

**Eating Attitudes and Behaviours in Young People
With or Without a Diabetic Sibling**

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Abstract

Objectives: Body image concerns and problematic eating attitudes and behaviours are recognised as an important concern for young people and clinicians. Identification of groups that might be at risk of developing such problems would enable prevention and early implementation strategies to be implemented. The aim of this study was to explore body image concerns and eating attitudes and behaviours in a community sample of young people aged between 12 and 17 years.

Design & Method: A cross sectional between groups design was employed. Participants completed self-report assessments measuring attitudes to body shape and weight, eating attitudes, behavioural features of eating disorders and eating disorder psychopathology. Siblings of young people with type 1 diabetes (n=12) were compared to a matched control group (n=12). Comparisons were also made between males and females and between age groups in a community sample (n=75).

Results: Compared with females without a diabetic sibling, females with a diabetic sibling reported more concerns about body weight and shape, greater disturbance in eating attitudes, and significantly higher levels of eating disorder psychopathology. Within the community sample, concerns about body shape and weight and disturbed eating attitudes were significantly higher in females than in males. The results highlighted a high prevalence of excessive exercise behaviour in both males and females. Excessive exercise was the only variable to differ significantly between age groups, with the highest prevalence reported in those aged 14 and 15 years.

Conclusions: The findings provide tentative support for the hypothesis that siblings of young people with type 1 diabetes are at increased risk of disturbed eating attitudes and behaviours, but require replication in a larger sample. Methodological implications of the study and suggestions for further research are discussed.

1: INTRODUCTION

The first aim of this study is to evaluate whether body image and eating attitudes and behaviour differ between young people with and without a sibling with type 1 diabetes. The second aim is to examine gender and age differences in attitudes and behaviours in a community sample of 12 to 17-year-olds. Diabetes is an increasing health problem in Scotland, and is currently the most common metabolic disease in children and adolescents (SIGN 55, 2001). As with other chronic conditions, diabetes not only impacts on the individuals themselves, but can also have significant implications for other members of the family, particularly as adapting to diagnosis and establishing a complex treatment regime demands considerable restructuring of family life. It is therefore important for Clinical Psychologists to develop their understanding of chronic illness beyond the perspective of the individual to the broader context of the family system.

Evidence suggests that there is an increased prevalence of eating disorders in young people with type 1 diabetes (Nielsen, 2002). A number of mechanisms have been proposed to account for this occurrence, including an increased focus on eating behaviour and dietary management in the treatment of type 1 diabetes. Siblings of children with chronic illnesses such as diabetes are reportedly at an increased risk for a range of adjustment problems (Sharpe & Rossiter, 2002). Furthermore, the siblings of children and adolescents with type 1 diabetes will be exposed, to some extent, to the same eating and diet focused environment as their diabetic counterparts. Therefore it seems possible that the siblings of children and adolescents with type 1 diabetes may

also be at increased risk of disturbed eating attitudes and behaviours. However, this possibility has yet to be investigated.

Eating disorders are recognised as an important concern for young people and clinicians. Identification of groups that might be at increased risk of developing such problems would enable prevention and early intervention strategies to be implemented. Such interventions are desirable as they are associated with improved prognosis (Bell, Clare & Thorn, 2001), therefore a greater understanding of eating attitudes and behaviours in siblings of children and adolescents with type 1 diabetes would make an important contribution to clinical practice.

Research into eating disorders, body image, weight and shape concern, and family functioning in chronic illness will be reviewed. Literature was identified from key word searches of the databases PsycINFO and MEDLINE. Key search terms included diabetes, sibling, illness, parent(al), adjustment, eating disorder, adolescent and child. The reference sections of appropriate studies were used to identify further studies.

1.1 Type 1 Diabetes

1.1.1 Background

The term diabetes mellitus, commonly referred to as diabetes, describes a group of chronic conditions which are estimated to affect more than two million people in the UK (Diabetes UK, 2007). One form of diabetes mellitus, type 1 diabetes, is currently one of the most common chronic conditions in children and adolescents, with Scotland claiming one of the highest incidence rates in the world (Diabetes Scotland, 2007).

The 2004 Scottish Diabetes Survey collated data submitted from 14 of the 15 NHS Boards in Scotland, and found there were 161,946 people with known diabetes across all age ranges. Of these, 15.6% were registered as having type 1 diabetes. The survey also provided a breakdown of number of known cases of diabetes by age group. Across Scotland there were 61 known cases of type 1 diabetes in children aged 0 to 4 years, 1302 cases in children aged 5 to 14 years and 3200 cases in those aged 15 to 24 years. The prevalence of type 1 diabetes in children and adolescents across Scotland is presented in Table 1 below.

In Highland, where the current study was based, the 2004 survey revealed 6 cases of type 1 diabetes in children aged 0 to 4 years, 101 cases in children and adolescents aged 5 to 14 years, and 156 cases in young people aged 15 to 24 years.

Table 1: Number of people registered with type 1 diabetes in the 2004 Scottish Diabetes Survey

	Ages 0-4yrs	Ages 5-14yrs	Ages 15-24yrs
Argyll and Clyde	1	106	243
Ayrshire and Arran	2	89	248
Borders	No data available		
Dumfries and Galloway	3	29	89
Fife	3	118	269
Forth Valley	1	67	147
Grampian	5	131	201
Greater Glasgow	11	251	644
Highland	6	101	156
Lanarkshire	9	61	400
Lothian	13	210	504
Orkney	1	7	12
Shetland	0	3	11
Tayside	6	129	276
Western Isles	No data available		
Scotland	61	1302	3200

1.1.2 Clinical features

Diabetes arises when the body is either unable to produce or unable to utilise insulin, the hormone responsible for regulating blood glucose levels. Glucose is the body's key source of energy, and comes from carbohydrates in the diet. There are two main forms of diabetes:

Type 1 (formerly described as insulin-dependent or childhood-onset)

Type 1 diabetes occurs when the insulin-producing cells in the pancreas are damaged or destroyed, resulting in a lack of insulin in the body. Individuals with type 1 diabetes require daily injections of insulin to survive.

Type 2 (Formerly described as non-insulin-dependent or adult-onset)

Type 2 diabetes occurs when the body is unable to utilise insulin effectively. According to the World Health Organization (2006), “Type 2 diabetes comprises 90% of people with diabetes around the world, and is largely the result of excess body weight and physical inactivity”. As such, this type of diabetes can often be managed with lifestyle changes alone. However, sometimes oral medication or insulin is required.

The current study focused on body image and eating attitudes and behaviours in siblings of children and adolescents with type 1 diabetes, because although the incidence of type 2 diabetes in children and adolescents is increasing, it is still relatively rare. There are only 34 individuals with type 2 diabetes under the age of 35 in Highland, where the current study was conducted. This represents only 0.7% of the total population with diabetes in this age range in Highland (Scottish Diabetes Survey, 2004). The remainder of the literature review will focus exclusively on type 1 diabetes.

1.1.3 Treatment

Treatment of type 1 diabetes is demanding, and requires the execution, monitoring and modification of a complex routine that can impact on the whole family. The treatment

regime is based on daily administration of insulin and self-monitoring of blood glucose levels, with the aim of keeping blood glucose levels within, or as close as possible to, the normal range. By doing so, the risk of long-term complications is decreased.

Hypoglycaemia, or blood glucose levels lower than the normal range, can be caused by not eating enough, injecting too much insulin, or extreme physical exertion (Wysocki, Greco & Buckloh, 2003). It can be avoided by balancing food consumption with insulin and levels of energy expenditure. Brief hypoglycaemia is easily treated by consuming simple sugars that can be absorbed rapidly, and has no lasting consequences. Although the majority of hypoglycaemic episodes are recognised and treated early, prolonged periods of hypoglycaemia can lead to permanent brain damage or death due to an inadequate supply of glucose reaching the brain (Tayside University Hospitals NHS Trust, 2000).

Hyperglycaemia, or raised blood glucose, can result from underdosing or omitting insulin injections, eating too much, high levels of stress, or infections (Wysocki, Greco & Buckloh, 2003). Hyperglycaemia is a common effect of uncontrolled diabetes. Prolonged or frequent episodes of high blood glucose can cause microvascular, macrovascular and neurologic complications, and are associated with increased morbidity and mortality (e.g. Diabetes Control and Complications Research Trial Research Group, 1994).

Insulin omission over a prolonged period leads to ketoacidosis, whereby the body begins to metabolise fat molecules to meet its energy demands because it is unable to use glucose. When fat is converted to energy ketones are produced as a by product and

the blood becomes dangerously acidic. If ketoacidosis is left untreated it can result in coma or death (NHS Direct, 2006).

Due to the long-term health implications of poorly managed diabetes, maintaining blood glucose levels as close as possible to the normal range is imperative. However, insulin administration constitutes only one aspect of treatment. In addition to insulin there are two other key variables involved in diabetes control: nutrition and exercise. These key components of diabetes management are illustrated in Figure 1.

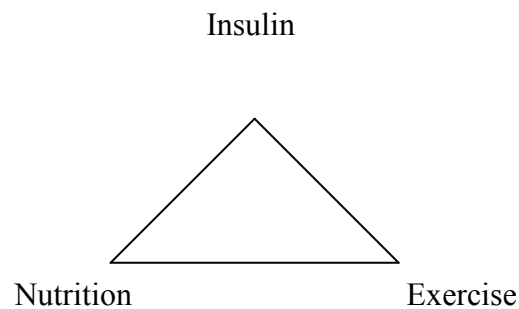


Figure 1: Key components of diabetes management

Generally speaking, consumption of food and drink causes the blood sugar level to rise, whereas insulin and exercise lead to a fall in blood sugar level. The task of maintaining a balance between insulin levels, nutritional intake and energy expenditure is crucial for sustaining good glycaemic control.

Insulin

The goal of insulin therapy is to provide adequate levels of insulin to enable the body to utilise sufficient glucose to meet its energy needs. Daily insulin requirements vary between individuals, and are influenced by factors such as age, weight, exercise

patterns, dietary patterns, and other lifestyle factors. The administration of insulin can be carried out by a number of means, involving a variety of insulin types and doses. Common methods of insulin administration include insulin pens (pen injector devices containing pre-filled units of insulin) and subcutaneous insulin pumps. Insulin pens usually look like a large pen and comprise insulin cartridges and disposable needles. The needle is inserted into the skin in the subcutaneous tissue between the fat layer and the muscle layer. A button is pressed on the end of the pen to deliver the dose of insulin. Subcutaneous insulin pumps deliver continuous doses of insulin via a tube with a needle at the end. The needle is placed under the skin and allows insulin to flow into the bloodstream at a rate controlled by the individual.

Nutrition

According to clinical practice consensus guidelines published by the International Society for Pediatric and Adolescent Diabetes (ISPAD, 2000), “Nutritional management is one of the cornerstones of diabetes care and education.” Good nutritional management can prevent episodes of hyperglycaemia and hypoglycaemia, and also reduce the risk of longer term complications.

The primary aim of nutritional management in type 1 diabetes is to offer a diet that:

- comprises a balance of each of the essential food groups
- is conducive to good physical and mental health
- is optimal for growth and development
- is able to offer the best possible glycaemic control.

ISPAD (2000) recommends that food intake should be adjusted to balance insulin action and exercise patterns. It is important that blood sugar levels are checked regularly to provide guidance on what type and quantity of food to consume and to avoid low or high blood sugar. This is usually achieved by carrying out a finger prick test, whereby the fingertip is punctured with a needle in order to obtain a drop of blood. The drop of blood is placed on a testing strip which is then inserted into a glucose meter, which provides a reading of the current blood sugar level.

It is a common misperception that diabetics are required to follow a special diet. In fact, dietary advice for children and adolescents with type 1 diabetes does not constitute a strict set of daily meal plans, but is in essence the advice offered to the general population in terms of healthy living. However, because insulin dose needs to be balanced against carbohydrate consumption, it is important that the individual is knowledgeable about different quantities and types of carbohydrate. Indeed, Colton et al. (1999) suggest that the necessity to eat specific quantities of carbohydrates at meal times, combined with an emphasis on the content and timing of food intake may create parallels between diabetic nutritional advice and weight-loss diets.

ISPAD dietary guidelines for the distribution of energy intake for children and adolescents with type 1 diabetes are shown in Figure 2 below.

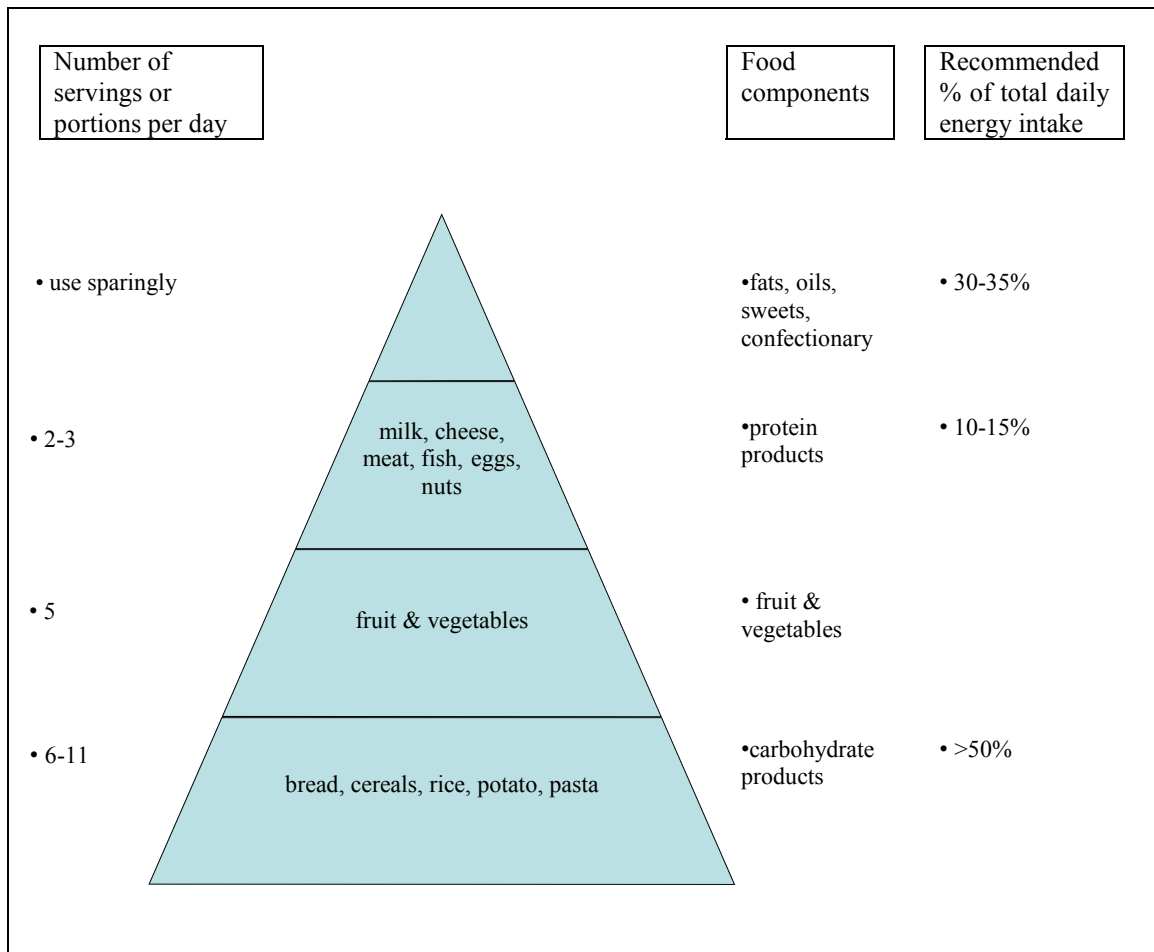


Figure 2: Dietary recommendations for the distribution of energy intake for children and adolescents with type 1 diabetes, reproduced from ISPAD (2000).

According to these dietary guidelines the overall distribution of total energy intake should be greater than 50% carbohydrate, 30-35% fat, 10-15% protein and five portions of fruit and vegetables each day. However, those under the age of five require a more energy-dense diet (ISPAD, 2000).

Although older children and adolescents might monitor their own carbohydrate intake, much of the responsibility falls to parents as they are usually the ones purchasing and preparing the family's meals. As a consequence, dietary restrictions may be imposed

on the whole family. Furthermore, ISPAD (2000) state that “It is unlikely that meal planning will be successful unless the whole family is involved in making appropriate changes based on healthy-eating principles”. Therefore in childhood, the healthy diet is not just emphasised for the affected individual but for all the family members.

Parents play a central role in the child’s feeding environment, and from the moment of birth they are responsible for meeting the child’s nutritional needs. Parents often attach a great deal of importance to the role of feeding, as they often believe that their child’s feeding behaviours are a direct reflection of their parenting success (Linscheid, Budd & Rasnake, 2003). Given the focus on dietary control that is essential to the management of diabetes, the need for the child to eat consistent quantities and types of food on a regular basis might generate parental anxiety in relation to food and eating. In a study exploring mothers’ experiences of raising young children with type 1 diabetes, Sullivan-Bolyai et al. (2002) found that of ten diabetes management variables, hypoglycaemia was rated as the biggest concern. Hypoglycaemia usually occurs in individuals with type 1 diabetes as a result of not eating enough. If diabetic dietary requirements cause parental anxiety, then parental anxieties about food, eating and weight might potentially be transmitted to and internalised by other members of the family. Although the mechanisms of transmission are still under investigation, there is considerable evidence for a connection between parental anxiety and child anxiety. For example, Turner, Beidel and Costello (1987) found that children of parents with an anxiety disorder are more than seven times more likely to meet criteria for an anxiety disorder than children of parents without an anxiety disorder.

Exercise

During exercise, the body may consume as much as 20 times more energy than usual (ADA/ACSM, 1997). To meet this energy requirement, a number of metabolic adjustments, by and large hormonally mediated, maintain normal blood glucose levels. These hormonal adaptations during exercise are effectively lost in individuals with type 1 diabetes. Subsequently, if the individual has too little insulin in his/her circulation due to inadequate insulin administration there is a danger of ketoacidosis. However, the presence of high levels of insulin due to excessive administration can result in hypoglycaemia.

Irrespective of these concerns, exercise is an important treatment component that offers both physical and psychological benefits. In addition to assisting with weight control and promoting cardiovascular health (Wysocki, Greco & Buckloh, 2003), regular exercise reduces the amount of glucose in the blood. Consequently, less insulin is required to control an individual's blood glucose level.

According to a position paper issued by the American Diabetes Association (ADA) and the American College of Sports Medicine (ACSM):

‘All levels of exercise, including leisure activities, recreational sports and competitive professional performance, can be performed by people with type 1 diabetes who do not have complications and are in good blood glucose control. The ability to adjust the therapeutic regimen (insulin and diet) to allow safe participation and high performance has recently been recognised as an important management strategy in these individuals’ (ADA/ACSM, 1997).

This guidance illustrates the importance of having satisfactory understanding of metabolic and hormonal responses to exercise and the ability to self-monitor blood glucose data and adjust insulin therapy accordingly. The ADA and ACSM provide the following summary guidelines to help those with type 1 diabetes regulate glycaemic response to exercise:

1. Metabolic control before exercise;
2. Blood glucose monitoring before and after exercise;
 - Identify when changes in insulin or food intake are necessary;
 - Learn the glycaemic response to different exercise conditions;
3. Food intake;
 - Consume added carbohydrate as needed to avoid hypoglycaemia;
 - Carbohydrate-based foods should be readily available during and after exercise.

Children may experience greater variability in blood glucose levels than adults, while adolescents may experience greater difficulty in controlling blood glucose levels due to hormonal changes (ADA/ACSM, 1997). These added problems might contribute to high levels of concern in the family, particularly if there are additional concerns about the competence of the child to take precautionary measures and adjust their therapeutic regimen when exercising.

As in the case of dietary management, much of the responsibility for implementing exercise guidelines will fall to parents, especially when the child is young. Any changes in behaviour to accommodate the treatment regime will affect the whole family and therefore impact on siblings.

1.2 Body Image and Dieting

1.2.1 Problem eating attitudes and behaviours

In western cultures great importance is placed on physical appearance. In general, females value being thin and males value being muscular, as these characteristics are often associated with attractiveness (Ricciardelli & McCabe, 2001). According to Ricciardelli and McCabe (2001), researchers have found evidence that these values are internalised by children as young as seven years old. Children aged between 7 and 11 years old consider overweight children to be lazier, less attractive, less happy and less popular than average size children (Tiggemann & Wilson-Barrett, 1998). Hill and Silver (1995) found similar negative attributions when they asked nine-year-old children to rate thin and overweight body shapes on a number of dimensions. An overweight body shape was associated with poor social functioning, impaired academic success and low perceived health.

Body image, or a person's perception of their physical appearance, has been extensively examined in children, adolescents, and adults. Studies examining body image concerns in children suggest it is one of the main risk factors in the development of problematic eating attitudes and behaviours (e.g. Killen et al., 1994; Thompson et al., 1995), although the mechanisms by which this development occurs have not yet been clarified.

Body image concerns in children and adolescents have been assessed using three main types of measure: figure preferences, video-projection techniques, and questionnaires (Ricciardelli & McCabe, 2001). Figure preferences require the respondent to indicate perceived and ideal body sizes from a series of approximately five to seven drawings

(e.g. the Children's Body Image Scale, Truby & Paxton , 2002). By comparing the perceived and ideal figure, an estimate of the degree of dissatisfaction is obtained. Video-projection techniques require the respondent to manipulate the width of a distorted image of their body on a video screen until they think it represents their actual body size. The degree to which body size is over or under-estimated is used as a measure of body image disturbance. Finally, questionnaires are often used to assess attitudes and beliefs about the body (e.g. the Body-Esteem Scale for Children, Mendelson & White, 1993).

Although measures of body image have been used reliably with children, Ricciardelli and McCabe point out that using such measures is more difficult with children than with adults. For example, children may have difficulties understanding some of the concepts and questions, and are often more distractible and more suggestible to questioning than adults (Waterman, Blades & Spence, 2000).

Concerns about weight, shape, and overall body image are common in the general population. For example, in a community sample of 11-16 year old girls (n=1068), Cooper and Goodyer (1997) found that more than one in ten 11-year-olds (14.5%) had significant concerns about weight and/or shape, as did almost one in five 16-year-olds (18.9%). Ricciardelli and McCabe (2001) reviewed studies that utilise figure preference tasks, and found that 28% to 55% of girls want to be thinner, whilst 4% to 18% would like a larger body size. In contrast, estimates of the number of boys who would like to be thinner range from 17% to 30%, whereas 13% to 48% would like a larger or broader body size. From their review of the literature, Ricciardelli and McCabe (2001) concluded that between 8.8% and 14% of girls, and between 4.7% and

8% of boys score above the threshold for disordered eating on the Children's Eating Attitude Test (ChEAT).

Research focusing on the development of image concerns in children has found consistent evidence for an association with gender, age and body mass index (BMI), which is a statistical measure of a person's weight scaled according to their height (Ricciardelli & McCabe, 2001). Girls generally desire a thinner body size than boys and this gender difference is repeatedly found in children as young as eight. With increasing age, body image concerns tend to become more marked, especially in girls. Both boys and girls with a larger BMI want to be thinner.

Although evidence indicates body image concerns are common, it would seem that not all children and adolescents act on their concerns. While Cooper and Goodyer (1997) found high levels of weight and shape concern among their community sample of 11 to 16 year olds, only in 15 and 16 year olds was the occurrence of concerns associated with a significant degree of co-existing behavioural disturbance. Similarly, Schur, Sanders and Steiner (2000) found that although 50% of a sample of 62 eight to thirteen year olds desired a thinner body shape, only 16% indicated they were actively engaged in trying to lose weight.

1.2.2 Onset of dieting

A number of domains have been implicated in the onset of dieting. These include individual characteristics such as weight status and body satisfaction, as well as features of the family environment such as family dynamics and maternal eating attitudes and behaviours (Sinton & Birch, 2005).

Huon and Walton (2000) sought to identify variables that distinguish dieting girls from non-dieting girls by comparing girls aged 12 to 16 who had begun dieting in the past six months with those who have never dieted on measures of assertiveness, familial context and tendency to conform to other peoples wishes or expectations. Girls who had just started to diet could be distinguished from those who had never dieted by higher levels of perceived peer and parental influence. Peer influences included competition and appearance focused social comparison, whereas parental influences involved positive parental feedback when trying to lose weight and compliance with parental pressure to lose weight. A limitation of this study is that no mention was made of weight status or BMI, therefore it is not clear whether those who perceived greater levels of peer and parental influence had a higher BMI. This may be of particular relevance because research indicates that weight status may play a significant role in the onset of dieting. A longitudinal study conducted by Sinton and Birch (2005) explored the contribution of weight status to the onset of dieting in 183 pre-adolescent girls at age five, seven and nine. They found that weight status accounted for a large proportion of the variance in dieting behaviour, both independently and in combination with a range of psycho-social variables already identified as risk factors. High BMI in early childhood was associated with a greater probability of dieting at age nine. They did not find maternal feeding practices and family eating environment predicted the emergence of dieting.

To investigate the differential impact of social influences, perceptions of family relations, and modelling of mothers' attitudes and behaviours on body image and dieting behaviour, Byely et al. (2000) assessed 77 girls (aged 10 to 14) and their mothers. At baseline, age and BMI were found to significantly account for variance in

body image and were predictive of dieting behaviour. However, negative perceptions of family relations significantly accounted for variance in girls' dieting behaviour over and above the effect of age and BMI (Byely et al., 2000). Daughters' perceptions of negative family relations at baseline were also predictive of increased dieting 12 months later.

A series of research studies conducted by Birch and colleagues also provide evidence that family environment can impact children's eating attitudes and behaviours. For example, family environment can impact on children's ideas about dieting (Abramovitz & Birch, 2000), the development of disordered eating behaviours (Davison & Birch, 2001), and the development of disinhibited eating patterns (Birch, Davison & Fisher, 2003). In particular, there is a growing body of literature examining the transmission of parental eating attitudes and behaviours to their children, and the mechanisms by which this might occur. It would therefore seem reasonable to assume that parental beliefs and behaviours might be an influential factor in shaping a child's food and eating related attitudes and behaviours since they occupy a central role in the development of feeding skills and food preferences. Among the mechanisms proposed to date, Pike and Rodin (1991) suggest a role for the modelling of parental dieting and weight concerns, while Thelen and Cormier (1995) suggest direct encouragement from a parent to diet or lose weight may be important.

The transmission of eating attitudes and behaviours has been described by Baker, Whisman and Brownell (2000) as, "a process whereby children share and internalise values, attitudes, and beliefs held by their parents" (p.376). Studies that have attempted to examine the transmission of eating attitudes and behaviours have so far

produced mixed results. For example, Pike and Rodin (1991) found that mothers of daughters with disordered eating were themselves more eating disordered compared with mothers of girls who were not eating disordered. Conversely, Attie and Brooks-Gunn (1995) found that mothers' scores on the Eating Attitudes Test were not predictive of daughters' scores. Attempts to determine the mechanisms through which transmission might occur have identified a number of possibilities. For example, Smolak, Levine and Schermer (1999) examined the relative contributions of direct parental comments about a child's weight and parental modelling of weight concerns through behaviour on the child's body esteem, weight-related concerns and weight-loss attempts. They found direct parental comments, especially by the mother, to be a more powerful influence than parental modelling of weight and shape concerns. In a study of modelling and control theories of parental influence, Brown and Ogden (2004) found evidence that both of these mechanisms can influence children's eating attitudes and behaviours. Results indicated strong associations between parent and child snack food intake and body dissatisfaction, providing support for the modelling theory of parental influence. In addition, children whose parents reported a greater use of food to exercise control over their child's behaviour showed increased levels of body dissatisfaction.

According to Baker, Whisman and Brownell (2000), mixed results about whether parents transmit eating attitudes and behaviours to their children can be attributed to a number of factors such as the diversity of methods, samples and measures used. While some studies measure parent self-report, others measure child self-report, with few studies attempting to assess to what degree parents and children agree on ratings of attitudes and behaviours (Baker, Whisman & Brownell, 2000). It is difficult to

measure the transmission of parental attitudes and behaviours for a number of reasons. Firstly, it is hard to know whether parents and children give unbiased accounts of either their own beliefs and behaviours or their perceptions of the other's beliefs and behaviours. Parents may feel uneasy about reporting criticising their child, and similarly the child might be apprehensive about stating criticism on the part of a parent. Baker, Whisman and Brownell (2000) suggest that acquiring ratings from additional sources such as spouses may overcome this difficulty. Secondly, it is not easy to determine whether it is the transmission of beliefs and behaviours being measured or projection on the part of the child. In a study of college students and their parents, Baker, Whisman and Brownell (2000) found that students' eating and weight related attitudes and behaviours had a stronger association with their perceptions of parental behaviour than with parents' own reports.

Whether parental beliefs and behaviours are transmitted to their children or whether it is children's perceptions of their parents' beliefs and behaviours that are significant, it remains that the family system is capable of wielding considerable influence over the child's eating and weight/shape related attitudes and behaviours. Furthermore, while additional research is needed to determine possible mechanisms, it remains that weight and shape concerns indisputably comprise a fundamental ideational component of eating disorders.

1.3 Eating Disorders

1.3.1 Background

Eating disorders are characterised by extreme disturbances in eating behaviour and comprise a broad range of severity among sufferers. Addressing the needs of people with eating disorders presents a significant challenge to health care professionals, as they are one of the most complex disorders to treat and have the highest mortality rate of any psychiatric disorder (Bell, Clare & Thorn, 2001). On account of poor long-term prognosis and high mortality rates, prevention and early intervention is desirable, and identifying groups at increased risk of developing an eating disorder is therefore crucial.

1.3.2 Clinical features

A number of diagnostic criteria exist for classifying eating disorders, the range of which vary between the two most commonly used diagnostic systems, the International Classification of Diseases, 10th Revision (ICD-10) (WHO, 1992) and the Diagnostic and Statistical Manual of Mental Disorders, 4th Edition (DSM-IV) (American Psychiatric Association, 1994).

The range of eating disorder diagnoses available using the ICD-10 and DSM-IV systems are presented in Table 2 below.

Table 2: Eating disorder diagnoses. (For full DSM-IV criteria for AN, BN and EDNOS, see appendix 1).

ICD-10	DSM-IV
<ul style="list-style-type: none"> ▪ Anorexia Nervosa ▪ Atypical Anorexia Nervosa ▪ Bulimia Nervosa ▪ Atypical Bulimia Nervosa ▪ Overeating associated with other psychological disturbances ▪ Vomiting associated with other psychological disturbances ▪ Other eating disorders ▪ Eating disorder, unspecified 	<ul style="list-style-type: none"> ▪ Anorexia Nervosa <ul style="list-style-type: none"> - Restricting type - Binge eating/purging type ▪ Bulimia Nervosa <ul style="list-style-type: none"> - Purging type - Non-purging type ▪ Eating Disorder Not Otherwise Specified (EDNOS)

DSM-IV diagnostic criteria discriminate between three main eating disorders, anorexia nervosa (AN), bulimia nervosa (BN), and eating disorder not otherwise specified (EDNOS).

Anorexia Nervosa

Anorexia nervosa (AN) is typified by low weight and an extreme fear of becoming fat. Individuals often have a sense of dissatisfaction with regards to their appearance, characteristically holding distorted cognitions about being overweight when in fact they are typically underweight. In boys, concerns seem to centre more on body shape than body weight (Lask & Bryant-Waugh, 2000).

Preoccupation with food, eating, weight and body image leads individuals with anorexia nervosa to engage in one or more of the following strategies in order to lose weight or avoid gaining weight:

- Restriction of food intake;
- Self-induced vomiting;
- Excessive exercising;
- Laxative misuse.

Post-menarchal females with anorexia nervosa (AN) usually cease to have normal menstrual periods.

Bulimia Nervosa

Like anorexia nervosa (AN), bulimia nervosa (BN) is characterised by concerns about weight and body image. The individual engages in episodes of overeating (bingeing), which are accompanied by a sense of loss of control. In an attempt to minimise or prevent any weight gain that might result from overeating, the individual performs compensatory behaviours known as purging. Purging most commonly takes the form of self-induced vomiting or laxative misuse, but can also include diuretic misuse and fasting.

Eating Disorders Not Otherwise Specified (ED-NOS)

Eating Disorder Not Otherwise Specified (ED-NOS) refers to a group of disorders that do not meet the diagnostic criteria for a specific disorder such as AN or BN. For example, an individual might present with many of the symptoms of AN, but their Body Mass Index (BMI) is within the normal range, or they continue to experience a normal menstrual cycle, both of which are important in the diagnosis of AN.

Turner and Bryant-Waugh (2004) reported that of 190 adults with an eating disorder referred to a community eating disorder service 134 (70%) had EDNOS. This represents a substantial proportion of eating disorder presentations (Turner & Bryant-Waugh, 2004).

In clinical practice it is not uncommon for patients to present with difficulties that do not match up with diagnostic criteria, especially in child and adolescent populations. In such cases clients are usually offered intervention to meet their particular needs.

1.3.3 Prevalence of eating disorders amongst children and adolescents

Estimates of the prevalence of eating disorders among children and adolescents vary, which to some extent can be accounted for by discrepancies in definition and diagnosis across studies (Gowers & Bryant-Waugh, 2004). These difficulties are further complicated by the fact that very few research studies focus exclusively on children, while adolescent patients are often included in adult studies. Mitchell and Carr (2000) report that between three and four per cent of adolescent females are thought to suffer from an eating disorder (1% AN and 1-3% BN), while Gowers and Bryant-Waugh (2004) refer to a recent review that estimates the prevalence of AN to be 0.3% and the prevalence of BN to be about three times greater than this (van Hoeken, Seidell & Hoek, 2003).

Although eating disorders are largely viewed as a female problem (Cohane & Pope, 2001), males can and do develop eating disorders. Doyle and Bryant-Waugh (2000) reported that previous studies report male to female ratios of between 1:29 and 1:10. However, Doyle and Bryant-Waugh highlighted that these figures did not refer

specifically to children and that the situation seemed to be somewhat different in children. Fosson, Knibbs, Bryant-Waugh and Lask (1987) reported that of 48 children with AN, 13 (27%) were boys. Similarly, Higgs, Goodyer and Birch (1989) reported that of 27 children that met diagnostic criteria for AN, 8 (30%) were boys.

In one of the largest studies to date, Lucas et al. (1991; as cited in Doyle & Bryant-Waugh, 2000) consulted medical records from a 50 year period in Rochester, Minnesota. Between 1935 and 1984 the incidence rate of AN in those aged 10 to 14 years was 25.7 females per 100,000 of population per year and 3.7 males per 100,000 per year. In the 15 to 19-year-old category the incidence was higher, at 69.4 females and 7.3 males per 100,000 of population per year. There were no recorded cases of AN in children aged between 0 and 9 years.

Keel, Klump, Leon and Fulkerson (1998) describe that research on eating disorders in males is limited, largely due to clinical biases and small sample sizes. They suggest that to overcome this difficulty it is important to study disordered eating attitudes and behaviours rather than just diagnosable eating disorders. A major contribution of this study will be to examine gender differences in eating attitudes and behaviours in a community sample of 12 to 18-year-olds.

Eating disorders represent a wide range of severity, and although diagnostic criteria are useful, they fail to encompass the range of difficulties encountered in clinical practice (Mitchell & Carr, 2000). Whilst there is very little research dedicated specifically to eating disorders in children, a recent review by Gowers and Bryant-Waugh (2004) reported that, although AN does not usually occur before the age of eight years, and

BN is rare in those under the age of twelve, clinically significant variants do arise in children and adolescents, probably at higher rates than full syndromes.

Studies indicate that not all individuals suffering from an eating disorder are receiving treatment or are known to health services. For example, Fairburn and Cooper (1982) recruited bulimic subjects directly from the community and found that 97.5% of the bulimic subjects identified were not receiving treatment. Similarly, Welch and Fairburn (1994) found that 90% of bulimic subjects identified in a community sample were not in treatment. Fairburn et al. (1996) hypothesised that those receiving treatment might be predicted to exhibit greater symptom severity and longer time since symptom onset. As such, they conducted a study comparing clinic subjects with BN to those recruited from the community via GP lists. Although clinic subjects were found to have more severe eating disorders, they did not differ from community subjects in terms of demographic characteristics, the duration of disorder or the level of general psychiatric disorder.

Given that there are adults in the community suffering an eating disorder but not receiving treatment, it is also possible that there are children and adolescents with untreated disorders. Identification of groups at increased risk of developing an eating disorder offers potential for delivering early intervention and prevention programmes. The first 18 years of life are critical in terms of cognitive, physical and social development, therefore early intervention with children and adolescents might be considered particularly important to increase the likelihood of positive adjustment.

1.3.4 Risk factors for onset of eating disorders

The onset of an eating disorder is not associated with any one risk factor, rather it is likely to result from a range of interacting factors. However, as many studies are limited in their focus, little is known about the relative importance of the various risk factors and how they might interact. Lask (2000) cites evidence for the involvement of genetic, biological, personality, psychological, familial and socio-cultural factors, and emphasises the importance of differentiating between predisposing, precipitating and perpetuating factors.

Fairburn et al. (1997) found evidence to support their hypothesis that the onset of BN is associated with both general risk factors for psychiatric disorder and risk factors for dieting. When compared with general psychiatric control subjects, subjects with BN reported significantly greater levels of exposure to childhood obesity, parental obesity and critical comments by family about shape, weight or eating. This study demonstrates that factors that increase the risk of dieting are common amongst those with BN and supports the notion that family environmental factors are particularly influential in the onset of BN.

When compared to individuals with binge-eating disorder, those with BN show no difference in terms of individual risk factors, but have greater exposure to risk factors for psychiatric disorders in general (Fairburn et al., 1998).

Fairburn et al. (1999) looked at risk factors for AN, and found that in comparison to general psychiatric control subjects, those with AN displayed greater levels of perfectionism and negative self-evaluation, but no difference in terms of dieting

vulnerability factors (critical comments from family about weight, shape, or eating; childhood obesity; parental obesity). When subjects with AN were compared to those with BN, those with BN were found to have greater exposure to dieting vulnerability factors, earlier menarche and greater exposure to parental psychiatric disorder during childhood.

Lask (2000) presents a multifactorial model to understand the origins of eating disorders in terms of predisposing, precipitating and perpetuating factors. This is presented in Figure 3.

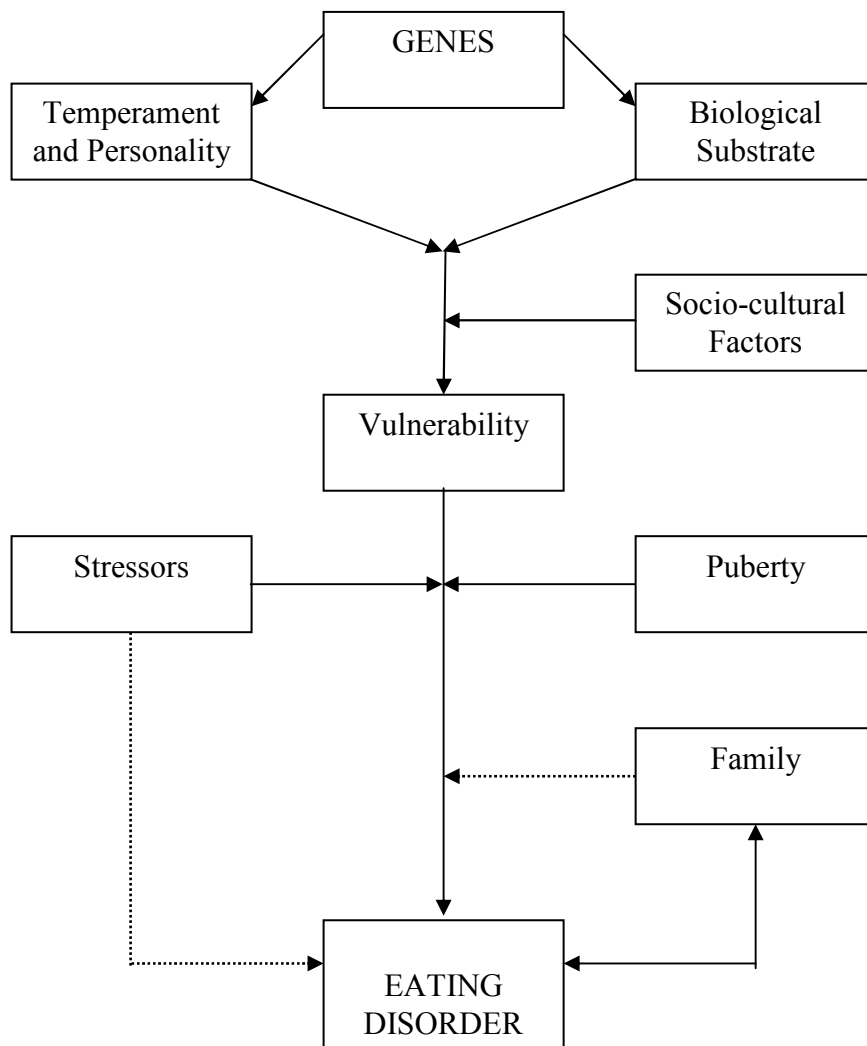


Figure 3: Multifactorial model to illustrate the development of an eating disorder, reproduced from Lask & Bryant-Waugh (2000, p.74).

According to Lask's model, predisposing factors such as a genetic vulnerability may be expressed via biological factors and personality traits and through socio-cultural demands. In turn, socio-cultural demands might serve to precipitate and perpetuate the difficulties. Other precipitating factors include "various stressors such as pubertal development, trauma, low self-esteem in which self-evaluation is based only on weight, shape and appearance, family tensions or problems, school and peer group pressures, illness or loss" (Lask, 2000; pp.73-74). These factors may also operate to perpetuate the difficulties.

1.3.5 Treatment

A recent review of the literature conducted by Gowers and Bryant-Waugh (2004) concluded that the evidence base for effective interventions for the treatment and management of eating disorders is weak. However, current guidelines advocate a comprehensive multi-disciplinary approach that encompasses the patient's physical, social and psychological needs.

In 2006 NHS Quality Improvement Scotland (QIS) published recommendations for healthcare professionals in Scotland in identification, management and treatment of eating disorders in adults, adolescents and children (NHS QIS, 2006). These recommendations were adapted from National Institute for Health and Clinical Excellence (NICE) guidelines for England and Wales (NICE, 2004), with changes to reflect differences in the legal framework and the way that services are provided in Scotland. Psychological intervention is recommended as the first choice treatment for AN, whereas self-help programmes, anti-depressant medication and specifically

adapted cognitive behaviour therapy are the treatment choices for BN. If researchers are able to identify groups at increased risk of developing an eating disorder, there is potential to deliver prevention and early intervention, as recommended by Bell, Clare and Thorn (2001).

1.4 Eating Disorders and Type 1 Diabetes

1.4.1 Prevalence

The notion that the presence of an eating disorder may be increased in type 1 diabetes has received a great deal of attention in the research literature. Although many studies have found evidence that eating disorders are more prevalent among the diabetic population than the non-diabetic population, differences are often not significant (Colton, Rodin, Olmsted & Daneman, 1999). However, sample sizes are frequently inadequate to provide the necessary statistical power (Colton et al., 1999). Furthermore, Peveler (2000) highlights that the assessment of eating disorders in this population is problematic as any appraisal of eating attitudes and behaviours is likely to be confounded by the presence of diabetes.

Peveler (2000) describes the clinical features of eating disorders as largely equivalent in both diabetic and non-diabetic populations. However, individuals with type 1 diabetes are able to deliberately reduce or exclude the prescribed dose of insulin as an additional method of weight reduction. This strategy is often referred to as insulin misuse (e.g. Affenito et al., 1997).

In one of the largest studies to date, Jones, Lawson, Daneman, Olmsted and Rodin (2000) found that female diabetics aged between 12 and 19 years were 2.4 times more

likely than controls to meet DSM –IV criteria for an eating disorder, with ED-NOS being the most common diagnosis. Those in the diabetic group were also 1.9 times more likely to have a sub-threshold disorder than controls. Similarly, in a population-based cohort of 89 female adolescents with type 1 diabetes compared with controls, Engström et al. (1999) found that 6.9% of the diabetic group met diagnostic criteria for ED-NOS, and a further 10% had a sub-threshold disorder. No cases of AN or BN were identified in either group.

Nielsen (2002) conducted a meta-analysis of studies investigating the prevalence of eating disorders in females with type 1 diabetes. There was not found to be any support for an increased prevalence of AN, but there was evidence that BN, ED-NOS and sub-threshold eating disorders are increased in type 1 diabetes.

1.4.2 Mechanisms

A number of hypotheses have been suggested to account for why individuals with type 1 diabetes might be at increased risk of developing an eating disorder.

Factors associated with the stress of living with a chronic illness

Adjustment to the diagnosis of a chronic illness represents a major transition in an individual's life. Diagnosis can trigger a range of emotions including anger, sadness and bereavement at a real or perceived sense of lost opportunities. It is thought that the stress of adapting to a diagnosis such as diabetes might lower the threshold for the onset of an eating disorder in those susceptible to such difficulties (Colton, Rodin, Olmstead & Daneman, 1999).

Weight gain associated with commencement of insulin treatment

Prior to being diagnosed with diabetes it is common for individuals to experience considerable weight loss owing to dehydration and insufficient insulin. Once insulin therapy commences and the individual's insulin levels begin to stabilise, the lost weight is usually regained quite rapidly (Colton et al., 1999). In addition, evidence indicates that adolescent girls with type 1 diabetes have a higher BMI compared to their peers (e.g. Engstrom et al., 1999). Increased BMI as a result of commencing insulin therapy, or generally high BMI might trigger the onset of dieting or a binge-purge cycle.

Availability of insulin misuse as a method of weight reduction

The omission or manipulation of insulin dose offers an accessible and convenient method of avoiding weight gain as without insulin the body is unable to metabolise glucose (Rodin et al., 2002).

Focus on dietary management in the treatment of type 1 diabetes

Although diabetics are recommended the same healthy eating guidelines as the general population, Colton et al. (1999) say that diabetic dietary advice is in many respects similar to a weight loss diet. For example, the individual may be encouraged to eat in accordance with a particular schedule rather than in response to internal cues of hunger. If you do not eat in response to internal hunger cues you may develop an external eating style (Schachter, 1971), which is associated with unhealthy eating patterns (Conner et al., 1999; Newman et al., 2007), binge eating episodes (Pinaquy et al., 2003), and a negative sense of self worth (Braet & van Strien, 1997). In addition to the emphasis on content and timing of food, there is a necessity to eat specific

quantities of carbohydrates at meal times and balance food consumption with energy expenditure.

Family functioning

Research indicates that family functioning is a risk factor for the onset of eating disorders in non-diabetic adolescents. More recently, investigators have started to consider the relationship between family functioning and eating disorders in individuals with type 1 diabetes. For example, Maharaj, Rodin, Olmsted, Connolly and Daneman (2003) found that deficits in self-concept, maternal weight and shape concerns, and impaired mother-daughter relationships are significant predictors of eating disturbances in females with type 1 diabetes. Together, these three factors accounted for 57% of variance, suggesting that the family environment may enhance vulnerability for eating disturbances in adolescents with type 1 diabetes.

Rodin et al. (2002) represent these factors in diagrammatic form and this is shown in Figure 4.

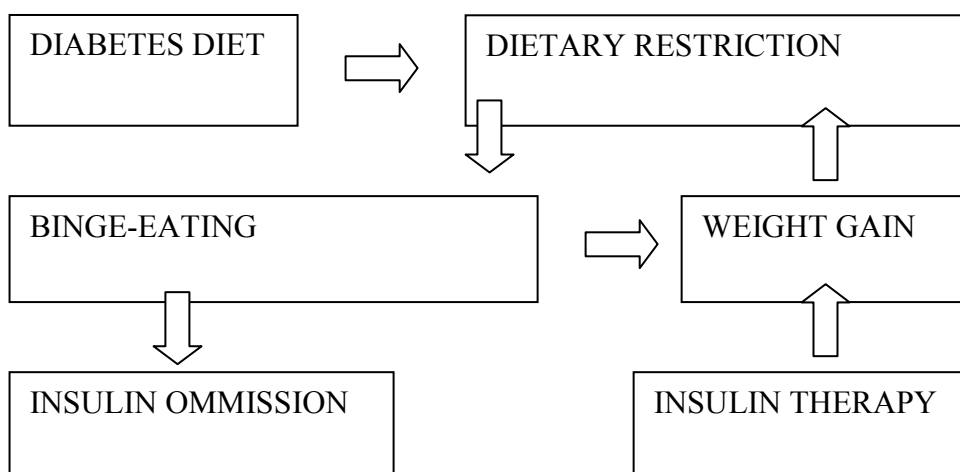


Figure 4: “Potentiation of eating disorders by type 1 diabetes”. Reproduced from Rodin et al., (2002).

The model set out by Rodin et al. (2002) illustrates that subsequent to diagnosis, the onset of insulin therapy often leads to considerable weight gain. Weight gain may lead to increased dissatisfaction with body weight and/or shape. Simultaneously, although there is no specific ‘diabetic diet’, the healthy eating advice given to diabetics might be perceived by the individual to impose a degree of dietary restriction. Perceived dietary restriction combined with weight gain has the potential to trigger a cycle of binge-eating and purging via insulin omission in those for whom body weight and shape are fundamental to self-esteem.

1.5 Family Systems

1.5.1 The Family

Relationships within families are central to the functioning of the child, as the family is the principal context within which physical, cognitive and social development occurs. Ideas of what constitutes a family have traditionally been based on the nuclear family structure, consisting of the mother, father, and child or children. However, with rising rates of separation, divorce, remarriage and single-parenthood, there is increasing variability in family structures. Carr (2006) describes families as unique social systems, to which members enter via birth, adoption, fostering or marriage and can only leave by means of death.

Models of the family lifecycle often define a series of distinct stages, each of which involves negotiating a series of unique challenges. For example, Carter and McGoldrick (1999) propose a model of the family lifecycle based on the nuclear

family. The model identifies eight stages of development, each of which requires completion of a number of developmental tasks.

The stages of Carter and McGoldrick's model are as follows:

1. Family of origin experience
2. Leaving home
3. Premarriage stage
4. Childless couple stage
5. Family with young children
6. Family with adolescents
7. Launching children
8. Later life.

Carter and McGoldrick's lifecycle model highlights a number of points at which several transitions may occur simultaneously, leading to an increase in family stress. The primary concerns in the early stages of development relate to differentiating from the family of origin, completing education, starting a career and choosing a partner. Most relevant to the current study are the fifth and sixth stages of development, during which the couple must first of all develop parenting roles, and then renegotiate these roles to allow their children more autonomy as they enter adolescence. The transition between these different stages necessitates renegotiation of family rules and roles and psychological difficulties often occur at these times (Carr, 2006). The successful navigation of these transitions may be even more complex in the presence of diabetes, as adjustment to diagnosis represents a major life event that may erode coping resources and promote problem-maintaining patterns of interaction (Altschuler, 1997). In the later stages of development the parents have to adjust to living as a couple again

as young adult children leave the parental home, and then the family must cope with physiological decline and preparation for death.

1.5.2 Systems theory

When considered in the context of family relationships, systems theory can offer a useful starting point for understanding the onset and maintenance of psychological problems. According to Dallos and Draper (2005), “A system is seen as existing when we can identify an entity made up of a set of interacting parts which communicate with and influence each other” (p.24). Families can be viewed as self-regulating systems in which family members represent individual components in interaction with one another in a relatively stable manner over time. Human systems are considered to demonstrate circular interaction: individuals both elicit and react to feedback from those with whom they interact, thereby maintaining or altering the system.

The theoretical framework for applying systems theory to family structure and functioning was offered by Bateson (e.g.1972, 1979) and draws on theoretical principles and concepts from cybernetics (Weiner, 1948, 1961) and General Systems Theory (von Bertalanffy, 1968). A central notion to have been introduced from these frameworks relates to the role of feedback in the regulation of systems – the means by which information about past performance is employed to maintain stability.

The argument that siblings of children and adolescents with diabetes might be at increased risk of disturbed eating attitudes and behaviours rests on one of the primary assumptions of systems theory: the assumption that the existence of a family member

with a chronic health condition inherently impacts on the entire family system (Altschuler,1997).

The diagnosis of chronic illness can be viewed as a major transition that the family must negotiate and adjust to, and the process of adaptation is likely to challenge both personal and shared beliefs. This may result in the development of a new or altered family identity, in which roles and expectations may change depending on the personal meaning of the diagnosis. Altschuler (1997) describes that, “Adaptation to the discovery of illness demands radical reorganisation of individual and family life ... each family member has to find a way of redefining their expectations of themselves and their relationships to one another” (p.11); what implications does this have for siblings?

Consideration of the role of systems theory in families where chronic illness is present led to the question of whether focus on nutrition as a major component of diabetes treatment might create food related anxieties within the family, thereby raising susceptibility to disturbance in food related attitudes and behaviours in the siblings of those with type 1 diabetes.

1.6 Family Functioning and Chronic Illness

Increasingly, researchers are turning their attention to the parents and siblings of children with a chronic illness, revealing that they may be at risk of a range of adjustment problems. From a systems perspective, childhood chronic illness intrinsically impacts upon the entire family, not just the child (Altschuler, 1997). In the case of type 1 diabetes, the child and family are required to apply and monitor a

complex treatment regime that is likely to necessitate considerable changes in lifestyle, particularly in relation to diet and exercise (IPSAD, 2000). Although studies exploring the impact of having a child with type 1 diabetes in the family are limited, it is recognised that various types of paediatric chronic illness share common issues such as treatment demands, restricted lifestyle, emotional and financial strains, long term burden of care, and differences in family experiences (Altschuler, 1997). Kazak (1989) maintains that psychological distress within the family system seems to be associated with a number of variables, including the nature and course of the illness; individual coping resources; family structure and function; and medical, psychosocial and educational resources.

1.6.1 Parental mental health

To date, studies examining the impact of having a child with a chronic illness have focused almost exclusively on mothers, with little attention paid to fathers. The existing evidence suggests that the parents of children with a chronic illness report increased rates of psychological distress both immediately after diagnosis and at long term follow up. For example, mothers of children with a chronic illness report higher levels of parenting stress (Quittner et al., 1998) and depression (e.g. Kovacs et al., 1985) than parents of healthy children.

Specific to diabetes, Kovacs et al. (1985) reported that mild depression and emotional distress (including anxiety, anger, and somatisation) were common in the mothers of children who were newly diagnosed. However, it was not possible to determine whether this reflects a reaction to diagnosis or whether it is indicative of pre-existing mental health problems. More recently, researchers have found evidence of increased

post-traumatic stress disorder (PTSD) symptoms in parents of children with a range of chronic illnesses. Landolt et al. (2002) were the first to explore PTSD in parents of children newly diagnosed as having type 1 diabetes by administering a self-report questionnaire to 38 couples. Although the study was limited in terms of small sample size and absence of a control group, a significant number of parents were found to meet full or partial criteria for PTSD. Twenty-four percent of mothers and 22% of fathers met full DSM-IV criteria, and a further 51% of mothers and 42% of fathers met criteria for partial PTSD. These rates are similar to those found in parents of children with other illnesses such as cancer (e.g. Pelcovitz et al., 1996). This demonstrates that diagnosis of type 1 diabetes may represent a traumatic event with considerable implications for the psychological functioning of the parents. Furthermore, exposure to a range of chronic stressors subsequent to diagnosis may lead to persistent psychological difficulties. In a longitudinal study of the mothers of children newly diagnosed with type 1 diabetes over a six year period, Kovacs et al. (1990) found evidence that maternal depression and emotional distress increased slightly with illness duration. Mothers' adjustment after diagnosis was strongly predictive of long term symptomatology and was found not to be related to medical aspects of living with type 1 diabetes. However, the findings of the study are limited as the absence of a control group means comparisons cannot be made with other chronic illnesses or with the mothers of healthy children.

The significance of increased distress in the parents of children with type 1 diabetes becomes relevant to the current study when considered in conjunction with evidence that parental distress is associated with psychological outcomes for children. For example, Williams et al. (1999) found that maternal mood had a considerable influence

on the siblings of children with a chronic illness. Twenty-two siblings of children diagnosed with diabetes, cancer, cystic fibrosis or spina bifida, and their parents, completed a battery of self-report questionnaires. Maternal mood was found to have an indirect but significant affect on sibling mood via its effects on family cohesion, self-esteem, and sibling social-support.

Mothers of children with diabetes are known to have high levels of concern about hypoglycaemia (Sullivan-Bolyai et al., 2002) and worries about diet (Parker et al., 1994). Given that parental psychological functioning is known to impact on the child, it is possible that there is a transactional association between such concerns in parents and their children.

1.6.2 Impact on siblings

Although the sibling system is an important sub-system within the family, the impact of a child's illness on his/her siblings has little comparative research. Family systems theory would suggest that diabetes and its treatment has many direct and indirect effects on siblings which might impact on their functioning. Ferrari (1987) found that siblings of children with type 1 diabetes had worse overall self-concept when compared with siblings of healthy children, and also had concerns about their intellectual and school status, and happiness and life satisfaction.

In one of the few qualitative studies to be conducted, Smith (1998) asked 14 adults to reflect on what it was like to grow up with a sibling who had type 1 diabetes. Among the themes that emerged, siblings described changes in family patterns and sibling relationships that were both positive and negative. Participants reported that the

diagnosis of type 1 diabetes resulted in changes in daily routines including eating habits, “We just didn’t buy anything like that (sweets) ... J couldn’t have it so we just didn’t get it ... Mother never made desserts anymore”. This suggests that having a sibling with diabetes can result in considerable changes in diet for the whole family. As family dynamics change, the family identity and the identity of each member of the family sub-system may shift in accordance.

A meta-analysis of more than 50 research studies published between 1976 and 2000 demonstrated that being the well sibling of a child with a chronic physical illness is associated with significant psychological distress (Sharpe & Rossiter, 2002). Larger effects were found for internalising disorders such as depression and anxiety than for externalising disorders.

While it might seem that elevated rates of distress are more common in siblings of children with a chronic illness, within the existing research there are considerable discrepancies in outcome. Studies report both positive and negative outcomes for this group and the overall picture may be skewed if the research is more heavily weighted towards examining correlates of risk as opposed to resiliency. Williams (1997) reviewed over 40 studies of the effects of paediatric chronic illness on siblings conducted between 1970 and 1995. Sixty per cent of studies reported siblings were at increased risk of a range of problems including anxiety, depression, anger, low self-esteem, poor peer relationships, somatic complaints, behaviour problems and school related problems. However, 30% of studies did not find any evidence that siblings were at increased risk of adjustment problems, and 10% of studies found both positive and negative outcomes. Williams (1997) concluded that there are four general factors

that influence sibling adjustment: family characteristics, parent characteristics, illness characteristics and sibling characteristics.

1.7 Summary and Hypotheses

In summary, diabetes is an increasing health concern for children and adolescents in Scotland. In accordance with systemic theory, evidence indicates that the siblings of children and adolescents with chronic health conditions such as diabetes are at risk of a range of adjustment problems. Previous research has already revealed a link between type 1 diabetes and eating disorders, which may be due to an increased focus on nutrition and food-related anxiety within the family. This family environment will be shared by the siblings of children and adolescents with type 1 diabetes. Furthermore, it is known that problematic eating attitudes and behaviours can be transmitted between family members, with evidence implicating family factors in the development of food preferences and the onset of both dieting behaviours and eating disorders. Therefore it is suggested that siblings are also at increased risk of developing problematic eating attitudes and behaviours.

The role of systems theory in families where chronic illness is present forms the conceptual foundation for this study. It prompted the question of whether focus on nutrition as a major component of diabetes treatment might create food related anxieties within the family, thereby raising susceptibility to disturbance in food related attitudes and behaviours in the siblings of those with type 1 diabetes. To test this question, the present study aimed to explore whether eating attitudes and behaviours differed between the siblings of children and adolescents with type 1 diabetes and the siblings of healthy children and adolescents.

Previous research focusing on the development of image concerns in children has found consistent evidence for an association with gender, age and body mass index (BMI). Girls generally desire a thinner body size than boys and this gender difference is repeatedly found in children as young as eight. With increasing age, body image concerns tend to become more marked, especially in girls. Research on eating disorders in males is limited due to clinical biases and small sample sizes therefore it is important to study disordered eating attitudes and behaviours rather than to focus exclusively on diagnosable eating disorders. This study aims to examine gender and age differences in eating attitudes and behaviours in a community sample of 12 to 18-year-olds.

Hypothesis 1

Higher levels of concerns about shape or weight will be observed in young people with a sibling with type 1 diabetes than in those without a sibling with type 1 diabetes.

Hypothesis 2

Greater disturbance in eating attitudes and behaviours will be observed in young people with a sibling with type 1 diabetes than in those without a sibling with type 1 diabetes.

Hypothesis 3

Concern about shape and weight and disturbance in eating attitudes and behaviours will be disproportionately observed in females compared with males.

Hypothesis 4

Concern about shape and weight and disturbance in eating attitudes and behaviours will increase as a function of age.

2: METHODOLOGY

2.1 Design

The study employed a quantitative survey design to assess concerns about body shape and weight, eating attitudes and behaviours and eating psychopathology. Comparisons were made between siblings of children and adolescents with type 1 diabetes and a matched control group. Additional comparisons were made between gender and age groups in a community sample. The sibling sample was recruited through letters sent to the parents of all children and adolescents in Highland with a diagnosis of type 1 diabetes. The community sample was recruited through the Guiding and Scouting Movements within the Highland region and two local secondary schools. The matched control group were selected from within the community sample. All participants completed a questionnaire booklet containing a section on demographics and three standardised scales. The purpose of the design was to compare scores on measures of eating attitudes and behaviours, weight and shape concern, and eating disorder psychopathology between groups, gender and ages.

Previously it has been claimed that interviews should be the preferred method of assessment as they enable the researcher to clarify difficulties with definition and individual perception inherent in some of the core features of eating disorders (e.g. Cooper, Cooper & Fairburn, 1989). However, Fairburn and Beglin (1994) recognise that it is not always feasible to conduct an interview, and acknowledge that an interview methodology presents limitations such as lengthy administration time and being personally intrusive for the interviewee. Fairburn and Beglin (1994) conclude that it is acceptable to use self-report questionnaires in place of interviews though

caution must be exercised when assessing eating disorder features that are complex or not well defined. As the purpose of the current study was to compare attitudes and behaviours between the sibling group and the control group rather than to establish the presence of clinically significant levels of psychopathology, self-report questionnaires were considered to be acceptable measures. Self-report measures were also considered to be the most convenient option because the researcher did not have to meet individually with participants and the anonymity of participants was protected.

2.2 Participants

A power analysis was conducted to determine how many participants would be required to detect any effects in the data. Using a significance level of 0.05 and a power of 0.8, Cohen (1992) estimates that 393 participants are required per group to detect a small effect size. To detect a medium effect size 64 participants are required in each group and to detect a large difference between the two sample means 26 participants are required in each group. The possibility that siblings of children and adolescents with type 1 diabetes may be at increased risk of disturbed eating attitudes and behaviours has yet to be tested, therefore it was not known what magnitude of difference was expected between the two sample means. However, a typical study within the behavioural sciences will have a medium effect size (Cohen, 1988). Therefore the aim was to recruit a minimum of 64 participants in each group.

The lower age limit for participation was set at 12 years, as this was the youngest age group that the measures had been used with previously. The upper age limit was set at 18 years.

2.2.1 Recruitment of sibling group

Young people in the sibling group were recruited through NHS Highland Paediatric Diabetes Service. It was not possible to obtain records of which patients had siblings in the target age range of 12 to 18 years therefore recruitment packs were posted from the Consultant Paediatrician to the parent(s) of all 126 children and adolescents with type 1 diabetes registered with the service. Twelve completed consent forms and questionnaires were returned. A reminder letter was sent to all families who did not respond to the initial invitation to participate. An additional questionnaire booklet and set of consent forms were included with the reminder letter, however no further responses were received.

2.2.2 Recruitment of community sample/ matched control group

The control group was a convenience sample of young people involved with the Scouting and Guiding Movements and pupils attending two local secondary schools.

The original plan was that the control group could be recruited entirely from secondary schools. Permission to approach Head Teachers about becoming involved in the research was initially declined by the Director of Education for Highland because it was decided that the research would overlap with a study exploring pupil lifestyle which was about to commence. However, the pupil lifestyle study was later postponed and the Director of Education selected three schools in Highland to be invited to take part in the study. The schools were approached by email and two of these agreed to participate. The researcher liaised with one of the guidance teachers from each of the schools, who selected a number of Personal and Social Education (PSE) classes to

participate in the study. Eight classes were selected in total. Research packs were given to a total of 160 pupils aged between 12 and 17 years.

After permission to approach secondary schools was initially declined, the researcher contacted the Area Commissioners of the Scouting and Guiding Movements in Highland to seek permission to approach local Scout, Guide and Explorer units. Permission was granted, and the leaders of individual Scout, Guide and Explorer units were approached by telephone or email and invited to take part. Of eight units approached, five agreed to participate.

Scout units involve boys aged 10 to 14 years, Guide units involve girls aged 10 to 14 years and Explorer units involve young people of both sexes aged between 14 and 18 years. One Scout unit, three Guide units and three Explorer Scout units were invited to participate in the study. One Scout unit, two Guide units and two Explorer Scout units agreed to become involved. Young people aged 12 or over who were interested in taking part in the study were given a research pack to take home to their parents. A total of 41 research packs were given out.

2.3 Measures

The measures used in the current study were three standardised self-report questionnaires to assess eating attitudes and behaviours and weight and shape concerns; and a non-standardised questionnaire to gather demographic information from participants.

2.3.1 Participant information

A general information questionnaire was designed specifically for the study. The questionnaire asked participants to report age in years, gender, and postcode, and record any current health problems. Postcodes were requested in order to calculate Carstairs scores (McLoone, 2004) to aid with the selection of a matched control group to compare with the sibling group. Carstairs scores are derived from information from Census data and provide a method of quantifying levels of relative deprivation or affluence in a particular locality. Deprivation category (DEPCAT) scores for postcode sectors range from DEPCAT 1 (the most affluent postcode sectors) to DEPCAT 7 (the most deprived).

The participant information questionnaire also asked for current height and weight and ideal weight. Also, participants were asked if they were currently eating less to lose weight, eating more to gain weight, or exercising to change their body shape, size, or muscle tone. Those in the sibling group were asked to indicate how long ago their brother or sister had been diagnosed with diabetes.

Female participants were asked to indicate whether they had started their periods, as evidence indicates that the BMI is not a valid indicator of weight status in premenarcheal girls (O'Dea & Abraham, 1995, as cited in Carter, Stewart & Fairburn, 2001).

2.3.2 *The Eating Disorder Examination Questionnaire (EDE-Q; Carter, Stewart & Fairburn, 2001)*

This measure is a 36-item self-report questionnaire based on the EDE-Q (Fairburn & Beglin, 1994) for adults. Carter, Stewart and Fairburn (2001) adapted the EDE-Q for use with girls aged between 12 and 14 years in order to provide normative data for adolescents. The two main modifications were the simplification of selected words and phrases and the reduction of the time frame from 28 days to 14 days. The authors believed a shorter time frame to be more developmentally appropriate for adolescents. The EDE-Q is adapted from the Eating Disorder Examination (EDE; Fairburn & Cooper, 1993), the ‘gold standard’ investigator-led interview for the assessment of eating disorder psychopathology. A comparison of the EDE and the EDE-Q in a clinical sample of 70 children and adolescents aged between 9 and 19 years found that the two measures yield similar results on three out of four subscales (Binford, Le Grange & Jellar, 2005), lending support to the use of self-report measures in adolescent eating disorder samples.

The questionnaire produces data on the frequency of key behavioural features of eating disorders and subscale scores that indicate the severity of the psychopathology. The subscales are Restraint (5 items; e.g. Item 1: ‘Have you been trying to cut down on food to control your weight or shape?’), Eating Concern (5 items; e.g. Item 34: ‘How worried have you been about other people seeing you eat?’), Shape Concern (5 items; e.g. Item 10: ‘On how many days out of the past 14 have you really wanted your stomach to be flat?’), and Weight Concern (8 items; e.g. Item 29: ‘Over the past two weeks has your weight affected how you think about (judge) yourself as a person?’).

Respondents indicated the frequency of particular attitudes, feelings and behaviours over a specified time frame on a seven-point scale (0-6). A score of four or more is considered more likely to indicate clinical severity. Four subscale scores are obtained by adding the ratings for each item in the subscale, then dividing the total by the number of items in that subscale. An overall score can be calculated by adding the four subscale scores and dividing the total by the number of subscales. Luce and Crowther (1999) found all four subscales to have excellent internal consistency and good test-retest reliability over a two week period. In the current study the Cronbach alpha coefficient coefficient was above .70 for the EDE-Q and each of its subscales (global score $\alpha = 0.96$, restraint $\alpha = 0.81$, eating concern $\alpha = 0.74$, shape concern $\alpha = 0.94$, weight concern = $\alpha 0.88$), indicating satisfactory to good levels of internal consistency (Nunnally, 1978).

2.3.3 Body Shape Questionnaire (BSQ; Cooper, Taylor, Cooper & Fairburn, 1987)

This is a self-report instrument developed to measure concerns about body shape (e.g. ‘Has worry about your shape made you feel you ought to exercise’). It was developed from interview data with both eating disorder patients and community samples, and demonstrates acceptable concurrent and discriminant validity (Cooper et al., 1987). The measure was designed for use with adult populations, but has also been used in numerous studies involving adolescents (e.g. Cooper & Goodyer, 1997).

The original 34 item questionnaire asks the respondent to rate their state over the previous four weeks on a six-point Likert scale from 1 (Never) to 6 (Always). The responses are summed to give a total score. However, Evans and Dolan (1993) believe that “The BSQ may be unnecessarily long for use in studies when body disparagement

is not the main focus of the investigation” (p.315). Accordingly, they devised a series of shortened scales from the original measure. Two of the 34 items were deleted, and the other 32 items were allocated to two 16-item scales and also to four 8-item scales. The two 16 item scales were found to have equivalent means and excellent internal consistency, and correlations with the original 34 item BSQ were found to range from .96 to .99. In the current study the Cronbach alpha coefficient for the shortened 16 item version was 0.96, showing very good internal consistency.

It was decided that a shortened 16-item questionnaire would be preferable for the present study, in part to reduce the time required for questionnaire completion and in part to exclude items that might be considered inappropriate when asked of young people (for example, item 16, ‘have you imagined cutting off fleshy area of your body?’). Copies of the original 34-item questionnaire and the 16-item questionnaire selected for use in the study can be found in appendices 2a and 2b respectively.

2.3.4 Children’s Eating Attitude Test (ChEAT; Maloney, McGuire & Daniels, 1988)

The ChEAT is a 26-item self-report inventory based on the Eating Attitudes Test (EAT) for adults and adolescents (Garner & Garfinkel, 1979). Maloney, McGuire and Daniels (1988) reported that the EAT had not been used in a published study with anyone under the age of 15 years. The wording on certain items was thought to render it unintelligible to children; consequently they altered some of the wording to make it simpler for children to understand. The resulting Children’s Eating Attitude Test (ChEAT) was tested on 318 children between the ages of eight and thirteen. Test-retest reliability and internal reliability coefficients of the ChEAT were found to equate satisfactorily to studies with adult populations. In addition, Smolak and Levine (1994)

found significant correlations between ChEAT scores and independent measures of body dissatisfaction and weight management behaviour, suggesting the measure has good concurrent validity.

The ChEAT requires respondents to make a forced choice on a six-point likert scale. The questions are designed to assess eating attitudes in children and encompass four main dimensions: Dieting (11 items; e.g. Item 23: 'I have been dieting'), restricting and purging (9 items; e.g. Item 26 'I have the urge to vomit after eating'), food preoccupation (5 items; e.g. Item 3 'I think about food a lot of the time') and oral control (4 Items; e.g. Item 13 'Other people think I am too thin').

Each item is rated on a likert scale (Always, Very Often, Often, Sometimes, Rarely, Never). The most symptomatic response receives a score of 3, the next most symptomatic receives a score of two, and the next is scored 1. The other three response choices have a score of 0. A score of 20 or more is deemed to fall within the anorectic range. In the current study the overall ChEAT and two of its subscales had good internal consistency (overall ChEAT, $\alpha = .72$, dieting subscale $\alpha = .83$, restricting and purging subscale $\alpha = .72$). The remaining two subscales did not have good internal consistency (food preoccupation subscale $\alpha = .11$, oral control subscale $\alpha = .57$).

Although the ChEAT is intended for use with children under the age of 15, it was decided that this measure would be used with 12 to 18 year olds in the present study in order to ensure uniformity in measures across the sample. The ChEAT is fundamentally the same as the EAT excepting minor differences in language, and

should therefore be appropriate for older participants as well younger participants. The EAT-26 and the ChEAT-26 are available in appendices 3a and 3b respectively for comparison.

2.4 Procedures

2.4.1 Sibling group

The parents of children and adolescents with type 1 diabetes were sent a recruitment pack through the post. The packs were sent out by the Consultant Paediatrician involved with the diabetes service, as it was not considered ethically appropriate for the researcher to be given direct access to the personal details of the patient group.

Each pack contained an invitation letter (appendix 4), information sheet (appendix 5) and consent form for parents (appendix 6), and an equivalent set of documents for young people (appendices 7, 8 & 9). A slip was enclosed for the parent to complete if they had more than one child eligible to participate and required additional consent forms and questionnaire booklets. Participants were asked to place completed consent form(s) in a small envelope provided.

A questionnaire booklet was also included in the pack (appendix 10), attached to which was a set of instructions detailing how to complete the questionnaire booklet and how to return the consent form(s) and questionnaire booklet to the researcher (appendix 11). Participants were requested to place their completed questionnaire booklet and the small envelope containing their consent form(s) inside a large stamped, addressed envelope and return it to the researcher by post.

One hundred and twenty-six packs were sent out to families. The invitation letters to parents asked them to read the information enclosed in the pack if their child with diabetes had any brothers or sisters between the ages of 12 and 18 years. They were requested to forward the set of documents for young people to the sibling(s) of their diabetic child.

Informed written consent was obtained from all participants, and also from the parents of those aged less than 16 years. Participants were asked to place their completed consent form(s) in the small envelope provided. They were then asked to complete the questionnaire booklet. Once this was completed participants were requested to place both their completed questionnaire booklet and the small envelope containing their consent form(s) into the large stamped addressed envelope provided and return it to the researcher. Participants were asked to place their consent form(s) and questionnaire booklet in separate envelopes to ensure confidentiality. All participants were assigned a participant number which was printed on both their consent form and questionnaire booklet. Only the consent forms contained identifying information such as the participant's name and address. Signed consent forms were stored separately from completed questionnaire booklets in a locked filing cabinet, but could have been matched to identify a participant in the event that their scores on the questionnaires had raised serious cause for concern.

2.4.2 Community sample/matched control group

Guide, Scout and Explorer Units

The researcher attended the meetings of Guide, Scout and Explorer Units to give a brief description of the research study. Those aged 12 years or above who were interested in taking part were given a pack to take home. The packs were equivalent to those sent to the parents of the sibling group sample. Each one contained an invitation letter (appendix 12), information sheet (appendix 13) and consent form for parents (appendix 6) and corresponding documents for young people (appendices 14, 15 & 9). Each pack also contained a questionnaire booklet (appendix 16).

Young people were asked to read through the pack at home and pass the relevant section to their parents. Completion and return of the consent form(s) and questionnaire booklet followed the same procedure as that for the sibling group.

School Pupils

The researcher visited the two participating secondary schools to discuss the research study with Guidance Staff. One hundred research packs were given to staff at School A and 70 packs were given to staff at School B to distribute to pupils in the eight classes selected by the Guidance Teachers to participate in the study. School B returned ten unused packs to the researcher. The majority of documentation in the packs was equivalent to that in the packs given to young people in the Guide, Scout and Explorer units. However, changes were made to wording on the information sheet for young people requesting that they return their completed consent form(s) to school (appendix 17) rather than post them to the researcher and questionnaire booklets were not included in the packs.

The researcher attended the Personal and Social Education (PSE) lessons of the eight classes selected to participate in the research study to distribute questionnaire booklets to those who wished to participate in the study and to deliver a body image workshop. Research packs without questionnaires were given out to pupils by their teacher a week before the PSE lesson attended by the researcher.

Questionnaires booklets were completed by all those who wished to participate at the start of the PSE lesson, before any workshop activities took place. Completed questionnaires were collected at the end of the lesson from all of those who had returned all of the necessary consent forms. At School A those who had not obtained parental consent but who still wished to participate were given a stamped addressed envelope and spare consent forms. They were requested to post the completed questionnaire booklet and consent form to the researcher once they had obtained parental consent. At School B questionnaires completed by young people who did not yet have parental consent but who wished to participate in the study were kept by the class teacher. Once parental consent was returned to the class teacher the completed questionnaire booklets and their corresponding consent forms were posted to the researcher. Different methods were used at each of the schools because of the preferences of the Guidance Teachers. However, there was little difference in the process of questionnaire completion between the two schools.

2.5 Ethical Considerations

Ethical approval for the study was granted by Highland Research Ethics Committee (appendix 18a). The key ethical considerations related to confidentiality and informed consent, potential distress to participants and heightened scores on measures of weight and shape concern and eating disorder psychopathology. Accordingly, a number of safeguards were put in place for the protection of participants.

Informed consent was obtained from all participants. To ensure confidentiality, participants were not required to provide any personal identifying information on their questionnaire booklet. Personal information such as name, date of birth and address were required only on the consent form. However, measures were taken to make sure appropriate action could be taken in the event that a participant's scores on the questionnaires raised serious cause for concern. Each participant was allocated a unique identification number which was printed on both their consent form and questionnaire booklet. This would enable the questionnaire booklet to be matched with the consent form to obtain personal details if necessary.

Participants were advised on their information sheet that in the unlikely event that their answers on the questionnaires should raise serious cause for concern, the researcher would contact them. After speaking to the participant, the researcher would then alert the participant's GP (and also their parent(s) if the participant was under the age of 16). Participants were asked to provide details of their GP on their consent form.

Because the questionnaire booklet addressed sensitive issues, participants were advised on their information sheet that they should contact the researcher or their GP if completion of the questionnaire booklet should raise issues that they wanted to discuss.

2.6 Analysis of the Data

Data analysis was carried out using SPSS for Windows (Version 14). Because some of the data was positively skewed analysis was undertaken using non-parametric tests. The Mann-Whitney U test and Kruskal-Wallis test were used for between group comparisons of eating attitudes and eating psychopathology and Kendall's Tau Correlation was used to explore the relationship between variables. The decision was made to use non-parametric tests rather than transform the data as different sets of data would have required different transformations. Also, it is perhaps to be expected that data on body shape, eating attitudes and behaviours and eating disorder psychopathology will be skewed in a community sample.

3: RESULTS

The initial focus of this section is a description of the method of statistical analysis. Following this, preliminary exploration of the data will focus on descriptive characteristics of the sample. Subsequently, exploratory investigations will be carried out and the main hypotheses of the study will be tested.

3.1 Statistical Analysis

Preliminary analysis of the data revealed a significant deviation from normality, therefore non-parametric tests were performed. The main hypotheses of the study were tested using Mann-Whitney U tests, Kruskal-Wallis tests and Kendall's Tau Correlations as the main statistical analyses. One-tailed tests of statistical significance were used because the hypotheses predict the direction of the difference between scores.

Data for each of the measures are presented as median scores for the comparison groups. Median scores are also given for individual subscales where relevant. Data for behavioural items on the EDE-Q are presented as the number of individuals reporting the occurrence of the behaviour.

SECTION 1: Sibling Group and Matched Control Group Comparisons

3.2 Characteristics of the Sample

3.2.1 Sibling group

The sibling group consisted of 4 males and 8 females. The mean age of the participants in the group was 15 years (SD=1.76; range=12-17 years). The average weight was 60.9 kg (SD=9.84; range=44-82 kg) and the average height was 1.68m (SD=9.84; range=1.52-1.83m) corresponding to a mean body mass index (BMI; kg/m²) of 21.84 (SD=2.61; range=18.31-27.40). One participant had a BMI above 25 and one participant had a BMI below 18.5. All eight of the females in the sibling group had reached menarche. The mean length of time since siblings had received a diagnosis of type 1 diabetes was 77.6 months (SD=60, range= 12-208).

One male (25%) and three females (37.5%) indicated that they were currently eating less to lose weight. None of the participants indicated that they were eating more to gain weight. One male (25%) and four females (50%) said they were currently exercising to change their body shape, size or muscle tone. Six participants (50%) reported an ideal weight that was different from their current weight. All six (one male, five females) wanted to weigh less than their current weight.

3.2.2 Matched control group

The control group was matched with the sibling group for age, gender and DEPCAT score. Four males and eight females aged between 12 and 17 years (mean = 15years, SD = 1.76) completed questionnaires. The average weight was 53.2 kg (SD=8.32;

range = 43-67 kg) and the average height was 1.66m (SD = 10.33; range = 1.42-1.83m) corresponding to a mean body mass index (BMI; kg/m²) of 18.68 (SD = 2.48; range = 15.59-24.61). None of the participants had a BMI above 25 but six participants had a BMI below 18.5. All eight of the females in the matched control group had reached menarche.

One male participant indicated that he was currently eating less to lose weight and one male indicated he was eating more to gain weight. None of the females was either eating less to lose weight or eating more to gain weight. Four males (100%) and six females (75%) said they were currently exercising to change their body shape, size or muscle tone. Six participants (50%) reported an ideal weight different from their current weight. Five participants (one male, four females) wanted to weigh less than their current weight and one male wanted to weigh more than his current weight.

It was not possible to make between group comparisons of characteristics such as weight, BMI or eating less to lose weight because the sample was not large enough to carry out statistical analysis.

3.3 BSQ, ChEAT and EDE-Q Scores

Median scores and interquartile ranges for participants in the sibling group and matched control group are presented in Table 3.

Table 3: Medians and interquartile ranges by group and gender.

	BSQ		ChEAT		EDE-Q	
	Mdn	IR	Mdn	IR	Mdn	IR
Sibling Group						
▪ Males (n=4)	16	2	4	8	0.16	0.11
▪ Females (n=8)	37.5	11	4	5	1.57	1.19
▪ All (n=12)	32.5	24	4	6	0.99	2.01
Matched Control Group						
▪ Males (n=4)	19	6	4.5	2	0.13	0.31
▪ Females (n=8)	30	22	5	2	0.63	1.17
▪ All (n=12)	23.5	17	4.5	2	0.30	0.73

Note. Mdn = Median, IR = Interquartile Range.

3.3.1 Attitudes to Body Shape and Weight

Attitudes to body shape and weight were measured by the Body Shape Questionnaire. A number of female participants in both the sibling group and the matched control group endorsed responses that represented higher levels of concern (often, very often, always) on individual BSQ items. The item on which participants responded with the highest levels of concern was the same in both the sibling group and matched control group (item 2, ‘have you thought that your thighs, hips or bottom are too large for the

rest of you?’). For a summary of the number of female participants who gave a response of often, very often or always on each item please refer to Appendix 19.

Table 3 shows that participants in the sibling group had a greater median score on the BSQ than those in the matched control group. However, a Mann-Whitney U test revealed that the difference was not significant ($U = 68.5$, $Z = -0.203$, $p = 0.426$). Female scores within the sibling group and matched control group were significantly higher than male scores ($U = 13.5$, $Z = -3.114$, $p < 0.01$).

3.3.2 *Eating Attitudes*

Eating attitudes were measured using the Children’s Eating Attitude Test (ChEAT), a 26-item self-report inventory. None of the participants in either the sibling group or the matched control group had a total ChEAT score that fell within the anorectic range (≥ 20). Male scores ranged from 0-10 in the sibling group and 3-5 in the matched control group. Female scores ranged from 1-12 in the sibling group and from 3-8 in the matched control group. Female scores in the sibling group and matched control group did not differ significantly from male scores ($U = 55.0$, $Z = -0.564$, $p = 0.573$).

Young people in the sibling group did not differ significantly from young people in the matched control group in terms of eating attitudes ($U = 61$, $Z = -0.65$, $p = 0.268$).

3.3.3 *Eating Disorder Psychopathology*

Eating disorder psychopathology was measured using the Eating Disorder Examination Questionnaire (EDE-Q). The questionnaire produces data on the frequency of key behavioural features of eating disorders and subscale scores that indicate the severity of the psychopathology. Participants indicated the frequency of particular attitudes, feelings and behaviours over a specified timeframe on a seven-point scale (0-6). A score of four or more is considered more likely to indicate clinical severity.

None of the participants scored within the clinically significant range on the Restraint subscale, the Eating Concern subscale or the Global score. However, one female participant in the sibling group scored within the clinically significant range on both the Shape Concern and Weight Concern subscales of the EDE-Q.

Young people in the sibling group had a higher median score than young people in the matched control group on the measure of eating disorder psychopathology, but this difference was not statistically significant. Female scores in the sibling group and matched control group were significantly higher than male scores ($U = 14.0$, $Z = -3.069$, $p < 0.01$). In addition, females in the sibling group had significantly higher score on the EDE-Q than females in the matched control group ($U = 14$, $Z = -1.89$, $p < 0.05$).

In terms of the behavioural features of eating disorders, no participant in either group reported that they had used diuretics, used laxatives, or made themselves sick to control shape or weight within the past 14 days. However, participants in both the

sibling group and the matched control group reported going for long periods of time without eating (extreme dietary restraint) and exercising hard to control body shape or weight (excessive exercise). Four female participants in the sibling group reported dieting on 7 or more days out of the past 14 compared with one female in the matched control group. All of the dieting females were within the normal weight range. The frequencies of these behavioural features of eating disorders are shown in Table 4.

Table 4: Frequency of behavioural features of eating disorders by group and gender.

	Sibling Group		Matched Control Group	
	Males (n=4)	Females (n=8)	Males (n=4)	Females (n=8)
Vomiting	0	0	0	0
Use of Diuretics	0	0	0	0
Use of Laxatives	0	0	0	0
Excessive Exercise	0	1	1	2
Extreme Dietary Restraint	0	3	1	1

3.4 Summary of Research Findings in Relation to Core Hypotheses

Concern about shape and weight was measured by the BSQ. The results suggested that concerns about body shape and weight did not differ significantly between groups. Disturbance in eating attitudes and behaviours was measured using the ChEAT and the EDE-Q. Although the data did not reveal significant differences between sibling group attitudes and matched control group attitudes as measured by the ChEAT, females in the sibling group had significantly higher score on the EDE-Q than females in the

matched control group. In addition, the only participant to score within the clinically significant range on any of the EDE-Q subscales was a female participant in the sibling group.

No participant in either group reported that they had used diuretics, used laxatives, or made themselves sick to control shape or weight within the past 14 days. Females in both the sibling group and the matched control group reported engaging in excessive exercise and extreme dietary restraint (going for 8 hours or more without eating) to control shape or weight.

SECTION 2: Age and Gender Comparisons Within the Community Sample

Exploratory analysis and hypothesis testing with regards to gender and age differences in eating attitudes and psychopathology was conducted within the community sample.

3.5 Characteristics of the Sample

Seventy-five young people (33 males, 42 females) from one of two Secondary Schools or a Guide, Scout or Explorer Unit completed questionnaires. The mean age of the participants in the community sample was 14.8 years (SD=1.58; range= 12-17 years). The average weight was 56.3 kg (SD=11.4; range=35-82kg) and the average height was 168.4cm (SD=10.4; range=142-188cm) corresponding to a mean body mass index (BMI; kg/m²) of 19.6 (SD=2.6; range=15.4-27.3). It was only possible to calculate the BMI of 58 of the 75 participants because 17 participants failed to report either their height or their weight. One participant (1.7%) had a BMI above 25 and 21 participants (36.2%) had a BMI below 18.5. BMI is not a valid index of weight status in premenarcheal girls (O'Dea & Abraham, 1995) therefore BMI is not reported for five of the female participants in the community sample.

Twenty-five participants (33.3%) reported an ideal weight different from their current weight. Twenty-one participants (2 males, 19 females) wanted to weigh less than their current weight and 4 participants (all males) wanted to weigh more than their current weight. Only three people reported their current weight to be their ideal weight; however, 47 participants failed to respond to the question. Eleven participants (one male (3%) and ten females (25.6%)) indicated that they were currently eating less to lose weight while two males (6%) and no females indicated they were eating more to gain weight. There was a significant association between gender and eating less to

lose weight ($\chi^2(1) = 5.55, p = 0.018$) but no significant association between gender and eating more to gain weight ($\chi^2(1) = 0.710, p = 0.399$). Twenty males (64.5%) and 27 females (71.1%) said they were currently exercising to change their body shape, size or muscle tone. The assumption that in a 2x2 table all expected frequencies should be greater than 5 was not met for gender and exercising to change body shape, size or muscle tone. The association between gender and exercising to change body shape, size or muscle tone was analysed using Fisher's Exact Probability test. The significance value for this test was 0.206, indicating that the association was not significant.

3.6 BSQ, ChEAT and EDE-Q Scores in the Community Sample

Tables 5 and 6 present median scores and interquartile ranges for the BSQ, the ChEAT and the EDE-Q by gender and by age.

<i>Table 5: Medians and interquartile ranges by gender.</i>	BSQ	ChEAT	EDE-Q
Males (n=33)			
▪ Median	19.0	4	0.10
▪ IR	6	4	0.43
▪ Range	16-38	0-16	0-1.46
Females (n=42)			
▪ Median	36.5	7	1.03
▪ IR	24	10	2.30
▪ Range	17-83	0-30	0-4.78

Table 6: Medians and interquartile ranges by age.

	BSQ	ChEAT	EDE-Q
12-13 yrs (n=23)			
▪ Median	23	5	0.46
▪ IR	21	7	1.58
▪ Range	16-76	0-22	0-3.67
14-15 yrs (n=16)			
▪ Median	32	6	0.82
▪ IR	21	10	2.13
▪ Range	16-83	0-30	0.3-4.78
15-17 yrs (n=36)			
▪ Median	22	4	0.37
▪ IR	21	5	0.87
▪ Range	16-71	0-23	0-3.87

3.6.1 Attitudes to Body Shape and Weight

Attitudes to body shape and weight were measured by the Body Shape Questionnaire. A high proportion of females endorsed responses that indicate a high level of concern on many of the items. Forty-five per cent of females gave a response of ‘often’, ‘very often’ or ‘always’ to the question ‘have you thought your thighs, hips or bottom are too large for the rest of you?’. Item 16, ‘has worry about shape made you feel you ought to exercise?’ generated the second highest levels of concern, with 43% of females responding in the often to always range. This is consistent with the high number of participants reporting that they were currently exercising to change body shape, size or muscle tone. For a summary of the number of female participants who gave a

response of often, very often or always on each item, please refer to Appendices 20 and 21. Only two males responded ‘often’, ‘very often’ or ‘always’ to any of the items. The first male responded in this range to items 2, 6 and 10, and the second male responded in this range to items 3 and 16 (refer to Appendix 20).

Female participants reported significantly more disturbed attitudes to body shape and weight than male participants ($U = 144.5$, $Z = -5.87$, $p < 0.01$). Results of the Kruskal-Wallis test revealed no significant association between age and attitudes to body shape and weight ($H(2) = 1.25$, $p = 0.54$).

3.6.2 Eating Attitudes

Eating attitudes were measured using the ChEAT. Male scores ranged from 0-16 and female scores ranged from 0-30. Although none of the male participants scored within the anorectic range (≥ 20), five of the female participants’ scores fell within this range. There was a significant difference between male and female respondents in eating attitudes, as measured by the ChEAT ($U = 408.5$, $Z = -3.048$, $p < 0.01$), indicating higher scores within the female sub-sample. Results revealed no significant association between age and eating attitudes ($H(2) = 1.31$, $p = 0.54$). For a breakdown of the number of participants scoring in the most symptomatic range (a score of 1-3) on each individual ChEAT item, see appendix 22.

3.6.3 Eating Disorder Psychopathology

Eating disorder psychopathology was measured using the EDE-Q, on which a score of four or more is considered more likely to indicate clinical severity. A number of female participants in the community sample obtained a mean score of four or more on

the global score and/or one or more subscale. None of the male participants obtained a score within the clinically significant range. Table 7 below shows the number of female participants scoring within the clinically significant range by age group.

Table 7: Distribution of females scoring within the clinically significant range.

	12-13 years (n=13)	14-15 years (n=11)	16-17 years (n=18)
Restraint	0	2	0
Eating Concern	0	0	0
Shape Concern	3	2	5
Weight Concern	3	2	2
Global Score	0	2	0

As can be seen from Table 7, those scoring in the clinically significant range on the EDE-Q span all age groups. However, only those females aged 14 or 15 scored within the clinically significant range on the Global score and on the Restraint subscale.

Female eating disorder psychopathology scores were significantly higher than male scores as measured by the EDE-Q ($U = 222.5$, $Z = -5.03$, $p = < 0.01$). Results revealed no significant difference in eating disorder psychopathology between the age groups.

In addition to measuring attitudes and feelings, the EDE-Q provides data on the frequency of key behavioural features of eating disorders. These behavioural features include making yourself sick (vomiting), using diuretics, using laxatives, exercising hard (excessive exercise), or going for long periods of time without eating (extreme dietary restraint) to control shape or weight. Tables 8 and 9 present the number of participants who had engaged in key behavioural features of eating disorders over the previous 14 days by gender and by age.

Table 8: Frequency of five behavioural features of eating disorders by gender.

	Males (n=33)	Females (n=42)
Vomiting	0	2
Use of Diuretics	0	0
Use of Laxatives	0	0
Excessive Exercise	10	15
Extreme Dietary Restraint	3	12

Table 9: Frequency of five behavioural features of eating disorders by age.

	12-13 years (n=23)	14-15 years (n=16)	16-17 years (n=36)
Vomiting	0	1	1
Use of Diuretics	0	0	0
Use of Laxatives	0	0	0
Excessive Exercise	8	10	7
Extreme Dietary Restraint	4	5	6

Pearson chi-square revealed there was no significant association between gender and excessive exercise ($\chi^2(1)=0.052$, $p=0.82$, 2-tailed). However, there was a significant association between age and excessive exercise ($\chi^2(2)=8.87$, $p<0.05$, 2-tailed). The highest prevalence of excessive exercise was reported by those aged 14 and 15 years. Pearson's chi-square analyses could not be conducted for the association between age and vomiting after eating or going for long periods of time without eating as the assumptions for the test were not met.

3.7 Relationship between Attitudes to Shape and Weight, Eating Attitudes, and Eating Disorder Psychopathology across Gender and Age Groups

The relationship between attitudes to body shape and weight (as measured by the BSQ), eating attitudes (as measured by the ChEAT) and eating disorder psychopathology (as measured by the EDE-Q) was investigated using Kendall's tau, a non-parametric correlation. The results are presented in Tables 10 and 11.

Table 10: Kendall's Tau correlation coefficients between measures by gender.

	Males (n=33)	Females (n=42)
BSQ & ChEAT	0.08	0.513**
BSQ & EDE-Q	0.53**	0.744**
EDE-Q & ChEAT	0.247	0.577**

*p<0.05, **p<0.01 (2-tailed)

With regards to the relationship between measures, it was observed that the association between attitudes to body shape, eating attitudes and eating disorder psychopathology was significant in females.

Table 11: Kendall's Tau correlation coefficients between measures by age.

	12-13 years (n=23)	14-15 years (n=16)	16-17 years (n=36)
BSQ & ChEAT	0.368*	0.524**	0.358**
BSQ & EDE-Q	0.653**	0.831**	0.742**
ChEAT & EDE-Q	0.493**	0.536**	0.401**

*p<0.05, **p<0.01 (2-tailed)

The association between concerns about body shape and weight, eating attitudes and eating disorder psychopathology was significant across all age groups. The researcher was also interested in whether disturbance in attitudes was associated with disturbance in behaviour. Correlations between attitudes and exercise are presented in Tables 12 and 13 below.

Table 12: Correlations between attitudes and behaviour by gender.

	Males (n=33)	Females (n=42)
BSQ & Exercise	0.175	0.353**
ChEAT & Exercise	0.373*	0.453**
EDE-Q & Exercise	0.320*	0.505**

*p<0.05, **p<0.01 (2-tailed)

As Table 12 shows, in females the relationship between excessive exercise behaviour and attitudes is significant across all three measures. In males, excessive exercise is significantly associated with attitudes as measured by the ChEAT and the EDE-Q but not the BSQ. Table 13 shows that there is a significant relationship between excessive exercise and attitudes as measured by the EDE-Q in 12-13 years olds and a significant relationship between excessive exercise and attitudes as measured by the ChEAT in 16-17 years olds. However, the majority of relationships were not significant.

Table 13: Correlations between attitudes and behaviour by age.

	12-13 years (n=23)	14-15 years (n=16)	16-17 years (n=36)
BSQ & Exercise	0.342	0.191	0.123
ChEAT & Exercise	0.320	0.348	0.482**
EDE-Q & Exercise	0.407*	0.272	0.253

*p<0.05, **p<0.01 (2-tailed)

3.8 Summary of Research Findings in Relation to Core Hypotheses

Concern about shape and weight was measured by the BSQ. Concern about body shape and weight differed significantly between males and females, with females reporting higher levels of concern. In particular, a large number of female participants endorsed responses that indicate a high level of concern on the item, ‘have you thought your thighs, hips or bottom are too large for the rest of you?’ There was no significant difference in concern about shape and weight between the age groups. Disturbance in eating attitudes and behaviours were measured by the ChEAT, the EDE-Q Global score and EDE-Q data on the frequency of key behavioural features of eating disorders. The data revealed significant gender differences in attitudes and significant age differences in exercising hard to change body shape or weight. The prevalence of exercising hard was highest in those aged 14 and 15 years. Females reported greater disturbance in eating attitudes and behaviours than males. There was a significant association between gender and eating less to lose weight but no significant association between gender and eating more to gain weight or exercising to change shape, size or muscle tone.

4: DISCUSSION

The main aim of this study was to compare subgroups of young people on measures of attitude to body shape and weight, eating attitudes and behaviours and eating disorder psychopathology. Eating attitudes, behaviours and eating disorder psychopathology were compared between young people with and without a sibling with type 1 diabetes, and between genders and age groups. The main findings of the study will be highlighted and discussed in terms of their clinical implications. Limitations of the study will be examined and suggestions will be made for future research.

4.1 Interpretation of Results

4.1.1 Comparisons between young people with and without a sibling with type 1 diabetes

It was predicted that higher levels of concern about shape and weight and greater levels of disturbance in eating attitudes and behaviours would be observed in young people with a sibling with type 1 diabetes than in those without. The results revealed no significant difference between young people with and without a sibling with type 1 diabetes in terms of concern about shape and weight as measured by the BSQ, or eating attitudes as measured by the ChEAT. However, females in the sibling group scored significantly higher than females in the matched control group in terms of eating disorder psychopathology as measured by the EDE-Q. Those in the sibling group tended to have higher scores on the BSQ than those in the matched control group, indicating greater body shape concerns, however this difference was not statistically significant. Furthermore, frequency data suggested that females in the sibling group were more likely than those in the matched control group to endorse

responses that represented higher levels of concern. These findings suggested a trend for greater levels of disturbance in young people with a sibling with type 1 diabetes. However the size of the effect may be such that the group sizes were too small to detect significant differences. The results would need to be replicated with a larger sample.

It would have been interesting to test whether eating attitudes and behaviours were related to length of time since diagnosis in the sibling group. However, this was not possible in the current study due to the modest sample size. Further investigation would be required to examine the hypothesis that length of time since diagnosis of type 1 diabetes impacts on shape and weight concerns or eating attitudes and behaviours in siblings.

As a result of differences in the way participants in the two groups were recruited, it is possible that the number of young people choosing not to take part in the study was greater in the sibling group than in the matched control group. It may have been more likely that those with higher levels of concern chose not to take part when participation involved return of a postal questionnaire, rather than when the researcher attended Scout, Guide and Explorer meetings and PSE lessons in schools. It is also possible that in families with a child with type 1 diabetes, parents with higher levels of anxiety were more likely to choose not to pass the relevant section of the research pack to the sibling, thereby preventing participation. These factors may have led to biases arising within the sibling sample. Despite efforts being made to recruit male and female participants from across the Highland region, the sibling sample may not be representative of all young people with a sibling with type 1 diabetes. The large

community sample of males and females aged between 12 and 17 years is likely to be a more representative sample than the sibling sample.

The levels of concern about shape and weight reported in the current study are generally comparable with previous research findings. When compared to the findings of Cooper and Goodyer (1997) mean BSQ scores in the current study are slightly higher in 13 to 14 year old females and lower in 15 and 16 year old females. However, unlike Cooper and Goodyer, who found that mean BSQ score increases significantly with age, the current study found the highest scores were obtained by those in the 14-15 age range rather than the 16-17 range. This is consistent with evidence that there is a peak in the onset of eating disorders at the age of 14 years (Kerig & Wenar, 2006), and may indicate heightened concerns about body shape at this age. However, this finding should be interpreted with caution as the sample was small.

Unlike Maloney, McGuire and Daniels (1988), who found that in a sample of 813 children aged 8 to 13 years almost 7% scored within the anorectic range, the current study did not find any participant in the sibling group or matched control group scored within the anorectic range. The results of Maloney, McGuire and Daniels' study are consistent with other studies that have reported similar percentages in adolescent and adult samples, therefore the findings of the current study are likely to be attributable to small sample size.

Normative EDE-Q data for adolescent females suggest a mean global score of 1.6 (SD=1.4) among girls aged between 12 and 14 years (Carter, Fairburn & Cooper, 2001). In the current study there were only four female participants aged 12-14 years

in the sibling group and matched control group. Three of these obtained a global EDE-Q score of less than 1.6 and one participant in the sibling group obtained a score of more than 1.6. On the basis of these findings it appears that eating disorder psychopathology may be lower in the current study, but again, small sample size may affect the reliability of these results. An absence of normative data for older adolescents means it is not possible to make similar comparisons for those aged between 15 and 17 years.

Carter, Fairburn and Stewart (2001) also reported prevalence figures for eating disorder behaviours among their standardisation sample. They reported prevalence rates of 4% self-induced vomiting, 1% laxative misuse, 0.4% diuretic misuse, 38% exercising hard to control shape or weight and 8% regular binge eating. The current study found comparable prevalence figures for eating disorder behaviours.

The prevalence of exercising hard to control body shape or weight can be considered high in the current study and is comparable to prevalence rates reported in previous research. This behaviour was reported by 12% of females in the sibling group and 25% of females in the matched control group. Consistent with previous research, those who reported dieting were all within the normal weight range.

Excessive exercise and overactivity are common features of anorexia nervosa (Close, 2000). Although the desire to exercise among participants may have started as an attempt to lose weight, change shape or build muscle, the data suggest that this might have escalated to an excessive level. The measures used in the current study are not diagnostic instruments, therefore it would have been useful to interview a selection of

young people to clarify the nature and extent of their exercise practices. For example, it would be interesting to explore the type of exercise that young people engage in, whether exercise is solitary or takes place with peers, and how demanding and compulsive the routine has become. It is possible that the prevalence of excessive exercise is high in the current study due to the nature of the population from which the sample was drawn. Participants live in a rural area where outdoor pursuits are popular, which may contribute to the onset and maintenance of compulsive exercise. Anecdotal evidence would support this hypothesis, for example, when collecting data in one of the secondary schools one participant commented that she was exercising to change her muscle tone in preparation for a ski competition. Matched controls tended to reside in more rural areas than young people in the sibling group, which might account for the difference in prevalence of excessive exercise between groups. These hypotheses would need to be substantiated by further investigation.

4.1.2 Comparisons between gender and age groups in the community sample

One strength of the current study was the large number of male and female participants in the community sample. It was predicted that females would have greater concerns about shape and weight than males and also have greater disturbance in eating attitudes and behaviours. When compared on the BSQ, the ChEAT and the EDE-Q, female scores were found to be significantly higher than male scores on all measures in terms of concerns and attitudes. This finding is consistent with the literature, as previous studies have reported male to female eating disorder ratios of between 1:29 and 1:10 (Doyle & Bryant-Waugh, 2000). However, when compared on the behavioural features of eating disorders, the prevalence of excessive exercise did not differ significantly between males and females. This finding suggests that degree of body

concern may not differ between males and females but the nature of the concerns may differ considerably. Future research should aim to thoroughly investigate motivation for exercise and the extent to which it is intended to influence shape and weight.

It was also predicted that concerns about shape and weight and disturbance in eating attitudes and behaviours would increase as a function of age. Although the majority of findings indicate no significant differences in concerns or attitudes, there was a significant association between age and excessive exercise. The highest prevalence of excessive exercise was in those aged 14 and 15 years. As discussed previously, this is consistent with evidence that there is a peak in the onset of eating disorders at the age of 14 years and therefore may signify the onset of body image difficulties or eating disorders in some participants. Davis, Blackmore, Katzman and Fox (2005) suggest that excessive exercise has the potential to develop into more complex difficulties and is one of the first eating disorder symptoms to appear.

The results of this study are consistent with Maloney, McGuire and Daniels's (1988), finding that almost 7% of children score within the anorectic range on the ChEAT. Five participants in the community sample scored within the anorectic range, which corresponds to a prevalence of 6.7% across genders. However, when male and female scores are considered separately, the prevalence rate in females is 11.9% which is considerably higher than that in previous studies. Because the ChEAT is not a diagnostic instrument, individuals scoring within the anorectic range would need to be followed up with a face to face interview to establish the presence of a diagnosable eating disorder.

Unlike Cooper and Goodyer (1997), who found that mean BSQ score increases as a function of age, the current study found that the median BSQ scores was highest in those aged 14 and 15 years and lowest in those aged 16 and 17 years. Higher levels of body shape and weight concern in 14 and 15 year olds corresponds with the finding that excessive exercise behaviour was also most prevalent in this age range. Several studies have suggested a significant association between high levels of concern and concurrent disturbance in behaviour. Many of those in the current study who reported higher levels of concern and greater disturbance in attitudes also reported that they were eating less to lose weight or exercising to control shape or weight. However, the small sample size within the present study prevented statistical exploration of this relationship.

In comparison to previous studies, the prevalence of both exercising hard to control shape or weight and binge-eating was generally comparable. Carter, Fairburn and Cooper (2001) reported prevalence rates of 4% self-induced vomiting, 1% laxative misuse, 0.4% diuretic misuse, 38% exercising hard and 8% regular binge eating. In the current study the prevalence of binge-eating in the community sample was 6.7% and the prevalence of exercising hard was 34%. Although these prevalence rates are generally comparable to Carter, Fairburn and Stewarts they are slightly lower. A number of factors may account for this difference. For example, Carter, Fairburn and Stewart's standardisation sample was drawn from single sex schools, therefore may not generalise to females from mixed sex schools. Alternatively, the differences may be due to the sample in the current study being drawn from a more rural area than those in the standardisation sample. However, it is also possible that the questionnaires ask young people to make judgements about variables that are outwith

their comprehension, therefore the measures may not be reliable. Although all measures used in the current study have been used with young people aged between 12 and 17 years in previous studies, a number of participants asked the researcher to define key terms when questionnaires were being completed in schools. For example, young people asked for definitions of the terms laxative, diuretic and brood, and also asked the researcher if going to bed at night would be considered 'going for a long period of time without eating anything to control your shape or weight' (EDE-Q item 2).

4.2 Limitations of the Study

4.2.1 Statistical power analysis

Cohen's tables (1992) were used to determine the sample size necessary to detect a large, medium and small effect size for a power of 0.8 with an alpha of 0.05. It was anticipated that 64 participants in each group would be required to detect a medium effect size.

To address whether there are any differences in eating attitudes and behaviours in the siblings of young people with type1 diabetes compared with controls the study would need to be replicated with a larger sample. Replication with a larger sample would also allow further investigation of possible age differences on each of the measures.

4.2.2 Self-report

The BSQ, the EAT, and the EDE-Q are all self-report questionnaires that were completed retrospectively with regards to attitudes and behaviours over the previous two to four weeks. As such, the measures relied on both accurate recall and the assumption that participants would give truthful responses. To encourage participants to be as truthful as possible in their responses they were informed that their questionnaires would remain anonymous, unless their questionnaire responses suggested significant psychopathology. In such circumstances, participants were told that the researcher would get in touch to discuss the concerns before contacting their GP. The parents of those aged under 16 would also be informed. This safeguard may have acted as a deterrent to young people with problematic eating attitudes and behaviours as they might not have wanted their problems to be identified.

Because those with problematic eating or shape and weight concerns may have self-selected not to take part in the study, the sample may not be representative of all young people in the age range. Evidence indicates that eating disorder psychopathology is high among those who choose not to take part in such research. For example, Johnson-Sabine, Wood, Patton, Mann and Wakeling (1988) screened 1010 schoolgirls aged between 14 and 16 years from 8 London schools to identify a cohort at risk of developing an eating disorder. Those who scored above the cut-off on the screening questionnaire were assessed by clinical interview. Johnson-Sabine et al attempted an analysis of those who avoided completing the screening questionnaire by refusal or absence from school, and found evidence that eating problems were common in this group. Attempts to follow-up non-responders were not feasible within the scope of the current study.

An additional limitation of the study was the use of self-reported height and weight to calculate BMI. Although self-report is the most practical method within the limits of the present study and has the advantages of being quick and convenient, there is the disadvantage of not knowing the accuracy of the estimates. Calculations based on self-reported height and weight revealed that 36.2% of participants in the community sample had a BMI below 18.5. Given that such a high proportion of participants could be considered underweight, the accuracy of self-reported height and weight should be questioned. However, previous studies with both clinical and general population samples have consistently found significant correlations between actual and self-reported weight and height. Although research with adults reveals that women tend to under-report weight; generally the tendency to under-report increases as a function of increased BMI. It is hypothesised that the tendency to under-report weight reflects a desire to conform to the societal expectation that women should be slim. McCabe, McFarlane, Polivy & Olmsted (2001) investigated the accuracy of self-reported weight in four samples of women: anorectics, bulimics, dieters, and non-dieters. Those in the anorexia and bulimia groups were very accurate at reporting their weight. Both dieters and non-dieters significantly under-reported weight, with dieters under-reporting to a greater extent. Despite the tendency to under-report weight, correlation between actual and self-reported weight was highly significant in all four samples. Fewer studies have investigated self-reported height and weight in children and adolescents, but those that have report a similar pattern to that found in adults (e.g. Wang, Patterson & Hills, 2002, as cited in Abraham, Luscombe, Boyd & Olesen, 2004). With regard to clinical samples, Swene, Belfrage, Thrifjell & Engstrom (2005) investigated accuracy of self-reported height and weight in 211 girls aged between 13 and 17 years who had a diagnosis of anorexia nervosa, bulimia nervosa or eating disorder not otherwise

specified. The overall correlation between actual and self-reported weight was high, and there was no tendency to under-report. In addition, the authors did not find that accuracy of self-report differed between diagnostic categories. Nevertheless, using self-reported height and weight represents a limitation to the current study.

4.2.3 Recruitment

A possible limitation of the study with regards to recruitment is the method used to recruit the siblings of children and adolescents with type 1 diabetes. Response rate from this group was low, possibly due to the use of a postal questionnaire. Efforts were made to extend recruitment of the sibling group to another Health Board area, but this was not achievable within the time constraints of the study. Response rate in the control group was higher, possibly because the researcher met with young people to explain what participation in the research study involved and deliver research packs in person. In the control group research packs were given to young people to give to their parents, whereas research packs were addressed to the parents of children and young people with type 1 diabetes. It is possible that parents did not pass the relevant section of the pack to their child(ren), and therefore potential participants did not have the option of taking part in the study. Perhaps if the researcher had attended paediatric diabetes clinics and met with families to give out research packs in person response rate might have been higher. However, this was not possible in the current study due to the large geographical nature of the clinical population and the constraints of participating in the paediatric diabetes clinics. Attendance at clinics outwith Inverness would have involved up to five hours of travel and would have reduced the time available for the researcher's clinical work.

4.3 Methodological Implications

While previous research has provided normative EDE-Q data for girls aged between 12 and 14 years, currently there is no equivalent data available for boys. Similarly, although the BSQ has been used previously with males, normative data has not been reported. Normative data is essential for the interpretation of whether scores are disproportionately common or rare. Data that is currently available is based on a Caucasian sample within a narrow age range. This prompts the question of whether the findings extend to other races and age ranges.

It is possible that the BSQ is not useful with males, as body fat is distributed differently on males and females. Questions on the BSQ are weighted towards female concerns and fat-bearing body parts (Crisp, 2006), therefore inclusion of separate measures of concern about body shape and weight for males and females might have been more informative.

There are questions about the accuracy of information provided in self-report measures, either deliberately or inadvertently. None of the self-report questionnaires used in the current study provides definitions of key terms such as 'binge', however participants were required to answer questions such as, 'on how many days out of the past 14 have you had eating binges?' Anecdotal evidence suggests some participants experienced difficulties understanding the language in some of the measures. For example, a number of participants asked the researcher for a definition of the term 'brood' in order to respond the BSQ item, 'has feeling bored made you brood about your shape?' Consequently, there may be some variation in scores due to differences

in understanding and interpretation of questions. Future studies could address this issue by providing definitions of key terms to promote consistency in comprehension.

The use of measures of psychopathology alone could be considered a further limitation of the study, as Altschuler (1997) considers that by doing so we limit our understanding of resilience factors and coping strategies. The choice of measures in the current study would be able to detect an absence of negative eating attitudes and behaviours but would not establish the presence of positive eating attitudes and behaviours. Subsequently, the measures do not allow exploration of the possibility that having a sibling with type 1 diabetes might be a protective factor contributing to more positive eating attitudes and behaviours in comparison to those who do not have a sibling with type 1 diabetes.

4.4 Future Research

In the current study both body shape and weight concerns and eating attitudes differed significantly between males and females. However, prevalence rates of excessive exercise did not differ between genders, suggesting that the choice of measures did not tap into male concerns. Future research comparing males and females should consider the use of separate measures and should aim to thoroughly investigate motivation for exercise and the extent to which it is intended to influence shape and weight.

There is also scope for more work comparing young people with and without type 1 diabetes in a larger sample. This would help to establish whether the significant difference between females in the sibling and control group on the measure of eating disorder psychopathology, found in the current study, represents a genuine effect.

Replication with a larger sample would also provide opportunity to explore whether length of time since diagnosis of type 1 diabetes impacts on shape and weight concerns and eating attitudes and behaviours in siblings. To increase response rate, researchers should consider attending paediatric diabetes clinics to recruit families rather than send out a postal questionnaire.

In the future it is also recommended that research is carried out investigating whether having a sibling with type 1 diabetes might be a protective factor. It is possible that children and adolescents with a sibling with type 1 diabetes are better informed about healthy diet and exercise than those without a sibling with type 1 diabetes. They may therefore have fewer shape and weight concerns and more positive eating attitudes and behaviours.

4.5 Clinical Implications

Although the majority of findings indicate no significant difference between young people with and without a sibling with type 1 diabetes on the BSQ and the ChEAT, females in the sibling group had significantly higher score on the EDE-Q than females in the matched control group. This suggests that females with a sibling with type 1 diabetes have higher levels of eating disorder psychopathology than those without. This finding offers support for clinicians providing information and education to the whole family when a young person is diagnosed with type 1 diabetes. Family psycho-education sessions allow the family to develop a shared understanding of the illness (Carr, 2006). It may be useful to spend time identifying and discussing concerns about diet and exercise to clarify any confusion and reduce anxiety.

In addition, the high prevalence of exercising hard to change body shape or weight in the sibling sample, control sample and the community sample highlights a possible focus for prevention and early intervention. Excessive exercise may lead to the development of physical problems such as local joint problems, which if left untreated can lead to permanent damage and early onset of oosteoarthritis (Close, 2000). With this in mind, young people might benefit from education about excessive exercise behaviour.

4.6 Conclusion

The first aim of this study was to explore body shape and weight concerns and eating attitudes and behaviours in young people with and without a sibling with type 1 diabetes. Results reveal that females with a sibling with type 1 diabetes have higher levels of eating disorder psychopathology than females without a sibling with type 1 diabetes. Concerns about body shape and weight and disturbance in eating attitudes did not differ significantly between groups. This hypothesis would need investigated further before any definite conclusions could be drawn about differences between young people with and without a sibling with type 1 diabetes.

The second aim of the study was to examine gender and age differences in attitudes and behaviours in a community sample of 12 to 17-year-olds. In line with the hypotheses, concerns about body shape and weight and disturbed eating attitudes were significantly higher in females compared with males. Despite low male scores on measures of concern and attitude, the results highlighted a high prevalence of excessive exercise behaviour in both males and females. This suggests that male body concerns were not detected by the measures used in the current study. Excessive exercise was the only variable to differ significantly between age groups, with the highest prevalence reported in those aged 14 and 15 years.

Although a number of limitations may affect the ability to generalise the results of the study, the study has generated interesting data on body image concerns and eating attitudes and behaviours in a community sample of young people living in a rural area.

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A) DSM-IV Criteria for Anorexia Nervosa

- A. Refusal to maintain body weight at or above a minimally normal weight for age and height (e.g. weight loss leading to maintenance of body weight less than 85% of that expected or failure to make expected weight gain during period of growth, leading to body weight less than 85% of that expected).
 - B. Intense fear of gaining weight or becoming fat, even though underweight.
 - C. Disturbance in the way in which one's body weight or shape is experienced, undue influence of body weight or shape on self-evaluation, or denial of the seriousness of the current low body weight.
 - D. In postmenarchal females, amenorrhea ie, the absence of at least three consecutive cycles. (A woman is considered to have amenorrhea if her periods occur only following hormone, e.g. estrogen administration.)
- **Restricting Type:** During the current episode of anorexia nervosa, the person has not regularly engaged in binge-eating or purging behaviour (i.e. self-induced vomiting or the misuse of laxatives, diuretics, or enemas).
 - **Binge-Eating/Purging Type:** During the current episode of anorexia nervosa, the person has regularly engaged in binge-eating or purging behaviour (i.e. self-induced vomiting or the misuse of laxatives, diuretics, or enemas).

B) DSM-IV Criteria for Bulimia Nervosa

- A. Recurrent episodes of binge eating. An episode of binge eating is characterized by both of the following:(1) Eating, in a discrete period of time (e.g. within any 2-hour period), an amount of food that is definitely larger than most people would eat during a similar period of time and under similar circumstances.(2) A sense of lack of control over eating during the episode (e.g. a feeling that one cannot stop eating or control what or how much one is eating).
 - B. Recurrent inappropriate compensatory behaviour in order to prevent weight gain, such as self-induced vomiting; misuse of laxatives, diuretics, enemas or other medications; fasting or excessive exercise.
 - C. The binge eating and inappropriate compensatory behaviours both occur, on average, at least twice a week for 3 months.
 - D. Self-evaluation is unduly influenced by body shape and weight.
 - E. The disturbance does not occur exclusively during episodes of anorexia nervosa.
- **Purging type:** During the current episode of bulimia nervosa, the person has regularly engaged in self-induced vomiting or the misuse of laxatives, diuretics or enemas.
 - **Nonpurging type:** During the current episode of bulimia nervosa, the person has used inappropriate compensatory behaviours, such as fasting or excessive exercise, but has not regularly engaged in self-induced vomiting or the misuse of laxatives, diuretics or enemas.

C) Eating Disorder Not Otherwise Specified

Includes disorders of eating that do not meet the criteria for any specific eating disorder. Examples include:

- A. For females, all of the criteria for anorexia nervosa are met except that the individual has regular menses.
- B. All of the criteria for anorexia nervosa are met except that, despite significant weight loss the individual's current weight is in the normal range.
- C. All of the criteria for bulimia nervosa are met except that the binge eating and inappropriate compensatory mechanisms occur at a frequency of less than twice a week or for duration of less than 3 months.
- D. The regular use of inappropriate compensatory behaviour by an individual of normal body weight after eating small amounts of food (e.g. self-induced vomiting after the consumption of two cookies).
- E. Repeatedly chewing and spitting out, but not swallowing, large amounts of food.

Binge-eating disorder: recurrent episodes of binge eating in the absence if the regular use of inappropriate compensatory behaviours characteristic of bulimia nervosa.

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Invitation Letter for Parents (Group A)
Version 3 (10/03/2007)

Enquiries to: Rachel Smith

To whom it may concern,

My name is Rachel Smith and I am a Trainee Clinical Psychologist. I am carrying out a research study which looks at eating attitudes and behaviours in **young people with a brother or sister who has diabetes** compared to young people with a brother or sister who does not have diabetes.

If your child with diabetes has any brothers or sisters between the ages of 12 and 18, I would be grateful if you would read the information enclosed.

Parental consent is required for all young people under the age of 16. Before you decide whether to give consent for your child/children to take part, it is important to understand why the research is being done, and what it will involve. I have **enclosed an information sheet** about the research study and a **consent form**. Please read these carefully, and take time to decide whether you wish your child/children to take part.

I have also included an invitation letter, information sheet and consent forms for your child/children. Please pass these on.

If you have any questions about the research, please contact me either:

by phone **(01463) 704665** or by email rachelsmith@nhs.net

Thank you for considering allowing your child/children to take part.

Yours sincerely,

**Rachel Smith
Principal Researcher
Trainee Clinical Psychologist**



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Invitation Letter for Parents (Group B)
Version 3 (10/03/2007)

Enquiries to: Rachel Smith

To whom it may concern,

Your child has been invited to take part in a research study which looks at eating attitudes and behaviours in young people with a brother or sister who has diabetes compared to young people with a brother or sister who does not have diabetes.

Parental consent is required for all young people **under the age of 16**. Before you decide whether to give consent for your child to take part, it is important to understand why the research is being done, and what it will involve. I have **enclosed an information sheet** about the research study and a **consent form**. Please read these carefully, and take time to decide whether you wish your child/children to take part. If you have any questions about the research, please contact me either:

by phone **(01463) 704665** or by email rachelsmith@nhs.net

Thank you for considering allowing your child to take part.

Yours sincerely,

**Rachel Smith
Principal Researcher
Trainee Clinical Psychologist**

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Information sheet for Parents (Group A)
Version 3 (10/03/2007)

Enquiries to: Rachel Smith



Parent information sheet

An exploration of eating attitudes and behaviours in children and young people who have a brother or sister with diabetes.

I would like to invite your child to take part in a research study. Before you decide whether you wish your child to take part, it is important to understand why the research is being done and what it will involve. **Please take time to read the following information carefully** and talk about it with other people such as friends, relatives or your GP if you wish. If there is anything you do not understand, or anything you would like more information about, please feel free to get in touch with me. My address and my secretary's telephone number are printed at the top of this sheet.

What is the study about?

This study aims to look at eating attitudes and behaviours in young people who have a brother or sister with diabetes.

By comparing young people with a brother or sister who has diabetes (group A) with young people with a brother or sister who does not have diabetes (group B) we hope to find out some of the differences between these two groups.

We hope that by finding out more about any difficulties that exist for those young people whose brother or sister has diabetes, this will lead to better help being available for the young people and their families.

Who is doing the research?

The research is being carried out by Rachel Smith, a Trainee Clinical Psychologist at the Clinical Psychology Service for Children and Young People based in Inverness. The research is part of her qualification of Doctorate in Clinical Psychology at the University of Edinburgh.

Anne Woodhouse, Consultant Clinical Psychologist at the Clinical Psychology Service for Children and Young People in Inverness and Dr Emily Newman, Lecturer in Psychology in the Clinical Psychology Department at the University of Edinburgh, will supervise the research.

Who is being asked to take part?

Two groups of people are being asked to take part in the study:

- **Group A** – young people aged 12 -18 with a brother or sister who has diabetes
- **Group B** – young people aged 12-18 with a brother or sister who does not have diabetes

Having these two groups will allow us to compare them to see if there are any differences in eating attitudes and behaviours depending on whether their brother or sister has diabetes or not.

Your child has been asked to take part because he/she fits in to one of these two groups. If there is more than one young person in your family who wishes to take part, please complete the slip and return it to me in the same envelope as the consent forms. I will put additional consent forms and questionnaires in the post to you.

What is involved?

If you wish your child to participate in the research study, **he/she will be asked to fill in a booklet containing four short questionnaires.** These questionnaires will ask about their eating habits and how they feel about their body weight and shape, and should take no longer than 30 minutes to complete. If completing any of the questionnaires raises any issues that your child feels they would like help with, they will be advised to contact the researcher (Rachel Smith) who will be able to discuss these issues with them.

Will my child's responses be kept confidential?

All information in your child's questionnaires will be kept strictly confidential. The only people who will see the information is the researcher and her two supervisors. The questionnaires will not have your child's name on them, but they will have a participant number. The questionnaires will be kept separately from the consent forms that you and your child have signed. Only the consent forms will contain both your child's name and participant number.

However, in the **unlikely event** that your child's answers on the questionnaires raise serious cause for concern, the questionnaire and the consent form will be matched up. This will enable me to contact your child to discuss my concerns and bring your child's name to the attention of his/her GP. You will be asked to provide the contact details of your GP on the consent form.

Neither you nor your GP will have access to your child's questionnaires or answers.

What will happen to the results of the study?

The results will be included in a thesis submitted to the University of Edinburgh by the researcher (Rachel Smith). Your child will not be identified in any publication that might be produced from this research. **You can request a summary of the results by ticking the relevant box on the consent form. The summary will be posted to your home in September 2007.**

Who has reviewed this study?

The study has been reviewed by the Highland Health Board Research Ethics Committee.

If you would like to speak to someone other than the researcher about the study, Dr Anne Woodhouse is available to offer independent advice. If you have any questions or would like more information, Dr Woodhouse can be contacted at the address below:

Dr Anne Woodhouse
The Alligin Centre
Larch House
Stoneyfield
Inverness
IV2 7PA

You can also contact the researcher, Rachel Smith, at the same address.

If you would prefer to speak to either Dr Woodhouse or Rachel Smith, you can telephone Alison Mackintosh, their secretary, on 01463 704665. Alison will be able to put you through to whoever you wish to speak to.

What do I do if I would like my child to take part?

If your child is under the age of 16 and you are happy for him/her to take part, please complete the green consent form and put it in the envelope in your child's pack. If you have more than one child who wishes to take part, please fill in the slip to request additional forms and I will post them out to you.

If your child is aged 16 or over, you do not need to complete a consent form.

Your child will be asked independently to decide whether they wish to participate in the study.

Obviously, only those young people whose parent(s) sign consent forms will be allowed to take part. It is **completely up to you to decide whether you wish your child to take part.**

You are free to change your mind at any time, and you will not be asked to give a reason. If you decide you no longer wish your child to take part once the consent form has been returned, please contact me and your child will be withdrawn from the study.

Please keep this information for your own records.

Thank you for your time and consideration.

Yours sincerely

RACHEL SMITH

Trainee Clinical Psychologist
(Supervised by Dr Anne Woodhouse, Consultant Clinical Psychologist)

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Information Sheet for Parents (Group B)
Version 3 (10/03/07)

Enquiries to: Rachel Smith

Parent information sheet



An exploration of eating attitudes and behaviours in children and young people who have a brother or sister with diabetes.

I would like to invite your child to take part in a research study. Before you decide whether you wish your child to take part, it is important to understand why the research is being done and what it will involve. **Please take time to read the following information carefully** and talk about it with other people such as friends, relatives and your GP if you wish. If there is anything you do not understand, or anything you would like more information about, please feel free to get in touch with me. My address and my secretary's telephone number are printed at the top of this sheet.

What is the study about?

This study aims to look at eating attitudes and behaviours in young people who have a brother or sister with diabetes.

By comparing young people with a brother or sister who has diabetes (group A) with young people with a brother or sister who does not have diabetes (group B) we hope to find out some of the differences between these two groups.

We hope that by finding out more about any difficulties that exist for those young people whose brother or sister has diabetes, this will lead to better help being available for the young people and their families.

Who is doing the research?

The research is being carried out by Rachel Smith, a Trainee Clinical Psychologist at the Clinical Psychology Service for Children and Young People based in Inverness. The research is part of her qualification of Doctorate in Clinical Psychology at the University of Edinburgh.

Anne Woodhouse, Consultant Clinical Psychologist at the Clinical Psychology Service for Children and Young People in Inverness and Dr Emily Newman, Lecturer in Psychology in the Clinical Psychology Department at the University of Edinburgh, will supervise the research.

Who is being asked to take part?

Two groups of people are being asked to take part in the study:

- **Group A** – young people aged 12 -18 with a brother or sister who has diabetes
- **Group B** – young people aged 12-18 with a brother or sister who does not have diabetes

Having these two groups will allow us to compare them to see if there are any differences in eating attitudes and behaviours depending on whether their brother or sister has diabetes or not.

Your child has been asked to take part because he/she fits in to one of these two groups.

What is involved?

If you wish your child to participate in the research study, **he/she will be asked to fill in a booklet containing four short questionnaires.** These questionnaires will ask about their eating habits and how they feel about their body weight and shape, and should take no longer than 30 minutes to complete. If completing any of the questionnaires raises any issues that your child feels they would like help with, they will be advised to contact the researcher (Rachel Smith) who will be able to discuss these issues with them.

Will my child's responses be kept confidential?

All information in your child's questionnaires will be kept strictly confidential. The only people who will see the information is the researcher and her two supervisors. The questionnaires will not have your child's name on them, but they will have a participant number. The questionnaires will be kept separately from the consent forms that you and your child have signed. Only the consent forms will contain both your child's name and their participant number.

However, in the unlikely event that your child's answers on the questionnaires raise cause for concern, the questionnaires will be matched with the consent form. This will enable me to contact your child to discuss my concerns and bring your child's name to the attention of his/her GP. You will be asked to provide the contact details of your GP on the consent form.

Neither you nor your GP will have access to your child's questionnaires or answers.

What will happen to the results of the study?

The results will be included in a thesis submitted to the University of Edinburgh by the researcher (Rachel Smith). Your child will not be identified in any publication that might be produced from this research. **You can request a summary of the results by ticking the relevant box on the consent form. The summary will be posted to your home in September 2007.**

Who has reviewed this study?

The study has been reviewed by the Highland Health Board Research Ethics Committee.

If you would like to speak to someone other than the researcher about the study, Dr Anne Woodhouse is available to offer independent advice. If you have any questions or would like more information, Dr Woodhouse can be contacted at the address below:

Dr Anne Woodhouse
The Alligin Centre
Larch House
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IV2 7PA

You can also contact the researcher, Rachel Smith, at the same address.

If you would prefer to speak to either Dr Woodhouse or Rachel Smith, you can telephone Alison Mackintosh, their secretary, on 01463 704665. Alison will be able to put you through to whoever you wish to speak to.

What do I do if I would like my child to take part?

If your child is under the age of 16 and you are happy for him/her to take part, please complete the blue consent form and put it in the envelope in your child's pack.

If your child is aged 16 or over, you do not need to complete a consent form.

Your child will be asked independently to decide whether they wish to participate in the study. Obviously, only those young people whose parent(s) sign consent forms will be offered a chance to take part. It is completely **up to you to decide whether you wish your child to take part.**

You are free to change your mind at any time, and you will not be asked to give a reason. If you decide you no longer wish your child to take part once the consent form has been returned, please contact me and your child will be withdrawn from the study.

What do I have to do if I don't want my child to take part?

If you do not want your child to take part, you do not have to do anything. Only young people whose parents have completed consent forms will be allowed to take part.

Please keep this information for your own records.

Thank you for your time and consideration.

Yours sincerely

RACHEL SMITH

Trainee Clinical Psychologist
(Supervised by Dr Anne Woodhouse, Consultant Clinical Psychologist)

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Participant number:

Parent Consent
Version 2 (19/02/2007)

Enquiries to: Rachel Smith

PARENTAL CONSENT FORM

(to be completed by parents of young people under the age of 16)

Study: **An investigation of eating attitudes and behaviours in siblings of children and adolescents with type 1 diabetes compared with controls**

Main researcher: **Rachel Smith (Trainee Clinical Psychologist)**

Please put a **tick** in each of the boxes to show that you have read the information:

I have **read** and **understood** the information sheet on the above study.

I know that I can **contact the researcher** (Rachel Smith) if I have any questions or need more information about the study.

I understand that my son/daughter is **free to withdraw** from the study at any time, without giving a reason. This will not affect any future treatment.

I understand that **this study has been reviewed** by the NHS Highland Research Ethics Committee.

PLEASE TURN OVER



I agree to my son/daughter taking part in the study

My child's name is _____

My child's date of birth is _____

My name is _____

My relation to the child is _____

My signature _____

Today's date _____

I would like to receive a summary of the results of the study in September 2007

YES NO

(please circle)

My address is

If you **agree to your child participating** in the study, I would be grateful if you would provide details of your GP. This will enable me to seek assistance for your child in the unlikely event that your child's responses on any of the questionnaires should raise serious cause for concern. I would of course contact your child before making contact with his/her GP.

My child's GP is _____

GP's address _____

Thank you



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Invitation Letter Group A
Version 3 (10/03/07)

Enquiries to: Rachel Smith

To whom it may concern,

I would like to invite you to consider getting involved in a research study looking at eating attitudes and behaviours in young people with a brother or sister who has diabetes.

Before you decide whether you would like to take part, it is important to understand why the research is being done, and what it will involve for you. I have enclosed an information sheet about the research study and a consent form. Please read these carefully. Talk about it with your family and friends if you want to. If you have any questions about the research, please contact me either:

by phone **(01463) 704665** or by email [**rachelsmith@nhs.net**](mailto:rachelsmith@nhs.net)

Please take time to decide whether you wish to take part.

If you are **under the age of 16**, you will need to get permission from a parent/guardian to take part in the research study. They will have a green consent form in their pack.

Thank you for considering taking part.

Yours sincerely,

**Rachel Smith
Principal Researcher
Trainee Clinical Psychologist**

Clinical Psychology Service for Children
and Young People
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Telephone **01463 704665**
www.show.scot.nhs.uk/nhshighland/



Invitation Letter Group B
Version 3 (10/03/07)

Enquiries to: Rachel Smith

To whom it may concern,

I would like to invite you to consider getting involved in a research study looking at eating attitudes and behaviours in young people with a brother or sister who has diabetes compared to young people with a brother or sister who does not have diabetes.

Before you decide whether you would like to take part, it is important to understand why the research is being done, and what it will involve for you. I have **enclosed an information sheet** about the research study and a **consent form**. Please read these carefully. Talk about it with your family and friends if you want to. If you have any questions about the research, please contact me either:

by phone **(01463) 704665** or by email rachel.smith@nhs.net

Please take time to decide whether you wish to take part.

If you are under the age of 16, you will need to get permission from a parent/guardian to take part in the research study. They will have a blue consent form in their pack.

Thank you for considering taking part.

Yours sincerely,

Rachel Smith
Principal Researcher
Trainee Clinical Psychologist

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Information Sheet - Group A
Version3 (10/03/2007)

Enquiries to: Rachel Smith

Information for participants (group A)



Study title: An exploration of eating attitudes and behaviours in children and young people who have a brother or sister with diabetes.

You are being asked to take part in a research study. Before you decide whether to take part, it is important to understand why the research is being done and what it will involve. **Please take time to read the following information carefully** and talk about it with other people if you wish. If there is anything you do not understand, or anything you would like more information about, please feel free to get in touch with me. My address and my secretary's telephone number are printed at the top of this sheet.

What is the study about?

This study aims to look at attitudes and behaviours associated with eating in young people who have a brother or sister with diabetes.

By comparing young people with a brother or sister who has diabetes (group A) with young people with a brother or sister who does not have diabetes (group B) I hope to find out some of the differences between these two groups.

I hope that by finding out more about any difficulties that exist for those young people whose brother or sister has diabetes, this will lead to better help being available for the young people and their families.

Who is doing the research?

The research is being carried out by Rachel Smith, a Trainee Clinical Psychologist at the Clinical Psychology Service for Children and Young People based in Inverness. The research is part of her qualification of Doctorate in Clinical Psychology at the University of Edinburgh.

Anne Woodhouse, Consultant Clinical Psychologist at the Clinical Psychology Service for Children and Young People in Inverness and Dr Emily Newman, Lecturer in Psychology in the Clinical Psychology Department at the University of Edinburgh, will supervise the research.

Who is being asked to take part?

Two groups of people are being asked to take part in the study:

- **Group A** – young people aged 12-18 with a brother or sister who has diabetes
- **Group B** – young people aged 12-28 with a brother or sister who does not have diabetes

Having these two groups will allow us to compare them to see if there are any differences in eating attitudes and behaviours depending on whether their brother or sister has diabetes or not. You have been asked to take part because you have a brother or sister with diabetes.

What will happen if I choose to take part?

If you decide you would like to take part in the research study, you will be asked to fill in a questionnaire booklet containing **four short questionnaires**. This should take about 30 minutes. The questionnaires will ask you about your eating habits and how you feel about your body weight and shape.

If you would like me to visit you at home to explain how to complete the questionnaire booklet, please phone or email me and I will contact you to arrange a time. All the information you provide will be confidential. You are not asked to give your name on the questionnaires, so nobody will know which responses are yours. When you have completed the questionnaires, there will be an envelope for you to place them in. You can seal this envelope straight away so that nobody can see your answers. If you do agree to take part, you will be free to withdraw at any time without giving a reason, and your future care will not be affected.

If completing any of the questionnaires raises any issues that you feel you would like help with, please contact the researcher (Rachel Smith) who will be able to discuss these issues with you.

What do I do if I want to take part?

Included in this pack there is a white consent form.

If you want to take part and you are **under the age of 16**, please fill in the white consent form and put it in the small envelope provided. You will also need to ask your parent(s) to complete a consent form. Your parent(s) should have received a green letter, information sheet and consent form in the pack I sent them. If your parent(s) do not sign the consent form, you will not be able to complete the questionnaires.

If you want to take part and you are **aged 16 or over**, please fill in the white consent form and put it in the small envelope provided. You **do not** need to ask your parent(s) to complete a consent form.

Once you have filled in the consent form, please fill in the questionnaire booklet.

Details about how to return your consent form(s) and questionnaire to me attached to the front of the questionnaire booklet.

What if I don't want to take part?

It is completely **up to you to decide whether to take part**. If you do not want to take part, you do not have to do anything.

What will happen to the forms I fill out?

All information in your questionnaires will be kept confidential. The only people who will see the information is the researcher and her two supervisors. Your

questionnaires will not have your name on, and they will be kept separately from the consent form you fill out that does have your name on.

However, in the **unlikely event** that your answers on the questionnaires raise serious concerns about your wellbeing, the questionnaire and the consent form will be matched up. I will get in touch with you to discuss my concerns, and after speaking to you I will contact your GP to let him/her know my concerns. If you are under the age of 16, I will also be required to inform your parent(s) of my concerns.

If you are over the age of 16 you will be asked to provide the contact details of your GP on your consent form. If you are under 16, your parent(s) will provide these details.

Your parent(s) and your GP will NOT have access to your questionnaires or answers.

What will happen to the results of the study?

The results will be included in research project submitted to the University of Edinburgh by the researcher (Rachel Smith). You will not be identified in any publication that might be produced from this research. **You can be sent a summary of the results by ticking the relevant box on the consent form. The results will be posted to your home in September 2007.**

Who has reviewed this study?

The study has been reviewed by the Highland Health Board Research Ethics Committee.

If you would like to speak to someone other than the researcher about the study, Dr Anne Woodhouse is available to offer independent advice. If you have any questions or would like more information, Dr Woodhouse can be contacted at the address below:

Dr Anne Woodhouse
The Alligin Centre
Larch House
Stoneyfield
Inverness
IV2 7PA

You can also contact the researcher, Rachel Smith, at the same address.

If you would prefer to speak to either Dr Woodhouse or Rachel Smith, you can telephone Alison Mackintosh, their secretary, on 01463 704665. Alison will be able to put you through to whoever you wish to speak to.

Please keep this information for your own records.

Thank you for your time and consideration.

Yours sincerely

RACHEL SMITH

Trainee Clinical Psychologist
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Information Sheet - Group B
Version 3 (10/03/07)

Enquiries to: Rachel Smith

Information for participants (group B)



Study title: An exploration of eating attitudes and behaviours in children and young people who have a brother or sister with diabetes.

You are being asked to take part in a research study. Before you decide whether to take part, it is important to understand why the research is being done and what it will involve. **Please take time to read the following information carefully** and talk about it with other people if you wish. If there is anything you do not understand, or anything you would like more information about, please feel free to get in touch with me. My address and my secretary's telephone number of are printed at the top of this sheet.

What is the study about?

This study aims to look at attitudes and behaviours associated with eating in young people who have a brother or sister with diabetes. By comparing young people with a brother or sister who has diabetes (group A) with young people with a brother or sister who does not have diabetes (group B) we hope to find out some of the differences between these two groups.

We hope that by finding out more about any difficulties that exist for those young people whose brother or sister has diabetes, this will lead to better help being available for the young people and their families.

Who is doing the research?

The research is being carried out by Rachel Smith, a Trainee Clinical Psychologist at the Clinical Psychology Service for Children and Young People based in Inverness. The research is part of her qualification of Doctorate in Clinical Psychology at the University of Edinburgh.

Anne Woodhouse, Consultant Clinical Psychologist at the Clinical Psychology Service for Children and Young People in Inverness and Dr Emily Newman, Lecturer in Psychology in the Clinical Psychology Department at the University of Edinburgh, will supervise the research.

Why have I been chosen?

Two groups of people are being asked to take part in the study:

- **Group A** – young people with a brother or sister who has diabetes
- **Group B** – young people with a brother or sister who does not have diabetes

Having these two groups will allow us to compare them to see if there are any differences in eating attitudes and behaviours depending on whether their brother or sister has diabetes or not. **You have been asked to take part because you have fit into one of these groups.**

What will happen if I choose to take part?

If you decide you would like to take part in the research study, you will be asked to fill in a questionnaire booklet containing **four short questionnaires**. This should take about 30 minutes. The questionnaires will ask you about your eating habits and how you feel about your body weight and shape.

If you would like me to visit you at home to explain how to complete the questionnaire booklet, please phone or email me and I will contact you to arrange a time. All the information you provide will be confidential. You are not asked to give your name on the questionnaires, so nobody will know which responses are yours. When you have completed the questionnaires, there will be an envelope for you to place them in. You can seal this envelope straight away so that nobody can see your answers. If you do agree to take part, you will be free to withdraw at any time without giving a reason, and your future care will not be affected.

If completing any of the questionnaires raises any issues that you feel you would like help with, please contact the researcher (Rachel Smith) who will be able to discuss these issues with you.

What do I do if I want to take part?

Included in this pack there is a white consent form.

If you want to take part and you are **under the age of 16**, please fill in the white consent form and put it in the small envelope provided. You will also need to ask your parent(s) to complete a consent form. Your parent(s) should have received a blue letter, information sheet and consent form in the pack I sent them. If your parent(s) do not sign the consent form, you will not be able to complete the questionnaires.

If you want to take part and you are **aged 16 or over**, please fill in the white consent form and put it in the small envelope provided. You **do not** need to ask your parent(s) to complete a consent form.

Once you have filled in the consent form, please fill in the questionnaire booklet.

Details about how to return your consent form(s) and questionnaire to me attached to the front of the questionnaire booklet.

What if I don't want to take part?

It is completely **up to you to decide whether to take part**. If you do not want to take part, you do not have to do anything.

What will happen to the forms I fill out?

All information in your questionnaires will be kept confidential. The only people who will see the information is the researcher and her two supervisors. Your

questionnaires will not have your name on, and they will be kept separately from the consent form you fill out that does have your name on.

However, in the unlikely event that your answers on the questionnaires raise serious concerns about your wellbeing, your questionnaires will be matched up to your consent form. I will get in touch with you to discuss my concerns, and after speaking to you I will contact your GP to let him/her know my concerns. If you are under the age of 16, I will also be required to inform your parent(s) of my concerns.

If you are over the age of 16 you will be asked to provide the contact details of your GP on your consent form. If you are under 16, your parent(s) will provide these details.

Your parent(s) and your GP will NOT have access to your questionnaires or answers.

What will happen to the results of the study?

The results will be included in a research project submitted to the University of Edinburgh by the researcher (Rachel Smith). You will not be identified in any publication that might be produced from this research. **You can be sent a summary of the results by ticking the relevant box on the consent form. The results will be posted to your home in September 2007.**

Who has reviewed this study?

The study has been reviewed by the Highland Health Board Research Ethics Committee.

If you would like to speak to someone other than the researcher about the study, Dr Anne Woodhouse is available to offer independent advice. If you have any questions or would like more information, Dr Woodhouse can be contacted at the address below:

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You can also contact the researcher, Rachel Smith, at the same address.

If you would prefer to speak to either Dr Woodhouse or Rachel Smith, you can telephone Alison Mackintosh, their secretary, on 01463 704665. Alison will be able to put you through to whoever you wish to speak to.

Please keep this information for your own records.

Thank you for your time and consideration.

Yours sincerely

RACHEL SMITH

Trainee Clinical Psychologist
(Supervised by Dr Anne Woodhouse, Consultant Clinical Psychologist)

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Information Sheet - Group B
Version 3 (10/03/07)

Enquiries to: Rachel Smith

Information for participants (group B)



Study title: An exploration of eating attitudes and behaviours in children and young people who have a brother or sister with diabetes.

You are being asked to take part in a research study. Before you decide whether to take part, it is important to understand why the research is being done and what it will involve. **Please take time to read the following information carefully** and talk about it with other people if you wish. If there is anything you do not understand, or anything you would like more information about, please feel free to get in touch with me. My address and my secretary's telephone number of are printed at the top of this sheet.

What is the study about?

This study aims to look at attitudes and behaviours associated with eating in young people who have a brother or sister with diabetes. By comparing young people with a brother or sister who has diabetes (group A) with young people with a brother or sister who does not have diabetes (group B) we hope to find out some of the differences between these two groups.

We hope that by finding out more about any difficulties that exist for those young people whose brother or sister has diabetes, this will lead to better help being available for the young people and their families.

Who is doing the research?

The research is being carried out by Rachel Smith, a Trainee Clinical Psychologist at the Clinical Psychology Service for Children and Young People based in Inverness. The research is part of her qualification of Doctorate in Clinical Psychology at the University of Edinburgh.

Anne Woodhouse, Consultant Clinical Psychologist at the Clinical Psychology Service for Children and Young People in Inverness and Dr Emily Newman, Lecturer in Psychology in the Clinical Psychology Department at the University of Edinburgh, will supervise the research.

Why have I been chosen?

Two groups of people are being asked to take part in the study:

- **Group A** – young people with a brother or sister who has diabetes
- **Group B** – young people with a brother or sister who does not have diabetes

Having these two groups will allow us to compare them to see if there are any differences in eating attitudes and behaviours depending on whether their brother or sister has diabetes or not. **You have been asked to take part because you have fit into one of these groups.**

What will happen if I choose to take part?

If you decide you would like to take part in the research study, you will be asked to fill in a questionnaire booklet containing **four short questionnaires**. This should take about 30 minutes. The questionnaires will ask you about your eating habits and how you feel about your body weight and shape.

All the information you provide will be confidential. You are not asked to give your name on the questionnaires, so nobody will know which responses are yours. When you have completed the questionnaires, there will be an envelope for you to place them in. You can seal this envelope straight away so that nobody can see your answers. If you do agree to take part, you will be free to withdraw at any time without giving a reason, and your future care will not be affected.

If completing any of the questionnaires raises any issues that you feel you would like help with, please contact the researcher (Rachel Smith) who will be able to discuss these issues with you.

What do I do if I want to take part?

Included in this pack there is a white consent form.

If you want to take part and you are **under the age of 16**, please fill in the white consent form and put it in the small envelope provided. You will also need to ask your parent(s) to complete a consent form. Your parent(s) should have received a blue letter, information sheet and consent form in the pack I gave you. If your parent(s) do not sign the consent form, you will not be able to complete the questionnaires.

If you want to take part and you are **aged 16 or over**, please fill in the white consent form and put it in the small envelope provided. You **do not** need to ask your parent(s) to complete a consent form.

Please return the envelope containing your consent form(s) to school.

What if I don't want to take part?

It is completely **up to you to decide whether to take part**. If you do not want to take part, you do not have to do anything.

What will happen to the forms I fill out?

All information in your questionnaires will be kept confidential. The only people who will see the information is the researcher and her two supervisors. Your questionnaires will not have your name on, and they will be kept separately from the consent form you fill out that does have your name on.

However, in the unlikely event that your answers on the questionnaires raise serious concerns about your wellbeing, your questionnaires will be matched up to your consent form. I will get in touch with you to discuss my concerns, and after speaking

to you I will contact your GP to let him/her know my concerns. If you are under the age of 16, I will also be required to inform your parent(s) of my concerns.

If you are over the age of 16 you will be asked to provide the contact details of your GP on your consent form. If you are under 16, your parent(s) will provide these details.

Your parent(s) and your GP will NOT have access to your questionnaires or answers.

What will happen to the results of the study?

The results will be included in a research project submitted to the University of Edinburgh by the researcher (Rachel Smith). You will not be identified in any publication that might be produced from this research. **You can be sent a summary of the results by ticking the relevant box on the consent form. The results will be posted to your home in September 2007.**

Who has reviewed this study?

The study has been reviewed by the Highland Health Board Research Ethics Committee.

If you would like to speak to someone other than the researcher about the study, Dr Anne Woodhouse is available to offer independent advice. If you have any questions or would like more information, Dr Woodhouse can be contacted at the address below:

Dr Anne Woodhouse
The Alligin Centre
Larch House
Stoneyfield
Inverness
IV2 7PA

You can also contact the researcher, Rachel Smith, at the same address.

If you would prefer to speak to either Dr Woodhouse or Rachel Smith, you can telephone Alison Mackintosh, their secretary, on 01463 704665. Alison will be able to put you through to whoever you wish to speak to.

Please keep this information for your own records.

Thank you for your time and consideration.

Yours sincerely

RACHEL SMITH

Trainee Clinical Psychologist

(Supervised by Dr Anne Woodhouse, Consultant Clinical Psychologist)

Clinical Psychology Service for Children
and Young People
The Alligin Centre
Larch House
Stoneyfield
Inverness
IV2 7PA
Telephone 01463 704665
www.show.scot.nhs.uk/nhshighland/



Participant number:

Consent form for Young People
Version 3 (10/03/07)

Enquiries to: Rachel Smith

CONSENT FORM

Study: An investigation of eating attitudes and behaviours in siblings of children and adolescents with type 1 diabetes compared with controls

Main researcher: Rachel Smith (Trainee Clinical Psychologist)

Please put a **tick** in each of the boxes to show that you have read the information below:

I have **read** and **understood** the information sheet on the study

I know that I can contact the researcher (Rachel Smith) if I have any questions about the study

I understand that I am free to stop taking part in the study at any time, without giving a reason. I understand that this will not affect any future treatment



I agree to take part in the study

PLEASE TURN OVER

Your **name** _____

Your **date of birth** _____

Your **address** _____

Your **phone number** _____

Your **signature** _____

Today's **date** _____

I **would like a summary of the results** of the study to be posted to me in September 2007

OR

I **do not wish** to receive a summary of the results

If you are **aged 16-18** only

I would be grateful if you would provide details of your GP. This will enable me to seek assistance for you in the unlikely event that your responses on any of the questionnaires should raise serious cause for concern. I would of course inform you before making contact with your GP.

My GP is Dr _____

GP's address _____

Please place this form in the small envelope, and return it in the large envelope along with your questionnaire

**If you would like to take part in the research study,
please read this information carefully**

1. Fill in your consent form and put it in the small envelope.
2. If you are under the age of 16, please ask your parent(s) to fill in a separate consent form. Put this consent form in the small envelope along with your own.

3. Fill in the questionnaire booklet.

You should have a booklet containing copies of four different questionnaires:

- A questionnaire asking for general information about you
- A Body Shape Questionnaire
- An Eating Attitude Test
- An Eating Questionnaire

If you think that any of these things are missing, please contact me either by phone on **(01463) 704665** or by email **rachel.smith@nhs.net**.

Please read each question carefully, and try to answer each question as best you can. If there are any questions you are not happy to answer, it is okay to leave them blank. Once you have filled in the questionnaire booklet you can return it to me in the large stamped addressed envelope provided.

If you have any difficulties filling in the questionnaires, please get in touch with me.

4. Put your completed questionnaire booklet **and** the small envelope containing your consent form(s) into the large envelope.
5. Post the large envelope back to me. **You do not have to pay for postage.**

Thank you for your help.

General Information Questionnaire – Group A

Please answer all questions as best you can.

1. Age
2. Sex: **Male / Female** (please circle)
3. What are the first four digits of your postcode? _ _ _ _
(e.g. if your postcode is IV2 7PA, you would write IV2 7)
4. How long has your brother / sister had diabetes?
(If you are not sure, please ask a parent or your brother or sister)
Years..... Months
5. Do **YOU** have any health problems? **Yes / No** (please circle)
(e.g. asthma, cystic fibrosis, diabetes)
If yes, what is the health problem?
6. Please give your current:
 Height
- Weight
7. If you are unhappy with your current weight, what would be your **IDEAL** weight?
 Ideal weight
8. Are you currently doing any of the following:
(please circle)
 - Eating less to lose weight? **Yes / No**
 - Eating more to gain weight? **Yes / No**
 - Exercising to change your body shape, size or muscle tone? **Yes / No**

If you are female, it would be helpful if you could answer the following questions.

9. Have you started your periods yet? **Yes / No**
If yes, how often do you have your periods? (please tick)
 - I have regular periods
 - I never know when my period is going to start
 - I have started my periods but they have stopped at the moment

Body Shape Questionnaire

I would like to know how you have been feeling about your appearance over the PAST FOUR WEEKS. Please read each question carefully and put a tick in the box that you feel most applies to you. Please answer all the questions.

Over the past FOUR WEEKS:

	Never	Rarely	Sometimes	Often	Very often	Always
1. Has feeling bored made you brood about your shape?						
2. Have you thought that your thighs, hips or bottom are too large for the rest of you?						
3. Have you worried about your flesh not being firm enough?						
4. Have you felt so bad about your shape that you have cried?						
5. Have you avoided running because your flesh might wobble?						
6. Has being with thin people made you feel self-conscious about your shape?						
7. Have you worried about your thighs spreading out when sitting down?						
8. Has eating even a small amount of food made you feel fat?						
9. Have you avoided wearing clothes which make you particularly aware of the shape of your body?						
10. Has eating sweets, cakes, or other high calorie food made you feel fat?						
11. Have you felt ashamed of your body?						
12. Has worry about your shape made you diet?						
13. Have you felt happiest about your shape when your stomach has been empty (e.g. in the morning?)						
14. Have you felt that it is not fair that other people are thinner than you?						
15. Have you worried about your flesh being dimply?						
16. Has worry about your shape made you feel you ought to exercise?						

Eating Attitude Test

Please read each statement and place a tick in the box that you feel best applies to you.

	Always	Very Often	Often	Sometimes	Rarely	Never
1. I am scared about being overweight.						
2. I stay away from eating when I am hungry						
3. I think about food a lot of the time.						
4. I have gone on eating binges where I feel that I might not be able to stop.						
5. I cut my food into small pieces.						
6. I am aware of the energy (calorie) content in foods that I eat.						
7. I try to stay away from foods such as breads, potatoes, and rice.						
8. I feel that others would like me to eat more.						
9. I vomit after I have eaten.						
10. I feel very guilty after eating.						
11. I think a lot about wanting to be thinner.						
12. I think about burning up energy (calories) when I exercise.						
13. Other people think I am too thin.						
14. I think a lot about having fat on my body.						
15. I take longer than others to eat my meals.						
16. I stay away from foods with sugars in them.						
17. I eat diet foods.						
18. I think that food controls my life.						
19. I can show self-control around food.						
20. I feel that others pressure me to eat.						
21. I give too much time and thought to food.						
22. I feel uncomfortable after eating sweets.						
23. I have been dieting.						
24. I like my stomach to be empty.						
25. I enjoy trying new rich foods.						
26. I have the urge to vomit after eating.						

Eating Questionnaire-A

Instructions

These questions are about the **PAST TWO WEEKS ONLY (14 DAYS)**. Please read each question carefully and circle the number on the right. Please answer ALL the questions.

EXAMPLES:		No days	1-2 days	3-6 days	7 days	8-10 days	12-13 days	Every day
ON HOW MANY DAYS OUT OF THE PAST 14 DAYS.....								
Have you tried to eat vegetables?	0	1	2	3	4	5	6	
How many times have you walked to school?	0	1	2	3	4	5	6	

ON HOW MANY DAYS OUT OF THE PAST 14 DAYS.....	No days	1-2 days	3-6 days	7 days	8-10 days	12-13 days	Every day
1. ...Have you been <u>trying</u> to cut down on food to control your weight or shape?	0	1	2	3	4	5	6
2. ...Have you gone for long periods of time (8 hours or more) without eating anything to control your shape or weight?	0	1	2	3	4	5	6
3. ...Have you <u>tried</u> not to eat any foods you like to control your weight and shape?	0	1	2	3	4	5	6
4. ...Have you <u>tried</u> to keep to any strict rules about eating to control your shape or weight? For example, a calorie limit, a set amount of food, or rules about what and when you should eat?	0	1	2	3	4	5	6
5. ...Have you wanted your stomach to be empty?	0	1	2	3	4	5	6
6. ...Has thinking about food or calories made it much harder to concentrate on things you are interested in; for example, reading, watching tv, or doing your homework?	0	1	2	3	4	5	6
7. ...Have you been scared of losing control over eating?	0	1	2	3	4	5	6
8. ...Have you had eating binges?	0	1	2	3	4	5	6

ON HOW MANY DAYS OUT OF THE PAST 14 DAYS.....	No days	1-2 days	3-6 days	7 days	8-10 days	12-13 days	Every day
9. ...Have you eaten in secret? (Do not count binges.)	0	1	2	3	4	5	6
10. ...Have you really wanted your stomach to be flat?	0	1	2	3	4	5	6
11. ...Has thinking about shape or weight made it much harder to concentrate on things you are interested in; for example, reading, watching TV, or doing your homework?	0	1	2	3	4	5	6
12. ...Have you been really scared that you might put on weight and get fat?	0	1	2	3	4	5	6
13. ...Have you felt fat?	0	1	2	3	4	5	6
14. ...Have you had a strong wish to lose weight?	0	1	2	3	4	5	6

OVER THE PAST TWO WEEKS (14 DAYS).....

15. ...How often have you felt guilty after eating because of the effect on your shape and weight? (Do not count binges.) (Circle the number which applies.)
- 0. None of the times
 - 1. A few of the times
 - 2. Less than half the times
 - 3. Half the times
 - 4. More than half the times
 - 5. Most of the time
 - 6. Every time

16. ... Over the past two weeks (14 days), have there been any times when you have felt that you ate what other people would think was a very large amount of food given the situation? (Please circle). **0- NO**
1- YES

17. ...How many such times have you done this over the past two weeks? _____

18.During how many of these episodes of overeating did you have a sense of having lost control? _____

19. Have there been other times when you felt that you lost control and felt you ate too much, but did NOT eat a very large amount of food given the situation? (Please circle) **0- NO**
1- YES

20. ...How many times has this happened over the past two weeks? _____

21. Over the past two weeks have you made yourself sick (vomit) to control your shape or weight? (Please circle).	0- NO 1- YES
22. ...How many such times have you done this over the past two weeks?	_____
23.Have you taken laxatives to control your shape or weight? (Please circle)	0 ----NO 1 ----YES
24. How many times have you done this over the past two weeks?	_____
25. Have you taken diuretics (water tablets) to control your shape or weight? (Please circle)	0 ----NO 1 ----YES
26. How many times have you done this over the past two weeks?	_____
27. Have you exercised <u>hard</u> to control your shape or weight? (Please circle)	0 ----NO 1 ----YES
28. How many times have you done this over the past two weeks?	_____

OVER THE PAST 2 WEEKS (14 DAYS).....
(Please circle the number which best describes your behavior)

	NOT AT ALL			SLIGHTLY			MODERATELY		MARKEDLY
	0	1	2	3	4	5	6		
29.Has your weight affected how you think about (judge) yourself as a person?	0	1	2	3	4	5	6		
30.Has your shape affected how you think about (judge) yourself as a person?	0	1	2	3	4	5	6		
31.How much would it upset you if you had to weigh yourself once a week for the next four weeks?	0	1	2	3	4	5	6		
32.How unhappy have you felt about your weight?	0	1	2	3	4	5	6		
33.How unhappy have you felt about your shape?	0	1	2	3	4	5	6		
34. How worried have you been about other people seeing you eat?	0	1	2	3	4	5	6		

OVER THE PAST 2 WEEKS (14 DAYS).....

(Please circle the number which best describes your behavior)

	NOT AT ALL			SLIGHTLY			MODERATELY		MARKEDLY
35. How uncomfortable have you felt seeing your body: for example, in the mirror, in shop windows, when you undress or when you have a bath or shower?	0	1	2	3	4	5	6		
36.How uncomfortable have you felt about others seeing your body; for example, in shared changing rooms, when swimming or wearing tight clothes?	0	1	2	3	4	5	6		

Thank you for taking the time to complete this questionnaire

General Information Questionnaire – Group B

Please answer all questions as best you can.

1. Age
2. Sex: **Male** / **Female** (please circle)
3. What are the first four digits of your postcode? — — — —
(e.g. if your postcode is IV2 7PA, you would write IV27)
4. Do you have a brother or sister with diabetes? **Yes** / **No** (please circle)
5. Do you have a brother or sister with any other health problem? **Yes** / **No**
(e.g. asthma, cystic fibrosis)

If yes, what is the health problem?

6. Do **YOU** have any health problems? **Yes** / **No** (please circle)
(e.g. asthma, cystic fibrosis, diabetes)

If yes, what is the health problem?

7. Please give your current:

Height

Weight

8. If you are unhappy with your current weight, what would be your IDEAL weight?

Ideal weight

9. Are you currently doing any of the following:
(please circle)

- Eating less to lose weight? **Yes** / **No**
- Eating more to gain weight? **Yes** / **No**
- Exercising to change your body shape, size or muscle tone? **Yes** / **No**

If you are female, it would be helpful if you could answer the following questions.

10. Have you started your periods yet? **Yes** / **No**

If yes, how often do you have your periods? (please tick)

- I have regular periods
- I never know when my period is going to start
- I have started my periods but they have stopped at the moment

Body Shape Questionnaire

I would like to know how you have been feeling about your appearance over the PAST FOUR WEEKS. Please read each question carefully and put a tick in the box that you feel most applies to you. Please answer all the questions.

Over the past FOUR WEEKS:

	Never	Rarely	Sometimes	Often	Very often	Always
1. Has feeling bored made you brood about your shape?						
2. Have you thought that your thighs, hips or bottom are too large for the rest of you?						
3. Have you worried about your flesh not being firm enough?						
4. Have you felt so bad about your shape that you have cried?						
5. Have you avoided running because your flesh might wobble?						
6. Has being with thin people made you feel self-conscious about your shape?						
7. Have you worried about your thighs spreading out when sitting down?						
8. Has eating even a small amount of food made you feel fat?						
9. Have you avoided wearing clothes which make you particularly aware of the shape of your body?						
10. Has eating sweets, cakes, or other high calorie food made you feel fat?						
11. Have you felt ashamed of your body?						
12. Has worry about your shape made you diet?						
13. Have you felt happiest about your shape when your stomach has been empty (e.g. in the morning?)						
14. Have you felt that it is not fair that other people are thinner than you?						
15. Have you worried about your flesh being dimply?						
16. Has worry about your shape made you feel you ought to exercise?						

Eating Attitude Test

Please read each statement and place a tick in the box that you feel best applies to you.

	Always	Very Often	Often	Sometimes	Rarely	Never
1. I am scared about being overweight.						
2. I stay away from eating when I am hungry						
3. I think about food a lot of the time.						
4. I have gone on eating binges where I feel that I might not be able to stop.						
5. I cut my food into small pieces.						
6. I am aware of the energy (calorie) content in foods that I eat.						
7. I try to stay away from foods such as breads, potatoes, and rice.						
8. I feel that others would like me to eat more.						
9. I vomit after I have eaten.						
10. I feel very guilty after eating.						
11. I think a lot about wanting to be thinner.						
12. I think about burning up energy (calories) when I exercise.						
13. Other people think I am too thin.						
14. I think a lot about having fat on my body.						
15. I take longer than others to eat my meals.						
16. I stay away from foods with sugars in them.						
17. I eat diet foods.						
18. I think that food controls my life.						
19. I can show self-control around food.						
20. I feel that others pressure me to eat.						
21. I give too much time and thought to food.						
22. I feel uncomfortable after eating sweets.						
23. I have been dieting.						
24. I like my stomach to be empty.						
25. I enjoy trying new rich foods.						
26. I have the urge to vomit after eating.						

Eating Questionnaire-A

Instructions

These questions are about the **PAST TWO WEEKS ONLY (14 DAYS)**. Please read each question carefully and circle the number on the right. Please answer ALL the questions.

EXAMPLES:		No days	1-2 days	3-6 days	7 days	8-10 days	12-13 days	Every day
ON HOW MANY DAYS OUT OF THE PAST 14 DAYS.....								
Have you tried to eat vegetables?	0	1	2	3	4	5	6	
How many times have you walked to school?	0	1	2	3	4	5	6	

ON HOW MANY DAYS OUT OF THE PAST 14 DAYS.....	No days	1-2 days	3-6 days	7 days	8-10 days	12-13 days	Every day
1. ...Have you been <u>trying</u> to cut down on food to control your weight or shape?	0	1	2	3	4	5	6
2. ...Have you gone for long periods of time (8 hours or more) without eating anything to control your shape or weight?	0	1	2	3	4	5	6
3. ...Have you <u>tried</u> not to eat any foods you like to control your weight and shape?	0	1	2	3	4	5	6
4. ...Have you <u>tried</u> to keep to any strict rules about eating to control your shape or weight? For example, a calorie limit, a set amount of food, or rules about what and when you should eat?	0	1	2	3	4	5	6
5. ...Have you wanted your stomach to be empty?	0	1	2	3	4	5	6
6. ...Has thinking about food or calories made it much harder to concentrate on things you are interested in; for example, reading, watching tv, or doing your homework?	0	1	2	3	4	5	6
7. ...Have you been scared of losing control over eating?	0	1	2	3	4	5	6
8. ...Have you had eating binges?	0	1	2	3	4	5	6

ON HOW MANY DAYS OUT OF THE PAST 14 DAYS.....	No days	1-2 days	3-6 days	7 days	8-10 days	12-13 days	Every day
9. ...Have you eaten in secret? (Do not count binges.)	0	1	2	3	4	5	6
10. ...Have you really wanted your stomach to be flat?	0	1	2	3	4	5	6
11. ...Has thinking about shape or weight made it much harder to concentrate on things you are interested in; for example, reading, watching TV, or doing your homework?	0	1	2	3	4	5	6
12. ...Have you been really scared that you might put on weight and get fat?	0	1	2	3	4	5	6
13. ...Have you felt fat?	0	1	2	3	4	5	6
14. ...Have you had a strong wish to lose weight?	0	1	2	3	4	5	6

OVER THE PAST TWO WEEKS (14 DAYS).....

15. ...How often have you felt guilty after eating because of the effect on your shape and weight? (Do not count binges.) (Circle the number which applies.)
- 7. None of the times
 - 8. A few of the times
 - 9. Less than half the times
 - 10. Half the times
 - 11. More than half the times
 - 12. Most of the time
 - 13. Every time

16. ... Over the past two weeks (14 days), have there been any times when you have felt that you ate what other people would think was a very large amount of food given the situation? (Please circle).

0- NO
1- YES

17. ...How many such times have you done this over the past two weeks?

18.During how many of these episodes of overeating did you have a sense of having lost control?

19. Have there been other times when you felt that you lost control and felt you ate too much, but did NOT eat a very large amount of food given the situation? (Please circle)

0- NO
1- YES

20. ...How many times has this happened over the past two weeks?

21. Over the past two weeks have you made yourself sick (vomit) to control your shape or weight? (Please circle).	0- NO 1- YES
22. ...How many such times have you done this over the past two weeks?	_____
23.Have you taken laxatives to control your shape or weight? (Please circle)	0 ----NO 1 ----YES
24. How many times have you done this over the past two weeks?	_____
25. Have you taken diuretics (water tablets) to control your shape or weight? (Please circle)	0 ----NO 1 ----YES
26. How many times have you done this over the past two weeks?	_____
27. Have you exercised <u>hard</u> to control your shape or weight? (Please circle)	0 ----NO 1 ----YES
28. How many times have you done this over the past two weeks?	_____

OVER THE PAST 2 WEEKS (14 DAYS).....
(Please circle the number which best describes your behavior)

	NOT AT ALL			SLIGHTLY			MODERATELY		MARKEDLY
	0	1	2	3	4	5	6		6
29.Has your weight affected how you think about (judge) yourself as a person?	0	1	2	3	4	5	6		6
30.Has your shape affected how you think about (judge) yourself as a person?	0	1	2	3	4	5	6		6
31.How much would it upset you if you had to weigh yourself once a week for the next four weeks?	0	1	2	3	4	5	6		6
32.How unhappy have you felt about your weight?	0	1	2	3	4	5	6		6
33.How unhappy have you felt about your shape?	0	1	2	3	4	5	6		6
34. How worried have you been about other people seeing you eat?	0	1	2	3	4	5	6		6

OVER THE PAST 2 WEEKS (14 DAYS).....

(Please circle the number which best describes your behavior)

	NOT AT ALL			SLIGHTLY			MODERATELY		MARKEDLY
35. How uncomfortable have you felt seeing your body: for example, in the mirror, in shop windows, when you undress or when you have a bath or shower?	0	1	2	3	4	5	6		
36.How uncomfortable have you felt about others seeing your body; for example, in shared changing rooms, when swimming or wearing tight clothes?	0	1	2	3	4	5	6		

Thank you for taking the time to complete this questionnaire

	Siblings (n=8)	Matched Controls (n=8)
1. Has feeling bored made you brood about your shape?	3	0
2. Have you thought your thighs, hips or bottom are too large for the rest of you?	4	3
3. Have you worried about your flesh not being firm enough?	1	1
4. Have you felt so bad about your shape that you have cried?	0	0
5. Have you avoided running because your flesh might wobble?	0	0
6. Has being with thin people made you feel self-conscious about your shape?	1	1
7. Have you worried about your thighs spreading out when you sit down?	2	1
8. Has eating a small amount of food made you feel fat?	0	0
9. Have you avoided wearing clothes which make you particularly aware of the shape of your body?	2	1
10. Has eating sweets, cakes or other high calorie food made you feel fat?	2	1
11. Have you felt ashamed of your body?	2	2
12. Has worry about your shape made you diet?	1	0
13. Have you felt happiest about your shape when your stomach has been empty?	1	1
14. Have you felt that it is not fair that other people are thinner than you?	1	0
15. Have you worried about your flesh being dimply?	1	0
16. Has worry about your shape made you feel you ought to exercise?	3	2

BSQ item	Females (n=42)
1. Has feeling bored made you brood about your shape?	2 (5%)
2. Have you thought your thighs, hips or bottom are too large for the rest of you?	19 (45%)
3. Have you worried about your flesh not being firm enough?	9 (21%)
4. Have you felt so bad about your shape that you have cried?	6 (14%)
5. Have you avoided running because your flesh might wobble?	2 (4%)
6. Has being with thin people made you feel self-conscious about your shape?	12 (29%)
7. Have you worried about your thighs spreading out when you sit down?	11 (26%)
8. Has eating a small amount of food made you feel fat?	7 (17%)
9. Have you avoided wearing clothes which make you particularly aware of the shape of your body?	12 (29%)
10. Has eating sweets, cakes or other high calorie food made you feel fat?	14 (33%)
11. Have you felt ashamed of your body?	13 (31%)
12. Has worry about your shape made you diet?	11 (26%)
13. Have you felt happiest about your shape when your stomach has been empty?	7 (17%)
14. Have you felt that it is not fair that other people are thinner than you?	13 (31%)
15. Have you worried about your flesh being dimply?	5 (12%)
16. Has worry about your shape made you feel you ought to exercise?	18 (43%)

BSQ item	12-13 years (n=13)	14-15 years (n=11)	16-17 years (n=18)
1. Has feeling bored made you brood about your shape?	0	2	0
2. Have you thought your thighs, hips or bottom are too large?	6	7	6
3. Have you worried about your flesh not being firm enough?	4	1	4
4. Have you felt so bad about your shape that you have cried?	2	2	2
5. Have you avoided running because your flesh might wobble?	1	1	0
6. Has being with thin people made you feel self-conscious about your shape?	5	2	5
7. Have you worried about your thighs spreading out when you sit down?	3	5	3
8. Has eating a small amount of food made you feel fat?	3	2	2
9. Have you avoided wearing clothes which make you particularly aware of the shape of your body?	3	3	6
10. Has eating sweets, cakes or other high calorie food made you feel fat?	4	2	8
11. Have you felt ashamed of your body?	4	2	7
12. Has worry about your shape made you diet?	4	2	5
13. Have you felt happiest when your stomach has been empty?	1	3	3
14. Have you felt that it is not fair that other people are thinner than you?	4	5	4
15. Have you worried about your flesh being dimply?	3	1	1
16. Has worry about your shape made you feel you ought to exercise?	6	4	8

	Males (n=33)	Females (n=42)
27. I am scared about being overweight.	14	6
28. I stay away from eating when I am hungry	5	0
29. I think about food a lot of the time.	9	8
30. I have gone on eating binges where I feel that I might not be able to stop.	3	0
31. I cut my food into small pieces.	5	2
32. I am aware of the energy (calorie) content in foods that I eat.	8	9
33. I try to stay away from foods such as breads, potatoes, and rice.	1	1
34. I feel that others would like me to eat more.	7	3
35. I vomit after I have eaten.	1	0
36. I feel very guilty after eating.	2	1
37. I think a lot about wanting to be thinner.	8	6
38. I think about burning up energy (calories) when I exercise.	15	7
39. Other people think I am too thin.	4	3
40. I think a lot about having fat on my body.	9	4
41. I take longer than others to eat my meals.	15	3
42. I stay away from foods with sugars in them.	0	2
43. I eat diet foods.	5	2
44. I think that food controls my life.	3	1
45. I can show self-control around food.	26	16
46. I feel that others pressure me to eat.	1	0
47. I give too much time and thought to food.	1	0
48. I feel uncomfortable after eating sweets.	5	3
49. I have been dieting.	5	4
50. I like my stomach to be empty.	6	1
51. I enjoy trying new rich foods.	22	16
52. I have the urge to vomit after eating.	3	0