Young People with Type I Diabetes Mellitus:
The influence of the school environment on self-care

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Dedication

This thesis is dedicated to my God-daughter Olivia Cecily Rose Prees (Livi) and to my husband Robin Lewis.

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PART 1

1. Supporting young people with Type 1 diabetes mellitus: has the school environment been utilised? : A review of Literature

Abstract

Increasing numbers of children and young people in the United Kingdom are being diagnosed with Type 1 diabetes mellitus. The complications of the condition include cardiovascular disease and subsequent early death, and microvascular damage leading to retinopathy and neuropathy. Adherence to diabetes self-care is vital in reducing the risk of such complications.

Research indicates the importance of the family in children and young people's adherence to diabetes self-care, and adjustment to the condition. However, separating from the influence of one's parents and developing closer relationships with peers is a normal part of adolescent development. Young people with type 1 diabetes mellitus have reported withdrawing from parental involvement in their self-care. Young people spend a significant proportion of their time at school, or engaged in school activities. It is not clear what role the school environment (teachers, peers, school establishment) plays in diabetes related self-care and adjustment. To this end a systematic literature review was carried out to determine what is known about the influence of the school environment on young people's self care.

The search resulted in 16 articles that were reviewed and categorized by their content. The majority of the articles were North American. They reported on measures or research interventions to improve teachers' knowledge of diabetes. Some articles reported finding that teachers had poor knowledge of diabetes, but their survey style precluded examination of the implications for young people. Four studies indicated the importance of peer support but restricted sampling and lack of integrative theory limits the generalizability of findings. Only one study directly sought the opinions of young people themselves regarding teacher and peer influences on self-care.

A review of the literature suggests that there is a need for further sophistication to address how the school environment may influence the self-care of young people with type 1 diabetes mellitus. The limitations of self-report methodologies and suggestions for future research are discussed.

Key words: young people, adolescents, diabetes, school, teachers, personnel.

Target Journal: British Journal of Health Psychology
1.1 Rationale for the review

With a twofold increase in incidence in the last decade Type 1 Diabetes Mellitus (T1DM) is now the third most common chronic illness in children and young people in the United Kingdom, with prevalence rates of approximately one in 700 (Feltbower, McKinney, Parslo, Stephenson, & Bodansky, 2003). Although the current mean age at diagnosis is seven years approximately 22% of sufferers are diagnosed during adolescence (Diabetes UK, 2002; Feltbower et al., 2003). The burden on the NHS is substantial with 5% of NHS resources consumed to provide care each year (Department of Health, 2001). The term diabetes mellitus refers to a heterogeneous group of metabolic disorders characterized by chronic hyperglycaemia (Dunning, 2003; Lewis, 1999). Type 1 diabetes mellitus is thought to arise through auto-immune or idiopathic destruction of pancreatic cells, leaving the body unable to utilize glucose, fat, and protein due to absolute insulin deficiency (Dunning, 2003; Lewis, 2000). If left untreated ketoacidotic coma and death will eventually result (Redermeker, 2005). Hence insulin replacement by injection is necessary for survival (Dunning, 2003).

Given the increase in incidence it is likely that a typical UK secondary school currently educates at least two pupils with the condition, and this number may rise (Diabetes UK, 2004). Young people spend up to eight hours a day at school or engaged in school leisure activities. The following chapter sets to review the existing empirical evidence examining the utility of the school environment in diabetes self-care. In this context the school environment encompasses personnel, peers, and the educational establishment.
Complications of T1DM in young people

Mortality in young people with T1DM is significantly higher than that in the general adolescent population (Laing, Swerdlow, Slater, Botha, Burden, Waugh, Smith, Hill, Bingley, Patterson, Qiao, & Keen, 1999). Diabetic ketoacidosis (DKA) is a major cause of death and a profoundly serious complication of the illness, occurring as a result of hyperglycaemia (Dunning, 2003), itself caused by infection, excessive stress, inadequate insulin dosage, and poor adherence to self-care (Bennet-Johnson, Periwen, & Silverstein, 2000). By strict diabetes regimen adherence young people reduce the risk of hypo or hyperglycaemia (Dunning, 2003).

Episodes of hypoglycaemia (low blood glucose) are a common complication of T1DM (Hoffman, 2004) with 13% of young people experiencing moderate hypoglycaemic events and 4-7% suffering hypoglycaemic coma within a period of one year (Davis, Keating, Byrne, Russell, & Jones, 1997; Egger, Gschwend, Smith, & Zuppinger, 1991). If effective treatment is not administered, hypoglycaemia compromises consciousness, with progression to seizures, coma, and possibly death (Bennet-Johnson et al., 2000; Davis et al., 1997).

During the episode the individual is likely to experience negative affect, and behave in an aggressive or uninhibited manner (Bennet-Johnson et al., 2000). Given that adolescence is a period of intense self-consciousness it is not surprising that those experiencing severe hypoglycaemia risk intense fear of re-occurrence (Gonder-Frederick, Fisher, Ritterband, Cox, Hou, DasGupta, & Clarke, 2006). Episodes are also socially disabling as time absent from school or leisure activities is often necessary (Nordfeldt & Jonsson, 2001). Hypoglycaemic episodes and minor
fluctuations in blood glucose levels can also lead to transient cognitive impairments, which may impede classroom learning (Rovet, 2000). The cognitive impairment experienced during hypoglycaemic episodes and diabetes related school absences increase the risk of academic underachievement and poorer employment prospects (Overstreet, Holmes, Dunlap, & Frentz, 1997; Rovet, 2000).

The long-term complications of T1DM include increased risk of cardiovascular disease and early death, and microvascular damage causing retinopathy and neuropathy (Diabetes Control and Complications Trial Research Group, 1994). Even brief periods of poor adherence have been found to accelerate the onset of complications (Diabetes Control and Complications Trial Research Group, 1994). Despite the risks evidence indicates that 48% of young people with T1DM in the UK are unable to achieve an HbA1c <9.0%, a threshold above which the risk of long-term microvascular and cardiovascular complications rises steeply (Diabetes UK, 2004). Consequently empirical examination of the correlates of regimen adherence and metabolic control in young people with T1DM remains a priority.

1.2 Self-care and young people with T1DM

Self-care, to maintain or improve quality of life and health is integral to the young person’s daily management of T1DM (Diabetes Control and Complications Trial Research Group, 1993). Self-care is burdensome, complex and demanding and it requires the young person to demonstrate comprehensive understanding of the condition and adhere to sustained life style modifications, often conflicting with typical adolescent behaviours (Faro, Ingersoll, Fiore, & Ippolito, 2005). The regimen is monotonous and includes adherence to a low-sugar low-fat diet, “balancing”
carbohydrate intake with injected insulin, blood sugar monitoring, self-administered insulin injections at least twice daily with dose adjustment during periods of stress or illness, and undertaking regular aerobic exercise (Herrman, 2006; Selekman, Scofield, & Swenson-Brousell, 1999). Familiarity with personal signs and symptoms of the condition and being prepared to adjust self-care accordingly are an additional component of self-care (Selekman et al., 1999; Herrman, 2006).

However it is apparent that adolescence is a time of particular difficulty in managing diabetes related self-care (Dashiff, McCaleb, & Cull, 2006), with poorer metabolic control and poorer psychological adaptation to T1DM (Grey, Cameron, & Thurber, 1991; Hamilton & Daneman, 2002; Mortensen & Hougaard, 1997). Whilst this may be partially attributed to hormonal changes (Hamilton & Daneman, 2002), the psychosocial changes and behaviours associated with adolescence are also implicated (Dashiff et al., 2006). For example erratic eating and exercise patterns, “sub clinical” eating disorders, and risk taking behaviour compromise care (Chiarelli & Capanna, 2004; Frey, Guthrie, Loveland-Cherry, Pack, & Foster 1997; Loman & Galgani, 1996). For young people with T1DM the demands of the condition may conflict with the developmental tasks of adolescence, changing body image, peer group pressure, developing autonomy from parents, and identity formation (Dashiff et al., 2006; Dovey-Pearce, Doherty, & May, 2007).

Evidence indicates that young people continue to require the support of their parents to promote diabetes related care (Giordano, Petrila, Banjon, & Neuenkirschen, 1992; LaGreca, 1990), which may constrain the development of autonomy. Whilst young people with T1DM may be receptive to engaging in self-care behaviours (Allen,
empirical findings indicate that poorer metabolic control is more likely if full responsibility is assumed too early (Anderson et al., 1997; Giordano et al., 1992).

1.3 Psychological morbidity in young people with T1DM

The diagnosis of T1DM requires a dramatic change in lifestyle, coupled with the acceptance of chronic illness and the impending possibility of related morbidity and mortality (Diabetes Control and Complications Trial Research Group, 1994). Having a sense of one’s mortality at such an early stage in life can reinforce a sense of difference in young people, threatening the developing sense of self (Dovey-Pearce, Doherty, & May, 2007). Pursuing career aspirations may also be restricted by the demands of the condition (Ingberg, Palmer, Aman, & Larsson, 1996). It is therefore not surprising that psychological morbidity appears considerably increased in children and young people with the condition (Kanner, Hamrin, & Grey, 2003; Northam, Matthews, Anderson, Cameron, & Werther, 2005), with young people with T1DM demonstrating significantly higher rates of anxiety and depression than healthy peers (Kanner et al, 2003). Kokkonen and Kokkonen (1995) reported incidence of depression in 18% of young people with T1DM, two to three times that of the incidence in those without the condition. Kovacs and colleagues (1997) demonstrated that depression was a frequent response to the initial diagnosis of T1DM and that symptoms tended to dissipate by six months following the diagnosis. However, Grey and colleagues (Grey, Cameron, Lipman, & Thurber, 1995) found that symptoms of depression were evident in young people with T1DM two years following diagnosis. The authors associated this with the end of the “physiologic honeymoon” period, and
the realisation of the prospects of living with T1DM throughout one’s life (Grey et al., 1995).

Other factors indicated in the increased prevalence of depression in young people with T1DM include fear of complications or hypoglycaemia, having to adhere to a strict self-care regimen, the controlling attitude of parents, and poor self-esteem and altered body image associated with having a chronic illness (Kanner et al., 2003).

Research also indicates that young people who are depressed have a poorer quality of life (Grey, Boland, Davidson, Yu, Sullivan-Bolyai, & Tamborlane, 1998), lower feelings of self-worth (Grey, Lipman, Cameron, & Thyrerber, 1997), and poorer metabolic control (Grey et al., 1995).

2. Factors Influencing the Outcomes of T1DM in Young People

Both individual and systemic factors have been implicated in young people’s self-care. Emotion focused coping has been associated with poorer adherence to self-care behaviours such as diet, and poorer metabolic control (Grauce, Hanestad, Wentzel-Larsen, Sovik, & Bru, 2004) and problem-focused coping has been associated with both greater metabolic control and psychological adjustment (Grauce et al., 2004; Kliwer, 1997). An internal locus of control is associated with positive self-care behaviours (Leonard, Skay, & Rheinberger, 1998) and self-efficacy is implicated in better self-care and psychological adjustment (Ott, 2000).

Family structure and the beliefs and behaviours of family members are also implicated in moderating diabetes related self-care (see Amer, 1999 for a review). Family cohesion and adaptability and lower levels of family conflict enhance young
people's self-care behaviours (Amer, 1999; Streisand, Cant, Rodriguez, & Richards, 2000) and lower parental support and high parent-child conflict is associated with reduced adherence (Stevenson, Sensky, & Petty, 1991). Positive care behaviours have been correlated with the ability of the child and family to normalize the care of diabetes into their daily processes and routines (McDougal, 2002).

The role of social support from friends has not been as extensively researched as family influences. Studies have indicated that emotional and cognitive readiness to undertake care is heightened when peers have knowledge about the condition and are able to provide support (Christian, D'Auria, & Fox, 1999). Higher levels of social support from family and peers are associated with better dietary self-care, well-being, and higher affect, in young people with the condition (Skinner, John, & Hampson, 2000; Skinner & Hampson, 1998). The increasing importance of peer support during the teenage years is also indicated (Olsen & Sutton, 1998; Shroff-Pendley, Kasmen, Miller, Donze, Swenson, & Reeves, 2002).

Diabetes-related service provision has also been implicated in T1DM outcomes in young people. Although child and adolescent diabetes care is increasingly provided by a specialized paediatric multidisciplinary team, services are not yet equitable and thus fall short of proposed national standards (Betts, Jefferson, & Swift 2002). Significant differences in young people's metabolic control between centres has been identified, following adjustment for factors associated with poor HbA1c (Scottish Study Group for the care of Young People with Diabetes, 2001).
Supporting young people with diabetes: how has the school environment been utilized?

Family functioning, as well as personal characteristics of the individual, appear to impact on adherence to self-care and illness-related adjustment in young people with T1DM (Amer, 1999; Grauce et al., 2004; Kliewer, 1997). The structure and functioning of healthcare services has also been implicated in metabolic control in young people with the condition (Scottish Study Group for the care of Young People with Diabetes, 2001). Evidence would suggest the environment (particularly the family) significantly influences adherence and adaptation (Amer, 1999).

However, young people with T1DM report becoming progressively independent from the influences of their family, and parental support is construed less positively (Furman & Buhrmester, 1992; La Greca et al., 1995; Olsen & Sutton, 1998). The developing importance of peer relationships is an integral part of adolescence (Roisman, Masten, Coatsworth, & Tellegen, 2004). Consequently it is pertinent to consider the role of non-family in diabetes care. Young people spend up to eight hours a day in school and school related activities, in the company of school personnel and their peers. Young people with chronic illnesses have reported experiencing difficulties at school, e.g. teachers’ reactions to their illness and peer relationships (Lightfoot, Wright, & Slopper, 1999). It is therefore likely that this context has a significant impact on diabetes related self-care, and adjustment to the condition. To this end it is pertinent to review the literature examining the influence of schools on self-care in relation to young people with T1DM.
3. Grounded Theory and the literature review

There is confusion regarding the role of the literature review in grounded theory research, with some authors advocating a short *a priori* review of the literature to justify the need for the study, followed by a main review following completion (McCann & Clark, 2003a). Due to time and word constraints a comprehensive single review was conducted prior to undertaking the current study. However attempts were made to avoid imposing existing theories on the emerging data through ongoing reflection and supervision (Charmaz, 2006).

**Review Aims**

The author aimed to systematically review studies examining young people’s experiences of managing their diabetes during school and school related activities, and studies examining teachers and peers attitudes and beliefs regarding pupils’ management of T1DM to:

- Identify the extent to which school personnel and school culture may influence young people’s management of and adjustment to T1DM
- Identify the extent to which peers influence young people’s diabetes management and adjustment
- Identify the extent to which school timetabling and rules influence young people’s management of T1DM
- Provide an overview of research quality
- Identify further research needs in this area
4. Method

Searches to identify relevant literature for inclusion in the review were undertaken in January 2007. Articles published between 1965 and January 2007 were retrieved using the following electronic databases: Psychlit, Psychinfo, Medline, and Embase. The searches were conducted using the key words "young people" and "adolescents" and "diabetes" and "school" and "teachers" and "personnel". Only English language articles were used.

Search Selection

The search procedure yielded 121 papers of which 22 were duplicates. The remaining 99 abstracts were then examined using the following inclusion criteria:

- **Population** - young people aged 11-18 years who have a diagnosis of T1DM, or teachers/school personnel/peers of young people aged 11-18 years who have a diagnosis of T1DM
- **Study environment (school)** - studies examining pupils’ experiences of managing their diabetes at school and peer/personnel experiences of teaching/supporting young people with T1DM in school
- **Intervention studies** - examining school personnel and peer understanding of T1DM (and the effectiveness of interventions to improve peer and school personnel’ knowledge of T1DM and its management)
- **Study designs** - no specific inclusion criteria by study design was used due to the circumscribed nature of the research

*The term teenager was not used as it was considered a lay term*
Paper Retrieval

Forty potentially relevant abstracts were identified:

- Two studies examining the experiences of school nurses caring for young people with T1DM were excluded as they examined the nurses work related stressors
- Four studies solely examining the academic performance of young people with T1DM were excluded
- Ten studies solely examining the outcomes of diabetes treatment regimes/summer camps/ diabetes education programmes for young people with T1DM and their parents were excluded
- Four studies examining psychological outcomes in young people with T1DM were excluded
- Three studies which assessed teachers’ knowledge of diabetes were excluded as they were undertaken before 1989, and it was considered that changes to education systems and the significant increase in the number of pupils with T1DM since their undertaking may significantly undermine the current relevance of findings
- Sixteen studies were selected as relevant papers and were included for systematic review
5. Results

The key features of the studies reviewed are summarised in table 1, page 33.

5.1 Educating school personnel

Four studies examined outcomes of diabetes education programmes for North American school personnel. The authors omitted to incorporate theory in both the educational interventions and measures of study outcomes. With the exception of Jarrett and colleagues (Jarrett, Hillam, Bartsch, & Lindsay, 1993) changes in teachers’ knowledge of diabetes over time were not measured.

Jarrett and colleagues (1993) investigated the effectiveness of parents educating teachers regarding diabetes management, using a pre and post intervention assessment tool to measure changes in teachers’ knowledge. Six to eight weeks following the intervention a significant increase in teachers’ knowledge about hypoglycaemia was recorded, but no improvement in the recognition of hyperglycaemic symptoms. Significant knowledge deficits remained, with 46% of the participating teachers demonstrating a lack of understanding of the necessity of insulin for children with T1DM.

A 31% non response rate in potential participants implies that the effects of sampling bias must be considered when interpreting findings, also no demographic data on the participating parents or teachers was recorded. Parents’ knowledge of diabetes and their ability to educate others regarding the condition was not considered. In addition the long-term effectiveness of the intervention was not assessed via behavioural indices (i.e. change in teachers behaviour toward their children).
Two further studies examined diabetes education programmes for school personnel, with teachers’ knowledge of T1DM as the major outcome measure (Gestaland, Sims, & Lindsay, 1989; Siminerio & Koerbel 2000). Gestaland and colleagues (1989) examined the effectiveness of two different approaches to diabetes education of teachers. One intervention group combined viewing a videotape which reported what teachers should know about children with T1DM and reviewing two pamphlets together with the researcher. The second intervention offered the same materials but was self-directed. A control group received no intervention until testing was completed; they then received the first group intervention.

Measures of participants’ knowledge regarding T1DM were taken eight to ten weeks following the intervention. Improvement in teachers correct responses to questions about treatment were found in the first intervention group. There was no improvement in knowledge of management of T1DM in either intervention group. The statistical significance of findings or longer term assessment of outcomes (e.g. teachers’ responses to questions about T1DM treatment) were not measured, which significantly limits the salience of findings. The authors also omitted to adequately incorporate adult education learning theories in the intervention.

Trained diabetes educators were employed by Siminerio and Koerbel (2000) to provide an hour long diabetes education lecture to 156 school personnel (nurses and teachers). A ten item brief assessment of school personnel’s knowledge about T1DM was administered, immediately prior to and following the presentation. Overall knowledge scores improved significantly, but deficit scores remained regarding signs of high blood sugar, and appropriate treatment of adolescents with T1DM who are
seen eating sweets. The salience of findings are limited by the absence of longer term measures of participants’ knowledge of T1DM, demographic data on the participants was also not recorded. In addition the authors omitted to undertake measures of participant’s behaviour towards young people with T1DM.

These three studies examining the effectiveness of methods of educating school personnel about T1DM management highlight the difficulties encountered when attempting to improve teachers’ knowledge and subsequent management of young people with the condition. Teachers’ knowledge deficits regarding T1DM management could have potentially serious implications for young people. However, the studies reviewed lacked rigor, prospective designs were not utilized, comparison groups were not adequately employed, and the long-term efficacy of the methods of educating the teachers was not measured. Consequently, an accurate picture of the effectiveness and implications of the interventions is not known. The studies highlight a need for a more comprehensive set of outcomes focused on transition of knowledge and behaviour. All of the studies were undertaken in the USA, limiting the generalizability of study findings to educating UK school teachers.

One study examined the relationship between metabolic control in young people with T1DM and their school related experiences. A mixed (cross sectional/qualitative) design was utilized to investigate the relationship between participants’ perceived experiences of managing their T1DM at school, diabetes control, and quality of life (Wagner, Heapy, James, & Abbott, 2006). Participants completed a survey examining their child’s diabetes management at school and metabolic control, and the young
people undertook a structured interview that assessed their diabetes related school experiences.

Young people whose parents reported that personnel at their school received diabetes training showed significantly better diabetes control (HbA1c), than those reporting untrained personnel. However, the cross sectional design did not allow determination of the direction of associations between training, glycaemic control, and quality of life. Also measures of the content and timing of staff training were not taken. Better glycaemic control was found in young people who reported being given greater flexibility at school to decide where to perform self-care. However, the structured nature of the interviews and the lack of integration of psychological theories into the study design prohibited detailed examination of this finding. Other correlates of metabolic control (family functioning, individual characteristics) were not considered and generalizability of study outcomes are constrained as 38% of those approached refused to take part. The vast majority (81%) of participants were from white educated two parent families, and all were attending a diabetes camp with a higher rate of insulin pump use (which enhances metabolic control) than that in the overall population.

This dearth of high quality research means that options for educating school personnel regarding T1DM management are currently unclear. In addition, whilst knowledge of T1DM is certainly required to facilitate care, the studies fail to incorporate examination of the impact of teachers’ attitudes and behaviour and the theories that explore these. The study outcome measures are also restricted to teachers’ knowledge of T1DM and its management, and/or adolescents’ blood glucose measurements. With
the exceptions of Wagner and colleagues (2006) who measured quality of life in young people with T1DM, the relationship between teachers understanding of T1DM, and both physiological and psychological outcomes in adolescents with T1DM are not contemplated. Consequently the studies reviewed provide little meaningful empirical evidence regarding the impact of educating school personnel on the care and mental well-being of young people with diabetes.

5.2 Teachers' Beliefs and Attitudes

Four studies undertook to examine teachers' beliefs regarding the impact of T1DM (Cunningham & Wodrich, 2006; Olsen, Blair, Seidler, Goodman, Gaelic, & Nordgren, 2004; Rickabaugh & Saltarelli, 1999; Wodrich, 2005). Rickabaugh and Saltarelli (1999) completed a survey of American Physical Education teachers’ knowledge and attitudes regarding exercise in adolescents with T1DM. Participants were recruited via a newsletter sent to schools in three cities. Fifty per cent of the teachers surveyed were unsure of exercise limitations for children with T1DM, or considered that specific limitations exist for all children with T1DM (Rickabaugh & Saltarelli, 1999). This finding indicates that some teachers may treat children with T1DM differently, potentially hindering their physical and emotional development. However, the survey style of this study prevents further exploration of this hypothesis. In addition the small restricted sample (32 physical education teachers) limits the significance and generalizability of findings.

Attitudes of teachers' regarding the impact of chronic illness in the classroom were quantitatively assessed by Olsen and colleagues (Olsen et al., 2004). Professionals in elementary schools were surveyed about their opinions regarding the impact of having
a child with each of six chronic conditions (AIDS, asthma, congenital heart disease, T1DM, epilepsy, and leukaemia) in the classroom. Findings indicated that giving extra time or attention and personal risk or liability was the educators’ primary concern. Concerns regarding the risk of classroom emergencies were disproportionate to the known risk of the conditions, indicating that teachers may misjudge or be misinformed of the functional impact of T1DM (Olsen et al., 2004). The survey style of this study prevents further exploration of this hypothesis or meaningful examination of the implications of school professionals’ attitudes for young people with T1DM.

Two studies proposed to assess the effect of giving teachers information regarding the impact of T1DM on adolescents learning related behaviour. Wodrich (2005) undertook a vignette-based study demonstrating the effect of disclosing information about difficulties with learning which children with epilepsy and T1DM may experience, on teachers understanding of (and attributions for) such difficulties. Teachers were presented with written and videotaped information (a teacher/school psychologist conference) about a pupil which matched either the symptoms of epilepsy or T1DM. The teacher of the (fictitious) adolescent with T1DM told the school psychologist about concerns with poor rate of work completion, fluctuations in performance, lack of motivation, and occasional moodiness and irritability.

Participants were randomly assigned to one of three experimental levels: no knowledge of any specific illness for either pupil, diagnosis only, or diagnosis and facts. For the child with T1DM facts included problems with concentration and mood.
Participants were given a questionnaire which asked them to rank 12 possible causes of the student's classroom problems. When no illness related information was disclosed only 2.6% of participants rated "health factors" as the most likely source of classroom difficulties, compared with 16.6% when diagnosis was disclosed, and 50% when diagnosis and a list of illness specific classroom manifestations were provided.

The study findings indicate that teachers are more likely to attribute classroom difficulties to T1DM after receiving further information regarding the difficulties experienced by pupils with the condition. However, such attributions were evident in only 50% of teachers' responses, implying that receiving T1DM related information in this form may not adequately impact upon some teachers' opinions of adolescents learning related difficulties. The vignette design of the study prevented both the observation of teacher's behaviour in a classroom setting (to test this hypothesis) and examination of changes in teacher's behaviour over time.

A further vignette study, examining the effect of information provision on teachers' accommodation of classroom difficulties found that teachers given information about T1DM demonstrated increased ability to accommodate the students learning needs (Cunningham & Wodrich, 2006). A lower proportion of illness specific accommodations were evident in teachers receiving no illness information, and teachers receiving basic illness information, or basic illness information and classroom implications. Such findings would suggest that tailored information on specific learning needs of adolescents with T1DM enhances teachers' ability to create classroom accommodations if only using the vignette format. Not only may such a format suggest socially desirable responses but teachers' ability to hypothetically
produce accommodations may differ from their ability to apply accommodations behaviourally in a real classroom setting. Factors which affect implementation of real world professional change were not considered. Random sampling techniques were also not utilized, limiting generalizability of findings.

5.3 Diabetes-related Support within School

Two studies specifically examined barriers and supports to young people undertaking diabetes-related care in school. A survey of American school nurses examined the barriers to young people undertaking this process (Nabors, Troillett, Nash, & Masiulis, 2005). Questionnaire findings indicated that participants considered young people, teachers, and school staff all need to improve their knowledge about T1DM, and that young people shaped their communication about their T1DM with peers and professionals alike.

However, the statistical analysis was restricted to the numbers of participants indicating agreement with each questionnaire item, and the written retrieval of qualitative data (as opposed to using interviews) preventing further meaningful analysis of nurses’ statements. In addition, triangulation which incorporated the opinions of young people or other school personnel was not sought. Neither were outcomes from the young people measured, so the implications of the barriers to care reported remain unknown.

However, a complimentary study was conducted by the same authors using focus groups to examine young people’s opinions of managing their diabetes at school (Nabors, Lehmkuhl, Christos, & Andreone, 2003). Participants comprised of children
and adolescents attending a specialized diabetes camp with directed exploration of how friends, teachers, and nurses could help them manage diabetes at school. Transcripts were subjected to constant comparative method. Young people reported that school staff's knowledge of T1DM was inadequate, supplies and snacks were sometimes not available, and they required more help from staff and peers with hypoglycaemic episodes. Participants reported the need for teachers to be more flexible, and allow them to leave class to test their blood glucose or eat a snack.

Yet this too is a limited study. Over half of the participants described control of their T1DM as good and only a proportion of those attending the camp volunteered to participate. Demographic data regarding participants' socio-economic and family status was not provided; the number of participating adolescents is also unclear. Effects of focus groups on participants' responses (the requirement for participants to speak in front of peers or conform to social norms) may also have affected some participant's responses.

5.4 The Role of Peers

Only three studies examined the role of peers in diabetes management, and the focus of these was not peer support at school. Quantitative assessment of the role of peers support was explored by Skinner and Hampson (1998). Participants with T1DM, recruited from hospitals in the United Kingdom, completed questionnaires assessing their self-management, affective state, perceived social support and personal constructions of diabetes. Peer support appeared a significant predictor of depression, as was perceived impact of T1DM, but not perceived seriousness. Family support was a significant predictor of all self-management measures. The psychological
implications of the short and long-term threats of the illness were also reported. Perceived impact of and efficacy of treatment to control T1DM (short term effects) was a predictor of anxiety and depression.

The restricted study sample (50% of adolescents who were approached completed the questionnaires) and the reliance on self-report measures are weaknesses of this study. Moreover the questionnaire design prevents in-depth exploration of the relationships between peer support and mood, including the directionality of this relationship and its evolution over time.

A longitudinal analysis of 52 adolescents' perceptions of diabetes self-management, social support, and well being was undertaken by Skinner and colleagues (2000). Participants were recruited from a UK hospital. The researchers utilized questionnaire measures of depression and anxiety, diabetes self-management, perceived social support from family, and perceived social support from friends at baseline and six months following baseline. Higher levels of support from family and friends were prospectively predictive of better dietary self-care. However, this relationship was mediated by personal beliefs regarding T1DM. In particular beliefs about the effectiveness of T1DM treatment regimes was predictive of better dietary self-care.

General social support at baseline, and change in general social support were significant predictors of depression, positive well being, diet, and total well being, indicating the importance of social support for adolescents with T1DM in promoting diabetes related self-care, and mental health. The study would have been further
enhanced had it been undertaken over a period of longer than six months with a larger sample size, subsequently allowing examination of the significance of developments in the nature of peer and family support.

A qualitative study was undertaken in the UK utilizing interviews and focus groups, to provide a more detailed analysis of relationships between young people with T1DM and their families and friends (Olsen & Sutton, 1998). Participants reported progressive independence from family life with age, and individual differences were apparent in their reports of peer support. Some participants reported the need for privacy and independence, and reliance on peers not to mention their diabetes. Other participants reported valuing the support of their peers in managing their diabetes e.g. in encouraging dietary adherence. Giving participants individual choice in the method of data collection is strength of this study. However, focus groups and in-depth interviews may provide differing information which could limit the robustness of findings. The restricted sample (there was a response rate of between 20-26% from potential participants) is an additional weakness of this study.

5.5 Peer and school intervention Studies

Three studies initiated intent to incorporate peers and/or the school environment in interventions to promote children and young people's diabetes related self-care. Only one of these incorporated the school environment, and intended to promote diabetes care for "high risk" youth (Faro et al., 2005). Participants were a convenience sample of children and young people treated at an American Paediatric diabetes centre. The intervention involved monthly consultations with a Paediatric Nurse Practitioner for
one year, incorporating review of glucose readings, teaching on improving diabetes related problem solving skills and healthy eating.

No statistically significant differences were seen between pre and post intervention mean scores on the Self-Efficacy for Diabetes tool, or in self-care practices or diabetic control (HbA1c). However, the frequency of insulin administration at school doubled, and blood glucose monitoring at home increased. The small number of participants (27), the convenience sample, and the absence of a control group are significant limitations of the study. Potential participants were identified by healthcare providers as “high risk” in terms of their competence in diabetes management; this arbitrary measure may have facilitated sampling bias. The ages and socio-economic status of the participants were also not recorded, effectively disregarding implications of socio-economic status and adolescent development in participants’ diabetes management.

A structured intervention for integrating peers into diabetes care was devised by Greco and colleagues (2001). Twenty one participating adolescents were recruited from diabetes clinics and an age matched peer attended four diabetes education and support group sessions led by psychologists. The aims of the intervention were to integrate friends into the adolescents diabetes management in a healthy and adaptive manner, to increase levels of social support for participants, and to determine the generalization of the effects of this peer intervention to diabetes functioning.

Following the intervention participants reported that peers provided a greater proportion of support relative to family members, and parents of participants reported less diabetes related conflict. No significant changes in adherence were reported by
participants. However, the lack of control group, small sample size, and short follow up period seriously limit the utility of findings, and possibly hindered the detection of broader statistically significant treatment effects. In addition the intervention was complex, involving education, problem solving and stress management. Consequently it is difficult to accurately establish the outcomes of the matched peers' involvement, or the effectiveness of specific components of the intervention.

A multisystemic home based intervention study incorporated peer support, to examine peer and family involvement in relation to T1DM management within a developmental context (Shroff-Pendley et al., 2002). Participants in the intervention group identified at least three individuals from his/her family, friends, and school as a "support team" who were asked to support the participant with an identifiable diabetes related task throughout the study period. Questionnaire measures of peer support revealed that adolescent participants perceived greater peer support than younger participants, supporting the hypothesis that peer support is important to young people with T1DM.

However, the method of intervention and the timing of the post intervention measures are unclear; hence meaningful interpretation of outcomes is not possible. The small sample size (21) and the lack of clarity regarding the number of adolescent participants also restrict the interpretation and generalizability of findings.

6. Conclusion and implications for further research
A minority of papers reviewed focused on the outcomes for young people managing their diabetes at school, with only one study directly seeking the opinions of
adolescents themselves (Nabors et al., 2003). However, the restricted sample limited generalizability of findings, and the lack of integrative theory constrains the applicability to the practical implications of diabetes care. Studies of social support indicated an association between higher levels of support from family and peers with better dietary self-care, well-being, and higher affect, in young people with the condition (Skinner & Hampson, 1998; Skinner et al., 2000). The increasing importance of peer support during adolescence is also indicated (Olsen & Sutton, 1998; Shroff-Pendley et al., 2002). However, in-depth examination of the role of peers is currently limited by small numbers of study participants, and restricted sampling (Olsen & Sutton, 1998, Skinner et al., 2000; Skinner & Hampson, 1998). In addition peer support at school was not specifically examined.

The empirical evidence indicated that teachers have demonstrated poor understanding of the management and implications of T1DM, implying that they may treat young people with the condition inappropriately, risking constraining their development (Jarrett et al., 1993; Olsen et al., 2004; Rickabaugh & Saltarelli, 1999). However, studies were undertaken in America limiting the generalizability of findings to young people in the UK. The studies were restricted by the biases associated with self-report, and the survey style precludes meaningful examination of the impact of teachers’ beliefs regarding T1DM (Jarrett et al., 1993; Olsen et al., 2004; Rickabaugh & Saltarelli, 1999). A need for further research in this area is indicated.

Evidence indicates that even brief lapses in adherence to self-care significantly increase the risk of the microvascular and macrovascular complications of T1DM (Diabetes Control and Complications Trail Research Group, 1994). Poorer adherence
is also associated with psychological morbidity (Dantzer, Swendsen, Maurice-Tison, & Salmon, 2003). Consequently, the role of peers and school personnel in self-care behaviours and well-being is worthy of empirical examination. It may be that the ethical and practical difficulties associated with interviewing young people may have previously inhibited researchers from undertaking face to face interviews. The author considers that the need for comprehensive empirical examination of influences on self-care at school far outweighs such issues.
<table>
<thead>
<tr>
<th>Author(s)/year</th>
<th>Sample</th>
<th>Location</th>
<th>Design</th>
<th>Measures</th>
<th>Findings</th>
<th>Comments</th>
</tr>
</thead>
<tbody>
<tr>
<td>Jarrett et al (1993)</td>
<td>49 families/teachers</td>
<td>USA</td>
<td>Pre/post intervention</td>
<td>Questionnaire measure of teachers understanding of T1DM management</td>
<td>Significant improvement in teachers knowledge regarding hypoglycaemia</td>
<td>No demographic data on teachers or parents, unclear sampling procedure, 31% non response rate</td>
</tr>
<tr>
<td>Gestaland et al (1989)</td>
<td>244 teachers</td>
<td>USA</td>
<td>Quasi experimental design Pre/post</td>
<td>Questionnaire measure of teachers understanding of T1DM management</td>
<td>No improvement in T1DM related knowledge in either group</td>
<td>No statistical analysis</td>
</tr>
<tr>
<td>Siminero &amp; Koerbel (2000)</td>
<td>156 school personnel</td>
<td>USA</td>
<td>Pre/post test</td>
<td>Ten item measure of diabetes knowledge</td>
<td>Overall knowledge scores improved, deficit regarding recognizing signs of hyperglycaemia</td>
<td>No long-term measures of knowledge No demographic data</td>
</tr>
<tr>
<td>Wagner et al (2006)</td>
<td>58 young people with T1DM aged 8-15 years (mean age 12 years) Mean</td>
<td>USA</td>
<td>Mixed</td>
<td>Scoiodemographic HbA1c Parental survey re: education of peers/school</td>
<td>Significantly better diabetes control (HbA1c) found in children whose parents reported</td>
<td>Participants were attendees at a diabetes summer camp Analysis statistical examination of</td>
</tr>
<tr>
<td></td>
<td>time since T1DM diagnosis 5 years</td>
<td>diabetes</td>
<td>interview(young people)</td>
<td>personnel</td>
<td>trained school personnel</td>
<td>covariates</td>
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<td></td>
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<td>summer camp</td>
<td></td>
<td>Diabetes quality of Life for youth questionnaires</td>
<td>Children who reported greater flexibility in performing diabetes care tasks at school</td>
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<td></td>
<td></td>
<td></td>
<td>Structured interview(young people)</td>
<td>had better HbA1c</td>
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<tr>
<td>Rickabaugh and Saltarelli (1999)</td>
<td>32 physical education teachers 25 young people with T1DM 28</td>
<td>USA (three</td>
<td>Survey</td>
<td>Questionnaire measure of pupils exercise behaviour</td>
<td>50% of teachers surveyed were unsure of exercise limitations for young people with T1DM</td>
<td>No information regarding teachers who declined to participate</td>
</tr>
<tr>
<td></td>
<td>parents</td>
<td>cities)</td>
<td></td>
<td>DEKAT (diabetes and exercise knowledge and attitudes)</td>
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</table>

Table 1: The key features of the studies reviewed
<table>
<thead>
<tr>
<th>Reference</th>
<th>Participants</th>
<th>Country</th>
<th>Study Design</th>
<th>Primary Intervention</th>
<th>Measures</th>
<th>Findings/Implications</th>
</tr>
</thead>
<tbody>
<tr>
<td>Wodrich (2005)</td>
<td>122 teachers</td>
<td>USA</td>
<td>Randomised controlled trial (different levels of health information)</td>
<td>Questionnaire measure of teachers attributions for pupils behaviour</td>
<td>Teachers receiving higher level of disease related information were more likely to attribute classroom difficulties to health</td>
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<tr>
<td>Cunningham and Wodrich (2006)</td>
<td>99 Teachers</td>
<td>USA</td>
<td>Randomised controlled trial (different levels of health information)</td>
<td>Measures of numbers of disease specific accommodations/total accommodations, teachers level of confidence in their accommodations</td>
<td>Higher level of disease specific information lead to classroom accommodations</td>
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<tr>
<td>Faro et al (2005)</td>
<td>27 “high risk” youth</td>
<td>USA</td>
<td>Year long School based intervention monthly visits from Nurse practitioner</td>
<td>Questionnaire measures of self-efficacy for diabetes and parental reports of their child’s self-care behaviours, HbA1c</td>
<td>No statistically significant differences found</td>
<td></td>
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<tr>
<td>Greco et al (2001)</td>
<td>21 adolescents with T1DM (aged 10-18 years), 21 age matched healthy peers</td>
<td>USA</td>
<td>Intervention Four diabetes education and support group sessions</td>
<td>Pre/post intervention questionnaire measures of participants and peers diabetes related knowledge Participants reports of diabetes support, adherence, adjustment, self-perception and social functioning</td>
<td>Post intervention participants reported peers provided a greater proportion of support, parents reported reduced diabetes related conflict</td>
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<tr>
<td>Shroff Pendley et al (2002)</td>
<td>68 (8-17 year olds) with T1DM</td>
<td>USA</td>
<td>Home based intervention incorporating family/peers</td>
<td>Questionnaire measures of self-care, Diabetes related family conflict, Diabetes related social support, Participants knowledge of diabetes, HbA1c</td>
<td>Adolescents reported significantly more peer support for diabetes management</td>
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</tr>
<tr>
<td>Nabors et al (2005)</td>
<td>110 school nurses</td>
<td>USA</td>
<td>Survey</td>
<td>Questionnaire measure of perceived barriers to care in schools</td>
<td>Young people, teachers, and school staff need to improve diabetes knowledge</td>
<td></td>
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<tr>
<td>Nabors et al (2003)</td>
<td>105 children/adolescents (aged 6-14 years)</td>
<td>USA</td>
<td>Qualitative</td>
<td>Focus groups</td>
<td>Reported need for availability of snacks at school, support with hypoglycaemia, improvement in school personnel diabetes knowledge</td>
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<td></td>
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<td></td>
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<td></td>
<td>Participants had good metabolic control Recruited from diabetes summer camp</td>
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<tr>
<td>Study</td>
<td>Sample Description</td>
<td>Location</td>
<td>Methodology</td>
<td>Measures</td>
<td>Findings</td>
<td>Participants</td>
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<tr>
<td>Skinner and Hampson (1998)</td>
<td>74 adolescents (12-18 years old)</td>
<td>UK</td>
<td>Quantitative</td>
<td>Measures of depression and anxiety (well-being questionnaires) Summary of diabetes self-care (questionnaire) Perceived social support from family and friends questionnaires Diabetes family behaviour checklist Diabetes inventory of peer support</td>
<td>Perceived impact of diabetes and peer support were significant predictors of depression Family support was a significant predictor of all self-management measures</td>
<td>50%</td>
</tr>
<tr>
<td>Skinner et al (2000)</td>
<td>52 adolescents with T1DM (aged 12-18 years)</td>
<td>UK</td>
<td>Longitudinal (six months)</td>
<td>Questionnaire measures of self-management, well-being, social support</td>
<td>Peer and family support were predictive of wellbeing Perceived impact of diabetes was predictive of well being Belief regarding the effectiveness of diabetes treatment were predictive of better dietary self-care</td>
<td>50%</td>
</tr>
<tr>
<td>Olsen and Sutton (1998)</td>
<td>21 adolescents with T1DM (aged 14-19 years)</td>
<td>UK</td>
<td>Qualitative (Framework)</td>
<td>Focus groups/interviews examining relationships between participants and family/friends</td>
<td>Participants reported progressive withdrawal from family life and services</td>
<td>20%</td>
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Part 2: Research Report

Young people with type 1 diabetes mellitus: the influence of the school environment on self-care

Susannah Joy Lewis

Abstract

Type 1 diabetes mellitus is now the third most common chronic illness in children and young people in the United Kingdom, with a twofold increase in incidence in the last decade. Diabetes self-care is integral to the young person's survival, and significantly reduces the risk of cardiovascular disease and microvascular damage associated with the condition. Parental involvement and family support is known to promote adherence to self-care. However, adolescence is a period strongly associated with poorer adherence, as young people separate from the influence of their parents and form closer relationships with peers. Young people spend increasing periods of time at school in the company of personnel and peers, but little is known of how the school environment influences self-care.

A qualitative study was undertaken, using a grounded theory approach to examine the role of the school environment in self-care. Nine young people with type 1 diabetes mellitus aged between eleven and sixteen years were interviewed, regarding their experiences of managing their diabetes at school.

A core concept of negotiating threats to self-regulation emerged, both to homeostasis and to the self. Threats included stigma in relation to having diabetes and associated self-care, and also the threat of self-exposure through the behaviours associated with hypoglycaemic and hyperglycaemic episodes. Participants sought to manage threats through negotiating the disclosure of their diagnosis, and concealing or omitting self-care. School personnel, peers, and school rules played a part in this dynamic and evolving process. Friends acted as advocates, moderating threats to self-regulation and promoting self-care. School personnel and the application of school rules also influenced threats to self-regulation. Findings implicated the significance of the school environment in participants' self-care.
7.1 Introduction

Type 1 diabetes mellitus (T1DM) is a chronic illness characterised by the body’s incapacity to utilize glucose, fat, and protein due to absolute insulin deficiency (Bennett-Johnson et al., 2000; Dunning, 2003). The condition is thought to arise through auto-immune or idiopathic destruction of pancreatic cells necessitating daily insulin replacement for survival (Dunning, 2003). With a twofold increase in incidence in the last decade T1DM is now the third most common chronic illness in children and young people in the United Kingdom, with prevalence of approximately one in 700 (Diabetes UK, 2004; Feltbower et al., 2003). Although the current mean age at diagnosis is seven years a significant proportion of sufferers are diagnosed during adolescence (Feltbower et al., 2003).

Given the increase in prevalence is it likely that a typical UK secondary school currently will educate at least two pupils with the condition, and this number may rise (Diabetes UK, 2004). Schools are subsequently faced with the task of educating young people with T1DM whilst accommodating their ongoing health-care needs (Lightfoot et al., 1999). The cost of providing health care for children and young people with T1DM is burdensome consuming 5% of NHS resources per year (Department of health, 2001).

7.2 Diabetes and adolescent development

Developing a sense of self, acquiring autonomy in all areas of life, and adjusting to bodily change are integral to adolescence (Roisman et al., 2004). One’s perception of the self expands to represent the increasing number of roles and experiences (Harter, Bresnick, Bouchey, & Whitesell, 1997). For older adolescents life decisions regarding
careers and intimate relationships emerge (Roisman et al., 2004). Young people with T1DM are faced with these typical developmental challenges, and also the relentless demands of their illness (Grauce et al., 2004). The diagnosis of T1DM requires a dramatic change in lifestyle, coupled with the acceptance of chronic illness and the impending possibility of related morbidity and mortality (Diabetes Control and Complications Trial Research Group, 1994). Career choices may also be restricted by the demands of the condition (Ingberg et al., 1996). Having a sense of one’s mortality at such an early stage in life can reinforce a sense of difference in young people, thus threatening the developing sense of self (Dovey-Pearce et al., 2007). Findings from a study comparing young people with T1DM with healthy controls indicate that diabetes challenges a young person’s ability to become autonomous and the growing awareness of the long-term complications of diabetes can be experienced as persistent threat (Sayer, Hauser, & Jacobsen, 1995), potentially constraining typical adolescent development (Sayer et al., 1995).

An essential component of young people’s diabetes management, self-care is seen as burdensome and relentless, often conflicting with typical adolescent behaviours (Loman & Galgani, 1996; Doherty & Dovey-Peace, 2005). Self-care in the context of T1DM often includes complex dietary management i.e. adherence to a low-sugar low-fat diet whilst “balancing” carbohydrate intake with injected insulin, blood sugar monitoring, self-administered insulin injections at least twice daily with dose adjustment during periods of stress or illness, and undertaking regular aerobic exercise (Herman, 2006; Selekman et al, 1999). Given that adolescence is a period of rapid physical maturation, frequent adjustments to insulin dosage and related self-care are required (Herman, 2006). A comprehensive understanding of diabetes and its
treatment, familiarity with personal signs and symptoms of the condition and being prepared to adjust self-care accordingly are additional components of self-care (Selekman et al., 1999; Herman, 2006).

Self-care is cited as a major source of parent-adolescent conflict (Giordano et al., 1992). Evidence indicates that young people with T1DM continue to require the support of their parents to promote self-care, conflicting with the adolescent task of developing autonomy (Giordano et al., 1992). However, poorer care is more likely if complete responsibility is assumed too early in adolescence (Allen et al., 1994; Frey et al., 1997; Giordano et al., 1992; LaGreca, 1990). Young people report having difficulties in undertaking self-care, and a decline in regimen adherence during adolescence has been recorded (Dashiff et al., 2006, Mortensen & Hougaard, 1997). As a result, adolescence is typically associated with deteriorating metabolic control (Anderson et al., 1997; Mortenesen, 1998), and whilst this may be partially attributed to hormonal changes (Amiel et al., 1986), poorer adherence to self-care is also implicated (Mortensen & Hougaard, 1997).

Barriers to self care during adolescence include erratic eating and exercise patterns which are typically associated with this developmental period (Loman & Galgani, 1996). Eating disorders in young people with T1DM, particularly “sub clinical” problems are common with studies indicating that up to 30% of young females with T1DM report having used insulin omission as an aid to weight loss (Chiarelli & Capanna, 2004). Risk taking behaviours are also correlates of poorer metabolic control in young people with T1DM (Peverler, Boller, Fairburn, & Dunger, 1992). The need to conform with peers is also implicated, with study findings suggesting
young people with T1DM may omit care e.g. missing injections to conform with peers routines (Kyngas, Hentinen, & Barlow, 1998).

7.3 Morbidity and Mortality in young people with T1DM

The complications of T1DM are also emotionally burdensome for young people and endanger life (Diabetes Control and Complications Trial Research Group, 1994; Nordfeldt & Jonsson, 2001). Hypoglycaemic episodes (excessively low blood glucose levels) are relatively common, with studies indicating 13% of young people experience moderate hypoglycaemic events, and up to 7% diabetic coma in one year (Davis et al., 1997). If the episode is not treated effectively consciousness is compromised and death may occur (Davis et al., 1997). The young person is likely to experience negative affect, and behave in an uncharacteristically aggressive or uninhibited manner (Bennet-Johnson et al., 2000). Given that adolescence is a period associated with extreme self-consciousness this is concerning and hypoglycaemic episodes risk engendering severe anxiety regarding reoccurrence (Gonder-Frederick, 2006). Episodes are socially debilitating, as assistance from others is often required and sufferers often require absence from school or leisure activities (Nordfeldt & Jonsson, 2001).

Classroom learning may also be impeded by the cognitive impairments induced by hypoglycaemia (Rovet, 2000). This, and other diabetes-related school absences increases the risk of academic underachievement in young people with T1DM and poorer employment prospects in adulthood (Overstreet et al., 1997). Hypoglycaemia occurs if the young person's carbohydrate intake is inadequate, or if they have
injected too much insulin (Hoffman, 2004); consequently regimen adherence is essential to reduce the risk and associated morbidity and mortality.

Poor regimen adherence induces hyperglycaemia and the risk of serious long-term complications associated with T1DM, including retinopathy, heart disease, renal failure, neuropathy, and limb amputation (Diabetes Control and Complications Trial Research Group, 1994). Irreversible microvascular complications may begin to occur during adolescence if regimen adherence is poor (Cook & Daneman, 1990; Diabetes Control and Complications Trial Research Group, 1994). Evidence indicates that individuals diagnosed with T1DM before 15 years of age experience substantially worse retinopathy than those developing the condition later in life (Alibrahim et al., 2006).

Severe hyperglycaemia (usually caused by infection, severe stress, and under-dosing of insulin) can result in diabetic ketoacidosis (Hoffman, 2004); this extremely serious complication of T1DM is the major cause of hospitalization for young people with the condition, with up to 14% of episodes resulting in death (Davis et al., 1997). Despite the risks evidence indicates that 48% of young people with T1DM in the UK are unable to achieve an HbA1c <9.0%, a threshold above which the risk of long-term microvascular and cardiovascular complications rises steeply (Diabetes UK, 2004). Consequently empirical examination of the correlates of regimen adherence and metabolic control in young people with T1DM remains a priority.
Considering the daily demands and long-term complications of T1DM it is not surprising that psychological morbidity appears considerably increased in children and young people with the condition (Kanner et al., 2003; Northam et al., 2005) with significantly higher rates of anxiety and depression found in young people with T1DM when compared with healthy peers (Kanner et al., 2003). Kokkonen and Kokkonen (1995) reported incidence of depression in 18% of young people with T1DM, two-three times that of the incidence in young people without the condition. Kovacs and colleagues (1997) demonstrated that depression was a frequent response to the initial diagnosis of T1DM and that symptoms tended to dissipate by six months following the diagnosis. However, Grey and colleagues (1995) found that symptoms of depression were evident in young people with T1DM two years following diagnosis. The authors associated this with the end of the "physiologic honeymoon" period, and the realisation of the prospects of living with T1DM throughout ones' life (Grey et al., 1995).

Several other factors have been implicated in the increased prevalence of depression including fear of complications or hypoglycaemia, having to adhere to a strict self-care regimen, the controlling attitude of parents, and poor self-esteem and altered body image associated with having a chronic illness (Kanner et al., 2003). Young people with T1DM have also reported negative self-evaluation, related to experiencing a sense of stigma associated with the condition, requiring assistance with hypoglycaemia, and feelings that their self-care is substandard (Dovey-Peace et al., 2005). White (2001) has suggested that this negative feedback loop could increase the likelihood of depression in young people with T1DM.
Research indicates that young people who are depressed have poorer quality of life (Grey et al., 1998), and lower feelings of self-worth (Grey et al., 1997). Some researchers have also found an association between depression and poorer metabolic control (Grey et al., 1995; Dantzer et al., 2003). The mechanisms behind this are unclear, although the role of helpless attributional style in poorer regimen adherence has been implicated (Kuttner, Delamater, & Santiago, 1990).

8.1 Coping and individual differences

Despite the difficulties described, individual coping characteristics have been found to moderate self-care behaviours and psychological adjustment in young people with T1DM. Emotion focused coping i.e. efforts to reduce emotional distress caused by a stressful event has been associated with poorer adherence to self-care, and poorer metabolic control (Grauce et al., 2004). Problem focused coping aimed at changing the situation causing distress has been associated with greater metabolic control, and also with better psychological adjustment (Grauce et al., 2004; Kliewer, 1997).

Evidence also implicates conscientiousness as a moderator of self-care, although this is mediated by the young person’s beliefs regarding the effectiveness of diabetes treatment (Skinner, Hampson, & Fife-Schaw, 2002). Since there is little obvious immediate short term reward to regimen adherence it is difficult for young people to appreciate the need for self-care. The moderating influences of locus of control and self efficacy in young people’s management of T1DM have also been reported (Leonard et al, 1998; Ott, 2000). Young people who have reported having an internal locus of control describe undertaking more positive self-care behaviours than those with an external locus of control (Leonard et al, 1998). Self-efficacy is implicated in
better self-care and psychological adjustment, and has been found to mediate the relationship between self-care experience and adherence to treatment (Ott, 2000).

8.2 Family and Health service influence on self-care and adjustment

A considerable number of studies have assessed both the implications of family structure and the beliefs and behaviours of family members in moderating diabetes related self-care. Family cohesion and adaptability and lower levels of family conflict are implicated in enhancing young people’s self-care behaviours (Amer, 1999; Streisand et al., 2000). Marteau and colleagues (1987) reported that children living in families where there is cohesion, emotional expressiveness, lack of conflict, and maternal marital satisfaction had better diabetic control than those living in families with opposite characteristics. Young people without both birth parents at home are more likely to have poorer metabolic control (Scottish Study Group For The Care of Young People with Diabetes, 2001). Research suggests that the stress of coping with T1DM coupled with the stresses of single parenting or blended families can lead to problematic behaviour in the young person, which in turn affects the management of T1DM (Overstreet, Goins, Chen, Homes, Greer, Dunlap, & Frentz, 1995). There is also some evidence associating family environment with individual coping styles in young people with T1DM. Hanson and colleagues (1989) found that high ventilation and avoidance coping in young people were predicted by high perceived stress, low family cohesion, and older adolescent age.

Parental behaviour also appears significant, with lower parental support and high parent-child conflict associated with reduced adherence in young people (Stevenson et al., 1991). Observational studies of parent-child interactions have indicated the
relationship between parental levels of emotional support and skills in conflict resolution in parent-child dyads, and treatment adherence and metabolic control (Martin et al., 1998). Higher maternal self-efficacy and confidence has also been correlated with greater diabetes related self-care in young people (Leonard et al., 1998).

Normalization in the family is considered to influence the young person’s appraisal of, and response and adaptation to T1DM (Kazak, 1989). Normalization is characterized by the family’s acknowledgement of the condition, minimization of the abnormalities relating to the illness, and engagement in behaviours that demonstrate the normalcy of their family to others (Knafi & Deatrick, 1986). Young people from families who normalized the daily care of diabetes into their daily processes and routines have demonstrated considerably better diabetic control (McDougal, 2002).

Diabetes related service provision has also been implicated in T1DM outcomes in young people. Although young people’s diabetes care is increasingly provided by a specialized paediatric multidisciplinary team services are not yet equitable, and thus fall short of proposed national standards (Betts et al., 2002). Significant differences in young people’s metabolic control between centres has been identified, following adjustment for factors associated with poor HbA1c (Scottish Study Group for the care of Young People with Diabetes, 2001)
9. Rationale for the present study

There is evidence that even brief periods of poor control during adolescence accelerate the onset or progression of microvascular and cardiovascular complications associated with diabetes, and the self-behaviours established in adolescence often continue into adulthood (Diabetes Control and Complications Trial Research Group, 1994). Poorer metabolic control is also associated with psychological co-morbidity and impaired school performance, increasing the risk of academic underachievement and social disadvantage in adulthood (Grey et al., 1997; Milton, Holland, & Whitehead, 2006).

Whilst parental involvement in self-care is associated with better adherence, young people with T1DM report separating from the influence of their parents and construe parental support less positively (Olsen & Sutton, 1998). Withdrawal from services is also common in later adolescence (Doherty & Dovey-Pease, 2005), and it is therefore pertinent to consider the impact of individuals other than the family on adherence to care. Young people spend increasing periods of time at school and engaging in school activities, and peer relationships become more intimate and increasingly important during this time (Roismen et al., 2004). The role of peers and school personnel is worthy of investigation. The authors of a study examining the acceptability of a diabetes education programme for a new self-care regime noted that participants reported having difficulty practising the new regimen whilst at school (Waller et al., 2005). However, a literature review revealed a dearth of research examining the role of school personnel and peers in self-care at school (Part 1). Consequently the role of others in self-care at school requires further empirical investigation.
Research Question

The current study sought to explore the following research domains:

1) Young people’s perceptions of the ways in which school personnel and peers’ attitudes and behaviours affect their ability to self-manage their T1DM in school.

2) Young people’s perceptions of the ways in which school personnel and peers’ attitudes and behaviours affect their feelings regarding their diabetes.

3) Young people’s perceptions of the influence of the structure and processes directly running their school on their ability to self manage their condition.

10. Method

This section outlines the reasons for the study design and addresses the methodological issues arising from the study. The use of grounded theory as a methodology for investigating and developing further understanding of the phenomenon under investigation is also discussed.

10.1 Choice of Methodology: Grounded Theory

Investigating the influence of the school environment on the self-care of young people with Type 1 Diabetes Mellitus (T1DM) has been little researched. A systematic literature review (part 1) revealed a paucity of research in this area. The majority of studies examined school personnel’s knowledge of diabetes, with few directly examining the experiences of young people themselves. Since studies were North American the applicability of the studies findings to UK settings is diminished. This
dearth of research and subsequent lack of comprehensive theory regarding the influence of the school context may compromise a full understanding of diabetes care for young people, and restrict potential developments in clinical practice. The development of theory should facilitate understanding of the nature of the challenges faced by young people managing their diabetes at school, and subsequently inform clinical practice and schooling. Given the lack of previous research for the current study a qualitative approach was selected to allow young people to discuss experiences and concepts most meaningful to them, in their own words.

A grounded theory approach was selected since it has a number of strengths and is considered an ideal method for developing substantive theory and capable of providing a framework to explain the complex social and psychological processes that are involved in the research question (Charmaz, 2006; Glaser & Strauss, 1967). Grounded theory has enabled qualitative research to evolve beyond descriptive studies into the realm of explanatory theoretical frameworks (Strauss & Corbin, 1990); a "grounded theory" is one that is inductively derived from the study of the phenomena that it represents (Strauss & Corbin, 1990). The underlying assumption in grounded theory is that people make sense of and order their social world, even though to the outsider the world may appear irrational. It is argued that individuals sharing common circumstances will experience common perceptions, thoughts, and behaviours (Glaser & Strauss, 1967).

The key processes that comprise grounded theory include: researchers simultaneous involvement in data collection and analysis, constructing analytic codes from data (not from preconceived hypotheses), making constant comparisons during each
The current study was informed by the procedures/philosophy set out by Charmaz (Charmaz, 2006). The grounded theory approach proposes researchers generate theory without theoretical preconceptions (Coyne, 1997); therefore the literature review was undertaken in parallel to data collection and analysis. This ensured that the analysis remained grounded (Rennie, Phillips, & Quartaro, 1988).

10.2 The researcher’s position

The researcher approached the study from a social constructivist epistemological stance. This theoretical perspective assumes that people create social realities through individual and collective actions (Charmaz, 2006). The aim of the social constructivist approach is to provide multiple voices, views, and perspectives on lived experience. This involves the researcher constantly questioning and reviewing the data, in order to develop new ideas (Charmaz, 1990). The approach recognizes that the researcher creates the data and the subsequent analysis of the data through interaction with the researched (Charmaz, 2000).

The potential influence of the researcher’s knowledge, values, experiences, culture and beliefs has been widely acknowledged by grounded theory writers (Charmaz, 1990; Turner, 1981). Consequently a process of reflexivity was applied, whereby the researcher scrutinised her research experience, decisions, and interpretations to allow the reader to assess how her interests, positions, and assumptions influenced inquiry.
(Charmaz, 2006). The researcher also considered the impact of her presentation on her rapport with the young participants, and participants’ subsequent disclosure during interviews.

The current researcher had previously worked within a Child Health setting, as a nurse on an Acute Paediatric Medical ward. During this time she had observed the emotional responses and behaviour of children who were diagnosed with T1DM and also the response of their parents. In addition she had completed a Masters Degree in Health Psychology which included studying theories conceptualizing health beliefs and behaviours. Consideration was also given to the role of the researcher’s age and gender in relating to participants.

In terms of the research context, the researcher was on a part-time, clinical placement within a Paediatric (Neurodisability) team during the study. To reduce the likelihood that subjective views were communicated, open-ended questions were asked that elicited participant centred responses.

10.3 Methodological rigour

The issue of rigour in qualitative research has fuelled a great deal of debate in recent years. Although there is not an agreed consensus regarding appropriate quality criteria, many researchers have proposed some standards (Whitemore, Chase & Mandle, 2001). Lincoln and Guba (1989) proposed the use of “trustworthiness”, including the credibility, dependability, confirmability, and relevance of the research (Stiles, 1993).
In the current study the researcher retained engagement and familiarity with the data through listening to each interview recording immediately following its completion, and again before undertaking line by line coding. A research diary was kept throughout the process which included recording general reflections, dilemmas and uncertainties, and sampling decisions, to assist the development of theory and provide a means of auditing. The researcher also recorded personal reflections to mitigate against obscuring the analysis, and to provide an audit trajectory (Charmaz, 1990; Lincoln & Guba, 1989). The credibility of the analysis was enhanced through membership of a peer attended qualitative research group undertaking open coding of some of the original data. A validity check throughout the analysis used reflections from an experienced supervisor who read drafts of the final write-up.

The use of the constant comparison method in the data analysis also contributed to developing a coherent theory. This principal approach to data analysis in the development of grounded theory requires the researcher to “tease out” categories and their properties (McCann & Clark, 2003a). According to Glaser & Strauss (1967), there are four key stages in the process:

1. Comparing incidents applicable to each category
2. Integrating categories and their properties
3. Delimiting the theory
4. Writing the theory
11. Procedure

11.1 Study Site and Population

The researcher made initial contact by letter with a Consultant Paediatrician who specialised in the medical care of children and young people with diabetes at a local teaching hospital. The letter outlined the purpose of the study, and requested an initial exploratory meeting between the researcher and Paediatrician to discuss the purpose of the research and consider potential participants.

11.2 Obtaining Ethical Approval

Following the initial meeting a formal application was submitted to the Central Office of Research Ethics Committees (COREC), and also to the Research and Development department of the teaching hospital from which participants would be recruited. The major ethical issues to be considered were permitting the researcher contact with potential study participants through the Consultant Paediatrician, and the researcher conducting face to face interviews with young people under the age of sixteen.

11.3 Approaching potential participants

Potential participants and their parent/guardian were approached by the Consultant Paediatrician in person (during their visits to the Paediatric Diabetes Clinic) or by telephone. Those who expressed an interest were given a Young Persons and Parents information letter (Appendices 1 and 2). The parent’s letter included a reply slip (and prepaid envelope) giving parental permission for the researcher to contact them and their child by telephone, to discuss participation in the study. Fifteen young people (and their parents) were approached by the Consultant Paediatrician, ten of whom agreed to participate.
Participants

The study inclusion criteria were that:

- Participants had been diagnosed with type 1 diabetes mellitus (T1DM), were aged 11-16 years and had commenced their secondary school education by September 2006.

- Participants and their parent/guardian understood the nature of the study and its implications, and the terms of informed consent.

Exclusion criteria were:

- A diagnosis of T1DM for less than eighteen months, since the Consultant Paediatrician considered it un-ethical to approach young people to participate in research during the initial adjustment period following the diagnosis of T1DM

- Concerns expressed by the Consultant Paediatrician responsible for the medical care of potential participants that participation in the study could be harmful to the participant or their parent/guardian.

Sample size:

Due to time constraints it was anticipated that no more than ten interviews could be conducted. Data collection continued until theoretical saturation was reached i.e. when no new or relevant data seemed to be emerging (Strauss & Corbin, 1998). An anonymised table of participants' demographic details is provided in Table 1.
### Table 1: Participant Demographic Information

<table>
<thead>
<tr>
<th>Participant</th>
<th>Age at time of Interview</th>
<th>Age at time of diagnosis</th>
<th>Length of time since diagnosis</th>
<th>Gender</th>
<th>Ethnic Origin</th>
</tr>
</thead>
<tbody>
<tr>
<td>P1</td>
<td>12 years 4 months</td>
<td>1 year 2 months</td>
<td>11 years, 2 months</td>
<td>Female</td>
<td>White British</td>
</tr>
<tr>
<td>P2</td>
<td>11 years 4 months</td>
<td>7 Years</td>
<td>4 years 4 months</td>
<td>Female</td>
<td>White British</td>
</tr>
<tr>
<td>P3</td>
<td>15 years 8 months</td>
<td>13 years</td>
<td>2 years 8 months</td>
<td>Female</td>
<td>White British</td>
</tr>
<tr>
<td>P4</td>
<td>12 years 6 months</td>
<td>7 years</td>
<td>5 years 6 months</td>
<td>Male</td>
<td>White British</td>
</tr>
<tr>
<td>P5</td>
<td>14 years 5 months</td>
<td>12 years 6 months</td>
<td>1 year 11 months</td>
<td>Male</td>
<td>South Asian</td>
</tr>
<tr>
<td>P6</td>
<td>16 years 6 months</td>
<td>7 years</td>
<td>9 years 6 months</td>
<td>Female</td>
<td>South Asian</td>
</tr>
<tr>
<td>P7</td>
<td>15 years 5 months</td>
<td>12 years</td>
<td>3 years 5 months</td>
<td>Male</td>
<td>White British</td>
</tr>
<tr>
<td>P8</td>
<td>11 years 1 month</td>
<td>2 years 6 months</td>
<td>8 years 7 months</td>
<td>Male</td>
<td>South Asian</td>
</tr>
<tr>
<td>P9</td>
<td>11 years 11 months</td>
<td>3 years</td>
<td>8 years 11 months</td>
<td>Female</td>
<td>White British</td>
</tr>
</tbody>
</table>

**11.4 Theoretical sampling**

Theoretical sampling is a significant component of grounded theory; it involves progressing emergent ideas by the use of more deliberate and selective sampling of the key issues (Strauss & Corbin, 1990). Purposeful sampling was initially used to maximise the likelihood of obtaining meaningful data (Coyne, 1997). The initial interviews were then analysed, thus commencing theory development. To expand the developing theory, participants who might validate, disconfirm, and develop or refine the emerging theory were then sampled (Pidgeon & Henwood, 1996). This process continued until subsequent interviews did not reveal any new categories implying that theoretical saturation had been reached.
Sampling initially focused on males and females across the study age range. Three participants were Asian (which is representative of the population of young people residing in the study geographical area). Additional theoretical sampling resulted in interviewing two participants who had been diagnosed with T1DM since starting their secondary school education.

The interview schedule

The interviews were guided by a general Interview Schedule, which was developed from the research questions (See Appendix 5). The interviews were preceded by questions regarding demographic details, and the initial interview questions were of general orientation to put participants at ease. The Schedule was not rigidly adhered to, but was used as a guide to prompt exploration of participant’s issues and personal experiences, thus avoiding narrowing of the theoretical or analytic framework. The interviews ended by asking participants if there were any issues regarding managing their diabetes at school that had not been discussed. As the research developed the researcher refined the Interview Schedule. Early theoretical conceptualizations were tested and developed through the addition of further interview questions (Charmaz, 2003). Correspondingly, questions became more focused towards the end of the study (See appendix 5 for examples).

Data collection

Interviews were conducted in participant’s homes at a time agreed with them and their parents in order to minimise disruption to the young person and their family, and to provide an environment in which participants would feel relaxed. Before commencing each interview the researcher reviewed the young person’s and parent’s information
sheets with the participant and their parents(s) (Appendices 1 and 2). The participant and their parent were then asked to sign individual consent forms (Appendices 3 and 4). Participants were asked if they would like their parent present during the interview or in a nearby room. Four of the participants chose to have their parent present. The interviews were audio-taped using a digital recorder and lasted between 45 and 60 minutes, and were subsequently transcribed verbatim. Written notes recording the participant's and parents non-verbal behaviour and the researcher's general reflections were also made immediately after the interviews. Following each interview the young people and their parents were thanked for their participation and the researcher reiterated issues regarding confidentiality. The researcher also explored whether the young person felt distressed, and whether they would like further support.

11.5 Data analysis

Coding

If data analysis is to drive emergent theory, the process of constant comparison between the data being sampled and emergent ideas must begin immediately. To this end, the transcription and coding of the interviews took place as soon after the event as possible. Participants' names and other identifying features were erased from the transcripts to protect participants' anonymity. To fulfil grounded theory criteria of fit and relevance, open (line by line) coding was undertaken (Charmaz, 2006). Examples of line by line coding are found in appendix 6. Initially the codes used were "in vivo" codes using participants’ words and expressed meanings were used. Enabling the codes to be truly grounded in the data and minimise the risk of theoretical or conceptual preconceptions on the part of the researcher. Figure 1 below shows
examples of open codes, with a combination of "In vivo" codes (in quotation marks and sociological construct (Theoretical) codes.

Figure 1: Examples of open codes

"and when I moved up to (schools name) some teachers some teachers actually didn't know and I would sort of have to explain it to like them"
Participants perceived that some teachers didn’t know that they had diabetes.

"in secondary school I've not really told them because I get a bit nervous about that really"
Some participants experienced anxiety disclosing their diagnosis.

"and if I'm doing my injection in the medical room or something they come with me"
A number of participants reported that their friends accompanied them to undertake self-care

Once analytic directions emerged, coding was then focused using the most significant earlier codes to sift through data. Focused coding was used to identify core categories and establish links between categories. It is important to note that coding was a cyclical process with interplay between the different levels of coding and levels of analysis. Examples of focused coding are shown in figure 2 below.

Figure 2: Examples of focused codes

"I didn’t want people to make fun of me and think that I was actually different to them"
Participants reported experiencing stigma in relation to having diabetes and related self-care behaviours

"And my friends they’ll help me out no matter what"
Friends provided emotional and practical support with diabetes related care

"the office lady sorts me out"
School personnel provided care during hypoglycaemic episodes
As the analysis developed, the codes became more abstract and conceptual relationships were formed between categories. This theoretical coding facilitated the integration of a final comprehensive conceptual analysis. Examples of theoretical coding are found in figure 3.

Figure 3: Examples of theoretical coding

"and remembering my lunch pass as well its kind of hard all the time"
The transition to secondary school forced participants to conduct self-care under new school rules

"I used to have nothing finished"
Participants perceived that diabetes related absences threatened academic performance.

The constant comparison method

Constant comparative analysis is one of the principal approaches to data analysis in the development of a grounded theory and requires the researcher to "tease out" categories and their properties (McCann & Clark, 2003a). This method consisted of systematic comparison of incidents, codes, participants and categories, to identify their similarities and differences. This process enabled the generation of successively more abstract concepts and theories and clarified the relationships and links between them.

Category Integration

As data collection and the analysis progressed the researcher developed a deeper understanding of the data. The final categories were refined and integrated into a theory. The relationships between the categories and their subcategories were clarified, which enhanced the theoretical coherence.
The aim of grounded theory is to develop the emergent theory as fully as possible. When undertaking the current study, the later research interviews did not reveal any new properties or yield further theoretical insights about the emerging grounded theory. This indicated that sufficient data had been collected to provide a comprehensive account of the phenomena. Researchers have previously highlighted that studies employing grounded theory vary on the level of abstraction that they achieve e.g. some researchers generate higher-order theories, whilst others aim to elaborate the phenomenon under study by developing a comprehensive conceptual analysis (Henwood & Pidgeon, 1995). In keeping with the time and resources available, producing a comprehensive conceptual analysis presented in written and diagrammatical form was the aim for the current study. The presentation of excerpts are italicized and identified by the participant number and page. Square brackets [ ] denote omission of text which is considered repetitive or irrelevant, and three dots … denote a pause.

12. Analysis and discussion

Contemporary researchers consider that the tradition of examining the lives of young people with diabetes from an illness-focused perspective has not yielded optimal health outcomes (Yeo and Sawyer, 2003). The current study contributes to the emergent literature examining the relationship between the tasks of adolescent development and the challenges of living and coping with diabetes. In particular the study is the first to specifically examine the school experiences of young people with T1DM in the United Kingdom.
Core category: the role of school as a potential threat or benefit to self-regulation. “I don’t have no problems at home, but it’s just like at school I can’t be bothered to do it half of the time...”

Data analysis revealed a core category in which school was identified as having a significant influence on the individual’s ability to successfully manage their condition. It was evident that school was regarded as a potential threat to participants self-regulation, in comparison to the threats experienced when managing their diabetes at home. Self-regulation in this context included the biological self (i.e. glucose homeostasis) and the self-care required to maintain homeostasis. School was seen as a potential threat to the psychological self when participants experienced stigma in relation to having diabetes and related self-care, and their behaviour during hypoglycaemic or hyperglycaemic episodes. However, participants also reported experiences where school was a benefit to self-regulation. Self-regulation was dependent on a dynamic and evolving relationship between the self, the school system, friends, peers, school personnel, parents, and health professionals (see figure 4). Particularly friends promoted self-regulation, both in terms of providing support with self-care and reducing stigma. The threats themselves and the process required for their containment caused participants varying degrees of distress. As participant 3 surmised:

P3. “I don’t have no problems at home, but it’s just like at school I can’t be bothered to do it half of the time. Because my mates we normally go out of school for lunch and we’ll be walking around and I sometimes don’t get chance to do my insulin”
12.2 Self-exposure and stigma

The most distinct and overwhelming threat to self-regulation was stigma, which participants reported they feared regardless of whether they had directly experienced it or not. Participants reported the desire to present a particular “self” according to the given social context, for example they exposed a different self to friends as oppose to non-friend peers. Adolescence is a period associated with differentiation of the self, with one’s conception of the self expanding to represent the increasing number of roles and experiences (Harter et al., 1997).

However, undertaking diabetes care and the physiological and behavioural changes associated with the condition limited young people’s control of which facet of self they exposed, they subsequently risked unwanted exposure and associated stigma. In particular the behavioural changes associated with fluctuating blood glucose hampered participants control of exposure of the self. Participant nine reflected on her difficulties controlling self-exposure when hyperglycaemic and the subsequent threat of being humiliated in front of older pupils:

P.9 “like if there’s a year nine in there that looks quite tough I wouldn’t want to do an injection in there because I know they’d watch me and you know, ask loads of questions and I wouldn’t want that because when I’m high I’m really funny”.

Stigma in this context is interpreted as a distinct threat to the self, in keeping with Goffman’s early proposal that stigmatizing attributes are culturally defined as deeply discrediting and set individuals apart from others in a negative manner (Goffman, 1963; MacLeod & Austin, 2003). Participants' experiences of stigma also included a
sense of “being” different from others because they have diabetes, and experiencing
difference from others due to diabetes self-care such as having to inject insulin. This
finding is supported by previous studies of young people with diabetes (Buchbinder,
Detzer, Welsch, Christiano, Patashnick, & Rich, 2005; Dovery-Pearce, Doherty, &
May, 2007; Schur, Gamsu, & Barley, 1999).
Participants reported on their experiences of self-care highlighting their difference
from peers:

P3 “I wouldn’t have minded if like I had it since I was born or something, but it’s
just soon as I turned teenager I go diabetic {} because all my mates they don’t have
to do insulin or anything and I have to”

P6. “It’s kind of strange. It doesn’t make me feel like one of them sometimes
because like they’ll be in the middle of a test or something, something that might be
really important and I’ll start shaking and I’ll be going oh no, and I have to just put
my hand up and say Miss can I go downstairs, and they’ll ask questions when they
see you, oh why did you have to go?”

The fear of being discredited was an overwhelming theme. Threats to self included
the loss of personal dignity during self-care, and the lack of control over one’s
behaviour during hypoglycaemia. This idea is endorsed by previous studies of young
people experiencing hypoglycaemic episodes, with fear of further episodes and
reprisals regarding one’s behaviour a recurrent theme (Nordfeldt & Jonsson, 2001).
Participants reflected on their fears, for example participant eight feared being caught
out and exposed whilst undertaking self-care activity:
P8 "...if like people are watching me then they will kind of pass it on to people saying, he's like taking his trousers off and he's doing his kind of insulin in class. So they'll make a crowd or something and try to pass it on or something...yeah?"

Others feared being discredited by their behaviour during hypoglycaemic episodes, for example participant two feared becoming aggressive. Participant eight feared being perceived as strange.

P2 "So although I wouldn't happen to remember anything I can get quite aggressive, and if I got aggressive I might have got detention just because of that"

P8 "Because it would be like everybody's kind of looking at me and thinking, what's he kind of going for and why is he acting kind of strange. And then in the future they might kind of say like oh no you were acting strange or something and I'd be a bit annoyed".

Participant nine articulated the reality of being a focus of attention during a diabetic collapse.

P9 "well obviously it did bother me because I was in front of everyone who was getting changed"

Concerns that one's identity would be overshadowed by the value judgements others made about diabetes and related behaviours was also a significant theme. This feature of stigma has been an enduring finding in studies of the experiences of individuals with chronic illness (Goffman, 1963; Lightfoot et al., 1999; Radley, 1994). Participant
nine for example, in this excerpt reported her fears of being "type-cast" as a diabetic by peers:

P9 "I don't really like people to think of me as the diabetic girl that goes into lunch early. I'd want people to know me as Poppy who is a nice friend".

It is clear from the findings that the need to conform with peers is a survival skill of adolescence (Buchbinder et al., 2005). Findings from the current and previous studies indicate that having diabetes challenges this. In particular it was clear from the study findings that there was a sense of conflict between the demands of diabetes care, school rules, and the desire to conform to peers, thus rendering young people with diabetes as "different" during a developmental period when they are intensely self-conscious (Buchbinder et al., 2005).

12.3 Stigma and experiences of being discredited or normalizing diabetes:
"...because it would be like everybody's kind of looking at me"

"Well I'm happy because quite a few people I know are diabetic and in my year as well... it's normal really"

Sadly some participants reported having been bullied in relation to their diabetes, in keeping with theories of stigma setting them apart from peers in a deeply discrediting manner (Goffman, 1963; MacLeod & Austin, 2003). Incidents included peers questioning the validity of the young person's existence, mocking their behaviour during a diabetic collapse, and using their diabetes as a means of discrediting them and their friends. For example participant four detailed an incident at school:
Participant six described having her very existence questioned by a peer, whereas participant two described experiencing the disdain of a peer during her diabetic collapse:

P6. “The boy said 'oh I see you're still alive', and I'd come out of hospital like a month or two before”.

P2. “I actually fell over so I grabbed hold of him so that I didn't hit my head, and he went 'urghh', and wiped his arm…”

Others reported school experiences which normalized diabetes to a degree, with participants reporting having at least one peer who also had diabetes. They perceived that peers or school personnel with diabetes facilitated a culture of understanding and acceptance of diabetes within their school. This helped to normalize their diagnosis, effectively reducing their sense of stigma. This is endorsed by previous studies where young people indicated that meeting with others with diabetes reduced feelings of isolation and difference (Schur et al., 1999). There was a sense that young people endeavoured to avoid the stigma associated with diabetes whilst relishing the sense of unity with others with the condition. Participants reflected on their experiences of others with diabetes at their school. One mother considered that the school educating several pupils with the condition facilitated improved understanding of T1DM.

Mother of P1 “One in your year is there another one? So you know it's quite handy because you don't have to explain everything you know because they understand”
Participant four and seven described how having others in the school with diabetes engendered a sense of being supported and feeling less different from others:

P4 “That I'm not the only one and it's pretty much normal because most of their mates must know and a few hundred people must know about diabetes then”

P7 “one of the reception ladies has actually got diabetes as well and she's given me some ideas and tips and stuff, she's always there for me”.

An interface between normalization and stigma was apparent, which has been illustrated by previous researchers (Joachim & Acorn, 2000). One participant reported that his teacher was subsequently very skilled at recognizing his symptoms of hypoglycaemia, but that he experienced a level of discomfort that a teacher also has the condition.

P.8 “once I was in the library and I wasn't kind of concentrating or something then she knew I was having a 'hypo'... its kind of strange really having like a teachers okay that is diabetic and you are diabetic as well, yeah so its kind of strange, but it makes a big help to like my concentration and my kind of lifestyle at school”

Overall there was a clear sense from the study findings that having other people at school who had the condition helped with the process of normalization. This also had the effect of increasing the understanding of others in relation to the daily demands of diabetes.
12.4 Negotiation and the process of disclosure: walking the tight rope. "But in secondary school I've not really told them because I get a bit nervous and that really".

Controlling exposure

In an attempt to conform with peers participants reported executing degrees of disclosure of their diabetic "self" and associated self care. This is reported in previous studies of young people with chronic illnesses (Lightfoot et al., 1999). Expectations of how others will react (the internal process of self-perceived stigma) as described by previous authors e.g. Link & Phelan (2001) influenced individual's degree of disclosure. Consequently participants who feared being mocked or perceived as different employed degrees of "passing" concealing self-care in order to be perceived as part of the "normal" peer group, this is widely reported in literature examining stigma and illness (Joachim & Acorn, 2000). Participants reflected on their decision to undertake "passing". For example participant seven stated:

P7 "well not many people know I'm actually really a diabetic because I don't go round telling anyone. Some of the teachers don't know either".

P4. "Well because you're not really meant to eat in school so I do it sort of secretly because it saves explaining it, but if I get caught I just tell them {} Yeah, because then everybody in my class would know and that I'm not really bothered them knowing but its easier them not knowing"

Both participants seven and four had clearly decided not to disclose their condition at school. Participant eight reflected on his fears of being bullied, despite the reality of the situation.
P8 "Well I think they might like kind of complain on me and kind of really bully me, like saying you have diabetes and all that. But it's never happened really"

From the study findings it was clear that the disclosure of having the condition was a significant concern to the participants, with some choosing not to disclose and others employing a process of protective disclosure.

**Protective Disclosing: “I don't want the whole school knowing that I have diabetes... I think half of the year sixes know”**

Protective disclosing has been identified in previous studies of individuals with invisible chronic conditions (Charmaz, 1991). The aim of protective disclosing is to control how, what, when, and who individuals tell about their condition (Joachim & Acorn, 2000). Consequently, although classmates may be aware of the person's diagnosis some participants in the current study sought to arrange care so as not to be discredited by behaving differently from their peers. This behaviour is reported in previous literature examining stigma and chronic illness (Joachim & Acorn, 2000). Participant eight reported planning his snacking very carefully to coincide with peers, and avoid appearing different by eating during lessons.

P8 “Because really like people do look at me, keep on, but I really just don't like kind of eating in front of the class... the children aren't looking at me when I'm standing outside because everybody else is having snacks outside, so I'm like them, so really nobody's looking at me”.

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An internal process of self-perceived stigma and anticipated response of others was evident from the study findings (Link & Phelan, 2001). Participants weighing up the perceived threats and gains of disclosure or exposure were also evident. For example participant eight eloquently summed up this dynamic process:

P. 8 "It's kind of a balance sort of, I don't want people to know because they'll be like oh you have diabetes and that, but then I do want people to know because they will be...it will be a better chance of me like kind of surviving in a hypo or anything, yeah, its kind of a balance sort of, it's like an argument really"

Some participants whose peers knew their diagnosis reported feeling comfortable undertaking self care such as eating/drinking and blood glucose testing during lessons. However others considered that this exacerbated the risk of stigma e.g. receiving an adverse reaction from peers who disliked the sight of blood or needles, or peers associating having needles with drug addiction. Individual differences in participants' perceptions of peers’ reactions to care were evident, as participant nine reflected:

P9 “People in my classes know that I'm diabetic because I am frequently doing blood tests. And those people who don't know, when they see me doing a blood test they will ask, you know what's that and I say its a blood test that I use to test my sugar levels as I'm diabetic, and I don't really say any more than that”

However, participant three irrationally feared being mistaken for an intravenous drug user. She was under the misapprehension that people would equate needles with drug
taking. This arose because she lived in an environment in which drug taking was commonplace.

P3 “yeah they don’t like blood, they don’t like looking at blood so I just kind of hide it from them {} Like injections because I don’t like people staring at me when I do them because it makes me think Oh they’ll think I’m a druggie or something {} if I inject I feel like, I don’t like doing it in public places”

Interestingly one participant reported that he considered that the behavioural changes associated with diabetes made peers perceive him as more appealing and esoteric, as his changing glucose levels altered his behaviour, subsequently giving him different “personalities”.

P7 “it kind of made some people like me more...I don’t know I think it was just because I have kind of different personalities”

A developmental facet was also evident in participants’ perceptions of stigma, with reports that explaining the nature of diabetes was less threatening as young people matured and developed understanding of the condition. Participant six reflected on this trajectory.

P.6 “I was in year seven. I think it was trying to go into a new school and explain to everyone how, what diabetes is and I didn’t really like talking about it much, I wasn’t too sure of it myself. And then after a few years when people ask I find it easier to explain”.
The study findings indicated that participants assessed peers’ understanding of their condition, for example peers who had relatives with diabetes were deemed less threatening by some as they demonstrated a greater understanding of the condition, freeing the young person from the responsibility of providing an explanation. As participant four noted:

P.4 “Yeah because I’ve told a few already and they know like their Grandma or Granddad or something they’re diabetic so they sort of know what it is….well I feel better really because they know what it is already so I don’t have to explain it”.

They were also perceived as skilled in assisting with blood glucose testing during a hypoglycaemic episode. However, others perceived that peers having relatives with diabetes increased the threat of stigma, as they were more likely to question the young person’s care and associate diabetes unfavourably with older adults. Participant five reflected on this dichotomy:

P5. “Yeah because then if I have, if I ever feel really ill and um unable to do it myself then they could do it for me{ } but It just felt a bit weird, just a bit weird because like their grandparents are much older than I am”

Participant six feared being questioned by peers who had relative with diabetes

P6 “My friends would say, oh my mums diabetic, or my Dads diabetic and um they have to do this, is this what you have to do? Is this what you have to do? I m like at first I don’t know I don’t know”
There was a sense from the findings that there had to be a perceived benefit to warrant disclosure, in keeping with theories of protective disclosing (Joachim & Acorn, 2000). Disclosing to friends was considered advantageous, in terms of it being a sign of friendship and enabling friends to give diabetes related support:

P. 5 “And my friends know as well so if I need any help then they help me out with my stuff”

P. 9 “Well obviously I tell my friends, and other people in my class know that I’m diabetic because I am frequently doing blood tests”

P. 6 “My close friends if they question I don’t mind them asking because whatever I tell them they’ll help me out, whatever the problem. But I think the people who don’t really talk to and they ask they might ask more personal questions about it and I don’t really like answering questions to people I don’t really talk to”

Questions from friends regarding one’s diagnosis were acceptable to participants as they believed that their friends would provide them with support. However being questioned by others was regarded as intrusive since participants appeared to be suspicious of their motives.

12.5 Disclosing after diagnosis: “I found it a bit hard to think that I had it so it was hard telling them”.

The participants who were diagnosed during adolescence reported having perceptions of their illness and associated stigma that were distinctly different from those
diagnosed in childhood. Participants’ descriptions of the period following diagnosis were infused with loss of a former self. This is echoed by previous researchers, Charmaz (1995, 2002) proposing that long-term conditions can force rapid changes in personal identity in young people, diabetes implies premature ageing causing a shift from a perceived normal trajectory to one that is abnormal (Bury, 1982). Participants reported that they initially perceived diabetes as an aversive threat to self, and that disclosure highlighted the distress associated with this appraisal. As participant five reflected:

1. “What was it like telling your friends then?”

P5. “I found it a bit hard to think that I had it so it was hard telling them, like”.

Given that the majority of study participants were diagnosed during childhood the relationship between participants’ experiences of threat to self regulation and the duration of diabetes requires further investigation.

Existing Theories of Stigma and adolescent development

Participants’ experienced threats to self included stigma, but also the threat of exposing the wrong “self” within a given social context. There was a sense of diabetes being part of a private “self”, with participants’ appraisal of the personal nature of diabetes and their level of intimacy with others in the given social context influencing the decision to disclose. Developing a sense of self is a known normative task of adolescence, and the fear of self exposure is a familiar product of this developmental process (Roismen et al, 2004). However, present theories of stigma and chronic illness are orientated towards adults, and consequently fail to incorporate this
important facet of adolescent development. Thus such theories only partially explain the experiences of the study participants managing diabetes at school.

12.6 Friends: supporting self-regulation. "They usually have something for me and just look out for me, or they'll take me to the office"

There was overwhelming consensus that school friends supported the participants with the emotional and practical aspects of diabetes, with friends and peers described as distinctly separate entities. Friends played a crucial role in facilitating participants' self regulation, which seemed to surpass that of teachers, in respect of promoting good glycaemic control by reminding participants to inject their insulin and staying with the young person in the school canteen for lunch. There was a sense that friends normalized the young person's diabetes, fitting care into their daily school routines. The role of families normalizing diabetes in promoting adherence and well-being has been indicated by previous studies (McDougal, 2002), however studies have yet to examine this concept with peers. Participants reflected on friends reminding them to undertake care and fitting care in with their routines:

P6 “they'll say have you taken your insulin and things, they know everything about me”

P3” I stay in the canteen now, you know, because it's easier for me my mates said they don't mind”

Participants reported that their friends also acted as their advocate, protecting their integrity by confirming their diagnosis when teachers queried self-care such as eating during lessons. Where participants were distressed by the self exposure accompanying disclosing their diagnosis friends also disclosed on the young person's behalf.
Participants reported that their friends undertook an essential role in buffering the physical and psychological effects of hypoglycaemic episodes. Friends were able to recognize the initial signs of hypoglycaemia and encouraged the young person to do a blood test, called teachers for help, prepared blood testing equipment, and escorted them to the school office to receive treatment. Given the physical and psychological seriousness of hypoglycaemia (Nordfeldt & Jonsson, 2004) this role is clearly not to be underestimated in the context of successful adjustment.

Findings indicated that the tension created by participants' self-care needs and fear of stigma was mitigated by friends, who facilitated social integration whilst encouraging self-care (e.g. eating together, escorting participants to the medical room to inject). However, there were also instances of friends encouraging non-adherence e.g.
skipping meals and injections to spend the lunch break with them. This is echoed in previous studies where young people were found missing insulin injections to fit in socially (Kyngas et al., 1998).

P3. "Because my mates we normally go out of school for lunch and well be walking around and I sometimes don’t get chance to do my insulin”

Young people have previously reported having difficulties maintaining their adherence when they anticipate peer pressure (Kyngas et al., 1998). Studies have also highlighted the role of negative attributions of friend and peer reactions to diabetes management in social situations (Hains, Berlin, Davies, Parton, & Alemzadeh, 2006). This was resonant within the current study, a social information processing model of adjustment has been proposed, which suggests that young people with T1DM may perceive adherence behaviour as difficult in social situations due to a fear of negative peer evaluations (Hains et al., 2006). Young people who make negative attributions about expected friend reactions and/or non-friend peers are consequently likely to find adherence difficult in social situations and experience increased stress (Hains, et al., 2006). This is supported by the current study findings, with participants who reported fearing negative reactions from peers concealing or omitting self-care. However, this model does not explain young people’s desire to control disclosure/self exposure when predicted peer evaluations are favourable; for example not wishing to disclose whilst coming to terms with the diagnosis of diabetes.
The nature of friendship

Participants in the present study clearly valued friends’ emotional and practical support, and considered that it was indicative of robust relationships. The importance of peers as a source of emotional support for young people with diabetes is evident in other research, and is associated with adherence to care (LaGreca, 1995a) and enhanced metabolic control (Skinner et al., 1999). A study of the nature of adolescent friendships found that those with diabetes reported having more close friends and receiving more support from friends than their healthy peers (Helgeson et al., 2005). This is partially supported by the current study findings, there was a sense that participants experienced close friendships and received high levels of friend support.

P7 “Well we look out for each other so it doesn’t really matter (friends name) has got some illnesses as well so we just look out for each other so its alright”

P6 “And it makes my friendship a lot better because I’m not keeping anything away from them, I can just tell them what’s wrong”

However, some researchers have found that young people may feel stigmatized by peers showing concerns regarding self-care (Buchbinder et al., 2005), and friends who worry about diabetes or overly monitor the young persons self-care behaviours may be deemed unhelpful (Dovey-Pearce et al., 2007). There were however no reports of concerns regarding peers overly monitoring self-care behaviours in the current study. Nevertheless, being asked too many or personal questions regarding one’s diabetes by peers who participants did not consider to be their friends was perceived as threatening. There was a sense that exposing one’s diabetic self also exposed
participants' vulnerability, consequently they endeavoured to discuss their illness only with those who they believed would offer support.

Participants considered that having their friends support reduced their sense of isolation in relation to having diabetes, for example friends asking their parents to provide sugar free foods during sleepovers. This is endorsed by a qualitative study conducted by Schur and colleagues, who proposed that peers can provide positive experiences that make the young person feel less different (Schur et al., 1999). In addition data from a prospective study associated peer support with better psychological adjustment in young people with diabetes, although both supportive family and friends were required for adjustment to be optimal (Skinner and Hampson, 2000). Participant six reflected on her feelings of inclusion when her friend’s parents provided her with suitable foods.

P6 “and it was really nice because they would they would if I'm going round they would get like loads of sugar free stuff in for me and they'd be saying like it makes me feel more comfortable when I'm there”.

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Figure 4: The influence of school on self-regulation

Benefits to self-regulation

Friends supporting
"They'll usually have something for me and just look out for me"
"They'll just explain for me"

Normalizing:
"I'm happy because quite a few people I know are diabetic"

Protective disclosing
"It will be a better chance of me like kind of surviving in a hypo"

Self Regulation

Threats to self-regulation

Controlling disclosure
Self care "I do it sort of secretly because it saves explaining it"
Diagnosis: "not many people actually know I'm a diabetic"

Stigma
Having diabetes: "It doesn't make me feel like one of them sometimes"
Self-exposure: "they might kind of say like oh no you were acting strange or something"
Being discredited: "he just comes past me and calls me diabetic boy"
Self-care: "they'll think I'm a druggie"
13. Transition to secondary school: "I was worrying a lot because I didn't really know what it would be like..."

Participants reported that attending secondary school bought additional threats and for some benefits to self-regulation (see Figure 5). Apprehension regarding new teachers and peers reactions to their diagnosis was evident, with fears of vulnerability to bullying a finding which is supported by other studies (Schur et al., 1999). Evidence indicates that the transition from primary to secondary school and its accompanied environmental and social changes is a critical and challenging life event for young people (Chung, Elias, & Schneider, 1998). Applying transactional stress-theory (Sirsch, 2003) the current study found that having diabetes magnified participants’ experience of this challenge. Participants summarised their worries during this transition, participant two feared being stigmatized by her condition.

P2. "I just didn't want people to make fun of me and think that I was actually different to them".

Whilst participant seven feared others reactions to his disclosure of his diagnosis on starting secondary school.

P.7 "I was worrying a lot because I didn't really know what it would be like because it's a different school and not many people would understand. But it was alright once I told people. I made friends and they understand so it's OK".
Not one but many: “changing round for every teacher”

The study findings indicated that the presence of numerous teachers at secondary school challenged self-regulation, with apparent diffusion of responsibility of teachers in relation to the young person’s diabetes. Having more than one teacher meant that participants were forced to represent their care needs themselves. When teachers were not aware of their diagnosis young people had to take on responsibility for disclosure. This forced burden of responsibility caused some participants considerable stress:

As participant two and her Mother reported

P.2 “I found things easier in primary school because people knew a bit more about me. But of course I wasn’t like changing round for every teacher, I only changed round like once and all the teachers knew that I was diabetic”.

Mother of P2 “she doesn’t feel like she could say to a teacher - well this is what she said to me - oh I feel low and they’ll go, oh we’ll deal with it, it’s more throwing back at her and she’s expected, although she’s only 11 still, to act like an adult”

Participants inferred that poor communication was often at the root of some teachers’ lack of familiarity with their diabetes. There was a consensus that shared knowledge regarding their diabetes was lost as they moved to secondary school, forcing them to undertake the responsibility for representing themselves. This is endorsed by evidence from professionals, who identified that barriers to providing school-based support for young people with chronic illnesses included poor inter-agency collaboration (Leonard, 1992; Larcombe, 1995) and a lack of health–related information, advice, and support available for teachers (Eiser & Town, 1987; Court, 1994). Participant two
and her Mother reported on her distress at having to repeatedly explain her condition and care needs to teachers.

P.2 “Well it was really bad communication, because the teacher she came out and said you’re not supposed to be eating right now it isn’t break time, so I had to explain all over again about my blood sugar being low”

Mother of P2 “You had a lot of teething problems at high school didn’t you? We found that initially they weren’t communicating with each other and we had to bang their head against a brick wall”

13.1 Changes to the rules

Uncertainty was also generated by the recognition that school rules had changed, but that specific procedures were unknown. Participants noted that formal permission was required to leave a classroom to undertake care, whereas at primary school it was sufficient to informally approach their teacher. Some participants experienced difficulties engaging with these new demands. For example participant seven described the following situation:

P7 “I hadn’t known about it before that they were giving out the toilet cards and things like that, but I was never told about it so I didn’t know I’ve known for about a month though and I’ve not had the time to ask him really because he’s not been in”

Engaging in these new demands was difficult, as participant two reflected:

P.2 “it’s kind of a bit scary because I thought I was going unconscious at one point. And remembering my lunch pass as well is kind of hard all the time”
However, threats to self-regulation were considered to ease as participants progressed through secondary school and familiarised themselves with new school rules and context. There was also a sense that adolescent development and facing the implications of diabetes were part of this evolving process, as participant six surmised:

"I think it's been a bit hard sometimes, like there's a lot of kids who are allowed to have different things um and then so I have to take insulin, I have to go outside of classrooms and get passes and it was quite hard at first, my first three years of school, but I've kind of got used to it now"

Of the participants who had been diagnosed with diabetes prior to or whilst attending primary school only one reported having fewer difficulties managing her diabetes at secondary school. Her mother attributed this to her daughter no longer being unique (in having diabetes) at her junior school, but now being one of several pupils with diabetes.

Mother of P1  “We had more problems in the junior school, um... I think because she was the only one they couldn’t quite get their heads round stuff, and if she had a hypo they thought ‘oh we’ve got to ring the ambulance’...”

There is a dearth of research examining the experiences of young people with diabetes commencing secondary school, with attention being given to the shift from parental care to self-care during adolescence. Evidence indicates that there is a positive relationship between parental involvement in young people’s diabetes care and
"metabolic control (Anderson et al., 1997), however, there is an absence of studies examining whether this also applies to teachers involvement. Whilst young people with T1DM may be receptive to engaging in self-care behaviours (Allen et al., 1994; Frey et al., 1997), empirical findings indicate that poorer metabolic control is more likely if full responsibility is assumed too early (Giordano et al., 1992; LaGreca, 1990). The health risks associated with young people's premature assumption of responsibility for diabetes care could also be applied to being forced to represent themselves and their care needs on entry to secondary school. Consequently this transition is worthy of further examination.

13.2 School personnel: roles and regulations: "I'm actually quite scared to go unconscious at (school) because I don't think they'll know what they're doing".

There was an overall sense that school personnel and the school system played a significant part in young people's diabetes management. This finding is supported by previous studies (Nabors et al., 2003). The role of school personnel, in easing or exacerbating participants' fear of hypoglycaemia was evident in the study findings. Studies have implicated the importance of the application of treatment in reducing the risk of anxiety regarding hypoglycaemic collapse in young people (Nordfeldt & Jonsson, 2003). Participant two reflected on her doubts regarding school personnel's ability to provide her with treatment during a diabetic collapse.

P2 "I'm actually quite scared to go unconscious at (school's name) because I don't think they'll know what they're doing. If I had a hypo went low or something like that I think if I went unconscious they'd have to just ring 999 because they wouldn't know what to do".
Conversely participant seven reflected on his confidence in his school's ability to provide treatment during hypoglycaemic episodes.

P7 “Like Mr (Teacher's name) is a really cool teacher so he's ran back to the gym for me to get some dextrose for me so....there's some teachers who are quite good, really good with my diabetes”.

Breaking the school rules: “... and she said put that in the bin and you get a sanction”

Particularly there was a sense from the study findings that some teachers were not orientated to young people's health needs, but focused entirely on their education and the enforcement of school rules. Several participants reported being reprimanded for eating or drinking in class, by teachers who did not know that they had diabetes or who they perceived did not understand the importance of self-care. Participants also reported teachers questioning them undertaking self-care in front of their peers, which was considered discrediting (Link & Phelan, 2001), highlighting their difference from peers. This finding is endorsed by other studies of young people with chronic illnesses (Blanz, Rensch-Riemann, Fritz-Sigmund, & Schmidt, 1993; Dovey-Pearce et al., 2007, Lightfoot et al., 1999).

Participant eight reflected on being questioned undertaking care during a lesson, and his peers acting as advocates confirming his diagnosis and need to eat.
P8 "I was eating class and I thought everybody and the teachers knew but then when I went to French the French teachers she was like, I took my apple out and started eating okay and she said put that in the bin and you get a sanction. And everybody's like but he's diabetic, and then she was like oh sorry"

Participant two reported on being treated as if she was violating a school rule by asking to leave the lesson.

P.2 "well you're only allowed to get a drink of water if you've bought your bottle. Well I have forgotten my bottle and I have to say can I go and get a drink of water and teachers have said, you can but you're not allowed to”.

Participant seven also reported having been refused permission to leave the class to undertake care, which he attributed to teachers lack of understanding of diabetes.

P7. "when I first started it was kind of hard because the teachers wouldn't let me...well some of them didn't understand what diabetes was and well a few still don't, and they don't understand that I have to do blood tests like in lessons sometimes. So some of them won't let me out"

Not only was there the experience of being discredited in terms of being disciplined for breaking the school rules, but (although it is difficult to believe) some participants were clearly under the impression that teachers doubted their diagnosis.

P3. “Just I can't believe that people didn't believe me, even after I showed them my injections and everything”

P7 “Actually it's really bad because it's just... they're trying to ...they think you're a liar really, they don't believe you, so it's not too good".
Conversely, being allowed to leave the classroom enhanced participants’ confidence in their schools’ ability to provide support, and reduced the fear of being discredited through breaking school rules and peers observing care (Link & Phelan, 2001).

Participant six reflected on the reassurance she received from teachers when undertaking care during lessons.

P6 “they’ll go quick just go down now, get yourself sorted out and come back when you’re ready, so they know a lot more as well, so it’s like good yeah { } It’s quite helpful, its like if I’m eating a biscuit or having glucose tablets or something they’ll say are you OK?, if you need anything just tell me, and then I’m, not worried like, its not sneaky anymore”

**Being misunderstood**

There was a sense that changing glucose levels limited participants’ control over their representations of themselves, and they subsequently feared being misunderstood and thus discredited by teachers. The role of teachers’ understanding of diabetes in their attributions for pupils’ behaviour has been indicated in other studies (Cunningham & Wodrich, 2006). Participants reflected on their experiences in this regard:

P7. “Because obviously there’s some times in the day, I have my lessons at different times in the day and sometimes that can affect how my behaviour will be, I’m not like, I don’t strike at anyone, I’m not bad”

P4 “Well he (teacher) thought that I was acting naughty but like looking in the records and that it seems like I was having a low most of the times”
P9. “He should have understood a bit more that I was low and didn’t know what I was doing because I was talking complete nonsense”

14. Threats to academic achievement: “I don’t like missing school, because I’m getting behind with my school work”

Having diabetes presented a potential threat to self in terms of academic achievement. Several participants considered that diabetes-related absence, and leaving the class to undertake care had an impact on their academic work, namely falling behind with coursework and creating gaps in their understanding of some subjects. Previous studies have indicated that diabetes related school absences and cognitive impairments associated with fluctuating blood glucose levels may lead to academic underachievement (Nordfeldt & Jonsson, 2001; Rovet, 2000). The study findings indicated that some teachers moderated this threat, allowing participants to undertake coursework in lessons and encouraged their classmates to provide a resume of the part of the lesson missed whilst undertaking care.

P6 “I use to leave bits and bobs, and I used to have nothing finished”

P7 “I don’t like missing school, because I’m getting behind with my school work. Although I’m doing pretty well to get back to the level that I am at the minute

P9 “well the teachers don’t mind if I say miss ten minutes of a lesson because they know if I do miss something the person next to me will tell me and I will pick it up”
15. Healthcare professionals and parents: "Before she started that school me and my husband went in anyway and spoke to them..."

An interface between the role of schools in self-regulation and parents and health providers was evident. This is evidenced in previous studies implicating inter-agency collaboration in the quality of care for young people with chronic illness in schools (Leonard, 1992; Larcombe, 1995). It was clear that participants’ parents and diabetes health care team played a significant role in their self-regulation at school. Parents and Health providers acted as advocates representing the self-care needs of participants, particularly during incidents when school rules (e.g. being permitted to leave the classroom during lessons) and personnel’s poor understanding of the severity of hypoglycaemia threatened self-regulation. For example participant two reported her schools mismanagement of hypoglycaemic episodes (being sent unescorted across the school to receive treatment), and that her Physician wrote to the school and her Diabetes Nurse Specialist met with the Head Teacher to instigate changes in their management. Her Mother reflected on this process;

**Mother of P2.** "Because they were still sending her with blood sugar readings of 2.4 across to the mobile wing, down stars on her own, across the school, and what if there’s nobody there you know? The nurses and that were saying no you need to come to her, but they’re still taking no notice”

An ongoing process of negotiation between the young people and their parents was evident, with participants moderating their parent’s role as their advocate and intermediary with school personnel. Several participants reported that their parents and Diabetes Nurse Specialist had met with their teachers to explain their care needs prior to attending secondary school.
The Mother of participant one reflected on this preparation process:

Mother of P1 “before she started that school me and my husband went in anyway and spoke to them before the holidays started. And when she started off my husband went in again and had a meeting with them, with Julie the diabetic nurse and so we sort of prepared them anyway”

Another reported that she had received a poor school report following diabetes related absence, and that her father and Diabetes Nurse Specialist had negotiated with her school for her to receive support from learning mentors and extra tuition.

P6 “my diabetic nurse, she rang the school up and said we need to sort some things out. { } on the Monday I went back and the teacher said what can we do for you?”

One participant reported that her mother had telephoned the school to complain on her behalf when she had received a verbal warning from a teacher for eating in class

P9 “and I though they’d put a mark against my name and that was a green slip, but my Mum phoned up and actually he said I had no marks against my name”.

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Figure 5: Transition to secondary school: the influence of school on self-regulation

Benefits to self-regulation

- **Parents**
  - "Before she started the school me and my husband went in"

- **Professionals**
  - "My diabetic nurse she rang the school up"

- **School personnel**
  - "Some teachers are good, really good with my diabetes"

Self Regulation

Threats to self-regulation

- **Academic under achievement**
  - "I don’t like missing school because I’m getting behind with my school work"

- **Changing round for every teacher**
  - "We found initially they weren’t communicating with each other"
  - "I found things easier at primary school because people knew a bit more about me"

- **Roles and regulations**
  - "He should have understood a bit more that I was low"
  - "I have my lessons at different times of the day and sometimes that can affect my behaviour"

- **Changes to the rules:**
  - "I hadn’t known about it before that they were giving out the toilet cards"
  - "She said put that in the bin and you get a sanction"
16. Summary

The study findings indicated that participants experienced significant threats to their self-regulation whilst attending school, greater than the threats experienced at home. Threats to self included being perceived by peers only in relation to one's diabetes, being perceived as different by peers, and being discredited (bullied) by peers. This is in keeping with earlier theories examining chronic illness and stigma (Goffman, 1963, MacLeod & Austin, 2003), and is endorsed by previous studies of young people with diabetes (Dovey-Pearce et al., 2007).

Undertaking self-care at school increased the risk of disclosure of the young person's diagnosis of diabetes and exposure of their difference. Participants reported avoiding exposure by making decisions regarding whom they would disclose their diagnosis to and where and with whom they would undertake self-care. Participants undertook degrees of "passing" and protective disclosing described by previous authors (Joachim & Acom, 2000). Participants' appraisals of peers' attributions for self-care were part of this process, as indicated by previous authors (Susman-Stillman et al., 1997).

Negotiating with others and within the school system to avoid exposure whilst maintaining homeostasis was a significant theme, and the ambiguous nature of self and different context within which participants operated was also key in this oscillating process. However, theories regarding stigma and chronic illness failed to capture the many facets of the adolescent self.
School personnel, friends, and Healthcare Professionals played an important role in moderating threats. Threats were reduced when teachers allowed the young person to discreetly undertake self-care during lessons, and provided assistance and support during hypoglycaemic episodes. The running of the school system also moderated threats, with teachers ensuring that all personnel were aware of the young person's diagnosis and providing a pass permitting them to eat in the classroom and attend the toilet during lessons facilitating care.

Friends moderated threats to self-regulation, by providing practical and emotional support with self-care, escorting the young person to undertake care, and acting as an advocate by confirming the young person's diagnosis and care needs. The importance of friends in promoting self-care is supported by other studies (Schur et al., 1999). In addition, a relationship between moderating self-regulation at school and the behaviour of parents and Healthcare Professionals was evident. Parents, Specialist Nurses, and Paediatricians acted in an advocacy capacity, educating and negotiating with school personnel regarding their management of participants' care needs. This has been indicated in previous studies, although only from the perspective of healthcare providers (Leonard, 1992; Larcombe, 1995; Nabors et al., 2003).

16.1 Clinical implications: Stigma and young people with diabetes

Findings from the current study indicated that young people with diabetes may experience a degree of stigma regarding their condition and related care behaviours whilst at school. Particularly in situations involving non-friend peers. A relationship between participants' personal experience of stigma and the visibility of self-care was evident, with participants going to some lengths to hide (and possibly omit) aspects of
care, and conceal their diagnosis from others. This is a significant cause for concern given the known associations between poorer self-care and the physical and psychological complications of T1DM (Diabetes Control and Complications Trial Group, 1994).

Even brief lapses in young people’s self-care increases the risk of the irreversible cardiovascular and microvascular damage associated with T1DM (Diabetes Control and Complications Trial Group, 1994), and the likelihood of potentially fatal hypoglycaemic episodes or ketoacidosis (Bennet-Johnson et al., 1997; Davies et al., 1997). Poorer self-care and subsequent diabetes related school absences can lead to academic underachievement and lesser employment prospects (Milton et al., 2006). Poor glycaemic control as a consequence of poor self-care is also associated with an increased risk of depression in young people with T1DM (De Groot, Jacobson, Samson, & Welsh, 1999). Depression in young people with diabetes is a serious occurrence which may be more severe and more difficult to treat than in individuals without diabetes (Kokkonen & Kokkonen, 1995). Moreover there is a significant risk of suicide (Groholt, Ekenberg, Wichstrom, & Hakldorsen, 1998), and young people with T1DM who are depressed are likely to have poorer quality of life and lower feelings of self-worth (Grey et al., 1998; Grey et al., 1997).

Individual differences in participants’ perceptions of others attributions for care were apparent. For example, one participant feared that peers would think she was a drug addict if they discovered her needles. There is clearly a role for Clinical Psychologists and other Health Professionals in shaping young people’s cognitions regarding diabetes and related-care, by providing therapeutic intervention e.g. Cognitive
Therapy and fostering awareness amongst professionals of the development and importance of cognitions in self-care. Previous studies have indicated a role for cognitive based interventions in promoting self-efficacy and thus self-care (Silverman et al., 2004). However, there appears to be scant empirical evidence regarding their role in the management of stigma.

16.1.1 School personnel, rules, roles, and stigma

Findings also highlighted the importance of the school system and school personnel in controlling participants' level of exposure. Educating personnel regarding their role of the school and that of the system in containing stigma and providing privacy and support with care is warranted, for example the importance of staff being informed of the young person's diagnosis, and the use of equipment such as Medical Alert cards and toilet passes to facilitate young people's control. The absence of nurturing from teachers was evident in some accounts, and this caused participants anxiety and could endanger their health in terms of their fear of not receiving adequate treatment during hypoglycaemia. Contemporary disability legislation demands that schools must accommodate the health care needs of students (Disability Discrimination Act, 2005). However, it would appear from the findings of this study that schools require further intervention to fulfil this requirement.

16.1.2 The role of health personnel

The importance of Health Professionals acting in an advocacy capacity for both the young people and their parents was evident, particularly the need to promote a school system which perceives the child holistically and accommodates health and educational needs.
16.2 Weaknesses of the study

The study participants were resident within a restricted geographical area. They were also self-selected, and this significantly limits the generalizability of findings. Participants’ ages ranged from eleven to sixteen years, a period over which huge leaps in development are made. Whilst the qualitative design enabled participants to reflect on their earlier experiences at school, inevitably their perceptions of experiences may have changed over time, and a depth of data lost. The diversity of participants’ development may also have clouded the researcher’s perceptions of emergent issues. Also the period of time since diagnosis was variable, with only two participants having been diagnosed during adolescence. Whilst theoretical saturation was reached it was evident that the differences in experiences of those diagnosed in childhood and adolescence require further research.

16.3 Directions and recommendations for future research

Researchers have recommended that greater attention is given to the wider social context within which the young person with diabetes lives, as studies have traditionally focused on the role of the family (Glasgow & Anderson, 1995). As adolescence is a time when friendships develop and peers become increasingly important, the role of peers has become a particular research interest. The current study endorses the importance of peer relationships in young people’s diabetes management, and promotes further examination of their role and potential for involvement in therapeutic intervention. The study also promotes further examination of school personnel’s influence on self-care from a psychological perspective, and supports the view that studies examining teachers’ knowledge of diabetes are extremely limited in their applicability to young peoples lives. As already
acknowledged the current study sample was from a small geographical area, and
included young people from a wide age range. It is therefore recommended that the
study is replicated on a much larger scale using a longitudinal design, with a number
of participants in each age group recruited from different geographical areas.

17. Critical appraisal

Summary
Due to word constraints it is not possible to document my entire research journey in
detail. The aim of this chapter is to provide a summary of the experience, and to
indicate salient issues which emerged. The chapter reflects on the research experience
from the choice of study area through to completion of the written thesis. The chapter
is intended to be reflective, documenting the highs and lows of the research process
and the insight and skills I developed as a result.

17.1 Choice of area for the study
During my former career as a paediatric nurse I spent several years caring for children
and young people in hospital, and subsequently developed an interest in the impact of
chronic illness on the child and family. My specific interest in children and young
people with type 1 diabetes mellitus grew when my God-daughter Olivia (then
eighteen months old) was diagnosed with the condition. Olivia and I had regular
telephone conversations about her life, and how she managed her diabetes as her
social life flourished and she attended school. As Olivia neared the end of her primary
school years I was concerned as to how a large secondary school could accommodate
her health needs, as she learned to live with a chronic condition such as diabetes.
My concerns for Olivia's welfare prompted me to conduct a search of the literature examining care of young people with diabetes in schools. I was astounded by the paucity of studies in this area, which were predominantly North American in origin, and focused on teachers' knowledge of the condition as opposed to young people's experiences at school. This rather depressing discovery provided me with all the motivation I needed to examine myself the school experiences of young people with diabetes, and in particular to seek the opinions of the young people themselves.

17. 2 Choice of methodology

The aim of the research was to gain an understanding of how young people manage their diabetes at school, and how they view the role of school personnel and peers in this process. Consequently a qualitative method of enquiry was deemed most suitable. In addition as I had substantial experience conducting quantitative research and little conducting qualitative research I was keen to develop my knowledge and skills in qualitative methodology. The dearth of literature in this area indicated the salience of using a methodology that would generate theory. Grounded theory was chosen for this purpose, and also because a clear account of this structured methodology is provided by Charmaz (2006).

Epistemological stance

The social constructivist stance was considered to be the most suitable, as I would be interviewing young people (and possibly their parents) from a diverse range of backgrounds. This stance was considered to be capable of capturing the divergent range of contexts relevant to their experiences (Charmaz, 2006). Furthermore, when conducting the interviews I found that participants constructed their experiences
through the discussion, and that some appeared to be considering their experiences for
the first time. This confirmed to me that the constructivist standpoint was the most
appropriate.

17.3 Data Collection
My field supervisor, a Consultant Paediatrician in the Paediatric diabetes centre
undertook a lead role in recruiting. I think that her involvement helped to confirm the
authenticity of the study, and promoted a smooth process of recruitment. It was also
important for me to build up a relationship with the staff at the diabetes centre as I
was heavily reliant upon their goodwill for the recruitment process. I also consider
that my role as an external researcher allowed participants to speak more freely
regarding their experiences of managing their diabetes.

The Research Interviews
Contemplating and undertaking the interviews raised some interesting issues. I was
initially unsure as to how readily the young people would engage in the interview
process, and how their perceptions of me would influence this. The first participant
appeared quite hesitant to talk, and much of the interview was conducted with her
Mother. At this initial stage of the process I became concerned that I may not retrieve
sufficient data from the young people themselves. However, whilst some subsequent
participants were initially a little hesitant they spoke very freely of their experiences.
This could represent a self-selection bias, with the young people who agreed to
participate being willing to share their experiences, and those who were possibly
reluctant to share them choosing not to take part. I was also struck by the maturity of
the majority of participants, and wondered if this was a result of having experienced a chronic illness in childhood, or again a result of sampling bias.

According to Kvale (1996), the interview may be seen in terms of “a site for the construction of knowledge” which implies that the context of researcher and respondent is central to the data collection process. This necessitates the researcher exploring this context as part of the research process and as a result the context which frames the respondent’s descriptions of their experiences also becomes central to the data collection and analysis. From a grounded theory perspective, the researcher and the researched produce this knowledge together in partnership.

I interviewed participants using open ended questions, and strove to allow the participants account to guide the interview, generating a process by which both interviewer and interviewee contributed to creating and interpreting meaning, in keeping with grounded theory (Charmaz, 2006). I soon became aware that some participants and their parents were reflecting on their experiences for the first time. Participants made comparisons between their former and current experiences and constructed more elaborate accounts as they did this.

As the interviews were arranged via the Consultant Paediatrician I was curious as to how I would be perceived by the young people and their parents. As part of my preamble it was made clear the research was part of my Clinical Psychology training. This had a number of effects; following the interviews parents sometimes enquired as to whether the information was useful. This is a commonly identified phenomenon in which respondents attempt to please by giving the answers they anticipate the
interviewer will want to hear (Britten, 1995). I was also aware that participants sometimes spoke in medicalized terms, for example giving me blood sugar readings. This created a challenge for me as a researcher as there was an obvious temptation for me to fall into a nursing role and discuss means of managing care. The temptation to act as a clinician rather than a researcher in these situations is a well recognised problem for novice researchers such as myself (Britten, 1995).

There was also a risk that the interview process could elicit distress in participants or their parents, particularly as some described their experiences of being bullied in relation to their diabetes, or their feelings when they were first diagnosed. Subsequently I observed participants for the signs of distress and paced the interview accordingly. At times I was aware of my desire to act in a therapeutic capacity, particularly when participants described upsetting experiences. Through supervision I reflected on this tension between the role of researcher and clinician, and endeavoured to conduct interviews using an empathetic stance without commencing therapy. Interestingly, none of the participants became distressed during the interviews; rather many appeared to find the process cathartic and reported that it was helpful to reflect on their experiences.

17.4 Data analysis

The data collection and analysis were conducted in parallel, in keeping with grounded theory methodology (Charmaz, 2006). Initially data collection felt daunting, as a number of categories emerged and I was uncertain as to how to label and contextualize them. Once I had decided on focused codes I sought reassurance from original line by line coding that these were faithful to the data. Having agreed on the
final categories and themes I returned again to the original transcripts to confirm the “fit” of the theory and to reassure myself that it was faithful to participant’s accounts. Using my research diary, I recorded decisions regarding data analysis, and the outcomes of reflections on this process during supervision.

Revisions to the model

A number of revisions were required before the final model was complete. The initial model was too biomedical in emphasis, and failed to demonstrate the dynamic bidirectional interactions between the young person and others which influence self-regulation. In addition the initial model failed to accurately portray the shifting and many facets of self in the young people.

Supervision

I attended meetings with my academic supervisor which promoted an emergent theory that was grounded in the data and facilitated reflections on the developing model. Supervision also enabled me to articulate the emergent themes in a coherent manner, and to resist the temptation to be drawn into a biomedical viewpoint, as a result of my former experience as a nurse. My field supervisor and members of the Paediatric diabetes team added a contextualised view of the data, which fuelled my interest. The team were immensely supportive, and highlighted the clinical importance of the study. This provided me with further motivation to complete the project to the highest standard.
17. 5 Ensuring the quality of the research

It was reassuring to attend a qualitative support group together with my peers, where I undertook line by line coding and shared the final model with additional quality checks of the data. I also met with a peer from this group on a monthly basis to code transcripts together and reflect on the development of the model. The use of peer reviewed coding is a well-recognised method of ensuring the trustworthiness of the data analysis. However, there were also times when the group was a source of anxiety, particularly when peers appeared to be ‘ahead of me’ in terms of the completion of their study.

Reflexivity

Critiques of social constructivism highlight the researcher’s role in determining the enquiry through the experience, interpretation, and meaning they bring to it (Henwood & Pidgeon, 1992). Reflexivity informs the reader of how the researcher’s beliefs influence the analytic process (Charmaz, 2006). Consequently the reader is able to trace the process of analysis more easily. Undertaking a reflexive stance also promotes faithfulness to participants’ accounts in the analysis.

As Northway (2000) notes, the current positivist emphasis upon objectivity in health research means that researchers have tended to write themselves out of the text in the belief that to do otherwise would contaminate the data. The current view in qualitative research acknowledges that the researcher and the research cannot be separated, making any attempt at neutrality both undesirable and impossible to achieve. It is argued that reflexivity is a basic tenet of qualitative research, and making clear the reciprocal nature between the researcher and researched is a key aspect of this.
To facilitate the process I kept a reflective journal, documenting thoughts and decisions regarding the research process. This, together with copies of transcripts, coding, and memos facilitated ongoing evaluation of the research to take place (Charmaz, 2006). Reflexivity allowed me to observe how my own constructions of participant’s accounts guided the interviews and model development. It also enabled me to remain aware of how my previous experience as a nurse could influence the analysis, and to be explicit about where my ideas originated from.

17. 6 Limitations of the research project

The time constraints of the current research project meant that no more than nine participants could be recruited. Although theoretical sampling was employed, enabling me to pursue emergent lines of enquiry and to reach theoretical saturation, I considered that further research questions surfaced as the project developed, which I would also have liked to have pursued. In particular differences in the experiences of those participants who had been diagnosed during childhood, and those who had been diagnosed during adolescence were apparent. Also the sample was self-selecting, consisting of respondents to the initial invitation, who were subsequently eager to discuss their school experiences. However, whilst remaining within ethical boundaries and the constraints of the given project it was difficult to overcome this.

17. 7 Development of research knowledge

Completing the research project gave me invaluable insight into the process of undertaking grounded theory, in particular the need to remain reflexive and open to ideas whilst simultaneously taking steps to guide the data gathering process as issues emerged. I consider that undertaking the research interviews developed my skills in
this area, particularly in developing a style which gathers data (as oppose to providing therapy). I developed skills in guiding the interview process, remaining mindful of developing themes, but also being aware of new emergent issues. I was also able to experience and tolerate the anxiety created by “negative cases” and to see this as part of the ongoing research process. As a researcher I was able to develop and fine tune my interview style to adopt a more direct approach when required. The use of theoretical sampling also encouraged me to be comfortable with an emergent process, rather than one that is set from the beginning (as in my former quantitative research projects).

However, I encountered difficulties in writing up the findings, due to the word constraints of the thesis. In particular having to “ration” the length of participants quotes in the results section proved frustrating, and I had concerns that the reader would not receive a full picture of the findings but rather a snapshot. In order to manage this I attempted to write succinctly in other areas of the thesis to allow room for fuller quotes within the results section.

As a clinician I gained invaluable insight into the salience of young peoples experiences at school and the importance of considering these as part of the assessment of the young person and their difficulties as a whole. I was struck by the powerful role of others in shaping young participants’ experiences. Undertaking the interviews within the participant’s homes as opposed to a clinic enabled me to contextualize their experiences and consider the importance of the environment when conducting interviews.
Final reflections on conducting qualitative research

Prior to undertaking the research interviews I had made preparations for managing participants and parents distress. However, despite the fact that many were describing distressing experiences several participants and their parents had reported that they found the process cathartic, reflecting on how they had overcome their difficulties at school, and impressing upon me the importance that young people’s views regarding managing their diabetes at school were heard. This and the dearth of literature on young people’s management of their diabetes at school was confirmation that the study was worthwhile. One of the most positive aspects of the study was the idea that this could facilitate further examination of this important area.

As a final thought, I found undertaking this qualitative research project a valuable and enjoyable experience for me as a researcher, and I feel that I gained a number of very important practical research skills during the study. For example, one of the most important skills I learned was the need to “soften” my approach to research and reserve my previously highly structured approach for quantitative ventures.
References


Charmaz, K. (1990) Discovering chronic illness using grounded theory. Social Science and Medicine, 30, 1161-1172.


