A thesis submitted to the University of Birmingham in partial fulfilment of the regulation for the degree of

DOCTOR OF CLINICAL PSYCHOLOGY (CLIN.PSY.D)

VOLUME 1

Research Component

The role of motivation, self-efficacy, illness representations and family responsibility in relation to diabetes outcomes: perceptions of adolescents with Type 1 Diabetes and their parents.

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January 2010

Acknowledgements

I would like to thank all of the families that kindly agreed to take part in the research. Without their support this study would not have been possible. Thanks also to the staff at the two Diabetes clinics for their assistance in recruitment.

I would also like to thank my supervisors, Arie Nouwen and Gary Law for their support and guidance throughout the research process.

Finally, I would like to thank Jon, my family and friends for all their encouragement and support, and my daughter Maria who has helped keep me strong and see things in perspective.

Overview

This thesis is divided into two volumes, representing the research and clinical elements submitted to the Univeristy of Birmingham in partial fulfilment of the degree of Doctor of Clinical Psychology (Clin.Psy.D.).

Volume I (the research component) contains three papers relating to adolescents with Type 1 Diabetes. The first is a literature review of 29 papers that have explored family functioning in relation to adherence and metabolic control in adolescents with Type 1 diabetes Mellitus (T1DM). The paper has been written with intention to submit to the journal 'Diabetes Review'. The second paper reports on an empirical study, which examined three constructs (motivation, self-efficacy, and illness representations) in relation to dietary self-care, metabolic control and diabetes related distress in adolescents with T1DM. To bring the cognitive theories into a social context, family responsibility, and the perceptions of parents and their distress levels were also evaluated. This paper has been written with intention to submit to the journal 'Health Psychology'. The third paper is a Public Domain Briefing Paper, which summaries the main findings of the literature review and empirical study, for dissemination to a wider audience.

Volume II (the clinical component) comprises five Clinical Practice Reports that relates to work completed on the assessed clinical placements over the three years of the Clinical Psychology Doctorate course. The first report describes a case study of a seventy-nine year old woman with generalised anxiety,

formulated from a cognitive-behavioural and psychodynamic perspective. The second report is a qualitative service evaluation of an older adult psychiatric ward round. The third report is a case study of a twelve year old boy with a phobia of dogs. The fourth report is a single case evaluation of a ten year old boy with moderate learning disabilities referred for compulsive cleaning/tidying behaviour. The final report is an abstract of a case study, given as a presentation, about a twenty-seven year old with social anxiety.

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LITERATURE REVIEW

Do aspects of family functioning influence metabolic control and adherence in adolescents with Type 1 Diabetes?

Abstract

For individuals with Type 1 Diabetes, adolescence is frequently marked by declines in self-care behaviours and control of diabetes. Previous research has identified that the family have an important role in diabetes management, but the specific processes behind how family functioning influences diabetes outcomes remain unclear. In order to develop a clearer understanding of how family functioning relates to adolescents' treatment adherence and metabolic control, 29 studies were critically reviewed and integrated into Walsh's (2002) Family Resilience Framework. The review identified several key components of family functioning that influence diabetes outcomes such as: family cohesion, involvement, monitoring, support, expressed emotion, perception of adolescent self-efficacy, parent wellbeing and parenting style. However, the influence of these components on diabetes outcomes appears to vary depending upon whose perception of family functioning is assessed, and the characteristics of the adolescent in terms of age, sex, pubertal status, presence of an eating disorder, self-efficacy and autonomy. Higher levels of family conflict were found to be consistently related to poorer diabetes control regardless of whose perception was measured. The review concludes by discussing the studies limitations, identifying potential avenues for future research, and highlighting key areas for clinical interventions.

Introduction

Type 1 Diabetes Mellitus (T1DM) is one of the most common chronic childhood conditions, with a prevalence of 3 per 1000 in Europe and rising at approximately 2-5% per year (Daneman, 2006). T1DM is characterised by a nonexistent supply of insulin, such that the body cannot control blood glucose levels. Individuals are advised to regulate their own blood glucose levels through daily monitoring and injections of insulin, and matching insulin to diet and exercise (Hanas, 2007). Without adequate self-care behaviours to control glucose levels, complications can arise which, left untreated, may lead to coma or even death (Diabetes Control and Complications Trial, DCCT, 1993). Research that attempts to predict and improve diabetes management is therefore very important. Outcome variables tend to be measures of adherence[1] that assess self-care behaviours (e.g. insulin monitoring, injections, diet and exercise) and metabolic control (blood sugar level), which is typically assessed by measuring the percentage concentration of haemoglobin A1c (HbA1c) in the blood[2].

For individuals with T1DM, adolescence is frequently marked by a decline in self-care behaviours and overall control of diabetes (Cameron, 2006). This is of great concern given that research has shown that adolescents who fail to establish positive health behaviours (e.g., diabetes self-care behaviours) have reduced life

[1] Most researchers use the term adherence, but mean self-care activities. As the term was widely used in the reviewed studies, the current review paper has also used the term adherence.

[2] HbA1c level gives an indication of metabolic control over the preceding 3 months and is recommended for monitoring the long-term care of persons with diabetes (Goldstein, Little, Wiedmeyer, England & McKenzie, 1986).

expectancy and are at risk of developing diabetes complications (such as hypoglycaemia[3]), depression and anxiety (DCCT, 1993).

In an attempt to address this issue, research has focused on a number of different variables that may help explain the observed decline in adolescents' diabetes self-care behaviours. One of these variables has been the family as this is typically seen as key to how adolescents adjust to their illness (Gustafsson, 2005; Wertlieb, 2003; Wood, 2005). For example, due to the complexity of the treatment regime, parents are often involved to provide emotional and instrumental support (La Greca**,** Auslander, Greco, Spetter, Fisher & Santiago, 1995). Indeed, interventions designed to improve diabetes outcomes have been found to be ineffective when problematic family interactions persist (Maharaj, Rodin, Olmsted, & Daneman, 1998). In a review of psychological therapies aimed at improving metabolic control, family therapy was identified as being more effective than individual therapy for young people with T1DM (aged 6 to 17 years) (Winkley, Landau, Eisler & Ismail, 2006). More recently, a review of nine randomized control trials, found that family-centred interventions improved metabolic control in young people aged 8–17 years, reduced diabetes-related conflict and improved family relations (McBroom & Enriquez, 2009). Together, these findings highlight the importance of family involvement in the care of adolescents with T1DM.

[3] Hypoglycaemia occurs when there is not enough glucose in the blood stream. Symptoms vary but can include; dizziness, blurred vision, slurred speech, difficulties hearing, headache, drowsiness, confusion, trembling, irritability, cold sweats, seizures and lapses in consciousness (Hanas, 2007).

Patterson (1988) proposed that family research can be separated into two distinct constructs: family structure (i.e. people within and outside of the family system, and sets one family apart from another) and family functioning (i.e. patterns within relationships that connect family members). To enhance the quality of research with families, Sabatelli and Bartle (1995) recommended that the construct of the 'family' must be used in a precise and theoretically meaningful way. Taking these factors into account, this review uses The Family Resilience Framework (Walsh, 1994, 2002) to integrate identified research into a clear conceptualisation of how family functioning may relate to adolescents' treatment adherence and metabolic control. This framework is selected because it is informed by clinical practice and is based on three leading empirically based family systems models: the Beavers' Systems Model (Beavers, Hampson, Hulgus, 1985); the Olson Circumplex Model (Olson, Russell & Sprenkle, 1989) and the McMaster Model (Epstein, Bishop, Ryan, Miller & Keitner, 1993). The framework is useful in allowing both clinicians and researchers working with families to be mindful of the multiple recursive influences that occur between individuals, families and their social environment (Walsh, 2002). It therefore assumes that no single model fits all, and can be used to develop a conceptual map to help identify and target key family processes that will help families cope with adversity (Walsh, 2002).

The Family Resilience Framework (Walsh, 2002) identifies three common components of family functioning:

1) family organisational patterns (family adaptability in roles and rules to changes in external or internal circumstances and developmental issues, flexibility, involvement and family cohesion);

2) communication processes (problem solving, emotional sharing and clarity); and

3) the Family life cycle and belief system (beliefs, values, response to stress, outlook on life).

Anderson & Auslander (1980) conducted the last published review on diabetes management and family functioning, but that review did not focus on adolescents. Moreover, given the DCCT (1993) identified that diabetic complications can be reduced with better metabolic control and that since 1993 new equipment to achieve optimum control has come onto the market (e.g. insulin pumps, glucose monitoring systems), families are now faced with different treatment regimes which pose additional challenges. In an attempt to address these issues this review has two aims:

1) to use Walsh (2002) family resilience framework to review and synthesise literature, post DCCT (1993-2009) that has investigated family functioning in relation to diabetes treatment adherence and metabolic control in adolescents with T1DM. It is hoped that this will assist practitioners in identifying adolescents at risk of having poor control of their diabetes and help promote

optimal family environments that will facilitate effective diabetes management; and

2) to identify key components of family functioning, that are associated with adherence and metabolic control in adolescents with T1DM, and to explore the methodological quality of papers. As a result, this review will identify directions for future research and guide the development of explanatory models as to how family members' functioning may interact to influence diabetes adherence and metabolic control.

Search Strategy

A computerised literature search was conducted using four databases: PsychINFO, Web of Science, Medline and PubMed. The main search terms were: 'family', 'families', 'family functioning', 'parent$', 'mother', 'father', 'sibling', 'young person', 'adolescent$', 'type 1 diabetes', 'adherence' and 'metabolic/metabolic control'. The titles, abstracts and where necessary full papers were examined. Secondary search terms also included variables of family functioning outlined by Walsh's family resilience framework[4], but the author was also open to additional family variables that were prevalent in the literature that were not identified by the framework, so long as it remained related to family functioning (e.g. family conflict and family stress). The reference sections of retrieved papers were also examined for relevant papers.

[4] Secondary search terms taken from Walsh's Family Resilience Framework included; adaptability, involvement, family beliefs, problem solving, support, cohesion and roles.

Selection criteria

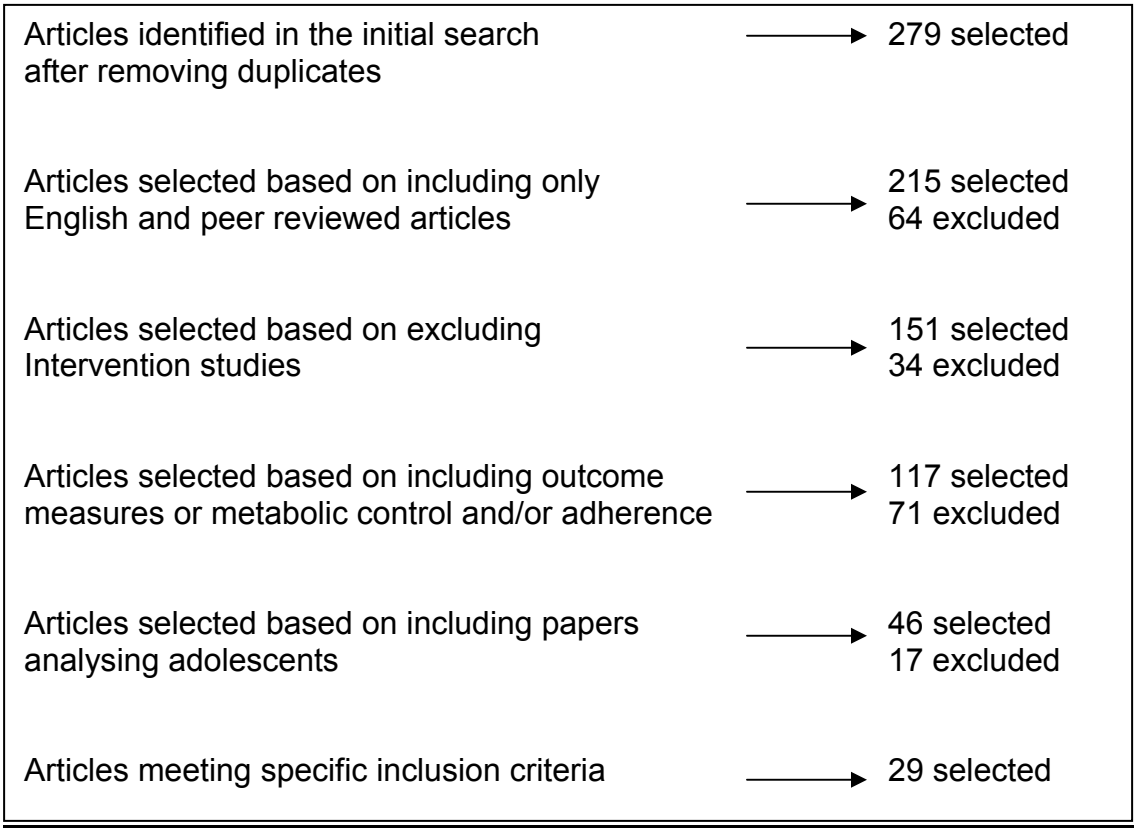
Research studies were included if they met the following criteria:

- participants with a diagnosis of T1DM;
- participants were described as belonging to an adolescent sample (10–18 years)[5];
- studies that assessed family functioning in relation to adherence, self-care behaviours and/or metabolic control (studies that also assessed family structure and quality of life were included but findings in relation to these variables were not reviewed). Interventions and studies focusing exclusively on family structure were not included;
- studies published in peer reviewed journals between January 1993 and June 2009;
- the article was written in English.

Figure 1 shows a flow chart of the selection process. A total of 279 articles were identified from the search. Once the selection criteria had been applied, a total of 29 were suitable for review.

[5] Studies differed in their operational definition of adolescence and age ranges varied (i.e., 10–18 years).

Figure 1 Flow chart of selection process



Results

Study Details

Sample sizes, participant details and general findings are summarised in Appendix A. Regarding sample characteristics the number of participants used in the studies reviewed ranged from 18 to 2062, and the participation rate ranged from 25% to 100%. The criteria for defining adolescence varied between studies, ranging from 10-18 years, with the majority controlling for age. To define adolescence more accurately three papers included pubertal status as a measure of adolescence (Miller & Drotar, 2003; Palmer, Berg, Wiebe, Beveridge, Korbel, et al. 2004; Palmer, Berg, Butler, Fortenberry, Murray et al. 2009). In general, an even proportion of males and females were included in each study. Mothers were typically recruited as the parental component to the research, and nine studies recruited mothers only. Six studies reported on the ratio of mothers, fathers or significant other and thirteen did not describe any caregiver details. The majority of studies participants were Caucasian. Only two studies had a wider representation of ethnicities (Ellis, Podolski, Frey, Naar-King, Wang & Moltz, 2007; Hanson, De Guire, Schinkel & Kolterman, 1995).

With regards to research design, the majority of studies (26) used cross-sectional designs. Two studies were longitudinal, and studied participants over one year (Dashiff, Vance, Abdullatif & Wallander, 2009) and three years (Helgeson, Reynolds, Siminerio, Escobar & Becker, 2008). One study was qualitative (Leonard, Garwick & Adwan, 2005).

Appendix B shows the measures used in the reviewed studies. All but one study that was qualitative (Leonard et al. 2005) used self-report questionnaires to measure various aspects of family functioning. Three studies also used interviews to assess parental involvement in diabetes tasks (Anderson, Ho, Brackett, Finkelstein & Laffel, 1997; Anderson, Vangsness, Connell, Butler, Goebel-Fabbri & Laffel, 2002; Wiebe, Berg, Korbel, Palmer, Beveridge et al. 2005), and one study audio-taped and coded parent-adolescent communication (Miller & Drotar, 2007). For outcome measures, twenty-three studies used metabolic control, while nineteen studies measured adherence to diabetes self-care behaviours. Seven studies obtained adherence reports from adolescent and parent which allowed the researchers to explore differences in perceptions.

Reviewed studies integrated into Walsh's (2002) Family Resilience Framework.

Family organisational patterns

Cohesion.

Olson (1989) defined cohesion as 'the emotional bonding that family members have toward one another". The two extremes of family cohesion are families that are disengaged from one another and families that are enmeshed. Optimal family functioning is believed to arise when families have balanced levels of separateness and togetherness (Olson, 1989).

Hanson, et al. (1995) used the Family Adaptability and Cohesion Evaluation Scale (FACES-III: Olson, Portner, & Lavee, 1985) to assess parental and

adolescent reports of cohesion. Hanson et al. (1995) found that the families in their study, compared to normative data, were twice as likely to be in the disengaged range (defined by families scoring lower than 32 out of 50 on the FACES-III), with the average HbA1c of the 157 12-20 year olds being 9.47[6]. The authors did not explore whether this specific variable was related to self-care or metabolic control, but recommended that care teams, when addressing youths self-care behaviours, need to consider individual, environmental and interpersonal factors (Hanson et al. 1995).

The two studies that have explored cohesion in relation to metabolic control found contradictory results. Pereira, Berg-Cross, Almeida & Machado (2008) identified in their sample of 157 Portuguese 10-18 year olds that parental reports of cohesion, using a translated version of the Family Environment scale (FES: Moos & Moos, 1981), were not related to metabolic control or adolescent reports of adherence to their diabetes treatment regime. In contrast, Maharaj et al. (1998) also used the FES but obtained adolescent reports of cohesion as well. They found that the presence and severity of an eating disturbance moderated the relationship between cohesion and metabolic control. In their study of 113 female adolescents, they concluded that girls with highly disturbed eating patterns can achieve better metabolic control in families which are more cohesive and controlled, where as females with no disturbed eating patterns achieve better optimal control in more adaptable and less cohesive families (Maharaj et al. 1998). These findings suggest that the influence of cohesion on diabetes management may vary in relation to the characteristics of the adolescent, and

[6] The recommended blood glucose level for adolescence is <7.5% (Silverstein, Klingensmith, Copeland, Plotnick, Kaufman et al. 2005).

when considering HbA1c levels of the adolescent's perception of family cohesion maybe more significant than parent's perceptions.

The identified discrepancy in results between cohesion and metabolic control may also be due to measurement differences, as Pereira et al.'s (2008) HbA1c values represent an average of 4-6 samples taken throughout the year, whereas Majaraj et al.'s (1998) HbA1c values represent metabolic control at one point in time. The non-significant relationship between cohesion and adherence found in the Pereira et al. (2008) study may reflect a genuine finding, but may also reflect a weakness in the measure of adherence used as it was developed by the authors and, although it was validated with the participants in the study, no psychometric details were reported. The contradictory results may also reflect cultural differences (Portuguese versus US) and highlight the importance of future studies assessing potential mediating variables and multiple perspectives.

Involvement

Involvement refers to both the quality and degree of interest family members have with one another, which can either help or hinder task accomplishment (Skinner, Steinhauer & Sitarenios, 2000). In the diabetes literature, involvement is often related to who is responsible for carrying out a diabetes related task (Berg, Butler, Osborn, King, Palmer, et al. 2008).

Anderson et al. (1997) grounded their research in developmental theories emphasising the important role a parent has in facilitating interdependence in the parent-adolescent dyad. Anderson et al. (1997) interviewed 51 10-12 year olds,

and 38 13-15 year olds and their mothers about their level of involvement in specific diabetes self management tasks. A physician measured adherence. Although parental involvement in blood glucose monitoring (BGM) was not related to adherence to meal planning, exercise or insulin administration, it was related to more BGM. In turn, metabolic control was greater in those adolescents who performed the greatest number of blood glucose checks per day (irrespective of the number of insulin injections performed). In a later study Anderson et al. (2002) again found that parental involvement predicted adherence to BGM and more frequent monitoring was related to lower blood glucose levels. Thus, parental involvement in one task facilitates an improvement in adolescents' performance on that one task, but not others.

Gowers, Jones, Kiana, North & Price (1995) also found that those adolescents with optimal metabolic control were more likely to have their parents involved in administering injections than those with poor control. Conversely, when no one assumes responsibility for diabetes management, adolescents have been found to have poor metabolic control (Lewin, Heidgerken, Geffken, Williams, Storch, 2006). These findings suggest that parental involvement in blood glucose tasks (as assessed by researcher interviews) facilitates optimal metabolic control.

Helgeson et al. (2008) explored collaborative responsibility using the Diabetes Family Responsibility Questionnaire (DFRQ: Anderson, Auslander, Jung, Miller & Santiago, 1990) with 132 adolescents with T1DM, aged 11–13 years, and one of their parents (92% mothers). The strength of this study was that it also re-assessed participants over 2 consecutive years and used multilevel modelling to

examine individual variability across the 3 years. The study found that when both adolescent and parents reported responsibility as shared, the adolescent had better adherence (as assessed using 8 self-care items devised by the authors and the Diabetes Self-Care Inventory; La Greca, Swales, Klemp & Madigan, 1988). In addition, for those aged 13 years, high HbA1c levels were associated with low shared responsibility (i.e. parent or child took more sole responsibility for diabetes related tasks). Longitudinally, Helgeson et al. (2008) found that parental reports of shared responsibility and child reports of parent responsibility predicted improvements in adherence, whilst child reports of shared responsibility predicted improvements in metabolic control. These findings suggest that perceptions of responsibility are related to different diabetes outcomes.

Perceptions of enjoyment in collaboration have also been found to relate to adherence. In a cross-sectional study of 84 adolescent-mother dyads, Berg, Schinderl & Maharajh (2008) found a positive relationship between mother and adolescent reports of adherence and adolescent perceptions of enjoying shared responsibility. Greater mothers' perceptions of enjoyment predicted her own perceptions of better adolescent adherence (Berg et al. 2008).

Rather than focusing on views of shared responsibility, one study has explored how discrepancies between parents' and adolescents' views of responsibility may influence HbA1c levels. Cameron, Skinner, De Beaufort, Hoey, Swift, Aanstoot et al. (2008) used the DFRQ (Anderson et al. 1990) with 2062 parents and adolescents across 19 different countries and found that the greater the

parent–adolescent discrepancy in responsibility, the higher the adolescents HbA1c levels were. Further item-specific analysis identified that, even after controlling for age, sex and duration of diabetes, this relationship was attributable to the item concerning who was responsible for remembering to monitor blood glucose (Cameron et al. 2008).

Research has also focused on how parents 'deliver' their level of involvement and how it is experienced by the adolescent. Adolescents of all ages (12-18 years) have reported better adherence when they find enjoy working collaboratively with their parents on diabetes tasks (Berg et al. 2008). Leonard et al. (2005) found in their qualitative study, that 14-16 year olds with high HbA1c resisted reminders to manage their diabetes and were more annoyed by them than those with low HbA1c. Adolescents' perceptions of unhealthy family functioning (specifically affective involvement) as assessed using the Family Assessment Device (Epstein, Baldwin & Bishop, 1983) has also been found to be related to poor metabolic control in a cross-sectional study of 226 11-18 year olds (Leonard, Jang, Savik & Plumbo, 2005). Wiebe, et al. (2005) also found appraisals of maternal involvement as intrusive or controlling were associated with poor metabolic control and adherence for older adolescents. Collaborative responsibility was associated with better outcomes across all ages, with adherence mediating the relationship between appraised collaboration and metabolic control. Wiebe et al. (2005) also identified sex differences where appraisals of maternal control among female adolescents were associated with poorer adherence relative to male adolescents. These findings suggest that an

adolescent's diabetic control can be influenced by how they interpret parental behaviour and involvement.

Developmental issues in relation to involvement. Typically, as the age of the child increases, parental involvement/responsibility (Anderson et al. 1997; Palmer et al. 2004; 2009) and monitoring (Leonard et al. 2005; Berg et al. 2008) in diabetes related tasks decreases. Two studies have examined factors other than age that may influence the transfer of diabetes responsibility from parent to adolescent. Palmer et al. (2004) recruited a sample of 127 adolescents (10 -15 years) and found that adequate metabolic control was achieved when adolescent perceptions of maternal involvement were high and autonomy (or self-reliance) was low. In contrast, when maternal perceptions were explored, this relationship was not apparent. In a later study, Palmer et al. (2009) explored parental perceptions (185 mothers and 145 fathers) of how self-efficacious they perceived their child to be at diabetes management, and identified that metabolic control was better when parental responsibility was high and when adolescents were perceived as having low self-efficacy. These findings suggest that optimum diabetes management may be achieved if parents transfer responsibility based upon how autonomous or competent they believe their child is, rather than by the age or physical maturity of their child.

Monitoring

Monitoring has been researched as a separate entity to the closely linked variable 'involvement'. Berg et al. (2008) defined monitoring as a parental

behaviour that involves knowledge about and supervision of diabetes tasks. Ellis et al. (2007) were the first to explore parental monitoring of adolescent diabetes care in promoting adherence, using their own Diabetes Specific Monitoring (DSM) scale. They recruited 99, 12–18 yr olds and found that higher levels of adolescent and parental reports of DSM (parental knowledge about whether their adolescent had completed their diabetes care or were present during its completion) had significantly better adherence than those who reported less DSM; and those with better adherence had lower HbA1c. General parental monitoring (knowledge of adolescent's daily activities, peer group or whereabouts) was not related to adherence or HbA1c.

In a later study, Berg et al. (2008) developed their own DSM scale and found that adherence was predicted by adolescents (10-14 year old) perceptions of parental acceptance and monitoring predicted adherence rather than parents' perceptions. Although fathers monitored less than mothers, only fathers monitoring (as reported by both adolescent and father) were correlated with HbA1c levels, which highlight the importance of encouraging fathers to be more involved in their adolescents diabetes care and collaborate with mothers (Berg et al. 2008).

Support.

Ellis et al. (2007) identified that measures of parental monitoring have sometimes included items related to parental support and argued that because support is an

affective element of parenting behaviour, whereas monitoring is an instrumental behaviour, both need to be explored as separate constructs.

Findings of parental support relating to diabetes treatment outcomes have been mixed. Leonard et al.'s (2005) qualitative study found that adolescents with optimal HbA1c tended to describe their families as more supportive than those with high HbA1c levels. Lewin et al. (2006) also found that higher levels of parental support were associated with better metabolic control. In comparison, Pereira et al. (2008) found that reports of family social support mediated the relationship between adherence and HbA1c. Furthermore, for females (and not males), family support accounted for 10% of the variance in adherence. Ellis et al. (2007) also found that adolescents' reports of parental support for diabetes care (assessed by the supportive subscale of the Diabetes Family Behaviour Checklist (Schafer, McCaul & Glasgow, 1986) were significantly related to adolescent reports of adherence, but not to HbA1c. However, parental reports of their supportive behaviours were not related to either parental or adolescent reports of adherence or HbA1c. Furthermore, in multivariate analyses of adolescent reports, when parental monitoring was also examined, support moderated the relationship between parental monitoring and adherence. The authors propose that support, in the absence of careful monitoring, may be insufficient to help adolescents achieve optimum diabetes control (Ellis et al. 2007). This study also highlights the importance of exploring both adolescent and parental views in relation to diabetes outcomes, and using large sample sizes to identify additional influencing variables, allowing for more complex statistical analysis.

Figure 2 summaries the key findings of how family organisational processes may influence diabetes adherence and metabolic control.

Figure 2 Summary of organisational patterns

The majority of studies exploring organisation patterns within the family have used theories to guide research exploring the role of parental involvement/responsibility and monitoring of diabetes related tasks. The general findings have found that parents who are more involved or monitor diabetes related tasks (particularly blood glucose monitoring), and when adolescents enjoy collaboration and perceive this role as supportive and shared, then optimal metabolic control and self-care behaviours are more readily achieved.

Typically, as the age of the child increases, parental involvement/responsibility in diabetes related tasks decreases. Psychological factors, such as family perceptions of competence, self-efficacy and autonomy needs also seem to influence the process of transferring responsibility from parent to their child as they get older. Adolescents' perceptions of family support, as opposed to parental perceptions, have been found to be related to adherence, and act as a moderating variable between parental monitoring and adherence. Furthermore, family support seems not to be directly related to HbA1c levels, but may moderate the relationship between adherence and metabolic control. There also appears to be gender differences, with females benefiting more from family support than males.

Studies exploring the role of family cohesion in relation to diabetes management have found mixed results. These differences may reflect variations in who reports cohesion (parent or adolescent) or other influencing variables such as culture and eating behaviour.

Communication processes

Decision-making

Decision-making competence, defined as 'the ability to form effective plans for managing different situations' (Miller & Drotar, 2007, pp.178) has been studied in an attempt to identify factors that influence adherence, in particular how decisions are made in relation to who is responsible for diabetes related tasks.

Hanna & Guthrie (2003) asked 31 mothers of 11-17 year olds who made the decisions for performing 34 different diabetes related tasks (adapted from the DFRQ, Anderson et al. 1990). They found that parental decision-making was not related to adolescent HbA1c levels, nor was parental involvement. It is not clear however how or when HbA1c levels were obtained. There was also variation in how data were collected which was either at clinic appointments or over the telephone; this may have influenced the validity and reliability of the results. Despite these limitations, three further studies have found non-significant findings suggesting that there is no relationship between diabetes outcomes and decision-making autonomy (Miller & Drotar, 2003), discrepancies (Lewandowski & Drotar, 2007), and competence (Miller & Drotar, 2007).

Miller & Drotar (2003) argued that these non-significant findings indicate that decision-making measures may either not accurately reflect self-care behaviours, or that families may not actually experience decision-making as they follow an 'automatic' routine. More recently, Miller & Drotar (2007) suggested that decision-making may only influence adherence when adolescents are older, however it is unclear how this conclusion was drawn as they did not explore the effects of age. This issue is compounded by the fact that participants had a wide age range (11-17 years).

Conflict.

Researchers have theorised that adolescents and their parents are likely to have different perspectives with regards to when and how to transfer responsibility for

diabetes related tasks between them, and that these differences are likely to result in conflict (Dashiff, Bartolucci, Wallander & Abdullatif, 2005). Poor metabolic control has been found to be consistently related to high levels of general conflict, both quantitatively (Wysocki, 1993) and qualitatively (Leonard et al. 2005), as has diabetes specific family conflict (Anderson et al. 2002; de Wit, Delemarre-van de Waal, Bokma, Haasnoot, Houdijk et al. 2007; Lewandowski & Drotar, 2007). de Wit et al. (2007) also identified that parents and adolescents agreed on the topics of conflict, with most reporting conflict around logging blood sugar results, remembering to check blood sugars, and meals.

Studies measuring both HbA1c and adherence have found the latter to act as a mediating variable. Hanson et al. (1995) assessed both family cohesion and family conflict and found that positive family relations (high cohesion and low conflict) were indirectly related to good HbA1c through positive adherence. Furthermore, this relationship was particularly strong during the first few years of being diagnosed. This research had several strengths as the study was theory driven, used a relatively large sample (N=157) with a relatively diverse ethnic mix (58.6% African American) and used structural equation modelling to examine several variables simultaneously to evaluate their unique importance.

The findings in relation to measures of adherence are mixed. Dashiff et al. (2005) explored the relationship between diabetes-specific conflict, general conflict and adherence in 158 adolescents (11-15 years) and their parents using the Diabetes Family Conflict Scale (DFCS: Rubin, Young-Hyma & Peyrot, 1989), the Issues Checklist (Prinz, Foster, Kent & O'Leary, 1979) and a structured

interview to assess adherence. Neither general levels of conflict nor diabetes related conflict predicted adherence. However, as internal consistency coefficients are not reported, it is not possible to assess the reliability of the adherence measure. In a later study, Dashiff et al. (2009) again found that developmental conflict (113 mothers using the Issues Checklist) was not related to adolescent adherence.

Miller & Drotar (2003) using a smaller sample (N=82), also found that maternal reports of conflict (assessed using the DFCS) were not related to nurse reports of adherence. However, they did find that maternal reports of conflict were negatively correlated with adherence as reported by mothers (but not to adolescent or nurse reports), and adolescent reports of conflict were negatively related to nurse reports of adherence.

In contrast, Lewandowski & Drotar (2007) used similar measures and found maternal reports of diabetes related conflict were not associated with chart reviews or number of glucose tests per day, but higher levels of conflict were related to poor nurse reported adherence. The observed differences could be due to chart reviews only assessing one aspect of self-care behaviour (number of blood glucose tests per day) whereas nurse-reports provide a more reliable assessment of different aspects of self-care behaviours. Indeed the internal consistency of the latter measure was high (0.91) and used a validated questionnaire (Health Care Provider Rating, La Greca, Follansbee & Skyler, 1990). Unfortunately the generalisability of these findings is limited due to a small sample size (N=51) and the participation rate being very low (25%) despite a $25 incentive.

Given these inconsistent findings, researchers have attempted to identify factors that may contribute to family conflict. Characteristics of the adolescent have been found to influence conflict, with higher levels of conflict occurring in families with girls who have more disturbed eating behaviours than those with non-disturbed eating behaviours (Maharaj et al. 1998), and when adolescent decision-making-autonomy occurs at odds with adolescent physical or cognitive development (Miller & Drotar, 2003). Lewin et al. (2006) proposed that a lack of diabetes-specific behaviours and attitudes (e.g. family support, warmth, guidance and control) increases family conflict which in turn reduces adolescents' willingness to adhere to their treatment, and parents' ability to monitor them. Lewandowski & Drotar (2007) found that higher levels of support can 'buffer' the effects of family conflict.

Expressed emotion.

In this review, no study directly studied the construct of expressed emotion (a form of negative communication involving excessive criticism and emotional over-involvement). However, three studies investigated elements of the construct. Wysocki (1993) found that families (115 adolescents aged 11-18 years, 113 mothers and 78 fathers) with better communication skills as assessed by the Parent-Adolescent Relationship Questionnaire (PARQ: Robin & Foster, 1989) achieved better metabolic control. In comparison, Gowers et al. (1995) found that adolescents with well controlled diabetes (N=40) tended to rate their family as having poor affective responsiveness and affective involvement. However, the study is potentially flawed as the group of well controlled diabetes

(N=40) was based on HbA1c levels of 10% or lower which is much higher than the recommended 7.5% (NICE, 2004).

Miller & Drotar (2007) identified that adolescents with higher HbA1c levels and lower adherence (as reported by nurse and parent) displayed more negative communication during a problem solving task. Positive communication or parental negative communication was not related to HbA1c (Miller & Drotar, 2007). In a later study, Maharaj et al. (1998) found that adolescent females without disordered eating behaviours (N=56) achieved good metabolic control within families that promoted open expression of thoughts and feelings. In contrast, females who had highly disturbed eating behaviours (N=20) had better metabolic control in families who showed less expressed emotion.

Figure 3 summaries the key findings of how family communication patterns may influence diabetes self care behaviours and metabolic control.

F*igure 3 Summary of family communication patterns*

Mother-adolescent discrepancies, autonomy and competence in decision making have been found to be unrelated to diabetes outcomes. Researchers have speculated that these non-significant relationships maybe due to decisions being made out of conscious awareness, age differences or measures lacking content validity. Levels of conflict (diabetes specific and non-specific) are positively related to metabolic control (i.e. as conflict increases, HbA1c levels increase). In relation to adherence the findings are inconsistent and maybe influenced by who completes the measures, parental perceptions of adolescent autonomy, study limitations and characteristics of the family and adolescent (e.g. family support and eating behaviours).

Overall, the findings exploring the relationship between expressed emotion and diabetes outcomes are inconsistent and it seems likely that additional factors (such as eating behaviours, and who is reporting) may be influential. A clear definition of expressed emotion would also assist assessment and analysis of future research to facilitate study comparisons and the development of explanatory models.

The Family Life Cycle and Belief System

Parental anxiety.

Cameron, Young & Wiebe (2007) identified that although a large body of research had found that anxiety can influence an individual's illness regulation, it is not known how an adolescent's diabetes management may be influenced by their carers' anxiety. Cameron et al. (2007) therefore recruited 47 adolescents (13-18 year olds) with T1DM. For younger adolescents higher maternal trait anxiety was associated with higher HbA1c and greater parental responsibility. This was independent of duration of diabetes. The authors conclude that parental efforts to be involved in diabetes self-care to manage their own anxiety, may undermine their child's adaptive ability to manage themselves, especially as they try to establish independence in early adolescence (Cameron et al. 2007). However, maternal trait anxiety was not related to adherence as assessed using the self-care inventory (SCI; La Greca et al. 1990). It is important to bear in mind that the adolescent measure of adherence was completed 3 months after the parental measure of anxiety, whereas HbA1c levels were obtained at the time of the assessment and 3 months previously. The validity and reliability of the assessment is therefore likely to have been compromised.

Maternal trait anxiety has also been associated with higher maternal involvement and over-protectiveness (Butler, Skinner, Gelfand, Berg & Wiebe 2007; Cameron et al. 2007).

Parental stress.

Only one study examined the role of parental stress, and found that higher levels of family stress, as reported by parents, were related to higher HbA1c levels (Hanson et al. 1995). This relationship was independent of adherence behaviours. High levels of family stress also predicted poor family relations (low cohesion and high conflict). The authors propose that even when adherence is optimal, problems with HbA1c may persist in the presence of high family life stress.

Empowerment

Empowerment has been defined as "the ongoing capacity of individuals or groups to act on their own behalf to achieve a greater measure of control over their lives and destinies" (Staples, 1990, p. 30). Florian & Elad (1998) recruited 88 12-17 year olds to explore maternal empowerment in relation to attitudes, knowledge, and behaviour within the context of their family in her dealings with her child, the service system, and with her involvement in the community. They found that the more mothers' felt empowered the better their child's adherence and metabolic control. Mothers' self-esteem and self-mastery did not explain any proportion of the variance in either adherence or metabolic control (Florian & Elad, 1998). The authors propose that empowerment is a specific target-orientated resource that would be more functional in coping with the unique demands of T1DM, whereas self-esteem and self-mastery are general

psychological resources, which are more valuable in relation to dealing with common life events.

Beliefs

Two studies exploring different beliefs family members have in relation to diabetes outcome variables found non-significant results. Cameron et al. (2007) explored the beliefs mothers had about their adolescent's diabetes management (e.g. 'my child makes good choices about food') and found that they were unrelated to adolescent reports of adherence or HbA1c. Wysocki (1993) found that adolescent, maternal or paternal scores on the Beliefs-Expectation subscale of the PARQ (Robins & Foster, 1989) were not related to HbA1c. The validity and reliability of the findings in relation to metabolic control is questionable though as the HbA1c levels were obtained over a 6 month period of participation and questionnaires were completed at home without being overseen by a researcher. The authors postulated that beliefs and expectations may contribute to conflict without impacting self-care behaviours.

In a more recent theory driven study, Butner, Berg, Osborn, Butler, Godri et al. (2009) explored how discrepancies between parent-adolescent beliefs in self-efficacy for performing diabetes tasks and problems and independence in managing diabetes, may impact upon metabolic control. In a sample of 185 adolescents, 185 mothers and 145 fathers, the authors used a latent discrepancy method to examine consistent ways in which parent-adolescent beliefs may differ. They found that adolescents whose beliefs were more discrepant than

their mothers (not fathers) had higher HbA1c levels. The authors proposed that mothers' may be more involved in diabetes tasks than fathers, and use HbA1c levels to gauge how competent they and their adolescent are at diabetes management.

Parenting style

Butler et al. (2007) proposed that as there was an extensive amount of literature highlighting the affects of parenting style on a range of child outcomes, that parent-adolescent diabetes transactions are likely to be affected by maternal parenting style. They therefore recruited 78 mother-adolescent dyads to complete a questionnaire on parenting style (control and acceptance) and adherence. In contrast to their hypothesis they found that adolescents' perceptions of maternal parenting style were not related to adherence. The authors argued that this finding may have been due to using a non-diabetes specific parenting style measure in relation to a diabetes specific measure of adherence. Another potential weakness of this study was that the validity of the adherence measure was threatened as 20% of the responses were missing and were therefore computed by averaging applicable items.

To investigate diabetes specific parenting styles, Lewin et al. (2006) used two subscales of the Diabetes Family Behaviour Scale (Waller, Chipman, Hardy, Hightower, North et al. 1986) with 63 adolescents. They found that poor metabolic control and adherence were strongly correlated with critical, negative

and un-supporting parenting. However parental guidance and control were unrelated to metabolic control.

Dashiff, et al. (2009) explored whether maternal attachment influenced their child's autonomy and self-care in 113 families. They found that mothers who reported less separation anxiety when their adolescent was 11-15 years of age, had adolescents who exhibited higher levels of cognitive autonomy one year later. Adolescents with greater cognitive autonomy had better self-care one year later.

Figure 4 summaries the key findings of how the family life cycle and beliefs may influence diabetes self care behaviours and metabolic control.

Figure 4 Summary of family life cycle and belief systems

Research exploring variables related to the family life cycle is limited. Emerging research seems to suggest that parental anxiety, family stress and how empowered mothers feel are related to adherence and/or metabolic control. Research exploring family beliefs is limited and inconsistent. Speculation has been made that they may influence levels of conflict rather than self-care behaviours. High levels of parent-child discrepancies have been linked to higher HbA1c levels. Non diabetes specific parenting styles appear unrelated to diabetes outcomes, whereas parenting styles which are more diabetes specific and negative appear detrimental to adherence and metabolic control. Adolescents exhibit better self-care behaviours when they were more securely attached to their mothers, and live with mothers who felt more empowered.

Conclusion

Study limitations

Appendix A shows the studies methodological weaknesses which may bias the conclusions drawn and have implications for future research.

Sample characteristics

Four studies did not report on the participation rate (Hanna & Guthrie, 2003; Wysocki, 1993; Weibe et al. 2005; Pereira et al. 2008). This is an important variable to consider as participants who chose not to return questionnaires have been found to have worse adherence than participants (Riekert & Drotar, 1999). Seven studies did not identify the gender ratio (Bunter et al. 2009; Cameron et al. 2008; Hanna & Guthrie, 2003; Leonard et al. 2005; Pereira et al. 2008; Wiebe et al. 2005; Wysocki 1993). This is a concern as gender differences in relation to family functioning and diabetes management have been identified (Wiebe et al. 2005).

Generalisability of findings. A particular limitation of this review is that only English language studies were included thereby reducing the findings to only English speaking cultures. Furthermore, four papers (Anderson et al. 1997; Gowers, 1995; Maharaj et al. 1998; Pereira et al. 2008) did not report on the ethnicity of the participants, which again makes it difficult to generalise the findings or replicate the study.

Confounding variables Nine papers described the type of treatment regime that participants were on (Anderson et al. 1997, 2002; Berg et al., 2008, 2008; Ellis et al. 2007; Palmer et al., 2004, 2009; Miller & Drotar, 2007; Wiebe et al. 2005). Although the majority of participants were on insulin injections of 2 or 4 times a day, some used insulin pumps. These different treatment regimes are likely to require different self-care behaviours (Hanas, 2007), yet it is unclear how these different regimens may relate to family functioning and/or diabetes management.

Interpretation of findings. Significant correlations were generally interpreted as family functioning influencing adherence or HbA1c levels. However, as the majority of studies used cross-sectional designs, the causal relationships between family functioning and diabetes outcomes are not possible to determine.

Outcome measures. Overall, research predicting metabolic control seems more consistent than variables predicting adherence. This maybe due to a number of factors such as variation in who is rating the measure (e.g. nurse, chart reviews, parent or adolescent) and level of parental anxiety (Cameron et al. 2007), which may all influence perceptions of diabetes self-care behaviours. In addition, measures varied from clinical interviews, self-rating scales completed by adolescent or parents, clinician reports and chart reviews. The variety of assessment measures used makes it difficult to compare studies as one cannot be confident that these measures assess the same construct. This issue is compounded further by the lack of studies reporting validity and reliability coefficients as only nine of the authors reported such statistics.

In comparison to measures of adherence, metabolic control is perhaps less susceptible to bias as it is measured from a routine blood test. Although family conflict and stress seem particularly related to HbA1c levels, it is important to bear in mind that family conflict may increase stress hormones which elevate glucose levels (Anderson et al. 2002). Conversely, poor metabolic control may create parental concern which triggers family conflict. Physiological factors, exacerbated by hormonal fluctuations and stress in puberty may also contribute to poorer metabolic control in adolescents with diabetes (Tfayli & Arslanian, 2007). To investigate this hypothesis it would be beneficial to assess, concurrently, hormonal levels such as cortisol, perceived stress, family conflict and HbA1c over time.

Recommendations for future research

In light of the review findings it seems pertinent that future research uses well validated and reliable assessment measures of family functioning which assess multiple dimensions of diabetes-specific family factors such as the FES (Moos & Moos, 1986) or McMaster Family Assessment Device (Epstein, et al. 1983) with as many family members as possible to assess how different perspectives may influence diabetes management. Other systems such as peer groups or school environment also need investigating as these systems typically become increasingly more important and influential as adolescents grow up.

Natural observations of family interactions and more qualitative research is also needed to identify aspects of family functioning which have yet to be explored

and may impact successful diabetes management. For example, when considering Walsh's (2002) family resilience framework, one of the three components of family functioning, 'the family life cycle', had limited research. For clinicians, researchers and families to have a fuller understanding of how family functioning influences self-care behaviours, future research is needed to explore the effects of family beliefs which provide meaning, organise experience and guide action (Walsh, 2002). In addition, as Wood (2005) highlighted, paediatric illness is also likely to have profound negative and positive effects on family functioning and well being. It maybe of potential benefit to families if research explored the possible positive effects T1DM may have on family functioning. If positive aspects were identified, then clinicians could help strengthen them and share them with other families who may see more negative aspects.

It is important to bear in mind that family structure (e.g. ethnicity, single parent families and educational level) may also influence aspects of family functioning and diabetes management, which may account for some of the reviewed differences. For example Pereira et al. (2008) found that family support predicted a higher proportion of variance in adherence in families with a low socio-economic status. In addition, family conflict only predicted metabolic control for families with a high socio-economic status. Future research and clinicians would therefore benefit from reviews synthesising studies that have explored family structure and functioning and the potential influence they may have on diabetes management.

Clinical Implications

Despite the limitations, this review has identified that adolescents do not manage and cope with their diabetes in a vacuum, but live within a system of complex reciprocal interactions. The characteristics of these relationships appear to influence diabetes outcomes. The general goal of the reviewed studies has been to try and disentangle different aspects of one of these systems, family functioning, to identify specific variables which can then inform interventions to achieve successful diabetes management.

This review has been able to identify several key components of family functioning, which can be integrated into Walsh's (2002) Family Resilience Framework, to facilitate effective diabetes management. It has also identified that the influence of family functioning on diabetes outcomes can vary depending upon the characteristics of the adolescent and whose perception of family functioning is assessed.

It is hoped that the findings from the review will assist both families and clinicians working with adolescents with T1DM to promote aspects of family functioning that will foster optimal control of diabetes, reduce the risk of complications and strengthen families to cope successfully in living with a chronic illness. In the hope of adolescents achieving optimum diabetes control, the clinical implications of the reviews findings are shown in Figure 5 which highlights the key factors and processes that seem pertinent for families and clinicians to consider.

Figure 5 Key factors and processes that may need promoting:

Organisational patterns

- Parental involvement of diabetes related tasks (especially blood glucose monitoring) that are either shared or viewed by the adolescent as supportive and nurturing.
- As the child with T1DM grows up, for parents to gradually transfer responsibility, taking into consideration their child's level of autonomy, self-efficacy and competence.
- Characteristics of the child and family culture may need to be taken into consideration when considering how cohesive or adaptable families need to be.
- Walsh (2002) proposes that these elements can be enhanced by promoting community networks, encouraging families to re-organise and adapt to fit to challenges over time, develop mutual respect of each individual family member and establish boundaries and stability within the family unit.

Communication patterns

- How open families need to be with their emotions and communication seems to depend upon the needs of the individual child.
- Minimise conflict around diabetes related tasks. How this will be achieved is likely to vary depending upon how the family functions as a unit and the different needs and developmental stage of each family member.
- Walsh (2002) proposes families need to develop effective problem solving skills, clarifying ambiguous information, enhance negotiation skills, learn from failure and build upon success as a means for promoting communication patterns.

Family life cycle

- Teach effective coping and communication skills to minimise parent-child discrepancies and reduce stress levels within families. Walsh (2002) suggests families need to accept things that cannot be changed, normalise the situation and contextualise distress to help minimise stress.
- Enhance mothers' sense of empowerment and minimise parental anxiety, perhaps by offering additional support, encourage family collaboration and focus on family strengths and potentials (Walsh, 2002).

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EMPIRICAL PAPER

The role of motivation, self-efficacy, illness representations and family responsibility in relation to diabetes outcomes: perceptions of adolescents with Type 1 Diabetes and their parents.

Abstract

Objective Three constructs; motivation (Deci & Ryan, 2000), self-efficacy (Bandura, 1997), and illness representations (Leventhal, et al. 1984), were examined in relation to dietary self-care, metabolic control (HbA1c levels) and diabetes related distress in adolescents with type 1 diabetes mellitus (T1DM). To bring the cognitive theories into a social context, family responsibility, and the perceptions of parents and their distress levels were also evaluated. *Method* 85 adolescents, aged 12-18 years, and 80 parents/carers completed self-report questionnaires. *Results* Multiple regression analysis identified that parents' perceptions of adolescent motivation and parent-child discrepancies in self-efficacy accounted for 18% of the variance in HbA1c levels. Age moderated the relationship between no-one taking responsibility and HbA1c levels. The relationship between motivation and dietary self-care was mediated by dietary self-efficacy. Adolescent consequence beliefs, motivation and self-efficacy accounted for 36% of the variance in adolescents' distress levels. Parents' perceived consequences and perception of adolescent motivation accounted for 14% of the variance in parent diabetes related distress. *Conclusion* Adolescent and parent perceptions of motivation, self-efficacy and consequences are important variables to consider when assessing different diabetes outcomes. The study concludes by discussing study limitations and areas for future research, as well as highlighting the clinical implications of the findings.

Introduction

Type 1 Diabetes Mellitus (T1DM) is a chronic health condition characterised by a nonexistent supply of insulin. Consequently the body cannot control blood glucose levels. Without adequate self-care behaviours, individuals are at risk of physical health complications, reduced life expectancy and quality of life (Diabetes Control and Complications Trial, 1993). To regulate blood glucose levels individuals must therefore follow a complex regime, including daily monitoring of blood glucose levels and adjusting insulin dosages on the basis of their blood glucose levels, in addition to physical activity and food intake (Silverstein, Klingensmith, Copeland, Plotnick, Kaufman et al. 2005). Healthy dietary practices are regarded as one of the most difficult aspects of the diabetes treatment regime (Silverstein et al., 2005). During adolescence, a period marked by biological, physical, cognitive and emotional change, adherence to diabetes self-care to control blood glucose levels often declines as adolescents drive for independence, social identity and peer acceptance (Cameron 2006). Research that attempts to identify variables associated with adolescent dietary self-care and well-being are therefore very important.

Previous research has identified three cognitive constructs that are particularly relevant in accounting for the variation in diabetes outcomes of dietary self-care, metabolic control and quality of life. The constructs are motivation (Deci & Ryan, 2000), self-efficacy (Bandura, 1997) and illness representations (Leventhal, Nerenz & Steele, 1984). Despite their identified importance, to date no study has examined the three constructs concurrently.

Motivation is a key element of self-determination theory (Deci & Ryan, 2000). This theory proposes that in order for an individual to achieve optimal and healthy functioning they must have a sense of autonomy (motivation), relatedness (belonging) and competence (a construct similar to self-efficacy) (Williams, Freedman & Deci, 1998). The theory also states that there are several distinct types of motivation, which are characterized by different levels of autonomy, each of which has specifiable consequences for performance, personal experience, and well-being (Deci & Ryan, 2000). *Amotivated* individuals either do not act or act without intent. The spectrum of motivation then ranges from *extrinsically* motivated individuals who are less autonomous and initiate and regulate their behaviour based upon external demands to *intrinsically* motivated individuals, who are autonomously regulated and more likely to adhere to treatment regimes, and feel competent in doing so, because it supports their values and goal systems (Ryan & Deci, 2000).

Research has identified that intrinsically motivated adolescents with T1DM report less depressive symptoms (Butner, Berg, Osborn, Butler, Godri et al. 2009), have better dietary self-care (Austin-Fernet, Senécal**,** Guay & Nouwen, 2009) and adhere to their treatment more (Greening, Stoppelbein, Moll, Palardy & Hocking 2004). Only one study has examined motivation in relation to HbA1c levels and unexpectedly found that HbA1c levels were positively associated with intrinsic motivation (Greening et al. 2004). However the sample size was small (n=43) and the authors did not explore the role of self-efficacy. This is an important construct to measure alongside motivation because research suggests that in

order for intrinsically motivated individuals to take effective action, they must also feel highly self-efficacious (Deci & Ryan, 1985).

Self-efficacy is a key construct of social-cognitive theory (Bandura, 1986). Self-efficacy beliefs are defined as a judgement about one's capability to carry out specific behaviours in specified situations (Bandura, 1997). Like motivation, it is influenced by personal experience and environmental factors (Bandura, 1997; Ryan & Deci, 2000).

Previous research has found that adolescents with a strong sense of self-efficacy have better dietary self-care (Johnston-Brooks, Lewis & Garg, 2002; Nouwen, Law, Hussain, McGovern & Napier, 2009) and have lower levels of depression (Grey, Sullivan-Volyai, Boland, Tamborlane & Yu, 1998). In addition, when adults' levels of self-efficacy have been increased, through interventions, they have been found to increase their dietary self-care (Glasgow, Toobert & Hampson, 1996). The relationship between self-efficacy and metabolic control has however been less consistent with some finding a negative association (Grossman, Brink & Hauser, 1987; Johnston-Brooks et al. 2002; Iannotti, Schneider, Nansel, Haynie, Plotnick et al. 2008; Palmer, Berg, Butler, Fortenberry, Murray et al. 2009) whilst others have not replicated these findings (Butler, Berg, King, Gelfand, Fortenberry, Foster & Wiebe, 2009; Nouwen et al. 2009; Pinar, Arslenogleu, Isguven, Cizmeci & Gunoz, 2003).

Illness representations are an individual's beliefs about an illness. Illness representations are central to Leventhal's Self-Regulation Theory (Leventhal,

Meyer, & Nerenz, 1980), which proposes that individuals form their own beliefs about their illness which then guide health related behaviours and coping responses. The illness representations are structured around five broad cognitive dimensions: (1) *identity:* the illness label and associated symptoms; (2) *cause:* the possible cause; (3) *time line:* the duration, predictability and variability of the illness; (4) *consequences:* the perceived physical, psychological or financial consequences of the illness; and (5) *controllability:* how controllable and effective the treatment is believed to be (Leventhal et al. 1984).

Previous research has identified that greater perceptions of diabetes having a negative impact on adolescents' lives have been consistently associated with lower levels of emotional wellbeing (Edgar & Skinner, 2003; Olsen, Berg & Wiebe, 2008; Skinner & Hampson, 1998; Skinner, John & Hampson, 2000; Nouwen et al. 2009) and poor dietary self-care (Skinner et al. 2000; Skinner, Hampson & Fife-Schaw, 2002; Nouwen et al. 2009). The few studies that have explored illness representations in relation to HbA1c levels have had mixed results, with some finding no direct association in adolescents (Nouwen et al. 2009; Skinner, Howells, Greene, Edgart, McEvilly et al. 2003), and others finding significant relationships with both consequence and treatment effectiveness beliefs (Griva, Myers & Newman, 2000).

With regards to treatment effectiveness beliefs, previous research has identified that adolescents' illness representations, in particular short-term treatment effectiveness to control diabetes, have been proximal determinants of dietary self-care both concurrently (Nouwen et al. 2009; Skinner & Hampson, 1998;

Skinner et al. 2002) over a period of 6 months (Skinner et al., 2000) and 1 year (Skinner & Hampson, 2001). Long-term treatment effectiveness to prevent complications has also been positively associated with, but not predictive of, dietary self-care (Skinner et al. 1998; 2002). There have been mixed results in relation to treatment effectiveness beliefs being associated with other diabetes self-care behaviours, with some finding no association (Skinner et al. 2000; Skinner & Hampson, 2001) and others finding a significant relationship (Skinner et al. 2002; Iannotti et al. 2008). This suggests that illness representations maybe better predictors of dietary self-care than other aspects of diabetes management.

The three constructs (motivation, self-efficacy and illness representations) are all closely related, as the latter represents an individual's beliefs about their illness, self-efficacy represents an individual's belief about their ability to cope with a particular behaviour related to their illness, and motivation accounts for the regulation process behind a health related behaviour. Despite their importance in diabetes management, no study has explored all three constructs in one study, and only a few have examined the joint effect of two constructs. Austin-Fernet, et al. (submitted) assessed motivation and self-efficacy in relation to dietary self-care in adolescents with T1DM and found that dietary self-care was better when adolescents were more autonomous (intrinsically motivated) and more self-efficacious. Similar findings have been found in adults with T2DM (Senecal, Nouwen & White, 2000). The joint effects of these constructs and HbA1c levels in adolescents have not yet been studied. In adults with T1DM, perceived competence mediated the relationship between autonomous self-regulation and

HbA1c levels over 12 months (Williams, Freedman & Deci, 1998). These findings highlight the importance of assessing motivation and self-efficacy concurrently, as both have a role in accounting for variation in diabetes outcomes.

Griva et al. (2000) assessed illness representations and self-efficacy, and found that young people who adhered more to their dietary recommendations had significantly higher self-efficacy and believed more in treatment effectiveness than those reporting less adherence to dietary self-care. Furthermore, individuals who perceived fewer consequences, held stronger treatment effectiveness beliefs and were more self-efficacious had better metabolic control (Griva et al. 2000). In relation to dietary self-care, Nouwen et al. (2009) found that adolescents who did not believe they had the ability to follow their diet plan and/or did not believe in the effectiveness of their diabetes treatment were less likely to adhere to dietary self-care behaviours. Dietary self-efficacy and perceived consequences also both independently predicted diabetes related distress (Nouwen et al. 2009). These findings clearly warrant further investigation, as interventions that target illness representations in isolation of self-efficacy may be limited.

Cognitive theories of health behaviours in a social context

Due to the complexities of the diabetes treatment regime, parents are encouraged to provide adolescents with emotional and instrumental support (Silverstein et al. 2005). Given that social and cultural factors can shape an individual's cognitive appraisal and action in response to a health threat (Lau-

Walker, 2006), researchers have stated that cognitive variables need to be examined within the family so that explanatory models as to how the family may influence or impact adolescent adaptation to diabetes can be explored (Butner et al., 2009; Drotar, 1997, Iannotti et al. 2006; Nouwen et al. 2009; Skinner & Hampson, 1998). Despite the proposed importance of researching cognitive constructs and diabetes management within the family, only a few studies have examined illness representations and self-efficacy within the family context.

Differences between the mean scores of mother and adolescent illness representations have been found to be un-related to adolescent wellbeing (Law, 2002; Olsen et al. 2008). However, when the amount of variance between mother and adolescent illness representations have been explored (i.e. any difference was considered important) greater dissimilarity in illness representations of personal control and illness coherence were related to higher levels of negative adjustment (depression and lower quality of life) (Olsen et al. 2008). Dissimilarity in consequence beliefs and chronicity illness representations were unrelated to wellbeing (Olsen et al. 2008). These findings warrant further investigation as interventions that target adolescent beliefs in isolation of their parents may be limited. Furthermore it is not known if any discrepancy is associated with diabetes self-care behaviours, HbA1c levels and parent wellbeing. The latter is important to consider as parenting stress can negatively impact diabetes outcomes (Hanson, DeGuire, Schinkel, Kolterman, Goodman, & Buckingham, 1996).

Parental perceptions of low adolescent self-efficacy have been associated with higher levels of HbA1c (Butler et al. 2009; Palmer, Berg, Butler, Fortenberry, Murray et al. 2009). High levels of HbA1c levels have also been associated with greater discrepancies between adolescent's self-efficacy and their mother's perception of adolescent self-efficacy (Butner et al. 2009). Greater discrepancy was also associated with more depressive symptoms among mothers, but not fathers or adolescents (Butner et al. 2009). .

In relation to dietary self-care, adolescents' perceptions of social support have been found to mediate the association between perceived consequences and short-term treatment effectiveness beliefs and dietary self-care (Skinner et al. 2002). No association was found with any other self-care behaviour. The authors argued that the family are more likely to be involved with dietary self-care than any other self-care behaviours and consequently recommended that future research should measure family responsibility to assess this further (Skinner et al. 2002). The importance of assessing family responsibility for diabetes related tasks, alongside cognitive constructs of family members has been echoed by other researchers (Law, 2002; Nouwen et al. 2009; Olsen et al. 2008) as it may explain the process through which cognitive constructs influence diabetes outcomes.

Family responsibility is an important variable to consider in diabetes management, because when responsibility is shared and collaborative, HbA1c levels are lower (Anderson, Holmbeck, Iannotti, McKay, Lochrie et al. 2009; Helgeson, Rynolds, Siminerio, Escobar & Becker, 2008; Wysocki, Nansel,

Holmbeck, Chen, Laffel, et al. 2009), wellbeing is better (Helgeson, et al., 2008; Wyscoki et al. 2009) and self-efficacy is higher (Helgeson et al. 2008). Conversely, metabolic control is worse when parents are less involved in blood glucose monitoring (Anderson, Vangsness, Connell, Butler, Goebel-Fabbri & Laffel, 2002), when no one assumes responsibility (Anderson, Auslander, Jung, Miller & Santiago, 1990; Lewin, Heidgerken, Geffken, Williams, Storch, et al. 2006), when parent-child discrepancies in responsibility exist (Cameron, Skinner, De Beaufor, Hoey, Swift, Aanstoot et al., 2008; Helgeson et al. 2008), and when adolescents experience parental responsibility as too interfering and controlling (Leonard, Garwick & Adwan, 2005; Wiebe, Berg, Korbel, Palmer, Beveridge et al. 2005). In relation to parent wellbeing, too much parental responsibility can also increase parental stress (Streisand, Swift, Wickmark, Chen & Holmes, 2005), which may then negatively impact upon diabetes management (Hanson et al. 1996).

Despite evidence suggesting family responsibility can facilitate diabetes management, adolescents as they get older try to be more independent, and move away from parental control. Thus, family involvement often decreases with the child's age, pubertal status and autonomy (Anderson, Ho, Brackett, Finkeistein, Laffell, 1997; Palmer et al. 2004; 2009). It is currently unclear from the literature what the optimal age for transferring responsibility of diabetes tasks from parent to adolescent is, and what factors may facilitate a successful transfer of responsibility.

Given the lack of studies that have concurrently explored elements from the three previously mentioned cognitive constructs within a social context, or examined how they may influence diabetes outcomes and family responsibility, the proposed research had four aims. First, to determine the extent to which dietary motivation, self-efficacy and illness representations predicted diabetes outcomes (distress, metabolic control and dietary self-care) in adolescents with T1DM. Second, to determine if discrepancies between parents' and adolescents' perceptions of motivation, self-efficacy, and illness representations are related to diabetes outcomes. Third, to examine if the cognitive constructs and diabetes outcomes are related to family responsibility. Finally, previous research has identified that as adolescents get older both family involvement (Anderson, Ho, Brackett, Finkeistein, Laffell, 1997; Palmer et al. 2004; 2009) and diabetes self-care behaviours (Cameron 2006) decline. In addition, age has been found to moderate the relationship between family responsibility and HbA1c levels (Lewin et al. 2006). Thus, the fourth study aim was to examine if age moderates the relationship between level of family responsibility and diabetes outcomes.

Method

Participants

Adolescents, aged 12–18 years, and a parent/carer were recruited from two diabetes clinics in the UK. After obtaining ethical approval from the NHS Research Ethics Committee, potential participants attending their out-patient clinic appointment were approached if they met the following inclusion criteria: a) had a diagnosis of T1DM for at least 12 months; b) aged 12-18 years; c) English literate; and d) no known co-morbid medical condition(s). The parent/carer of adolescents fitting the inclusion criteria were also invited to participate.

Data collection occurred over an 8 month period, during which time 129 adolescents were approached. Eighty-five adolescents chose to participate, giving a response rate of 66%. Eighty parents/carers[7] also participated. The majority of participants took part at their clinic appointment (84%) with 6% choosing to return questionnaires by post. Of those choosing not to participate (n=44), 63% had taken the questionnaire booklet home but did not return it, and 37% refused because they had no time (n=4), were not interested (n=7) or were upset (n=6). Table 1 shows the demographic and clinical features of participants who took part in the study.

[7] Of the 80 parents/carers that participated, one was a grandparent. To make the text more readable, the term 'parent' was used in the rest of the study to denote parent/carer.

Table 1

Demographic and clinical features of participants

Age (years) (M and S.D)	15.04 , 1.87
Gender (%)	
Male	49
Female	51
Caregiver (%)	
Mother	80.5
Father	18.3
Grandparent	1.2
Single parent family (%)	21
Number of children at home (M, S.D, and range)	2.4, 1.25, 1 – 8
Ethnicity (%)	
Caucasian	96
Asian	4
Duration of diabetes (years) (M, S.D, and range)	5.11, 3.6, 1 -15.67
Insulin regime (%)	
2 injections per day	64.9
4 injections per day	30.5
Basal Bolus regime	4.6

Abbreviations: M (Mean), S.D. (Standard Deviation).

Procedure

The respective diabetes care teams identified potential participants who fitted the inclusion criteria. They were then approached by the researcher, informed about the study and given a letter and information pack inviting them to participate. Upon receiving written informed consent, participants were given several choices as to when and where they would like to complete the questionnaires: a) at home and return them in a pre-paid envelope; b) at their next scheduled clinic appointment; c) request that the researcher visits their home; or d) at their current appointment.

Measures

The self-report measures were given in the same order of presentation for all participants. Adolescents and parents completed similar measures except for the measure of diabetes self-care behaviours, which was completed by adolescents only. Details of the questionnaires, in the order in which they were presented, are described below.

Demographic information included adolescent date of birth; gender; diagnosis date; treatment regimen; number of children living at home and marital status of the parent.

Responsibility for diabetes management was assessed using the Family Responsibility Questionnaire (FRQ Anderson et al. 1990). This 17-item questionnaire assessed the sharing of diabetic responsibilities between parents and their child. For each item, asking about a specific aspect of diabetes self-care, respondents had to rate whether responsibility was primarily with: (1) the adolescent, (2) shared, or (3) the parents. From a possible range of scores between 0-51, higher scores indicated increasing levels of parental responsibility for diabetes related tasks. Acceptable Cronbach's alpha coefficients for the present sample were $\alpha = 0.80$ (parents) and $\alpha = 0.83$ (adolescent).

As recommended by Anderson et al. (1990) a dyadic parent-child score was also constructed for each dyad. Thus, by considering each parent-child response, one of three possible response patterns was produced for each of the 17-items:

(a) if parent and adolescent agreed precisely as to who takes responsibility, the item was allocated into an 'agreed' category, (b) if a parent (or adolescent) claimed more responsibility than the adolescent (or parent) or if the parent (or adolescent) reported the responsibility was shared and the adolescent (or parent) thought they had more responsibility, then the item was allocated into a 'disagreement but responsibility taken' category, and (c) if parent and adolescent completely disagreed, with each reporting the other person takes more responsibility for the task, the item was allocated to a 'no-one taking responsibility' category (Anderson et al. 1990). For each dyad the three categories of responsibility were totalled, with scores for each category ranging from 0-17. Higher scores reflected either more: (a) agreed responsibility, (b) disagreement but responsibility taken, or (c) no-one taking responsibility.

Illness representations about diabetes were assessed using items taken from the Illness Perception Questionnaire (IPQ) (Weinman, Petrie, Moss-Morris & Horne, 1996). Only items that have consistently been shown to relate to diabetes self-care and distress were included; long-term treatment effectiveness (three items; e.g. 'how likely do you think it is that healthy eating will prevent future complications?'), short-term treatment effectiveness (two items, e.g. 'how important do you believe healthy eating is for controlling diabetes?'), and consequences (three items, e.g. 'my diabetes strongly affects the way others see me'). Items were rated on a 6-point Likert scale (0-5). Higher scores reflected greater beliefs in treatment effectiveness and greater perceived negative consequences of diabetes. These scales have been used previously with adolescents with T1DM, with internal consistencies ranging from α= 0.58 to 0.89

(Edgar & Skinner, 2003; Law 2002; Nouwen et al. 2009; Olsen et al. 2008). In the present study internal consistencies were acceptable for the consequences sub-scale for both parent (α= 0.76) and adolescent (α= 0.63), and for long-term treatment effectiveness beliefs for adolescent (α= 0.68), and parent short-term treatment effectiveness beliefs (α= 0.63). However, the Cronbach's alpha for parent long-term treatment effectiveness beliefs (α= 0.47) and adolescent short-term treatment effectiveness beliefs (α= 0.40) were below acceptable levels and were therefore excluded from subsequent analysis.

Dietary self-efficacy was assessed using a Dietary Self-Efficacy scale (Senecal, Nouwen & White, 2000). This questionnaire consisted of twenty seven items that required adolescents to rate how confident they felt in their ability to follow, on a regular basis, recommended dietary self-care activities. Parents were required to rate how confident they perceived their child was. Scores on each question range from 0 (not at all confident) to 10 (totally confident). Cronbach's alphas for the current sample were 0.98 for parents and 0.95 for adolescent.

Motivation toward dietary self-care activities was assessed using the Dietary Self-care Motivation Scale for Adolescents with Diabetes (Senécal**,** Guay, Austin-Fernet, & Nouwen, 2007). Adolescents were required to answer 12 statements in response to the question 'why do you follow your diet?,' with parents answering similar statements in response to 'why do you think your child follows their diet?' Three items assessed intrinsic motives (e.g. 'for the satisfaction for eating healthily;' α= 0.83 parent, α= 0.68 adolescent), identified motives (e.g. 'to feel better' α= 0.76 parent α= 0.64 adolescent), extrinsic motives (e.g. 'because

my doctor asks me to,' α= 0.64 parents α= 0.70 adolescent) and amotivation (e.g. 'but I don't know what I'm getting out of it,' α= 0.80 parents α= 0.70 adolescent). Items are scored on scale of 1 (do not agree) to 5 (completely agree). An overall score for motivation was computed using the formulae recommended by Grolnick & Ryan, 1987[8]. Higher overall scores reflect more intrinsic motivation.

Self-care for diabetes was assessed using the Summary of Diabetes Self-Care Schedule (Toobert & Glasgow, 1994). The twelve item self-report measure assesses four areas of diabetes self-care (diet, exercise, blood glucose monitoring and injecting) over the previous week. As the study was focussing on dietary self-care, only the five items related to diet were subsequently analysed. A single score was generated for the diet subscale by standardizing the scores for each item and then summing them. Higher scores reflect better dietary self-care. This scale has been validated on adult samples and modified in previous research to make it appropriate for an adolescent UK sample (Nouwen et al. 2009; Skinner & Hampson, 1998; Skinner et al. 2002). In the present sample, internal consistency for the diet subscale was similar to that of other studies (α=0.66).

Diabetes specific emotional distress was assessed using the Problem Areas in Diabetes questionnaire (PAID: Polonsky, Anderson, Lohrer, Welch, Jacobson et al. 1995). The PAID consisted of twenty items that covered a range of emotional problems related to living with diabetes (e.g., 'feeling alone with diabetes' and

[8] 2(Intrinsic motivation) + (identified motivation) – (extrinsic motivation) – 2(amotivation).

'worrying about the future'). Each item was scored from 1 ('Not a problem') to 6 ('Serious Problem'). The sum of the 20 items was totalled to yield a final score. Cronbach's alphas for the present sample were 0.94 (parents) and 0.94 (adolescent).

Metabolic control. Glycosylated haemoglobin (HbA1c) was taken from adolescents' medical files. HbA1c levels provide an estimate of the average glycemic concentration over the prior 2 to 3 months (Hanas, 2007). The recommended blood glucose level for adolescence is <7.5% (Silverstein et al., 2005).

Results

Analysis and Data Analytic Plan

As there were some missing values, correlations 'excluding listwise pairs' were conducted to minimise bias. This resulted in examining 71 complete cases[9]. Where appropriate, data were checked for assumptions of normality and homogeneity of variance prior to parametric or non-parametric analyses. Descriptive data of the measures used in the study are shown in Table 2.

Table 2 Descriptive data

Measure	Mean	Standard Deviation
Adolescent:		
Dietary self-care	0	3.2
HbA1c levels	9.9	1.9
PAID	54	20.4
Consequence beliefs	2.7	0.8
Long-term treatment effectiveness beliefs	3.8	0.7
Motivation	19	17
Self-efficacy	6.4	1.9
Overall responsibility	30.3	5.6
Parent:		
PAID	57.5	19.6
Consequence beliefs	3.1	.87
Short-term treatment effectiveness beliefs	4.6	.43
Motivation	16	20
Self-efficacy	5.9	2.2
Overall responsibility	34.5	5.4
Family responsibility:		
No-one taking responsibility	2.4	1.9
Agreed responsibility	9.2	3
Disagree but responsibility taken	5.1	2.9

[9] For the adolescent data, the only change when the correlations included all variables in the analysis vs those which included the 'excluding listwise' correlations, was that age became insignificantly related to dietary self-care ($r=-0.19$, $p<0.08$). For the parent data, the only change related to predictor variables was the relationship between parents' perceptions of adolescent self-efficacy and HbA1c levels which changed from a significance level of $p<0.01$ to $p<0.05$.

Bivariate Analyses of Demographic Variables

Pearson's product moment correlations showed that as adolescents' age increased adherence to dietary self-care activities decreased ($r= -0.24$, $p<.05$). The longer a person had diabetes for, the more parents felt distressed ($r= -0.40$, $p<.01$) and reported more negative consequences ($r= 0.45$, $p<.01$). With more children living at home, more negative consequences were reported by adolescents ($r= 0.31$, $p<.01$) and parents ($r= 0.28$, $p<.05$). Mann-Whitney U tests identified that single parent families were less likely to share responsibility for diabetes tasks ($U(71)=292.5$, $z= -2.34$, $p<.05$) and more likely to disagree over who completes diabetes tasks ($U(71)=323.5$, $z= -1.92$, $p<.05$). No significant differences were found between gender and study variables. Kruskal-Wallis H tests showed that there were no significant differences between the type of insulin regime participants were using (Basal Bolus, or injections twice or four times a day) and any predictor or outcome variable.

Bivariate analyses of predictor variables

Adolescent data

Table 3 shows the inter-correlations between adolescent perceptions and dietary self-care, HbA1c and diabetes related distress.

Table 3 Inter-correlations of adolescent variables

	1	2	3	4	5	6
1. HbA1c	_					
2. Dietary self-care	- 0.16	_				
3. PAID	0.35**	-0.44**	_			
4. Self-efficacy	- 0.12	0.48**	-0.47**	_		
5. Motivation	- 0.20	0.34**	-0.40**	0.36**	_	
6.Consequence beliefs	0.13	- 0.23	0.45**	-0.33*	-0.41*	_
7. Long-term treatment effectiveness beliefs	-0.09	0.28*	0.10	0.02	0.20	0.03

*p<0.05, **p<0.01.
Abbreviations: PAID (Problem Areas in Diabetes)

The analyses identified that higher levels of HbA1c were significantly related to greater diabetes related distress (r= 0.35). Dietary self-care was lower among adolescents who had lower levels of self-efficacy (r= 0.48), were less intrinsically motivated (r=0.34), believed less in the long-term treatment effectiveness (r= 0.28) and were more distressed by their diabetes (r= -0.44). Adolescents who were more distressed by their diabetes had lower levels of self-efficacy (r= -0.47), intrinsic motivation (r= -0.40), had more negative consequences beliefs (r= 0.45).

Parent data

Table 4 shows that when adolescents reported less dietary self-care, parents' perceptions of adolescent self-efficacy (r= 0.48) and motivation (r= 0.29) were lower. Parental diabetes related distress was positively related to child distress (r=0.42). Parents who were more distressed by diabetes held more negative consequence beliefs (r=0.42) and perceived their child to be less self-efficacious

(r= -0.38) and less intrinsically motivated (r=-0.36). Higher HbA1 levels were also associated with lower perceptions of adolescent self-efficacy (r= -0.29) and motivation (r= -0.35).

Table 4

Inter-correlations between parent perceptions and diabetes related distress and adolescent dietary self care, HbA1c and diabetes related distress

	1	2	3	4	5	6	7
1.HbA1c	_						
2 .Dietary self-care	- 0.16	_					
3. A PAID	0.35**	-0.44**	_				
4. P PAID	0.17	- 0.08	0.42**	_			
5. P Self-efficacy	-0.29*	0.48**	-0.33**	-0.38**	_		
6. P Motivation	-0.35**	0.29*	-0.41**	-0.36**	0.59**	_	
7. P Consequence beliefs	- 0.14	- 0.14	0.29*	0.42**	-0.22	- 0.26*	_
8.P Short-term treatment effectiveness beliefs	0.03	0.02	0.08	0.15	-0.03	-0.08	0.02

*p<0.05, **p<0.01.
Abbreviations: P (Parent); A (Adolescent); PAID (Problem Areas in Diabetes)

Differences between parent and young people

Rather than examine mean differences between parent and child scores, Olsen et al. (2008) proposed that that the amount of variance between the scores should be examined as *any* difference between parent and child may be problematic. Therefore, to measure differences between parent and child perceptions, a measure of variance on each item was calculated and then

summed for each scale[10]. Higher scores reflected greater variance (or dissimilar perceptions), whereas lower scores reflected greater similarity.

As can be seen from Table 5, HbA1c levels were higher when there was greater discrepancy between parent-child perceptions of self-efficacy (r= 0.38). Discrepancies in parent-child perceptions were not related to dietary self-care or adolescent and parent diabetes related distress.

Table 5

Correlations of the discrepancy between parent and adolescent perceptions and dietary self-care and diabetes related distress

Discrepancy variable	HbA1c	Dietary self care	Adolescent PAID	Parent PAID
Self-efficacy	0.38**	-0.12	0.07	0.10
Motivation	0.21	-0.14	0.06	-0.03
Consequence beliefs	-0.06	0.18	-0.22	0.21

*p<0.05, **p<0.01
Abbreviations: PAID (Problem Areas In Diabetes)

Multivariate analysis

The key predictors of HbA1c, dietary self-care and diabetes related distress, identified from the correlations, were then entered into hierarchical multiple regression analyses. To avoid Type 1 errors, only predictor variables that were related to outcome variables at a significance level of p<0.01 were entered into the regression analyses. If any demographic variable correlated with a predictor

[10] Variance calculated by dividing the obtained value of the squared difference of parent and child scores by N-2 (N= number of variables, namely parent and child).

variable, they were controlled for in the first step. To assess for collinearity, the tolerance and variance inflation factors were calculated for each regression (Kinnear & Gray, 2006). No significant collinerarity was identified. In order to minimise the risk of making a Type 1 error, Kinnear & Gray (2006) propose entering the most theoretically relevant variables first.

Predictors of dietary self-care

Bivarate analyses identified that the only variables significantly related to dietary self-care were adolescent and parent perceptions of self-efficacy and adolescent motivation. Age was controlled for in the first step. In line with self-determination theory (Williams, Freedman & Deci, 1998; Deci & Ryan, 2000), motivation was entered in the second step, followed by self-efficacy in the final step. Table 6 shows that adolescent motivation accounted for 10% of the variance in dietary self-care, and adolescent and parent perceptions of self efficacy predicted a further 20% of the variance.

Table 6 *Multiple Regressions to Predict Dietary Self-Care*

Predictors	B	Std error	Beta	Adjusted R Squared	R Square Change
Step 1					
Constant	1.28	0.65			
Age	-0.09	0.04	-0.23*	0.04	0.05*
Step 1					
Constant	0.87	0.63			
Age	-0.08	0.04	-0.20		
A motivation	0.01	0.00	0.33**	0.14	0.11**
Step 3					
Constant	-0.38	3.09			
Age	-0.06	0.04	-0.16		
A motivation	0.01	0.00	0.19		
A self-efficacy	0.09	0.04	0.25 *		
PPA self-efficacy	0.09	0.03	0.32*	0.34	0.21 **

*p<0.05, **p<0.01.
Abbreviations:PPA(Parents Perception of Adolescent)

As the addition of self-efficacy reduced the effect of motivation, data were examined to test whether self-efficacy mediated the relationship between adolescent motivation and dietary self-care. Baron & Kenny's (1986) guidelines for mediation were followed where: (1) the predictor should be significantly associated with the outcome; (2) the predictor should be significantly associated with the mediator; (3) the mediator should be associated with the outcome variable and; (4) the addition of the mediator to the full model should reduce the relation between the predictor and the outcome variable.

As previously identified in Table 3, the first condition (motivation associated with dietary self-care), second condition (motivation was associated with self-efficacy) and third condition (self-efficacy was associated with the dietary self-care) were met. To assess the fourth condition, motivation and self-efficacy were regressed onto dietary self-care, with motivation entered at the first step and self-efficacy entered at the second step. Table 7 shows that when self-efficacy was added, the effect of motivation on dietary self-care was no longer significant. The Sobel (1982) test of mediation was significant, $z=2.57$, $p<0.01$, confirming a significant full mediation effect.

Table 7

Adolescent self-efficacy fully mediating the relationship between motivation and dietary self-care

Predictors	B	Std error	Beta	Adjusted R Squared	R Square Change
Step 1					
Constant	-1.27	0.53			
A motivation	0.06	0.02	0.33 **	0.11	0.11 **
Step 2					
Constant	-4.64	1.12			
A motivation	0.03	0.02	0.18		
A self-efficacy	0.62	0.18	0.37 **	0.20	0.11**

*p<0.05, **p<0.01.
Abbreviations: A (Adolescent)

Predictors of HbA1c

As identified in Tables 4 and 5 there were two predictor variables that correlated with HbA1c (parent perceptions of adolescent motivation and parent-child discrepancy in self-efficacy). Motivation was entered in the first step as self-determination theory has been studied more rigorously in diabetes research than theories related to discrepancies in self-efficacy. Table 8 shows how, in the final model, both motivation and discrepancies in self-efficacy independently predicted HbA1c and together they accounted for 18% of the variance in HbA1c levels. Thus HbA1c levels were higher when parent's perceived adolescent's to be more extrinsically motivated and when there was greater parent-child discrepancy in perceptions of adolescent self-efficacy.

Table 8

Multiple Regressions to Predict HbA1c

Predictors	B	Std error	Beta	Adjusted R Squared	R Square Change
Step 1					
Constant	10.6	0.25			
PPA Motivation	-0.04	0.01	-0.39 **	0.14	0.15**
Step 2					
Constant	9.92	0.38			
PPA Motivation	-0.03	0.01	-0.30**		
Discrepancy in self-efficacy	0.09	0.04	0.24 *	0.18	0.05*

*p<0.05, **p<0.01.

Predictors of Adolescent Distress

As there were a number of adolescent and parent variables that correlated with adolescent distress, only adolescent variables were examined. It was hoped that this would reduce the effect of making a Type 1 error and improve the effect size. In line with Leventhal's self-regulation theory illness representations (consequence beliefs) were entered in the first step, with motivation entered in the second step, and in the final step, self-efficacy was entered. The analysis (Table 9) showed that in the final model, consequence beliefs, motivation and self-efficacy were all significantly independently predictors of distress, accounting for 36% of the variance.

Table 9

Adolescent variables predicting diabetes related distress

Predictors	B	Std error	Beta	Adjusted R Squared	R Square Change
Step 1					
Constant	1.27	0.32			
Consequence beliefs	0.54	0.11**	0.47 **	0.21	0.22**
Step 2					
Constant	1.97	0.39			
Consequence beliefs	0.41	0.12	0.26**		
Motivation	-0.07	0.02	-0.30**	0.28	0.08**
Step 3					
Constant	3.29	0.53			
Consequence beliefs	0.30	0.12	0.26*		
Motivation	-0.05	0.02	-0.20*		
Self-efficacy	-0.18	0.05	-0.34**	0.36	0.09**

*p<0.05, **p<0.01.

Predictors of Parent Distress

After controlling for demographic effects (duration of diabetes), parents' consequence beliefs were entered first, followed by parents' perception of adolescent motivation and finally parents' perception of adolescent self-efficacy. No adolescent variables were associated with parent's distress levels. Table 10 shows that after controlling for duration of diabetes, parents' perceived consequence accounted for a further 9% of the variance in parents' diabetes related distress. The addition of parents' perceptions of adolescent motivation accounted for a further 5% of the variance. In the final model, the addition of parent's perception of adolescent self-efficacy did not significantly add further variance to the prediction of parental distress, and both duration of diabetes and consequence beliefs remained significant independent predictors of parents' distress levels.

Table 10

Multiple Regressions to Predict Parent Distress

Predictors	B	Std error	Beta	Adjusted R Squared	R Square Change
Step 1					
Constant	3.66	0.22			
Duration of diabetes	-0.12	0.04	-0.43 **	0.17	0.19 **
Step 2					
Constant	2.04	0.64			
Duration of diabetes	-0.09	0.04	-0.30*		
P Consequence beliefs	0.44	0.16	0.34*	0.26	0.10*
Step 3					
Constant	2.42	0.64			
Duration of diabetes	-0.08	0.04	-0.29*		
P Consequence beliefs	0.37	0.16	0.29*		
PPA Motivation	-0.13	0.01	-0.26*	0.31	0.06*
Step 4					
Constant	2.76	0.74			
Duration of diabetes	-0.08	0.04	-0.28*		
P Consequence beliefs	0.36	0.16	0.29*		
PPA Motivation	-0.01	0.01	-0.17		
PPA Self-efficacy	-0.07	0.07	-0.14	0.31	0.01

*p<0.05, **p<0.01.
Abbreviations: P (Parent); PPA (Parent Perception of Adolescent)

The Role of Family Responsibility.

Bivariate analysis identified that age was significantly related to overall scores of family responsibility as reported by both parent (r= -0.30, p<0.05) and adolescent (r= -0.47, p<.01). Parents who reported more overall responsibility also felt more distressed by diabetes (r= 0.33, p<.05). Adolescents who were more intrinsically motivated reported significantly less 'no one taking responsibility' for diabetes tasks (r= -0.30, p<0.05). Reports of 'no one taking responsibility' was higher when there was greater discrepancy between parent-child perceptions of adolescent self-efficacy (r= 0.27, p<0.05). The more responsibility was shared,

the less parent-child 'disagreed but responsibility taken' ($r= -0.74$, $p<0.01$) and 'no one took responsibility' ($r= -0.34$, $p<0.05$).

Family responsibility was not directly correlated to any adolescent outcome measure. However, for young people aged 14 years and under (N=34), higher HbA1c levels were significantly associated with higher reports of 'no responsibility' ($r= 0.43$, $p<0.05$). Previous research has identified that age negatively correlates with family responsibility (Anderson, Ho, Brackett, Finkeistein, Laffell, 1997; Palmer et al. 2004; 2009). Furthermore, Lewin et al. (2006) found that age moderated the relationship between family responsibility and HbA1c levels. It therefore seemed important to examine whether age moderated the relationship between the three different levels of family responsibility and diabetes outcomes. To explore the possible moderating effect of age on the relationship between responsibility and diabetes outcomes, a three-step hierarchical regression analysis was carried out. Aiken & West (1991) propose that moderation can be inferred when the interaction term significantly predicts the outcome variable and is associated with a significant increment in the explained variance.

HbA1c levels were therefore regressed on age at the first step, on age and 'no-one taking responsibility' in the second step, and on age, 'no-one taking responsibility' and the multiplicative age by 'no-one taking responsibility' (the mean centred interaction term) at the final step (Table 11). The mean centred interaction of age x 'no-one taking responsibility' predicted HbA1c levels and accounted for 5% of the variance, suggesting age moderated the relationship

between HbA1c and ‘no-one taking responsibility’ being taken for diabetes tasks within the family.

Table 11

Age fully moderating the relationship between ‘no one taking responsibility’ and HbA1c levels

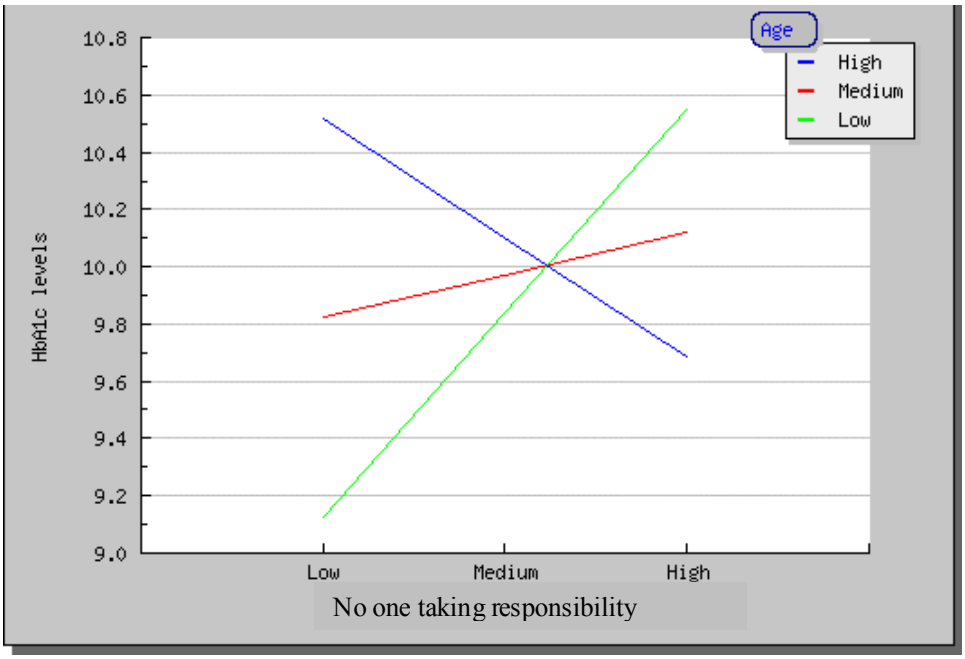
Predictors	B	Std error	Beta	Adjusted R Square	R Square Change
Step 1					
Constant	10.04	0.22			
Age	-0.10	0.13	-0.09	-0.01	0.01
Step 2					
Constant	10.1	0.22			
Age	0.11	0.13	0.10		
No-one taking responsibility	0.09	0.11	0.09	-0.01	0.01
Step 3					
Constant	9.97	0.22			
Age	0.07	0.13	0.07		
No-one taking responsibility	0.08	0.11	0.08		
Age*no-one taking responsibility	-0.16	0.07	-0.27 *	0.05	0.07 *

*p<0.05, **p<0.01.

The graph in Figure 1 shows how age moderates the relationship between no one taking responsibility and HbA1c levels.

Figure 1

The effect of no one taking responsibility and HbA1c levels by age



Note: High age (n=23 16-18 year olds); Medium age (n=22 14-16 year olds); Low age (n=34 12-14 year olds)

Further analysis of the slopes identified that, for the 'low age' slope only, Hba1c levels were significantly different between the low and high levels of no-one taking responsibility ($t=2.29(72), p<0.03$). This suggests that for young adolescents (12-14 years old), high levels of no family responsibility were associated with higher HbA1c levels, while low levels of no-one taking responsibility were associated with lower HbA1c levels. The slope for was insignificant for both the medium age ($t=-0.69(72), p<0.49$) and high age ($t=-1.37(72), p<0.18$) slope.

Age did not act as a moderating variable in relation to any other diabetes outcome (dietary self-care or distress) and level of family responsibility ('shared responsibility' or 'disagree but responsibility taken').

Discussion

When considering the three cognitive constructs from the main theories of health related behaviour, namely, motivation (Deci & Ryan's 2000 self-determination theory); self-efficacy (Bandura's 1997 social-cognitive theory) and illness representations (Leventhal, et al.'s 1984 self-regulation model), the study identified that the constructs are associated with diabetes outcomes in different ways.

With regards to dietary self-care, parent and adolescent perceptions of dietary self-efficacy, and adolescent motivation accounted for 30% of the variance in dietary self-care. Mediation analysis showed that the relationship between motivation and dietary self-care was mediated by self-efficacy. Thus, increased intrinsic motivation was related to better self-efficacy, which was then related to better dietary self-care. These findings would support self-determination theory (Deci & Ryan, 1985) and previous research with adolescents (Austin-Fernet et al. 2009) and adults with T1DM (Senecal et al. 2000; Wiliams et al. 1998) that perceptions of autonomy and self-efficacy are both important to consider in relation to dietary self-care in adolescents with T1DM, and should not be evaluated independently of each other. The findings add to the literature by highlighting the unique importance of both adolescent and parent perception of self-efficacy in predicting dietary self-care. Thus, when parents perceive their child to be highly self-efficacious and the adolescent also perceives themselves to be intrinsically motivated and highly self-efficacious, dietary self-care is better.

When considering social-cognitive variables that influence HbA1c levels, parents' perceptions of adolescent motivation and parent-child discrepancies in self-efficacy accounted for 18% of the variance in HbA1c levels. Parents also perceived their adolescent to be less intrinsically motivated and competent than the adolescent did. This would support previous findings that have also found discrepancies in parent-child perceptions of self-efficacy to be related to HbA1c levels, and that adolescents perceive themselves to be more competent than their parents do (Butner et al. 2009). The results add to the literature by finding that parents' perceptions of adolescent motivation are also associated with adolescent metabolic control.

In trying to explain these findings, it is hypothesised that parents may use HbA1c levels to gauge how competent (Butner et al. 2009) and motivated their adolescent is. Conversely, when a parent perceives their adolescent to be less competent and autonomous than the adolescent does, then parents, in an attempt to assist their adolescent's motivation and competence, 'step in' or confront their child about diabetes related tasks. This may then lead to conflict and increased HbA1c levels. Previous research has identified that high levels of diabetes specific family conflict are consistently related to poor metabolic control (Anderson et al. 2002; de Wit, Delemarre-van de Waal, Bokma, Haasnoot, Houdijk et al. 2007; Lewandowski & Drotar, 2007). In addition, high levels of family conflict can reduce adolescents' willingness to adhere to their treatment regime, and reduces their parents' ability to effectively monitor diabetes tasks (Lewin et al. 2006). In support of this notion, greater discrepancy in perceptions of self-efficacy was related to greater likelihood of 'no one taking responsibility'

for diabetes related tasks. Furthermore, for younger adolescents (12-14 year olds), high levels of 'no family responsibility' were associated with higher HbA1c levels.

Illness representations were not associated with HbA1c levels which replicate previous findings in a similar age group (Iannotti et al. 2008; Nouwen et al. 2009). The findings contrast with Griva et al. (2000), who found illness representations were related to HbA1c levels. However, Griva's study recruited older participants (average age 20.6years), with a lower average HbA1c level (8.66) than the current sample; the discrepant results may therefore be due to differences in sample characteristics. Adolescent illness representations (consequence beliefs) did however account for 21% of the variance in adolescents' distress levels, with self-efficacy and motivation explaining a further 15%. Thus, highly distressed adolescents perceive diabetes as having more negative consequences on their lives, have low self-efficacy in their ability to manage dietary self-care behaviours, and are more extrinsically motivated than adolescents who are less distressed.

These results concur with a recent study that also found self-efficacy and perceived consequences to independently predict diabetes related distress (Nouwen et al. 2009), and earlier studies that have separately considered self-efficacy (Grey, Boland, Davidson, Yu, Sullivan-Volyai & Tamborlane, 1998) consequence beliefs (Edgar & Skinner, 2003; Olsen et al. 2006; Skinner & Hampson, 1998; 2001; Skinner et al. 2000) and motivation (Butner et al. 2009) to predict wellbeing. The study adds to the literature by highlighting the unique

importance of all three constructs in explaining variation in adolescents' distress levels.

After controlling for duration of diabetes, parents' illness representations (consequence beliefs) and perception of adolescent motivation accounted for 18% of the variance in parent diabetes related distress. Parents' perceptions of adolescent self-efficacy did not account for any significant proportion of variance in distress levels. These findings suggest that parents experience higher levels of distress when they perceive more negative consequences of having diabetes in their lives and perceive their adolescent to be more extrinsically motivated.

The finding that parents' beliefs about negative consequences of diabetes relate to their wellbeing fits with Leventhal's (1984) theory of self-regulation. With regards to motivation, the data extends Deci & Ryan's (2000) theory that individual motivation is related to wellbeing, by finding that parents' perception of adolescent extrinsic motivation was associated with higher distress levels. It is hypothesised that parents who perceive their adolescent to be more extrinsically motivated, may find managing diabetes more frustrating and distressing as they may feel they have to constantly 'nag' their adolescent to adhere to their diabetes self-care behaviours. In support of this notion, a qualitative study found that parents get upset when their adolescent appears unmotivated to comply with diabetes self-care activities (Leonard et al. 2005). Previous research has also identified that adolescents with T1DM associate parental 'nagging' with parental worry (Weinger, O'Donnell, & Ritholz, 2001). Conversely, parent's perceptions of adolescent motivation may be clouded by parent's distress levels, or parent's

own motivation may influence their perceptions of adolescent motivation. Further research is needed though before conclusions can be made, and only longitudinal research would be able to identify the direction of relationships.

With regards to family responsibility, the results found that parental involvement in diabetes tasks, as reported from both parent and adolescent, reduced as adolescent age increased. This replicates previous findings (Anderson et al. 1997; 2002; Palmer et al. 2004; 2009). The study also identified that family responsibility is associated with factors other than age, and these factors are different for adolescents and parents. Adolescents who were more intrinsically motivated, were less likely to have 'no one take responsibility' for diabetes tasks. Parent reports of greater overall family responsibility were associated with more perceived consequences and higher levels of distress. This would support similar studies finding a positive association between parent responsibility and distress (Streisand et al. 2005).

Higher levels of parent-adolescent discrepancy in perceptions of self-efficacy were associated with higher levels of 'no one taking responsibility.' Furthermore, age moderated the relationship between 'no one taking responsibility' and HbA1c levels. For younger adolescents (12-14 year olds), high levels of no family responsibility were associated with higher HbA1c levels, while low levels of no-one taking responsibility predicted lower HbA1c levels. Despite the small sample size, studies that have used a similar method of scoring the responsibility measure have also found higher levels of 'no-one taking responsibility' to be associated with higher levels of HbA1c (Anderson et al. 1990; Lewin et al. 2006).

Studies that have explored 'shared responsibility,' without assessing 'no-one taking responsibility' have found similar results, with low shared responsibility to be associated with higher HbA1c for adolescents aged 13-14 years (Helegeson et al. 2008) and 9-14 years (Wysocki et al. 2009).

These findings suggest that low levels of family responsibility are detrimental to young adolescents. However, for adolescents aged over 14 years, family responsibility was found not to relate to HbA1c levels. It would seem that factors other than family involvement were related to HbA1c levels in the older age group. This fits with developmental theories that propose that as adolescents get older, they are more motivated to seek independence and move away from parental control (Eccles, Lord, Roeser, Barber & Jozefowicz, 1996; Cameron, 2006). According to the data, to achieve optimum metabolic control, transfer of responsibility should not occur between the ages of 12-14years. Furthermore, to facilitate the transfer of responsibility, adolescents and their parents need to be in tune with how competent and motivated the child is.

Responsibility was not associated with dietary self-care. This maybe because the predictor variables were primarily diet related and the measure of responsibility was not diet specific, such as who chooses and prepares meals. Previous research has identified that family responsibility for diabetes specific tasks (blood glucose monitoring) is only related to improved adherence to that specific task only (Anderson et al. 2002; Gowers, Jones, Kiana, North & Price, 1995), and when discrepancies in family responsibility for this specific task exists,

HbA1c levels are higher (Cameron et al. 2008). It is not known of any other study has explored family responsibility in relation to dietary self-care only.

Methodological Issues and Future Research

There are a number of limitations to the study and ways in which it could be improved. First, the majority of the sample were Caucasian, which thereby limits the generalisability of the findings to other ethnicities. Second, the study was cross-sectional and consequently it is not possible to determine causal inferences. It is possible that dietary self-care, distress or HbA1c levels may influence the perceptions and beliefs family members have, conversely family perceptions may influence diabetes outcomes. In order to assess the direction of influence, longitudinal studies, or interventions designed to monitor the effects of changing a particular behaviour, are needed.

Third, only a small proportion of variance in HbA1c levels was accounted for. HbA1c levels may be influenced by hormonal fluctuations (Tfayli & Arslanian, 2007), or stress hormones as a result of family conflict (Anderson et al. 2002), or the coping strategies the parent-adolescent dyad utilise. Future research would benefit from assessing perceptions of self-efficacy, motivation, cortisol, family conflict and coping strategies in relation to HbA1c over time. A large proportion of variance in parent distress levels was also unaccounted for. Factors such as a parent's own self efficacy (Streisand et al. 2005) and their level of support may also contribute to distress levels and are areas for future research. These

findings highlight how the studies outcome variables are complex composites of multiple factors and difficult to capture in one study.

Fourth, the sample size of each age group in the moderation analysis was very small, which may have given rise to a Type 1 error (observing a statistical difference when in truth there was none) or a Type 2 error (failing to observe a difference when in truth there was one). Studies with a larger sample size than the current study would have more statistical power allow for more accurate analysis of subgroups, such as, age, duration of diabetes or treatment regime, and enable the investigation of additional predictor variables.

Fifth, regarding the measures the majority were self-reports, and dietary self-care was subjectively reported from the adolescent only. To obtain more objective and perhaps reliable data, future research could benefit from obtaining multiple perspectives of dietary self-care (such as parents or peers), or observe parent-child interactions during meal times, and measure dietary specific family responsibility.

Mothers typically participated in the study, primarily because they accompanied their child to clinic appointments. Although mothers are believed to be more involved in their child's diabetes regime (Berg et al. 2008; Butner et al. 2009), more recently fathers' monitoring levels have also been found to influence diabetes outcomes (Berg et al. 2008). Future research would benefit from exploring the different roles and beliefs mothers and fathers have in comparison to adolescents, and how they may influence diabetes outcome and wellbeing.

The views of siblings may also be relevant, especially in light of the finding that larger family sizes were associated with both adolescents and parents reporting more negative consequences.

Clinical Implications

Despite these limitations, the study has several strengths. It has contributed conceptually to the area of social-cognitive theories in explaining different diabetes related outcomes from the perspectives of both adolescent and parent. In summary, the data supports constructs from Leventhal's (1984) and Bandura's (1997) social-cognitive theories in explaining variation in diabetes related distress, whilst constructs from Bandura's (1997) and Deci & Ryan's (2000) theory best explained variation in dietary self-care and HbA1c levels. The study has also contributed to the literature of family responsibility by assessing different levels of responsibility, and exploring factors associated with them. As a result, the data seems to suggest that parents can facilitate adolescent independence in diabetes tasks during mid-adolescence, and when parents and adolescents are in tune with the adolescent feeling intrinsically motivated and competent.

The study has also highlighted key areas that interventions could target. To improve dietary self-care; motivational interviewing may enhance adolescent's intrinsic motivation for change, by focusing on problem recognition, ambivalence regarding change and self-efficacy (Welch, Rose & Ernst, 2006). To reduce distress levels; cognitive-behavioural therapy may help adolescents and their parents identify links between thoughts, feelings and behaviours. Any irrational

thoughts regarding consequences or treatment effectiveness of diabetes management, or erroneous perceptions of adolescent competence or motivation, could then be discussed, challenged and replaced with more rational and supportive beliefs. To promote effective family responsibility and enhance diabetes outcome; parents need to be involved with adolescent therapy, or clinicians need to speak jointly with parent and adolescent, so that families openly communicate their perspectives and reach a shared understanding about diabetes and its management.

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PUBLIC DOMAIN BRIEFING PAPER

The literature review and research project detailed below were conducted by Victoria Queralt, Clinical Psychologist in Training, University of Birmingham. They were submitted as partial fulfilment for the degree of Doctorate in Clinical Psychology.

Literature Review

Do aspects of family functioning influence metabolic control and adherence in adolescents with Type 1 diabetes?

For individuals with Type 1 diabetes, adolescence is frequently marked by declines in self-care behaviours and control of diabetes. Previous research has identified that the family has an important role in diabetes management, but to date no paper has reviewed the specific components of family functioning (patterns within relationships that connect family members) and how they may relate to diabetes outcomes. Twenty-nine nine studies were reviewed.

The key components of family functioning that influence diabetes outcomes were: how connected family members were; level of family involvement and monitoring in diabetes tasks, support, perception of adolescent competence, parent wellbeing and parenting style. However, the influence of these components on diabetes outcomes appears to vary depending upon whose perception of family functioning is measured, and the characteristics of the adolescent in terms of age, sex, pubertal status, presence of an eating disorder, self-efficacy and autonomy. Higher levels of family conflict were found to be

consistently related to poorer diabetes control regardless of whose perception was measured.

The review concludes by recommending areas for clinical intervention such as to: minimise family conflict; ensure family collaboration is viewed by the adolescent as supportive and nurturing; take into consideration the characteristics of the adolescent and family culture and; enhance parents' sense of empowerment and wellbeing by offering additional support.

Empirical Paper

The role of motivation, self-efficacy, illness representations and family responsibility in relation to diabetes outcomes: view of adolescents with Type 1 diabetes and their parents.

Background

During adolescence adherence to diabetes self-care often declines. Healthy dietary practices are regarded as one of the most difficult aspects of the diabetes treatment regime. Research that attempts to identify variables associated with adolescent dietary self-care and well-being are therefore very important.

Previous research has identified three constructs that are relevant in accounting for the variation in adolescents' diabetes outcomes. These are: adolescent motivation (i.e. whether diabetes tasks are carried out for personal satisfaction or because other people have said they have to; Deci & Ryan, 2000); how competent an adolescent feels about carrying out their diabetes tasks (Bandura, 1997) and an individual's beliefs about an illness (Leventhal, Nerenz, Steele, Taylor & Singer, 1984). Despite their identified importance, to date no study has

examined the three constructs at the same time, in a sample of adolescents with T1DM. As the family has an important role in adolescent diabetes management, family responsibility, and the perceptions of parents and their distress levels were also evaluated.

Aims

The study had three aims: First, to find out if adolescent motivation and competence to follow a diabetes diet, and the beliefs they had about diabetes, predicted diabetes outcomes (distress, metabolic control and dietary self-care). Second, to determine if discrepancies between parents' and adolescents' perceptions of motivation, competence, and beliefs are related to diabetes outcomes. Third, to explore the role of family responsibility.

Method

Eighty-five adolescents, aged 12-18 years, and 80 parents/carers were recruited from two diabetes clinics. Adolescents and parents completed similar measures except for the measure of dietary self-care which was completed by adolescents only. All measures were self-report questionnaires. Metabolic control was assessed by obtaining HbA1c levels from adolescents' medical files.

Results

Adolescents dietary self-care was worse when they were motivated to follow their dietary plan because other people told them to (rather than for personal satisfaction), and when they did not feel competent to follow their dietary plan. Metabolic control was worse when parents' thought their adolescent followed their dietary plan because other people told them to, and when adolescents' level of competence differed from their parents perception of their competence.

Furthermore, for young adolescents (12-14years old), high levels of 'no family responsibility' were associated with worse metabolic control. Adolescents' distress levels were higher when adolescents did not feel very competent in following their dietary plan, believed they had to follow their dietary plan because other people told them to, and thought their diabetes had negative consequence on their lives. Parents' distress levels were also higher when parents believed diabetes had negative consequences on their lives, and when they thought their adolescent was motivated to follow their dietary plan because other people told them to.

Conclusion

Adolescent and parent perceptions of motivation, competence, and beliefs about the consequences of having diabetes, are important variables to consider when assessing different diabetes outcomes. The findings highlight several areas for clinical interventions. Cognitive-behavioural therapy would help adolescents and their parents identify links between thoughts, feelings and behaviours, so that any irrational thoughts regarding consequence beliefs or erroneous perceptions of adolescent competence or motivation could be discussed and replaced with more supportive beliefs. Motivational interviewing may enhance adolescent's motivation for change so that they follow their treatment regime for personal satisfaction rather than because they are told to. Finally, parents need to be involved with adolescent therapy, or clinicians need to speak jointly with parent and adolescent, so that families openly communicate their perspectives and reach a shared understanding about diabetes and its management.

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Summary of reviewed papers, including participant details, major outcomes and study limitations

Abbreviations: P.r (Participation rate); N.R. (Not reported).

Authors	Participant Details				Major Outcomes	Study Limitations
	Age range (yrs)	N	% Male	% P.r*		
Anderson et al. (1997).	10–15	89	49	64	Increased parental involvement in blood glucose monitoring was related to better adherence in this activity. Better adherence predicted better HbA1c levels.	Behavioural logs of adherence were not collected so retrospective reports were relied upon. Full descriptions of parent participants were not reported therefore making it difficult to generalise the findings. Cross sectional study.
Anderson et al. (2002).	13-17	35	45	81	Increased diabetes-related conflict was related to higher HbA1c levels. Parental involvement in blood glucose monitoring and insulin injections decreased as adolescents got older, even after controlling for duration of diabetes. Increased parent involvement was related to increased frequency of blood glucose monitoring, which in turn was related to lower lHbA1c.	Cross sectional study. Reliability coefficients for the adherence measures used are not reported. Ethnicity of the participants is also not reported

Authors	Participant Details				Major Outcomes	Study Limitations
Berg et al. (2008).	12-14	185	47	66	Adolescents' perceptions of acceptance and monitoring (rather than parents' perceptions) predicted diabetes outcomes (HbA1c).	94% of participants were Caucasian. Self report questionnaires were not overseen by a researcher as they were completed at home and returned via mail. Cross-sectional study.
Berg et al. (2008).	12-18	84	53	66	Both adolescents and mothers perceived less enjoyment of collaboration with increasing adolescent age. Better adherence occurred when mothers and adolescents perceived enjoying collaboration regardless of age.	Cross-sectional study. Participants were recruited 1.5 years after participating in Wiebe et al. 2005) studies. 97% of the sample was Caucasian. It is unclear why Parenting style were measured but not analysed in relation to adherence.
Butler et al. (2007).	12-17	78	53	61	Parenting style was not associated with adherence. Increased maternal anxiety was associated with increased levels of involvement.	Only 80% of the self-care inventory was completed by adolescents. Cross sectional study. Self report questionnaires were not overseen by a researcher as they were completed at home and returned via mail. 99% were European-American.
Butner et al. (2009).	10-14	185	N.R.	66	Discrepancies between mother and child perceptions of competence were related to higher HbA1c levels. Paternal-child discrepancies were unrelated to HbA1c levels.	40 Fathers did not complete the measures. 94% of the participants were Caucasian. Cross-sectional study.

Authors	Participant Details				Major Outcomes	Study Limitations
Cameron et al. (2007).	13–18	47	45	76	Maternal trait anxiety was associated with increased maternal involvement and over-protectiveness and, in younger adolescents, with poor metabolic control. Older adolescents with more anxious mothers did not exhibit relatively worse adherence or metabolic control than older adolescents with low-anxious mothers.	Some adherence measures were administered three months after maternal trait anxiety was assessed. Self report questionnaires were not overseen as they were completed at home and returned via mail. Cross sectional study. 83% of participants were New Zealand European.
Cameron et al. (2008).	11-18	2062	N.R	91	Parental over involvement and adolescent-parent concordance on responsibility for diabetes care were strong predictors of metabolic outcomes. Significant differences in family dynamics and communication style were found between different centers.	All questionnaires were translated into several different languages. Reliability coefficients are not provided for the involvement measure. Details of how metabolic control was assessed are not reported. Details of the ratio of participants from 19 different countries are not reported. Cross sectional study.
Dashiff et al. (2005).	11-15	161	50	52	Neither general conflict nor diabetes specific conflict was related to adherence to diabetes self-care.	Cross-sectional study. A large proportion of participants chose not to take part. Recruitment lasted 2 years, with 27% of participants dropping out. Details of those not participating were not explored. The majority of the sample was Caucasian (81%). Only 23% were on insulin pumps. Details of the remaining 77% treatment regime were not mentioned. Internal consistency of the measure of adherence was not reported.

Authors	Participant Details				Major Outcomes	Study Limitations
Dashiff et al. (2009).	11-15	131	53	53	Mothers who reported greater levels of separation anxiety when their child was 11-15 years of age had adolescents who exhibited lower levels of cognitive autonomy 1 year later. Adolescents who reported more cognitive autonomy had adhered more to their diabetes self-care 1 year later.	The alpha coefficients of the adherence inventory are not reported. Details of the type of insulin regime adolescents are on are not described. 82% of the sample was Caucasian. Longitudinal study.
de Wit et al. (2007).	13–17	91	52	47	Increased family conflict was associated with higher HbA1c levels.	More females used a pump, and more males used three insulin injections per day, but regime was considered in the analysis. Those not participating were more likely to be of another ethnicity (89% of the study sample was Caucasian). Details of how HbA1c were obtained were not reported. Reliability coefficients for the measures used were also not reported. Cross sectional study.
Ellis et al. (2007).	12–18	99	52	77	Parental monitoring of diabetes care behaviours had a direct effect on 12-18 year olds adherence and through adherence, an indirect effect upon metabolic control. Parental support moderated the relationship between parental monitoring and adherence.	Cross sectional study. Although participants were on different treatment regimes, these differences were not explored or controlled for in analyses. Adolescents were provided with a gift certificate for participating. .

Authors	Participant Details				Major Outcomes	Study Limitations
Florian & Elad (1998).	12–17	88	56	73	Mothers' sense of empowerment explained a significant proportion of the variance in their child's metabolic control and adherence, particularly for girls aged 16-17yrs. Age, gender and illness duration explained a significant proportion of the variance in adherence as well.	All participants were of the same religious orientation (Jewish). Cross sectional study.
Gowers et al. (1995).	12–16	116	60	91	Adolescents with better metabolic control had parents who were more involved in administering injections than those with poor control. Adolescents with good metabolic control also perceived families as poor on affective involvement and responses.	Format of data collection varied across participants (interview or postal questionnaires). How HbA1c were analysed changed during data collection. Participants in the well controlled group had HbA1c levels higher than what would be considered normal (10% HbA1c). The authors to not provide reliability coefficients of the measures used. Characteristics of the participants', such as ethnicity, socio-economic status, or treatment regime are not reported. Cross sectional study.

Authors	Participant Details				Major Outcomes	Study Limitations
Hanna & Guthrie (2003).	11–18	31	N.R	N.R.	Level of parental involvement in diabetes management did not differ during different stages of adolescence (early to mid or mid to late adolescence). Parental involvement was not related to HbA1c.	Cross-sectional study. No details of how HbA1c levels were obtained are described. Completion of self-report questionnaires varied from at the clinic or over the telephone. All measures were devised, or adapted, by the authors and validated in the current study. Details of the content of the measures were not provided. 90% of the participants were Caucasian.
Hanson et al. (1995).	12–20	157	50	73	High family cohesion and low family conflict, especially during the first years of illness, was indirectly related to good HbA1c through positive self-care. Increased family life stress was associated with higher HbA1c. Participants who had diabetes for longer had mothers' who perceived more life stress. Adherence mediated the relationship between age and HbA1c, with younger participants achieving better metabolic control than older adolescents.	Cross sectional study. The majority of the sample were Caucasian (82%). Reliability coefficients of the measures used were not reported.

Authors	Participant Details				Major Outcomes	Study Limitations
Helgeson et al. (2008).	11-13	132	47	77	Shared responsibility between parent and child (as opposed to individual responsibility) was associated with better adherence and metabolic control.	93% of sample were Caucasian. Reliability coefficients of the diabetes responsibility questionnaire were not reported.
Leonard et al. (2005).	11–18	226	N.R	97	Older adolescents viewed their family as more unhealthy than younger adolescents on affective involvement and behaviour control. Greater reports of family dysfunction in affective responsiveness predicted higher HbA1c levels.	Cross sectional study. 96% of the samples were Caucasian. Reliability coefficients of the measures used were not reported.
Leonard et al. (2005).	14–16	18	71	100	Only adolescents in the high HbA1c group described high levels of conflict with their parents regarding diabetes management. More adolescents in the low HbA1c group described how supportive their families were of them, than those in the high HbA1c group. Adolescents tended to rely on their mothers for helping manage diabetes, the role of fathers varied. Both groups identified their parents monitored their diabetes, but less frequently than when they were younger.	All participants were Caucasian and the majority used insulin pumps. Inter-rater reliability between coded transcripts was not reported. Qualitative study.

Authors	Participant Details				Major Outcomes	Study Limitations
Lewin et al. (2006).	8–18	109	49	N.R	Adherence mediated the relationship between family factors and HbA1c levels. Age moderated the relation between aspects of family functioning and HbA1c. In teenagers (age 13 and above; *N* = 63), poor metabolic control was strongly correlated with critical and negative parenting. However, this relation was not found in younger children.	Cross sectional study. Participation rate not reported. Only some of the variables were examined by separating the sample into different age groups.
Lewandowski & Drotar (2007).	13-18	52	47	25	Increased levels of mother-adolescent conflict and discrepancies in decision-making autonomy predicted increase HbA1c levels. Higher levels f mother-reported spousal support was associated with less conflict and greater adherence.	88% of the sample were Caucasian. Details of how HbA1c levels were collected were not reported. Cross sectional.
Maharaj et al. (1998).	11-19	113	100	71	The presence and severity of eating disturbance mediated the influence of family functioning on metabolic control. Optimal metabolic control was achieved in females with no eating disturbance when the family environment was rated as less controlled and promoted open expression of thoughts and feelings.	Cross sectional design. Validity and reliability of the measures used in the study are not reported. The ethnic mix of the participants is not reported.

Authors	Participant Details				Major Outcomes	Study Limitations
Miller & Drotar (2003).	11-17	82	55	63	Discrepancies between mother and adolescent perceptions of decision making autonomy were related to greater maternal reports of diabetes-related conflict. Discrepancies were not related to adherence.	Compared to participants, non-participants were significantly more likely to be African American than Caucasian. 92% of the participants' were Caucasian. Cross sectional study.
Miller & Drotar (2007).	11-17	64	54	36	Higher levels of parent positive communication were associated with better adherence. Lower levels of both parent and adolescent negative communication were related to improved adherence. Parent-adolescent communication was not associated with adolescent decision-making competence.	Non participants were significantly older than those choosing to take part. The measure of decision-making had a low internal consistency (α =0.56) and was still used. Cross sectional study
Palmer et al. (2004).	10–15	127	52	68	Mothers' reasons for transferring responsibility included responding to the child's competence, promoting competence and maturity in their child and minimizing conflicts. Transfer of responsibility without sufficient adolescent autonomy and when pubertal status was low was related to higher HbA1c levels.	Of the mothers, 97% were Caucasian. Reliability coefficients of the devised 'maternal reasons for transferring diabetes responsibility scale' were not reported. Cross sectional study.

Authors	Participant Details				Major Outcomes	Study Limitations
Palmer et al. (2009).	10-14	185	47	66	Metabolic control was poor when parental responsibility was low and parents they viewed their adolescent has having low self-efficacy.	Participants who chose not to take part were significantly younger. Cross sectional (part of longitudinal study). 97% of participants were Caucasian.
Pereira et al. (2008).	10-18	157	49	N.R	Metabolic control was worse among upper-class families with higher levels of conflict. Family cohesion was not related to adherence or metabolic control. Family social support moderated the relationship between adherence and metabolic control.	All assessment measures were validated within the sample that participated. Internal consistency of adherence measure not reported. Cross-sectional study.
Wiebe et al. (2005).	10–15	127	N.R.	68	Appraisals of controlling involvement were associated with poorer adherence among older children and females. Appraised collaboration and metabolic control was mediated by adherence.	97% of participants were Caucasian. Cross-sectional design. Gender ratio was not reported. Only 7'% of participants HbA1c levels were obtained.
Wysocki (1993).	11-18	115	N.R.	48%	Better family communication was associated with better metabolic control.	Cross sectional study. Gender ratio was not reported. 91% of the participants were Caucasian. HbA1c levels were assessed at a separate time to completion of the questionnaires.

Measures of family functioning, adherence and metabolic control

Authors	Family functioning	Adherence	Metabolic control
Anderson et al. (1997).	* Parental involvement for insulin injections and blood glucose monitoring was assessed on a rating scale, during an interview developed by the authors.	*Modified version of the Adherence Scale (Jacobson, Hauser, Lavori, Willett, Cole et al. 1990). Only blood glucose monitoring frequency used in study. Completed by adolescent's care provider (physician), assessing adherence in past 3-4 months.	Blood samples were taken at the time of the medical visit to measure HbA1c.
Anderson et al. (2002).	* Parental involvement was assessed on a rating scale during an interview (Anderson et al. 1997). * Diabetes Responsibility Questionnaire (Anderson et al. 1990). * Diabetes Family Conflict Scale (Rubin, Young-Hyman & Peyrot, 1989).	* Clinician rating scale (Jacobson et al. 1990) and parent and child self-reports of frequency of blood glucose monitoring during the preceding 3-4 months.	Blood samples were taken at the time of the medical visit to measure HbA1c.
Berg et al. (2008).	* Parental monitoring (Berg et al. 2008) Cronbach's α = 0.86-0.91. * Mother-Father-Peer scale (Epstein, 1983) Cronbach's α = 0.71-0.83.	* Self-care inventory (La Greca, Follansbee & Skyler 1990) Cronbach's α = 0.85.	HbA1c levels were obtained from medical records at the initial clinic recruitment.

Authors	Family functioning	Adherence	Metabolic control
Berg et al. (2008).	* Perceptions of Collaboration Questionnaire (Berg et al. 2008).). Internal consistencies for the subscales ranged from α =0.64 to 0.77 * Report of Parent Behaviour Inventory (Schaefer, 1965). Cronbach's α = 0.93 to 0.90.	* Self-care inventory (La Greca et al. 1990). Cronbach's α = 0.73 – 0.75.	Not assessed.
Butler et al. (2007).	* Report of Parent Behaviour Inventory (Schaefer, 1965). Internal consistencies for the subscales ranged from α =0.77 to 0.90.	* Self-Care Inventory (La Greca et al. 1990). Internal consistency α=0..73.	Not assessed.
Butner et al. (2009).	* DRCS (Rubin et al. 1989) revised. Internal consistencies for the subscales ranged from α =0.92-0.93. * Self efficacy for Diabetes Management Scale (Iannotti et al. 2006). Internal consistencies for the subscales ranged from α =0.81 – 0.91. * Peds-QL Diabetes Specific Module (Varni, Burwinkle, Jacobs, Gottschalk, Kaufman et al. 2003). Internal consistencies for the subscales ranged from α =0.65 -0.66.	* Self-Care Inventory (La Greca et al. 1990). Internal consistency α=0..81-0.85.	Blood samples were taken at the time of the medical visit to measure HbA1c.

Authors	Family functioning	Adherence	Metabolic control
Cameron et al. (2007).	* State-Trait Anxiety Inventory (Spielberger, Gorsuch & Lushene, 1974). Internal consistency α = 0.86. * Personal control subscale of the Illness Perceptions Questionnaire (Moss-Morris, Weinman, Petrie, Horne, Cameron & Buick 2002). Scale adapted. Internal consistency α = 0.76 to α = 0.86. * Diabetes Responsibility and Conflict scale (Rubin et al. 1989). Internal consistency α = 0.81 to α = 0.87. * Beliefs of child's diabetes management skills (Wiebe, Berg & Palmer, 2005).α = 0.87. * Parental over protectiveness (3 items from the Diabetes Quality of Life (DCCT Research group, 1988). Internal consistency α = 0.81.	* Treatment Self-regulation Questionnaire (Williams, Freedman & Deci, 1998). . Internal consistency α = 0.77 to 0.85. * Self-care Inventory (La Greca et al. 1990). Internal consistency α = 0.83.	HbA1c levels were taken during the clinic visit, and readings for the visits 3 months prior to and 3 months following questionnaire completion.
Cameron et al. (2008).	* Diabetes family responsibility (Anderson et al. 1990). Internal consistency α =0.74 to 0.80. * Parental Invovlement Scale from the Diabetes Quality of Life for Youth Short Form (Skinner, Hoey, McGee & Skovlund (2006). * Maternal control over diabetes (Moss-Morris et al. 2002). Internal consistency α = 0.76 to 0.86.	Not applicable.	Not reported.

Authors	Family functioning	Adherence	Metabolic control
Dashiff et al. (2005).	* Issues checklist (Prinz, Foster, Kent & O'Leary, 1979). α = 0.86 to 0.89. * The diabetes Conflict Scale (Rubin et al. 1989). α = 0.83.	* The Self-Care Adherence Inventory (Hanson, De Guire, Schinkel, Kolterman, Goodman et al. 1996).	Not assessed.
Dashiff et al. (2009).	* Individual Adequacy subscale of the Psychosocial Maturity Inventory-Form B (Greenberger & Bond, 1984). α = 0.91. * Issues Checklist (Prinz et al. 1979)α=0.89 *The autonomy and relatedness Coding System (Allen & Hauser, 1996). * Parental separation anxiety scale (Dashiff & Weaver, 2008).	* The self care inventory (Hanson, et al,1996). * The Denyes Self-care practice instrument (Denyes, 1988). α = 0.84	Not assessed.
de Wit et al. (2007).	* Diabetes specific Family Conflict Scale (Rubin et al. 1989). * Child Health Questionnaire (Landgraf, Abetz & Ware, 1996).	Not assessed.	Not assessed.
Ellis et al. (2007).	* Diabetes Family Behaviour Checklist (Schafer, McCaul & Glasgow, 1986). Internal consistency α = 0.79 to = 0.82. *Parental Monitoring of Diabetes Care Scale (Ellis et al. 2007). Internal consistency α = 0.79 to 0.80. * Monitoring Scale (Chilcoat & Anthony, 1996). α = 0.62 to 0.69. * The Diabetes Management Scale (Frey, Ellis, Naar-King & Gregor, 2004). α = 0.70	Not assessed.	A retrospective record of HbA1c during the past 2 – 3 months was obtained from medical records.

Authors	Family functioning	Adherence	Metabolic control
Florian & Elad (1998)	* Family Empowerment Scale (Koren, Dechillo & Friesen, 1992).). Internal consistency α = 0.91. * Mastery Scale (Pearlin & Schooler, 1978). Internal consistency α = 0.79.	Self-Care questionnaire (Glasgow, McCaul & Schafer, 1987). α = 0.76.	Blood samples were taken at the time of the medical visit to measure HbA1c.
Gowers et al. (1995).	* McMaster Family Assessment Device (Epstein, Baldwin & Bishop, 1983).	* General questions about level of involvement.	Medical records were examined to obtain an average of 3 measures covering 6 months.
Hanna & Guthrie (2003)	* Diabetes Family Responsibility Questionnaire (Anderson et al. 1990) with additional items. Internal consistency α =0.81. * Parental involvement in decision making for diabetes management checklist (Hanna & Guthrie. 2003). Internal consistency α =0.87. * Communication about Diabetes Checklist (Hanna & Guthrie, 2003). Internal consistency α =0.84 to 0.96. * Parental support for Diabetes management checklist (Hanna & Guthrie, 2003). Internal consistency α = 0.89.	Not assessed.	Not reported.

Authors	Family functioning	Adherence	Metabolic control
Hanson et al. (1995)	* Family Adaptability and Cohesion Evaluation Scale (Olson, McCubbin, Barnes, Larsen, Muxen & Wilson, 1985). * Family Environment Scale (Koren et al., 1992). *Adolescent-Family Inventory of Life Events and Changes (McCubbin, Patterson, Bauman & Harris, 1985). * Family Stressors, Strains and Distress Index (McCubbin & Thompson, 1987).	*Adherence Interview (Hanson et al., 1995).	Blood samples were taken at the time participation, and medical records were examined to obtain levels 6 months earlier.
Helgeson et al. (2008).	* Diabetes Family Responsibility Questionnaire (Anderson et al. 1990) * Self Perception Profile for Children (Harter, 1985). Internal consistency α = 0.60 to 0.76.	* Self-care inventory (La Greca et al. 1990). α = 0.78 – 0.80. * Multi-dimensional Diabetes Questionnaire (Talbot, Nouwen, Gingras, Gosselin & Audet, 1997) α = 0.78 -0.80.	HbA1c levels were obtained at clinic appointment.
Leonard et al. (2005).	* McMaster Family Assessment Device (Epstein et al. 1983).	Not assessed.	HbA1c levels were obtained at time of recruitment and from medical records.
Leonard et al. (2005).	Open ended questions about living with diabetes and adolescents relationship with their parents and involvement in diabetes management.	Not assessed.	HbA1c levels over the previous year were obtained from medical records.

Authors	Family functioning	Adherence	Metabolic control
Lewandowski & Drotar (2007).	* Social Support Questionnaire (Sarason, Levine, Basham & Sarason, 1983) α =0.83 to 0.98. * Social Provisions Scale – Spousal version (Cutrona, 1989).) α =0.92. * Deciding about Diabetes Treatment (Saletsky, 1992). α =0.92 to 0.93. * Diabetes Family Conflict Scale (Rubin, et al., 1989). Internal consistency α =0.93.	* Health Care Provider Rating questionnaire (La Greca, et al. 1990). Internal consistency α =0.91. * Average frequency of blood glucose testing in previous 2 weeks.	Not reported.
Lewin et al. (2006).	* Diabetes Family Behaviour Scale (Waller, Chipman, Hardy, Hightower, North, et al., 1986). Internal consistency for the subscales ranged from α = 0.69 to 0.76. * Diabetes Family Behaviour Checklist (Schafer et al., 1986). α = 0.76. * Diabetes Responsibility Questionnaire (Anderson et al., 1990). α = 0.89.	* Diabetes Self-Management Profile (Harris, Wysocki, Sadler, Wilkinson, Harvey et al. 2000). Internal consistency α=0.69 to 0.72.	HbA1c levels obtained at time of recruitment.
Maharaj et al. (1998).	* Eating Disorders Inventory (Garner & Olmsted, 1983). * Diagnostic Survey for Eating Disorders (Johnson, 1985). * Family Environment Scale (Moos & Moos, 1981) * Inventory of Parent and Peer Attachment (Armsden & Greenberg, 1987) * Mother-Father-Peer Scale (Epstein, 1983).	Not assessed	HbA1c levels were obtained at the time of participation.

Authors	Family functioning	Adherence	Metabolic control
Miller & Drotar (2003)	*Diabetes related autonomy (Saletsky, 1991). Internal consistency α = 0.87 to 0.93. * Diabetes Responsibility and conflict scale (Rubin et al. 1989). Internal consistency α = 0.85 to 0.94.	*Self care Inventory (La Greca et al. 1990). α = 0.83 to 0.86, *Health Care Provider Rating questionnaire (La Greca, et al. 1990). α = 0.91. * Medical chart to obtain the average number of glucose tests performed each day.	Not assessed.
Miller & Drotar (2007).	*Issues checklist (Robin & Foster, 1989) * Diabetes-Specific Conflict Questionnaire (Saletsky, 1991). * Interaction Behaviour Code (Robin & Foster, 1989) during a problem-solving task. Inter-rater reliability α = 0.74-0.98. * Modified version of The Melbourne Decision Making Questionnaire (Mann, Burnett, Radford & Ford, 1997). Reliability α =0.56-0.75.	* Self-Care Inventory (La Greca et al. 1990). * Health Care Provider Rating questionnaire (La Greca, et al. 1990). Validity α = 0.85 (Miller & Drotar, 2007). * Medical records reviewed to obtain average number of glucose tests performed each day over previous two weeks.	HbA1c obtained at time of participation.
Palmer et al. (2004).	* Diabetes Responsibility and Conflict Scale (Rubin et al. 1989). Internal consistency α = 0.89. * Psychosocial Maturity Inventory (Greenberger, Josselson, Knerr & Kneert al. 1974). Internal consistency α = 0.62. * Maternal reasons for transferring diabetes responsibility (Overstreet et al. 1995).	Not assessed.	Average HbA1c levels were recorded at the time of assessment and 2-12 months after participation.

Authors	Family functioning	Adherence	Metabolic control
Palmer et al. (2009).	* Diabetes Responsibility and Conflict Scale (Rubin et al., 1989). Internal consistency α =0.91. * Self-efficacy for Diabetes Management Scale (Iannotti et al. 2006) α = 0.81 to 0.90.	Not assessed.	HbA1c levels obtained from medical records at the time of recruitment.
Pereira et al. (2008).	* Diabetes Family Behaviour Scale (McKelvey et al., 1993). Adapted version. α = 0.60 to 0.91. * FES (Moos & Moos, 1986). α = 0.68 to 0.70.	* Self report questionnaire developed by the authors.	Four to six samples of HbA1c were collected at clinic appointments over a year.
Wiebe et al. (2005).	* Structured interview to assess maternal involvement in coping with diabetes stress (Wiebe et al. 2005). * Diabetes Responsibility and Conflict Scale (Rubin et al. 1989). α = 0.89 .	Self-care Inventory (La Greca et al. 1990). Internal consistency α = 0.72.	HbA1c levels obtained from medical records for the preceding 3-4months (available for 74% participants).
Wysocki (1993).	* Parent-Adolescent Relationship Questionnaire (Robin & Foster, 1989). Internal consistency α = 0.62 to 0.82.	Not assessed.	HbA1c levels were obtained from medical records within 6 months prior to participation and then over 1 year.

If you have any questions about this study or wish to speak to the researcher, then please contact:

Victoria Queralt
Trainee Clinical Psychologist:

Write to:
School of Psychology
Birmingham Univeristy
Edgbaston
B15 2TT

Telephone:

Email:

This research project is supervised by:

Dr Arie Nouwen
and
Dr Gary Law

School of Psychology
Birmingham Univeristy
Edgbaston
B15 2TT

Tel:

The research is organised and funded by the Birmingham Doctoral Course in Clinical Psychology.

The East Birmingham Local Research Ethics Committee has approved the study.

Information sheet for young person (aged 12-15 years)

You are being invited to take part in a research study:

Exploring dietary self-care in type 1 diabetes: views of young people and their parents

Before you decide, Please take time to read the following information carefully.

Talk about it with your family, friends, or nurse if you want to.

Please ask if there is anything that is not clear or if you would like more information.

What's the project about?

The study wants to find out several things;

- Your thoughts about having diabetes, how you manage your diabetes, what part of your diabetes diet you find enjoyable and not so enjoyable, and how you are coping.

- The study also wants to find out what your parent/guardian thinks about diabetes, how they think you manage, how they are coping and who takes responsibility for managing your diabetes.

Who can take part?

Young people, aged 12–18 years, with type 1 diabetes and their parent or guardian, take part.

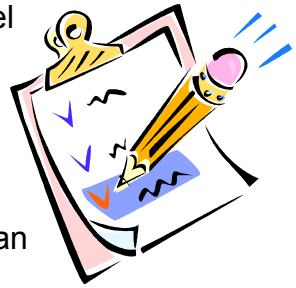
Do I have to take part?

No! It is up to you and your parent(s) to decide whether or not to take part. If you decide to take part, you can stop at any time during the research without giving a reason**.** The care you receive at the clinic will not change in anyway.

If I do take part, what will happen?

If you decide to take part you will be asked to sign a form saying that you understand what you have been asked to do and want to take part. The researcher will then either meet with you at your clinic appointment, or she may contact you by telephone.

You and your parent (guardian) will then be asked to fill out some questionnaires, about what you think and feel about having diabetes, how you are coping and who manages diabetes in the family.



It should not take more than 30 minutes to complete.

You can either; complete them at the clinic, take them home and return them by post, or the researcher can visit your home and go through them with you.

If you agree, we may also contact you in one year and ask whether you would be interested in answering the same questions.

What if there's a problem?

If at any time you want to speak with a researcher, then please use the contact details on the other side of this leaflet. You can also speak with the nurse or doctor at your diabetes clinic.

What are the possible benefits of taking part?

There are no direct benefits for you. However, by learning how young people and their families manage and think about diabetes, we hope to develop services that improve the lives of young people and their families who have to manage diabetes.

What are the possible disadvantages of taking part?

There are no risks involved. However, if taking part in this study upsets you in anyway, then you may want to speak with your family and/or friends. You should also speak with your diabetes nurse/doctor or contact the researcher.

What happens to the information?

All information collected about you and your family will be kept strictly confidential (private). Your name and address will be removed from the information you give and replaced by a code number so that you or your family cannot be recognised from it.

The results will reported in a thesis and in a professional journal. The results will be available to everyone who takes part.

If you have any questions about this study or wish to speak to the researcher, then please contact:

Victoria Queralt
Trainee Clinical Psychologist:

Write to:
School of Psychology
Birmingham Univeristy
Edgbaston
B15 2TT

Telephone:

Email:

This research project is supervised by:

Dr Arie Nouwen
and
Dr Gary Law

School of Psychology
Birmingham Univeristy
Edgbaston
B15 2TT

Tel:

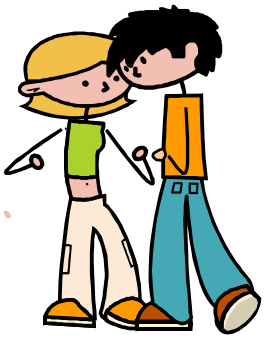
The research is organised and funded by the Birmingham Doctoral Course in Clinical Psychology.

The East Birmingham Local Research Ethics Committee has approved the study.

Information sheet for young person (aged 16-18 years)

You are being invited to take part in a research study:

Exploring dietary self-care in type 1 diabetes: views of young people and their parents



Before you decide, Please take time to read the following information carefully.

Talk about it with your family, friends, or nurse if you want to.

Please ask if there is anything that is not clear or if you would like more information.

What's the project about?

The study wants to find out several things;

• Your thoughts about having diabetes, how you manage your diabetes, what part of your diabetes diet you find enjoyable and not so enjoyable, and how you are coping.

• The study also wants to find out what your parent/guardian thinks about diabetes, how they think you manage, how they are coping and who takes responsibility for managing your diabetes.

Who can take part?

Young people, (aged 12–18 years), who have type 1 diabetes and their parent, or guardian, can take part.

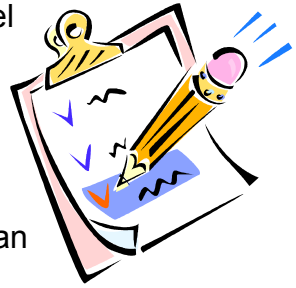
Do I have to take part?

No! It is up to you and your parent(s) to decide whether or not to take part. If you decide to take part, you can stop at any time during the research without giving a reason**.** The care you receive at the clinic will not change in anyway.

If I do take part, what will happen?

If you decide to take part you will be asked to sign a form saying that you understand what you have been asked to do and want to take part. The researcher will then either meet with you at your clinic appointment, or she may contact you by telephone.

You and your parent (guardian) will then be asked to fill out some questionnaires, about what you think and feel about having diabetes, how you are coping and who manages diabetes in the family.



It should not take more than 30 minutes to complete.

You can either; complete them at the clinic, take them home and return them by post, or the researcher can visit your home and go through them with you.

If you agree, we may also contact you in one year and ask whether you would be interested in answering the same questions.

What if there's a problem?

If at any time you want to speak with a researcher, then please use the contact details on the other side of this leaflet. You can also speak with the nurse or doctor at your diabetes clinic.

What are the possible benefits of taking part?

There are no direct benefits for you. However, by learning how young people and their families manage and think about diabetes, we hope to develop services that improve the lives of young people and their families who have to manage diabetes.

What are the possible disadvantages of taking part?

There are no risks involved. However, if taking part in this study upsets you in anyway, then you may want to speak with your family and/or friends. You should also speak with your diabetes nurse/doctor or contact us using the details at the end of this sheet.

What happens to the information?

All information collected about you and your family will be kept strictly confidential (private). Your name and address will be removed from the information you give and replaced by a code number so that you or your family cannot be recognised from it.

The results will reported in a thesis and in a professional journal. The results will be available to everyone who takes part.

Nobody will be able to identify anyone who takes part in the research.

Appendix F

Version 2 (13/02/2007)

UNIVERSITY OF BIRMINGHAM

Dear Young Person and Parent (or guardian),

Re: Exploring dietary self-care in type 1 diabetes: views of young people and their parents.

A research project is being carried out at this clinic. The study aims to improve families and health professionals understanding of how to best help young people manage diabetes in their lives. Previous research has recommended that we need to know more about how families understand diabetes and manage the treatment demands. As a result, young people (aged 12 – 18 years) with type 1 diabetes and their parent (or guardian) are being asked to complete questionnaires about their experiences and thoughts about diabetes.

As you are currently attending this clinic for diabetes, the responses you both give would be very valuable. There is more information about the study on the information sheet enclosed. Should you have any questions or require any further details, then please either speak to the researcher at the clinic, use the contact details below, or request that a researcher contacts you to discuss the project further by completing the enclosed contact information sheet.

If, after reading the information sheets, you think would both like to take part in the study please complete the consent form enclosed and return it to the diabetes team or researcher. You have the choice of completing the questionnaires now, at your next diabetes clinic appointment, for the researcher to come to your home and go through the questions with you or to return the questionnaires by post. Completing the questionnaires would take no more than 30 minutes.

I would like to thank you for taking the time to read this letter and hope to hear from you soon. If you have any queries, please contact me on the telephone number below.

Yours sincerely,

Victoria Queralt
Trainee Clinical Psychologist

Contact details
Clinical Psychology Doctorate Course
School of Psychology
University of Birmingham
Birmingham
B15 2TT
Telephone: [redacted]

Appendix G

Version 2 (13/02/07) Code number:

Contact information form

Title of Project:

Exploring dietary self-care in type 1 diabetes: views of young people and their parents

Name of Researcher: Victoria Queralt

If you would like to take part in this research or would like more time to think about it, please tick your preferred choice below:

☐ I would like to complete the questionnaires now.

☐ I would like to complete the questionnaires at our next out-patient visit.

☐ I would like to take the questionnaires home and return them by post.

☐ I would like to complete the questionnaires at home with the researcher.

My contact details are:

☐ I would like a member of the research team to contact me to discuss the project further. My contact details are:

Name of Young Person **Date** **Signature**

Name of Parent / Guardian **Date** **Signature**

Name of Person taking details **Date** **Signature**

Appendix H

Version 2 (13/02/2007) Code number: _____

JOINT CONSENT FORM (Parent of Young Person 12- 15 years)

Title of Project:

Exploring dietary self-care in type 1 diabetes: views of young people and their parents

Name of Researcher: Victoria Queralt

If you have decided that both yourself and your parent/guardian would like to take part in this research, then please initial each box below to show that you have understood what the research is about.

☐ I confirm that I have read and understand the information sheet dated 13/02/2007 (version 2) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.

☐ I understand that participation is voluntary and that I am free to withdraw at any time, without giving any reason, without my child's medical care or legal rights being affected.

☐ I understand that relevant sections of my child's medical notes may be looked at by the research team from Birmingham University where it is relevant to my taking part in this research and agree that this can be done.

☐ I agree for me and my child to take part in the above study.

☐ I agree to my child's GP being informed of our participation in the study

☐ Please tick if you are happy to be contacted in 1 year to complete similar questions.

Name of Parent / Guardian	**Date**	**Signature**
Name of Young Person	**Date**	**Signature**
Name of Person taking consent	**Date**	**Signature**

Appendix I

Version 2 (13/02/2007) Code number: ____

Consent form (young person 16 - 18 years)

Title of Project:

Exploring dietary self-care in type 1 diabetes: views of young people and their parents

Name of Researcher: Victoria Queralt

If you have decided that you would like to take part in this research, then please initial each box below to show that you have understood what the research is about.

☐ I confirm that I have read and understand the information sheet dated 13/02/2007 (Version 2) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.

☐ I understand 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.

☐ I understand that relevant sections of my medical notes may be looked at by the research team from Birmingham University where it is relevant to my taking part in this research and agree that this can be done.

☐ I agree for me and my parent to take part in the above study.

☐ I agree to my GP being informed of my participation in the study

☐ Please tick if you are happy to be contacted in 1 year to complete similar questions.

Name of Young Person	**Date**	**Signature**
Name of Person taking consent	**Date**	**Signature**

Appendix J

Version 2 (13/02/2007) Code number: _____

CONSENT FORM (Parent)

Title of Project:

Exploring dietary self-care in type 1 diabetes: views of young people and their parents

Name of Researcher: Victoria Queralt

If you have decided that you would like to take part in this research, then please initial each box below to show that you have understood what the research is about.

☐ I confirm that I have read and understand the information sheet dated 13/02/2007 (version 2) (version 1) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.

☐ I understand my participation is voluntary and that I am free to withdraw at any time, without giving any reason, without my child's medical care or legal rights being affected.

☐ I understand that relevant sections of my child's medical notes may be looked at by the research team from Birmingham University where it is relevant to my taking part in this research and agree that this can be done.

☐ I agree to take part in the above study.

☐ I agree to my child's GP being informed of my participation in the study

☐ Please tick if you are happy to be contacted in 1 year to complete similar questions.

_____	_____	_____
Name of Parent / Guardian	**Date**	**Signature**
_____	_____	_____
Name of Person taking consent	**Date**	**Signature**

Appendix K

UNIVERSITY OF BIRMINGHAM

Clinical Psychology Dept.
Birmingham University
Edgbaston
Birmingham
B15 2TT

Dr

Re:

The parent/guardian of the above named child has given me consent to inform you that they are currently participating in a research project that is titled 'Exploring dietary self-care in type 1 diabetes: views of young people and their parents'. The study aims to improve families and health professionals understanding of how to best help young people manage diabetes in their lives.

Participation requires a parent and young person with type 1 diabetes to complete a booklet of questionnaires about their experiences and thoughts about diabetes. Completion of the questionnaires takes about 30 minutes.

Should you require any additional information or have any queries please contact me at the above address or on [redacted]

Yours sincerely

Victoria Queralt
Trainee Clinical Psychologist
School of Psychology
University of Birmingham

Research supervisors
Dr Arie Nouwen and Dr Gary Law
University of Birmingham

Appendix L

Version 1 (01/08/2006)

Code number:

Exploring dietary self-care in type 1 diabetes: views of young people and their parents

YOUNG PERSONS

QUESTIONNAIRE BOOKLET

Thank you for agreeing to take part in this study

This booklet will take no more than 30 minutes to complete. Please take care to answer all the questions.

Please do not look at your parent's responses

Many thanks

General information

1) Today's date…….

2) What is your date of birth?…….(day/month/year)

3) What was your last blood glucose reading? …….

4) On average, how many times per day do you measure your blood glucose level? ……..

5) What type(s) of insulin do you use? ……..

6) On average, how many injections do you need each day?
……

Diabetes family responsibility

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

1 – You take or initiate responsibility for this almost all the time.
2 – You and your parent(s) share responsibility for this about equally.
3 – Your parents(s) take or initiate responsibility for this almost all 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 injections/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 an insulin reaction.			
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 an insulin reaction.			
14	Explaining absences to school to teachers or other school personnel.			
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.			

Beliefs about your diabetes

We are interested in your own personal views of how you see your diabetes. Please circle the answer that best describes how you feel about these statements.

1) How important is following your self-care recommendations (for example, diet, exercise and glucose testing) for controlling your diabetes?

Not at all important	Slightly important	Fairly important	Very Important	Extremely important

2) How important is controlling your blood glucose levels for avoiding complications from diabetes?

Not at all important	Slightly important	Fairly important	Very Important	Extremely important

3) How much has having diabetes changed your activities (that is your family and social events, work, and hobbies)?

None	Slightly	Moderately	A lot	Completely

4) How important do you believe healthy eating is for controlling your diabetes?

Not at all important	Slightly important	Fairly important	Very Important	Extremely important

5) How likely do you think it is that healthy eating will prevent future complications of your diabetes?

Not at all likely	Slightly likely	Fairly likely	Very Likely	Extremely likely

6) How likely do you think it is that physical activity will prevent future complications of your diabetes?

Not at all likely	Slightly likely	Fairly likely	Very Likely	Extremely likely

7) My diabetes strongly affects the way others see me.

Strongly disagree	Disagree	Neither agree nor disagree	Agree	Agree Strongly

8) My diabetes has major consequences on my life.

Strongly disagree	Disagree	Neither agree nor disagree	Agree	Agree strongly

Following your dietary plan for diabetes

Sometimes it's hard to follow a dietary plan for diabetes in lots of situations. Some of these situations are listed in this questionnaire. We would like to know how confident you are that you will be able to regularly follow your dietary plan in these situations.

Using the scale below, please indicate how confident you are in your ability to follow your dietary plan on a regular basis by writing a number between 0 and 10 on the line provided. If the statement does not apply to your situation, please write N/A.

For example, 'Going to the cinema with my friends'

When I go to the cinema with my friends they buy lots of foods that are high in calories and sugar. I feel like buying the same foods. In that situation I am not very confident that I would not buy those foods. My confidence score = 2.

If I always stick to my diabetes diet when I go with friends to the cinema, my confidence score = 10.

Confidence Scale

0	1	2	3	4	**5**	6	7	8	9	**10**
Not at all confident					Moderately confident					Totally confident

	CONFIDENCE (0-10)
1. When watching television	_____
2. When feeling tired or bored	_____
3. When alone at home	_____
4. When feeling wound up or worried	_____
5. When seeing friends eat sugary foods	_____
6. When I am upset	_____
7. When eating out	_____
8. When feeling annoyed or angry	_____
9. When very hungry	_____
10. When feeling sad	_____
11. When celebrating with others	_____

Questions continued on next page

Confidence Scale

0	1	2	3	4	5	6	7	8	9	10
	Not at all confident					Moderately confident				Totally confident

CONFIDENCE
(0-10)

12. When offered the 'wrong' foods e.g. chocolate, sweets, biscuits _____
13. When the 'wrong' (sugary) foods are available at home _____
14. When it is difficult to get hold of the foods I should eat for my diabetes (fruit, vegetables, etc.) _____
15. When ill _____
16. When going out with friends _____
17. When on holiday _____
18. At parties, when the 'wrong' (sugary or fatty) foods are offered to me _____
19. When I am in a hurry _____
20. When preparing my own meal _____
21. When faced with appealing foods that are sugary or fatty in a supermarket or vending machines _____
22. When my life doesn't go to plan _____
23. When I need to eat (snacks, regular meals) even though others are not eating _____
24. When feeling well _____
25. When I want more variety in my diet _____
26. When craving for high calorie foods _____
27. When on the way to or from school _____

Beliefs about following a diabetes dietary plan

During your visits to the clinic or hospital, the dietician and/or doctor have given you dietary recommendations that will help to better control your diabetes. There are many reasons as to **why you would chose to follow this dietary plan**. The following items might explain why you would follow such a dietary plan. For each item, chose a number which shows how strongly each is a reason for you to follow your dietary plan.

For example, if you follow your dietary plan because you do not want to gain weight, and you 'moderately agree' with this reason, then you circle the number '3'

I do not agree at all	I agree a little bit	I moderately Agree	I considerably agree	I completely agree
1	2	3	4	5

I follow my dietary plan…

1)	… because I want to remain healthy as long as possible.	1	2	3	4	5
2)	… for the satisfaction of eating healthily.	1	2	3	4	5
3)	… but I feel that I'm wasting my time in trying to have healthy eating habits.	1	2	3	4	5
4)	… because I don't want to be told off by my parents.	1	2	3	4	5
5)	… because I do enjoy meals and snacks that allow me to keep good control of my blood glucose.	1	2	3	4	5
6)	… but I can't see what I'm getting out of it.	1	2	3	4	5
7)	… because my doctor asks me to.	1	2	3	4	5
8)	… but I don't know why I'm doing it.	1	2	3	4	5
9)	… because it's a good idea to follow the dietary recommendations so that I won't get other health problems.	1	2	3	4	5
10)	… because my parents would be upset if I didn't.	1	2	3	4	5
11)	… to feel better.	1	2	3	4	5
12)	… because I like eating food that is good for my health..	1	2	3	4	5

Identifying your problem areas in diabetes

Directions: Living with diabetes can sometimes be difficult. In day-to-day life, there may be many problems and hassles with your diabetes. The problems may range from minor hassles to major life difficulties. Listed below are a variety of possible problem areas which people with diabetes may have. Think about how much each of the items below may have upset or bothered you **DURING THE PAST MONTH** and circle the appropriate number.

Please note that we are asking you how much each item may be bothering you in your life, NOT whether the item is merely true to you. If you feel that an item is not a bother or a problem for you, you would circle '1'. If it is very bothersome to you, you would circle '6'.

		not a problem			moderate problem		serious problem
1	Not having clear and specific goals for my diabetes care.	1	2	3	4	5	6
2	Feeling discouraged with my diabetes treatment plan.	1	2	3	4	5	6
3	Feeling scared when I think about my diabetes.	1	2	3	4	5	6
4	Uncomfortable social situations related to my diabetes care, e.g. people telling me what to eat.	1	2	3	4	5	6
5	Feeling deprived regarding food and meals.	1	2	3	4	5	6
6	Feeling depressed when I think about my diabetes.	1	2	3	4	5	6
7	Not knowing if my mood or feelings are related to my diabetes.	1	2	3	4	5	6
8	Feeling overwhelmed by my diabetes.	1	2	3	4	5	6
9	Worrying about having low blood sugar reactions.	1	2	3	4	5	6
10	Feeling angry about my diabetes.	1	2	3	4	5	6
11	Feeling constantly concerned about my food and eating.	1	2	3	4	5	6
12	Worrying about the future and the possibility of having serious complications.	1	2	3	4	5	6
13	Feelings of guilt or anxiety when I get off track with my diabetes management.	1	2	3	4	5	6
14	Not 'accepting' my diabetes.	1	2	3	4	5	6
15	Feeling unsatisfied with my diabetes doctor.	1	2	3	4	5	6
16	Feeling my diabetes is taking up too much of my mental and physical energy every day.	1	2	3	4	5	6
17	Feeling alone with my diabetes.	1	2	3	4	5	6
18	Feeling that my friends and family aren't supportive of my efforts to help me manage my diabetes.	1	2	3	4	5	6
19	Coping with the complications of my diabetes.	1	2	3	4	5	6
20	Feeling 'burned out' by the constant effort needed to manage my diabetes.	1	2	3	4	5	6

Diabetes self-care

The questions below ask about your diabetes self-care activities during the past 7 days. If you were ill during the past 7 days, please think back to the last 7 days that you were not ill. Please answer the questions as honestly and accurately as you can.

1) How often did you follow your recommended diet over the last 7 days? (If you have not been given a specific diet by the diabetes care team, please answer according to the general guidelines you have been given).

Always	Usually	Sometimes	Rarely	Never
☐	☐	☐	☐	☐

2) How much of the time did you successfully limit calories as recommended in your healthy eating for diabetes control?

None of the them	A few of the them	Some of the them	Most of the them	All of the them
☐	☐	☐	☐	☐

3) During the past week, how many of your meals included high fibre food, such as fresh fruits, fresh vegetables, and peas, bran?

None of the them	A few of the them	Some of the them	Most of the them	All of the them
☐	☐	☐	☐	☐

4) During the past week, how many of your meals included high fat foods, such as butter, ice cream, oil, nuts and seeds, mayonnaise, fried food, salad dressing, crisps, pies, pizzas and sausages?

None of the them	A few of the them	Some of the them	Most of the them	All of the them
☐	☐	☐	☐	☐

5) During the past week, how many of your meals included sweets and desserts, such as pastries, cake, jam, soft drinks (not diet), chocolate and cream biscuits?

None of the them	A few of the them	Some of the them	Most of the them	All of the them
☐	☐	☐	☐	☐

6) How often did you exercise the amount suggested by your doctor or diabetes nurse specialist?

None of the time	A little of the time	Some of the time	Most of the time	All of the time
☐	☐	☐	☐	☐

7) On how many of the last 7 days did you exercise for at least 20 minutes?

0	1	2	3	4	5	6	7
☐	☐	☐	☐	☐	☐	☐	☐

8) On how many of the last 7 days did you exercise on top of what you do at school or as part of your work?

0	1	2	3	4	5	6	7
☐	☐	☐	☐	☐	☐	☐	☐

9) On how many of the last 7 days (that you were not ill) did you did you test your glucose (blood sugar) level?

0	1	2	3	4	5	6	7
☐	☐	☐	☐	☐	☐	☐	☐

10) Over the last 7 days how many of the glucose (blood sugar) tests recommended by your doctor did you actually do (covering all meals and pre bed)?

None of the them	A few of the them	Some of the them	Most of the them	All of the them
☐	☐	☐	☐	☐

11) How many of your recommended insulin injections / medication did you take in the last 7 days that you were supposed to?

None of the them	A few of the them	Some of the them	Most of the them	All of the them
☐	☐	☐	☐	☐

12) How many of your recommended insulin injections / medication did you have at the time you were supposed to?

None of the them	A few of the them	Some of the them	Most of the them	All of the them
☐	☐	☐	☐	☐

THANK YOU FOR COMPLETING THIS BOOKLET

Appendix M

Version 1 (01/08/2006) Code number:

Exploring dietary self-care in type 1 diabetes: views of young people and their parents

PARENT

QUESTIONNAIRE BOOKLET

Thank you for agreeing to take part in this study

This booklet will take no more than 30 minutes to complete. Please take care to answer all the questions.

Please do not look at your child's responses

Many thanks

General information

1) The date today ……(years and months)

2) How old is your child? ……. (years and months)

3) Is your child: male or female (please circle appropriate)

4) How many children are living in your family home? ……

5) Do you have a partner with whom you live? Yes / No (please circle)

Diabetes family responsibility

For each of the following parts of your child's diabetes 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 the time.
2 – Parent(s) and child share responsibility for this about equally.
3 – Parents(s) take or initiate responsibility for this almost all 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 injections/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 an insulin reaction.			
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 an insulin reaction.			
14	Explaining absences to school to teachers or other school personnel.			
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.			

Beliefs about your child's diabetes

We are interested in your own personal views of how you see your child's diabetes. Please circle the answer that best describes how you feel about these statements.

1) How important is following self-care recommendations (for example, diet, exercise and glucose testing) for controlling your child's diabetes?

Not at all important	Slightly important	Fairly important	Very important	Extremely important

2) How important is controlling blood glucose levels for avoiding complications from diabetes?

Not at all important	Slightly important	Fairly important	Very important	Extremely important

3) How much has your child having diabetes changed your activities (that is your family and social events, work, and hobbies)?

None	Slightly	Moderately	A lot	Completely

4) How important do you believe healthy eating is for controlling your child's diabetes?

Not at all Important	Slightly Important	Fairly important	Very important	Extremely important

5) How likely do you think it is that healthy eating will prevent future complications of your child's diabetes?

Not at all Likely	Slightly Likely	Fairly likely	Very likely	Extremely likely

6) How likely do you think it is that physical activity will prevent future complications of your child's diabetes?

Not at all Likely	Slightly Likely	Fairly likely	Very likely	Extremely likely

7) Diabetes strongly affects the way others see my child.

Strongly Disagree	Disagree	Neither agree nor disagree	Agree	Agree Strongly

8) Diabetes has major consequences on my child's life.

Strongly Disagree	Disagree	Neither agree nor disagree	Agree	Agree strongly

Following a dietary plan for diabetes

Sometimes it's hard to follow a dietary plan for diabetes, this happens in lots of situations. Some of these situations are listed in this questionnaire. We would like to know how confident you are that YOUR CHILD would be able to regularly follow his/her dietary plan in these situations.

Using the scale below, please indicate how confident you think YOUR CHILD'S ability would be to follow his/her dietary plan on a regular basis by writing a number between 0 and 10 on the line provided. If the statement does not apply to your child, please write N/A.

For example, 'Going to the cinema with friends'

When my child goes to the cinema with their friends, they buy lots of foods that are high in calories and sugar. I think my child would feel like buying the same foods. In that situation I am not very confident that he/she would not buy those foods. My confidence score = 2.

OR

I think my child always sticks to their diabetes diet when they go out with friends to the cinema, my confidence score = 10.

Confidence Scale

0	1	2	3	4	**5**	6	7	8	9	**10**
Not at all confident					Moderately confident					Totally confident

	CONFIDENCE (0-10)
28. When watching television	_____
29. When feeling tired or bored	_____
30. When alone at home	_____
31. When feeling wound up or worried	_____
32. When seeing friends eat sugary foods	_____
33. When he/she is upset	_____
34. When eating out	_____
35. When feeling annoyed or angry	_____
36. When very hungry	_____
37. When feeling sad	_____
38. When celebrating with others	_____

Questions continued on next page

Confidence Scale

0	1	2	3	4	5	6	7	8	9	10
Not at all confident					Moderately confident					Totally confident

CONFIDENCE
(0-10)

39. When offered the 'wrong' foods e.g. chocolate, sweets, biscuits _____
40. When the 'wrong' (sugary) foods are available at home _____
41. When it is difficult to get hold of the foods he/she should eat for his/her diabetes (fruit, vegetables, etc.) _____
42. When ill _____
43. When going out with friends _____
44. When on holiday _____
45. At parties, when the 'wrong' (sugary or fatty) foods are offered to him/her _____
46. When he/she is in a hurry _____
47. When preparing their own meal _____
48. When faced with appealing foods that are sugary or fatty in a supermarket or vending machines _____
49. When his/her life doesn't go to plan _____
50. When he/she needs to eat (snacks, regular meals) even though others are not eating _____
51. When feeling well _____
52. When he/she wants more variety in his/her diet _____
53. When craving for high calorie foods _____
54. When on the way to or from school _____

Beliefs about why your child follows a diabetes dietary plan

During your visits to the clinic or hospital, the dietician and/or doctor have given your child dietary recommendations that will help to better control their diabetes. There are many reasons as to **why they would chose to follow this dietary plan**. The following items might explain why your child would follow such a dietary plan. For each item, chose a number that shows how strongly you believe each explains why your child follows their dietary plan.

For example, if you think your child follows their dietary plan because they do not want
to gain weight, and you 'moderately agree' with this reason, then you circle the number '3'

I do not agree at all	I agree A little bit	I moderately agree	I considerably agree	I completely agree
1	2	3	4	5

I believe my child follows their dietary plan……

1)	… because he/she wants to remain healthy as long as possible.	1	2	3	4	5
2)	… for the satisfaction of eating healthily.	1	2	3	4	5
3)	… but feels that he/she is wasting their time in trying to have healthy eating habits.	1	2	3	4	5
4)	… because he/she doesn't want me to tell him/her off.	1	2	3	4	5
5)	… because he/she enjoys meal and snacks that allow him/her to keep good control of his/her blood glucose.	1	2	3	4	5
6)	... but he/she can't see what he/she's getting out of it	1	2	3	4	5
7)	…because his/her doctor asks him/her to.	1	2	3	4	5
8)	… but he/she doesn't know why he/she's doing it	1	2	3	4	5
9)	… because it's a good idea to follow the dietary recommendations so that I won't get other health problems.	1	2	3	4	5
10)	…because I would be upset he/she didn't.	1	2	3	4	5
11)	… to feel better.	1	2	3	4	5
12)	… because he/she likes eating food that is good for his/her health..	1	2	3	4	5

Identifying problem areas in diabetes

Directions: Living with diabetes can sometimes be difficult. In day-to-day life, there may be many problems and hassles with your child's diabetes. The problems may range from minor hassles to major life difficulties. Listed below are a variety of possible problem areas which people who care for children with diabetes may have. Think about how much each of the items below may have upset or bothered you **DURING THE PAST MONTH** and circle the appropriate number.

Please note that we are asking you how much each item may be bothering you in your life, NOT whether the item is merely true to you. If you feel that an item is not a bother or a problem for you, you would circle '1'. If it is very bothersome to you, you would circle '6'.

		not a problem		moderate problem		serious problem	
1	Not having clear and specific goals for my child's diabetes care.	1	2	3	4	5	6
2	Feeling discouraged with my child's diabetes treatment plan.	1	2	3	4	5	6
3	Feeling scared when I think about my child living with diabetes.	1	2	3	4	5	6
4	Uncomfortable social situations relating to my child's diabetes care, e.g. people telling them what to eat.	1	2	3	4	5	6
5	Worrying that my child feels deprived regarding food and meals.	1	2	3	4	5	6
6	Feeling depressed when I think about my child living with diabetes.	1	2	3	4	5	6
7	Not knowing if my child's mood or feelings are related to their diabetes.	1	2	3	4	5	6
8	Feeling overwhelmed by my child's diabetes.	1	2	3	4	5	6
9	Worrying about my child having low blood sugar reactions.	1	2	3	4	5	6
10	Feeling angry when I think about my child living with diabetes.	1	2	3	4	5	6
11	Feeling constantly concerned about my child's food and eating.	1	2	3	4	5	6
12	Worrying about the future and the possibility of my child having serious complications.	1	2	3	4	5	6
13	Feelings of guilt or anxiety when my child gets off track with his/her diabetes management.	1	2	3	4	5	6
14	Not 'accepting' my child's diabetes.	1	2	3	4	5	6
15	Feeling unsatisfied with my child's diabetes doctor.	1	2	3	4	5	6
16	Feeling my child's diabetes is taking up too much of my mental and physical energy every day.	1	2	3	4	5	6
17	Feeling alone with my child's diabetes.	1	2	3	4	5	6
18	Feeling that my friends and family aren't supportive of my efforts to help my child manage his/her diabetes.	1	2	3	4	5	6
19	Coping with the complications of my child's diabetes.	1	2	3	4	5	6
20	Feeling 'burned out' by the constant effort needed to manage my child's diabetes.	1	2	3	4	5	6

THANK YOU FOR COMPLETING THIS BOOKLET