

Peer Mentoring with Parents of Children Newly Diagnosed with Type 1 Diabetes

Laura Barcroft

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Supervised by Dr Sue Channon

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ABSTRACT

A diagnosis of type 1 diabetes mellitus (T1DM) in childhood can have wide reaching implications for the child and their wider family system. The child and family's physical and emotional wellbeing can be significantly impacted by the psychological adjustment and coping of the parents. Experienced peer mentoring is an intervention aimed at promoting wellbeing and adjustment amongst parents of children with chronic conditions. The intervention involves an experienced parent of a child with T1DM (Link Parent) offering informational, affirmational and emotional support to a parent of a newly diagnosed child (Recipient Parent). The aim of this study was to explore the experiences of such support from both Link and Recipient Parents' points of view.

Five Recipient Parents and seven Link Parents were recruited from a wider sample of parents who participated in the mentoring programme. They took part in a semi-structured interview about their experiences of providing or receiving peer mentoring. An Interpretative Phenomenological Analysis produced four super-ordinate themes for the Recipient Parents: Build up to and Initial Impact of Diagnosis; Content of support; Process of support; Impact of support. Four super-ordinate themes were also produced for the Link Parents: Attitudes towards the project; Support provided; Relationship with Recipient Parent; Understanding the impact of support.

The results provided insight into the positive impact that offering and receiving such support can have on parents of children with T1DM. The results also highlighted the idiosyncratic nature of such experiences. The implications for future clinical application of the intervention were discussed as well as directions for further research.

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Chapter 1
Introduction

1. Chapter 1 Overview

This chapter aims to provide a context for the research described in chapters 2-4. The chapter is separated into three sections: Firstly, an overview of chronic childhood conditions which will focus on implications for the family system as a whole as well as on the individual child and their parents. Secondly, a description of type 1 diabetes mellitus (T1DM) as an example of a childhood chronic condition will be provided along with a discussion of the impact on the child and their family. Particular focus will be placed on the impact of the parent on the child in the context of T1DM. Finally, a systematic review of psychological interventions promoting psychological wellbeing and/or adjustment for parents of children with T1DM will be presented.

1.1 Childhood Chronic Conditions

1.1.1 Defining Childhood Chronic Conditions

Defining childhood chronic conditions (CCC) is a challenging task as the criteria varies across studies (Champaloux & Young, 2015). The broad range of definitions has resulted in prevalence ratings ranging from 0.22% to 44% (Van der Lee, 2007). Nevertheless, four slightly different definitions have been cited as being the most widely used (Van der Lee, 2007). They share the following criteria:

1. Duration- a condition which lasts (or has the potential to last) over 3 months
2. Impact- potentially negative impact or limitation on development, social and educational activities
3. Assistance- requires medical input for management of symptoms/side effects

For children this most commonly includes, but is not limited to, conditions such as asthma, arthritis, diabetes, cystic fibrosis and cancer (Newacheck & Haldfen, 1998).

For the purposes of this paper 'chronic conditions' will be used as a general term to refer to chronic illnesses, diseases and physical health conditions which meet the criteria above. Mental health disorders or learning disabilities are often included under

the umbrella of chronic conditions (Van Cleave *et al.*, 2010). Whilst such conditions clearly impact on the lives of children, for the purposes of this paper the literature reviewed will only refer to chronic physical health conditions. Furthermore, use of the word 'child' or 'children' refers to any person under 18 years old, unless otherwise specified.

1.1.2 Prevalence of Childhood Chronic Conditions

Issues such as reliance on parental third party reporting and differing definitions has caused difficulties with estimating the prevalence of CCC (White, 2009). However, the Office of National Statistics (ONS, 2013) published rates of CCC amongst British children under the age of 16 between 1998 and 2011. The rates for children under four years old has ranged from 2% to 4% during this time and in 2011, the rate for girls and boys under four years old was 4% and 3% respectively. The 2011 rates for girls and boys between four and sixteen years old were 5% and 9% respectively. Such statistics illustrate that CCC are by no means rare and indicate that over 630,000 British children under 16 years old are currently living with a CCC (ONS, 2014).

1.2 Understanding the Impact of Childhood Chronic Conditions on the Family System

Children with chronic conditions (CWCC) are most often living within an immediate and extended family system. Systems theory, when applied to a family illustrates the interconnection between the family members and therefore the perturbation caused by difficulty experienced by one member (Hoffman, 1981). According to Kazak (1989, p. 26) the four most important elements of systems theory in relation to family distress are:

- “(a) that systems are composed of interrelated parts,
- (b) that change in one part is associated with change in all others
- (c) that systems maintain a regular state of balance (homeostasis)
- (d) that systems maintain a balance of periods of change and stability”

A chronic condition can be understood as a change in the system to which the parts have to respond. One of the models which has made a significant contribution to the

thinking about the experience of families living with CCC is John Rolland's Family Systems Illness model:

1.2.1 The Family System and Chronic Illness

Rolland (1994)'s Family Systems-Illness Model describes the psychosocial demands for families of living with CCC. It integrates three core influences on and of a family system in relation to a CCC: illness type, family life cycle and beliefs about the illness (Figure 1).

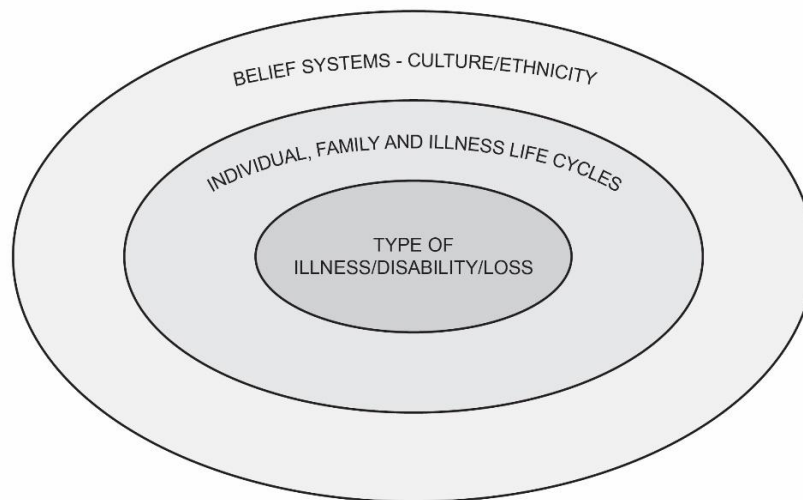


Figure 1. Family Systems-Illness Model (Rolland, 1999, p. 243).

1.2.1.1 *Illness Type*

Under the umbrella of CCC, there is significant variability which has implications for adjustment of families. Rolland (1988)'s typological model described four dimensions of the illness which can impact on adjustment:

1. Onset (gradual versus sudden)
2. Course (progressive versus constant versus relapsing/episodic)
3. Outcome (recovery versus terminal)
4. Degree of incapacitation

The model also describes time phases of the illness that the family moves through which affect the impact of illness of a family system (Rolland 1994). Movement through the three time phases, (crisis, chronic and terminal) as illustrated in Figure 2 presents new

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challenges to a family as they also interact with changes in onset, course, outcome and incapacity.

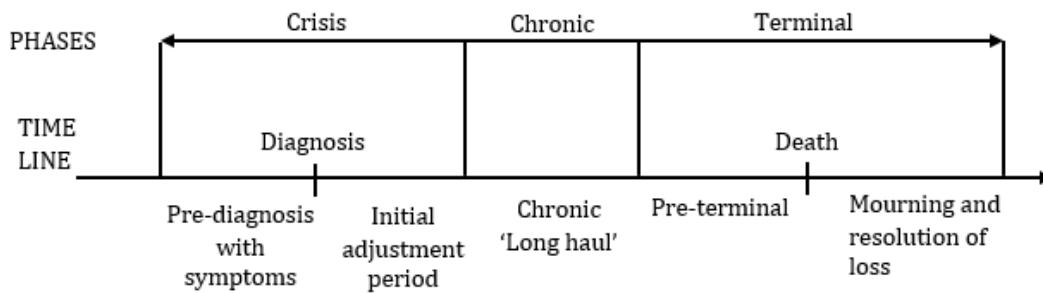


Figure 2. Time line and phases of illness diagram (Rolland, 1994, p. 154)

1.2.1.2 *The Family Life Cycle*

Carter and McGoldrick (2005) described the family as a multi-layered system moving through time which is subject to impact by factors outside and within the system. The presence of a CCC acts as a stressor whose impact cuts across not only the immediate family system but the broader societal system. Figure 3 represents the individual in the context of the levels of system around them. Carter and McGoldrick (2005) describe horizontal and vertical stressors which impact on the system. Vertical stressors refer to the community, family or individual factors 'which brings past and present issues to bear reciprocally on all other levels' (p. 5). On the other hand horizontal stressors, of which CCC is one, are 'developmental and unfolding' and therefore cut across all layers of the system to varying degrees over time.

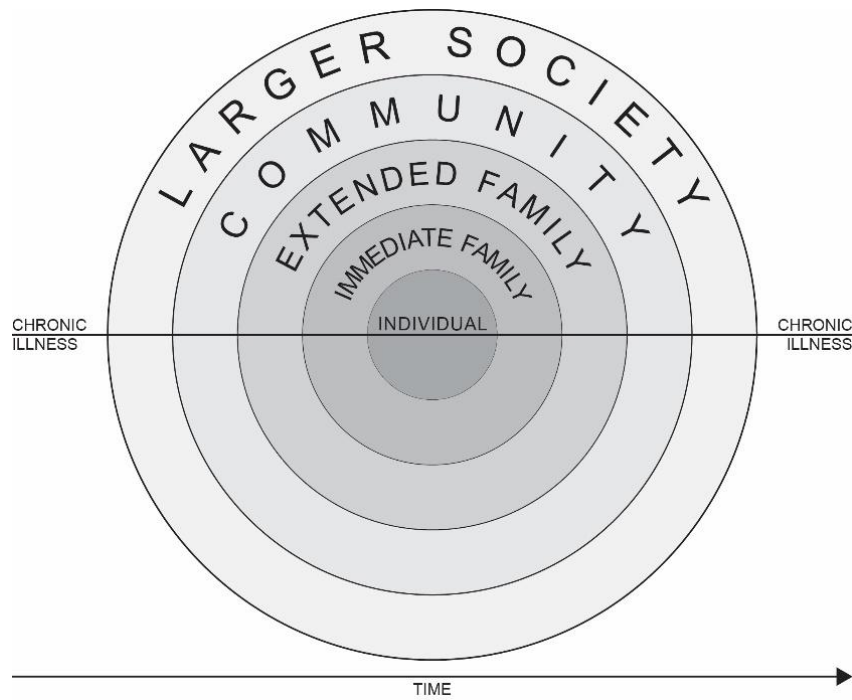


Figure 3. Family life cycle and chronic illness (Carter & McGoldrick, 2005)

The concept of centrifugal versus centripetal phases have also been applied to examine the nature of the interaction between the child, their family system and the CCC (Beavers, 1982). Centrifugal phases refer to periods where there is distancing within a family, compared to centripetal phases where the family system moves closer together. As a child moves through its own individual life cycle, the centrifugal and centripetal phases will fluctuate. Beavers and Voeller (1983) propose that CCC would tend to impose a centripetal force on a family system as members are united to focus on the new task of caring for their child and socialise to the demands of the CCC. However, the tendency for centrifugal versus centripetal pull to be enacted on the family by the CCC will depend on the phase the family were in previously. For example, if a child is in adolescence and therefore occupying a centrifugal phase in relation to the family system as they develop their own independence, the diagnosis of a CCC could reinforce the centrifugal phase, particularly if the CCC management involves restrictions to the adolescent's life. Alternatively, the CCC may act to pull the family into a centripetal phase which is at odds to the adolescent's developmental stage (Newby, 1996).

1.2.1.3 Family Beliefs

Rolland noted that a family's beliefs in relation to the illness are important factors in terms of adjustment and coping (Rolland, 2012). Beliefs about the origins of illness for example, if a family holds a belief that the origins are genetic, could be result in the parent(s) blaming themselves for passing on a condition and therefore experience guilt. Alternatively they may view a genetic origin as beyond their control and therefore feel more accepting. Rolland also described beliefs about the management of the condition, for example the perceived locus of control around management of the condition could influence how families cope. Finally, Rolland described the importance of beliefs about the implications of the disease such as ideas about mortality, identity of the family and child or quality of life. The combination of these beliefs and how they evolve over time impact of the family's adjustment and coping with CCC.

The model illustrates the multi-faceted influences on how a family adjusts and functions in response to such stress within their system and therefore its impact on the wellbeing of the unwell child. The evidence of impact of living with CCC on the family as proposed by the model is explored below in terms of adjustment and family functioning:

1.2.2 Adjustment

One or both parents in a family most often hold a position of leadership and responsibility. Understandably, research into the adjustment of families to CCC often centres round the adjustment of the parental figures and how this filters down to the CWCC or siblings. However, measurement of adjustment is inconsistent across studies, with authors using different markers to denote adjustment, for example some use depression and anxiety scales whereas others use specifically designed measures of adjustment.

There are a number of factors influencing the adjustment of a family to a CCC diagnosis. Family hardiness and sense of coherence around the condition have been identified as a positive predictor of adjustment (Svavarsdottir *et al.*, 2005). Conversely, low socio-economic status and insecure attachment between child and parent prior to diagnosis have been associated with adjustment difficulties (April *et al.*, 2012; Berant *et al.*, 2001; Maunder & Hunter, 2001; Mrazek *et al.*, 1987).

1.2.3 Family Functioning

As described in Rolland (1994)'s and Kazak (1989)'s models, the experience of a CCC could alter how the family system functions. However, the horizontal stressor described by Carter and McGoldrick (2005) may not always result in a negative impact of functioning. Wray & Maynard (2005) found that following a child's diagnosis of CCC, 49% of families reported no change in family relationships, 43% reported it bringing them closer and only 16% reported it causing separation in the family. There is some evidence of the varying influence of specific stakeholders within the system. Higher maternal difficulties in adjustment regarding the diagnosis have been significantly negatively correlated with children's perception of family cohesion and expressiveness. Maternal difficulties were also positively correlated with perceived family conflict. If both parents were reporting high adjustment difficulties there was also significantly higher perceived family conflict (Popp *et al*, 2014).

The management of a condition following diagnosis can also impact overall functioning of a family. Knafl *et al.* (2013) studied the relationship between family management style in response to the diagnosis and family functioning. Better family and child functioning was associated with a family focused pattern of coping ('conveyed a picture of families who were managing child's chronic condition effectively, whilst not having to focus family life on condition management'; p. 529).

The models and research described illustrate the implications for the family system as a whole of a CCC. The impact on the individual child and parents will now be discussed.

1.3 Impact of Living with Childhood Chronic Conditions on the Child

'It's just like living life but there is just an extra modifier thrown in and I just have to deal with that. It's just like getting glasses or something, it's more severe of course.' (16 year old boy with CCC; Woodgate, 1998, p. 215).

Living with a chronic condition can have wide reaching effects for a child. Four key areas of impact emerge from the literature: education, social, psychological and quality of life.

1.3.1 Education

The education system sits within the 'community' system surrounding the child within Carter and McGoldrick (2005)'s systems model. The constant pressures from educational system, means that any factors leading to physical or psychological absence from learning, can lead to a child falling behind their peers in educational terms. Thies (1999) described three aspects of chronic conditions that could account for such an impact on schooling:

1. The 'disease process', i.e. The biological aspects of the disease or condition which will impact on a child's ability to learn.
2. Medication and treatments can cause short term or long lasting effects for children.
3. Absenteeism from school because of fluctuations in the illness or hospital appointments means that a child's access to learning can be inconsistent.

Evidence from large scale national surveys has shown consistently that CWCC have poorer outcomes in school. American and Irish national survey data of over 15,000 children, revealed that those with CCC achieved significantly lower educational attainment, compared to their healthy counterparts (Champaloux & Young, 2015; Layte & McCrory, 2013). There is also evidence that CWCC are significantly less likely to graduate from high school compared to healthy children (Daley *et al.*, 20080; Maslow *et al.*, 2011). However, the impact of CCC on schooling is not as linear as described by Thies (1999). Mediating factors such as psychological wellbeing, economic status and behavioural difficulties have been identified as influencing the degree of impact of CCC, illustrating the influence of both individual and broader systemic factors on the degree of impact CCC have (Champaloux & Young, 2015; Layte & McCrory, 2013). Furthermore, children's knowledge of any life limiting aspects of their condition can lead them to feel unmotivated, angry and/or upset about being required to learn (MacAllister *et al.*, 2007; Pinguart & Shen, 2011).

1.3.2 Social

Social development sits closely alongside a child's education as they move through their individual life cycle to learn the social skills they will need in later life. A child would normally move through centrifugal phases as they develop independence and social

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skills outside their family (Newby, 1996). It therefore follows that disruption to normal activities of childhood would affect such phases and therefore lead to social development difficulties (Tansella, 1995). In some studies CWCC have been found to have lower social competence and delayed psychosocial development compared to their healthy peers (Mackner & Crandall, 2006; Stam *et al.*, 2006). CWCC have reported having fewer friends compared healthy children, but there was no difference in opportunities to see friends (Mackner & Crandall, 2006). The latter finding is supported by a survey of 1616 CWCC in which less than eight percent perceived an impact on their ability to socialise Denny *et al.* (2014). Furthermore, there is evidence for children with juvenile arthritis, that even where lack of independence exists there was no difference in perceived social competence compared to healthy counterparts (Huygen *et al.*, 2000). In this domain, there are differences in terminology and inconsistencies in use of concepts such that “social development” “social competence” and “social activity” are not clearly delineated at times so comparisons and conclusions are difficult. Nevertheless, such variations may reflect the influence of family adjustment and belief systems around CCC in terms of interpretations families make about the implications they have for a child’s access to ‘normal’ activities.

In terms of social risk behaviours such as, smoking and drinking there are mixed reports regarding their prevalence (Nylander *et al.*, 2014; Stam *et al.*, 2006). Authors have suggested that higher rates could be accounted for by a desire to ‘live life to the fullest’. On the other hand lower rates could be accounted for by a desire to be cautious due to concerns about health implications.

1.3.3 Psychological

Children’s developing skills in emotional coping and regulation may lead them to be more vulnerable to emotional difficulties in response to the psychosocial stressors of chronic conditions (Packham, 2004). It is consistent with findings that CWCC report higher rates of clinically significant symptoms of depression and anxiety (Mackner & Crandall, 2006; Surís *et al.*, 1996). There has been an association identified between the levels of restriction on activity or socialising and levels of low mood. It is therefore possible that restriction of activity mediates the relationship between symptoms of chronic illness and symptoms of depression (Denny *et al.*, 2014; Walter & Williams,

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1999). The association between anxiety and CCC appears to operate in a two way process in some conditions: Anxiety symptoms have been found to play a role in exacerbating the symptoms of some chronic conditions especially those vulnerable to immunosuppression (Richardson *et al.*, 2006; Goodwin *et al.*, 2005). For children with asthma, the management of anxiety symptoms has been shown to result in a reduction in their physical symptoms (Katon *et al.*, 2007; McCauly *et al.*, 2007).

Further to difficulties with mood, invasive procedures and treatments required in the management of some CCC has been linked with symptoms of trauma (Trickey *et al.*, 2012). Ingerski *et al.* (2010)'s study of 64 children and their parents reported a significant positive correlation between the number of traumatic medical procedures and symptoms of trauma. Compared to other types of trauma such as physical abuse, medical trauma has been found to result in more signs of PTSD (35% vs. 7%; Pelcovitz *et al.*, 1998). However, the findings are based on a small sample size (n=73) and no attempts to replicate the results have been published since.

Tying together the psychological and social impact of CCC, it follows that there can be an impact on a child's sense of self. Pinquart *et al.* (2013a)'s meta-analysis of 621 studies of self esteem and CCC revealed CWCC have significantly lower self esteem. Adolescents are particularly vulnerable as are girls, children from developing countries and those with chronic conditions resulting in visible differences. In a meta-analysis of studies into body image and chronic illness (Pinquart 2013b) CWCC which resulted in visible differences were at the greatest risk of developing a negative body image, particularly if they were female or from ethnic minorities. Such results support the importance of the societal level within a child's wider system on how they cope or adjust to a CCC.

1.3.4 Quality of Life

Finally, combining the elements of education, social and psychological difficulties that CWCC encounter, research has been conducted into overall quality of life. The most widely used measures of health related quality of life in children is the Pediatric Quality of Life Inventory (PedsQL; Varni *et al.*, 2003). It assesses four areas of functioning: physical, emotional, social and schooling. Varni *et al.* (2005) measured the quality of life of 2888 children across 33 disease categories (including psychiatric disorders)

compared to 9566 healthy children. Children across all disease categories reported significantly worse quality of life compared to healthy children. Children with cerebral palsy reported the most impaired quality of life and children with diabetes the least. The idiosyncrasies of each CCC's impact on quality of life has resulted in the development of condition specific modules to be used in conjunction with the general scale (Varni *et al.*, 2007).

1.4 Impact of Childhood Chronic Conditions on the Parent

Consistent with Carter and McGoldrick (2005)'s model, CCC impact the parents as they are part of the system around the child. The issues confronting parents of CWCC mirror many of the psychological difficulties that affect their children. The challenges of raising a child with additional needs makes it unsurprising that some parents struggle emotionally. In a narrative review of papers exploring psychosocial consequences for parents of living with CWCC, significantly higher emotional difficulties were reported compared to parents of healthy children (Barlow and Ellard 2006). However, the review also points to the limitations of the evidence as it is often based on small sample sizes with few papers making comparisons across disease categories. More recently, in a paper comparing the psychological wellbeing of 650 parents of CWCC and 216 parents from the general population, the rates of anxiety and depression were significantly higher amongst parents of CWCC (Besier *et al.*, 2011).

A key factor in long term psychological distress amongst parents may be how the parent processes their psychological response to the diagnosis (Pianta & Marvin, 1993). The authors proposed that the difficulty in resolving feelings about the loss inherent to a diagnosis can result in parents struggling to cope with the day to day changes required. Their findings have been supported by subsequent research into the adjustment process following diagnosis (Trollvik & Severinsson, 2004; Yeh, 2003).

Adjustment to and coping with a CWCC can be affected by the course of the condition, as described in Rolland (1988)'s typological model. For parents whose children's conditions fluctuate such as cancer, levels of depression and anxiety reduced over time, however, levels of uncertainty and worry about their child's future and loneliness

persisted (Boman *et al.*, 2003; Grootenhuis & Last, 1997). There has been growing recognition of this pattern of fluctuation and persistence in emotional distress amongst parents (Lowes & Lynne, 2000). Previously it was believed that at diagnosis parents would initially experience an intense emotional response but would adjust back to a normal psychological state after a period of time. The presence of chronic negative emotions was first noted amongst parents of children with learning disabilities and was termed “chronic sorrow” (Olshansky, 1962). Olshansky observed that parents of children with learning disabilities grieved for the loss of a normal child. However, unlike other grief reactions which eased over time, chronic sorrow was maintained as the child’s dependency served as a daily reminder of the loss (Gordon, 2008). The idea of chronic sorrow has since been applied to chronic health conditions with evidence of its occurrence across a number of conditions such as juvenile arthritis, epilepsy, cerebral palsy and T1DM (Hobdell *et al.*, 2007; Lowes & Lynne, 2000; Whittingham *et al.*, 2013; Wiedebusch *et al.*, 2007).

Beyond the level of adjustment, long term psychological effects for parents can include trauma, in a similar way to their children. Cabizuca *et al.* (2009) conducted a meta-analysis of 16 studies into the prevalence of post traumatic symptoms. The results showed a 22.8% prevalence rate of post-traumatic stress disorder (PTSD) amongst parents of CWCC with mothers at greater risk compared to fathers. There was a large spread between the papers in the time between the traumatic event and assessment for PTSD, ranging from 5.1 weeks to 6 years and 8 months. However, the time between the event and assessment did not account for a significant amount of variance in PTSD symptoms ($p > .20$).

1.4.1 Parental and Child Mental Health

Parental adjustment and coping with a CWCC can also impact on the child’s emotional wellbeing and ability to cope with their condition, consistent with McGoldrick and Carter (2005)’s model which described the interconnectivity between elements of the system. Thompson and Gustafson (1996)’s ‘Stress and Coping Model’ proposed a more causal link that a child’s coping and adjustment was reliant on their mother’s psychological wellbeing. This specific interconnection has been supported in recent research which illustrates how a child’s reaction will mirror their parents’, particularly

their mothers. Parental distress was significantly associated with behavioural problems and negative affect (Anthony *et al.*, 2011; Fedele *et al.*, 2011; Frank *et al.*, 1998). Participants within these studies were all between the ages of 8-16, therefore the interconnectivity between child and parent cannot be wholly explained by a developmental dependence on the parent. The results may however represent a tendency towards entering a centripetal phase in response to CCC diagnosis as the child mirrors their parents' response (Beavers and Voeller, 1983).

In addition to the emotional difficulties that parental adjustment and coping can have, there is also evidence of the impact it can have on the physical condition of the child, particularly functional disability and hospital admission rates (Bartlett *et al.*, 2001; Logan & Scharff, 2005; Palermo *et al.*, 2007; Wainwright *et al.*, 2007). However, initial difficulties may not always be predictive of longer term problems. Barnett *et al.* (2006) found that in the initial phase of adjustment maternal perception of disease and state of mind has a significant negative impact on their attachment with their child. However, after a one year follow up there was a significant increase in secure attachment, illustrating that some initial challenges can be overcome and that difficulties at the early stages may not always be predictive of longer term problems.

1.5 Childhood Chronic Conditions Conclusion

The research detailed provides an overview of the implications of chronic conditions on the family system as a whole and individual family members. It also illustrates the interconnection between parental and child adjustment and coping with the impact of chronic conditions. However, the precise impact can vary across different conditions as they present idiosyncratic challenges to children and families. The impact of one childhood chronic condition, diabetes mellitus type 1 (T1DM), will now be discussed in more detail.

1.6 Diabetes Mellitus Type 1 (T1DM)

Diabetes Mellitus Type 1 (T1DM) is a disease where the pancreas does not produce any or enough insulin to metabolise glucose in the body (NHS, 2014). Patients with T1DM therefore have to replace the insulin their body lacks, to be able to metabolise the carbohydrates in food. The lack of insulin can cause blood sugar levels to rise to a dangerous level. In the UK adult population, T1DM accounts for only 10% of diabetes cases with the vast majority being diagnosed with type 2 diabetes. However, amongst children, T1DM is the most common form (NHS, 2014). For details regarding routes to diagnosis, see Appendix I.

T1DM cannot be cured. Patients must closely manage their blood sugars levels through monitoring diet and administration of insulin. Patients can use one of two main methods of insulin delivery to manage the condition; regular insulin injections or using a programmable pump which releases a regular or continuous amount of insulin via a subcutaneous needle or cannula (NICE, 2004). Children and their families are able to monitor their blood glucose levels through pricking a finger with a small needle and testing the drops of blood that are produced. In addition the child's endocrinologist is able to test metabolic control over time by measuring glycated haemoglobin (HbA1c). This generates a picture of average blood sugar levels over an extended period of 8-12 weeks. Research which examines the management of T1DM will often use HbA1c as a marker of metabolic control, indicating how well the T1DM is managed.

T1DM is a challenge to manage, especially in children who struggle to understand why they need to inject themselves or not eat certain foods, compared to other children. Significant efforts have been made in recent years to improve the management of T1DM in children and lessen the challenges facing families (Dost *et al.*, 2010). However, there remain risks of entering into a state of hyperglycaemia (high glucose) or hypoglycaemia (low glucose.). Hyperglycaemia, if left untreated, can lead to ketoacidosis which can be fatal. For further information regarding long term effects of T1DM, see Appendix I.

1.7 T1DM in Childhood

As mentioned previously, T1DM is the most common form of diabetes in childhood. Like other CCC, the management and risk inherent to the condition can have a significant impact on the child and their family. In addition, the active role both the child and the family have to take in managing the disease means that there is a complex interplay between psychosocial and disease-related factors.

1.7.1 Impact of T1DM on the Child

Adjusting to the limitations imposed by a diagnosis of T1DM can be a difficult process for children. There is evidence that emotional reactions vary across age groups. Young children often react with anger as they are required to have painful procedures performed on them during the diagnosis period and then adjust to frequent finger prick blood tests and injections (Therlund *et al.*, 1996a; Therlund *et al.*, 1996b). For older children, feelings of anxiety and grief are more common and mirror those of their parents. However, in line with Rolland (1988)'s model regarding time phases of coping with CCC, the initial reaction is rarely a fixed entity and changes as the child and their broader system come to terms with the diagnosis (Wennick & Hallström, 2006; Povlsen & Ringsberg, 2008).

Further to coping with the immediate demands of the disease, the initial adjustment process has also been linked with later psychological and metabolic control outcomes. Early difficulties with emotional adjustment are related to poorer adherence to treatment regimens, difficulties with metabolic control and greater psychological distress at later follow ups (Berg *et al.*, 2008; Berg *et al.*, 2007; Therlund *et al.*, 1996a).

A mixed picture emerges from studies examining the risk of psychological distress for children with T1DM: there is some evidence for greater risk of depression (Kovacs *et al.*, 1997; Kokkonen & Kokkonen, 1995; Zeng & Chen, 2013), however, in other research, using larger samples of children with T1DM, there were found to be no significant differences in reported wellbeing compared to healthy counterparts (Northam *et al.*, 2010; Helgeson *et al.*, 2007). Referral rates to mental health services have been used as an alternative marker of psychological distress. Mental health referral rates for children

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with T1DM have been reported as 19% higher than non-affected peers (Northam *et al.*). Mental health service use in this study was associated with poorer metabolic control. It may therefore be that there is a bi-directional relationship between mental health and metabolic control, or potentially the referral might be triggered by parental concern over a lack of control of T1DM rather than the child's mental distress.

Psychological distress amongst children with T1DM can have an impact beyond psychological wellbeing to influence metabolic control. Symptoms of depression and anxiety have been associated with poor metabolic control and management behaviour (Herzer & Hood, 2009; Whitmore *et al.*, 2003; Northam *et al.*, 2013). However the connection between metabolic control and mood has been found to be significantly impacted by behavioural (such as poor self care) and environmental factors (Kongkaew *et al.*, 2014). Psychological distress can also have a purposeful link with poor diabetes control amongst young people with T1DM and eating disordered behaviour. Children with T1DM and clinically significant eating disturbance can seek to control their weight through poor diabetes management (Jones *et al.*, 2000; Mannucci *et al.*, 2005). This greater risk is reflected in higher levels of eating disturbance amongst children with T1DM particularly in girls and young women (Helgeson *et al.*, 2007, Peveler *et al.*, 2005 Goebel-Fabbri, 2009).

Research has also been undertaken to examine the impact on the overall quality of life of children with T1DM. Self-assessed quality of life is often perceived by children with T1DM as similar to their non-affected peers (Whittemore *et al.*, 2003; Laffel *et al.*, 2003; Faulkner & Chang, 2007). However, there are a number of variables which can affect quality of life for those with T1DM, particularly treatment regimens (Whittemore *et al.*, 2010). Despite advances in treatment regimens designed to ease management of the disease, regimen improvements have not illustrated the extent of impact on perceived quality of life predicted (Valenzuela *et al.*, 2006; Whittemore *et al.*, 2003).

1.7.2 Impact of T1DM on the Parent

In line with other chronic health conditions, coping with the diagnosis and management of T1DM in your child, places mental and physical demands on parents. It is unsurprising therefore, that many struggle emotionally following their child's diagnosis

and beyond. Coping following diagnosis, the presence of chronic sorrow and implications for the role of the parent will now be discussed.

1.7.2.1 Coping Following a Diagnosis

The events prior to diagnosis of T1DM often involves a rapid deterioration in a child's physical health. For some parents, reaching a state of ketoacidosis prior to the diagnosis can be a shocking and frightening experience (Whittemore *et al.*, 2012). The symptoms can be mislabelled as other serious diseases such as leukaemia or the implications of the T1DM are misunderstood, leading to intense emotional reactions before and after the diagnosis is made (Wennick & Hallstrom, 2006; Hatton *et al.*, 1995). A recent systematic review found that on average 33% of parents experience clinically significant psychological distress at diagnosis. The rate drops to 19% after a year, illustrating the initial intensity but also longer term impact (Whittemore *et al.*, 2012). Following the diagnosis there can be little relief as the magnitude of the task being undertaken is realised. Sullivan-Bolyai *et al.* (2003a)'s interviewed fathers of children newly diagnosed. One father summarised the monumental task after their child was diagnosed as: "It was like being handed a big city phone book and you have to learn all the names before you go home" (p. 27).

1.7.2.2 Chronic Sorrow

For some parents the intense emotional response to diagnosis does reduce as they adjust to their new life with a child with T1DM. However, for others the emotional distress never disappears entirely. As mentioned previously, the idea of chronic sorrow developed from the experiences of parents with learning disabled children and has subsequently been applied to chronic health. Lowes and Lynne (2000) challenged the idea of a time bound response to the diagnosis which has an end point where parents will return to emotional normality. They instead proposed that the emotional distress may decrease but will continue to fluctuate as the child continues through life. The authors reviewed research regarding the immediate and long term emotional responses of parents of children with T1DM. They found evidence for both a time bound model and chronic sorrow. However, they stated that even in the context of coping and adapting to life with a child with T1DM, there was a lingering sadness for many parents.

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Aspects such as the relentlessness of the T1DM treatment regime and constant fears of future harm coming to their child contributed to the ongoing emotional distress.

The principle of chronic sorrow from Lowes and Lynne's paper has been supported by further research since its publication. Lowes *et al.* (2005) interviewed 38 parents regarding their adjustment and coping with a child with T1DM. Although the participants had been able to learn and adapt to the presence of T1DM a year after diagnosis, the process of adjustment was not viewed as an endpoint but rather a process that would continue for the foreseeable future. The findings were supported by a further paper which examined chronic sorrow amongst 17 parents, seven to ten years post diagnosis. Only one participant was able to achieve 'full acceptance and closure', whereas the others noted resurgences in their emotional distress (Bowes *et al.*, 2009) with triggers identified such as hospital admissions, difficulties with metabolic control and fears about risks of complications.

Further research has found that psychological distress experienced by parents can reach a clinically significant level, post diagnosis. Jaser *et al.* (2009) tested anxiety and depression levels amongst 67 mothers with children who were less than eight years old at the time of diagnosis. Twenty-one percent reported clinical levels of anxiety and 24% reported clinical levels of depression. Mothers who reported that they struggled to cope with the demands of T1DM were significantly more likely to experience clinical levels of anxiety or depression. In the context of hospital admissions and medical procedures inherent to T1DM, it follows that there is also evidence of post traumatic stress (PTS) responses amongst parents of diabetic children (Landolt *et al.*, 2003; Landolt *et al.*, 2005). Stoppelbein & Greening (2006) compared rates of PTS symptoms between parents of children with T1DM versus children with cancer. It was expected that given the life threatening nature of cancer, there would be greater incidence of trauma, however there were no significant differences between groups.

Rates of psychological distress seem to differ between mothers and fathers. The rates of psychological distress have been found to be higher for mothers than fathers, perhaps reflecting their primary caring role or coping strategies. Fathers reported significantly lower stress levels and emotional distress compared to mothers (Haugstvelt *et al.*, 2011;

Mitchell *et al.*, 2009). Both studies also reported significantly lower involvement or responsibility for T1DM related parenting tasks amongst fathers. Comparison of the impact of emotional distress between mothers and fathers have also revealed a difference. Malerbi *et al.* (2012) compared factors impacting on quality of life in 1079 parents. Thirty seven percent of mothers reported anxiety to be a primary factor in their quality of life, compared to 25% of fathers. Similarly, 53% of mothers reported depression as a concern compared 32% of fathers.

1.7.2.3 Parenting Stress

A further element of the impact of T1DM is the impact it can have on the experience of parenting a child. Sullivan-Bolyai *et al.* (2003b)'s qualitative study, reflected the stress of parenting a child with T1DM as being in a state of constant vigilance. T1DM can cause parents to question their role, arousing feelings of incompetence in being able to care for their child. The feelings of incompetence can instil fear due to a sense of compromised ability to protect them (Whittmore *et al.*, 2012). These themes were also noted in Hatton *et al.* (1995)'s study where participants spoke of the intense responsibility of caring for a young child with T1DM. One participant reflected that the pressure to care in the right way can result in a feeling of 'feeding the insulin, not the child' (p. 573).

There are a number of factors relating to a greater risk of perceived parenting stress, particularly supportive resources from the wider system at the parents' disposal. Single parenthood and lower socioeconomic status are associated with higher levels of stress (Streisand *et al.*, 2003). A family environment which is perceived to be supportive or caring is associated with lower negative impact of T1DM (Moreira *et al.*, 2013). Higher psychological distress is also associated with greater frequency and intensity of parenting stress (Streisand *et al.*, 2005; Streisand *et al.*, 2008).

1.7.3 Impact of the Parent in Childhood T1DM

As described earlier, Carter and McGoldrick (2005)'s model illustrate the interconnectivity between the systemic layers around a child. The psychological distress associated with having a child with T1DM is concerning in of itself in terms of safeguarding parents' wellbeing. However, the interconnectivity between child and

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parent means, psychological distress or difficulties adjusting is also associated with secondary negative outcomes for the child. Literature regarding the psychological impact of parental distress within broader CCC has been discussed earlier. For T1DM specifically, metabolic control and responsibility over disease management can also be impacted by the parents' psychological state, approach to parenting and family adjustment. Whittemore *et al.* (2010) devised a model to illustrate the multifaceted processes within a family's adjustment to T1DM. The model focuses on the immediate family system, including individual/family characteristics, psychosocial responses, individual/family responses and adaptation (Figure 4). It is a revised version of an original model which focused much more heavily on the child's individual characteristics and responses (Grey & Thurber, 1991). The updated model takes greater account of the familial influences. It also accounts for the two way feedback of psychosocial aspects and coping for both the individual and the family.

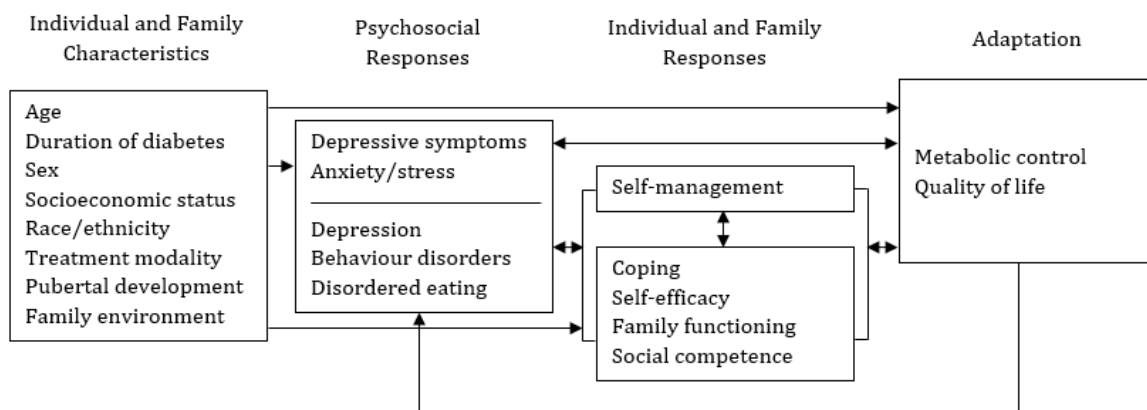


Figure 4. Conceptual Model of Childhood Adaptation to T1DM (Whittemore *et al.*, 2010, p. 244).

From the child's perspective, the model illustrates that an important aspect of adjustment for them lies in the adjustment of the parent. However, there is evidence that the connection between parental psychological state and metabolic control varies across different types of psychological distress. Depressive symptoms are associated with poorer metabolic control and higher risk of hospitalisation (Driscoll *et al.*, 2010; Butwicka *et al.*, 2013). The link between depressive symptoms and poor metabolic control has been found to be mediated by low parental involvement, rather than a direct

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impact on metabolic control (Struempf, 2012). Conversely, parents who struggle with anxiety are more likely to play an active role in T1DM management and perceive their child to be less able to manage their T1DM (Butler *et al.*, 2009; Cameron *et al.*, 2008). For adolescents such an active role can be perceived as over involvement and be associated with poor metabolic control (Cameron *et al.*, 2008). In terms of parenting stress, the impact is less clear on T1DM management. There has been a link between higher stress and better metabolic control (Stallwood, 2005). However, the level of stress is also related to perception of poor diabetes related behaviour in the child with T1DM, with no significant impact of actual blood sugar levels (Hillard *et al.*, 2011).

The stance a parent takes in terms of managing their child's T1DM can have an important impact on the wellbeing and health of their child. Adopting a collaborative role with the child is associated with better metabolic outcomes (Wiebe *et al.*, 2005; Worrall-Davies *et al.*, 2002). Furthermore, collaborative approaches are associated with fewer depressive symptoms amongst children with T1DM and their mothers (Berg *et al.*, 2007). Similarly, parents who adopt a supportive communication style with their child is associated with less depressive symptoms, better self-management by the child and better metabolic control (Berg *et al.*, 2007; Dashiff *et al.*, 2008). Conversely, hostile or controlling communication styles are associated with poor metabolic control, self-care and quality of life in the child (Dashiff *et al.*, 2008; Worrall-Davies *et al.*, 2002).

The correlational nature of such studies means it is possible that the negative communication or parenting styles have been adopted in response to poor metabolic control. However, research into the impact of family functioning amongst parents, supports the link between parental stance and child outcomes. A four year follow up from diagnosis has found that families exhibiting high expressed emotion, low cohesion and high conflict are linked with poor metabolic control (Jacobson *et al.*, 1994; Lewin *et al.*, 2006). Leonard *et al.* (2005) replicated the results linking family dysfunction to poor metabolic control. The authors also reported a discrepancy between parental and child reported dysfunction. The resulting outcomes for the child, followed their appraisal of the family, not the parents, indicating that the child's perception of the family is more important.

1.7.4 Psychosocial Interventions for Children with T1DM and their Families

The research reviewed illustrates the degree of difficulty posed by adjusting and coping with a diagnosis of T1DM for families. As Whittmore *et al.*'s model illustrated (Figure 4), there is an interconnection between child adjustment, parent adjustment and T1DM management. It therefore follows that targeting support towards parents of children with T1DM, could impact on the wellbeing of the parent, the child and the wider system. In view of the potential for psychological and physical complications as a result of T1DM, interventions have been developed to promote physical and psychosocial wellbeing. T1DM is the most researched single disease category amongst CCC, accounting for 27% of papers (Distelberg *et al.*, 2014). A range of interventions at different stages of disease have been explored and will be discussed below.

1.7.4.1 Psychoeducational Interventions

Psychoeducational interventions target knowledge of the mechanism and management of T1DM. An enhanced understanding is designed to improve insight and therefore management and coping with the disease. Hampson *et al.*, (2001) conducted a systematic review of papers testing psychoeducational interventions between 1980 and 2000. The results indicated small to medium effect sizes on psychosocial outcomes. However, the authors report a number of methodological issues common across the papers included. Less than half used randomised control designs and all had small sample sizes. Further difficulties arose with comparing results across studies due to variations in the modalities and settings used. A later systematic review reported similar methodological issues in more recent papers (Murphy *et al.*, 2006). However, a greater proportion used psychosocial outcomes which results in greater evidence for impact in those domains compared to metabolic control. The authors raised the hypothesis that the lack of consistency of modality of intervention meant that questions remain regarding the outcome relating the social contact rather than content of interventions. Robling *et al.* (2012) attempted to remedy the difficulties with previous papers in terms of consistency. In a cluster randomised trial healthcare professionals across 13 services were trained in delivering a psychosocial intervention, based on shared agenda-setting. The results indicated no impact on metabolic control but a short term impact on coping within the child.

1.7.4.2 Behavioural Interventions

Behavioural interventions are aimed at promoting positive behaviour around T1DM management. Strategies such as goal setting, self-monitoring and positive reinforcement are used in conjunction with parents. Delameter *et al.* (2001)'s narrative review of parent/adolescent behavioural interventions indicated a positive impact on metabolic control and parent-child relationship. Similar results were found in a systematic review of child based behavioural interventions. A small to medium effect size was found in terms of T1DM management. However, the authors noted that less than half the papers were theoretically driven and those with a theoretical underpinning had greater effect sizes. In terms, of applying the finding, the authors also felt the interventions required a high degree of commitment and time to be effective. However, the coping skills interventions of Anderson *et al.*, (1989) and Grey *et al.* (1999, 2000) were identified as the most effective and achievable of those included in the review.

1.7.4.3 Family and Individual Therapy

One to one and family based psychological therapy has been researched as a means of managing the psychological impact of T1DM. A systematic review of behavioural and systemic family therapies indicated positive results in terms of metabolic control and family conflict (McBroom & Eriquez, 2009). However, there was a lack of research with single parent or separated families. Considering the stress family discord could place on the ability of families to manage T1DM, the reviewers highlighted that it was a neglected area of research. In terms of one to one therapeutic interventions for children, there is much less evidence than parent or family based interventions, supporting Whitemore *et al.* (2010)'s model which highlights the interconnectivity between parent/child reactions (Winkley *et al.*, 2006). However, Winkley *et al.*'s systematic review revealed a small effect size in terms of metabolic control and psychosocial outcomes for one to one child interventions. Within the review, the majority of interventions were aimed at adolescents rather than younger children and the mean duration of the disease was 5.6 years. This perhaps points to therapeutic interventions waiting until a crisis point in adolescence rather than proactive psychological care closer to diagnosis. There is evidence that the impact of psychosocial and educational interventions for T1DM is longer lasting if delivered earlier (Hampson *et al.*, 2001). The same may be true in terms of therapeutic interventions, if they are designed to prevent and protect psychological

wellbeing from the offset. However, families are often excluded from studies if they are within the first year post diagnosis due to unstable diabetes management, leading to interventions during the initial adjustment phase being under-researched (Hampson *et al.*, 2001).

1.8 Type 1 Diabetes Mellitus Conclusion

The research discussed has illustrated that adjustment and coping with T1DM is dependent on a combination of psychosocial responses in the child and family. The interventions covered focus on work with the child directly or in conjunction with their parent. The literature indicates promising results in terms of the impact that can be had on the psychological and physical wellbeing of children with T1DM. Interventions directed at the parents alone have not been discussed thus far. Considering the direct impact a parent's adjustment and wellbeing can have on a child with T1DM, proactive interventions which promote adjustment and wellbeing in the parent would be expected to filter through to the child. The final section of this chapter will cover a systematic review of interventions directed solely at parents of children with T1DM with the aim of promoting wellbeing or adjustment.

1.9 Systematic Review: Interventions to Improve Psychological Adjustment and Wellbeing in Parents of Children with T1DM

1.9.1 Rationale for Review

The impact of parental adjustment and coping on the physical wellbeing of a child with T1DM and the psychological wellbeing of both parent and child has been described. Based on these findings interventions to promote psychological wellbeing in parents could impact on both the short and long-term psychological and physical health outcomes for the parents, child and family.

A systematic review was undertaken of psychosocial, family and educational interventions for children with T1DM and their parents in 2000 (Grey, 2000). The family interventions included were defined as those where 'the target of the

intervention had to be the family members of a child or adolescent with diabetes rather than the index child' (p. 162). Two papers were included (Guthrie *et al.*, 1990; Satin *et al.*, 1989) which described interventions aimed solely at the parents, however only Satin *et al.*'s paper measured coping in the parent. Guthrie *et al.*'s paper sought to train parents in relaxation techniques, however only biological markers of T1DM management were collected. Building on Grey *et al.*'s results the following systematic review will focus on interventions for parents with the aim of improving their psychological adjustment and wellbeing, published after 2000.

1.9.2 Review Method

A systematic review of literature was conducted to examine the evidence for interventions aimed at improving psychological wellbeing and/or adjustment in parents of children with T1DM. The question for the systematic review was as follows:

What is the impact of interventions aimed at improving psychological adjustment and/or wellbeing amongst parents of children with T1DM?

The review was performed following the recommendations outlined in the 'Cochrane Handbook for Systematic Reviews of Interventions' (Higgins & Green, 2011).

1.9.3 Search Strategy

Four databases were selected for the search of research evidence as they contained journals relating to both psychological and medical research. The databases were searched on 2nd March 2015 using the OvidSP platform:

- AMED (Allied and Complementary Medicine)
- HMIC Health Management Information Consortium
- Ovid Medline (1946-Present)
- PsychInfo (1806-Present)

1.9.4 Search Terms

The search strategy involved four layers of search terms (see Appendix II), combined using Boolean operators (e.g. AND, OR, ?) detailed below:

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- 'Diabetes type 1' OR 'Diabetes Mellitus type 1'
- Parent? OR Mother? OR Father?
- Intervention OR support
- Wellbeing OR Depression OR Anxiety OR Adjustment OR Adaptation

1.9.5 Inclusion Criteria

- Intervention delivered solely to parent(s)
- Child with diabetes is under 18 years old
- Outcome measures include those relating to psychological wellbeing and/or adjustment

1.9.6 Exclusion Criteria

- Papers published before 2000 (A similar review of support interventions for parents was published in 2000; Grey, 2000)
- Diagnosis of type 2 diabetes
- Solely medical adherence based outcomes
- Not in the English language
- Intervention focussed on the family or child

1.9.7 Search Process

Figure 5 presents a diagrammatic representation of the search. The initial search yielded 244 papers, reduced to 240 after removing duplicate studies. The titles and abstracts were reviewed according to the inclusion and exclusion criteria. Thirteen papers met the inclusion/exclusion criteria at this stage. The cited and citing references were reviewed of these 13 papers, producing a further six results. Full text versions of the 19 papers were then retrieved and reviewed to ensure relevance to the review criteria leading to the exclusion of seven papers (see Appendix III for details of excluded papers). Of the remaining 12 papers, ten were quantitative studies and two were qualitative studies. Two quantitative papers contained qualitative aspects which were not included in the review: Sullivan-Bolyai et al., (2004)'s qualitative analysis could not be assessed in the qualitative framework as there was insufficient detail regarding the qualitative methodology. Ridge *et al.* (2014)'s qualitative data was not included because

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it related to the content of the intervention not the outcome or experience for participants. A summary of papers included in the review is in Table 1.

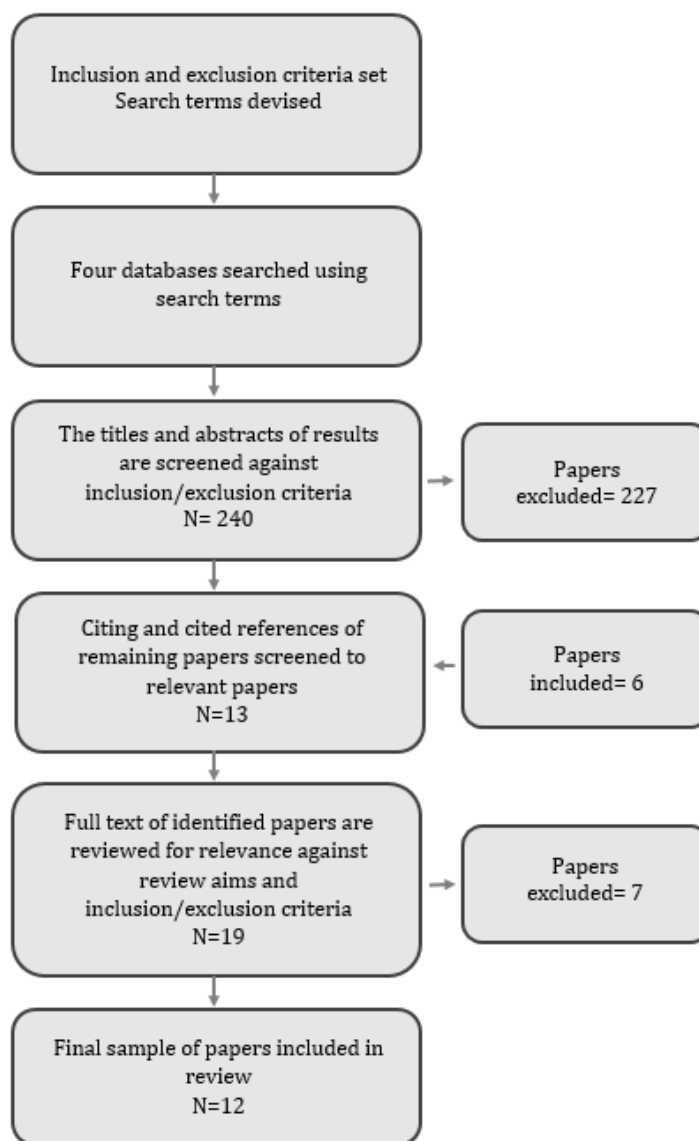


Figure 5. Systematic Review Search Process

Table 1. Summary of systematic review papers

| Reference | Methodology | Intervention | Outcome Measures | Key Results |
|-------------------------------|---|---|---|--|
| Grey <i>et al.</i> (2011). | <u>Design</u> Randomised controlled trial <u>Participants</u> 75 in intervention group 48 in control group | <u>Intervention group</u> Coping skills intervention over 6 sessions, each lasting 1.5 hours in groups of 2-5 families. <u>Control group</u> Group diabetes education | Self report measures: CES-D; DRC; ICC; PDQOL | Intervention and control group showed significant difference in parental coping ($p < .001$), QOL ($p = .005$) and parental responsibility ($p < .001$). Significant change in difficulties and upset in coping with diabetes ($p = .005$). |
| Hoff <i>et al.</i> (2005). | <u>Design</u> Randomised controlled trial <u>Participants</u> 31 in intervention group (17 mothers, 11 fathers) 28 in control group (17 mothers, 11 fathers) Average age of mothers = 38.41 Average age of fathers = 40.04. | <u>Intervention group</u> Two 2.5 hour group sessions with aim of reducing illness uncertainty through improved understanding and management. <u>Control group</u> Child continued to receive routine medical care and illness education from the treating physicians. | Self-report measures: BASC-P; PPUS; SC90-R | <u>Parental psychological distress-</u> Intervention group- significant change between baseline and one month. Change maintained at six months. Control group- no significant changes <u>Child internalising</u> Intervention group- Mothers- significant change between baseline and one month, maintained at six months. Fathers- no significant changes Control group- Mothers- no significant change. Fathers- Significant change between baseline and one month, not maintained at six months. <u>Child externalising-</u> Intervention group- Mothers- Significant change between baseline and 1 month, not maintained at six months. Fathers- No significant changes |
| Merkel & Wright (2012). | <u>Design</u> Single group pre/post test descriptive design <u>Participants</u> 9 parents | Web based support based on social support platform model | Self report measures: DES; SED | Significant change in self efficacy ($p = 0.0171$) Non significant change in empowerment ($p = 0.0689$) |
| Monaghan <i>et al.</i> (2011) | <u>Design</u> Case control pilot <u>Participants</u> 24 parents (88% female) | Peer support intervention based on Sullivan-Bolyai <i>et al.</i> , (2004). Modality is unclear. | Self-report measures: CES-D; MSPSS; PIP; STAI | Significant changes in Paediatric Inventory for parents. |

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| Newell & Hahessy (2013) | <p><u>Design</u> Qualitative ethnographic study- observing intervention group and semi-structured interview</p> <p><u>Participants</u> 8 parents</p> | Weekly support group format. Facilitation and topics determined by attendees. | <p>Observational data collected over seven months</p> <p>Semi structured interviews</p> | <p>Two themes were identified</p> <ol style="list-style-type: none"> 1. The culture of the group – ‘A different kind of support’. Emphasis placed on shared experiences and identity 2. The benefits of the group- ‘You are so lost in the beginning’. Emphasis on the social support and solidarity amongst parents |
| Rearick <i>et al.</i> (2011) | <p><u>Design</u> Qualitative study- semi-structured interviews</p> <p><u>Participants</u> 13 parents (9 mothers, 4 fathers)</p> | Participants were drawn from the pool of participants in Sullivan <i>et al.</i> (2010)’s quantitative study. | Semi-structured interviews | <p>Three themes were identified:</p> <ol style="list-style-type: none"> 1. Availability- mentors were flexible in providing support and took responsibility for meetings/calls 2. Practical tips- providing advice from a position of experience 3. Common ground- shared experiences and identity through diabetes parenthood. |
| Ridge <i>et al.</i> (2014) | <p><u>Design</u> Quasi-experimental</p> <p><u>Participants</u> 17 (15 female, 2 male)</p> | Diabetes Orientated Learning Family Intervention (DOLFIN) | <p>Self report measures: DFCS; DFRQ; GADS; PHQ;</p> | <p>Change in mean scores across all measures.</p> <p>Authors report they conducted t-tests but only report pre/post mean differences, no t-test or p-values.</p> |
| Saßmann <i>et al.</i> (2012) | <p><u>Design</u> Randomised controlled trial</p> <p><u>Participants</u> 24 parents (no information about gender split)</p> | <p><u>Intervention group</u> DELFIN program- Structured group intervention for up to 7 families. Aim to develop skills in diabetes related communication and handling conflict</p> <p><u>Control group</u>- wait list control</p> | <p>Self report measures: DASS; PS; SDQ</p> | <p><u>Parenting Scale</u> Greater significant change in intervention group versus control (p>.001 vs. p=.05) Larger effect size for intervention group (.84 versus .18)</p> <p><u>Depression-Anxiety Stress Scale</u> - Significant change in control and intervention group - Significant change in depression subscale for intervention group, non significant change in control group - Non significant change in intervention group, significant change in stress in control group.</p> |
| Sullivan-Bolyai <i>et al.</i> , (2004) | <p><u>Design</u> Mixed method randomised controlled trial psychometric and qualitative outcome measures</p> <p><u>Participants</u> 42 mothers</p> | <p><u>Intervention group</u> Parent to parent mentoring via home visit and telephone over a six month period. Experienced parent mentors were provided with training</p> <p><u>Control group</u>- Telephone support by untrained parents</p> | <p>Self report measures: BDMCQ; HCRI; IFS; PCQ</p> | <p><u>Banion diabetes management concern questionnaire</u> Significant changes in intervention group versus control. (p= .02)</p> <p><u>Impact on family scale</u> Significant changes in intervention group versus control (p=.05)</p> <p><u>Parental confidence questionnaire</u> No significant difference in changes between control and intervention group (p=.44)</p> <p><u>Home care resources</u> No significant difference in changes between control and intervention group (p=.06)</p> |

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|--------------------------------------|--|---|--|--|
| Sullivan-Bolyai <i>et al.</i> (2010) | <p><u>Design</u> Randomised controlled trial</p> <p><u>Participants</u> 51 mothers</p> | <p><u>Intervention group</u> Same intervention as Sullivan-Bolyai <i>et al.</i>, (2004). Format changed to flexible support via telephone, email or face to face.</p> <p><u>Control group</u>- Telephone support by untrained parents.</p> | Self report measures: BDMCQ; IFS; PCQ; SSI; WS | No significant difference in change between control and intervention groups across any outcome measure. |
| Sullivan-Bolyai <i>et al.</i> (2011) | <p><u>Design</u> Randomised controlled trial</p> <p><u>Participants</u> 9 fathers in control group 18 fathers in experimental group</p> | <p><u>Intervention</u> For fathers only following Sullivan-Bolyai <i>et al.</i> (2010)'s intervention and control groups.</p> | Self report measures: BDMCQ;DADS; IFS; PCQ; SSI; WS | <p><u>Parental Confidence Scale</u> Significant change in intervention group versus control (p<.05).</p> <p>All other measures non-significant difference in change versus control.</p> |
| Tsiouli <i>et al.</i> (2014) | <p><u>Design</u> Randomised controlled trial</p> <p><u>Participants</u> Intervention group - 19 (78.9% women, av. Age= 43.95) Control group - 25 (80% women, av. Age= 42.6).</p> | <p><u>Intervention group</u> - Trained in relaxation techniques and encouraged to practice 2x day. - Encouraged to engage in healthy/active lifestyle.</p> <p><u>Control group</u> - Encouraged to engage in healthy/active lifestyle</p> | Self report measures- HLCS; PSS; PSI-SF; Lifestyle parameters questionnaire | <p><u>Perceived Stress Scale</u> Significant change over time versus control (p=.01)</p> <p>No other significant changes versus control.</p> |

BASC-P=Behaviour assessment system for children- parent rating scale; **BDMCQ**= Banion diabetes management concern questionnaire; **CES-D** =Center for Epidemiological Studies-Depression; **DADS**=Dad's active disease support scale; **DASS**=The depression-anxiety stress scale **DES**=Diabetes empowerment scale short form parent modified; **DFCS**=Diabetes Family Conflict Scale; **DFRQ**=Diabetes Family Responsibility Questionnaire; **DRC**=The Diabetes Responsibility and Conflict Scale; **GADS**=Generalised Anxiety Disorders subscale; **HCRI**=Home care resources instrument; **HLCS**=Health Locus of Control scale; **ICC**=Issues in coping with **IDDM**-Parent scale; **IFS**=Impact on family scale; **MSPSS**=Multidimensional scale of perceived social support; **PCQ** =Parental confidence questionnaire; **PDQOL**=The Parents Diabetes Quality of Life Questionnaire; **PHQ**=Patient Health Questionnaire; **PIP**=Paediatric inventory for parents; **PPUS**=Parent Perception of Uncertainty Scale; **PSI-SF**=Parenting stress index-short form; **PS**=The parenting scale; **PSS**=Perceived stress Scale; **SC90-R**=Symptom checklist 90- revised; **SDQ**=Strengths and difficulties questionnaire; **SED**=Self efficacy for diabetes scale parent modified; **SSI**=Social Support inventory; **STAI**=State-trait anxiety inventory; **WS**=Worry Scale.

Table 1. Summary of systematic review papers

1.9.8 Quality Appraisal

The quality frameworks developed by Cardiff University's Specialist Unit for Review Evidence (SURE) were used to evaluate the papers. The criteria for 'randomised controlled trials and other experimental studies' was used to evaluate the quantitative papers included in the review (SURE, 2013a). The two qualitative studies included in this review were also appraised against SURE checklist for qualitative papers (SURE, 2013b). Each paper was reviewed against a checklist of questions which are answered yes, no or can't tell. A scoring system was developed in conjunction with the researcher's supervisor to weight the clinical significance of the papers. Each score was rated based on the following scale:

- Good = score of 2
- Mixed = score of 1
- Poor or unreported = score of 0

The scores for each paper are presented in Table 2 (see Appendix IV for specific scoring details).

Table 2. SURE Quality Framework Assessment of Quantitative Papers

| Criteria | Grey <i>et al.</i> (2011) | Hoff <i>et al.</i> (2005) | Merkel & Wright (2012) | Monaghan <i>et al.</i> (2011) | Ridge <i>et al.</i> (2014) | Sassmann <i>et al.</i> (2012) | Sullivan-Bolyai <i>et al.</i> , (2004) | Sullivan-Bolyai <i>et al.</i> (2010) | Sullivan <i>et al.</i> (2011) | Tsiouli <i>et al.</i> (2014) |
|--|---------------------------|---------------------------|------------------------|-------------------------------|----------------------------|-------------------------------|--|--------------------------------------|-------------------------------|------------------------------|
| 1. Does the study address a clearly focused question/hypothesis? | 2 | 2 | 1 | 2 | 2 | 2 | 2 | 2 | 2 | 2 |
| 1.1 Population/ Problem? | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 2 |
| 1.2 Intervention? | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 2 |
| 1.3 Comparator/control? | 2 | 2 | 0 | 0 | 0 | 0 | 2 | 2 | 2 | 0 |
| 1.4 Outcomes? Can you identify the primary outcome? | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 2 |
| 2. Was the population randomised? | 2 | 2 | 0 ⁺ | 1 | 0 ⁺ | 1 | 1 | 1 | 1 | 2 |
| 3. Was allocation to intervention or comparator groups concealed? | 0* | 0 | 0 | 0* | 0 | 0 | 0* | 0* | 0* | 0* |
| 4. Were participants/ investigators blinded to group allocation? | 0* | 0* | 0 | 0* | 0 | 0* | 0* | 0 | 0 | 0 |
| 5. Were interventions well described and appropriate? | 1 | 1 | 0 | 1 | 1 | 1 | 1 | 1 | 1 | 1 |
| 6. Was ethical approval sought and received? | 0* | 0* | 0* | 0* | 2 | 2 | 0* | 0* | 0* | 2 |
| 7. Was a trial protocol published? | 0* | 0* | 0* | 0* | 0* | 0* | 0* | 0* | 0* | 0* |
| 8. Were the groups similar at the start of the trial? | 1 | 2 | 0 ⁺ | 2 | 0 ⁺ | 2 | 2 | 1 | 2 | 2 |
| 9. Was the sample size sufficient? | 2 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 1 | 2 |
| 10. Were participants properly accounted for? | 2 | 1 | 0 | 1 | 2 | 2 | 2 | 2 | 1 | 2 |

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|--|-----------|-----------|-----------|-----------|-----------|-----------|-----------|-----------|-----------|-----------|
| 11. Data analysis | 2 | 2 | 2 | 2 | 2 | 1 | 0 | 2 | 2 | 2 |
| 11.1 Are you confident with the authors' choice and use of statistical methods? | | | | | | | | | | |
| 11.2 Were estimates of effect size given? | 0 | 2 | 0 | 0 | 0 | 2 | 0 | 0 | 2 | 2 |
| 11.3 Were the analytical methods appropriate? | 2 | 2 | 2 | 2 | 2 | 1 | 0* | 2 | 2 | 2 |
| 11.4 Was the precision of intervention effects given? | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 2 |
| 12. Results | 2 | 2 | 0 | 2 | 0* | 2 | 2 | 2 | 2 | 2 |
| 12.1 Were outcome measures reliable? | | | | | | | | | | |
| 12.2 Were outcome measures complete? | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 2 |
| 12.3 Were all important outcomes assessed? | 1 | 0 | 0 | 0 | 0 | 0 | 0 | 2 | 0 | 2 |
| 12.4 Are the authors' conclusion adequately supported by the results? | 1 | 2 | 0 | 2 | 1 | 1 | 2 | 2 | 2 | 2 |
| 13. Is any sponsorship/ conflict of interest reported? | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 2 |
| 14. Did the authors identify any limitations? | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 2 |
| 15. Are the conclusions the same in the abstract and the full text? | 0 | 1 | 0 | 2 | 2 | 2 | 2 | 2 | 0+ | 0 |
| Total | 34 | 35 | 19 | 31 | 28 | 33 | 30 | 35 | 34 | 39 |

+ = not applicable * = can't tell

Table 2. SURE Quality Framework Assessment of Quantitative Papers

1.10 Review Results

The review results produced 10 quantitative papers and two qualitative papers. The quantitative papers will be presented and reviewed first, followed by qualitative papers.

1.11 Quantitative Synthesis and Critical Review

The results of the critical review are summarised in Table 2. Each study has an attached total score relating to the above scoring scale. The total scores reported reveal all but one of papers to be within a similar range in terms of quality (28-39). However, Merkel and Wright (2012) is markedly lower than the others with a score of 19.

1.11.1 Design/Methodology

The studies included in this review reflected a range of methodologies. The majority of studies (seven) adopted a randomised controlled trial (RCT) methodology. However, there were a number of issues with the design of the RCT's. Only three of the papers described the method by which they randomised their participants. In terms of blinding, none of the papers blinded or reported blinding the participants to their allocation. It is acknowledged that blinding participants in studies of psychological interventions is challenging as allocation to a control group is often easy to detect. However, some of the researchers endeavoured to devise control conditions which were different from treatment as usual. For example, Sullivan-Bolyai et al., (2004)'s equivalent of non-trained telephone support from parents versus one to one support from trained parents. In such circumstances, the potential for blinding and therefore greater scientific rigour would have been possible.

Three studies adopted quasi-experimental designs, with a single pre/post group methodology. The authors of the quasi-experimental designs highlighted that their studies were pilots aimed at testing feasibility and therefore were not able to invest the resources needed for an RCT design. However, the lack of a control group made the results difficult to value in terms of impact and generalisability. This is particularly the case when the intervention is being targeted close to diagnosis where normal

adjustment will take its course. Therefore without a control group it is difficult to establish the cause of any positive change. The children with T1DM of Ridge *et al.* (2014)'s participants for example, had an average time since diagnosis of 4.53 years (SD= 3.5). The standard deviation indicates the range of the time since diagnosis which could influence the degree of change accounted by the normal course of adjustment post diagnosis. However, the authors do not account for this in their analyses. Merkel and Wright (2012) do not include any information about the amount of time since diagnosis, which again could account for the significant change, over and above the impact of the intervention.

1.11.2 Participants

All the studies included had difficulties with attaining a large and representative sample. As mentioned earlier only Grey *et al.* (2011) recruited a sufficiently large enough sample (123; 75 experimental group, 48 control group) according to their power analysis. In other RCT's, the majority of papers contained less than 60 total participants. The smallest sample size for an RCT was 27 (Sullivan-Bolyai *et al.*, 2011). In the non-RCT studies, the sample sizes were also small, the largest sample being 24 (Monaghan *et al.*, 2011). The reasons for the small sample sizes ranged from small pool of participants to draw from to high drop-out rates following randomisation (see Appendix V). All papers cited a limitation of having a homogenous sample which was predominantly female, white and middle/upper middle class. The dominant female sample may reflect the role of the mother in carrying the emotional and practical burden of managing a child with T1DM (Mitchell *et al.*, 2009), also pragmatically their more frequent attendance at the majority of clinic visits and therefore greater availability for recruitment. However, as Sullivan-Bolyai *et al.* (2011) stated, previous research has shown the increasing role of fathers in childcare. However, Sullivan-Bolyai *et al.*'s study which attempted to recruit only men, had the smallest sample of only 27. The lack of diversity indicates that future research should endeavour to investigate the barriers to their engagement with supportive interventions.

1.11.3 Intervention Content

The results of this review have highlighted a broad range of interventions that have been piloted with parents. To summarise the interventions, they are separated into three subgroups:

1.11.3.1 Peer Support

The most commonly used intervention was peer support via mentoring or group sessions. Sullivan-Bolyai et al., (2004) pioneered the application of Ireys *et al.* (1996) peer mentoring to parents of children with T1DM. Sullivan-Bolyai paired newly diagnosed parents with experienced parents who had been trained to support other parents using a model of practical/informational, affirmational and emotional support. Sullivan-Bolyai *et al.* (2010, 2011) Rearick *et al.* (2011) and Monaghan *et al.* (2011) continued to explore the use of such support in face to face formats rather than telephone support used in the 2004 paper. One to one peer support was the only intervention in this review that was investigated across a number of studies. Merkel and Wright (2012) explored the use of peer led social support via an online support forum.

1.11.3.2 Coping Skills

Three papers examined the use of coping skills training to enhance adjustment and coping. Grey *et al.* (2011) examined a six session coping skills intervention which was aimed at enhancing skills in communication, social problem solving, conflict resolution, cognitive restructuring and stress management skills. Hoff *et al.* (2005) investigated a two session intervention aimed at enhancing understanding and management of uncertainty. The intervention was based on literature surrounding a cause of parental distress lying in difficulties managing illness uncertainty. Finally, Tsiouli *et al.* (2014) examined the impact of relaxation techniques training as a specific method of coping with stress inherent to parenting a child with T1DM.

1.11.3.3 Parenting Skills

The final group of interventions aimed to enhance parenting skills of participants in order to increase their ability to cope with the new challenges of parenting a child with T1DM. Ridge *et al.* (2014) provided training over six sessions in motivational interviewing techniques. Saßmann *et al.* (2012) examined the use of the DELFIN program which was designed to build on existing T1DM education programs available

to parents by developing new communication and conflict resolution skills. The program ran for five sessions plus weekly telephone contact to provide interim support in applying new parenting skills. The supplementary support described in this paper, although designed to reinforce learning, may have also served to provide support for parents which may account for a proportion of impact of the intervention which the authors did not account for.

The skills based interventions offered more control in terms of the intervention delivered and therefore offer greater methodological rigour. The peer based support, whilst more ecologically valid is dependent on participants' fidelity to the intervention model. Although attempts to monitor intervention fidelity were made there is a possibility for more unaccounted variables, particularly the content of supportive interactions.

1.11.3.4 Control Groups

The RCT studies included in the review employed a range of control conditions with which to compare their intervention. Five of the seven RCT's used a 'treatment as usual' equivalent, which meant access to T1DM education from professionals or continued care under diabetes team (Grey *et al.*, 2011; Hoff *et al.*, 2005; Saßmann *et al.*, 2012; Sullivan-Bolyai *et al.*, 2011, 2010). In the context of such studies being designed as pilots their use of treatment as usual is understandable in terms of relating change to current resources. However, particularly for group interventions, the lack of a comparative group intervention meant it was difficult to ascertain if the impact was due to the supportive group space or the active intervention element. Other papers adopted control conditions which utilised a variation on the active intervention. Sullivan-Bolyai *et al.*, (2004) provided access to telephone peer support to control participants, however unlike those in the intervention group the supporters were not trained. Tisouli *et al.* (2014) provided healthy living educational materials to both the control and intervention group, whilst the intervention group were provided with relaxation techniques as well. Whilst this paper offers one of the most closely comparable control groups, the authors state that adherence to the healthy living was not as rigorously monitored in the control group, leaving unaccounted for variables between groups.

1.11.4 Outcome Measures

In keeping with the search terms, all quantitative papers examined the impact of their intervention on psychological wellbeing and adjustment around T1DM:

1.11.4.1 Psychological Wellbeing

All but one of the papers used only self report measures of psychological distress and most commonly measures of disorder specific symptoms such as depression or anxiety. For example Grey *et al.* (2011) focused on depressive symptoms as a marker of psychological distress. Others used measures of anxiety or worry as the authors stated that anxiety/worry is a more common emotion in coping with T1DM, compared to depression (Sullivan *et al.*, 2010, 2011; Monaghan *et al.*, 2011; Ridge *et al.*, 2014). Hoff *et al.* (2005) and Saßmann *et al.* (2012) utilised broader psychological measures of symptoms, increasing the field of potential impact. Saßmann *et al.* was also the only paper to include a non self report measure of psychological distress as they measured salivary cortisol as a marker of stress, alongside two self report measures of stress.

1.11.4.2 Adjustment/Adaptation

Perceived self-efficacy and empowerment were used as markers of self perceived adjustment by Merkel and Wright (2012). Similarly, Sullivan-Bolyai *et al.* (2004, 2010, 2011) assessed parental confidence in management of diabetes. Wider family adjustment was measured by Ridge *et al.* (2014), Sullivan *et al.* (2004, 2010, 2011) and Saßmann *et al.* (2012). Finally, an assessment of the impact on the child with T1DM was also used. Saßmann *et al.* and Hoff *et al.* measured parent reported child behaviour. Ridge *et al.* collected data directly from the child regarding their perception of diabetes responsibility and family conflict.

All but one of the quantitative studies used solely self report measures of change. Although the majority of outcome measures used report strong reliability and validity, Merkel and Wright (2012) and Ridge *et al.* (2014) used measures with little information regarding their reliability or validity. Furthermore, Merkel and Wright, modified their two outcome measures but failed to report the findings of the review they state took place. Besides the reliability or validity of the measures, reliance on self report measures could inhibit the ability to detect change (Stoppelbein & Greening, 2007). Utilising second person reporting such as a partner or child could enhance sensitivity to

detect change. Saßmann *et al.* (2012) adopted a biological marker of psychological distress which illustrated the disparity between self reported and more objective measures. Eight out of ten of the papers included were pilot studies which may account for the limited specificity in terms of outcome measures. The fact that so many are pilot studies may also explain the spread of results between interventions as only Sullivan-Bolyai *et al.* (2004, 2010, 2011) has sought to follow up their pilot study.

1.11.5 Intervention Outcomes

The outcome of interventions will be compared according to the intervention content to assess efficacy between similar interventions.

1.11.5.1 Peer Support

Of the five peer support studies were all but one were from one research group and present equivocal findings: Sullivan-Bolyai *et al.*, (2004) was the earliest study in this review of peer support interventions, and reported the most change. The authors reported significant between group change in parental concern and impact on the family. However, there was no significant change in parental confidence. Sullivan *et al.* (2010) attempted to replicate the results with changes to the format of the intervention and the focus on parents of younger children. There were no significant differences in change between the control and intervention group in any of the outcome measures reported. Furthermore, in Sullivan-Bolyai *et al.* (2011) where the intervention was aimed at only fathers, there were significant between group changes parental confidence reported but not in social support, parental concern, impact on family or anxiety. Therefore, showing polarised effects to the original paper which targeted the same intervention at only mothers.

In terms of less formal group based support, investigated by Merkel and Wright (2012), they reported a significant change post intervention in empowerment but not self efficacy. However, they did not utilise a control group so it is unclear if the changes could be attributed to the intervention rather than normal adjustment.

1.11.5.2 Coping Skills

The results for coping skills interventions were mixed in terms of the range of outcomes measures across the three papers. Two papers reported significant changes in their markers of parental distress. Hoff *et al.* (2005) reported significant reduction in psychological distress which was maintained at the six month follow up. There was no significant change in treatment as usual group, however the small sample size limited the power to detect between group differences and therefore a between group analysis was not conducted. Tisouli *et al.* (2014) reported significant change in perceived stress in the intervention group, over time and compared to the control group. However, there were no significant between group changes on any other outcome measures. Grey *et al.* (2011) only measured psychological distress at baseline to control for depressive symptoms in the analyses. Significant changes were reported in terms of parental coping, quality of life and parental responsibility. However, the significant change over time was present in both the control and intervention group, with no significant difference between groups. Hoff *et al.* (2005) also measured parental uncertainty and perceived behavioural problems in the child. There was no change in parental uncertainty in either of the groups, which was surprising considering the intervention was aimed at parental uncertainty. There were mixed reports in terms of child behaviour, with mothers in the intervention group reporting significant changes in internalising behaviour, whereas fathers reported no significant changes in internalising.

1.11.5.3 Parenting Skills

The two studies which examined parenting skills showed consistent results with one another. Saßmann *et al.* (2012) reported significant positive effects on The Parenting Scale, which measures a parents' skills in managing conflict, and on depression and anxiety subscales of the Depression-Anxiety Scale. Compared to the control group, the intervention group had larger effect sizes for the Parenting Scale (Cohen's $d = .84$ versus Cohen's $d = .18$). However, significant depression and anxiety scale changes were also present in the control group and the intervention group produced only a marginally larger effect size of .39 compared to .35 in the control group. Furthermore, there were no significant changes in the other measure of parenting behaviour and on parental perceived child behaviour in the intervention or control group. In Ridge *et al.* (2014),

the results are less clear as the paper had no control group and only reported the mean difference between baseline and intervention. Nevertheless, the mean differences showed an improvement on family conflict (both child and parent rated), child responsibility for diabetes and parental depression and anxiety.

A difficulty with outcome measurement relates to the follow up period utilised. The majority of studies had the last follow up at least six months after baseline. However, three studies only followed up between three and six weeks after the intervention (Merkel & Wright, 2012; Monaghan *et al.*, 2011; Tsouli *et al.*, 2013). A longer follow up in these studies may have led to more consistent results. Particularly for Tsouli *et al.* who reported a discrepancy between salivary cortisol and reported stress, perhaps a longer follow up would be led to less perceived stress.

1.12 Qualitative Synthesis and Critical Review

1.12.1 Qualitative Themes

The qualitative data from Newell and Hahessy (2013) and Rearick *et al.* (2011) revealed insight into the experiences of parents accessing two different types of peer support interventions. Rearick *et al.* (2011)'s content analysis of parents who received one to one support from experienced peers presented three themes which were reportedly held unanimously amongst participants. Firstly, 'availability' which reflected the degree of flexibility of the support and the freedom of access the recipient parents had. In addition, parents were grateful to the mentor for taking a lead in organisation initially, as the recipient parents struggling with the overwhelming situation post diagnosis. The second theme related to the sharing of practical advice, from the mentor's position of experience. A similar theme was reflected in Newell and Hahessy's ethnographic analysis. The participants from the peer support group reflected the value of sharing experience and learning from one another. Whereas, Rearick *et al.*'s results focused on the practical value, Newell and Hahessy's focused on the emotional impact of the shared experience which reduced the feelings of loneliness and normalised experiences. Rearick *et al.*'s third theme related to the sense of common ground between the mentor and recipient parent. The author cites the following quote as representing the sense of shared identity through experience: 'The parent mentor made you feel like you're not

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the only one going through this' (p. 516). A similar theme was extracted by Newell and Hahessy, as membership in the group offered a 'sense of belonging, solidarity and equality' (p. 30). One area of difference between the two studies was that in Newell and Hahessy they were all at differing stages of adjustment which may have fostered a greater sense of equality of experience compared to a clear 'mentor'-'mentee' model in Rearick *et al.* However, it is difficult to be sure as Newell and Hahessy do not provide information regarding the length of time since diagnosis of the participants' children.

1.12.2 Critical Review

The qualitative papers were appraised against the SURE checklist for qualitative papers (SURE, 2013b). The scores are summarised in Table 3 (see Appendix VI for specific scoring details). The scoring system indicates that Newell and Hahessy's paper was of marginally higher quality, primarily due to the greater detail provided regarding the methodology.

| Criteria | Rearick <i>et al.</i> (2011) | Newell & Hahessy (2013) |
|---|------------------------------|-------------------------|
| Does the study address a clearly focused question Setting? Perspective? Intervention or Phenomena Comparator/control (if any)? Evaluation/Exploration? | 2 | 2 |
| Is the choice of qualitative method appropriate? | 2 | 2 |
| Is the sampling strategy clearly described and justified? | 1 | 2 |
| Is the method of data collection well described? | 1 | 2 |
| Is the relationship between the researcher(s) and participants explored? | 2 | 0 |
| Are ethical issues explicitly discussed | 1 | 1 |
| Is the data analysis/interpretation process described and justified? | 2 | 2 |
| Are the findings credible? | 2 | 2 |
| Is any sponsorship/conflict of interest reported? | 0 | 2 |
| Did the authors identify any limitations? | 1 | 2 |
| Are the conclusions the same in the abstract and the full text? | 1 | 2 |
| Total Score | 15 | 19 |

Table 3. SURE Quality Framework for Qualitative Research

The SURE quality framework raised a number of methodological concerns which are discussed below:

1.12.2.1 Researcher's Position and Credibility

A marker of quality within qualitative research is providing a context for the analysis, from the researcher's point of view. This may include providing information regarding the author's position in relation to the topic and external checks of the emergent themes. Neither study offered information to position to author of the study in order to frame the themes that emerged. Newell & Haheesy (2013) also did not provide evidence of external credibility checks. Rearick *et al.* (2011) on the other hand provided details of credibility checking by other researchers of emergent themes.

1.12.2.2 Grounding in Examples

Another element of producing credible qualitative result is grounding the themes in examples from the data. Newell & Hahessy (2013)'s results, although brief, were rich with direct quotes. Conversely, Rearick *et al.* (2011) provided only brief quotes from the data and they were used scarcely. It was therefore more difficult to establish a direct perspective from the participants, compared to the Newell & Hahessy's account.

1.12.2.3 Situating the Sample

Finally, information about the participant sample of the research is important in terms of framing the perspective they provide. Neither of the studies provided details regarding the participant's demographics although Rearick *et al.* (2011) provided information regarding the gender split of participants. In Rearick *et al.* the authors state that there was a pool 33 potential participants from the quantitative arm of the study and 13 were interviewed. However, they do not provide further information regarding why those 13 were chosen or chose to participate. Similarly, Newell and Hahessy provide no information about the sample, besides their attendance at the support group.

1.13 Systematic Review Conclusion

The systematic review revealed mixed results regarding the impact of interventions for parents of children with T1DM. A broad range of interventions have been tested but the

inconsistencies across methodologies leaves questions unanswered. Outcomes relating to parent, family and child adjustment and wellbeing were measured. However, the results have been mixed, even across papers reporting the same intervention such the peer mentoring. The papers have been challenged by an array of methodological issues which may have compromised the results. Nevertheless, only one paper found no significant difference made by an intervention and none found a negative impact of the intervention. In addition, the qualitative papers revealed positive experiences of parents in response to support, particularly regarding shared identity and experience with other parents.

Further research to re-assess the promising interventions with larger, more representative samples are needed to determine the impact of such interventions. In addition, use of more varied outcome measures and more rigorous quantitative and qualitative research may help to enhance the knowledge base about the impact of such interventions on the parents and more widely.

1.14 Peer Support Interventions

The systematic review has indicated that the most consistent evidence base for parent targeted interventions around T1DM is peer to peer support interventions. The peer to peer support intervention examined by Sullivan-Bolyai *et al.* (2004, 2010, 2011), Monaghan *et al.* (2011) and Rearick *et al.* (2011) is the only intervention that has been researched across a number of papers. Although the papers have struggled to recruit participants, they have some of the highest scores in terms of quality of those included in the review. Whilst the quantitative results have been variable, with authors struggling to quantify the impact, the qualitative support from Rearick *et al.* illustrates the impact the intervention has on the day to day life and parental identity of the participants. A discussion of what peer support encapsulates, the evidence for its application to paediatric and broader health services and its theoretical underpinning will now be discussed.

1.14.1 Defining Peer Support

Peer support sits within a wider context of social support offered to individuals within the healthcare service. What is meant by a peer is often loosely defined. For example, one definition that is widely cited defines peer support as being from between those ‘with lived experience who are employed to support others who face similar challenges’ (Repper & Carter, 2011, p. 393). This key characteristic distinguishes it from support from those who have professional experience of the particular condition or challenge.

In an attempt to establish a coherent distinction between peer and other supportive networks, Dennis (2003) created a classification system of supportive relationships in a health care context, distinguishing between social and professional relationships (Figure 6). Peer relationships were classed under a banner of ‘created social networks’ i.e. those which would not otherwise exist if not the individual was not a member of a specific healthcare community. The classification also draws a distinction between those providing social support but with extensive training (paraprofessionals) as opposed to those who are relying on a shared personal experience with others. It also classifies shared experiences in individuals’ personal lives versus health lives as different types of support although both under the banner of ‘peer support’.

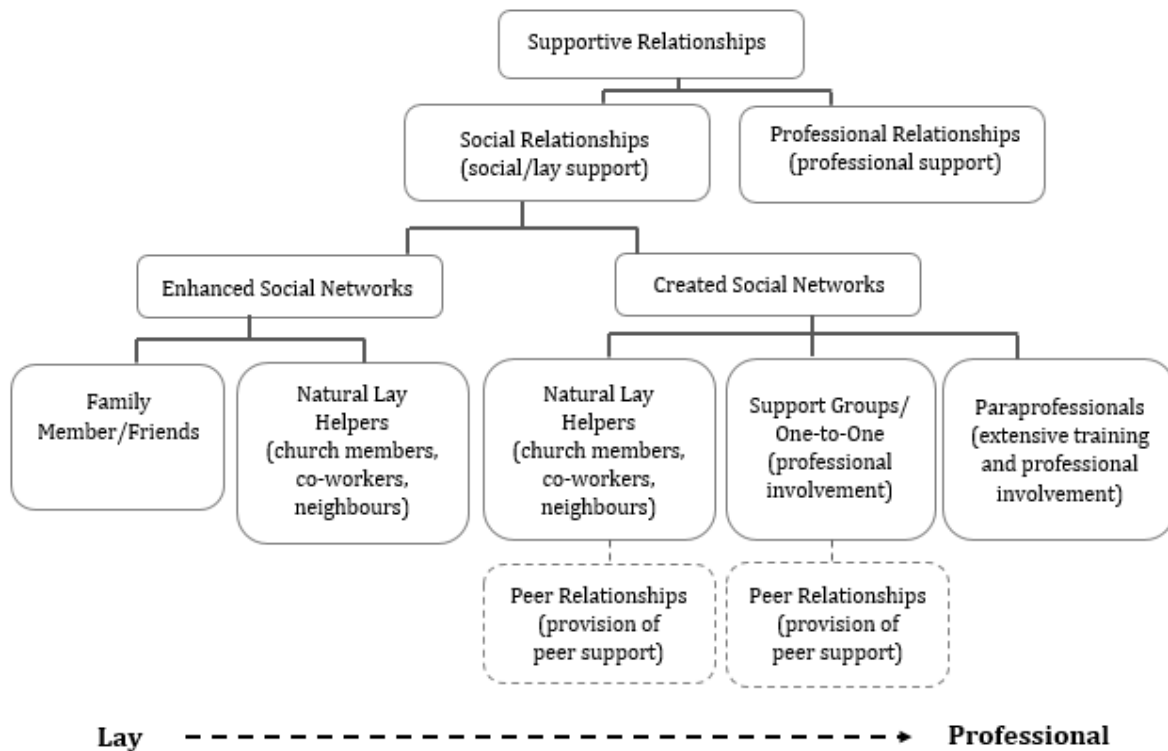


Figure 6. Social Relationships Classification (Dennis, 2003, p. 322)

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The most comprehensive exploration of what encapsulates a 'peer' within the peer support banner was conducted by Faulkner and Kalathil (2012). The authors examined peer support in the context of mental health specifically. They surveyed 44 representatives of providers or receivers of peer support in order to gather insight into clinically relevant characteristics of a peer and what constitutes peer support. The paper reported themes around shared understanding of the condition and its management as being important in terms of being classed as a peer. This may be of particular importance in the context of mental health where there is particular variance and controversy around the understanding and management of mental distress. Nevertheless the authors highlight the idiosyncrasies in experiences of all healthcare users which can be glossed over when facilitating peer support as sharing a condition does not necessarily tally with a shared experience. The authors also point to the importance of shared demographic characteristics being importance to over half (55%) of respondents, such as gender, ethnicity and age.

The open definition of a peer, leaves room for interpretation in terms of individual peer support provisions. However, one factor that is clearly acts to distinguish a 'peer' is the element of *lived* experience rather than just experience of working with a health condition. In the health care system, whilst a professional or carer may have experience of a condition they could not act as a peer if as they do not have *lived* experience of that condition. Similarly, a service user could not act as a peer to support a professional as their *lived* experience is different again (Faulkner and Kalathil, 2012; National Voices, 2015; Repper & Carter, 2011). This emphasis on lived experience means that carers or family members can also be conceptualised as providers of peer support, as carers can act as peers to one another just as service users can (as shown in the systematic review literature, section 1.9).

1.14.2 Peer Support: Empirical Evidence

1.14.2.1 Use in Paediatrics

The evidence for the application of peer support in wider paediatric services reflect the results of the systemic review of psychological interventions for parents of children with T1DM (section 1.9). A systematic review of peer support interventions for parents of CWCC was recently carried out (Shilling *et al.*, 2013). The quantitative papers

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revealed positive experiences from those receiving the support as well as positive impacts of psychological health and family function. Qualitative papers reflected similar positive results in terms of personal growth from the parents' point of view. They also revealed similar results to Newell and Hahessy (2013) and Rearick *et al.* (2011) relating to the shared identity of being supported by someone in a similar situation and the normalisation and validation that provided. However, there were also reflections on the difficulties of such support. Although no studies reported a negative impact of support, there were reports of a lack of impact. Factors such as parents not prioritising their own psychological wellbeing, a lack of personal drive to access support and a lack of personal connection, were important barriers to utilisation and impact of support. Overall, the Shilling *et al.*'s review illustrated the quantitative results as being mixed compared to the more positive qualitative results. The disparity may indicate that thus far the quantitative results are not tapping into the true impact of the interventions from the participants' point of view.

The qualitative and quantitative results reveal promising results of peer support from the supported parents' point of view. Insight has also been gathered into the supporting parents' perspectives. Sullivan-Bolyai and Lee (2011) interviewed parents who were supporting parents of newly diagnosed T1DM children. Their results revealed the participants to be providing informational, affirmational and emotional support for parents, in line with Sullivan-Bolyai *et al.*, (2004)'s intervention model. There were also reflections about the benefits for the supporting parents of being trained alongside other parents which allowed for informal support between them. In terms of the impact supporting another parent had on them, participants spoke of the empowerment and personal growth they experienced from being able to support others.

1.14.2.2 Use in Adult Services

The use of peer support interventions in adult services has grown substantially over the last two decades which culminated in the World Health Organisation launching a consultation into the efficacy and application of such interventions amongst adults with Diabetes (WHO, 2008). This has resulted in the formation of 'Peers for Progress', an organisation which seeks to gather evidence of peer interventions to inform future research and provision of services across health conditions. The largest amount of peer

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support research has been conducted with the diabetes population, which is understandable considering it was research in this area which ignited the WHO's interest in the subject. Recent reviews have continued to illustrate the positive impact peer interactions can provide in diabetes. Dale *et al.* (2012) reviewed 25 studies of peer support for adults with diabetes. Whilst medical outcomes were the most consistently measured (e.g. glycaemic control in 14 trials), it was psychological outcomes which showed the most consistent positive outcomes. In terms of the physical outcomes measured across papers, significant changes were reported in only 25% of the measures. Significant changes in psychological outcomes were however reported in 72% of the measures. It was also highlighted that modality or type of peer support did not have a significant impact on physical or psychosocial outcomes.

Beyond its use in diabetes, National Voice (2015) completed a systematic review of 524 outcome studies of peer interventions across physical and mental health conditions and delivered to service users, carers or wider family. The most consistent findings were in peer interventions aimed at providing education, social and emotional support, compared to much a less consistent impact on health outcomes or behaviours. The reviewers also highlighted that the research in this area was problematic in terms of the methodological rigour, with only 17% of papers included being reviews or randomised trials.

Peers for Progress also funded a global systematic review of peer interventions in broader physical health conditions (Elstad *et al.*, 2010). The review included 40 papers from 8 countries examining use of peer interventions for a variety of health behaviours or conditions. Thirty three papers reported modest or strong evidence of positive outcomes in terms of physical or psychological outcomes. Peer interventions have also been developed for use with service users of mental health care. Repper and Carter (2011)'s systematic review of peer support for mental health service users presents a less clear picture of impact on mental health 'symptoms' as would be measured in physical health services. It did however highlight the positive impact on a wider range of psychosocial outcomes: 'PSWs (peer support workers) appear to be able to do more successfully than professionally qualified staff is to promote hope and belief in the possibility of recovery; empowerment and increased self-esteem, self-efficacy and self-

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management of difficulties and social inclusion, engagement and increased social networks' (p. 400). Outside of the healthcare system there is also growing evidence for the use of peer support in schools and the workplace as a means of fostering positive educational and professional development (Sykes *et al.*, 2009; Visser, 2004).

There is also qualitative evidence which predominantly examines the experiences of accessing peer support (Glenton *et al.*, 2011). Whilst there have been a significant number of qualitative papers, there have been relatively few review papers across disease categories. However, two large review studies have recently been published; one examining peer support for chronic health conditions in adults and the other for mental health.

Embuldeniya *et al.* (2013)'s review of peer support with service users and carers of chronic health conditions found a number of themes across the 25 papers included. The number of qualitative papers enabled a rich insight to be gained into the experiences and impact of such interventions. Themes during the intervention emerged as a 'sense of connection', 'experiential knowledge' 'finding meaning' and (reduced) 'isolation'. Such themes may be more challenging to assess using quantitative means but reflect the depth of connection between peers. In terms of the impact of the peer support, themes emerged around changing participants' outlooks to be more positive and positive impact on health related knowledge and behaviour.

From the peer mentors' points of views positive themes emerged around the reciprocity of the role in that they felt they had gained from support as well as more general role satisfaction in supporting others. However, some negative themes emerged, which are not reflected in the quantitative data. The theme of 'emotional entanglement' emerged from peer mentor data, representing the consequences of the emotional and experiential closeness to the mentees: 'a mentee's personal or health problems became overwhelming and placed the mentor's well-being at risk; when mentors revisited negative emotions related to their personal experiences; when relational boundaries became blurred; and when severing peer relationships led to a sense of loss' (p. 9). Other negative elements emerged, particularly if a peer is in a negative emotional state and which created a negative dynamic for others, particularly in a group setting.

The themes from peer support with mental health service users was slightly different in that it reflected the journey towards recovery which those affected by chronic health conditions may not have available to them (Walker & Bryant, 2013). As such themes around role modelling and fostering hope were prominent across papers. The lack of professional distance meant that greater meaning could be gained for those accessing the support. However, there were also reflections that their identity as a previous service user was enduring and therefore were perceived as not capable of offering sufficient support.

1.14.3 Peer Support: Theoretical Underpinning

The establishment of a theoretical basis to frame the empirical findings for peer interventions has been problematic as 'The literature on peer-related health interventions is largely atheoretical' (Simoni et al., 2011, p. 353). More recent review papers have therefore attempted to hypothesise the theoretical basis behind the mechanism and impact of such interventions. Dennis (2003) attempted to theorise the positive findings about the impact of peer interventions in a healthcare setting. Dennis hypothesised that there may be three modes of action by which peer interventions bring about a positive effect:

1. Direct Effect

The direct effect model hypothesises that peer support has a direct impact on physical and emotional outcomes. Within this model Dennis highlights a number of modes of action. In terms of emotional outcomes the peer support provides opportunities for social integration which may have otherwise been lost due to the impact of the physical condition. It therefore decreases feelings of isolation which could hamper emotional wellbeing. A further mechanism is that it provides a source of information beyond that of the medical and allied health professionals, which aids the day to day management of the challenge being faced.

2. Buffering Effect

The buffering effect model hypothesising that peer support acts as a buffer between the individual and the negative effects of a physical health condition. Dennis (2003) refers

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to Lazarus and Folkman (1984)'s model of stress and coping to explain the impact of peer support in terms of coping with the implications of health conditions. Lazarus and Folkman discuss the problem and emotion solving skills that are needed to cope with stressors. It is these emotional and problem coping skills that Dennis hypothesising peer support provides by reducing perceived harm, enhancing coping skills, reducing blame and decreased maladaptive coping skills via the examples from lived experience.

3. Mediating Effect

The mediating effect model hypothesising that peer support serves to positively impact health via improvement in emotions, behaviours and cognitions. Dennis highlights one example of influencing self efficacy through peer support using the social cognitive theory (Bandura, 1986). Perceived self-efficacy affects an individual's thoughts and behaviours. Highly – efficacious individuals are therefore more likely to hone behaviours due to factors such as greater initiative and perseverance. The mediating effect of peer support therefore acts to 'modify an individual's self-efficacy through influencing these sources of self-efficacy information' (Dennis, 2003, p. 327). The position of a peer results in the person feeling more able to reach a higher level of self-efficacy as they witness someone else in the same or similar situation achieving positive outcomes.

Simoni *et al.* (2011) expanded on Dennis (2003)'s theoretical ideas in terms of the mechanism of peer support impact. Simoni *et al.* separated the impact made by peer support into four modes of support offered: education, social support, social norms and self-efficacy.

1. Education

Simoni *et al.* (2011) refer to Dynamic Social Impact Theory (DSIT) to understand the impact of education based peer support. DSIT proposes that communication has the potential to increase an 'individual's likelihood of changing behavior if the communicator is similar and credible; the communication is socially, physically, or temporally immediate; and there are multiple persuasive change agents communicating about a new practice' (p. 354). Simoni *et al.* therefore proposes that a peer fills this criteria and is therefore more prone to have an impact on behaviour than

other stake holders. Simoni *et al.* also refers to social comparison theories (Festinger, 1954) that propose social interactions have three purposes: self evaluation, self enhancement and self improvement. Positive peer interactions can serve all three purposes in a meaningful way due to the social proximity which would maximise positive change, if the peer is a positive presence.

2. Social Support

Simoni *et al.* (2011) refer to Lazarus and Folkman (1984) stress and coping model, in a similar way to Dennis (2003) to explain the social support impact of peer interaction. Simoni *et al.* point specifically to the informational, instrumental and emotional support provided by peers which develops new and evolving ways of coping with stress from a point of view of lived experience.

3. Social Norms

Simoni *et al.* discuss the use of peer interventions to change or enhance behaviours in a healthcare context. They refer to 'diffusions of innovations theory' (Rogers, 1995) which proposes that change is most likely brought about when it is 'congruent with existing practices, advocated by trustworthy change agents and already accepted by key opinion leaders' (p. 355). In this way peer modelling is primed to fulfil these characteristics and therefore could explain the impact formal or informal peer modelling rather than professional guidance can have a significant impact on behaviour.

4. Self-efficacy

Simoni *et al.* discuss similar theoretical frameworks to Dennis in terms of theorising the impact on self-efficacy. They refer to social cognitive theory (SCT) but discuss the specific mechanism which may enhance self-efficacy amongst peers to a greater extent rather than professionals: 'SCT proposes that self-efficacy develops through mastery experiences, vicarious or observational learning, and social persuasion, each of which is amenable to peer approaches' (p. 356).

The theoretical frameworks discussed provide a synthesis of evidence in terms of mechanism underlying the impact of peer interactions. The combination of a shared

position and shared experience provide a basis for a myriad of positive consequences for such interventions.

1.15 Study Aims

The aim of the current study is to expand the understanding of the impact of peer mentoring for parents of children with T1DM. Sullivan-Bolyai *et al* (2004, 2010, 2011) and Rearick *et al.* (2011) have established some promising results in terms of the effect of such interventions. However, the results indicate that the intervention has failed to consistently deliver the positive outcomes.

The current study will therefore investigate the experience of peer mentoring from both the newly diagnosed parents' and the mentors' perspectives, using qualitative methods. The peer mentor programme that the parents engaged with is the first of its kind in the UK. Previous qualitative studies of parents on either side of the mentoring dyad have been reported previously by Rearick *et al.* (2011) and Sullivan-Bolyai and Lee (2011). It is hoped that this in depth analysis of both mentor and mentee experience will provide deeper insight into the impact of such interventions to inform the provision of future support for parents for T1DM parents.

The present study therefore has two primary aims:

1. To provide insight into the experience of parents who access peer mentoring following their child's diagnosis of T1DM
2. To provide insight into the experience of providing support as a parent of a child with T1DM to parents of a child with newly diagnosed T1DM.

Chapter 2

Methodology

2. Chapter 2 Overview

Chapter 2 will outline the aims of the research and the research questions. An overview of the qualitative methodology, the rationale for taking this approach and the steps taken to ensure the quality of the research are described. The specific methods for the current research are then detailed including ethical considerations, sampling and recruitment of participants, written materials, data collection procedure and analysis process.

2.1 Aims & Research Questions

The present research is the qualitative arm of a broader study: 'Parents: Listen, Understand, Support' (PLUS). The PLUS project piloted a parent to parent mentoring programme in which experienced parents offered support to parents of children with newly diagnosed type 1 diabetes, based on Sullivan-Bolyai *et al.* (2004, 2010, 2011)'s work. Link Parents with more than two years' experience of parenting a child with type 1 diabetes were recruited to support Recipient Parents of children with newly diagnosed type 1 diabetes. The support moves beyond that of informal support which parents of children with chronic conditions often offer to one another. The project context provides structure and training for the support whilst maintaining the lived experience-based expert aspect of parent to parent support (Sullivan-Bolyai *et al.*, 2004). In the PLUS project the Link Parents were provided with training and support in mentoring the Recipient Parents (Appendix VII) within a six month time frame in which to offer the support. Pre and post quantitative measures were included in the pilot project to evaluate outcomes of the intervention however these will not be reported in this qualitative study.

The aim of this study is to explore the experiences of both the Link Parents and Recipient Parents within the PLUS project. A qualitative methodology was adopted to enable in depth insight into the experiences of participants who have taken part in the

project which is the first known adaptation in the UK of the US support programme reported by Sullivan Bolyai *et al.* (2004, 2010, 2011).

The specific research questions for the Link Parents and Recipient Parents are detailed below:

Recipient Parents:

Why did they want support in the context of their child's diagnosis?

What was their experience of receiving that support?

What was their experience of the impact of the support?

Link Parents:

Why did they want to support other parents?

What was their experience of preparing to support another parent?

What was their experience of supporting another parent?

What was the impact of providing that support on themselves and the Recipient Parent?

2.2 Overview of Qualitative Methodology

The systematic review detailed in chapter 1, illustrated that quantitative methods are most often used for the evaluation of interventions. However, for the present study, a qualitative methodology has been adopted. Quantitative and qualitative studies differ from an epistemological perspective. Quantitative research holds a positivist position, rooted in a belief that there is truth and falsehood and therefore research aims to find truth (Richardson, 1996). Qualitative methodologies on the other hand stem from an interpretivist position which emphasises the layer of interpretation and are therefore subjective (Richardson, 1996). Quantitative and qualitative methodologies therefore differ in their aims, whereas a quantitative study may aim to determine if an intervention is effective, a qualitative study may aim to gain insight into the experiences, interpretations or perspectives of those who received the intervention. The literature review revealed how challenging it is to ascertain the impact of interventions for parents via quantitative methods. Qualitative methodologies have been used sparsely but have provided different insight into the perspective of participants, in their own words.

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Besides the epistemological differences qualitative methods also allow the collection and analysis of a rich data set which can enable insight into a new or emerging field of interest (Roberts & Ilardi, 2005). The experiences of participants who have provided or received this specific type of peer support in the context of T1DM has not been explored in the UK before and would therefore benefit from qualitative exploration. Furthermore, qualitative methodology 'explored the textured meanings and subjective interpretations of a fluid, uncertain world' (Finlay, 2011; p. 6). It was therefore felt that exploration of participants' experiences through flexible and open qualitative methods would allow a greater insight into the phenomena of their experience, compared to the restrictive field of enquiry within quantitative methods. Furthermore, the impact of therapeutic interventions are often underestimated by quantitative methods (Finlay, 2011). Qualitative methodologies allow for greater responsiveness to the participants' lived experience. This is particularly important when the outcome variable of the intervention is unclear as it appears to be in peer support and is often the case in an emerging field (Creswell, 2013).

2.2.1 Justification of Specific Qualitative Methodology

Interpretative phenomenological analysis (IPA) was used to analyse the data. 'IPA is a qualitative research approach committed to the examination of how people make sense of their major life experiences' (Smith *et al.*, 2009, p. 1). IPA is therefore viewed as having a dual commitment to 'giving voice' and 'making sense' of participants' experiences (Larkin *et al.*, 2006). IPA is most often utilised when a significant experience has occurred which is removed from normal experience or leads to a different experience of everyday events. The approach aims to stay close to the experience at the core of enquiry rather than forcing them into highly abstract or rigid constructs (Smith *et al.*, 2009).

This approach was taken in this study for a number of reasons. Firstly, the aim of IPA is to gain insight into the experiences of participants (phenomenological) and how they makes sense of these experiences (interpretative) which fits with our aims to understand the experiences of the parents. Secondly, IPA is designed for use with a homogenous group with shared experiences. Both Recipient and Link Parents share the experience of living with a child with type 1 diabetes as well as the experience of being

involved on either side of the support within the project. Thirdly, the method places the importance of reflexive positioning as central to the process of analysis. This seems particularly important as the researcher has experience of working with children with type 1 diabetes and currently works in a broader child health service, therefore the active consideration of the position held by the researcher and its influence is crucial. Furthermore, this qualitative study is part of a broader research project which includes quantitative data. Although the qualitative research has been conducted separately, consideration of the interaction between the two arms of the wider research project is important. Finally, IPA was originally developed in healthcare context with research into the experiences of patients which maps well onto the context of the current research.

2.3 Interpretative Phenomenological Analysis (IPA)

IPA draws on three conceptual philosophical areas: phenomenology, hermeneutics and idiography. They will each be explored below.

2.3.1 Phenomenology

Phenomenology refers to the study of experience. The field of phenomenology is broad and differing in points of emphasis, however there is a shared interest in understanding what matters to human beings within their experience. Furthermore, phenomenologists may extend their interest to how people comprehend their experiences (Smith *et al.*, 2009).

Within the field of phenomenology there are four prominent theorists who have contributed to ideas in this area. At its origins, philosopher Edmond Husserl developed ideas regarding the examination of experience. His interest lay in how a human being could truly know their own experience in ways which would allow the identification of critical qualities of the experience (Husserl, 1927). He emphasised the need to put aside our 'natural attitude' and adopt a 'phenomenological attitude'. In order to do this we must place our perception of the experience itself at focus of the inquiry. This involves taking a reflexive stance: 'we need to bracket, or put to one side, the taken-for-granted world in order to concentrate on our perception of that world' (Smith *et al.*, 2009, p.13).

Martin Heidegger built on Husserl's ideas by noting that our interpretations of the world are central to our experience. Heidegger referred to intersubjectivity of our relationship to the world, in that we are not and never can be separate but will always be an involved participant in our world (Rennie, 2009). Larkin *et al* (2006) summarised Heidegger's central idea: 'It is a mistake to believe that we can occasionally choose to take up a relationship with the various somatic and semantic objects that 'make up' our world, because such relatedness is a fundamental part of our constitution' (p. 106).

Merleau-Ponty further developed ideas regarding our interaction with experience further. He described humans as 'body subjects', in that our bodies are not passive beings in the world but our vehicle for interacting with it (Merleau-Ponty, 1962). He argued that we see ourselves as different from the world around us and that our perception or interaction with others is shaped by our position of physical and psychological difference (Smith *et al.*, 2009). Finally, Satre extended Heidegger's ideas about our interactions of the world to the importance of our social interactions. He theorised about the importance of our interpersonal relationships and their influence on our expectations and experiences (Smith *et al.*, 2009). Satre described our existence as an ongoing process of becoming rather than being and at the centre of the process of becoming is our interactions and relationships with others. In terms of IPA this emphasis on the relationships at the centre of experiences is important as relationships in human research are so dominant.

2.3.2 Hermeneutics

Hermeneutics is the theory of interpretation. In Heidegger's work on phenomenology the issue of interpretation was present but not explicitly noted. In his early work he argued we are always participants not passive observers in the world. Later he wrote about the inevitable influence of our past experiences/assumptions on our experience of new stimuli (Heidegger, 1962). Importantly for IPA this binds together experience and interpretation resulting in phenomenology being inherently bound by interpretation.

Hermeneutics is extended further by the idea of a hermeneutic circle. A hermeneutic circle refers to circular relationship between the part and the whole of any stimulus. For

example, a word in a sentence is understood through the context of the whole sentence but likewise the whole sentence can only be understood through understanding each individual word. This is an important consideration for the analysis of research data as 'the interpretation of this piece of text is seen within the context of the reader's history of textual interpretation, and that history is changed by the encounter with this new piece of text' (Smith *et al.*, 2009, p.28).

Research using IPA also involves a 'double hermeneutic' process (Smith & Osborn, 2007). The participant is making sense of their experience whilst the researcher makes sense of the participant. The researcher and participant therefore appear somewhat alike in that they are both making sense of a phenomenon. However, the participant can be seen as making first order interpretations as it is their experience at the centre and the researcher makes second order interpretations of the participant's interpretations (Smith *et al.*, 2009). A further aspect of the double hermeneutic process within IPA is the approach the researcher adopts in terms of their interpretation. Larkin *et al.* (2006) notes that it is possible for a researcher to enter a participant's experience from many angles, all of which are valid as long as they remain grounded in the participants' account. During the process the researcher attempts to balance Ricoeur (1970)'s hermeneutics of suspicion (an attempts to recreate the participant's experience, on its own terms) versus hermeneutics of suspicion (utilising external theoretical frameworks to interpret the experience). The process of bracketing, which seeks to explore the position of the researcher in relation to the research area is a useful way of contextualises the researcher's position. Bracketing therefore enables greater insight into the origins and drives behind interpretations and therefore helps the reader to form their own interpretation of the results.

2.3.3 Idiography

IPA's idiographic approach refers to its concern with the particular as opposed to the general. It is a departure from approaches aiming to extrapolate findings to wider groups or populations. IPA's idiographic approach functions at two levels. Firstly, the level of depth and detail attended to within the analysis process. Secondly, it is concerned with particular events in particular contexts occurring with particular people

rather than seeking widely held experiences amongst a broad spectrum of people (Smith *et al.*, 2009).

2.4 Ensuring Quality in an IPA Study

Assessing quality of qualitative research has been the subject of much debate. The desire to establish and assess credibility amongst qualitative research has led to the development of numerous quality assessment guidelines (Elliott *et al.*, 1999). However, their often prescriptive nature can detract from the need to remain grounded in human experience at the heart of qualitative psychology research. Elliott *et al.*'s paper offer broad guidelines which can be applied across research areas and used in flexible way. The guidelines will therefore be used as a framework for ensuring quality within the present research:

2.4.1. Owning One's Perspective

Qualitative researchers should aim to identify their own values, ideas and experiences relevant to the subject matter they are investigating. Mindfulness of one's perspective helps the researcher to consider their approach to data and the impact they may have on the perception and understanding of data. Stating the researcher's perspective also allows the reader to frame the results in the context of the researcher perspective and consider other interpretations (Elliot *et al.*, 1999).

In the current research, identifying and acknowledging the researcher's perspective was done in a number of ways across the timeframe of the research. A position statement was written to frame the researcher's personal and professional position in regards to the research. A reflective diary was also kept throughout the research process which kept a record of the evolution of the researcher's perspective (Appendix VIII). A bracketing interview was also used as a means of enhancing reflexivity through discussion of the researcher's position with a peer. The discussion allows deeper reflection and the possibility of uncovering unconscious thoughts or values which may be relevant to the research. The role of the interview is to facilitate and provoke reflection beyond that which has arisen through the reflective diary (Rolls & Relf, 2006).

2.4.1.1 Position Statement

I am a white British female age 26 years old. I am younger than all participants within the study. I grew up in north east England but my family now live near the border of north Wales. At the time of collecting data I was living in Cardiff and was working in the geographical area many of the participants were from which allowed me some insight into the culture of this area.

I grew up with my biological parents, my sister (18 months my junior) and my brother (seven years my junior). My maternal Aunt and her husband both died when I was 11. Their two daughters (my cousins) have since become part of our family and I consider them to be my adopted sisters. This has shaped my ideas about family protecting and caring for each other in times of crisis. It has also highlighted the gulf an absent parent(s) can leave in an individual's ability to cope with adversity, especially when dealing with difficult life transitions.

There were no significant physical health problems in my family growing up. However, I experienced significant mental health difficulties as a teenager for which I received two years of psychiatric intervention and have been in recovery for the decade since. This had a profound effect on my family, particularly my relationship with my mother. We were in battle for several years either side of my diagnosis and intervention. These experiences had an important formative effect on my interest in the functioning of families particularly when a family member is psychologically distressed. Such experiences have had an impact on my ideas about maternal responsibility to protect and fight for the wellbeing of their child, a fight many of the participants were undertaking against the threat of diabetes to their child. It has also impacted on my ideas about the relatively passive role fathers may take in this domain. However, this view has shifted more recently as my peers are starting to have children and I am witnessing the greater role many of my male friends have in parenting their children compared to my parents' generation. The bracketing interview also led me to reflect on my experience of maternal desire to protect the individual child when they are vulnerable, compared to paternal emphasis on protecting the family unit and their quality of life.

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During the development of questions for the project one of my adopted sisters gave birth to a baby with Epidermolysis bullosa. It is a rare inherited skin condition which causes skin to blister with only slight touch or friction. The condition threatened his life initially however he survived but will require lifelong management of infection and pain. Witnessing the distress caused by having a child with additional physical needs increased my level of empathy for participants and their families. It also altered my perspective on families who chose not to access support, as my sister did not accept the support from other parents that was offered. She feared it would trigger worries for the future and she wanted to live in the moment with her child. This was a perspective I had not considered and I was mindful of being drawn to elements within the transcripts which alluded to negative elements of being supported by other parents.

I am currently in my final year of clinical psychology training. As such I believe strongly in the power of psychological support being helpful in times of distress. I am therefore perhaps more likely to attend to positive reports of the impact of support as it fits with my value system in terms of how people should cope. My current placement is in children's cancer services in Cardiff. The service provides psychological support for children and young people (0-25 years old) and their families being treated or in remission from cancer. The experience has impacted on my understanding of what families can cope with. Families have often described finding normality even with something as life-altering as cancer. This theme of adaptation is something that has come through many of the participants' accounts as well. I have also been mindful of the timing of my analysis sessions in terms of my work in cancer. I found it affected my perception of what can cause distress. Diabetes, though incredibly threatening to the wellbeing and physical health of children, sometimes appeared less significant when compared to the families I worked with who were on the cusp of losing their child or had lost their child to cancer. I therefore made efforts to put distance between the two parts of my working week to reduce their impact on each other.

I chose to undertake this research because I am interested in working with children and families. The project was part of an already established broader research study which was also attractive as I was aware of the difficulties previous doctoral students had in balancing clinical work and finding participants in their final year. The bracketing

interview led me to reflect on my initial attitude towards the impact of diabetes. Previous clinical work had led me to work with teenagers with diabetes but rarely with the broader family. This, coupled with a lack of insight into day to day life with type 1 diabetes, contributed to my underestimation of the impact of diabetes for the wider family. However, this perspective changed as soon as I began to explore living with type 1 diabetes in preparation for undertaking the research and continued to change as I undertook the interviews.

I have been supervised in this research by the PLUS project lead, Dr Sue Channon, who is also my line manager. In the bracketing interview, we discussed how the combination of the supervisory relationship and Dr Channon's personal investment in the project could have impact on how I view the data. There may have been a tendency to read into positive elements of the data and place less emphasis on negative elements, for fear of damaging our relationship. I feel that mine and Dr Channon's desire to engage with the data in meaningful way has been paramount over finding positive results, nonetheless this has been raised and discussed throughout the research process.

2.4.2 Situating the Sample

Situating the sample refers to the researcher providing information regarding the characteristics and circumstances of the participants. This enables the reader to assess the broader relevance of the findings. In the current research demographic and circumstantial information is provided in the participants section of this chapter and further information in chapter 3 (sections 2.5.6, 3.1 and 3.6).

2.4.3 Grounding in Examples

The researcher is required to provide examples illustrating the analytic process and the resulting themes. This enables the reader to assess the analysis and results and allows consideration of alternative interpretations and conclusions. In the current research, an example of coded text, illustrating the stages of analysis is provided (Appendix IX). In addition, themes developed have reported quotes attached to them to allow readers to assess the link between themes and original text.

2.4.4 Providing Credibility Checks

The researcher is required to illustrate they have taken steps to assess the integrity of their themes and categories. Elliott *et al.* (1999) provide a number of means of credibility checking. The current research was credibility checked by the supervisor of the project via submission of draft results and communication through the analytic process. In addition, the results were reviewed by a clinical psychologist who does not work in child health and was not involved in the research project so could provide a credibility check from a third party point of view.

2.4.5 Coherence

The research should be presented in a manner that is coherent and clear. This should enable a reader to follow the narrative of the research through a clear and systemic presentation of results, whilst maintaining the nuance and detail of the original data. In the current research the results are presented in diagrammatic form at the start of the result section to frame the overall themes. Each theme and subtheme is then systematically explored with related quotes. A results draft was also submitted to the research supervisor to assess for coherence of the presentation of results.

2.4.6 Accomplishing General vs. Specific Research Tasks

Elliott *et al.* (2009) require the establishment of intent in terms of research task. The research may have an aim of establishing general understanding, thus a range of participants or experiences is required. Conversely, a researcher may aim to understand a specific individual or instance in which case a narrower field of enquiry is required. For the present research the aim was to understand the experiences of parents involved in parent to parent mentoring. The researcher therefore endeavoured to gather data from a range of parents being supported by or supporting parents.

2.4.7 Resonating with Readers

The final guideline was to produce results which resonated with the reader in a way that expands or enhances their existing understanding or insight into the phenomenon being investigated. Achieving such resonance in the present study was established through review of draft results by supervisors to assess their contribution and impact. In addition, the completion of a literature review, following the data analysis process

enabled a context for the results to relate to in terms of its contribution to the evidence base.

2.5 Participants

Participants were recruited from parents who took part in the PLUS project. The pool of participants for the wider PLUS project were drawn from three services within the Abertawe Bro Morgannwg University Health Board. The hospitals were chosen on the basis of mixed demographics and size of patient groups as well as not having any other research regarding families at the point of T1DM diagnosis. In order to protect the anonymity of participants the hospitals will be referred to as Hospital 1, 2 and 3.

Two groups of participants were sampled from PLUS project pool of participants: the parents of newly diagnosed children who received support (Recipient Parents) and parents of children who were diagnosed 2 years ago or more, who provide the support (Link Parents).

2.5.1 Inclusion Criteria

The inclusion criteria for this study was any parent who had offered or received support as part of the PLUS project. However, prior to their inclusion in the PLUS project, participants were subject to broader inclusion criteria:

- Link Parents who delivered the intervention were parents who had a child diagnosed with diabetes more than 2 years ago.
- Recipient Parents were parents of children diagnosed with diabetes in the last six months including those diagnosed within the first six months of the study.

2.5.2 Exclusion Criteria

The exclusion criteria for the PLUS project was as follows:

- Parents with learning difficulties who were unable to complete the outcome measures
- Parents with a diagnosed psychiatric disorder who may have required more specialist support
- Parents with children on the Social Services Department at risk register

- Parents who required an interpreter

2.5.3 Recipient Parent Sampling

Sampling for the broader PLUS project involved a list being compiled of families whose children were diagnosed within six months before the start of the study and who were eligible to participate. They were then contacted and provided with an information sheet (Appendix X) by the Paediatric Diabetes Specialist Nurses (PDSNs). This allowed the family to ask questions of their PDSN or the research team. If they were interested they contacted the research team for further information.

All eligible families diagnosed within the first six months of the study were made aware of the study within a month of their child's diagnosis. The timing of the introduction of the support followed two broad guidelines:

- If a family had mentioned a desire to meet a family experienced with diabetes, then information about the project was provided.
- If two weeks had passed without the family spontaneously mentioning the idea of meeting another family then the PDSN informed them of the study, provided an information sheet and answered any questions.

Sampling for this study began at the end of the six month intervention period when a letter was sent informing them of the end of the contact. They were informed that a researcher would be in touch to arrange a follow up interview as per the initial information sheet (Appendix X). Following the receipt of this letter families were contacted to invite them to be interviewed about their experiences.

2.5.4 Link Parent Sampling

Potential Link Parents were identified by clinical staff at the three hospitals based on a list of qualities to be considered that had been drawn up by the research team with a Parents Advisory Group (Appendix XI). The clinical staff identified potential Link Parents and contacted them regarding the study. If the potential Link Parents expressed interest they were provided with an information sheet, including details of the researchers for them to contact if they wished to take part. Potential Link Parents then attended an information session or were seen individually by the research team,

following which they decided whether to consent to take part. Link Parents received training and supervision from the research team throughout the year-long study period. At the last meeting of the Link Parents with the PLUS research team they were reminded of the follow-up interview, given the researchers name, and told she would be in touch. For those Link Parents not at the meeting a follow-up letter was sent. (Appendix XII). Following the receipt of this letter families were contacted to invite them to be interviewed about their experiences.

2.5.5 Parent Recruitment

Nine Recipient Parents received support from a Link Parent. Five Recipient Parents agreed to be interviewed about their experiences of support. Eleven Link Parents were recruited to provide support, eight of whom were linked with Recipient Parents. Seven of the eight Link Parents who had provided support agreed to be interviewed. The three Link Parents who were not linked were also interviewed, but their data is not included in this study as the focus is on the experience of providing or receiving parent to parent support not the experience of being trained to do so or not being linked.

2.5.6 Demographic Information

2.5.6.1 Recipient Parents

The sample included three women and two men. One participant was recruited from Hospital 2 and the remaining four were recruited from Hospital 1. The average age of their child at the point of diagnosis was 9.20 years (range, 6-12; SD 2.68). Their children were diagnosed between May 2012 and March 2013. Two of the Recipient Parents were seen as a couple by a Link Parent couple, the remaining three were supported one to one.

2.5.6.2 Link Parents

The sample included five women and two men. Four participants were recruited from Hospital 3, two from Hospital 1 and one from Hospital 2. The average age of their child at the point of diagnosis was 8.29 years (range 1-15; SD 5.09). At the point of recruitment, the average years since their child was diagnosed was 5.14 (range 2-9; SD 2.34). Two of the Link Parents offered support as a couple to a Recipient Parent couple, the remaining Link Parents offered one to one support. The support provided by the

Link Parents varied widely in both type and frequency of contact: the minimum being one phone call and two text messages, the maximum being four face-to-face meetings combined with regular text messages and contact via social media. The majority of Link Parents met face to face with their Recipient Parents. Two pairs did not meet face to face, one pair had four phone calls lasting up to an hour each whilst the other pair had one phone call of 15 minutes.

2.6 Written Materials

2.6.1 Information Sheet (Appendix X)

An information sheet was provided once an interest in offering or receiving support was expressed by parents. Information sheets for both potential recipient and Link Parents outlined the following: the purpose of the study; why they have been invited; information regarding the voluntary nature of their involvement and their right to withdraw at anytime; what will happen if they agree to take part and what their involvement will entail; details of advantages and disadvantages of taking part; information about the procedure if anything goes wrong or there is a problem; details regarding confidentiality including situations where it may be broken; information about what will happen to data collected; details of the ethical review and approval; who is organising and funding the study, including who to contact for more information. The Link Parent information sheet also had information about claiming expenses incurred through their participation.

2.6.2 Consent Form (Appendix XIII)

After Link and Recipient Parents had read the information sheet and met with a researcher they signed a consent form. The consent form outlined the following: that the participant had read, understood and been given the option of discussing the contents of the information sheet; the participant understood that their participation was voluntary and they were free to withdraw at any time without any implications for themselves or their child; the participant agreed to take part in the study; the participant agreed to be contacted at the end of the study to take part in an interview regarding their experiences; the participant agreed for the interviews to be audio recorded and for the use of non-identifiable anonymised quotes in any publications. In

the Recipient Parent consent form it also sought consent for the parent's GP to be informed of their participation.

2.6.3 Semi-structured Interview (Appendix XIV)

The aim of an IPA study is 'facilitate an interaction which permits participants to tell their own stories, in their own words' (Smith *et al.*, 2009, p. 57). Semi-structured interviews are often the preferred collection method of choice (Reid *et al.*, 2005). A semi structured format allows the researcher to frame the interview to ensure it taps into the experiences relevant to the research question whilst allowing a degree of flexibility to enable the greatest depth to be yielded (Smith *et al.*, 2009). Throughout IPA there is a balance between holding the aims of the research in mind whilst being responsive to the experiences of participants during the interview (Smith & Osborn, 2007).

Semi-structured interviews are not without difficulties however. Compared to structured interviews they provide less control for the researcher over the direction and course of the interview. This can result in data which is difficult to synthesise if the content of interviews varies significantly between participants. However, such complexity is the consequence of generating a rich data set which is more closely aligned to the participants' experiences rather than the researchers preconceived beliefs (Smith & Osborn, 2007).

Two semi structured interview schedules were developed for use in the present study, one for the Recipient Parents and one for the Link Parents. The questions were designed to follow the chronological order of their involvement and therefore provide a framework for their reflections. There are three broad time phases for both the Recipient and Link Parents of the experience prior, during and after the support was provided/received. For the Recipient Parent the time phases translated into a schedule which was based on five broad areas of experience: their child's diagnosis; becoming involved with the project; the support they received; their relationship with the Link Parent; the impact of their involvement. Similarly, for the Link Parent schedule the time phases translated in a schedule based on five broad areas of experience: becoming involved with the project; the preparation for supporting others; the process of offering

support; the support offered; the impact of the support offered. Within both interview schedules each area had further questions to probe deeper if needed.

The interview schedules were piloted with a Link Parent and a Recipient Parent. On the basis of the pilot the content of the questions remained the same but changes were made to the order of questions to match the process of support more closely. In line with IPA methodology the research was flexible and responsive to content which the participants raised in each interview which was relevant to the other aims but did not follow the questions set.

2.7 Ethical Considerations

Ethical approval was granted by South East Wales Research Ethics Committee, Cardiff and Vale University Health Board Research and Development Department and Abertawe Bro Morgannwg University Health Board (Appendix XV).

It was noted that the nature of the emotional content being discussed could trigger psychological distress in both Link and Recipient Parents. This possibility was made clear to participants prior to giving consent at the beginning of their involvement in the project. As mentioned previously further permission to proceed with the qualitative research element at the end of the project was gained before conducting the interview. In the event of concern about the emotional wellbeing of participants, advice would have been sought from the project lead Dr Sue Channon. Additional risks to the researcher of conducting interviews in participants' home were also considered therefore Cardiff and Vale University Health Board lone worker guidelines were followed.

2.8 Procedure

2.8.1 Recruitment

Participants were recruited from the existing pool of participants who were involved in the PLUS project. None of the existing participants stated that they did not wish to be interviewed therefore all Link and Recipient Parents were contacted.

2.8.2 Interview

The interviews were undertaken in the participant's homes. If both parents of a child were both involved in the project they were interviewed separately. Information sheets and consent forms had been completed prior to the interview. However, it was reiterated that they could stop the interview at any time and the contents of the interview would be anonymised and not fed back directly to the Link/Recipient Parent. If any issues with the project arose during the interview, participants were either asked at the end if they would like anything fed back directly to the project leads or encouraged to seek advice from the project leads directly.

2.8.3 IPA Analysis

The IPA literature highlights the degree of flexibility within the analytic process whilst the focus remains on 'our participants' attempts to make sense of their experiences' (Smith *et al.*, 2009, p.80). Smith *et al.* have developed guidelines for the process of analysis which are designed to provide structure whilst enabling flexibility within analysis. Their guidelines have been used as blue print for analysis on the present data which comprised the following steps:

Step 1: Reading and Re-reading

The first step is designed to enable the researcher to become immersed in the story of the participant by repeated reading of the transcript. It aims to move the researcher away from a synopsis based approach and to place the voice of the participant at the centre of the analysis. In addition, listening to the original recording whilst reading helps to bring the story and participant to life. The process can also involve noting any ideas or thoughts that come to mind whilst reading the transcript. This can help to contain them and allow the focus to remain with the data. Repeated reading also enables the researcher to grasp the overall structure and pattern of the interview.

Step 2: Initial Noting

The second step aims to build on the familiarity already developed with the transcript. The researcher further develops any notes that have been written during step 1. However, the aim is to engage with the data at a descriptive level as well as the meaning underlying it. Smith *et al.* (2009) emphasis the need to avoid the superficial reading

which dominates our engagement with most text. The researcher should aim to engage with text at three levels to ensure the production of a rich set of notes/comments on the data.

i) Descriptive comments

This level of analysis takes the text at face value and aims to describe the content. It helps the researcher to identify what is important to the participant such as particular people, places or events. It enables the researcher to position the participants' experiences in terms of things which are important to them.

ii) Linguistic comments

The analyst should also attend to the use and meaning of language and how it relates to the narrative of the transcript. Particular features of the language may be attended to such as the rhythm of speech, pronoun use and repetition of particular words or phrases.

iii) Conceptual comments

This level of analysis aims to attend to the transcript at an interpretative level. The analysis moves from what is being said to the meaning behind it and the overall view of the participant. This level of analysis is particularly prone to influence from the researcher's own experiences and beliefs which should be noted and attended to. The researcher may begin to explore different interpretations as they move through the transcript. Through this process some interpretations will be reinforced by further reading whereas others will not. Throughout this process interpretations should be closely wedded to and inspired by the text rather than introduced from outside.

Step 3: Developing Emergent Themes

At step 3 the researcher has accumulated a detailed set of notes and comments and a familiarity with a transcript itself. The researcher then uses the detailed comments to explore emergent themes from the text. This process involves chunking the transcripts into discreet parts to identify emergent themes. Thus illustrating the hermeneutic circle at play as the transcript is separated into parts during analysis which then leads to new whole at the end of analysis. The development of themes involves the production of concise statements representing important elements of previous notes and comments. The themes should aim to 'reflect a synergistic process of description and interpretation... should feel like they have captured and reflect an understanding'

(Smith *et al.*, 2009, p.92). Again the hermeneutic circle plays a part in that the researcher should aim to focus on each specific element of the transcript but will inevitably be influenced by their knowledge of the transcript as a whole.

Step 4: Searching for Connections across Emergent Themes

This step involves pulling together the themes and mapping them together. Smith *et al.* (2009) recommend creating a list of themes for the researcher to examine and look for themes, using the following strategies (at the researcher's discretion):

Abstraction. This can be seen as basic form of connection themes as it looks to cluster themes on basis of similarities.

Subsumption. This is similar to the process of abstraction but instead of creating a new super-ordinate theme, a subtheme is used as a super-ordinate theme as it is seen to pull together other related themes.

Polarisation. This focuses on making connections based on differences stated around one point of interest.

Contextualisation. Connections are made on the basis of shared contextual or narrative elements such as around particular events or moments.

Numeration. The number of times a theme emerges may be attended as a possible marker of relative importance within the transcript.

Function. This relates to examination of themes based on their particular function within the transcript. It seeks to add a layer of interpretation to what the participant has stated for example extracted super-ordinate themes of emotion based on positive or negative presentation of themes.

The researcher may experiment with different groups which may enable greater depth of analysis. Once the final connections have been made these should be summarised in tabular form to represent the super-ordinate/subordinate themes. The researcher should also record reflections about the process before proceeding to the next case.

Step 5: Moving to the Next Case

The researcher then moves onto the next case and repeats steps 1-4. Each transcript should be explored on its own terms, hence the importance of bracketing thoughts about the previous analysis. It is noted that there will be some influence between

transcripts however Smith *et al.* (2009) postulate that by following a set protocol treating each case as individually is enhanced.

Step 6: Looking for Patterns across Cases

Once step 1-4 have been completed for all participants the research moves to find patterns in themes across cases. The research should look for connections in themes and how the themes may relate or influence each other. This may involve relabelling or reconfiguring of themes in light of each other. The final super-ordinate and sub-ordinate themes are again presented in a systemic way to illustrate their connections.

Chapter 3 Results

3. Chapter Overview

Chapter 3 will present the results of the IPA analysis in two sections; one for the Recipient Parents and one for the Link Parents.

3.1 Recipient Parents

This section will detail the results for the five Recipient Parents. As described in the method section, the transcript for each participant was analysed individually. Following this the analyses were reviewed and important themes across cases were extracted. The themes have been organised into four super-ordinate themes, each with corresponding subordinate themes which are summarised in Figure 7.

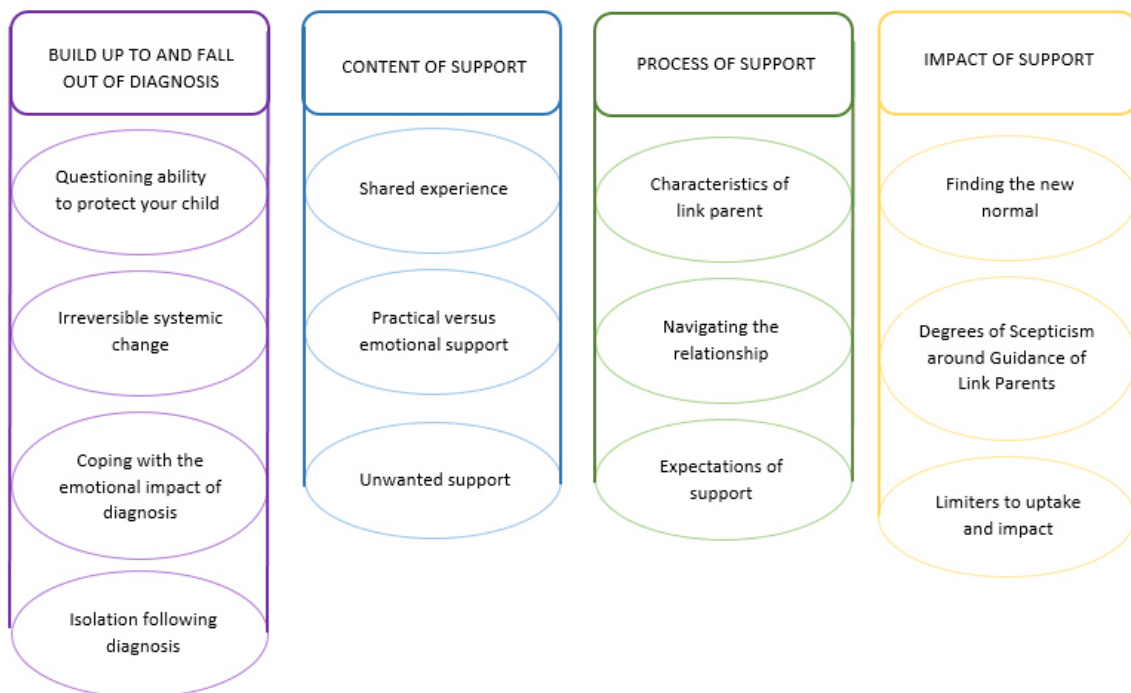


Figure 7. Recipient Parent super-ordinate and subordinate themes

Each super-ordinate and subordinate theme will be described and related to quotes from the interviews. Words which are added to quotes in order to enhance the clarity of the text or to remove identifiers will be in brackets. Sections of omitted text will be represented using ellipsis (...).

As detailed in the chapter 2, the focus of the study is on the experience of parents who have been supported by experienced parents following their child's diagnosis of type 1 diabetes. Given the small sample from a small south Wales community, details about the parent pairings, date of diagnosis and clinic have not been reported in order to protect the anonymity of participants. The Recipient Parents' pseudonyms and their child's age at diagnosis are described in Table 4.

| Name | Age of child at diagnosis |
|-------------|----------------------------------|
| Lucy | 6 |
| Helen | 8 |
| William | 8 |
| Hannah | 12 |
| James | 12 |

Table 4. Summary of Recipient Parents

3.2 Super-ordinate Theme 1: Build up to and Initial Impact of Diagnosis

All interviews started with a question about the process of diagnosis. The description the parents gave was often fact based initially. However, all participants naturally moved to reflect on the impact it had on all aspects of their lives and how they coped and adjusted to it. The impact was clearly important for all participants as they had subsequently signed up for support from other parents. Within the reflections regarding their experiences post diagnosis, four subordinate themes emerged: desire to protect your child; irreversible systemic change; coping with emotional impact of diagnosis; isolation of diagnosis.

3.2.1 Build up to and Initial Impact of Diagnosis Subordinate Theme 1:

Questioning ability to protect your child

To protect and keep your child safe is perhaps one of the most fundamental roles of a parent and one that is jeopardised by any ill health. Several parents described this as difficult to come to terms with following their child's diagnosis. For some it stemmed from a degree of powerlessness during the lead up to diagnosis as they tried to find answers for their child's deteriorating health. This was reflected in Helen's account of her attempts to be heard by the doctors assessing her son:

'I said 'I don't know whether he has diabetes or not' so I told them all the symptoms and they agreed that I should go see the out of hours doctor now. (I) took him... the doctor were quite, he was quite... 'no... if he had diabetes you would know about it'... (Doctor) dipped his urine and remember turning to (Husband's name) and saying 'watch him now he's (going to) change his tune' and he (doctor) looked, I saw him looking. (He) took (son's name)'s blood, it was so high, it didn't register on the monitor, it just said high, so we had to rush him straight down...'

The issue of initially fighting to be heard appeared to be something that the mothers experienced more so than the fathers. The two Recipient Fathers did not describe the lead up to diagnosis in the same level of detail compared to the Recipient Mothers. Helen reflected on the possibility of different emotional processing between parents:

'I think with women it's different being a mother. I think it's terrible, but as a mother, men don't show their emotions, not many men show their emotions anyway... with a mother it's more... (it's) inevitable but I think that would happen to most mothers...'

Hannah found that she also had to fight on behalf of her child to convince her partner before they could seek medical help. The relentlessness of the task was reflected in her use of direct speech as if she was reliving the conversations she had with her husband:

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'I kept saying to (husband's name), there's something wrong. (He said) 'Oh she's fine she just doing too much sport' and then she was just, she was just seemed weak and she lost a lot of weight and she's a very small child you see, she's quite small and she lost too much weight for her size. So, on the Sunday she was drinking a lot of fluid and I said to (husband's name) 'That's not normal' so we took her to the doctors (on) Monday and I took a urine sample and he (doctor) said 'she's diabetic.'

The participants' desire to protect their children was further enhanced following the diagnosis as their child seems more vulnerable than ever. The impact of this was reflected in the emotive language and tone of the participants' accounts. Lucy talked about the self blame she felt for any fluctuations in her daughter's blood sugars. Furthermore she equated her perceived failure to control the diabetes with her abilities as a mother who could not care for her daughter:

'Like if (daughter)'s sugars are high I tend to blame myself even though sometimes if she gets a cold then they go up. But I sit there and blame myself: 'oh I'm doing it wrong, I'm not a good mum.'

For Lucy this fear about her ability to protect her child led her to restrict her daughter's activities because she was worried about herself and others' ability to manage the diabetes:

'I don't let her go out of my sight unless she's at school whereas other people her age on our street like seven year olds, they're playing out.'

Hannah discussed the shocking implications of diabetes dawning of the family soon after the diagnosis which is reflected in her use of powerful language (e.g. 'Oh my god'). She too described an instinctive desire to protect their daughter physically and but also mentally:

'At the beginning... you're thinking 'oh my God you just want to protect her'. And one day she's (daughter) going to move out and she's got to do it for herself so... that was hard accepting in the beginning... She gets upset now and again you've just got to keep ahead for her... you've got to. There's nothing worse than if we all start falling apart.'

Other parents' reflected a desire to protect their child which extended to a desire to shield their child from the reality of diabetes and absorb any worry on their child's behalf. Perhaps this represents a limited confidence in managing their physical wellbeing and therefore focusing on emotional wellbeing. Helen described the regret she felt about wanting to shield her son from the implications of diabetes but not being able to:

'...for a fortnight after (son), even now he chews his sleeve and things, he's like a mouse that's been at his sleeve love him. It('s) down to anxiety because... I could remember the first few meetings we had with (the diabetic nurse) obviously she had to tell us if he collapses (recovery) position, emergency injection, 999 and things like that and nobody explained it to (son's name). He('s) sitting there he's hearing '999, emergency' he thought he was going to die, for a fortnight (Helen starts to cry). It was really hard I just wish- we didn't know he was taking it all but he sat on and that's what I regret.'

3.2.2 Build up to and Initial Impact of Diagnosis Subordinate Theme 2:

Irreversible systemic change

The 'irreversible systemic change' subordinate theme relates to the realisation following the diagnosis of the lifelong implications of diabetes. The implications were not restricted to the child but were perceived to apply much more broadly to the lives of the family members and beyond. For all participants there was no history of type 1 diabetes in the family so its sudden entrance made the adjustment even more challenging. William described the whirlwind journey from diagnosis to being expected to cope alone as a family:

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'...(We went) straight to (hospital) and he was diagnosed then and there, so that was how we found out... then he was let out and then it just turns everything upside down doesn't it?

For other parents the realisation of the long lasting irreversible nature of diabetes came later. As Lucy described it quite bluntly: *'Basically it's forever, isn't it?'* Helen discussed her initial naivety and the comfort it gave her. Her use of repetition seems to reflect the degree of underestimation she initially made:

'... (From) my dealings with diabetics type 1... I thought we just have to cut out his chocolate and things like that and he'll have one injection a day, two (at) the most. How wrong was I, how wrong was I? When he was initially diagnosed we were upset, but no I think it hit us a couple of days later when we knew the extent of everything that it entailed so in the beginning in the initial diagnosis... (it) didn't really phase as much we just thought get on with it, a couple of days later that's (when) it sunk in.'

Participants also discussed the wider impact it had on their 'normal' lives and the sense that the change had been systemic rather than just related to the child. Helen talked about activities that would have been enjoyable for the family become transformed and a source of insurmountable anxiety:

'...it (was) five weeks after diagnosis... we were going (abroad), we were like shall we cancel it? What if we do... when we're abroad it's so new to us...'

The theme of systemic change was also reflected in the impact on familial relationships as family life shifts around diabetes. For some this was a positive shift where the parents worked together, however for others it was more difficult. Lucy, for example, was a single parent, therefore the changes in the family lifestyle were directed by her and had an impact on the relationship with her daughter:

'...if (daughter)'s sugars are high at bedtime I think to myself what have you done wrong today?... But it ain't always what I've done or what she's done. She might not have snuck a sweet and that's another one, I'm always trying to moan at her 'oh you've snuck this' and she's 'no I haven't mum, I promise' I'm always moaning at that one.'

Other parents described the impact it had on their parental relationship as they tried to adapt to the change. Hannah described the diabetes as putting a stress on the limits of what she and her partner could cope with but also relief when they worked together effectively:

'It was stressful in the beginning together, because it does put a strain on your marriage. But... we're good, we're quite close knit... her brother's quite protective as well... he looks after her, he feels it for her you know.'

3.2.3 Build up to and Initial Impact of Diagnosis Subordinate Theme 3:

Coping with the emotional impact of diagnosis

The female participants discussed in detail their emotional response to their child's diagnosis. Lucy's emotional reaction was discussed at various stages of the interview and appeared to reflect how deeply it had affected her. However, relating back to the theme of the role of a parent to protect their child, Lucy feared the judgement of others if she showed her emotions:

'I went to the doctors I was really in a bad stage of depression. I was crying basically, all day every day whenever the children weren't around... I would cry. And I didn't want to go and talk to the nurse about it because I thought I'd be judged: 'Oh she can't cope with (daughter) or we going to have to take (daughter) off of her' and whatever else.'

Lucy appeared to internalise the blame for her daughter's ill health and its management which further reinforced her negative emotional reaction compared to other families who appeared to adapt to a greater degree. Helen described an initial calm before the

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full emotional reaction hit her. Helen almost seemed to relive that realisation which is reflected in her emphatic use of language:

'When he was initially diagnosed we were upset, but... I think it hit us a couple of days later when we knew the extent of everything that it entailed. So, in the beginning in the initial diagnosis (it) didn't really, didn't really phase as much we just thought get on with it, a couple of days later that it sunk in. When the doctor said it's four injections a day for the rest of his life, I said 'What? Really!' That was, yeah it was scary, horrific and our lives changed from then on...'

Comparatively the Recipient Fathers appeared to play down their emotional reaction, perhaps reflecting a genuine difference in response or because they did not feel comfortable sharing their emotional experience. William emphasized the need to adapt and move on rather than dwell on the experiences compared to his partner Helen:

'...you just got to try and, just go to try and get on with it... it was, it was upsetting but it was ok we got through it.'

James focused on the desire for knowledge and information as a means of coping. Again this may reflect a parental desire to protect and the need for knowledge in order to do that. James did acknowledge that it may have been an unusual reaction but that it felt right for him. This may reflect the different roles between him and his partner:

'I remember sitting at her (daughter) bedside reading you know all the information rather than probably... rather than sort of giving her (daughter) attention I was... all the information she had lying on her bed I was reading it all because I didn't know anything about it. That's my sort of first impressions of what happened... other than that you know you're always worried when you see children ill but it was lack of knowledge.'

3.2.4 Build up to and Initial Impact of Diagnosis Subordinate Theme 4:

Isolation following diagnosis

The participants all had intense medical support following the initial diagnosis but it was following discharge that theme four of the 'isolation following diagnosis' became apparent. Participants reflected on the realisation that they did not have the safety of the hospital and the care of their child was now their responsibility. The sense of sole responsibility was most evident for Lucy who was a single parent caring for her daughter leading to worry about her ability to fulfil that role:

'I found it hard to sleep at night in case she (daughter) doesn't wake up... that's my main one (worry)... her not waking up... (because) she's going to go too low and then she goes into a diabetic coma and I'll miss it.'

Helen echoed the feelings of vulnerability when she brought her son home especially in contrast to the care received in hospital. The curse word used to represent her and her partner's mutual panic seems to speak to the level of vulnerability they felt:

'I think when your child is diagnosed you're on your own, the nurses are brilliant, the doctors are all brilliant. Then you come home and you're here you think 'Oh Christ', in different situations, like we've looked at each other and we've been like 'What should we do, I don't know. Do you know?''

Participants moved onto discuss their perception of barriers to accessing medical staff. The barriers spoke less to the concrete availability of staff and more to the psychological barriers within parents. Some parents talked about not feeling able to contact their diabetic nurse about incidental worries:

'...you're all over the place when you first find out and you know... so many questions in your head and you can ask (the diabetic nurse) all these questions but... it's nice to speak to someone who has a child the same.'

Helen took this theme further in reflecting that the diabetic nurse could not understand their lived experience and therefore could not use it as a source of support:

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'I think that as a parent nobody knows how you feel, how your life is going to change. The doctors can tell you this... the nurses can, unless you (are) an actual parent living it nobody can comment like a parent can. Nobody can tell you the things that you (are) too frightened to ask the doctors and the nurses.'

The result of a lack of perceived support led some participants to find alternative sources of support, particularly through the internet. However, many reflected on it being a passable but not adequate source of support. William spoke of the possible dangers of accessing online support:

'I'd much rather preferred the face to face really, definitely, you wouldn't know what these people (writing online posts)... now that I think back you know someone could write something on there (internet) and you don't really know what if they, if they mean it what they're writing or you don't know. Speaking to someone face to face... you know you're having sincere information and advice.'

Furthermore, the potential dangers of accessing unfiltered information about the possible consequences of diabetes could have a substantial impact on the parent's mental wellbeing. Hannah described the desire for information but the double edged sword of it provoking worries she hadn't otherwise thought of:

'At the beginning you know you're reading stuff on the diabetic website, hearing these things... what do you call it... shortage of life and if you don't look after yourself. So all of that could get you apprehensive about it.'

3.3 Super-ordinate Theme 2: Content of Support

Super-ordinate theme 2 speaks to the content of the support sessions conducted between the participants and their Link Parents. Link Parents were not given strict guidelines about the exact content of support which is reflected in the variation of accounts by participants. However the common thread of coping with a child's diabetes

runs throughout the accounts. Theme 2 is divided into three subordinate themes: shared experience; practical versus emotional support; unwanted support

3.3.1 Content of Support Subordinate Theme 1: *Shared experience*

The theme of 'Shared experience' speaks to the grounding of support in common experience between the Recipient and Link Parents. 'Shared experience' was used as a means of support in various ways with participants. Unlike the medical or professional experience of health care professionals, Link Parents drew on their lived experience to support Recipient Parents. Lived experience as opposed to professional experience was highly valued amongst participants. Helen reflected on the added value and reassurance when support stems from lived experience:

'..I just wanted to know how... another parent deals with it that... cause in the beginning (I thought) I am never ever going to deal with all this, I'm never going to deal with all this in million year(s). I just said oh my dear god but you do and it's nice to know, and it's nice to have someone say... it's hard, I know how you're feeling but it does kind of get better.'

The power of lived experience resulted in the stories of Link Parents' journeys through diabetes being placed at the heart of the support provided to Recipient Parents. William spoke of his Link Parents sharing positive examples from their experiences of diabetes in a non-directive way:

'It was great not telling me what to do, telling me what he (Link Parent) does. That's what he (Link Parent) does and that's what he (Link Parent) found helpful, so it was good... really good... it was pretty much all about that, telling me about his son, and when he was diagnosed and what he can do now and things he does now, you know how he copes, and his kind of hypo treatment and things like that and I was just telling him the little things that we had done in the short space of time before I met him...'

Hannah similarly found value in hearing the Link Parent's experience even when it was different to hers. It seems that there was a comfort from just knowing they were not the only person with a diabetic child:

'But (Link Parent)'s got different things to (Hannah's daughter), (Hannah's daughter)'s on injections, they (Link Parent has) got the... pump. So they've got different experiences but it was nice to hear another story... it was nice to hear someone else coming across with their experience...'

Lucy spoke of the reassurance she felt from sharing emotional experiences having heard that her Link Parent had struggled in a similar way to her. It seemed to have a normalising effect on her experience especially as she did not have a partner to compare her reaction to:

'...if (daughter)'s sugars are high I tend to blame myself... (Link Parent) just-basically she helped to say we all go through this but we all have to keep the fight up for our children.'

3.3.2 Content of Support Subordinate Theme 2: Practical versus emotional support

Theme 2 relates to the two patterns of support which emerged from the data in how the Link Parents used the lived experience of managing diabetes. Lucy and Helen focused on the emotional impact of managing diabetes. Helen spoke of the comfort she felt from knowing that other diabetic parents had emotionally struggled. For Lucy her Link Parent normalised her feelings and provided a future based reassurance regarding the adjustment to managing diabetes:

'I went to the doctors I was really in a bad stage of depression... So it helped having (Link Parent) and (Link Parent) said 'Oh I went through it, most parents go through it and it's not just diabetic parents, a lot of people get depressed and have down days, we all do sort of thing'... it did help talking to her about it, it kind of stopped me thinking about it so much, dwelling on it myself.'

Other parents focused more on practical implications of adapting to life with diabetes. Some participants reflected on the relative barrier of opening up to a stranger about their private emotional world which may reflect the focus on the more concrete practical elements. William explicitly avoided the emotional content, focusing on practical advice such as how his child could continue to play sport or how to manage going on holiday. When the interviewer asked about any emotional content he used quite dismissive language perhaps reflecting his perception of its importance:

'I could have (talked about emotions), maybe even in the beginning sort of like, maybe we did mention it to each other kind of you know how crazy it felt or whatever... but never really went deeply into that...'

James seemed to treat the support as a resource to be utilized in quite practical terms rather than a source of ongoing support. In contrast to other participants who wanted ongoing emotional support, James felt that once that experience had been accessed there was less need for the support going forward:

'I got what I needed out of speaking to them (Link Parent) and you know I wouldn't want to make friends with them and socialize with them or whatever anyway so I didn't feel like meeting up with them again would have given me anymore than what I already got out of them.'

3.3.3 Content of Support Subordinate Theme 3: Unwanted support

The final subtheme relates to the less helpful aspects of the support offered by Link Parents to participants. None of the participants described the overall experience as negative but some elements of the support offered were not helpful at that time or for their circumstances.

One element of unwanted support was the use of examples from the Link Parents' difficult experiences in managing their child's diabetes. A notable response to this was from Helen who found it a challenge to digest her Link Parent's reflections on difficult times in the context of still adapting to life with a child diagnosed with T1DM:

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'... (I) guess she frightened me half to death and I just thought I've got enough going on without hearing every horror story about diabetes, not straight after (the diagnosis).'

Helen use of words such as 'frightened' 'death' and 'horror' seemed to reflect to depth of distress it caused her. Later in the interview she expanded on how the fear arose from applying her Link Parent's experience to her own life which planted previously unconsidered worries about the future:

'...we talked about our feeling(s) more about the way we felt and how we- how the rest of the family (felt). (Be)cause she('s) got just one child, 'cause I got three, I got three boys... (son with T1DM is) middle of three so it's so hard 'cause she was saying that, she find(s) it hard juggling the rest of her life with (Link Parent's child with T1DM)... I was off work and trying to get into routine and sort everything out and I just thought oh my god she's given up work, I came home thinking I can't afford to give up work so you know it did scare me a little bit.'

Helen reflected on the impact of the timing of such information as she accepted that difficult times may happen in the future but she did not want to know everything all at once and therefore overwhelming an already overwhelmed person. This feeling was echoed by James who felt that the Link Parent was overwhelming them with information. He made sense of it by discussing the potential mismatch in styles between parents, creating a dissonance in reactions and subsequent coping. However, even when discussing a relatively negative account the pauses and disjointed nature of the speech seemed to speak of their reluctance to speak negatively about the Link Parent (a subject which will be discussed further under heading 3.3.1.):

'I did think mind that they (Link Parent) sort of- Obviously it's- they sort of laid it on a bit thick you know? It is very important and very- it's going to last for life and everything but I thought they were a bit on the negative side of things. You know- they weren't very upbeat I didn't think, about it (diabetes). It was all

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what we mustn't do and you must be careful of this because this could happen rather than saying... I tried to look at it from... a positive side of things...'

The unwanted elements of support also related to Link Parents shining a light into a future of difficulty. This may reflect a difficulty dealing with a challenge to the Recipient Parents' hope that coping with diabetes gets easier because they were finding it so difficult at present. Therefore, raising the possibility of future difficulty was unexpected and unwanted. Hannah spoke of her Link Parent discussing the ongoing difficulties they were encountering and the struggle she had in reconciling them in an area of diabetes management she felt was going well:

'(The Link Parent) talked about the girls, he said 'they're on the pump' and he said 'now and again they get an infection because... the line' and the other thing he was saying about was, he said 'has she (Hannah's daughter) been in hospital since?' I said no and he was saying he's frightened in the night sometimes he goes in to check on (child with T1DM)... He said that was frightening, I said well she's only been to the hospital when they've called for her, not any emergencies or anything. She's quite level on it at the minute. So I was shocked to hear that they was saying that them being into hospital and stuff.'

Hannah appeared to cope with this through finding difference between her child and Link Parent's child as a way of reassuring herself that as her child grew up it would be different for them.

3.4 Super-ordinate Theme 3: Process of Support

Theme 3 refers to the process of being supported by another parent. The Recipient Parents described their broader experience beyond the content of the support, particularly the interpersonal aspects of the interaction. This super-ordinate theme is comprised of three subordinate themes: characteristics of Link Parents; navigating the relationship; expectations of support.

3.4.1. Process of Support Subordinate Theme 1: Characteristics of Link Parent

Theme 1 relates to the Recipient Parents' perceptions of their Link Parents. There was no direct question about their perception of the Link Parent however all participants reflected in some way on their views of their Link Parents, representing the importance of this element in this type of program. William and James, who as mentioned previously appeared to value practical over emotional support, focused on characteristics relating to degree of competence and knowledge. James reflected on his perception that his Link Parent had supported Recipient Parents before due to his perception of their professionalism:

'... they spoke as if they were in control and as if they knew what they were doing you know? There was no sort of wondering 'Oh what shall we say here?' They were quite professional.'

Similarly William perceived his Link Parent as experienced and knowledgeable which mapped well onto his desire for practical support. However, at the same time he expected that the pressure to do a 'good job' may have made him nervous although that did not affect his perception of him as a competent source of support:

'... I think he (Link Parent)... probably (would) have been quite nervous speaking to someone, having the questions firing at him. Obviously he had answered, because... 10 years his son had been diagnosed for. So... he was very experienced but I suppose, he know(s) himself that he had to be careful what advice he gave in case he couldn't say to me that 'my son err blah blah blah it would have been alright for yours', but because it is different, it would have been nervous, it would have been nerve racking I should imagine. It didn't, it didn't seem though in all fairness.'

Participants also reflected on the difficult task of supporting other parents. There appeared to be a perception of a need for Link Parents to be in balanced mental state to in order to support others. Hannah spoke about her Link Parent having some personal issues before they started the support. It seemed both she and the Link Parent were of the opinion that the Link Parent needed to be in a stable place to support others:

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'She'd (Link Parent) had trouble with her brother... so I said 'leave it a while, you phone me when you are ready' and she phoned me about three weeks later then and it had settled down and then we met up then and she was great.'

Helen's experience illustrated the flip side of not being emotionally stable prior to providing support. She seemed to describe the emotional impact on the Link Parent as listening to Helen's story triggered her own emotional response which in turn left Helen feeling uncontained emotionally.

'... she (Link Parent) was upset, I think it brought everything back... it's her, hearing what I going through and things like that it brought all the feeling back you have in the beginning.'

The acknowledgement of the difficulty of the task was also reflected in participants' feelings of indebtedness to the Link Parents for their time and energy in supporting them. William spoke of his feelings of gratitude for his Link Parent making a sacrifice to meet him.

'I did give a text. I texted him (Link Parent) to thank him, when I came back from holidays because you know, the advice he gave me... it's just simple things to take... but that you might not think about. I text him to thank him and it was just, I hadn't been...not that I hadn't wanted to meet up with him again, it's just sort of of being set on the right path...'

Finally, Helen who had a more difficult experience than others still acknowledged the investment her Link Parent had made and that her core intention to help was genuine:

'(I) shouldn't really be slating her you know, she gave her time and she was, I suppose what she was doing was the right thing.'

3.4.2. Process of Support Subordinate Theme 2: Navigating the relationship

Navigating the relationship speaks to the issues surrounding the boundaries and structure of the relationship. Many participants found themselves struggling to make

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sense of the relationship as it seemed to sit somewhere between friendship and professional relationship which meant the parameters of the relationship were difficult to understand.

Lucy spoke of her Link Parent relationship sitting somewhere near friendship but not quite in that area. The difficulty defining the relationship was reflected in her struggle to articulate how she viewed it:

'No, I wouldn't say we're friends. Like I've seen her round shopping and stop and have a two minute chat. It's more social but we're not friends...'

Similarly, when asked about his relationship with the Link Parent James struggled to define it but was clear that they were not friends, but perhaps their relationship was friendly:

'In between I would say, a bit of both really. Obviously you know to say they're friends we... I've never met them before... Yeah it was in between I would say. A little bit of both (friendship and professional).'

Navigating the relationship also related to difficulties in negotiating boundaries and structure, especially in the context of difficulty defining the relationship. Some participants felt quite clear about the boundaries of the interaction. For Lucy, her Link Parent was clear about her remit from the beginning. Although the parameters were different from her expectations, Lucy described the process in a way that appears to be a joint decision:

'...me and (Link Parent) both spoke when we first spoke (the Link Parent said) 'I ain't here to tell you to change the change the insulin ratios, I ain't here tell you how to bring your daughter up, I'm just here for a bit if support so...' I didn't think of it like that at all.'

For other participants a lack of clarity around who was in control of the support and what the etiquette was in terms of frequency and length of support was challenging.

Helen struggled with knowing who should be contacting who and had some sense that her Link Parent was in a similar dilemma but neither made the first move leading to disengagement:

'I just feel it goes so long in between contact that you don't want to, I would feel a bit... just picking up the phone and texting her now and saying now that 'do you fancy meeting up for a coffee?' and you know cause she's probably getting on with her life, she's probably thinking 'oh now perhaps I should text (Recipient Parent) see if she's ok but she's probably getting on with her life, she's probably fine and doesn't want me', but perhaps if there was a set thing where you meet up and you know perhaps that would be beneficial.'

The difficulty with a lack of formal structure was reflected by James as well, although he placed a joint ownership between the link and Recipient Parent which potentially contributed to the difficulties, alongside it being both parents' first experience of such support:

'...if we'd just met them for a brief time and then you could have gone back and met them again and other things could have come up then but... I think we over did it on that session when we spoke to them.'

3.4.3 Process of Support Subordinate Theme 3: Expectations of support

None of the participants had experienced this type of support in relation to their child's diagnosis. As a result, a broad range of expectations emerged regarding the support and how those expectations mapped onto reality.

As expected, all participants entered the project with a degree of optimism regarding its utility, as it was this which motivated them. Some participants were relating this optimism to an expectation of positive or optimistic support from their Link Parents. Helen did not have explicit expectations of a positive attitude in her Link Parent at the outset. However, the negative narrative from her Link Parent led her to reflect on implicit expectations of an optimistic story which she apports blame to herself for:

'...I just expected to meet... a parent what had gone through exactly the same... and shared her experiences with me... it just happened her experiences weren't very positive. She can't help that, that is just her honest opinion, I wasn't expecting perhaps it's my fault I wasn't expecting, I knew none of this and I wasn't expecting to hear all that I wasn't expecting to hear all that.'

James discussed the influence of his own positive attitude of his expectation of the Link Parent having a similar approach. Therefore, when the Link Parent deviated from that approach he found it difficult to reconcile which may have affected his level of engagement:

'...Obviously they (Link Parent) were trying to hit it home to you... what you'd let yourself in for but what going to be coming to you but I think if I was doing it with somebody else I'd try to concentrate a little bit more on how to overcome these things rather than the bad things.'

A further element of expectations related back to navigating the parameters of the relationship. Participants also had some expectations about the degree of formality within the support. Hannah had predicted the interaction would be formal, perhaps relating it to her experiences of health professionals as the only other source of support. For her, the Link Parent not meeting these expectations was a positive surprise and enhanced her engagement with the support:

'I thought it (the support) might have been more formal but it was so, you felt at ease you know? It was good. You could say what you wanted to and you know they (Link Parent) were going through the same thing.'

3.5 Super-ordinate Theme 4: Impact of Support

The final super-ordinate theme relates to the effects of engaging with support from other parents. In terms of the future of such support it may be seen as the most important element but it is in fact the culmination of the previous themes as they all influenced the participants' perception of overall impact. 'Impact of support' is

comprised of four subordinate themes which relate to different elements of impact and broader influences on the participants' uptake of support: finding the new normal; degrees of scepticism around guidance of Link Parents; influences on uptake of support; looking to the future.

3.5.1. Impact of Support Subordinate Theme 1: *Finding the new normal*

Prior to the input of support participants had begun to adapt their lives around the diabetes but were struggling to find their way back to normality. In this domain several participants found the Link Parents played a key role in helping them find the balance needed to live successfully with diabetes in the family. Lucy found discussions around balancing safety of her daughter whilst maintaining quality of life useful in adjusting to her child's diagnosis. The diagnosis had made her highly fearful for her daughter's safety and led to a restriction in activities but her Link Parent helped her find a balance:

'Talking to (Link Parent) made me realise it (diabetes) is to worry about but to keep at the back of your mind and not dwell on it every day basically because life's for living.'

For other participants the support enabled them to engage in activities which had been previously normal and enjoyable but had become frightening because of worries about diabetes. Therefore guidance from experience helped them to find a way forward for their family. For example, William discussed his fears about going on holiday and was considering cancelling. The support enabled him to feel safe and confident to travel with their child and not feel they were unnecessarily endangering him:

'...with our situation going on holiday 6 weeks after, that would have been a lot more frightening. That was made easier... more relaxed getting everything we needed to go because we had had that good advice from (Link Parent).'

For other participants 'finding the new normal' related more to generating acceptance of diabetes and its implications, through conversations with someone further down the road. Hannah felt this to be the primary benefit for engaging with the support at that time and reflected the match in timing of the support in terms of her needs:

'I think it would have taken a bit longer to sort of accept what she's (daughter) got. I know it was like eight weeks before we met the couple but it gave us time to get our heads round it and then it (was) nice to hear other people saying look we've done this, it's alright you're going to get through it.'

3.5.2. Impact of Support Subordinate Theme 2: Degrees of scepticism around guidance of Link Parents

Theme 2 represents the degree of impact the experiences or advice the Link Parents provided had on Recipient Parent behaviour or thinking. Participants such as Lucy, absorbed the support with little scepticism. On the other hand participants such as William, appreciated that the Link Parent actively encouraged flexibility in the extent to which guidance was seen as personally relevant. The approach was in line with William's perception of differences between children with T1DM and he therefore felt experiences offered should be considered in terms of their specific relevance to his situation:

'...Certain things he (Link Parent) would say about his son (he) wouldn't necessarily say for my son because all cases are... different. He was very clear about that which was great, so you could take a lot of advice off him and any shared experiences I knew from the start that could not apply to mine...'

Parents who felt out of kilter with the approach or perspective of their Link Parent, seemed more inclined to adopt a sceptical stance in terms of the advice given and therefore carefully chose what to integrate into their lives. For example, Helen struggled with the position of her Link Parent as she had expected a more positive outlook. As a result she chose to disengage with elements of what the Link Parent had said, possibly as a means of self preservation which she described as 'zoning out'. In a similar fashion James took some elements away which he found helpful, using the support as a resource, as mentioned previously. However, he was able to step back and mentally challenge elements that did not fit with his approach, reflecting his relative confidence in managing his child's condition:

'I remember (Link Parent saying) 'Oh our daughter's going to university and I'm terrified' and this that and the other. (the Link Parent said) 'I'm thinking I'm going to be phoned in the middle of the night and she's going to be in some coma.' (I thought) Yeah alright but I'd hope not to be like that I'd rather be thinking 'oh she's having a good time and that these things happen.'"

3.5.3. Impact of Support Subordinate Theme 3: Limiters to impact and uptake

The final theme relates to parents making sense of any limitations to the impact of the support or their engagement with the support. Parents who identified the experience as a positive one still identified areas which limited its uptake or impact. For several participants the emergence of support from other sources had limited the uptake or impact. James had an alternative source of support within the family which emerged around the start of the project. The familiarity and accessibility of a family member trumped the outside support of a Link Parent, therefore contributing to less need:

'I think possibly more (engagement with Link Parent) if I didn't have the sister (in-law) because obviously we know (her) and any questions that I've got like that wouldn't have gone back to (diabetic nurse) for... as you know official support and conversation I would ask my sister in law.'

Lucy noted that she felt the timing of the support meant that a greater impact could have been felt if she had received the support sooner:

'I think it would have been better if (the support) did happen straight away because then I would have had more understanding and I wouldn't have read into it as much! Because when you read, you read all the bad bits don't you? That's what (Link Parent) helped with all the good bits. Yeah so if she had been there at the beginning I think I wouldn't have got into the depression stage to be honest.'

The change in intensity of the need for support as time passed was reflected in several participants who felt there would have been a greater need immediately following the

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diagnosis but the support would have looked different. Hannah felt the timing was right in terms of accessing the support:

'Well this (offer of parent support) was about May when we met (Link Parent). So she'd only been diagnosed March. So it gave me a bit of time to get my head round what she had so it was about right.'

Finally, the degree of gratitude or value attributed to the support appeared to be reflected in the level of regret across participants who had engaged fully or found the support less helpful than expected. William found the support of one meeting to be a positive experience and did not feel a need for more support. However, he worried that the meaning attributed to only needing one session would be related to a lack of utility rather than the opposite:

'... maybe I could have contacted him more really I don't know, maybe, every now and then maybe I think, I almost forget that it was going on, if you know what I mean? Once we had the initial meeting and you know, it's a lot and (I) learnt a lot from him really and what things to expect and all that, different tricks and things that differ. For want of a better word I do feel a little bit guilty that maybe I never spoke to him a bit more really, you know, but I really didn't think I needed to after that... maybe he thought I don't like him or whatever, or that he was no good. I just never felt the reason to contact him again after that. That's what I feel a little bit guilty about.'

3.6 Link Parents

This section will detail the results for the seven participants representing the Link Parents. As with the Recipient Parents, the transcript for each participant was analysed individually. Following this the analyses were reviewed and important themes across cases were extracted. The themes have been organised into four super-ordinate themes, each will corresponding themes which are summarised in Figure 8.

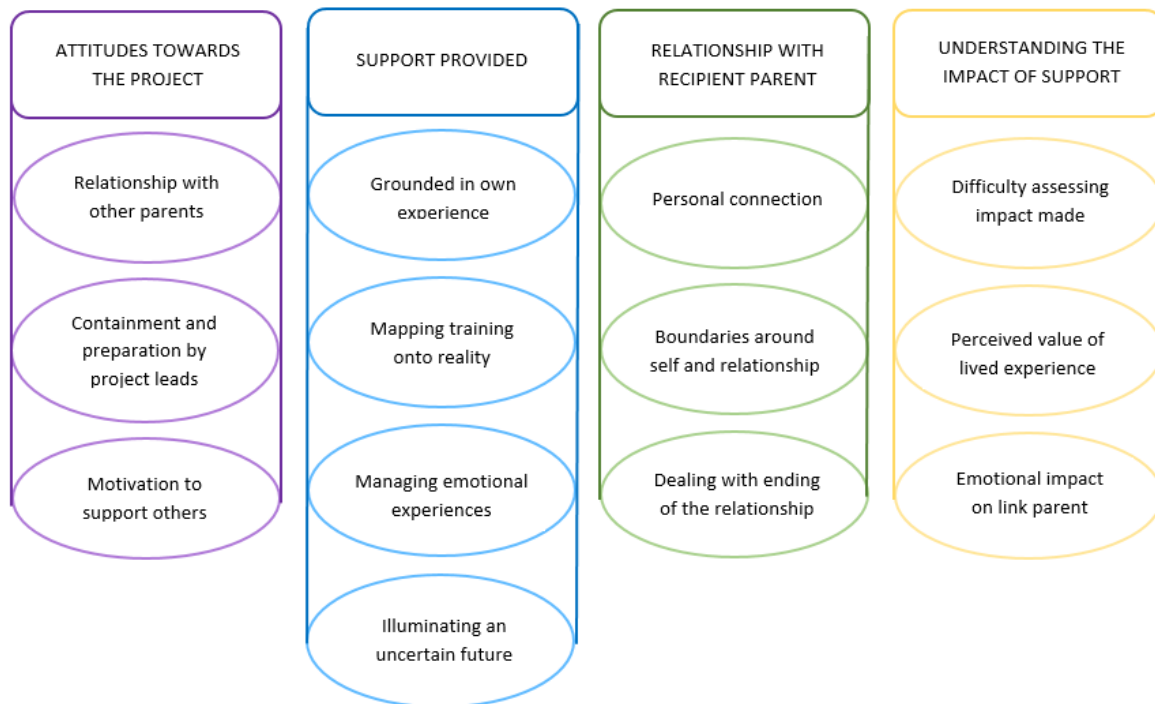


Figure 8. Link Parent super ordinate and subordinate themes

Each super-ordinate and subordinate theme will be described and related to quotes from the data. Words which are added to quotes in order to enhance the clarity of the text or to remove identifiers will be in brackets. Sections of omitted text in a quote will be represented using ellipsis (...).

As detailed in the chapter 2, the focus of this study is on the experience of parents of children with type 1 diabetes supporting parents of newly diagnosed children with type 1 diabetes. As with the Recipient Parents data, due to the small sample from a small south Wales community, details about the parent pairings, the number of years since diagnosis and clinic have not been reported in order to protect the confidentiality of

participants. The Link Parents' pseudonyms and their child's age at diagnosis are described in Table 5.

| Name | Age of child at diagnosis |
|-------------|----------------------------------|
| Catherine | 10 |
| Charlie | 4 |
| Georgina | 7 |
| Peter | 7 |
| Annie | 7 |
| Debbie | 14 |
| Sarah | 1 |

Table 5. Summary of Link Parents

3.7 Super-ordinate Theme 1: Attitude towards the Project

Link Parents, unlike the Recipient Parents interacted with a broader system within the project, involving a greater investment of time and effort than their Recipient Parent counterparts. As a result more discussion regarding their interactions and attitudes towards the project and the people within it emerged compared to the Recipient Parents. Three subordinate themes emerged from this super-ordinate theme: relationships with other Link Parents; containment and preparation by project leads; motivation to support others.

3.7.1 Attitude towards the Project Subordinate Theme 1: *Relationships with other Link Parents*

The first subtheme relates to the relationship between Link Parents through the training process and subsequent support sessions. For many of the participants the level of support between Link Parents was an unexpected benefit of their involvement with the project. As will be mentioned later (section 3.6.3) many of the participants were motivated to support others by the lack of the support they received following diagnosis. As a result the opportunity to forge relationships with parents who had similar experiences was a welcome surprise. Participants described varying degrees of common bond with the other Link Parents during training because of their shared experiences. For some the connection focused on the shared negative emotional

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experiences of diabetes. Catherine discussed the interaction with the other Link Parents regarding their grief over the loss of a normal child which perhaps would not have been expressed in other relationships, illustrating the emotional vulnerability Link Parents still experience:

'...to meet different people with different ideas and things it's been nice being with (other Link Parents) as well and seeing her side of, and how she coped with her son and everything from that point of view. I think it would be nice just to keep giving something back for somebody who felt like how we all feel, you know when your kids are diagnosed, I just, just grieved I just wanted a normal baby.'

Value was also placed on hearing stories from other people and being supported in exploring their own diabetes stories. It highlighted to some that there was no right or wrong way to manage diabetes and that even after years of living with diabetes there is still room for learning and growth. Debbie spoke of the relief that came from being in a room with people who knew exactly how she felt and the degree of empathy led to an openness not present in other relationships:

'So I think it's (diabetes) quite a big thing for everyone so when people (parents of diabetic children) get together then and start talking about it they do all, everyone's sort of relaxes and it is that sort of 'oh you know where I'm coming from' but you could see people like 'yeah yeah, I know I know' so that was great, and everyone was really friendly and you know we were like you say in the same position.'

The level of connection felt between the Link Parents led some to feel a sense of loss at the end of the project which may reflect the lack of support they still experience in their life. Annie described her regret over not finding a way to contact others after the end of the project as she valued their input and was upset when it was withdrawn:

'I didn't take any of their (other Link Parents) telephone numbers so no I wouldn't stay in contact but I was a bit disappointed when I realised it was

coming to an end to be honest... it meant that you know you would lose that bit of contact and support with the other parents.'

The value placed on the support from other Link Parents was also reflected by the disappointment in the differing degrees of investment in the project. Towards the end of the project fewer Link Parents attended the support meetings. Peter attended the final meeting with one other parent and regretted the lack of attendance from others as he valued their input:

'(In the) last meeting (on) Tuesday it was only... 4 parents... whether some would adhere to it I'm not sure, or maybe some thought it wasn't, wasn't worth the effort and... I don't know I thought it was worth the (effort), I would have liked to have a bit more input into it.'

3.7.2 Attitude towards the Project Subordinate Theme 2: Containment and preparation by project leads

The second theme refers to Link Parents' experiences with the leaders of the project whose role was to train and support them to support others. Their perception of this relationship was at times enmeshed with their perception of the training or supportive system. However, themes emerged relating the physical or mental presence of the leaders.

Patterns emerged about the subtle presence of the two facilitators during the training process. Participants described being set tasks and then being allowed to take control over the experience of training although the facilitators presence was always there. Charlie spoke of the creation of a containing but not constraining structure of support:

'They (project leads) weren't heavy handed at all they just gave out the directions, they explained why... like 'don't become like don't be in the room with the child on his own even if the mother's making a cup of tea'... they made that quite clear and they were good at that and yet they let everything else just let people have their says and then they would chip in obviously every now and then with some comments I think but no they were really good in fairness.'

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Through the training process their presence was perceived as non-threatening and non-judgemental as the experience of the Link Parents was perceived by the facilitators as equated to expertise. Annie described the egalitarian approach the leaders took to both the training and allocation of Recipient Parents:

'They (project leads) were explaining things but we had a lot of group discussions as well, so everybody... took part in discussing really what we'll do and what we were trying to achieve etc, so I think it was useful from that point of view... and... one of the things that anybody who'd been paired was encouraged to say if you thought the pairing was suitable so that if they had got it slightly wrong they could learn from that, and I think they did slightly change their policy during the session.'

In terms of the broader running of the project the Link Parents also valued the safety net of support the leaders provided when they were supporting the Recipient Parents. All but one of the participants had never engaged in supporting another parent of a child with T1DM, therefore a high value was placed on back up support if needed. Sarah never needed additional support from the project leads but the knowledge of its presence seemed to allow for more confident engagement in the support process:

'I knew it (support) was there, if I needed it 'cause you know, 'cause some, some could have been totally different experience, not as positive as I found it and it would have been nice to know I had Sue and Lesley there as back up, to you know, go back and make me feel comfortable.'

Catherine also reflected on the need for the supporters to be supported, especially when dealing with emotionally charged situations. Therefore, an atmosphere of open and flexible support was perceived creating a safe environment to be supporting others:

'I think just the emotional support that we were going to be given as well as what we expected to give to others were good... the sort of pastoral care for all of us then... was almost all the time then in the training I felt... and knowing

that either Lesley or Sue was at the end of the phone if we did need anything... that was good.'

3.7.3 Attitude towards the Project Subordinate Theme 3: Motivation to support others

The final subordinate theme relates to the physical and emotional experiences which motivated the Link Parents to engage in the project. Many described their apprehension at taking on the task but all had a personal story which had moved them to support others. These motivating factors emerged not only from reflections on their decision to take part but discussions regarding how their experiences shaped interactions with the project and the support they provided to Recipient Parents.

The dominant theme amongst the parents was feeling unsupported when their child was diagnosed. The feeling of a shared purpose and drive was noted by Peter in the first meeting: *'(We were) all (from) different walks of life do you know we were all there for the same reason'*. Catherine reflected this notion quite simply in a desire for someone to talk to who was in the same situation:

'...I would have liked somebody to have been there when my daughter was diagnosed. (I) think there wasn't enough emotional support at all... (be)cause you're kind of sent off with your packs, read this, read that and do everything... but you, you're just in shock and it's not something that you can have a couple of days or a couple of weeks to get used to it's there and then. So I just felt that if I could give something to somebody else whose...struggling in the first sort of month or whatever then that would be a good thing.'

Participants were also motivated by a desire to protect others from the emotional responses they went through. Charlie accepted that helping others did not change the distress his family went through, but could gain some solace in paying support forward. Sarah similarly related it back to the isolation she felt in her struggle and a desire to lessen that feeling in others:

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'It (the support) might benefit... newly diagnosed parents that (are) going through the same things and sometimes it's just nice to know that you're not on your own, that there are other people out there...(be)cause I don't really know any other parent with children with diabetes and sometimes you do think is it just me?'

Beyond the idea of contributing from a position of empathy, participants also discussed the skills and experiences they possessed which they felt prepared them for the task of supporting others. Participants also related the value they added compared to professionals in terms of their lived experience. Sarah spoke of the expertise gained from experience and the perspective gained through years of living with diabetes which would be a useful resource for others:

'I think it's one of those kind of things you know, you learn through experience and you know the nurses don't live with you 24/7. They don't have to go through what we go through every day, no offense to them you know, but they don't so I think, you know you can't empathise with somebody if you're not going through it yourself. But they can obviously offer on the medical side the support of things but not the emotional side I don't think.'

The caveat to using experience based expertise is the emotional toll it can take on the supporter which was also discussed by participants. Just as the leaders were required to operate a degree of containment, so too did the Link Parents. Annie spoke of importance of resolving her own experiences through the training in order to be prepared to take on other people's experiences:

'...We talked about it (own experience of child's diagnosis) quite a lot really because this is something that we would expect to maybe have to talk about with parents we were mentoring, because they would be you know parents of newly diagnosed children, so we did talk about our own experiences.'

3.8. Super-ordinate Theme 2: Support Provided

The second super ordinate theme relates to the pattern of support provided by participants to their Recipient Parents. They were all broadly trained in the support to provide but as seen in the Recipient Parent results, the support showed significant variety in its execution. Within the breadth of support provided four subordinate themes emerged: grounded in own experience; mapping training onto reality; managing emotional experiences; illuminating an uncertain future.

3.8.1. Support Provided Subordinate Theme 1: *Grounded in own experience*

Participants' implicit or explicit use of their own experience was at the core of the support they provided. It was seen by many as the key factor they could contribute to the supportive relationship. Participants used their experience in varying ways from providing reassurance and normalising experiences to providing practical advice. Some participants were concerned about the vulnerability of exposing your own experiences, particularly distressing ones. Catherine described her worry about the appropriateness of bringing in her own experience but found it a challenge not to. She described her motivation for engaging in the project as being related to feeling that the parents were walking down the same path, therefore emphasising their shared experience. Catherine found it difficult to know how much of herself to give especially when her Recipient Parent sought advice around taking antidepressants, which was something Catherine had experience of:

'I wasn't sure how much of myself I should have shared... so I just sort of said look I've been on them (antidepressants) and been fine and it was 18 months and I was fine to come off them after 18 months and it worked and at the time that's what I needed to function so... from that point of view I wasn't quite sure whether or not how much, whether I should have said I've been on them but then I just thought well, then maybe she (Recipient Parent) would feel a little more empathy as far as yeah I know what you're going through.'

Other participants used their experience of difficult situations to provide practical support and reassurance to enable the participants to move forward. Sarah described

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her Recipient Parent raising an issue she herself had grappled with and used her empathy and experience to guide her. Their shared experience and the emotions attached to them are reflected in her account of the conversation:

'...she (Recipient Parent) wanted to go to the beach for the day and she had never taken (child with T1DM) to the beach so she wanted to know... how to go about it and I think, I got the impression that she was on the verge of not going because she just thought it would be too hard. I found that, quite, quite sad (be)cause I'd been there and sometimes (it is) easier not to... but hopefully, I helped her with that...'

Participants showed some variability in the presentation of their experiences in terms of how they may apply to the Recipient Parent's situation. Peter presented some of the more difficult times in his relationship with his daughter as an inevitable life stage his Recipient Parent would enter with his child as well. Charlie used his experiences in an explicitly directive way in terms of advising his Recipient Parent about how to do certain activities. Within their relationship this directive advice seemed to reflect the confidence Charlie felt in managing his own child's diabetes and also the similarities he saw between him and his Recipient Parent:

'...we led onto what's he do(es) sports wise and how you cope because again I did use my son as an example because he (Recipient Parent) said 'oh he (Recipient Parent's son) plays football every week' so this is what will happen with football... I go onto how my son... I give him reassurance that like he does karate... stuff like that. That everybody's understanding don't panic about it 'cause I used to say 'oh what's he going to say now' ... but it was good and then we talked about experiences like he said 'I only got one tester' and I said 'go to your doctor, ask for three. Get them.' You know what I mean?'

Other parents were more reflexive in their use of their own experience and anxious to frame it as not being an inevitable truth but a reflection of what has happened to them. Georgina was keen to stress that any experiences they spoke of should not be seen as unavoidable for the Recipient Parent:

'...You (are) used to dealing with your child you know your child and things (that) work for them but you're not qualified to give any advice to anybody else. Sort of emotional support and ... 'I remember that situation what works for us', but that's all you're giving them, it's an alternative of what worked for you.'

3.8.2 Support Provided Subordinate Theme 2: Mapping training onto reality

The second theme represents the attempts and difficulties participants had in translating the training they received into the support they provided. Some participants found the boundaries around their role to be containing and a helpful guidance to their work. Georgina found the concrete boundaries a useful tool, especially in terms of dually protecting herself and the Recipient Parent:

'...(We were instructed) Not to give them (Recipient Parent) medical advice or anything medical refer back to diabetic specialist nurse. And we were told not to help them fill in the DLA form. So I suppose it's just safeguarding you know. You('re) used to dealing with your child you know your child and things work for them but you're not qualified to give any advice to anybody else.'

Peter felt that the training served to frame the process of support but felt the content was the responsibility of the Link Parent. He too felt that training applied to the safeguarding elements for the Recipient Parent and Link Parent. He described it using words such as 'rigorous' 'rule' and 'regulations' but seemed less bound by these words outside the process of setting up and maintaining support:

'I did take on a few points I think there are certain questions that you shouldn't ask and vice versa or whatever... they do it for the best, the points are there, it's for your own protection in both cases you know. Obviously we stuck to some of the rules, we met (in a) place that was convenient for both of us, we didn't go to anybody's house you know? We didn't give any details out or whatever but the training is a matter of fact, it's there for health and safety I expect but it doesn't how can I say, it didn't filter out in the meeting...'

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Many participants struggled to apply the content of the training especially restricting themselves to certain topics or ways of interacting. Sarah reflected that there was training in terms of interacting with Recipient Parents but felt resigned to the futility of being able to use it in the way the project leaders intended. She appeared to place greater stock in being true to herself rather than true to the training:

'I don't know really, 'cause when we (were) obviously given the training we were given scenarios and what you can do. It's just not the way it is and at the end of the day I'm just going to be myself, if she asks me a questions I'm going to answer her and that's all we did really.'

An acceptance of self was also reflected by Debbie who appeared accepting of not being able to change her way of interacting with others to reflect the training. In addition the difficulty of attempts to adhere to training whilst the Recipient Parent is looking for something different and how challenging it can be to not be responsive to the Recipient Parent in the moment:

'I don't think I'm that type of person, no unfortunately not... I'd have to sort of train myself to be that way. I (am) just sort of naturally, naturally a talker. So maybe from that point of view of just sitting and listening and not (responding). But again a lot of it was her (Recipient Parent) asking me the questions as well you know, asking me things like either my opinion on things or just generally asking like how he's (Link Parent's son) getting on and things like that so, I think I'd have to train myself.'

Finally, participants spoke of the desire to remain Recipient Parent orientated and that adhering to the training meant it was more difficult to be responsive to Recipient Parent's changing needs. Participants found that as the relationships developed conversations naturally deviated away from diabetes or became friendlier. Although many admitted this degree of flexibility was not the project's intention it was felt to be important from a human point of view. Debbie found that the 'mission creep' within her relationship was natural and perhaps reflects the desire for the Link Parent to connect with someone who understands their experience as well:

'...by the end it was more of just like friends chatting, so a lot of it was related to the diabetes, and then a lot of other times, (be)cause we once sat there for a few hours, obviously there's only so much you can say, it's only a few hours isn't it? So you know we would always be talking about you know, things that had gone on or hospital appointments that are coming up and things like that but then there was a lot of chat about like our other children and just life in general.'

3.8.3. Support Provided Subordinate Theme 3: *Managing emotional experiences*

The need for support following a child's diagnosis could be viewed as indicative of the emotional impact. The degree of emotional management that was undertaken in the supportive meetings between the Link-Recipient Parents varied, but it was at least a fleeting feature of all the pairings. Charlie for example made passing reference to the discussion of his Recipient Parent's emotional adjustment. This transient reference may be a product of his or the Recipient Parent's discomfort in or lack of priority placed with discussing emotional content. Certainly compared to the female Link Parents their discussions were much less emotionally centred. When asked about the discussions Charlie used quite dismissive language which may reflect his reluctance to discuss it with and/or a lack of importance between him and the Recipient Parent:

'... it was related to his (Recipient Parent) son first of all, we tried to be a bit reassuring you know. We talked about his you know how he's coping and that sort of stuff and then we led onto what's he do(es) sports wise...'

Debbie spoke of the importance she placed on providing emotional support from a position of shared experience. She felt it was central to their role and true empathy attached to the emotional support created added value which a Recipient Parent would not have found elsewhere:

'I think it's like just a different kind of support, it's more like an emotional support and I, again like you know, some of those nurses are fantastic, but,

unless it's something you been through yourself... I think having another parent is more emotional support, you know from medical staff you('ve) got to get the medical support and I suppose you would still get the emotional support if you needed it but it's that coming from the same you know, coming from the same place, I think that's the difference...'

Tying the emotional reactions together with the shared experience meant the Link Parents were able to normalise the responses of Recipient Parents. Catherine spoke of the connection she felt with her Recipient Parent because of the shared experiences she had outside of diabetes. As a result she felt more deeply tied to her emotional experience and provided a more flexible and responsive support:

'...I saw a lot of things in (Recipient Parent) and myself. From that point of view that I suppose I felt the loss for her. When she (Recipient Parent) went home for the weekend I always made sure I messaged her on Facebook to say: 'hi, how did things go? Did you have a good weekend?' And then by the end of the week she would always send one to say 'oh I really miss everybody (Recipient Parent's family)'... which we all feel is... a sort of a home sickness thing so I think I felt that from her point of view.'

3.8.4. Support Provided Subordinate Theme 4: *Illuminating an uncertain future*

The final theme relates to support naturally occurring when the supporter is at a later life stage than the person being supported. All the Link Parents had children which were older than the Recipient Parent as well as having more experience of diabetes. It followed therefore that the conversations would serve to illuminate a future which felt uncertain for Recipient Parent prior to the support.

The view of the future was linked to how the Link Parent copes with the diabetes as well as broader challenges as children grow older. For some Link Parents this was an actively positive reflection as they tried to foster optimism in their Recipient Parent. Charlie presented an optimistic picture of coping with diabetes, so positive that he felt not including his son in the conversation was a loss. He was able to present a picture of a possible future which is unlimited by diabetes:

'I thought that they (children with T1DM) should have been involved a bit more. Because I was in honesty I was prepared to say if my son wanted to go to it that I would take him. Because he was diagnosed at four... and he's done really well. He's excellent at (sport)... and I just would have used him as an example for a parent of look you can still do this even with diabetes from four.'

Conversely, other participants presented a forewarning of future difficulties. This may have reflected a desire by Link Parents to prepare the Recipient Parent, especially if they had felt unprepared themselves. Peter described warning his Recipient Parent that there was the potential for damage to relationships with the view of reducing potential distress in the Recipient Parent should they find the same situation:

'I left it (the mentoring meeting) and did say to him (Recipient Parent) that 'I had issues, you might have issues, you might not! You might turn out fine and but you know, one day she (daughter with T1DM) might rebel or reject you for a couple of weeks you just (going to) put up with it and overcome that situation.'

3.9. Super-ordinate Theme 3: Relationship with Recipient Parent

The third super-ordinate theme reflects the interpersonal relationship central to the project between the Link and Recipient Parent. It is grounded on shared experience of diabetes but as with all relationships was a complicated and evolving construct. Reflecting its complicated nature there are three subordinate themes under the banner the Recipient Parent relationship: personal connection; boundaries around self and relationship; dealing with challenges in the relationship.

3.9.1. Relationship with Recipient Parent Subordinate Theme 1: *Personal connection*

Contrary to the perceived boundaried parameters set out by the project leads many of the Link Parents found a personal connection was made between them and the Link Parent. This was accounted for by the bond of common experience, a similar

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phenomenon between Link Parents themselves and reflected in the difficulty applying training to reality. For Peter the connection was confined to an informal social interaction centred around diabetes with the relationship extending no further:

'...it was quite easy quite relaxing, quite comfortable, I suppose a lot of common sense in finding questions, you fire one I answer them it was a general conversation... I think it was a healthy conversation, didn't feel the pressure...'

Debbie and Sarah's relationships developed beyond the confines of diabetes as they began to form a relationship akin to a friendship. For Debbie there appeared to be a shared open attitude between her and Recipient Parent, which was reflected in an earlier quote from Debbie in terms of her struggling to deviate from her useful way of interacting. The personal connection between them appeared to be perceived as central to the support as the warmth she feels towards her Recipient Parent is evident in her use of language:

'(in) the first meeting, you know, she's a lovely lady, really lovely who I think, we're both quite open people, and instantly got on, and you know talk quite a lot about it, but talked a lot about other things and the children and sort of just life really, you know spend 3 hours just, it felt like we been friends for a long time, so I think that was really nice, and she is a lovely lady. So I was mindful to try not to you know jump in when she was talking and things like that, um I think she was open.'

Sarah spoke of the emotional connection they had as they shared information which they would not share with others. A deeper connection was therefore formed potentially as a result of the meaning they both place in their experience:

'I was really positive actually, really kind of, it even felt in a way kind of emotional, you kind of talking about things you don't really talk about with anybody and even though they were total strangers, it was weird because you talk about the way you felt when you were diagnosed and how you deal with

certain situation that came up and it was kind of, it was quite emotional because I don't talk to anybody about that.'

The difficulty in balancing the professional mentoring versus the social elements was a concern of Annie's especially if the desire for the relationship to move in a certain direction is one sided:

'... The only downside is that I mean obviously you're not there to meet a new friend are you? You're sort of there to offer support and I mean it is possible to meet a new friend and there's no harm in that... of course the downside is that maybe that if one parent, and it could be either the mentor or mentee becomes a bit too pushy with the relationship, there has to be the exit from the relationship as well.'

3.9.2. Relationship with Recipient Parent Subordinate Theme 2: Boundaries around self and relationship

The social element of the support led to patterns in the data about how to establish and maintain boundaries first between the relationship and the outside world and secondly between the Recipient and Link Parent at the heart of the relationship. Matters such as confidentiality and privacy arose in connection with boundaries around the relationship. Catherine struggled with establishing boundaries around her mentoring relationship as she mentored two Recipient Parents who knew each other and was concerned about where information would be taken. Similarly, Debbie was concerned with her children attending the same school as her Recipient Parent. It raised issues about balance of privacy within the relationship but the convenience of mentoring someone close by, especially when it is a volunteer role:

'The only real difficult(y) like I say was the fact that, we know common people... as well so we talked a little bit you know a bit about that, I would say like I say a conflict of interest there, just in the fact that we do know, there is the crossover of people you know and things. Obviously I was mindful not to say anything about it, and I didn't really chat much about her or anything, so I just think you know, I wouldn't want, I wouldn't have wanted her to go back and

say... I don't think that's the best, but I think that's something that only came up after we'd been matched, that could possibly be an issue.'

A further element related boundaries was managing the control over the relationship. The Link Parents were encouraged to empower the Recipient Parent to direct the support. However, as seen in themes from the Recipient Parents, the sense of indebtedness to Link Parents meant an impasse in support was sometimes reached where neither party contacted the other for fear of stepping over a boundary and engaging in unwanted contact. For example, Annie had concerns about whether to contact her Recipient Parent following a period of no contact. She, like all other participants in this situation, sought advice from the project leads thereby placing responsibility for the consequences with the leaders, perhaps believing they would have a greater insight:

'... I didn't hear anything and then we had a meeting as it turned out, I said to Sue, it's been a few weeks now do you think it's okay to contact her again and she said yes. So I did then send her a text basically to say, just to remind her that if you want to contact me or anything because I gave her my number again but she didn't contact me so I didn't then push it because I thought well she knows I'm here and if she wants to contact me she can.'

3.9.3. Relationship with Recipient Parent Subordinate Theme 3: *Dealing with ending of the relationship*

The final theme relating to the relationship between the Link and Recipient Parents' concerns the challenges in the how the relationship ended and the factors affecting that ending. For the participants in this research it was an artificial break in the relationship as the support was structured to end after six months. The break was difficult for some to come to terms with especially when a deeper relationship had formed. Sarah struggled to reconcile the overarching structure of the project and her desire to continue the relationship as her identity as a mentor continues:

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'...it was kind of like, it came to an end and I don't know what to do here now, do I just text her and say I'm still... just because this has ended you can still contact me if need be, I'm still here, I haven't gone away and I've still got the 10 years of living with it.'

For other participants there was an ending in the relationship sooner than the one imposed by the project. There was a variety of levels of support from short phone calls, to one off meetings to multiple contacts through multiple means. Several participants encountered premature endings to their support as a result of the Recipient Parent requesting no further support, for which they found different reasons. Peter attributed the lack of further uptake to the adjustment and stability of the child with T1DM:

'...they (Recipient Parent and family) were quite comfortable in life and their daughter was level headed I think and you know there wasn't many big issues... the bigger issues that would occur, as they call it the honeymoon period it comes to an end you know that's when it starts so perhaps that's when you need a bit more support or a bit more advice.'

Charlie and Georgina both sought similarly external reasons for the lack of uptake, citing busy lives of Link and Recipient Parents preventing prioritizing such support. Georgina seemed to reassure herself that should more support have been needed the Recipient Parent was in control:

'there was no request for another meeting... you know, everybody's got busy lives, obviously if they felt like they needed to have another chat that would have been fine as well.'

Finally, Annie was the only participant who was paired with a Recipient Parent who did not take up the support she offered, creating a much more abrupt ending than anticipated. Annie had made sense of the lack of uptake through concrete reasoning such as timing but through conversations with others she began to attribute blame to herself. Annie's attributions illustrate the psychological vulnerability of Link Parents when their help is perceived as not wanted:

'... there was one gentleman (Link Parent) there (at Link Parent support meeting) who had, he'd met somebody (Recipient Parent) and he thought... because I said she (Annie's Recipient Parent) didn't want to meet me, and he said... 'I didn't give them a choice' ... and I did think that 'oh maybe I should have been a bit more forceful.' But then I think well I did give the opportunity you know so, but he'd met somebody and he sort of spent quite a long time chatting to them... I thought then... perhaps it was me, perhaps it was the way that I... (it) must have come across in the meeting because they did say to me 'oh it's not your mind, don't worry about it', but as I said I was feeling a bit like that to be honest.'

3.10 Super-ordinate Theme 4: Understanding the Impact of Support

The third theme covers the participants' attempts to make sense of impact the support they offered may have had on their Recipient Parents and themselves. Assessing the impact was something the participants found difficult to quantify nevertheless the emergent subordinate themes under the umbrella of impact of support are: difficulty assessing impact made; perceived value of live experience; emotional impact on Link Parent.

3.10.1. Understanding the Impact of Support Subordinate Theme 1:

Difficulty assessing impact made

Participants found it a challenge to pin point the impact they had on the Recipient Parent. Most had not sought feedback and therefore relied on incidental anecdotal comments from the Recipient Parents which may reflect a lack of confidence in the impact they made. Georgina's account seemed to reflect an underlying uncertainty about the impact made to the Recipient Parent as she seems to doubt the positive feedback. :

'...from what they said they you know they gained from it, at least they were saying that to us I don't know...'

Sarah also seemed to place doubt in the positive feedback she had from her Link Parent, perhaps doubting they would provide negative feedback in person resulting in a lingering uncertainty:

'I don't know, I'd like to think it had a positive impact on her (Recipient Parent) but I don't know I didn't have any kind of feedback. I mean she was really positive when I spoke to her on the phone and she was very grateful for anything that I could discuss with her but apart from that I can't comment really, all the feelings I got from her was positive but I don't know.'

In the face of some uncertainty about impact, other participants remained hopeful of making a positive impact and felt satisfied with their contribution of support. Debbie had a particularly close relationship with her Recipient Parent which appeared to influence her optimistic viewpoint:

'I felt really good when I came away and I hoped she would come away feeling the same. I think it was nice that I was matched with someone and we did just get on really well you know, it was just, it was like we'd been friends for a long time.'

3.10.2. Understanding the Impact of Support Subordinate Theme 2: *Perceived value of lived experience*

The second theme relates to the specific impact of the lived experience of Link Parents in the supportive relationship. As identified previously this was a key element participants felt they had to contribute therefore its impact was an important factor for them.

Charlie recounted an example of lived experience being used to enable the Recipient Parent to move back to towards normality. He described a strategy he uses when on holiday of sharing insulin between bags to lessen anxiety of losing bags when flying. The practical advice enabled the Recipient Parent to feel confident and able to go on holiday. Sarah described a similar scenario where her experience enabled the family to return to normal childhood activities:

'she (Recipient Parent) wanted to go to the beach for the day and she had never taken (child with T1DM) to the beach so she wanted to know, how, how to go about it... and I think, I got the impression that you was on the verge of not going because she just thought it would be too hard... I helped her with that.'

Georgina discussed her sense of their experiences providing hope for the Recipient Parent that they could find their way through the struggle to adjust because the Link Parent was a living example that it could be done:

'... from the human aspect of it and being a parent in the same situation um I think you can help them because they can see you've been through it and obviously come out the other end. (You) just have to, life doesn't stop it has to go on and you do work your way through it.'

Finally, lived experience was also identified as a key factor in the formation of shared identity between the link and Recipient Parent. Sarah noted an example where the sense of shared identity had reduced the feeling of isolation through struggling to adjust:

'She'd (Recipient Parent) been up all night checking (Recipient Parent's child) at 3 o'clock in the morning and she said 'I just stopped and thought you know, I'm not the only person doing (this) thing' and she thought of me being up of, not the same time but kind of same situations, early hours of the morning checking Jack as well, she said it gave her some comfort knowing she wasn't the only one going through that.'

3.10.3. Understanding the Impact of Support Subordinate Theme 3:

Emotional impact on Link Parent

The emotional impact of supporting someone who is in a challenging life stage is inevitable, particularly when the supporter has been through the same experience. The challenge of emotions and thoughts resurfacing from their memories of diagnosis was

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something certain Link Parents found difficult. Sarah reflected on the emotional impact it had on her as she relived the experience of her child being diagnosed with her Recipient Parent:

'It just brings all the memories back and the feelings back of how we felt at the time, it was awful it is, it was an awful time you know, I still, still remember it 'til this day and some of things I thought at the time.'

A more positive element of impact for the parents was the opportunity to learn from the experiences of other Link Parents whose children were older or had different experiences. Mirroring the impact of support of the Recipient Parents, Link Parents also found that discussion helped to shine a light on an otherwise uncertain future. Annie's daughter was on the cusp of a new life stage as she moved into adolescence, therefore being able to access support from others was a beneficial by-product for her family:

'...it was really nice to speak to other parents to be honest and it helped me because my daughter's... in her teenage (years) so parents there had older children than me so it was quite useful to hear you know other experiences that parents have been through.'

A final important idea emerged regarding the enduring identity as a parent of a child with T1DM who may continue to struggle with managing a chronic illness. The participants all continued their lives alongside providing support for the Recipient Parent. The dual role of parent and supporter of parents was sometimes difficult for participants to reconcile. Catherine spoke of the difficulty in attending clinic appointments where she was in the role of a concerned parent and her Recipient Parent being present as well. The two roles felt in conflict as she struggled to determine who to prioritise:

'...having a clinic appointment where (Recipient Parent)... with her son and I had gone with my daughter and my husband who are not part of the project. I wasn't sure how I felt about that I sat there and felt...I mean I introduced them because you just thought what else can I do?... (you) don't want to go to clinic when you're thinking about somebody else's child.'

Chapter 4

Discussion

4. Chapter Overview

Chapter 4 will provide a discussion of the results in the context of existing literature. The clinical and service implications of the results will then be discussed. Finally, the strengths and limitations of the study will be described followed by an overview of directions for future research.

4.1 Research Findings in Relation to Existing Literature

The aim of this study was to explore the experiences of parents supporting and being supported by other parents of children with T1DM. This is the first qualitative study in a UK healthcare context to explore the experiences of peer mentoring for parents of children with T1DM from the perspectives of both supporting (Link Parents) and being supported (Recipient Parents). It therefore enables greater insight to be gained into the process and content of support by examining experiences from both sides of the dyad. The results described in Chapter 3 were comprised of four super-ordinate themes and 13 subordinate themes for the Recipient Parents and four super-ordinate themes and 13 subordinate themes for the Link Parents. The themes emerging from the data and their contribution to existing literature will be discussed below.

4.1.1 Recipient Parents Super-ordinate Theme 1: *Build up to and Initial Impact of Diagnosis*

The 'Build up to and Initial Impact of Diagnosis' subthemes represented the impact on Recipient Parents' identity as a parent, implications for the family and emotional ramifications of diagnosis. The super-ordinate theme was comprised of four subordinate themes: questioning ability to protect your child; irreversible systemic change; coping with emotional impact of diagnosis; isolation following diagnosis.

4.1.1.1 *Questioning ability to protect your child*

The first subtheme reflects the implications for parents in terms of their ability to parent their child in the context of T1DM. For the Recipient Parents in this study the

questioning of parenting ability stemmed initially from the events prior to the diagnosis where there was a decline in physical health. The uncertainty around the child's health and worries about finding a possible cause, relate the previous findings by Whittmore *et al.* (2012) in terms of the negative emotional experiences pre-diagnosis. The findings revealed a gender difference in the perception of 'fighting' for a diagnosis. A perception of needing to fight for a diagnosis was expressed more often by mothers than fathers. This finding could provide insight into previous reports of mothers experiencing greater psychological distress following their child's diagnosis compared to fathers (Haugstvelt *et al.*, 2011; Mitchell *et al.*, 2009). It may also reflect the differing parenting roles between mothers and fathers, where mothers continue to hold the majority of responsibility and therefore experience greater emotional distress when that role is compromised.

Questioning the ability to protect their child continued following the diagnosis of T1DM. This element of the theme maps closely onto the work of Sullivan-Bolyai *et al.* (2003b) in terms of the constant vigilance experienced by parents post diagnosis as they relearn and adjust their parenting skills. Similarly, Hatton *et al.* (1995) and Wennick and Hallstrom (2006) described experiences of parents feeling pressure from medical professionals to rise to the challenge but also feeling helpless in the face of a steep learning curve. The pressure may also reflect Recipient Parents' children's life stage as they were all pre-adolescent at diagnosis and are therefore more dependent on their parents for protection. The results within this theme may also reflect the experiences which are unique or more pronounced in those who seek support compared to those who find the transition less challenging.

One element of the theme which has not been reflected in previous T1DM literature was the desire by Recipient Parents to absorb the emotional experiences of their children. It reveals the concern parents have in terms of protecting their children from the emotional consequences of T1DM as well as the physical implications.

4.1.1.2 Irreversible systemic change

The change felt by Recipient Parents reflects the existing evidence base specific to the impact of a diagnosis of T1DM as well systemic models such as Rolland (1994) and

Carter and McGoldrick (2005) which detail the extensive impact chronic conditions can have for a family. The results indicated a different nuance to the impact of the diagnosis on the system in terms of the timings of adjustment. The Recipient Parents reflected on both the sudden and immediate change that occurs following diagnosis but also the time it took for the irreversibility of it to be processed. The realisation of the irreversible nature of T1DM supports literature around chronic sorrow which proposes that the emotional impact comes in waves rather than a linear grief response (Lowe & Lynne, 2000).

Recipient Parents also reflected on the impact the diagnosis had on the family as a whole. Recipient Parents spoke of the family functioning adjusting around the need to accommodate for the existence of T1DM in the family. There were reports of negative impact on relationships by some and positive growth in family dynamics by others. Such reports are consistent with Wray and Maynard (2005)'s findings in terms of the variation in impact of T1DM on family relationships and functioning.

4.1.1.3 Coping with the emotional impact post diagnosis

In keeping with previous research, participants described the negative emotional experiences following their diagnosis (Whittemore *et al.*, 2012). However, the results also revealed new information about the feared consequences of struggling to cope with negative emotions. As mentioned previously (section 4.1.1.1), the task of caring for a child with T1DM is a significant undertaking which parents feel pressure to be competent at. One Recipient Parent also reflected on the need to also appear emotionally stable, particularly with medical professionals. Whilst this is an interpretation of one participant's account it could point to an additional layer of vulnerability amongst newly diagnosed parents if they feel worried that they will be judged for struggling emotionally. This may relate to perceptions of a wider societal stigma around psychological distress being present in the adjustment process of chronic conditions.

The results revealed gender differences in terms of the expressed emotions of parents. Recipient mothers all described their emotional experiences in detail compared to the fathers. This reflects previous findings in terms of differences in emotional distress

between genders (Haugstvelt *et al.*, 2011; Mitchell *et al.*, 2009). However, the cause of such differences remains unclear. Are fathers experiencing less negative emotional experiences or do they feel uncomfortable reflecting on it publically? The fathers' accounts do indicate their acknowledgement of an emotional impact however their mode of coping was through practical problem solving. The focus on practical elements of care was also reported in Sullivan-Bolyai *et al.* (2003a)'s research with fathers of children with newly diagnosed T1DM.

4.1.1.4 Isolation following diagnosis

The isolation felt by Recipient Parents following diagnosis encapsulated in this theme relates to the isolation felt following diagnosis when the safety net of intense medical care is removed but also psychological isolation from Recipient Parents' usual sources of support. The sense of responsibility following discharge from hospital of taking on the daily management of T1DM has been reflected in previous work (Whittmore *et al.*, 2012). However, the results of this study add an additional layer of insight in terms of Recipient Parents' relationship with medical teams. Fears about appearing incompetent or over anxious were perceived as barriers to Recipient Parents accessing the support they needed to feel comfortable in caring for their child.

Broader reflections on emotional isolation felt by Recipient Parents present new insight into the motivation of parents who may access peer support in particular. Recipient Parents in this study placed a high value on the lived experience of other parents of children with T1DM which therefore acted as barrier to access support from usual sources of support. In addition Recipient Parents reflected on the unfiltered nature of communications from other unknown parents of children with T1DM on the internet. Such findings could be followed up in future research by comparing the motivating factors in parents accessing different sources of support.

4.1.2 Recipient Parents Super-ordinate Theme 2: Content of Support

The 'Content of Support' subordinate themes represented the elements of the support that were provided to the Recipient Parents by the Link Parents. The super-ordinate theme was comprised of three subordinate themes: shared experience; practical versus emotional support; unwanted support.

4.1.2.1 Shared experience

The sense of added value of support someone with lived experience compared to support available from medical staff was reflected by participants in a similar way to Rearick *et al.* (2011). The depth of analysis and reporting allowed for greater insight into the idiosyncratic nature of the use of shared experiences, with each pair generating something unique in terms of contact and content in their communication. Recipient Parents' accounts indicated the particular value that was placed on experiences being used in a non-directive way. The results reflects the work of National Voices (2015) that the value of peer support lies in what the individual perceives to be important elements of their lived experience of coping with a physical health condition, and that the support provided should reflect that.

The use of shared experience extended to a sense of shared identity. For some Recipient Parents who found their experiences differing from those of the Link Parents, the sense of shared identity as parents of children with T1DM was enduring and central to the support. This is a phenomenon reported in other peer mentoring programs (Shilling *et al.*, 2012) but has not been reported in research with parents of children with T1DM before. It also supports Simoni *et al.* (2013)'s hypothesis regarding the direct impact peer interventions have by acting to lessen social isolation and enhance social integration through connection with elements of shared identity.

4.1.2.2 Practical versus emotional support

The second subtheme reflected the balance between practical versus emotional support received and valued by Recipient Parents. This reflects broader peer literature which describes the wide spectrum of roles peers can offer, especially when provided with the freedom within their role to acts responsively to their fellow peers (National Voices, 2015; Embuldeniya *et al.*, 2013). The qualitative papers in the systematic review also reported different levels of emphasis on emotional versus practical support with Rearick *et al.*, focusing on practical implications and Newell and Hahessy (2013) focusing on emotional support. Within this study, participants' reflections indicate the degree of influence the Recipient Parent can have in directing the content of the support depending on their own needs. This level of variation may provide insight into difficulties consistently quantifying changes made in previous research as the impact of

practical versus emotional support may be different (Sullivan-Bolyai *et al.*, 2004; 2010; 2011). For example, one participant reflected on the emotional impact of their Link Parent normalising their psychological distress whilst another viewed their Link Parent as a practical resource. Careful consideration was taken by the PLUS project leads in matching the Link and Recipient Parents and such variations point to the need for such consideration to continue if the intervention is replicated in the future.

4.1.2.3 Unwanted support

The final subtheme related to unwanted aspects of support. Shilling *et al.* (2012)'s review referred to the barriers to uptake in support that can occur where there is a mismatch between the parents' needs. However, they highlighted that this should be overcome by individualised one to one support and did not report unhelpful or unwanted support occurring in those who accessed peer support. This may reflect a sampling bias within the papers including in Shilling *et al.*'s review as those with the most positive experiences may be more likely to volunteer for participation in follow up research.

The results of this study indicate that a mismatch can still occur when an individualised approach is provided, illustrating the reliance on the Link Parent to be sensitive and responsive to the needs of the Recipient Parent. Link Parents who provided information about future difficulties or reflecting on negative experiences were, for some Recipient Parents, perceived as unwanted or unhelpful. The results also illustrate the potential for harm to be done which was not reported in Shilling *et al.*'s review. Although only one participant reported psychological distress as a result of the support, it highlights the vulnerability of those receiving the support. This supports the findings of Embuldeniya *et al.* (2013)'s review which highlighted the negative impact that can be felt when a peer reflects heavily on negative experiences.

4.1.3 Recipient Parents Super-ordinate Theme 3: Process of Support

The 'Process of Support' super-ordinate theme related to the broader experience of Recipient Parents in relation to the support provided, particularly the perception of the Link Parent and their relationship. This super-ordinate theme is comprised of three

subordinate themes: characteristics of Link Parents; navigating the relationship; expectations of support.

4.1.3.1 *Characteristics of Link Parent*

The perception of Link Parents from a Recipient Parent point of view was explored in depth for the first time in the study. As mentioned in the Chapter 3, despite there being no direct questions in the interview protocol about the Recipient Parents' perceptions of their Link Parents, all reflected on how they perceived their Link Parent. The results revealed a broad range of appraisals of the Link Parents' characteristics from practical competence to emotional stability. Such broad range of reflections feed into the pool of characteristics for future research in terms of what is valued by Recipient Parents in their Link Parents.

In terms of Recipient Parents' perceptions of Link Parents' attitude towards providing support, even those who had a less positive experience felt the Link Parents' intent was to be helpful. Such a positive evaluation of Link Parents' intentions may influence the overall experience as more positive, compared to those who have financial or other incentives.

4.1.3.2 *Navigating the relationship*

This subtheme encapsulates various elements ranging from practical arrangements to defining and negotiating the relationship. The challenges posed by practical difficulties such as whether the Link Parent or Recipient Parent takes the lead in the organisation of support have been reported previously. Shilling *et al.* (2012)'s review reported the challenges practical constraints can have in terms of posing barriers to support. However, the current study revealed more nuanced difficulties in negotiating the support, perhaps because of differing expectations of participants. Some Recipient Parents reported being unclear about who should be facilitating the support, and therefore assuming it was the role of the Link Parent.

The interpersonal aspect of the relationship was also included under this subordinate theme. The variations between Recipient Parents in how the relationship was perceived

and challenges in defining the relationship were reported. The fluidity of the relationship has not been explored in paediatric research. The shared identity or sense of solidarity between participants has been explored previously (Shilling *et al.* 2012). However, the current findings have detailed the consequences of such connection sometimes developing into something more akin to a friendship. Such themes have emerged from adult peer mentor qualitative data regarding the difficulties in coping with the blurring of boundaries in peer relationships (Embuldeniya *et al.*, 2013). The potential for blurred boundaries between peers has not emerged in paediatric qualitative accounts and is therefore important to consider in terms of future research, particularly as challenges in this domain were also reported by Link Parents (section 3.9.2).

4.1.3.3 Expectations of support

The final subordinate theme supports previous research regarding the challenges of navigating a peer relationship when neither the mentor nor mentee has experience of such support. Recipient Parents' expectations were understandably optimistic considering their voluntary participation in the study. This is in keeping with Shilling *et al.* (2012)'s findings that where support is felt to be imposed, engagement and expectations are lower. However, the results have revealed the potential for negative consequences when expectations are high, particularly when peer support is the only supportive option.

The results regarding expectations also related to the expectations of the process of support, particularly around levels of formality. The positive surprise that the support was more informal than the support offered by medical professionals is in keeping with Rearick *et al.* (2011) regarding the positive degree of flexibility.

4.1.4 Recipient Parents Super-ordinate Theme 4: Impact of Support

The 'Impact of support' super-ordinate theme is comprised of four subordinate themes which relate to different elements of impact and broader influences on the participants' uptake of support: finding the new normal; degrees of scepticism around guidance of Link Parents; influences on uptake of support; looking to the future.

4.1.4.1 Finding the new normal

The first subtheme is most consistent with previous literature as it relates to the normalisation and validation of feelings which is described by Rearick *et al.* (2011) and Shilling *et al.* (2012). Recipient Parents reported feeling reassured that it was possible to adapt to life with diabetes whilst having their emotional reaction validated. It also illustrates the impact on the normal adjustment process described in Whittmore *et al.* (2012)'s review but demonstrates the impact that can be had in containing that process.

The results provide insight into the variation that can occur in terms of what adjustment meant for the Recipient Parents. For some, being able to practically cope and therefore resume a 'normal life' was more helpful. For others, being able to feel emotionally validated and able to process their feelings was useful. It again highlights the very individual reactions and therefore the need for sensitive and responsive support from Link Parents which is in keeping with findings from adult peer literature regarding the idiosyncratic nature of such support (National Voices, 2013). The results support Simoni *et al.* (2011) and Dennis (2003)'s hypotheses that peer support serves to enhance self efficacy and social norms. Normalising experiences enhanced the Recipient Parents' perception of their ability to cope and feel part of a different set of social norms.

4.1.4.2 Degrees of scepticism around guidance of Link Parents

The second subtheme of degrees of scepticism around guidance of Link Parents provided new insight into how parents who receive peer support, process and use the support provided to them. Unlike Rearick *et al.* (2011) and Shilling *et al.*'s (2012) findings which paint Recipient Parents as more passive in receiving support, the current findings provide evidence of them actively processing the information to determine what will be useful for them. It also provides evidence of Recipient Parents' adjustment process developing in conjunction with support as they become more comfortable and therefore more willing to trust their own judgement over others. However, this was a period of great change for the parents so it is important to be mindful that the interviews were undertaken months after the end of the support therefore the processing of support content may have happened after the support was provided as the adjustment process continued, rather than as the support was provided. The degree

of processing information before integrating it into practice has been reflected in Embuldeniya *et al.* (2013)'s qualitative review. However, the timeline in relation to diagnosis has not been reflected before and brings together ideas from adjustment and peer mentor literature.

4.1.4.3 *Limiters to impact and uptake*

The final subtheme represents the limiters to the uptake and utilisation of support. The results support the barriers described by Shilling *et al.* (2012) in terms of the difficulties in confiding with a stranger being felt by some participants as they chose to use other sources of support instead. It also provides new insight into the changing support needs of Recipient Parents as they adjust at different rates and therefore have different needs for support. Such insight would be useful in preparing future Link Parents for the possibility of decline in need due to the normal adjustment process not their skills in supporting.

4.1.5 Link Parents Super-ordinate Theme 1: Attitudes towards the Project

The first super-ordinate theme for the Link Parents relates to their attitudes towards various elements of the project, including the wider project system. The super-ordinate theme is comprised of three subordinate themes: relationships with other Link Parents; containment and preparation by project leads; motivation to support others.

4.1.5.1 *Relationships with other Link Parents*

Link Parents described the unexpected support they received from other Link Parents through training and subsequent meetings. The empathy between Link Parents and opportunity to explore their experiences was a welcome bonus to many parents. This theme replicates findings of Sullivan-Bolyai and Lee (2011)'s regarding the relationship between mentors. Sullivan-Bolyai and Lee reported the 'informal bonds' between mentors particularly around continuing to learn new ways of coping with T1DM. In the present study the practical elements were reported however there was also a feeling of emotional support between Link Parents. The results indicated an enduring vulnerability amongst Link Parents, as their identity as a parent of a child with T1DM is constant despite supporting others. The results also revealed the degree of value placed on the support from other Link Parents as some parents reported a feeling of loss at the

end of the project. This enduring vulnerability and sense of loss maps onto Embuldeniya *et al.* (2013)'s theme of 'emotional entanglement'; their experience that makes them a positive presence as a peer also leaves them vulnerable to getting lost in the experience of their mentee and being a mentor.

The degree of value placed on the support from other Link Parents may also reflect the lack of support the Link Parents had following their diagnosis. Whilst this was a key factor in motivating many of the Link Parents to engage with the project (see section 3.7.3), it also provides insight into the need to safeguard the wellbeing of Link Parents and ensure they are supported through the process.

4.1.5.2 Containment and preparation by project leads

The second subtheme relates to the perception of the training and trainers which comprised the wider system of support around them. Previous results from Sullivan-Bolyai and Lee (2011), revealed that mentors did not enjoy certain elements of the training. The authors stated that changes would be made to the training to reflect their views in future peer mentoring programs. The current study has expanded on these findings as the Link Parents reflected on the collaborative approach to training which enabled them to feel that they had some agency in the process of training. Compared to the more prescriptive approach of Sullivan-Bolyai and Lee, this appeared to be well received.

This subordinate theme also relates to the support provided beyond the initial training. The results indicated the value of knowing there was support available if needed throughout the project. Sullivan-Bolyai and Lee (2011) results described participants appreciating the availability of easily accessible and responsive support. This was replicated in the current study, indicating that even if the support is not needed, it is viewed as an important safety net for Link Parents to be able to do their work.

4.1.5.3 Motivation to support others

The current study provides new insight into the motivation of those who seek to support others. The notion of volunteering in order to spare others the difficulties Link Parents had faced in coming to terms with their child's diagnosis illustrates that the

grounding in personal experience goes beyond the content of support to the philosophical perspective of participants. Mentors' own experiences being central to the support provided has been explored in previous research (Sullivan-Bolyai & Lee, 2011; Shilling *et al.*, 2012). The sense of protecting others from the negative experiences mentors have endured has not been explored in paediatric peer mentoring previously, however it links to a theme from adult peer data in terms of a desire to foster hope for the future (Embuldeniya *et al.*, 2013; Walker & Bryant, 2013). Link Parents' connection with their ongoing negative emotions in terms of their own adjustment could also provide further support for Lowes and Lynne (2000)'s chronic sorrow model as the Link Parents remain in tune with negative emotional experiences years after their child's diagnosis.

4.1.6 Link Parents Super-ordinate Theme 2: Support Provided

The findings relating the Link Parents' perceptions of the support they provided map closely onto Sullivan-Bolyai *et al.* (2004)'s intervention model of informational, affirmational and emotional support on which the PLUS programme is based. Within the support provided four subordinate themes emerged: grounded in own experience; mapping training onto reality; managing emotional experiences; illuminating an uncertain future.

4.1.6.1 *Grounded in own experience*

The position of Link Parents' own experience as central to the support provided mirrors the intervention model of Sullivan-Bolyai *et al.* (2004). It also reflects previous findings regarding mentors accounts of their application of the model (Sullivan-Bolyai & Lee, 2011). The results reflect use of personal experience to provide affirmational and informational support in varying degree across participants, in line with Sullivan-Bolyai *et al.*'s model and the training provided by PLUS project leads. The findings also reflect the multi-dimensional mode of action the support operates in hypothesised by Dennis *et al.* (2003) and Simoni *et al.* (2013). The personal experience is at the centre of the support but can be used for varying ends from practical/educational to social/emotional support.

Whilst previous research has reflected the idiosyncratic nature of such support (National Voices, 2015; Simoni *et al.*, 2011), the results provide new information regarding the difficulties that can be experienced in judging how best to utilise Link Parents' personal experiences. The Link Parents used their practical experiences in varying ways with some being directive in how to cope whilst others were keen to not communicate their ideas as the only option. In terms of emotional experiences, the results illustrate the challenging task of deciding how to use your own experiences to normalise and validate whilst also protecting yourself.

4.1.6.2 Mapping training onto reality

The results reflect the first exploration of the reality of applying training to the mentor relationship. Sullivan-Bolyai and Lee (2011) referred to difficulties in training especially in terms of role plays, they did not report difficulties in translating training to reality. The results of this study speak to the difficult balance between providing flexible, personal support to Recipient Parents versus providing containing preparation for the Link Parents. The containment and 'rules' were felt to be helpful in terms of setting up support and protecting the Link Parents' safety. However, the results revealed to presence of self in Link Parents' approaches to providing support. The need to interact with the Recipient Parent in an authentic way and keep the Recipient Parent's needs at the core of the contact was felt by some to be at odds with adhering to the training.

4.1.6.3 Managing emotional experiences

This subordinate theme relates to the 'emotional support' within Sullivan-Bolyai *et al.* (2004)'s model for intervention. The results replicate those of Sullivan-Bolyai and Lee (2011) in that all Link Parents provided an opportunity for Recipient Parents to reflect on their emotional experiences. However, the results provide new information about how some Link Parents dealt with emotional accounts of Recipient Parents. Sullivan-Bolyai and Lee (2011)'s results indicate that mentors provided an 'active listening' form of support, by acknowledging and validating the emotional experiences. The results of the current study reveal broader ways that Link Parents dealt with emotional accounts. The 'managing' element of the subordinate theme is indicative of the more active role Link Parents took in supporting Recipient Parents, beyond active listening. The Link

Parents in this study described more accounts of using their own experiences to normalise the Recipient Parents' experiences.

The use of personal experiences led some parents to develop a stronger personal connection with their Recipient Parents. Whilst this was perceived as a helpful experience by both Link and Recipient Parents, the emotional exposure of using their own experiences has wider implications for protecting the boundaries of the relationship. Difficulties with boundaries has not been raised in paediatric research but again reflects the 'emotional entanglement' mentioned previously (Embuldeniya *et al.*, 2013). However, in keeping with Shilling *et al.* (2012)'s findings, Link Parents reflecting on their previous emotional experiences can have a positive impact in terms of helping them gain insight into the progress they have made.

4.1.6.4 Illuminating an uncertain future

The act of Link Parents 'illuminating an uncertain future' for the Recipient Parents was a feature with more emphasis being placed on Link Parents position in time compared to the Recipient Parents. The nature of experienced peer mentoring means that Link Parents had lived through what the Recipient Parents still had to come. The impact of such negative reflections in peer support relationships has been reflected in group adult peer data (Embuldeniya *et al.*, 2013) however it has not been raised in one-to-one qualitative accounts of peer mentoring. The results indicate a variability in how this time difference was used. For some participants it was used as a means of providing reassurance that the future will be easier. On the other hand other participants provided warnings with the intention of notice of difficulties that may be to come. The benefit of having Recipient Parents and Link Parents in the current study means insight into the negative perception of this type of warning was gained.

4.1.7 Link Parents Super-ordinate Theme 3: Relationship with Recipient Parent

The relationship between mentors and recipients has been reflected on by previous research, particularly in terms of the personal connection that differentiates their relationship from professionals. The relationship from the mentors' point of view has not been explored in depth previously. Three subordinate themes are included:

personal connection; boundaries around self and relationship; dealing with ending of the relationship.

4.1.7.1 *Personal connection*

The first subtheme of a 'personal connection' replicates previous research from Sullivan-Bolyai and Lee (2011) and Shilling *et al.* (2012), particularly because of the sharing of personal experiences as a means of supporting the Recipient Parents. It also supports the hypotheses of Dennis (2003) and Simoni *et al.* (2011), that the implications of a shared experience are the cornerstone of the efficacy of such support. However, the current research provides deeper understanding of the implications of such a personal connection for the parameters and boundaries of the relationship. For some Link Parents the personal connection was welcome as it transformed the relationship to something akin to a friendship. However, for others the transformation was more challenging to manage as they did not feel such a connection and did not want the relationship to move beyond the boundaries of mentor/mentee.

4.1.7.2 *Boundaries around self and relationship*

The second subordinate theme reflects the difficulties in managing the boundaries around the relationship, both practically and personally. In terms of personal boundaries, the natural consequence of the personal connection between Link and Recipient Parents is a need to renegotiate parameters of the relationship. Personal boundaries have not been explored in the paediatric peer support literature before, although such boundaries have been examined extensively in literature relating to professional therapeutic relationships and in adult peer literature (Embuldeniya *et al.*, 2013; Kagle & Giebelhausen, 1994; Okamoto, 2003; Peternej-Taylor, 2002).

The subordinate theme also relates to the practical boundaries. Link Parents reflected a difficulty in balancing a communication of availability to support the Recipient Parent and desire not to impose their support. This subtheme provides new information regarding the application of Sullivan-Bolyai *et al.* (2004)'s model which emphasised a Recipient Parent led approach in which the mentor is responsive to their needs. However, if a Recipient Parent experiences feelings of indebtedness as the Link Parent

provides a voluntary service (section 3.4.1) then they may not feel able to take a lead on organising support, creating an impasse.

4.1.7.3 Dealing with ending of the relationship

The third subtheme refers to the difficulties in managing endings amongst the Link Parents. Although the intervention followed the same six month pattern used in Sullivan-Bolyai *et al.* (2004; 2010), the issue of endings was noted by Link Parents in this study which was not reported in Sullivan-Bolyai and Lee (2011) or Shilling *et al.* (2012). This may represent the difficulties in boundaries and navigating the relationship that was raised by Recipient Parents and Link Parents that has been reflected in previous findings in adult peer mentoring (Embuldeniya *et al.*, 2013). Where the relationship becomes more than a professional one, the issue of endings becomes more challenging to manage.

The results also provide new information about the impact an unsatisfying or unclear ending can have on Link Parents. Some Link Parents experienced Recipient Parents' needing only a small amount of support which was unexpected. Whilst the Link Parents in the current research rationalised the lack of uptake, the results provide information about the vulnerability that Link Parents could have in terms of internalising the reasons for lack of uptake. The results also provide further evidence of the need for close support from project leads to help Link Parents navigate such transitions which go beyond the need for clear communication of endings from the research team and touch on the more personal nature of the experience.

4.1.8 Link Parents Super-ordinate Theme 4: Understanding the Impact of Support

The final super-ordinate theme refers to Link Parents' attempts to make sense of the impact their support had on the Recipient Parents. The super-ordinate theme is comprised of three subordinate themes: difficulty assessing impact made; perceived value of live experience; emotional impact on Link Parent.

4.1.8.1 *Difficulty assessing impact made*

Link Parents experienced difficulties in gauging the impact their support had provided. The Link Parents in this study appeared less certain of their impact yet hopeful of making a positive impact. Sullivan-Bolyai and Lee (2011)'s results reflected more confidence from the mentors in terms of the impact they had. The results of this study may represent a cultural difference between North American and British populations in terms of self-confidence or a genuine difference in perceived impact. The lack of confidence may also reflect the knowledge Link Parents had that the researcher was also interviewing Recipient Parents, and therefore not wanting to appear confident in case the Recipient Parent provided a less positive account.

More broadly the difficulty measuring impact may again provide some insight into the challenges of quantifying the impact of this type of peer support. The results of this study illustrate the breadth of relationships and support that have been provided within even a small group of participants. This mirrors the broad nature of attempts to theorise the mechanism of peer support by Dennis (2003) and Simoni et al. (2011). The hypotheses generated have proffered a range of mechanisms of action for what appears to be a simple intervention. The variability provides insight into the challenges in measuring the impact of peer support interventions through quantitative methods (Sullivan-Bolyai *et al.*, 2004; 2010; 2011; Shilling *et al.*, 2012). Quantitative methods may only assess specific modes of action and therefore not represent the range of impact that peer interventions have.

4.1.8.2 *Perceived value of lived experience*

Despite difficulties in determining the impact made, Link Parents' who reported a perceived impact, accounted for it by the value of lived experience. The centrality of shared experience and shared identity within the results replicates previous findings of Newell and Hahessy (2013), Shilling *et al.* (2012) and Sullivan-Bolyai and Lee (2011). As mentioned previously (section 4.1.6.4), the position of Link Parents as being ahead in terms of time dealing with T1DM, is reflected more prominently in this study than previously. As a result the perceived value of lived experience lay in a perception of offering hope for the future. This hope was sometimes through Link Parents providing practical advice to help the Recipient Parent move forward. However, unlike previous

findings, some Link Parents reflected that they felt the Recipient Parent being able to witness someone who has adjusted and is coping, had impact in of itself. In this way the findings reflect those of mental health services peer interventions where the distance in time is felt to be of value in of itself (Walker & Bryant, 2013).

4.1.8.3 Emotional impact on Link Parent.

Link parents also reflected on the impact providing support had on them personally, both negative and positive. The effect of reflecting on difficult memories is a challenging process although for some it meant using negative memories for a positive process, thereby replicating Shilling *et al.* (2012)'s results regarding the use of memories in support. In addition, the positive outcome of being able to process memories and build relationships with other Link Parents was reported. Sullivan-Bolyai and Lee (2011) reported similar results in terms of the positive connection mentors made with one another.

4.2 Clinical and Service Implications

The results of this study provide insight into the experiences of parents involved in an experienced peer mentor intervention. It also provides evidence of the positive impact the intervention can have for both those receiving and providing support. However, there are lessons which can be carried forward to future work and application of this intervention. As such, the research has three main clinical and service implications:

4.2.1 Unique Contribution of Peer Support

The results have illustrated the unique contribution this type of support can provide compared to professional led support. The validation and normalisation provided by Link Parents from a position of personal rather than professional experience is a distinctive feature of this type of support. The sense of genuineness perceived by Recipient Parents within the Link Parents was therefore significant in terms of the subsequent impact. In addition, reflections by the Link Parents regarding the type of support they would have wanted being a key motivator reveals the desire for such support by parents.

The results illustrate the idiosyncratic nature of the impact such support can have. The benefit of research through an IPA methodology enables exploration of such complexity. It provides further evidence for the consideration of the needs of the Recipient Parent in relation to their pairing with a Link Parent. The results have shown the consequences of a mismatch in pairing between Recipient and Link Parents even when their pairing is carefully considered. For Recipient Parents to benefit from the unique contribution peer support can have to their adjustment process, careful planning and monitoring of the pairing is crucial.

Beyond the implications for the individual, the results provide evidence for service user based interventions within a broader healthcare context. For the UK, where an increasingly pressured economic climate within the NHS places strains on clinical support services, such routes of support provide an economically sustainable alternative intervention. The results have illustrated that with the investment of training and supervision, the Link Parents were able to provide a flexible and responsive service which the NHS would struggle to provide. In terms of the evidence discussed in Chapter 1 of the implications for parents and children with T1DM of a difficult adjustment process, investment in such interventions could have long term positive outcomes for the coping and management of families.

4.2.2 Protecting the Link Parents

The study has provided insight into the effect providing such support can have on Link Parents. The Link Parents reflected on two areas of negative impact: memories resurfacing of the challenging period post diagnosis and balancing the enduring challenges of managing T1DM. These themes pointed to the vulnerable position Link Parents can hold because of their ongoing position as a parent of a child with T1DM. Therefore considerations need to be taken into account in future application of such support. The screening of prospective Link Parents is crucial to identify parents who are psychologically ready and able to provide such support. The PLUS project worked closely with local diabetes teams to identify those who could provide support. Such knowledge of a parent's coping and general wellbeing were vital in selecting those who would be able to comfortably provide support therefore minimising psychological risk to either the Link or Recipient Parents. However, the nature of T1DM means that its

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management can fluctuate particularly as a child develops their own sense of autonomy with age. Link Parents who are coping well at the point of volunteering to provide support may encounter difficulties at some point in the process. Therefore careful support and monitoring of the Link Parents is important in order to protect them from overstretching themselves but also the Recipient Parent whose support may be compromised.

The results from the Recipient Parents' accounts illustrate the potentially negative experience when Link Parents are currently or have recently struggled with the management of T1DM. Whilst, it would not be in the Recipient Parents' interest to shield them entirely from the reality of T1DM, exposure to Link Parents' raw emotional responses can be detrimental to the Recipient Parents' adjustment process. The PLUS project offered frequent meetings for the Link Parents throughout the process to monitor the progress and provide support. However, for future research perhaps monitoring of the Recipient Parents' experiences or closer links between the supervising team and the Recipient Parents would also be helpful. This study was time limited in that Link Parents only offered support from six months. If such support was developed over a longer period the scope for fluctuations in Link Parents' coping would be greater therefore increasing the need for the provision of support and monitoring of progress.

A final aspect of safeguarding the Link Parents whilst also enabling them to develop their supportive skills is in providing a space for them to process their own experiences prior to supporting others. The results indicated how many of the Link Parents were motivated to support others because of their own lack of support. Whilst such motivating factors are to be expected, if this lack of support has led to unresolved experiences, supporting a Recipient Parent through a similar period could be psychologically difficult. The PLUS project provided a space for Link Parents to recall and reflect on their own experiences of diagnosis in the context of role playing. However, the results showed that outside of practicing supporting others, this experience enabled them to reconnect with their experiences of diagnosis in a safe and supportive environment. Providing such opportunities would be crucial for future

provision of such interventions to psychologically support the Link Parents before they support others.

4.2.3 Adjusting Training of Link Parents

The insight gained from the results could be used in varying ways to inform the training of future cohorts of Link Parents should the model of intervention be taken forward in the UK. The training provided to the Link Parents within PLUS project was based on that described in Sullivan-Bolyai *et al.* (2004, 2010, 2011) which was developed for use with a North American population. As mentioned previously, this was the first known adaptation of this model and training materials for a UK population and the qualitative results could provide information regarding any further adaptations that need to be made.

In general terms the Link Parents provided support which was close to the training provided. However, themes from the Recipient Parent accounts could be used to inform future Link Parents of experiences of those who have already been through the peer mentoring process. Generalisation of qualitative results such as those described would be inappropriate. However, given that this is the first exploration of such support in the UK, any points of learning that can be passed onto future Link Parents would be important. For example, reflections on the barriers to uptake of support from the point of view of the Recipient Parents could be communicated to Link Parents. Factors such as the normal adjustment process differing between individuals affecting the need for the support changing over time and between different parents. Knowledge that factors beyond their control can affect uptake may safeguard the wellbeing of Link Parents and reduce the chance of reaching conclusions that the lack of engagement is due their own skills in supporting the Recipient Parent. In addition, Link Parents could be informed of the barrier that confiding in an unfamiliar person can pose to engagement with support, particularly when a familiar person is available as an alternative. Again such reflections could provide Link Parents with reassurance and context for any difficulties with engagement from the outset. Furthermore, the accounts of lack of familiarity as a barrier to engagement on the one hand and the value of support from a Link Parent when the relationship is close on the other hand, could be used to emphasise the need for focus on developing a trusting relationship with the Recipient Parent.

In terms of informing future training in what support to provide, the results from the Recipient Parents' point of view, particularly the idiosyncratic use of support, should be reflected to Link Parents. Training Link Parents in asking direct questions about the type of support they would like may help the steam line the supportive relationship. If trainers acknowledge that the Recipient Parents may differ in terms of the type of support they desire compared to Link Parents, it may prevent Link Parents defaulting to the type of support they would have liked. An additional element of direction would be to provide explicit caution in Link Parents' use of their own negative experiences. Again by training Link Parents to ask questions about what will be helpful to hear, it would safeguard Recipient Parents from exposure to difficult reflections before they feel ready.

4.2.4 Suitability Assessment of Link Parents

The results have raised the need for further development of the suitability assessment of Link Parents. In the current study potential mentors' suitability was assessed on the basis of a Consultant Clinical Psychologist and Clinical Nurse Specialist's clinical judgment against a number of criteria (Appendix XI). This was in line with previous parent peer mentoring programs such as Sullivan-Bollyai *et al.* (2004; 2010). However, as this was pilot study of a mentoring program, the inclusion of less appropriate mentors may have reflected inexperience of the clinical leads' in running such programs. Therefore, future application of mentoring schemes by this research team can now draw on the study's findings based on their experience of facilitating the process. For future clinical application, services may consider having the decisions made by the metabolic multidisciplinary team in order to pool the knowledge and experience of professionals and their interactions with parents and families. Whilst this may not be possible within the tight time scheduling of research trialling it may be possible if such programs are applied directly to clinical services.

A further future option may also be to develop a more formalised assessment of peer mentors for future provision of such services. There are instances of such formalised measures being developed in educational mentoring schemes (van Rensburg & Roodt, 2005). Operationalisation of the criteria used in this study alongside that used in Sullivan-Bollyai *et al.* (2004; 2010) may be possible. In addition, conducting further

research with previous Recipient Parents to collate desired characteristics, from their point of view may be used as a basis of suitability assessments. The results have highlighted the importance of Link Parents' previous experiences, ways of coping and emotional processing in terms of the support that they offer. Therefore use of formalised measures of coping such as the MultiDimensional Coping Inventory (Endler & Parker, 1990) or of adjustment such as the Parent and Family Adjustment Scales (Sanders *et al.*, 2013) may provide helpful insight. It is however important to acknowledge that even the most finely tuned psychometric assessment procedures can guarantee perfect eligibility across individuals. Therefore, any formalised measure would need to be used alongside the clinical judgement of the professionals who have working experience of the particular mentors.

4.2.5 Matching Recipient and Link Parents

The results of this study and that of previous research (Rearick *et al.*, 2011; Sullivan-Bolyai & Lee, 2011) have provided evidence of the need for close consideration of how Link and Recipient Parents are matched. Compared to others types of peer support where participants are at similar stages of adjustment, this type of support brings together people who are at very different stages. Whilst this allows experience based support to be provided, the intensity of such one to one support provides greater potential for a negative impact of mismatching participants. The results have illustrated the varying degree of practical versus emotional support provided and desired by Link and Recipient Parents.

The participants were matched based on the PLUS project leads' clinical judgement. For future exploration of the intervention more systematic assessment of Recipient Parents needs prior to matching would be helpful in considering how an appropriate match is made. Based on the findings of this study an assessment could be carried out regarding the following dimensions of the peer mentoring experience:

1. Their expectations of the type of relationship (friendship versus professionalism)
2. Their needs in terms of support (practical versus emotional)
3. Any type of support or information they would not like to received
4. How they would prefer to be supported (i.e. frequency, modality)

Use of such information alongside the information gained from the suitability assessment could be used in the pairing of Link and Recipient Parents. In addition, understanding the approach Link Parents take to T1DM management would be helpful in matching them with a Recipient Parent. The training process enables the PLUS project leads to gain some insight into different Link Parents' approaches. Educational mentoring programs use pre-match social activities to allow mentors and mentees to interact (Mentoring Australia, 2000). This may allow mentees and mentors to feedback on possible matching based on previous interactions rather than a blind meeting. Such events may also serve as an 'ice breaker' to ease the start of the relationship.

4.3 Strengths and Limitations of the Study

The study aimed to provide in depth insight into the experiences of parents supporting and being supported by other parents. As described in Chapter 2, a qualitative methodology was adopted in order to meet these aims. Chapter 2 also outlined key markers of quality in qualitative papers (Elliott *et al.*, 1999). With these in mind, the current study has a number of strengths and weaknesses in terms of its methodology:

4.3.1 Strengths of the Study

The current study has a number of strengths according the Elliott *et al.* (1999)'s criteria. The researcher provided an in depth position statement to provide a context for their perspective. In addition a reflective diary was kept through the research process and an abstract from different stages of research was provided. This enabled the researcher to consider their own thought process throughout the research.

The result section was consistently grounded in examples from the direct text. Each subtheme was supported by a number of extended quotes. This provided the reader with direct material by which to appraise the themes. In addition to direct quotes the results were further ratified through review by external readers who were not involved in the qualitative analysis process. This offered an additional perspective to enhance the quality of the results and provide an assessment of their resonance in terms of the current research base.

Beyond the quality of the specific qualitative methodology the current study has strengths in terms of its overall design. The study provided insight into the perspectives of those on both sides of the supportive dyad which has not been reported previously. The qualitative design meant that in depth study of the experiences of participants could be gathered.

4.3.2 Limitations of the Study

Despite attempts to ensure the methodological quality of this study, there are a number of limitations in terms of methodology. Firstly, Elliott *et al.* (1999) sets out that qualitative research should 'situate the sample' by providing information regarding the participants to contextualise their accounts. However, due to constraints over confidentiality between the Link and Recipient Parents, information regarding the specific hospital locations and demographic information for the participant and child with diabetes could not be reported. Ultimately concerns about safeguarding the privacy of participants were prioritised over implications for quality.

A further limitation according to Elliott *et al.*'s criteria is in relation to providing credibility checks. The researcher did provide external credibility checks via review of results by other researchers and clinicians. However, credibility checks with participants were not provided which would have raised the level of credibility overall.

Outside of Elliott *et al.*'s criteria there are further limitations to the current study, particularly surrounding the sampling used. An opportunity sampling technique was used to gather participants for the study. All Link and Recipient Parents were contacted to arrange an interview however as stated in Chapter 2, not all were willing to participate. It is therefore possible that the sample is skewed towards those who had a more positive experience of this study. There are examples of negative accounts amongst the participants interviewed for the study however it is possible that those who chose not to participate had a markedly different experience which was not captured in this study. A second limitation of the study is the lack of synthesis between the accounts of Link and Recipient Parent pairs in the study. Synthesis of the accounts would have allowed for greater enrichment of insight if the accounts of both members

of the pair were presented alongside each other throughout the study. However, as mentioned previously, the small sample from a small community meant this was not possible without breaching the participants' confidentiality.

A final limitation for this study relates to the IPA methodology being used to analyse two samples separately. There are some examples of themes overlapping with one another, particularly around the process and content of support. It is therefore possible that the analysing of Link Parent data, which was analysed second, was influenced by analysis of the Recipient Parent data. However, attempts to utilise and reflect on the contents of the reflective diary through the analysis process was used to increase awareness of this. In addition, grounding in examples and credibility checks provides assurances that emergent themes are relevant to the Link Parent data rather than the Recipient Parent data set.

4.4 Future Directions

This study sought to gain insight into an intervention about which data has not been published in the UK before. It therefore follows there are a number of directions future research in this area could take:

4.4.1 Further Investigation of the Intervention

The systematic review undertaken in Chapter 1, highlighted the lack of replication of results for interventions with parents of children with T1DM. It is unclear why attempts have not been made to replicate results when authors have reported promising outcomes. A key aspect of further work to be done for the research outlined in this study is therefore to conduct repeated delivery of the intervention to understand its effect in the broader population. This intervention, as with many of those included in the systemic review, was based in real services. It may therefore be that for previous research, the initial positive results provided enough impetus to deliver the intervention more widely without collecting further data regarding its effect. It is acknowledged that time and resources for research within services is often constrained which may be the reason behind the lack of replication of results. However, it is creating gaps in the literature which contributes to a lack of evidence based interventions for

parents of children with T1DM. It is therefore important that the PLUS intervention outlined in this study is further researched both through quantitative and qualitative methodologies to provide depth of insight into its impact.

Furthermore, there is a need to research the impact and experience of those receiving and delivering such interventions from a broader population. In keeping with IPA methodology, the population in this study have been relatively homogenous which has provided insight into the shared experiences of the particular group. However, future research could explore the experiences of participants from non white-British ethnic groups, single parent families and varying geographical regions. Research with more diverse populations would provide valuable information about the utility and effect of such interventions and therefore support provision of future services.

4.4.2 Further Development Link Parent Training

The insight gained from this study has raised possible alterations that could be made to future training of Link Parents (see section 4.2.3). As a result future research should endeavour to take these issues into account when designing training. Insight gained from this research into factors which reduce or halt the need for support could be provided to the Link Parents when they are trained. For example, reflecting that Recipient Parents will move through a normal adjustment process which is different for everyone and they may therefore need only a small amount of support. Measuring the differences in terms of the support provided and the impact it has on Link Parents' perceived self-efficacy would in turn help develop and refine the training.

An additional element of preparation for the Link Parents would be placing an emphasis on developing a relationship with the Recipient Parent. The results of this study illustrated that some Recipient Parents sought support elsewhere, often within their existing support network which replaced the need for Link Parent support. This together with evidence from Shilling *et al.* (2012)'s review provides evidence that difficulties confiding in a stranger was a key barrier to uptake of support. Further research could measure the difference made by adjusting the training to place more emphasis on fostering a relationship in terms of uptake and psychological adjustment.

Balancing the intimacy of that relationship with boundaries between the Link and Recipient Parents would also need to be considered.

4.4.3 Synthesis of Link and Recipient Parent Accounts

A key limitation of the current study is the lack of synthesis across Link and Recipient accounts, due to confidentiality constraints. The lack of synthesising across the results meant an opportunity for another layer of insight in terms of the similarities and differences between accounts of a shared experience was missed. Future research should therefore endeavour to study paired accounts. There would be challenges in terms of issues of confidentiality if this type of data analysis and reporting were pursued. The participant would recognise their own account and therefore the paired parent's account. Knowledge of this may limit the degree of honest reflection on the experiences particularly if they are negative. However even if such challenges meant that only pairings which were felt by both parents to be successful were included greater understanding of the components of a positive peer mentor relationship would be gained. This understanding could then be used to promote positive practice, emphasising what makes for good support rather than avoiding factors constituting poor support.

4.5 Conclusion

The current study sought to gain insight into the experience of parents of children with T1DM supporting and being supported through an experienced peer mentoring program. The study was undertaken based on a large evidence base concerning the impact CCC can have on a child and their wider family system. Evidence that the adjustment and coping of parents has a key role in the psychological and physical wellbeing of the child therefore led to exploration of parent based interventions. This is the first reported study which has explored the use of experienced peer mentoring for parent of children with T1DM in the UK.

The results of this IPA study revealed in depth insight into the experiences of parents receiving and providing support. Themes from the Recipient Parents provided insight into coping following their child's diagnosis, the process and content of the support

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provided and the effect the support had. Themes from the Link Parents provided insight into their attitudes towards the project, the support provided, their relationship to the Recipient Parents and the perceived impact. The results have illustrated the idiosyncratic experiences of those providing and receiving support. However, the results have provided a promising picture in terms of the positive experiences and impact on Recipient Parents and Link Parents. Further exploration of this intervention with a broader UK population alongside continued refinement of the facilitation of the programme is important in moving forward.

References

References

- Anderson, B.J., Wolf, F.M., Burkhart, M.T., Cornell, R.G., & Bacon, G.E. (1989). Effects of peer group intervention on metabolic control of adolescents with IDDM. Randomized outpatient study. *Diabetes Care*, *12*, 179–183.
- Anthony, K. K., Bromberg, M. H., Gil, K. M., & Schanberg, L. E. (2011). Parental perceptions of child vulnerability and parent stress as predictors of pain and adjustment in children with chronic arthritis. *Children's Health Care*, *40*, 53-69.
- April, K. T., Cavallo, S., Feldman, D. E., & Ni, A. (2012). The associations among economic hardship, caregiver psychological distress, disease activity, and health-related quality of life in children with juvenile idiopathic arthritis. *Quality of Life Research*, *21*, 1185-1191.
- Bandura, A. (1986). *Social foundations of thought and action: A social cognitive theory*. Englewood Cliffs, NJ: Prentice-Hall, Inc.
- Barlow, J. H., & Ellard, D. R. (2006). The psychosocial well-being of children with chronic disease, their parents and siblings: an overview of the research evidence base. *Child: Care, Health and Development*, *32*, 19-31.
- Barnett, D., Clements, M., Kaplan-Estrin, M., McCaskill, J. W., Hunt, K. H., Butler, C. M., et al. (2006). Maternal resolution of child diagnosis: stability and relations with child attachment across the toddler to preschooler transition. *Journal of Family Psychology*, *20*, 100.
- Bartlett, S. J., Kolodner, K., Butz, A. M., Eggleston, P., Malveaux, F. J., & Rand, C. S. (2001). Maternal depressive symptoms and emergency department use among inner-city children with asthma. *Archives of Pediatrics & Adolescent Medicine*, *155*, 347-353.
- Beavers, W. R. (1982). Healthy, midrange and severely dysfunctional families. In F. Walsh (Ed.). *Normal Family Processes* (pp 19-45). New York: Guilford Press.
- Beavers, W. R., & Voeller, M. N. (1983). Family models: Comparing and contrasting the Olson circumplex model with the Beavers systems model. *Family Process*, *22*, 85-97.
- Berant, E., Mikulincer, M., & Florian, V. (2001). Attachment style and mental health: A 1-year follow-up study of mothers of infants with congenital heart disease. *Personality and Social Psychology Bulletin*, *27*, 956-968.

References

- Berg, C. A., Schindler, I., & Maharajh, S. (2008). Adolescents' and mothers' perceptions of the cognitive and relational functions of collaboration and adjustment in dealing with type 1 diabetes. *Journal of Family Psychology, 22*, 865.
- Berg, C. A., Wiebe, D. J., Beveridge, R. M., Palmer, D. L., Korbel, C. D., Upchurch, R., *et al.* (2007). Mother-child appraised involvement in coping with diabetes stressors and emotional adjustment. *Journal of Pediatric Psychology, 32*, 995-1005.
- Boman, K., Lindahl, A., & Björk, O. (2003). Disease-related distress in parents of children with cancer at various stages after the time of diagnosis. *Acta Oncologica, 42*, 137-146.
- Bowes, S., Lowes, L., Warner, J., & Gregory, J. W. (2009). Chronic sorrow in parents of children with type 1 diabetes. *Journal of Advanced Nursing, 65*, 992-1000.
- Butler, J. M., Berg, C. A., King, P., Gelfand, D., Fortenberry, K., Foster, C., *et al.* (2009). Parental negative affect and adolescent efficacy for diabetes management. *Journal of Family Psychology, 23*, 611.
- Butwicka, A., Zalepa, A., Fendler, W., Szadkowska, A., & Mlynarski, W. (2013). Maternal depressive symptoms predict acute hospitalization among children with type 1 diabetes. *Pediatric Diabetes, 14*, 288-294.
- Cabizuca, M., Marques-Portella, C., Mendlowicz, M. V., Coutinho, E. S., & Figueira, I. (2009). Posttraumatic stress disorder in parents of children with chronic illnesses: a meta-analysis. *Health Psychology, 28*, 379.
- Cameron, F. J., Skinner, T. C., De Beaufort, C. E., Hoey, H., Swift, P. G., Aanstoot, H., *et al.* (2008). Are family factors universally related to metabolic outcomes in adolescents with Type 1 diabetes? *Diabetic Medicine, 25*, 463-468.
- Carter, B., & McGoldrick, M. (2005). Overview: The expanded family life cycle individual, family and social perspectives. In B. Carter, & M. McGoldrick (Eds.), *The Expanded Family Life Cycle: Individual, family, and social perspectives* (pp.3-28). Boston; Pearson.
- Champaloux, S. W., & Young, D. R. (2015). Childhood chronic health conditions and educational attainment: a social ecological approach. *Journal of Adolescent Health, 56*, 98-105.
- Channon, S., & Lowes, L. (2012). *Parents Listen Understand and Support: The PLUS study. Setting up a parent-to-parent support network for parents with a child recently*

References

- diagnosed with type 1 diabetes*. Unpublished research protocol, Cardiff University.
- Chernoff, R. G., Ireys, H. T., DeVet, K. A., & Kim, Y. J. (2002). A randomized, controlled trial of a community-based support program for families of children with chronic illness: pediatric outcomes. *Archives of Pediatrics & Adolescent Medicine*, *156*, 533-539.
- Creswell, J. W. (2013). *Research design: Qualitative, quantitative, and mixed methods approaches*. London, UK: Sage publications.
- Dale, J. R., Williams, S. M., & Bowyer, V. (2012). What is the effect of peer support on diabetes outcomes in adults? A systematic review. *Diabetic Medicine*, *29*, 1361-1377.
- Dashiff, C., Hardeman, T., & McLain, R. (2008). Parent-adolescent communication and diabetes: An integrative review. *Journal of Advanced Nursing*, *62*, 140-162.
- Delamater, A. M., Jacobson, A. M., Anderson, B., Cox, D., Fisher, L., Lustman, P., *et al.* (2001). Psychosocial therapies in diabetes report of the psychosocial therapies working group. *Diabetes Care*, *24*, 1286-1292.
- Dennis, C-L. (2003). Peer support within a health care context: a concept analysis. *International Journal of Nursing Studies*, *40*, 321-332.
- Denny, S., de Silva, M., Fleming, T., Clark, T., Merry, S., Ameratunga, S., *et al.* (2014). The prevalence of chronic health conditions impacting on daily functioning and the association with emotional wellbeing among a national sample of high school students. *Journal of Adolescent Health*, *54*, 410-415
- Diabetes UK (2010). *Diabetes in the UK 2010: Key statistics on diabetes*. http://www.diabetes.org.uk/Documents/Reports/Diabetes_in_the_UK_2010.pdf
- Distelberg, B., Williams-Reade, J., Tapanes, D., Montgomery, S., & Pandit, M. (2014). Evaluation of a family systems intervention for managing pediatric chronic illness: Mastering each new direction (MEND). *Family Process*, *53*, 194-213.
- Dost, A., Rosenbauer, J., Rohrer, T., Knerr, I., Gerstl, E. M., & Holl, R. W. (2010). Metabolic control in children with type 1 diabetes. *European Endocrinology*, *6*, 35-38.
- Driscoll, K. A., Johnson, S. B., Barker, D., Quittner, A. L., Deeb, L. C., Geller, D. E., *et al.* (2010). Risk factors associated with depressive symptoms in caregivers of children with type 1 diabetes or cystic fibrosis. *Journal of Pediatric Psychology*, *35*, 814-822.

References

- Elliott, R., Fischer, C. T., & Rennie, D. L. (1999). Evolving guidelines for publication of qualitative research studies in psychology and related fields. *British Journal of Clinical Psychology, 38*, 215-229.
- Elstad, E. A., Boothroyd, R., Henes, A., Maslow, G., Nelson, K., & Fisher, E. (2010). *Global systematic review of peer support for complex health behaviour*. Paper presented at the International Congress of Behavioral Medicine, Washington, D.C., August, 2010.
- Embuldeniya, G., Veinot, P., Bell, E., Bell, M., Nyhof-Young, J., Sale, J. E., & Britten, N. (2013). The experience and impact of chronic disease peer support interventions: A qualitative synthesis. *Patient education and counseling, 92*(1), 3-12.
- Endler, N. S., & Parker, J. D. (1990). Multidimensional assessment of coping: a critical evaluation. *Journal of personality and social psychology, 58*, 844.
- Faulkner, M. S., & Chang, L. I. (2007). Family influence on self-care, quality of life, and metabolic control in school-age children and adolescents with type 1 diabetes. *Journal of Pediatric Nursing, 22*, 59-68.
- Faulkner, A., & Kalathil, K. (2012). *The freedom to be, the chance to dream: Preserving user-led peer support in mental health*. London, UK: Together for Mental Wellbeing.
- Fedele, D. A., Ramsey, R. R., Ryan, J. L., Bonner, M. S., Mullins, L. L., Jarvis, J. N., *et al.* (2011). The association of illness uncertainty to parent and youth adjustment in juvenile rheumatic diseases: Effect of youth age. *Journal of Developmental & Behavioral Pediatrics, 32*, 361-367.
- Festinger, L. (1954). A theory of social comparison processes. *Human relations, 7*, 117-140.
- Finlay, L. (2011). *Phenomenology for therapists: Researching the lived world*. Oxford, UK: John Wiley & Sons.
- Frank, R. G., Hagglund, K. J., Schopp, L. H., Thayer, J. F., Vieth, A. Z., Cassidy, J. T., *et al.* (1998). Disease and family contributors to adaptation in juvenile rheumatoid arthritis and juvenile diabetes. *Arthritis & Rheumatism, 11*, 166-176.
- Glenton, C., Lewin, S., & Scheel, I. B. (2011). Still too little qualitative research to shed light on results from reviews of effectiveness trials: a case study of a Cochrane review on the use of lay health workers. *Implement Sci, 6*, 53.

References

- Goebel-Fabbri, A. E. (2009). Disturbed eating behaviors and eating disorders in type 1 diabetes: Clinical significance and treatment recommendations. *Current Diabetes Reports, 9*, 133-139.
- Goodwin, R. D., Messineo, K., Bregante, A., Hoven, C. W., & Kairam, R. (2005). Prevalence of probable mental disorders among pediatric asthma patients in an inner-city clinic. *Journal of Asthma, 42*, 643-647.
- Gordon, J. (2008). An evidence-based approach for supporting parents experiencing chronic sorrow. *Pediatric Nursing, 35*, 115-119.
- Grey, M. (2000). Interventions for children with diabetes and their families. *Annual Review of Nursing Research, 18*, 149-170
- Grey, M., Boland, E. A., Davidson, M., Yu, C., & Tamborlane, W. V. (1999). Coping skills training for youths with diabetes on intensive therapy. *Applied Nursing Research, 12*, 3-12.
- Grey, M., Cameron, M. E., & Thurber, F. W. (1991). Coping and adaptation in children with diabetes. *Nursing Research, 40*, 144-148.
- Grey, M., Jaser, S. S., Whittemore, R., Jeon, S., & Lindemann, E. (2011). Coping skills training for parents of children with type 1 diabetes: 12-month outcomes. *Nursing Research, 60*, 173-181.
- Grey, M., & Thurber, F. W. (1991). Adaptation to chronic illness in childhood: Diabetes mellitus. *Journal of Pediatric Nursing, 6*, 302-309.
- Grootenhuis, M. A., & Last, B. F. (1997). Predictors of parental emotional adjustment to childhood cancer. *Psycho-Oncology, 6*, 115-128
- Guthrie, D. W., Sargent, L., Speelman, D., & Parks, L. (1990). Effects of parental relaxation training on glycosylated hemoglobin of children with diabetes. *Patient Education and Counseling, 16*, 247-253.
- Hampson, S. E., Skinner, T. C., Hart, J., Storey, L., Gage, H., Foxcroft, D., et al. (2001) Effects of educational and psychosocial interventions for adolescents with diabetes mellitus: A systematic review. *Health Technology Assessment, 5*, 1-79.
- Hatton, D. L., Canam, C., Thome, S., & Hughes, A. M. (1995). Parents' perceptions of caring for an infant or toddler with diabetes. *Journal of Advanced Nursing, 22*, 569-577.
- Haugstvedt, A., Wentzel-Larsen, T., Rokne, B., & Graue, M. (2011). Perceived family burden and emotional distress: similarities and differences between mothers

References

- and fathers of children with type 1 diabetes in a population-based study. *Pediatric Diabetes*, 12, 107-114.
- Health and Social Care Information Centre (2013). *Children's longstanding illnesses*. Retrieved from: <http://www.hscic.gov.uk/catalogue/PUB16076>
- Heidegger, M. (1962). *Being and time* (trans. J. Macquarrie and E. Robinson). New York, NY: Harper & Row.
- Helgeson, V. S., Snyder, P. R., Escobar, O., Siminerio, L., & Becker, D. (2007). Comparison of adolescents with and without diabetes on indices of psychosocial functioning for three years. *Journal of Pediatric Psychology*, 32, 794-806.
- Herzer, M., & Hood, K. K. (2009). Anxiety symptoms in adolescents with type 1 diabetes: association with blood glucose monitoring and glycemic control. *Journal of Pediatric Psychology*, 34, 1-11.
- Higgins, J. P. T., & Green, S. (2011). *Cochrane Handbook for Systematic Reviews of Interventions*. Retrieved from: <http://handbook.cochrane.org/>
- Hilliard, M. E., Monaghan, M., Cogen, F. R., & Streisand, R. (2011). Parent stress and child behaviour among young children with type 1 diabetes. *Child: Care, Health and Development*, 37, 224-232.
- Hobdell, E. F., Grant, M. L., Valencia, I., Mare, J., Kothare, S. V., Legido, A., et al. (2007). Chronic sorrow and coping in families of children with epilepsy. *Journal of Neuroscience Nursing*, 39, 76-82.
- Hoff, A. L., Mullins, L. L., Gillaspay, S. R., Page, M. C., Van Pelt, J. C., & Chaney, J. M. (2005). An Intervention to Decrease Uncertainty and Distress Among Parents of Children Newly Diagnosed With Diabetes: A Pilot Study. *Families, Systems, & Health*, 23, 329-342.
- Hoffman, L. (1981). *Foundations of family therapy: A conceptual framework for systems change*. New York, NY: Basic Books.
- Husserl, E. (1927). *Phenomenology*. For *Encyclopedia Britannica* (R. Palmer, Trans, and revised). Retrieved from: <http://www.hfu.edu.tw/~huangkm/phenom/husserl-britanica.htm>
- Huygen, A. C. J., Kuis, W., & Sinnema, G. (2000). Psychological, behavioural, and social adjustment in children and adolescents with juvenile chronic arthritis. *Annals of the Rheumatic Diseases*, 59, 276-282.

References

- Ingerski, L. M., Modi, A. C., Hood, K. K., Pai, A. L., Zeller, M., Piazza-Waggoner, C., *et al.* (2010). Health-related quality of life across pediatric chronic conditions. *The Journal of Pediatrics*, *156*, 639-644.
- Ireys, H., Sills, EM., Kolodner, KB., & Walsh, B. B. (1996). A social support intervention for parents of children with JRA: results of a randomized trial. *Journal of Pediatric Psychology*, *21*, 633-641.
- Jacobson, A. M., Hauser, S. T., Lavori, P., Willett, J. B., Cole, C. F., Wolfsdorf, J. I., *et al.* (1994). Family environment and glycemic control: a four-year prospective study of children and adolescents with insulin-dependent diabetes mellitus. *Psychosomatic Medicine*, *56*, 401-409.
- Janse van Rensburg, K., & Roodt, G. (2005). A normative instrument for assessing the mentoring role. *SA Journal of Human Resource Management*, *3*, 10-19.
- Jaser, S. S., & Grey, M. (2010). A pilot study of observed parenting and adjustment in adolescents with type 1 diabetes and their mothers. *Journal of Pediatric Psychology*, *35*, 738-747.
- Jaser, S. S., Whittemore, R., Ambrosino, J. M., Lindemann, E., & Grey, M. (2009). Coping and psychosocial adjustment in mothers of young children with type 1 diabetes. *Children's Health Care*, *38*, 91-106.
- Jones, J. M., Lawson, M. L., Daneman, D., Olmsted, M. P., & Rodin, G. (2000). Eating disorders in adolescent females with and without type 1 diabetes: cross sectional study. *British Medical Journal*, *320*, 1563-1566.
- Kagle, J. D., & Giebelhausen, P. N. (1994). Dual relationships and professional boundaries. *Social Work*, *39*, 213-220.
- Katon, W., Lin, E. H., & Kroenke, K. (2007). The association of depression and anxiety with medical symptom burden in patients with chronic medical illness. *General Hospital Psychiatry*, *29*, 147-155.
- Kazak, A. E. (1989). Families of chronically ill children: a systems and social-ecological model of adaptation and challenge. *Journal of Consulting and Clinical Psychology*, *57*, 25.
- Kichler, J. C., Kaugars, A. S., Marik, P., Nabors, L., & Alemzadeh, R. (2013). Effectiveness of groups for adolescents with Type 1 diabetes mellitus and their parents. *Families, Systems, & Health*, *31*, 280.

References

- Knafel, K. A., Deatrick, J. A., Knafel, G. J., Gallo, A. M., Grey, M., & Dixon, J. (2013). Patterns of family management of childhood chronic conditions and their relationship to child and family functioning. *Journal of Pediatric Nursing, 28*, 523-535.
- Kokkonen, J. & Kokkonen, E. R. (1995). Mental health and social adaptation in young adults with juvenile-onset diabetes. *Nordic Journal of Psychiatry, 49*, 175-182
- Kokkonen, K., Taanila, A., & Kokkonen, E. R. (1997). Diabetes in adolescence: The effect of family and psychologic factors on metabolic control. *Nordic Journal of Psychiatry, 51*, 165-172.
- Kongkaew, C., Jampachaisri, K., Chaturongkul, C. A., & Scholfield, C. N. (2014). Depression and adherence to treatment in diabetic children and adolescents: a systematic review and meta-analysis of observational studies. *European Journal of Pediatrics, 173*, 203-212.
- Konradsdottir, E., & Svavarsdottir, E. K. (2011). How effective is a short-term educational and support intervention for families of an adolescent with type 1 diabetes?. *Journal for Specialists in Pediatric Nursing, 16*, 295-304.
- Kovacs, M., Obrosky, D. S., Goldston, D., & Drash, A. (1997). Major depressive disorder in youths with IDDM: a controlled prospective study of course and outcome. *Diabetes Care, 20*, 45-51.
- Kumar, P., & Kumar, C. M. (2005). *Clark's clinical medicine*. Edinburgh, UK: Saunders Elsevier.
- Laffel, L. M., Connell, A., Vangsness, L., Goebel-Fabbri, A., Mansfield, A., & Anderson, B. J. (2003). General quality of life in youth with type 1 diabetes relationship to patient management and diabetes-specific family conflict. *Diabetes Care, 26*, 3067-3073.
- Landolt, M. A., Ribbi, K., Laimbacher, J., Vollrath, M., Gnehm, H. E., & Sennhauser, F. H. (2002). Brief report: Posttraumatic stress disorder in parents of children with newly diagnosed type I diabetes. *Journal of Pediatric Psychology, 27*, 647-652.
- Landolt, M. A., Vollrath, M., Laimbacher, J., Gnehm, H. E., & Sennhauser, F. H. (2005). Prospective study of posttraumatic stress disorder in parents of children with newly diagnosed type 1 diabetes. *Journal of the American Academy of Child & Adolescent Psychiatry, 44*, 682-689.

References

- Landolt, M. A., Vollrath, M., Ribi, K., Gnehm, H. E., & Sennhauser, F. H. (2003). Incidence and associations of parental and child posttraumatic stress symptoms in pediatric patients. *Journal of Child Psychology and Psychiatry, 44*, 1199-1207.
- Larkin, M., Watts, S., & Clifton, E. (2006). Giving voice and making sense in interpretative phenomenological analysis. *Qualitative Research in Psychology, 3*, 102-120.
- Layte, R., & McCrory, C. (2013). Paediatric chronic illness and educational failure: the role of emotional and behavioural problems. *Social Psychiatry and Psychiatric Epidemiology, 48*, 1307-1316.
- Lazarus, R. S., & Folkman, S. (1984). *Stress, appraisal, and coping*. New York, NY: Springer
- Leonard, B. J., Jang, Y. P., Savik, K., & Plumbo, M. A. (2005). Adolescents with type 1 diabetes: Family functioning and metabolic control. *Journal of Family Nursing, 11*, 102-121.
- Lewin, A. B., Heidgerken, A. D., Geffken, G. R., Williams, L. B., Storch, E. A., Gelfand, K. M., et al. (2006). The relation between family factors and metabolic control: The role of diabetes adherence. *Journal of Pediatric Psychology, 31*, 174-183.
- Logan, D. E., & Scharff, L. (2005). Relationships between family and parent characteristics and functional abilities in children with recurrent pain syndromes: an investigation of moderating effects on the pathway from pain to disability. *Journal of Pediatric Psychology, 30*, 698-707.
- Lowes, L., Gregory, J. W., & Lyne, P. (2005). Newly diagnosed childhood diabetes: a psychosocial transition for parents? *Journal of Advanced Nursing, 50*, 253-261.
- Lowes, L., & Lyne, P. (2000). Chronic sorrow in parents of children with newly diagnosed diabetes: a review of the literature and discussion of the implications for nursing practice. *Journal of Advanced Nursing, 32*, 41-48.
- MacAllister, W. S., Boyd, J. R., Holland, N. J., Milazzo, M. C., & Krupp, L. B. (2007). The psychosocial consequences of pediatric multiple sclerosis. *Neurology, 68*, S66-S69.
- Mackner, L. M., & Crandall, W. V. (2006). Brief report: psychosocial adjustment in adolescents with inflammatory bowel disease. *Journal of Pediatric Psychology, 31*, 281-285.

References

- Malerbi, F. E. K., Negrato, C. A., Gomes, M. B., & Brazilian Type 1 Diabetes Study Group. (2012). Assessment of psychosocial variables by parents of youth with type 1 diabetes mellitus. *Diabetology and Metabolic Syndrome*, *4*, 1-10.
- Mannucci, E., Rotella, F., Ricca, V., Moretti, S., Placidi, G. F., & Rotella, C. M. (2005). Eating disorders in patients with type 1 diabetes: a meta-analysis. *Journal of Endocrinological Investigation*, *28*, 417-419.
- Marshall, M. N. (1996). Sampling for qualitative research. *Family practice*, *13*, 522-526.
- Maslow, G. R., Haydon, A. A., Ford, C. A., & Halpern, C. T. (2011). Young adult outcomes of children growing up with chronic illness: an analysis of the National Longitudinal Study of Adolescent Health. *Archives of Pediatrics & Adolescent Medicine*, *165*, 256-261.
- Maunder, R. G., & Hunter, J. J. (2001). Attachment and psychosomatic medicine: developmental contributions to stress and disease. *Psychosomatic Medicine*, *63*, 556-567.
- McBroom, L. A., & Enriquez, M. (2009). Review of family-centered interventions to enhance the health outcomes of children with type 1 diabetes. *The Diabetes Educator*, *March 19*, 1-11.
- McCauley, E., Katon, W., Russo, J., Richardson, L., & Lozano, P. (2007). Impact of anxiety and depression on functional impairment in adolescents with asthma. *General Hospital Psychiatry*, *29*, 214-222.
- Mentoring Australia (2000). Mentoring: Benchmarks for Effective and Responsible Mentoring Programs. Retrieved from: <http://www.m.eane.org/assets/DocMan2/NewFolder/Mentoring-Materials/mentoring-benchmarks.pdf>
- Merkel, R. M., & Wright, T. (2012). Parental self-efficacy and online support among parents of children diagnosed with type 1 diabetes mellitus. *Pediatric Nursing*, *38*, 303-308.
- Merleau-Ponty, M. (1962). *Phenomenology of perception*. London, UK: Routledge.
- Miller, R. G., Secrest, A. M., Sharma, R. K., Songer, T. J., & Orchard, T. J. (2012). Improvements in the life expectancy of type 1 diabetes the Pittsburgh Epidemiology of Diabetes Complications Study Cohort. *Diabetes*, *61*, 2987-2992.
- Mitchell, S. J., Hilliard, M. E., Mednick, L., Henderson, C., Cogen, F. R., & Streisand, R. (2009). Stress among fathers of young children with type 1 diabetes. *Families, Systems, & Health*, *27*, 314-324.

References

- Monaghan, M., Hilliard, M. E., Cogen, F. R., & Streisand, R. (2011). Supporting parents of very young children with type 1 diabetes: Results from a pilot study. *Patient Education and Counseling, 82*, 271-274.
- Moreira, H., Frontini, R., Bullinger, M., & Canavarro, M. C. (2013). Caring for a child with type 1 diabetes: Links between family cohesion, perceived impact, and parental adjustment. *Journal of Family Psychology, 27*, 731.
- Mrazek, D. A., Casey, B., & Anderson, I. (1987) Insecure attachment in severely asthmatic preschool children: Is it a risk factor? *Journal American Academic Child Adolescent Psychiatry, 26*, 516-520
- Murphy, H. R., Rayman, G., & Skinner, T. C. (2006). Psycho-educational interventions for children and young people with Type 1 diabetes. *Diabetic Medicine, 23*, 935-943.
- Murphy, H. R., Wadham, C., Hassler-Hurst, J., Rayman, G., & Skinner, T. C. (2012). Randomized trial of a diabetes self-management education and family teamwork intervention in adolescents with Type 1 diabetes. *Diabetic Medicine, 29*, e249-e254.
- National Voices (2015). *Peer support: What is it and does it work?* Retrieved from: http://www.nationalvoices.org.uk/sites/www.nationalvoices.org.uk/files/peer_support_-_what_is_it_and_does_it_work.pdf
- Newacheck, P. W., & Halfon, N. (1998). Prevalence and impact of disabling chronic conditions in childhood. *American Journal of Public Health, 88*, 610-617.
- Newby, N. M. (1996). Chronic illness and the family life-cycle. *Journal of Advanced Nursing, 23*, 786-791.
- Newell, E., & Hahessy, S. (2013). Social support for the parents of children with type 1 diabetes: an ethnographic study. *Journal of Diabetes Nursing, 17*, 27-31.
- NHS (2014). *Type 1 Diabetes*. Retrieved from: <http://www.nhs.uk/conditions/diabetes-type1/Pages/Introduction.aspx>
- NICE (2004). *Type 1 diabetes: Diagnosis and management of type 1 diabetes in children, young people and adults*. Retrieved from: <http://www.nice.org.uk/guidance/cg15/chapter/1-recommendations>
- Northam, E. A., & Cameron, F. J. (2013). Understanding the diabetic brain: new technologies but old challenges. *Diabetes, 62*, 341-342.

References

- Northam, E. A., Lin, A., Finch, S., Werther, G. A., & Cameron, F. J. (2010). Psychosocial wellbeing and functional outcomes in youth with type 1 diabetes 12 years after disease onset. *Diabetes Care*, *33*, 1430-1437.
- Nylander, C., Seidel, C., & Tindberg, Y. (2014). The triply troubled teenager—chronic conditions associated with fewer protective factors and clustered risk behaviours. *Acta Paediatrica*, *103*, 194-200.
- Office for National Statistics (2013). *Chapter 7 - General health (General Lifestyle Survey Overview - a report on the 2011 General Lifestyle Survey)*. Retrieved from: http://www.ons.gov.uk/ons/dcp171776_302351.pdf
- Office for National Statistics (2014). *Population Estimates for UK, England and Wales, Scotland and Northern Ireland, Mid-2013*. Retrieved from: <http://ons.gov.uk/ons/taxonomy/index.html?nscl=Population#tab-data-tables>
- Okamoto, S. K. (2003). The function of professional boundaries in the therapeutic relationship between male practitioners and female youth clients. *Child and Adolescent Social Work Journal*, *20*, 303-313.
- Olshansky, S. (1962). Chronic sorrow: A response to having a mentally defective child. *Social Casework*, *43*, 190-193.
- Packham, J. C. (2004). Overview of the psychosocial concerns of young adults with juvenile arthritis. *Musculoskeletal Care*, *2*, 6-16.
- Palermo, T. M., Putnam, J., Armstrong, G., & Daily, S. (2007). Adolescent autonomy and family functioning are associated with headache-related disability. *The Clinical Journal of Pain*, *23*, 458-465.
- Pelcovitz, D., Libov, B. G., Mandel, F., Kaplan, S., Weinblatt, M., & Septimus, A. (1998). Posttraumatic stress disorder and family functioning in adolescent cancer. *Journal of Traumatic Stress*, *11*, 205-221.
- Peternelj-Taylor, C. (2002). Professional boundaries. A matter of therapeutic integrity. *Journal of Psychosocial Nursing and Mental Health Services*, *40*, 22-29.
- Peveler, R. C., Bryden, K. S., Neil, H. A. W., Fairburn, C. G., Mayou, R. A., Dunger, D. *et al.* (2005). The relationship of disordered eating habits and attitudes to clinical outcomes in young adult females with type 1 diabetes. *Diabetes Care*, *28*, 84-88.
- Pianta, R. C., & Marvin, R. (1993). *Patterns of parents' reactions to their child's diagnosis: Relations with child-parent interaction*. Paper presented at the meeting of the Society for Research in Child Development, New Orleans, LA.

References

- Pinquart, M. (2013a). Self-esteem of children and adolescents with chronic illness: a meta-analysis. *Child: Care, Health and Development*, *39*, 153-161.
- Pinquart, M. (2013b). Body image of children and adolescents with chronic illness: A meta-analytic comparison with healthy peers. *Body Image*, *10*, 141-148.
- Pinquart, M., & Shen, Y. (2011). Behavior problems in children and adolescents with chronic physical illness: a meta-analysis. *Journal of Pediatric Psychology*, *36*, 1003-1016
- Popp, J. M., Robinson, J. L., Britner, P. A., & Blank, T. O. (2014). Parent adaptation and family functioning in relation to narratives of children with chronic illness. *Journal of Pediatric Nursing*, *29*, 58-64.
- Povlsen, L., & Ringsberg, K. C. (2008). Learning to live with type 1 diabetes from the perspective of young non-western immigrants in Denmark. *Journal of Clinical Nursing*, *17*, 300-309.
- Rearick, E. M., Sullivan-Bolyai, S., Bova, C., & Knafl, K. A. (2011). Parents of children newly diagnosed with type 1 diabetes experiences with social support and family management. *The Diabetes Educator*, *37*, 508-518.
- Reid, K., Flowers, P., & Larkin, M. (2005). Explored lived experience: An introduction to interpretative phenomenological analysis. *The Psychologist*, *18*, 20-23.
- Rennie, D. L. (2009). Logic, Hermeneutics, or Both?. *Pragmatic Case Studies in Psychotherapy*, *5*, 126-135.
- Repper, J. & Carter, T. (2011). A review of the literature on peer support in mental health services. *Journal of Mental Health*, *20*, 392-411.
- Richardson, J. (1996). *Handbook of qualitative research methods for psychology and the social sciences*. Oxford, UK: Wiley-Blackwell.
- Richardson, L. P., Lozano, P., Russo, J., McCauley, E., Bush, T., & Katon, W. (2006). Asthma symptom burden: relationship to asthma severity and anxiety and depression symptoms. *Pediatrics*, *118*, 1042-1051.
- Ricoeur, P. (1970). *Freud and philosophy: An essay on interpretation*. New Haven: Yale University Press.
- Ridge, K., Thomas, S., Jackson, P., Pender, S., Heller, S., Treasure, J., et al. (2014). Diabetes-Oriented Learning Family Intervention (DOLFIN): A feasibility study evaluating an intervention for carers of young persons with Type 1 diabetes. *Diabetic Medicine*, *31*, 55-60.

References

- Roberts, M. C., & Ilardi, S. S. (2005). *Handbook of research methods in clinical psychology*. Oxford, UK: Blackwell.
- Robling, M., McNamara, R., Bennert, K., Butler, C. C., Channon, S., Cohen, D., *et al.* (2012). The effect of the Talking Diabetes consulting skills intervention on glycaemic control and quality of life in children with type 1 diabetes: cluster randomised controlled trial (DEPICTED study). *British Medical Journal*, *344*, 1-17.
- Rogers, E. M. (1995). Diffusion of Innovations: modifications of a model for telecommunications. *Die Diffusion von Innovationen in der Telekommunikation*, *17*, 25-38.
- Rolland, J. S. (1988). Family systems and chronic illness: A typological model. *Journal of Psychotherapy & the Family*, *3*, 143-168.
- Rolland, J. S. (1994). *Families, illness, and disability: An integrative treatment model*. New York, NY: Basic Books.
- Rolland, J. S. (1999). Parental illness and disability: a family systems framework. *Journal of Family Therapy*, *21*, 242-266.
- Rolland, J. S. (2012). *Chronic Pediatric Illness & the Family: An Integrative Treatment Model*. Paper presented at The Chadwick Center's Annual San Diego International Conference on Children and Family Maltreatment.
- Rolls, L., & Relf, M. (2006). Bracketing interviews: Addressing methodological challenges in qualitative interviewing in bereavement and palliative care. *Mortality*, *11*, 286-305.
- Royal College of Physicians (2004). *Type 1 diabetes in adults – National clinical guidelines for diagnosis and management in primary and secondary care*. Retrieved from: <https://www.rcplondon.ac.uk/sites/default/files/documents/type-1-diabetes-guideline.pdf>
- Sanders, M. R., Morawska, A., Haslam, D. M., Filus, A., & Fletcher, R. (2014). Parenting and family adjustment scales (PAFAS): Validation of a brief parent-report measure for use in assessment of parenting skills and family relationships. *Child Psychiatry & Human Development*, *45*, 255-272.
- Saßmann, H., de Hair, M., Danne, T., & Lange, K. (2012). Reducing stress and supporting positive relations in families of young children with type 1 diabetes: A randomized controlled study for evaluating the effects of the DELFIN parenting program. *BMC Pediatrics*, *12*, 152.

References

- Satin, W., La Greca, A. M., Zigo, M. A., & Skyler, J. S. (1989). Diabetes in adolescence: effects of multifamily group intervention and parent simulation of diabetes. *Journal of Pediatric Psychology, 14*, 259-275.
- Shilling, V., Morris, C., Thompson-Coon, J., Ukoumunne, O., Rogers, M., & Logan, S. (2013). Peer support for parents of children with chronic disabling conditions: a systematic review of quantitative and qualitative studies. *Developmental Medicine & Child Neurology, 55*, 602-609.
- Simoni, J. M., Franks, J. C., Lehavot, K., & Yard, S. S. (2011). Peer interventions to promote health: conceptual considerations. *American Journal of Orthopsychiatry, 81*, 351.
- Smith, J. A., Flowers, P., & Larkin, M. (2009). *Interpretative Phenomenological Analysis*. London, UK: Sage Publications.
- Smith, J. A., & Osborn, M. (2007). Interpretative Phenomenological Analysis. In J. A. Smith (Ed.). *Qualitative psychology: A practical guide to research methods*. (pp. 53-82). London, UK: Sage Publications.
- Stallwood, L. (2005). Influence of caregiver stress and coping on glycemic control of young children with diabetes. *Journal of Pediatric Health Care, 19*, 293-300.
- Stam, H., Hartman, E. E., Deurloo, J. A., Groothoff, J., & Grootenhuis, M. A. (2006). Young adult patients with a history of pediatric disease: impact on course of life and transition into adulthood. *Journal of Adolescent Health, 39*, 4-13.
- Stoppelbein, L., & Greening, L. (2007). Brief report: the risk of posttraumatic stress disorder in mothers of children diagnosed with pediatric cancer and type I diabetes. *Journal of Pediatric Psychology, 32*, 223-229
- Streisand, R., Mackey, E. R., Elliot, B. M., Mednick, L., Slaughter, I. M., Turek, J., *et al.* (2008). Parental anxiety and depression associated with caring for a child newly diagnosed with type 1 diabetes: opportunities for education and counseling. *Patient Education and Counseling, 73*, 333-338.
- Streisand, R., Swift, E., Wickmark, T., Chen, R., & Holmes, C. S. (2005). Pediatric parenting stress among parents of children with type 1 diabetes: the role of self-efficacy, responsibility, and fear. *Journal of Pediatric Psychology, 30*, 513-521.
- Streisand, R., Tercyak, K., & Kazak, A. E. (2003). Pediatric-specific parenting stress and family functioning in children treated for cancer. *Child Health Care, 32*, 245-56.

References

- Struempf, K. M. (2012). *Maternal depressive symptoms and disease care behaviors in youths with type 1 diabetes: A mediational model*. Unpublished doctoral thesis, Virginia Commonwealth University.
- Sullivan-Bolyai, S., Bova, C., Lee, M., & Gruppuso, P. A. (2011). Mentoring fathers of children newly diagnosed with T1DM. *MCN: The American Journal of Maternal/Child Nursing, 36*, 224-231.
- Sullivan-Bolyai, S., Bova, C., Leung, K., Trudeau, A., Lee, M., & Gruppuso, P. (2010). Social support to empower parents (STEP) An intervention for parents of young children newly diagnosed with type 1 diabetes. *The Diabetes Educator, 36*, 88-97.
- Sullivan-Bolyai, S., Deatrck, J., Gruppuso, P., Tamborlane, W., & Grey, M. (2003). Constant vigilance: Mothers' work parenting young children with type 1 diabetes. *Journal of Pediatric Nursing, 18*, 21-29.
- Sullivan-Bolyai, S., Grey, M., Deatrck, J., Gruppuso, P., Giraitis, P., & Tamborlane, W. (2004). Helping other mothers effectively work at raising young children with type 1 diabetes. *The Diabetes Educator, 30*, 458-461.
- Sullivan-Bolyai, S., & Lee, M. M. (2011). Parent mentor perspectives on providing social support to empower parents. *The Diabetes Educator, 37*, 35-43.
- Sullivan-Bolyai, S., Rosenberg, R., & Bayard, M. (2003). Fathers' reflections on parenting young children with type 1 diabetes. *MCN American Journal of Maternal Child Nursing, 31*, 24-31.
- Surís, J. C., Parera, N., & Puig, C. (1996). Chronic illness and emotional distress in adolescence. *Journal of Adolescent Health, 19*, 153-156.
- Svavarsdottir, E. K., Rayens, M. K., & McCubbin, M. (2005). Predictors of adaptation in Icelandic and American families of young children with chronic asthma. *Family & Community Health, 28*, 338-350.
- Svavarsdottir, E. K., Sigurdardottir, A. O., & Tryggvadottir, G. B. (2014). Strengths-Oriented Therapeutic Conversations for Families of Children With Chronic Illnesses Findings From the Landspítali University Hospital Family Nursing Implementation Project. *Journal of Family Nursing, 20*, 13-50.
- Sykes, T. A., Venkatesh, V., & Gosain, S. (2009). Model of acceptance with peer support: A social network perspective to understand employees' system use. *Mis Quarterly, 37*, 371-393.

References

- Tansella, C. Z. (1995). Psychosocial factors and chronic illness in childhood. *European Psychiatry, 10*, 297-305.
- Tennant, M. (2006). *Psychology and adult learning*. Oxon, UK: Taylor & Francis.
- Therlund, G., Dahlquist, G., Hägglöf, B., Ivarsson, S. A., Lernmark, B., Ludvigsson, J., *et al.* (1996). Psychological reactions at the onset of insulin-dependent diabetes mellitus in children and later adjustment and metabolic control. *Acta Paediatrica, 85*, 947-953.
- Therlund, G., Dahlquist, G., Ivarsson, S. A., Ludvigsson, J., Sjöblad, S., & Hägglöf, B. (1996). The initial psychologic reactions of the parents at the onset of insulin-dependent diabetes mellitus in children and short-time adaptation. *Nordic Journal of Psychiatry, 50*, 199 -206
- Thies, K. M. (1999). Identifying the educational implications of chronic illness in school children. *Journal of School Health, 69*, 392-397.
- Thompson Jr, R. J., & Gustafson, K. E. (1996). *Adaptation to chronic childhood illness*. Washington, DC: American Psychological Association.
- Trickey, D., Siddaway, A. P., Meiser-Stedman, R., Serpell, L., & Field, A. P. (2012). A meta-analysis of risk factors for post-traumatic stress disorder in children and adolescents. *Clinical Psychology Review, 32*, 122-138.
- Trollvik, A., & Severinsson, E. (2004). Parents' experiences of asthma: Process from chaos to coping. *Nursing & Health Sciences, 6*, 93-99.
- Tsiouli, E., Alexopoulos, E. C., Stefanaki, C., Darviri, C., & Chrousos, G. P. (2013). Effects of diabetes-related family stress on glycemic control in young patients with type 1 diabetes Systematic review. *Canadian Family Physician, 59*, 143-149.
- Valenzuela, J. M., Patino, A. M., McCullough, J., Ring, C., Sanchez, J., Eidson, M., *et al.* (2006). Insulin pump therapy and health-related quality of life in children and adolescents with type 1 diabetes. *Journal of Pediatric Psychology, 31*, 650-660.
- Van Cleave, J., Gortmaker, S. L., & Perrin, J. M. (2010). Dynamics of obesity and chronic health conditions among children and youth. *Journal of American Medical Association, 303*, 623-630.
- van der Lee, J. H., Mokkink, L. B., Grootenhuis, M. A., Heymans, H. S., & Offringa, M. (2007). Definitions and measurement of chronic health conditions in childhood: a systematic review. *Journal of American Medical Association, 297*, 2741-2751.

References

- Varni, J.W., Burwinkle, T. M., & Seid, M. (2005). The PedsQL™ as a pediatric patient-reported outcome: Reliability and validity of the PedsQL™ Measurement Model in 25,000 children. *Expert Review of Pharmacoeconomics and Outcomes Research*, 5, 705-719.
- Varni, J. W., Burwinkle, T. M., Seid, M., & Skarr, D. (2003). The PedsQL™ 4.0 as a pediatric population health measure: Feasibility, reliability, and validity. *Ambulatory Pediatrics*, 3, 329-341
- Varni, J.W., Limbers, C.A., & Burwinkle, T.M. (2007). Impaired health-related quality of life in children and adolescents with chronic conditions: A comparative analysis of 10 disease clusters and 33 disease categories/severities utilizing the PedsQL™ 4.0 Generic Core Scales. *Health and Quality of Life Outcomes*, 5, 1-15.
- Visser, M. J. (2004). Implementing peer support in schools: Using a theoretical framework in action research. *Journal of Community & Applied Social Psychology*, 14(6), 436-454.
- Wainwright, N. W. J., Surtees, P. G., Wareham, N. J., & Harrison, B. D. W. (2007). Psychosocial factors and incident asthma hospital admissions in the EPIC-Norfolk cohort study. *Allergy*, 62, 554-560.
- Walker, G., & Bryant, W. (2013). Peer support in adult mental health services: A metasynthesis of qualitative findings. *Psychiatric Rehabilitation Journal*, 36(1), 28.
- Wennick, A., & Hallström, I. (2006). Swedish families' lived experience when a child is first diagnosed as having insulin-dependent diabetes mellitus an ongoing learning process. *Journal of Family Nursing*, 12, 368-389
- White, C. (2009). An update to measuring chronic illness, impairment and disability in national data sources. *Health Statistics Quarterly*, 42, 40-53.
- Whittemore, R., Jaser, S., Chao, A., Jang, M., & Grey, M. (2012). Psychological experience of parents of children with type 1 diabetes a systematic mixed-studies review. *The Diabetes Educator*, 38, 562-579.
- Whittemore, R., Jaser, S., Guo, J., & Grey, M. (2010). A conceptual model of childhood adaptation to type 1 diabetes. *Nursing Outlook*, 58, 242-251.
- Whittemore, R., Urban, A. D., Tamborlane, W. V., & Grey, M. (2003). Quality of life in school-aged children with type 1 diabetes on intensive treatment and their parents. *The Diabetes Educator*, 29, 847-854.

References

- Whittingham, K., Wee, D., Sanders, M. R., & Boyd, R. (2013). Predictors of psychological adjustment, experienced parenting burden and chronic sorrow symptoms in parents of children with cerebral palsy. *Child: Care, Health and Development, 39*, 366-373.
- Wiebe, D. J., Berg, C. A., Korbel, C., Palmer, D. L., Beveridge, R. M., Upchurch, R., *et al.* (2005). Children's appraisals of maternal involvement in coping with diabetes: Enhancing our understanding of adherence, metabolic control, and quality of life across adolescence. *Journal of Pediatric Psychology, 30*, 167-178.
- Wiedebusch, S., Ganser, G., Saenger, N., & Muthny, F. (2007). Chronic Sorrow in Parents of Children with Juvenile Idiopathic Arthritis. *Aktuelle Rheumatologie, 32*, 349-354.
- Winkley, K., Landau, S., Eisler, I., & Ismail, K. (2006). Psychological interventions to improve glycaemic control in patients with type 1 diabetes: systematic review and meta-analysis of randomised controlled trials. *British Medical Journal, 333*, 65.
- Woodgate, R. L. (1998). Adolescents' perspectives of chronic illness: "It's hard". *Journal of Pediatric Nursing, 13*, 210-223.
- World Health Organization (2008). *Peer Support Programmes in Diabetes: Report of a WHO Consultation 5-7 November 2007*. Geneva, Switzerland: WHO.
- Worrall-Davies, A., Owens, D., Holland, P., & Haigh, D. (2002). The effect of parental expressed emotion on glycaemic control in children with Type 1 diabetes: Parental expressed emotion and glycaemic control in children. *Journal of Psychosomatic Research, 52*, 107-113.
- Wray, J., & Maynard, L. (2005). Living with congenital or acquired cardiac disease in childhood: maternal perceptions of the impact on the child and family. *Cardiology in the Young, 15*, 133-140.
- Wysocki, T., Harris, M. A., Greco, P., Bubb, J., Danda, C. E., Harvey, L. M., *et al.* (2000). Randomized, controlled trial of behavior therapy for families of adolescents with insulin-dependent diabetes mellitus. *Journal of Pediatric Psychology, 25*, 23-33.
- Wysocki, T., Miller, K. M., Greco, P., Harris, M. A., Harvey, L. M., Taylor, A., *et al.* (1999). Behavior therapy for families of adolescents with diabetes: Effects on directly observed family interactions. *Behavior Therapy, 30*, 507-525.

References

- Yeh, C. H. (2003). Dynamic coping behaviors and process of parental response to child's cancer. *Applied Nursing Research, 16*, 245-255.
- Zheng, X. P., & Chen, S. H. (2013). Psycho-behavioral changes in children with type 1 diabetes mellitus. *World Journal of Pediatrics, 9*, 261-265.

Appendix I
Further Information about Diabetes Mellitus Type 1 (T1DM)

Diagnosis

Children with T1DM most often present with a two to six week history of a classic triad of symptoms (Kumar & Clark, 2005). Firstly, polyuria (frequent urination) which occurs because 'blood glucose levels exceed the renal threshold' (p. 1108). Secondly, feeling thirsty more often than usually, because of the loss of electrolytes and fluid as a result of frequent urination. Thirdly, weight loss due to water loss and the lack of insulin causing a breakdown of fat and muscle.

Patients who present with these symptoms will have their urine tested for glucose. Glucose would not normally be present in urine but would be in those with type 1 diabetes. If glucose is detected then, then the diagnosis is confirmed by a blood test. If it is not detected then a glucose tolerance test can be undertaken to detect signs of type 1 diabetes (NHS, 2014).

For some patients, the journey to diagnosis is less smooth. If it is not detected at an early stage and the disease remained unmanaged, patients can present with diabetic ketoacidosis (Kumar & Clark, 2005). This occurs when the body breaks down fat as fuel as there is no insulin to break down glucose. The by-product of this process is the production of ketones, which can build up in the body. Patients present with hyperventilation, nausea, vomiting and abdominal pain. Such a presentation is a medical emergency and if untreated cause the patient fall into a coma and be fatal (RCP, 2004).

Long term effects

Following diagnosis, children and adults with T1DM are at long term risk of cardiovascular disease, kidney disease, retinopathy, nerve damage and loss of limbs, compared to the general population (NHS, 2014). People with T1DM have traditionally had significantly shortened life expectancy compared to the general population, with recent estimates from a longitudinal study of patients with T1DM indicating a difference of between 8-12 years compared to the general population. (Miller et al., 2012).

Appendix II

Systematic Review Search Terms

1. "type 1 diabetes".mp. [mp=ab, hw, ti, ot, nm, kf, px, rx, an, ui, tc, id, tm]
2. "diabetes mellitus type 1".mp. [mp=ab, hw, ti, ot, nm, kf, px, rx, an, ui, tc, id, tm]
3. 1 or 2
4. (parent? or father? or mother?).mp. [mp=ab, hw, ti, ot, nm, kf, px, rx, an, ui, tc, id, tm]
5. (intervention or support).mp. [mp=ab, hw, ti, ot, nm, kf, px, rx, an, ui, tc, id, tm]
6. 3 and 4 and 5
7. limit 6 to abstracts
8. limit 7 to english language
9. limit 8 to yr="1990 -Current"
10. remove duplicates from 9
11. remove duplicates from 9
12. limit 11 to yr="2000 -Current"
13. wellbeing.mp. [mp=ab, hw, ti, ot, nm, kf, px, rx, an, ui, tc, id, tm]
14. depression.mp. [mp=ab, hw, ti, ot, nm, kf, px, rx, an, ui, tc, id, tm]
15. adjustment.mp. [mp=ab, hw, ti, ot, nm, kf, px, rx, an, ui, tc, id, tm]
16. anxiety.mp. [mp=ab, hw, ti, ot, nm, kf, px, rx, an, ui, tc, id, tm]
17. adaptation.mp. [mp=ab, hw, ti, ot, nm, kf, px, rx, an, ui, tc, id, tm]
18. 13 or 14 or 15 or 16 or 17
19. 12 and 18

Appendices

Appendix III

Details of Excluded Papers from Systematic Review

| Author and Article Title | Reason for exclusion |
|--|--|
| Chernoff <i>et al.</i> (2002) <i>'A randomized, controlled trial of a community-based support program for families of children with chronic illness: Pediatric outcomes.'</i> | No separate data reported for children with T1DM. |
| Jaser & Grey (2010) <i>'A pilot study of observed parenting and adjustment in adolescents with type 1 diabetes and their mothers.'</i> | Not an intervention study. |
| Kichler <i>et al.</i> (2013) <i>'Effectiveness of groups for adolescents with Type 1 diabetes mellitus and their parents.'</i> | Intervention aimed at parent and child. |
| Konradsdottir & Svavarsdottir (2011) <i>'How effective is a short-term educational and support intervention for families of an adolescent with type 1 diabetes?'</i> | Intervention aimed at parent and child. |
| Murphy <i>et al.</i> (2012) <i>'Randomized trial of a diabetes self-management education and family teamwork intervention in adolescents with Type 1 diabetes.'</i> | No parental psychosocial outcomes measured. |
| Svavarsdottir <i>et al.</i> (2014) <i>'Strengths-Oriented Therapeutic Conversations for Families of Children With Chronic Illnesses Findings From the Landspítali University Hospital Family Nursing Implementation Project.'</i> | No separate parental wellbeing data for children with T1DM |
| Wysocki <i>et al.</i> (2000) <i>'Randomized, controlled trial of behavior therapy for families of adolescents with insulin-dependent diabetes mellitus.'</i> | No parental psychosocial outcomes measured. |
| Wysocki <i>et al.</i> (1999). <i>'Behavior therapy for families of adolescents with diabetes: Effects on directly observed family interactions.'</i> | Publication date outside of inclusion criteria. Intervention aimed at family not parents alone. |

Appendices

Appendix IV. SURE Quantitative Review Scoring Criteria Table – Detailed View.

| Criteria | Grey et al. (2011) | Hoff et al (2005) | Merkel & Wright (2012) | Monaghan et al (2011) | Ridge et al (2013) |
|--|---|---|---|---|--|
| 1. Does the study address a clearly focused question/ hypothesis? | Yes | Yes | Yes | Yes | Yes |
| <i>Details</i> | Outlines two aims of the study and four hypotheses regarding the outcome of the intervention | Outlines three hypotheses regarding outcome of the intervention | General aim identified in terms of impact of intervention on parental self efficacy. Introduced prior to introduction so not framed by research base initially. | Outlines two hypotheses regarding outcome of the intervention | Outlines aims of pilot study to examine trends of impact |
| 1.1 Population/Problem? | Yes | Yes | Yes | Yes | Yes |
| <i>Details</i> | Parents of preadolescent children (1-12years old) with type 1 diabetes versus 'attention-control' group | Parents of children under 18 years old with diagnosis of T1DM | Parents of children with T1DM | Parent of child with T1DM who is 2-5 years old | Parents of child with T1DM for more than 1 year, aged 10-18 years old. |
| 1.2 Intervention? | Yes | Yes | Yes | Yes | Yes |
| <i>Details</i> | Coping skills training intervention | Uncertainty management group session | Online social support platform | Supporting Parents program | Diabetes Orientated Learning Family Intervention (DOLFIN) |
| 1.3 Comparator/control? | Yes | yes | No | Yes | No |
| <i>Details</i> | Group diabetes education intervention | TAU | No comparison group | TAU | No comparison group |
| 1.4 Outcomes? Can you identify the primary outcome? | Yes | Yes | Yes | Yes | Yes |

Appendices

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|---|---|--|---|---|--|
| <i>Details</i> | Clear outcome measures identified of depression, diabetes responsibility and parents diabetes quality of life | Clear outcome measures identified of Perception of uncertainty, psychological distress and behaviour of child | Two outcome measures identified | Clear outcome measures identified of depression, perceived social support, illness related parenting stress, anxiety and treatment satisfaction | Limited information regarding outcome measures- authors identified that they were unsure what they would find therefore sought to measure a broad range of outcomes. Only identified in the results. |
| 2. Was the population randomised? If YES, were appropriate methods used? | Yes | Yes | n/a | Yes | n/a |
| <i>Details</i> | Randomised using 'sealed envelope approach' | Staff member unfamiliar with participants 'randomly selected sealed slips of papers on which numbers indicated group assignment' | n/a | Method not reported | n/a |
| 3. Was allocation to intervention or comparator groups concealed? | Can't tell | No | No | Can't tell | No |
| <i>Details</i> | No details regarding participants being informed of group allocation | TAU group were aware of being in group and offered the intervention at later date from the outset. | Group given information about the support platform. | No details regarding participants being informed of group allocation | All eligible families in the hospital's catchment area were included. |
| 4. Were participants/ investigators blinded to group allocation? | Can't tell | Can't tell | No | Can't tell | No |

Appendices

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|--|--|---|--|---|---|
| <i>Details</i> | No details provided regarding blinding | No details provided regarding blinding | No blinding | No details provided regarding blinding | No blinding |
| 5. Were interventions (and comparisons) well described and appropriate? | Yes | Yes | No | Yes | Yes |
| <i>Details</i> | Theory based intervention drawing on literature regarding parental coping with chronic illness. Authors described appropriate alternative intervention as comparative sample | Theory based intervention targeting illness uncertainty. Structure and training well described and detailed | Very brief description. Frequency and interactional nature of use was not examined | Theory and evidence based supportive program used in adolescents with T1DM being applied to parents | Theory based intervention using motivational interviewing techniques and provide opportunity for social support |
| 6. Was ethical approval sought and received? | Can't tell | Can't tell | Can't tell | Can't tell | Yes |
| <i>Details</i> | No details regarding ethical approval | No details regarding ethical approval | No details regarding ethical approval | No details regarding ethical approval | Quoted ethical approval number from university |
| 7. Was a trial protocol published? | Can't tell | Can't tell | Can't tell | Can't tell | Can't tell |
| <i>Details</i> | No details reported | No details reported | No details reported | No details reported | No details reported |
| 8. Were the groups similar at the start of the trial? | No | Yes | n/a | Yes | n/a |
| <i>Details</i> | IG had significantly greater issues with coping, impact of QoL and diabetes related family conflict compared to control group. Difference was controlled for in analyses | No significant differences in demographic parameters or baseline variables between groups. | No comparison group | No significant differences in demographic parameters or baseline variables between groups. | No comparison group |
| 9. Was the sample size sufficient? | Yes | No | No | No | No |

Appendices

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|---|--|---|--|---|--|
| <i>Details</i> | 75 vs. 48 - Authors merged two data sets to achieve sufficient power. Power calculation not reported | Authors reported power analysis required 65 participants per group. However, only 31 participants in IG and 28 in control were recruited and retained. | Limited data analysis possible. N= 9 | Author identified inadequate statistical power. N=24 | Author identified inadequate statistical power. N=17 |
| 10. Were participants properly accounted for? | Yes | Yes | No | Yes | Yes |
| <i>Details</i> | Participants were followed up 3, 6 and 12 months after intervention. 10 lost from intervention group and 7 from control group. Authors distinguished between those lost to follow up and those who dropped out | Participants were followed up at 1 month and 6 months intervals. Authors distinguished between those lost to follow up and those who dropped out. However, there is some confusion in changing between 'families' recruited and individual parents recruited. | Follow up after 6 weeks. No information provided on the 35% lost to follow up. | Participants were followed up 3 weeks post intervention. Authors of the participants who were lost to follow, withdrew etc. | Participants were followed up 3 months from baseline. Authors cited reasons from participants for 16 of 22 participants no attending all sessions. Did not have ethical approval to acquire information regarding drop out |
| 11. Data analysis 11.1 Are you confident with the authors' choice and use of statistical methods? 11.2 Were estimates of effect size given? 11.3 Were the analytical methods appropriate? 11.4 Was the precision of intervention effects (confidence intervals) given? | 11.1 Yes 11.2 No 11.3 Yes 11.4 Yes | 11.1 Yes 11.2 Yes 11.3 Yes 11.4 Yes | 1. Yes 2. No 3. Yes 4. Yes | 1. Yes 2. No 3. Yes 4. Yes | 1. Yes 2. No 3. Yes 4. Yes |

Appendices

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|--|---|---|--|--|--|
| <i>Details</i> | 11.1 Authors gave detailed, well referenced justification of data analyses. 11.2 No effect size were reported. 11.4 Exact p values were reported, unless $p < .001$. | 11.1 Authors gave detailed, well referenced justification of data analyses. 11.2 Calculation of effect size were reported. 11.4 Exact p values were reported, unless $p < .001$. | 11.1 Provided justification of limited statistical analysis due to small sample size. 11.2 Precise p values were provided 11.4 No effect size provided due to small sample size. | 11.1 Provided justification of limited statistical analysis due to small sample size. 11.2 Precise p values were reported. 11.4 No effect size reported. | 11.1 Provided justification of limited statistical analysis due to small sample size. 11.2 Precise confidence intervals were reported. 11.4 No effect size reported. |
| 12. Results 12.1 Were outcome measures reliable (e.g. objective or subjective measures)? 12.2 Were all outcome measurements complete? 12.3 Were all important outcomes assessed? 12.4 Are the authors' conclusions adequately supported by the results? | 12.1 Yes 12.2 Yes 12.3 Yes 12.4 Yes | 12.1 Yes 12.2 Yes 12.3 Yes 12.4 Yes | 12.1 No 12.2 Yes 12.3 No 12.4 No | 12.1 Yes 12.2 Yes 12.3 Yes 12.4 Yes | 12.1 Can't tell 12.2 Yes 12.3 No 12.4 Yes |

Appendices

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|--|--|--|--|--|---|
| <i>Details</i> | 12.1 Cronbach's alpha's reported for all instruments used. 12.2 All outcome measures fully assessed and reported. 12.4 Conclusions are fair but overall optimistic considering the lack of intervention effect | 12.1 Cronbach's alpha's reported for all instruments used. 12.2 All outcome measures fully assessed and reported. 12.4 Conclusions are fair, reflecting the impact on distress but not uncertainty of parents. | 12.1 Little information provided about reliability or validity of methods, especially considering one measure had been adapted for use in this study 12.2 All outcome measures were completed by retained participants 12.3 No assessment of interface with the social support or perceived social support measure 12.4 Authors appear to generalise results with disproportionate confidence considering small sample size | 12.1 Cronbach's alpha reported for all outcome measures 12.2 All outcome measures were completed by retained participants 12.4 Tentative conclusion about the future potential. Authors describe intent to further develop and conduct RCT of intervention | 12.1 No information regarding validity/reliability of outcome measures 12.2 All outcome measures completed by retained participants 12.3 No assessment of perceived social support considering that was one of their aims to foster amongst parents 12.4 Focus lay on the qualitative feedback |
| 13. Is any sponsorship/conflict of interest reported? | Yes | Yes | Yes | Yes | Yes |
| <i>Details</i> | Author acknowledges funding grant from National Institute of Nursing Research, USA. | Authors acknowledges funding from Oklahoma Center for Science and Technology | States no actual or potential conflict of interest identified. | States funding through grant from National Institute of Diabetes and Digestive and Kidney Diseases and an internal Research Advisory Council grant | States sources of funding from Biomedical Research Centre (BRC) and by the National Institute for Health Research (NIHR) Collaborations for Leadership in Applied Health Research and Care (CLAHRC) for South Yorkshire. |

Appendices

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|--|--|---|--|--|--|
| 14. Did the authors identify any limitations? | Yes | Yes | Yes | Yes | Yes |
| <i>Details</i> | White middle to upper class population Children predominantly on pumps resulting in better diabetes control Does not assess impact of child characteristics on changes in parent affect | Small sample size Homogenous sample 68% retention rate - speculate that this may skew the sample towards well functioning, motivated group. | Short follow up time frame Small sample size | Small sample size Homogenous sample of mothers in middle-upper middle class income levels | Sample size Homogenous white British sample- challenge to retain those from diverse backgrounds |
| 15. Are the conclusions the same in the abstract and the full text? | No | Yes | No | Yes | Yes |
| <i>Details</i> | States that group interventions are promising in improving coping and quality of life. However, fails to state the lack of effect of active intervention and fails to show difference from natural changes over time | Highlights changes in distress and child behaviour. Does not identify lack of change to uncertainty which the intervention was aimed at. | Fails to identify small sample size and implications for results inferring generalisability of significant results | Highlights promises results but identifies further work to confirm results | Recognises challenge in recruitment/retention but points to promising preliminary results |
| ----- | ----- | ----- | ----- | ----- | ----- |
| Criteria | Sassmann et al (2012) | Sullivan-Bolyai et al (2004) | Sullivan-Bolyai et al (2010) | Sullivan et al (2011) | Tsiouli et al (2014) |
| 1. Does the study address a clearly focused question/hypothesis? | Yes | Yes | Yes | Yes | Yes |
| <i>Details</i> | Outlines two hypotheses relating to parental wellbeing and child behaviour | Outline aim to investigate impact of peer mentoring for parents of child with T1DM | To build on findings from Sullivan-Bolyai et al's 2004 study to extend use to father | Outlines three aims regarding testing outcomes for application of peer mentoring to fathers | Outlines three aims |
| 1.1 Population/Problem? | Yes | Yes | Yes | Yes | Yes |

Appendices

| <i>Details</i> | Parents of child with T1DM aged 2-10 years old. | Parents of child newly diagnosed with T1DM | Parents of children with newly diagnosed T1DM | Fathers of child with T1DM | Parents of children with T1DM |
|--|---|---|---|---|---|
| 1.2 Intervention? | Yes | Yes | Yes | Yes | Yes |
| <i>Details</i> | DELFIN parenting program | Telephone parent mentoring | Telephone and face to face parent mentoring by trained experienced parents | Same intervention at Sullivan-Bolyai et al (2010) | Relaxation technique training and healthy living instructions |
| 1.3 Comparator/ control? | Yes | Yes | Yes | Yes | Yes |
| <i>Details</i> | Wait list control | TAU | Telephone parent mentoring by non trained parent | Telephone parent mentoring by non trained parent | Healthy living instructions |
| 1.4 Outcomes? Can you identify the primary outcome? | Yes | Yes | Yes | Yes | Yes |
| <i>Details</i> | Clear outcome measures identified to assess parenting skills, depression, anxiety, child behaviour. | Clear outcome measures identified for measurement of diabetes management, parental confidence, impact on the family, home care resources and child related costs. | Clear outcome measures identified for measurement of diabetes management, worry, confidence, impact on family of illness and social support | Clear outcome measures identified for measurement of perceived support, disease concern, worry, confidence, impact on family and social support | Clear outcomes measures identified for measurement of salivary cortisol, lifestyle (health), perceived stress, parental stress and perception of health |
| 2. Was the population randomised? | Yes | Yes | Yes | Yes | Yes |
| <i>Details</i> | Method not reported | Method not reported | Method not reported | Method not reported | Computer randomisation program (random.org) |
| 3. Was allocation to intervention or comparator groups concealed? | No | Can't tell | Can't tell | Can't tell | Can't tell |

Appendices

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|--|---|---|--|--|--|
| <i>Details</i> | Families informed of group | No details regarding participants being informed of group allocation | No details regarding participants being informed of group allocation | No details regarding participants being informed of group allocation | No details regarding participants being informed of group allocation |
| 4. Were participants/ investigators blinded to group allocation? | Can't tell | Can't tell | No | No | No |
| <i>Details</i> | No details provided regarding blinding | No details regarding participants being informed of group allocation | Parents informed of allocation | Parents informed of allocation | Parents informed of allocation |
| 5. Were interventions (and comparisons) well described and appropriate? | Yes | Yes | Yes | Yes | Yes |
| <i>Details</i> | Theory based intervention using behaviour therapy techniques. Details of each session's content are provided. | Based on evidence from peer mentoring from rheumatoid arthritis, seeks to apply principle to T1DM | Based on previous studies by Ireys et al and Sullivan-Bolyai. | Based on previous studies by Ireys et al and Sullivan-Bolyai. | Based on evidence of stress management for parents impact on metabolic control in children with T1DM |
| 6. Was ethical approval sought and received? | Yes | Can't tell | Can't tell | Can't tell | Yes |
| <i>Details</i> | Ethical approval granted by Hanover University | No details regarding ethical approval | No details regarding ethical approval | No details regarding ethical approval | Ethical approval provided by Agia Sofia Paediatric Hospital |
| 7. Was a trial protocol published? | Can't tell | can't tell | can't tell | can't tell | Can't tell |
| <i>Details</i> | No details reported | No details reported | No details reported | No details reported | No details reported |
| 8. Were the groups similar at the start of the trial? | Yes | Yes | Yes | Yes | Yes |

Appendices

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|--|---|--|---|--|--|
| <i>Details</i> | Fathers in DELFIN group significantly more educated DELFIN group parents scored significantly higher on one subscale of the Parenting Scale Otherwise no significant differences | No significant differences in demographics or baseline scores | Difference between groups in birth order of child with T1DM. No description of differences being taken account of in analyses. | No significant differences in demographics or baseline scores | No significant difference in demographics or baseline scores |
| 9. Was the sample size sufficient? | No | No | Yes | No | Yes |
| <i>Details</i> | Author identified limitations of small pilot sample N=65 | Author identified limitations of small pilot sample N=41 | Author does not cite small sample size as limitation of the study. N=58 | Author identifies lack of power to achieve statistical significance. N=27 | Authors set probability level for significance at $\alpha=0.05$ to allow for small sample size impact on type 2 errors |
| 10. Were participants properly accounted for? | Yes | Yes | Yes | Yes | Yes |
| <i>Details</i> | Participants were followed up at 3 and 12 months. Authors provided details of those lost of followed up or discontinuation of intervention. | Participants were followed after 6 month trial period. Authors provided details of those lost of followed up or discontinuation of intervention. | Participants were followed up at 3, 6 and 12 months. Authors noted the difference in demographics of those who dropped out being more likely to be less educated, divorced or separated or working full time. | Participants were followed up at 12months. Author did not provide details of participants lost to follow up. | Participants were followed up at 8 weeks. Authors provided details of reasons for drop out at different stages of the study. |

Appendices

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|--|--|---|---|---|--|
| <p>11.1 Are you confident with the authors' choice and use of statistical methods? 11.2 Were estimates of effect size given? 11.3 Were the analytical methods appropriate? 11.4 Was the precision of intervention effects (confidence intervals) given?</p> | <p>1. Yes 2. Yes 3. Yes 4. Yes</p> | <p>11.1 No 11.2 No 11.3 Can't tell 11.4 Yes</p> | <p>11.1 Yes 11.2 No 11.3 Yes 11.4 Yes</p> | <p>11.1 Yes 11.2 Yes 11.3 Yes 11.4 Yes</p> | <p>11.1 Yes 11.2 Yes 11.3 Yes 11.4 Yes</p> |
| <p><i>Details</i></p> | <p>11.1 Provided brief overview of analysis plan but no justification for chosen course. 11.2 Effects sizes reported using cohen's d. 11.4 Exact p values were only provided for insignificant results, otherwise it was presented as $p < .05$ or $p < .001$.</p> | <p>11.1 No details of statistical analysis undertaken is given, only p values and f statistic are reported. . 11.2 No effect sizes provided. 11.4 Exact p values were reported.</p> | <p>11.1 Provided overview of statistical analyses and details of possible biases in the data. 11.2 No effect sized provided. 11.4 Exact p values were reported.</p> | <p>11.1 Provided overview of statistical analyses and details of taking small sample size into account. 11.2 Effects sizes reported 11.4 Exact p values are reported.</p> | <p>11.1 Provided overview of statistical analyses and details of taking small sample size into account. 11.2 Effect sizes were reported using Cohen's <i>d</i>. 11.4 Exact p values were reported.</p> |
| <p>12.1 Were outcome measures reliable (eg objective or subjective measures)? 12.2 Were all outcome measurements complete? 12.3 Were all important outcomes assessed? 12.4 Are the authors' conclusions adequately supported by the results?</p> | <p>12.1 Yes 12.2 Yes 12.3 No 12.4 Yes</p> | <p>12.1 Yes 12.2 Yes 12.3 No 12.4 Yes</p> | <p>12.1 Can't tell 12.2 Yes 12.3 Yes 12.4 Yes</p> | <p>12.1 Yes 12.2 Yes 12.3 No 12.4 Yes</p> | <p>12.1 Yes 12.2 Yes 12.3 Yes 12.4 Yes</p> |

Appendices

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|--|---|--|--|---|--|
| <i>Details</i> | 12.1 Cronbach's Alpha reported for all outcome measure 12.2 All outcomes measures were completed by retained participants 12.3 No comparison of significant difference between control and intervention group 12.4 Identifies tentative positive results however fails to mention the lack of statistical analysis between control and intervention group. | 12.1 Cronbach's Alpha reported for all outcome measure 12.2 All outcomes measures were completed by retained participants 12.3 No assessment of parental wellbeing outside of diabetes 12.4 Identifies promising piloting data that needs to be further developed | 12.1 Cronbach's Alpha reported for all outcome measure 12.2 All outcomes measures were completed by retained participants 12.4 Reflects the disparity between formal outcome measures and anecdotal reports of impact. | 12.1 Cronbach's Alpha reported for all outcome measure 12.2 All outcomes measures were completed by retained participants 12.3 Did not account for interaction between parents as both were in the same group 12.4 Reflect the preliminary results in the context of methodological issues | 12.1 Steps were taken to ensure reliability and validity of salivary cortisol e.g. different timing and mixture of participant and staff administration. All but the questionnaire assessing life style parameters had Cronbach's alpha reported. 12.2 All outcomes measures were completed by retained participants 12.4 Reflects the conflicting impact on cortisol versus perceived stress. |
| 13. Is any sponsorship/conflict of interest reported? | Yes | Yes | Yes | Yes | Yes |
| <i>Details</i> | Declared the absence of any conflicts of interest | Declared funding by grant from National Institute of Nursing Research and postdoctoral aware from Friends of the National Institute of Nursing Research. | Declare funding by NIH-NINR | Declared part funding by NIH-NINR. | Declared no conflict of interest or financial support was received |
| 14. Did the authors identify any limitations? | Yes | Yes | Yes | Yes | Yes |

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|--|--|--|--|--|--|
| <i>Details</i> | Self selection in pilot sample as those in control refused to participate once randomised therefore resulting in positive parenting status in remaining control. Small sample size Good metabolic control amongst population compared to other populations | Small sample size and short intervention period Only included mothers Lack of cultural diversity | Homogenous sample with low cultural diversity 49.2% refusal rate at first contact Issues with randomisation as those randomised to control showed higher rates of drop out despite being offered support at later date | Homogenous sample Intrafamilial contamination Differences in communication between fathers and mothers | Small sample size Self reported questionnaires No control of possible confounders such as personality or health Less systematic control in control group Lack of longer term follow up |
| 15. Are the conclusions the same in the abstract and the full text? | Yes | Yes | Yes | n/a | No |
| <i>Details</i> | Highlights promises results but identifies further work to confirm results | Highlights possible feasibility and potential for future use. | Reflects the disparity between formal outcome measures and anecdotal reports of impact. | No conclusion in the abstract, only clinical implications | Reflects positive impact on perceived stress but does not reflect the lack of change to cortisol levels |

Appendix V

Summary of Participant Flow through Systematic Review Papers

| Author | Participants assessed for eligibility | Participants Randomised | Participants prior to intervention | Final sample |
|---|---|--|---|---|
| Grey <i>et al.</i> (2011) | 367 (186 excluded- 17 ineligible 117 declined 52 re-approach) | 181 (52 could not schedule intervention) | 129 (drop out/lost to follow up ratio unclear) | 123 |
| Hoff <i>et al.</i> (2005) | 69 (23 excluded- 12 ineligible 6 declined 6 time/travel barriers) | 46 (4 did not receive intervention- practical barriers) | 42 (8 lost to follow up) | 34 |
| Merkel and Wright (2012) | Not stated | n/a | 14 | 9 |
| Monaghan <i>et al.</i> (2011) | 50 (26 excluded- 1 ineligible 22 unable to reach 3 declined to consent) | 24 | 24 (5 did not attend all sessions) | 19 |
| Ridge <i>et al.</i> (2014) | 106 (no information provided) | n/a | 31 (14 did not attend all sessions) | 17 |
| Saßmann <i>et al.</i> (2012) | 58 families (21 excluded- 6 ineligible 12 declined 3 'other reasons') | 73 parents (8 discontinued) | 65 parents | 24 (drop outs/lost to follow up unaccounted for) |
| Sullivan-Bolyai (2004) | 54 (5 declined to participate) | 49 (7 unreachable/ practical barriers) | 42 | 42 |
| Sullivan-Bolyai <i>et al.</i> (2010) | 118 (30 declined 28 did not consent) | 60 | 60 (9 lost to follow up or unreachable) | 51 |
| Sullivan-Bolyai <i>et al.</i> (2011) | Unclear | 28 | 28 | 28 |
| Tsiouli <i>et al.</i> (2014) | 360 (280 excluded- 157 declined 123 ineligible) | 80 (20 did not receive intervention or materials due to practical barriers 2 had different expectations) | 58 (14 refused to continue) | 44 |

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Appendix VI. SURE Qualitative Review Scoring Criteria Table – Detailed View.

| Criteria | Newell & Haheesy (2011) | Rearick <i>et al.</i> (2011) |
|---|---|---|
| Does the study address a clearly focused question? Setting? Perspective? Intervention or Phenomena Comparator/control? Evaluation/Exploration? | Yes <i>'The study aimed to describe the culture of social support group for parents of children with type 1 diabetes and elicit data that would offer an understanding of the parental experience.'</i> | Yes <i>'The purpose of this article is to describe the parents' perspectives of the social support provided, the helpfulness of the support of those who received the intervention'</i> |
| Is the choice of qualitative method appropriate? | Yes <i>Authors provided an overview of their justification of ethnography in the context of becoming embedded in the environment of the participants in order to access 'real-life' data.</i> | Yes <i>Authors aimed to gain insight into the experiences of parents who had been provided with support (evaluated quantitatively in another paper). Therefore semi structured interviews with those who received the intervention are considered appropriate.</i> |
| Is the sampling strategy clearly described and justified? | Yes <i>Authors provide justification for subjective selection of participants in context of the 'ethnographic methodology'. However, they do not provide details of their specific approach.</i> | Yes <i>Authors report that they attempted to make contact with all participants who received the intervention and were not lost to follow up in the quantitative arm of the study. However, only 13 of the 33 possible participants were interviewed. The authors provide reasons for those who did not take part.</i> |
| Is the method of data collection well described? | Yes <i>Authors describe the process of observation, however do not provide details of semi-structured interview questions.</i> | Yes <i>Author described the interview procedure including field notes to supplement verbal accounts.</i> |
| Is the relationship between the researcher(s) and participants explored? | Yes <i>Details were provided in acknowledging the need to recognise and reflect on the position of the researcher in terms of the participants. Field notes were used to increase awareness of position.</i> | No <i>No information regarding the positioning of researchers to participants was provided.</i> |
| Are ethical issues explicitly discussed | Yes <i>Issues such as consent and confidentiality were discussed. However, no considerations were noted in terms of the impact on participants in observing and discussing their personal experiences.</i> | Yes <i>Issues such as consent and confidentiality were discussed. However, no considerations were noted in terms of the impact on participants in observing and discussing their personal experiences.</i> |
| Is the data analysis/ interpretation process described and justified? | Yes | Yes |
| | <i>Authors provide a brief overview of their analysis process in the context of previous justification of using an ethnographic methodology.</i> | <i>Authors provide a brief overview of their analysis process.</i> |

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|---|---|--|
| Are the findings credible? | Yes | Yes |
| | <i>The researcher grounds the results in quotes from the data to enhance credibility.</i> | <i>Authors provide details of steps taken to enhance credibility such as use of field notes and independent coding and verification of themes.</i> |
| Is any sponsorship/conflict of interest reported? | No | Yes |
| | <i>No information provided regarding conflict or interests of sponsorship.</i> | <i>Authors provided detailed of financial support for project.</i> |
| Did the authors identify any limitations? | Yes | Yes |
| | <ul style="list-style-type: none"> - <i>Limited generalisability as inherent to qualitative work.</i> - <i>Lack of fathers in sample.</i> | <ul style="list-style-type: none"> - <i>Small, homogenous sample</i> - <i>Participants who did not want to participate may have had a different experience which would have provided further/different insight into the process.</i> |
| Are the conclusions the same in the abstract and the full text? | n/a | Yes |
| | <i>No abstract included.</i> | <i>The wording is almost identical referring to the support being perceived as 'emotional, affirmational, and informational'.</i> |

Appendix VII

Information regarding Training Process (Channon & Lowes, 2012, p. 5-6).

Training for Intervention

The PI will deliver the training, with the possibility of recruiting another trainer if numbers of LPs are high. The training programme will be based on the programme used by the Family to Family Network. Adaptations for the UK and for the broader patient group including teenagers have been started in conjunction with current members of the Parents' Advisory Group.

There will be 15 hours of training delivered in a pattern most acceptable to the prospective LPs (options presented to them will include a Friday evening/all day Saturday or a weekend/evening combination). The programme will include training to enhance skills in active listening, reflection and appropriate use of own experience to support others. This will be developed using role-play, practice interviews and information exchange.

Intervention

The focus of the intervention is to promote parental adjustment and coping by providing three types of support:

1. Informational Support – ensuring families have contact information regarding support networks, local community resources, common experiences of adjustment in terms of parental experience, children's behaviour, different approaches to coping etc
2. Affirmational Support – identifying and pointing out examples of effective parenting, special qualities and competences that the family have, enhancing the parents' confidence in parenting, re-assurance that their concerns are normal and understandable in context of the stress of diagnosis and living with a chronic condition. Eliciting and enhancing opportunities for strengthening support.
3. Emotional Support- listening to concerns and experiences, using non-directive active listening skills, conveying acceptance and understanding.

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Appendix VIII

Extract of Reflective Diary

Extracts from diary during interview process

7th October 2013

I was in there for over an hour, but got such a rich account of what she had experienced as she was in the unique position of supporting more than one person. I was mindful that she didn't seem to be having a very good time with her daughter. It made me realise that just because the link parents are experienced doesn't mean all the hard times have gone away in terms of diabetes. I also found it interesting that she reflected on how she felt she was on a level with her recipients because of her background but at the same time had moved past that and saw herself as different to them now.

18th October 2013

I was really struck by how much impact the service had on today's interviewee. My interviews so far have been mixed, a lot of people who the system hadn't worked out so well for. It seemed revelatory for her which was lovely. I was particularly struck by how much burden is placed on the parent to grasp quite complex medical information overnight and how abandoned they may feel.

24th October 2013

It was difficult to manage the participant's child coming in and out but generally felt successful. I was struck by her anecdote about thinking about there being somebody else out there who was also up in the night. It was also interesting how difficult and artificial it may seem to all of a sudden stop all contact at the end of six months especially when they have become close and that maybe this is something that needs examining in future.

8th November 2013

Pre interview: I'm feeling quite nervous about interviewing my first man in the project. I'm not sure what to expect. Will he be as forthcoming and open as the women?

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Post interview: My worries were unfounded! He was such a nice man and so open. It was clearly a different experience for him than the women. He focused more on the practicalities of coping with diabetes than the emotion. He reflected at the end that he would have definitely continued as he felt the support was really worthwhile.

14th November 2013

I was struck during that interview by how much less anxiety provoking it must be to have met with the recipients as a pair, it is quite an intimidating process otherwise. It was so sad to hear one of the participant's story of how shut out he felt when both his daughters were diagnosed and he was the sole male in the household. He seemed to really value the input of the whole process. Again reflecting how valuable the mentors themselves have found the process.

Extracts from diary during analysis process

18th July 2014

I had a discussion with Sue today about starting the analysis process which led to a broader conversation about the project. I'm very surprised to hear the lack of quantitative evidence. It feels like it is almost overwhelmingly positive from participants' point of view. What is being mistranslated? We also reflected on feeling more involved in the material when reading/transcribing without having to worry about what to say next as I did in the interview. Sue raised that she thought that maybe the link parents felt the same things, worries about content stops involvement in the moment.

10th November 2014

As soon as I saw who was the first link parent to be read through I thought how appropriate. I've always seen her as the queen of the link parents, not sure where that's come from. Maybe it has come from her having two recipient parents, maybe it's the authority with which I remember her speaking. I'm surprised how soft her voice sounds, I remember her being quite tough and powerful.

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23rd November 2014

I remember this participant's story being very emotive. She was really open about her experience which I really valued as I had been really worried about the level of detail I was getting from participants up to that point.

1st December 2014

I've generally found going through this transcript to be a lot more straight forward than the others. At times her language meanders all over the place so in that way it's still difficult. I'm wondering if it's to do with feeling so enmeshed with my data at the moment. I'm pushed for time in handing in drafts so I am spending every spare minute thinking about or analysing the data. A lot of the time I worry I'm not doing it right. But then today a mother I visited for my clinical work reflected several themes that have been brought up my research such as timing of support, the focus of parents on protecting their children and therefore neglecting themselves and the differing ways of coping between men and women. It's reassuring that I'm not a million miles away with what I'm extracting but I'm finding it to be a mentally exhausting process. It is difficult seeing the transcripts with fresh eyes when I've analysed the other side of pairing but I'm trying to focus on what they are saying and not what happened from the other account. I realised I've not attended much to the idea of hope coming through from these families whose children have survived and thrived. Maybe reflects that most interactions have had some negativity or worry from the LP side in them.

2nd December 2014

I'm struggling with this transcript on second reading. I'm interpreting his desire to be involved when his daughters 'rejected' as his need to have a role or be needed. This is difficult with my feminist views about the wrongness of men needed to be the head of the family. I'm finding myself much less empathetic. It seems that he wants the recipient parents to struggle with the role of the parent because he has struggled.

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Appendix IX

Example of Coded Text

Descriptive comments

Conceptual comments

Language comments

| Transcript | Exploratory comments | Emergent theme |
|---|--|--|
| <p>P: I found it hard to sleep at night in case she don't wake up... a lot of things really. But um that's my main one... her not waking up...</p> <p>R: What do you worry is going to happen in the night?</p> | <p>Emotional/physical reaction to threat</p> <p><i>Mother's sole responsibility to protect her child</i></p> <p><u>Pauses in speech indicating level of emotion</u></p> | <p>Catastrophic worries</p> |
| <p>P: She's going to go too low and then she goes into a diabetic coma and I'll miss it.</p> <p>R: And did you talk to (link parent) about that?</p> | <p>Worries about diabetes</p> <p><i>Feelings of lack of control and responsibility to protect.</i></p> | <p>Catastrophic worries</p> <p>Sole responsibility</p> |
| <p>P: Yeah I spoke to (link parent) about it, she said like does night checks, she said it's up to everyone I do night checks and... same as like I agree with her- each</p> | <p>Examples of the help provided by link parent</p> <p><i>Normalising presence of link parent and empowerment of recipient parent.</i></p> <p>Aligns self with link parent</p> | <p>Normalising</p> <p>Qualified to reduce responsibility</p> <p>Adopting link parent point</p> |

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|---|---|--|
| <p>to their own but I had Annaleese one time she was 1.2 during the night, she was foaming in the mouth and her eyes were rolling and I couldn't get consciousness out of her. So like it is a main worry of mine and reading didn't help. It tells you how it can affect their feet, their eyes, their limbs, it affects everything. It's all like the body parts...</p> <p>R: So it kind of really worried you about that?</p> <p>P: Yeah and all that bit but that's why talking to Paula made me realise it is to worry about but to keep at the back of your mind and not dwell on it every day basically because life's for living.</p> <p>R: And was that helpful?</p> <p>P: Yeah it was helpful.</p> <p>R: What do you think it would have been like if you</p> | <p>position. <i>Respecting link parent position.</i></p> <p><u>'Foaming' 'eyes were rolling' 'consciousness'</u> <u>referring back to symptoms of diagnosis.</u> <i>Emotional associations of diagnosis resurfacing.</i></p> <p>The physical implications of child with diabetes. <i>Feelings of powerlessness, 'other' taking over child's body.</i></p> <p>Emotional support from the link parent and its impact. <i>Validation of feelings but redirection.</i></p> <p><u>'Dwell' 'back of your mind' almost feels like link parent's words being echoed</u></p> <p><i>Balance safety and adventure, parent has a life too.</i></p> <p>Implications of no support</p> | <p>of view</p> <p>Legacy of diagnosis trauma.</p> <p>Dangers of unfiltered information</p> <p>Diabetes invading body</p> <p>Emotional guidance</p> <p>Safety versus living</p> |
|---|---|--|

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|---|--|---|
| <p>hadn't had her to support you?</p> | <p><i>Desire for external support – not matching needs</i></p> | |
| <p>P: I most probably still would have been quite depressed. I went to the doctors and he give me antidepressants which I didn't take, I didn't want to take them. But I just... I always... I still feel it now like if Annaleese's sugars are high at bedtime I think to myself what have you done wrong today? And I sit there and all day I sit there and I keep playing on myself like what have you done? What have you done? But it ain't always what I've done or what she's done. She might not have snuck a sweet and that's another one, I'm always trying to moan at her 'oh you've snuck this' and she's 'no I haven't mum, I promise' I'm always moaning at that one.</p> | <p><i>Confusion about feelings, struggling to understand</i> Lingering emotional impact of diagnosis. <i>Self blame, critical, placing responsibility with self.</i> Questioning ability to parent child <i>Shift negative thinking- because of link parent influence?- voice of link parent?</i> '<u>Snuck</u>' infers a change in relationship where child doesn't understand restrictions. <i>Broader implications of diabetes on relationship with child</i></p> | <p>Implications of no support Experience of unwanted support Sole responsibility of parent Powerlessness Self critical rumination Impact on mother/daughter responsibility</p> |

Appendix X

Information Sheet

Recipient Parent Information Sheet



GIG
CYMRU
NHS
WALES

Bwrdd Iechyd Prifysgol
Caerdydd a'r Fro
Cardiff and Vale
University Health Board



Parents Listen
Understand & Support

INFORMATION SHEET FOR PARENTS

**Research Study: The PLUS Study (Parents Listen Understand & Support).
Setting up a parent-to-parent support network for parents with a child recently
diagnosed with type 1 diabetes.**

Dear Parent,

We would like to invite you to take part in this study but, before you decide whether or not to participate, it is important for you to understand why the study is being done and what it will involve. Please ask one of the doctors or nurses in clinic if there is anything that is not clear or if you would like more information.

1. What is the purpose of the study?

We know how important it is to support families when a child is diagnosed with type 1 diabetes but we are unsure what ways are best. In America there has been a project in which experienced parents who have a child with diabetes provide support for families whose child has been diagnosed more recently. The families have found this type of support from another parent helpful. This study aims to work with parents in Wales to see whether we can do something similar here.

2. Why have I been invited?

You have been invited to take part in the PLUS study because your child has recently been diagnosed with type 1 diabetes.

3. Do I have to take part?

No it is entirely up to you – and one or both parents can take part. We will describe the study in this information sheet and if you think you would like to know more you

contact the research team. They will arrange to meet with you, answer any questions you have and then, if you decide you do want to take part, ask you to sign a consent form. You are free to withdraw at any time, without giving a reason. This would not affect the standard of care you or your child receives.

4. What will happen if I decide to take part?

If you think you would like to take part you will contact Sue Channon who is leading the PLUS study and she will arrange for herself or another member of the research team to meet with you at a place that is convenient to you (maybe your home or clinic). They will answer any questions you have and explain the confidentiality of the contact with the Link Parents as well as the rare circumstances in which information will be shared (if for example they were extremely worried about your safety). They will ask you to sign the consent form, spend 30 minutes or so filling in questionnaires about your experience of living with diabetes and give you the name of the Link Parent who will be contacting you. They will let your GP know you are taking part in the study.

5. What will it involve?

The Link Parent will meet with you three times over the next six months at a time and place that suits you both. You will have each other's phone number and can also stay in touch by phone during that time. If during this time you decide you would rather not hear from them you can let them or the PLUS team know and they will pass on that information.

The Link Parents have been trained to provide support in different ways including providing information about local resources, practical ideas about managing day-to-day activities and also emotional support as someone who has "been there". They themselves are being supported and supervised by the PLUS team.

After the six months the contact with PLUS will stop. Then at the end of the year, when the project finishes, you will be asked to fill out the questionnaires again and asked if you would be willing to be interviewed by the research team, individually or as part of a small group, about your experiences of taking part. We may audio-record the discussion about the study with the research team but if we do you we will let you know exactly when we are recording.

6. What are the possible disadvantages and risks of taking part?

We know that the early months after diagnosis are an upsetting time for parents so talking about it with the Link Parents may cause you some upset.

8. What are the possible benefits of taking part?

We do not know for sure if you are going to benefit from the support of a Link Parent but if you take part you will help us in making the decision about whether parent-to-parent support is helpful and whether it is possible to set up a service in South Wales for families whose child has been diagnosed with Type 1 diabetes.

9. What if there is a problem?

If you have a concern about any aspect of this study, you should contact Sue Channon (02920 875047) or Lesley Lowes (02920 745163) who will do their best to

answer your questions. You may also contact your clinician. If you remain unhappy and wish to complain formally, you can do this through the normal NHS procedure.

10. Will your taking part in this study be kept confidential?

All information collected during the course of the research will be kept strictly confidential (with the exception of information about risk in section 4). This information will be stored securely by Sue Channon at her professional base, in compliance with the Data Protection Act. Similarly, if audiotapes of the review sessions are made, these will be stored securely along with any transcription that is made and the audiotapes will be destroyed at the end of the study. Any names or other identifiable information will be removed during transcription. Anonymised quotations may be included in future publications but no-one other than the research team will be identifiable in any such publication of the findings.

11. What will happen to the results of the research study?

If the results show that parent to parent support at diagnosis is possible and acceptable to parents then an application will be made for a larger multi-centre study to determine its impact. The results of this study will be submitted for publication in a medical or psychology journal to inform other researchers and clinicians about the possibilities of parent to parent support at diagnosis. A parent summary will be written which will be sent to participating centres which can then be given out to participants.

12. Who is organising and funding the study?

This study is being organised by Sue Channon and Lesley Lowes on behalf of the Sponsor of the Study, Cardiff and Vale UHB. The National Institute for Social Care and Health Research (NISCHR) is funding the study.

13. Who has reviewed the study?

All research in the NHS is looked at by an independent group of people called a Research Ethics Committee to protect your safety, rights, wellbeing and dignity. This Study has been given favourable opinion by the Research Ethics Committee. This Study has also been reviewed independently by the funders of the Study, NISCHR

Contact for further information?

If you think you might like to take part and would like more information please contact Sue Channon on 02920 875047 or email sue.channon@wales.nhs.uk

Link Parent Information Sheet



INFORMATION SHEET FOR PARENTS : (LINK PARENTS)

**Research Study: The PLUS Study (Parents Listen Understand and Support).
Setting up a parent-to-parent support network for parents with a child recently diagnosed with type 1 diabetes.**

Dear Parent/carer(s),

We would like to invite you to take part in this study but, before you decide whether or not to participate, it is important for you to understand why the study is being done and what it will involve. Please ask one of the doctors or nurses in clinic if there is anything that is not clear or if you would like more information.

1. What is the purpose of the study?

We know how important it is to support families when a child is diagnosed with type 1 diabetes but we are not sure how best to do that. In America there has been a project in which parents who have a child with diabetes provide some support for families whose child has more recently been diagnosed and the families involved have found it helpful. This study aims to work with parents in Wales to see whether we can do something similar here. Experienced parents (whose child was diagnosed with diabetes at least two years ago) will be invited to train as Link Parents and link with families who have a child recently diagnosed with diabetes. Link Parents will receive ongoing support and all participating parents will be asked about their experience of the programme.

2. Why have I been invited?

You have been invited to take part in this study because your child has been diagnosed with type 1 diabetes for two years or more and we are inviting you to find out more about being a Link Parent. We are hoping to involve between three and six parents in each of the three participating centres, Neath, Bridgend and Swansea.

3. Do I have to take part?

No it is up to you to decide to join the study. We will describe the study in this information sheet. If you agree to take part, we will then ask you to sign a consent form. You are free to withdraw at any time, without giving a reason. This would not affect the standard of care you or your child receives..

4. What will happen if I decide to take part?

You will be invited to meet with the researchers Lesley Lowes (Paediatric Diabetes Specialist Nurse) and Sue Channon (Clinical Psychologist) who will then explain the project in more detail.

5. What will I be asked to do?

If you decide you would like to take part you will then join a small group of other parents and complete Link Parent training lead by Sue Channon and Lesley Lowes. This will involve up to 15 hours training - we will try to fit with times to suit people such as a weekend or a few evenings in the local area.

Once you have completed the training you will be asked to provide support for local families with a child who has recently been diagnosed with diabetes. We don't know how many newly diagnosed families there will be but the study runs for a year and the most you will be asked to do is support a maximum of two families at a time (with the highest total in the whole year being four families). This will include meeting each family up to three times and offering fortnightly phone contact in between for a maximum of six months. During this time you will be supported by Sue and Lesley in person and on the phone. At the end of the year, when the project finishes, you will be asked about your experiences of taking part. We may audio-record parts of the training and also the discussion about your experiences but if we do you we will let you know exactly when we are recording.

6 Expenses

The role of Link Parent is a voluntary role so there will be no payment for your time but all phone costs and travel costs will be met and any additional costs associated with training eg parking, accommodation, food etc will be covered.

7. What are the possible disadvantages and risks of taking part?

By taking on the role of Link Parent we are asking you to offer your time and experience to the project. Meeting with families close to the time of diagnosis means that you may be dealing with their distress and that may be upsetting for you which is why we offer support and supervision. Although we will refund travel expenses you will be asked to use your own transport.

8. What are the possible benefits of taking part?

There are no direct benefits to you or your child through taking part in this study. However, you will have the opportunity of contributing to our understanding of parent to parent support and also whether it is possible to set up such a service in South Wales for families whose child has been diagnosed with Type 1 diabetes.

9. What if there is a problem?

If you have a concern about any aspect of this study, you should ask to speak to the Sue Channon (02920 206464) or Lesley Lowes (02920 745163) who will do their best to answer your questions. You may also contact your clinician. If you remain unhappy and wish to complain formally, you can do this through the normal NHS procedure. Details can be obtained from [insert details]

10. Will your taking part in this study be kept confidential?

All information collected during the course of the research will be kept strictly confidential. This information will be stored securely by Sue Channon at Archway House, her professional base, in compliance with the Data Protection Act. Similarly, if audiotapes of the training and review session are made, these will be stored securely along with any transcription that is made and the audiotapes will be destroyed at the end of the study. Any names or other identifiable information will be removed during transcription. Anonymised quotations may be included in future publications but no-one other than the research team will be identifiable in any such publication of the findings.

11. What will happen to the results of the research study?

If the results show that parent to parent support at diagnosis is possible and acceptable to both the Link Parents and those parents who receive it then an application will be made for a larger multi-centre study to determine its impact. The results of this study will be submitted for publication in a medical or psychology journal to inform other researchers and clinicians about the possibilities of parent to parent support at diagnosis. A parent summary will be written which will be sent to participating centres which can then be given out to participants.

12. Who is organising and funding the study?

This study is being organised by Sue Channon and Lesley Lowes on behalf of the Sponsor of the Study, Cardiff and Vale UHB, who are also providing indemnity for the Link Parents as volunteers within the NHS in Wales. The National Institute for Social Care and Health Research (NISCHR) is funding the study.

13. Who has reviewed the study?

All research in the NHS is looked at by an independent group of people called a Research Ethics Committee to protect your safety, rights, wellbeing and dignity. This Study has been given favourable opinion by the Research Ethics Committee. This Study has also been reviewed independently by the funders of the Study, NISCHR

Contact for further information

If you have any queries or would like more information please contact Sue Channon on 02920 206464 or your clinician or diabetes nurse at your diabetes centre..

Appendix XI

Desired Qualities of Potential Link Parents

- Reliable clinic attendance
- Child HbA1c consistently < 86 mmol/mol (10%)
- Optimistic realist
- Balanced view of diabetes
- Reasonable confidence in managing diabetes
- Flexible attitude

Appendix XII

End of Intervention Letter



Dear (Participant name)

It's coming up to six months since you joined the PLUS parents' project, meeting up with me and then I linked you up with (link/recipient parent name). As we said then, the contact with (link/recipient parent name) and PLUS lasts for six months, which ends on (end date).

We set up PLUS because it seemed to fit with what parents were saying they wanted: We received a small amount of funding for one year to train and support the volunteer parents to see whether it was possible to organise in South Wales. Now you have been part of PLUS we would be really interested to find out what you thought of it – did you find it helpful, what was good and what could make it better? Is it worth doing from your point of view? Everyone's views are important including those who maybe haven't used it much or not at all – we would be really interested to know why that might have been.

You may remember from the original information that we want to arrange a time for someone to come and meet with you and talk about your experience of PLUS. The person who will come to meet you is called Laura Barcroft who is a trainee Psychologist working in Cardiff. What you say to Laura will be made anonymous, it will not be directly shared with your (link/recipient) Parent and it will be put with all the comments from all the other parents and your name will not appear on anything once Laura has arranged to meet with you. Laura will be in touch by phone over the next few weeks to find out when would be a good time for you to meet with her. In the meantime if you have any questions please give me a ring.

Many thanks for joining PLUS

Best wishes

Sue Channon

Appendix XIII

Consent form

Recipient parent consent form



CONSENT FORM FOR PARENTS

Title of Study: The PLUS Study (Parents Listen Understand and Support). Setting up a parent-to-parent support network for parents with a child recently diagnosed with type 1 diabetes.

Names of Researchers: Sue Channon & Lesley Lowes

- | | Initial box |
|---|--------------------------|
| 1. I confirm that I have read and understand the information sheet (version 2, dated 19/10/12) for the above study and have had the opportunity to ask questions about PLUS. | <input type="checkbox"/> |
| 2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, without my medical care or that of my child or our legal rights being affected. | <input type="checkbox"/> |
| 3. I understand that at the end of the study the research team may request to interview me about my experience of taking part in PLUS; that with my consent this may be audio-recorded and from this anonymised quotations in which I cannot be identified may be used in subsequent publications | <input type="checkbox"/> |
| 4. I understand that my GP will be informed that I am taking part in PLUS | <input type="checkbox"/> |
| 5. I agree to take part in the above Study | <input type="checkbox"/> |

| | | |
|--------------------|-------|-------------------------|
| _____ | _____ | _____ |
| Name of Parent | Date | Signature of Parent |
| _____ | _____ | _____ |
| Name of Researcher | Date | Signature of Researcher |

When completed, 2 copies need to be made, 1 for parent, 1 for researcher site file.

Link parent consent form



GIG
CYMRU
NHS
WALES

Bwrdd Iechyd Prifysgol
Caerdydd a'r Fro
Cardiff and Vale
University Health Board

CONSENT FORM FOR PARENTS

Title of Study: The PLUS Study (Parents Listen Understand and Support).

Setting up a parent-to-parent support network for parents with a child recently diagnosed with type 1 diabetes.

Names of Researchers: Sue Channon and Lesley Lowes

- | | Initial box |
|---|--------------------------|
| 1. I confirm that I have read and understand the information sheet (version 5), dated 2/7/12 for the above study and have had the opportunity to ask questions. | <input type="checkbox"/> |
| 2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, without my medical care or that of my child or our legal rights being affected. | <input type="checkbox"/> |
| 3. I understand that at the end of the study the research team may request to interview me about my experience of taking part in PLUS; that with my consent this may be audio-recorded and from this anonymised quotations in which I cannot be identified may be used in subsequent publications | <input type="checkbox"/> |
| 4. I agree to take part in the above Study | <input type="checkbox"/> |

Name of Parent

Date

Signature of Parent

Name of Researcher

Date

Signature of Researcher

When completed, 2 copies need to be made, 1 for parent, 1 for researcher site file

Appendix XIV

Semi structured interview schedule

Recipient parent interview schedule

1. Getting involved with the project

1.1. What was your experience of diagnosis?

1.2 How did you get involved with the PLUS project?

- How did your nurse describe it?

1.3 Why did you join?

- What did you hope to gain?
- What were your hopes?
- Did you have any reservations?
- How did the timing of the support fit in with where you were adapting to diabetes

2. Process of receiving support

2.1. What was the first contact like?

- How did you feel?
- What did you discuss?
- How did you feel at the end of the first meeting/manage possible future meetings?

2.2. What kind of support was offered?

2.3. How did you find the support?

- What was good?
- What was bad?
- Were there any problems?
- Was there anything you would have done different?

Appendices

2.4 How would you describe your relationship?

2.5 How was it being support by a fellow parent?

- Any drawbacks?

3. Impact of the support

3.1. What impact did the support have?

- On you/child/feelings about diabetes/future?

3.2. What would it have been like without it?

3.3. Do you think it had an impact on your link parent?

3.4. How does the future feel now?

3.5. Based on your experiences would you be a link parent in the future/recommend it to others?

Link parent interview schedule

1. Getting involved with the project

1.1. What led you to sign up to the plus project?

1.2. Can you tell me about the process of signing up?

- How was it described?
- How did the diabetic nurse pitch it to you?

1.3. What were your expectations?

- What did you hope to gain?
- Did you have any worries or reservations?

2. Training

2.1. Can you describe the training?

- was it what you expected?
- how did it feel?

2.2. What was it like being with other diabetic parents?

Appendices

2.3. How was it to discuss your own process of diagnosis?

2.4. What support were you offered?

3. Experience of supporting

3.1. Can you tell me about the first contact?

- What did you talk about?

- How did it feel?

- How was the process of setting it up?

3.2. What type of support were you offered?

3.3. How would you describe the relationship?

- Did it change over time?

3.4. How did it relate to what you'd been taught?

3.5. What are the good/bad things about a parent offering support to another parent?

3.6. How do you think parents have been/should be linked together?

3.7. Looking back, would you do anything differently?

4. Impact of support

4.1. How has the project affected you?

- Has it impacted your life?

4.2. How had it affected how you feel about diabetes?

4.3. How did the memories of your child's diagnosis affect the support?

4.4. Has it brought back feelings about your child's diagnosis?

- What support was offered?

- How did you cope?

4.5. How has the support offered affected the parent?

- Did they gain anything?

- Did anything not go so well?

Appendix XV

Evidence of Ethical Approval



GIG
CYMRU
NHS
WALES

Bwrdd Iechyd Prifysgol
Abertawe Bro Morgannwg
University Health Board



Dyddiad/Date: 23 November 2012

Mrs Geraldine Phillips
Paediatrics Diabetes Specialist Nurse
ABMU Health Board
Department of Paediatrics
Singleton Hospital
Swansea

☎ 01792 704056
Fax: 01792 545774
✉ jemma.hughes@wales.nhs.uk
✉ cynthia.davis@wales.nhs.uk
✉ abm.rd@wales.nhs.uk

Dear Geraldine

**Re: Parents Listen Understand and Support: The PLUS study: Part II
Setting up a parent-to-parent support network for parents with a child recently diagnosed
with type 1 diabetes.
IRAS Ref: 112264
Sponsor: Cardiff and Vale UHB**

Thank you for submitting your proposal to us for approval for the above named study to be carried out within our Health Board. The attached listed documents were reviewed.

Health Board Governance checks have been completed and passed. Please accept this letter as confirmation of local Health Board approval.

As part of Research Governance, you are required to:

1. Adhere to the protocol approved and inform the R&D office of any changes (including changes to the end date of the project) and ensure any changes are reported to the Research Ethics Committee(s), for review/approval.
2. Inform the R&D office of any local adverse/serious events that may occur, whilst also reporting these according to the sponsor's protocol and procedures.
3. Complete any interim and final reports requested by the R&D office. If sponsored by this Health Board, you will be asked by the Joint Scientific Review Committee to complete a 6 monthly progress report along with your final report at study completion.
4. Ensure that your research complies with any relevant regulatory requirements and legislation relating to: Clinical Trials, Data Protection Act 1998, Health & Safety, Caldicott Guidelines, the use of Human Tissue for research purposes, Mental Capacity and ICH Good Clinical Practice (GCP).
5. Ensure that all training courses requested by the Sponsor are completed by all relevant members of the research team before any research activity is carried out. All research staff undertaking clinical trials of an investigational medicinal product (CTIMPs) must be GCP trained, and should continue to update their GCP training every 2 years. Copies of GCP certificates should be filed in the Trial Site File, with a copy forwarded to the R&D Department.
6. Ensure the research is undertaken in compliance with all Health Board R&D Standard Operating Procedures (SOPs). The latest versions of all SOPs can be obtained by contacting the R&D Department.

Bwrdd Iechyd ABM yw enw gweithredu Bwrdd Iechyd Lleol Prifysgol Abertawe Bro Morgannwg
ABM University Health Board is the operational name of Abertawe Bro Morgannwg University Local Health Board
Pencadlys ABM / ABM Headquarters, 1 Talbot Gateway, Port Talbot, SA12 7BR. Ffon / Tel: (01639) 683344

www.abm.wales.nhs.uk

Appendices

NISCHR Clinical Research Portfolio Studies

If your study has been adopted onto the NISCHR Clinical Research Portfolio (CRP), it will be a condition of our permission that the Chief Investigator uploads local recruitment data onto the portfolio database.

For more information on the process of uploading recruitment data please look at the following link: <http://www.crncc.nihr.ac.uk/aboutus/processes/portfolio/precruitment>

Uploading of recruitment data will enable NISCHR to monitor research activity within Health Boards, resulting in NHS R&D allocations to be driven by activity.

To apply for your study to be adopted onto the NISCHR CRP, details can be found at: <http://www.wales.nhs.uk>

For more information and advice on the NISCHR Clinical Research Portfolio please email: portfolio@wales.nhs.uk

Should you wish to extend your study to other NHS organisations you must obtain the approval of all NHS bodies concerned. If the study is sponsored by ABMU Health Board you must notify the R&D Office of your intention to open the study in other sites.

Indemnity Arrangements

The Sponsor indemnifies and holds harmless ABM University Health Board, its employees and agents for any harm caused by negligence on behalf of the Sponsor, including any harm caused to participants by the administration of the investigational product. However, please note that the Sponsor will not indemnify ABM University Health Board for any harm caused by negligence on behalf of the research team or other individual or agent.

Researchers employed by ABM University Health Board, including those holding Honorary Contract status are indemnified against actions for negligent harm via standard arrangements with Welsh Risk Pool (WRP). Provision for 'no-fault' compensation is limited under the scheme and is only available on an ex gratia, discretionary basis where the Sponsor is a NHS Organisation.

ABM University Health Board reserves the right to suspend approval of any research study where deviation from appropriate RG & GCP standards is uncovered.

May I take this opportunity to wish you well in undertaking the research. We will write to you in the future to request updates on the progress of the research and look forward to receiving outcomes of the study.

Yours sincerely,



PP **Professor SC Bain**
Assistant Medical Director (R&D)
ABMU Health Board

Enc: List of SSI and R&D documents submitted

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www.abm.wales.nhs.uk

Appendices



South East Wales Research Ethics
Committee, Panel C
Sixth Floor, Churchill House
17 Churchill Way
Cardiff CF10 2TW
Telephone : 029 2037 6823

E-mail : jagit.sidhu@wales.nhs.uk
Website : www.nres.nhs.uk

Dr Sue Channon
Principal Lead Year 2
Doctoral Training Programme in Clinical Psychology
Cardiff and Vale UHB
School of Psychology
11th Floor Tower Block
Park Place Cardiff
CF10 3AT

26 September 2012

Dear Dr Channon

Study title: Parents Listen Understand and Support: The PLUS study:
Part II Setting up a parent-to-parent support network for
parents with a child recently diagnosed with type 1 diabetes.
REC reference: 12/WA/0284

The South East Wales Research Ethics Committee - Panel C reviewed the above application at their meeting held on the 21ST September 2012.

Thank you and Dr Lowes for attending to discuss the study, the clarification that you provided was most helpful.

Ethical opinion

The Committee noted that the aim of this pilot study was to develop a parent mentoring model and to assess feasibility of its delivery in the UK. It was further noted that this study was linked to a previous study the PLUS Part 1 which involved recruitment and training of Link Parents.

The Committee noted that experienced parents who have lived with and successfully managed diabetes in their child for two years or more will be recruited from three local clinics and invited to train as volunteer Link Parents (LPs). It was further noted that once trained the Link Parents will be invited to work with parents who have a child recently diagnosed with diabetes for a period of up to six months. It was also noted that the Link Parents will see up to two families at any one time and they will receive ongoing supervision throughout the year of the study. The recipient parents will have a child who has been diagnosed with type 1 diabetes within the previous six months and who attends one of the participating clinics to receive their diabetes care.

The Committee were reassured to note that you have over 20 years experience in paediatric settings and therefore are very familiar with the types of issues that are likely to emerge. It was further noted that you are also an experienced trainer and frequently work with groups around emotive material.

Appendices

The Committee noted your reassurance that as well as working in conjunction with clinics to ensure that this study can fit alongside their service, there has been full involvement of parents at each stage in this project. It was also noted that the ideas within this application have been formed in conjunction with a Parents Advisory Group, all of whom have a child with diabetes. The Committee noted that this group of parents have influenced key aspects of the design such as the name for the mentor (Link Parent), recruitment, contact with clinics, time since diagnosis, numbers of families per Link Parent and duration of contact and that they have also reviewed the questionnaires selected.

The Committee noted that potential participants would initially be identified and approached by healthcare professionals involved in their care.

The Committee noted that potential participants will be provided with written information about the purpose of the study, why they have been invited to participate, who is conducting the research, how the data would be used and what participation will require of them. They will also be given the opportunity to ask any questions about the study. Written consent will be obtained prior to participation in the study. It will be made clear throughout the study that participation is entirely voluntary and that they can withdraw at any point for any reason.

The Committee also noted that the Cardiff and Vale University Health Board had assessed the scientific quality of the research and that they would be acting as sponsor for the above study in accordance with the Research Governance Framework. The Committee noted that normal NHS indemnity arrangements would apply to this study.

The Committee further noted your clarification that NHS Indemnity is in place for the volunteers participating in the research.

The Committee noted your reassurance that a policy similar to a 'lone worker' policy will be in place for the volunteers.

The Committee noted from Q (A43) of the application form that study data would be stored for between 6 to 12 months after the end of the study. The Committee asked that you ensure that all data is stored and destroyed in line with the Data Protection Act (1998).

The members of the Committee present gave a favourable ethical opinion of the above research on the basis described in the application form, protocol and supporting documentation, subject to the conditions specified below.

Ethical review of research sites

NHS Sites

The favourable opinion applies to all NHS sites taking part in the study, subject to management permission being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" below).

Conditions of the favourable opinion

The favourable opinion is subject to the following conditions being met prior to the start of the study.

The Committee noted that General Practitioners would be informed of their patients' participation in this study, and that the participant's permission will be sought prior to informing their GP. The Committee asked that you update the information sheet and consent form to reflect this.

Appendices

Management permission or approval must be obtained from each host organisation prior to the start of the study at the site concerned.

Management permission ("R&D approval") should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements.

Guidance on applying for NHS permission for research is available in the Integrated Research Application System or at <http://www.rdforum.nhs.uk>.

Where a NHS organisation's role in the study is limited to identifying and referring potential participants to research sites ("participant identification centre"), guidance should be sought from the R&D office on the information it requires to give permission for this activity.

For non-NHS sites, site management permission should be obtained in accordance with the procedures of the relevant host organisation.

Sponsors are not required to notify the Committee of approvals from host organisations

It is responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).

You must notify the REC in writing once all conditions have been met (except for site approvals from host organisations) and provide copies of any revised documentation with updated version numbers. The REC will acknowledge receipt and provide a final list of the approved documentation for the study, which can be made available to host organisations to facilitate their permission for the study. Failure to provide the final versions to the REC may cause delay in obtaining permissions

Approved documents

The documents reviewed and approved at the meeting were:

| <i>Document</i> | <i>Version</i> | <i>Date</i> |
|--|-----------------------|----------------|
| GP/Consultant Information Sheets | 1 | 02 July 2012 |
| Investigator CV | 3 | 20 August 2012 |
| Other: Blake and McKay Single Item Measure of Social Support | | |
| Other: PLUS study Part II Flowchart | 1 | 02 July 2012 |
| Other: MHI-5 | | |
| Other: Letter re funding from NISCHR | | 14 March 2012 |
| Other: Plus Leaflet | 1 | 08 June 2012 |
| Participant Consent Form | 1 | 02 July 2012 |
| Participant Information Sheet | 1 | 02 July 2012 |
| Protocol | Plus Part II Protocol | 02 July 2012 |
| Questionnaire: Pediatric Inventory for Parents | | |
| Questionnaire: Family Empowerment Scale | | |
| REC application | 3.4 | 24 August 2012 |

Membership of the Committee

The members of the Ethics Committee who were present at the meeting are listed on the attached sheet.

Appendices

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

After ethical review

Reporting requirements

The attached document "After ethical review – guidance for researchers" gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Adding new sites and investigators
- Notification of serious breaches of the protocol
- Progress and safety reports
- Notifying the end of the study

The NRES website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.

Feedback

You are invited to give your view of the service that you have received from the National Research Ethics Service and the application procedure. If you wish to make your views known please use the feedback form available on the website.

Further information is available at National Research Ethics Service website > After Review

12/WA/0284

Please quote this number on all correspond

With the Committee's best wishes for the success of this project

Yours sincerely



Professor N Frude
Alternative Vice Chair, Panel C
South East Wales Research Ethics Committees
(Dictated but not signed)

E-mail: jagit.sidhu@bsc.wales.nhs.uk

Enclosures: List of names and professions of members who were present at the meeting and those submitted written comments

"After ethical review – guidance for researchers" [SL-AR2]

Emailed to: (sue.channon@wales.nhs.uk)

R&D Office for Cardiff & Vale NHS Trust