Adolescents' Experience of 'Adjustment' to Life with Diabetes: An Interpretative Phenomenological Analysis

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ABSTRACT

Aim: A wealth of quantitative literature exists exploring the adjustment of children and young people with Type 1 Diabetes Mellitus. However, results are often confusing and contradictory, at least partly due to studies using different definitions and measures. Studies have been criticised for over relying on parental reports and failing to consider young people's own perceptions. Furthermore, they have often conceptualised adjustment as an outcome, rather than exploring the process involved. Additionally, although peers are considered to play an important role in young people's lives, their role in young people's adjustment to living with diabetes has rarely been examined. To address this gap, this study attempted to gain a rich understanding of young people's experiences of adjusting to life with diabetes and explore how they feel their peers have contributed to this process, with the hope of informing clinical practice and improving support to young people and their families.

Method: A qualitative approach was chosen and six young females aged 12 – 15 with a diagnosis of Type 1 diabetes were interviewed using semi-structured interviews. Interpretative Phenomenological Analysis was used to analyse the transcripts.

Results: Five main themes emerged from participants' accounts: Developing a balanced relationship with diabetes; the uncomfortable position of difference; grappling with the fall out of diabetes; making diabetes more bearable; and the role of parents and friends. The findings are discussed in relation to the relevant literature. Clinical implications, methodological limitations and directions for future research are presented.

Conclusions: This study provided an insight into the complex and dynamic process of young people's adjustment to life with Type 1 diabetes. It highlighted the challenges and struggles they faced as a result of their diagnosis and the different strategies they employed to manage these. It also emphasised the valuable role both parents and friends provide in supporting young people with their illness.

LITERATURE REVIEW AND INTRODUCTION

This section provides a review of the literature concerning how children and adolescents adjust to chronic illness, focusing on Type 1 Diabetes Mellitus (DM1). A brief description of the illness is followed by a short discussion of the impact of the illness during adolescence. Empirical literature on the adjustment of children and young people to chronic illness is reviewed with reference to conceptual and methodological issues, with a particular focus on DM1. New approaches to the study of young people, and consideration of existing conceptualisations of adolescence, provide a point of departure for qualitative exploration of young people's experiences of chronic illness. Subsequently the review will examine the literature on young people's own experiences of DM1. Since peer relationships have been shown to be an important part of adolescent development, the literature on peer relationships in adolescents with DM1 is then explored. Finally, important avenues for future research will be considered.

Type 1 Diabetes Mellitus (DM1)

DM1 is a chronic health disorder caused by the autoimmune system destroying the pancreatic islet cells that produce insulin, resulting in permanent insulin deficiency. To survive, DM1 sufferers require daily insulin injections, three to four times per day, to restore glucose metabolism. However, as blood glucose levels can deviate from the normal range, patients have to self monitor levels regularly to evaluate fluctuations and adjust their regimens accordingly. Abnormally high blood glucose levels (hyperglycaemia) can be caused by under-dosing or omitting insulin, overeating, stress or infections. Prolonged hyperglycaemia can lead to hospitalisation for diabetic ketoacidosis, a potentially life threatening complication where the body breaks down fat reserves and produces acidy ketones, causing serious dehydration and other complications. Alternatively, abnormally low blood glucose levels (hypoglycaemia) can be caused by too much

insulin, under eating and excessive physical activity. Short-term effects include sweating, shakiness and dizziness, and may lead to a coma.

The longer term complications of DM1 include damage to the heart, kidneys, eyes and nerves, yet maintaining blood glucose levels can reduce the risk of such complications.

DM1 in young people

DM1 is a common paediatric chronic illness. It is currently estimated that in the UK one per 700-1000 young people will receive a diagnosis of DM1; the peak age for diagnosis is between 10-14 years old (DoH, 2007). The Diabetes Control and Complications Trial (DCCT, 1993) highlights the importance of good diabetes management (i.e. good glycaemic control) during early life to reduce the likelihood of longer term complications. Adolescence is considered a critical time for young people with DM1: in addition to dealing with developmental changes, they have to manage the complexities of DM1 (Skinner, Channon, Howells & McEvilly, 2000) and cope with the biological, social and psychological differences related to having a chronic illness (Amer, 1999). The complexity of managing all these demands has instigated a wealth of literature looking at how young people 'adjust' to their illness.

What is 'adjustment'?

The concept of 'adjustment' has its roots in biology, which often uses the term 'adaptation', arising from Darwin's Theory of Evolution (1859; as cited in Lazarus, 1969). This biological concept has been renamed 'adjustment' by psychologists and represents the psychological processes by which an individual deals with or masters demands made upon them by their social, interpersonal and internal environment (Lazarus, 1969). Lazarus (1969) notes that adjustment can be looked at in two ways: as an endpoint that is achieved, or as a process. When considering it as an endpoint, judgements are made about whether or not a

person has achieved adjustment. This can be evaluated in three ways: by signs of maladjustment (negative approach), ability to succeed in their physical and social surroundings (positive approach), or by comparing performance to a statistical norm (statistical approach). By contrast, when considering adjustment as a process rather than an achievement, the concern is not with evaluating the adequacy of adjustment (i.e. whether or not someone has adjusted) but with *how* an individual adjusts, the conditions that influence adjustment, and the consequences of adjustment. However, Lazarus (1969) highlights that adjustment is a difficult concept to define and thus evaluations of adjustment as an endpoint are complicated. This critique will be taken up further below.

Childhood adjustment to chronic illness

Although there is a wealth of literature exploring the 'adjustment' of children with chronic illness, results are often confusing and contradictory, at least partly due to studies using different definitions and measures (Lavigne & Faier-Routman, 1992; Wallander, Thompson & Alriksson-Schmidt, 2003).

Definitions of 'adjustment' in psychological studies of childhood illness
Few studies have attempted to define what they mean by problems of 'adjustment', and differing terms such as 'adjustment', 'adaptation', 'coping', 'stress', 'competence' and 'dysfunction' have been used interchangeably (Eiser, 1990). It has been acknowledged within this literature that 'adjustment' is a difficult concept to define (Pless & Pinkerton, 1975, as cited in Bradford, 1997), and this is a major factor in the range of operationalisations that have been employed. For example, these include: a lack of a psychiatric condition (i.e. depression or anxiety), a child achieving 'developmentally appropriate' tasks, a lack of 'sick role behaviour', an acceptance of limitations imposed by the disease (Bradford, 1997); high self esteem, lack of social isolation, a child's self-concept and achievements at school (Boekaerts & Roder, 1999); and good quality of life

(Wallander et al, 2003). Additionally, measures of physiological functioning are sometimes taken as 'proxies' of psychosocial adjustment (e.g. metabolic control; Fonagy, Moran, Lindsat, Kurtz & Brown, 1987). It should be noted, however, that many of these concepts are themselves open to interpretation, for example, as illustrated by the wealth of literature debating the concept of 'quality of life' and its measurement. Additionally, these definitions imply that 'adjustment' is an endpoint or reaching a desirable state and do not take into account the process by which individuals adjust to illness.

Measures of adjustment in studies of childhood illness

To gain information about child 'adjustment', it is common for researchers to use standardised questionnaires completed by the child, the child's parents, teachers or health professionals (Boekaerts & Roder, 1999). The Child Behaviour Checklist (CBCL) (Achenbach & Edelbrock, 1983) is one of the most common measures of psychosocial adjustment in children with chronic illness (Wallander et al 2003). Amer (1999b) states, however, that the CBCL is not necessarily the best tool for this purpose, as it was originally designed to be used to detect behaviour problems in the general population, not those with a chronic illness. Eiser (1990) criticises the use of such questionnaires, stating that often researchers do not consider whether the questionnaires have any theoretical relevance to the child's 'adjustment'. Researchers have also been criticised for their over-reliance on paper and pencil methods, completed mainly by mothers (Wallander et al, 2003). In their meta analysis of studies considering adjustment of children to chronic illness, Lavigne & Faier-Routman (1992) note differences in measures of adjustment between teachers, mental health professionals and parents. Pertinently, Amer (1999) observes that children have not played an active role in describing their perceptions of adjustment to chronic illness.

Given the lack of a consensus regarding the definition of 'adjustment', it is not surprising that discrepancies are found in its measurement, and that different people (parents, teachers, children) have different perspectives of it. Studies apparently have often assumed that children, and their parents and teachers, would agree regarding whether a child is 'well-adjusted', failing to consider different conceptualisations of adjustment these individuals may hold and how these may influence their responses. It is therefore compelling that, in order to adequately assess adjustment in children, multiple informants and measures should be used.

Child adjustment to chronic illness

Lavigne & Faier-Routeman (1992) reviewed 87 studies of child adjustment to physical disorders in a meta-analysis. They included studies that used a quantifiable outcome measure of overall adjustment (most commonly the CBCL), and a measure of self esteem or self concept. They found that children with a chronic illness were, on average, more likely than those in comparison groups (physically healthy, age matched peers), to have psychological 'adjustment' problems, including internalising symptoms (e.g. anxiety, depression, social withdrawal) and externalising symptoms (e.g. hyperactivity, aggression). Where the self concept of children with chronic illness was considered, across all studies children with a chronic illness were found to have a significantly lower self concept than that of healthy children, although the differences were not significant for studies that included careful matching or comparison with norms.

Lavigne & Faier-Routeman (1992) outlined various methodological flaws in the research they reviewed, including the fact that studies used a range of different informants, often neglected children's own self reports and relied on small samples of convenience. Further criticisms of the review include the fact that it solely focused on particular aspects of adjustment, predominantly the presence

of a psychiatric condition and the self concept of children. A large majority of the studies reviewed used potentially insensitive measures (i.e. CBCL; Piers-Harris Self Concept Inventory (Piers, 1977)), which have been criticised for having little theoretical relevance to a child's adjustment (Eiser, 1990). Furthermore, in the studies reviewed, the age range of the children varies hugely, from three to nineteen years, and there is little reference made to how this may influence the findings.

Adolescent adjustment to DM1

Research consistently suggests that during adolescence there is a decline in metabolic control (Bryden, Peveler, Stein, Neil, Mayou & Dunger, 2001). This has been attributed to physiological changes that occur at this time (Dunger, 1992), difficulty adhering to treatment regimens (Morris, Boyle, McMahon, Greene, MacDonald & Newton, 1997) and disengagement from services (Schur, Gamsu & Barley, 1999). Adolescence is therefore considered a critical time for young people with DM1 and consequently, despite the inconsistencies in definitions of 'adjustment' (Amer, 1999b), various researchers have investigated adolescent adjustment to DM1. Results have been conflicting and comparisons across studies are difficult.

Kovacs, Goldston, Obrosky & Bonar (1997) followed 92 youths with DM1 over a decade to determine prevalence rates and risk factors for psychiatric disorders following the diagnosis of DM1. The Interview Schedule for Children and Adolescents, a standardised semi-structured symptom based interview, was used to assess psychiatric status, with parents and children interviewed. 47.6% of the sample were shown to have developed a psychiatric disorder, with major depressive, conduct and generalised anxiety disorders being the most prevalent. The authors concluded that the onset of DM1 is associated with adjustment reactions that seem to indicate an increased risk for later psychiatric problems.

Yet there a number of methodological flaws of this study which could have affected the interpretations of the findings. A control group was not included; the professionals who conducted the interviews were not blind to the research aims and thus their ratings of the interviews are likely to have been biased; and the same professional interviewed both the parent and child. It is likely therefore that parental responses influenced the professional's interpretation of the children's interviews and visa versa, possibly affecting the validity of the findings.

In a similar study, Jacobson, Hauser, Willett, Wolfsdorf, Dvorak, Herman & De Groot (1997) conducted a ten year follow up of 57 child and adolescent patients with DM1, but this study benefited from the inclusion of a control group. To assess psychological adjustment, they used the Rosenberg Self-Esteem Scale (Rosenberg, 1965), the Symptom Checklist 90 revised (Derogatis, 1983), a measure of psychiatric symptoms, and the Diabetes Adjustment Scale (Sullivan, 1979), used to assess attitudes and feelings towards diabetes. In contrast to the findings of Kovacs et al (1997), they concluded that young people with DM1 showed no difference in the level of psychiatric symptoms compared to young people without a chronic illness, and concluded that young people with DM1 appear to be psychologically well adjusted (i.e. did not report more criminal activity, drug use, psychiatric treatment or hospitalisation, school performance failures or unemployment). Nevertheless, they did find indications of lower self esteem in patients with DM1 and suggested that this could predispose them to a risk for future depression.

There is much variability in the outcomes of these longitudinal studies, and this could be accounted for by the use of different measurement instruments and different measurement strategies. The use of a comparison sample in Jacobson et al.'s (1997) study may also have influenced the conclusions about the prevalence of psychopathology. Furthermore, the Jacobson et al (1997) study

focused only on the views of the young people, and did not incorporate the views of parents.

The variability in outcomes of adjustment in young people with DM1 mirrors the findings for other chronic illnesses. In studies of young people with asthma, for example, some studies have documented minimal behavioural differences between children with asthma and healthy controls (Graham, Rutter, Yule & Pless, 1967), whereas others have found that children with asthma show greater internalising behaviour problems compared to healthy controls (Austin, Smith, Risinger & McNelis, 1994). Likewise, studies of young people with Cystic Fibrosis (CF) present mixed results. Blair, Cull & Freeman (1994) found no difference in psychological distress between young people with CF and healthy controls, whereas Thompson, Gustafson & Gill (1995) found that 51% of adolescents with CF met the criteria for a psychiatric diagnosis.

How can the variability in apparent outcomes in such studies be accounted for? As noted above, differences in definitions and measures employed may have influenced this, as may the natural differences in people's perceptions (e.g. children and parents) and differences in the extent to which these are considered. Furthermore, it can also be seen that the majority of these studies have conceptualised 'adjustment' as an end point or a position to be reached, whether characterised by good metabolic control (Northam, Matthews, Anderson, Camerson & Werthert, 2004), adherence to treatment regimen (Wysocki, Harris, Greco, Bubb, Danda, Harvey, McDonell, Taylor & White, 2000), positive self esteem and lack of psychiatric symptoms (Jacobson et al, 1997) or behaviour (Hamlett, Pellegrini & Katz, 1992). A large majority of research, therefore, has focused on measuring adjustment as an outcome as opposed to a process, and further consideration of adjustment processes may cast light on the existing

empirical data. The following section focuses in more detail on theoretical approaches to the processes of childhood adjustment to chronic illness.

Theoretical approaches to childhood adjustment

In considering the apparent variability in the psychological 'adjustment' of children with chronic illness, Wallander et al (2003) state that a simple, direct relationship between chronic illness and psychosocial adjustment does not exist, with individuals displaying a wide range of responses to their illness instead. They conclude that children with chronic illness are at an increased risk for psychological adjustment problems, but that this is not always the most common outcome. A number of models attempt to chart the processes contributing to the course of this adjustment. For example, research has attempted to investigate whether specific risk and resilience factors influence child and family adjustment.

Two major theoretical models have been proposed which attempt to make sense of how these risk and resilience factors may influence 'adjustment': The Disability-Stress-Coping model (Wallander, Varni, Babani, Banis, Dehaan & Wicox, 1989) and The Transactional Stress and Coping model (Thompson, Gustafson, Hamlett & Spock, 1992).

Disability-Stress-Coping model (Figure 1)

Integrating earlier conceptual models of adjustment put forward by Pless and Pinkerton (1975, as cited in Bradford, 1997), Moos and Shaefer (1984) and Lazarus and Folkman (1984), this model proposes that a chronic illness is viewed as a continual strain for both the child and their parents to which they must adjust. Adjustment is thus understood as being a function of the level of strain experienced, which is influenced by the type of problems encountered by an individual and their ability to successfully cope with these.

The various factors that are considered to play a role in adjustment are organised into a risk and resilience framework (Wallander, et al., 1989). Factors considered to increase the risk of poor adjustment include features relating to the child's disease and disability, the child's level of functional independence in activities of daily living, and psychosocial stressors, which include stresses related to the illness in combination with more general stress occurring in their everyday lives. The impact of these risk factors on adjustment is moderated by three categories of resilience factors: interpersonal factors (i.e. competence, temperament); social-ecological factors (i.e. family environment and social support); and stress processing factors (i.e. cognitive appraisal and coping strategies). The outcomes indicating child adjustment are represented by social functioning, mental health and physical health.

Figure 1: *Disability-Stress-Coping model (Wallander, et al 1989)*
Round corner boxes indicate resilience factors; square corner boxes
indicate risk factors
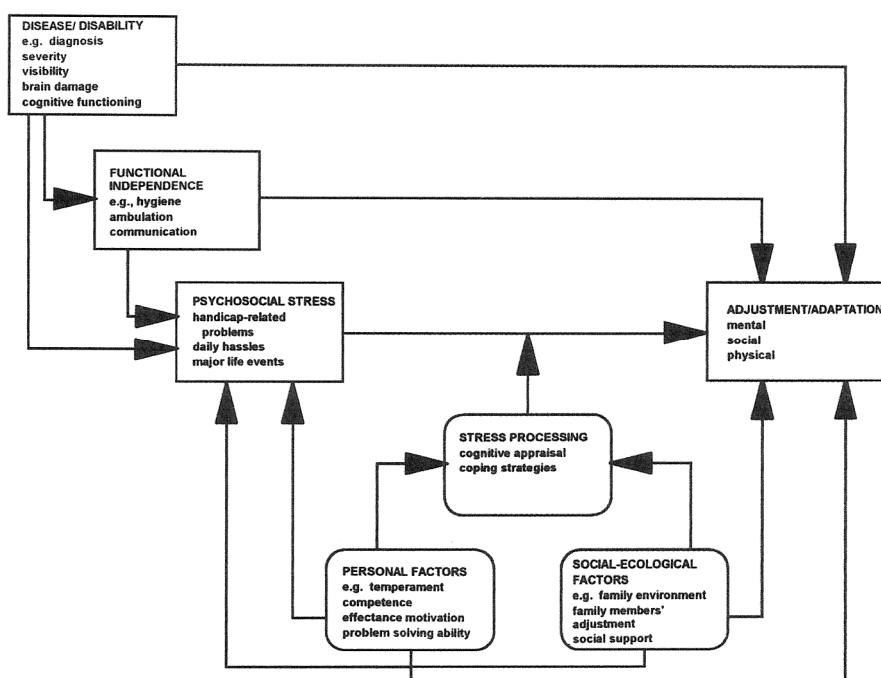
Transactional Stress and Coping model (Figure 2)

Set within an ecological systems theory (Bronfenbrenner, 1979), this model advocates that a chronic illness is viewed as a potential stressor to which the individual and family systems endeavour to adapt. The relationship between the illness and adjustment is hypothesised to be a function of transactions among biomedical, developmental and psychosocial processes. The main focus is on the child and family adaptational processes (cognitive processes and methods of coping), which are hypothesised to influence the adjustment of children above the contribution of biomedical and demographic parameters. Within an ecological systems theory perspective, it is hypothesised that the psychological adjustment of children is affected by levels of stress and symptoms experienced by other family members, highlighting the relevance of a child's family context. Within this model, adjustment is therefore considered in terms of maternal adjustment, child adjustment and the interrelationship between the two, highlighting the relevance of a child's environment. The psychosocial meditational processes included in the model are guided by Lazarus and Folkman's (1984) cognitive stress and coping model, in which adjustment to a stressor is mediated by the use of different coping processes.

Figure 2: *Transactional Stress and Coping Model (Thompson et al, 1992)*
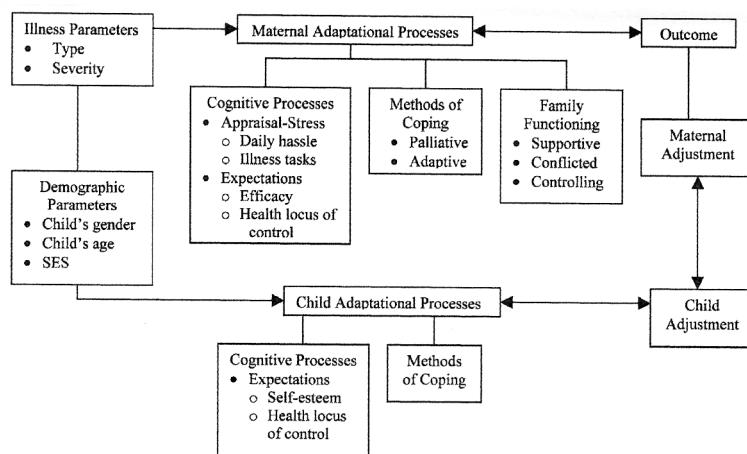
Wallender, Varni, Babani, Banis & Wilcox (1988) have argued that these models are applicable to any paediatric disorder, as it is hypothesised that commonalities between diseases are greater than differences. Many researchers argue for a non-categorical approach to the psychological studies of children with chronic illness, stating that it allows treatment of the 'whole' child rather than the diseased organ or system (Stein & Jessop, 1982). Furthermore, it is considered that this approach will enhance our understanding of the impact of chronic illness on 'adjustment', thereby improving quality of care. Yet although there is value in a non-categorical approach, there is a failure to consider the uniqueness of different illnesses and the different ways in which children may experience them. This approach thus may not be able to offer a focused, rich analysis of specific experiences.

Various criticisms of the models have been made (Wallander et al, 2003; Hocking & Lockman, 2005). It has been suggested that more varied models need to be proposed that incorporate "richer perspectives, novel concepts and more explicit causal processes" (Wallander et al, 2003; pp153). Greater consideration should be given to the influence of other family members, rather than solely the mother (Wallander et al, 2003). Bradford (1997) suggests that future models need to develop a multi level approach that understands the child, family and wider care system, and how they interrelate and impact upon each other, rather than solely considering risk and resilience factors. He also suggests that models should move away from defining adjustment purely in terms of the absence of pathology.

Furthermore, whilst these models identify various factors that are considered relevant to adjustment, they do not make clear how each variable actually influences the adjustment process. By attempting to identify who will and who will not adjust, and what variable might moderate, mediate or impair adjustment,

adjustment is conceptualised as an 'end goal', rather than as a process in flux. As a result, the models do not explore the complex and dynamic nature of the process of adjustment. Wallander et al (2003) state that when measuring adjustment, quantitative methodology has been used to the exclusion of qualitative. They suggest that use of more qualitative research will be enlightening, especially during descriptive and exploratory phases of research.

Theoretical models in relation to DM1

Various reviews of the literature into childhood adjustment to DM1 have been carried out in relation to the two main models of adjustment. Amer (1999b) uses the Disability-Stress-Coping model (Wallander, et al., 1989) as a framework for her review, whereas Hocking and Lochman (2005) guide their review with the Transactional Stress and Coping model (Thompson et al, 1992). Factors that have been found to positively influence a child's adjustment to DM1 include: high levels of support from both family and friends (La Greca et al, 1995; Skinner, John & Hampson, 2000); a cohesive family, lack of family conflict and family acceptance of DM1 (Hauser, Jacobson, Lavori, Wolfsdorf, Herskowitz & Milley (1990); and use of cognitive restructuring as a child's coping method (Edgar & Skinner, 2003). Factors that have been found to negatively influence adjustment to DM1 include: high maternal stress, poor self perception and high stress levels (Kager & Holden, 1992); and the use of emotional focused coping, mental disengagement and fewer active coping strategies (Graue, Wentzel-Larsen, Bru, Hanestad & Sovik, 2004).

Although these reviews illustrate the relevance of both models in relation to adjusting to DM1, they also highlight how some variables included in the models do not pertain to DM1. In the Disability-Stress-Coping model, the majority of the disease disability parameters are considered to be irrelevant to DM1 (Amer, 1999b). The role of maternal adaptational processes and child cognitive

processes are called into question in the Transactional Stress and Coping model, with greater research in these areas recommended (Hocking & Lockman, 2005). Hocking & Lockman (2005) also identify variables that have not been accounted for by the Transactional Stress and Coping model, such as feelings of efficacy, social support, behavioural competence and adaptive behaviour skills.

Given the ongoing difficulties of conceptualising 'adjustment', the relative lack of an in-depth understanding of the psychosocial processes involved, and the relative absence of 'voice' of the children and young people themselves, it is argued that there is a need for a different approach. A more personal focus, exploring a young person's experience of their illness, would help to develop our understanding of the concept of adjustment, in addition to providing enlightening information on the process of adjustment, something that has previously been neglected.

A different approach to adjustment
The work of Charmaz (1983; 1995) and Bury (1982) provides a differing perspective on adjustment by exploring the process from a sociological perspective. Unlike previous work in this area, their work focuses on the implications of chronic illness for sense of self. Their research is based on interviews with adults experiencing a range of chronic illnesses, analysed using grounded theory (Glaser & Strauss, 1967), and thus takes a more experiential focus by exploring the experience of living with a chronic illness.

Charmaz (1983) outlines four factors contributing to suffering amongst people with a chronic illness: leading restricted lives; experiencing social isolation; being discredited; and burdening others. Moving on to discuss the idea of adapting to chronic illness, Charmaz (1995) defines 'adapting' as individuals acknowledging their illness, and altering their life and self in a way that fits both socially and

personally. Adjustment is therefore conceptualised not as a static end point but as a process. Three stages are proposed for adapting to illness. Firstly, one makes sense of the illness in terms of the impact on the body and sense of self. Secondly, one assesses one's changed body and self in order to find a balance between the losses and gains since this change; future identity goals are also revised. Lastly, one surrenders to the sick self by relinquishing control over the illness and by flowing with the experience of it (Charmaz, 1995).

This research emphasises how adopting a qualitative methodology, which takes a more personal focus, can help to develop our understanding of the complex process of adjustment. It highlights the value of providing a space to explore individual personal experiences of illness. It is an approach that generally has been neglected in research with children and adolescents, and it will be considered in greater detail below.

Conceptualising adolescence: why consider the illness experience of adolescents?

Adolescence has been conceptualised as a transitional developmental stage between childhood and adulthood, characterised by greater biological, psychological and social role changes than any other stage of life (Williams, Holmbeck & Greenley, 2002). This section provides a brief review of the theories of adolescent development relevant to the research; for a more detailed discussion see Miller (2002) and Muuss (1996).

Most psychosocial models consider adolescence as a period of transition from dependence to independence, when a young person begins to adopt a range of new emotional and social roles and has to cope with hormonal and bodily changes (Kyngas, Henitnen & Barlow, 1998). Dovey-Pearce, Doherty and May (2007) suggest that Havinghurst's (1953; cited in Dovey-Pearce et al, 2007)

outline of developmental tasks for adolescence is a useful framework for understanding the demands of adolescence. These tasks include: accepting one's own body, adopting appropriate social roles, developing close peer relationships, preparing for occupational roles, preparing for intimate relationships, achieving emotional independence from parents, establishing personal values and ethics and striving for social responsibility. In adjusting to life with chronic illness, adolescents with DM1 are forced to consider the limitations imposed on them as a result of their illness and how these may interfere with their achievement of developmental tasks, perhaps complicating the adjustment or developmental process.

Various theories or models consider adolescence as a period of human development from birth to death, whereby certain stages are reached before moving onto the next. They identify different sets of 'tasks' as defining adolescence. Erikson (1968) for example, considers that a central task for adolescents is the development of identity, which is found through interaction with others, especially the peer group. This has interesting implications for young people with chronic illnesses, particularly in relation to the work of Bury (1982) and Charmaz (1983; 1995), who discuss the implications of chronic illness for sense of self. Adolescents with chronic illnesses possibly may experience a loss of self and may therefore find it difficult to develop a sense of personal identity.

Piaget (Inhelder & Piaget, 1958) instead focuses on cognitive development, suggesting that adolescents move into a final stage of cognitive development, known as the formal operational stage. This is characterised by more abstract, logical and flexible thinking, indicating that as young people move through adolescence, they should increasingly be able to reflect on their experiences and consider possibilities for their future. This therefore suggests that adolescence is a pivotal time to explore young people's experience of chronic illness.

Although such Stage theories indicate potential developmental processes specific age groups may face, they are limited by their basis on culturally specific norms and generalisations. They fail to acknowledge that human development does not follow a linear course and that a young person exists within a family unit and broader cultural system. As Bronfenbrenner's ecological perspective of human development (1979, as cited in Muuss, 1996) acknowledges, for every individual, a continuously interacting set of complex social relationships exists and interactions within these system can influence a person's developmental course.

Given the developmental processes central to adolescence, it is possible that the focus of a young person with chronic illness would be on the impact of the development of independence, separation and identity, and how these are negotiated in the context of their illness. However, it is noted that the developmental perspective is only one conceptualisation of adolescence and there is huge variation in individual development, which is influenced by the young person's social and cultural backgrounds and experiences (see Prout & James, 1997 for more detailed discussion). As such, it is recognised that normative models can only give an indication about possible processes that are relevant. Nevertheless, the developmental perspective dominates in western societies and therefore is likely to be a familiar discourse, influencing the perceptions and expectations of young people, their families and the wider social context.

Child and adolescent views

In recent decades, a growing body of literature has emerged that recommends greater inclusion of children and childhood in social study, along with a consideration of their specific roles and relations in our society (James & Prout, 1997). Drawing on new political agendas in Children's Rights, such as the United

Nations Convention on the Rights of the Child (1989), this approach rejects the notion of children as passive beings, arguing that they are instead active, competent social beings who are capable of speaking for themselves, rather than simply responding to categories imposed by adult models. In the context of chronic illness, children are thus considered as experts on their condition, who can provide valuable insights into their illness from a patient's perspective (Guell, 2007).

Despite these developments, there is little research examining children's own experience of chronic illness (Guell, 2007). Perhaps, within the medical field, children are still seen within a developmental model, whereby they are not yet considered capable of rational judgments and complex thinking. As a result, others, such as parents or caregivers, are asked to speak on behalf of children (Guell, 2007), thus neglecting the children's own views and experiences. As a result, we learn not about young people's perspectives, but about adults' concepts of childhood (Oakley, 1994, as cited in Woodgate, 2001).

In the last decade, a number of studies have begun to explore children's experiences of chronic illness through their own voices. Woodgate (1998) interviewed 23 adolescents aged between 13 and 16 diagnosed with diabetes, asthma, arthritis, Crohn's disease or ulcerative colitis, to gain detailed descriptions of their chronic illness experience. Their accounts highlighted ways in which having a chronic illness made life more difficult: they experienced extra effort, restrictions, pain and additional worries, yet they also demonstrated strategies to help them deal with their illness. Similarly, Guell (2007) explored 7-16 year olds' experience of living with juvenile arthritis, in which their accounts highlighted their expertise about their illness, providing a valuable insight into their lives and abilities to manage and cope with their illness.

There has been relatively little work to date in this vein regarding diabetes. Amer (1999) suggests that children have not played an active role in describing their perceptions of adjustment to DM1, with the majority of research focusing on views of parents, teachers and professionals. In line with developments in the social study of childhood, she proposes that in order to develop a more focused understanding of young people's adjustment to DM1, more information needs to be directly elicited from young people. She suggests that this should include young people's views on school, home, friends, health and how they perceive and manage their illness. Furthermore, it has been suggested (Woodgate, 1998; Miller, 1999) that where children's views have been sought, this mainly has been using quantitative approaches, with an overreliance on the use of questionnaire data. It has been proposed that such measures may not be sensitive enough to capture possible thoughts, feelings and experiences of young people with chronic illness (Woodgate, 1998), and they reduce the opportunity for young people to discuss issues of personal concern (Miller, 1999).

One way to access information from young people themselves is by conducting qualitative research, which aims to provide rich, descriptive accounts of the phenomenon under investigation (Smith, 2008). Instead of trying to fit people's experiences into predetermined categories derived from existing theories, it enables the wholeness and complexity of the phenomenon to be studied and represented (Orford, 1995). Qualitative methods focus on verbal analyses rather than mathematical ones, with researchers attempting to make sense of people's lived experience (Nelson & Quintana, 2005). They are generally concerned with exploring, describing and interpreting the personal and social experiences of individuals (Smith, 2008). Woodgate (1998) states that further qualitative studies are needed to increase our understanding of young people's experience of chronic illness.

Young people's experiences of DM1

There are now a handful of studies using qualitative methodology to explore young people's own experiences of living with DM1, developing our understanding of what it is like for young people to live with diabetes and the processes involved in 'adjustment'.

Using Interpretative Phenomenological analysis (IPA; Smith & Osborn, 2008), Schur et al (1999) interviewed eight young people (aged 16-22 years) about their experience of living with diabetes. Their findings led them to develop two core themes, namely 'developing a relationship with diabetes' and 'managing threats from diabetes'. They found that young people identified an inherent vulnerability associated with having DM1, fearing that it would take over their lives and overwhelm them. Acceptance of their relationship with diabetes was facilitated through parental involvement and sharing, alongside the use of intrapersonal and interpersonal self protective strategies to manage the ongoing threats they felt diabetes presented. Control over diabetes was also considered to be fundamental in order to protect the young people from the perceived threats of diabetes. Furthermore, participants reported a general sense of difference from others as a result of their diabetes and in order to manage this, they appeared to develop an identity that was independent of diabetes.

Schur et al (1999) concluded that the richness and elaboration gained by exploring young people's experience highlights pivotal issues in living with diabetes. One criticism of this study was that it focused on the young people aged sixteen and over, neglecting the views of the younger age range.

Using Van Manen's phenomenological approach (Van Manen, 1990), Dickinson & O'Reilly (2004) interviewed ten adolescent females (aged 16-17) from a diabetes camp regarding their experience of living with DM1. In accordance with

Schur et al (1999), participants described their sense of difference as a result of diabetes, encapsulated by the theme 'standing out and being watched'. In addition, they identified four further themes: 'blending in with the adolescent culture', 'weighing the options and making choices', 'being tethered to the system and to diabetes' and 'struggling with conflicts'. Whilst this study helps develop understanding of the experience of living with diabetes, it focused solely on females within a narrow age range. Participants were recruited from a group of females who were participating in a 'Counselor-In-Training' program at a diabetes camp and it could be argued that this experience influenced the way they responded to the interview. Additionally, the interviews only lasted between 15 to 35 minutes, a duration that one could question as not being sufficient to obtain rich enough data.

Carroll & Marrero (2006) used focus groups to explore how DM1 influences adolescent perceptions of quality of life in general and their relationships with parents, peers, school and their physician. They conducted five focus groups with a total of 31 adolescents aged between 13 and 18. From discussions within the focus groups, the following themes emerged: 'personal perceptions of living with diabetes', 'impact on relationships', which included parental, peer and physician relationships, and 'impact on school'. The authors concluded that DM1 can have a significant impact on an adolescent's normal progression to independence and adulthood, suggesting that adolescents become afraid to do appropriate developmental activities because of the demands of managing DM1. Although this study provides insights into the impact of living with DM1, the authors failed to clarify the type of analysis used, and it is thus difficult to establish the validity of the study. In addition, the use of a focus group methodology may have made it difficult for participants to air different views and thus certain opinions may not have been raised.

Based on a Framework Approach (Ritchie & Spencer, 1994), Dovey-Pearce, Doherty & May (2007) interviewed 19 young people aged between 16 and 25 to explore their accounts of the developmental impact of DM1. Two main themes emerged from the data, namely the impact of DM1 and coping with DM1. Similar to Schur et al (1999), they concluded that DM1 can disrupt personal development, challenging an individual's personal identity and self concept. In accordance with Carroll & Marrero (2006) they found that it can also influence peer and family relationships, with individuals describing the challenge of separating and individuating. When considering coping with DM1, it was apparent that balancing daily life with future threats was an important goal for the young people, where a key challenge was coming to terms with risk and threat of death. This research formed part of a larger scaled study exploring developmentally appropriate health care services for young people, and it is possible therefore that the researchers' agenda influenced their interaction with the data. It is also worth noting that the Framework approach used to analyse the data is a method used for policy research and this may have influenced the researchers' focus.

Although these studies employed slightly different methodologies (IPA, Van Manen's phenomenological approach, Framework approach), had slightly different aims and participants from somewhat different backgrounds (two studies were American, two were British), their findings share some commonalities and highlight the valuable nature of qualitative research. They provide a general sense that diabetes impacts a wide range of areas of a young person's life and as a result young people are faced with a range of challenges. Consequently, young people appear to experience a sense of difference from others which can impact their sense of self. These studies are not without methodological concerns, however, and future research in this area would help further develop our understanding. All research has focused on white participants in higher education and as a result little is known about the experience of those from ethnic

and lower socioeconomic groups. Moreover, the majority of studies focus on the older age range of adolescence (aged 16+) and thus the views of younger adolescents (12 to 15) are not represented. It is possible that the meaning of living with diabetes may be quite different for the younger age groups. Furthermore, we have learnt little about how these young people manage or cope with these challenges, with only one study addressing this (Schur et al, 1999). Additionally, these studies have not yet explored the process of adjustment to DM1, with the focus being purely on the influence of diabetes in different areas of the young people's lives.

Peer relationships in adolescence

It is well recognised that during adolescence, relationships outside the family become increasingly important (Giordano, 2003). As adolescents decrease their dependence on their parents, they often rely on peers for support. It is considered that these relationships provide a critical source of emotional support (Hartup, 1996), contributing to adolescents' self concept and well being (Furman & Buhrmester, 1992). Adolescents spend a large proportion of their day in the company of friends and peers, and rate friendships as significantly important relationships (Berndt, 1992). Peer relationships have been found to have an important influence on adolescents' attitudes, behaviour and development (Berndt, 1992).

Peer relationships in chronic illness

Adolescents with chronic illness are faced with a range of demands and stressors including distress about their condition, teasing from peers, restrictions on activities, difficult or painful medical procedures, and demanding treatment regimens (La Greca, Bearman & Moore, 2002). Support from close friends has been found to be important for adolescent disease adjustment and treatment

management (La Greca, Auslander, Grecci, Spetter, Fisher & Santiago, 1995; Burroughs, Harris, Pontious & Santiago, 1997).

Peer relationships in adolescents with DM1

Although peer relationships are an integral part of an adolescent's development, this area has received minimal attention from previous studies. The focus instead has been on the family relationships of adolescents with DM1 (Helgeson, Reynolds, Shestak & Wei, 2006). Research has begun to address this, with interesting findings.

Support from close friends and peers has been found to be important for adolescent adaptation to illness and adherence to the medical regimen. Using a structured interview, La Greca et al (1995) asked 74 adolescents with diabetes (29 girls and 49 boys) aged between 11-18 to describe the ways family members and friends provided support for diabetes management and helped them to 'feel good about their diabetes'. Family members were found to offer more tangible support for regimen adherence, while friends were found to provide companionship and emotional support, helping the adolescent feel accepted and improving their self esteem. Although family members were also found to offer emotional support, it was exceeded by emotional support from friends. One criticism of the research is that it used a structured interview and thus young people were restricted by predetermined categories. As a result, other novel instances of peer or family support may have been missed. La Greca et al (1995) concluded that friends are an important source of emotional support for adolescents with DM1, and suggested further investigation of how friends can assist with adjustment to chronic disease. This view is supported by Burroughs et al (1997) who, in their review exploring social support in adolescents with DM1, highlight that additional research is needed to examine the role friends play in adjustment to DM1.

Despite the positive emotional support friends can offer young people with DM1, evidence suggests that many youngsters with DM1 are concerned about the impact of their illness on their peer relations (Thomas, Peterson & Goldstein, 1997). Various studies (Storch, Lewin, Silverstein, Heidgerken, Strawser, Baumeister & Geffken, 2004; Van Cleave & Davies, 2006) have found that children with chronic illness are more likely to be bullied that those who are not chronically ill. Storch et al (2004) found that compared to children without a medical condition, children with DM1 received less supportive behaviour from peers. They asked 64 children (46 girls and 18 boys aged between 8 and 18; 32 with DM1 and 32 with no medical condition) to complete a range of questionnaires and found that adolescents with DM1 were more likely to be bullied than those without DM1. They found that such victimisation was positively associated with depressive symptoms, social anxiety and loneliness. This is the first study to investigate peer victimisation in young people with DM1 and one should be therefore cautious when making generalisations about the results. In addition, this study was based on a small sample size and relied on the use of self report measures. The findings appear to be consistent, however, with studies of peer victimisation in samples of children with other medical conditions (Van Cleave & Davies, 2006). Furthermore, following a survey of young people's experience of bullying, the organisation Diabetes UK (2009) has recently released a video called 'Set the Record Straight' which aims to stop young people with DM1 being bullied. Although there is minimal detailed research in this area, this suggests that bullying is an area of concern for young people with DM1 and warrants further research.

Thomas et al (1997) suggest that in the presence of their peers, adolescents often do not adhere to their regimens as they are concerned about being perceived as 'different' and not fitting in with their peer group. They recommend

interventions focusing on managing peer impressions as a more developmentally appropriate strategy for aiding adherence in adolescents with DM1.

Following on from this research, Greco, Shroff Pendley, McDonell & Reeves (2001) devised a peer group intervention for 21 adolescents with DM1 and their best friends. The average ages of the adolescents and their peers were 13.1 and 13.6 and there were ten pairs of females and eleven pairs of males. Each adolescent-peer pair attended 4 two hour education and support groups. They found that following the intervention, peers had a greater knowledge of DM1 and the support they could provide, peers provided a greater proportion of support compared to family members, and parents reported a reduction in family conflict as well as improved adjustment. However, the researchers emphasised that this study was a pilot based on a very small sample size and did not include a control group. They also discussed their uncertainty regarding the psychometric properties of one of the measures used. They therefore highlighted that the findings should be interpreted with caution and future research in this area would be advantageous. The study nevertheless offers a promising insight into the potentially positive role peers can have in a young person's adjustment to diabetes.

To encourage further study of the specific way that adolescents' friends provide support for their DM1 care, Bearman & La Greca (2002) developed the Diabetes Social Support Questionnaire – Friends Version. They suggest that the large majority of current research focuses on the link between peer relationships and health risk behaviours, and additional attention is needed to examine the potentially positive influences that friends may have on adolescent disease management and adaptive health behaviours. In developing this questionnaire, they concluded that further research was needed into the ways in which friends

contribute to an adolescent's adjustment to DM1, in addition to investigating potential mediators that link friend support with positive outcomes.

Although peer relationships have been found to be important for the adjustment to a chronic illness and adherence to medical regimens, there has been minimal detailed research in this area (La Greca, Bearman, Moore, 2002). Helgeson, et al (2006) state that studies of children with DM1 rarely focus on peers, even though establishment of a peer group is a major task that can be negatively affected by DM1. The small quantity of research that exists in this area suggests that peers can play a vital role in adolescent adjustment to chronic illness, providing both positive and negative influences. Methodological limitations make it difficult, however, to generalise the findings and point to a need for greater research in this underdeveloped area. Indeed, La Greca et al (2002) recommend further studies focusing on the positive and negative aspects of peer support for adolescents with chronic illness. It therefore seems important to focus on the role of peer relationships in young people's adjustment to DM1.

Aims of the research

The above research demonstrates that adjusting to, and managing, DM1 during adolescence is a complex process that is significantly influenced by a range of physiological, psychological and social variables. While attempts have been made to explore young people's adjustment to DM1, a large proportion of the research has measured 'adjustment' as an outcome as opposed to studying it as a process. Findings are often inconsistent, partly due to the varying definitions and conceptualisations of adjustment used. Furthermore, research appears to have neglected the views of young people themselves, focusing on parent, teacher or professional perspectives. Thus our understanding of childhood adjustment to DM1 is based on adult concepts. Qualitative research has began to redress this balance by exploring young people's own experience of living with DM1, however the younger age range of adolescence (i.e.12-15) appears to have

been neglected and few studies have specifically investigated the experience and process of adjustment. Furthermore, the role of peers in the adjustment of young people with chronic illness has rarely been examined and where it has this has been predominantly using quantitative methodology. Wallander et al (2003; pp150) suggest that more research is needed into this "important area of children's lives".

The general impression of research to date is that further qualitative research in this area will make a useful contribution to the evidence base, allowing participants to define and explore issues important to them without being constrained by the concepts set out in questionnaires (Dovey-Pearce et al, 2007). Similarly, Wright & Kirby (1999; pp 271) "call for researchers to adopt a more holistic view of 'adjustment' in further research into outcomes amongst people with a chronic illness".

Thus, the objectives of this study were to explore the personal experiences of adjustment in young people aged between 12 and 15, with a diagnosis of DM1 using a qualitative approach. The aim was to offer a rich, descriptive and interpretative account paying attention to the contradictions, complexities and context of adolescent experiences. This approach is in line with new approaches to the social study of young people (James & Prout, 1997), viewing individuals as experts of their own experiences who can provide valuable insights from their own perspectives.

Research question
With the above aims in mind, the main research questions were:
• How do adolescents experience adjustment to life with DM1?
• How do adolescents experience their peers during the process of adjustment to life with DM1?

METHODOLOGY

A qualitative approach

There is a paucity of research examining young people's own experiences of chronic illness, with parents or caregivers often being asked to speak on their child's behalf (Guell, 2007). It is suggested, therefore, that our knowledge of chronic illness in young people is based on adult rather than child concepts (Oakley, 1994, as cited in Woodgate, 2001). Woodgate (1998) indicates that where the views of young people have been sought, there has been an overreliance on quantitative approaches. This existing research can be enriched, however, by qualitative research, which explores, describes and interprets the personal and social experiences of individuals (Smith, 2008). This type of qualitative research aims to learn how people make sense of their experiences, rather than focusing on outsiders' views of what people do (Fiese & Bickman, 1998). Its goal is to understand a relatively small number of participants' own experiences in depth, rather than testing a preconceived hypothesis on a large sample (Smith, 2008). This approach was thus considered suitable for this study.

Interpretative Phenomenological Analysis (IPA)

Theoretical foundations of IPA

IPA has been informed by the concepts and debates from three key areas of the philosophy of knowledge: phenomenology, hermeneutics and idiography (Smith, Flowers & Larkin, 2009). This section will briefly outline these philosophies, considering their connections to IPA. For a more detailed discussion see Smith, Flowers and Larkin (2009).

Phenomenology, the study of what an experience is like, has been a major influence in the development of IPA. Smith, Flowers and Larkin (2009) discuss

the contribution of four major phenomenological philosophers: Husserl, Heidegger, Merleau-Ponty and Sartre. Husserl's work highlights the importance of focusing on experience and individuals' personal understandings of this experience. Heidegger, Merleau-Ponty and Satre developed this further, suggesting that individuals exist in a lived world rather than in isolation, signifying that an individual's involvement in the lived world influences their perspective on their lives and experiences. This is an important aspect of IPA as researchers have come to appreciate the complex, relative, sense making processes of their participants.

Hermeneutics, the theory of interpretation, is the second theoretical underpinning of IPA. Here the works of hermeneutic theorists Schleiermacher, Heidegger and Gadamer are considered to be influential (Smith et al, 2009). Within hermeneutics, interpretation is considered to be an art, whereby the interpretative analyst is able to offer an understanding to an experience that the author cannot. Within this theory the complexity of the relationship between the interpreter and the interpreted is acknowledged. It highlights that access to another person's experience depends on and is complicated by the researchers own conceptions, emphasising the importance of an awareness of one's own bias and preconceptions and maintaining a spirit of openness (Smith et al, 2009). Smith and Osborn (2008) discuss that in IPA a double hermeneutic is involved, whereby the researcher is trying to make sense of the participants trying to make sense of their world, thus recognising that the production of an interpretative account is a function of the relationship between a researcher and participant, constructed and shaped by their encounter. Finally, the theory recognises that the production of an interpretative account is iterative, based on the concept of the hermeneutic circle. During the process of analysis, one moves back and forth through a range of different ways of looking at the data, whereby to understand any given part,

one looks at the whole, and to understand the whole one needs to look at the parts.

The final major influence upon IPA is idiography. In contrast to traditional nomothetic approaches which focus on the generalisability of findings, an idiographic approach is concerned with the particular by investigating, in detail, how particular lived experiences have been understood from the perspective of a small group of particular people, in a particular context (Smith et al, 2009).

IPA (Smith, 2008) was chosen as a suitable methodology for this study for a number of reasons that are now discussed.

The aim of IPA is to get an insider perspective by exploring in detail how participants make sense of their personal and social world. Its philosophy is embedded in symbolic interactionism, a concern for how meanings are constructed by individuals within both a social and personal world (Smith & Osborn, 2008).

IPA views individuals as experts on their own experiences who can offer researchers an understanding of their thoughts, commitments and feelings through telling their own stories, in their own words, in as much detail as possible (Reid, Flowers & Larkin, 2005). It is a phenomenological approach concerned with exploring individuals' experiences and perceptions of an object or event, as opposed to producing an objective truth regarding an object or event. Its underlying philosophy, therefore, is that there is no objective reality. Instead, people's experiences are influenced by their perceptions, which are constrained by social constructions.

Simultaneously, IPA emphasises that research is a dynamic and interpretative process, in which a researcher's attempts to make sense of a participant trying to make sense of their experience results in a double hermeneutic process (Smith & Osborn, 2008). Access to another person's experience is partial and complex, so IPA highlights the value of considering a researcher's role in influencing the process (Smith & Osborn, 2008). As a researcher's own views, assumptions and beliefs will influence an interpretation of a participant's account, IPA stresses the importance of reflexivity to aid transparency. It recognises that the production of an interpretative account is a function of the relationship between a researcher and participant, constructed and shaped by their encounter (Larkin, Watts & Clifton, 2006).

Reasons for choosing IPA

IPA is a valuable tool in researching many areas relevant to both clinical and health psychology (Reid, Flowers & Larkin, 2005; Brocki & Wearden, 2006). In health psychology, IPA facilitates the description and understanding of individuals' accounts of the processes by which they make sense of their illness experiences (Brocki & Wearden, 2006), thus contributing to increasingly recognised biopsychosocial perspectives (Reid, Flowers & Larkin, 2005). In line with the biopsychosocial approach, IPA allows human experiences to be explored within a cultural context, highlighting contextual factors within an individual's life that directly or indirectly may play a part in the meaning making process (Shaw, 2001).

IPA helps to provide new and differing perspectives on a phenomenon by learning from those who are experiencing it, rather than learning from or being biased by old theories, predetermined notions in existing research, or, pertinent for a study focusing on adolescents, theories based on the perceptions of adults (Shaw, 2001). The idiographic nature of IPA therefore fits with the objective of

this research, to investigate in detail the lived experiences of a small group of individuals, rather than generalising notions for larger populations (Smith & Osborn, 2008). Indeed, Smith (2004) suggests that this type of analysis can enable learning about important generic themes in addition to each participant's individual story. The opportunity to investigate phenomena from a new perspective by learning from those who are experiencing it, rather than from pre-existing theories or knowledge (Shaw, 2001), fits well within the current NHS agenda of taking a 'patient centred perspective' and listening to the views of service users (Reid, Flowers & Larking, 2005).

Furthermore, IPA is particularly useful for investigating complexity, process or novelty (Smith & Osborn, 2008). Thompson, Kent & Smith (2002) advocate the need for further research using IPA to explore *process* rather than adjustment *outcome*, fitting with this study's aim to explore the process of adjustment. An additional benefit to a novice researcher is the clear guidelines provided regarding its application (Smith & Osborn, 2008).

Limitations of IPA

Although IPA recognises the importance of the researcher's perspective, it has been criticised for not providing guidelines on how to incorporate this reflexivity into the research process and for not specifying how researcher conceptions influence analysis. Willig (2001) suggests therefore that findings invoke a sense of discovery rather than construction, although Smith & Osborn (2008) argue that IPA is an approach rather than a rigid method, allowing flexibility to meet the researcher need and context.

The role of language can be problematic in IPA. Social constructionists argue that language constructs rather than describes reality. It could be said therefore that an interview transcript tells us more about the way in which an individual talks

about a particular experience, within a particular context, than about the experience itself (Willig, 2001). IPA acknowledges the role of social constructionism and the fact that pure experience is never accessible. It recognises the action-orientated nature of language yet challenges the narrow view of people only as discursive agents (Eatough & Smith, 2006).

Furthermore, the ability of participants to communicate the rich texture of their experience successfully is a question that has been often asked of IPA. Individuals may struggle to use language in a way that accurately conveys the subtleties and nuances of their experience (Willig, 2001). Smith & Osborn (2008) accept that people often struggle to express what they are thinking and feeling yet argue their emotional state should be interpreted by a researcher, by analysing what they say and by asking critical questions about what is not said.

IPA as opposed to other qualitative methodologies
In deciding on this study's methodology, grounded theory was ruled out, despite similarities with IPA. It has been suggested that grounded theory is best suited to address sociological research questions, as it focuses on theory construction and social processes that account for phenomena, whereas IPA adopts a more psychological approach focused on gaining a detailed understanding of the quality and texture of individual experiences (Willig, 2001).

Discourse Analysis was also felt inappropriate due to its focus on the role of language in the construction of social reality (Willig, 2008). Its goal of understanding how people use language to create and enact identities and activities contrasts with focusing on the detailed understanding of a particular lived experience (Starks & Brown Trinidad, 2007).

Narrative analysis is concerned with the narratives people construct to bring order and meaning to an ever changing world (Murray, 2008). Although it has a strong intellectual connection with IPA (Smith, Flowers & Larkin, 2009), it was deemed unsuitable as its application to psychological studies is relatively new. IPA offered greater availability of expert supervision, training and workshops, and overall was deduced to be the most appropriate methodology to address the research question.

Participants

Recruitment

An NHS paediatric diabetes clinic was used to recruit participants for the research. The clinic identified sixteen potential participants who met the inclusion and exclusion criteria and sent them and their parents an invitation letter (Appendix 2&3) and an information sheet (Appendix 4&5). On return of an opt in slip (Appendix 6), those interested in participating were contacted to arrange interviews. This generated four participants and approximately six weeks after sending the first letter, a reminder (Appendix 7) was sent to all parents, generating a further two participants.

Inclusion and exclusion criteria

To ensure a sufficiently homogenous sample, participants had to meet the following requirements:

1. Female
    As IPA literature recommends obtaining a fairly homogenous sample, particularly if you are a newcomer to IPA (Smith et al, 2009), the current study only recruited females. In addition, past research has indicated differences in the way in which males and females respond to living with DM1 (La Greca,

Swales, Klemp, Madigan, Skyler, 1995), with females finding it more difficult to manage their diabetes (Hanna & Guthrie, 1999) and being more prone to anxiety and depression (Bryden, Peveler, Stein, Neil, Mayou & Dunger, 2001).

2. Aged between 12-15 years:

The age band commonly used in research with adolescents is 12-18 years (Coleman & Hendry, 1999). However, as identified in the literature review, the younger age range of adolescence has often been neglected and thus this range was the focus for this research.

3. Diagnosis of DM1 for at least a year:

Kovacs, Kass, Schnell, Goldston & Marsh (1989) suggest that in the first 9-12 months of diagnosis, diabetes control and usual family functioning are difficult. It was therefore considered that it would not be appropriate to interview adolescents during this initial transition phase.

4. English speaking:

As qualitative research relies heavily on language, non-English speaking participants were excluded as there was a concern that the richness and meaning of language might get lost in the process of translation.

The sample

Smith & Osborne (2008) recommend that five to six participants is a reasonable sample size for a student IPA project. Participants were six females who had a diagnosis of DM1 (see Table 1 for details). Four lived with both parents and the remaining two with a single parent.

Table 1: Participants

For reasons of confidentiality all names have been changed.

Participant pseudonym	Gender	Age	Ethnicity	Age of diagnosis	Family members with diabetes
Holly	Female	13	White British	9	Great grandparents (Type 2 diabetes)
Alice	Female	14	White British	8	Not any
Abigail	Female	15	White British	13	Aunt (DM1)
Hannah	Female	13	White British	6	Not any
Emma	Female	12	White British	9	Father, uncle, aunt, grandmother and great grandmother (DM1)
Jess	Female	13	White British	10	Grandfather (Type 2 diabetes)

Context of the study

Participants were recruited from an outpatient paediatric diabetes clinic in the South East of England, consisting of two paediatricians and a diabetes nurse specialist with input from a clinical psychologist. The clinic's current caseload is 130 children and adolescents aged 2-16 years, with a ratio of 61 girls to 69 boys. 75% are White British, 20% are of Asian origin and 5% are of Afro-Caribbean origin.

Ethical issues

Ethical approval was granted by the Hertfordshire Research Ethics Committee (Appendix 1).

Informed consent

Prior to participants agreeing to participate in the research, they and their parents were sent an introductory letter outlining the purpose of the research and information sheets detailing what participation involved (Appendix 4&5). They were able to consider this in their own time before deciding whether to participate. This information was also provided verbally prior to interviews and participants and their parents were given the opportunity to ask questions. Before each interview began, participants were reminded they could withdraw at any time without giving a reason. Participants signed an assent form (Appendix 8) and parents signed a consent form (Appendix 9) both of which were countersigned by the researcher.

Confidentiality

Confidentiality and its limits were clearly detailed in the information sheets and explained verbally to participants and their parents. They were informed that all personal identifying information would be removed from written transcripts and any quotes used within the write up would be sufficiently anonymised. Participants were also informed that information would not be shared with their parents or the diabetes clinic unless the researcher was concerned there was a risk of harm to themselves or others. All data was kept securely and confidentially at the author's home.

Affiliation of study

An ethical concern was that participants may assume the service they received from the diabetes clinic could be affected in some way by their decision to

participate. Invitation letters and information sheets clearly stated that the research was independent of the service and would not affect their standard of care.

Potential distress

Although it was hoped that the participants would appreciate the opportunity to share their experiences, an ethical consideration was the potential distress young people may experience when asked about how DM1 has impacted their lives. Every measure was taken to minimise the risk of distress. The interviewee was told in writing in the information sheet, and verbally prior to starting the interview, that they could stop the interview at any time and did not have to answer questions they did not feel comfortable answering. The author is a trainee clinical psychologist with experience of dealing with people who are distressed and interviews were conducted as sensitively as possible. Each interview was followed with time to debrief and the author's supervisor (a local paediatric clinical psychologist) agreed in advance to offer a follow up session if further support was needed.

Data collection

Interviews

Smith & Osborn (2008) recommend the use of semi-structured interviews for an IPA study. This facilitates a more informal, flexible conversation, enabling the interviewer to probe particular areas of interest that arise or follow novel areas pertinent to the research question. A semi structured interview schedule (Appendix 10) was developed based on relevant literature, discussion with research supervisors and relevant guidance on constructing an interview schedule (Smith & Osborn, 2008).

The schedule guided interviews rather than dictating them, facilitating the participants' ability to tell their own story in their own words. Questions were initially delivered in an open-ended and non-directive style in order to get as close as possible to the participants' views without them being led too much by the interviewer's questions. The interviewer followed each interview by making detailed notes about the experience, recording initial thoughts, feelings and impressions as well as documenting anything that might have affected the interview, such as interruptions or salient points about the environment in which the interview had taken place.

Participants were given a choice about whether they would prefer to be interviewed at home or at the hospital. All participants chose to be interviewed at home. Interviews lasted between 35 to 60 minutes and were audio recorded and then transcribed, with all identifying information either removed or disguised.

Data analysis

Data was analysed using IPA, as detailed by Smith & Osborn (2008) and discussed above. The analysis was also guided by documentation on quality in qualitative research (Elliot, Fischer & Rennie, 1999; Spencer, Ritchie, Lewis & Dillon, 2003; Yardley, 2008) and through supervision from an experienced qualitative researcher and clinical psychologist working in a paediatric setting.

Transcripts were analysed individually in turn. This process began with becoming familiar with each account by reading and listening to it a number of times, during which notes were made in the left hand margin of the transcripts to record anything interesting or significant about what the interviewee had said. This included summarising the content of what was said, as well as commenting on connections, similarities, differences, contradictions and preliminary interpretations.

Transcripts were then re-read and the right hand margin was used to document emerging themes. This involved moving to a higher, interpretative level of abstraction, general enough to allow theoretical connections within and across cases, whilst remaining grounded in what the participant had actually said.

The emergent themes were then listed in order of appearance and attempts were made to look for and make sense of connections between them, creating theme clusters. Smith & Osborn (2008: pp70) suggest imagining a magnet, "with some themes pulling others in, helping to make sense of them". These clusters were then titled, creating superordinate themes. It was essential to continually return to the transcripts throughout this process, to verify the superordinate themes still reflected what the participant had actually said. A table of superordinate themes, together with associated sub-themes and supporting verbatim text extracts was then produced.

This process was repeated for all six interviews, each time putting the previous interview to one side and working on the next one from scratch. Although commonalities in themes began to be identified, care was taken to acknowledge new issues emerging in each transcript, thus paying attention to ways in which accounts from participants were similar but also different (Smith & Osborn, 2008).

When all six interviews had been analysed, the superordinate themes and theme clusters for all interviews were examined and clustered together to create a master list of themes and component sub themes for all participants (Appendix 11). The master theme titles provided a coherent framework to understand the adolescents' experience of adjusting to life with diabetes.

Writing up

The master list of themes and corresponding sub themes was translated into a narrative account that expanded the analysis and explained the themes, illustrated with verbatim extracts. Care was taken to ensure a distinction was made between what the participants had said and the researcher's interpretation.

Quality in qualitative research

In the literature a debate has ensued about whether concepts of quality and rigour used to assess quantitative research can be applied to qualitative research. Quantitative research, underpinned by a realist philosophy, mostly bears the assumption that participants' data exists 'out there' and a researcher's challenge is to uncover and present it with as little bias as possible. In contrast, most qualitative research acknowledges the constructed nature of 'data', particularly the interpretative aspects of analysis. The researcher's challenge then shifts to demonstrating as far as possible the process through which these constructions in the data generation are made. It has therefore been recognised that "qualitative research should be assessed on its 'own terms' within premises that are central to its purpose, nature and conduct" (Spencer, Ritchie, Lewis & Dillon, 2003; pp 4). Various guidelines (Elliott, Fischer & Rennie, 1999; Spencer et al, 2003; Yardley, 2008) have been developed to facilitate the assessment of quality and rigour in qualitative research. The principles set out by Yardley (2008) were used as a guide to this study, as detailed below.

Sensitivity to context

Yardley (2008) identifies two important ways in which a qualitative study can be shown to be sensitive to context:

1. Consideration of relevant theoretical and empirical literature:

The theoretical and empirical literature relevant to the study is outlined in the literature review and introduction. Its consideration aided identification of current gaps in our understanding, helping to formulate a suitable research question. The analysis was also reviewed in its light and consideration was given to how findings could contribute to clinical practice.

2. Sensitivity to perspective and socio-cultural context of participants: The research was designed with consideration given to the possible impact on participants of the characteristics of the researcher (age, gender, culture) and the setting in which the research took place (see Ethical issues, above). It was ensured that the research was sensitive to participants' perspectives through the use of open-ended questions (see Data collection, above).

Commitment and rigour

Yardley (2008) identifies four key factors for consideration in this area: thorough data collection, depth/breadth of analysis, methodological competence/skill, and in-depth engagement with the topic. A thorough explanation of the choice of design in relation to the research question is discussed above, emphasising the four key factors and highlighting the way in which this study demonstrates commitment and rigour. To ensure methodological competence, the researcher also attended a conference and speciality lectures on IPA, as well as consulting a range of relevant literature in order to develop her related skills and knowledge.

Coherence and transparency

Yardley (2008; pp248) defines coherence of a study as "the extent to which it makes sense as a consistent whole". She emphasis that the clarity and power of the argument one can make for a study and the way in which it is carried out can

partly determine its coherence. Furthermore, she highlights that a coherent piece of qualitative research must have a solid grounding in the methods used and their theoretical background. A detailed rationale for this study is provided in the literature review and introduction, and the theoretical background of IPA, and why it was considered appropriate over other qualitative methods, is discussed above.

In Yardley's (2008) framework, the transparency of a qualitative study is concerned with how well a reader can understand exactly what was done and why. An audit trail of the analysis process is thus provided in Appendix 11. Peer review was also utilised and two supervisors, both specialising in paediatrics, one of whom has expertise in qualitative research, simultaneously audited one of the transcripts. They agreed with the themes produced, thereby illustrating triangulation and the data's sound trustworthiness. Regular discussions with the supervisors and peer IPA researchers ensued throughout the analysis process, enabling emerging themes, and similarities and differences, to be considered. This also provided the space to consider alternative perspectives and to reflect on how the researcher's own assumptions and biases may be influencing the data. Angen (2000) states that although peers can never have the same involvement with a topic as its researcher, they can help by ensuring that themes make coherent sense.

Quotes and verbatim extracts from the transcripts are included to illustrate the themes, to enable readers to evaluate the fit between the data and its interpretation (Yardley, 2008; Elliott et al, 1999). As reflexivity is considered an important aspect of a study's transparency, a section on self reflexivity has been included below, to illustrate as far as possible the researcher's values, interests and assumptions, with consideration of how these may have influenced the research process (Elliott et al, 1999).

Impact and importance

Yardley (2008) proposes that there is no value in conducting research unless the findings have the potential to make a difference. The relevance of and need for this study is outlined in the literature review and introduction, and suggestions will also be made regarding how this research can contribute to clinical practice and how it may facilitate our general understanding of the adjustment process in young people. As recommended by Elliott et al (1999), the sample characteristics and study context are outlined above to enable the reader to judge the transferability and relevance of the findings.

My position as a researcher

My training in clinical psychology has been within a programme guided by constructivist and social constructionist philosophies. These ideas have guided both my clinical practice and research, and encouraged me to question my previously held assumptions and to challenge dominant narratives within society. I have been led to a belief that there are multiple, socially constructed realities which have no universal or timeless validity (Appleton & King, 1997). Consequently, my ontological position is relativist as opposed to realist (Willig, 2001).

Constructivist approaches focus on the ways in which individuals construct knowledge and meaning from their experiences (Burr, 2003). Social constructionist approaches focus on the power of socially dominant accounts (narratives and discourses) in constructing realities (Willig, 2001; Burr, 2003). Both positions highlight complexities and subjectivities, and lend themselves to qualitative research methodologies (Burr, 2003).

The literature is unclear about whether to place IPA within a constructionist or constructivist approach. Eatough and Smith (2006; pp. 485) describe IPA as a

"light constructionist" stance, suggesting that it fits well with the philosophy on which the study is based.

Self reflexivity

I am a 28 year old white British female and I grew up in a middle class area in the English Home Counties. I have worked for the NHS in the field of psychology for five years. My theoretical orientation has been informed by my clinical psychology training, my experience of working in the NHS, and my personal values, leading to favouring social constructionist and systemic ideas in both clinical practice and research. My understanding of chronic illness is informed by the biopsychosocial model of health and illness, which advocates that biological, psychological and social influences all interact and play a significant role in an individual's functioning in the context of illness. From my experience of working as a psychologist with individuals with a range of chronic illnesses, I have become increasingly aware of the impact of psychological and social factors in the response to and management of illness.

My interest in young people with chronic illness began when, at fifteen, I spent time volunteering for an organisation that ran residential activity weekends for young people with chronic illness and disabilities. I became astounded by the resilience, motivation and positivity of these young people, yet also aware of the daily challenges that faced them and impact of their illness or disability on their daily life. My interest developed as I spent time as an undergraduate working on projects for children and young peoples with illness and disability. This also included working with their families and recognising the impact on the wider system.

My awareness of chronic illness was significantly extended when, as an undergraduate, I was diagnosed with hypothyroidism. I had to adapt to a difficult

routine of visiting the doctor weekly, having regular blood tests and taking daily medication. This experience was somewhat eased by the fact my father already had a similar diagnosis, and when having check ups with my endocrinologist, I remember him stating how he valued clinical psychology input in his clinics although it was a scarce resource. This inspired me to investigate the role of clinical psychology in physical health settings, increasing my desire to work in this area.

In the second year of my clinical training, I worked on placement in a Child and Adolescent Mental Health Team which had links with a paediatric diabetes service. This experience led me to realise that a large proportion of referrals to its psychologist were termed as difficulty 'adjusting' to the illness. 'Adjusting' seemed to implicate an array of difficulties; I was intrigued to consider how a psychologist may begin to work on these areas. Consulting relevant literature revealed that the construct of 'adjustment' was rarely formally defined, and although there is plentiful literature on it, the views of young people themselves were often neglected, relying instead on parent or professional views.

My interest in young people, chronic illness and social constructionism therefore led me to develop this study. I hope to draw attention to what can be learnt from hearing young people's own stories about their experiences, without being biased by the predetermined notions that often guide research. Hearing their voices could help to develop a greater understanding of the complex process by which they adjust to DM1.

In line with IPA, I endeavoured to begin each interview with an open mind and, as much as possible, to attempt to enter the personal world of the young people. It is important to note, however, that my questions and non-verbal communication may have encouraged or discouraged certain responses and a different

researcher may have elicited different responses. My own beliefs and assumptions may also have influenced the way in which I engaged with and made sense of the data. I kept a reflexive journal throughout the research process in order to raise my awareness of such issues and to ensure I was constantly mindful of them.

RESULTS

This section presents the results of the Interpretative Phenomenological Analysis of the six participants' accounts of adjusting to life with diabetes. Through this analysis, five master themes emerged:

- *Developing a balanced relationship with diabetes*
- *The uncomfortable position of difference*
- *Grappling with the fall out of diabetes*
- *Making diabetes more bearable*
- *The role of parents and friends*

These themes form one possible account of how young people experience adjustment to life with diabetes. IPA emphasises that the process of discovering such themes is based on the researcher being engaged in a double hermeneutic (Smith, Flowers & Larkin, 2009), whereby they attempt to make sense of the participant trying to make sense of their experiences. This account, therefore, is partial and subjective and other researchers may have highlighted different aspects. The themes generated do not cover every aspect of the young people's experiences but were selected due to their relevance to the research questions. The table below illustrates the five master themes and related sub themes, which will each be explored and illustrated with verbatim extracts from the interview transcripts.

Table 2: Main themes

Master Themes	Sub Themes
Developing a balanced relationship with diabetes	The difficult experience of diagnosis
	Getting to know diabetes
	Accepting the permanency and relentlessness of diabetes
	Learning to live with diabetes without making it 'the main thing'
The uncomfortable position of difference	Uncomfortable position of being the only one
	Introducing diabetes to others
	Threat to personal identity
	Loss of childhood
Grappling with the fall out of diabetes	Grappling with diabetes for control
	Struggle to make space for emotions
	Struggle with independence
Making diabetes more bearable	Coping by evading the impact of diabetes
	Coping by focusing on the positives
The role of parents and friends	The safety net of parental support
	The value of friends' support
	Parental role of friends

For the purpose of this research, minor changes have been made to the text extracts. To ensure confidentiality, participants have been given pseudonyms and all personal or identifying information has been either removed or altered. Where a word is implied, but not stated, it has been included in square brackets [ ]. In

some cases, where material has been omitted, blank square brackets are used [ ].

The table below provides a summary of participant details to facilitate the reading of this section.

Table 3: Participant information

Participant pseudonym	Gender	Age	Ethnicity	Age of diagnosis	Family members with diabetes
Holly	Female	13	White British	9	Great grandparents (Type 2 diabetes)
Alice	Female	14	White British	8	Not any
Abigail	Female	15	White British	13	Aunt (DM1)
Hannah	Female	13	White British	6	Not any
Emma	Female	12	White British	9	Father, uncle, aunt, grandmother and great grandmother (DM1)
Jess	Female	13	White British	10	Grandfather (Type 2 diabetes)

1. **Developing a balanced relationship with diabetes**

1.1 Overview

This theme encapsulates the process the young people appeared to go through following their diagnosis of diabetes. They described the experience of diagnosis and their reactions to this. It appeared as if their reactions were embedded in a general lack of understanding about what was happening to them and for some

this was the first time they had been admitted to hospital. The young people described a process of getting to know diabetes, which for some helped them to manage the difficult emotions linked to diagnosis. This process appeared to begin in hospital and develop following their discharge. For some, this seemed to be initially facilitated by health professionals and then continued by their parents and their own experiences. As their relationship with diabetes developed, some discussed their realisation that diabetes was permanent and they needed to learn to live alongside it. What seemed to follow was a necessity for managing their relationship with diabetes, whereby participants were able to live with diabetes without making any drastic changes to their everyday lives.

1.2 The difficult experience of diagnosis

All the young people described a difficult and often traumatic experience of diagnosis which was surrounded by a sense of confusion and uncertainty. For some, this began when they first noticed unusual symptoms and continued through to diagnosis, as Hannah described:

> *Well at first my doctor like diagnosed me with just an infection. But then I got like so ill that I couldn't walk and I couldn't go to the toilet or nothing. So I went back to the doctors and my doctor was away so I had another doctor and she told me that I had to go to hospital straightaway. But by the time I got into the hospital my veins started to collapse and I had to have loads of injections like all around my body, but they like struggled to give me the injections, but in the end they got them. And then I was on a drip for a long time and I had to have like loads of tests done every day. (Hannah)*

Following receiving their diagnosis, the young people expressed experiencing a range of emotions indicating distress, which they attributed to their lack of

understanding about what diabetes was. When asked what it was like when she was diagnosed, Holly said:

Difficult (laugh). I didn't really understand what it was. (Holly)

Emma described feeling confused and scared:

I don't know I was just a bit confused because I wasn't really sure what was going on [….] I felt a bit scared because I wasn't sure what was gonna happen and uh like first of all I wasn't really sure what diabetes was. (Emma)

Jess described a level of confusion in combination with an emotional numbness. There was a sense that she should feel upset, perhaps because of her mother's reaction:

Well I didn't really know what it was so I didn't really know how bad it was or what I had to do or anything so it was just a bit like…I didn't really know what to feel. My mum burst out crying[…] [Laughs] And I was like, I wasn't…I was upset but I was like I don't know what it is, so if someone explained it to me maybe then I could be upset cause I don't know what I am doing. (Jess)

Others described the shock of diagnosis:

I didn't really like take it in sort of thing. Just sort of a shock. (Abigail)

At first I was a bit shocked, but I really didn't understand like what it was. (Hannah)

It seemed that for some, these difficult emotions continued as they began their treatment. Three girls described the difficulties they experienced following the realisation that they would need to inject themselves:

Like it was really encouraging and then it [injection] was alright once I started doing it more but it was painful getting to that like mode 'cause like you're wondering why you are sticking a needle into your arm. (Alice)

Yeah. I was just…like the thought of injecting yourself just was really weird for me cause it had always been like the nurse or the GP or whatever. (Jess)

I was upset a lot .because I didn't like the injections and things that was going on......and I didn't understand anything, but I got used to it after a while. (Hannah)

1.3 Getting to know diabetes

Following their diagnosis, all participants described a process of getting to know diabetes that involved developing an understanding of what diabetes was and what might be happening to them. For some, health professionals helped them to develop their understanding:

They [doctors] kind of told me like in an easy way to understand, like I had to do this and this and they explained what insulin does, like it brings your sugars down and controls it and they just explained it in a way that I could understand. (Holly)

I didn't really know a lot about it so they [doctors] had to explain it to me and they were telling me all the stuff so… I got…I got the idea eventually. (Emma)

As may be expected with young people, the majority also described that their parents played a key role in helping them to get to know diabetes:

My mum had to do all the injections for me and like try and explain to me like what was going on. (Hannah)

They were really helpful, like mum bought me loads of stuff on it and everything. (Alice)

For some, developing their understanding of diabetes helped them to manage the difficult emotions experienced following diagnosis:

When the diabetes nurse came in she explained it properly, I think that kind of made it a lot better (Jess)

At first I didn't know much about it, but then 'cause I was in there for four days […] I had to go on a computer and there's this programme that they give...that they made me go on. [..] So that was really good '.cause it helped me understand what's going on. (Abigail)

1.4 Accepting the permanency and relentlessness of diabetes
From the girls' accounts, there was a sense that the early stages of adjustment were focused on the practicalities of gaining sufficient knowledge and technique to keep them well. It appeared as if the more emotional aspects of adjustment began only when they felt more confident in this area. This seemed to involve a

realisation that diabetes was permanent and would be with them for the rest of their lives. There was a sense that previous to this young people had seen it as an acute illness. Jess described finding it weird and struggled to imagine living with diabetes for so long:

It was really weird cause when I kind of realised that it would be like for the rest of my life, and it was weird kind of imagining having to do it for the rest of my life[….]I was just like…I-I can't imagine it happening for that long. (Jess)

Alice described her frustration that she could never have a break from it:

'Cause it doesn't hold me back from anything but it's still sort of there and like it's not something like where you hit your knee and the pains there and it just goes sort of like everything you have to do everyday and it never goes away sort of thing. (Alice)

From Alice's description, there was a sense that it was different from any other illness she had experienced, which made it more difficult to grasp.

For some, this process appeared to involve learning to abide by the rules and routines of diabetes and an awareness that this was not a choice but had to become a way of life:

Because some people could be like...they probably like understand how like important it is to do it [injections, diet etc] and they might struggle to like get it into their heads that they have to do I .and it's not a….it's not a choice. (Hannah)

Which means that I have to eat at certain times as well, so everything was sort of like on a strict rota sort of thing like when we have breakfast, dinner and everything like that. But if you don't do what you're supposed to do it's gonna make yourself ill, so you've just got to do it. (Abigail)

There was a sense that the young people felt powerless to change the situation, yet reached a point of acceptance whereby they had incorporated diabetes into their identity and accepted that they would need to live with it for the rest of their lives:

I can't do nothing about it, it's part of who I am sort of thing…..can't change it. (Abigail)

Something you have to live with. It doesn't go away so you just have to get used to it. (Emma)

1.5 Learning to live with diabetes without making it 'the main thing'
A salient theme that emerged from the transcripts was the importance of participants learning to live with diabetes without letting it dominate their lives. From their descriptions, it seemed that this was a vital step in the process of adjusting to their illness. Alice described that if she had not managed to do this then life would be very different:

'Cause she [mum] always said that we don't fit in with the diabetes, the diabetes fits in with us which well without that like the whole thing would have been completely different. (Alice)

There was a sense that diabetes was quite powerful and could easily take over and control their lives if the young people let it. Abigail discussed how she feared that diabetes would change her life completely:

> *I thought it would just change my life completely, but it doesn't...it only does that if you want it...if you make it change your life sort of thing. (Abigail)*

> *Don't let it control your life, just do what you have to do. (Abigail)*

Others explained how initially diabetes had been overwhelming and all-encompassing, but that over time they had learnt to take control of it and 'put it in its place', minimising the disruption to their lives:

> *'Cause at first it's like a big burden and then it was like a big deal. But now it's just….couple of injections a day and couple of sugar levels and that's it. It doesn't really….don't let it kind of take control of anything. (Jess)*

> *Well like, I was still doing it when I come down with diabetes but it hasn't stopped me at all. I still do it. I just have to have a chocolate bar or something before. (Emma)*

Control over diabetes appeared to be an important way for participants to protect themselves from its impact. It seemed as if control involved taking practical steps to manage diabetes and keep it in its place, so that that the young people could continue with the rest of their lives. For some, part of this process involved incorporating diabetes into their everyday day routine and thinking of it as part of their life, as Abigail and Jess suggested:

Not putting...not making sure that your life goes around diabetes, but sort of just involving it in your life...I don't know adapting to it, but not making it the main thing[…]. Just find a way that it goes into what you already do sort of thing. (Abigail)

So you kind of know what you're doing and to kind of think of it as part of your life now really. To think of it as something that you've got to do and kind of it becomes second nature really to do it automatically and to have it as something that's part of your routine. Instead of something that you have to keep thinking about and keep reminding yourself to do. It's kind of learning to do it. (Jess)

Jess's account suggests that by incorporating diabetes into her life, she spent less time thinking about it and it thus automatically became a less serious issue.

Hannah's statement sums up this subtheme. It suggested that although diabetes had an impact on her life, she learnt to live with it without making 'the main thing':

Although it isn't like big deal to like my life but it has affected it. (Hannah)

Interestingly, there was some indication from Alice that this ongoing struggle to manage diabetes, without letting it govern life, had wider implications:

So it's alright now but you can't keep up to the standards of it all the time, you've got better things to do you know like it can't take over your life. (Alice)

Alice's comments suggested a decision to prioritise some areas over others, so that 'getting on with your life' might be more important than 'keeping up the standards', with possible implications for glycaemic control and health.

2. The uncomfortable position of difference

2.1 Overview

This theme aims to capture the sense of difference the young people experienced in various areas of life due to living with diabetes. They described their dislike of how the self-care behaviours and routines they had to engage in made them stand out from others and feel as if they were 'the only one'. They expressed their reluctance to tell others about diabetes due to a fear that they would be treated or viewed differently and to protect themselves from standing out. Some girls also explained how receiving a diagnostic label was enough to impact their sense of self, resulting in them losing their own 'normal' identity in place of becoming 'a diabetic'. Finally, participants described the position of responsibility for self-care imposed by diabetes, which at some level appeared to rob them of their childhood, reinforcing their sense of difference.

2.2 Uncomfortable position of being the only one

All girls described how, due to the self-care behaviours and routines they had to engage in, they felt as if they were 'the odd one out'. This was illustrated by the way in which they compared their lifestyles to those of others:

> *All my friends don't have to wear a coat, like their parents want them to [..]*
> *but mum wants me to because obviously of my circulation [..] you know it*
> *just adds to like having to do things so like I have to get a good nights*
> *sleep because it will mess up my sugar levels and stuff so it's a bit like all*
> *my friends can go to bed at like whatever time, not whatever time they*

want, but they could if they actually wanted to whereas I could but it would mess me up a little bit. (Alice)

I have to be a little more careful about you know where I'm going and what I'm eating and who I'm going with, if they know. […] I feel like I have a lot more responsibility to deal with than everyone else, cause everyone else can just… if they feel like going out they can just go. With me I have to like prepare my insulin pack and everything, and like…I can't eat some of the things… well I can't like drink some of the things they drink or…You know there's just certain things like, they can do things a lot more freely than I can. (Jess)

Alice and Jess's accounts suggested that they were envious of the perceived simplicity of their friends' lives, and resented the way diabetes made their lives different and, to an extent, more complex.

Abigail, Hannah and Emma specifically expressed the difficult emotions they experienced as a result of feeling and being different to others:

Uh, pretty annoyed, cause like everyone else doesn't really have to worry about anything and there's me who has to worry about what I'm doing. (Abigail)

When you see other people with like eating chocolate it makes you feel like jealous, because you can't have what they can have. (Hannah)

I think it's not really fair for me because my dad eats it, and my mum and my sister but […] And I'm just sitting there watching them and it's not nice. (Emma)

Emma's statement, *"I'm just sitting there"*, conveyed a sense of feeling alone and isolated as a result of her difference.

Some young people expressed their dislike at being noticed as different:

> *Because when you get to the airport you have to take your insulin there [..] and you get on the aeroplane and you have to tell them that you've got insulin and everyone stares at you when you do your injection on the plane. (Alice)*

> *Emily:*   *And how is that at school when you don't feel well and you have to go…*

> *Holly:*   *It's quite embarrassing.*

> *Emily:*   *What's embarrassing about it? I can imagine.*

> *Holly:*   *I don't know cause like you go I don't feel well and everyone like looks at you [laugh].*

From Alice and Holly's accounts, it seemed that being noticed and identified as 'different' was almost harder than the practical side of managing their diabetes.

2.3 Introducing diabetes to others

The majority of the young people expressed a concern about introducing diabetes to others:

> *I didn't really wanna tell people at first. I just told my best friend,*

cause I tell her everything obviously [laughs], and obviously my mum told my family and everything […] and we had to tell the school, cause I have to let them know [..] but then like I didn't like go round publicising it I sort of kept it to myself. I didn't know what people would think. (Abigail)

Uh, I think telling people, and people finding out, because you know when you first meet people, you need them to know but you can't just go by the way, I'm diabetic [laughs]. You have to kind of let them know without telling them. (Jess)

It was unclear exactly what Abigail and Jess imagined people would think, but there is the suggestion of fearing that they might not be acceptable to others in some way if they knew about their illness.

Hannah explained how she did not tell people she did not get along with, as she feared it would make things worse. Although she struggled to explain why this was, there was a sense that she was concerned that if they found out she had diabetes then she would be further ostracised:

Hannah: *But, like I won't tell people that I don't really get along with. I won't tell them, because it just makes things worse and like I just tell people that I'm close too.*

Emily: *How does it make things worse?*

Hannah: *It's like...cause if I don't get along with them and they're like...I just feel like they're gonna...it's gonna make things worse like by them like...I don't know really, it just makes me feel different..*

For Holly, there was a sense that she held a fear about being perceived as different and opted not to tell others to protect herself.

> *No, I didn't feel that I needed to, like (pause) like yeah (pause) they [friends] didn't need to know about it.*

2.4 Threat to personal identity

This theme encapsulates the way in which, for some participants, diabetes appeared to impact their sense of self.

For Abigail and Hannah, receiving a diagnostic label appeared to result in them shifting their personal identity, whereby they no longer considered themselves as 'normal':

> *Well obviously I didn't think like I'd be able to play football...I don't know really. Just wouldn't be able to do anything that a normal kid would do sort of thing. (Abigail)*

> *At first they was just like...well I was just like normal like them. But after a while like they grew up they got to like know what was going on. (Hannah)*

Alice discussed how she was labelled as a '*diabetic kid'* and how this changed the way people treated her. There was a sense that she had lost her own individual identity, becoming buried under the identity diabetes imposed on her:

> *They'll remember me as a diabetic kid which is a bit annoying [..] because it's a bit annoying when people label you [..] and they sort of treat you a bit like you don't know what you are doing and they patronise you a little bit. (Alice)*

Like if I'm ill at school mum always thinks it is to do with diabetes and if I'm moody or something she'll think it is to do with my diabetes which can be annoying because it can just be me. (Alice)

In Abigail's explanation of how her parents reacted to her blood sugars, instead of directly referring to her blood sugars, she used the words *'I'm high'* and *'I'm usually well controlled'*, providing a sense that she had almost become diabetes, no longer having a separate identity:

And even though I'm high they're still okay with it sort of thing, cause they know that I'm usually well controlled sort of thing and just going through a little phase. (Abigail)

Jess's description of knowing other diabetics as 'people' conveyed a sense that a young person's identity as a 'person' can get lost under the identity of a 'diabetic':

There's a couple older than me [others with diabetes], I know them but I don't know them because of the diabetes, like we never talk about that, I just know them like as people. (Jess)

Holly and Emma's accounts gave the impression that they had an expectation of a diabetic identity, suggesting that the threat to identity was a concern. It seemed that this identity, however, had not manifested itself in the way they had expected, enabling them to maintain their old sense of self, despite receiving the diagnostic label of being a 'diabetic':

Nobody treats me any different so that's fine. (Holly)

It's… sometimes you forget that you're diabetic cause you just... it's just a normal life just having injections instead. (Emma)

2.5 Loss of childhood

All participants described the position of responsibility imposed by diabetes which resulted in them having to grow up quickly, suggesting a sense of a lost childhood.

Alice and Jess's accounts illustrated how the responsibility of diabetes changed their characters, making them more cautious and responsible, demonstrating the way in which they had had to grow up:

I think diabetes has changed me a little bit [..] it's made me a bit more cautious because like they'd [friends] go off somewhere and if I didn't have anything on me then I couldn't you know or they'd just eat loads of stuff and I couldn't eat loads of stuff or I think it makes me more responsible without realising it and it makes me worry. (Alice)

I suppose just made me grow up. Yeah. And just made me kind of more aware of what I'm doing. And you have to make sure that I don't drink this kind of stuff I don't eat this kind of stuff, that I don't walk too far, you know, in case I have a hypo. Which made me kind of more aware what I'm doing and…kind of conscious of…and like responsible for what I'm doing as well. (Jess)

It was evident that the young people were no longer able to be as carefree and spontaneous as they once were, having to adopt a responsible adult position. There was a sense that this resulted in them standing out from their friends

because the level of responsibility was not age appropriate or in time with their peers:

> *It just makes you feel like you're really tied down with things and you've got a lot of responsibilities too. (Jess)*

> *You just have to look after yourself more and [..] like don't skip injections and make sure you have them and that. And make sure you have the right one. (Emma)*

> *If I go out with my friends I normally have to like keep coming back to like make sure I'm alright. (Hannah)*

Abigail described how diabetes altered her outlook on life, robbing her of the naivety of her childhood:

> *It's like made me realise that life's just not simple sort of thing [laugh]. (Abigail)*

Holly described the position of responsibility she had had to take at school, whereby the teachers relied on her to inform them what to do regarding her diabetes:

> *The school don't really understand I don't think, they just go by what I say so they go 'what do we do now?' and I'll just say um what, yeah. (Holly)*

Overall, this master theme illustrates how living with diabetes results in the young people experiencing a sense of difference to the 'well-world' and their peers. In an attempt to manage this, it seemed that participants often chose not to tell

others due to a fear they would be treated differently. For some, this fear was real, as they experienced a difference in the way they were treated following their diagnosis, losing their sense of self. Finally, the responsibility imposed by diabetes set the young people apart from their peers, enforcing them to adopt a responsible, adult outlook towards life.

3. Grappling with the fallout of diabetes

3.1 Overview

This theme aims to capture additional struggles young people were faced with as a consequence of living with diabetes. Control was a salient theme that emerged from the transcripts, with the girls describing how they felt as if they were constantly struggling with diabetes for control. A further struggle was their ability to make space for emotions. It was evident that the young people experienced a range of distressing emotions linked to diabetes however, for varying reasons appeared to find it difficult to make space for these in their everyday life. The final struggle they described related to independence; they described a dilemma of wanting to be independent and look after themselves while at the same time recognising that they had to be dependent on others.

3.2 Grappling with diabetes for control

At times it was hard for the young people to feel as if diabetes wasn't ruling them, dictating how they felt and what they could do. For Holly and Hannah, there was a sense that the variability and uncertainty of their blood sugar levels made it difficult for them to feel in control:

> *Sometimes I have like a week where it [blood sugars] is going low all the*
> *time and like last week I was like off school cause I had like a cold and it*

was really high and we couldn't get it back down and when it came down it would just go back up. (Holly)

Sometimes it [low blood sugar] could be like every day for like a long time, but sometimes it can like not happen for like a long time it depends on how my insulin goes. (Hannah)

Alice described feeling powerless; she felt as if her injections were in control, ruling what she could do:

It was horrible cause I wasn't in control like they [injections] were in control so it was a bit sort of annoying cause it sort of held you back a bit at school as well cause you had to go and have a snack and everything. (Alice)

For Abigail, the much more comfortable position of being 'in control' of her illness was something she felt she really had to strive for and even then something she did not always achieve:

Like I haven't got it under control yet, but I'm trying [laughs] […] like sometimes I've only ate what I was supposed to sort of thing. I've done the right insulin and still high. (Abigail)

For Jess, there was a sense of needing to be in control of diabetes in order to avoid long-tem complications. Nevertheless, as she explained, this did not mean she would be able to control what happened in the future. This indicated the power of diabetes and the constant battle for control she was faced with:

I just thought like when my mum first told me that if you didn't have good sugars, when you're older you'd have eyesight problems or you'd have other problems…and it was when I asked her about it when I got my eye screening thing and she said, you know, it could be you have good ones and just by chance you have, like, whatever problems [..] Like the fact that even if I did have good control, I might not be able to control that like happening later. (Jess)

Emma and Alice described the various practical steps they took in an attempt to gain control over diabetes, enabling them to continue with their lives:

I was still doing it [swimming] when I come down with diabetes but it hasn't stopped me at all. I still do it. I just have to have a chocolate bar or something before. (Emma)

A little upset [when can't do things friends are doing] but then you can change that so now I go out with you know a full pack of glucose tablets or something.(Alice)

On the other hand, for some, there was a sense that at times the practical steps were not successful and once again, diabetes resumed control, again illustrating its power and the constant struggle young people are engaged in to be in control:

Although there is loads of sweets there and stuff but it's just not a nice feeling when you get low so it's like you'd rather not go there but so then you end up eating more to stop yourself getting low so you get high and it's a bit annoying like you can't you can get it in the medium. (Alice)

3.3 Struggle to make space for emotion

All the girls described a range of difficult emotions as a result of living with diabetes and there was a sense that it was difficult for them to make space for them.

Alice described feeling angry and upset, but explained how she tried to ignore her emotions as a way of managing them. In a sense, she appeared resistant to experiencing negative emotions:

Alice: *But then I think there's no point getting angry about it because there is not much you can do so I just get on with it but*

Emily: *Ok and when your feeling angry what do you do to help you?*

Alice: *[laugh] Nothing. I know it's really bad but just thinking of it and then if you get upset there's no point because it is not going to do anything to help it so there's no point.*

Her comment *"I know it's really bad"* seemed to indicate that she knew that this was not the best way to manage, but that it was the only way she was able to in the circumstances. There was a sense that if she spent too much time focusing on her emotions then they may overwhelm her.

For some, it seemed that it was unacceptable to experience difficult emotions and they therefore chose to keep them to themselves:

Abigail: *Just angry, cause I don't know why it's happening.*

Emily: *And what do you...how do you manage that kind of feeling angry?*

Abigail: Just keep it to myself [laughs].

> *Not really, I don't really talk about it [feeling stressed]. I don't like to tell*
> *anyone [..] Like, I just kind of keep it to myself and just get on with*
> *it myself. [..] I just don't think…I won't bother anyone else with it. (Jess)*

Abigail's laugh after her comment *"just keep it to myself"* suggested that she was aware that perhaps this was not the most effective way of managing her anger. Jess's statement *"I won't bother anyone else with it"* provided a sense that she somehow felt she would be a burden if she disclosed her feelings to others. There was a sense that these young people struggled to make space for their emotions as perhaps they were unsure how to successfully manage them.

For others, it seemed difficult for them to discuss their distressing emotions, quickly moving to a more positive stance which could be construed as 'putting on a brave face':

> *I was upset a lot because I didn't like the injections and things that was*
> *going on [..] .and I didn't understand anything, but I got used to it after a*
> *while. (Hannah)*

> *I don't know I was sort of okay with it at first, cause I didn't really know*
> *much about it. And then (pause).but I thought, "I've just got to deal with it"*
> *sort of thing. (Abigail)*

Similarly, when Holly discussed her variable blood sugars she described that it was a pain and hard. After this she laughed, which suggested she found it uncomfortable to consider her negative emotions. When specifically asked how this was for her, her response was *"it's fine"*. The pauses in Holly's final sentence

indicated that perhaps it was not 'fine' but she was unsure how to vocalise and explain her difficult feelings:

Holly: *They've been good and then sometimes they go not good, it's a pain, it's hard (laugh)*

Emily: *How is that for you when they're..*

Holly: *It's fine…. yeah (pause), ok(pause), it's fine [laugh].*

There was a sense that the girls wanted to avoid thinking about what was difficult perhaps because it was too painful to acknowledge their difficult emotions. Furthermore, they may have wanted to portray an image of managing and coping well and felt expressing negative emotions did not fit with this desired image.

This theme illustrated how the emotional impact of a physical health difficulty can often be neglected.

3.4 Struggle with independence

Independence was a prominent theme that emerged from the transcripts. There was a sense that the girls needed to be independent in order to manage their treatment regimen, and to some extent they craved independence. At the same time, though, there was an idea that a level of dependency on others was still required.

Hannah discussed the value of becoming independent in her diabetes management, including being able to do more things and becoming more confident:

It was different, because I was doing more things to what I would normally do, but it was maybe like better, because I could have done things on my own without my mum. (Hannah)

Emily: *Can you remember when you started to feel more confident?*

Hannah: *it must have been like when I started high school, cause I was older and had to do things for like myself and that.*

At the same time, she explained how she remained dependent on her mother and people at school:

Yeah because my mum, she normally sorts everything out for me and changes my needles and all that. So she helps. (Hannah)

Because I've had to...I have to tell them [people at school], just in case anything happens in that class and they've got to sort things out. (Hannah)

Holly's account also demonstrated the paradox of simultaneously needing to be independent yet dependent. When discussing how she managed her diabetes at school, she indicated a level of independence by explaining that she did what she wanted. A little later in the interview, though, she explained how she managed diabetes by doing what others told her, suggesting a level of dependency:

I just do what I want [laugh]. (Holly)

Emily: *What do you do to manage the change [of having diabetes]?*

Holly: *Just do what they tell me.*

Some expressed frustration at being dependent on others, illustrating their desire and struggle for independence:

> *We wanted to go for a walk and I didn't have anything mum would be like don't worry about it like I'm here like you are safe but it's not, I hate being dependent on someone [..] I'd rather just be independent even though I know she'd look after me I just don't like the fact that she has to look after me.(Alice)*

Likewise, Abigail described how she was dependent on the nurses in the medical room at school to get her injections. She expressed a wish to be independent, but did not think this would be possible within the rules of the school:

> *But I'd like rather have it [injection] on me sort of thing and just do it, but I don't think we're allowed. (Abigail)*

Others described their annoyance at the involvement of their parents, although they were aware that they were just trying to help, suggesting a yearning to be independent:

> *My mum, […] and my dad because they're always trying to help, […] I think I try to like ignore them but they're just trying to help me and like whenever I shout at them because they're annoying me it's just because they're trying to help. (Emma)*

Similarly, Jess expressed a desire to be independent reflected in a frustration at her mother's nagging, although it seemed as if she questioned her ability to cope

on her own. This suggested an element of apprehension towards complete independence:

Jess: *I think she still like worries and stuff when we go out she always makes sure I've got everything in my bag and all that. I think she kind of trusts me to deal with it, but, I don't know, as soon as she kind of stops nagging me about it that's when my levels go all over the place so I think she kind of feels like she has to kind of get involved a bit more.*

Emily: *And how is it when she's sort of nagging you to do your injections?*

Jess: *Really annoying. Uh, I'm just like leave me alone I know what I'm doing I've got it, but… I know she's only doing it cause she wants me to cope with it properly, but I just sometimes it just gets really annoying.*

4. Making diabetes more bearable

4.1 Overview
This theme aims to capture the different ways in which the young people coped with the impact of diabetes, enabling them to live with it on a daily basis. From the transcripts, there appeared to be two main ways they did this: attempting to evade the impact of diabetes, and focusing on the positives. The use of a range of these strategies appeared to make diabetes more bearable for them.

4.2 Coping by evading the impact of diabetes
Participants described a variety of ways in which they attempted to evade the impact of diabetes, for example through distraction, avoidance, denial and minimising the impact of the diabetes. It was apparent that the strategies they

employed served the purpose of making diabetes more bearable and enabled them to continue to live their lives as they would like.

A common coping strategy used by the young people was that of avoidance. It seemed that the majority of the girls attempted to avoid thinking about diabetes to evade distressing emotions. There was a sense that if they allowed themselves to think about diabetes too much then they would feel overwhelmed. It would be as if diabetes was taking over and having too greater impact on their lives:

> *I don't really like to think about it because I just can't be bothered cause then your finding that it is affecting your life and the it makes you a bit angry because it shouldn't be affecting your life and it shouldn't be in your thoughts, it's really stupid. (Alice)*

> *Not thinking about it too much. Cause if you think about it then you start to kind of think about everything. Whereas if you don't think about it you just get on with it, you don't really notice it, and it's not something that affects you. But if you sit there and think about it for ages like when I was first diagnosed you think-sit and think about everything that you've gotta do and everything that could happen with it, then it kind of starts to stress you out more.. But if you just get on with it then it doesn't seem to really bother me. (Jess)*

> *I suppose I cope with it pretty well. Like I do what...I just get on with it sort of thing and don't really think about it [laughs]. (Abigail)*

Doing her daily injections was difficult for Hannah, as it bought up difficult emotions about feeling different. She described how distraction helped her to cope with these feelings and continue with her injections:

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*Like when I'm doing it [injections] I try to think of other things or if I'm doing
it like my friends are like normally with me, I try to talk about something.
So it like puts me off. (Hannah)*

Denial appeared to be a further method used to manage the impact of diabetes.
Holly's account illustrated how she used this strategy to manage her feelings of
annoyance:

Emily: *Is there anything you do to manage it being a pain. How does it
make you feel?*

Holly: *Just annoyed*

Emily: *And what do you do you do when you're annoyed? Is there
anything in particular that you do?*

Holly: *I don't do anything [Laugh]*

Her laugh following her statement of *"I don't do anything"* conveys a sense that
she believes she should do something but instead chooses to ignore it.

Alice also mentioned that her way of coping with diabetes initially had been to
use denial:

*'Cause it got a bit sort of annoying 'cause I didn't realise it was going to be
all my life although people had told me I was a bit in denial sort of thing.
(Alice)*

For Alice this appeared to serve as an adaptive method of coping. It was as if she did not acknowledge that diabetes would be with her for the rest of her life until she was in a place to be able to manage this.

Minimising the impact of diabetes seemed to be a functional way for some of the young people to manage living with diabetes. There was a sense that if they spent time thinking about how diabetes had changed or impacted their lives, then this would be too overwhelming, upsetting and difficult to bear. Instead, it appeared as if it was important for them to emphasise that their lives had not really changed.

When Abigail was asked how diabetes impacted things at school, she initially stated that it had not really changed anything, but went on to list exceptions to this. Despite listing the various ways diabetes impacted her school life, she concluded her sentence by saying that "*it doesn't really affect anything mainly*", as if she was trying to persuade herself that this was the case:

> *But other than that it hasn't really changed it except for when sometimes I've got P.E. and my blood sugar drops, I can't do P.E. cause it doesn't bring me up in time and stuff like that so […]well sometimes I just randomly go low...like my blood sugar drops so I'd have to go to the medical room, but it's not like...it doesn't really affect anything mainly. (Abigail)*

The use of the words *"really"* and *"mainly"* suggested that she was aware of the impact of diabetes, but was unable to fully acknowledge this as it would be too overwhelming.

Emma used a similar strategy; throughout the interview she repeatedly told me that her life had not changed since being diagnosed with diabetes. However she would often follow this statement with the ways in which her life had changed:

Emma: I don't think my life's changed a lot since I've got it, I just don't have as much sweets and chocolate and sugar.

Emily: Right, okay, and how is that, not having as much?

Emma: That's okay, yeah, but I-I've been losing a bit of weight.,

The multiple use of the word *"and"* in between the words sweets, chocolate, sugar suggested that this was a big change for Emma, illustrating the noticeable impact of diabetes. However, as with Abigail, it seemed that Emma's way of managing this was to minimise this impact by telling herself that her life has not really changed.

When asked how diabetes impacts her life at school, Holly used a similar strategy of minimising the impact:

Not really I just go to the medical room to do my insulin and sometimes if I get a low blood sugar I have to go to reception and eat chocolate. (Holly)

She then described in detail how every few months, due to variable blood sugar levels, she has to have time off school, suggesting that diabetes has quite a significant impact on her school life:

Sometimes I have like a week where it is going low all the time and like last week I was like off school 'cause I had like a cold and it was really high and

we couldn't get it back down and when it came down it would just go back up.
(Holly)

Strategies of distraction, avoidance, denial and minimising the impact appeared to be functional ways for the young people to manage the impact of diabetes and make their lives more bearable.

4.3 Coping by focusing on the positives

Focusing on the positives was a salient theme that emerged from the interview transcripts and, as with the previous theme, it felt as if acknowledging the positives of their situations enabled the young people to live side by side with diabetes.

Most of the young people were able to name a number of positive characteristics, such as determination, confidence and organisation, which they attributed to having diabetes. It was as if it was a way for them to 'laugh in the face' of diabetes, by saying that even though diabetes tries to take over their life and make it more difficult, they have actually been able to grow because of it.

> *Sport it probably encouraged me to do more because obviously you are*
> *eating more as well so but just because it made me more like determined*
> *to not let it stop me. (Alice)*

> *And I think I've come a bit more confident [..] and I'm a bit more active*
> *now, I'm more committed to my swimming I think. I don't know, I've*
> *overcome some of my fears as well. Like needles and…I didn't used to*
> *like blood. Now, I don't mind it. (Emma)*

> *And I suppose it's [diabetes] just made me a lot more kind of organised.*
> *(Jess)*

A further coping strategy some girls used involved recognising the positive things they were able to do as a result of having diabetes. This felt like an important way for the young people to rationalise the fact that they could no longer have snacks or sweet foods when they wanted to:

> *And I've been having some really low ones at night. [..] So I just had to*
> *have some snacks and chocolate. Which is nice 'cause I don't have a lot*
> *of chocolate. (Emma)*

> *If I'm going through a growth spurt or if I'm hungry I get to have that snack*
> *at the end of the day. (Alice)*

Looking at the positives of potentially difficult situations seemed to be another method used by some girls to help them manage and contain the difficult emotions that could arise in these situations:

> *I didn't realise that there was an easy way to do it [injections], but it's a good*
> *thing I weren't scared of needles. (Abigail)*

> *It's alright I suppose [not going on school trip], because it's only for a day and*
> *then I can just go there on holiday or something. (Hannah)*

Both Hannah and Abigail were quick to acknowledge the positive aspects of their situation, seemingly making it more bearable.

5. The role of parents and friends

5.1 Overview

This theme focuses on the role that both parents and friends had in supporting the young people with diabetes. All girls described the vital role their parents played in helping them to learn to live with diabetes. Although at times young people found their involvement frustrating, they all unreservedly expressed the value in the help they offered. Friends seemed to play a key role in helping them manage their diabetes, offering both practical and emotional support. From the young people's accounts, it seemed as if friends often adopted a parental role, looking after and protecting them. Although this was viewed positively, for some there was a sense that they found this annoying and wanted their friends to be friends rather than protectors.

5.2 The safety net of parental support

This theme explores the valuable role parents played in supporting their children with diabetes and links with theme 3.4 'struggle with independence', which discusses the struggles young people expressed with gaining independence from their parents.

All the girls highlighted the vital role their mothers played immediately following their diagnosis in supporting them to do their injections and for some, helping them to understand what was happening. There was a sense that during this time, the young people were completely dependent on their mothers for survival, almost returning to a mother and baby position.

> *My mum had to do all the injections for me and like try and explain to me like what was going on. (Hannah)*

My mum did them, like in my arm. (Jess)

When I first started doing it my arm, .I had to get my mum to like hold my arm, 'cause I didn't know what to do until one day I was at school and...cause there's like about three other people that are diabetic at school. (Abigail)

Emma explained how her mother provided emotional support, stopping her from feeling scared:

I think it was better with my mum there 'cause otherwise I would be a bit scared. (Emma)

The initial dependency on mothers appeared to reduce as the young people learned to do their own injections, although the period of time this took varied for each girl:

I think it [doing injections herself] was like a month or a couple of months. (Alice)

I only started doing my injections when I was eleven or twelve, because I was like so afraid to do it and I just couldn't do it. (Hannah)

As the young people developed their relationship with diabetes, learned to live with it and became more independent in its management, parents appeared to be there as a back up they could rely on if needed:

'Cause I've always like got mum and dad to remind me to do stuff sort of thing. (Abigail)

My mum and my dad like help me do all the things and remind me about things. (Hannah)

Sometimes I might forget but my mum will remind me and she'll-and then I'll do it straight away. (Emma)

When I didn't understand, my dad did. (Holly)

For some, the reminders their parents offered frustrated them; however, there was expressed recognition that their parents were only trying to help and had their best interests at heart:

My mum, because… and my dad because they're always trying to help, I think I try to like ignore them but they're just trying to help me. (Emma)

Really annoying. I'm just like leave me alone I know what I'm doing I've got it, but… I know she's [mum] only doing it cause she wants me to cope with it properly, but I just sometimes it just gets really annoying. (Jess)

5.3 The value of friends' support

All the young people spoke about the value of the support offered by their friends. It was apparent that friends had a vital role in helping the young people manage diabetes on a day to day basis. From their accounts it appeared that friends offered two different types of support: practical and silent.

Regarding practical support, all the girls explained how friends would go with them to the medical room when they had to do their injection. This seemed to

make doing injections less of a chore and as young people did not have to leave their group of friends, made it more likely that they would not miss their injection.

> *Like when I went to this new school like cause I have to go and do my injection at lunch I made new friends and then they'd come with me and wait for me while I'd done it. (Alice)*

> *One girl in my form, like, my friend, will come with me to reception and sit with me. (Holly)*

> *Instead of me leaving the group to go and do my injection they'll come with me and stuff like that. (Abigail)*

For some, this provided a sense of reassurance that friends would have a greater knowledge about how to react in an emergency, since they regularly observed what they had to do:

> *I think like with my best friend [..] she used to come with me to medical and she used to see what I was doing so it kind of made me feel like someone knew what was going on and they knew what to do, and she kind of had it explained to her quite a lot. And so it was like kind of a reassurance that she was there and she knew what she was doing so if anything happened, you know. (Jess)*

> *So that was okay, and my friends all know about it so if they know… like so they can take me to medical or something if I'm not well. (Emma)*

In addition to accompanying them to do their injections, friends also provided practical support by offering them some of their food when needed. This seemed

to reassure the young people that their friends knew how to look after them if needed:

> *The other week I needed something to eat like cause I was low and I was talking to [best friend's name] and [..] this girl in my year was walking past and she was like, "Do you want a Kit-Kat?" So like she was like...she understood that I needed something and [..] she gave that to me [..] Most people know do what they have to do sort of thing. (Abigail)*

> *If I'm low, she'll [friend] give me something of hers just so I'm alright. (Alice)*

Besides practical support, some girls described the importance of what could be construed as 'silent support' from friends. They explained how just knowing that their friends were there, and were understanding, helped them to cope with diabetes. Some described that this was the most helpful support offered to them:

> *I don't know [laughs], just knowing that they're [friends] always there sort of thing. (Abigail)*

> *My mates like.. It's just them understanding that helps me like cope with everything. They like just understanding what I have to do and that, and they'll like...they'll come with me to do everything I need to do. (Hannah)*

Alice described how her friends' silent support, and their response to her diagnosis, was the *"only thing"* that kept her stable, illustrating the vital role friends play in helping young people adjust to their illness:

Just being there, yeah. Especially like [name] who is my best friend. Just sort of sticking by me like I know it sounds stupid like why shouldn't they but yeah just by understanding and not making a big thing out of it, they were the only thing that sort of kept me stable. (Alice)

There was a sense that the silent support offered by friends enabled the young people to feel understood and accepted, perhaps helping them to manage the feelings of difference described in an earlier theme.

5.4 Parental role of friends

Four of the six girls discussed how their friends adopted a position of looking after and checking up on them. The young people's descriptions of their friends' involvement provided a sense that their friends were taking up a parental role, where their friends saw it as their responsibility to ensure the young people were following their regimens.

For Emma and Hannah, there was a sense that this did not bother them:

My friends they're always checking up on me just to make sure I'm okay and to make sure that I do everything I need to do.(Emma)

Hannah referred to her friends as like her Nan:

I laugh, because I find it funny how they're reminding me. They're like your Nan telling you to do something and it just really makes me laugh. It's like, "Have you done this, have you done that?" [Laughs]. (Hannah)

In contrast, although others were grateful that their friends were looking out for them, they found their involvement annoying, wanting to be treated as an equal

rather than a child. For Alice, this seemed to present a dilemma of whether or not she wanted her friends to know about diabetes:

> *My friends, if say were at a party with my mum and like their mum and they would have a sip of their mum's [drink] and then they'll say that I can't have like my friends will be like oh aren't you having any and then my other friend will speak for me and like I know they are trying to look after me but it's a bit like I'd rather them sometimes, I wouldn't, but I'd rather them not know. (Alice)*

Jess: *And they're just like constantly looking after me, they won't let me do anything. Like all my older friends they won't let me have any sugar or anything. I go in their house and they're like "no you're not having it. [Laughs]*

Emily: *[Laughs] And how is that when they do that?*

Jess:: *Well it's a bit like, wait I have to eat. [Laughs] And they're just….I suppose it's quite nice though, 'cause I know that they're like protecting me kind of [..] I'll go round to their house and they'll be like, "You have to stick to water and you're not having any sweets." And it's a bit annoying but, it's nice to know that they're kind of protecting me.*

This master theme highlights the valuable role both parents and friends provide in helping young people adjust to and manage their diabetes, illustrating how each provide different support at different times throughout the young person's process of adjusting to their illness.

DISCUSSION

The findings of the current study will now be considered in relation to the research questions, existing theory and literature. Potential clinical implications of the research, methodological issues and areas for future research are discussed, and the research is reflected upon. IPA and other qualitative approaches often lead to new and unexpected themes emerging during interviews and analysis, thus some of the literature introduced below is new (Smith, Flowers & Larkin, 2009).

The following section discusses the main findings of this study in relation to the two main research questions, which were:

- How do adolescents experience adjustment to life with DM1?
- How do adolescents experience their peers during the process of adjustment to life with DM1?

How do adolescents experience adjustment to life with DM1?

Developing a balanced relationship with diabetes
The core of participants' experience of adjusting to life with DM1 seemed to be about developing a balanced relationship with diabetes. This finding supports that of Schur and colleagues (1999), who from their interviews with eight young people with DM1, came to similar conclusions. The girls' descriptions of developing a relationship with diabetes can be interpreted within the concept of 'externalisation' (White & Epston, 1990). This can be summed up by the phrase 'the person is not the problem, the problem is the problem'. The problem becomes located outside the individual (Carey & Russell, 2002). Seeing diabetes as a separate entity, rather than internalising it, seemed to help the young people

maintain an identity relatively separate from diabetes. Rather than being a 'diabetic', they were a 'person with diabetes' (Knight, Bundy, Morris, Higgs, Jameson, Unsworth & Jayson, 2003). Techniques from narrative approaches, including externalising conversations, can facilitate this process (Carey & Russell, 2002). Indeed, Knight and colleagues (2003) found that in combination with motivational interviewing, the use of externalising conversations helped young people with diabetes to accept their diagnosis, feel less threatened and more in control.

Participants initially described feeling a range of emotions, indicating a level of distress which they appeared to attribute to their lack of understanding regarding what diabetes was, and the confusion and uncertainty that enveloped the experience. This is consistent with accounts of children and young people reported by Schur et al (1999) and Moreira & Dupas (2005) following diagnoses of DM1, which describe diagnosis as a shock, accompanied by emotions including anger and sadness. Morse and Johnson (1991) emphasise that during the early stages of chronic illness, patients are likely to feel powerless and out of control, which is considered to be due to their inability to change the outcome, the unpredictability of symptoms and lack of resources and support.

As the young people got to know diabetes, they described a process of learning to live with it without making it 'the main thing', that is, without letting it dominate their lives. This repeats the findings of Schur and colleagues (1999) and Woodgate (2001), whose interviews with young people led them to report that adolescents expressed the view that chronic illness should not become the number one priority in their lives. Paterson and Sloan (1994) describe this process as 'growing up as a diabetic', explaining how when newly diagnosed, individuals faithfully follow structured routines (i.e. diabetes is dominating their lives), but with time they begin to experiment with this, adapting it to suit their

lifestyle. The final stage, termed 'adulthood', occurs once people recognise that perfectionism in self-management is impossible, because body responses are sometimes unpredictable. Further consideration of this balance with respect to identity will be considered below.

Taylor's (1983) theory of adapting to chronic illness in terms of adjustment to threatening events is perhaps a useful model for conceptualising the idea of developing a relationship with diabetes. Based on analysis of 78 interviews of women with breast cancer, Taylor suggests that the adjustment process centres around three key mechanisms: a search for meaning in the experience, gaining a sense of mastery and enhancing self esteem. It is suggested that the search for meaning involves a need to understand why a crisis has occurred and what its impact has been. Echoing this, the girls described how gaining knowledge enabled them to attribute greater meaning to their experience and make sense of what was happening to them. The subsequent stage, gaining a sense of mastery, entails feeling in control over the threatening event in order to manage it. For the girls, gaining knowledge and experience of their illness helped them to identify different things that could help with their diabetes, thus developing an increased sense of mastery and control over it, enabling them to continue with their lives. The final stage, enhancing self esteem, will be discussed later under the section 'making diabetes more bearable'.

The uncomfortable position of difference
This study adds further support to the idea emerging across the literature that young people with DM1 experience a sense of difference from others as a result of their illness (Schur et al, 1999; Dickinson & O'Reilly, 2004; Dovey-Pearce et al, 2007). The young people in this study described a sense of difference as a result of living with diabetes, and expressed their dislike at the way diabetes made them feel as if they were the odd one out. From their accounts, this was due to the self-

care behaviours and routines they had to engage in, in addition to the way in which diabetes forced them to have a more responsible and grown up outlook on life. The previous studies in this area interviewed young people over sixteen years old, thus it is of note that these issues also appear evident for young people aged 12-15.

This sense of difference also appeared to impact the girls' sense of self, whereby they no longer considered themselves as 'normal', appearing to lose their own individual identity in place of becoming a diabetic. Dovey-Pearce et al (2007) suggest that receiving a diagnostic label is sufficient to impact upon a young person's sense of self. According to the theoretical perspective of symbolic interactionism, the self is developed and maintained through social relations over a lifetime (Charmaz, 1983). Personal identity is described as the way in which a young person defines, locates and differentiates themselves from others, acknowledging present identities and hopes for future identities (Dovey-Pearce et al, 2007). As Dovey-Pearce et al (2007) discuss, it could be argued that receiving a diagnosis and learning to live with diabetes impacts how a young person classifies themselves in relation to others, in addition to altering their current and future identity goals, resulting in them questioning their personal identity. The girls' accounts support this idea: receiving a diagnosis and learning to live with diabetes resulted in the young people changing the way they saw themselves in relation to their peers. They viewed themselves as more grown up and responsible and no longer 'normal'. Thus the diagnosis could be interpreted as precipitating a loss of childhood identity. Charmaz (1983) proposed that 'loss of self' was the fundamental form of suffering for adults living with a chronic illness, and the findings of this study indicate this aspect is also of relevance to young people with DM1. Considering this stage in life is thought to be important for identity development (Erikson, 1968), this could have significant psychological implications for these young people.

Participants described a dilemma about introducing diabetes to others. This appeared to centre on a concern regarding how others would perceive or treat them if they knew about their diagnosis. The girls appeared to fear that somehow they would be unacceptable to others, or judged or stigmatised if others knew about their diagnosis, and for this reason were often reluctant to tell others. Peer group affiliation is an important part of adolescence and perhaps they did not tell others in an attempt to avoid exposing their difference to peers (Havinghurst, 1953, as cited in Dovey-Pearce et al, 2007). This has important health implications as, if friends are unaware of a young person's diabetes, they may be unable to provide adequate support in times of emergency. Schur et al (1999) describe how, for the young people in their study, telling others about their diabetes was both a threat and a self protective strategy. Yet the young people in this study did not describe telling others as a self protective strategy. This could be due to the age difference of participants; those in the Schur et al (1999) study were aged between 16 and 22 and were therefore more likely to be more independent from their families than this study's participants. Those in younger age groups may therefore need greater support in telling others about their diagnosis.

Kelly and Field (1996) propose that people have both private and public accounts of illness. They suggest that within social interactions, people often attempt to present a social identity that is acceptable and comfortable to others. Individuals with an invisible illness like diabetes may therefore present a public account, which reinforces their identity as a well person who can participate in the healthy world. The importance of maintaining a non-stigmatised identity would also help to explain why young people appear keen to ensure that their illness does not become a defining feature of their lives. In contrast, private accounts refer to the subjective experience of the self in relation to the illness. These include socially

unacceptable aspects of the illness experience (for diabetes, this may include injections, testing blood sugar levels), not exposed in an effort to maintain social acceptance. As Schur et al (1999) highlight, this could explain the difficulties young people encounter in deciding whether to tell others about their diabetes. The more information they disclose about their diabetes, the more likely it is that they will expose an element of their subjective experience of their illness and thus the likelihood of being perceived as different or ill increases. Schur at al (1999) propose that once a young person has told others about their illness, they have gone through a process of re-establishing their identity as someone who can participate in a healthy world. In addition, it is suggested that the people they disclose to have to go through a process of learning that a person with diabetes does not need to occupy a sick role.

Grappling with the fall out of diabetes

Within this study, control was a dominant theme, with the young people describing how control over diabetes was essential in preventing the illness taking over their lives. Furthermore, as a result of the variability of blood sugars and the persistent demands of diabetes, participants described that they felt as if they were constantly struggling with diabetes for control. Moreira & Dupas (2005) also describe how young people with diabetes aged between 7 and 14 felt as if they were living under the control of diabetes. The young people in Schur et al's (1999) study highlighted control over diabetes as fundamental in order to protect themselves from the anxieties and emotional fear about the illness, and to prevent it taking over their lives.

Perceptions of control are thought to be an essential aspect of adapting to chronic illness (Affleck, Tennen, Pfeiffer & Fifield, 1987). Reid (1984) suggests that optimal adaptation to chronic illness occurs when an individual is able to come to terms with what they can and cannot control. Although the girls in this

study expressed frustration that at times diabetes was ruling them due to the variability and uncertainty of their blood sugars, there was a sense that they accepted that they had little control over this, so instead asserted their control in other areas, such as taking practical steps to manage diabetes and 'put it in its place'. Taylor (1983) proposed that where control over a condition is restricted, identifying other areas of one's life where control can be exerted can assist with adaptation and coping, suggesting that young people with DM1 should be encouraged to consider areas where they can assert control.

The young people in this study also described their struggle with independence. Participants appeared to be faced with a dilemma of needing and wanting to be independent, yet at the same time aware that a certain level of dependency on others, in particular their parents, was still required. Although this resulted in frustration, they simultaneously indicated that they valued their parents' support. This study appears to build on previous research that highlights the struggles with independence young people with diabetes are faced with (Carroll and Marrero, 2006). Interestingly, Schur et al (1999) stated that young people valued and remember the support provided by parents, yet did not mention frustration at their involvement. This could be accounted for by the differing age range of participants; those in the Schur et al (1999) study were above seventeen years old and perhaps had already negotiated a move to independence, while the younger participants of both this study and Carroll and Marrero's (2006) study were in currently involved in this process. This perhaps indicates that the struggle for independence is of greater significance for the younger age range of adolescence and suggests that further exploration of this area would be of benefit.

Theories of adolescence (Havinghurst, 1953, as cited in Dovey-Pearce et al, 2007) propose that one task of adolescence is to achieve emotional

independence from their parents, suggesting that parents 'standing back' at adolescence facilitates development. However, this study's findings challenge this perspective, suggesting that whilst adolescents require changing relationships with their parents and value a move towards autonomy, ongoing connectedness remains important as they value the safety net of support that parents offer.

The findings provide support for the current theories of adjustment to chronic illness in childhood (Wallander et al, 1989; Thompson et al, 1992), which propose that parents play a key role in a young person's adjustment. These models often focus on the support provided by mothers (e.g. the transactional stress and coping model, Thompson et al, 1992), however the findings of this study suggest that this should be broadened to include fathers and other key figures within the family environment.

Making diabetes more bearable
The young people in this study described a range of ways of coping with diabetes, including distraction, avoidance, denial, minimising the impact and focusing on the positives. In addition, they struggled to make space for negative emotions, which could be considered as an element of denial. Coping strategies are considered to be an important factor in mediating a young person's adjustment to chronic illness, being recognised in both the Disability-Stress-Coping model (Wallander et al, 1989) and Transactional Stress and Coping model (Thompson et al, 1992). The findings add support to the palliative methods of coping outlined in the Transactional Stress and Coping model, and point to a need for the Disability-Stress-Coping model to provide greater detail regarding methods of coping. Schur and colleagues (1999) found that the use of denial helped participants to manage their fears regarding diabetes. Likewise, Seiffge-Krenke (1990, as cited in Schur et al, 1999) found that adolescents with chronic

illness who used adaptive denial (alongside other coping strategies) appeared to adapt well. It is considered that adaptive denial may enhance adolescents' ability to cope with uncertain and unchangeable conditions. Within the literature on coping mechanisms in young people with diabetes, denial is often considered as a maladaptive coping response (Grey, Cameron & Thurber, 1991; Frank, Blount & Brown, 1997), and has been linked to poor adjustment and psychological distress. However Goldbeck (1997) proposes that it can have an adaptive value and have positive mood regulating effects. It is suggested that denial can provide protection against the perception and processing of painful and distressing information, and if exhibited in the face of an unalterable situation (such as a chronic illness) can provide relief and comfort and enhance coping. Lazarus (1983) suggests that it becomes maladaptive if it inhibits appropriate action and mastery in an unalterable situation. In the case of the girls in this study, it seemed to serve as adaptive denial, enhancing their ability to cope with diabetes.

A further consideration is that the girls struggled to make space for their difficult emotions because they felt it was unacceptable to experience them and were unsure how to manage them. Although the psychological and emotional issues related to diabetes are well documented in the literature (Anderson, 2001; Grisby, Anerson, Freedland, Clouse & Lustman, 2002; NICE, 2004), it has been identified that gaps still remain in the provision of these services (Diabetes UK, 2006). Arguably, young people may therefore be inadvertently given the message that emotions are not acceptable and may lack the skills to know how to successfully manage them.

A surprising finding was coping by focusing on the positives. All participants described something positive that had come from being diagnosed with diabetes, for example becoming more organised, determined or confident, and focusing on these appeared to result in diabetes being more bearable, thereby facilitating

their adjustment. Schur and colleagues (1999) report that when describing how living with diabetes might have influenced aspects of their selves, participants focused on positive and socially acceptable attributes. Likewise, Damiao & Pinto (2007) explain how adolescents often reflected on the benefits of living with diabetes. Taylor's (1983) theory of cognitive adaption to threatening life events states that the adjustment process centres around three themes (two of these were discussed above), of which the final theme includes an effort to restore self esteem through self-enhancing evaluations. One of the key components of the self-enhancement strategy includes thinking that focuses on the personal benefit from living with a chronic illness, a strategy demonstrated by the participants in this study. An additional part of this strategy involves downward social comparisons, where people compare themselves to others who are less fortunate. Although other studies with young people with chronic illness have reported this as a coping strategy (i.e. Schur et al, 1999), interestingly the girls in this study did not mention use of this. It could be argued that this was due to their younger age and the possibility that within their life experience they had not yet come in to contact with others who had experienced extreme difficulties in their lives. Although Taylor's (1983) model accounts for some aspects of the process of adjusting to DM1 found in this study, it fails to consider the impact of illness on an individual's sense of self and how this may influence the adjustment process. Additionally, it views an individual in isolation and does not account for the role of support from others. Findings from this study and others (i.e. Schur et al, 1999; Dovey-Pearce et al, 2007) suggest that both of these aspects are important in a young person's adjustment to DM1. However, it is worth noting that this model was developed based on research with adults with cancer and it is thus unsurprising that it does not address some of the aspects that appear pertinent to young people.

The girls' accounts of their experience of adjusting to life with diabetes appear to resonate with Charmaz's (1995) description of the three stages in the process of adjustment to chronic illness:

1. Making sense of the illness in terms of impact on the body and sense of self. This can be seen by the current participants' descriptions of the process of developing a balanced relationship with diabetes.

2. Assessing one's changed body and self, finding a balance between losses and gains since the change and revising one's future identity goals. The current participants' descriptions of the uncomfortable position of difference, grappling with the fall out of diabetes and making diabetes more bearable could be considered to fall within this stage.

3. Surrendering to the sick self by relinquishing control over the illness and flowing with the experience of it. The current participants' descriptions of learning to live with diabetes without making it 'the main thing' would fit within this stage.

Charmaz (1995) proposes that to successfully adapt to a chronic illness, an individual needs to live with their illness without living for it. This was a theme expressed by most of the girls and appeared to be a vital step in the process of adjusting to their illness.

A criticism of this model is that it views an individual in isolation and gives little consideration to the role of others in the process of adjustment. Alternatively, a salient theme that emerged from this study was the valuable role others (in particular parents and friends) played in facilitating the young person's adjustment. This has been highlighted by others (Schur et al, 1999; Carroll & Marrero, 2006; Dovey et al, 2007), suggesting that it is an important part of the process of adjustment. Again it is worth noting that this model was developed with adults and although there appear to be areas of 'fit' in studies with young people with chronic illness, there are certain aspects that require greater

consideration, such as greater emphasis on loss of future self and perhaps greater focus on the role of peer comparison in relation to assessing one's changed body and self.

How do adolescents experience their peers during the process of adjustment to life with DM1?

Within this study, the accounts of the young people identify peers as playing a vital role in their adjustment to diabetes. The girls suggested that as they began to gain a little more independence from their parents, peers became an additional important source of support. This is consistent with the literature exploring the experiences of those in the older age range (above 16) (i.e. Dovey-Pearce et al (2007), and it is interesting to note that peers are equally important to those as young as 12. This would fit with developmental theories of adolescence, which suggest that as adolescents decrease their dependence on their parents and move towards autonomy, they rely more on their peers for support.

Participants described that friends offered two different types of support: practical support (accompanying them to do their injections, offering them their food, carrying their injections, reminding them about their regimen tasks), and silent support (being understanding, just being there). It was apparent that this support helped participants to feel understood and accepted. This is consistent with La Greca and colleagues (1995), who in their quantitative study, reported that friends offered companionship (excising together, sharing snacks) and emotional support to young people with diabetes, helping them to feel accepted and improving their self esteem. In addition they stated friends offered a level of tangible support to young people, reminding them to do injections or helping out when they were feeling unwell. Similarly, it supports the findings of various other qualitative researchers who acknowledged the valuable support friends can offer

to young people with diabetes, including reminding them about self-care (Kyngas, Hentinen & Barlow, 1998), offering care and emotional support (Dickinson & O'Reilly, 2004) and providing support when they were feeling unwell (Carroll & Marrero, 2006).

Literature proposes that as well as offering support, peers can have a negative influence on young people's adjustment. For example, Storch and colleagues (2004) found that adolescents with DM1 were more likely to be bullied than those without DM1. Thomas and colleagues (1997) found that young people were less likely to adhere to their treatment regimens in front of their peers for fear of being perceived as different. Interestingly, findings from this study did not support this idea, with participants reporting that the support offered from peers was always helpful. Bearman and La Greca (2002) state that the focus of the majority of research had been the link between peer relationships and health risk behaviours, with peers considered to encourage participation in health risk behaviours, such as non-compliance with treatment in diabetes. Again, the findings of this study contradict this, with participants reporting that peers often took a parental role, for example checking they had followed their treatment regimen and ensuring that they did not eat the wrong foods. It is interesting to note the recent high media profile of diabetes and to consider the positive influence this may have had on reducing the stigma attached to diabetes. Additionally, this study solely focused on the experience of white British girls, hence the experience of boys and also young people from different ethnic backgrounds could be very different. As there appears to de a dearth of research in this area, it seems relevant to suggest that further research should investigate the negative influence peers may have on the adjustment of young people with diabetes and other chronic illnesses.

Following research into the role of peers in the adjustment of adolescents with diabetes, Greco et al (2001) devised a peer group intervention for adolescents with DM1 aged between 10 and 18 and their best friends, aimed at increasing knowledge of diabetes and social support of diabetes care. The group had positive outcomes, with peers demonstrating a greater knowledge about diabetes and the support they can provide and parents reporting a reduction in diabetes-related conflict. This type of intervention is supported by the findings of this study, as the young people really valued the support provided by their close friends. However, widening this intervention to include the broader peer group may also be beneficial.

With regard to the role of peers in the adjustment of young people with DM1, this study's findings add support to the Disability-Stress-Coping model (Wallander et al, 1989), which postulates that social support is a resilience factor in young people with a chronic illness and facilitates a young person's positive adjustment. Findings suggest that this could be further developed to include the different types of social support considered to be beneficial to young people. Regarding the Transactional Stress and Coping model (Thompson et al, 1992), the findings point to a weakness of this model, as it fails to consider the contribution of social support. In conjunction with the findings of other studies, a compelling argument is provided to include social support within this model.

Theoretical approaches to childhood adjustment
As discussed in the Introduction, currently the two main theoretical models of childhood adjustment are the Disability-Stress-Coping model (Wallander et al, 1989) and the Transactional Stress and Coping model (Thompson et al, 1992). Although these models outline a number of important risk and resilience factors thought to influence a young person's adjustment, they fail to account for the complex and dynamic process of adjustment. The current models imply that adjustment is a unidirectional, linear process and conceptualise it as an endpoint

to be achieved. It would seem therefore that adjustment has mainly been conceptualised within the framework of a medical model, whereby it has been defined purely in terms of the absence of pathology (Bradford, 1997). However, the study findings indicate that this is an overly simplistic view which focuses on a single dimension of adjustment. The findings of this study suggest that adjustment is a complex, multidirectional process and imply that individuals may be required to adjust repeatedly as they are faced with new challenges, suggesting more circular rather than linear processes.

The study findings therefore point to a need for a more comprehensive model of young people's adjustment to chronic illness that does not conceptualise adjustment solely as an end goal but considers it as a process in flux. Adopting an approach similar to Charmaz (1995) may facilitate this process, whereby adjustment is not considered in isolation from the fabric of participants' lives. This study demonstrates the value of seeking young people's own perspectives on their experience of illness and suggests that future models should draw on ideas from young people themselves rather than developing models based on the views of parents, professionals and teachers (Amer, 1999).

Findings from this study support Bradford's (1997) view that rather than solely considering risk and resilience factors, future models need to develop a multi level approach that understands the child, family and wider care system, and how they interrelate and impact upon each other. The current models prioritise the role of the mother in adjustment and although the study findings echo the important role a mother plays, they also highlight the need for greater consideration of other family members, as well as peers and the wider care system, in particular school and health professionals.

Clinical implications arising from the current study

Potentially important implications for clinical practice emerged from the findings. The young people all described the value of being given developmentally appropriate information regarding what diabetes was at the point of diagnosis. This appeared to help them to manage their shock, confusion and distress following diagnosis, highlighting the value of providing information at this time. The girls spoke about the value of receiving written information but also of various other creative ways of developing their understanding, such as computer packages or CD ROMs. It may be worthwhile, therefore, for services to think about the different methods available for providing this information.

Parents seemed to play a crucial role during this process and thus services should ensure that they are given sufficient information to develop their own understanding, while also being advised on ways of helping their children develop their knowledge. Diabetes UK, a charity for people with diabetes, recently published a report (Diabetes UK, 2006) outlining key strategic issues for the development of diabetes services. One of their recommendations was that professionals' role in signposting and referring patients to the full range of support services was not being fully exploited. The findings of this study suggest that parents would benefit from being advised on helpful resources they could access to facilitate their child's understanding, such as information provided by charitable organisations.

The majority of participants spoke about other people's lack of understanding of what diabetes was. This appeared to impact the way in which the young people were treated and emphasised their position of feeling as if they were 'the only one'. It seemed peers and teachers in particular often had a limited understanding about diabetes and what it entailed. Diabetes UK (2006) recommends that stronger links are needed between specialist diabetes teams

and schools to ensure children and young people do not feel isolated or unsupported in their daily lives. The findings from this study endorse this. Fostering stronger links with schools could help to manage the stigma attached to diabetes and may make it easier for young people to talk more openly with their peers about their illness. Friends appear to play a crucial role in a young person's adjustment to diabetes and providing education about diabetes could also facilitate the support friends' offer.

Participants spoke about their struggle to make space for emotions, and there was a sense that emotions were somehow unacceptable and that the young people should be able to cope. Services could thus take a preventative and proactive approach (Dovey-Pearce et al, 2007) and offer courses or groups focusing on the psychological impact of diabetes, providing teaching for young people on how to manage difficult emotions they may be experiencing. Running such groups could also serve a dual purpose of providing informal support to young people and the opportunity to meet others in similar situations, helping to reduce feelings of difference. The benefits of running such groups has been well documented, with findings suggesting that they enhance a young person's ability to deal with chronic illness (Grey, Boland, Davidson & Tamborlane, 2000; Christie, Romano, Thompson, Viner & Hindmarsh, 2008).

The findings suggested that adolescence is a time when young people are keen to become a little more independent in their diabetes management. It is apparent, though, that they still value their parents' support. Services could provide help and training for parents to facilitate the management of this shift, supporting them to assist their child's independence, whilst remaining in the background to provide support when needed. Part of this process could involve group work putting parents in touch with other parents, providing a network of support and

drawing on their collective expertise. This supports guidance suggested by the National Institute of Clinical Excellence (2004).

Diabetes UK (2006) stated that greater efforts are needed to promote peer support as an effective source of emotional support. Findings from this study also suggest support from others is crucial for these young people, however services perhaps still have work to do in promoting this. Services could perhaps consider establishing their own support groups for both young people and their parents. In addition, the young people and their parents should be informed about the current support networks and groups that exist, through charities such as Diabetes UK.

The findings of this research calls for adjustment to be considered in more holistic terms, whereby it is not considered as an outcome but a continual process, with individuals required to adjust repeatedly as they are faced with new challenges. Professionals are encouraged to consider whereabouts individuals may be in the process of adjustment and consider tailoring interventions to match this.

Furthermore, the study findings illustrate the importance of professionals recognising that young people have a separate identity to diabetes. Young people discussed how they often felt that they lost their identity in place of becoming diabetic, with people seeing their illness rather than them. As developmental models state that identity development is a key task of adolescence, this obviously has important psychological implications. Within diabetes clinics where time is limited, it would be easy for the illness identity to dominate and professionals could be encouraged to adopt an 'externalising approach', whereby they separate the illness from the person by personifying it and relating to it as if it is an external entity. Techniques like this have been found to assist with young people's acceptance of their illness (Knight et al, 2003).

Methodological considerations: strengths and limitations

A strength of this study was the use of qualitative methodology, which provided the opportunity for young people aged 12 to 15 to voice their experience and meaning of adjusting to life with diabetes, something previously neglected in the literature. The use of IPA appeared to fit well with the aims of this study, allowing a rich and detailed understanding of the young people's experiences.

As IPA is an idiographic approach that does not seek to find definitive or positivist answers, it is not possible to make claims about the generalisability of these results for the wider population of young people with a diagnosis of DM1. Therefore, although others may have had similar experiences, it is necessary to acknowledge that the findings provide an in depth insight into the salient themes of the participants' experiences in this particular study. It is important to consider the transferability of these findings within this context. Similarly, although every attempt was made to be rigorous and transparent throughout analysis and interpretation, it is important that what is presented is the researcher's interpretation and other researchers may have highlighted different aspects.

When conducting the interviews, it became apparent that it may have been beneficial to have conducted multiple interviews with the young people in order to have gained richer accounts. The researcher was aware of being a stranger to the girls and although the majority were willing to converse, meeting them on a number of occasions may have helped develop a rapport and made it easier for them to share their experiences. A practical consideration would be the time and commitment required from the young people to do this.

Another consideration is the settings in which the interviews took place. All young people were interviewed at home and, although not present during the interview, their parents were usually in the next room. This may have influenced the young

people's accounts, as perhaps they felt restricted in what they could say in case their parents heard. Nevertheless, interviewing the young people at home provided a relaxed and familiar atmosphere and probably made the experience less anxiety provoking than if the interviews had taken place in the hospital.

A further factor to consider is the potential selection bias amongst those choosing to participate. It is worth noting that the young people self-selected to take part in the research and all appeared to be managing well. Therefore, the experiences of those choosing not to participate may have been quite different to those taking part. In addition, the participants were all female and white British. Literature (i.e. Williams, 2000) suggests that gender-related differences are apparent in the way in which young males and females respond to chronic illness; it is therefore likely that the experiences of males are different to those of females. It is also probable that a sample from other racial and cultural backgrounds could face other issues.

A final consideration is the use of member validation, of which there is a debate in the literature regarding its usefulness as a method of establishing credibility of the findings (Angen, 2000). It is suggested that it is a useful method to check the researcher's understanding and to ensure that the participants' views are not misrepresented (Elliott et al, 1999; Yardley, 2008). On the other hand, it is argued that it may lead to confusion, as participants may have changed their minds about an issue, may not understand the interpretations made and may not feel comfortable to comment on the researcher's interpretations (Angen, 2000; Yardley, 2008). Furthermore, it relies on the assumption that there is a fixed truth or reality against which accounts can be measured, continuing the positivist assumption of an external foundational reality (Angen, 2000). It was therefore decided that use of member validation would not be appropriate for this study, as the interpretative element of analysis may have made it difficult for participants to relate to the analysis. However, every effort was made to be rigorous and

transparent in the analytical process, and recommendations for ensuring the credibility of results were adhered to (Yardley, 2008), as discussed earlier in the methodology.

Suggestions for further research

This study has demonstrated the value of exploring young people's experiences of adjusting to life with diabetes, helping us to understand the processes involved in learning to live with diabetes. Although qualitative research exploring young people's experiences of living with chronic illness has began to increase in recent years, very few studies have explored the process of adjustment and our understanding of this generally comes from adult models (i.e. Charmaz, 1995). The findings from this study suggest that although there are similarities in the process of adjustment for adults and young people, there are certain areas which are not accounted (such as the role of peers or parents). Therefore further qualitative research could build on the findings of this current study, helping to develop our understanding of young people's adjustment to chronic illness. Specifically, as this study solely focused on girls, it would be of value to explore the experiences of boys, allowing for the consideration of the impact of gender issues on the experience of adjusting to DM1. Additionally, as this study focused on young people aged between 12 and 15, it would be of benefit to explore young people's experience of adjusting to DM1 at different developmental stages and investigate how age of diagnosis and duration of illness influences the adjustment process. Furthermore, little is know about the influence of culture on the experience of diabetes and chronic illness in general (Woodgate, 1998), and therefore it would be interesting to explore the experience of adjusting to DM1 from the perspectives of young people from different cultural backgrounds. One interesting avenue for further research is to further explore the contribution of peers in the adjustment to chronic illness. This could include investigation of the prevalence and impact of bullying, further exploring the value of group

interventions involving young people's peer groups and greater consideration of the role that others with chronic illness can play in providing support. There is a dearth of literature in this area and findings from this study suggest that peers play a vital role. Future research could also take a longitudinal approach, whereby participants are interviewed shortly after diagnosis and then at regular follow ups for a particular time period, to provide a more comprehensive understanding of the process of adjustment over time.

Study reflections

Reflexivity in qualitative research is essential in terms of considering how the researcher's own values, interests and assumptions influence interactions with the analysis (Elliott et al, 1999). Throughout this research, I found it invaluable to spend time reflecting on the process. This was accomplished by keeping a reflective journal, through supervision with my research supervisors and discussion with peers also pursuing IPA projects.

Before beginning my interviews, I felt very nervous and was anxious as to whether the young people would feel comfortable to share their experiences with me. In my preparatory reading, I was aware of potential challenges I may be presented with when interviewing young people and as a novice researcher was concerned as to how this may impact my project. Prior to embarking on the process, I was aware that I held the assumption that the young people may be difficult to engage and unwilling to discuss their experience. As a result, after listening back to my first interview I became aware that perhaps I jumped in too quickly with questions, not allowing enough silences, for a fear that the participant would have nothing to say. Being able to reflect on this in supervision and with my peers was essential and ensured that I approached further interviews with a more open mind. As interviews continued, although at times the young people

found it difficult to find the words to express their experiences, in general they all engaged in their interview and were willing to share their experiences.

I was particularly struck by the way in which the young people and their parents welcomed me into their homes and the interest they showed in the project. I felt privileged that the young people shared their experiences with me and felt a responsibility to do justice to their experience when analysing the data. At times, this made it difficult to let go of certain themes and I constantly questioned whether I had sufficiently captured the essence of their individual experiences.

During the interviews, the young people often shared some of the struggles they were faced with as a result of their illness. At times, I was tempted to slip into my role as therapist rather than researcher and was mindful of this throughout. Although at the end of each interview, time was spent debriefing the participant regarding the nature of the research, I often left the interviews wondering how the young people felt. For some I was aware that this may have been the first chance for them to speak openly about their experience. I was mindful that they had openly shared their experiences with me, however were unlikely to ever see me again, and this left me feeling a little uneasy. Lillrank (2002) and Sandahl and Wilbery (2006) discuss the dilemmas inherent in the combined role of being a therapist and a researcher and the uncomfortable difficulties this can present.

I was aware that prior to taking part in my research, the young people's experience of interviews was probably in the context of their three-monthly checks at the hospital, where the focus was very much on their physical health. I took this into consideration when compiling my interview schedule, ensuring I set the interview up in a very different way. I was mindful, however, of how this context may have influenced their responses with physical health information being prioritised. I was also conscious of how the young people and their family

perceived me as a trainee psychologist, taking into consideration the stereotypes that are often linked to the occupation. For example, one family seemed eager to explain that although they sometimes had arguments around their daughter's diabetes management, she generally managed things very well. There was a sense that I would be assessing them in some way and I was therefore mindful of how this may have influenced the young people's responses.

The overall experience of carrying out this research has taught me a great deal about the process of conducting research and the challenges one can face along the way. I learnt the importance of developing good relationships with those who are assisting in the recruitment process to ensure the research proceeds. Furthermore, through conducting, listening to and transcribing the interviews I have learnt a lot about my interview style: I realised how I seem to be uncomfortable with silences and quickly try and fill the space. I also became aware of how I often ask two questions at once, potentially confusing interviewees. I have developed skills in the knowledge and use of open ended questions and this awareness is already helping to inform my clinical practice.

CONCLUSION

The aim of this study was to adopt a holistic approach to adjustment by exploring it as a process instead of taking a reductionist stance and attempting to measure it as an outcome. Previous research in this area had neglected the views of young people and thus understanding of childhood adjustment to chronic illness was based on adult concepts. The young people were able to provide rich accounts of their experiences of adjusting to life with diabetes. The findings emphasise the complex and dynamic process of adjusting to diabetes, highlighting the challenges and struggles young people are faced with as a result of their illness. In line with developmental theories, the findings suggest that young people are in the process of forming identities, negotiating new relationships and developing autonomy from their parents. In this context, DM1 can pose a threat to young people on psychological and psychosocial levels. However, this study provides an insight into the various strategies young people adopt in an attempt to manage these threats, make diabetes more bearable and continue with their everyday lives. Furthermore, it highlights the valuable role both parents and peers play in the adjustment process and the role services can take in encouraging and promoting this support. Developing understanding of this process from young people themselves can help guide clinical practice and focus attention on how young people with DM1 and their families can be best supported.

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Appendix 1 – Ethical approval documents

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Our ref: CMT/js/LDH0308

22nd October, 2008

Miss Emily Foster
Trainee Clinical Psychologist
University of Hertfordshire
College Lane, Hatfield
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Dear Miss Foster,

Re: Adolescents' experience of 'adjustment' to life with diabetes: An Interpretative Phenomenological Analysis

Thank you for submitting your research application in respect of the above. I am pleased to inform you that this study, which has been designated as exempt from site-specific assessment ethics approval to be carried out at the Luton & Dunstable Hospital, has been approved by the Research & Development Department.

I would like to take this opportunity of informing you that should any amendments be made to the study, e.g. protocol, consent form, patient information sheet, etc. it is your responsibility to inform not only the Ethics Committee but also the Research & Development Department of these changes. I would also like to inform you that, as part of the monitoring process, at the end of your study we require documented evidence that the findings from your research are published and made available to those participating in the study. This can take the form of an individual letter, or you could provide an article to be published in our Research & Development Newsletter, which is sent to each participant.

I should be grateful to receive a follow up on the progress of the study in six months and attach a form for this purpose. Thereafter, please update me on progress at six monthly intervals.

Yours sincerely,
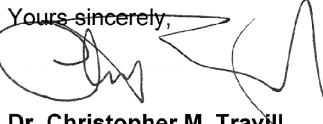
Dr. Christopher M. Travill
Director of Research & Development

c.c. Dr. Helen Davies, Clinical Psychologist, Bedfordshire & Luton Mental Health & Social Care Partnership Trust Family Consultation Clinic, Trend House, Dallow Road, Luton LU1 1LY
Dr. Beryl Adler, Clinical Director of Paediatrics, Luton & Dunstable Hospital

Enc:

Chairman Professor Soraya Dhillon MBE *Chief Executive* Mr Stephen Ramsden OBE
The Luton and Dunstable Hospital is an Associate Teaching Hospital of the University of London

Accredited by
HQS
The Health Quality Service

POSITIVE ABOUT DISABLED PEOPLE

222

National Research Ethics Service

Hertfordshire REC
9th Floor, Terminus House
The High
Harlow
Essex
CM20 1XA

Telephone: 01279 418 439
Facsimile: 01279 419 246

09 October 2008

Miss Emily Foster
Trainee Clinical Psychologist
University of Hertfordshire
College Lane, Hatfield
Hertfordshire
AL10 9AB

Dear Miss Foster

Full title of study: Adolescents' experience of 'adjustment' to life with diabetes: An Interpretative Phenomenological Analysis

REC reference number: 08/H0311/140

Thank you for your letter of 01 October 2008, responding to the Committee's request for further information on the above research and submitting revised documentation.

The further information has been considered on behalf of the Committee by the Chair .

Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised, subject to the conditions specified below.

Ethical review of research sites

The Committee has designated this study as exempt from site-specific assessment (SSA). The favourable opinion for the study applies to all sites involved in the research. There is no requirement for other Local Research Ethics Committees to be informed or SSA to be carried out at each site.

Conditions of the favourable opinion

The favourable opinion is subject to the following conditions being met prior to the start of the study.

Management permission or approval must be obtained from each host organisation prior to the start of the study at the site concerned.

Management permission at NHS sites ("R&D approval") should be obtained from the relevant care organisation(s) in accordance with NHS research governance arrangements.

This Research Ethics Committee is an advisory committee to East of England Strategic Health Authority
The National Research Ethics Service (NRES) represents the NRES Directorate within the National Patient Safety Agency and Research Ethics Committees in England

Guidance on applying for NHS permission is available in the Integrated Research Application System or at http://www.rdforum.nhs.uk.

Approved documents

The final list of documents reviewed and approved by the Committee is as follows:

Document	Version	Date
Academic Supervisor's CV	WS	
Covering Letter		
Protocol		28 August 2008
Investigator CV		31 July 2008
Application	EF	28 August 2008
Participant Opt In Slip		01 September 2008
Field Supervisor's CV	1	27 August 2008
Findings Request Form	HCD	
Assent Form for adolescents	1	27 August 2008
Participant Consent Form: Young People over 16	1	27 August 2008
Participant Consent Form: Parents	1	27 August 2008
Letter of invitation to participant	1	27 August 2008
Questionnaire: Background Information	Adolescents, v1	27 August 2008
Interview Schedules/Topic Guides	1	27 August 2008
UMAL Insurance Cover	1	27 August 2008
Letter from Sponsor		01 August 2008
Letter of Invitation to Parent		27 August 2008
Letter of Invitation to Adolescents	2	01 October 2008
Response to Request for Further Information	2	01 October 2008
Participant Information Sheet: Parent		01 October 2008
Participant Information Sheet: Adolescents	2	01 October 2008
	2	01 October 2008

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees (July 2001) and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

After ethical review

Now that you have completed the application process please visit the National Research Ethics Website > After Review

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.

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
- 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.

We would also like to inform you that we consult regularly with stakeholders to improve our service. If you would like to join our Reference Group please email referencegroup@nres.npsa.nhs.uk.

08/H0311/140	**Please quote this number on all correspondence**

With the Committee's best wishes for the success of this project

Yours sincerely

PP Jenny Ash
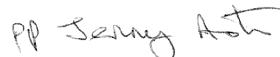
Dr Steve Eckersall
Chair

Email: jenny.austin@nhs.net

Enclosures: "After ethical review – guidance for researchers" (SL-AR2)

Copy to:
Prof John Senior
University of Hertfordshire
College Lane, Hatfield
Hertfordshire
AL10 9AB

Diana Hardy
R&D Manager
Luton & Dunstable Hospital NHS Foundation Trust
Lewsey Road
Luton, Beds
LU4 0DZ

Appendix 2 – Invitation letter to adolescents

1st October 2008, Invitation letter (adolescents) Version 2

3rd November 2008

Dear

Adolescents' experience of 'adjustment' to life with diabetes

Emily Foster, a Trainee Clinical Psychologist, is doing some research into what it is like for young people to have diabetes.

We would like to invite you to take part in the study. The study is about diabetes and the impact this has on your life. We are asking you to participate because you have diabetes.

With your help we would like to find out more about young people with diabetes and what it is like for people your age to get used to living with diabetes. It is hoped that the results will provide a better understanding of the issues and better services to young people with diabetes in the future.

The study involves Emily asking you some questions, for about an hour, about what it is like to have diabetes. As we are interested in what it is like for you to have diabetes, it would be best if Emily could speak to you by yourself, without your parents in the room. We hope that it will be a positive experience for you and a chance to share your own views and experiences.

We have enclosed an information sheet about the study for you to read and discuss with family and friends. Please also feel free to contact the researchers to discuss any questions that you may have. Contact details for the researchers can be found on the last page of the information sheet.

If you feel you would like to take part in the study and your parents are happy for you to do this, you can complete the 'opt in slip' (included with the information sheet) and send it to Emily Foster in the stamped addressed envelope provided. She will then contact you to arrange a good time to meet with you and complete the interview.

Whilst we would be grateful for your help, you do not have to take part in the study if you don't want to. Your choice will not have an affect on the help you are receiving.

Many thanks for your time.

Dr Nisha Nathwani   Denise Morrison
Consultant Paediatrics, Endocrinology, Diabetes   Diabetes Nurse Specialist

Appendix 3 – Invitation letter to parents

1st October 2008, Invitation letter (parents) Version 2

3rd November 2008

Dear

Adolescents' experience of 'adjustment' to life with diabetes

Emily Foster, a Trainee Clinical Psychologist, is conducting a study into the process of 'adjustment' for young people with diabetes.

We would like to invite your child to take part in the study. The study is about diabetes and the impact this has on a young person's life, in particular how they 'adjust' to life with diabetes. We are asking your child to participate because they have diabetes. With your child's help we would like to find out more about the impact diabetes has on young people's lives. It is hoped that the results will provide a better understanding of the issues and therefore better services to young people with diabetes in the future.

The study involves completing about an hour long interview with your child, asking questions about their experience of 'adjusting' to life with diabetes. As we are interested in gaining your child's own experience, it would be most helpful to interview them by themselves, without you present in the room. It is expected that this will be a positive experience for your child, as many young people enjoy having the opportunity to give their personal views.

We have enclosed an information sheet about the study for you to read and discuss with your child. Please also feel free to contact the researchers to discuss any questions that you may have. Contact details for the researchers can be found on the last page of the information sheet.

If your child would like to take part in the study and you are happy for them to do this, please complete the 'opt in slip' (included with the information sheet) and send it to Emily Foster in the stamped addressed envelope provided. She will then contact you to arrange a convenient time to meet with you and your child and complete the interview.

Whilst we would very much appreciate your child's help they are not obliged to take part and if they decide not to take part, it will not affect the standard of care they receive.

Many thanks for your time.

Dr Nisha Nathwani   Denise Morrison
Consultant Paediatrics, Endocrinology, Diabetes   Diabetes Nurse Specialist

University *of*
Hertfordshire   UH

1ˢᵗ October 2008, Information sheet (adolescents) Version 2

Information sheet for adolescents

Information about the research

Study title: Adolescents' experience of 'adjustment' to life with diabetes

Hello, my name is Emily Foster and I am a researcher. I am inviting you to take part in some research I am working on. I am finding out what it is like for people your age to get used to living with diabetes.

Before you decide if you want to take part, it's important to understand why the research is being done and what it will involve for you. So please take time to look at the following information carefully before saying yes or no.

You can talk about it with your family, friends, doctor or nurse if you want to. Please ask me if there is anything that is not clear or if you would like more information.

Why are we doing this research?

As you know, when you are diagnosed with diabetes you have to make lots of changes to your life. I want to find out what it is like for you to have diabetes. With this information we can know more about what it is like for young people to have diabetes. We can then provide better services to young people with diabetes in the future.

Why have I been invited to take part?

I have asked you to take part because you have diabetes and you come to see the doctors at the hospital. Also, I think that your views will be valuable. In total I hope to get 6 to 8 young people to participate.

Do I have to take part?

It is up to you and your parents to decide whether or not you take part in this project. You do not have to take part if you don't want to. Your choice will not have an affect on the help you are receiving.

If you do decide to take part, I will ask you to sign a form to say you are happy to take part. You will be given a copy of this information sheet and your signed form to keep.

You are free to stop taking part at any time during the research without giving a reason.

What will happen to me if I take part?

If you agree to take part, I will arrange a time to meet with you, either at your home or at the hospital (wherever you prefer. If we meet at the hospital, I will be able to pay you back for any travel costs, up to £10, if you give me a travel receipt).

I will ask you and your parents to sign a consent form to say you are happy to take part in the research. You will need to fill in a short information sheet about yourself. I will then ask you some questions about what it is like to have diabetes. Because I am interested in what it is like for you to have diabetes, it would be best if I could speak to you by yourself, without your parents in the room, as they may be tempted to talk about what it is like for them. I expect that we will be talking for about one hour. The conversation will be tape recorded and then later written down word for word. When I write all this down, all information that identifies you will be removed.

What are the possible benefits of taking part?

Some people enjoy talking about their own views and experiences. Taking part in this study will give you a chance to speak openly and honestly about what it is like to have diabetes. The information we get from this study might help us to gain a better understanding of what it is like for young people to have diabetes. This will mean that we can give better help to young people with diabetes.

What are risks of taking part?

There are no known risks to taking part in this study. However, in the interview I may ask you some questions about how you feel about yourself and how diabetes has affected your life. It may be that thinking about these things makes you feel upset. If this happens you will be able to talk to me or another psychologist about how you feel. We have had special training to support people with upsetting feelings or emotions.

During the interview, if I am worried that you might hurt yourself I might ask if you want to speak to someone. You can then talk about these feelings in private if you want.

If I am worried that you might hurt yourself, or I am worried that someone else might be harming you I may have to talk to other people about these issues.

What if there is a problem or something goes wrong?

If you want to talk about anything to do with the research you can speak to me or speak to your parents.

If you want to complain about the study, or the way you have been treated, you or your parents can speak to me, Emily Foster, or contact the Patient Advice and Liaison Service (PALS). You can ring them on 01582 497990 or speak to them in person. They have a desk in the main entrance of the hospital which is open between 9am and 6pm Monday to Friday. If PALS are unable to help you, you can make a formal complaint by writing to the Chief Executive, Mr Stephen Ramsden, Luton and Dunstable Hospital NHS Foundation Trust, Lewsey Road, Luton LU4 0DZ or ringing the Patient Affairs Office on 01582 497002.

Will my answers be kept private?

We will keep your information in confidence. This means we will only tell those who have a need or right to know. All information will have your name and address removed so that no-one can tell who you are.

Your diabetes doctor or nurse will be told if you agree to take part in the study. I will not tell them any information from the interview unless I am worried that you might hurt yourself, or I am worried that someone else might be harming you.

If you agree to take part in the study your information will be stored in a safe locked location which will only be accessible by me and my supervisors.

The results of the project will be written up in a report. This report will not have your name or details on it and no-one will be able to tell who you are from it. When I write the report I may use quotes from your interview but I will change names and recognisable details so no one will be able to tell who you are.

If you would like a copy of the findings of the project you can complete the 'Do you want to know the results?" form. Once the study is finished I can send you a written summary of the findings.

The written transcript of your interview will be kept in a safe locked location for five years and then it will be destroyed.

Who has reviewed the study?

Before any project like this goes ahead, it has to be checked by a Research Ethics Committee. They make sure that the research is fair. Your project has been checked by the Hertfordshire Research Ethics Committee.

Who can I speak to if I have more questions?

You can speak to or email:

 Emily Foster, Trainee Clinical Psychologist, on 07977 468574 or
e.foster@herts.ac.uk

Or

Dr Helen Davies, Clinical Psychologist, on 01582 708162 if you have more questions.

Or you can speak to your parents who have also been given an information sheet.

This information sheet is for you to keep.

Thank you for reading this – please ask any questions if you need to.

University of
Hertfordshire **UH**

Information sheet for parents

Information about the research

Study title: **Adolescents' experience of 'adjustment' to life with diabetes**

Your child is being invited to take part in a research study. Before deciding whether to take part, it is important for you and your child to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with your son or daughter and others if you wish. Ask us if there is anything that is not clear or if you would like more information. Take time to decide whether or not you would like your son or daughter to take part.

What is the purpose of the study?

As you are aware, being diagnosed with diabetes has a big impact on an individual's life. We know that adjusting to life with diabetes can be difficult for some people. However, we do not know much about the adjustment process from the perspective of young people with diabetes. We know that at the time of adolescence, friends become quite important in a young person's life. However we do not know much about how friends contribute to the process of adjustment. We are therefore interested in finding out about adolescents' experience of adjusting to diabetes and how they feel their friends have contributed to this process. We hope that if we have more information and a greater understanding about the process of adjustment, we can help to inform services that young people with diabetes use.

Why has your child been chosen?

Your child has been chosen to participate because they have been diagnosed with diabetes. In total we hope to get 6-8 adolescents to participate.

Does your child have to take part?

It is up to you and your child to decide whether or not to take part. If your child does decide to take part you will be given this information sheet to keep and will both be asked to sign a consent form. If your child does decide to take part they are still free to withdraw at any time and without giving a reason. A decision to withdraw at any time, or a decision not to take part, will not affect the standard of care they receive.

What will happen to your child if they take part and what will they have to do?

I will arrange a convenient time to meet with you and your child, either at your home or at the hospital (wherever you both prefer. If we were to meet at the hospital, we would reimburse your travel expenses, up to £10, on the production of a travel receipt). I will ask you and your child to sign a consent form to say that you are happy to be involved in the research. Your child will need to complete a brief information sheet about themselves. I will then ask them some questions about their experience of adjusting to life with diabetes, and how they feel their friends have contributed to this process. As I am interested in gaining your child's own experience of adjusting to life with diabetes, it would be most helpful to interview them by themselves, without you present in the room. It is expected that the interview will take approximately one hour to complete. The interview will be audio recorded and later transcribed verbatim. All identifying details will be removed from the transcripts.

What are the possible disadvantages and risks of taking part?

There are no known risks to taking part in this study. However, in the interview I may ask your child some questions about how they feel about themselves and how diabetes has influenced their life. It may be that thinking about these things is distressing for your child. If they become upset during the interview, they will be able to talk about these issues with the researcher or another clinical psychologist in confidence.

During the interview, if I am concerned that your son or daughter is at risk of hurting themselves or is very low or depressed we might contact you and your child to raise this concern. Together with a clinical psychologist, your child can discuss these issues in confidence.

If you also feel worried about your son or daughter following their participation in the study you can speak to the researcher, or clinical psychologist, in confidence.

What are the possible benefits of taking part?

Many young people enjoy the opportunity to give their personal opinions. Additionally, some people find it helpful to speak to someone about particular experiences. Taking part in this study will give your child an opportunity to speak openly and honestly about what it is like to live with diabetes. It is hoped that the information we get from this study might help us to gain a better understanding of this area. In the long term, it is hoped that this information can help us have a better understanding of patients' needs and therefore help us to provide a better service for young people with diabetes.

What if something goes wrong?

It is extremely unlikely that taking part in the interview will cause your son or daughter any harm. However, if they are distressed following participation in the study, they will be offered the opportunity to meet with a clinical psychologist to talk about these issues.

However, if you wish to complain, for whatever reason, about the study, or the way you have been treated, you can speak to me, Emily Foster, or contact the Patient Advice and Liaison Service (PALS) at the hospital. They can be contact by telephone on 01582 497990 or in person at the PALS desk, located in the main entrance of the hospital. The desk is open between 9:00 and 18:00 Monday to Friday. If PALS staff are unable to resolve your concerns you may wish to make a more formal complaint. This can be done by putting your concerns in writing to Chief Executive, Mr Stephen Ramsden, Luton and Dunstable Hospital NHS Foundation Trust, Lewsey Road, Luton LU4 0DZ or by telephoning the Patient Affairs Office directly on 01582 497002.

Will your child's taking part in this study be kept confidential?

All information which is collected will be kept strictly confidential. Any information about your child which leaves the hospital will have their name and address removed so that they cannot be recognised from it. Information will be stored in a locked filing cabinet and will only be able to be accessed by the researcher and her supervisors. The researcher and supervisors will have a duty of confidentiality to your child as a research participant.

Your child's paediatrician and/or diabetes nurse will be informed that your child is taking part in the study. However, disclosure of any personal information from the interview will only occur in exceptional circumstances if your child revealed information that may indicate a risk to themselves or others.

If the researcher is worried about your child (for example, if they become distressed when taking part in the interview), she will discuss it with your son or daughter in the first instance. If she is concerned that your child might harm themselves or other people, or is worried that someone else might be harming your child, she may have to talk to other professionals about these issues.

What will happen to the results of the research study?

The results of the research will be written up by the researcher as part of her clinical psychology doctorate. A copy of the research will be kept in the University of Hertfordshire library. In addition, it is hoped that the research will be submitted for publication in a peer-reviewed journal. I may use quotes from your child's interview when writing up the research to illustrate various findings that may arise. If I do this, I will conceal their identity by removing any personal identifiable information, for example change names and recognisable details.

The written transcript of your child's interview will be kept in a locked filing cabinet for five years. After this time, it will be destroyed.

If you wish to receive a summary of the results, please indicate this on the "Do you want to know the results?" form that you and your child will be asked to sign if they give their consent to participate.

Who is organising and funding the research?

The University of Hertfordshire is funding the research and is being undertaken by Emily Foster, Trainee Clinical Psychologist, as part of her doctoral qualification in Clinical Psychology.

Who has reviewed the study?

The Hertfordshire Research Ethics Committee have reviewed the study. They have found it to be ethically sound.

Contacts for Further Information

If you have any questions or queries please do not hesitate to contact us.

Emily Foster
Trainee Clinical Psychologist
Doctor of Clinical Psychology Training Course, University of Hertfordshire, Hatfield, AL10 9AB. Tel: 07977 468574; email: e.foster@herts.ac.uk

Helen Davies
Clinical Psychologist
Family Consultation Clinic, Trend House, Dallow Road, Luton LU1 1LY Tel: 01582 708162; email: Helen.davies@blpt.nhs.uk

This information sheet is for you to keep. If your child wishes to participate in the study you will have a copy of the consent form to keep as well.
Thank you for time!

University of
Hertfordshire

U H

27th August 2008, Opt in slip Version 1

Opt in slip

Is your child willing to take part in the study?
Are you happy for your child to take part in the study?

Please let us know by both you and your child completing the slip below and returning to Emily Foster in the stamped addressed envelope provided. If you indicate that your child is wiling to take part, Emily Foster will be in contact shortly to arrange a convenient time to meet with you and your child.

Child to complete:

Child's name:_____

Please tick the right box :

☐ I am happy to take part in the study looking at adolescents' experience of 'adjustment' to life with diabetes.

☐ I do not want to take part in the study looking at adolescents' experience of 'adjustment' to life with diabetes.

Parent to complete:

Parent's Name:_____

I am/ am not willing for my child to take part in the study exploring adolescents' experience of 'adjustment' to life with diabetes. (Please delete as appropriate).

If you are willing for your child to be involved please provide contact details so Emily Foster can arrange to meet with you and your child

Contact telephone number or email address:
_____
_____

What is the best way to contact you?_____

What is the best time to contact you?_____

Appendix 7 – Reminder letter

University of Hertfordshire **UH**

Doctorate in Clinical Psychology Training Course
University of Hertfordshire
College Lane
Hatfield
Hertfordshire
AL10 9AB
Email: e.foster@herts.ac.uk
Tel: 07977 468574

29th December 2008

To the parents/carers of

Adolescents' experience of 'adjustment' to life with diabetes

My name is Emily Foster and I am a Trainee Clinical Psychologist conducting a study into the process of adjustment for young people with diabetes.

You should have recently received a letter from Dr Nisha Nathwani and Denise Morrison, from Luton and Dunstable Hospital, inviting your child to take part in the study. In addition, you should have received some information about the study plus an opt in slip and stamped addressed envelope to let us know whether or not your child would be willing to take part.

If you have not already returned the opt in slip to indicate whether or not your child would be willing to take part in the study, I would be most grateful if you could do this as soon as possible. If you have any questions or queries, or would like another copy of any of the information, please feel free to contact me. My contact details are at the top of the letter.

Whilst we would very much appreciate your child's help they are not obliged to take part and if they decide not to take part, it will not affect the standard of care they receive.

Many thanks for your time.

Best wishes

Emily Foster
Trainee Clinical Psychologist

Appendix 8 – Assent form

27th August 2008, adolescent assent form Version 1

University of Hertfordshire UH

ASSENT FORM FOR ADOLESCENTS

Participant Identification Number:

Project title: Adolescents' experience of 'adjustment' to life with diabetes

Young person to circle all they agree with:

Have you read (or had read to you) about this project?	Yes/No
Has somebody else explained this project to you?	Yes/No
Do you understand what this project is about?	Yes/No
Have you asked all the questions you want?	Yes/No
Have you had your questions answered in a way you understand?	Yes/No
Do you understand it's OK to stop taking part at any time?	Yes/No
Do you understand that you will be audio taped as part of the study?	Yes/No
Are you happy to take part?	Yes/No

If <u>any </u>answers are 'no' or you don't want to take part, don't sign your name!

If you <u>do </u>want to take part, you can write your name below

Your name _____

Date _____

The researcher who explained this project to you needs to sign too:

Print Name _____

Sign _____

Date _____

Thank you for your help.

1 copy for patient; 1 copy for researcher; 1 copy for medical file

Appendix 9: Consent form (parents)

27th August 2008, Consent form (parents) Version 1

University *of* Hertfordshire **UH**

CONSENT FORM (Parents)

Patient Identification Number:

Title of Project: Adolescents' experience of 'adjustment' to life with diabetes

Name of Researcher: Emily Foster, Trainee Clinical Psychologist

Please initial box

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

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

3. I understand that the interview with my child will be audio taped. I understand that when a report is written about the study, quotes from my child's interview may be used but all identifying information will be removed.

4. I give agreement for my child to take part in the above study.

_____   _____   _____
Name of Patient   Date   Signature

_____   _____   _____
Name of Parent/Legal Guardian Date   Signature

_____   _____   _____
Researcher   Date   Signature

When completed: 1 copy for patient; 1 copy for parent / legal guardian; 1 copy for researcher; 1 copy for medical file

Appendix 10 – Interview Schedule

Interview schedule

Pre amble – explain purpose of interview and structure. Explain what my questions are for.

1. **Can you tell me a bit about yourself and your family?**

   Whose in family?

   what do you like doing?

   what are your interests?

   How do you spend your spare time?

   Anyone else with diabetes?

2. **Let's take you back to when you were diagnosed, can you tell me about what happened and what it was like?**

   When and where diagnosed?

    By whom?

   Who told you?

   how did you feel about being diagnosed?

   How did your family feel?

   was there anything you were worried about?

    who did you tell about diagnosis? Why?

   How did they react?

   What did they say?

   How did that make you feel?

   Who did you not tell? Why?

   Understanding of diagnosis?

3. **what was happening before that led to diagnosis?**

4. How do you feel about having diabetes?

5. Can you tell me what it is like for you having diabetes?

What does diabetes mean to you?

how do you manage your diabetes?

What is your regime?

6. Can you tell me about how having diabetes has impacted your life?

how has your life changed since being diagnosed with diabetes?

What was life like before diabetes?

what areas of your life (if any) does it affect? (school, home, family, friends)?

Does diabetes make it difficult to do certain things?

Part of life most significantly influenced?

What things do you have to do, that your friends don't, because you have diabetes?

Anything positive about having diabetes?

What would life be like if you didn't have diabetes?

7. Can you tell me about how having diabetes has impacted you as a person?

Medically

Psychologically (emotions/feelings)

Socially

at home

school

friends

family.

what is the hardest part of having diabetes, what bothers you the most? At first? Now?

what is the easiest part of having diabetes, what least bothers you?

8. **on a day to day basis how do you deal with having diabetes?**

How do you cope with having diabetes?

medically, psychologically, socially, at home, school, friends, family.

Who helps?

Particular things that help?

Activities?

Strengths/things that help you?

Do you talk to anyone about your diabetes?

9. **You might have heard people talk about adjusting to your illness. I'd be really interested to know what you think it means to adjust (cope / deal/ manage) to diabetes.**

10. **have you got an idea of what not adjusting to diabetes would look like?**

Why might you think someone might struggle to adjust?

what might you say to someone who was struggling? What might help them/not help them?

What's difference between the two?

11. **What do you think about your adjustment to diabetes?**

Do you reckon you have adjusted?

How do you know?

How come you have / haven't managed to adjust?

what has been helpful? why?

What has not been helpful? why?

Who has helped? Who hasn't helped?

What would like be like if you hadn't adjusted to diabetes?

12. **what would your best friend or family say about your adjustment?**

How come? Why?

13. **what would your doctor or nurse say about your adjustment?**

How come? Why?

14. **have you got any ideas about why some people can adjust and others can't?**

15. **We've already talked a bit about how your family help you with your diabetes. I'd be really interested to find out about how your peers (friends/colleagues at school) have contributed to your adjustment to diabetes.**

who did you tell? Why?

Who did you not tell? Why?

reactions of peers?

Support received from peers?

What has been helpful? why?

What has not been helpful? why?

change in peer relationships since diagnosis?

What your friends make of diabetes?

Do you know others with diabetes?

16. Is there anything else you that is important for me to know about to understand your experience?

17. Any questions I didn't ask you that you thought I might ask?

18. How has it been talking with me today?

Appendix 11 – Audit trail

<u>Chronological list of emerging Themes: Interview 2</u>

Emerging themes	page.line
throwing self into sport	1.2
diagnosis: confusion and uncertainty	4.145
factual account of diagnosis	5.184
emotionally detached	5.184
initial excitement	5.209
cycle of confusion	5.21
lack of choice / control	6.23; 37.1691
ignorance of youth	6.236; 43.1966
age related increase in awareness	6.238
dealing with practicalities	6.245
parental support	6.24; 38.1722
restrained by diabetes	6.257
lack of control	32.1449; 35.1597
Injections in control	6.255
strangeness of situation	6.269
confusion	6.269
emotional rollercoaster	7.298
cycle of fear	7.297
achievement of injections = realisation of seriousness	7.299
terrifying responsibility	7.306
reality difficult	7.316
denial of situation	7.318; 8.331
avoidance	8.34
getting to know diabetes = realisation of seriousness	8.341
minimising	8.346-347;13.58; 22.984

initial simplicity	8.346
no escape	8.348; 30.1372; 31.1381; 32.1465; 34.152; 46.2081
hold of diabetes	8.365
constant	9.368
denial of emotions	9.377
emotions don't help	9.388
following routines and rules	10.422
injections control what can do	11.474; 11.479
loss of identity	11.492
being labelled	11.497
infantilised	11.502;12.525;13.572;
loss of own voice	12.526
mothering friends	12.526
dependence vs independence	12.53; 26.1187; 46.2093
diabetes stealing identity	12.536
concern of others	13.577
dilemma: being looked after vs looking after self	13.577-581
friends - look after	13.586; 20.907
friends – infantilise	14.598
good friends vs people know at school	13.593
No-one understands	14.605; 23.1037; 23.1047
friends – practical support	14.631; 23.1017
being judged	15.654
best friend – mothering/takes care of me	15.633; 16.704
Being the only one	27.1193
different to others	15.666; 19.838-842; 23.1053; 29.1297;

	38.1718
familiarity = relaxed	15.67; 42.1883
minimising emotional content	15.676
best friend – practical support	16.708
support of best friend vs support of other friends	16.723
friends can be interfering	16.731
confusion of friends	16.732
difficult for others to understand	17.737
independence	17.74
identity – seeing me for me not just diabetes	17.751
friends/friends parents – being prepared	18.808
friends/friends parents – looking after her	18.821
diabetes impacts personality – makes more cautious	19.834
responsibility	19.841; 25.1122-1123; 29.1291; 45.2041
taking away childhood	19.838
Unconscious impact	19.841
hold of diabetes	19.846
identity	19.852; 31.138; 43.1956
uncertainty - what if…	20.873; 35.1596
worry	19.842; 20.837
Emotional avoidance	20.892
difficult to stay with emotion	20.903-908
difficult to express emotion	20.916
diabetes takes control	22.980-984
anger at diabetes	22.982; 25.1112
avoidance of diabetes	22.1006-1008; 23.1016; 22.980-984; 32.146

looking after self vs. dependence on others	23.101
judged by others	23.1031; 45.2035
invalidation of own experience	23.1032
not being believed	23.1045; 25.1116
value of friends support at school	24.1067
friends make diabetes more bearable	24.1071
practical changes	24.1098
changes personality	25.111
control of diabetes	25.111; 27.1197
no longer carefree	25.1122-1123; 27.1203; 29.1295; 29.1311; 40.1813
determination (positive influence)	25.1145
putting diabetes in its place	26.115; 41.1843
denial - difficult to acknowledge impact	26.1156
identity: self separate from diabetes 'lost self'	26.1162-1175
different to others - protective mum	26.1187
enforced restrictions	27.1201
control - diabetes forcing you to do things	27.1218
no choice	27.1236
being looked after	28.1252
impact on social life	28.128
out of control	29.1319
uncertainty	29.1312; 32.145
control	30.1332
permanency	30.1353; 30.1363; 32.1451
routine and rules of diabetes	32.1451
cycle of difficult emotions	32.1453-1456
trapped - can't avoid emotions	32.1456
cope: avoidance	33.1476

no space for emotion	33.1475-1477
cope: over indulgence	33.1482-1487
cope: distraction	33.1499; 34.1557
power of diabetes	34.1518
difficult emotions	34.1521
emotional trap	34.1525
fear	34.1558
powerless	35.1564
anxiety	35.1597
adjustment = catering for diabetes	36.1625
adjustment = getting on with it	36.1636; 40.1808
avoidance/denial	36.1638
adjusting = developing a relationship with diabetes	36.1642
not adjusting = carrying on as before	36.1649
questioning: why me?	37.169
adjustment = food changes	38.1706
restrictions	38.171
framing positively	38.1735
family support	39.1758
Silent support	40.179
friends - being understood	40.179; 39.1762
maintaining my identity	40.1799
importance of parents in adjustment	40.1832
keeping your life	42.1911
difficult to incorporate into identity	43.1961
future concerns - passing to own children	44.1986
diabetes takes away fun	45.2026
planning ahead	45.2042/2047/46.2078

Clustered themes and superordinate themes – Interview 2

<table>
<tr><th colspan="4">Developing a relationship with diabetes</th></tr>
<tr><th>Emerging themes</th><th>Page numbers</th><th>Sub Themes</th><th>Quotes</th></tr>
<tr>
<td>Reality difficult
Initial excitement
Achievement of injections = realisation of seriousness
Getting to know diabetes = realisation of seriousness
Adjusting = developing a relationship
Adjustment = getting on with it</td>
<td>7.316
7.305
5.209
7.299
8.34
36.1642
36.1636
6.236</td>
<td>**Building a relationship with diabetes**</td>
<td>p.8.34
erm (pause 3 secs) I didn't really think because you don't realise what it is like until you've had it for a little while so now I get a bit more like annoyed about it</td>
</tr>
<tr>
<td>Age related increase in awareness
Ignorance of youth</td>
<td>6.236
43.1966</td>
<td>**Age related increase in awareness**</td>
<td>p.6.236
er I didn't really have much feeling because I was only little so I didn't really know what was going on so I just thought it was like a nothing serious and then as I got older it stayed with me so I sort of realised a bit more like so but they were really helpful, like mum bought me loads of stuff on it and everything</td>
</tr>
</table>

Fighting with diabetes for control			
Emerging themes	**Page numbers**	**Sub Themes**	**Quotes**
Responsibility/no longer carefree Control of diabetes Power of diabetes powerlessness Diabetes takes control	25.1121 34.1518 35.1564 36.1608	**Power of diabetes**	p.34.1518 It will just hit me like that I am diabetic and I've had it for ages and I've got it for the rest of my life and it will sort of hit me p.34.1564 so it's nice just to be able to sit there but if mum tries to talk to me I'll go like, get all because you are so weak like you can't do anything sort of thing
Lack of control / out of control Injections in control Hold of diabetes Diabetes forces you to do things	6.230 6.255 8.365 11.477 19.846 27.1193	**Lack of control**	p. 6.255 it was horrible cause I wasn't in control like they were in control so it was a bit sort of like annoying cause it sort of held you back a bit at school as well cause you had to go and have a snack and everything
Putting diabetes in its place determination Emotional avoidance	20.832 25.1145 41.1843	**Putting diabetes in its place**	p.41.1843 cause she always said that we don't fit in with the diabetes, the diabetes fits in with us

Learning to share your life with diabetes			
Emerging themes	**Page numbers**	**Sub Themes**	**Quotes**
No escape/trapped Constant permanency	8.348 9.368 30.1353 32.1456 34.152	**permanency**	p.9.368 everything you have to do everyday and it never goes away sort of thing
Unconscious impact of diabetes Hold of diabetes Changes personality	19.841 19.846 25.111	**Unconscious impact of diabetes**	p. 19.846 because without like, subconsciously it's in there sort of thing so it will make me more cautious about other things p. 19.852 with my friends and they'll be like why you know why are you like that then I don't realise it but it is to do with the diabetes because it sort of affects me a bit

Resistance to experiencing different emotions			
Emerging themes	**Page numbers**	**Sub Themes**	**Quotes**
Cycle of fear Emotional rollercoaster Cycle of difficult emotion Emotional trap	7.297 32.1453 34.1225	**Cycle of difficult emotions**	p. 7.297 erm it took me like half an hour to do it, it was really bad cause I was shaking and like erm.. I dunno ..erm.. a little bit sort of scared and then a bit like I've achieved it and then like once you've done it a couple of times it is a bit sort of like yeah I've done it now like can I stop
Anger	32.1454 32.1466 34.1521	**Anger at diabetes for impact**	p.32.1454 what's the point in getting down and then it gets me angry cause I'm thinking it's getting me upset and when I get angry it gets me upset and then it's like vicious circle.. but then you try and forget about it and then the next month it will come along again
Emotions don't help Emotional avoidance Difficult to express emotions Denial of emotions Difficult to stay with emotions	9.388 9.377 20.891 20.903 20.916	**Emotions don't help**	p.9.388 I know it's really bad but just thinking of it and then but then if you get upset there's no point because it is not going to do anything to help it so there's no point

Coping with the impact of diabetes by avoidance and distraction			
Emerging themes	**Page numbers**	**Sub Themes**	**Quotes**
Denial of situation	8.331	**Avoidance of diabetes**	p.8.331 cause I knew but I actually didn't sort of think about it
Avoidance Denial of emotion Cope = avoidance Coping by distraction Avoidance/denial	22.98 33.1476 33.1499 34.1557 36.1638	**Coping with the impact of diabetes by avoidance and distraction**	p.32.146 but then you try and forget about it and then the next month it will come along again p.33.1499 then it'll take my mind off not being able to have a lot of food or not being able to have a lot of sugar

The value of family support			
Emerging themes	**Page numbers**	**Sub Themes**	**Quotes**
Parental support	6.24; 38.1722	**Practical support**	p.6.24 they were really helpful, like mum bought me loads of stuff on it and everything
Family support Importance of parents in adjustment Framing positively	38.1735 39.1758 40.1831	**Positive parental attitude**	p.38.1722 urgh so like I dunno, mum helps like adjust and stuff so cause she knew what she was doing and stuff it helps so she like sort of guided me as to what I could have and what I couldn't and got new stuff in and made it positive rather than negative that I had it

Feeling different			
Emerging themes	**Page numbers**	**Sub Themes**	**Quotes**
Different to others Being the only one	15.666 27.1193 38.1718	**Being the only one**	p.27.1193 all my friends like um…don't have to wear a coat like their parents want them to but they don't have to but mum wants me to because obviously of my circulation
No-one understands Confusion of others Difficult for others to understand Not being believed	14.598 16.729 17.737 23.1045	**No-one understands**	p.14.598 they think they know what they are talking about and they'll start telling me about what I should be doing and it's a bit like sort of weird cause they don't have it and they think they know and there like think it's like type 2 and they think there is a type 3 ... we'll have this argument because they think they know what they are taking about and they won't listen to me who actually has it.
Questioning: why me?	37.169	**Questioning – why me?**	p.37.169 why should I have it? so why should I? why should I have it? so then why should I go along with it? I didn't choose to have it

Struggling for independence			
Emerging themes	**Page numbers**	**Sub Themes**	**Quotes**
Dependence vs independence	12.53 13.577	**Being looked after vs looking after self**	p.46.2094 and like and we wanted to go for a walk and I didn't have anything mum would be like don't worry about it like I'm here like you are safe but it's not, I hate being dependent on someone
Being looked after vs looking after self	17.74 28.1187 23.101 46.2094		

Paradox of support between close friends and peers			
Emerging themes	**Page numbers**	**Sub Themes**	**Quotes**
Friends look after	15.663	**Friends looking after me**	p.15.663 my best friend looked after me sort of she still does like sort of you know like takes care of you and stuff
Mothering best friend	20.907		
Importance of friends	16.704		
friends can be interfering	13.593	**Interfering friends**	p.13.593 some of them will be alright like the ones that really know me but some sometimes the ones that I like I know but I don't particularly I wouldn't call them my good friends they think they know what they are talking about and they'll start telling me about what I should be doing and it's a bit like sort of weird cause they don't have it
friends infantilise	16.731		
Good friends vs people know at school	13.595 14.631	**Practical support**	p.14.631 I have to go and do my injection at lunch I made new friends and then they'd come with me and wait for me while I'd done it
Practical support from friends	16.708		

Best friend practical support			p.16.708 she's um she won't be like that but if I have some chocolate or something or if I'm low, she'll give me something of hers just so I'm alright or if I'm out to lunch, she'll hold my injection if I can't store it anywhere or something
Confusion of friends Difficult for others to understand	16.723 17.737	**Friends who keep out of it**	p.16.723 it's nice yeah cause like my other friends they try and be like that but it's a bit more like they don't know me as well she does so yeah some of them don't really get involved because, they do get involved but they don't I suppose they are not as considerate about it cause they don't think it is so serious and some people think it is more serious.
Value of friends support Friends – being understood Friends make diabetes more bearable Support of best friend vs support of other friends	16.723 23.1017 24.1067 24.1071 40.1789	**Friends make diabetes more bearable**	p.40.1789 yeah just, just sort of sticking by me like I know it sounds stupid like why shouldn't they but yeah just by understanding

Learning to abide by the routines and rules of diabetes			
Emerging themes	**Page numbers**	**Sub Themes**	**Quotes**
Uncertainty – what if uncertainty	20.873 29.1317 35.1596	**Living with uncertainty**	p.35.1596 what if it doesn't, what if, if I'm eating still and it doesn't go up and I can't get it up and then it will go up and I know it will but in my mind I'm thinking like you know

Taking away childhood No longer carefree responsibility Diabetes takes away fun	19.838 25.1122 29.129 40.1813 45.2026	**Responsibility**	p.19.838 because like they'd go off somewhere and if I didn't have anything on me then I couldn't you know or they'd just eat loads of stuff and I couldn't eat loads of stuff or I think it makes me more responsible without realising it and it makes me worry
Practical changes Dealing with practicalities	25.1103 38.171 38.1706	**Dealing with practicalities**	p. 25.1103 I used to love dr pepper and a snicker I know it sounds stupid but I used to have it, I used to love it and I can't have that anymore
Planning ahead	45.2047 46.2078	**Planning ahead**	p. 46.2078 um well we always have to make sure we have loads of sugar on the plane just in case I get low cause you can't exactly land um and it doesn't bother mum so much cause she hasn't got it but it bothers me like it's always on my mind, like mums more like if you get low then we'll go to the shop but I'd rather have something on me
Following routines and rules Rules and routines of diabetes Enforced restrictions Restrained by diabetes	10.422 32.1451 27.1201 6.257	**Abiding by the rules**	p.32.1451 is always there and you have to make sure it's on time and like it's right so

The way diabetes causes me to be labelled			
Emerging themes	**Page numbers**	**Sub Themes**	**Quotes**
Being labelled Diabetes stealing identity Identity – seeing me for me Identity – self separate from diabetes (lost self) Maintaining my identity Difficult to incorporate into identity Loss of identity	11.492 11.497 12.536 17.751 26.1162 40.1799 43.1956	**Threat to identity**	p.11.492 they'll they'll remember me as a diabetic kid which is a bit annoying it's a bit annoying when people label you. p.12.536 so I'd rather they'd just treat me for me rather than what I have
Infantilised	11.502 12.525 14.598	**Infantilised**	p.12.525 they'll say that I can't have like my friends will be like oh aren't you having any and then my other friend will speak for me
Being judged Judged by others	15.654 23.1031 45.2035	**Judged by others**	p.23.1031 and people will be bothering you and you'll be like no just go away cause like I don't feel well and they're like they don't believe how bad you feel I don't know maybe they think I'm making a thing out of it I think but um… or they just sometimes they just don't think about what it is like cause they don't I think they just think you have a headache or something

Appendix 11 – Audit trail

Superordinate themes from all interviews

Interview 1
The vulnerable position of being the only one
Struggle to voice emotional impact
The need to be independent and responsible yet mindful of the constraints of diabetes
The back up of support
The importance of getting to know diabetes in being able to incorporate it into your life and maintain your identity

Interview 2
Developing a relationship with diabetes
Fighting with diabetes for control
Learning to share your life with diabetes
Resistance to experiencing difficult emotions
Coping with the impact of diabetes by avoidance and distraction
The value of family support
Struggling for independence
Paradox of support between close friends and peers
Learning to abide by the routines and rules of diabetes
The way diabetes causes me to be labelled
Feeling different

Interview 3
Putting on a brave face in spite of difficult emotions
Loss of individual control
Loss of carefreeness
The value of different types of support
Involving diabetes in your life but not making it the main thing
The impact of diabetes on identity

Interview 4
The difficult emotions experienced by me and my family
Learning to live a different life: living side by side with diabetes
Becoming independent whist others support is always in the background
Worries of being the odd one out
Strategies for coping

Appendix 11 – Audit trail

Superordinate themes clustered and master themes for all interviews

Master themes	Sub themes	Emerging themes
	Getting to know diabetes	Developing a relationship with diabetes
		Building a relationship with diabetes
	Accepting the permanency and relentlessness of diabetes	Learning to share your life with diabetes
		Learning to live a different life: living side by side with diabetes
	Learning to live with diabetes without making it the main thing	Involving diabetes in your life but not making it the main thing
		Learning to live with diabetes without letting it take over
		Diabetes becoming second nature
		The importance of getting to know diabetes in being able to incorporate it into your life and maintain your identity
Developing a balanced relationship with diabetes	The difficult experience of diagnosis	The difficult emotions experienced by me and my family
		The difficult experience of being diagnosed and beginning treatment
	Introducing diabetes to others	The difficulty telling others
	Loss of childhood	The need to be independent and responsible yet mindful of the constraints of diabetes
		Loss of carefreeness
		Learning to abide by the routines and rules of diabetes
	Uncomfortable position of being the only one	Feeling different
		The vulnerable position of being the only one
		Worries of being the odd one out
		Managing the uncomfortable position of feeling different
The uncomfortable position of difference	Threat to personal identity	The impact of diabetes on identity
		The way diabetes causes me to be labelled
Grappling with the fall	Grappling with diabetes for	Trying to stand on my own two feet

out of diabetes	control	Fighting with diabetes for control
		Loss of individual control
	Struggle to make space for emotions	Struggle to voice emotional impact
		Resistance to experiencing difficult emotions
		Putting on a brave face in spite of difficult emotions
		Struggling for independence
		Becoming independent whist others support is always in the background
	Struggle with independence	Desire for independence whilst feeling daunted by this too
		The back up of support
	The safety net of family support	The value of family support
		The value of different types of support
	The value of friends' support	The value of peer support
The role of parents and friends		The differing role of friends
	Parental role of friends	
	Coping by evading the impact of diabetes	Coping with the impact of diabetes by avoidance and distraction
Making diabetes more bearable	Coping by focusing on the positives	Strategies for coping
		Strategies for coping