered more carefully in future research. In line with previous studies, parents viewed T1D as more severe than the child (Edgar & Skinner, 2003) but a shared sense of the predictability, understanding, controllability and distress associated with the illness was found.

The overall findings in this study support the hypotheses and existing research (Edgar & Skinner, 2003; Wheatcroft & Cresswell, 2007) that anxiety and illness beliefs are associated, with higher anxiety being associated with more severe beliefs about diabetes, including its coherence, consequences, variability and the distress it causes. Feeling less personal control over the illness is also associated with the illness being perceived as more severe. In line with existing literature (Cameron, Young & Wiebe, 2007), it may be hypothesised that anxiety and increased vigilance lead to perceiving the illness as more severe, which in turn increases anxiety. A thorough history of any diabetes complications may help predict whether issues within diabetes management have created the representation of a severe illness. Further research would be needed to establish cause and effect and build upon this theory. Parents appear to provide a containing¹⁷ role in the dyad. The sense of containment appears to stem from the dyad having a shared understanding of the illness which is protective and reduces emotional distress in times when the diabetes is perceived as variable. It appears that coherence and containment are as, if not more, important in managing diabetes than focusing on medical symptoms and consequences. This supports the need to be mindful of psychosocial as well as medical factors in T1D care (ISPAD, 2009). These results need to be interpreted with some caution however, due to the modest sample size in this study.

¹⁷ Containment refers to the process in which one person holds and contains their own or another's emotions, preventing them feeling overwhelming.

Responsibility taken by children and parents is influenced by each other but there are some differences in who responsibility is perceived to lie with which may lead to poor management and may need further examining. It appears that parents' beliefs about the illness being variable and their own anxiety lead to them taking responsibility, whilst the child reports responsibility when parents understand the illness and after a time of being diagnosed; their responsibility was however, also dependent on age. It is hypothesised that these factors make it feel more or less necessary to assume responsibility as a means of coping and managing a variable and life threatening illness. Surprisingly personal control was not a predictor. For children it seems that taking responsibility is dependent on their age, regardless of their perceptions of the illness. Supporting this and existing research, the only between age group difference was in responsibility with older children reporting more (Anderson & Brackett, 2005; La Greca et al., 1990). From this we may start to query how clinics support families and children with the transition to self management and on what basis they judge a child's readiness, as inappropriate and untimely responsibility may have negative outcomes (Anderson et al., 2003; Wysocki et al., 1996). Due to the small sample size these interpretations must be taken with caution. It seems that longer term, larger studies are required in T1D to build upon existing theory and to avoid the statistical issues that come with moderate sampling and cross sectional design.

The findings of this study are limited in a number of ways. Firstly, as discussed the sample size is moderate and the nature of the analysis raises the potential for errors to occur, though efforts have been taken to reduce these, it is possible that some significant results are lost or misleading. The sample was taken across three clinics in different counties but lacks variation in nationality and in many ways lacks generalisability. There are also discrepancies in the sizes of the age groups as fewer younger children were available. Future research may be mindful of this difficulty and

consider means to overcome such issues. The drop outs after consent may have created bias in the sample as it is not known if they differed as information was not obtained. Families experiencing high degrees of anxiety or poorer metabolic control may have been distressed or overwhelmed and not completed the study so limiting the findings.

Despite the limitations there are a number of strengths. The study allowed for the participation of both mothers and fathers so as to avoid exclusion. It pulled together literature across a number of areas and attempted to understand them within a model (CSM). It also compared anxiety, beliefs and management across age groups which both allows comparison and follows development, adding to an understudied population. As a suitable measure of illness beliefs did not exist, one was developed and although it requires further testing, it appears to have good validity and reliability and can be used in future research.

In terms of the developed measure, it was not possible to gain test- retest results due to limited numbers. Ideally, a pilot study testing and adjusting the Child IPQ-R would have been conducted prior to its use, though time limitations made this impossible to accomplish. The measure showed satisfactory reliability and validity and future use of the measure could further confirm its value as an edition for younger children. The availability of the researcher in clinic to support its completion may not always be possible and further testing may examine if their presence biased results.

Within the IPQ-R the subscale for chronicity showed little variation, implying the length of T1D was understood, but making the scale redundant. It seems that in relation to T1D, the control and cure subscales may cause confusion as they exist on one subscale but for a chronic (incurable) illness may have very different meanings. Similarly, participants may interpret personal and treatment control as referring to either the control or cure of T1D which may explain their lower internal consistency. This may require further revision for use in chronic illness.

This study highlights a number of areas worthy of further examination, some of which have been discussed. In order for families to experience positive wellbeing and to make sense of T1D more research is required examining the role that shared understanding, predictability and parental containment. Qualitative research could provide rich data around the perception of these factors in parents and children with view to creating greater understanding in the literature to be passed through the system and inform clinical practice. Research examining the actual management is needed in relation to anxiety and beliefs to assess practical aspects of care without losing sight of the psychosocial aspects of the illness. Interventions for diabetes using systemic and cognitive behavioural approaches would be a natural progression in the research when firmer theoretical groundings are built.

There are a number of clinical implications from this study. Both the CSM, including emotion, cognition and behaviour and also a cognitive-behavioural approach may be beneficial in understanding and working with T1D. It is important to consider parental factors such as beliefs to promote health and well-being in T1D to support parents and it may be possible to in develop positive outcomes and affect change indirectly by working with parents. It seems important to assess the shared understanding and responsibility for diabetes and to develop this with narrative techniques to develop protective factors. Professionals may want to consider how responsibility is transferred to children across this period and how much recognition the child has of their readiness. Regular T1D education may also be useful in assessing and developing helpful beliefs.

To conclude, this study provides further evidence of the importance in maintaining both a systemic and individual perspective in managing diabetes. It offers new understanding in to the dynamic nature of anxiety, illness beliefs and regimen

responsibility between parents and children with clinical implications and applications discussed.

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PART THREE

Appendices

Appendix 1: Reflective Statement

My reflections throughout the research process were recorded. These were based on discussions with professionals and my research supervisor, as well as personal reflection stemming from reading, observation and experience.

I will begin with a brief explanation of why I chose the Journal of Pediatric Psychology (JPP) to submit to. I will discuss some of the difficulties experienced in the research process, particularly in recruiting children and reflect on my role as a Trainee Clinical Psychologist and also Researcher in diabetes clinics. It felt important to include my reflections from an epistemological perspective which will be discussed here. I will then move on to discuss my experiences of the parallel process and transference experienced in developing and writing the research and finally my awareness of my own change and development over the three years of conducting the empirical research. In conclusion I acknowledge the families' contribution and shared experience.

Journal Choice

Deciding which journal to submit to seemed like it might be a difficult decision, however, in reality one journal stood out amongst all others. The Journal of Pediatric Psychology is the official journal of the Society of Pediatric Psychology, which is a division of the American Psychological Association and has been established over 40 years. My decision to submit both articles to this journal as a first option was based on the following reasons. i) The journal has an impact factor of 3.05 (2009), meaning that the articles would be likely to achieve good exposure within professional circles and therefore the findings and theory are likely to be integrated in to the field. ii) Many articles I read and referenced as part of this research can be found in the JPP. Research

in the field is easier to access, follow and make sense of if within the same journal as that which it stems from or extends. iii) There appear to be a number of key researchers in the diabetes psychology field who have studies published in the JPP and who have also written on Leventhal's Common Sense Model (1984) and developed measures; one measure which is included in this research. Permission to use this measure was gained from the author and so contact has been made. To maintain coherence within the literature base, it will be useful to have research using similar measures and models together for ease of comparison. iv) New research by these authors is being continually published within the JPP and so they are likely to see the development of their own work which in turn may inspire further research.

Despite these points which provide evidence for submission to the JPP, one issue arose. The journal's limit of 25 pages for original research and 30 pages for systematic reviews felt limiting due to the empirical paper being of considerable complexity due to the multiple research questions, new measure, analyses and model. For the systematic review 30 pages felt more achievable, particularly as a relatively small number of papers were reviewed. After careful thought and consideration, it seemed that another learning point in the research process may be my development of concise and relevant scientific reporting. Submitting to a journal with a more lenient page count, although possible and justifiable did not feel the best first choice given the relevance of the JPP and impact factor. The articles within this journal are concise, to the point and although still complex, they offer an ease of understanding because of this. It became a final aim, to try and develop a writing style that would allow this new research to reach its most suitable target audience in a way that merited its value. This proved more difficult than many other parts of the process and I can only hope at the moment that I have done the research justice.

Recruitment Process

In terms of the recruitment procedure, before beginning I was aware that working with young children would have its difficulties and that recruiting dyads could lead to conflict if both parties did not wish to take part. This was mirrored in concerns by the ethics committee who wished to confirm that this had been considered and accounted for. In actual fact, the nature of the families to want to promote diabetes research and possibly because they feel indebted to the care teams, meant that a high consent rate was achieved. The development of measures that were suitable for a primary school population and yet still achieved the aim of accessing illness beliefs was long and involved input from teachers and children of the age. The ethics committee were concerned that this age range would not take part or complete the measures in full and so to offer support I made myself available in diabetes clinics every week for almost a year. This was a time consuming and labour intensive exercise during an already busy training period. As an alternative method of recruitment was not trialled I can only hypothesise that my presence in clinic to offer support, encourage and explain was helpful in achieving the numbers. Unfortunately recruitment was cut short due the length of time it took to gain research approval from each Trust and also due to clinic cancellations which left participants unreachable. In future research endeavours I would remedy this with more thorough practical background work before thinking about study designs.

Continuing on the theme of recruitment, at one point as a Trainee Clinical Psychologist, I was both working in Paediatrics as well as planning the research. I reflected on my role within the diabetes clinics as a Researcher but yet also being required to use some clinical skills to reduce distress if needed and support families. This required balance

and awareness so as not to slip in to the more natural Psychologist role. For the most part this was achievable with no complications but on occasion the families who did not have immediate access to psychological input would request information from me around formulation and intervention for a diabetes related complaint of their child's. It felt uncomfortable to hold the information they requested but to have to repress the Psychologist role in order to work ethically and competently as a Researcher. Through contracting and sensitive teams this issue was managed and families were directed back to the team by me.

Epistemology

As part of my reflection I have thought about the nature of research, knowledge and the scientific study of psychological concepts which have influenced my thinking and approach to research (refer to Appendix 2 for full statement).

Transference and Parallel process

My next reflections stem from the process of making sense of the research and the issues that families face in diabetes. At times during writing up my research I noticed myself feeling somewhat disconnected from it. I struggled to find meaning or purpose to what I was studying and began to question everything about it. Suddenly it became something very separate from me. This led to a lack of motivation to continue with it, despite looming deadlines and my usual work ethic being to get things done in an enthusiastic and efficient way. To make sense of this I made use of supervision and formulation skills developed in clinical practice which were invaluable in the process.

On beginning the research process I had felt strong in my conviction that I would own and feel responsible for the project and everything that it encompassed as I chose and

developed it and I imagined this to be a well adjusted and well managed process.

Studying diabetes was initially new and exciting; a collaborative venture with my then current supervisor who was interested in diabetes. I retained some ambivalence of the quantitative nature this research would take, as maths and science are not my strong points, however I felt that collaboratively these skills could be developed and supported. During the research process my original supervisor left and I began a contract with my current supervisor. Although this was a smooth transition, in some ways it felt that the ground work was missing as diabetes became a new topic for both of us to stumble through. The process involved both of us learning together about this new area, making sense of it and deciding how to manage the research between us.

At times, the research felt difficult to hold in mind in its entirety. In my efforts to pull together fragmented pieces of literature and combine within a model that helped it make sense, I ended up overwhelmed by the complexity of diabetes and the interplay between all of the components influencing it. The complex nature of the illness is discussed in diabetes literature and diabetes clinics and provides good reasons to study and understand it further. When diabetes was combined with statistics in an empirical paper, it began to feel unmanageable and I felt I wanted to push it away. Trying to get to grips with all that it encompassed began to take over my life and I wanted to reject it, give up or have somebody tell me the answers or do it for me. These were new and unusual experiences, far removed from my regular work ethic, determination and enthusiasm.

It was on reflection of the unusual nature of this experience that my supervisor and I saw potential parallels with the child process. It seemed that one issue often seen in the diabetes clinics during recruitment was the need for families to understand the ins and

outs of the regimen and to get to grips with the mathematics which involved ratios and counting in the insulin and dietary routines. An emphasis was placed by clinics on controlling the diabetes using a range of medical and practical means in order to avoid drastic consequences. Below this, there seemed to be a deeper need for the families to understand why the diabetes had developed and to make sense of and adjust to the impact it had on the family. Within my own process understanding the diabetes and making sense of the complexity of it led to better adjustment to the research process and feeling able to manage it and make progress. This was only accomplished once the statistical aspects were planned and executed and to do this a collaborative approach was taken with supervisors and statisticians. It didn't seem to matter that I knew the consequences of not completing the research because the more pressing matter was understanding it enough to make progress. I wondered if the children also felt like the threat of drastic consequences of failure made little difference in managing an illness that was overwhelming and confusing.

When my supervisor had a congruent understanding of the research, a collaborative management began which felt containing and improved my own belief that what I was doing was correct and making sense. Her own reflections were around the responsibility she felt in supervising a new area and making sense of this. Again, this seemed not far removed from the process for children who need support from families and professionals, to come to a congruent understanding of the diabetes and learn to manage it collaboratively; otherwise, the process becomes overwhelming, confusing and distressing. I wondered whether they also felt an improved sense of control and efficacy when things began to go to plan and containment when those around them had a shared understanding.

A Clinical Psychologists role is diverse; research and clinical practice are combined in one profession but in some ways require very different skill. This came to light in the recruitment and parallel processes. Within the clinical role formulation and therapy are used, both requiring empathy and the interpretation of transference and parallel process to provide additional information. Within research, these factors are often less acknowledged, in order to provide objectivity and unbiased studies. This has led me to query the value or role of transference and parallel process interpretation as an additional field of information in psychological research, along side structured, scientific methods. This is an area I plan to learn more about as it appears to be overlooked and I aim to write an article discussing these ideas.

Clinical Psychologist and Researcher

Since beginning the training and research process I am aware of how much I have learnt, grown and changed, both personally and professionally. In my clinical work I am now consolidating and playing with my own style; finding models and ways of working that suit me and trying to marry these with service requirements, policy and best practice. There are a number of influencing factors on my development, one of these is inevitably the research area I have chosen and which has allowed me access to hospital settings, time with diverse staff teams and to visit various Trusts. Child work remains a passion and has throughout the three years, in this sense the research has provided a continual attachment to the area. I have learnt to adapt, to fit in, to build working alliances but as a Researcher rather than a Psychologist. Another defining factor has been the view of Psychology as a profession in current times. It feels that Psychology is the battleground between Science and Philosophy, of Knowledge and Intuition and depending on the time, the culture and the model, these dichotomies have greater force. Currently the emphasis on evidence based practice and research has

likely had an impact on my developing sense of myself as a Psychologist and role as a Researcher.

Shared Experience

The process of being allowed to share and experience the difficulties of the children and families, I have met as part of my recruitment, have been touching and I feel privileged for the opportunity; for their openness, acceptance and their enthusiasm in helping others. I have also been amazed and humbled by their resilience, compassion and strength as they have faced a life time of complication, adaption and threat. The way that the children have coped with, accepted and fought against professional involvement, parental input and the impact of illness has been at times frustrating and intriguing. The families who have been equally affected by these diagnoses and who go through such a range of emotions have taught me a lot about adjustment, care and coping, in relation to themselves and also their child.

Appendix 2: Epistemology

As part of my reflection I have thought about the nature of research, knowledge and the scientific study of psychological concepts. The reflection has been influenced in part by the work of the Philosopher Immanuel Kant (1724-1804). At various points in time psychology seems to stand nearer to science or philosophy, dependent on the needs of society and the cultural movement. Currently, psychology feels pulled towards science which focuses on fact, truth and reason. Policies driving the profession focus on providing evidence based practice, research, outcomes and proof. Although this is combined with reflection, at times this feels more to provide competent and thorough practice rather than to acknowledge or debate deeper issues. Psychology as I have held it, has been more focused on pattern, possibility, likelihood and individual difference, whilst few definitive answers exist. This led me to query, not whether research has value in psychology, but what is really being studied and how?

Research, generally sets out to look at existing theory, to develop hypotheses in order to question and extend theory or search for a truth. Experiments, controlled trials, questionnaires and interviews, among other techniques are used to test these hypotheses. The findings are interpreted from the view of the researcher as well as fitting with existing assumptions and the end product, we hope, is to further our knowledge or ideas, unbiased and with minimal error. Of course everything cannot be examined at once or controlled for and so error will always occur to some degree. This process can be more or less scientifically rigorous dependent on the methods used, but always aims to control for extraneous variables and to be approached with an objective view.

Both the systematic review and the empirical paper led me to think about this process from an epistemological position. It felt important to take a step back and reflect on what is being asked of researchers, rather than to accept the process and follow procedure. I imagine that the need to do this is born partly from my nature to question and analyse and partly from the clinical training in which curiosity and reflection are nurtured. Further more, by including illness beliefs, which as a notion are based on subjective experience and perception, the research and review were built upon an abstract concept. Assumptions such as that, illness beliefs exist and are definable and therefore accessible and measurable, are required to turn representation in the abstract in to the concrete.

Illness beliefs are an individual's unique interpretation of an illness which gives it meaning. They stem from the person's exclusive experience, are influenced by their existing representation of reality and are expressed through a culturally developed model. No other being will hold the exact same beliefs and all that they entail, nor will they have developed in the same way or be expressed or acted upon identically. In many ways, the concept of illness beliefs do not exist, as they have been produced within a culture and language that define what they can be, therefore both creating and limiting their existence. Despite this, there does seem to be some form of illness representation within the mind which is real for that person; how this is given meaning is now dependent on the shape and model offered in theory. The need to create these labels and boxes, to categorise a complex world and to create a shared, meaningful reality is a defining factor of what is understood to be human cognition. A measure of illness beliefs allows a shared understanding of an illness and the external and concrete expression of an internal idea. Unfortunately, in creating a framework and measure for the inner world to be accessed we may not be understanding the rich and varied

information available but we may actually act to limit, bias and reduce it. A further point is that, even after definition, there is a cultural and linguistic bias within the definition which may limit generalisability.

In quantitative research, measurement requires a defined variable which can be recorded in a way that is reliable and valid; this being determined statistically and through subjective and objective opinion. Although this allows particular information to be collected which is hopefully the information set out to be collected, it doesn't incorporate individual difference. For example, a child's beliefs about diabetes which may be of importance to them would be missed if not present on the measure.

The human mind, being incapable of processing or holding every thought and experience of another, finds it much easier to conceptualise simple information. This whole process of accessing people's unique and inner reality rests upon the assumption that people can recognise, comprehend and express their inner experience in order for it to be reduced, defined and categorised. Further more, as people don't express their full experience, this procedure has already been reduced by the person's capacity to perceive the world, the schemas they understand the world within and their desire and ability to regurgitate it. This allows much room for bias and missing information and so only limited control is possible in this particular field.

In conclusion, it has felt important to reflect on these issues; to acknowledge that in measurement of the variables of interest or seeming importance there are numerous assumptions being made and limitations being emplaced in order to objectify an individual's representation of illness. The assumptions are necessary to form ground work from which to build upon ideas but need awareness so as not to become a truth or

to produce unrealised bias. Reflection helps to maintain an awareness of the fluidity of this science and to hold the uncertainty that comes with trying to concretely define and measure, whilst more loosely look for patterns, possibilities and relationships.

Hopefully, in thinking about this standpoint, my research write-up will be less likely to suffer from researcher bias or over confidence in results as being fact and will hold the theory open to further interpretation and understanding.

MANUSCRIPT PREPARATION

Instructions to Authors

The main emphasis of the journal is on original research. Analytical reviews of research, scholarly case studies, and commentaries are also considered for publication. The Web site (<http://www.jpepsy.oxfordjournals.org>) includes book reviews in addition to general information on the journal. Submissions are welcomed from authors in psychology and other disciplines serving children and families.

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Definition:

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Manuscripts (text, references, tables, figures, etc.) should be prepared in detailed accord with the Publication Manual of the American Psychological Association (6th ed.). There are two exceptions:

(a) The academic degrees of authors should be placed on the title page following their names, and

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Objective (brief statement of the purpose of the study);

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Conclusions (statement of implications of these data).

Key words should be included, consistent with APA style. Submissions should be double-spaced throughout, with margins of at least 1 inch and font size of 12 points (or 26 lines per page, 12-15 characters per inch). Authors should remove all identifying information from the body of the manuscript so that peer reviewers will be unable to recognize the authors and their affiliations. E-mail addresses, whenever possible, should be included in the author note.

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The clinical relevance of research should be incorporated into the manuscripts. There is no special section on clinical implications, but authors should integrate implications for practice, as appropriate, into papers.

Authors should indicate in the Method section of relevant manuscripts how informed consent was obtained and report the approval of the study by the appropriate Institutional Review Board(s). Authors will also be asked to sign a statement, provided by the Editor, that they have complied with the American Psychological Association Ethical Principles with regard to the treatment of their sample.

Terminology should be sensitive to the individual who has a disease or disability. The Editors endorse the concept of "people first, not their disability." Terminology should reflect the "person with a disability" (e.g., children with diabetes, persons with HIV infection, families of children with cancer) rather than the condition as an adjective (e.g., diabetic children, HIV patients, cancer families). Nonsexist language should be used.

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Details of all funding sources for the work in question should be given in a separate section entitled 'Funding'. This should appear before the 'Acknowledgements' section.

The following rules should be followed:

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- The full official funding agency name should be given, i.e. ‘the National Cancer Institute at the National Institutes of Health’ or simply ‘National Institutes of Health’, not ‘NCI’ (one of the 27 subinstitutions) or ‘NCI at NIH’ (full RIN-approved list of UK funding agencies) .
- Grant numbers should be complete and accurate and provided in parentheses as follows: ‘(grant number xxxx)’
- Multiple grant numbers should be separated by a comma as follows: ‘(grant numbers xxxx, yyyy)’
- Agencies should be separated by a semi-colon (plus ‘and’ before the last funding agency)
- Where individuals need to be specified for certain sources of funding the following text should be added after the relevant agency or grant number ‘to [author initials]’.

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This is intended as "anticipatory editorial guidance" to help you craft the manuscript that best characterizes the science of your work and to facilitate our reviewers' ability to fully understand and appreciate the scientific content and value of your work. We encourage you to use this checklist. Although its use cannot guarantee acceptance of your manuscript, it will certainly enhance the probability of your success.

Checklist for Preparing and Evaluating Review Articles

1. What is the significance of the topic or question addressed by the review to the field of pediatric psychology?

How specifically does this review advance knowledge of science, theory, or practice?

What is the significance or special novel contribution of the review? (e.g. provides new insight in specific content areas; calls attention to a critical new issue, suggests new

solutions to methodological issues; suggests new intervention models)?

Is the significance of the research topic and review for the field of pediatric psychology sufficiently clear?

2. Level of scholarship:

Is the review sufficiently comprehensive and scholarly?

Does the review summarize all the information in a domain of interest?

Are the references appropriate and up-to-date?

Are there any major omissions?

3. Is the level of the review appropriate in terms of the purpose/focus/depth of citations for the audience of the Journal of Pediatric Psychology?

4. Quality of method and method description

What type of literature search was conducted?

Over what time periods?

Using what key words?

What other data retrieval efforts were conducted? (e.g. reference lists, contact with authors, etc.).

What was the rationale for the literature described?

Was this method well described and appropriate to the topic and question?

Does the method clearly define the domain of the review, the inclusion and exclusion criteria, and rules for including and excluding articles with a rationale?

What process was used to determine eligibility of studies for the review?

Can the method be replicated?

What is the quality of the statistical methods used?

5. Clarity and substantiveness of the presentation of content

Are the major findings clearly presented?

Are suitable methods used for analyzing, synthesizing, and evaluating the studies?

Does the review organize, synthesize, and explicate findings including inconsistent findings.

Does the review evaluate research critically?

6. Conciseness, liveliness, and impact of the findings presented (is the material presented in a clear, engaging manner?)

7. Are the major conclusions and implications clear and appropriately drawn from the findings?

8. Is the generalizability of the findings discussed?

9. Are limitations of the review discussed?

10. Quality and potential impact of the recommendations for future research based on the review.

Does the review develop specific questions for future research?

Does the review suggest novel research ideas and/or hypotheses?

11. Clinical relevance: Quality and potential impact of the recommendations for clinical care and/or policy based on the review

Does the review develop specific suggestions for clinical care; diagnosis and interventions and/or health-related policy?

Note: Meta-analytic reviews require special attention to the presentation and analysis of effect size data etc. Please consult the meta-analyses reporting standards in APA's reporting standards for research in psychology (*American Psychologist* (2008) 63, 839-851).

Authors' Checklist for Manuscript Submission to JPP

Abstract

Make sure that your abstract includes the following headings:

- Objectives (brief statement of the purpose of the study)

- Methods (summary of participants, design, measures, procedures)
- Results (primary findings)
- Conclusions (statement of implications of the data)

Introduction

- Make sure that the study's relevance to pediatric psychology is explicit (e.g., how does your study relate to the field of pediatric psychology?) (see vision statement for Society of Pediatric Psychology, SPP Executive Board 2006)
- Clarify the conceptual or theoretical rationale for your study
- Describe and clearly articulate the value-added significance of your research (e.g., how does this study extend scientific knowledge and/or clinical practice beyond what is already known?)
- Describe primary aims and the central scientific question(s) for the study
- Describe a clear rationale for examining the variables that are measured and analyzed in relation to the study goals and significance
- State hypotheses clearly together with a theoretical and/or empirical rationale and/or framework (unless the study is explicitly exploratory in nature)
- If your study is exploratory, state the rationale and significance of an exploratory approach given current scientific knowledge

Method

- *Participants*
- Explain and provide rationale for eligibility (e.g., inclusionary and exclusionary criteria).
- Describe the initial pool of eligible participants (e.g., what was the specific sample from which the study sample was drawn?)
- Include details regarding the participant sample(s) (e.g., age, gender, socioeconomic status, race/ethnicity).

- Provide details on how participants were selected
- Report participation rates and reasons for nonparticipation
- Describe characteristics of participants versus nonparticipants, including those who refuse
- Describe and compare characteristics of different groups if more than one are included in the sample
- For prospective studies, describe characteristics of attrition versus non-attrition sample if relevant and reasons for attrition and/or withdrawal from the study

Statistical Analysis

- Include brief overview of the overall approach to statistical analysis

Procedure

- Describe how participants were recruited
- Describe how the measures were administered and to whom
- Describe who conducted the procedures and where the procedures were conducted
- Describe how informed consent from parents was obtained as well as child assent
- Acknowledge approval of the study by the Institutional Review Board
- For Treatment Studies: if this is a randomized trial, the CONSORT guidelines (www.consort-statement.org) should be used. If this is a nonrandomized trial then the TREND statement should be used (http://www.trendstatement.org/asp/documents/statments/AJPH_Mar2004_Trendstatement.pdf) should be used.
- For treatment studies: explain procedures in detail, e.g.:
 - How was the intervention conducted and by whom?
 - What were the training procedures for interventionists?
 - How often was it administered
 - How long were the sessions?

- Indicate information on the availability of treatment manuals or additional information concerning treatment implementation that is available from the authors along with relevant contact information (email address)
- How was intervention fidelity monitored?
- What were the results of the intervention fidelity analyses
- How was participant adherence to intervention monitored?

Measures

- Describe empirical and/or theoretical rationale for inclusion of specific measures in the study design
- Describe who administered the measures and whether they were aware of group assignment
- Describe each measure briefly, including:
 - content area
 - scoring procedures
 - reliability and sample on which it is based
 - validity and sample on which it is based
 - psychometric properties for the current sample
 - validity of physiologic measures (e.g., hemoglobin A1c) as relevant

Results

- Use APA format to describe results and statistics
- Include alpha level and appropriate corrections for multiple statistical tests and/or violations of assumptions
- Organize results around the questions/hypotheses posed in the introduction
- Describe rationale for sample size, statistical power, and detectable effect sizes in study design
- Include effect sizes for all results (see Vacha Haase & Thompson, 2004)

- Include confidence intervals for results (See Cumming & Finch, 2005; Wilkinson and the Task Force on Statistical Inference, 1999)
- Indicate whether and how statistical differences were clinically significant (as relevant)
- Describe violations of assumptions for statistical analyses (as relevant)

Discussion

- Describe the value-added contribution of your manuscript to science or practice, and/or theory
- Provide a summary of findings as they relate to the primary hypotheses
- Describe alternative competing explanations of findings
- Include a discussion of your study's limitations, especially factors that might limit the Nature and scope of inferences that can be drawn
- Describe generalizability of findings, including limitations in the generalizability of findings to different samples, settings, and to clinical practice (See Green & Glasgow, 2006)
- Describe specific directions for the “next steps” in research that will advance the field that are suggested by your findings
- Address the potential clinical implications of your findings
- Discuss statistical and clinical significance

General Issues

- Is your manuscript carefully proofread?
- Did you use the APA format throughout your manuscript (APA, 2001)?
- Did you use “people first” sensitive terminology to refer to individuals with a chronic illness or disability throughout your manuscript (Roberts, 1991) (see attached)
- When possible, did you use active rather than passive voice?
- Did you double check your references so that all are present, in order, and properly

formatted?

- Are your figures and tables properly labeled and formatted (e.g., double-spaced for tables).

Appendix 4: Data Extraction Tool ¹⁸

Data	Information
Title name	
Year	
Author	
Country of origin	
Design	
Aim	
Model of Illness Beliefs Used	
Sample size (parents/ children)	
Response rate/ Drop outs	
Parent participant demographics (age/ gender etc)	
Child participant demographics (age/ gender etc)	
Type 1 diabetes information: mean duration/ time since diagnosis	
Measures used	
Main results	
Main Conclusions	

¹⁸ Included as supporting evidence for thesis, not to be submitted to journal.

Appendix 5: Articles Not Included in Systematic Review

- Beveridge, R.M., Berg, C.A., Wiebe, D.J., & Palmer, D. L. (2006). Mother and Adolescent Representations of Illness Ownership and Stressful Events Surrounding Diabetes. *Journal of Pediatric Psychology, 31* (8), 818- 827.
- Brownlee- Duffeck, M., Peterson, L., Simonds, J.F., Goldstein, D. K. C., & Hoette, S. (1987). The Role of Health Beliefs in the Regimen Adherence and Metabolic Control of Adolescents with Diabetes Mellitus. *Journal of Consulting and Clinical Psychology, 55*(2), 139-144.
- Butler, J.M., Berg, C A., King.P., Gelfand,D., Fortenberry,K., Foster.C., & Wiebe. D. (2009). Parent Negative Affect and Adolescent Efficacy for Diabetes Management. *Journal of Family Psychology, 23*(4), 611-614.
- Butner, J., Berg, C.A., Osborn, P., Bulter, J.M., Godri, C., Fortenberry, K.T., Barach, I., Le. H., & Wiebe, D.J. (2009). Parent- Adolescent Discrepancies in Adolescent Competence and the Balance of Adolescent Autonomy and Adolescent and Parent Well-being in the Context of Type 1 Diabetes. *Developmental Psychology, 45*(3), 835-849.
- Farrel, S.P., Hains, A.A., Davies, W.H., Smith, P., & Parton, E. (2004). The impact of cognitive distortions, stress and adherence on metabolic control in youths with type 1 diabetes. *Journal of Adolescent Health, 34*(6), 461-467.
- Gillibrand, R., & Stevenson, J. (2006). The extended health belief model applied to The experience of diabetes in young people. *British Journal of Health Psychology, 11*(1), 155-169.
- Greening, L., Stoppelbein, L., & Reeves, C.B. (2006). A Model for Promoting Adolescents' Adherence to Treatment for Type 1 Diabetes Mellitus. *Children's Health Care, 35*(3), 247-267.

- Hoff, A.L., Mullins, L.L., Page, M.C., Carpentier, M.Y., Chaney, J.M., & Hommel, K.A. (2005). The relationship of control-related beliefs to depressive symptomology among children with type 1 diabetes and asthma: A disease specific approach. *Children's Health Care, 34(4)*, 261-272.
- Iannotti, R., Scheider, S., Nansel, T.R., Haynie, D.L., Plotnick, L.P., Clark, L.M., Sobel, D.O., & Simons-Morten, B. (2006). Self Efficacy, Outcome, Expectations and Diabetes Self Management in Adolescents with Type 1 Diabetes. *Journal of Developmental and Behavioral Pediatrics, 27(2)*, 98-105.
- Johnson, S.B. (1984). Knowledge, attitudes, and behavior: Correlates of health in childhood diabetes. *Clinical Psychology Review, 4(5)*, 503-524.
- Koopman, H.M., Baars, R.M., Chaplin, J., & Zwinderman, K.H. (2004). Illness through the eyes of the child: the development of children's understanding of the causes of illness. *Patient Education and Counseling, 53(3)*, 363-370. Special issue: Educating and Counseling Children about Physical Health, 363-370.
- Mann, D.M., Ponieman, D., Leventhal, H., & Halm, E.A. (2009). Predictors of adherence to diabetes medications: The role of disease and medication beliefs. *A Journal of Behavioral Medicine, 32(3)*, 278-284.
- Nouwen, A., Law, G.U., Hussain, S., McGovern, S., & Napier, H. (2009). Comparison of the role of self-efficacy and illness representations in relation to dietary self care and diabetes distress in adolescents with type 1 diabetes. *Psychology & Health, 24(9)*, 1071-84. ¹⁹
- Palardy, N., Greening, L., Ott, J., Holderby, A., & Atchison, J. (1998). Adolescents' health attitudes and adherence to treatment for insulin-dependent diabetes mellitus. *Journal of Developmental and Behavioral Pediatrics, 19(1)*, 31-37.

¹⁹ Article requested as not available freely but was not accessible.

- Rabiau, M.A., Knauper, B., Nguhen, T-K., Sufrategui, M., & Polychronakos, C. (2009). Compensatory beliefs about glucose testing are associated with low adherence to treatment and poor metabolic control in adolescents with type 1 diabetes. *Health Education Research, 24(5)*, 890-896.
- Rodrigue, J.R., Geffken, G.R., Clark, J.E., Hunt, F., et al. (1994). Parenting satisfaction and efficacy among caregivers of children with diabetes. *Children's Health Care, 23(3)*, 181-191.
- Skinner, T C., Hampson, S.E., & Fife-Schaw, C. (2002). Personality, personal model beliefs and self care in adolescents and young adults with Type 1 Diabetes. *Health Psychology, 21(1)*, 61-70.
- Wiebe, D.J., Alderfer, M.A., Palmer, S.C., Lindsay, R., & Jarrett, J. (1994). Behavioral self regulation in adolescents with Type 1 diabetes: Negative affectivity and blood glucose symptom perception. *Journal of Consulting and Clinical Psychology, 62(6)*, 1204-1212.

Appendix 6: Quality Assessment Tool²⁰

	Question	Score 1 if 'yes'/ Score 0 if 'no' or unable to determine.
1	Does the study examine a clear hypothesis, aim or question (s)?	
2	Are the factors to be measured clearly stated in the introduction or methods section?	
3	Is the definition of illness beliefs or related conceptualisation clearly defined in the introduction or methods section?	
4	Is the nature of the sample representative of the entire population from which they were recruited? Is any bias explained?	
5	Are the sample characteristics clearly defined (time since diagnosis, age , gender etc)?	
6	Is there a comparison group? Is this groups characteristics clearly defined and reason for inclusion given?	
7	Are figures and reasons for drop outs, non-consent provided?	
8	Are the measures clearly defined?	
9	Were the main outcome measures appropriate (valid and reliable)?	
10	Where the statistical tests used to analyse the main outcomes appropriate?	
11	Are the findings clearly reported in the results section?	
12	Have actual probabilities been reported for the main outcomes, except where the probability is <0.001?	
13	Was there adequate adjustment for confounding variables in the analyses from which the main findings were drawn?	
14	Is the aim or objective answered?	

²⁰ Included as supporting evidence for thesis, not to be submitted to journal.

Appendix 7: Quality Assessment Scores (including inter-rater scores)²¹

Authors: Quality Item	Bond, Aiken & Somerville (1992)	Edgar & Skinner (2003)	Griva, Myers & Newman (2000)	Olsen, Berg & Wiebe (2008)	Patino, Sanchez, Eidson & Delameter (2005)	Skinner & Hampson (2001)	Skinner, John & Hampson (2000)	Urquhart- Law (2002)	Urquhart- Law, Kelly, Huey & Summerbell (2002)
1. hypothesis/ aim	1	1	1	1	1	1	1	1	1
2. variables defined	1	1	1	1	1	1	1	1	1
3. illness beliefs explained	1	1	1	1	0	1	1	1	1
4. sample representative or bias explained	0	1	1	0	0	1	1	1	1
5. sample described	1	1	1	1	1	1	1	1	1
6. comparison group	1	0	1	1	0	1	0	0	0
7. reason drop outs given	0	0	1	0	1	1	1	0	0
8. measures defined	1	1	1	1	1	1	1	1	1
9. measures suitable	1	1	1	1	1	1	1	1	1
10. statistics suitable	1	1	1	1	1	1	1	1	1
11. findings clear	1	1	1	1	1	1	1	1	1
12. actual probabilities reported	1	0	0	0	1	0	1	1	1
13. confounding variables controlled	1	1	1	0	1	1	1	1	1
14. aim answered	1	1	1	1	1	1	1	1	1
Total	12	11	13	10	11	13	13	12	12
Inter-rater Total	11/12	11/11	13/13	11/10	11/11	13/13	13/13	12/12	12/12

²¹ Included as supporting evidence for thesis, not to be submitted to journal.

Appendix 8: Ethical Approval Documents (To be removed)

Appendix 9: R&D Approval Documents (To be removed)

Parent Participant Information Sheet
Parental and Child Anxiety, Illness Beliefs and Management of
Type 1 Diabetes.

We wish to invite you to take part in a research study. Before you decide to do so, please read the following information carefully and discuss it with your relatives or the researcher if you wish. Please ask if there is anything you are unclear about or if you would like more information.

What is the purpose of the study?

Having a child with diabetes can be worrying for parents and the child.

This study aims to examine if there is a relationship between parent and child anxiety, beliefs about diabetes (e.g. how it can be controlled) and how it is managed by the parent and child (e.g. who gives injections). Understanding such relationships may help develop ways for parents and children to better adjust to their diagnosis and to develop future treatments to help living with diabetes easier for everyone.

Why have I been invited?

You have been invited to take part as your child falls within the age group of 6- 11 years and has a diagnosis of Type 1 Diabetes. We would like the parent with the most input in to your child's diabetes to take part. This can be decided by your family.

What will happen if I decide to take part?

If you decide to take part in the study you and your child will both be asked to complete a number of questionnaires about your general levels of anxiety, your beliefs about diabetes and how it is managed by yourself and your child. You and your child will be asked to complete the questionnaires independently. The questionnaires can be completed with the help of the researcher either whilst at the Diabetes Clinic or at your home. (I will then note your child's blood glucose reading from their medical notes.) I will contact you in clinic or by phone to arrange a time and place to provide and complete the questionnaires.

What do I have to do?

You will be asked to provide some general back ground information and to fill in 3 questionnaires. This should take approximately 30 minutes. (This may need extra time on a parking ticket if driving.)

²² Included as supporting evidence for thesis, not to be submitted to journal.

Do I have to take part?

Only if you want to.

Participation is voluntary. You may decline to participate or withdraw from the study at any time, but please let us know if you are unable to fully take part, as doing only parts of the study, rather than all of it, will likely affect the value of the research. You do not need to tell us why you do not want to take part. If you choose to withdraw or not to participate, your decision will in no way affect you or your child's future treatment or care. It may be that the researcher consider that it is in your or your child's interests to withdraw your information or stop the study altogether. If this is the case we will let you know.

Are there any costs involved?

There are no costs involved in taking part in the study, except for the time you may choose to give.

Risk

There are no risks identified in taking part in the study. If you or your child feel any distress in completing the questionnaires or they raise any issues for you, you can be directed to people who may be able to offer further support.

Confidentiality

All information that you give will be kept confidential and anonymous.

This means you can not be identified from the information you give. All information you provide will only be used for the purpose of this study.

In order to ensure that medical staff not involved with the study are aware of your participation in it, an alert notice will be attached to the cover of your child's hospital notes.

By signing the attached consent form you give permission for the above to occur.

Your rights

You have the right to withdraw from the study at any point; if you have already completed the questionnaires the data will be destroyed. If you do not wish to participate in the study it will not effect any continuing treatment you or child receive.

Who is organising and funding the research?

The study has been sponsored by Humber Mental Health Teaching Trust.

Thank you very much for your time and cooperation

Yours sincerely

On behalf of the Diabetes Clinic Team and
Jade Smith (Researcher and Trainee Clinical Psychologist)

Please call [REDACTED] if you would like any further information.

Child Participant Information Sheet

Parental and Child Anxiety, Illness Beliefs and Management of Type 1 Diabetes.

We would like to invite you to take part in a research project.



Research is a way we try to find answers to questions.

Before you decide if you would like to take part, read this information carefully and talk about it with your parents or with me if you want to. Please ask me if there is anything you are not sure about or if you would like some more information.

What is the purpose of the project?



Having diabetes can be a worry for children and their parents.

This project aims to look at any worries children with diabetes and their parents may have.



It also wants to look at what you think about your diabetes and how you and your parents manage your diabetes. (For example, we would like to know things like how you think your diabetes can be treated, who does injections and these sorts of things.)

We can't promise that the project will help you but finding out about these things might help us find ways to help other children manage to live with their diabetes more easily.



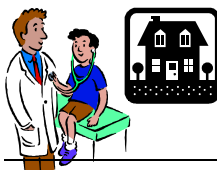
Why have I been invited?



You have been invited to take part because you are between 6 and 11 years old and you have Type 1 Diabetes. As many as 150 children may be doing this project.

What will happen if I decide to take part?

If you decide to take part you and your parents will be asked to answer some questions about what you think and feel about your diabetes and how you manage it with your parents.



The questionnaires can be filled out with my help whilst you are at the Diabetes Clinic or at your home at a time that suits you.

²³ Included as supporting evidence for thesis, not to be submitted to journal.

I will then make a note of your blood sugar reading from your notes that your Doctor keeps and I will let your Doctor know you are taking part.

What do I have to do?

You will be asked to answer a few questions about yourself, like your age and how long you have had diabetes and to fill in 3 questionnaires.



Do I have to take part?

Only if **YOU** want to.

You can say ‘no’ or stop taking part at any time you choose, just let me know. You won’t need to tell us why you have decided to say ‘no’ or stop.

If you choose to say ‘no’ or stop, this won’t affect the help you get from the clinic or the nurses in anyway either now or in the future.

Risk

There are **NO** risks identified to taking part in the project. We **won’t** be asking you to take any different medicines or have any injections.



Next time you go to clinic you will be asked if you and your parent would like to take part.

Thank you very much you for your time and help.

On behalf of the Diabetes Team

and 

Participant I.D Number for study:
Site Number:

Parent Consent Form

Title: **Anxiety, Illness Beliefs and Management of Type 1 Diabetes**

Lead researcher: Jade Smith

- 1 I confirm that I have read and understand the information sheet datedfor the above study and have had the opportunity to ask questions.
- 2 I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, without my medical care or legal rights being affected.
- 3 I agree to take part in the above study.
- 4 I give consent for my child to participate in the study.
- 5 I understand that sections of my child’s medical records relating to the project may be accessed by responsible individuals (from The Humber Mental Health Teaching Trust). I give consent for this.
- 6 I give consent for my child’s GP to be informed of their participation if required.
- 7 I would like a summary of the results to be sent to me.

Participant Name

Date..... Signature.....

Name of person taking consent.....

Date..... Signature.....

Researcher Name.....

Date..... Signature.....

If you have any queries please contact me on [REDACTED] and leave a message with your name and number.

²⁴ Included as supporting evidence for thesis, not to be submitted to journal.

Participant I.D. Number for project:

Site number:

Child Consent Form

Title: Anxiety, Illness Beliefs and Management of Type 1 Diabetes

Researcher: Jade Smith

1 I have read and understand the information sheet dated (version.....) for the above project. I have had the chance for this to be explained to me and to ask questions.

2 I understand that I have the choice to take part and that I can stop at any time. I don't have to give a reason and my care will not be affected.

3 I would like to take part in the project.

Participant Name

Date..... Signature.....

Name of person taking consent.....

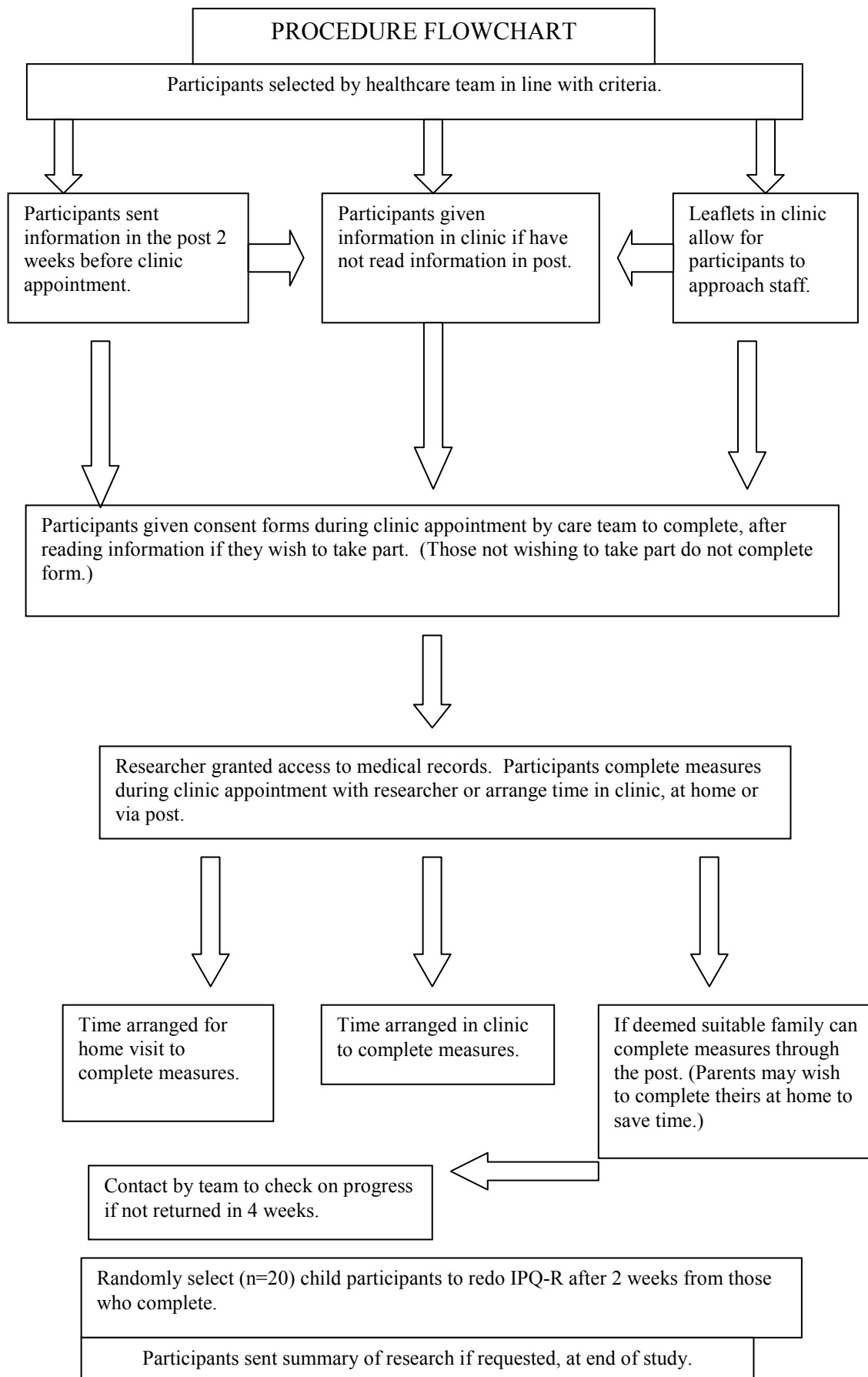
Date..... Signature.....

Researcher Name.....

Date..... Signature.....

²⁵ Included as supporting evidence for thesis, not to be submitted to journal.

Appendix 14: Procedure Flowchart ²⁶



²⁶ Included as supporting evidence for thesis, not to be submitted to journal.

ILLNESS PERCEPTION QUESTIONNAIRE – REVISED (CHILD VERSION)

YOUR VIEWS ABOUT YOUR DIABETES



Underneath is a list of symptoms you might have had since you found out you have diabetes.



Please put a circle round YES or NO whether you think YOU have had any of these symptoms.

Also, put a circle round YES or NO whether you think these symptoms are part of YOUR diabetes.

SYMPTOM	I have had this symptom		I think this is part of diabetes	
	Yes	No	Yes	No
Pain	Yes	No	Yes	No
Sore throat	Yes	No	Yes	No
Feeling sick	Yes	No	Yes	No
Hard to breath	Yes	No	Yes	No
Losing weight	Yes	No	Yes	No
Feeling tired	Yes	No	Yes	No
Stiff joints	Yes	No	Yes	No
Sore eyes	Yes	No	Yes	No
Wheeziness	Yes	No	Yes	No
Headaches	Yes	No	Yes	No
Upset tummy	Yes	No	Yes	No
Trouble sleeping	Yes	No	Yes	No
Feeling dizzy	Yes	No	Yes	No
Feeling weak	Yes	No	Yes	No
Being thirsty	Yes	No	Yes	No



²⁷ Included as supporting evidence for thesis, not to be submitted to journal.

DIABETES VIEWS

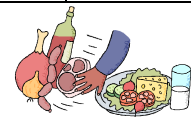
We are interested in finding out about what you think of your diabetes at the moment. Please mark how much you agree or disagree with each statement about your diabetes by ticking the box.

	YOUR VIEW OF YOUR DIABETES	AGREE A LOT	AGREE A BIT	DON'T AGREE OR DISAGREE	DISAGREE A BIT	DISAGREE A LOT
IP1	My diabetes will last a short time.					
IP2	My diabetes will last forever rather than a short time.					
IP3	My diabetes will last a long time.					
IP4	My diabetes will go away quickly.					
IP5	I think I will have diabetes all my life.					
IP6	My diabetes is a serious illness.					
IP7	My diabetes has a big effect on my life.					
IP8	My diabetes does not have much effect on my life.					
IP9	Other people see me differently because I have diabetes.					
IP10	My diabetes costs people a lot of money.					
IP11	My diabetes can be difficult for my family and friends.					
IP12	There is a lot I can do to control my symptoms.					
IP13	What I do can make my diabetes get better or worse.					
IP14	What happens with my diabetes is down to me.					
IP15	Nothing I do will change or help my diabetes.					
IP16	I have the power to change my diabetes.					
IP17	What I do will make no difference to my diabetes in the end.					
IP18	My diabetes will get better with time.					
IP19	There is not much that can be done to make my diabetes better.					
IP20	My treatment will help get rid of my diabetes.					
IP21	The bad parts of my diabetes can be helped or avoided by my treatment.					

	YOUR VIEW OF YOUR DIABETES	AGREE A LOT	AGREE A BIT	DON'T AGREE OR DISAGREE	DISAGREE A BIT	DISAGREE A LOT
IP22	My treatment can control my diabetes.					
IP23	There is nothing that can help my diabetes.					
IP24	The symptoms of my diabetes are confusing for me.					
IP25	My diabetes is a mystery to me.					
IP26	I don't understand my diabetes.					
IP27	My diabetes does not make sense to me.					
IP28	I have a clear picture or good understanding of my diabetes.					
IP29	The symptoms of my diabetes change a lot each day.					
IP30	My symptoms come and go over and over again.					
IP31	It's hard to know what my diabetes will do.					
IP32	Sometimes my diabetes is better and sometimes worse.					
IP33	I feel down when I think about my diabetes.					
IP34	When I think about my diabetes I get upset.					
IP35	My diabetes makes me feel angry.					
IP36	My diabetes does not worry me.					
IP37	Having diabetes makes me feel anxious.					
IP38	My diabetes makes me feel afraid.					



CAUSES OF MY DIABETES



We are interested in where YOU think your diabetes might have come from. People all think different things so there is no right or wrong answer to this. We are most interested in what you think rather than what the doctor or your family might have explained to you. Below is a list of some causes that people have thought of, we would like you to mark how much you agree or disagree with them by ticking the box.

	POSSIBLE CAUSES	AGREE A LOT	AGREE A BIT	DON'T AGREE OR DISAGREE	DISAGREE A BIT	DISAGREE A BIT
C1	I think a cause of diabetes is stress/ worry					
C2	I think a cause of diabetes is that it runs in the family					
C3	I think a cause of diabetes is a germ/ virus					
C4	I think a cause of diabetes is diet and what I eat					
C5	I think a cause of diabetes is chance/ bad luck					
C6	I think a cause of diabetes is my health not being looked after when I was younger					
C7	I think a cause of diabetes is pollution in the environment					
C8	I think a cause of diabetes is the things that I do (my behaviour)					
C9	I think a cause of diabetes is my attitude- thinking negatively about things					
C10	I think a cause of diabetes is family problems and worries					
C11	I think a cause of diabetes is doing too much work					
C12	I think a cause of diabetes is from my emotions or how I feel					
C13	I think a cause of diabetes is getting older					
C14	I think a cause of diabetes is having an accident or getting hurt					
C15	I think a cause of diabetes is my personality and what I am like					
C16	I think a cause of diabetes is how my body fights germs (immunity)					

On the lines below we have left a space for you to put what YOU think are the 3 most important causes of YOUR diabetes.

These might be from above or you might have extra ideas of your own.

Please put them in order with the one you believe the most as number 1.



The causes that are most important to me are:

1.....

2.....

3.....

**Diabetes Family Responsibility Questionnaire
(Anderson & Auslander, 1990)**

For each of the following parts of your care, choose the number of the answer that best describes the way you handle things at home.

- 1—Child takes or initiates responsibility for this almost all of the time.**
- 2—Parent(s) and child share responsibility for this about equally.**
- 3—Parent(s) take or initiate responsibility for this almost all of the time.**

	Responsibility		
	Child	Equal	Parent
	1	2	3
1. Remembering day of clinic appointment.			
2. Telling teachers about diabetes.			
3. Remembering to take morning or evening insulin injection/bolus by pump.			
4. Making appointments with dentists and other doctors.			
5. Telling relatives about diabetes.			
6. Taking more or less insulin according to results of blood sugar monitoring.			
7. Noticing differences in health, such as weight changes or signs of an infection.			
8. Deciding what to eat at meals or snacks.			
9. Telling friends about diabetes.			
10. Noticing the early signs of high or low blood sugar.			
11. Giving insulin injections or boluses by pump.			
12. Deciding what should be eaten when family has meals out. (restaurants, friends' homes)			
13. Carrying some form of sugar in case of high or low blood sugar.			
14. Explaining absences from school to teachers or other school staff.			
15. Rotating injection sites or infusion set-ups for pump.			
16. Remembering times when blood sugar should be monitored.			
17. Checking expiration dates on medical supplies.			
18. Asking questions in clinic about diabetes such as diet or injections.*			
19. Remembering to take things to clinic such as diabetes diary.*			

²⁸ Included as supporting evidence for thesis, not to be submitted to journal.

Appendix 17: Analysis Explanations

Independent Sample T-test

This is used to compare the mean score between two different groups of subjects.

Pearson's Correlation

This is used to examine the relationship between two variables and provides a value between -1 and +1.

Hierarchical Multiple Regression

This is an analysis used to explore the relationship between a dependent variable and a group of independent variables. The independent variables can be controlled for one at a time or in groups and can be examined to see if they predict the dependent variable. There must be a statistical or theoretical reason for including the chosen independent variables.

Appendix 18: Extension of Leventhal's Model²⁹

Leventhal et al's Common Sense Model (1984) suggests that a person's beliefs about an illness will be triggered by a stimulus (e.g. a symptom) which is perceived by the individual. This trigger evokes a set of illness beliefs that represent the illness to the individual both cognitively and emotionally. This representation of the illness is said to lead to management behaviours which are then appraised as being helpful or not (e.g. controlling glucose levels, reducing distress). These appraisals feed back in to the cycle, influencing the representation of the illness and further behaviour.

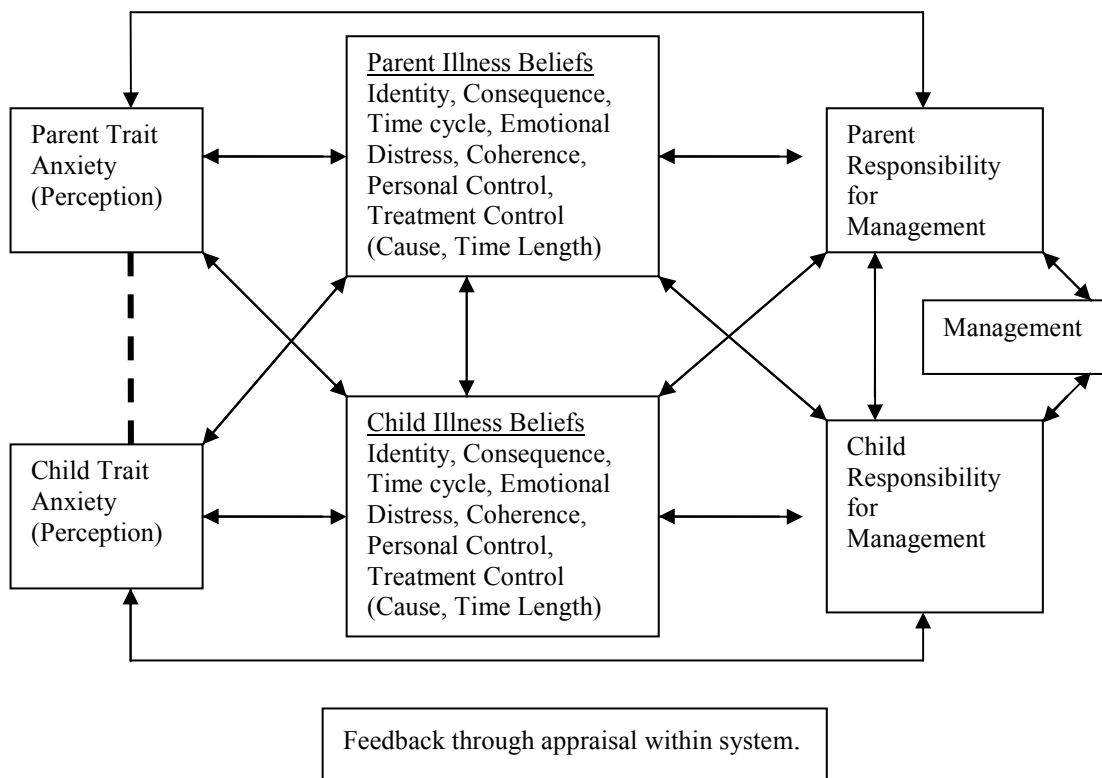


Figure 1. Systemic extension of the Common Sense Model (1984).

The findings of the empirical paper along with existing literature offer information that can be applied to Leventhal's model as an extension. Trait anxiety increases an individual's perception of risk and so more symptoms and threat are seen, this increases anxiety. Within a system this anxiety is often positively correlated. The triggers of

²⁹ Included as supporting evidence for thesis, not to be submitted to journal.

illness evoke the beliefs the individual holds about the illness, but within a dyad who manage illness, the beliefs of the other intertwine and influence each other. In turn, these beliefs and the anxiety within the dyad feed in to each other. The direction appears not to be linear but rather a dynamic process with anxiety and beliefs inter-related.

Responsibility for managing the illness is shared; this is also a dynamic process. Of course reporting that responsibility is taken is only the first step in management behaviour and does not mean it is actually performed. As proposed by Leventhal et al., (1984) the outcome of the management is appraised and adaptations are made, or not. A poorly managed illness is likely to increase anxiety and distress whilst feeling anxious or distressed makes managing the illness feel overwhelming. Illness beliefs may mediate this process both individually and between the dyad.