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Managing Diabetes in Adolescence: An Exploration of the Relevant Literature and Lived Experiences

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**Managing Diabetes in Adolescence:
An Exploration of the Relevant Literature and Lived Experiences**

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North Wales Clinical Psychology Programme

Thesis submitted for the degree of Doctor of Clinical Psychology
June 2016

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Declarations

This work has not been previously accepted in substance for any degree and is not being concurrently submitted in candidature for any degree.

Signed

Date

Statement 1

This thesis is the result of my own investigations, except where otherwise stated. Other sources are acknowledged by footnotes giving explicit references. A list of references is appended.

Signed

Date

Statement 2

I agree to deposit an electronic copy of my thesis (the Work) in the Bangor University (BU) Institutional Digital Repository, the British Library ETHOS system, and /or in any other repository authorized for use by Bangor University and where necessary have gained the required permissions for the use of third party material.

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Thesis Abstract

This thesis explores the roles of family and healthcare professionals in type 1 diabetes (T1D) in adolescence. The first paper is a systematic review of literature regarding family-based interventions for adolescents with T1D. Adolescence is known to be a particularly challenging time, associated with deterioration in diabetes management and increased family conflict. A systematic search of three electronic databases plus hand-searches of relevant papers, identified 26 papers reporting on 16 intervention studies that met the inclusion and exclusion criteria. Interventions varied considerably in their content and duration. A narrative synthesis considers the effectiveness of these interventions on health, family-related and adolescent psychosocial outcomes. The most intensive interventions had the most support, however there is also promising evidence regarding less intense, quarterly psychoeducational and problem-solving interventions.

The empirical paper explored the lived experience of eight healthcare professionals' working with adolescents with T1D and poor adherence to treatment. Data was analysed using interpretative phenomenological analysis and four superordinate themes were identified; "empathy and insight", "negotiating relationships", "impact on self" and "coping". Professionals empathised with the adolescents whilst also being driven by insight of the risks of poor adherence that the adolescents could not comprehend. They valued a close relationship with the adolescents but also had to balance parental involvement. Poor adherence had a personal impact on each professional, including a sense of powerlessness and failure, but also reward. Professionals coped with these experiences in different way, including negotiating when to do more and when to let go. Clinical implications include a potential benefit of acceptance-based training and reflective practice.

Contributions to theory and clinical practice considers the overall impact of these findings. Particular reference is made to the systemic factors involved in adolescent diabetes management and the role of clinical psychology within paediatric diabetes teams.

Parent and Family-based Interventions for Adolescents with Diabetes:

A Systematic Review.

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Abstract

Background: Adolescence is a particularly challenging time for diabetes management. It is associated with poor glycaemic control and treatment adherence, as well as increased family conflict and a reduction in parental support. Interventions aimed at improving family-functioning could have positive implications for adolescents' health and well-being. *Aims:* This paper systematically reviewed the literature to evaluate the evidence for family-based interventions for adolescents with diabetes. Identifying the different types of intervention and considering the effectiveness of these interventions on health, family-related and adolescent psychosocial outcomes. *Method:* Three electronic databases (PsycInfo, Web of Science, CINAHL) were searched for family-based intervention studies that met the inclusion criteria. *Results:* Twenty-six papers were identified that described 16 intervention studies. The interventions varied considerably but could be categorised into five groups: quarterly psychoeducation and problem-solving interventions; behavioural family systems therapy; multisystemic therapy; group interventions; and self-directed parenting interventions. The most intensive interventions had the greatest support, however there was also promising evidence regarding less intense, quarterly psychoeducational and problem-solving interventions. Results were considered with regard to quality of the included studies and limitations. *Conclusions:* Family-based interventions can have beneficial effects on adolescent health, family-functioning and psychosocial outcomes. However, the considerable variability in the type of intervention and outcome measures used makes it difficult to draw conclusions. Intensive and individualised family therapy and behavioural interventions are most well-supported but require cost-benefit analysis. Further research is needed to better understand the mechanism of change, and the generalisability of findings. Future research should aim to include more long-term follow-up measures and assess adolescent well-being.

Key words: adolescence; diabetes; family; parents; glycaemic control; systematic review.

1.0 Introduction

Type 1 Diabetes (T1D) is life-long condition characterised by an inability to produce the hormone insulin. In order to regulate blood-glucose, individuals must follow an exhaustive and complex daily treatment regime of regularly testing blood-glucose levels, closely monitoring diet and exercise, and administering insulin (National Institute for Health and Care Excellence, NICE, 2015). Failure to regulate blood-glucose levels, or maintain glycaemic control, can have serious and long-term health implications, including kidney failure, coronary heart disease and amputation (Diabetes UK, 2015). Suboptimal glycaemic control has also been associated with psychological implications, including depression, anxiety and eating disorders (Bernstein, Stockwell, Gallagher, Soren & Rosenthal, 2013; Lustman et al., 2000; Peterson, Fischer & Young-Hyman, 2014).

Adolescence is a particularly challenging time for diabetes management. It is well documented that adolescents are at increased risk of poor glycaemic control (Bryden et al., 2001; Hilliard et al., 2013; Rausch et al., 2012). Physiological changes that occur during puberty can decrease the body's sensitivity to insulin (Bloch, Clemon & Sterling, 1987). In addition to this, emotional, behavioural and social factors associated with adolescence can also adversely affect glycaemic control and diabetes management (La Greca, Follansbee & Skyler, 1990; Delamater, 2009).

Treatment adherence has been found to decrease significantly as young people transition into adolescence (Morris et al., 1997; Johnson et al., 1992), particularly the frequency of blood-glucose monitoring (Rausch et al., 2012). Family discord and diabetes-related distress have also been found to be predictors of suboptimal diabetes management and control (Hilliard et al., 2013).

Adolescence has been identified as a time of increased conflict over diabetes management (Hessler, Fisher, Polonsky & Johnson, 2016). Dysfunctional family interactions,

authoritarian parenting styles and diabetes-related stress have all been found to be negatively correlated with glycaemic control (Tsiouli et al., 2013). Parental involvement in diabetes care is associated with better glycaemic control (Wysocki et al., 2009). However, research has shown that parental involvement in diabetes care diminishes over the course of childhood, into adolescence (Schilling, Knafl & Grey, 2006) and is complicated by the developing autonomy and transition of responsibility. Qualitative research suggests parents of adolescents often struggle to know when and how to relinquish responsibility (Carroll & Marrero, 2006). Associations between family-functioning and diabetes management suggest that interventions aimed at improving family-functioning could have positive implications for adolescent health and well-being.

NICE guidelines (2015) recommend that diabetes treatment for young people consist of both medical and psychological care. A number of papers have explored the effectiveness of psychological interventions on diabetes control. Two systematic reviews have included meta-analyses of psychological and family-based interventions for children and adolescents (Armour, Norris, Jack, Zhang & Fisher, 2005; Winkley, Landau, Eisler & Ismail, 2006). Both reported moderate effects of family-based interventions on glycated haemoglobin (HbA1c), a measure of glycaemic control. Winkley et al. (2006) found a small to moderate effect size for psychological interventions that increased slightly when restricted to family interventions. This suggests that family interventions may be more effective for children and adolescents' health outcome. However, there was significant variation in the type of intervention and outcome measures that was not explored. Given this, and the small number of studies included, these results should be interpreted with caution.

A later review did explore the different types of family-based interventions aimed at enhancing health outcomes in children and adolescent with T1D (McBroom & Enriquez, 2009). This review consisted of nine randomised controlled trials published between 1985 and

2007. The interventions varied considerably in their duration, method of delivery (e.g. group vs. individual) and theoretical background (e.g. behavioural therapy, systemic theory). Overall, family-centred interventions were found to be effective in enhancing health outcomes, although outcomes varied according to the different interventions used. However, each of these reviews focused predominantly on health outcomes. Family-interventions for adults with T1D have been found to demonstrate beneficial effects on a range of psychosocial outcomes, including self-efficacy and perceived support (Baig et al., 2015). Given the mental health risks associated with T1D, and the psychosocial factors associated with glycaemic control, it is important that the effect of interventions on outcomes such as, family-functioning and well-being, is also explored.

Previous reviews have tended to consider children and adolescents as a single population. However, as explored earlier, adolescence involves unique challenges regarding emotional, social and behavioural development and family functioning (La Greca, Follansbee & Skyler, 1990; Delamater, 2009). Lohan, Morawski and Mitchell (2012) recently reviewed parenting interventions for parents of children under ten years with T1D. They proposed that the developmental tasks particular to childhood and adolescence warrant distinction as they have different implications for both the psychological interventions and outcomes measured. Although adolescence is the more common age group included in diabetes intervention studies (McBroom & Enriquez, 2009) the effectiveness of interventions for this age group has not been reviewed specifically.

Considering the crucial time of adolescence and the important role that parents and families can play in diabetes-management, this current paper aims to review family-based interventions for adolescents with T1D. Given the evidenced associations between parental involvement, conflict and glycaemic control, it is thought that interventions aimed at targeting family-functioning could be beneficial in improving adolescent diabetes outcomes.

This paper will provide an up-to-date systematic review of the evidence. The significant variability in both what constitutes family-based interventions and the types of outcomes measured, suggests that a quantitative synthesis, such as meta-analysis, would not be appropriate. A narrative synthesis will enable more in-depth exploration of the following questions:

1. What is the evidence on the effectiveness of family-based interventions with adolescents with T1D?
2. How do the interventions vary across the studies?
3. What are the different outcome variables assessed, and what is the effect of the interventions on health, family and psychosocial-related outcomes?

2.0 Method

2.1 Search Strategy

A systematic search for relevant papers was conducted using three electronic databases (Psycinfo, Web of Science and CINAHL) covering a twenty year time period (March 1996 - March 2016). The following search terms were used, '*diabetes*' AND '*child**' OR '*paediatr**' OR '*pediatr**' OR '*adolescen**' OR '*teenag**', AND '*parent*' OR '*family*', AND '*intervention*' OR '*treatment*' OR '*trial*'. The title, keywords and abstract of all papers were screened for relevance. The full texts of all relevant papers were obtained and reviewed for eligibility. This process is outlined in Figure 1, which includes the numbers of papers retrieved and accepted/rejected at each stage. In addition to this, a hand search of the reference lists of all included studies and three relevant review papers (Armour et al., 2005; Winkley et al., 2006; McBroom & Enriquez, 2009) were also screened for additional papers. No further eligible studies were found.

2.2 Inclusion Criteria

Eligible studies were required to meet the following criteria:

- i) An intervention study (controlled or uncontrolled) published in a peer reviewed journal that evaluated the effectiveness of a family and/or parent interventions for adolescents with T1D.
- ii) Participants were adolescents aged between 12 and 19 years (if age range extended beyond this then mean age must be >12.0 years and <19.0 years)
- iii) Participants had a diagnosis of T1D (if sample included participants with Type 2 diabetes, condition must be insulin-dependent and $<20\%$ of sample)
- iv) The intervention involved at least one parent or care-giver, and had a focus on parenting and/or family functioning (family member involvement must be clearly described)
- v) The study reported quantitative outcome measures relating to one or more of the following; adolescent health (e.g. glycaemic control, adherence), family functioning (e.g. diabetes related conflict, responsibility for diabetes care), and adolescent well-being (e.g. quality-of-life, self-concept).

Studies were excluded on the basis of the following criteria.

- i) Published before March 1996
- ii) Not published in English
- iii) No relevant outcome measures reported
- iv) Parent/family involvement in intervention not clearly reported or described

[INSERT FIGURE 1]

2.3 Data Extraction

Relevant data was systematically extracted from the selected papers by the primary author. In order to summarise findings relating to the effectiveness of the interventions the follow data

was extracted from each paper; year of publication, country in which study was conducted, characteristics of participants, summary of intervention used (including number of session, group or individual), whether a control group was included (and if so the type of control group), outcome measures used, and a summary of findings. Extracted data is presented in Table 1.

2.4 Quality Assessment

Each study was assessed for quality according to study design, randomisation, and risk of bias regarding selection, detection and attrition. A checklist (see Appendix A) was developed based on the quality assessment tools of Jadad and colleagues (1996) and informed by Greenhalgh and Brown (2014) and the quality assessments undertaken in related systematic reviews (Armour et al., 2005; Winkley et al., 2006).

2.5 Data Synthesis

Due to significant heterogeneity between studies regarding the interventions, method and outcome measures used, it was considered more appropriate to synthesise and present the data narratively, rather than conducting a meta-analysis. This review aims to explore in depth the variation in family-based intervention and outcome measures, which has been beyond the scope of previous meta-analysis. Results are presented in four sections: the first provides a descriptive overview of the studies included; the next two sections explore the different types of interventions used and the various outcomes measures assessed; lastly the final section reviews the effectiveness of the interventions for each of the main outcome variables.

3.0 Results

[INSERT TABLE 1]

3.1 Overview of Studies

As outlined in Table 1, the systematic search resulted in 26 papers describing 16 intervention studies¹. All studies were published between 1999 and 2015. The majority of interventions were conducted in the United States (n=14) and two were conducted in the UK (Doherty et al., 2013; Murphy et al., 2012). Sample sizes ranged from 18 to 390, and a total of 2171 young people with diabetes were included across all studies. All studies focused on adolescents. The age of participants ranged from 8 to 19 years, and the overall mean age was 13.7 years. The percentage of females in each sample varied from 33% (Harris et al., 2005) to 58% (Carpenter et al., 2013).

Twelve studies consisted of only participants with T1D. Four studies (Carpenter et al., 2013; Ellis et al., 2012; Wysocki et al., 1999; Wysocki et al., 2006) included young people with type 2 diabetes that were insulin-dependent and in all cases made up less than 10% of the sample.

All studies used community samples. The majority were recruited via the diabetes clinic with which they received their routine diabetes care. One study recruited participants via diabetes charities (Doherty et al., 2013). Another recruited adolescents under the care of a diabetes clinic that had been referred to a mental health centre for psychosocial support (Kichler et al., 2013).

The duration of diabetes diagnosis varied across studies. Three studies had no restriction on duration for eligibility, one stipulated a duration of over three months, three stipulated a duration of at least six month, eight stated participants must have been diagnosed for over one year and one study stated two years. The mean duration ranged from 2.7 years to 6.5 years.

¹ The primary reference will be used to refer to each study throughout.

Seven studies had eligibility criteria regarding baseline glycaemic control, as measured by glycated haemoglobin level (HbA1c). Anderson et al. (1999) recruited participants with “reasonable” glycaemic control, operationalised as HbA1c between 6.6% and 10.4%. Three studies recruited only participants with HbA1c readings $\geq 8\%$ (Ellis et al., 2005; Ellis et al., 2012; Wysocki et al., 2006), two required HbA1c readings $\geq 9\%$ (Harris et al., 2005; 2015) and one included only participants with HbA1c readings $\geq 10\%$ (Ellis et al., 2004). The mean baseline HbA1c level ranged from 8.4% to 11.9%. Given that recent guidelines recommend children and young people aim for an HbA1c level of 6.5% (NICE, 2015) this indicated that all study samples had average HbA1c readings above the optimal level, denoting suboptimal control.

Fourteen studies were described as randomised controlled trials (RCT) and included comparison to a control group or groups. The remaining two studies used a within group pre and post design. Of the studies including comparison groups, two used a waiting-list control and four studies compared the intervention to standard diabetes care only, which involved continuing with routine diabetes medical appointments and treatment. Two studies (Ellis et al., 2004; 2005) stated that no restriction was placed on participants in the standard care group accessing mental health services for the duration of the study, however the number of participant that received such care was minimal. Five studies involved two comparison groups, standard care and an attentional control group in the form of educational support. This tended to be restricted to education about diabetes management without any focus on family functioning. One study compared the family intervention to telephone support, a weekly call using a non-directive counselling approach. Another study compared an in-clinic family-based intervention to one delivered via Skype (internet-based video calling).

3.1.1 Quality of Studies

Studies were assessed for quality and risk of bias according to the criteria presented in Table 2. Studies were given a score between one and six, a higher score denoting higher quality. As shown in Table 2, the majority of studies were of moderate quality, scoring between three and four points. Only one study (Nansel et al., 2012) was rated of particularly high quality with six points. All of the studies clearly stated their eligibility criteria and this was deemed to be appropriate and representative of the study population. Only two studies reported the assessor being blind to the experimental condition, and this was recorded as being to the extent possible in a behavioural study. Only half of the studies clearly reported the number and reason for participant drop out. In only two cases where attrition was reported was more than 20% of the sample lost to follow-up and/or intention-to-treat analysis was not used.

[INSERT TABLE 2]

3.2 Overview of the Interventions

The studies reviewed were all parenting or family-based interventions but varied substantially in their content, duration, intensity and mode of delivery. The length of intervention ranged from a total of four sessions (Anderson et al., 1999; Holmes et al., 2014) to a minimum of two sessions per week over a six month period (Ellis et al., 2005; Ellis et al., 2012). The length of study period ranged from between 5-8 weeks (Harris et al., 2005) to two years (Katz et al., 2014; Nansel et al., 2011).

A descriptive summary of each type of intervention is presented in Table 3. The majority of interventions (n=11) involved individual sessions for adolescent and parent (or care-giver) dyads. Five studies evaluated quarterly psychoeducation and problem-solving interventions. These interventions were fairly low intensity and consisted of three or four sessions per year, often coinciding with the adolescent's routine diabetes clinic appointment. Sessions lasted between 15 and 40 minutes. Three of these described the interventions as family

teamwork (TW; Anderson et al., 1999; Holmes et al., 2014; Laffel et al., 2003) that took place over one year. The “WE CAN manage diabetes” intervention (Nansel et al., 2012) was held over two years and also included telephone contact between sessions. Katz et al. (2014) also evaluated a psychoeducation intervention delivered over two years. This was a multifaceted intervention where families were assigned a non-medical care ambassador as well as attending psychoeducation sessions.

Four studies evaluated Behavioural Family Systems Therapy (BFST; Robin & Foster, 1989), an individualised therapy aimed at addressing parent-adolescent conflict (Wysocki et al., 1999; Harris et al., 2005; Wysocki et al., 2006; Harris et al., 2015). In each of the four studies adolescents and their parent(s) attended ten 90-minute sessions with a therapist trained in BFST, who was supervised and video-recorded to ensure adherence to the model. In the two later studies (Wysocki et al., 2006; Harris et al., 2015) revisions were made to BFST to include diabetes-specific adaptations (BFST-D) as outlined in Table 3. Harris et al. (2015) also further adapted BFST-D to be delivered via Skype (internet-based video calling).

Three studies evaluated the effectiveness of multisystemic therapy (MST; Henggeler, Schoenwald, Bordum, Rowland & Cunningham, 1998) for young people with diabetes and their families (Ellis et al., 2004; 2005; 2012). This consisted of multiple individual sessions per week (minimum of two) over six months, and included peer and community-based work in addition to the family intervention. Contact varied from individual sessions held in clinic or at home, to attending school meetings and/or diabetes clinic appointments. Treatment consisted of a range of evidence-based intervention techniques, including cognitive behavioural therapy (CBT), parenting training and BFST.

Three studies evaluated group-based interventions (Carpenter et al., 2014; Kichler et al., 2013; Murphy et al., 2012). Again these varied in their duration, content and structure.

Duration ranged from four to six sessions. In two studies adolescents and their parents attended the group together, whereas for one study (Kichler et al., 2013) adolescents and parents attended separate groups with their respective peers for the first portion of each session, and then all families came together for the second half.

One study evaluated a self-directed intervention for parents (Doherty et al., 2013), that was based on the Triple P: Positive Parenting Program (Sanders, 1999). The self-directed intervention involved ten weeks of structured learning tasks for parents, delivered via the internet, with no therapist contact.

[INSERT TABLE 3]

3.3 Overview of Outcome Variables

Each of the studies assessed a number of outcome measures relating to the various intervention components and aims. The measures used and timescale of assessment and follow-up varied considerably across the studies, although every study included outcome measures relating to one, or a combination of, health-related outcomes, family-functioning and adolescent psychosocial outcomes. As detailed in Table 1, seven studies had only two assessment points; pre and post intervention. Other studies included follow-up assessments, commonly 6, 12 and 18 months but ranging from three months to three years.

3.3.1 Health-Related Outcomes

All studies, except one (Doherty et al., 2013), included a physical measure of glycaemic control in the form of glycated haemoglobin level (HbA1c) from a blood sample. Adherence to diabetes-management regime was another common outcome variable, reported in 11 of the studies. A number of assessment tools were used across the studies to measure adherence, these included adolescent (self) and parent-reported questionnaires, a 24-hour recall interview, and direct measurement of the frequency of blood-glucose monitoring taken from the monitor

readings. Three studies also included frequency of diabetes-related hospital admissions as a measure of health-related outcomes (Ellis et al., 2004; 2006; Kichler et al., 2013).

3.3.2 Family-Related Outcomes

Many of the studies measured the effectiveness of the interventions on aspects of family-functioning, including diabetes-related conflict, responsibility-sharing, parental support and monitoring of diabetes care. Seven studies measured the effect of the intervention on diabetes-related conflict (according to standardised adolescent and parent self-reports). In terms of the effect of the interventions on parental involvement in the diabetes care, 11 studies reported on this, but it was assessed by a number of different assessment tools, as detailed in Table 1. Additional measures also included responsibility for diabetes care (according to parent-report), parental stress and parenting strategies used. Two papers included a measure of parent-adolescent problem solving discussions as assessed by behavioural coding of family interactions (Wysocki et al., 1999; 2006).

3.3.3 Adolescent Psychosocial Outcomes

Nine studies reported measures relating to the adolescent psychosocial outcomes. Variables included adolescent behaviour, as reported by parents, adolescents' adjustment to illness, from both parent and adolescent-report. Five studies included measures of self-reported quality of life and three measured adolescent self-efficacy.

3.4 Outcomes of Studies

3.4.1 Quarterly Psychoeducation and Problem-solving Interventions

The quarterly psychoeducation and problem-solving interventions were all evaluated using RCT designs. Two compared the intervention to standard care only (Laffel et al., 2003; Nansel

et al., 2012), whereas the others compared the intervention to both standard care and an educational support intervention.

All of the quarterly psychoeducation and problem-solving interventions included HbA1c level as a measure of glycaemic control. Two studies demonstrated positive effects regarding glycaemic control; the 'WE CAN manage diabetes' intervention (Nansel et al., 2012) a two-year intervention had a significant effect on reducing HbA1c from baseline to post-intervention, when compared with standard diabetes care. Their analysis identified a significant age-effect, in that the intervention had a significant effect on HbA1c for adolescents (>12 years) but not for those in the 9-11 year age bracket. For Laffel and colleagues (2003) the quarterly TW intervention did not improve glycaemic control, but the intervention group demonstrated significantly less deterioration in HbA1c, compared to standard care. Interestingly when TW was compared to an educational support intervention (Holmes et al., 2014) the educational support group showed significantly improved HbA1c compared to TW, suggesting that educational support was superior to the TW intervention. The remaining two studies found no significant difference in HbA1c level across the intervention, educational support or standard care groups from pre to post-intervention.

Two quarterly psychoeducation and problem-solving interventions reported adherence outcomes. 'WE-CAN manage diabetes' (Nansel et al., 2012) had no effect on adherence, which was surprising given the intervention did improve glycaemic control. However, adherence was based solely on parent-report. Holmes et al. (2014) found the educational support intervention to again be superior to TW on adherence outcomes. Self- and parent-reported adherence improved for the educational support group, whereas it was maintained in the TW group, and declined in the standard care group.

Regarding family-related outcomes Anderson et al. (1999) found the TW intervention significantly reduced diabetes-related conflict, compared to an educational support intervention and standard care. However, these findings were not supported by three other TW studies (Holmes et al., 2014; Katz et al., 2013; Laffel et al., 2003). The effect of quarterly psychoeducation and problem-solving interventions on parental support and responsibility was mixed across the studies. Holmes et al. (2014) found that both families in the TW and educational support interventions demonstrated a deterioration in parental involvement over time, suggesting neither was effective on this outcome. Anderson et al. (1999), on the other hand, found TW led to significantly less deterioration in parental support than the educational support control. Both Laffel et al. (2003) and Katz et al. (2013) found that the TW intervention maintained or improved parental involvement compared to the control condition.

In terms of adolescent psychosocial outcomes, three studies included measures of adolescent well-being and self-efficacy. They each found no significant effects of the interventions when compared to control groups (Holmes et al., 2014; Katz et al., 2013; Laffel et al., 2003).

3.4.2 Behavioural Family Systems Therapy

Four studies evaluated Behavioural Family Systems Therapy (BFST; Robin & Foster, 1989). Wysocki et al. (1999) conducted a large-scale RCT comparing BFST to an educational support intervention or standard care. BFST sessions were conducted in-clinic, whereas Harris and colleagues (2005) modified the intervention to be conducted in the family home. This smaller scale study looked at BFST for the most difficult-to-treat patients, characterised as those with chronically poor glycaemic control and clinic attendance. In another large scale RCT (Wysocki et al., 2006), BFST-D was compared to both an educational support intervention and standard

care. Harris et al. (2015) further modified BFST-D to be delivered via Skype (internet-based video calling). In this RCT study BFST-D via Skype was compared to in-clinic BFST-D.

Regarding the effectiveness of the intervention on glycaemic control, BFST was not found to have a significant effect on HbA1c level in both a large-scale RCT (Wysocki et al., 1999) or when delivered in-home in a small, within group study (Harris et al., 2005). When the BFST intervention was modified to include diabetes-specific components (Wysocki et al., 2006), both BFST-D and educational support groups showed a reduction in HbA1c compared to standard care, and there was a trend towards greater improvements in the BFST-D group, although this did not reach significance. Harris et al. (2015) found both BFST-D delivered in-clinic and via skype significantly reduced HbA1c level from pre-post intervention. However, this was not compared with a non-intervention or educational support control.

Wysocki and colleagues (1999; 2006) found BFST and BSFT-D, respectively, to have a significant effect on adherence as measured by a recall interview (adolescent) and questionnaire, although in the first study the effect on adherence only emerged at 6 and 12 month follow-up. Harris et al. (2015) found both in-clinic and skype-delivered BFST-D to significantly improve adherence although again, this was not compared to any non-intervention control. When BFST was delivered at home to adolescents with chronically poor control and poor attendance the intervention had no effect on self-reported adherence (Harris et al., 2005).

With regards to family-related outcomes, two studies found in-clinic BFST to be effective in reducing family conflict (Wysocki et al., 1999, 2006). Although no effect was found for in-home BFST for adolescents with chronically poor glycaemic control (Harris et al., 2005). Again this was a within-group test with no control group, the sample also consisted of a disproportionately high number of single parent families, from ethnic minority group and low socio-economic status. One study found BFST to be effective in improving parent-adolescent

relations but not diabetes-management (Wysocki et al., 1999). Harris et al. (2005) found no difference in diabetes management from pre to post intervention for in-home BFST.

For adolescent psychosocial outcomes, in-home BFST was not found to have any effect on adolescent behaviour over time for adolescents with chronically poor diabetes management (Harris et al., 2005). In clinic-BFST also had no effect on adolescent adjustment when compared to a control group in a larger RCT (Wysocki et al., 1999). These were the only adolescent psychosocial measures included for BFST interventions.

3.4.3 Multisystemic Therapy

MST was compared to standard diabetes care, in both a small-scale pilot study (Ellis et al., 2004) and a larger RCT (Ellis et al., 2005). Standard care was typically attending quarterly diabetes clinics, however no restrictions were placed on adolescents in this condition accessing mental health services, and one and three adolescents respectively, were reported to receive such care. In the most recent study Ellis and colleagues (2012) compared MST to weekly telephone support. This condition focused on support for diabetes care using a client-centred, non-directive counselling approach.

Regarding the effectiveness of MST on health-related outcomes, MST was effective in reducing HbA1c when compared to standard care in the pilot study (Ellis et al., 2004), although this involved a very small sample these findings were supported in the larger RCT (Ellis et al., 2006). However, in this study the effect on HbA1c was not maintained at six-month follow-up. Ellis et al. (2012) also demonstrated a positive effect of MST on HbA1c when compared to a telephone support intervention. The effect again decreased from post-intervention to the six month follow up (average decrease of 1.01% to 0.74%) but remained significant.

Two MST studies included a measure of frequency of hospital admission (Ellis et al., 2004; 2006), and both found MST significantly reduced hospital admissions across time,

compared to standard care. MST was also found to be effective in improving adherence across all three studies (Ellis et al., 2004; 2005; 2012), as measured by a 24-hour recall interview, frequency of blood-glucose monitoring and questionnaire.

With regards to family-related outcomes, none of the MST studies included measures of family conflict. MST was found to be effective in reducing parental overestimation of adolescent responsibility compared to standard care, however an increase in parental support was only found in two-parent families and no effect on parental support was found in single-parent families (Ellis et al., 2006). Parental involvement was not measured in the other MST studies.

Only one study included an adolescent psychosocial measure. MST was found to have a significant effect on reducing adolescent stress (Ellis et al., 2005), although this measure was not repeated in the other MST studies and the studies also did not include any measures of adolescent behaviour or quality of life.

3.4.4 Group interventions

Three studies evaluated group-based interventions (Carpenter et al., 2014; Kichler et al., 2013; Murphy et al., 2012). One study used a within group, pre and post design (Carpenter et al., 2014). The other two studies were RCTs and compared the group intervention to waiting-list or standard care control.

In terms of the effect of group interventions on health-related outcomes, Carpenter et al. (2014) found that the number of sessions attended was associated with improvement in HbA1c level. However this used only binary categories (1-2 session vs. 3-4 sessions). It was correlational, therefore not possible to ascertain any causal direction, and the study did not compare to a control group. Neither, Kichler et al. (2013) or Murphy et al. (2012) demonstrated an effect of the group interventions on HbA1c when compared to control groups.

The KIDS program intervention had no effect on self-reported adherence when compared to a waiting list control (Kichler et al., 2013). Nor did it have a significant effect on frequency of hospital admissions (Kichler et al., 2013).

No group intervention included a measure of family conflict. The group TW intervention was found to have no significant effect on parental involvement or responsibility when compared to standard care (Murphy et al., 2012). The KIDS program also had no significant effect on parental involvement or responsibility when compared to a waiting list control (Kichler et al., 2013).

Regarding adolescent psychosocial outcomes, group TW had no effect on adolescent well-being (Murphy et al., 2012). Kichler et al. (2013) found the KIDS program did significantly improve adolescent quality of life, compared to the control group. However, no significant effects were found for other measures of adolescent well-being.

3.4.5 Self-directed Parenting Intervention

The Triple P self-directed intervention for parents, delivered via the internet, was compared to a waiting list control in a relatively large RCT (Doherty et al., 2013). The study did not include a physical measure of HbA1c because of the timescale of the study. It also did not report on measures of adherence or any other health-related outcome.

The majority of outcome measures included related to family or parent outcomes, and all were parent-reported. Parents in the Triple P intervention used significantly more positive parenting strategies and were more confident in their parenting post-intervention, compared to the waiting-list control (Doherty et al., 2013). However, this study did not include a measure of responsibility or diabetes-management, to assess how this translated to real-life parental support.

Regarding adolescent psychosocial outcomes parents in the self-directed Triple P group reported significantly fewer adolescent behaviour problems than the waiting list control group (Doherty et al., 2013), however, this study did not included any adolescent-reported outcomes.

4.0 Discussion

This paper aimed to conduct an up-to-date systematic review of family-based interventions for adolescents with T1D. The purpose was to identify studies examining the effectiveness of these interventions, to explore the different types of family-based interventions used, and consider the various outcome variables relating to health, family-functioning and adolescent psychosocial factors. Past reviews have examined the effectiveness of family interventions for young people with T1D on health-related outcomes. Two papers have examined this quantitatively (Armour et al., 2005; Winkely et al., 2006) and found small to moderate effects on glycaemic control. However this current paper aimed to further explore the heterogeneity regarding both the intervention delivery and outcome variables, which has been beyond the scope of previous reviews.

The search identified 26 papers published in the past 20 years, reporting on 16 intervention studies. Fourteen of the papers were RCTs and most were rated of moderate quality. Nine studies were published post-2009 and had not been included in any previous reviews. Results identified that family-based interventions varied considerably but could be categorised into five groups; quarterly psychoeducation and problem-solving interventions, behavioural family systems therapy, multisystemic therapy, group interventions and self-directed parenting interventions. These were similar to the interventions included in previous reviews for children, young people, and adults. The only unique intervention for adolescents with T1D was Teen Triple P, the self-directed parenting intervention.

As found in previous reviews, the majority of studies focused on health, and particularly glycaemic control, as the main outcome variable. However, all of the papers included a large range of additional outcome variables relating to the different components and aims of the interventions. Whilst many of the outcome variables overlapped, all studies used a different combination of measures, making it difficult to draw direct comparisons.

The most compelling evidence was for the intensive, individualised interventions. MST consisted of multiple, individual sessions per week over six months, and included peer and community-based work in addition to the family intervention. In two large-scale RCTs and a pilot study MST was found to be effective in improving adherence, reducing hospital admissions and improving HbA1c, although this was not always maintained long-term. BFST also had promising results regarding adherence and family-functioning, particularly when the intervention was modified to include diabetes-specific adaptations, which included parental simulation of living with diabetes and the option to extend the intervention to include peers, siblings and teachers. However, the effectiveness of BFST(-D) on improving glycaemic control was less well supported.

Five studies evaluated quarterly psychoeducation and problem-solving interventions and found some support for the less intensive interventions. In particular, the ‘WE CAN manage diabetes’ intervention study by Nansel et al. (2012) was rated as the highest quality of the included studies. This RCT found the intervention to have a lasting significant effect on HbA1c level at two years. However, this study compared to standard care only. When Holmes et al. (2014) compared a quarterly intervention to an educational support control that was more comparable in terms of attention and contact, educational support was in fact found to be superior on a range of measures. These interventions would benefit from more large-scale studies comparing the family intervention to another intervention or comparable control to better identify the mechanism of change. Nansel et al. (2012) did not include any family or

adolescent outcome measures. Whilst other quarterly interventions demonstrated some benefit for maintaining or improving parental support and reducing family conflict, more research is needed to explore the effectiveness of these interventions on family and adolescent-related outcomes.

Group-based interventions were the least well supported. Although all categorised as groups, these varied considerably in their design and duration. Given this variability it is difficult to draw any conclusions about group interventions as a whole. Each intervention would benefit from more robust research with the inclusion of outcomes relating to family functioning and including follow-up assessments.

4.1 Clinical & Theoretical Implications

Poor diabetes management and glycaemic control is a common problem of adolescence, which has implications for long-term health and psychological well-being. Adolescence is also a time of increased family conflict and reduced parental involvement in diabetes care, which have been found to be correlated with poor diabetes control. This review aimed to explore whether interventions that target family functioning could be effective in improving diabetes management and well-being for adolescents with T1D. The findings suggest that family-based interventions can have a beneficial effect on a range of health, family and psychosocial outcome variables. This supports the most recent NICE guidelines (2015) that recommend that young people with T1D should be given access to psychological interventions and that family-based intervention are recommended when there is concern regarding diabetes-related conflict. However, this review has also identified the considerable variation in the interventions described as ‘family-based’ and suggests that consideration needs to be given to the different types of interventions and who they might be most suited for.

Intensive and individualised interventions appeared to be most well-supported. Particularly those that involve peers, siblings and the wider system. This suggests that adolescents may benefit from a more holistic approach to diabetes management. However, the multi-component nature of these interventions makes it difficult to ascertain the most important aspect, and whether in fact it is the family-based component, or some other aspect of the intervention, that is effective. Further to this, both MST and BFST require professionals to undergo specific training and supervision. The level of intensity of these interventions has cost and resource implications for services that need to be considered.

The quarterly psychoeducation and problem-solving interventions offer promise of an intervention that can be more easily integrated into standard diabetes care for adolescents with T1D, as many already attend routine clinic appointments on a quarterly basis. Although there is less compelling evidence with regard to health and adolescent psychosocial outcomes, these interventions have been found to be particularly beneficial for improving or maintaining parental support, which is known to diminish throughout adolescence. These interventions may be particularly suited to adolescents presenting with more mild to moderate difficulties. However, they would benefit from more research to further explore their impact, particularly in the long-term.

This review identified two internet-based interventions. In some health services, particularly those covering large geographic areas transport can be a barrier to accessing services. Therefore it was promising that internet-delivered BFST-D was found to produce comparable outcomes to clinic-based interventions. The limited resources in health services need to be considered in terms of viable and cost-effective options for adolescents with T1D and their families. The self-directed internet-based parenting intervention offers promise of a cost-effective and easily accessible intervention that could be offered as an early or preventative intervention. However, participants in this study were recruited via their

involvement in diabetes-charities which may indicate a particular level of investment and motivation to engage. More research is needed to establish whether the intervention could be effective for a wider demographic, and importantly to investigate whether there is any effect on adolescent health and well-being.

The effectiveness of the interventions on adolescent psychosocial variables was the least well-supported outcome across all intervention types. Considering the increased risk of mental health problems in people with diabetes and poor control (e.g. Bernstein, Stockwell, Gallagher, Soren & Rosenthal, 2013; Lustman et al., 2000; Peterson, Fischer & Young-Hyman, 2014) and the emotional and social factors associated with poor diabetes management through adolescence (La Greca, Follansbee & Skyler, 1990; Delamater, 2009) it is important to consider interventions aimed at improving adolescent well-being. Past research on psychological interventions (individual and family based) has focused on physical health outcomes (Armour et al., 2005; Winkley et al., 2006), but further assessment of the impact on psychosocial outcomes is clearly warranted.

4.2 Limitations

The results of this review need to be considered with regards to both the limitations of the included studies and of the systematic review. Whilst the majority of included studies were RCTs rated of moderate quality, a number of outcomes were based on small or uncontrolled studies, making it difficult to draw reliable conclusions. Future research should aim to be more robust, consisting of larger samples, and stating the method of randomisation and dropout rate. The studies all consisted of fairly homogenous samples, with a tendency towards two-parents, non-ethnic minority families. More research is needed that includes ethnic minority groups and non-traditional families to increase generalisability of results. The vast range of outcome

measures used across the studies limits the ability to draw comparisons. Future research should aim for more consistency in the measures used.

One limitation of this review was the restriction to papers published in English and in peer-reviewed journals. This may have created a risk of bias towards positive reporting of results, and may have missed relevant interventions conducted in other languages. It is also acknowledged that as the systematic search, quality assessment and data extraction were all completed by a single author, this review may have benefitted from an independent-rater to assess reliability. Despite extracting quantitative data this review did not include any statistical assessment of effect sizes. Because the interventions varied considerably it did not seem appropriate to pool effect sizes, and rather the aim was to explore the heterogeneity. However, as this research area grows quantitative synthesis of studies reporting on each type of intervention would be beneficial.

4.3 Research Implications

More research is needed to further explore the effectiveness of family-based interventions. It would be beneficial to compare family-based interventions to individual interventions for adolescents to identify whether there is any added benefit of including family. More detailed research is also needed to establish the mechanisms of change, particularly as many of the included studies consisted of multiple components. This would further our understanding of how best to support diabetes management for adolescents with T1D. MST for example, consisted of peer and community-level interventions in addition to family. As this is a more labour-intensive and costly intervention it would be important to know what, if any, aspects were more effective.

Whilst all of the studies included adolescent samples, the age of the participants tended to be early adolescence. More research would be beneficial with older adolescents (≥ 15 years)

as the need to establish diabetes management and autonomy is arguably more pertinent for those closer to transitioning to adult services.

Attendance was low in a number of the included studies, particularly the group-based and high intensity interventions. This research area would benefit from qualitative analysis to explore adolescents and their families' experiences of these interventions. This could provide valuable information about the acceptability of these interventions and how they could be improved.

4.4 Conclusions

There is promising evidence that family-based interventions can have a beneficial effect on adolescent health, family-functioning and psychosocial outcomes. There is considerable variability in the types of interventions available, however the variety of outcomes measures used makes it difficult to draw comparisons between interventions. Intensive, individualised family therapy and behavioural interventions have the most supporting evidence, but require further cost-benefit analysis. There is evidence that quarterly psychoeducation and problem-solving interventions could be easily incorporated into routine diabetes care for adolescents, however, more research is needed to establish what the most effective component of the interventions is, and who they are most effective for.

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Table 1.

Summary of studies evaluating the effectiveness of family-based interventions included in this review

| Number, Reference(s), Country | Participant Characteristics (number; age; gender; diagnosis; recruitment) | Study Design | Intervention (n; number of sessions; mode of delivery) | Comparison group (n) | Outcome measures used | Assessment Time Points | Summary of Findings | Limitations |
|---|---|----------------------------|---|---|--|---|--|---|
| 1. Anderson, Brackett, Ho & Laffel (1999); USA | N=85; 10-15 years (mean=12.6); 49% female; duration of T1D >1 year (mean duration =5.5 years) with reasonable glycaemic control (HbA1c from 6.6 to 10.4%); community. | RCT | Teamwork; (n=28); 4 sessions (20-30 minute duration) over 12 months; delivered to parent-adolescent dyads individually. | Educational Support (n=30) vs. Standard Care (n=24). Education support group received traditional didactic diabetes education with no focus on parental involvement and responsibility sharing. | Glycaemic control (HbA1c); Diabetes management (interview, DFRQ); Conflict (DFCS, DFBC); | Baseline, 12 months (post intervention) and 24 months (follow-up) | No significant difference in HbA1c at 24 months across all groups although trend of improvement in teamwork. Teamwork group showed significantly greater decrease in diabetes-related conflict at 12 months. Significantly more parents showed deterioration in involvement in the comparison. No significant differences between standard care and educational support groups at 12 months for glycaemic control, diabetes management and conflict. | Homogenous group of families. Relatively low risk. Short study period. Relatively small sample size. |
| 2. Carpenter, Price, Cohen, Shoe & Pendley, (2014); USA | N=67; 11-19 years (mean=14.2); 58% female; T1D (92.5%) or insulin-dependent T2D (7.5% of sample), mean duration of diagnosis =5.6 years; recruited without regard to HbA1c level (mean=10.1%); community (via diabetes charity) | Single group, pre and post | Multi-group problem solving; (n=67); 4 weekly sessions (75 minute duration) | None | Glycaemic control (HbA1c); Session attendance; Patient satisfaction. | Baseline (approx. 5 weeks pre-intervention) and 9 weeks (post-intervention) | After controlling for age and diabetes duration the interaction of pre-treatment HbA1c and binary sessions attended (1-2 vs. 3-4) significantly predicted posttreatment HbA1c and likelihood of improving HbA1c by 0.5%. Adolescents with both high pretreatment HbA1c and high intervention attendance exhibited lower posttreatment HbA1c and were more likely to evidence clinically significant | No control group. Small sample size. Low intervention attendance. Limited outcome measures. No follow-up measure. |

| Number, Reference(s), Country | Participant Characteristics (number; age; gender; diagnosis; recruitment) | Study Design | Intervention (n; number of sessions; mode of delivery) | Comparison group (n) | Outcome measures used | Assessment Time Points | Summary of Findings | Limitations |
|--|---|--------------|---|---|---|---|---|---|
| | | | | | | | improvement (as opposed to worsening) at posttreatment. | |
| 3. Doherty, Calam & Sanders (2013); UK | N=79; 11-17 years (mean=13.0); 43% female (adolescent), 99% female (parent); T1D; mean duration of diagnosis =5.17 years; recruited without regard to HbA1c level (mean=8.5%); community sample | RCT | Triple P (self-directed); 10 weekly sessions (1 hour) | Waiting List; n=42; no contact from research team or Triple P resources during 10 week period, received intervention after | Conflict (DFCS); Parental stress (PIP); Parenting (ECBI, PS, PSOC) | Baseline (pre-intervention) and post-intervention | Triple P group reported significantly less conflict, less behaviour problems (ECBI), more productive parenting strategies (PS) and high self-confidence in parent (PSOC) post-intervention compared to control. No significant difference in parental stress. | No measure of glycaemic control due to short intervention length, 65% completion rate and significantly more drop-out in intervention group. Possible selection bias due to recruitment via diabetes charities. |
| 4. Ellis et al., (2004) | N=25; mean= 13.6 years; 44% female; T1D > 1 year (mean diagnosis duration not reported); HbA1c>10% (mean= 14.0%); community | RCT | MST (n=13); at least 2 sessions per week over approx.6 months | Standard Care (n=12); quarterly clinic visits, no restriction placed on access to mental health services (n=1 reported receiving such care) | Glycaemic control (HbA1c, rate of hospital admission); Adherence (24 hour recall interview, DSM, frequency of BGM); Parent satisfaction | Baseline, 6 months (post-intervention) | MST group had significant improvements in HbA1c, significant increase in frequency of BGM, significant decrease in hospital utilization. No significant differences from baseline to post-treatment on any outcomes for Standard Care group. | Small sample size, low recruitment rates, no follow-up data. |
| 5. Ellis et al., (2005a, 2005b, 2007a, 2007b); Naar-King et al (2007); USA | N=127; 10-17 years (mean =13.2); 51% female; T1D diagnosis duration > 1 year (mean = 5.3 years) and HbA1c | RCT | MST (n=64); at least 2 sessions per week over | Standard Care (n=63); quarterly clinic visits, no restriction placed on access | Glycaemic control (HbA1c, hospital admission); Adherence (24 hour recall | Baseline, 7 months (post-intervention) , 12, 18 and | Significant reduction in HbA1c and hospital admission for intervention compared to control group at post-intervention, but not maintained at follow-up. Intervention group | No attentional control. Multiple systems involved (peers, sibling, schools) difficult to evaluated |

| Number, Reference(s), Country | Participant Characteristics (number; age; gender; diagnosis; recruitment) | Study Design | Intervention (n; number of sessions; mode of delivery) | Comparison group (n) | Outcome measures used | Assessment Time Points | Summary of Findings | Limitations |
|--|---|--------------------------------------|---|--|--|---|--|---|
| | ≥8% (mean =11.3%); community. | | approx.6 months | to mental health services (n=3 reported receiving such care) | interview, frequency of BGM); Family relationships (DFBC, FES); Responsibility (DFRQ) Adolescent stress (DSQ); | 24 months (follow-up) | showed significant improvement in frequency of BGM. No significant difference for insulin or diet adherence. Intervention group showed significant reduction in diabetes-related stress. Significant improvement in responsibility and parental support. Effects found for two-parent families but not single-parent families. | effectiveness of parent involvement alone. |
| 6. Ellis et al., (2012); USA | N=146; 10-18 years (mean =14.2); 56% female; T1D or insulin-dependent T2D (10%); duration >1 year (mean duration of diagnosis = 4.7 years) and HbA1c ≥8% (mean =11.7%); community | RCT | MST (n=74); at least 2 sessions per week over approx.6 months | Telephone support, weekly phone call focusing on support for diabetes care using a client-centred, non-directive counselling approach. | Glycaemic control (HbA1c); Adherence (DMS) | Baseline, 7 months (post-intervention) , 12 months (follow-up) | MST group had significantly greater reduction in HbA1c compared to control (1.01% decrease at 7 months and 0,74% decrease at 12 months). Parents of MST group reported significantly improved adherence (at 7 and 12 months) | Relies on parent-reported adherence. Multiple systems involved (peers, sibling, schools) difficult to evaluate effectiveness of parent involvement alone. |
| 7. Harris, Harris & Mertlich (2005); Harris, Freeman & Beers (2009); USA | N=18; 13-18 years (mean=16.0); 33% female; T1D, mean duration of diagnosis, 6.2 years; HbA1c>9% (mean=11.4%); community. | Within subject, single group design. | In-home BFST (n=18); 10 sessions (1.5 hours) over 5-8 weeks. | None. But post-hoc comparisons made to sample of adolescents with poorly controlled diabetes (n=40) from previous | Glycaemic control (HbA1c); Adherence (SCI); Diabetes management (DMQ, DFBC), conflict (DRC, CBQ), | Baseline (pre-intervention) , post-intervention, 6 months (follow-up) | No significant difference in HbA1c for pre-post intervention. No significant difference in self-reported adherence, diabetes management or conflict from pre to post intervention. Clinically significant improvements were determined | Only post-hoc comparison and not randomised to control group.55% of those recruited declined to participate, clinically |

| Number, Reference(s), Country | Participant Characteristics (number; age; gender; diagnosis; recruitment) | Study Design | Intervention (n; number of sessions; mode of delivery) | Comparison group (n) | Outcome measures used | Assessment Time Points | Summary of Findings | Limitations |
|---|--|--------------|--|---|--|---|---|---|
| | | | | study (Wysocki et al., 2006, 2007) | Adjustment (AIS), Adolescent behaviour (CBC) | | by calculating standard deviation difference between BFST and comparison group on measures of parent-adolescent conflict (DRC, CBQ) | significant improvements but not statistically significant-change may reflect regression to the mean. |
| 8. Harris, Freeman & Duke (2015); USA | N=90; 12-18 years (mean=15.0); 45% female; T1D duration >1 year (mean duration of diagnosis, 6.5 years); HbA1c ≥9% (mean=11.1%); community | RCT | BFST-D in clinic (n=44); up to 10 session (1-1.5 hours) in 12 weeks | BFST-D via Skype (n=46); up to 10 sessions (1-1.5 hours) in 12 weeks | Glycaemic control (HbA1c); Adherence (DSM, interview) | Baseline (within 4 weeks before intervention) , 3 months (post intervention) , 6 months (follow-up) | No significant difference between groups for adherence or control. Groups collapsed for within subject analysis: significant difference in adherence from pre to follow-up, and post to follow-up. Significant improvements in HbA1c from before to after intervention and maintained at follow-up. | No (non-BFST) control group. Small effect sizes. |
| 9. Holmes, Chey, Mackey, Grey & Streisand (2014); USA | N=226; 11-14 years (mean=12.8); 52% female; T1D duration >1 year (mean diagnosis duration, 5.0 years); recruited without regard to HbA1c (mean not reported); community. | RCT | Family teamwork coping programme, (n=137); 4 quarterly sessions (30-40 minutes) over 1 year. | Educational Support (n=89), with parent/youth dyads, no discussion of parental involvement, parenting style or practice plans occurred. 4 quarterly sessions (30-40 minutes) over 1 year. | Glycaemic control (HbA1c); Adherence (DBRS); Conflict (DFCS); Parental support (PMDC); Parent and adolescent self-efficacy (SEDSM); Adolescent well-being (PQOL) | Baseline (pre-intervention) ,12 months (post-intervention) ; follow-up occurred at 3.5 month intervals for up to 3 year follow-up | Educational Support group performed as well or better than Teamwork group on all study outcomes. Glycaemic control significantly improved in Educational Support compared to Teamwork group. Adherence improved for Educational Support group across all follow-ups and more over time relative to Teamwork group. Teamwork demonstrated sustained adherence that did not deteriorate. Both Teamwork and Educational showed lower | Participants not randomised to post-hoc Standard Care control. |

| Number, Reference(s), Country | Participant Characteristics (number; age; gender; diagnosis; recruitment) | Study Design | Intervention (n; number of sessions; mode of delivery) | Comparison group (n) | Outcome measures used | Assessment Time Points | Summary of Findings | Limitations |
|---|---|--------------|--|--|---|---|---|--|
| | | | | Standard Care, HbA1C levels from a group of adolescent (n=205) were obtained post hoc (non-randomised) to provide a standard care comparison. | | | levels of parental monitoring over time. Group scores remained similar for both family conflict over time. No effect of intervention on self-efficacy. Both groups improved QoL over time. | |
| 10. Katz, Volkening, Butler, Anderson & Laffel, (20130; USA | N=153; 8-16 years (mean=12.9); 56% female; duration of T1D> 6months (mean diagnosis duration, 6.3 years); recruited without regard to HbA1c level (mean=8.5%); community. | RCT | Care Ambassador Ultra (n=50); quarterly sessions (30 minutes) over 2 years. | Standard Care (n=52) and Care Ambassador one (n=52); Care Ambassador group received monthly outreach via telephone or email in addition to usual diabetes care and care co-ordination. | Glycaemic control (HbA1c); Parental Involvement (DFRQ); Conflict (DFCS); adolescent well-being (PQOL) | Baseline (pre-intervention) , 1 year and 2 years (post-intervention) | No differences in HbA1c across treatment groups at 2 years. Among youth with suboptimal control (HbA1c>8%) more youth in intervention group maintained or improved HbA1c and maintained or increased parent involvement than youth in other 2 groups combined. No difference in conflict across all three groups. Significant intervention effect for parental involvement. No difference in PQoL between groups. | Despite randomisation significant demographic differences between groups at baseline. |
| 11. Kichler, Kaugers, Marik, Nabors & Alemzadeh, (2013) | N=30; 13-17 years (mean=15.2); 53% female; T1D duration >6 months (mean diagnosis duration, 5.6 years); recruited without regard to HbA1c (mean= | RCT | KIDS (n=15); 6 groups sessions (30-45 minutes separate groups + 20-30minutes | Waiting List (n=15) | Glycaemic control (HbA1c, frequency of hospital utilisation); Adherence (SCI), Diabetes management | Baseline (pre-intervention) , 2 months (post-intervention) , 6 months (follow-up) | No significant changes in HbA1c or hospital utilization. Significant difference in PQOL, but no other differences on any other outcome measures. | Small, pilot study. Small effect sizes. Despite randomisation differences in psychosocial and diabetes-related functioning |

| Number, Reference(s), Country | Participant Characteristics (number; age; gender; diagnosis; recruitment) | Study Design | Intervention (n; number of sessions; mode of delivery) | Comparison group (n) | Outcome measures used | Assessment Time Points | Summary of Findings | Limitations |
|--|---|--------------|--|--|---|--|---|--|
| | 10.0%); community (from diabetes clinic and referred to mental health services). | | altogether) over 2 months. | | (DFRQ, RCBRS), Adolescent wellbeing (PQOL, BS1-18, BASC-2) | | | between groups at baseline. No attentional control. |
| 12. Laffel et al., (2003); USA | N=100; 8-17 years (mean=12.1); 47% female; T1D duration >6 months but < 6 years (mean diagnosis duration, 2.7 years); recruited without regard to HbA1c (mean=8.4%); community. | RCT | Teamwork (n=50); 4 quarterly sessions (15-20 minutes) over 1 year. | Standard Care (n=50); quarterly sessions without any discussion about family teamwork. | Glycaemic control (HbA1c); Parental involvement (interview, DFRQ); Conflict (DFCS), Adolescent well-being (PQOL) | Baseline (pre-intervention) , 1 year (post-intervention) | HbA1c in Teamwork group did not deteriorate as it did in control group. Parental involvement was maintained or increased in Teamwork group compared to control. Over twice as many families in Teamwork group increased or maintained family involvement post-intervention compared to control. No effect of intervention on conflict at 1 year. No effect on PQoL. | No attentional control group. Some baseline differences between groups (e.g. weight). |
| 13. Murphy, Wadhan, Hassler-Wurst, Rayman & Skinner (2012); UK | N=305; 11-16 years (mean=13.1); 52% female; T1D duration >1 year (mean diagnosis duration, 5.6 years); recruited without regard to HbA1c (mean=9.1%); community. | RCT | FACTS (n=158); 6 monthly group session (90 minutes). | Standard Care (n=147); conventional diabetes care. | Glycaemic control (HbA1c); Parental support (DFRQ); diabetes management (PAID), Adolescent well-being (DQOLY-SF, HBSC), | Baseline (pre-intervention) , 6 months (post-intervention) , (months, 12 months and 18 months (follow-up) | No significances difference between groups across time on all outcome measures. | 30% did not attend any intervention sessions, less than 50% attended 4 sessions or more. |

| Number, Reference(s), Country | Participant Characteristics (number; age; gender; diagnosis; recruitment) | Study Design | Intervention (n; number of sessions; mode of delivery) | Comparison group (n) | Outcome measures used | Assessment Time Points | Summary of Findings | Limitations |
|--|--|--------------|--|---|---|---|--|--|
| 14. Nansel, Iannotti & Iu (2012); USA | N=390; 9-14 years (mean=12.5); 51% female; T1D duration > 3months (mean 4.9 years); recruited without regard to HbA1c level (mean=8.4%); community. | RCT | WE-CAN manage diabetes (n=201); quarterly sessions (30 minutes) for 21 months. | Standard Care (n=189) | Glycaemic control (HbA1c); Adherence (DSMP, frequency of BGM); | Baseline (pre-intervention), 9/12 months (midpoint), 24 months (post-intervention) | Intervention had a significant negative effect on HbA1c from baseline to 24 months. Significant age effect: no effect among younger (9-11 yrs) but significant intervention effect on HbA1c for 12-14 group at follow up. No intervention effect on parent-reported adherence. | Adherence based on self-report (parent) |
| 15. Wysocki et al (1999; 2000; 2001), Harris, Greco, Wysocki & White (2001); USA | N=199; 12-17 years (mean=14.3); 57% female; T1D duration >1 year (mean diagnosis duration, 5.2 years); recruited without regard to HbA1c (mean=11.9%); community | RCT | BFST (n=39); 10 sessions within 3 months | Educational Support or Standard care C. Educational Support group attended 10 group meetings within 12 weeks. | Glycaemic control (HbA1c); Parent-adolescent relationship (PARQ), family problem solving (observation coded with IBC); conflict (DRC), adherence (24 hour recall interview, SCI) adolescent adjustment (TADS) | Baseline (pre-intervention), 3 months (post-intervention), 6 and 12 month (follow-up) | No effects on treatment adherence and HbA1c. BFST demonstrated significantly more improvement in parent-adolescent relations and reduced conflict. No effects on adjustment and diabetes management. Delayed effects on adherence emerged at 6 and 12 month follow-up. | Despite randomisation groups differed at baseline, limiting ability to assess treatment effects. |
| 16. Wysocki et al. (2006, 2007, 2008); USA | N=104; 11-16 years (mean= 14.2); 45% female; T1D or insulin dependent T2D duration > | RCT | BFST-D (n=36); 12 sessions over 6 months. | Standard Care (n=32) and Educational Support (n=36); Educational | Glycaemic control (HbA1c); Adherence (DSM); Parent- | Baseline (pre-intervention), 6 months (post- | BFST-D significantly improved family conflict and adherence compared to Standard Care and Educational Support, especially among those with HbA1c>9%, | Study conducted under optimal circumstance (Ps paid to participants and |

| Number, Reference(s), Country | Participant Characteristics (number; age; gender; diagnosis; recruitment) | Study Design | Intervention (n; number of sessions; mode of delivery) | Comparison group (n) | Outcome measures used | Assessment Time Points | Summary of Findings | Limitations |
|-------------------------------|---|--------------|--|--|--|---|---|--|
| | 2years (mean diagnosis duration, 5.5 years) ; HbA1c \geq 8% (mean=9.6%); community. | | | Support group attended 12 over 6 months (family communication and conflict was excluded from session content). | Adolescent relationship (PARQ), Conflict (DRC) | intervention) , 12 months and 18 months (follow-up) | Both BFST and Educational Support significantly improved HbA1c compared to Standard Care in those with baseline HbA1c >9%. BFST significantly improved communication of adolescents and mother but no fathers, BFST significantly improved quality of family interaction compared to both comparison groups. | free intervention) which may limit generalisability. Small effect sizes. |

Note. AIS, Adjustment to illness scale (Felton & Revenson, 1984); BASC-2, Behavioural Assessment Scale of Children (Reynolds & Kamphaus, 2004); BGM, Blood Glucose Monitoring; BSI-18, Brief Symptom Inventory (Derogatis, 1993); CBC, Child Behaviour Checklist (Achenbach, 1991); CBQ, Conflict Behaviour Questionnaire (Robin & Foster, 1989); DBRS, Diabetes Behaviour Rating Scale (Iannotti et al. 2006); DFBC, Diabetes Family Behaviour Checklist (Schafer et al. 1986); DFCS, Diabetes Family Conflict Scale (Rubin et al., 1989; Hood et al. 2007); DFRQ, Diabetes Family Responsibility Questionnaire (Anderson et al. 1990); DMS, Diabetes Management Scale (Frey et al. 2004); DMQ, Diabetes Management Questionnaire (Weissberg-Benchell et al., 1995); DRC, Diabetes Responsibility and Conflict Scale (Rubin et al. 1989); DQOLY-SF, Diabetes Quality of Life Youth Scale (Skinner et al, 2006); DSMP, Diabetes Self-Management Profile (Harris et al. 2000); DSQ, Diabetes Stress Questionnaire (Boardway et al., 1993); ECBI, Eyberg Child Behaviour Inventory (Eyberg & Robinson, 1983); FES, Family Environment Scale (Moos & Moos, 1994); HbA1c, Glycated Haemoglobin; HBSC, Health Behaviour in School Children (WHO); IBS, Interactive Behaviour Code (Prinz et al. 1979); PAID, Problem Areas in Diabetes Scale (Polnsky et al. 1995); PARQ, Parent-Adolescent Relationship Questionnaire (Robin et al. 1990); PIP, Paediatric Inventory for Parents (Streisand et al. 2001); PMDC, Parental Monitoring of Diabetes Care Scale (Ellis et al 2007, 2008); PQOL, Pediatric Quality of Life (Varni et al. 2003); PS, Parenting Scale (Arnold et al, 1993); PSOC, Parenting sense of competence scale (Johnston & Mash, 1989); RCT, Randomised Controlled Trial; RCBRS, Readiness to Change the Balance of Responsibility Scale (Kaugars et al. 2011); SEDSM, Self-Efficacy for Diabetes Self-Management Scale (Iannotti et al. 2006); SCI, Self Care Inventory (Greco et al. 1990); TADS, Teen Adjustment to Diabetes Scale (Wysocki et al. 1993); T1D, type 1 diabetes.

Table 2.

Assessment of Study Quality.

| Study | Inclusion of Comparison Group | Appropriate Randomisation | Unbiased Selection | Unbiased Data Collection | Unbiased Attrition (i) | Unbiased Attrition (ii) | Total Score (out of 6) |
|--|--------------------------------------|----------------------------------|---------------------------|---------------------------------|-------------------------------|--------------------------------|-------------------------------|
| 1. Anderson et al. (1999) | 1 | 0 | 1 | 0 | 1 | 1 | 4 |
| 2. Carpenter et al. (2014) | 0 | - | 1 | 0 | 0 | N/S | 1 |
| 3. Doherty et al. (2013) | 1 | 1 | 1 | 0 | 1 | 0 | 4 |
| 4. Ellis et al. (2004) | 1 | 0 | 1 | 1 | 1 | 1 | 5 |
| 5. Ellis et al (2005a;b; 2007a;b); Naar King et al (2007) | 1 | 0 | 1 | 0 | 0 | 1 | 3 |
| 6. Ellis et al (2012) | 1 | 1 | 1 | 1 | 0 | 1 | 5 |
| 7. Harris et al. (2005; 2009) | 0 | - | 1 | 0 | 0 | 1 | 2 |
| 8. Harris et al. (2015) | 1 | 1 | 1 | 0 | 0 | 1 | 4 |
| 9. Holmes et al. (2014) | 1 | 0 | 1 | 0 | 0 | 1 | 3 |
| 10. Katz et al. (2014) | 1 | 0 | 1 | 0 | 1 | 1 | 4 |
| 11. Kichler et al. (2013) | 1 | 0 | 1 | 0 | 0 | 1 | 3 |
| 12. Laffel et al (2003) | 1 | 0 | 1 | 0 | 1 | N/S | 3 |
| 13. Murphy et al. (2012) | 1 | 1 | 1 | 0 | 1 | 0 | 4 |
| 14. Nansel et al (2011) | 1 | 1 | 1 | 1 | 1 | 1 | 6 |
| 15. Wysocki et al. (1999); Harris et al. (2001); Wysocki et al. (2000; 2001) | 1 | 0 | 1 | 0 | 0 | 1 | 3 |
| 16. Wysocki et al (2006, 2007, 2008) | 1 | 0 | 1 | 0 | 0 | 1 | 3 |

Table 3.

Descriptive summary of family-based interventions reviewed.

| Intervention | Studies evaluating the intervention | Description |
|---|---|---|
| <i>Quarterly psychoeducation and problem-solving interventions:</i> | | |
| Teamwork (TW) | Anderson et al., 1999; Holmes et al., 2014; Laffel et al., 2003 | Quarterly sessions over one year for adolescent and parent dyads. Education and discussion aimed at maintaining parent-adolescent teamwork in diabetes management tasks without increasing family conflict. Modules focused on responsibility sharing and avoiding conflict. At each session active discussion was encouraged and families were provided with brief written materials, and parent and adolescent developed a responsibility-sharing plan. |
| Care Ambassador Ultra | Katz et al., 2014 | Quarterly psychoeducational intervention in addition to monthly outreach and diabetes care co-ordination (care ambassador). Psychoeducation materials related to family management of diabetes, included problem-solving exercises and role-playing of realistic expectation for family teamwork. Session topics included teamwork and communication, avoiding diabetes-related conflict, weight gain and hypoglycaemia awareness, decreasing feelings of burnout and isolation, session review, and research and technology update. |
| “WE-CAN manage diabetes” | Nansel et al., 2011 | Grounded in social cognitive theory, self-regulation models and systems theory. The intervention aimed to help families improve diabetes management by facilitating problem-solving skills, communication skills and appropriate responsibility sharing. WE-CAN acronym for; working together, exploring barriers, choosing solutions, acting on our plan, and noting results. |
| <i>BFST:</i> | | |
| Behavioural Family Systems Therapy (BFST) | Wysocki et al., 1999; Harris et al., 2005 | Integration of behavioural and family systems theoretical perspectives. The goal was to reduce problematic family-processes and establish a family environment more conducive to developmental needs of adolescents. Intervention consisted of 10 x 90 minute sessions for adolescent and parent dyads. Individualised treatment plans developed for each family based on assessment. Treatment incorporates four key therapy components: 1) problem-solving training, 2) communication skills training, 3) cognitive restructuring, and 4) functional and structural family therapy. Behavioural homework for adolescent and parent assigned at each session and reviewed. |
| Behavioural Family Systems Therapy for Diabetes (BFST-D) | Wysocki et al., 2006; Harris et al., 2015; | Revision of BFST intervention outlined above. Diabetes-specific adaptations included, explicit training in behavioural contracting technique, parental simulation of living with T1D for one week, plus the option to extend the intervention to other social networks (peers, siblings, teachers). |
| <i>MST:</i> | | |

| | | |
|---|--|--|
| Multisystemic Therapy (MST) | Ellis et al., 2004; Ellis et al., 2005; Ellis et al., 2012 | <p>An intensive, family-centred, community-based treatment that was originally developed for young people presenting with serious mental health problems and their families (Henggeler et al., 1999). Scope of therapy encompasses the individual adolescent, the family-system and the broader community (e.g. school and healthcare).</p> <p>An individualised intervention, therapists were required to meet with families a minimum of two times a week for six months. Contact varied from individual sessions held in clinic or at home, to attending school meetings and/or diabetes clinic appointments. Treatment consisted of a range of evidence-based intervention techniques, including cognitive behavioural therapy (CBT), parenting training and Behavioural Family Systems Therapy (BFST). The family-based aspects of the interventions focused on: parental involvement, monitoring and discipline regarding diabetes care; developing family organisation; and teaching caregivers to communicate effectively.</p> |
| <i>Group Interventions:</i> | | |
| Multifamily Group Problem Solving (MGPS) | Carpenter et al., 2014 | Four-session weekly group intervention for adolescents and their parents. Based on behavioural components of BFST-D. The intervention aimed to increase family problem-solving and communication about diabetes, encourage shared responsibility and parent-youth diabetes care collaboration, provides families with blueprint for addressing ongoing and future diabetes-related challenges. |
| Family Adolescent and Children Teamwork Study (FACTS) | Murphy et al., 2012 | Six group sessions over six months for adolescents and their parents. Based on individual teamwork interventions (described above) sessions incorporated conventional diabetes self-management education, with training in family communication skills and responsibility sharing. |
| Kicking in Diabetes Support (KIDS) | Kichler et al., 2013 | A peer-group and family-based intervention based on a synthesis of treatment strategies from diabetes education, behavioural therapy and family therapy literature. Adolescents and parents attended separate groups with their respective peers for the first portion of each session before joining altogether for second half. Interventions for both parents and adolescents were guided by the participants' individual concerns and questions. Activities focused on building rapport with other group members, exploring shared diabetes experiences and enhancing diabetes knowledge, as well as role-plays on social, school and family-based scenarios. In the second half of the session, parent and adolescent dyads worked together on individual family-goals, including family-negotiation tasks. |
| <i>Self-directed Parenting Intervention:</i> | | |
| Triple P: Positive Parenting Program (self-directed) | Doherty et al., (2013) | A behavioural family intervention based on social learning principles (Sanders, 1999). The Teen Triple P family intervention was designed to promote healthy adolescent development, and parenting strategies focus on developing positive relationships and attitudes. The self-directed workbook involved ten weeks of structured learning tasks for parents, delivered via the internet with no therapist contact. Intervention consisted of four main categories of skill building; 1) increase positive parent-teenager |

relations, 2) increase desirable behaviour, 3) teach new behaviour and skills, and 4) manage problem behaviour. A Chronic Illness Tip sheet linked principles of Triple P to common themes that arise in chronic illness.

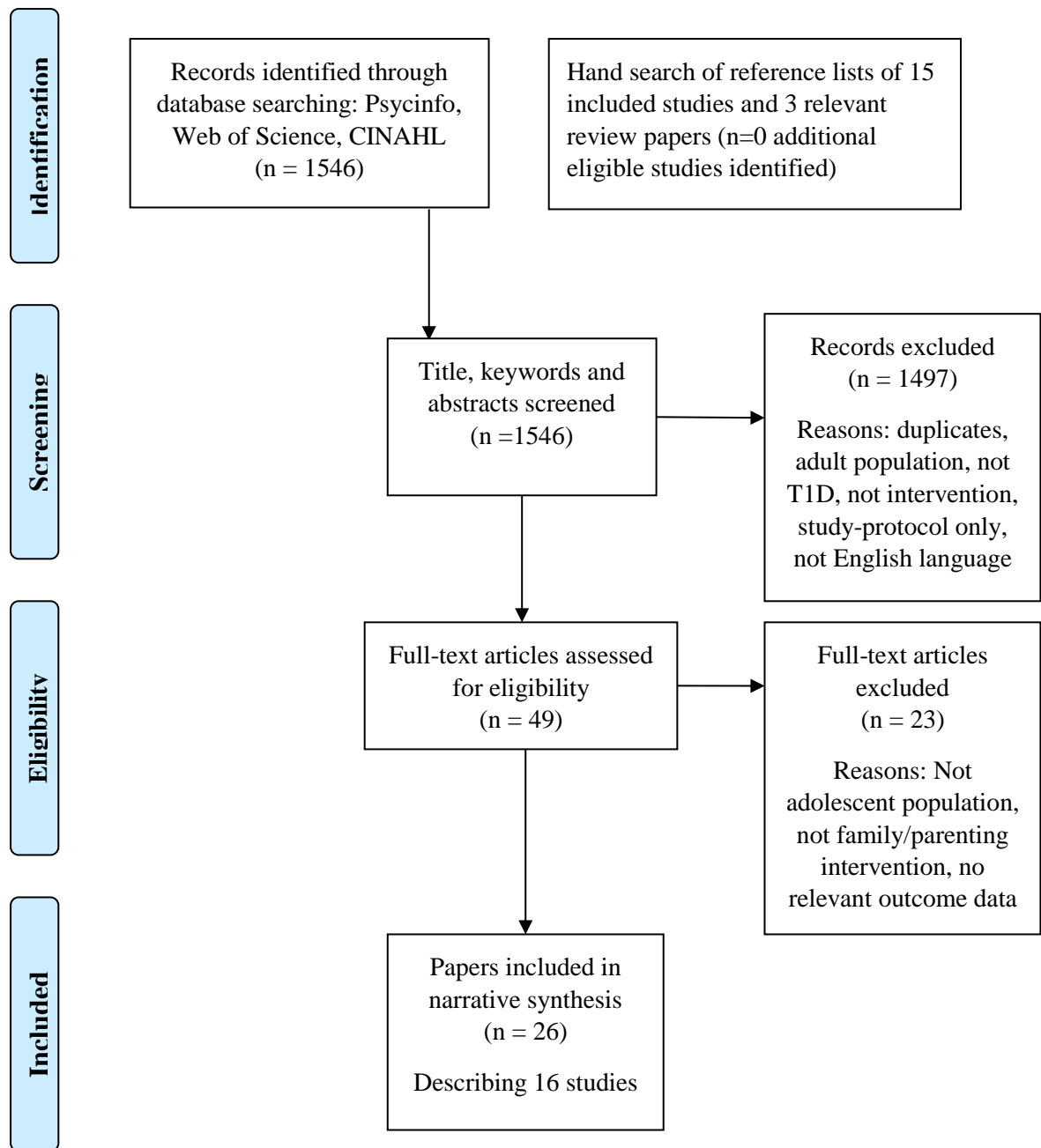


Figure 1. *PRISMA flow diagram detailing study selection process (based on Moher, Liberati, Tetzlaff & Altman, 2009)*

“A Really Tricky Disease”:

Healthcare Professionals’ Experiences of Working with Adolescents with Diabetes and Poor Adherence to Treatment.

SHORT TITLE: Working with Adolescents with Diabetes and Poor Adherence to Treatment

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Abstract

This study explored the experiences of healthcare professionals working with adolescents with type 1 diabetes (T1D) and poor treatment adherence. Semi-structured interviews were conducted with eight professionals – all from specialist paediatric diabetes teams. Data was analysed according to interpretative phenomenological analysis (IPA) principles. Professionals described numerous complexities to their work. They empathised with their adolescent patients whilst also being driven by insight that their patients could not comprehend. They valued a close relationship with their patients but also had to balance parental involvement. Poor adherence had a personal impact on each professional, they often felt powerless and responsible, but with this responsibility came potential reward. Professionals coped with these experiences in different ways, including negotiating when to do more and when to let go. Clinical implications suggest a potential benefit of acceptance-based training and reflective practice. There is need for further research into professional stress and burnout, and transitions.

Key words: diabetes; healthcare professional; adolescents; adherence; lived experience.

Type 1 diabetes (T1D) is one of the most common chronic conditions of childhood. It is estimated to affect around 30,000 young people under the age of 19 in the UK (Diabetes UK, 2015) and numbers are increasing (Royal College of Paediatrics & Child Health, 2015).

Individuals with T1D are unable to produce the hormone insulin and as such must follow a complex daily treatment regime in order to regulate blood-glucose levels (National Institute of Health & Care Excellence, NICE, 2015). Treatment involves regularly testing blood-glucose, closely monitoring diet and exercise, and administering insulin (NICE, 2015). Failure to regulate blood-glucose levels, or maintain glycaemic control, can have serious and life-threatening implications, including risk of cardiovascular disease, kidney failure, amputation and blindness (Diabetes UK, 2015).

Adolescence is known to be associated with a significant deterioration in adherence to diabetes treatment (Morris et al., 1997; Johnson et al., 1992) which negatively affects glycaemic control (Rausch et al., 2012). Guidelines recommend that children and adolescents aim for a glycated haemoglobin (HbA1c) level of 48 mmol/mol (6.5%) or lower (NICE, 2015). However, only around one sixth of young people manage optimal control and over 35% of adolescents aged 15 to 19 have HbA1c levels above 80 mmol/mol (9.5%) indicating poor glycaemic control (Royal College of Paediatrics & Child Health, 2015). Managing diabetes in adolescence is of particular importance as patterns established at this time have lasting implications for long-term diabetes management into adulthood (Bryden et al., 2001).

Research has increasingly employed qualitative methods to explore the management of diabetes in adolescence. A systematic review of qualitative literature (Spencer, Cooper & Milton, 2010) identified twenty studies that examined adolescents' experiences of T1D. Findings centred on the complexity of developing autonomy and independence, living with T1D and family relationships. Adolescents' ability to develop independence and manage their diabetes treatment was embedded within their relationships with peers, family and healthcare

professionals. However, the quality of studies varied, only six studies stated an epistemological stance and only three applied a theoretical framework.

Spencer, Cooper and Milton (2013) used interpretative phenomenological analysis (IPA) to explore the lived experience of 20 adolescents with T1D and 27 of their parents living in the UK. Findings indicated that experiential learning is essential for adolescents to develop independence regarding their diabetes management. However, poor communication from professionals and parental anxiety can impact upon adolescents' ability to self-manage. Furthermore, a recent doctoral thesis specifically exploring the experiences of adolescents with poor glycaemic control (Griffith, 2014) also found adolescents' relationships with healthcare professionals played an important role in their diabetes management. These adolescents experienced difficult relationships with healthcare professionals, often perceiving them as critical, and described attendance at clinic as a negative experience associated with feelings of guilt and shame.

Research to date has focused primarily on adolescents and their parents, and very little research has utilised healthcare professionals' perspectives as a potential source for further understanding. One survey study (Channon, Hambly, Robling, Bennett & Gregory, 2010) used semi-structured telephone interviews with 44 doctors and seven specialist diabetes nurses. The aim was to examine the challenges faced in delivering routine care and to explore the approaches used, to inform the development of a training package. The findings highlighted the complexity of engaging patients and families, the importance of communication skills and meeting the needs of young people at different developmental stages. The most frequent age-related comments were with regards to adolescents, referencing peer pressure, changing emotional relationship with diabetes, and the need for independence. However, the survey-design did not enable in-depth exploration of professionals' experiences of working with these young people. The sample was also limited to doctors and nurses and was therefore not

representative of the multidisciplinary paediatric diabetes teams typically involved in the adolescents' care (NICE, 2015).

Spencer and Cooper (2011) explored the experiences of a multidisciplinary healthcare team caring for adolescents with T1D in one UK hospital. In-depth semi-structured interviews were conducted with eight healthcare professionals (paediatric consultants, specialist nurses, dietician and psychologist). The key themes that emerged included the importance of multidisciplinary team working and the lack of resources. Professionals aimed to equip adolescents with skills to self-manage in preparation for transition to adult services, but the influence of family and need to find a balance between encouraging autonomy and maintaining parental involvement was also recognised. The study employed a rigorous hermeneutic analysis, however, the focus of the research was on the multidisciplinary team approach. There has not been any research to date that specifically explored healthcare professionals' experiences of working with adolescents with poor diabetes management.

The aim of the present study, therefore, was to explore the lived experiences of healthcare professionals working with adolescents with T1D and poor adherence to treatment. These individuals are at high risk of continuing poor glycaemic control and diabetes management through transition to adult services (Bryden et al., 2001). The aim was to further our understanding of what it is like to work with this population, the particular experiences and perceptions, with the hope of informing training and service development. To our knowledge this was the first study to address this research objective and therefore a qualitative methodology was adopted.

Method

Participants

Participants were eight healthcare professionals recruited from four paediatric diabetes teams across North Wales and Shropshire between June and September 2015. Eligible participants

were currently providing care to adolescents (aged 13-19 years) with T1D, and had experience of working with adolescents with poor treatment adherence. Recruitment targeted all professionals within the multi-disciplinary teams (MDT). Table 1 details participant demographic information.

[INSERT TABLE 1]

Procedure

Ethical approval was granted by Bangor University School of Psychology Ethics Committee. NHS Research and Development approval was provided by the relevant organisations (see Appendix B).

Potential participants were contacted via the primary researcher visiting each of the teams to introduce the study. Teams were given recruitment packs consisting of Participant Information and Opt-In forms (see Appendix C & D). Interested healthcare professionals contacted the primary researcher to arrange individual interviews. Written informed consent was obtained from all participants. There was no recompense for participation.

Individual semi-structured interviews were conducted by the primary researcher at the participant's workplace. Interviews were audio-recorded and lasted between 35 and 50 minutes. Interviews were transcribed verbatim after each interview. As recommended by Smith, Larkin & Flowers (2009) the interviews were guided by an interview schedule which was developed in collaboration with the research team (see Appendix F). A pilot interview was conducted with one supervisor to ensure that interview questions were open, expansive and avoided leading or making assumptions. The interview schedule was not followed rigidly, instead the researcher aimed to be guided by the participants' experiences, adopting a process of reflecting and probing.

Study Design

Interpretative phenomenological analysis (IPA; Smith, 2004) was chosen as the most appropriate qualitative methodology as this aims to explore participant's lived experiences and understand how participants make sense of their experiences. It is phenomenological in that it aims to explore a person's account of an event rather than producing an objective record of the event itself. IPA recognises the exploration of participants' experiences is dependent on the researcher interpretation, and in that sense involves a double hermeneutic; the researcher's interpretation of the participant's interpretation of their experience. IPA is also idiographic in that it is interested in the detailed examination of particular cases. It does not aim for generalisability, rather follows a process of detailed examination of the individual cases, to very cautiously making more general claims.

Data Analysis

Interviews were transcribed and analysed manually by the primary researcher. Beginning with the first transcript the researcher engaged in a process of reading and re-reading several times in order to become immersed in the data. As recommended by Smith, Larkin and Flowers (2009), the transcript was then analysed line by line making descriptive, linguistic and conceptual comments, enabling more abstract concepts to be identified (see Appendix G). The next step was to begin to identify themes, emergent patterns, commonalities, and linking themes to reflect wider concepts or shared meanings. A summary table was constructed clustering emergent themes and illustrative quotes. This process was repeated with each interview. Once all interviews had been analysed individually, a process of cross-case analysis was undertaken, looking for connections and patterns across the eight interviews, including similarities and idiosyncrasies. Themes were again clustered and organised into superordinate themes.

The primary researcher kept a reflective diary throughout the research process to help track and identify prior knowledge and assumptions, and consider how their own experiences

might influence their interpretations. The primary researcher had a particular interest in working with young people, but had no prior personal or professional experience of diabetes or any other chronic health condition. However, during the course of the research they began a placement which involved working directly with young people with diabetes and also liaising with a paediatric diabetes team. The researcher aimed to maintain an open and non-judgmental approach to the analysis, by acknowledging and attempting to hold at bay prior assumptions and understandings in order to remain present and open to data.

Two researchers simultaneously analysed one interview transcript and checked a second transcript against the emergent theme table and initial interpretations. Bearing in mind the individual nature of data collection and interpretation, the purpose of this was to ensure that the themes remained close to the data. There was a general consensus on the emergent themes for both interviews and it was agreed that any differences were due to valid individual interpretations rather than significant deviation from the original data.

Results

Four superordinate themes emerged from the data; “empathy and insight”, “negotiating relationships”, “impact on self” and “coping”. Each of these and the corresponding subthemes are outlined in Table 2, and explored in more detail below.

[INSERT TABLE 2]

Empathy and Insight

Recognising the enormity of diabetes. All professionals acknowledged that diabetes is a difficult condition to manage. They used words such as, “horrible” and “unpleasant” and spoke of it being an “awful lot” for the adolescents to deal with. Professionals described diabetes as something unwanted, by the adolescents and themselves. However, there was an overall sense that the available treatment was inadequate, and perhaps part of the problem.

I think diabetes is a, a really tricky disease, um, t-to help young people with, um, I think, the-the tools that we have for correcting high blood sugars, for monitoring, have improved a lot over the years .. significantly in fact, but I think nevertheless it's still as very crude way of managing a problem, you know, jabbing yourself with a needle so many times a day, testing your blood, uh, trying to keep track of numbers, trying to count carbohydrates, and the content of food, adding it all up, remembering when to do it, adjusting for exercise, adjusting for illness and on it goes .. uh, and I think it's .. very difficult, you know, under the best conditions, for somebody to look after themselves.

– David

David illustrated an exhaustive treatment regime. The repetition of “trying” suggested that fully adhering to the regime was difficult and not always possible. “Jabbing” also implied an unpleasant and almost violent experience, suggesting that if this is how diabetes is treated it is understandable that adolescents are avoidant of it. There was also recognition of the far reaching implications of having diabetes, how it “takes over their lives”. Professionals could empathise with this and recognised that what they were dealing with was more than the medical condition, and impacted the whole life of the adolescent.

Putting yourself in their shoes. All of the professionals experienced empathy for the adolescents. Many reflected on their own upbringing and experience of adolescence. As illustrated below, this was considered an important aspect of their work and shaped their understanding and compassion for their adolescent patients.

I think you have to find a way of seeing where they're coming from, and thinking about .. how you would have felt if you were in that situation, at that age, having to do that

sort of thing, I wouldn't want to do it now .. let alone when I was 14 or 15, so I-I think you have to put yourself in their .. shoes, it's the only way to try and see where they're coming from really. – Karen

The use of the phrase “to try and see where they're coming from” suggested that although considered something that they should be doing, putting themselves in the patients' shoes was not always easy or achievable. In fact, some professionals were explicit in outlining how they could not know exactly how their patients felt. Jane had experienced her own health condition and was able to draw on her experiences, but at the same time acknowledged that this was not the same.

I'll never say “I know how they feel”, cos I don't know how they feel, like I can only relate it to my own feelings about my own health problems but not, obviously not diabetes, it's completely different. – Jane

Professionals acknowledged that many factors could contribute to the adolescents' poor adherence. Some did not think they would be able to cope with the extensive treatment regime. This perception appeared to help professionals be more understanding of poor adherence, but also caused them moral conflict. David, in particular, spoke of the difficulty he experienced when his job role required him to ask of his patients more than he felt capable of himself, as if he was setting his patients up to fail: “Well it's unpleasant isn't it because you know you're asking them to do things that you're not too sure that you could accomplish yourself”.

Seeing something they can't see. The staff also had an insight of diabetes that they felt adolescents did not. Each of the professionals spoke of their awareness of the serious and potentially fatal complications of poor adherence and poor glycaemic control. It was apparent

that this was in the forefront of many of their minds, and contributed to a sense of pressure to help.

It's worrying, it's definitely um, a bit anxiety-provoking, especially if they have got some kind of acute physical consequences, so like being in DKA [diabetic ketoacidosis²] .. and that I-I think that that comes from both .. the young person's family, if they are anxious about it, and from the clinical team, the paediatric team that refer them, that you, you can sense their anxiety of [higher pitch] 'Um could you just see this young person cos I'm not sure that we're [trails off]' .. um ..and that they usually come to us as urgent cases. – Ellie

For Ellie, a psychologist, there was often a sense of urgency and anxiety regarding the adolescents with poor adherence. It seemed a referral to psychology came with an expectation that Ellie would be able to do something that the medical team could not, which contributed to a sense of pressure upon her. Ellie eluded to the patient's families not always being anxious, perhaps through lack of awareness or understanding themselves. In this sense Ellie was having to be aware and respond to potential risks that neither the patient, nor family, could see.

The professionals understood that developmentally their patients often could not comprehend the risks of their poor adherence. The insight appeared to motivate many professionals to do what they could to help; as the patients were not motivated by this information they as health professionals must take on that responsibility. The insight also had emotional implications for the professionals, causing anxiety and worry for the adolescents' safety, but also sadness, for the bleak future potentially facing them.

² Diabetic ketoacidosis is a serious, and potentially fatal complication of high blood-glucose.

I don't think, again, they appreciate how unwell they can be and you know it can be fatal as we, as we know, you know even though it's not common, um, but you know, people do still die of .. the diabetes don't they, sadly, um, but again it is a kind of a thought where, oh that will never happen to me, you know. – Kate

Kate's pause mid-sentence suggested that the life-threatening nature of diabetes was difficult for her to articulate, and talking about it was another reminder of the potential danger.

Negotiating Relationships

The importance of the relationship. All the professionals considered their relationships with the adolescent to be particularly significant. Kate, as others, described the importance of knowing their individual patients well and being person-centred in their work: "It's having that kind of relationship with them as well where you know, well so and so is happening to that person's mother so they might need a bit more support during that time". The relationship Kate had with her patients enabled her to be more flexible, and, in this case, provide more support where necessary. A good relationship meant knowing about her patient's lives beyond the diabetes and was linked to her ability to empathise.

Similarly, David's description of his relationship with his patients suggested a quality beyond simply medical care: "I think just being there for young people is important and even if they're d-doing poorly, um, just so they know that there's somebody they can come to, um, and ask for help ... when they need to". There seemed to be an emphasis on the personal, human nature of the relationship, which was important in its own right. A number of professionals also considered the relationship to be at the foundation of the diabetes care.

I often find that once I've got that engagement and that trust that then I can start to make some more changes .. to their adherence, to their diabetes, and I've also found that the

more I .. the better my relationship with the young person the more .. they want to actually please me, rather than .. you know, I think if they don't get on with their diabetes nurse and they don't want to interact with them they're just less likely to ever do anything that you ask them to do. – Jane

For Jane, the way the adolescents felt towards her was particularly crucial, if they had a good relationship the adolescents would be more likely to adhere, as she perceived them to be motivated to please her. In this sense, without a good relationship it would be very difficult for the professionals to provide the care and support needed. However, many professionals also reflected on adolescents being a particularly difficult group to engage.

The adolescent group are by far the most, um, difficult to engage with, um, they present .. the .. most difficult problems in terms of, of how they .. perceive their diabetes and how they manage it, um ..they often don't engage with us as a, as a team. – David

Some spoke of adolescents perceiving them as “old” or “out of touch”, whilst other described adolescents being dishonest with them about their diabetes. They perceived a good relationship to be crucial but at the same time difficult, and perhaps beyond their control, to attain.

Managing the adolescent-professional-parent triad. Professionals also experienced a complex relationship with their adolescents' parents. They often described feeling more aligned to the adolescent, for example David explained that he felt “naturally that I'm on their side”. However, many also empathised with the parents and shared the concern for the adolescent's safety. Professionals recognised that parents played an important role in the diabetes care, they often facilitated the adolescents' attendance at appointments as well as

continuing to hold parental responsibility. This caused dilemmas for a number of professionals, they were torn between having a duty to their patient, whilst keeping parents on board.

[It] just naturally causes a tension, because I'm always aware that I need to engage with the young people and talk to them, um, but it's the parents who are talking to us, um, and whilst we want to engage with the young person, um, I'm also aware that it's the parents who, who need to be doing to work, and so, it's a tension between all of those.
– David

David believed that parents ultimately held the responsibility for care. This guided how he managed the relationships, often speaking more to the parents. Others were more critical of parents and experienced conflicting ideas about how to manage the adolescent's poor adherence. Anita, for example, perceived an expectation from parents that she would reprimand the patient. She felt negatively evaluated by parents when not responding as they would expect.

It is really tricky, I find it very um .. challenging in the sense like .. parents are expecting something else from us, from me, whereas .. my role is to support the child, um .. they probably will, I feel they probably judge me if I don't tell off the child – Anita

There was a general consensus that the relationships needed to be managed carefully and professionals were constantly trying to balance different priorities across these relationships. Some spoke of being in a “difficult position”, wanting to maintain a relationship with the adolescent whilst not “alienating” the parents.

Impact on Self

All professionals spoke of the personal impact of their adolescent patients' poor adherence.

Feeling powerless. As explored earlier, professionals were motivated by their empathy and insight to do what they could to help. However, many described feeling limited in their ability to do so. Professionals faced many barriers to their work, including the lack of resources and high caseloads. Many also referred to the patients ultimately being in control of their adherence and at times unwilling to engage. These factors were perceived to be outside of the professional's control, often leaving them feeling powerless.

I sometimes describe myself as the old woman who lives in a shoe, [laughing] she's got so many children she doesn't know what to do ... because you just feel like, you've got this huge responsibility and .. and you're trying, you know, going against the tide really aren't you, because you're trying to help people that don't always want to be helped. – Jane

Jane described a great sense of responsibility for the adolescents, but felt that her ability to help was hampered by both the enormity of her caseload, and what she perceived as the adolescents' unwillingness to be helped. "Going against the tide" suggested Jane experienced a real struggle and effort to help the adolescents, which could be ultimately be futile if they did not want to be helped. This could be demoralising for staff, however Jane gave the sense that she continued to try, and perhaps the use of humour in this extract reflected a personal coping strategy in the face of these challenges.

Many described feeling "stuck" and reaching a "dead-end" with their patients who were not adhering to treatment. This created feelings of frustration but also concern about the risk of deterioration. A number of professionals spoke of wanting to "fix" their patients. However given the chronic and incurable nature of diabetes this was not ultimately possible. Karen explained: "that's always the things that's the worst, that you want to make it better for them

and we can't .. the things that they're struggling with we can't take away, we can't make better". For Karen, this sense of wanting to help but being powerless was "the worst" thing about her job. Perhaps also stemming from her empathy and compassion for her patients, she could appreciate how difficult it was but did not have the power to take the diabetes away.

Getting it wrong. Many professionals perceived their patient's poor adherence as a personal failure, that they had got it wrong or not done a good enough job. Some experienced feeling responsible, or to blame, for their patients' poor adherence. In the extract below Lindsey was asked to elaborate on why she found it "hard" when patients did not attend clinic.

Well because you think .. what have I done? .. And it makes you think, what have I done from your last clinic to this clinic, have I said something wrong? Have I treated you badly? Have I said something that you think is an insult? Or, you know, you always blame yourself .. think, so what was said in your last clinic that makes you not want to come to this one? - Lindsey

For some, feeling like they were personally responsibly created feelings of guilt and the sense that they had let the adolescents down. As David described: "You feel you haven't helped them .. um, that you feel guilty, that you've gone about things the wrong way, that you've maybe should have supported them differently."

As well as being a negative experience, a sense of getting it wrong also led professionals to reflect on their work and consider what could be improved or done differently. As such, the emotional impact of having patients who did not adhere could drive self- and service-development.

Sense of achievement. Despite feelings of powerlessness, when the adolescents showed improvements many professionals reported feeling like they had “achieved something” personally or “made a difference”, and this was a positive experience.

It can be really rewarding work, um .. if they can turn it around, if you can help them to be motivated that, um .. they can start to see the benefits on their physical health and their emotional well-being, and their attendance at school, they got a lot of praise from everybody when they turn it around .. um, which is really nice and um, the paediatric team are always really [smiling] um, really grateful and um .. reinforcing of that, with the young person and with me. – Ellie

In this extract Ellie places herself alongside the adolescent, both are praised and reinforced by the medical team. This suggests that she felt at least partly responsible for the changes. The opinion of her medical colleagues was also clearly important to her. Perhaps linking back to her feeling of expectation, discussed earlier, that she as a psychologist would be able to do something the medical team could not.

Coping

All professionals described the challenging nature of working with adolescent with poor adherence. Many described different ways of coping with the emotional impact and pressures of the work.

Seeing the positives. Many professionals described a sense of optimism and ability to look for the positives in the difficult situations with adolescents. Jane explained, “I tend to always look at the positive side, I try to stay positive so anything’s a positive for me”. Similarly Karen stated: “there’s always positives, anybody who does better, is a positive, and we do see them, it might be tiny steps and it might not be what we want at the beginning but you can

make .. tiny steps, better”. As Karen acknowledged, this outlook often involved modifying their initial expectations and perceptions of progress. This sense of optimism did not come easily. It was a process which, as described by Lindsey below, came with time and experience.

I’m getting less and less like that, it’s not that I’m becoming complacent about it, I think I just, think well, that last one was ok, this one’s not gone as well hopefully the next one will go better .. it’s trying, rather than thinking oh that was rubbish, not going to get any better, I’ve just got to think well hopefully it can get better .. and you try and think positively about it really. – Lindsey

Going above and beyond. For many professionals their response to the challenges faced was to do more. They perceived poor adherence as an indication that they needed to put in more effort, have more sessions, or involve more resources. Many reflected on the importance of “keeping going” or “not giving up” despite feeling like they were not getting anywhere. This was perhaps in response to their close relationship with the adolescents, their empathy and feeling like they may fail them in some way. Many professionals described adapting and modifying their approaches in response to the poor adherence.

Being flexible is important, so, um .. quite often the young people with [laughing] poor adherence aren’t great at attending so their attendance is .. um, a bit sporadic, quite often they wouldn’t show up for an appointment (...) it would be really unhelpful to then discharge those young people just because they missed an appointment, even if they’ve missed two or three, um .. that although that’s really unhelpful for our services, um, using our time effectively, these young people are only going to get more poorly if they don’t get what they need. – Ellie

Ellie described being flexible and not necessarily applying the same rules regarding attendance as she might for other patients, despite recognising that this was unhelpful for the service. This flexibility was linked to her concern about the adolescent's health deteriorating, and she perceived this approach to be helpful for the adolescents. However, by responding in this way Ellie, and many other professionals, were continuing to take responsibility, at a time when the patients were soon to be transitioning to adult-services and needing to take on more responsibility themselves. The professionals may have been aware that going above and beyond was not sustainable long-term, however, many appeared driven by their own concerns about their adolescent's safety and not wanting to feel that they had let them down. Perhaps this overshadowed their ability to recognise the longer-term implications, for the adolescent and the service.

Acceptance and letting go. Despite many feeling a need to persevere, a number of the professionals recognised when there was nothing more they could do for an adolescent. This did not come easily and was often associated with feelings of sadness.

I suppose they're the ones that we kind of, sadly, not give up on but end up having to accept that we've come to the end of the road, which in itself is, is difficult but I suppose ... y-you know, you have to accept that there is nothing more you can do sometimes –
Karen

Even when acknowledging that there was nothing more she could do Karen still felt the need to state that that this was not giving up, and it was clearly a difficult situation to face. The use of “have to” suggests she perceived this as a necessity rather than a choice. Similarly Anita described “drawing the line” as something professionals have to do.

That's a more difficult part, to see when can we just let it go? Um .. I think, as a professional at some point you have to draw the line and say, like, this is all we can do for this family, and, you have done all your work, like, you have educated them, you have warned them about future implications, complications, and tried to put maximum input within such a short resource .. um, if things can't improve then .. we can't do anything about that. – Anita

For Anita, the questions was of when she felt justified to let go, and this appeared to be once she had exhausted all possibilities. This could be very draining for professionals, and there was an acknowledgement by some that “letting go” enabled them to keep going in order to support other patients.

[It's] frustrating, really frustrating, sad .. have to try not to get too, um .. too hung up on it though because you can't, you can't, you can take a horse to water but [laughs] you can't make them drink can you? And you can't let .. all of those kind of situations bring you down, because you've still got all the rest of your patients to look after. – Jane

The use of “try” and “too hung up” indicated that acceptance did not come easily to Jane, but rather was something she made a conscious effort to do in order to cope and not become demoralised or burnt out. For Eleri, however, this appeared to come more easily. She described an acceptance that the challenges were just part of the job role.

To be honest .. I think I just take it now really, because it's nothing personal is it? (...) it's just, one of those things, isn't it, it's part of the work, and then sometimes, ok, after they've left the room you think, [exhales] oh that was awful, and you just sort of relax .. and then you have five minutes and then you call the next person in, but you know, it's that-, it's that job really - Eleri

As illustrated, Eleri recognised the challenges but appeared more resilient than some. Eleri's indication that this was something she did "now" suggested she had not always responded this way. It is interesting to note that Jane had been in role for a much shorter time, which might imply acceptance and resilience comes with more experience.

Discussion

This study aimed to explore healthcare professionals' experiences of working with adolescents with poor adherence to their T1D treatment. The four superordinate themes that emerged from the data indicated that the professionals empathised with the adolescents and their situation, but were also motivated by insight into the serious health implications that adolescents could not comprehend. The professionals experienced carefully negotiating relationships, wanting to maintain a close relationship with the adolescents, whilst also balancing parental involvement. The adolescents' poor adherence affected the professionals personally, they often felt powerless and limited in their ability to help. Some felt they had not done a good enough job with some adolescents. On the other hand, a sense of responsibility for the adolescents' adherence could be reinforcing, gaining a sense of achievement from any improvements. The professionals coped with their experiences in a number of ways. Many maintained an optimistic outlook. Some described going above and beyond their duties, despite the longer-term consequences for themselves, the service and adolescents. Professionals also recognised a need

to accept their limitations. Despite being difficult to do this appeared to be associated with the professionals' resilience and protection from burn-out.

Comparisons with published literature

Some of the emerging themes are consistent with existing literature. Spencer and Cooper (2011) found professionals recognised the importance of working with the individual, and how a good relationship with the adolescents enabled a better quality of care. They identified a difficult balance between encouraging adolescents' autonomy and keeping parents involved. The complexity of engaging patients and their families and the importance of communication was also identified by Channon and colleagues (2010).

Previous research into adolescents' experiences of T1D found they valued healthcare professionals' friendly manner and acknowledgement of life beyond diabetes (Spencer, Cooper & Milton, 2010). This current study found that professionals also valued the personal quality of their relationship with the adolescents. However, adolescents have also found poor communication with professionals to be a barrier to their care (Spencer, Cooper & Milton, 2013). Some have felt criticised (Griffith, 2014) or felt professionals lacked understanding of their circumstances (Lowe et al., 2015) or emotional experience (Dovey-Pearce, Hurrell, May, Walker & Doherty, 2005). This study has extended upon previous findings to explore the professionals' perspective, and in doing so identified the complex situation they face. Many have the ability to empathise but have conflicting priorities regarding safety and long-term health implications. Professionals often had to weigh-up maintaining the relationship with keeping the adolescent safe, whilst balancing the involvement of parents and lack of resources.

Spencer and Cooper (2011) identified many of the challenges faced by professionals caring for adolescents with T1D, however, this was the first time that professionals' experiences of powerless, guilt and efficacy, in responses to these challenges, has been

identified. Interestingly, guilt in response to poor diabetes management is an emotion shared by adolescents (Griffith, 2014).

Clinical Implications

The themes identified have a number of implications for clinical practice. Adolescents' poor adherence had a negative emotional impact on each of the professionals involved. Many felt constrained in their ability to help and perceived their patients' poor adherence as their own failure. Concerns about professional competence, achievement, and dilemmas of conscience have all been associated with an increased risk of stress and burnout among paediatric nurses in Sweden (Glassberg, Eriksson & Norberg, 2007; Sørli, Jansson & Norberg, 2003). The current professionals' perseverance in the face of challenges and desire to try all possible solutions could be exhausting and increase their risk of burnout. Psychological acceptance has been associated with less emotional exhaustion and work-related stress in professionals working in intellectual disability services (Noone & Hastings, 2011). Professionals working with adolescents with poor adherence may benefit from support to manage the emotional impact on themselves. Reflective practice sessions could help professionals to recognise pressures and manage feelings of guilt and failure. Teams may also benefit from acceptance-based approaches, such as Mindfulness or Acceptance and Commitment Therapy (ACT), which have previously been used with professionals at high risk of burnout (Martín-Asuero & García-Banda, 2010; Hayes et al., 2004).

Adolescents with T1D must develop increasing independence regarding their medical regime in preparation for transitioning to adult services. Previous research has suggested that adolescents benefit from opportunities for experiential or trial-and-error learning (Spencer, Cooper & Milton, 2013). However, the professionals interviewed often responded to poor adherence by doing more, increasing contact and sometimes going above and beyond their duties. Whilst understandably professionals have concern for the adolescents' safety, their

sense of responsibility and fear of getting it wrong may at times hamper adolescents' opportunities to develop autonomy. If professionals felt more supported within their teams and there was consensus on when to step back or increase intervention, professionals may be more able to allow trial-and-error learning, within reasonable limits, which could have potential benefits for the adolescents.

The balance of maintaining a relationship with the adolescent whilst keeping parents on board appears to be a common experience among healthcare professionals. This suggests that more could be done to prepare families for the gradual transition of responsibility throughout adolescence. Paediatric diabetes services being open about the changing expectations on parents, right from diagnosis, may help to ease the pressure on professionals and better prepare families for transition.

Limitations

The findings of this research need to be considered with regard to potential limitations. Firstly the sample consisted of a small number of participants from one area of the UK, which may limit generalisability. The small sample was selected because of the nature of the qualitative methodology: IPA is idiographic in that importance is placed on the lived experiences of particular individuals, rather than aiming to make more general claims. The mix of professionals in the sample is representative of a typical paediatric diabetes team, and given that each key theme was described by the majority of participants, it suggests that findings may have some wider applicability.

IPA is an in-depth exploration that requires participants to clearly articulate their interpretation of their experiences (Smith, Flowers & Larkin, 2009). Given the professional context of the interviews and the fact that the primary researcher was an employee of one of the participating organisations, concern about their professional reputation may have limited some participants' ability to openly articulate their thoughts and feelings. Whilst the researcher

aimed to be open and non-judgemental in their approach, and the richness of data suggests that participants were able to openly express their experiences, this still needs to be taken into consideration.

Further Research

The experiences of healthcare professionals, and particularly those working with adolescents with T1D, is an under-researched area. More research would help determine whether the findings have a wider application.

The emerging themes have highlighted a number of further research opportunities. Firstly, the findings of the current study were considered in the context of the adolescents' need to develop autonomy in preparation for adulthood. More in-depth qualitative research focusing on both adolescents' and professionals' experiences of the transition from paediatric to adult diabetes service would further increase our understanding of this process.

Secondly, this study highlighted the emotional challenges faced by healthcare professionals working in paediatric diabetes teams. Further research is required to better understand professionals' experiences of stress and burnout, which could help to shape services and the support available to teams. Finally, given many of the professionals described difficulty letting go, there is scope for investigating the potential benefit and acceptability of acceptance-based team interventions for healthcare professionals.

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Table 1.

Participant Demographic Information

| Participant* | Profession | Approximate length of experience** (years) |
|---------------------|---------------------------|---|
| “Ellie” | Clinical Psychologist | 1-5 |
| “Anita” | Paediatrician | 10-15 |
| “David” | Paediatrician | 15-20 |
| “Eleri” | Specialist Diabetes Nurse | 15-20 |
| “Jane” | Specialist Diabetes Nurse | 1-5 |
| “Kate” | Specialist Diabetes Nurse | 5-10 |
| “Lindsey” | Specialist Diabetes Nurse | 5-10 |
| “Karen” | Dietician | 1-5 |

**pseudonyms have to been used to preserve anonymity*

***approximate number of years spent working with adolescents with diabetes*

Table 2.

Summary of Themes

| Superordinate Theme | Subthemes |
|----------------------------|--|
| Empathy and insight | Recognising the enormity of diabetes Putting yourself in their shoes Seeing something they can't see |
| Negotiating relationships | The importance of the relationship Managing the adolescent-professional-parent triad |
| Impact on self | Feeling powerless Getting it wrong Sense of achievement |
| Coping | Seeing the positives Going above and beyond Acceptance and letting go |

Contributions to Theory and Clinical Practice

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Introduction

This research has explored the management of type 1 diabetes (T1D) during adolescence in two ways. Firstly, the literature review examined the effectiveness of family-based interventions on health, family and psychosocial outcomes of adolescents with T1D. Secondly, the empirical paper involved in-depth exploration of healthcare professionals' experiences of working with adolescents with T1D, who have poor adherence to treatment. This current paper aims to integrate findings from both to consider the overall impact. This will be presented as follows: 1) implications for further research and theory development; 2) implications for clinical practice; and 3) a reflective commentary on the research process.

Implications for Further Research and Theory Development

Overall this thesis has considered two systemic influences on adolescent diabetes management, namely the family and the healthcare team. Both papers contribute to the recognition that health conditions are not experienced in isolation and many factors influence and contribute to the management of diabetes in adolescence.

As explored in the literature review, family functioning has implications for adolescent diabetes management (e.g. Tsiouli et al., 2013; Wysocki et al., 2009) and although outcomes varied the review found that interventions aimed at improving parent-adolescent relations and responsibility sharing provide some promising evidence for improving health, family and psychosocial outcomes. The types of interventions varied substantially across the included studies and more research is needed to better establish what works for whom. The role of family was also prominent in the empirical paper. The theme 'negotiating relationships' described how healthcare professionals' often found the family around the adolescent an additional challenge. In particular, the professionals experienced dilemmas of knowing how and when to involve parents, as they wanted to engage with the adolescent and valued that relationship, but often parents were still involved in the care and facilitated attendance at clinic appointments.

Alternatively, some professionals found parents to be unsupportive, to have relinquished responsibility too early or to have not provided the level of support for the adolescent that the professionals had hoped. Overall, both papers in this thesis indicate that how families manage diabetes care during the transition through adolescence is of great importance.

The literature review looked specifically at family-based interventions for adolescent diabetes management. The included studies tended to compare family interventions to standard care or waiting list controls. There has not been any comparison in the literature of family-based interventions with individual psychological interventions for adolescents. One meta-analysis of psychological interventions aimed at improving health outcomes for people with T1D (Winkley et al., 2006) found a small to moderate effect size for all interventions, which increased slightly when restricted to family-based interventions, suggesting that family interventions may be more effective for young people's health outcomes. However, one implication for future research is the need for direct comparison of individual and family-based interventions in order to better understand what is more effective, and for whom. Some of the healthcare professionals interviewed in the empirical paper spoke of a tendency to focus on the parents in clinic sessions but experienced moral conflict when feeling that they should be working with the adolescent. This was based on their perceptions and experiences, however, further empirical evidence would be beneficial to help guide clinicians. Comparison of individual and family-based interventions would help to establish when to work with the individual adolescent and when it is indicated to involve the family.

Further to this, the literature review identified that the more intensive interventions, such as Multisystemic Therapy (MST; e.g. Ellis et al., 2004; 2005a;b; 2007a;b; 2012) were most well-supported across health, family and adolescent outcome variables. As well as a family-based component, these individualised interventions also included peer and community-level support. The multi-component nature of these interventions makes it difficult

to ascertain which aspect of the intervention is the most effective, and whether in fact it is the family aspect that is important. Normal adolescent development involves an increasing emphasis on peer relationships, as young people begin to move away from parental control (Anderson & Wolpert, 2004). Qualitative research has begun to explore the role of peers in adolescent diabetes management (Carroll & Marrero, 2006). In this focus group study adolescents with T1D generally described peers as playing a supportive role, but their lack of understanding of the condition or intrusive behaviours could be an additional challenge (Carroll & Marrero, 2006). There is also some positive evidence regarding group interventions specifically for young people with diabetes and their peers (Greco, Pendley, McDonnell & Reeves, 2001). Whilst both the literature review and empirical paper focused heavily on the role of parents and family in adolescent diabetes, this brings into question whether this should be the case. Given the developmental stage of adolescence, should research be focusing on the potential role of community and peer support. This may be particularly relevant as adolescents transition to adult services, where the emphasis is much more on the individual rather than the family. Further research in this area is needed to better understand what is most important in the intensive, multicomponent interventions and whether the role of peers would be beneficial for adolescent health and well-being. This would involve more investigation of the effectiveness of peer-based interventions for adolescents with T1D.

As described, the empirical paper explored healthcare professionals' experiences of working with adolescents with T1D and poor adherence to treatment. Previous qualitative research of the lived experiences of adolescents with T1D found that from the adolescents' perspective professionals can lack understanding, and poor communication can be a barrier to care (Dovey-Pierce, Hurrell, May, Walked & Doherty, 2005; Griffiths, 2014; Lowe et al., 2015; Spencer, Cooper & Milton, 2013). The current research presented in the empirical paper identified that professionals do empathise with the adolescents and place a great importance on

being able to see things from their perspective. Yet, their approaches to care are also driven by their insight into the potential risks, their knowledge of health care, and the balance of relationships with parents and the adolescent. A cluster randomised controlled trial (Robling et al., 2012) investigated the ‘Talking Diabetes’ programme, which provided training to healthcare professionals working in paediatric diabetes services. The aim of the training was to improve care and professionals were trained in constructive consultation skills, to guide communication and set shared agendas with families. The programme was not found to have an effect on adolescent glycaemic control and had a negative impact on some aspects of adolescent quality of life after one year. As such, it was recommended that the programme not be disseminated within NHS paediatric diabetes teams. Taken with the themes of the current empirical study, these findings suggest a more complex situation and indicate that there is more to improving diabetes care than training professionals in communication skills. Professionals experience conflicting demands and pressures that can be a barrier to effective care. Team interventions, therefore, need to target these complexities of providing care. This would include improving professionals’ ability to manage the pressure to take responsibility and their acceptance of their limitations. Further research is needed to explore team interventions that take into consideration the complexities of working with adolescents with T1D that include a focus beyond communication skills.

Further to this, the ‘Talking Diabetes’ study (Robling et al., 2012) did not include a measure of the healthcare professionals’ emotional experience. Given that the emotional impact on the professionals was a key theme emerging from the empirical study, and the risk of professionals stress and burnout (e.g. Glasberg, Eriksson & Norberg, 2007; Sørli, Jansson & Norberg, 2003; Noone & Hastings, 2011) future research would also benefit from measuring the emotional and psychosocial experience of healthcare professionals working in adolescent

diabetes. Future investigation of the impact of paediatric diabetes team-based interventions on the professionals' emotional well-being would also be beneficial.

Implications for Clinical Practice

A clear implication for clinical practice arising from both the literature review and empirical paper is the consideration of how and when to involve families in diabetes care for adolescents. The literature review highlights the important role that families play in adolescent diabetes management and, whilst outcomes varied, interventions that involve adolescents and their families can be beneficial for health, family functioning and well-being. The empirical paper found that healthcare professionals often experience dilemmas of how and when to involve parents. Many professionals experienced concern about their approach and feeling like they had got it wrong or failed their patients in some way. Perhaps exacerbated by the sense of uncertainty about what was the “right” way to manage the conflicting priorities.

Research suggests that adolescents appreciate the opportunity to see healthcare professionals on their own (Carroll & Marrero, 2006). This was recognised by professionals in the empirical study, but they often experienced weighing up seeing the adolescent on their own with not wanting to alienate parents and their concerns about risk to the adolescent's health. Clear protocol for services on how clinic appointments are managed as adolescents get closer to transitioning to adult-services may be beneficial for the adolescent, the professional and their parents. Paediatric diabetes services have a responsibility to better prepare families for the transition of responsibility during adolescence. This could be achieved by professionals being open with families from the outset that as young people get older clinic appointments will become increasingly centred on the adolescent. In adult services the focus is on the individual patient and families generally have much less involvement. Therefore it would also be beneficial in consideration of the transition from paediatric to adult diabetes teams.

Another implication for clinical practice is the need for preventative and early interventions. There was evidence from the literature review that interventions aimed at those with chronic poor glycaemic control and poor adherence were less effective. From the empirical study, healthcare professionals' experiences of working with these individuals is that it is challenging and demanding, both emotionally and on services and resources. In support of this, a recent paper from the British Psychological Society Faculty for Children Young People and their Families (CYPF; Mercer et al., 2015) recommend that young people with physical health needs would benefit from more early intervention and preventative measures, including the use of internet-based psychoeducation. Some of the internet and psychoeducation-based interventions explored in the literature review could be incorporated into routine diabetes care as an early and preventative measure.

Both papers support the role of clinical psychology in paediatric diabetes care. National Institute for Health and Care Excellence (NICE; 2015) recommend that all young people with T1D have access to mental health services. Whilst it is recognised that young people benefit from a psychological approach, the empirical study has also highlighted a role for clinical psychology beyond individual therapeutic interventions. Clinical psychologists are skilled in consultation and supervision (British Psychological Society, 2010). The empirical findings suggest that clinical psychologists can play a valuable role in multidisciplinary paediatric diabetes teams. Formulations can be used with adolescents and families to provide a shared understanding of the challenges and to recognise barriers to adherence. Formulations with healthcare professionals could also help to recognise when it might be more appropriate to relinquish some responsibility and allow trial-error-learning, which is suggested to be beneficial for developing autonomy for diabetes care (Spencer, Cooper & Milton, 2013).

Professionals in the empirical paper all described an emotional impact of working with adolescents with poor adherence to their diabetes treatment. In addition to this many also

responded to poor adherence by “going above and beyond” and had difficulty accepting when to let go. An implication of this is an increased risk of professional stress and burnout (Glasberg, Eriksson & Norberg, 2007; Sorlie, Jansson & Norberg, 2003; Noone & Hastings, 2011). Clinical psychologists can have a valuable role regarding emotional well-being and stress in paediatric diabetes teams. Medical professionals have been found to particularly value multidisciplinary team supervision from their psychology colleagues (Mercer et al., 2015). Clinical psychologists in child health psychology services could facilitate team supervision and reflective practice in diabetes teams. Psychologists trained in acceptance-based approaches could also have a role in facilitating team interventions aimed at increasing psychological acceptance, which have been used with professionals at increased risk of stress and burnout (Martin-Asuero & Garcia-Banda, 2010; Hayes et al., 2004).

In further consideration of the emotional impact on professionals, a number of professionals spoke of the adolescents’ poor adherence reflecting negatively on them as professionals, as if they had failed in some way. This appeared to at least in part stem from a focus on outcomes, and particularly average glycated haemoglobin (HbA1c) levels being used as a measure of service performance. Whilst it is important for services to monitor and measure outcomes, a central focus on HbA1c readings could lead some professionals to feel demoralised and as if they are “fighting a losing battle” when working with those adolescents with chronically poor diabetes management. It is important to consider how professionals’ can continue to feel motivated to work with the most challenging patients, whilst still evaluating services and being target-driven. There is scope for incorporating more client-centred outcomes, and service-user feedback, in the evaluation of services. This would take into account other important factors such as patients’ perception of their relationship with professionals, and their sense of feeling supported and understood.

Reflective Commentary

Reflection is an important aspect of qualitative research and particularly in interpretative phenomenological analysis (IPA) it is considered important for the researcher to reflect on and keep track of their own knowledge, understandings and assumptions of the research area (Smith, Flowers & Larkin, 2009). IPA considers the process of analysis to involve a double hermeneutic; the researcher is interpreting the participant's interpretations of their experiences. The researcher, therefore, must be aware of prior assumptions and knowledge that might influence how they interpret what is being said, and by being aware the researcher aims to be more open and non-judgmental in their interpretation (Smith et al., 2009). As the primary researcher I kept a reflective journal throughout the research process. I was also part of an IPA peer supervision group with colleagues from my cohort.

Starting Out

Before starting out with this research I had very limited knowledge of diabetes and had not previously worked in child health or any health psychology service. I was drawn to this research topic because of my interest in working with children and young people and a developing interest in child health psychology through academic teaching. In particular, I was interested in how young people manage a chronic health condition on top of the inevitable challenges that adolescence brings. I had limited knowledge of what having diabetes entailed, other than the need to administer insulin and monitor diet.

Reflecting on my position when starting the research. As someone around their mid-twenties I think that personally I was feeling at a cross-roads between whether I identified as a young person or as an adult professional, working in the NHS. As a trainee clinical psychologist you are both a student and a professional and I very much felt this dialectic. I think this linked in with who I felt most aligned to initially when considering the research topic. Despite having worked in a professional capacity with adolescents for three years prior to training I noticed

that I automatically felt I could relate more to the adolescents than the healthcare professionals. At that time, I was feeling less connected to the “professional” status. I had no experience of working in paediatric health care but did have an experience of being an adolescent myself.

Having been aware of a previous trainee’s research in to the experience of adolescents with diabetes (Griffith, 2014), I was aware of a preconception that healthcare professionals fail to “get” the adolescents and that perhaps their focus was more on the diabetes and healthcare needs rather than on the individual adolescent. As a trainee clinical psychologist I was also aware of a judgement that other healthcare professionals may pay less attention to the emotional experience of the adolescents, with a primary focus on the condition. I had thought about why adolescents might not adhere; perhaps a denial of the condition, or a desire to engage in “normal” adolescent behaviour at the expense of their health.

Starting out with this research I wondered about the different perspectives you might get from the different professionals. I had some concerns that IPA required a homogenous sample and whether this mix of professionals would fit the methodology. However, I was reassured by my research supervisor that the homogeneity was the shared experience of working with adolescents with diabetes and particularly those with poor adherence to treatment.

Conducting Interviews

Having not previously done any qualitative research I was nervous about conducting the interviews. I noticed that I felt an additional pressure with the participants being professionals themselves and had thoughts that it would have been “easier” to interview young people. I think this was linked to my struggle to identify myself as a professional and feelings of inferiority. I was conscious that this anxiety could impact on my ability to conduct the interviews. The process of conducting a practice interview with my supervisor and hearing her

reflections of her own anxiety about whether she had said the “right thing” or “elaborated enough”, was particularly beneficial.

Conducting the first interviews I was interested in the professional’s descriptions of their work and was genuinely fascinated by all the information. It made me realise how little I knew about the daily-life of someone with diabetes, or this area of work. This made me question; did I know enough to be doing my thesis research in this area? Also, I realised in listening back to the first interview that much of the content was description of their work, or of what it must be like for the young person. I had not been bringing the focus back to the healthcare professionals’ own experiences. I realised that what this research aimed to do was to explore what it was like for these professional to be working with these adolescents, but actually large portions of the initial interview were the professional telling me what it is like for the adolescent. I think because I was genuinely interested in this I had not realised. I re-directed myself to the principles of IPA (Smith et al., 2009) and going forward to the next interview I made sure to keep the research question in mind, and used prompts such as “and what did that feel like for you?”, or “what were you thinking when that happened?” to help identify the professionals own interpretation of their experience.

One participant at the very end of her interview session asked if I myself had diabetes. This made me think about how she may have been responding if she had thought I may myself have been through the system as an adolescent. I was concerned that she may have been more reserved in her answers because of this, and I wondered whether other participants had thought the same. This made me reflect on power-dynamics and how I as the interviewer could influence the participants’ expressions. As a trainee clinical psychologist, the participants’ responses could also be influenced by their current or prior experiences of psychology, or their perceptions of what I, as a psychologist, may value. Reflecting on this I realised it was

important for me to help the professionals feel relaxed, comfortable and able to express their experiences as openly as possible.

During one of the first interviews I noticed my surprise when the professional spoke of parents being unsupportive. Although I had worked with unsupportive parents in Child and Adolescent Mental Health Services (CAMHS) I realised that I had some assumption that when parents have a child with a medical condition they will be supportive no matter what. Although I realised this was an unreasonable expectation it made me consider how I had perhaps not taken into account quite what the professionals' job involved and the complexities they faced. At this point, and as I learned more about the severity and immediate risk to life of diabetic ketoacidosis (DKA; a complication of hyperglycaemia), I noticed increasing empathy for the professionals and what they were having to deal with.

Data Analysis

Whilst initially a daunting and overwhelming task, through the process of reading, re-reading and making initial notes I found I became more engaged with the principles of IPA and the theoretical underpinnings. In particular, considering that there is not one 'objective truth' regarding professionals' experiences of working with adolescents with diabetes and poor adherence. I came to realise that it is a complex and at times contradictory experience.

Having not previously worked in the area, I started a Child Health placement at the point of beginning analysis. I felt glad that I had been naïve during the interview task, as I felt that had helped me to be more open to the professionals' experiences. However, I was now wary of the placement experiences influencing my analysis, particularly as two of my supervisors also worked in Child Health. It seemed likely that these experiences might influence our interpretations. It was therefore important at this stage to regularly liaise with my third supervisor, who had no experience of working in this area, to ensure that my analysis remained close to the data.

Throughout the research process I was also involved in an IPA peer supervision group with trainees from my cohort. We met monthly and shared our analysis and interpretations. This was a really useful experience helping me to reflect on my analysis, making sure that my interpretations came from the data rather than being driven by any preconceptions or expectations. Talking through initial analysis with peers also helped me to become braver in my interpretations, moving beyond descriptions of what was said.

As I finished interviews I noticed a reluctance to move on to the cross-case analysis. I had concerns that the analysis would not be “deep enough” and was unsure about whether my analysis of each case was “finished”. However, beginning to draw comparisons across cases I came to realise that the whole process was fluid and not linear, as I looked across cases I also developed my analysis of the individual interviews. Smith and colleagues (2009) describe how the whole can illuminate the parts as well as vice-versa. The process of developing my themes was a lesson in my own cognitive flexibility, I noticed a tendency to want to hold on to certain themes that had emerged. At this point regular supervision and peer supervision, offering different perspectives, helped me to let go and allow the themes to develop in different ways. Regularly talking through my themes with peers and family helped to refine and shape them. Supervision also ensured themes emerged from the data rather than over-interpreting the findings based on my own assumptions or preconceptions.

Eight participants is considered a relatively large sample for a researcher novice to IPA (Smith et al., 2009). In developing my themes and writing up I was keen to represent every participant, as each had given their time and effort to share their experiences with me. With a larger sample I felt a conflict between making my writing concise and interesting whilst ensuring all participants’ voices were heard. I had to concede that due to some interviews being particularly rich compared to others, some participants are more represented in the text.

Being less familiar with Child Health services I had apprehension about whether my themes would be clinically relevant and resonate with my supervisors and others working in the service. When sharing my themes with my supervisors it was particularly reassuring that the themes that emerged were recognised but also new perspectives had emerged.

Conclusions

Overall I believe that the literature review and empirical paper contribute valuable insights about some of the systemic factors involved in adolescent diabetes management. The research has highlighted a number of areas for further exploration, including gaining a better understanding of when to involve families in psychological interventions, and when the role of peers and community may be beneficial. This research has also highlighted the need to consider the emotional impact on staff and indicates the need for further exploration of interventions aimed at professional well-being. I hope that future studies will further explore the management of diabetes as adolescents transition into adult services. Services would also benefit from the development of client-centred outcomes and service-user involvement in the evaluation of paediatric diabetes services.

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Appendices

Appendix A
Quality Assessment Checklist
for Literature Review

Score 1 point for each YES answer:

1. Did the study design include a comparison group?
2. Did the study state an appropriate method of randomisation?
3. Was the eligibility criteria for selection clearly stated and appropriate?
4. Did the study report blinding of assessor?
5. Was the dropout number and reason for dropout stated?
6. Was over 80% of sample retained at follow-up?

Appendix B

Ethics

NHS Research & Development Application

For Betsi Cadwaladr University Health Board

And

Shropshire Community Health NHS Trust

Bangor University Ethical Approval Email

Appendix C
Participant Information Sheet

Appendix D
Opt-In Form

Appendix E
Consent Form

Appendix F

Interview Schedule

Prior to commencing interview

Researcher to explain that the interview will be audio recorded and will be anticipated to last between 30 minutes to one hour. Participants will be reminded that anonymised information will be used in the analysis and reporting of the study but transcribed data will be anonymised so that individuals will not be identifiable. Limits of confidentiality will also be outlined regarding the specific case of a participant disclosing information that indicated that themselves or someone else they talk about may be a risk.

Participants to be reminded that they can withdraw and stop the interview, or request a break from the interview at any time.

Following this written informed consent will be gained.

Questions

Researcher to outline that the study is looking specifically at the adolescent age group (13-19 years) and that adherence in this study is defined as : not following their prescribed medical regime which could be failure to do one or a combination of the following: attending regular appointments, doing blood tests, taking insulin medication or monitoring diet (carb-counting).

Inform participant that study is interested in them and their experiences; there are no right or wrong answers.

State that the interview will be like a one-sided conversation; the interviewer will likely say very little.

Some of the interviewer's questions may seem self-evident but this is because they are trying to get to grips with how they understand things and not make any assumptions.

Remind participant to take their time in thinking and talking.

Their Role (demographic info)

What is your job role?

How long have you worked in this current role?

Working with adolescents with diabetes

Can you describe your work with adolescents with diabetes?

What proportion of your role involves working with adolescents with diabetes?

How do you find this work?

Working with adolescents with diabetes who have poor adherence to their treatment

How common is poor adherence in your work with adolescents with diabetes?

Can you describe what it is like working with adolescents with poor adherence?

How do you find this aspect of your role?

Can you give me an example?

What are the positives/challenges?

What is/was helpful/unhelpful?

How do you approach this work?

What works/doesn't work?

How do you think adolescents perceive this approach/approaches?

Implications of poor adherence

What is the impact of an adolescent's poor adherence?

For the client/ yourself/ the system?

Their understanding of adherence

What is your experience of why some adolescents have poor adherence?

What factors influence adherence?

What is important in working with adolescents with poor adherence?

Influences of approach

What influences how you work with adolescents with poor adherence?

What do you draw on? (personal/professional experiences? Training?)

Appendix G

Segment of Transcript from Empirical Paper

| Emergent Themes | Original Transcript | Exploratory Comments |
|--|---|--|
| <p>Inevitable challenge of adolescence.</p> <p>Going above & beyond to engage.</p> <p>Wasted efforts. Frustration. Barriers.</p> | <p>I: ok, so can you describe how your role involves working with adolescents with diabetes, in general?</p> <p>P: So, adolescents are always the .. can be the trickier .. age group to engage with I think um so .. we try and get them to come a minute of three-monthly to clinic so I try and see them then, um .. but we do have .. a fair amount of the teenagers that do tend to DNA to clinics because potentially of their .. blood glucose levels that they don't want to share with us and they're the ones that are quite tricky to get hold of on the phone or I'll try and do home visits and they might not be home when you actually turn up um .. but they're the ones that we try and engage, do extra education with at the moment as well, because I know the two psychologists that are with [NAME] at the moment, I know they've just done some education but .. for some of them it was quite a poor turn out, which is a shame really because I think they just want to block it out don't</p> | <p>Descriptive Comments: focus on describing the content of what the participant has said, the subject of the talk within the transcript (normal text). <i>Linguistic Comments</i>: focus on exploring the specific use of language by the participant (<i>italic</i>) <u>Conceptual Comments</u>: focus on engaging at a more interrogative and conceptual level (<u>underlined</u>)</p> <p>Adolescents are a difficult group to engage. <i>Repetition of try. A task? Not easy? Does she succeed?</i> Try to get them to attend regular clinics but a number don't attend. <u>Don't see these adolescents as much as would like?</u> Believes adolescents' attendance is related to blood-glucose level, <u>shame?</u></p> <p>Tries to adapt approach to enable attendance but not always successful. Does more work to try and engage the ones that don't attend.</p> <p>Psychologist colleagues have offered extra education sessions but poor turn out. <i>A shame – disappointment.</i> Empathises with young people- wanting to block it out.</p> |

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| <p>Unwillingness of young people.</p> <p>Stuckness.</p> <p>Finding solutions.</p> <p>Increased efforts.</p> <p>Big effort. “throwing everything at it”.</p> | <p>they, so .. it’s just trying to engage them to attend the meetings that we’re trying to put on for them, which can be quite frustrating when you haven’t got that contact with them, if that makes sense?</p> <p>I: Yeah, so can you describe what it’s like working with the adolescents with poor adherence?</p> <p>P: um, it’s a challenge, um again, can be frustrating because of their poor adherence .. they don’t necessarily want to see you .. so then it’s .. a vicious circle then, that I haven’t got contact with them, so they’re kind of lost a little bit when we can’t get hold of them and then .. their control kind of deteriorates further with a lot of them I think and that’s quite frustrating, so a new way that we’ve got now is, so when I go see them at home which is a little bit more successful than bringing them to clinic, is admitting them for a week or so, so for intense education on the ward, works for some, not for others um .. but it can be quite frustrating at time, just because they won’t engage ..</p> <p>I: And how do you find that, admitting them to the ward? That aspect of the work?</p> <p>P: um, again i-it means that we’ve got to try and get the whole team involved, so it does mean a little bit of shifting of work for other people, you know we want the consultant, myself, [psychologist], [dietician] all to be available for that on top of the ward staff giving it, um .. giving the education as well um so .. I think we’ve admitted</p> | <p><u>Trying- attempting but not succeeding? A chore? Draining?</u></p> <p>Frustrating to not have contact with the young people.</p> <p>Working with adolescent with poor adherence is challenging and frustrating. Young people not willing to see you. <u>Vicious cycle- stuck, get’s worse, trapped?</u> <u>Lost = can’t be found</u> – can’t be helped? Deterioration, situation with adherence and control gets worse. Frustration for professional. Have a new way of working with these young people. Seeing at home is more successful than clinic- flexible approach. <i>Little bit.</i> Have started admitting young people with poor adherence for intensive education – increasing contact. This works for some but still some where this increased contact is not effective. <u>Doing more and still not succeeding? Repetition of frustration- emphasis. Won’t = young people are unwilling- out of her control?</u></p> <p>Admitting them to ward means involving whole team. Involves flexibility, shifting work, <u>prioritising?</u></p> |
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| Balance of what young people like and what is necessary. | about three or four recently and its worked well .. um .. we have improved their control, one has kind of deteriorated a little but I think the threat of coming back in has been enough to get him back on track, so I think it has been a good exercise if you like, not so good for them potentially, because they're in for five days, a week, um ..but again but if it helps their health ... I-I guess a week isn't too bad is it? [small laugh] | Contact from medical team significantly increased for those on the ward, input from ward staff and diabetes team. |
| Importance of parents. | I: And you described working with the adolescents as being the trickier aspect, can you me a bit more about that, wh-what is trickier? P: .. again, the younger .. age group, the parents bring them in don't they, you know .. regardless of what their control is the parents do bring them, so when you get to the adolescent age group they're the one's that potentially they come in on their own, or are refusing to come in um, and I can't remember what you asked now sorry | Have admitted 3-4 recently. Positive outcome-improved control. One has deteriorate ' <i>kind of</i> ' ' <i>a little</i> ' – <u>what does this mean? Minimising?</u> Overall believes admitting to ward is beneficial- for health <u>but not necessarily positive in young persons eyes?</u> <u>Laughter- use of humour, positive outlook?</u> |
| Relationship with young person. | I: what makes it trickier? | With younger children parents are more involved, adolescents are more likely to come on their own, more likely to refuse. <i>Loses train of thought.</i> |
| Barriers faced. | P: yeah, so I don't think it the engaging with them it's .. you know, once they're here .. it's fine isn't it, but it's getting them here that is the problem the majority of the time .. so that's then when [psychologist] does a lot of work, like, which has been successful with at least a good handful that I can think of, that has given them that .. confidence to come to clinic even though maybe their control hasn't been good ... and working on their control, because I do joint | Doesn't think it is the engagement that is trickier. <u>Contradiction with earlier statement that adolescents are trickier to engage with?</u> Once adolescents are at clinic it is fine but getting them there is the main problem. <i>Isn't it?- reassurance?</i> Psychologist works with those not attending, this has been successful with a number of adolescents. Have confidence to come to clinic- <u>confidence important factor? More than the diabetes and adherence?</u> |
| Teamwork. | | |

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| <p>Barriers/limitations faced.</p> <p>Young people's unwillingness.</p> <p>Relationship- trust Relationship as barrier.</p> <p>Demands of role – overstretched.</p> <p>Barrier- resources.</p> | <p>one's with [psychologist] so when I'd have a look at the numbers and [psychologist] does .. what she does .. and um.. that seems to be quite successful .. but, it's just the trying to get hold of them that is the trickiest part of it .. because mobiles are quite handy aren't they, you can just turn them off when you've made arrangements to, right I'll ring you at half ten Thursday morning and miraculously their phone is off and there's no voice mail ..</p> <p>I: And what's that like for you when that happens?</p> <p>P: um it is again, I feel like I'm using the word all the time but frustrating .. because you know, y-you get them on the phone and they're like, oh hi! You know, yeah, yeah that's fine, I haven't got any readings now but ring me at that time and I will have, and then you ring them and it's, you know ... it's, and you know their control isn't good because we've had a hba1c recently and that's raised, so it's just annoying that we can't actually have that communication, so freely, as I'd like it to be because .. we've got over 130 patients, so the logistics of it as well makes it hard for me to you know, go visit every adolescent that we've got on a regular basis, um, unfortunately, but with hopefully more .. resources we would be able to manage that a little bit better but .. the number's that we've got at the moment is a little bit much to be doing home visits for everyone ... so it is a challenge ... which I like, because I do like the teenage groups</p> | <p>Has joint appointments with psychologist, have own roles in joint work, collaboration?</p> <p>Getting hold of the adolescents is difficult.</p> <p><i>Use of sarcasm.</i> Suggests that adolescent deliberately avoid her- unwillingness to engage.</p> <p><i>Repetition of frustration.</i> Relationship with adolescent appears to be OK but then they don't actually do what is asked when it comes to it. <u>What does this feel like for her? Deceived? Let down?</u> Frustration and annoyance. <u>Barriers get in the way of being able to do job?</u></p> <p>Logistics- practical limitations faced. High caseload, high demand, stretched resources. <u>Is this also a barrier?</u></p> <p>Because of caseload can't give attention she would like to all patients. <i>Unfortunate- unlucky.</i> Optimism- more resources would mean she would be able to do more.</p> |
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| <p>Sense of achievement/ reward.</p> <p>Not all about diabetes – impact on life.</p> <p>Not doing enough.</p> <p>Preparing for transition.</p> <p>Caring relationship.</p> | <p>I: I was going to say, what are the positives, or are there any positives aspects to working with the adolescents with poor adherence?</p> <p>P: I think, you know, you can get a lot from them, you know, when they feel better they kind of really appreciate that potentially their control wasn't good and they weren't kind of adhering to what we were asking them to do and, you know, it's kind of seeing them turn around and .. be happier as a person .. you know, feel a lot better, so that they've got that extra energy, and it's good to see that kind of transformation if we can get there .. but sadly, you know, when they have done their GCSEs we then kind of put them in the transition group, so some of them we haven't got there and it is really frustrating that we're kind of transferring them to adults without doing what I would have liked to have done with their control, so that's a little bit-</p> <p>I: What would you have liked to have done?</p> <p>P: Just, just improve their control, you know, before they go off the adults because it's such a different service that .. potentially they're not going to be hassled so much by the adult team as they would here, by us ringing them, you know, chasing them what have you, so you feel like .. that you want to turn them round a little bit so that they're control have improved before they go over that way and then think, oh well, no one cares so much now, so I'll just do what I want ... so it is a shame that we haven't m-managed it with some of</p> | <p>Likes working with adolescents but they do take a lot of work and <u>don't have the resources to do the level of work she would like? or that they require?</u></p> <p>Sense of reward, response? When adolescents are better they appreciate where they were and that they weren't adhering. <u>Does this lead to change?</u></p> <p>Results: seeing the change, "turn around", noticeable difference.</p> <p>Not all about diabetes, also how they feeling in themselves. Good to see transformation. "If" they get there not "when". Not a given, suggests doesn't happen for everyone.</p> <p>Sadness of transitioning some young people who haven't made changes. Having done what see would have liked to. <u>Own standards? Not done a good enough job?</u></p> <p><i>Just- implies simple, is it?</i> Adult service is different. Doesn't "hassle" <u>as they do?</u> Not same level of care. <u>Adult service don't go out of their way for the patients?</u></p> |
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| <p>Seeing the positives.</p> | <p>them but you know I think we- .. it is the smaller number that we haven't done it with I think, I think a lot of them we have kind of, with bringing them in and .. you know .. visiting them at home on a regular basis, we have pulled them back, majority of them though, which is good to see .. before we do say goodbye to them, so ..</p> | <p>Wants to get adolescents to a good place before transition- in preparation. <u>Because it's not going to happen otherwise?</u></p> <p>Suggests adult service don't care as much. <u>Does she care a great deal?</u></p> <p>Shame when haven't been able to achieve what had hoped.</p> <p>Small number- optimism? Positive outlook?</p> <p><u>The rest have been OK?</u></p> <p>Have done a good enough job with the majority.</p> <p>Saying goodbye- letting go.</p> |
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Appendix H

Example of Cross-Case Analysis; clustering emergent themes into subthemes and superordinate themes

| Emergent Themes | Subthemes | Superordinate Themes |
|---|---|---------------------------|
| Systemic Impact Impact on life More than diabetes Impossible task Enormity of diabetes Unwanted condition Interaction of life and diabetes | Recognising the enormity of diabetes | Empathy & Insight |
| Empathy Understanding Reflection on own adolescence Inevitable challenges of adolescence Typical adolescence On young person's side | Putting yourself in their shoes | |
| Awareness of risk Complications of diabetes Pressure to do something Foreseeing negative future outcomes Concern/worry Insight | Seeing something they can't see | |
| Relationship as foundation Personal nature of relationship Use of humour Maternal role Reciprocal relationship Getting to know the individuals Person-centred approach | The Importance of the Relationship | Negotiating Relationships |
| Importance of parental role Transition of responsibility Who is responsible? Mediator role Seeing both sides Parents as unsupportive Treading carefully Balancing act Fragility of relationship | Managing the Adolescent-Professional-Parent Triad | |

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| Powerlessness Barriers Limitations Overstretched & Under-resourced Young people's unwillingness Feeling fooled/deceived Young people ultimately in control Feeling unsupported Wasted effort | Feeling Powerless | Impact on Self |
| Guilt Not doing a good enough job Failing Letting patient down Sense of failure Poor adherence reflects badly on professional Not doing enough | Getting it Wrong | |
| Rewarding Making a different Observable change Achievement Pride | Sense of Achievement | |
| Optimism Adjusting expectation Modifying perception of progress Recognising small steps Hope Remaining positive Adolescent as a phase | Seeing the Positives | Coping |
| Flexibility Increasing input Looking for solution Finding a way Patience & Perseverance Not giving up Doing what can be done Blurred roles Extra Mile | Going Above and Beyond | |
| Recognising limits Detachment Coping strategy "just part of the job" Knowing when to let go Doing enough Acceptance of reality | Acceptance and Letting Go | |

Appendix I

Themes and Corresponding Example Quotations

| Superordinate Theme | Subthemes | Example Quotes (<i>page.line number</i>) |
|----------------------------|--------------------------------------|---|
| Empathy and insight | Recognising the enormity of diabetes | <p><i>Ellie</i>: “So um .. for the young people .. their poor adherence um, depending on how bad it is can affect everything.” (11.10-11)</p> <p><i>Anita</i>: “for everyday life, I think they-, it will impact on their mood, um, their behaviour, their learning ability, because they can’t concentrate they feel tired, if the blood sugars been up and down, um .. and .. it can .. um .. they might lose weight and feel ill and tired easily” (13.4-7)</p> <p><i>David</i>: “Well I think, um, diabetes is unpleasant, who wants to injects yourself, or test, or write down results or be told to inject now or not eat this or ... so managing diabetes is horrible, its, uh, um .. it’s a .. a real millstone around their necks” (12.3-5)</p> <p><i>Eleri</i>: “.. I mean most of them find it difficult to be actually checking their blood sugars really regularly and keeping to, you know, the carb counting for every single meal, but who wouldn’t, you know, the expectation is really, really, high isn’t it?” (2.5-8)</p> <p><i>Jane</i>: “it is quite a responsibility and there’s so much more than just diabetes, to .. for these young people I think, it’s just so much more ... going on in their lives, yeah....”(22.20-22)</p> <p><i>Lindsey</i>: “, I think, the psychological impact on the family is huge, the frustrations it causes, the arguments, the guilt that the parents feel , because their child isn’t adhering, isn’t doing well, and they can’t force them .. I think, I think that that’s the tension it causes in families is-is huge” (15.8-11)</p> <p><i>Karen</i>: “it’s hard, it takes over their lives and for some of them” (9.16)</p> |
| | Putting yourself in their shoes | <p><i>Ellie</i>: “can’t people see that they just need a bit more help, a bit more looking after” (4.21-22)</p> <p><i>Anita</i>: “[poor adherence] is pretty common, especially in adolescents, it kind of gets .. out of the window, I mean I can understand, its peer pressure and being teenagers and diabetic is hard” (1.19-20)</p> <p><i>David</i>: “I think personally if I were a young person with diabetes I’d be hopeless, um, I think there would be other more important things in my life as a young person” (2.9-10)</p> <p><i>Eleri</i>: “at fifteen I was in pubs .. drinking and .. skiving off school and doing a lot of things I shouldn’t have, and I remember those feelings quite, you know, quite clearly, wanting to be part of the gang, wanting to be worse behaved than any of the others because that pressure to be well behaved was there” (19.15-18)</p> <p><i>Jane</i>: “so I do try and put myself in their shoes, that’s something I do .. a lot of, um .. just to try and appreciate really what it might be like, I know if I have to take antibiotics four times a day I’m rubbish, I can’t remember to do it [laughs] so I think if I had diabetes would I be any better, you know?” (8.14-17)</p> |

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| | <p><i>Kate:</i> “I can see where they’re coming from you know, as a person who hasn’t got diabetes, we do ask a lot of them, even-, it doesn’t sound like much on paper, you know, do your bloods, inject” (16.12-13)</p> <p><i>Lindsey:</i> “I think having children as well myself, you see what they’re- what they’re like, what their patterns are and what frustrates them and how they cope with that, so I think having children myself does help” (8.11-13)</p> <p><i>Karen:</i> “I think trying to get your head inside where they’re coming from, I think you have to find a way of seeing where they’re coming from, and thinking about .. how you would have felt if you were in that situation, at that age, having to do that sort of thing, I wouldn’t want to do it now .. let alone when I was 14 or 15, so I-I think you have to put yourself in their .. shoes, it’s that only way to try and see where they’re coming from really, you’ve got to” (21.17-22.1)</p> |
| Seeing something they can’t see | <p><i>Ellie:</i> “I certainly think that that not understanding, either the, the potential impact of poor adherence on their long term future, I-I don’t think they always get that, or that they struggle to acknowledge it” (5.22-6.2)</p> <p><i>Anita:</i> “And it’s very difficult to make them understand that it can be life threatening, because, she’s been five times and she gets recovered, and goes home, um, so she thinks it’s not going to harm her, but at the same time, as a professional you know, it can be life threatening and it can- she can die [deep intake of breath] so that is concerning .. um, really” (2.12-16)</p> <p><i>David:</i> “cos as young people, um, a lot of the, uh, complications of poorly managed diabetes are-are not uh .. apparent, and, only emerge, you know, later on in life and, a-and so they don’t .. they don’t understand th-the importance or the danger of not looking after themselves” (8.5-8)</p> <p><i>Eleri:</i> “Because we’ve got targets, haven’t we, that we should be .. you know, we know that there’s long term risks and the targets for good hba1c is always being thrown at us isn’t it” (16.13-15)</p> <p><i>Jane:</i> “and it does make me feel sad that I know that he’s a young person and he’s going to be still be a young person when he’s suffering from complications of diabetes and it’s .. it’s sad really that they’re, he’s not going to, he can’t see that and his parents can’t see that, but ultimately he will .. you know, he won’t probably live to be .. an old man” (4.4-8)</p> <p><i>Kate:</i> “we can talk about DKA but if they haven’t actually experienced it I don’t think, again, they appreciate how unwell they can be and you know it can be fatal as we, as we know, you know even though it’s not common, um, but you know, people do still die of .. the diabetes don’t they, sadly, um, but again it is a kind of a thought where, oh that will never happen to me, you know” (23.19-24.1)</p> <p><i>Lindsey:</i> “when you’re 13-14-15, you can’t see twenty years down the line, its, they just don’t think it’s ever going to come .. and the problems that you’re going to have, so if I turn round and say you know in twenty years time you could have children of your own, you could have problems with eyesight, just they go, ‘so what? [laughs] ..it doesn’t matter’ ” (14.3-7)</p> <p><i>Karen:</i> “you know that actually they’re doing themselves real damage and the long-term consequences of that are what we see, and that’s the thing I suppose that’s ... a worry for them, because, they can’t see it at that age, but we do .. and .. you know, you know so were seeing something that they can’t even envision really” (19.7-10)</p> |

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| Negotiating relationships | Patient relationship as the foundation | <p><i>Ellie</i>: “because I worked with her for quite a while on and off, um I think, I think we build up a good relationship, she, I-I think that she trusted me, um .. she was definitely well engaged because she had to get herself to the appointments” (10.8-10)</p> <p><i>David</i>: “I always feel quite fond of them, no matter how poor or good a diabetic they have been .. but ..put it that way, um, um and hopefully they feel similarly” (6.20-7.1)</p> <p><i>Eleri</i>: “ok that was awful at the time but we’ve still got that relationship now, you know so, I think ..you know, that’s important as well really, and that helps, that has helped” (7.3-5)</p> <p><i>Jane</i>: “like I said it’s the engagement really, if you get the engagement with the young person then you’ve always got somewhere to manoeuvre, but it’s when you don’t get the engagement .. that that’s really difficult, cos there’s very little you can do then, if they don’t want to speak to you and they don’t want to see you” (3.15-18)</p> <p><i>Kate</i>: “so it’s having that kind of relationship with them as well where you know, well so and so’s happening to that person’s mother so they might need a bit more support during that time” (11.1-3)</p> <p><i>Lindsey</i>: “I think the other thing as well is , you know, you’ve got adolescents and they think somebody who’s over 20’s ancient, and so for, you know, as you are working with them you think they’re just looking at me thinking, you’re just like my mother, or my grandmother talking to me here, and we’re just a different generation, probably two generations ahead now, and so it’s getting over that, um, that what’s the word, generation barrier as well” (7.1-6)</p> <p><i>Karen</i>: “I think when we have long, you know, when we have ones that really struggle and we do get like a little bit of something with them long term, you know, it does get a little bit better they do see that you are just trying to help and you are accepting .. that they can’t do everything right and, you know, we’re making tiny steps forward, so sometimes yeah, they make th- w-, but I think it takes time to get to that” (12.11-16)</p> |
| | Managing the patient-professional-parent triad | <p><i>Ellie</i>: “I have found it difficult just to engage the parents at all to come to appointments, that they kind of see that it’s th-the adolescent’s problem, they are the ones that need to come talk and it’s not their job to come and, um, see a psychologist about why the young person isn’t doing what they are supposed to be doing .. Um, so I think that’s been the biggest barrier; getting them to see that-, that they have a role in managing the diabetes” (3.13-18)</p> <p><i>Anita</i>: “, I find it very interesting, some parents are fantastic um .. they do try to be sympathetic but .. some parents bring their children, um, to the clinic as if ... for us to tell them off like, um .. as is to victimi-, its not victimisation but, um .. it’s like, oh, they give a really, um, support-, as if they are supporting everything but even then the child is not doing anything, but you can clearly see how the parents are, um, are getting at their children you know, that at home probably she doesn’t do anything and its everything up the children but, um .. they feel our role is to tell them off, but it’s, I try to explain that this is not my role” (6.15-21)</p> <p><i>David</i>: “I think the important thing is to try and engage with [parents] and address worries that they have, and at the same time be inclusive of the young person, because, as I’ve mentioned before at almost every clinic it just naturally turns the way of you talking to parents rather than the young person ” (10.2-5)</p> |

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| | | <p><i>Eleri</i>: “..and it all comes out in clinic so it’s all anger and frustration and then I’m sort of in the middle between them, so that can be quite difficult really” (5.4-6)</p> <p><i>Jane</i>: ““cos most of my patients .. don’t really want their parents involved, um, although, you know, they consider their support to be nagging and it can detrimental” (5.15-17)</p> <p><i>Kate</i>: “it’s getting the parents on board as well .. um .. you know, because you’ll hear in clinic from some of them, well mum or dad or a combination of whatever, you know well they don’t seem to care so much anymore so I don’t bother so much, so it’s also getting them kind of back on board” (6.21-7.2)</p> <p><i>Lindsey</i>: “it puts us in a difficult position and it is difficult to manage as well, because if you, sort of, start to-, not criticise the parents but say maybe you need to be doing more, you need to be supporting them more, then you can alienate them as well, and you’ve still got to work with that family .. so yo-you’ve got to really walk a very, sort of, tight rope, you’ve got to .. get it right I think” (4.8-12)</p> <p><i>Karen</i>: “a lot of them are in front of me because mum and dad’s are telling them they need to be (...) and is being sort of held down by mum, with mum maybe .. ad-libbing in the corner and things, but .. unfortunately .. they wouldn’t be sitting there in front of me in any other way” (13.16-21)</p> |
| Impact on self | Feeling powerless | <p><i>Ellie</i>: “...and that’s not something that they can do anything about its rigid, it’s there, you can’t make it go away” (19.10-12)</p> <p><i>Anita</i>: “frustrating [laughs] um .. concerning, to some extent .. um .. it’s just sometimes, just a brick wall you know , hitting your head into a brick wall, kind of thing” (2.3-4)</p> <p><i>David</i>: “we simply don’t know whether they are, are adhering, as you pointed out, or not because they, um, they give us half-truths, or they, um, they cover up .. and it’s very easy to do that, you know...” (3.18-21)</p> <p><i>Eleri</i>: “frustration as well that you think, oh just, why can’t we just help them” (3.12-13)</p> <p><i>Jane</i>: “you just feel like, you’ve just got this huge responsibility and .. and your trying, you know, going against the tide really aren’t you, because you’re trying to help people that don’t always want to be helped” (5.6-8)</p> <p><i>Kate</i>: “it’s a challenge, um again, can be frustrating because of their poor adherence .. they don’t necessarily want to see you .. so then it’s .. a vicious circle then, that I haven’t got contact with them, so they’re kind of lost a little bit when we can’t get hold of them and then .. their control kind of deteriorates further” (2.20-3.1)</p> <p><i>Lindsey</i>: “I’m here to offer you help and support you as much as I can, but I can only do that if you are honest with me and tell me what’s really happening” (6.16-17)</p> <p><i>Karen</i>: “I mean it can be really difficult obviously if they’re just not interested in doing it it’s really frustrating, you don’t kind of get anywhere, um .. you can’t ..you know you know they can potentially do it but you’re just not able to get them to change the way they feel about it, um .. and that’s really difficult” (2.15-18)</p> |
| | Getting it wrong | <p><i>Anita</i>: “whether that, that’s the case, if, once they, if they develop complications, will they think that .. we haven’t done enough for them? That’s my biggest worry” (16.14-16)</p> <p><i>David</i>: “you know sometimes if we’ve, it’s difficult and we often make the wrong choices, say the wrong thing” (5.12-13)</p> |

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| | | <p><i>Eleri</i>: “.. I don’t know, maybe I’m getting it all wrong I don’t know [half laughs] I don’t know really, maybe I am .. yeah” (21.2-3)</p> <p><i>Jane</i>: “come out of them feeling quite fed up and a bit deflated and ‘am I doing a good enough job?’, ‘am I-‘ you, know, ‘maybe I should be doing something different” (14.14-16)</p> <p><i>Lindsey</i>: “I: This might sound like an obvious question but what makes it hard when they say that they don’t like coming to clinic, what is hard about it?</p> <p>P: Well because you think .. what have I done? .. And it makes you think, what have I done from your last clinic to this clinic, have I said something wrong? Have I treated you badly? Have I said something that you think is an insult? Or, you know, you always blame yourself .. think so what was said in your last clinic that makes you not want to come to this one? What was so bad about it? .. Um ..and why do you not find it helpful?” (19.16-22)</p> |
| | Sense of achievement | <p><i>Ellie</i>: “it can be really rewarding work, um .. if they can turn it around, if you can help them to be motivated” (13.20-21)</p> <p><i>David</i>: “Well, I mean I th- I think, it’s always, um, it’s always rewarding getting to know young people and .. and rewarding in attempting, I should say attempting, to help them with their diabetes ” (7.12-14)</p> <p><i>Anita</i>: “she is now taken control of it, she’s taking her medication, she’s involved in exercise and things, so , there are quite, they are all quite rewarding” (4.19-21)</p> <p><i>Kate</i>: “and I do .. like working with the adolescents because they are more challenging aren’t they, um .. but if you .. get to where you want them to be its, I think it’s more rewarding then as well” (14.19-21)</p> <p><i>Lindsey</i>: “.. if you see adherence improve, so if you put an intervention in, you work with the young person and it helps then it’s very positive” (14.10-12)</p> <p><i>Karen</i>: “.. if you can make a difference it m-, you know it’s a good feeling to know that actually, despite that maybe .. you found a way into th-, you know, you found a way in, you found a way of kind of .. you know, sort of getting them to engage with you and you made it better” (13.1-4)</p> |
| Coping | Seeing the positives | <p><i>David</i>: “a few years later things begin to improve as they .. um, I guess develop .. um, better insight into what they need to do” (14.8-9)</p> <p><i>Eleri</i>: “trying to take, you know, everything that’s improved a little, even if it’s only more tests, even if it’s only coming to clinic, when they haven’t been coming at all, even if they haven’t bought their metre with them, you know, anything, is just a positive” (10.4-7)</p> <p><i>Jane</i>: “I tend to always look at the positive side, I try to stay positive so anything’s a positive for me” (2.4)</p> <p><i>Lindsey</i>: “but I always try and hold that in my head and think well, it’s a blip, they will come out of it, you know, two-three years down the line things start to settle down .. the majority come out of it and you’ve just got to try and remember that, that it’s not .. that’s it, the end of the road for sort of, good diabetes care, um ..that most of them do come through and when they hit that level of responsibility” (14.17-21)</p> <p><i>Karen</i>: “there’s always positives, anybody who does better, is a positive, and we do see them it might be tiny steps and it might not be what we want at the beginning but you can make .. tiny steps, better” (11.12-14)</p> |

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| Going above and beyond | <p><i>Ellie</i>: “so we’d be trying to find ways of engaging with her and keeping that work regular enough for it to be meaningful enough was a constant challenge, um .. so I saw her for a bit in a, in a local community hospital that she could walk to, um, but she didn’t want to do that in the winter because it was after school and it was dark and .. that was perfectly reasonable, um .. so then I would see her for a while in school” (8.6-11)</p> <p><i>Anita</i>: “after a few months, it does take a few months, it’s not easy like for example there is a girl with type two diabetes initially didn’t want to engage but we pursued it” (4.17-19)</p> <p><i>Jane</i>: “so you end up .. moving away a little bit from a diabetes nurse to being a bit more of a kind of, mum” (22.11-12)</p> <p><i>Kate</i>: “so a new ways that we’ve got now is, so when I go see them at home which is a little bit more successful than bringing them to clinic, is admitting them for a week or so, so for intense education on the ward” (3.2-5)</p> <p><i>Lindsey</i>: “we’ve got a responsibility to both parents and the child to .. offer as much as we possibly can and encourage them to uptake that service” (5.17-18)</p> |
| Acceptance and letting go | <p><i>Anita</i>: “Um .. but maybe we should say, like we’ve done our best, and that’s all we can do for this family, but it’s very difficult to um .. come to that conclusion, you-you still want to do a bit more” (17.13-15)</p> <p><i>Eleri</i>: “I think it-, to be honest .. I think I just take it now really, because it’s nothing personal is it? (....) I-I never take anything like that personally I think, you know, it’s just, one of those things, isn’t it, it’s part of the work, and then sometimes, ok, after they’ve left the room you think, [exhales] oh that was awful, and you just sort of relax .. and then you have five minutes and then you call the next person in, but you know, it’s that-, it’s that job really” (6.1-7)</p> <p><i>Jane</i>: “.. have to try not to get too, um .. too hung up on it though because you can’t, you can’t, you can take a horse to water but [laughs] you can’t make them drink can you? And you can’t let .. all of those kind of situations bring you down, because you’ve still got all the rest of your patients to look after” (4.12-16)</p> <p><i>Kate</i>: “So, adolescents are always the .. can be the trickier .. age group to engage with I think” (2.5-6)</p> <p><i>Lindsey</i>: “ I can do everything within my power and offer everything I possibly can but it’s not necessarily going to make them change their minds and change their adherence .. so I think it, you’ve got to, at some point you’ve got to accept that” (16.11-13)</p> <p><i>Karen</i>: “I suppose they’re the ones that we kind of, sadly, not give up on but end up having to accept that we’ve come to the end of the road, which in itself is, is difficult but I suppose ... y-you know, you have to accept that there is nothing more you can do sometimes” (3.17-20)</p> |

Appendix J

Summary of Superordinate and Sub Themes for Each Participant

| | Empathy & Insight | | | Negotiating Relationships | | Impact on Self | | | Coping | | |
|-----------|--------------------------------------|---------------------------------|---------------------------------|--|---|-------------------|------------------|----------------------|----------------------|----------------------|-------------------------|
| | Recognising the enormity of diabetes | Putting yourself in their shoes | Seeing something they can't see | Patient relationship as the foundation | Managing the patient-professional-patient triad | Feeling powerless | Getting it wrong | Sense of achievement | Seeing the positives | Going above & beyond | Acceptance & Letting go |
| "Ellie" | √ | √ | √ | √ | √ | √ | | √ | | √ | |
| "Anita" | √ | √ | √ | | √ | √ | √ | √ | | √ | √ |
| "David" | √ | √ | √ | √ | √ | √ | √ | √ | √ | | |
| "Eleri" | √ | √ | √ | √ | √ | √ | √ | | √ | | √ |
| "Jane" | √ | √ | √ | √ | √ | √ | √ | | √ | √ | √ |
| "Kate" | | √ | √ | √ | √ | √ | | √ | | √ | √ |
| "Lindsey" | √ | √ | √ | √ | √ | √ | √ | √ | √ | √ | √ |
| "Karen" | √ | √ | √ | √ | √ | √ | | √ | √ | | √ |

Appendix K
Word Count Statement

Title: 13

Thesis abstract: 297

Literature review: 7243

Empirical paper: 6988

Contributions to theory and clinical practice: 4080

Thesis total: 18,609

Appendices: 14,272

Total word count: 32,881

**RHAGLEN SEICOLEG CLINIGOL GOGLEDD CYMRU
NORTH WALES CLINICAL PSYCHOLOGY PROGRAMME**

Research ID No.:

Participant Consent Form

Title of project: A Qualitative Exploration of Health Care Professionals' Experiences of Working with Adolescents with Diabetes and Poor Adherence to Treatment.

Name of Researcher: Louise Oakley

Name of Supervisors: Dr Jan Lackey, Dr Sarah Bailey-Rogers & Dr Gemma Griffith

| | Please initial |
|--|----------------|
| 1. I confirm that I have read and understood the Participant Information Sheet (Version 2, dated 12/02/2015) for the above study. I have had the opportunity to consider the information, ask questions, and have had these answered satisfactorily. | |
| 2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, without any of my legal rights being affected. | |
| 3. I confirm that I consent to the interview being audio recorded by the researcher as part of the study. | |
| 4. I give permission for the researcher to use anonymised quotes from the interview and for the anonymised interviews to be shared with any other researchers, or stored as data archives. | |
| 5. I agree to take part in the above study. | |
| 6. If I indicate that I would like to receive a summary of the study's findings upon completion, I agree to the researcher contacting me again in due course to provide this information. | |

Name of Participant Signature Date

Researcher Signature..... Date

When completed, 1 copy for participant, and 1 for research file.