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**Starting the Conversation about Eating and Body Image:
The Clinical Experience of Young Women with Type 1 Diabetes**

**A dissertation presented in partial fulfilment of the requirements for the degree of
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Abstract

A diagnosis of type 1 diabetes, in particular the concomitant restrictive eating and insulin regimen and the threat of short- and long-term complications associated with poor metabolic control, may introduce or exacerbate psychosocial or psychological stressors for young people. Moreover, the focus on eating and the increase in body mass index that is often associated with a diagnosis of type 1 diabetes may exacerbate eating, weight and body image issues for young women in particular. Whilst weight control measures can be healthy, there are a variety of disturbed eating behaviours that young women may employ for this purpose. These behaviours range from those that may be relatively benign through to more risky behaviours, including the practise of manipulating or omitting insulin for weight loss, which can jeopardise optimal health outcomes. To understand the milieu in which eating, weight and body image issues develop as well as talking about them in a clinical setting, this qualitative study aimed to explore the both lived and clinical experience of young women with type 1 diabetes. The participants in this research were 12 young women with type 1 diabetes attending diabetes services and 5 health professionals working with this group. The stories of both groups were explored thematically and analysed using a narrative methodology on two levels, namely the personal story and the public narrative. Firstly, the analysis demonstrated the variations and contradictions within the lived experience stories of the young women and the areas of congruence and discordance between the clinical experience stories of the young women and the health professionals. Secondly, the socially available narratives that shaped the stories were explicated. The analysis showed that there is often a paradigm clash between the biomedical goal of stable metabolic control and living a “normal” life. Whilst the health professionals described their collaborative approach, some of the young women perceived that their clinical interactions were dominated

by biomedical goals. These perceptions threatened the functionality of the clinical relationships. This suggests that health professionals should seek to minimise and manage the discordance that young people may experience between living a “normal” life and living with diabetes. Exploring the lived experience of diabetes, the young women experienced a range of eating, weight and body image issues, and 2 young women had engaged in insulin omission, culminating in serious health complications. The clinical experience stories indicated that, if weight was talked about at all clinically, it tended to be in medical terms, and weight gain was not always discussed if it fell within medically acceptable parameters. Moreover, health professionals were reluctant to ask about disturbed eating behaviours unless they had cause to suspect them. These findings suggest that there are two possible areas of intervention. Firstly, talking about weight and body dissatisfaction may help identify risk factors that foster the development of disturbed eating behaviours. Secondly, screening for disturbed eating behaviours may help identify them before they become entrenched.

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Chapter 1 – Introduction

Type 1 diabetes (T1D) is usually associated with more serious health complications than type 2 diabetes (T2D) (Williams & Pickup, 1999). Furthermore, T1D typically has an earlier onset than T2D, usually during childhood or adolescence, potentially interfering with the developmental tasks of these life stages. Therefore, the broader psychological and psychosocial implications of T1D make this condition the focus of this study. Adolescence and young adulthood can be conceptualised as a watershed; not only can adolescence be a tumultuous time, especially if combined with a disease like T1D and its associations with increased morbidity and mortality, but it is also a time when many health behaviours that form a lifetime template, are laid down (Viner & Barker, 2005). Accordingly, this developmental stage presents great possibilities (and pitfalls) to the health professionals that work in diabetes care. One of the particular challenges for health professionals may be helping young people, especially females, to negotiate the dual pressures arising from the diabetes-related factors that may potentiate eating, body image and weight problems, during a developmental stage when they may be particularly vulnerable to developing such problems.

The foundations for exploring the experience of having diabetes for an adolescent or young adult female, the concomitant encounters with health professionals, and the sensitivities associated with starting the conversation about eating, weight and body image are laid out in the next four chapters. Chapter 2 outlines what T1D is, its aetiology, prevalence, physiology and management. The following two chapters (3 & 4) explore the lived experience of diabetes. Firstly, the literature relating to the psychological and psychosocial issues that are associated with living with a chronic illness such as T1D, particularly during the often tumultuous adolescent developmental stage is reviewed. Secondly, the possible potentiating effects of T1D on eating, weight, and body image issues, in particular disturbed eating behaviours, is appraised. Because the optimal management of T1D in the adolescent years necessitates frequent interactions with health professionals, the next two chapters focus on the clinical experience of T1D. Chapter 5 explores the literature relating to the clinical experience of T1D, and what is known about the relationship between the perception of the clinical interactions and diabetes management, and Chapter 6 outlines what is currently known about identifying disturbed eating behaviour.

The next chapters relate to the current research. The method section (Chapter 7) describes the narrative approach to analysis, the procedural methods followed in this research, and introduces the participants. The following analysis chapters (8 & 9) explore the stories of the young women and the health professionals. Firstly, the young women are given voice to explicate their lived experience of having T1D. Secondly, the clinical experience, in particular, the ways in which eating, body image and weight are talked about, is told via the eyes of both the young women and the health professionals. Finalising the analysis section, the stories are viewed in the context of the public narratives that shape them. In the final chapter, the implications for the findings of the analysis are discussed.

Chapter 2 – Type 1 Diabetes

Chapter Overview

This chapter describes diabetes mellitus, in particular T1D. This chapter differentiates T1D from T2D, detailing the nature of type 1 diabetes, its aetiology, prevalence, and physiology.

Diabetes Mellitus

Diabetes mellitus is a condition in which blood glucose levels are chronically raised due to a relative or absolute lack of the hormone insulin (Williams & Pickup, 1999). Insulin functions to open up cells so that glucose can enter them. The glucose can then be used to create energy or stored as a future energy source by conversion to glycogen for short-term storage or fat for long-term storage (Galmer, 2008). In diabetes, the insulin insufficiency in the blood means that glucose is not taken up by the cells and hyperglycaemia, or raised blood glucose, ensues. There are three major presentations of diabetes mellitus, namely T1D, T2D, and gestational diabetes. T1D is an idiopathic autoimmune disease that destroys all insulin-producing cells, precipitating insulinopenia. Insulin insufficiency in T2D occurs due to impaired insulin secretion and increased resistance of its target cells to its action. T2D often occurs as a result of lifestyle factors. Gestational diabetes results from an inability to keep pace with the insulin demands of pregnancy. This type of diabetes usually abates on delivery of the child, but an increased risk of developing T2D later in life remains (Galmer, 2008).

Type 1 Diabetes

The lack of insulin in T1D stems from the autoimmune destruction of the insulin producing B cells of the islets of Langerhans in the pancreas, necessitating the administration of exogenous insulin for survival (Stene, Tuomilehto, & Rewers, 2008). Rarely, a form of T1D referred to as Type 1B diabetes occurs without signs of any autoimmune process and has an unidentified cause (Galmer, 2008). The destruction of B cells in the pancreas at the onset of T1D induces a state of insulinopenia (Diabetes mellitus, 2007). This insulinopenia led to the early nomenclature of T1D as “insulin dependent diabetes mellitus – IDDM.” This term is no longer preferred, as it is becoming increasingly common for insulin therapy to be administered in T2D. Another older term for T1D, “juvenile onset” diabetes, is no longer considered a reliable

differentiating tool. The term reflects the typical age of onset for T1D, but with increasing obesity due to western lifestyles and diets, the onset of T2D may occur during childhood, and, rarely, a subtype of T1D, latent autoimmune diabetes of adulthood (LADA), affects individuals over the age of 30 (Galmer, 2008).

Aetiology and prevalence of type 1 diabetes. T1D may manifest at any age, but most commonly, it arises in children and young adults, with a peak incidence before school age, and again at around puberty (Williams & Pickup, 1999). Whilst the aetiology of T1D is not certain, it is thought that people with T1D have a genetic predisposition which may remain dormant unless triggered by a virus or chemical, precipitating an attack on the immune system that results in destruction of the B cells in the pancreas (dlife, n.d). The presence of a chronic inflammatory mononuclear cell infiltrate associated with the residual B cells at the onset of T1D, is evidence that the destruction of the insulin-secreting cells is an autoimmune process (Williams & Pickup, 1999). Other indications that there is an immunological process at work include the presence of islet cell and islet cell surface antibodies in the circulation of individuals with newly diagnosed T1D, which decline after onset of the condition (Williams & Pickup, 1999). Furthermore, the presence of other autoimmune disorders, for example thyroid and coeliac disease, increases the risk of T1D (Galmer, 2008).

That there may be genetic and environmental factors involved in incidence of the disease is suggested by the marked variation in incidence between Northern European countries, such as Finland and Sweden (30 to 35 cases per year per 100 000 of the population) and Oriental countries, such as Japan, Korea and China (0.5 to 2.0 cases per year per 100 000 of the population) (Williams & Pickup, 1999). If there is no family history of T1D, the risk of developing the condition is less than 1%, which increases to 25% to 50% if an individual has an identical twin with T1D (Diabetes mellitus, 2007). If either parent has T1D, the risk increases, but differentially; the risk is greater if the individual's father has T1D, and the risk if the individual's mother has T1D varies with the mother's age at the time of the individual's birth (Diabetes mellitus, 2007). Although there are several genes thought to be involved with an inherited predisposition to T1D, differences in incidence between countries that could be considered genetically similar, for example Finland and Estonia, or Norway and Iceland, accentuate the case for an environmental trigger for the disease (Williams & Pickup, 1999).

Studies have connected exposure to viruses, for example coxsackie B, enteroviruses, adenovirus, rubella, cytomegalovirus and Epstein-Barr virus, with T1D (Galmer, 2008). When mice were administered a virus with and without an immunosuppressant, only the mice administered the virus alone experienced a rise in glucose levels, demonstrating that the virus acted as an external trigger for an immunological response that culminated in the onset of hyperglycaemic states (Galmer, 2008). Other triggers have been postulated. For example, exposure to dairy products in the first few months of life (Galmer, 2008), and exposure of the woman to nitrosamines in smoked meat eaten at the time of conception (Williams & Pickup, 1999) have been implicated in development of T1D. Additionally, there may be chemical B cell toxins. For example, exposure to the rat poison, vacor, has been associated with the development of T1D (Williams & Pickup, 1999).

T2D is more prevalent than T1D, accounting for almost 80% of cases in most European and North American countries (Williams & Pickup, 1999). Approximately 15 000 of the 270 000 New Zealanders that have diabetes, have T1D (Diabetes NZ, n.d.). Unlike T2D, T1D is more common in Caucasians than in those with a non-Caucasian background (dlife, n.d). In New Zealand, the incidence of T1D among European-origin children aged 0-14 years in 1999-2000 was 21.7 per 100 000 per annum, compared to, an incidence of 5.6 per 100 000 per annum among children of Māori ethnicity (Lipton, 2008).

Physiology of type 1 diabetes. Insulin is a fundamental hormone that enables the body to utilise glucose for energy. In addition to being the key that allows glucose obtained from the digestion and metabolism of carbohydrates to enter muscle tissue, or be converted to storage, as blood glucose levels rise after a meal, insulin suppresses glucose output from the liver by inhibiting glycconeolysis (glycogen breakdown) and gluconeogenesis (formation of glucose from non-carbohydrate sources such as amino acids supplied from muscle tissue, and glycerol supplied from fat). Consequently, when there is a lack of insulin, glucose remains in the bloodstream rather than being transported into the cells, feedback mechanisms that control glucose levels fail, and hyperglycaemia ensues.

Hyperglycaemia prompts the body to try and rid itself of the excess glucose via the renal system. However, the tubular absorptive capacity of the kidneys is quickly exhausted, and glycosuria (glucose in the urine) and polyuria (excessive urination) ensue. Despite the excess of blood glucose, there is a lack of glucose available for use, and the tissues begin to starve, and

neural tissue responds by increasing appetite (polyphagia). However, unable to utilise glucose, the body begins to consume stored protein and fat, resulting in weight loss (Diabetes mellitus, 2007). Without treatment, the catabolic process continues, and the breakdown of fat in body tissues in an effort to stave off the energy crisis leads to the production of fatty acids, which are broken down by the liver to ketoacids (Diabetes mellitus, 2007). The production of ketoacids is compounded by hepatic gluconeogenesis, and the pH of the body begins to fall. Osmotic loss, which begins as a result of hyperglycaemia, is exacerbated by ketone bodies in the urine, and diabetic ketoacidosis (DKA) ensues. DKA is a medical emergency, characterised by hyperglycaemia, ketosis, dehydration, and electrolyte imbalance (Diabetes mellitus, 2007), and is often accompanied by dry skin, vomiting, difficulty breathing, confusion, and, in severe cases, a diabetic coma (Galmer, 2008). In the past, most new cases of T1D presented to an emergency ward in state of DKA. However, more recently, most cases are identified before becoming ill with early glucose testing, or by symptoms, including polyuria, polyphagia, polydipsia, unexplained weight loss, bedwetting, yeast infections, flushed skin, fruity breath, severe abdominal pain, nausea and/or vomiting, and lethargy (Childs & Kruger, 2009). Hypoglycaemia, or low blood glucose, occurs usually as a result of a mismatch between the timing/amount of insulin and food, excessive exercise, intensive insulin treatment, or alcohol consumption (Williams & Pickup, 1999). Hypoglycaemia can cause disorientation, coma, and even death.

Management of type 1 diabetes. In non-diabetic individuals, glucose levels are maintained within a very narrow range by the continuous secretion of small amounts of insulin, termed basal insulin, with the addition of a bolus of insulin with each feeding (Childs & Kruger, 2009). The philosophy of insulin replacement in T1D is to mimic the insulin secretion patterns of the non-diabetic person (Williams & Pickup, 1999). Achieving good metabolic control, important for optimal health outcomes in diabetes, centres on maintaining blood glucose levels within a narrow, optimal range. Control is commonly measured using glycosylated haemoglobin (HbA1C), which averages out the blood glucose concentration over the preceding three months (Dunning, 2003).

Maintaining HbA1c levels within recommended limits requires a careful insulin and diet regimen, and assessment of control via blood glucose monitoring. Whilst the short-term effects of poor control, including hyperglycaemia, diabetic ketoacidosis and hypoglycaemia, can be severe, even life-threatening, there is considerable morbidity associated with the insidious effects of long-term poor control of diabetes. Repeated episodes of hyperglycaemia have been

shown to be associated with an increased risk of long-term complications of diabetes, particularly tissue damage to the eyes (retinopathy), kidneys (nephropathy) and nerves (neuropathy). Accordingly, maintaining stable blood sugars within an optimal range is desirable. However, despite the scientific rationale for diabetes management, optimal metabolic control may still be elusive. Accordingly, it may be difficult for young people with T1D to come to terms with the likelihood that, even if their adherence to their regimen is good, and they adopt healthier lifestyles than their non-diabetic peers, their metabolic control may still not be satisfactory (Serrabulho, Matos, & Raposo, 2012).

Chapter Summary

T1D is a life-long illness, the onset of which usually occurs during the important developmental stages of childhood, adolescence or young adulthood. Optimal management of diabetes to minimise the risk of short- and long-term, potentially life-threatening complications requires careful attention to an eating and insulin regimen to ensure stable metabolic control. However, a narrow focus on the mechanics of maintaining stable metabolic control, whilst providing an understanding of the demanding nature of the regimen, does not give voice to the lived experience of diabetes, and the psychological and psychosocial difficulties that may ensue when living with a life-threatening chronic illness.

Chapter 3 - The Lived Experience of Type 1 Diabetes

Chapter Overview

Living with a chronic and life-threatening illness such as T1D may culminate in psychological and psychosocial difficulties. Psychological difficulties, in particular clinical and sub-clinical depression and disturbed eating, are prevalent in this group. Moreover, especially for young people, the nature of diabetes management can introduce or exacerbate psychosocial difficulties, notably, becoming autonomous and conforming to the peer group. This chapter explores the lived experience of diabetes and details the difficulties that have been associated with T1D in the literature, in particular those faced in the developmental stages of adolescence and young adulthood. These psychological and psychosocial challenges in the lives of young people with diabetes may not only compromise quality of life and optimal diabetes management, but may also be associated with disturbed eating behaviours.

Psychological Factors in Type 1 Diabetes

Painting a bleak picture, Heller (2005) states that it is “difficult to conceive of a disease more likely to cause psychological problems than diabetes” (p. xv), referring to the heritable and chronic nature of the disease, the complexity of the diabetes regimen, and the potential complications which may culminate in blindness, amputation and cardiovascular disease. The psychological problems that sometimes occur may be clinically diagnosable, for example, depression, anxiety and eating disorders, but there may also be high levels of subclinical emotional distress as a consequence of common problems in living with diabetes (Rubin & Peyrot, 2001). As well as the day to day struggle of living with psychological problems, such problems may also complicate diabetes management.

Whilst maintaining that it is too simplistic to attribute poorly controlled diabetes to an underlying psychological problem, Snoek (2006) claims that psychological factors are integral in the self-management of diabetes. That there may be an increase in mental health issues associated with diabetes is supported by findings from a longitudinal study involving young people with T1D, aged 17 to 25 years at baseline (Bryden et al., 2001; Bryden, Dunger, Mayou, Peveler & Neil, 2003). The study, involving 113 patients of a UK outpatient diabetes clinic, demonstrated that the outcome for this cohort was generally poor in terms of both diabetes

outcomes and psychological outcomes. Approximately one quarter of participants, particularly women, developed psychiatric morbidity, representing, they claim, a prevalence of psychiatric problems considerably greater than the general population. Moreover, psychological problems at baseline were associated with poor metabolic control, and recurrent hospital admissions (Bryden et al., 2001). Of particular note, Bryden et al. (2003) describe the emergence of eating disorders, incidents of completed and attempted suicide and self-harm, and the development of depression in this cohort. Disordered eating, both clinical and subclinical, presents a major threat to health outcomes in diabetes, and will be discussed in a later chapter. The role of depression in diabetes has been the focus of other studies.

Diabetes and depression. Using meta-analytic techniques, Anderson, Freedland, Clouse, and Lustman (2001) have concluded that the presence of diabetes (Type 1 and Type 2) doubles the risk of co-morbid, clinically relevant depression in adults, including major depressive disorder, and minor and subclinical depression, and that as many as one in three individuals with diabetes may suffer from depression. The prevalence of co-morbid depression was significantly higher in women, which Anderson et al. (2001) suggest, mirrors the findings of studies on depression and gender in the general population. Reviewing the literature, Lustman and Clouse (2005) stress the importance of untreated depression in diabetes because, not only is concurrent depression associated with a decrease in metabolic control and adherence, but also they suggest that diabetes and depression negatively interact; the authors postulate that depression leads to poor metabolic control, and hyperglycaemia heightens depression. However, whilst they draw similar conclusions from their meta-analysis, De Groot, Anderson, Freedland, Clouse and Lustman (2001) caution that longitudinal studies are required to clarify the temporal associations between diabetic complications and depression.

The increased prevalence of depression in the diabetic population is also apparent amongst young people with diabetes. Kanner, Hamrin and Grey (2003) conclude from a review of the literature that youth with diabetes, particularly females, have significantly higher rates of depression than the general population, and there is a ten-fold increase of suicide and suicidal ideation in this group. The gender differences for depression prevalence amongst youth with diabetes appear to emerge at adolescence (Kanner et al., 2003). Korbel, Wiebe, Berg and Palmer (2007) found that, amongst adolescents with T1D aged 10 to 15 years, older adolescent girls reported greater levels of depression than younger girls and all males, which, in turn, predicted poorer adherence to regimen. However, Korbel et al. caution that the findings may reflect the

self-report nature of the study; it may be that boys are less likely to reveal both depression and poor adherence compared to girls. Furthermore, their study was cross-sectional, limiting the conclusions to correlational rather than causal. However, Korbel et al. propose that depression is a risk factor for poor diabetes self-management, and the comorbidity of depression and T1D in adolescents has been found to increase the risk of hospitalization for complications of T1D (Stewart, Rao, Emslie, Klein, & White, 2005). Moreover, Hillege, Beale, and McMaster (2011) concluded from their qualitative interviews with young adults with T1D that individuals with undiagnosed depression who present with poor diabetes management may be at risk for disengagement with diabetes care services. Accordingly, the authors recommend that health professionals be vigilant when managing young people with diabetes and dual diagnoses.

The longitudinal study conducted by Bryden et al. (2003) demonstrated that psychiatric outcomes and the concomitant association with poor metabolic control, were predicted by psychiatric symptoms in adolescence and young adulthood. However, whilst most individuals in the longitudinal study received individualised care and psychiatric referral when required, there was no access to formal psychological support. Accordingly, Bryden et al. suggest that the significant morbidity associated with the transition from adolescence to adulthood could be reduced by identification of at-risk individuals, and the introduction of targeted treatment. However, despite the growing evidence of the association between T1D and psychological difficulties, diabetes care and psychological care are poorly integrated (Snoek, 2006). Aiming to evaluate the role and management of psychological difficulties in diabetes, the Diabetes Attitudes, Wishes and Needs (DAWN) Survey was conducted.

The DAWN survey. Recognising that, despite access to efficacious treatments for diabetes, outcomes are often sub-optimal, a cross-sectional, international survey, the Diabetes Attitudes, Wishes, and Needs (DAWN) study, was initiated in 2001. Aiming to identify the psychosocial and behavioural barriers to successful diabetes management, structured interviews were conducted with over 4000 healthcare providers and over 5000 people with diabetes (T1D and T2D) to explore diabetes-care related factors, including levels of psychological distress among people with diabetes, and the relationships between people with diabetes and their care providers (Skovlund & Peyrot, 2005).

Reviewing the data from the DAWN study, Skovlund and Peyrot (2005) state that nearly three quarters of respondents with diabetes reported diabetes-related stress long after diagnosis

(mean duration of almost 15 years), with 32.7% endorsing “I feel stressed because of my diabetes,” 43.8 % endorsing “I am constantly afraid of my diabetes getting worse,” and 18.1% endorsing “I feel burned out because of my diabetes” (p. 137). The healthcare providers’ estimate, that 67.9% of their patients with T1D and 65.6% with T2D were suffering from psychological problems, was therefore reasonably accurate. However, whilst the majority of providers indicated that they believed the majority of their patients suffered from psychological problems, and that those psychological problems influenced regimen adherence, only a small minority of patients (3.3%) had received psychological treatment for diabetes-related problems in the five years prior to the study.

Funnell (2006) comments that the DAWN survey confirms that our current healthcare systems are poorly equipped to manage chronic diseases. In particular, the management of diabetes-related stress is a significant gap in healthcare provision, a gap which has been shown to compromise outcomes (Skovlund & Peyrot, 2005). Whilst the DAWN survey demonstrates that diabetes causes multiple psychosocial problems, and psychosocial problems impact on diabetes outcomes, Peyrot, Rubin and Siminerio (2006) suggest that healthcare strategies have yet to accommodate the psychosocial needs of diabetes patients. However, before considering the ways in which diabetes care may be more holistic and effective, it is important to understand the ways in which diabetes may make navigating the course of every-day life more difficult. The DAWN study was a useful start in understanding the lives of those with diabetes outside of the physiological paradigm. However, the DAWN study encompassed individuals with both T1D and T2D, and the average age of participants with T1D was 38 years (Skovlund & Peyrot, 2005). The period of the lifespan when metabolic control is poorest is during the period of adolescence (Helgeson, Snyder, Escobar, Siminerio, & Becker, 2007). Psychological problems that may compromise metabolic control in adolescence may stem from diabetes-related factors. For example, depression in adolescents may culminate from several factors concomitant with having diabetes, including the strict regimen, fear of complications and hypoglycaemia, a controlling attitude of parents, poor self-esteem, and altered body image (Kokkonen & Kokkonen, 1995, cited in Kanner et al., 2003, p. 17). Dovey-Pearce, Doherty, and May (2007) claim that there is a paucity of research in the area of the impact of diabetes on adolescent and young adult development and the implications of this for health care professionals, suggesting that this may be due to the fact that it sits between the disciplines of psychology, developmental psychology and clinical psychology. However, there is a growing body of research exploring the experience of having T1D as an adolescent, and the psychosocial issues that can ensue.

The Alchemy of Adolescence and Type 1 Diabetes – The Psychosocial Issues

Adolescence can be a challenging life-stage; it is a time of transition from childhood to independence. This life period has been described as a “time of ferment and potential, of energy and turmoil, of confusion and creativity” (Rich & Ginsburg, 1999, p. 377). The transition toward autonomy occurs concurrently with major hormonal changes associated with secondary sexual development and the pubertal growth spurt (Hamilton & Daneman, 2002, p. 116). It is also a time of the emergence of risky behaviours, for example experimentation with drugs and alcohol. Negotiating this transition with the added complication of a chronic illness, such as T1D, could be expected to escalate the challenges faced by young people. Accordingly, Woodgate (1998) has described having T1D for a young person as a “dual crisis” (p. 210). Young women interviewed about their lived experiences of diabetes have described their diagnoses as “psychologically overwhelming” (p. 84) and as “having a terrible room-mate that you have to live with” (Walker, 2008, p. 93). It has been recommended that health professionals be aware of, and be able to assess psychosocial distress, as it may complicate chronic disease management (Erickson, Patterson, Wall, & Neumark-Sztainer, 2005). However, whilst some may have difficulties coping with the realities of having diabetes, others may cope well. The experience of diabetes is not homogenous. The myriad of psychosocial issues that may manifest is testimony to the alchemy of adolescence and T1D.

Coping with everyday stress faced by adolescents with T1D may undermine psychosocial adaptation and metabolic control (Seiffge-Krenke & Stemmler, 2003). Using annual questionnaires to assess for frequent minor stressors, and ways of coping with those stressors, Seiffge-Krenke and Stemmler (2003) found that good, satisfactory, or poor metabolic control tended to be stable over time, and was linked to psychosocial adaptation. Those with poor metabolic control differed from those with stable metabolic control in the way that they perceived stressful everyday experiences, with those in the group with stable metabolic control reporting the lowest stress levels. In the group identified as having poor metabolic control, the most endorsed stressor was problems with peers, whereas in the group with good metabolic control, the perceived stress from peer relationships decreased over time. Whilst the findings are limited by being based on self-report measures, and there can be no conclusions drawn on the directionality of the link, the results indicate that psychosocial stress is a risk factor for

medical adaptation in adolescents with diabetes. Furthermore, those with poor psychosocial adaptation, suggest the authors, lack an important source of social support. Seiffge-Krenke and Stemmler describe these findings as a first step in determining the complex relationship between coping with chronic disease and everyday stress.

The research findings on whether psychosocial difficulties are more prevalent in adolescents with T1D compared to their non-diabetic peers are conflicting. Helgeson et al. (2007) suggest that it is difficult to draw conclusions from the research due to the small number of studies in this area, and methodological issues, for example varied designs, heterogeneous age ranges, small sample sizes, and, at times, a limited battery of assessment instruments. Attempting to mitigate these methodological concerns, the authors conducted a three year longitudinal study comparing a larger sample of adolescents with diabetes than had been used in previous research to a healthy comparison group. The study examined a wide range of indices of psychosocial functioning and concluded that, in general, diabetes was not associated with major psychosocial difficulties. However, they found evidence for difficulties with social acceptance, indicating that the establishment of a peer group may be made more difficult by diabetes, and that there are difficulties with eating behaviours. Difficulties with eating behaviours are a recurring theme in the research, and are discussed in later Chapters.

Helgeson et al. (2007) concluded that, taken collectively, there are few differences in terms of psychosocial difficulties and behavioural problems between children with diabetes and non-diabetic children as they transition into adolescence. This suggests that many adolescents with diabetes cope well with the demands imposed by having a diagnosis of T1D. However, these findings may underestimate the degree of psychosocial difficulties for a number of reasons relating to the ethnicity, socio-economic status, and age of the participants, and the methodology used in the research. Firstly the participants were largely white and middle-class, whereas diabetes may impact on different social groups in different ways. For example, data collected from 108 adolescents with T1D to explore the characteristics of adolescents with T1D who exhibit adverse outcomes revealed that participants with poorer metabolic control tended to come from single-parent lower income families, and were more likely to be African-American (Johns, Faulkner, & Quinn, 2008). Secondly, the Helgeson et al. study involved young adolescents (10.7-14.2 years at the beginning of the study). This was a deliberate choice on the part of the researchers, as they argued that early adolescence may be the time when psychosocial problems begin to emerge. However, it may be that psychosocial problems emerge later in

adolescence. For example, the nature of the slopes for the group difference for social competence over time suggested that a larger effect size might emerge with age. That mid- to late adolescence may present increased psychosocial challenges is supported by the findings of Madsen, Roisman, and Collins (2002). Using a three year longitudinal study to investigate the psychological distress associated with the treatment of T1D in adolescence, the authors found that age-related social changes, for example, starting high school, increased extra-familial activities, and establishment of intimate relationships with peers. Moreover, Madsen et al. suggest that developing cognitive skills, such as abstract thinking, in mid- to late adolescence could be associated with the adolescent being able to consider the potential long-term impact of T1D, which may add to their distress. Finally Helgeson et al. used a quantitative approach, and whilst the authors provided evidence that the measures of psychosocial functioning used were reliable and valid tools, measuring constructs such as anxiety, depression and self-esteem in this way fails to capture the lived experience of having diabetes as an adolescent. Researchers using a qualitative approach have unveiled richer data that allows the diverse voices of adolescents and young adults with T1D to be heard.

The voices of adolescents and young adults. In an early, qualitative, exploratory study involving 51 Finnish older adolescents aged between 13 and 17 years, Kyngas and Barlow (1995) found support for the suggestion that T1D may increase the risk for psychosocial problems. Two dichotomous themes emerged, namely diabetes as a threat to physical, psychological and social well-being, which disrupted the balance of life, and diabetes as a unique opportunity for a healthy life. The positive theme, where participants described diabetes as a “devil that reminds me to take care of myself,” and as a “natural part of me,” (p. 943) contrasts starkly with those participants whose experience of diabetes was negative, which, for example, was described as “a nightmare, stress, hell, death, and a prison” (p. 943). The adolescents reported feelings of fear of the future, that they would experience complications, notably going blind, amputation, or kidney disease, and that diabetes would interfere with their occupational choice and ability to have a family. Overall, the authors concluded that diabetes was perceived as a negative experience that impacted adversely on the lives of adolescents. Similarly, in interviews with young adults with T1D, Hillege et al. (2011) identified a theme of “curtailment of the future” (p. 60). Young people reported that complications arising from T1D affected their life plans and career aspirations. Some also expressed their fears for bearing children. Others reported fears of rejection. For example, one young person stated “what if no-one wants me because they think I’m sick and diseased” (Hillege et al., 2011, p. 61). Whilst it is likely that many

young people worry for their future, and fear rejection, the implications of a diagnosis of T1D are likely to provide a tangible basis for those worries.

The stressors and self-challenges described by a small group of teens and young adults with T1D (12 to 20 years) to Davidson, Penny, Muller, and Grey (2004) lend support to the findings of Kyngas and Barlow (1995). Whilst the young people tried to view diabetes as “just one part of their lives” (p. 76), all interviewees noted a sense of discouragement and confusion at the unrelenting nature of their condition, and the difficulty in controlling outcomes. The stressors faced by the young people have implications for self-care, claim Davidson et al., with compliance not being simply a “do or do not behaviour,” but the result of “evolving and complex algorithms” (p. 78) culminating from the interaction of many variables in their lives, including personal, situational and relational. Similar to the positive theme tapped by Kyngas and Barlow, participants reported to Davidson et al. that they had a sense of pride and accomplishment that they could manage the demands of diabetes. However, the authors found that the participants’ feelings tended to swing between the positive view and views that diabetes is always hard. The implications from the research, suggest Davidson et al., are that non-judgmental care from health professionals and parents can help support teenagers in their diabetes management throughout this turbulent time. However, for teenagers with T1D, the support that they need from parents is in direct conflict with the developmental tasks that they face, in particular, gaining autonomy from parents, and establishing oneself within a peer group.

Autonomy and type 1 diabetes. An increased desire for autonomy from parents, complicated by the reliance on parental help with self-care, may constitute a major developmental hurdle for adolescents with T1D. Adolescents with T1D reported that they believed that the move to independence from parents was different for teenagers with diabetes than for other teenagers (Huus & Enskar, 2007). The adolescents interviewed by Karlsson, Arman, and Wikblad (2008) conveyed that they perceived that parents of diabetic children were more worried about their children than parents of non-diabetic children, and, consequently, there was a fine line between parents’ reminders about self-care being construed as supportive and being seen as harassing. A similar dialectic has been described by other researchers. Dovey-Pearce et al. (2007) explain that whilst the family may be seen, and valued as a safe base by adolescents with diabetes, it is also likely that they may feel uncomfortable with the ongoing involvement in matters such as their diet, an ambivalence which the authors describe as an “oscillating process of separation and individuation from the family unit” (p. 83). Similarly,

teenagers interviewed by Davidson et al. (2004) described parents as a source of support, but also as a source of stress by way of “nagging, over-protecting, worrying, blaming” (p. 77).

Karlsson et al. (2008) characterised the transition for adolescents as vacillating between self-management and parental dependency, which inevitably leads to family conflict. Getting the balance between support and self-responsibility right may have important implications for diabetes management. For example, teens reported that because they anticipated negative feedback about care omissions (for example, taking an average dose of insulin based on an unchecked glucose level, or taking extra insulin to cover food excesses), they resorted to deceiving their parents about their self-care (Davidson et al., 2004). Furthermore, the adolescents interviewed by Karlsson et al. stated that nagging had no effect on their behaviour, but rather, it decreased their motivation for self-management activities, whereas an approving attitude on the part of parents was likely to foster progress toward self-management. Whilst those with T1D may, of necessity, be more reliant on their parents than their non-diabetic counterparts, the influence of parents at this developmental stage may be beginning to wane, and the importance of peers may be increasing.

Peer groups and type 1 diabetes. Young people living with a chronic illness often report that they perceive a sense of alienation from their peers (Yeo & Sawyer, 2005). Huus and Enskar (2007) describe the lived experience of having diabetes as a young person as like a “pendulum” (p. 31) between being different and being normal, with normality, as perceived as being like their friends, being the goal. Young people interviewed on the positive and negative influences of diabetes considered that diabetes rendered them as other at a time when they most wanted to conform (Buchbinder et al., 2005). Young people interviewed by Dovey-Pearce et al. (2007) describe experiences that set them apart from the well world. For example, one young woman talked of the ramifications that might ensue from a pregnancy for her compared to a pregnancy in a “normal” person. One adolescent female described herself as a “reject” (p. 81) because she had to have different foods from others. Similarly, young people related to Walker (2008) instances when the careful regimen required for optimal glycaemic control fostered a sense of being different. They noted, for example, the need to have food available when others are unable to eat in class to offset an episode of hypoglycaemia, the need to make diabetes-congruent choices of food, for example a granola bar rather than a double fudge chocolate cupcake at a school fair, and the upheaval often associated with school trips, because any change

to the schedule would upset the delicate balance of the regimen. A feeling of being different may hamper the adolescent with T1D in their efforts to establish themselves within their peer group.

Peers may be a source of invaluable support to teens with T1D (Davidson et al., 2004; Seiffge-Krenke & Stemmler, 2003). However, peers may also be perceived as another form of stressor. Young people interviewed by Davidson et al. (2004) explained that peer relationships could be stressful, for example, by friends being overprotective, and telling others about their diabetes or voicing questions in an inappropriate social setting. Madsen et al. (2002) explain that, whilst adolescents with T1D may share the goals of healthcare providers for good health, this may conflict with a stronger desire to fit in with their peers, which has implications for self-care. For example, most of the adolescents interviewed by Davidson et al. concealed care issues around friends to avoid attention being drawn to them and their diabetes. Insulin omission in adolescents, for example, may result from not wishing to draw attention to themselves in public, or a desire to just forget that they have diabetes (Williams, 1999). Non-adherence to self-care in social situations is exacerbated when youth expect negative reactions to their diabetes from friends (Hains, Berlin, Davies, Parton, & Davies, 2006). Hains et al. (2006) suggest that young people who expect negative reactions not only compromise their metabolic control by non-adherence, but their negative attributions also render a potential means of positive support unavailable.

The social pressure to conform is likely to be conflated at periods of change in the life of adolescents. Like many changes, the transition from high school to higher education may both positively and negatively influence diabetes control (Ramchandani et al., 2000). However, Ramchandani et al. (2000) claim that, like many others with a chronic disease, students with T1D often attend university whilst living at home, and therefore, little is known about those that attend college away from home. To explore this, college students living away from home were asked to rank the factors that were perceived to influence changes in metabolic control, and indicate the magnitude of the impact of that factor on a Likert scale. Whilst the authors reported no significant statistical evidence in this study that metabolic control worsened in the period from high school to college, many students perceived that diabetes management was much more difficult in college. Some factors, for example, exercise, were thought to improve metabolic control by most students, but others were perceived to present barriers to good control, namely irregular schedules, lack of parental involvement, finances, peer pressure, drugs and alcohol, and fear of hypoglycaemia. Because most students had managed to maintain a level

of control similar to that during high school, Ramchandani et al. concluded that most college students had developed skills to mitigate the barriers to metabolic control, for example by adhering to intensive regimens and testing blood glucose levels several times a day. However, the authors identified three categories of students engaging in high-risk behaviours, namely those with eating disorders, those who drank large amounts of alcohol, and those not being followed by a health-care provider.

Recognising that starting college was a cross-roads in many ways for adolescents with T1D, Miller-Hagan and Janas (2002) interviewed students about their drinking attitudes and behaviours. Almost all of the students in the study reported increased exposure to alcohol in college and pressure from peers to drink. Short-term diabetes management and long-term health outcomes may be jeopardised by drinking alcohol unwisely. Whilst some students had reasonable strategies to mitigate adverse outcomes of drinking, and some chose not to drink at all, others surrendered to peer pressure to drink, exposing themselves to an increased risk of hypoglycaemia and poor metabolic control. The pressure to drink for adolescent and young adult college students stems from a desire to identify with what they perceived to be normal student behaviour (Balfe, 2007b). Consequently many younger students interviewed by Balfe (2007b) engaged in what they considered to be risky drinking practices. Being “normal” reports Balfe, was especially important to first year students, who were still grappling with how diabetes fitted into their student lives. However, a decrease in desire to identify with the student body and a decrease in risky drinking practices in older students was underpinned by the ambivalence and guilt generated by the knowledge that drinking was detrimental to their health.

Psychological and psychosocial difficulties and disordered eating.

Ramchandani et al. (2000) also identified disordered eating as a risk to the health of young people with T1D. The association between disordered eating and psychological and psychosocial difficulties is not clear. However, the body of research of disordered eating in the general population suggests that there may be an association between them. For example, a study of randomly selected high school girls demonstrated that a majority (89.5%) of those with full-scale and sub-threshold eating disorders had at least one other co-morbid psychiatric disorder during adolescence (Lewinsohn, Striegel-Moore, & Seeley, 2000). Depression in particular may be associated with disordered eating in the general population. For example, Fay (2012) concluded that unhealthy and problematic eating trajectories in girls were associated with depressive symptoms. In a sample of college-age women considered at high risk for eating

disorders (due to their high weight and shape concerns), Jacobi et al. (2011) identified a history of depression as the risk factor with the highest potency out of seven independent risk factors for predicting eating disorder onset. Moreover, in a five-year longitudinal study of students from public schools, Ferreiro, Seoane and Senra (2012) concluded that there is a “reciprocally related” (p. 616) rather than a unidirectional association between depression and disordered eating. The authors found that low self-esteem, fear of getting fat and body dissatisfaction at time one and body dissatisfaction at time two predicted depressive symptoms in girls. Furthermore, depressive symptoms, body mass index and perfectionism at time one and body dissatisfaction at time two predicted disordered eating in girls. Ferreiro et al. postulate that there are pathways from the fear of getting fat to depressive symptoms and from depressive symptoms to disordered eating.

These studies examined eating disorders in the general population, which may not be able to be generalised to disturbed eating in T1D, and there is a dearth of literature examining the psychological characteristics of young women with both an eating disorder and T1D (Powers et al., 2012). However, it may be that depression contributes to disturbed patterns of eating in young women with T1D. For example, a young woman in a qualitative study of diabetes and depression noted “I’d get into a depression of some sort and I’d overeat, seek company in food and then I’d inject huge amounts of insulin to compensate” (Hillege et al., 2011, p. 62). Quick, McWilliams and Byrd-Bredbenner (2012) compared the psychological characteristics of young adults with diet-related chronic health conditions, including T1D, to young adults with no medical conditions. The scores for anxiety and depression were higher in the health condition group. Quick et al. suggest that these findings should concern health professionals because of the association of depression, anxiety and eating disorders. Similarly, health professionals should be aware of psychosocial pressures, particularly during adolescence. If adolescents do not feel that they “fit in” with peers, then they are more likely to succumb to social pressure to participate in diabetes-incongruent activities (Helgeson et al., 2007). Moreover, young people with chronic health conditions may be more likely to participate in risky behaviours, including disordered eating, to prove their “normality” (p. 1116) to their peers (Suris, Michaus, Akre, & Sawyer, 2008).

Chapter Summary

It is clear that, whilst some may develop resilience in the face of the challenges presented by having T1D during adolescence, and that some young people may consider aspects of having diabetes to be a positive experience, others may struggle to cope. Managing T1D requires attention to insulin regimen, diet, monitoring of blood glucose, and exercise, all of which, Hillege (2005) suggests, may “clash” (p. 3) with emerging developmental needs and priorities in the adolescent and young adult. A high-stakes struggle may ensue for the young people between the exacting measures required for metabolic control of T1D, the long-term consequences of less-than-optimal metabolic control, and psychosocial or psychological issues which can lead to behaviours incongruent with optimal diabetes management or non-compliance. Moreover, psychosocial difficulties, specifically fitting in with a peer group, and psychological difficulties, in particular depression, may be associated with disturbed eating. The emergence of disturbed eating as a concern during adolescence is a recurrent theme in the research (Bryden et al., 2003; Helgeson et al., 2007; Ramchandani et al., 2003), suggesting that, for female adolescents with T1D in particular, eating, body image, and weight issues may contribute significantly to the struggle for this group.

Chapter 4 – Eating, Body Image and Weight in Type 1 Diabetes

Chapter Overview

The management of T1D, with its focus on an eating and insulin regimen to promote stable metabolic control, may potentiate eating, body image and weight issues particularly in adolescent females and young adult women. Eating, body image and weight issues have been linked to a spectrum of disturbed eating behaviours in T1D that range from practices that are common amongst young females in the general population, and which might be relatively unproblematic in a non-diabetic group, such as food restriction or bingeing, to a clinical eating disorder. A particularly dangerous practice available to the diabetic population is the misuse of insulin for weight loss, referred to as diabulimia. This chapter details the difficulties that can be associated with achieving stable metabolic control, in particular, those which may contribute to eating, body image and weight issues, and the diabetes-related issues that may culminate in disturbed eating behaviour in young females. The nature of disturbed eating behaviour, including its definition, prevalence, aetiology and impact on metabolic control, is explored in this chapter.

Metabolic Control in Type 1 Diabetes

The importance of metabolic control was demonstrated in the Diabetes Complications and Control Trial (DCCT, 1993), which concluded that improved control of diabetes can prevent the onset, and stop the progression of, diabetic complications (Crow, Keel & Kendall, 1998). As outlined in Chapter 2, there are potentially serious, even life-threatening, short- and long-term complications associated with unstable metabolic control. However, the care protocols of T1D have been described as “complex, and behaviourally challenging” (Davidson et al., 2004, p. 72). Achieving stable metabolic control is often not straight forward, and often requires constant vigilance. For example, young women interviewed by Rasmussen, O’Connell, Dunning and Cox (2007) describe managing diabetes as “being in the grip of blood sugar levels” (p. 300). The young women identified this as a core social problem, as throughout their daily activities, they were aware of the possibility of hyperglycaemia and hypoglycaemia and the potential impact of these states on their short and long term health. They were also aware that it may compromise their employment opportunities or potential for a safe pregnancy.

Tattersall (1997) comments that “insulinologists” (p. 103) believe the answer to metabolic control lies in adjusting insulin, diet, and exercise. However, even those who are skilled in self-management may experience difficulty in achieving metabolic control (Wolpert & Anderson, 2001a), and only a small minority are able to maintain HbA1c levels within the recommended parameters (Hillege, 2005; Kyngas, 2000). For example, the DCCT demonstrated that in a group of highly motivated participants with T1D provided with extensive education and resources, only 5% maintained an average HbA1c within the optimal range of less than/equal to 6.05% (Jacobson, 1996). The period most associated with deteriorating metabolic control is adolescence (Bryden et al., 2001; Dabadghao, Vidmar, & Cameron, 2001; Hamilton & Daneman, 2002). Reviewing the labyrinth of reasons underpinning deterioration in metabolic control during adolescence, Hamilton and Daneman (2002) conclude that there is a complex interplay between physiological and psychosocial factors.

There are physiological factors during adolescence that may interfere with the delicate balance of insulin regulation. For example, Korbel et al. (2007) postulate that hormonal fluctuations may increase HbA1c values, and Hamilton and Daneman (2002) point to the triad of high HbA1c, high insulin dose, and weight gain that occurs during the pubertal years, especially in girls, which they claim indicates increased insulin resistance at this time. However, whilst metabolic control may be difficult to optimise during adolescence, even with careful attention to regimen, physiological changes alone are unlikely to account for blood glucose fluctuations (Bryden et al., 2001; Dovey-Pearce et al., 2007). Adolescence is a time when young people strive for autonomy from their parents, and for young people with T1D, this may mean assuming responsibility for a complex regimen. Adolescents whose parents remain involved in their care have better metabolic control than those whose parents grant them complete autonomy over their regimen (Ramchandani et al., 2000). As young people take their self-care over from their parents, Hamilton and Daneman suggest that there may be technical deficits in insulin delivery. For example, lipohypertrophy, a subcutaneous swelling, can cause unreliable insulin absorption, or there may be mixing and dosing errors. Furthermore, decreasing parental supervision increases the opportunity for non-adherence. Non-adherence, claim Hamilton and Daneman is a common problem during adolescence, and the reasons behind decreased compliance may be multi-faceted. A decline in self-care may be preceded by a period of deteriorating metabolic control despite apparent careful adherence to regimen and evidence of increasing levels of diabetes knowledge, claim Du Pasquier, Chwalow, PEDLAB Collaborative Group and Tubiana-Rufi (2005). This decline in self-care, the authors postulate, may reflect

waning parental involvement, an adolescent need to rebel, or a kind of “diabetes burnout” (p. 431). “Burnout,” suggest Du Pasquier et al., may be triggered by the perceived futility of conscientious adherence to regimen.

Non-adherence to insulin regimen is one of the major threats to metabolic control (Goebel-Fabbri, et al., 2008). Reviewing the literature, Hughes (2010) estimates that deliberate insulin omission is reported by approximately 2% of preteens, 15% of mid-teens, and 30-39% of older teens. Morris et al. (1997) reported similar findings in their elegant study comparing the volume of insulin prescribed to individuals under 30 years attending the paediatric and young adult clinics at a UK hospital to the volume dispensed. They concluded that failure to take insulin was common, occurring in up to 28% of the young people studied. Deliberate insulin omission may be for psychosocial reasons, for example, not wanting to administer insulin injections in a social setting (Walker, 2008), or due to psychological issues, such as injection-related anxiety and fear of hypoglycaemia (Stotland, 2005). However, insulin omission/restriction is often a weight-loss behaviour that is part of the spectrum of disturbed eating behaviour. To understand why some young people with T1D develop disturbances in their eating, it is helpful to consider the experience of having diabetes as a young person, particularly the complex web of eating, body image and weight-related issues that is often concomitant with diabetes, from within which the antecedents of disturbed eating behaviour may be fostered.

Body Image, Eating and Weight-Related Issues in Type 1 Diabetes

Body image issues, including eating and weight-related issues, are not unusual amongst teenage girls in general (Kelly, Wall, Eisenberg, Story, & Neumark-Sztainer, 2005). However, these issues may be exacerbated in female adolescents with T1D, and weight management may often be in conflict with diabetes management. The intricate dance for young people with T1D is described by Balfe (2008), who interviewed male and female college students with T1D. In general, the respondents were concerned with eating healthily and exercising regularly. However, achieving these goals was complicated by what Balfe referred to as engaging in separate, but interrelated “body projects” (p. 6), namely student bodies (being a “normal” student), toned bodies (concern with body shape), and healthy bodies (anxiety relating to long-term complications of diabetes). Their efforts to construct one body project, for example, managing diabetes, tended to undermine progress on another body project, for example, being a

normal student (toned, attractive, and being able to do what other students could). Whilst Balfe concluded that both males and females were engaged in the three separate but inter-related body projects, there were gender differences in their goals. For example, females reported wanting to be “toned and slim,” and males were focussed on being “toned and muscled” (p. 7). The gender differences in the group were elaborated on by Balfe (2007a) who found that the male respondents did not have the same concerns about losing weight as their female peers. One of the major concerns for female participants was the way in which diabetes could complicate weight control practices. The young women conveyed to Balfe (2007a) their ambivalence deriving from the consumption of carbohydrate suitable for the regulation of diabetes, but which is in conflict with weight management. The author also found that the risk of exercise-induced hypoglycaemia was a barrier to healthy practices for some young women. Some interviewees would load up on sugary food before or after exercise to minimise the risk of hypoglycaemia, which then compromised their weight loss activities. Balfe (2008) hypothesises that the idea of multiple body projects helps to explain why some students with T1D engage (or not) in risky health practices. Whilst no individuals reported generally engaging in risky weight loss practice, which may reflect, at least in part, the low participation rate of 17% in this study, the findings suggest that the struggle to balance health, identity and body image may be a salient issue for young people with T1D, particularly females.

There is a tendency for female adolescents with T1D to have a higher body mass index than non-diabetics (Bryden et al., 1999; Jones, Lawson, Daneman, Olmsted, & Rodin, 2000; Steel, Young, Lloyd, & MacIntyre, 1989). Kaufman (2006) suggests that there are a number of potential mechanisms that may explain the weight gain, including ingestion of extra calories to avoid hypoglycaemia, and insulin-related alteration in the regulators of adiposity. Steel et al. (1989) suggest that the systemic delivery of insulin may result in the over-stimulation of adipose tissue formation. Ahmed, Ong, Watts, Morrell, and Preece (2001) report a “sexual dimorphism” (p. 1189) in pubertal adolescents with T1D. They found that hyperinsulinaemia and raised leptin levels were associated with gains in fat mass throughout puberty in girls, but not boys. Intensive insulin regimens may also account for weight gain, as they allow for increased flexibility in diet, and, therefore facilitate the consumption of a greater number of calories (Holl, Grabert, Sorgo, Heinze, & Debatin, 1998).

Whatever the mechanism(s) responsible for weight gain, individuals with T1D perceive an association between insulin dose and obesity risk (Bryden et al., 1999). This may stem from

the weight loss that tends to accompany the onset of T1D which is often rapidly reversed after diagnosis of T1D owing to rehydration and the anabolic effect of insulin. Many have described this weight gain as “alarming” (Steel et al., 1989, p. 519). The significant weight loss, followed by rapid weight gain may serve to amplify weight and body shape concerns amongst female adolescents with T1D (Battaglia, Alemzadeh, Katte, Hall, & Perlmutter, 2006). Moreover, young females with T1D often believe that good metabolic control results in weight gain (Takii et al., 2002). In one study of female adolescents with T1D, there was 46.7% endorsement in the statement “I feel that it is difficult to lose weight and control my diabetes at the same time” (Howe, Jawad, Kelly, & Lipman, 2008). Accordingly, female adolescents with T1D may have increased weight and body shape concerns compared to their non-diabetic peers. For example, in a study of 89 female adolescents with T1D, 16.9 % scored above the cut-off scores on the Drive for Thinness subscale of the Eating Disorder Inventory, compared to 2.2% of an age-matched, non-diabetic control group (Engstrom et al., 1999). Scores on the Body Dissatisfaction subscale were also significantly higher, and whilst not reaching statistical significance, scores on the Bulimia subscale were higher. The participation rate was high in this study (92%), but Engstrom et al. (1999) noted that the body mass index was higher in the girls with diabetes who declined to participate. Therefore, the estimates of eating attitude pathology in female adolescents with T1D in this study may be conservative.

Female adolescents with T1D interviewed by Walker (2008) described difficulty during adolescence and puberty in accepting a new body image associated with the weight gains concomitant with insulin therapy. Weight and body shape concerns often induce young people to engage in weight control behaviours, some of which may be healthy, for example, increasing intake of fruit and vegetables, moderate exercise, and cutting down on fatty foods. However, in the general population, a large five-year longitudinal study demonstrated that lower body satisfaction is not usually associated with employment of healthy weight loss practices, but rather seems to motivate the use of behaviours that increase the risk of weight gain and poorer overall health (Neumark-Sztainer et al., 2006). These findings in the general population are reflected in a study with female adolescents with T1D (Howe et al., 2008). Those adolescents that reported weight dissatisfaction were most at risk for unhealthy weight control behaviours (for example, fasting, increased smoking, and using food substitutes), and very unhealthy weight control behaviours (for example, diet pills, vomiting, and skipping insulin) (Howe et al., 2008). Battaglia et al. (2006) suggest that the dietary restraint and emphasis on exercise concomitant with a diabetes regimen may further exacerbate body dissatisfaction and drive for thinness,

predisposing female adolescents with T1D to adopt disturbed eating behaviours. Smith, Latchford, Hall and Dickson (2008) concur, also noting that compounding the weight control pressures experienced by the female population in general, young women with T1D are also exposed to weight control advice from medical authorities.

Disturbed Eating Behaviour in Type 1 Diabetes

Disturbed eating behaviour has been characterised as eating disorder symptoms not yet at the level or frequency to meet the criteria for a diagnosis of an eating disorder, including dieting for weight loss, binge eating, or calorie purging through self-induced vomiting, laxative or diuretic use, excessive exercise, or insulin restriction (Olmsted, Colton, Daneman, Rydall, & Rodin, 2008). In another publication (Colton, Olmsted, Daneman, Rydall, & Rodin, 2007), the same authors widened their criteria to include both dieting for weight control, rather than weight loss, and full-syndrome eating disorder, rather than sub-threshold eating disorder, in their definition of disturbed eating behaviour. However, it seems counter-intuitive to pathologise individuals whose behaviours, even though employed for weight control/loss, are generally considered healthy, for example, cutting down on fatty foods and moderate exercise, by inclusion in a syndrome which is considered “disturbed.” Therefore, for the purposes of this study, whilst body image issues and body dissatisfaction, and therefore any form of weight control behaviours, are of interest, disturbed eating behaviour will describe what Pereira and Alvarenga (2007), using guidelines for disordered eating from the American Psychiatric Association, refer to as “troublesome eating behaviours” (p. 142). Furthermore, because cases of Anorexia nervosa, Bulimia nervosa, and Eating Disorder - Not Otherwise Specified may be comorbid with T1D, it is more precise to differentiate between those that meet the criteria for a clinical eating disorder, and those that display sub-threshold eating disturbances. Therefore, the term disturbed eating behaviour in this research describes a continuum from weight control/loss practices, which may be relatively benign in a non-diabetic individual, but which may compromise metabolic control in T1D, to a more serious eating pathology that stops just short of full-syndrome eating disorder.

Prevalence of disturbed eating behaviour. Most of the studies on disturbed eating behaviour in T1D have concentrated on females. Studies that have included males have had conflicting results as to whether males with T1D engage in disturbed eating behaviour. Neumark-Sztainer et al. (2002) concluded that, whilst male adolescents with T1D are not as

susceptible to disturbed eating behaviour as females, their weight control behaviours may still be of concern. The authors found that more female adolescents (92.4%) than males (53.6%) reported engaging in weight control behaviours. Healthy weight control behaviours were the most commonly reported practices. However, 18.2 % of females engaged in unhealthy weight control behaviours (for example, fasting and skipping meals), and 19.7% engaged in very unhealthy weight control behaviours (for example, vomiting and skipping insulin). Males engaged in the unhealthy and very unhealthy weight control behaviours considerably less than females (13.0% and 2.9% respectively). Of the very unhealthy behaviours, 10.3% of females reported skipping insulin, and 7.3% of females reported taking less insulin than they should to control weight, whereas only 1.4% of males reported either practice. Other studies have concluded either that males with T1D are at no increased risk of disturbed eating behaviour (Grylls, Haffner-Gattermayer, Schober, & Karwautz, 2004; Steel et al, 1989), or that there may be a small increase in risk compared to an age-matched non-diabetic control group, which remains inconclusive due to the small sample size (Svensson, Engstrom, & Aman, 2003). All these studies are small, have employed different measures to identify eating problems, and different criteria to define them, making comparisons between studies difficult. However, whilst eating problems may occur in males with T1D, the research suggests that disturbed eating behaviour is more prevalent in females.

A multi-site, case-controlled, large study classified females aged 12 to 19 years into three groups, namely, full syndrome eating disorder, a sub-threshold eating disorder, or no eating disorder, and concluded that eating disorders, and their sub-threshold variants are about twice as common in female adolescents with T1D as their non-diabetic peers (Jones et al., 2000). Integrating the findings of studies utilising optimal methodology, Nielsen (2002) concluded from his meta-analysis that the incidence of Anorexia nervosa is not increased, but the incidence of Bulimia nervosa, Eating Disorder – Not Otherwise Specified, and sub-threshold eating disorder is increased in a diabetic population. Nielsen operationalised optimal methodology to include studies that enrolled sufficient females in the relevant age group, included a relevant control group, utilised a validated clinical interview to supplement self-report instruments, recorded relevant physiological variables (for example weight, height and HbA1c), performed a power analysis, and reported low drop-out rates. Other studies have concluded that, whilst the incidence of a clinical eating disorder is no greater than in non-diabetic adolescent female populations, a significant continuum of disturbed eating behaviour exists in adolescent females with T1D (Bryden et al., 1999; Engstrom et al., 1999; Meltzer et al., 2001). Acknowledging the

disparity of results between different studies investigating the prevalence of disordered eating in T1D, Nash and Skinner (2005) suggest that this may reflect differences in method, age of participants, and sample size.

The method used is also likely to impact on prevalence figures obtained. The variance in reported prevalence of disturbed eating behaviour may stem from the instruments used to detect eating problems (discussed in a later Chapter, Screening for Disturbed Eating Behaviour), and, furthermore, self-report data on eating behaviours and insulin manipulation may be unreliable (Goebel-Fabbri et al., 2008; Neumark-Sztainer et al., 2002). Moreover, the criteria that researchers use to define disturbed eating behaviour in their studies vary considerably. For example, Grylli et al. (2004) state that they broadened the criteria for sub-threshold eating disorders from that used by Jones et al. (2000) to include concerns about weight and shape, because, they claim that such concerns markedly increase the risk of eating pathology. Despite this, the two studies identified very similar prevalence of full- and sub-threshold eating disorders. However, in some cases, the differing criteria used in a study may account for prevalence rates that vary from other studies. For example, in an explanation as to why their study may have found a low prevalence of eating problems (3.8% meeting DSM-III criteria for eating disorders, and 11.4% with eating problems) Pollock, Kovacs, and Charron-Prochownik (1995) discuss their criteria for identifying eating problems. Firstly, they state that, in contrast to a number of other studies, they only included insulin *omission*, rather than insulin *reduction*, which is also used as a method of purging for weight control. Furthermore, the criteria employed by Pollock et al. required *both* insulin omission, and a maladaptive eating practice together, whereas the authors note that other studies considered the presence of one behaviour to constitute an eating problem. Accordingly, when comparing different studies, it is important to be clear about exactly what the researchers considered to constitute disturbed eating behaviour.

The demographics of the participant sample used, particularly age, is also likely to impact on the prevalence of disturbed eating behaviours identified. Reviewing the literature, Nash and Skinner (2005) conclude that those studies which demonstrated that individuals with diabetes were at higher risk of eating pathology had higher mean ages of participants, compared to studies that did not demonstrate a higher risk. It has been hypothesised that binge eating (Colton, Olmsted, Daneman, Rydall, & Rodin, 2004) and insulin omission (Colton et al., 2004; Meltzer et al., 2001) may be behaviours that emerge later on in adolescence. Commenting on the studies that have used differing age ranges of participants in their samples, Nash and Skinner

consider that the lower prevalence of eating problems in younger age groups may be because weight and shape concerns are unlikely to have manifested, bulimia symptomology tends to emerge later on in adolescence, and furthermore, the involvement of parents in their children's diabetes routine is more likely during early adolescence, reducing the opportunities available to manipulate insulin.

In studies attempting to assess the prevalence of disturbed eating behaviour, a number of authors cite sample size as a limitation in their findings (see for example Ackard et al., 2008; Colton et al., 2007; Markowitz et al., 2010; Neumark-Sztainer et al., 2002; Olmsted et al., 2008; Peveler et al., 2005;). Fairburn, Peveler, Davies, Mann and Mayou (1991, cited in Nielsen, 2002, p. 250) conclude that the majority of the studies are small and may be lacking in sensitivity, with power analysis indicating that a sample comprising 1000 cases and 1000 controls is needed to demonstrate a two-fold increase in eating disorders in T1D. Moreover, participation rates of, for example 90% (Peveler et al., 2005), 71.2% (Olmsted et al., 2008), and 58% (Neumark-Sztainer et al., 2002) may impact on findings. In studies with a longitudinal design, the follow up rates, for example, 77.8% in a five-year study (Olmsted et al., 2008) and 72% at 8 to 12 years (Peveler et al., 2005) may also skew results. For example, Peveler et al. (2005) suggest that the prevalence rate of disturbed eating behaviour identified in their longitudinal study was subject to a possible conservative bias, postulating that people with eating problems may be particularly likely to be lost to follow-up.

Reported prevalence rates for disturbed eating behaviour amongst female adolescents with T1D may be conservative estimates, as many studies have relied on clinic attendees for their participants; samples made up of individuals who attend clinic may not be representative of the whole T1D population, as they may reflect a bias toward those that are committed to good management of their diabetes (Ackard et al., 2008; Surgenor, Horn, & Hudson, 2002). Furthermore, there is evidence that some female adolescents with T1D and disturbed eating behaviour refuse to participate in studies investigating disturbed eating behaviour (Ackard et al., 2008; Colton et al., 2004; Rodin, Daneman, Johnson, Kenshole, & Garfinkel, 1985; Svensson et al., 2003) or may be unwilling to disclose their disordered behaviours (Engstrom et al., 1999; Steel et al., 1989). The rates of non-participation in research may be especially pertinent, as the subject under investigation in these studies is disturbed eating behaviour. By reviewing the medical records of women who chose not to participate in studies of eating disorders in the general population, Beglin and Fairburn (1992) concluded that eating problems were over-

represented amongst non-participants, and that, accordingly, it may never be possible to get accurate figures for the prevalence of eating disorders. It is likely that accurate figures for the prevalence of disturbed eating behaviour in a T1D population may be similarly elusive.

Aetiology of disturbed eating behaviour. Most factors in the aetiology of eating disorders in the general population appear to be mediated through weight and shape concern, or the need for restraint (Gowers & Shore, 2001). Rigid dieting, but not flexible dieting, has been shown to be associated with the development of an eating disorder in non-obese, non-diabetic women (Stewart, Williamson, & White, 2002). Steel et al. (1989) note that people with diabetes are constantly educated to focus on diet and food, and are often made to feel guilty if they do not comply with their regimen. Therefore the rigid approaches to dietary management in T1D may heighten the risk of the development of disturbed eating behaviour (Rodin et al., 2002). Surgenor et al. (2002) concur, suggesting that the enforced dietary concern, externally imposed dietary restraint, the need to override internal cues, and weight and shape change concomitant with a diagnosis of T1D, replicate the factors and processes described as conducive to development of disordered eating.

Amongst adolescent females with T1D, a higher body mass index is associated with disturbed eating behaviour (Colton et al., 2007; Engstrom et al., 1999). However, Neumark-Sztainer et al. (2002) concluded that, whilst weight dissatisfaction was significantly correlated with disturbed eating behaviour, the associations between disturbed eating behaviour and body mass index were weak and inconclusive. Similarly, Steel et al. (1989) concluded that whilst weight appears to be important, there are underweight, normal-weight and overweight subjects with high eating pathology scores on screening tests. Accordingly, it seems that there are factors other than weight that may predispose adolescent females to develop disturbed eating behaviour.

Olmsted et al. (2008) conclude that the onset of disturbed eating behaviour can be predicted by concerns with weight and shape, lower self-esteem related to physical appearance, lower global self-esteem and depressive symptoms. Their longitudinal study found that girls with T1D who subsequently developed disturbed eating behaviour did not have elevated scores on predictor variables compared to normal controls, but did have elevated scores compared to girls with T1D who did not develop disturbed eating behaviour. The relatively low scores on predictor variables may be accounted for by the exclusion of girls with disturbed eating

behaviour identified at baseline, thereby biasing the sample toward the lower end of eating-related disturbance. However, whilst recognising this, Olmsted et al. suggest that the findings indicate that adolescent females with T1D may require particular protective strengths to avoid development of disturbed eating behaviour. In particular, the authors found that a cluster of factors, namely a lower body mass index, fewer weight and shape concerns, and more positive feelings about one's shape and self appear to be protective when combined with a lack of depressive symptoms. The age of onset of T1D may be related to the development of disturbed eating behaviour. In particular, Maharaj, Rodin, Olmsted, Connolly, and Daneman (2003) noted that the chronological close proximity of the onset of T1D and the onset of puberty appeared to heighten the vulnerability to the development of disturbed eating behaviour.

Diabetes clinic visits may include a focus on weight, and health care professionals and others, may provide positive reinforcement when weight loss is achieved. Health care professionals should be aware that it may be deleterious to affirm weight loss if there is a possibility it has been achieved at the expense of metabolic control by manipulating insulin (Kelly, Howe, Hendler, & Lipman, 2005). The association of raised body mass index and disturbed eating behaviour presents a management dilemma for clinicians, as both dietary restraint and higher weight are both risk factors for development of an eating disorder (Colton et al., 2007); efforts focused on maintaining weight below the overweight range may lead to an increased preoccupation with food and weight in vulnerable individuals, and culminate in reactive overeating and binge eating, but inattention to body weight may also fail to reduce the risk associated with an elevated body mass index.

Whilst many adolescent females may develop disturbed eating behaviour, many do not. Therefore, it is important to identify the intrapersonal and interpersonal factors that may mediate the risk (Maharaj et al., 2003). Evaluating coping styles and quality of life in youth with T1D, with and without disturbed eating behaviour, Grylli, Wagner, Hafferl-Gattermayer, Schober, and Karwautz (2005) reported that those with disordered eating presented with a more negative attitude to life, and perceived themselves as having more problems, specifically with relationships, health, entering into adulthood, and finances. Additionally, the use of more avoidant and negative coping strategies was evident in this group, with those adolescents – predominantly female - with eating disturbances tending to blame themselves when confronted with disease-related stressors. Furthermore, Grylli et al. found a limited capacity amongst this

group to perceive life events as joyful, and those with disturbed eating behaviour were found to have a lower self-esteem, and a more depressive mood.

Noting that family dysfunction has been implicated in the development of an eating disorder amongst non-diabetic females, and in the poor management of diabetes, Maharaj, Rodin, Olmsted, and Daneman (1998) investigated the role of family functioning in eating disturbances in adolescent girls (aged 11-19 years) with T1D. Those with disturbed eating perceived rejection and poor communication, and reported mistrust that their parents were available and responsive to their needs (Maharaj et al., 1998). Maharaj et al. explain that their findings suggest that a particular family dynamic, where families set high standards for achievement or independence, but fail to scaffold family members in attaining these goals, was associated with disturbed eating behaviour. Supporting these findings from self-report data, a later study by Maharaj, Rodin, Olmsted, Connelly, and Daneman (2001) investigated the quality of observed mother-daughter interactions. They concluded that “emotional misattunement” (p. 950) between mother and daughter, which is thought to undermine the journey to autonomy, is linked to eating problems. In an extension of these studies, Maharaj et al. (2003) found that eating disturbances in girls with T1D were not only associated with deficits in self-concept and dysfunctional mother-daughter relationships as previously demonstrated, but also that, compared to mothers of non-eating disturbed girls, mothers of eating disturbed girls expressed more dissatisfaction with their weight, and were more likely to diet, binge-eat, and use exercise for weight-control purposes. Therefore, the authors postulate that the family environment may increase the vulnerability to disturbed eating behaviour in adolescent females with T1D via two pathways, namely dysfunctional mother-daughter relationships, and heightened maternal weight and shape concerns. However, due to the cross-sectional nature of these studies, Maharaj et al. (1998, 2001, 2003) concluded that it is unclear whether dysfunctional family dynamics predispose female adolescents with T1D to, or are a consequence of, disturbed eating behaviour.

The aetiology of disturbed eating behaviour in adolescent females with T1D is complex, and may involve a number of psychological and psychosocial factors, as well as factors related to a diabetes regimen. Grylli et al. (2005) recommend a comprehensive examination of aspects of the lives of adolescents with T1D which may be factors in the development of eating problems. The importance of understanding how and why some female adolescents with T1D might be predisposed to develop disturbed eating behaviour is underlined by the literature suggesting

that, whilst the reported prevalence rates of disturbed eating behaviour and eating disorders in youth with T1D vary considerably between studies, the preponderance of studies indicate that the incidence of weight and eating pathology in adolescent females with T1D is significantly greater than that found in their non-diabetic peers.

Disturbed eating behaviour and metabolic control. In some studies of young women with T1D, eating pathology has been shown to be associated with impaired metabolic control (Bryden et al, 1999; Jones et al., 2000; Neumark-Sztainer et al., 2002), and an increased risk of diabetic complications (Peveler et al., 2005; Rydall, Rodin, Olmsted, Devenyl, & Daneman, 1997; Steel et al 1989). Some studies have not shown a significant difference in metabolic control between eating-disordered and non-eating disordered groups. For example, Engstrom et al. (1999) found no relationship between subclinical findings of disturbed eating behaviour and HbA1c or frequency of ketoacidosis. However, it was postulated that this may have been due to the small sample size of the study. Furthermore, failure to detect significant differences in metabolic control between eating disturbed and non-eating-disturbed adolescents with T1D may be because control of blood glucose in this group is unsatisfactory in general (Engstrom et al., 1999; Grylli et al., 2004).

The mixed findings about disturbed eating behaviour and its impact on metabolic control may be because, as discussed above, different criteria to identify disturbed eating behaviour have been used by different researchers. Furthermore, all disturbed eating behaviours are not equal. For example, in young women with T1D and Bulimia nervosa, Takii et al. (2002) found three distinct sub-types of Bulimia nervosa based on the purging behaviours utilised, specifically insulin omission only as the inappropriate control behaviour (ICB), insulin omission and self-induced vomiting and/or laxative abuse as the ICB, and an ICB not including insulin omission. Both the insulin omitting groups had poorer metabolic control than the non-insulin omitting group. Comparing patients with Bulimia nervosa to patients with Binge Eating Disorder, a group characterised by binge eating but not employing purging behaviours, Takii et al (2002) found that all three subgroups of Bulimia nervosa had more severe medical problems. A later study by Takii et al. (2008) investigated which disordered behaviours amongst young women with clinical eating disorders are associated with diabetic complications. Using multivariate analysis, the authors demonstrated that prolonged and severe insulin omission was the factor most closely associated with the retinopathy and nephropathy of young women with eating disorders. This reflects the findings from data collected in an 11-year follow-up of women

with diabetes where insulin restriction was found to be associated with increased rates of diabetes complications, shortened life-span, and increased mortality risk (Goebel-Fabbri et al., 2008). Therefore, whilst insulin omission is not the only manifestation of disturbed eating behaviour, it has been demonstrated to be one of the most risk-associated behaviours in disturbed eating behaviour (Crow et al., 1998; Herpetz et al., 2001).

Whilst the association between disturbed eating behaviour in T1D and diabetic complications renders disclosure of disturbed eating behaviour in a clinical setting important for optimal health outcomes in this group, there is a dearth of research in this area. The conflicting literature on prevalence of disturbed eating behaviour indicates that identifying disturbed eating behaviour in a research setting can be difficult. This may reflect that, even in a confidential research situation, there is a reluctance to disclose disturbed eating behaviour. However, much of the research has been quantitative, and little is known about those individuals who choose not to participate or disclose their behaviours. Furthermore, a research setting differs from a clinical setting, and it is possible that young women engaged in disturbed eating behaviours are less likely to want to talk about them in a clinical setting. Disclosure in a clinical setting may invoke a series of consequences that they may wish to avoid. There is some evidence from the general literature that individuals may resist disclosure from a desire to avoid any clinical interventions. For example, adolescents with chronic diseases interviewed by Beresford and Sloper (2003) indicated that they would not draw attention to “risky behaviours” because they did not wish to hear about restrictions to their lifestyle. Similarly, Whitehead (2001) reports that clients are often unwilling to relate their current or past health behaviours, as they are already aware of their limitations in this area, and do not necessarily want that situation reinforced. In order to understand how the conversation about eating, weight, body image and disturbed eating behaviour might begin, the literature relating to the clinical experience of those with diabetes is reviewed.

Chapter Summary

The preponderance of the literature suggests that, whilst eating disorders may or may not be more common in young women with T1D, there is an increase in a spectrum of sub-threshold behaviours, referred to as disturbed eating behaviour. Moreover, due to the importance of stable metabolic control, many weight control behaviours that may be unremarkable in the general population may threaten the health of young women with T1D.

Additionally, young women with T1D have a particularly dangerous tool available for weight control, omitting or reducing insulin administration. The literature suggests that there are diabetes-related antecedents to disturbed eating behaviour. These include an increased body mass index, and the exacting nature of balancing eating, exercise, and insulin for stable metabolic control. Disturbed eating behaviour, in particular insulin misuse, threatens short- and long-term health outcomes in young women with T1D.

Chapter 5 – The Clinical Experience and Type 1 Diabetes

Chapter Overview

The nature of the clinical experience and the clinical relationship has been shown to influence the management of diabetes. The perceptions of individuals with diabetes of their clinical experience are explored. Two models of healthcare, the biomedical model and the patient-centred model, are described, as well as the influence of these models on diabetes care.

The Clinical Relationship

Adolescence is a critical time for engaging people in health, claim Viner and Barker (2005), because new health behaviours are laid down at this time, which often track into adulthood and become lifelong. Because T1D is a chronic condition, involving numerous interactions with health professionals, the relationships between adolescents with T1D and health professionals may be pivotal in the management of their condition. For example, in a study of 300 Finnish individuals aged 13-17 years that aimed to identify predictors of good adherence, Kyngas (2007) concluded that feeling supported by physicians and nurses was a powerful predictor of adherence, and that those who feel competent in their diabetes management had increased motivation to adhere to their regimen.

Kyngas, Hentinen, and Barlow (1998) concluded that self-care is influenced by the nature of the relationships between the adolescents with T1D and health professionals. Their study involved adolescents with T1D (aged 13 to 17 years), who described physicians as either motivating (asks questions, listens, and takes notice), authoritarian (questioned them, but ignored their answers, and did not change their actions, pointed out their mistakes and told them how to avoid mistakes in the future), negligent (pays more attention to records, does not ask questions, and does not know anything about the individual's life or problems), routine (does not look upon young diabetic as an individual, asks the same questions at each visit, and opinion of young diabetic does not influence the action of the physician), or, as a combination of routine and negligent. The majority of adolescents (12 of 15) who described their physician as motivating had good compliance. There was no difference in the number of participants with good and bad compliance in the group that described physicians as authoritarian, negligent or routine, but, in the physicians described as routine/negligent group only one out of ten had good

compliance. Whilst this study utilised small convenience samples, and explored only one side of the relationship, the adolescent with T1D, Kyngas et al. concluded that the perception of the clinical experience by young people is linked to their compliance with their diabetes regimen. The message for health professionals working with adolescents with T1D, suggest Kyngas et al., is to endeavour to ensure consultations are not perceived to be dominated by disease monitoring activities. A focus on disease monitoring activities is inherent in a biomedical model of care, which, it has been suggested, is not suited to the care of people with chronic health conditions such as T1D (Hillege, 2005).

The biomedical model of care. In an early study of the clinical experience of adults with T1D, Wikblad (1991) concluded that the dominant model of patient care at this time was a traditional model. Wikblad described the clinical interactions as a “mechanical process,” during which illness is viewed as “a problem in need of repair” (p. 842). The individuals interviewed by Wikblad described interactions with health professionals that were based on drug prescriptions and laboratory findings, with scant attention paid to psychosocial factors. The interviewees perceived that communication was “threatening and unequal” (p. 839), with little attention to the patient as an individual. Wikblad noted that the mode of clinical communication, which interviewees perceived as negative, subverted the opportunities for meaningful dialogue. For example, the interviewees explained that they lied to avoid the negative responses associated with being truthful about times that they had, for example, eaten something that they should not have. This meant that the real reasons for unstable metabolic control were not discussed. Moreover, those with poor metabolic control tended not to keep appointments.

There were similar findings in another early qualitative study by Hernandez (1995). Interviewees related a real aversion to the use of the word control, which conjured up negative images. They explained that they only ever referred to the control of their diabetes when they talked to health professionals. Hernandez concludes that diabetes control is a term generated and promoted by health professionals and that for individuals with diabetes control is not the primary goal. The author concluded that for study participants, the priority was living with diabetes, not focusing on an educator-defined optimal blood-glucose level, and that relationships based on compliance and adherence have implications of unequal status between clients and care-givers and are counter-productive. Hernandez’ criteria for recruitment to the study included good metabolic control. It is therefore unclear whether individuals with unstable

or poor control may find the language such as control, adherence, and compliance even more intimidating than those interviewed by Hernandez.

This traditional model of healthcare, which focuses on numeric and long-term goals, that are formulated from a clinical perspective with a focus on biological end-points (Wolpert & Anderson, 2001a), is often referred to as a biomedical model of healthcare. Hillege (2005) argues that the model over-emphasises curing people using scientific knowledge, with a lack of attention to suffering. The research by Wikblad (1991) and Hernandez (1995) is close to two decades old, but more recent research (see for example, Davidson et al., 2004; Hillege, 2005; Murphy, Casey, Dinneen, Lawton, & Brown, 2011; Rasmussen et al., 2007) indicates that aspects of the biomedical model may continue to dominate some clinical relationships. Whilst accepting that the biomedical model may be suitable for the treatment of many diseases, Hillege claims that the nature of many chronic diseases, which often involve self-management, lifestyle choices and attitudes, and suffering, renders the biomedical model unsuited to the treatment of diseases such as T1D.

The biomedical model of healthcare tends to focus on the science of disease management. Young people with T1D interviewed by Hillege (2005) were critical of health professionals working within a biomedical model of care, whose focus was on how often blood sugars were tested and how much insulin was needed. Similarly, a prominent issue identified by Rasmussen et al. (2007) was that the young woman considered that blood glucose monitoring tended to dominate consultations with health professionals, which sometimes made them reluctant to continue consulting health professionals. The way in which laboratory findings are communicated may also impact on the clinical relationship. For example, the young people interviewed by Hillege noted that they perceived health professionals to be discouraging when outcomes are less than optimal. Similarly, some of the adolescents with T1D interviewed by Davidson et al. (2004) explained that they knew without being told that their metabolic control was compromised. Therefore, the reaction of the health professionals, for example, “these are bad numbers” (p. 77), was counter-productive. Rasmussen et al. (2007) identified a “good girl – bad girl dichotomy” (p. 304) from the stories of young women with T1D, who described feeling judged on the basis of their laboratory results. Further, the young women related that the “good-bad girl association” (p. 304) pervaded their life, and exacerbated their feelings of guilt if they did not comply with their regimen. Teasing out why being told that blood glucose results are poor can be upsetting, Wolpert and Anderson (2001a) explain that these results are more than

just measures of metabolic control, they represent a judgment of their behaviour, capability and self-worth. Hillege (2005) suggests that, whilst health practitioners have incorporated a more holistic approach to diabetes management, the need to validate the person, even if results are not so good, is not well understood.

For young people, diabetes management may clash with the rest of their lives. Hillege (2005) asserts that the way in which many young people manage living with a chronic illness such as T1D is to survive in the now and deal with complications later. Wolpert and Anderson (2001b) explain that, whilst individuals with T1D are likely to understand the benefits of optimal self-care, achieving this is often in competition with more immediate life concerns, and the resulting ambivalence may hinder self-care. Young people interviewed by Hillege (2005) perceived that health professionals failed to acknowledge the struggles involved in coping with T1D. This perception may undermine the clinical relationship and the outcomes of that relationship. For example, adolescents with T1D interviewed by Davidson et al. (2004) stated that, when faced with a health professional who did not listen to what they wanted, they may respond by surreptitiously doing what they wanted to do, without discussing adherence alternatives. Similarly, the adolescents interviewed by Kyngas and Barlow (1995) reported that, when health care staff were too strict with self-care and treatment requirements, they lied in order to avoid being nagged. Synthesising the qualitative research on the experiences of diabetes, Campbell et al. (2003) found that a balanced life can be attained by individuals with T1D by engaging in “strategic non-compliance” (p. 681). The authors explain that those who were able to achieve balance tended to monitor symptoms and manipulate regimen in order to live life as fully as possible, rather than limit social and work activities to comply explicitly with medical advice.

Hence, the biomedical model has limitations in terms of achieving optimal outcomes in diabetes management. Whilst young people with T1D and health professionals may share common goals in terms of optimal health outcomes, Wolpert and Anderson (2001a) suggest that a focus on metabolic control targets without accommodating the personal goals and life complexities of the individual is likely to culminate in failure, and possibly, disengagement from health services. Accordingly, it may be that a more collaborative, patient-centred model that makes allowances for the individual and adjusting the goals to suit the individual would improve outcomes. Wolpert and Anderson (2001a) describe this process of moving to a more holistic model of care that accommodates the goals and lifestyle of the individual as “reframing the

message” (p. 1302). Similarly, a more equal sharing of knowledge may alter the power balance in the clinical relationship. The biomedical model positions the health professional as the “expert” and the concomitant power balance tends to be unequal. For example, all participants in a recent study investigating the outcomes of an education programme for diabetes management described their relationships with health professionals prior to the programme as “paternalistic and judgmental” (p. 1287). Following the programme, interviewees noted the empowerment that they felt concomitant with their increasing knowledge of diabetes management. The interviewees noted that, prior to the power shift in their relationships with health professionals following their education programmes, their interactions often focused on admonishment. As a consequence of the unequal power balance that they perceived prior to the programme, they lied so that clinic visits were less upsetting. Following to the education programme, Murphy et al. (2011) reported that interviewees considered that they had increased power and that their relationships were more collaborative. However, there is evidence to suggest that health professionals may resist sharing their knowledge and power. For example, qualitative interviews of adults with T2D lead Cooper, Booth, and Gill (2003) to conclude that some health professionals resist working in partnership with their patients. For example, despite learning more about managing their condition, some individuals found that their health professionals withheld information about drug self-modification, which tended to reinforce the passive role of patients.

Patient-centred model of care. The bio-psychosocial model of medicine was articulated by George Engel more than three decades ago, challenging biomedicine and promoting a more patient-centred model of care. The term encompasses a general approach, associated with concepts such as “shared decision making,” “integrated medicine,” “dignity in healthcare,” “empowerment,” “informed choice,” and the “expert patient” (Robb & Seddon, 2006, p. 1245). There is growing evidence for the benefits of this model (Robb & Seddon, 2006). A patient-centred model can be especially important when managing chronic illness, as working with individuals with T1D in a more collaborative way has been shown to improve outcomes (Entwistle, Prior, Skea & Francis, 2008; Piette, Schillinger, & Potter, 2003). Accordingly, it has been recommended that health professionals should assist people with T1D to play a pivotal role in their own self-care goals, by providing them with the information they need to set priorities and solve problems, assist them in setting realistic goals for behavioural change, and provide emotional support and encouragement (Piette et al., 2003).

However, Robb and Seddon (2006) note that, whilst most health professionals would consider themselves to be patient-centred, many aspects of health-care work against effective patient-centred care. The authors cite physician and structural barriers, for example, limited resources and training of health professionals, and patient barriers, for example, lack of understanding about the nature of medicine as an inexact science and the nature of risk. However, whilst Robb and Seddon suggest ways to move toward patient-centred care, they accept that the concept is “complex and contested” (p. 1252), and some authors argue that the ideal of patient-centred care may remain unrealistic. For example, Agledahl, Forde, and Wifstad (2010) assert that patient autonomy, whilst in theory the ideal, is compromised by the circumstances in which “patients are, by definition, unwell and in need of help, and therefore often lack the competence and independence that the principle presupposes” (p. 212). Moreover, Agledahl et al. suggest that open choices are rare in healthcare. Their discourse analysis of patient and doctor interactions demonstrated that doctors were often limited in the choices they could offer by the healthcare system, and the confines of ethical considerations to offer evidence-based treatments where practicable. Accordingly, Agledahl et al. found that, even when presenting choices to a patient, a number of decisions had already been made by the doctor. Similarly, Pilnick and Dingwall (2011) argue that the asymmetry present in doctor-patient interactions is inherent in the nature of medicine.

Chapter Summary

The clinical experience and the nature of clinical relationships can influence self-care and self-management of diabetes. An older, traditional model of patient care, the biomedical model, with its focus on the scientific management of disease, has been shown to have shortcomings, especially in the management of chronic conditions, such as T1D. Empowerment of the individual, for example by increasing their knowledge of their condition, and working in a more collaborative, patient-centred way has been shown to improve outcomes. However, the research suggests that aspects of the biomedical model still operate. Whilst the clinical experience and the clinical relationship have been shown to impact on health outcomes, it is not clear how they may influence talking about eating, weight, and body image, including disturbed eating behaviour.

Chapter 6 – Identifying Disturbed Eating Behaviour

Chapter Overview

Much of the research investigating weight, eating and body image in T1D has focussed on disturbed eating behaviour and has been quantitative in nature. For example, there have been a number of studies investigating the prevalence of disturbed eating behaviour, body image, weight and eating issues associated with the behaviours, or the disturbances in metabolic control and diabetic complications that may occur as a result of the behaviours. There are indications from this body of work that there may be issues around disclosure of disturbed eating behaviour. However, identifying young women engaging in disturbed eating behaviour is clinically important. This chapter explores the ways in which health professionals could choose to screen for these behaviours. Health professionals could choose to use a screening tool, or alternatively, could ask young women directly if they engage in disturbed eating behaviour. The strengths and weaknesses of these different approaches, and the barriers that health professionals may perceive to talking about disturbed eating behaviour are explored.

Screening Tools for Disturbed Eating Behaviour

There is a general clamour for a brief disturbed eating behaviour screening tool to use in diabetes clinics. The Eating Disorder Examination (EDE) is considered the “gold standard” for the standardised assessment of eating disorders in the general population (Jones et al., 2000). However, whilst using a modified-for-diabetes EDE may be useful to diagnose disturbed eating behaviour, it is not a practicable tool to screen for disturbed eating behaviour in a clinic population, as the length of time taken to conduct the interview (approximately one hour) would not fit into a routine clinic setting. A sensitive, specific and reliable screening tool that ideally takes about 10 minutes to administer would therefore be useful in a diabetes clinic setting. However, to date, no such tool has been validated for use in a clinical population (Criego, Crow, Goebel-Fabbri, Kendall & Parkin, 2009).

Identifying disturbed eating behaviour in a research setting has often relied on instruments validated to diagnose eating disorders in the general population - screens, such as the Eating Disorder Inventory (EDI), and Eating Attitudes Test (EAT-26 or EAT-40), or semi-structured interviews, such as the EDE. The use of such instruments in a diabetic population is

fraught with problems. Diabetes *per se* and the concomitant diet and insulin regime is likely to affect the way an individual answers some questions. For example, adherence to a diabetic regimen is likely to invoke a positive response to the statement “Aware of the calorie content of the foods that I eat” regardless of whether the individual has eating pathology or not (Jones et al., 2000, p. 1564). Additionally, the instruments lack questions that are specifically important to a diabetic population regarding reducing or omitting insulin (Jones et al., 2000). Aware of these shortcomings, researchers have modified these instruments for use in a diabetic population, or developed new instruments, for example the Diabetic Eating Problems Survey (DEPS) (Antisdel, Laffel, & Anderson, 2001). The research findings on the usefulness of screening tests have been varied.

Specificity is less important in a screening test, if it is to be followed by a diagnostic interview. Such a process has been widely used in research. For example, in one study protocol, participants thought to be at risk of disordered eating because they scored above a pre-determined cut-off on self-report screening tests (EDI and EAT-26) were then interviewed using the EDE (Jones et al., 2000). However, the sensitivity of screening tests is extremely important if they are to be useful clinically. In some instances, studies using screening instruments have demonstrated prevalence of disturbed eating behaviour significantly less than that reported elsewhere in the literature. For example, Markowitz (2008), using a self-report questionnaire, the EDE-Q, found that female adolescents with T1D had less eating disorder characteristics than a comparison group. Additionally, using the DEPS as a screening instrument, Howe et al. (2008) found a relatively low prevalence of insulin omission and dose manipulation. There may be many reasons for these findings, including confidentiality concerns (Howe et al., 2008) and the unsuitability of the instrument used (Markowitz, 2008). However, the findings may reflect a lack of sensitivity inherent in self-report screening tools, and Howe et al. (p. 383) comment that their study, and other studies that have found a low prevalence of insulin omission, for example, Meltzer et al. (2001) (6%) and Colton et al. (2004) (2%) relied on self-report data, compared to the 35% prevalence reported by Peveler et al. (2005) using a semi-structured interview (EDE). There may be other factors that account for the differing results, such as the age group of the participants. For example, the Peveler et al. study was longitudinal, spanning 11 years, with participants aged 11 to 25 years at baseline, and participants in the Colton et al. study were aged 9 to 14. The prevalence of disturbed eating behaviour is thought to increase with age over the adolescent years (Nash & Skinner, 2005). Accordingly, the lower prevalence rates found in the Colton et al. study may reflect the lower prevalence of disturbed eating behaviour in this

younger age group. Nevertheless, the sensitivity of screening tools for disturbed eating behaviour remains unclear. Therefore, Grylli et al. (2004) suggest that a study should be conducted in which participants who do not reach the cut-off scores on screening tests should still be interviewed for disordered eating, using an instrument such as the EDE, to identify whether screening tests result in false negatives. A similar suggestion was advanced by Markowitz et al. (2010). The authors concluded that scores on the DEPS-Revised amongst adolescent youth demonstrated excellent construct validity, demonstrated via significant correlation with variables that may be influenced by the presence of disordered eating, such as HbA1c, and external validity, as assessed by the correlation of clinician-determined insulin restriction and scores on the DEPS-R. However, they suggested that the survey's validity should be confirmed against an established measure, such as the EDE. D'Emden et al. (2012) describe the DEPS as the only screening tool with validity evidence, but note that it does not measure body satisfaction or shape concerns, or have subscales that assess psychological traits that may inform clinical management.

Asking Directly about Disturbed Eating Behaviours

Instead of administering a screening instrument, health professionals could choose to ask direct questions about eating problems and risky weight loss practices. Whilst Goebel-Fabrizi et al. (2008) recommend routinely asking all adolescents and young women with T1D about insulin omission, there is a dearth of research exploring how useful this may be. Adding to the conundrum for health professionals working with young women with T1D are decisions relating to when and what questions should be asked. For example, health professionals could routinely ask about disturbed eating behaviour, or only probe if there is a marker, such as poor metabolic control. Further, they could ask about insulin omission, eating behaviours, and/or antecedents of disturbed eating behaviour, such as body dissatisfaction or poor body image. The limited research in this area suggests that there is no easy answer. Commenting on the clinical identification of disturbed eating behaviour, Criego et al. (2009) conclude that health professionals are often not aware of the early signs of disordered eating, and that this is not an easy discussion to initiate for either health professionals or clients.

Denial of disordered eating behaviours in individuals with an eating disorder in the general population is not uncommon, leading to their reputation as “notoriously unreliable informants” (Crowther & Sherwood, 1997, p.38). Denial of disordered eating behaviours

renders detection, assessment and treatment of eating disorders difficult (Swan & Andrews, 2003; Vandereycken & Vanderlinden, 1983; Vanereycken & Van Humbeeck, 2008; Vitousek, Daly, & Heiser, 1991). Vandereycken and Van Humbeeck (2008) draw attention to the dearth of research focussing on the reluctance of those with eating disorders to disclose their weight and eating concerns. This lack of empirical data concerning disclosure patterns in this group is also commented on by Becker, Thomas, Franko and Herzog (2005). Vandereycken and Van Humbeeck state that they are not aware of any research on disclosure of early stage or subclinical eating disorders, where they anticipate there may be an unwillingness to disclose personal information. They propose that this may be because it is not possible to study, as the assessment of self-disclosure is dependent on the openness and honesty of the individual. Part of the problem, comment the authors, is that patients in the denial phase of their ED will either be not detected, or will avoid healthcare.

There is evidence to suggest that direct questioning amongst eating disordered individuals in the general population may result in candid answers. For example, Vandereycken and Van Humbeeck (2008) found that, despite the ubiquity of concealing behaviours, 56 percent of those surveyed endorsed the response “if I had found a health-care professional who was familiar with the treatment of eating disorders,” they may have been helped to recognise their problem or willingness to seek help. This response has lead Vandereycken and Humbeeck to suppose that asking in a measured way in the context of good rapport may lead patients to be more open. Becker et al. (2005) suggest that the failure to disclose weight and eating concerns by those with eating disorder in the general population may be because they have never been asked. The authors investigated disclosure patterns of eating behaviours amongst eating disordered people in the general population, including those to health professionals. They found that 31.9% had spontaneously volunteered their eating and weight concerns to a health professional. Of the 68.1% who had not volunteered information about eating and weight concerns to a health professional, less than a quarter had ever been asked. Of those who had not volunteered the information, but were asked about their concerns in a healthcare setting, the majority (nearly 91%) disclosed the information on at least one occasion. However, in this study, the participants were adults who had been prepared to undergo an eating disorder screening and educational programme and to participate in a follow-up study. Therefore, these participants may not be representative of the eating disordered population generally. Furthermore, both studies were retrospective. Vandereycken and Van Humbeeck defend studying disclosure patterns retrospectively, claiming that waiting until the individual is ready

to acknowledge that they have a problem and are willing to discuss it will lead to a more reliable understanding of denial. However, Vitousek et al. (1991) comment on retrospective studies, stating that “one can only speculate on whether the advantages of decreased defensiveness outweigh the drawbacks of retrospectivity, post-hoc analysis, and acquired biases” (p. 654).

The studies by Vandereycken and Humbeeck (2008) and Becker et al. (2005) included a cross-section of the eating disorders, but Vandereycken and Humbeeck state that no specific answering pattern linked to eating disorder subtype was apparent, and Becker et al. did not categorise responses according to eating disorder subtypes. However, it has been proposed that individuals with different subtypes of eating disorder may have different motives underpinning concealment of behaviours. Vitousek et al. (1991) claim that, in cases of Anorexia nervosa, concealment represents a protective mechanism due to a desire not to discontinue the behaviours, and that in cases of Bulimia nervosa, concealment reflects a feeling of being ashamed of their bingeing and purging behaviours. Whilst Vitousek et al. explore the motivation for denial and distortion, and comment that “eating disordered individuals are disposed to deny anything and everything – even, as Vandereycken and Vanderlinden (1983) comment, their denial itself” (p. 649), they do not explore how this denial may manifest in a clinical situation according to type of eating disorder. Importantly, the majority of adolescents with T1D and disturbed eating behaviour do not meet the criteria for a diagnosis of a clinical eating disorder, and may substantively differ from young women with eating disorders in the general population. Therefore, the disclosure patterns seen in eating disordered individuals in the general population may not resemble those of individuals with T1D and disturbed eating behaviour. Moreover, there is a crucial difference between the two groups. Individuals with an eating disorder in the general population may not have reason to seek medical attention until they become unwell, which may be after their eating disorder is well established. In contrast, young people with T1D are encouraged to attend regular medical appointments, which means that they are likely to be consulting with health professionals before, during and after the onset of disturbed eating behaviour. In this way, there is likely to be a window of opportunity to identify disturbed eating behaviour before the behaviour becomes entrenched.

Contributing to the non-disclosure of eating disorders in the general population may be the desire to represent oneself positively or a tendency to fake good, especially when questions are of a sensitive and personal nature (Vandereycken & Van Humbeeck, 2008). Similarly, in their study of insulin restriction and associated morbidity and mortality, Goebel-Fabbri et al.

(2008) note that their findings were limited by reliance on the participants' willingness to report their insulin restriction, and suggest that social desirability biases may induce patients, especially those at a specialty diabetes centre, to underreport or minimise their insulin restriction. Pereira and Alvarenga (2007) postulate that individuals with T1D and disturbed eating behaviour may hide their behaviours because they do not understand their importance, believe that their techniques work to manage both their weight and health, or because they may fear being criticised.

Goebel-Fabbri et al. (2008) suggest that use of the screening item in routine practice "I take less insulin than I should" has the potential to identify at-risk women. Whilst the authors found that the insulin restriction as captured by that question was associated with increased risk of complications and mortality, insulin omission is only one of a range of disturbed eating behaviours. Therefore those engaging in other disordered behaviours, for example, excessive exercise or vomiting, and not insulin restriction, would remain under the radar of this screening. Furthermore, Pereira and Alvarenga (2007) warn about taking care to avoid giving ideas to patients who may never have thought of them. Therefore, it may be a concern that asking about insulin omission may suggest the practice to vulnerable individuals. In the general population, Vandereycken and Van Humbeeck (2008) described abuse of information about eating disorders, with 44.1% of eating disordered respondents endorsing "I wanted to know more about eating disorders to learn more tricks for myself" and 29.7% endorsing "I wanted to know more about eating disorders to learn more tricks for myself and avoid treatment." Therefore, individuals with disturbed eating behaviour and T1D may seek information to increase their repertoire of behaviours.

Health professionals could choose to ask about disturbed eating behaviour in a less direct way. For example, they could weave in questions about disturbed eating behaviour using a psychoeducational approach, warning of the health risks associated with risky weight loss practices. Adolescents with T1D have confessed to being highly anxious about the effects that the long-term complications of T1D could have on their bodies in the future (Balfe, 2008). Therefore raising concerns about health risks may be conducive to talking about eating problems. However, Vandereycken and Van Humbeeck (2008) demonstrated that warning of the health outcomes associated with risky behaviours was not helpful in an eating disordered group in the general population. The authors found that the great majority of respondents felt that "bad things won't happen to me" (p. 113) and that consequently information about health risks had

little or no impact on concealment and denial behaviours. Alternatively, health professionals could choose to introduce the issue more gently. Colton, Rodin, Bergenstal and Parkin (2009) suggest that, because disturbed eating behaviour is often associated with weight and shape concern, it may be helpful to start the conversation by addressing body image concerns. Commenting on screening for disturbed eating behaviour in T1D, Criego et al. (2009) endorse this way of encouraging disclosure, recommending the use of sensitive open-ended questions about the individual's current level of satisfaction with weight and shape, because disturbed eating behaviour is often difficult to identify. Furthermore, it is possible that enquiring about weight and shape concerns may help to identify those at risk of developing disturbed eating behaviour, or those on the cusp of emerging disturbed eating behaviour. Identifying disturbed eating behaviour in the early stages may prevent progression of more entrenched behaviours (d'Emden et al., 2012).

Barriers to Talking about Disturbed Eating Behaviour

The hints from the quantitative research that individuals with disturbed eating behaviour may avoid participating in studies, or may lie when they do participate are underscored by the findings of Tierney, Deaton, and Whitehead (2008) in their qualitative study involving healthcare professionals in the United Kingdom. The qualitative approach used by the researchers allowed them to tease out the feelings and perceptions that those dealing with individuals with T1D have around addressing disturbed eating behaviour in a clinical setting. Those interviewed by Tierney et al. reported that they generally avoided addressing disturbed eating behaviour due to the minefield of complexities involved. One of the barriers identified was that the health professionals believed that the young women would deny any disturbed behaviours. Health professionals were also concerned that they may suggest the idea of insulin omission to their patients. They also felt that, by asking about sensitive issues such as disturbed eating behaviour, they may alienate patients from the diabetes service. Moreover, they related that they were unsure how they might treat disturbed eating behaviour if the behaviours were disclosed. They perceived that psychological services would not be available in a timely manner, and that the psychologists did not have enough experience in diabetes management. This latter concern is echoed by Snoek (2006), who argues that psychotherapists have little knowledge of diabetes and related psychological issues, causing patients to feel "they are in the wrong place" (p. 241). Snoek advocates for a "new paradigm of psychologically oriented diabetes care" (p. 242). However, whilst health professionals interviewed by Tierney et al. were hesitant to raise

disturbed eating behaviour, many recalled the relief expressed by patients who had opened up to them, sometimes having dealt with disturbed eating or weight control behaviours for years.

Starting the Conversation about Eating, Weight, and Body Image

The preponderance of the literature in this area comes from a biomedical perspective and is largely quantitative in nature. From this it is understood that psychological and psychosocial factors during adolescence may contribute to the capricious nature of metabolic control (Hamilton & Daneman, 2002). A particular area of concern, particularly for young women with T1D, is the emergence of disturbed eating behaviour. There have been a number of studies indicating that disturbed eating behaviour occurs in a significant number of young women and can jeopardise their health outcomes (Peveler et al., 2005; Rydall et al., 1997; Steel et al., 1989). Of these behaviours, insulin manipulation in particular has been identified to be associated with diabetic complications (Crow et al., 1998; Goebel-Fabbri et al., 2008; Herpetz et al., 2001; Takii et al., 2008).

A particular focus in the literature is the identification of disturbed eating behaviours using screening instruments or diagnostic interviews. For example, a large and often cited study by Jones et al. (2000) identified eating disorders and sub-threshold eating disorders among diabetic and non-diabetic adolescent females using modified psychometric tests (Eating Disorder Inventory, Eating Attitudes Test and Eating Disorders Examination). The authors concluded that eating disorders and sub-threshold variants were about twice as common in young women with T1D than their non-diabetic peers and that impaired metabolic control was associated with these behaviours. This landmark study involving 356 females with T1D and 1098 age-matched non-diabetic controls overcame the methodological limitations of previous studies associated with small sample size. However, what is not understood from this genre of research is why young women with T1D might be more likely to develop eating problems than their non-diabetic peers.

It is postulated that factors contributing to eating disorders in the general population are potentiated in young women with T1D (Surgenor et al. 2000). Accordingly, there are a number of quantitative studies that explore factors contributing to eating disorders and their sub-threshold variants in young women with T1D. For example, a longitudinal study by Olmsted et al. (2008) identified that disturbed eating behaviours in young women with T1D could be

predicted by higher BMI, concerns with weight and shape, lower self-esteem related to physical appearance, lower global self-esteem and more reported depressive symptoms. However, one of the factors identified in this study, concerns with weight and shape, are so ubiquitous as to be considered normative amongst young women in high socioeconomic settings across world regions (Swami et al., 2009). Accordingly, whilst this study, along with other studies that make up this body of research, identifies factors associated with the onset of disturbed eating, they do little to advance the understanding of the milieu in which these factors emerge and develop into eating problems.

Therefore, whilst the quantitative literature identifies and outlines a problem which exists, the biomedical approach provides a narrow aperture from which to view the experience of eating, weight and body image issues of young women with T1D. Quantitative research uses limited measurable variables stripped of contaminating variables. Accordingly, what is not well understood from this body of research are the contextual factors that may be important. Chamberlain, Lyons and Stephens (1997) explain that health is not only a biological or psychological issue, but also includes the social context of the person experiencing ill health. Accordingly, the authors advocate for the use of qualitative research that includes individual experiences to address the gaps created by quantitative research. The use of qualitative methods, the authors argue, emphasises “meaning over measurement” (p. 695) by encompassing the experience of individuals. Because body image and weight concerns can invoke the use of weight control measures, and even patterns of eating that are only mildly disturbed may undermine metabolic control, the first aim of this research was to explore the relationship between the lived experience of diabetes and eating, weight and body image issues.

There are indications from the literature that the way in which young people perceive the clinical experience may influence self-care. There is also evidence to suggest that there may be issues around disclosure of disturbed eating behaviour, but the quantitative literature does little to elucidate why this might be the case, or aspects of the clinical experience that may facilitate disclosure. One qualitative study (Tierney et al., 2008) takes a giant leap into this gap. Tierney et al. (2008) identify that talking about disturbed eating behaviours may often be avoided in clinical consultations. However, only the perspectives of health professionals are explored by the authors, leaving the stories of clinical experience of young women with T1D untold. Therefore, the second aim of this research was to tell the stories of the clinical experience of both the young women and the health professionals, and identify the ways in which they are in harmony and the

ways in which they are discordant, focussing on the ways in which the clinical relationship might hinder or encourage starting the conversation about eating weight, body image, and disturbed eating behaviour.

Much of the literature is from overseas, albeit mostly from Western countries, in particular the United Kingdom and United States of America. This means that, whilst many of the findings may be similar to New Zealand, there may also be many important differences. Notably, there are cultural differences between New Zealand and other Western countries. New Zealand is a melting pot of many cultures, but has a unique bicultural nature manifesting as a partnership between the Crown and Māori. The cultural and socioeconomic diversity of each country means that there are limitations to the ways in which findings can be generalised, and the New Zealand story is largely untold in the literature. Importantly when studying health psychology, the ways in which healthcare is provided can be important. New Zealand citizens can expect free tertiary healthcare for most of their health needs. This is in contrast to countries such as the United States, where comprehensive private medical cover is needed. Accordingly, overseas research relating to diabetes management and the clinical experience may not reflect the New Zealand experience. For example, the findings of a United States study that the cost of insulin was a barrier to good metabolic control for adolescents leaving the care of their parents' medical cover (Ramchandani et al., 2000) would not be valid in a New Zealand context.

Chapter Summary

There is limited research relating to disclosure of eating disorders in the general population and disturbed eating behaviour in a diabetic population. What research there is indicates that identifying disturbed eating behaviour is fraught with difficulties, and health professionals working with young women with T1D have expressed reluctance to raise the issue. However, the complications associated with unstable metabolic control associated with disturbed eating behaviour, in particular, insulin omission, means that identifying disturbed eating behaviour should be a clinical priority. The question remains, however, as to how health professionals might best proceed. There are a number of options available, including using a screening test, asking about eating behaviours and/or insulin omission, or probing into weight and body shape concerns. Additionally, health professionals must decide whether to screen all female adolescents and young women with T1D, or whether to screen on an ad hoc basis on suspicion of disturbed eating behaviour. The frequent interactions between health professionals

and young women with T1D may provide an opportunity for the right questions to be asked in the right way at the right time to identify disturbed eating behaviour before the behaviours become entrenched. However, questions remain as to the nature and timing of these conversations.

The Present Study

The aims of the present study are:

- 1- To explore the lived experience of type 1 diabetes for young women, in particular the ways that this might relate to eating, weight and body image issues.
- 2- To explore the clinical experience of young women and health professionals working with young women with type 1 diabetes, in particular, how these interactions might inform starting the conversation about eating, weight and body image issues and disturbed eating behaviour.

Chapter 7 – Method

Chapter Overview

This chapter details the research method. Firstly, this chapter will explain the rationale for the qualitative methodology employed, and, specifically, for a narrative approach. The following sections present the ethical and cultural considerations. The process sections detail the interview and recruitment procedures. Following this, there is a brief introduction to the participants using vignettes that provide background to their stories. Lastly, because narrative analysis is interpretive (Josselson, 2007), a reflexive statement outlines the eating, weight, and body image “world view” of the interviewer.

A Qualitative Approach

Whilst there may seem to be a paradigm clash between quantitative and qualitative traditions, Chamberlain et al.(1997) suggest that it is best not to think of the two approaches as “antithetical, but rather as complementary” (p. 693); there are some research questions that may be best served by a quantitative approach, and others more suited to a qualitative approach. It was thought that the exploratory nature of the questions asked in this research did not lend themselves to a quantitative approach, which is useful to help answer the “what,” “whether or not,” and “how many” questions that are generated around a phenomenon (Rich & Ginsburg, 1999).

A qualitative approach to a research topic contributes to what Snape and Spencer (2003) refer to as “rounded understandings” (p. 4) of the phenomena under study. Therefore, using a qualitative approach was considered a useful way to explore the experiences of young women with T1D and health professionals, to begin to comprehend the cross-currents that may be present in the lived experience of diabetes and the clinical experience of diabetes relating to body image, eating and weight. Qualitative methods, according to Chamberlain et al. (1997) encompass no clear set of methods. Because stories are a useful way for people to make sense of their experience, a narrative approach was used in this research.

Narrative Methods

A diagnosis of a chronic illness such as T1D is more than a medical diagnosis; it may alter an individual's concept of themselves and of their place in the world. Bury (1982) refers to such an event as a "biographical disruption." In this way, stories of chronic illness have much more to tell than just the medical events of the illness, which until recent decades have been the focus of the medical literature. Frank (1994) describes a move forward in medical literature, from holding a disregard for the illness narratives of patients, favouring instead physicians' accounts of bodily states, to a time when the accounts of illness and suffering by patients has gained a voice. Narrative is a useful way for the telling of the experience of being diagnosed with and living with a chronic illness (Riessman, 2008).

Narrative analysis facilitates close inspection of the ways in which a small number of participants talk about their lived experience. Narrative analysis can be differentiated from other qualitative methods by a focus on narrative texts which encompass a life story, or aspects of it (Josselson, 2011). Discourse Analysis, a close relative of Narrative Analysis, is used to explicate variations and contradictions and the social positioning inherent in the language. This research is an example of the less than clear boundaries between modes of qualitative research, as the analysis includes both of these features of Discourse Analysis. However, the approach used diverges from the Discourse Analysis pathway in that these features are cameo performances in the script in which the story is the paramount feature. Another important feature in Discourse Analysis is the identification of dominant discourses that shape the ways in which people talk, and which are in turn shaped by talk. This analysis includes a similar concept in the identification of public narratives that are identifiable in the talk of the young women and the health professionals. Similarly, the approach used in this research borrows heavily from Thematic Analysis. However, as explained by Braun and Clarke (2008), Thematic Analysis can be seen as a method in its own right, or as an approach that can be used within other qualitative methods. The latter approach was used for this research, as representative excerpts were then chosen for analysis, but considered in the context of the whole story.

At the most basic level, narrative means story, and engaging in narrative facilitates the ordering of events across time, as well as the making sense of events for the narrator (Stephens,

2011). The proliferation of research has meant that a narrative approach constitutes a very broad mode of analysis, and a diverse range of methods can be accommodated under the narrative umbrella. Narrative-based analysis, according to Stephens does not refer to a particular method, but rather a “theoretical approach to interpreting talk” (p. 4). Josselson (2011) goes so far as to suggest that narrative research “eschews methodological orthodoxy” (p. 225) in favour of tailoring the method to capture the lived experience. However, the strength inherent in the lack of a prescriptive formula for conducting narrative analysis is that it can be tailored to accommodate the aims of the research.

What narrative methods generally have in common is that the analysis encompasses an entire story, or case, rather than looking between stories and picking out themes and ideas from within those stories as other qualitative methods set out to do. However, to answer the questions identified in this research, the similarities and differences between the stories about eating, body image and weight, and the clinical approach to talking about these, was an important feature of the analysis. Consequently, a thematic approach to narrative analysis was sought, and finding a way to accommodate this within the narrative structure was an important task in defining the methodology. Riessman (2008) sets out a thematic methodology for narrative enquiry, that differs from other thematic methods, and remains congruent with the narrative approach, by keeping the story intact. However, the questions in this research meant that participants were not telling one story as such, but rather many stories, and therefore, the thematic analysis as described by Riessman would not enable the many stories to be compared on a cross-case basis. Hence, a categorical approach, as set out by Josselson (2011) was thought to be best suited to analysing the data.

Josselson (2011) sets out two major dimensions along which narrative research can be conducted, namely holistic versus categorical, and content versus form. In the first dimension, Josselson explains that the researcher can attend to the life story as presented as a whole, with excerpts considered as part of the whole (holistic), or use coding strategies to gather abstracts which are then compared to similar abstracts from other interviews using cross-case analysis. The latter approach was selected for this research, and categories or themes, were identified and then looked at across cases. In this way, a montage of told experiences was used to consider the research questions. However, in keeping with a narrative “whole story” approach, the analysis was mindful of what Josselson refers to as the “Gestalt, the general narrative thread” (2011, p. 231). This was done using what Josselson, drawing on the ideas of Schleiermacher, described as

the “hermeneutic circle” (2011, p. 226). In this way, what was said was considered in light of the whole story. For example, some of what was said by participants was incongruent with the rest of their story, creating a juxtaposition for analysis. Using the second dimension, the researcher can emphasise what is said (content) or how it is said (form). Although, amongst the many nuances of language, the ways in which individuals tell their story is important, in this research the emphasis was placed on what was actually told (content). However, whilst the emphasis in this research was on content, the researcher did not take the stories as “fact.” As De Fina and Georgakopoulou (2008) caution, narratives should not be treated “referentially,” as if they are a “relatively unmediated and transparent record” (p. 383). Hyden (1997) suggests that it is not a case of “the narrative,” but rather of different “possible narratives” (p. 52).

Acknowledging the concept of “possible narratives,” and that the stories told are the product of a myriad of factors, different levels of analysis can be used. Drawing on the work of Murray (2000), Stephens and Breheny (2013) demonstrate the ways in which personal, interpersonal and public narrative levels play out and are inter-related. The personal story relates the *experience* of the participants or the story as it is presented. However, reflecting Murray’s statement that a narrator is not a “sole agent,” the interpersonal and public narrative levels consider the ways in which the interview is shaped by outside forces. At the interpersonal level, the interviewer co-constructs the interview with the participant. The interviewer’s influence on the interview is pervasive. For example, the interviewer may pursue one line of questioning and not another, and the verbal and non-verbal feedback given to the narrator may encourage or discourage aspects of the story. Moreover, the narrator may construct a self-image that they wish to portray to the interviewer (Hyden, 1997) or in ways that they perceive others will approve of (Riessman, 2003). At the public narrative level, the story is shaped by the societal and cultural milieu in play at that time. As Phibbs (2008), drawing on the theories of Karl Marx, notes, narrators are not free to construct narrative identities at will, but are limited by the public narratives available to them. Moreover, public narratives are not static and neutral, but rather they reflect, as Phibbs suggests, the understandings that a society has at that time, which will endorse one meaning rather than another. Therefore, as Murray states, an individual’s story is “not fully the narrator’s story: Its structure is conditioned by both the immediate presence of others, and the dominant plot lines in society” (p. 344).

Moreover, the world view of the researcher is an important ingredient in the final complexion of the analysis. As Josselson (2007) states, every stage of narrative research is

interpretive, for example, the framing of the questions, the recruitment process for participants, and choosing what to highlight. Rogers (2007) suggests that the voices of interviewees are “polyphonic” (p. 105) and that the perspective of the researcher can be pivotal in the way that stories are portrayed. Therefore, the world view of this researcher is summarised in the reflexive statement later on in this chapter. Furthermore, the researcher can take the stories told at face value by privileging the voice of the participant as presented in the interview, or look for the meanings behind what is actually said, which may be unconscious or so embedded in cultural context that they are not recognised (Josselson, 2007). Drawing on the work of Ricoeur (1970), Josselson describes these choices as the “hermeneutics of faith, and the hermeneutics of suspicion” (p. 8). In this research, what was said was taken at face value, but, at times, the possibility of other interpretations was raised as a point for discussion.

Typically, narrative consists of spoken or written language, and in this research, the stories of young women with T1D and health professionals were sought to answer the research questions. Data were collected using semi-structured interviews designed to elicit the personal accounts of the young women with T1D, and the views and experiences of health professionals.

Ethics

Consultation was sought with the supervision panel, which included three clinical psychologists, and a health psychologist, and health professionals working in the diabetes service, about the potential risks to the young women with T1D who participated in the research. Several concerns were identified, namely that asking about insulin omission could suggest the behaviour, that young women may disclose disturbed eating behaviour for the first time in the interview, or that talking about body image, weight, and eating may induce emotional discomfort in some young women. The consensus was that asking about insulin omission was of minimal risk in this age group, as their exposure to media, the internet and interactions with other young people with T1D would likely mean that they would already have knowledge of this weight loss behaviour. Some discussion took place as to what should occur should a participant disclose disturbed eating behaviours to the interviewer, not having disclosed them previously to a health professional. It was agreed that, despite the risks that disturbed eating behaviour posed to the health of the individual, the confidentiality of the informed consent agreement would mean that the interviewer was not at liberty to disclose this information. However, the interviewer would advise the participant that talking to their health professional is strongly

recommended. The discussion with health professionals ensured that there were steps available for the young women to take to mitigate emotional distress should it occur as a result of the interview process. The participant would be advised to contact the lead health professional at their service, at which stage the need for a referral to psychological services would be discussed. There were no identifiable risks to the health professionals who chose to participate.

Informed consent was sought prior to the interview. In particular, participants were told that they could stop the interview at any time, and were asked if they consented to the interview being audio-recorded. Participants were asked to sign an informed consent form (see Appendix E). Participants were given the opportunity to view the transcript of the interview, and to advise the researcher if they objected to any material within. A transcript consent form was sent with the transcript (see Appendix F). Participants were also asked if they would like a summary of the research findings. Ethical approval for this research was obtained from the Central Regional Ethics Committee, Wellington, New Zealand (CEN/11/EXP/008).

Cultural Considerations

The prevalence of T1D in a Māori population is less than that of the general population. Nevertheless, the pool of potential participants of young women attending a diabetes service includes some Māori. Therefore, a consultation took place with a cultural advisor, Dr Natasha Tassell-Matamatua of Massey University, to ensure that recruitment of participants was not likely to be discriminatory against Māori, and that the interview process was welcoming and culturally sensitive.

The Interviews

Semi-structured interviews for the young women and health professionals were developed (see Appendices G and H, respectively). The interviews were formulated in keeping with a narrative approach, and were influenced by the research questions and the body of existing research. As is usually the case in narrative interviewing, very broad, open questions to generate detailed accounts were used. For example, the interview with the young women opened with “tell me what diabetes has been like for you,” and the interviews with the health professionals began with “tell me about your experience of working with adolescents and young women with T1D.” However, in keeping with the research questions, which were generated

from the body of existing research and identified gaps in the research, particular questions were formulated to elicit specific information. For example, because talking about less than optimal laboratory results or weight issues may be distressing experiences for some young people, the young women were asked to consider their feelings as they thought about such discussions, and the health professionals were asked how they approached such potentially sensitive areas. Similarly, research from the UK (Tierney et al., 2010) identified barriers that health professionals perceive to talking about disturbed eating behaviours, including insulin omission. The health professionals were asked if they avoided such questions, or if and when they might introduce these questions. The young women were asked if they had ever been asked about insulin omission, and if so, their experience of being asked. Identified gaps in the research included, for example, how young women might feel about being weighed. Therefore, the young women were asked about their experience of being weighed, and talking about weight, and health professionals were asked if and how they incorporated weighing their patient into the clinical consultation.

Therefore, whilst participants were at liberty to narrate their own story, the researcher referred to the content of the semi-structured interview to ensure that all areas were covered. At times, more direct questions were used as needed to elicit specific details that the interviewer wished to know more about. In this way, even though the narratives were the stories of participants, they were co-constructed with the interviewer in the form of a guided conversation.

Recruitment of Participants

The diabetes services at two New Zealand District Health Boards were contacted and asked to forward recruitment packs to young women with T1D engaged with their service aged 16 to 20 for the first round of recruitment, then aged 20 to 25 for the second round of recruitment, and the health professionals working with this age group at their service. There were two rounds of recruitment as the age range for participation was adjusted upwards, as explained in the following paragraphs. There were no exclusion criteria for recruitment. Whilst the selection of any age range risks appearing arbitrary, the age range for the young women was determined after lengthy discussion. Based on the research, the age range most at risk for developing disturbed eating behaviours is mid- to late adolescence (see for example, Nash & Skinner, 2005). Therefore an age range to best capture the milieu around the emergence of such behaviours was proposed as the adolescent years. However, the research indicates that some

health professionals worry about asking about insulin omission as it may suggest the behaviour to the young person (see for example Tierney et al., 2008). Because the nature of this research included questions about insulin omission, after discussion with the supervision panel, and health professionals at one of the diabetes services, who thought that young people were likely to gain knowledge of such behaviours via the media, internet, and social interaction, this risk was deemed to be small. However, it was felt that asking such questions of younger adolescents presented a greater risk than asking older adolescents, who were less likely to have been exposed to information about insulin omission. Therefore, an age range was proposed with the lower end of the range at 16 years. Keeping in mind the problems associated with retrospectivity (Vitousek, et al., 1991), the upper limit of the age range was set at 20 years.

Two pilot interviews were conducted with young women aged 21 to 25 years at one diabetes service to ensure that the interview questions elicited relevant answers. An age range slightly out of the proposed age range for participants was selected for the pilot study, as the researcher was aware that the potential pool of participants was limited, and the researcher did not want to encroach on this pool for the pilot study. Prior to the interviews, the participants were asked to sign an informed consent form. These interviews were transcribed by the researcher, and reviewed with the supervision panel. Whilst the questions were deemed suitable, changes to the interviewing technique of the researcher were suggested, as, on occasion, what appeared to be promising threads in the story were shut down by the researcher abruptly changing the subject.

After this process, recruitment of young women aged 16 to 20 years commenced. This recruitment process did not garner sufficient participants, and a re-advertisement did not elicit further participants. The age range of participants was then reviewed and increased to 25 years for two reasons. Firstly, the pilot interviews with women aged 21 to 25 years revealed that eating and body image issues were still relevant issues in this age range. Secondly, it was considered that the problems associated with possible retrospectivity may be offset by the possibility that women may be more likely to discuss their body image, eating and weight issues looking back on them, a concept that is endorsed by the research on disclosure of disordered eating (Vandereycken & Humbeeck, 2008).

Based on estimates provided by the diabetes services about numbers of people who met this criteria, 58 recruitment packs for the young women, and 12 recruitment packs for health

professionals were provided to the services. The recruitment packs contained details about the research, and an invitation to participate. Potential participants sent a notice indicating that they would like to participate back to the researcher, who then made contact to discuss any further questions, and to establish a suitable time and venue for the interview.

Participants

In total, 12 young women (average age 19.8 years) and 5 health professionals agreed to participate, representing 22.4% (young women) and 42.9% (health professionals) of recruitment packs provided to the diabetes services (see Appendices A to D). After informed consent was obtained from participants, it was explained to participants that they did not have to answer any question if they did not wish to or could terminate the interview at any time. Depending on participant preference, interviews were conducted in a consultation room either at the Turitea Massey University Psychology Clinic, or at the diabetes service, or, in one case, at the young woman's home. Most participants were interviewed individually, but in two cases, the young women chose to have their mother present. The interviews were conducted by the researcher, sound recorded, and took approximately one hour to complete. Prior to the interview, participants were asked to sign informed consent forms.

About the young women. *Jo:* Jo is a 21 year old university student, who was diagnosed with T1D at the age of 19 in her first year of university. She initially dropped out of university as her unstable sugars meant that she was unable to concentrate. However, she has started at university again, and apart from a self-professed struggle with self-discipline and difficulties associated with irregular university meal breaks that make it difficult to manage her insulin regimen, she is coping well.

Gemma: Gemma is 20 years old and is in the workforce. She was diagnosed with T1D at 18 years of age. She is a serious athlete and exercise is an integral part of her life. The timing of her diagnosis prevented her from competing at an international sports event and she stated that this made her "hate" diabetes. Gemma has been warned by health professionals that she needs to get her blood glucoses under better control and she is finding that the support of her partner is helping her with the discipline of monitoring her bloods and adjusting her insulin.

Laura: Laura was diagnosed at the age of 10 and is 25 years of age. She too enjoys keeping fit and playing a lot of sport. She is living a full life and is working, but comments that

diabetes limits her freedom. For example, if at a party and her friends decided to stay the night, she cannot not unless she has planned to do so and brought extra insulin with her. She is also struggling with what she describes as a restrictive diet. Her blood glucoses have been raised for some time, but she believes that she is quite careful with her diet and taking her insulin. This leads to her feeling quite frustrated.

Jess: Jess is 24 years old and working, having recently graduated with a Masters degree. She is planning her wedding. Her diagnosis at the age of 10 was “not much of an issue really.” Active and sporty, she talks of the importance of exercise and fitness to her. She is having difficulty keeping her sugars under control, as she tends to put her diabetes on the “back foot” to living her life to the full. Moreover, she takes less insulin than she should due to a wariness of hypoglycaemia, which she believes she was particularly vulnerable to. Jess has been told that she has some early signs of diabetes-related eye damage.

Ruth: Ruth is 16 years old and has recently immigrated to New Zealand. Diagnosed at the age of 11, she describes the paradigm shift between diabetes services in her country of birth and New Zealand; in her country of birth, diabetes is generally considered a “killing disease,” is managed by a very strict diet and access to medical care and insulin supplies is very expensive. She is feeling more positive about her diabetes since being in New Zealand.

Lucy: Diagnosed at age 10, Lucy is 16. Lucy is working hard for good grades at school, which she claims, do not come easily for her. She has struggled since her parents divorced, as her mother has been out of work. She is attending a high decile school, where she believes she is “judged for her money situation.” She is experiencing raised glucose levels which she attributes to her “V addiction” and her surreptitious sausage roll snacking. She has recently found protein in her urine, indicating that she may have sustained some kidney damage. She has struggled with depression and at one stage tried to take her own life.

Sue: Sue has had T1D since the age of 8 and is currently 16 years old. She states that she felt “why me” when she was younger, but more recently has felt that she “has it sorted.” She keeps fit by practicing ballet up to five times per week and finds that her diabetes did not interfere with this. When she was younger, her paediatrician described her as his “star pupil,” but her control has been less stable lately, and she is working with health professionals to adjust her regimen.

Sian: Sian is 16 years old and was diagnosed five years ago. Her diagnosis was followed by a move from her home town and her parents separating, unsettling her further. Sian has been struggling with anxiety and depression to the point that she is unable to attend school. She has been home schooled for the past two years. After a fraught time with a diabetes service, a change in service providers had brought a large improvement in Sian's metabolic control and attitude to having diabetes.

Emma: Emma is 18 years old and enrolled in further education. She was diagnosed with diabetes at the age of 6. She did not find adjusting to diabetes "too bad" as some of her peers at school also had diabetes. She comments on how helpful diabetes youth camps have been for her. Whilst she had some difficulties in the past, she currently has stable metabolic control.

Mel: Mel was initially diagnosed with gestational diabetes when she had a baby. She was later diagnosed with T2D. She eventually found out she had T1D at the age of 19 after she went blind. Mel is 25. She has recently returned to the diabetes service after a period of insulin omission and disengagement. Unable to cope with diabetes, she ignored it and abandoned her regimen for a period of four months. She still has poor metabolic control, as struggles with binge eating and depression. However, the support of her family, and her determination not to become seriously unwell again is helping Mel maintain her insulin regimen and clinic attendance.

Lexi: Lexi was the young woman diagnosed at the earliest age, four. Hence she describes her early difficulties through to a time when diabetes is "second nature." She is currently 18 and is not working due to ongoing health problems, which seem to be unrelated to diabetes.

Charlee: Diagnosed at age 11 and currently 18, Charlee describes her diabetes as "pretty good for a while" until a large weight gain, an incident at netball, and hair loss culminated in Charlee "mucking round with my diabetes and not taking my insulin." She discovered that insulin omission caused weight loss, and manipulated her insulin for four years and disengaged with the diabetes service. As a result, she nearly died, went blind and is still suffering from neuropathy and drop foot. After corrective eye surgery and in recovery, she has recently re-engaged with the clinic. She states that she would not omit insulin for weight loss again.

About the health professionals. The five health professionals who agreed to participate represented a cross-section of disciplines, specifically two endocrinologists (health professional 2 and health professional 5 – HP 2 & 5), and a nurse (health professional 3 – HP 3),

who are working with older adolescents and young adults, a paediatrician (health professional 1 – HP 1), who is working with younger adolescents, and a dietician (health professional 4 – HP 4), who is working across both age groups. The paediatrician and endocrinologists are working in areas other than diabetes, but the dietician and nurse are working exclusively in diabetes-care. The range of experience of the health professionals of working in diabetes care is from three years to over twenty years.

Analytic procedure

The young women were given pseudonyms. The health professionals were assigned a number from 1 to 5 rather than a pseudonym so that their role in the story as a clinician was clear. The interviews were transcribed verbatim by the researcher, with the codicil that any talk that might serve to identify the participants was removed. The transcription process served to re-familiarise the researcher with the interviews. After transcription, each interview was read through on at least three occasions to get a sense of the theme or themes within the story. The stories of the young women and the health professionals were considered separately, and were examined to identify similarities, variations or contradictions within the two groups of participants. With no “method” available for narrative analysis, the researcher sifted amongst the plethora of ways that researchers have used to analyse data for a method which would best serve the research questions. What was most important to the research questions was the experience of the young women and the health professionals, and the similarities, differences and contradictions that emerged in the stories.

Excerpts from the transcripts that were thought to illustrate these similarities, variations, and contradictions were then used as data for analysis. Although stringent coding strategies were not employed, an informal coding process of reading, re-reading and identifying themes relevant to the research questions was used. Braun and Clarke (2008) explain it is difficult to define what defines a “theme.” As the authors suggest, more instances of a theme does not always indicate that it is more important. Accordingly, they maintain that rigid rules for coding may not be helpful. Therefore, the value of a theme depends less on a quantifiable measure than whether it represents something useful in relation to the research question (Braun & Clarke, 2008). In this research, themes were considered both in terms of how pervasive they were amongst the participants and the ways in which they illustrated the struggles of the young women.

The approach was most similar to Josselson's (2011) categorical approach. However, other parts of each participant's story were considered in looking at each excerpt. In this way, the research used what Josselson describes as Schleiermacher's hermeneutic circle, whereby "an understanding of the whole illuminates the parts, which in turn create the whole" (p. 226). Using parts of the blueprint set out by Josselson, reading of the interviews continued until the different "voices" that each participant might use for a strategic purpose were identified and a "good Gestalt" was developed, that encompassed contradictions within the patterns, forming a "coherent unity" (p. 228). Using Josselson's second dimension, the researcher can attend to *what* is told, or *how* it is told. In this research, the focus was on what participants actually said rather than how they said it.

Reflecting the typology suggested by Stephens and Breheny (2013), the excerpts were analysed on two of three levels, namely the personal story and the public narrative. The personal story formed the basis of the analysis. The stories were then subjected to cross-case analysis to discover patterns across the stories within each participant group, health professionals and the young women. After the analytic process, a comparison was made between the two groups of participants to identify where the stories were congruent, where they conflicted and where the gaps between the stories may be. At the second level of analysis, *Shaping the Stories*, the ways in which socially available, or *public*, narratives inform the stories of the young women and the health professionals was explicated. These public narratives both shaped and constrained the ways in which the stories were told, and created dissonance that the narrators had to work to mitigate. The interpersonal level proposed by Stephens and Breheny was not made explicit in the analysis, but its pervasive influence on the stories is acknowledged, from the nature of the questions asked and the threads of stories pursued, to the coding and analysis of the transcripts.

Reflexive statement

Acknowledging the interpersonal factors that will have influenced the interview, and that transcription and analysis are not neutral processes but are "driven by (implicitly and/or explicitly) preferred theories, interest, and values (Emerson & Frosh, 2004), a statement describing the researcher seemed necessary. The researcher is a middle-aged woman studying for a Doctorate in Clinical Psychology. These attributes will have influenced the nature of the interviews. For example, the young women may have perceived the researcher as a quasi-health professional rather than confidante, and health professionals may have perceived the circumstances as collegial.

The researcher does not have diabetes, nor known anyone closely who has had the condition. Consequently, whilst she had a working knowledge of the disease, having worked for a number of years in allied medical health, was naive to the complexity involved in managing the condition, and to the ways in which having the condition could transmute the adolescent experience.

However, the researcher has personal experience of body image, eating and weight issues, albeit in a non-pathological form. Since childhood, the researcher, whilst she would not truthfully describe herself as fat, has always been (slightly) on the wrong side of a medically optimal weight. Currently of the opinion that “diets” are counter-productive and that exercise and moderate eating are the key, she has long reconciled herself to carrying a bit more weight. However, in her adolescent years she experimented with weight loss practices, including restrictive eating, use of the anorectic drug, fenfluramine (which was at that time readily available on prescription from general practitioner on seemingly quite spurious context), and intensive exercise regimes.

Moreover, disturbed at her athletic (plays five sports, one at provincial representative level), trim, teenage daughter’s description of herself as “fat and ugly,” the researcher’s interest is strongly sparked by the pressures on young girls to be thinner, even when they do not have a weight issue. The researcher is also concerned about the ways in which society condemns and ridicules those who are overweight. In short, the researcher has long had a strong interest in and empathy for weight, body image and related issues, which have influenced her choice of dissertation topic, and her views on the stories told.

Chapter 8 – Diabetes: The Voices Beyond the Disease

Chapter Overview

The analysis of the narratives was conducted on two levels. The first level of the analysis, *Diabetes: The Voices Beyond the Disease*, reflected on the themes that emerged from the narratives. The second level of analysis, *Shaping the Stories* (Chapter 8), explicates the ways in which the stories are shaped by socially available or public narratives. The thematic analysis in the present chapter comprised two parts, namely *The Lived Experience of Diabetes* and *The Clinical Experience*. *The Lived Experience of Diabetes* draws attention to the themes that emerged from the narratives of the young women pertaining to the ways in which they have managed the changes in their lives associated with their diagnosis. These themes describe the young women's awareness that they live with a potentially life-threatening disease juxtaposed with their desire to blend in with their peer group, and the ways in which diabetes interacts with eating, body image and weight issues. In the second part of the theme analysis, *The Clinical Experience*, the interface between the lived experience of the young women and the medical system was explored. This includes both the narratives of the young women, and health professionals working in diabetes care. The narratives of the health professionals indicate that they are mindful that the short and long term consequences of poor metabolic control of diabetes can be debilitating, life-shortening or even fatal. As a result, their clinical bottom line is metabolic control. However, despite working within a biomedical paradigm, their narratives also indicate that the health professionals are cognisant that such medical imperatives clash with the lifestyles of many of their young patients. As part of the analysis of this theme, the narratives of the health professionals were looked at to draw attention to the ways in which the narratives that dominate their talk match or conflict with the views of the young women.

The Lived Experience of Diabetes

The narratives of the young women describe the ways in which they attempt to straddle living with T1D and managing the tasks of being a young woman in New Zealand. Optimal metabolic control can be elusive, especially around puberty, even when great care is taken to adhere to medical advice (Bryden et al., 2001; Dabadghao et al., 2001; Hamilton & Daneman, 2002). When “everyday life” is added to the mix, all of the young women interviewed had experienced at least some problems keeping their glucose levels within an optimal range at some time. Less than optimal control is unsettling, as it raises the spectre of diabetic complications,

which may include nephropathy, retinopathy, or neuropathy. Three major themes emerged from the stories of the young women, namely *Fear for the Future*, *Struggling to be Normal* and *Diabetes, Body Image and Weight*.

Fear for the Future. Almost all of the young women's stories suggest that they worry about the ways in which diabetes might affect their future. This worry tends to manifest in different ways; for some young women, the threat of complications culminates in them being largely compliant with their regimen, and for others, their stories suggest that they oscillate between worry and rebellion.

For some young women, the threat of complications has a protective function, deterring them from risky behaviours. For example, Lexi explains how the threat of complications overrides the inertia she sometimes feels about administering insulin:

Lexi (18 years): To be honest, I go a bit irrational, and I think "I don't want to die." I know it's a possibility, but not this huge possibility. I always think "no, I've gotta do it, or else I'll die," And that helps me, 'cos there are some mornings when I just don't want to have to worry about it. You know, I can't be bothered with it. I don't want to have to get up and do injections.

Similarly, Jo and Lexi talk of their feelings around insulin omission for weight loss:

Jo (21 years): Yeh, I've never done that [insulin omission]. But when I heard about it, I heard about it with the risk. Made it a lot less sensible. Why would you put yourself at risk like that?

Lexi (18 years): I've been tempted (laugh). I hate needles, I really hate them. So it's like, when I get up, it's like "really!" So you know, I have been tempted to kind of go, you know, it won't hurt. But I just tell myself "No, you can make yourself really sick, you can land yourself in trouble, you can stuff up your kidneys" and it's not worth the risk

However, whilst it seems that fear of complications serves as a deterrent for some of the young women for more extreme behaviours, faced with the day to day self-discipline, the balance between complications and compliance is more complex. As the stories of most of the

young women suggest, fear of complications may not always translate into staying on the straight and narrow, and some young women express fear for their future, but also explain that they often stray from their eating regimen. Sometimes, the young women use a rhetoric of nonchalance to mask their fear for the future. For example, Lucy describes her reaction to finding protein in her urine, which is an early sign of renal damage:

Lucy (16 years): Other things as well which have annoyed me. My kidneys – I have protein in my urine. I researched it, ‘cos I wanted to know what it means. And I found out about kidney disease and its relationship with diabetes. I’ve got a high chance of developing it. And they never told me about that if my control was better, I could have stopped this. This isn’t good, you know. Mmmm.

Interviewer: Did they talk about complications with you?

Lucy: When I was first diagnosed. I was quite young, so I s’pose they didn’t go into it too much. But they did tell my parents about good control; it affects your feet and everything.

Interviewer: When they talk to you about high HbA1cs, how do you feel about that?

Lucy: Ummm, I don’t really care too much. Ummm, I know I should. But because I am young, I want to live my life how I want. I don’t want to do carbohydrate counting, weigh my food – I don’t want to let that get in the way. So until I start seeing the actual, like, damaging effect, I’ll start to care. Which I have lately ‘cos there’s protein in my urine. But, umm it’s like 60% of diabetics have a chance of developing kidney damage. So yeh. I do exercise a lot. I could eat better, but you know.

Lucy’s talk suggests that she has a *laissez faire* attitude toward diabetes management. This may represent rhetorical work to deflect the interviewer from tapping into a well of pain that the narrator does not wish to go into. However, it also demonstrates the conflict she has in articulating her worry for the possible consequences of her unstable metabolic control versus seeking understanding for her need to live her life as a “normal” young person. She implies that, had she been told of her risks of sustaining kidney damage, she might take more care. However, she contradicts herself by stating that, even though she has protein in her urine, “*I don’t really*

care too much.” Lucy’s narrative demonstrates the state of conflict between living a normal life and the threat of complications, which seems to have consigned her to a state of inertia; she worries for her future, but whilst she describes taking some small steps to mitigate her risk, she is jeopardising her health with her eating behaviours and starting to experience some early complications of diabetes. This paradox may be underpinned by a belief that facilitates many risky adolescent behaviours that “it won’t happen to me.” This belief reflects what Elkind (1967, cited in France, 2000, p. 319) describes as the “personal fable,” a belief that is common in adolescence that, whilst their behaviours may be risky, they themselves are not at risk. For the young women, such a belief may serve to ameliorate the fears generated by the potential of diabetic complications, perhaps to a point where the fear of long-term complications may not be as tangible as the day to day challenges. Lucy then has to do a lot of rhetorical work to defend herself from being judged as irresponsible for not taking further steps to protect her health; she outlines how restrictive it is for a young person to have diabetes, states that she exercises a lot, and completes her self-justification with the claim that kidney damage is reasonably likely for diabetics anyway. Implicit in Lucy’s story is the underlying message that diabetes is “not fair.” Lucy relates engaging in behaviours that are likely to be common amongst her peers, and as a result, she faces the threat of damage to her kidneys. Lucy uses the coda “*you know,*” which has the effect of asking the interviewer for her understanding. Talk of this type has been described as “exonerating language to resist spoiled identity” (Broom & Whittaker, 2004, p. 2380).

Other stories suggest that, in the midst of grappling with living with a serious medical condition, the threat of complications and even experiencing complications is not always an effective deterrent from some extremely risky behaviours. For example, Mel’s unusual presentation meant that her diagnosis was protracted, and she had gone blind from cataracts by the time she knew she had T1D. Surgery was needed to repair the damage to her eyes. Despite going blind, she did not take her insulin at all for about four months, and was hospitalised with ketoacidosis. Whilst subsequent hospitalisations have reminded Mel of the importance of looking after herself, she describes her struggle with keeping “on track”:

Mel (25 years): Ummm Yep, yeh, they [sugars] were really high

Interviewer: What was that like?

Mel: Not good.

Interviewer: So does something like that happening help keep you on track, or does that put you off track?

Mel: Ummmm, keeps me on track for a while, but then (p), (laugh) I don't know what happens, I just get better, then I go off track anyway.

Mel laughs when trying to explain why she goes “*off track*,” suggesting that she is aware that her behaviour may not make sense to someone who is not walking in her shoes. She has experienced some of the harsh consequences of poor metabolic control, but in the midst of discouraging high sugars and struggling with depression, she cannot always find a way to keep herself “on track.” Her story is congruent with the literature on dual diagnoses of T1D and depression (see for example, Hillege et al., 2011; Korbel et al., 2007), and indicates that she may be feeling overwhelmed by her diabetes. Whilst Mel’s story embodies an extreme example, most of the stories of the young women suggest that the fear for the future often concomitant with having a life-threatening condition such as diabetes adds an extra complexity in comparison to the lives lead by their non-diabetic peers. This extra complexity is layered onto the other diabetes-induced hindrances experienced by the young women in their struggle to be “normal.”

Struggling to be Normal. Diabetes invokes a dilemma for young women. For long-term optimal health, an austere medical regimen must be followed that involves a restricted diet, intensive blood glucose monitoring, and insulin administration. The very nature of this regimen puts optimal diabetes management on a collision course with a major developmental task of adolescence, that of conforming to the peer group. The narratives of the young women indicate that having T1D has, at times, made them feel different from their peers, and, further, that this does not sit comfortably with them. Their stories, which include hiding that they have diabetes, understating the challenges of diabetes, and eating “normal” food, demonstrate the ways in which they resist being perceived as different.

Whilst many of the young women talked of being open about having diabetes, others talked about hiding their condition out of fear of being perceived as “different.” For example, Lexi talks of her early years at school:

Lexi (18 years): It was actually quite hard for me at school, 'cos nobody wanted to know. 'Cos it was almost as if you tell them you have got something, and then it's some sort of disease. (p). It was always the denial, or the shame, you know, when friends didn't want to know, it sort of felt like I used to have to hide it.

Lexi's story suggests that the actions of her peers made her feel like a social outcast, and that she felt like she had to hide her condition. Similarly, Lucy explains that she prefers to keep her diabetes from being public knowledge, but that her teacher exposed her "secret":

Lucy (16 years): I find it [going low] embarrassing eating in class. 'Cos a lot of people don't know I have diabetes. Another girl has it and she tells everyone – she's like proud of it. She likes the attention she gets. But umm when I go low in class, I usually have glucose tablets, but if I don't I'll put it off. I try and wait until the end of the period and then get something to eat. 'Cos in the past, when I have pulled out food, and the teacher just didn't know I had diabetes. And she said "why are you eating?" And I said "oh I'm low." And she said 'low?" And I said "I've got diabetes." And she said "Ahhh, you've got diabetes."

Lucy did not like her point of difference from others in her class broadcast into the public domain. It is not clear from Lucy's story whether she experienced negative reactions from others about her diabetes, or whether she was reticent to make her condition public because she anticipated negative reactions, or being treated as different. As part of not publicising her diabetes, Lucy delays eating when she should eat to mitigate her hypoglycaemia. She also talks of her efforts to absent herself when she administers her injections. Whilst Lucy does not relate that she delays or misses her injections, not being comfortable with administering insulin in public has been cited as a major reason for non-adherence to insulin regimens (Hains et al., 2006), which can have a deleterious effect on metabolic control.

Like many of the young women, Lucy's story of the challenges of diabetes is juxtaposed with comments that serve to understate how hard having diabetes has been for her:

Lucy (16 years): Well it's been alright. When I was first diagnosed, I was quite young, and I learnt to do my injections quite quickly. I dealt with it pretty good. I tried not to

let it get in the way of things, 'cos you know, I had to deal with it, and just adapt.....So, ummmm. Not really, because it's quite common – I know quite a few people with it.

Lucy's assertion that that she is able to “*just adapt*” to her diabetes belies the sense of helplessness that pervades most of her story, which describes her struggles with weight management, metabolic control, and mental health problems that culminated in a suicide attempt using a large bolus of insulin to induce potentially fatal hypoglycaemia. Her comments about diabetes being “*quite common*” have a normalising effect. Her rhetorical work perhaps serves to resist her being positioned as “other,” and to stake a claim that having diabetes does not make her any different from her peers.

Many of the young women struggled with their eating choices, between “normal” food that their peers eat and their food regimen, and most tended to “transgress” in minor ways. However, some of the young women, for example Lucy, mutiny against the prescribed constraints around their eating:

Lucy (16 years): Ummm, 'cos they don't really tell you all the bad things. I'm just starting to find out. 'Cos after having diabetes for 10 years, my control hasn't always been the best. I like to eat bad food, you know coke and V and stuff like that. And I just go “stuff it. I'm gonna live my life. I don't really care if it cuts 5 years off my life. I just want to be normal, eat what I want kind of thing.”

Lucy, like some of the other young women interviewed, often flouts the restrictions placed on her life by diabetes. Lucy implies that she know that she runs the risk of diabetic complications as a result of her eating choices, but this knowledge does not prevent her from eating “*bad food*” which she construes as being “*normal*.” Young people with diabetes have a double dilemma. Not only is eating junk food in conflict with their diabetes management, but as Wills (2005) notes, for young people in general, these peer influences on eating habits do not “fit comfortably” (p. 99) with controlling weight. There is a perception that T1D and the concomitant insulin administration are associated with weight gain (Bryden et al., 1999; Jones et al., 2000; Steel et al., 1989), indicating that controlling weight may be more difficult for young women with diabetes. Therefore, it is perhaps not surprising that most of the young women's stories suggest that body image and weight have been significant issues for them in their struggle to be like their peers.

Diabetes, Body Image and Weight. Some of the young women interviewed struggle with weight gain and others do not. However, all but two of the young women spoke overtly of the difficulties they have with body image, weight control and diabetes. These difficulties manifest in different ways, from the relatively benign to the life-dominating and life-threatening. Some of the young women do not have a weight problem, but their stories suggest that, in common with many of their non-diabetic peers, they perceive thin as good. For example, medical professionals have been concerned about Lexi's weight loss:

Lexi (18 years): There have been times when I have been asked "have you lost weight?" "Well yeh." Then it's like "are you intentionally trying?" It's like "well no. It's like I don't have a lot of weight to lose." It's just me, and on the whole I'll eat when I'm hungry, but if I'm not hungry I won't eat. I'm quite stubborn, and if the team doesn't like it, well I'll say "that's me."

Lexi takes umbrage at the implication that she has deliberately lost weight, and ascribes her weight loss to her eating and sleeping patterns which mean that she often only eats two meals per day. However, despite not having had problems with weight gain, several of her comments suggest that Lexi's attitude to weight, eating, and body image is not straight forward:

Lexi (18 years): I'm not unhappy with my weight. You know, there's always that voice, you know, it could be better (laugh)

....

Lexi: You go through being a teenager, and being a girl, you know, you go through "oh my thighs are fat. Does my bum look big?"

.....

Lexi: I think it kind of helps 'cos I think that out of all my friends, I am probably the smallest, but then there's always those times when I think that I don't want to be big like them. And if they start losing weight, I get kind of jealous (p) I think "I don't want them to lose weight, 'cos then I won't be the smallest."

.....

Lexi: And my parents are saying "you're looking quite skinny." "Thank you."

The ways in which Lexi talks about her weight suggest that she does like being thin, and being thinner than her friends. Hence, whilst Lexi may be only eating two meals per day, ostensibly because she is not hungry, her eating patterns are congruent with the value she places on being slim. Lexi, along with Sue, were in the minority of women who have not experienced weight gain. Sue talks of her feelings relating to diabetes and weight:

Sue (16 years): I lost a lot of weight before I was diagnosed. And I don't think I ever put that back on. So I don't think I ever put on weight because of it.....

Interviewer: So what sort of changes did it mean for you?

Sue: Not many for food, because we already had quite a healthy diet, but I always had really healthy dinners, good lunches and that kind of stuff. So, not so much for diet. (p). We sometimes had lollies, like once a week, go to the dairy. But Mum and Dad went overboard getting the sugar-free lollies that kind of stuff..... I have been doing ballet since I was 5, and I never stopped. I just built up the number of hours. I was doing 2 or 3 classes a week then, and now I am doing 4 or 5. Yeh.

Sue's story suggests she has adjusted well to managing body image and weight-related issues along with her diabetes. She describes her reaction to being weighed, a clinical experience that most of the other young women baulk at:

Interviewer: What was that [being weighed] like?

Sue: I was quite excited actually. I see where I was on the chart (laugh). I quite liked that.....I've always been underweight for my height, so I didn't have a problem.

Sue was “excited” about being weighed, implying that she was almost competitive about seeing her results. She liked the graphical representation that she was “underweight for my height,” reflecting the idea that thin equates with good. However, whilst she denied omitting insulin when her mother asked about this behaviour because her metabolic control had deteriorated, she reacted quite strongly to a question relating to the utility and acceptability of a diabetes eating questionnaire (DEPS) as part of a clinic visit:

Sue (16 years): Ummm. (laugh). I'm just looking at some of these things. I wouldn't want to be accused of doing these things. I would feel victimised really.

Interviewer: So even in a format like that, if you knew everyone was asked to do it, you wouldn't like it?

Sue: I wouldn't mind if everyone got it, if everyone did it, but if it was just given to you, I would think "what are these people saying about me?" (laugh)

Interviewer: Mmmm, you actually used the word "accused"....

Sue: Yeh...

Sue's choice of words "accused" and "victimised" belie her apparent lack of concern with her weight and body image. Like Lexi, Sue does not have any problems with weight gain. However, their stories suggest that their attitudes to weight and body image may be more complex than they would admit to.

The stories of most of the young women suggest that having diabetes introduces a specific set of challenges for them when trying to achieve a desirable weight that their non-diabetic counterparts do not face. The regimen may predispose them to weight gain, alter their eating patterns making weight control more difficult, and/or render healthy weight control practices, for example, exercise, more difficult or less effective. Some of the young women found that, after the initial weight loss followed by weight gain after diagnosis, their weight tended to stabilise at around their pre-diagnosis weight. However, Gemma was one of the young women who experienced a small weight gain that she has been unable to reverse:

Gemma (20 Years): To start off with, that first week I was diagnosed, I had lost about 7 kgs. I put that on in about a week again. And I used to be about 65 kgs before I was diagnosed. Umm but now I sit about 68 to 70. So I put on that weight, and I can't really get rid of it. (p) And I do way more training as my identical twin sister, and she's about the same weight as me, so it's really frustrating. But umm I'm reading a book at the moment about blood sugar control, and I can sort of help myself out a bit more.

Interviewer: How do you feel about those extra 3 kilos?

Gemma: Pretty frustrating. 'Cos I work extra hard at the gym, more than my twin sister, and we weigh the same. My partner said I look better, more toned than her, but you can't get away from the numbers.

.....

Gemma: I was talking to a nutritionist who has T1D, and who is a triathlete. He said that usually people do put on weight when they first become diabetic. He said, 'cos I was talking about how I couldn't lose it, and he said "you don't need to lose it. You are really fit and healthy, you don't need to lose it." Which made sense, when he said it, but I hadn't really thought of that before.

Comparing herself to her pre-diagnosis weight and her twin sister, Gemma feels a sense of dissatisfaction with her weight and of being on an uneven playing field as a consequence of having diabetes. Despite her partner pointing out to her that she looked more toned than her twin, she has become caught up with what she believed to be her ideal weight, and places more credence on the “numbers” than her partner’s opinion. Even with the opinion of a professional, which seems rational to her, her talk suggests that Gemma has not altered her mindset about her weight gain.

Some of the young women interviewed believe that controlling weight with diabetes is often difficult as it alters their eating patterns. Mel, Jo and Lucy describe what it is like for them:

Mel (25 years): [insulin] [laughs] makes me eat more. (p) Yeh, it makes me eat more.

Interviewer: Because you are hungry, or because you have got to eat because of the insulin?

Mel: Ummm. I don't know, It just makes you hungry (p). So, yeh, (p) it just makes me eat more.

.....

Jo (21 years): Ummm, I guess again it's just monitoring your portions, food portions. I know when I have low blood sugar, I go crazy and eat so much food, and then I go "wooo high blood sugar," but it's just that intense feeling of hunger. So if you just keep

those sugars under control, then you're not going to be having those cravings for food.
(p).

.....

Lucy (16 years): I'm not really into healthy eating, so that's kinda off the list. I'm into exercise. I walk to school every day over the hill. So that's about 25 min each way. And I go to the gym 3 or 4 times a week. But it doesn't really help really. It's building up my fitness levels, but it's not really helping. Which annoys me 'cos I expected more. I think it's the eating factor. But if I healthy eat, I'll go low again 'cos it affects my insulin. I can't really do much until my insulin is changed.

Mel, Jo and Lucy's rhetorical work serves to persuade the interviewer that diabetes creates extra barriers in weight control. Mel and Jo describe the physiological effects of diabetes and insulin on eating, which they suggest are hard to control. Lucy risks positioning herself as irresponsible by describing her unhealthy eating. However, she ameliorates this risk by claiming the virtue of exercise, and absolving herself of responsibility for some of her eating choices by asserting "I can't really do much until my insulin is changed." Therefore, like Mel and Jo, Lucy suggests that some of the factors in weight management with diabetes are outside of her control. Similarly, whilst most of the young women interviewed talk about healthy eating and exercise as the best way to control weight, several young women describe the ways in which using exercise for this purpose is rendered more difficult by diabetes.

Tailoring food and insulin to accommodate exercise and avoid hypoglycaemia can be complex. Jess, who likes to keep fit and enjoys sport, describes her experience of stabilizing blood glucose levels when she exercises:

Jess (24 years): I always carry lucozade. Like at the gym, I was 22 before I did my gym work out, so I did 4 units of insulin, and then 20 minutes later, I dropped down to 4. So I just felt really bad. I wanted to throw up. But I had that lucozade, so that was alright. I just had that, but I couldn't finish my gym session.

Lucy and Jo explain that the carbohydrates consumed to avoid hypoglycaemia can then negate the calorie-burning effects of exercise:

Lucy (16 years): Yeh, and I think trying to lose weight with diabetes is harder. I have noticed it is a lot harder. If I want to go to the gym, a couple of times I have been low in the afternoon, so I can't go. And then I have to eat. And after the gym, you go low, and you don't want to eat after the gym. And the food that I eat is carbohydrates and sugary food. And I think "what a waste that was." Yeh just little things like that add up.

.....

Jo (21 years): Umm. (p) Ummm (p) I find it quite hard to lose weight, because I find if you exercise, then you get low blood sugar and you have to eat more (p) like it's quite difficult, but otherwise (p) like you can still exercise obviously and keep fit - ish (p) I don't really find too much of an impact.

Like Jess, both women refer to exercise as a healthy weight control behaviour. However, they explain that the effects of exercise on blood sugar often mean that exercise is a less effective way to control weight for those with diabetes. Lucy uses the coda "*yeh, just little things like that add up,*" implying that whilst each hurdle in itself, might seem surmountable, in their entirety they create a barrier to keeping control of weight. Jo uses the term "*fit-ish,*" implying that being fit may not be an achievable goal. She also makes contradictory statements; she states that she finds it "*quite difficult*" and that she doesn't "*find it too much of an impact.*" The effect of this rhetorical work enables Jo to explain her point that diabetes introduces some complicating factors in exercising for weight control, whilst precluding her from being positioned as "other," which she risks by talking about her diabetes in ways that prevent her from participating fully in a "normal" life.

Young people without diabetes face "competing motivations" (Ahern, Bennett, Kelly & Hetherington, 2011, p.77) as they choose between indulging in foods that they desire and losing weight. Commonly, Ahern et al. (2011) note that the culmination of these choices is body dissatisfaction. For young people with diabetes, a different additional tension is introduced as their choices also reflect on their metabolic control. Hence they must find a balance between being "normal," by eating foods that they enjoy that their peers also eat, being slim, and being healthy. However, for a young person with diabetes, the goals of being slim and being healthy are not necessarily mutually exclusive. If being slim equates to a healthy weight, then the goals may work in harmony. However, for many young women, being slim equates with being thin

(Ahern et al., 2011; Burns & Gavey, 2004). Moreover, Burns and Gavey (2004) note that the pursuit of a healthy looking body for young women may involve unhealthy practices. Whilst it is not unusual for young women to employ potentially unhealthy practices, for example fasting, some of these practices can be more problematic for young women with diabetes than their non-diabetic counterparts due to the risks associated with both hyperglycaemia and hypoglycaemia. For example, Sian talks about less healthy options to control weight:

Sian (16 years): I think it would be helpful to talk about the body image thing, how it affects them a little bit more than normal girls....

Interviewer: Why a little bit more than normal girls?

Sian: 'Cos they have to struggle with it. 'Cos like its bad that some girls don't eat, skip meals or starve themselves, or turn into an exercise freak. But diabetes girls can't do that, 'cos if they don't eat, they'll die. And I think that some people (p) take advantage of things like that.

Sian refers to “normal” (non-diabetic) girls, which positions her, having diabetes, as “not normal.” Even though Sian talks of the weight loss mechanisms in derogatory terms, she implies that she is disadvantaged by not having these options. Rodin, Silberstein and Streigel-Moore (1985, cited in Burns & Gavey, 2004, p. 552) suggest that body dissatisfaction, concerns about weight, dieting and bingeing/purging are so ubiquitous that they can be described as normative. Accordingly, Sian adds her voice to other stories that suggest that diabetes makes it harder for young women to control their weight.

Despite the complex interactions between body image, eating, exercise and insulin, for differing reasons, most of the young women interviewed eschewed the use of behavioural extremes to control their weight:

Lexi (18 years): I've never gone to the stage of trying to throw up my food, or stop eating completely. You know, I've always had stomach bugs, so the thought of trying to make myself sick puts me off a bit to be honest.

.....

Lucy (16 years): Yeh. They did bring it [insulin omission] up. Because I know a while ago I did skip a couple. But that wasn't on purpose. It was during my holidays and I was busy. You know I was going out and I would leave my injection at home. I'm not too keen on the idea because I go really high, and I need to go toilet all the time and then it's ugh. No, I don't like it. I go high every morning anyway because of my insulin. It's a horrible feeling. I can't eat my breakfast. And I go to school, I go low because I haven't really eaten.

Interviewer: So you don't like the feeling of high blood sugars?

Lucy: No. It's horrible. You feel bloated. Ummm you can't eat. Your breath smells – smells really fruity. You're always needing to go to the toilet. You're very thirsty. Yeh, it's not a good feeling.

.....

Sian (16 years): I thought about it, but then I thought I'd rather be the size that I am and be, and live for a long time than not take my insulin and be sick and not go into hospital the whole time.

Whilst health-related decisions are unlikely to be attributable to a single reason, Lexi and Lucy identify that they choose not to employ risky weight loss practices largely because they do not like the physical effects, and Sian cites health reasons for avoiding extreme measures for weight loss. As these young women allude to, there is an array of unhealthy weight loss practices used by young women, including one practice that is uniquely available to people with diabetes, insulin omission. Some of the young women state that they do not take all their prescribed insulin, but cite reasons other than weight loss for this. For example, Jess talks about not taking all of her insulin:

Jess (24 years): Well I am the heaviest I have been ever. And I don't know if that has something to do with changing my pill, or changing my insulin. I've actually started seeing a personal trainer 'cos I'm getting married next March, so that was an incentive to do that. 'Cos the soccer season finished really early this year for the women's first division, so I haven't really been doing anything since then.

.....

Jess (24 years): Mmmm. Actually last time I had a checkup, or the time before that, I had lost 3 kgs. And I don't remember doing anything different, it was just because I was running so high.

Interviewer: So did they ask you whether you had not taken insulin?

Jess: Yep.

Interviewer: How did they ask you that?

Jess: They sort of asked it very subtly, like "did you forget to take your insulin?" And I'm like, "I don't think I ever forget." But I am running high quite a bit. Yeh, I'm pretty good. 'Cos I'm on 1 lantis a day, and I have that with my pill in the morning, so I never forget that. But I always skip my novorapid (laugh)....

Interviewer: Because?

Jess: I didn't have breakfast this morning. So I don't think I need novorapid, but my finger prick was 15. So I probably should have. But I have issues 'cos I am really sensitive to insulin. So if I had of done that, so if I had done like 2 units it would have dropped within half an hour.

Interviewer: So, you are kind of not having all your insulin, but because you don't want to go low?

Jess: Yep

Interviewer: So you are trying to gauge it to what you need?

Jess: Yeh. I hate going low. It's the worst feeling.

Interviewer: How does it feel?

Jess: Oh you just feel sick, hot flushes. You can't concentrate and I get really moody. It's just I've never ever gone so low that I have passed out or anything like that. But there's been a couple of times that I have been close.

Jess laughs when she states that she “skips” her novorapid, indicating that she is aware that it may not be a good habit. She is cognisant that her insulin omission has caused her to lose weight, and that the subsequent high glucose levels are detrimental to her health, as she has been told that she has some eye damage. Jess’ rhetorical work centring on her claim that she is not unhappy with her weight defends her insulin omitting by explaining her susceptibility to hypoglycaemia, elaborating on the unpleasantness of this state. Although she has never lost consciousness as a consequence of hypoglycaemia, by alluding to this as a possibility and alerting the interviewer to the danger inherent in hypoglycaemia, she further justifies her wariness of taking all the insulin that she is prescribed. Even though Jess states that her insulin omission stems from her sensitivity to insulin, her weight loss, which is congruent with her stated goal of getting down to 25% body fat for her wedding, is a by-product of this omission.

Whilst most of the young women state that they do not employ risky practices for weight control, their stories suggest that there is a complex array of conflicting emotions and behaviours that form a continuum, which at the extreme end denotes disturbed eating behaviours. The stories of two of the young women interviewed, Mel and Charlee, fall at this extreme end. During Mel’s episode of insulin omission, which lasted about four months, Mel’s weight dropped to about 45 kg. Mel expresses her feelings relating to her recent weight recovery up to about 60 kg:

Mel (25 years): Yeh – it’s just my weight that they were worried about. ‘Cos I was losing too much. But, yeh now (p) it’s just the weight. I think they are trying to put my weight up. Yeh, I don’t like that.

Mel’s weight recovery back up to 60 kg has clearly unsettled her. She states “*they are trying to put my weight up,*” which implies that weight gain is being imposed on her by health professionals. Her apparent concern at her weight gain, which, in reality, represents a return to her pre-insulin omission weight, belies her assertion that her insulin omission was attributable to “laziness.” Mel may not have taken her insulin initially because she was feeling overwhelmed, but her talk associates insulin with eating more and weight gain, which is distressing for her.

Charlee's story of insulin omission began in a similar way to Mel. When she was diagnosed with diabetes at the age of 12 years, Charlee gained about 12 kilograms in weight. At the time when Charlee was upset by her weight gain, her prized long blonde hair fell out, which her doctors attributed to an autoimmune reaction to diabetes. Her distress was compounded by two events which her mother describes as pivotal in her downward spiral:

Mother: Unfortunately you can put it down to, it just takes one comment, or one person to set your mindset into "oh I'm fat, I've got to do something about it." Someone saying something about "bet you she can't see her toes 'cos of her double Ds." Wasn't it?

Charlee (18 years): Mmmm

Mother: That was the comment that she remembers that triggered everything.

.....

Mother: And she was really, really good at netball. I mean she was in the reps and everything. And that was another crunch time.

Charlee: Mmmm....

Mother: Umm, she was (p) in the Junior As at school, and the coach was choosing her captain, and she said because Charlee had diabetes, she wasn't a suitable candidate, in front of everybody. That was a crunch too.

Charlee: Mmmm

Mother: She thought "well, what's the point?"

Charlee's mother often answered questions directed at Charlee. Therefore, whilst Charlee is heard to tacitly agree with her mother's story, these excerpts should be viewed as Charlee's mother's view as a participant in Charlee's story. Charlee was being teased for her "double Ds" And was also being called "baldy." Exacerbating her problems with weight and hair loss, the public action of the netball coach positioned Charlee as "not normal," flawed, and as a less valuable player because of her diabetes. Charlee's mother perceives these events as significant

triggers in Charlee's decision to stop taking her insulin. Charlee indicates that her initial insulin omission was an attempt to ignore that she had diabetes, but she quickly came to recognise that not taking insulin facilitated weight loss:

Interviewer: So, before you started not taking your insulin, you didn't know that that would make you lose weight?

Charlee: No.

Interviewer: So, do you remember why you didn't take your insulin?

Mother: Just probably because you were fed up.

Charlee: Yeh, I think that I just wanted to be normal.

Charlee states that she stopped taking her insulin initially because she “*just wanted to be normal.*” The chance discovery of the association between insulin omission and weight loss led to insulin-omitting behaviours that dominated Charlee's life for the next five years. Like Mel, Charlee went blind and required surgery to restore her vision. She was hospitalised with diabetic ketoacidosis on numerous occasions, and on one occasion, nearly died. At the time of the interview, Charlee still had ongoing nerve pain for which she was taking Tramadol, a powerful analgesic because Codeine had failed to control her pain. Analogous to anorexia nervosa in its intensity, Charlee's downward spiral into disturbed eating represents an extreme outcome to the difficulties often inherent in managing weight with diabetes:

Interviewer: Tell me what [not taking your insulin] meant to you at that time.

Charlee: Just the whole weight thing. Just didn't want to put on weight. And then, it was kind of like every time I took insulin, it was like I was freaked out that it was going to make me put on weight. So it was just all about my weight.

Interviewer: So when you say you didn't want to put on weight, were you overweight, or had you been overweight?

Charlee: I had been overweight, and then I just slowly started to get smaller and smaller and smaller....

Interviewer: And how did that feel?

Charlee: It was like I was never small enough. I just felt I was overweight still.

.....

Charlee: Like if I weighed, 'cos I was weighing myself all the time, and if I was a kilo more than I wanted to be, I wouldn't take my insulin for a week, like no insulin at all.....

Interviewer: How underweight did you get?

Charlee: 43 kgs. That was the lowest I got.

Interviewer: What was that like for you?

Charlee: Well it was not good enough (p) that's just how I felt (p). I dunno (p). Didn't have a goal or anything.....

Interviewer:Just low was good?

Charlee: Mmmm

Charlee's talk about insulin implies that she saw insulin as her enemy. She also describes body dysmorphic tendencies as despite weighing 43 kgs, she still felt overweight. Such was the intensity of her feelings around her weight, Charlee nearly died and has ongoing health problems as a consequence. She talks of her feelings around weight and insulin after her near-death experience:

Interviewer: So, now that you take insulin regularly, how do you feel about your weight?

Charlee: Umm, it's good at the moment (p) like it's climbed a lot, but it's stabilised now I've got to a good weight and it's not always changing. Cos for a while there, it got up and started coming right back down, and they were worried that I was going to slip back into my old ways. Cos my weight was (p). And then (p) now it's all right.....

Mother: You are very controlled in what you eat tho (p). It's very healthy food, and umm (p) Probably doesn't eat quite as much as she should tho...

Charlee: Mmmm, I'm doing it in a healthy way (p) It's not like I don't eat. (p) I always have breakfast, lunch and dinner.....

Interviewer: Does it still worry you? That you might put on weight?

Charlee: Ummm, it does. But (p) not to the extent that I would do anything like that again. (p) I have just realised that I have to do it like everyone else does it. (p). Mmmm.....

Interviewer: So, do you still sort see insulin as kind of the enemy?

Charlee: No, not really, cos when I lost all that weight this time when I got better, I was taking my insulin then. That just kind of made me realise that it was not the insulin, it was me, not the insulin.

Charlee and her mother have a verbal tussle over Charlee's eating. Her mother states that she thinks that Charlee does not eat enough, and Charlee defends herself against her mother's implication that her battle with disturbed eating is not over. Charlee's story suggests that she has come a long way from the time when she was omitting insulin regularly, but it is clear that she is not comfortable with gaining weight. She admits that she still runs high blood glucose levels due to her restriction of the amount of insulin she administers, suggesting that she may not be completely free of her distorted mindset about weight, body image and insulin.

Summary. The stories of the young women explore the minefield of issues relating to eating, weight and body image that are not uncommon amongst young women in the general population. However, the stories of the young women suggest that having T1D adds a

complicating and exacerbating factor to these issues. A minority of the young women had not experienced diabetes-related problems with eating and weight. However, their talk suggests that, despite not having a weight problem, they were invested in being thinner. Most of the women had either gained weight or perceived that having diabetes exacerbated their difficulties in controlling their weight and two of the young women omitted insulin pursuing the thin ideal, in one case, almost unto death. The stories demonstrate that all of the young women interviewed were influenced by issues relating to body image, eating and weight, suggesting that these may be pervasive issues amongst young women with diabetes.

The Clinical Experience

Two main themes emerged from the narratives of the young women that describe the ways in which they perceive their clinical experience, namely *Focus on Disease Monitoring Activities* and *Talking about Eating, Weight, and Body Image*. Because diabetes is a life-threatening condition, parameters that contribute to optimal health outcomes are important aspects of clinical consultations. However, the stories of the health professionals suggest that they attempt to accommodate “normal” life in their advice on diabetes management, and that they are aware of the sensitivity of many of the issues relevant to diabetes management. The thematic analysis explores ways in which the perceptions of the young women are congruent with, or disparate from, the stories of the health professionals.

Focus on disease monitoring activities. The hub of diabetes management is good metabolic control, which minimises the risk of long-term complications. Accordingly, diabetes check-ups are often dominated by disease-monitoring activities and advice on managing diet and insulin regimens. The challenge for health professionals is to find a balance between ensuring that the elements that contribute to optimal long-term health outcomes, for example, weight, insulin types and dosages, and diet, are managed, whilst being flexible enough to accommodate for the individual. They must also navigate the tricky area of underscoring the importance of metabolic control with education about diabetic complications to a population that is more likely to be focussed on the here and now. The way in which health professionals are perceived to conduct these activities has been shown in the literature to impact on the clinical relationship, and, further, to the individual’s self management of their diabetes (see for example Kyngas et al., 1998). The stories of the health professionals suggest that they are

cognisant of the uneasy marriage that exists between the science of diabetes, and the reality of everyday life. For example HP2 outlines the challenges:

HP2 (Endocrinologist): There are these competing tensions. On the one hand we want people to be in the position that people feel like they are managing their diabetes in a way that minimises their chances of complications later, and feel like they are in control of their diabetes rather than the other way round. But, on the other hand, we don't want them to feel like, to be miserable in other words (p). And you could live like a monk and live forever, and be miserable. So it's balance, and those are the sorts of conversations we have, and it can be difficult, because, again, there are pulls in all sorts of directions that patients have in terms of how they might want to live their lives.

Alluding to the shortcomings in the biomedical model of disease management, HP 2 explains why a focus purely on metabolic control is too narrow. HP2 describes a “balance” when managing the “pulls” that exist in diabetes care if having a “miserable” client is to be avoided. However, some of the young women told of times when they perceived that their health professionals did not find that “balance,” and this clearly impacted on their clinical relationships. For example, Lexi talks of her experiences with different diabetes services:

Lexi (18 years): I had to be taken out of school to go to the diabetes clinic. OK most kids don't like school, but I would have rather gone to school than go to these clinics. And I absolutely hated that they would, you know, they wanted diaries of what I would eat, and you know, a 4,5,6 year old – that's huge, You know they shouldn't be so restricted that way. (p) I ended up going to a child psychologist about anger, from that pressure, and the frustration..... I was more frustrated at the fact that it felt like I couldn't get [my HbA1c] right, and they couldn't stop pestering me about it. (p) Every time it was high, I was upset about it, 'cos I knew they were not going to be great.

Lexi's story suggests that her perceptions of service 1 are of a strong focus on biomedical matters, which she found aversive. She considers that the health professionals were “pestering” her, indicating that their approach increased her distress. Her rhetorical work includes a reference to seeking psychological help, emphasising the pressure that she felt under. Lexi's story suggests that her relationship with her health professionals at this stage was fraught, and

likely to be counterproductive in helping her manage her diabetes. Lexi's family shifted regions when she was 13, and as a result, she changed diabetes service providers (service 2) :

Lexi (18 years): But, when I came down here, I said "I will adjust my insulin." They said "all right, that's fine as long as you don't give yourself heaps of extra, or not take it at all," sort of thing. And I said "look, I know how I feel. I know what my body is telling me. I know what makes me feel good and what makes me feel yuk." And umm, you know you try and explain that up in [service 1] and it was in one ear and out the other. You know, "we know what's best." And I sort of got the impression up there, once I moved down here, it was we've got the qualifications, we know better than you do. And when I came down here, it was more relaxed, a better environment. And that would have been a big contributor to controlling my levels. I was actually relaxed and everything.

Lexi's story suggests that the shift was not just geographical, but also represents a line in the sand in terms of her perception of her diabetes care. Lexi indicates that the health professionals at service 1 did not listen to her, and were unwilling to integrate her experience with their knowledge to make her regimen more personalised and flexible. This authoritarian approach, "*we know what's best,*" positioned Lexi as a powerless recipient of information, whilst positioning the health professionals as dominant partners in the relationship. Lexi was able to reclaim some autonomy in her diabetes management in a partnership type relationship with the health professionals at service 2, and, she speculates, the concomitant reduction in her stress has been responsible, at least in part, for the improvement in her metabolic control.

Talking about metabolic control. Lexi talks of her distress when her metabolic control was unstable. Whilst her story suggests that, concomitant with what she perceives as a more collaborative approach, her control improved, it is hard to be clear whether it was the unstable metabolic control itself, or the way that she perceived the health professionals at service 1 talked about it, that underpinned her distress. However, Lexi's story demonstrates that talking about such results, especially if they reflect poor control can be anxiety-provoking for young people with diabetes. The stories of the health professionals suggest that they are cognisant of the delicate nature of such matters:

HP 2 (Endocrinologist): And I am conscious that a lot of the language we often use in consultations is kind of loaded with the sense that there are some things that are good – we talk about good control, and a good diet and a bad diet and good control and bad control. So I try and avoid those sorts of terms. So I'll try and talk about tight control and target HbA1c, so try and de-value- judgementise it. So I try and do that.

.....

So for glycaemic control we talk about the HbA1c and their home blood glucose monitoring (BGM). So sometimes for their BGM I ask "how do you think that is going? What are you aiming for?" I'll get them to explain to me how they think their diabetes should be managed and what their expectations are and what they are aiming for, and then maybe take it from there, and explore a little about again what the evidence is for possible consequences of falling outside certain parameters might be in the medium to longer term.

HP 2 states that he tries to avoid pejorative terms such as "good" and "bad." He describes a Socratic questioning type of approach, providing a space for the young person to talk about their perception of their control and what they would like to achieve. His story suggests that he tries to introduce a more collaborative way of discussing laboratory results, rather than him taking the role of an expert. However, like Lexi, the stories of many of the young women suggest that talking about raised HbA1cs has been distressing for them. For example, Laura describes her experience:

Laura (25 years): No matter what [lab result] it is, they are not happy with it (laugh). When it was fine, it was "it's not good enough." 'Cos it's slowly going, my last one was I think 8.2, which is really bad, but it's only just over the (p). When I was 7.8 a couple of years ago, it was "oh you need to get it down."

Interviewer: When it was say 5, what was it they said that made you think it was not good enough?

Laura: I can't remember, it was just "you need to do better," 'cos I don't really test my blood that often. After a few years, you know what your body is doing, you can feel it going high, you can feel it going low, and I've always taken around the same units of

insulin, so I just kind of, don't know how I know, but I just do. But they get annoyed with me, 'cos I don't write it all down

Interviewer: So when you say annoyed, what do they say?

Laura: Well last time they said "you're just kind of living life and taking insulin 'cos you have to." I do eat sugary foods, but I have got a couple of friends who are absolutely terrible, and I just kind of think "why do I get told off?" (laugh). It feels like whatever you do, it's never going to be good enough.

Interviewer: When you think about that, how do you feel?

Laura: Well, I think "you haven't got diabetes."

Interviewer: Mmm. Are you still happy to go to clinic?

Laura: Nah. Well I (p) yeh....

Interviewer: Do you always go?

Laura: Yeh, if I don't go to an appointment, I will reschedule it.

Interviewer: OK, so it's never made you not want to go?

Laura: Well they will hound you if you don't (laugh).

Laura describes her HbA1c result of 8.2 as *"really bad,"* suggesting that, even if her health professionals are using more neutral terms to relate her results, this is the message that Laura is hearing. Laura's story that her health professionals *"get annoyed"* with her and that she gets *"told off,"* implies that she feels admonished for her less than stable metabolic control and her unscientific way of monitoring her blood sugars. In response to the perceived criticism, she states that she thinks *"you haven't got diabetes,"* suggesting that she feels that the health professionals have little understanding of how onerous diabetes management can be. Her story

suggests that she is becoming ambivalent about attending clinic as her perception of the reaction of the health professionals is having an alienating effect.

Other stories of the young women suggest that they cope with “bad results” by employing a kind of passive resistance. For example, Gemma also relates that she feels “told off” by health professionals:

Gemma (20 years): Thinking back to when I was a teenager, I wouldn't want to say something like I was skipping lunch to lose weight. Even now they tell you off, so it would probably be a worse telling off if you were doing that [insulin omission]. But mmm...

Interviewer: How do you react when you are told off?

Gemma: I just stop listening. That's why I bring my partner along so he tells me afterwards what happened. Because, usually I just (p) I already know.

Interviewer: So what does the telling off mean for you?

Gemma: Doesn't really matter, 'cos I already know the reasons why I'm not taking my insulin. So them telling me it is bad, well I already know that.

Interviewer: Does it change your behaviour?

Gemma: No. It's like once when I went to see [nurse], and I took my partner with me, and she said something like my HbA1c was 9 or 10, and my partner just had no idea 'cos I just test myself, and I do things myself. So he had no idea my control was bad. So when we got home he drew up a whiteboard for me to write down my insulin and values. So I had to keep my insulin good or he would tell me off. Well, he didn't tell me off, he would just give me a disappointed look.

Interviewer: (laugh) And is that more effective than.....

Gemma: Probably

Gemma interprets some medical advice as a “*telling off.*” Because she perceives that she already knows what her health professionals are going to tell her, she just does not listen to health professionals when they talk this way to her. However, Gemma’s story suggests that she knows that the advice is important to her wellbeing. By taking her partner along to listen, and to act as an intermediary, he is then able to act as a conduit and encourage her to act on that advice.

Talking about complications. Just as talking about metabolic control can be a sensitive issue, so can talking about complications. One young woman’s experience suggests that being explicitly told about the threat of diabetic complications may be frightening. Ruth, a recent immigrant to New Zealand, was explicitly informed about complications by health professionals in the country of her birth:

Ruth (16 years): Yeh, they just told me about the eye, the blindness, and also you can have your legs removed, and also kidneys. Yeh – that’s what they told me (p). I felt so scared. I just wake up one day and feel scared. Sometimes I think “ooohh, what’s going to happen to me in the future?” But now I feel I can live long now (p) by keeping healthy.

In the country of her birth, Ruth was told quite bluntly what the ramifications of diabetes might be “*you can have your legs removed,*” a daunting statement for any young person. Her story suggests that her worry was exacerbated by the lack of easily affordable healthcare in her home country:

Ruth: Yeh, it’s very different now. Cos now I can see most of the people that are diabetic – ‘cos in my country they consider diabetes a killing disease. We always be treated like going to the hospital, and like you can die from it. But since I came here, I am living my life, I can live longer..... ‘Cos here you get checkups, but in my country you just have to pay for those. You don’t just go and see a dietician, you just have to pay. So sometimes you just have to live with that, ‘cos you can’t get treated, it is too expensive. Some people, they don’t have enough to buy, so they just have to live with that. And then they will have high blood sugars and they will die from it.

Ruth compares her country of birth, where there is no expectation that the state will take care of your health, to New Zealand, where public healthcare is a birthright for New Zealand citizens. Ruth's story suggests that, in the context of limited access to the healthcare in her home country, the graphic description of complications was very frightening. Ruth indicate that she is very compliant with her regimen. However, whether this stems from fear induced by graphic descriptions of complications, an appreciation of comprehensive free diabetes care, or some other factor is unclear.

The stories of the health professionals and the young women suggest that Ruth's experience of being starkly informed of complications is unusual and may reflect her country of birth's health system. The health professionals indicate that, drawing on the biomedical model they are mindful that young people should be informed about diabetic complications, but their stories suggest that they are aware that being explicit may be counterproductive. For example, HP5 describes the way that he approaches such conversations:

HP 5 (Endocrinologist): Usually I frame it as like "we all know the risk of complications." I sort of treat it a bit like an assumed thing. Once again in that adolescent age group, particularly the young adolescents, it's a pointless argument. They don't want to live to an old age (laugh); it's just not a relevancy to them. But umm I do tend to focus a lot more on their more immediate complications like going low at a party or something like that. Or just feeling like rubbish in general, a bit under the weather. Or not performing well on the sports field, something like that. The sort of things that are a bit more relevant to them. And then, there will be the long term benefit as well for them. And of course as they enter into adulthood, those long term things become a bit more important to them. But it's yeh, you know, you can't tell a 15 year old that eating fat is going to cause a heart attack. (laugh).

The ways in which the health professionals frame their message suggests that they understand that young people are more concerned with the here and now and do not generally focus on their future. Moreover, Beck (1992, cited in Balfe, 2007b, p. 243) proposes that technical knowledge alone does not deter young people from risk-taking. Reflecting this, the health professionals do not talk so much about kidney disease in middle age as problems they may face immediately if they do not manage their diabetes, for example the embarrassment of "going low at a party," which might be more likely to engage them in good practices than the threats to their health.

HP5's story that he tends to downplay explicit details of complications in favour of more immediate consequences that he perceives as more relevant to young people is congruent with the stories of many of the young women. Whilst they understood that good self-care increased their chances of long-term good health, unless they had experienced diabetic complications, their understanding of the consequences of poor control was somewhat amorphous. For example, Gemma comments:

Interviewer: So, what have they told you about complications?

Gemma (20 years): Just that they happen. I've probably read more about it in books than they actually told me, probably 'cos they don't want to scare me.

Gemma's story suggests that health professionals avoid being explicit about complications in order to avoid scaring young people. However, Charlee's story suggests that if health professionals perceive that young people are engaging in risky behaviours, that this may prompt them to be more detailed about the risks associated with poor metabolic control. However, as her story suggests, even stark warnings may not provide a deterrent for risky behaviours:

Interviewer: Did they, when they were talking to you about it, did they warn you about the sort of things that could happen?

Charlee (18 years): Yep (p) but until it happened, I didn't believe it (p) and even then I was still in denial about it.....

Interviewer: So when you say you didn't believe it, you thought it couldn't happen to anybody, or it couldn't happen to you?

Charlee: I just thought I was invincible.....

.....

Charlee: It was always about my kidneys and stuff, and because they did tests for that and the results were OK, I always thought I was going to be fine. What I am doing obviously doesn't matter.

Interviewer: Do you think they could have told you more?

Charlee: Ummmm. I don't think it would have phased me at all. Once I was in that mindset, I don't think they could have got me out of it. So I don't think (p) if they had talked to me before I got to that stage, that might have been a way to help me.

Interviewer: If they had used language like "you could go blind Charlee?"

Charlee: Well they did.

Interviewer: They did?

Charlee: Yeh

Interviewer: When did they say things like that to you?

Charlee: (p) I dunno (p). Probably after the 3rd or 4th time I had been in hospital. And they just asked if I was missing? It wasn't infections. It wasn't that my insulin had expired, or I was on the wrong insulin, or it had been left in the sun. There were just so many excuses that we came up with, or I tried to come up with to make everyone believe.....

Charlee thought she was “*invincible*.” Charlee implies that, because there was no demonstrable damage to her body, she was able to ignore the health professionals’ admonition. Whilst it is not clear whether earlier warnings may have deterred her from omitting insulin, once her weight loss obsession became entrenched, even stark warnings such as “*you could go blind*” had no impact on her behaviour.

The stories of the young women and the health professionals suggest that they are aware of a number of pitfalls when working with young people with diabetes. The health professionals describe the ways of talking about the quicksand issues of metabolic control and diabetic complications that they believe can establish, preserve and enhance the clinical relationship. The stories of the health professionals reflect a tension between fulfilling their obligations as a health professional in the medical sense, and their acknowledgement that the biomedical model

is but one aspect of care in a chronic illness such as diabetes. Hence they articulate the ways in which they tailor their message to their target audience, and “soften” the biomedical model approach. However, the stories of the young women suggest that some clinical experiences can undermine the functionality and resilience of the clinical relationship. Metabolic control and compliance form the nuts and bolts of a diabetes consultation, but are often underpinned by other issues, such as body image, eating, insulin, and weight.

Talking about eating, weight and body image. As in the general population, some young women with diabetes are likely to engage in eating behaviours that their health professionals might advise them not to, for example eating a diet with a large amount of junk food or restricting food. Young women with diabetes have an additional, dangerous, tool, insulin omission. The stories of both the health professionals and the young women suggest that body image, eating, insulin and weight issues can be sensitive and difficult issues to address in clinical consultations.

Talking about eating. The stories of the health professionals suggest that they are careful when talking about diet. Dieting and dietary restraint have been identified as risk factors for issues with eating (Colton et al., 2009). Therefore, the ways in which eating for diabetes is perceived by the young person may be important in avoiding eating disturbances. The stories of the health professionals suggest that they try to normalise eating for diabetes. Newer and more flexible insulin regimens mean that individuals are more able to eat a wider variety of food and adjust their insulin accordingly. HP4 describes the ways in which she talks about eating:

HP 4 (Dietician): But a lot of the diet sheets, there's the traffic light scenario – green eat lots, amber-have these but go easy – protein and carbohydrate, which you need for growth and development, and red – don't have. And there's a list of things, sugary things. But you know the written information and pamphlets and medical advice is geared to a level of understanding, somewhere like a 12 year old level of reading, so things are often put a bit black and white (p). I'm sure all dieticians generally would say “you can whatever you want, but it's just how much, and how often.” I mean for healthy eating you shouldn't be eating lollies every day. No-one should. You know things like tooth decay and things like that.” So we do try and have the allowance to have things, but it's how often they are doing it. So in her mind it might be like “gosh, I'm not allowed to have that anymore,” and you can like take that on board, and it's a

bit of a traumatic experience. It's all you can hear sometimes. So you have to be careful to repeat the message a number of times, and there are time constraints.

HP4 talks about “*healthy eating*” rather than dietary restrictions. However, whilst a healthy diet is advisable for all young people, this is in conflict with popular culture, which promotes foods laden in fat, salt and sugar and alcohol. This may create a gap between what HP4 considers to be healthy eating and what a young person might perceive as “normal” eating. Moreover, HP4 alludes to the problems with communicating such health messages. Between what is said and what young people actually hear, it may mean that young people will feel that their food options are quite restricted. Moreover, even though newer regimens made possible with the introduction of improved insulin options are less austere than older regimens, the matching of insulin with food may mean that young people with diabetes feel that they are on a diet with many rules and regulations. For example, Laura’s story suggests that eating and insulin regimens are a complex area:

Laura (25 years): Just how, they kind of want you to be really perfect; can't eat anything whatsoever with sugar. And it's kind of like well, I ordered sugar-free lollies and chocolate over the internet, and they are so horrible, I don't even bother. And I've done a few things with the dietician and you write down everything you eat and drink, and the fitness you do for 7 days. And it's been healthy, maybe a muffin here or there, and it's kind of like well “you shouldn't do that.” You know? (laugh). I just always have it in my mind “you don't have diabetes so how would you know?” I think if I had a doctor or nurse with diabetes, I would do what they say, but that's the way that I think when I see them.... But I mean, I understand why they do it. But I would listen and do more if the person had diabetes. Like last time I went, I had a meeting with the nurse, 'cos we were going to do insulin for the carbs I had, and we got our wires crossed. And I thought she said, 'cos she gave me a calculation. The dietician was there, and she said she wasn't sure how much carbs in margarine, bread, coffee – you know breakfast. So she made up what she thought the carbs were for each one. And she made up a calculation and said “this is the calculation that you would use.” And I said “would I do this every time I eat and take my insulin?” And she said “yes,” but she was meaning must for breakfast. And then I did it for a week, and I couldn't get my blood levels down from 20. And I was testing my blood every 2 hours, and doing the calculations, and taking the insulin to the calculations. And I had to ring, and I said “look, I can't control

this. My sugar has never been like this ever.” And that’s when we worked out that she only meant breakfast. And it actually took a month for me to get back to how I used to be. Yeh.

Laura was clearly distressed and frustrated by what she perceives as the mismanagement of her introduction to the carbohydrate counting method of managing eating and insulin, and her story describes the complex and technical nature of diabetes management. Her story suggests that she perceives that because her health professionals do not live with diabetes, she has a depreciatory view of the advice they offer. Moreover, her comment “*And it’s been healthy, maybe a muffin here or there, and it’s kind of like well “you shouldn’t do that.” You know? (laugh)*” suggests that the reality of eating for diabetes for her is restrictive. Her view contrasts to the eating for diabetes described by HP4, “*you can whatever you want, but it’s just how much, and how often,*” a statement in which she tries to normalise eating for diabetes, conveying that eating for diabetes is a matter of adjusting insulin to food intake. This contrast may represent a gap between how eating for diabetes is propounded by HP4, and what constitutes “normal” eating for a young person.

Perhaps reflecting what many young people may consider to be “normal” eating, most of the young women indicated that they often break the rules around eating and insulin, and a few of them admitted that they engage in less than healthy eating behaviours. The stories of those who are engaging in less than healthy practices suggest that some of them protect their eating behaviours in clinical situations. For example, Lucy describes how she behaves in clinical situations:

Lucy (16 years): I’m not too bad with my food. But I am addicted to V. So I have, it’s really bad – at least one V a day.

Interviewer: What did they say about that?

Lucy: I haven’t told them. I did try and stop. But it didn’t really work out.

I What do you think they’d say?

Lucy: "Oh, that's so bad. You shouldn't be drinking sugary stuff like that. What about water?" I do drink water and stuff as well.

Interviewer: Do they make a diet V?

Lucy: They do, but it's disgusting. (p). I also eat sausage rolls. When Mum and I come to Hastings, we go to BP and she gets a muffin. So, it's a habit.

Lucy's story suggests that she may perceive herself to be powerless over her V "addiction" and her sausage roll "habit." She also indicates that she knows what her health professionals would say about these eating behaviours, so she does not tell them. In this way, Lucy avoids the dissonance of being told not to do something that she has no intention of stopping. Lucy's story is congruent with findings in the literature that individuals with T1D "lie" to avoid admonishment from health professionals (Kyngas & Barlow, 1995; Murphy et al., 2011; Wikblad, 1991).

Despite the emphasis on healthy eating, and attempts to normalise eating for diabetes, the stories of the health professionals acknowledge that the science of managing food and insulin is imperfect. For example, HP3 comments:

HP3 (Nurse): Absolutely. In a perfect world this insulin would work for everyone, but it's not like that. And the reasons why it doesn't work will be vast and many. There are some people who have tricky diabetes, it's just tricky – they're not going to have good control. Their basal rate varies a lot. And if you have someone who has wide variation in what insulin they need before they put any food in their mouth, they're going to go low, or they're going to be high – they're never going to be in the middle. And those people pretty much need a pump. And with a pump, it doesn't matter what sort of insulin you've got. You just use a rapid insulin and the pump and in years to come, there will be much more of a technical aspect of it and most people will be on some sort of device like that, and you tell it what you are eating and bing bing bing it will give you the right amount. But until then, and until that becomes affordable, we're stuck with primitive, well not primitive, more primitive than the most flashiest way.

HP3's story acknowledges that, despite increasing knowledge and technical skill, diabetes management is still a matter of trial and error, because the response of individuals to insulin varies even "before they put any food in their mouth." Therefore, it seems that, whilst health professionals try and normalise a diabetes regimen when talking to young people, until HP3's "bing bing bing device" is invented and made widely available, young people are wedged between the complicated science of diabetes management and trying to live a full, "normal" life.

The complexity of the interactions between eating and insulin mean that, to achieve metabolic control within optimal limits, the individual should be mindful almost constantly, and attentive to blood glucose monitoring. HP5 comments on the possible ways that the eating and insulin interactions can impact:

HP5 (Endocrinologist): But I think there are some parents who are so scared of their children going hypo, which is a very real fear – it's not to say "don't worry about it," – who have probably I use the term "force-fed," which is probably a bit harsh (laugh), but who have kept them fed to protect them from going low. And whether this has had some impact on the child's eating, you know food, normality as they are growing up, I don't know. And certainly the adolescents are very frightened of going hypoglycaemic, because they look silly in front of their peers. But the problem is that they cut back their insulin to avoid that rather than eat more. You know in my experience, that's the bigger problem. They're not taking as much insulin rather than eating to protect themselves.

HP5 notes that fear of hypoglycaemia is an important issue for parents and young people alike. To mitigate the risk of hypoglycaemia, young people can protect themselves by being "force-fed" or taking less insulin. His story suggests that diabetes management can introduce disturbed patterns of eating or using insulin. This is congruent with suggestions that a diabetes regimen can be a risk factor for disturbed eating behaviour (Rodin et al., 2002; Surgenor et al., 2000).

Talking about weight and body image. The health professionals were asked how they might talk about weight with young women. They differed on whether they included routinely weighing young people as part of the clinic assessment. For example, HP1 and HP5 describe their thoughts:

HP 1 (Paediatrician): Well, I mean as a physician I think I probably have to [weigh them]. It's part of your assessment. It's a crude but reasonably helpful way of telling me if they are getting enough insulin, I mean if they are growing. And also, it's a reasonably sensitive way of telling me if they are insulin skipping – they won't put on weight, and if they have coeliac disease going on in the background they won't put on weight. So, I think I'm really stuck with it, but probably what I have to do, is just try and normalise it first and maybe just say "I always.." sometimes I always use the ploy, "I always discuss this with everybody I see.." again just to normalise it. So sometimes just say that "I always go through the growth chart with people, even though I don't always, but I do if I think there's a problem.

.....

HP 5 (Endocrinologist): No, no. Generally I don't [weigh them]. Not in diabetes clinic. Putting the focus on their weight for T1D is just wrong. Most young people, they are concerned enough about their weight.

HP 1 states "so I think I'm really stuck with it," articulating the tension she notes between the biomedical model, which holds that weight can be a useful measurement, and the potentially upsetting action of weighing young people. Hence, she seeks to normalise the practice, in an effort to ameliorate the potentially rapport-damaging effects of that procedure. However, HP5 states that he generally avoids weighing young people, as this may result in an emphasis on their weight that may exacerbate existing problems.

The concerns expressed by these health professionals are congruent with some of the stories of the young women. For example, Lexi and Mel describe their feelings around being weighed in clinic:

Lexi (18 years): I always get really nervous about that, 'cos I think "gosh, have I put any on?" You know it's that girl mindset. But in the last couple of years, I have gotten more confident, (p) 'cos my weight hasn't changed. (p) It's ummm, I always have that thought, just what happens if I have put on weight, and they say "you shouldn't be."

.....

Interviewer: So when you think about your weight, how do you feel?

Mel (25 years): Being weighed? Ummm, it's good. (p). But sometimes I don't like seeing what the numbers are.

Interviewer: Why is that?

Mel: Putting on too much weight.

Interviewer: Even though you know you had to put on weight?

Mel: Yeh, 'cos they said I just have to put on weight. (laugh) And then I can stop. But, I (p) just keep putting on more weight.

Interviewer: Are you worried that you might not stop gaining weight?

Mel: Yeh. 'Cos of the insulin. Makes me eat a bit more.

Despite not having had problems with weight gain, “*that girl mindset*,” means that Lexi finds the experience of being weighed anxiety-provoking. Mel’s story suggests that being weighed may be maintaining her body dysmorphic tendencies. Mel is recovering from a period of insulin omission when her weight dropped drastically, and health professionals are monitoring her weight and encouraging her to put on weight. As Mel was clinically underweight, her talk of “*not liking the numbers*” suggests that she has an unhealthy mindset about her weight, and being weighed may exacerbate that. Mel links insulin to weight gain, and her story suggests that she is fearful that when she reaches a medically approved weight, she may be unable to stop her weight from climbing. Accordingly, the stories of both the young women and health professionals suggest that the potential problems associated with talking about weight with young women can include fostering a mindset of weight control or weight loss.

The ways in which health professionals talk about weight in the clinical consultation may be pivotal in outcomes amongst this vulnerable group. HP2 takes a methodical approach to talking about weight gain:

HP2 (Endocrinologist): Often, ummm they will have, it may be one of the things that is of concern to them. So they may well have noticed that they have gone up a dress size, for example. So I start off by asking them how they they're doing. So, my general opening gambit is "how do you think things are going? Any problems you want to ask me about?" So that's an opportunity for them to raise the issue themselves. But if it's not raised at that point, then in order to make sure I don't miss anything, I tend to go through things systematically. So I think about glycaemic control and I think about microvascular complications, macrovascular complications and weight. So weight always gets thought about, and so it always gets discussed. And in general, it always gets discussed in the sense that I might just remark on the weight in terms of what it was before – and say "that's the same as before, or that's a bit less or that's a bit more." And if there's a significant change, that might be an opening, a way in to exploring why there might have been a significant change, and whether it's of concern to the patient, and whether something needs to be done about it, or are they not too worried about it at this stage – explore strategies by which changes in weight might be addressed.

HP2's story suggests that he leaves a space for the young women to bring up weight concerns themselves, and if they do not, he states that he finds a way to introduce the topic himself. However, some of the other health professionals' stories and the stories of the young women suggest that the parameters for talking about weight, if discussed at all, were in medical terms, rather than the young women's image of her body. For example, HP1 describes her "manoeuvring":

HP 1 (Paediatrician): Sometimes you can see that it is just a sensitive subject. They're not bringing it to you, but you can see that every time you see her, you can see that she is gaining weight. So sometimes that's an area of difficulty, if they're not bringing it to you as a problem. So, if her control is good, but she's putting on weight. If she's insulin omitting, it's not so difficult, because then you can explore that by saying that the glycaemic control is poor. But it's if she's putting on a bit more weight every time you see her, but then not complaining about it, then I do find that difficult. At what stage do you say, you know if she was on the 25th percentile and her height was on the, like this particular child that was on the pump, she was quite skinny for her height when I saw her 2 years ago, she was on the 25th percentile, and she is now heading up toward the 75th percentile. So she's not overweight, but I know that she has put on 10 kgs, and

that's when I find it difficult. I don't want her to think "The doctor has just said that I'm getting fat," and they're not bringing it to me, although I think she may be starting to with that comment from her brother. That is very tricky. I haven't got a good strategy for that. (p) Maybe what I should have done when she said "my brother's calling me a chipmunk," I should have said "how do you feel about that?" or maybe "why do you think he is doing that?" So maybe, once again I should have, but missed that opportunity.

HP1's story suggests that if the young person does not raise weight as a problem of their own volition then she is unlikely to talk about weight that is currently within a medically acceptable range. Accordingly, at least in this instance, HP1 talks about leaving an "opportunity" to talk about weight and body image untapped, as she worries that if she raises weight gain as an issue the patient may perceive this as admonishment. This concern may be valid, as this has been identified as a risk factor for eating disorders in the general population (Striegel-Moore & Bulik, 2007). However, health professionals are faced with a dilemma, as weight gain is also a risk factor for disordered eating in the general population (Gowers & Shore, 2001). Therefore, by not talking about weight gain, the health professional not only leaves the medical risks of increased weight unaddressed, but also any undisclosed issues relating to body image, weight gain and eating, which may be antecedents for disturbed eating behaviours.

The stories of some of the health professionals suggest that if weight is medically acceptable, then they may not raise weight as an issue, suggesting that they are mindful of how sensitive this may be for a young person. That there may be a reluctance to talk about weight, and feelings about weight, is congruent with the stories of the young women. Their stories suggest that whilst weight may be talked about in medical terms, their feelings about their weight and body image were not. For example, Laura relates her experience with weight loss pills:

Laura (25 years): Yeh, there was a thing about 3 years ago. I ordered some pills off the internet for weight loss, and it said not to take with diabetes, or ask your doctor. And I decided to take them anyway. And I think after, you still ate and everything, but you just took this pill. And after the 4th day, I was just walking to my car after work, and the side of my body just, I couldn't feel it. I felt like it had collapsed. So I stopped taking them, and I haven't had them ever since then.

Interviewer: What pills?

Laura: Ummm. Can't remember. It's when, you go on google, you know they always have advertising down the side. A couple of other people I know have taken them.

Interviewer: What tempted you to take them?

Laura: I think it's just that all my friends are petite (laugh).

Interviewer: 'Cos there hasn't really been a time that you have been worried about your weight? Or was there a time that you were?

Laura: I think it was more that I was tired all the time.

Interviewer: Did you tell your doctor?

Laura: No (laugh).

Interviewer: Do they talk about your weight at clinic, like are you happy with your weight?

Laura: No, they just go by weight, the percentage of fat and the HbA1c, and kidneys.

Interviewer: They don't ask how you're feeling about it?

Laura: No

Laura said several times in the interview that she was not concerned about her weight, yet she chose to access diet pills over the internet, even though the site stipulated that they were contraindicated in diabetes. She chose to take these unprescribed pills because her friends were “petite,” implying that whilst she is not overweight, she would like to be smaller. Laura’s story suggests that talk about weight at the clinic is limited to biomedical statistics, rather than a more holistic discussion around body image and satisfaction. By limiting such conversations to the nuts and bolts of weight, rather than a wider discussion around body image, it is possible that an

avenue of support for Laura was truncated. Similarly, Charlee's story suggests that her weight gain and her feelings about it were not addressed:

Charlee (18 years): I think maybe if they had (p) yeh, if they had talked to me about the weight when it first started happening, then maybe (p). Yeh (p) But I can't say that, cos I don't know.

.....

Charlee: I think (p) I dunno, no matter how old you are, or if you're a boy or if you're a girl, if you're having problems, you should have a counsellor to talk to (p) just cos it's such a big change in your life (p) so I think a counsellor, (p) mean if you don't want to see them, you don't have to, but it should be available....

.....

Mother: I think maybe they could have done something about her weight gain earlier. I mean, she put on, when she was first diagnosed, she was about 50 kilos, and she put on 3 kgs when she was 12. She went up to 75 kgs. Something should have been done in that time (p) to stop that happening (p). When she got up to 75 kgs and she was losing her hair(p). She was always really good at sport and she was always toned, really fit and healthy, but ummmm (p). Just with the extra weight and everything that was happening (p). Starting to get teased at school (p). She was called "Baldy." And "Double Ds." And I think if they had stepped in, just a couple of kilos over a healthy weight line, maybe if they had done something then, maybe she could have learnt to control it in a healthy way, rather than having to go to these extremes(p). But it was just glossed over. Same with the hair loss, it was just glossed over. We were thinking of getting a wig, but it was an autoimmune thing – they couldn't explain it. But, I mean at 13, she was just supposed to accept it – Ok I'm getting fat and I'm losing my hair. That's diabetes for you.

Charlee's mother uses the coda "that's diabetes for you" implying that she perceived that Charlee had little support from health professionals to manage her distress relating to weight gain and hair loss. Again, much of Charlee's story is narrated by her mother. Accordingly, her narrative should be viewed as her version of events. However, Charlee does not dispute her mother's interpretation of the unfolding events. By the time Charlee was referred to a Psychiatrist after her 8th or 9th hospital admission, her disturbed eating behaviours were well established, and she was very good at denying and hiding her behaviours. Charlee's story raises

the possibility of whether an earlier intervention to mitigate her distress and weight gain could have prevented her downward spiral into disturbed eating behaviour. However, these views are retrospective. Nobody, not even Charlee herself, can be sure that addressing her weight gain in the early stages could have been helpful.

Talking about disturbed eating behaviour. Disturbed eating behaviour may not be apparent. Even though insulin omission is often associated with unstable metabolic control, some of the milder disturbed eating behaviour may not be (Bryden et al., 1999), and poor metabolic control may be unrelated to disturbed eating behaviour (Hamilton & Daneman, 2002). The stories of the health professionals indicate that they do not routinely ask about disturbed eating behaviours including insulin omission, and that these behaviours are not usually obvious in the early stages. For example HP1 describes her thoughts:

Interviewer: OK. So, in general, you're sort of saying that you would only probe into disturbed eating probably only if you got some clues.

HP 1 (Paediatrician): Mmmm. Probably. I mean in an ideal world you would perhaps ask everybody, but the reality of clinical medicine is that you have a relationship with people first, and if you are too single-minded about it, you can blow that out of the water. So, and, it can be quite a touchy area, with, you know, parents either want you to ask, or they don't want you to ask, and you don't always know that ahead of time. You have to sort of judge it almost as you go. I certainly think it would be helpful if you thought there was a problem. But, as I say, there is that whole secrecy thing early on. Earlier on when you can, you know, really help to prevent it is probably when they're missing it really.

HP 1 refers to “blowing it out of the water,” alluding to the sensitivity associated with asking about such behaviours. In this way, she conveys the complexity of judging whether or not to ask about disturbed eating behaviour. Because these behaviours are not screened for, and are not always apparent, there may be young people who are engaging in these behaviours who are beneath the radar. HP 1 implies identifying disturbed eating behaviour early may allow for early intervention. Therefore, health professionals must gauge when and how to explore the possibilities of such behaviours with their patients. One of the possibilities open to health professionals is the use of a screening tool such as the DEPS. None of the health professionals

interviewed were using disturbed eating behaviour screening tools, and their views on their use were mixed. For example, HP2 and HP5 comment:

HP 2 (Endocrinologist): Those sorts of interactions, those sorts of intersections are really complex, and I wonder whether a “one size all” approach to those sorts of aspects of a person’s health is necessarily a good thing, and whether maybe approaching things in a kind of ad hoc kind of nebulous way is better.

.....

HP 5 (Endocrinologist): Don’t know, just don’t know. Yeh. I think, I would be a little bit worried if this was the only thing they did, they come in here and this is the only thing in front of them, and it’s like “oh oh, they are worried about my eating, and I thought I was here to talk about my diabetes.” (laugh). I’d be a little bit worried about that. But if it was put in the right context and frame of other checklists, it would be ok. Whereas as part of a general conversation, you can work out where in the conversation to plug it in. So I think there is the advantage of that, but in my experience you just often don’t have enough time, so the hard things get missed, or the serious underlying things. That’s where a screening test could be good.

The health professionals express their reticence about the use of screening tools, suggesting that using their clinical judgment may provide a useful way to probe into these behaviours. However, HP5 acknowledges that, with the limited time available for consultations, the more difficult issues may be missed. Whilst the HPs are not routinely asking about disturbed eating behaviours, their stories suggest that they have few qualms about asking about insulin omission if they suspect that this may be occurring, and were generally dismissive that asking about insulin omission might suggest the idea. For example, HP2 comments:

HP 2 (Endocrinologist): Nope. No. ‘Cos I think that there’s sometimes the same argument is used for screening about suicide isn’t it?

Interviewer: Yes...

HP 2: and there’s no evidence at all to suggest that that might be the case. So no. If, if ummm my intention in approaching things slightly indirectly sometimes is more to do

with keeping that level of engagement, not alienating them, rather than worries about putting ideas in their head.

HP2 indicates that asking about insulin omission might compromise rapport. Whilst most of the women indicate that they would be unperturbed if they were asked if they had used this practice, the stories of some of the young women suggest that the concerns that health professionals have about asking this question may be valid. For example, Lexi and Sian, who state that they were not omitting insulin for weight loss, describe their responses to being asked about it:

Lexi (18 years): I was like “What!!!! No!!!!” Because by this stage, I had grasped how important it was for me to have those injections, and it was like “you’re not taking them,” and I was like “I am doing everything you are telling me.” And I got out, and I was just about in tears..... I think it was more the trust. You know, I was doing everything I could, and I had been landed with this condition, and you know, it’s a lot to adapt to and to be asked, you know, “are you lying?” That’s pretty much what he was asking. (p) It was a huge deal to me (p) asking me this horrible question. (p) And it almost seemed to me that he was trying to shift the blame for my levels being up and down.

.....

Sian (16 years): I wasn’t taking my insulin ‘cos I don’t like needles, and they thought that I was doing it on purpose. And I was crying ‘cos I wasn’t doing it on purpose, and I didn’t even realise that that was why I was losing weight. I thought I must just be eating right and doing my exercise. But they kept telling me off and telling me I was doing it on purpose, but I wasn’t.

Interviewer: So, you say “telling you off.” What sort of language did they use?

Sian: They gave me like disappointed looks, and saying “you shouldn’t have done that.” And I just felt bad.

Sian states “*I just felt bad*” and Lexi refers to “*this horrible question.*” Their stories suggest that they were both very upset, and that the way in which they were asked about insulin omission was experienced by them as almost accusatory. These experiences occurred in the context of clinical relationships that Sian and Lexi describe as adversarial in many ways. Therefore, whilst

it is clear that asking about insulin omission was deeply upsetting for both young women, it is difficult to tease out how damaging this was in isolation from relationships that were problematic anyway.

When health professionals are considering if/how/when they might ask about disturbed eating behaviour including insulin omission, they are also mindful that young women may deny omitting insulin or disengage with services if they are omitting insulin:

HP 1 (Paediatrician): The ones that I have found difficult is when the child is quite compliant, denies there is a problem, but you can see her control is poor, and she denies skipping insulin. Mum's worried, but she doesn't, you know. I have had a few of those, and they are more troublesome. It almost doesn't matter what you say, they are not going to say that a) they are skipping or b) that they are skipping to control their weight. So, that can be more troublesome.

Interviewer: And why is that do you think?

HP 1: I think that that is the hallmark of eating disorders in general, the whole, secrecy, denial thing.

.....

HP 3 (Nurse): But quite frankly, the ones that strike me as scary are the ones we see in hospital who have had another admission for diabetic ketoacidosis, 'cos they've stopped taking their insulin. They underdose habitually. We hardly see them in here. We chase them. We go down little alleys, you know the dogs barking in a rundown place and all the letters from the letterbox are all over the driveway. And she is over 20, but you know, you think "there is something very wrong here." But engaging? I engaged with her when she was in ICU. Then tried to get her to come in. I visited her, but she's not home. And she doesn't have a cell phone. And in her instance there is drugs and alcohol as well. Tricky. And I talk with the specialist about how we might, you know, get her in, and sort of, yeh get some relationship, some bargaining piece. You know, and pretty much we will bargain whatever we need to – she needs insulin.

These concerns about denial and disengagement are congruent with Charlee's story. For five years, Charlee manipulated her insulin for weight loss, and denied that she was doing so.

Charlee (18 years): 'Cos I wouldn't admit it. I just denied, denied, denied.

.....

Charlee: Well they pretty much knew didn't they? Well, I had to come here and take my insulin. I had to come to the hospital and they would watch me take it, But, I was taking out my insulin and just putting water in the vial.

.....

Interviewer: When you were not taking your insulin, were you coming to the clinic?

Charlee: For a bit I was. Then I just realised they were going to find me out, so I stopped coming.

.....

Charlee: Yeh, 'cos for 2 or 3 years, I got really good at hiding it. Yeh, 'cos people would say "you haven't been in hospital for a while," Like "good on you" – stuff like that. Yeh, but it wasn't 'cos I was being good, it was 'cos I was hiding it so well.

Interviewer: Meaning that you were hiding how sick you were?

Charlee: Yeh, I was definitely sick enough to be in hospital...

Mother: Yeh, you were just taking enough insulin to sort of get you right. You'd treat yourself without telling anyone.

Charlee: I know when I had a really bad day, and I just had to shoot myself up....

It is clear that Charlee avoided medical surveillance to protect her insulin omitting behaviour by disengaging with the diabetes clinic and using just enough insulin to avoid hospitalisation. However, after what Charlee describes as her “wake up call” when she was admitted to Coronary Care and doctors told her family that she may die she states that she will not omit insulin again, and has re-engaged with the diabetes service:

Interviewer: OK, tell me what happens when you come to the clinic.

Charlee: Ummmm, it's like a big relief off my shoulders.....

Interviewer: Tell me about that.

Charlee: I dunno, it's just(p) ummmm (p). I kind of feel proud to come. Even though I'm not doing that great, but compared to what I was. And I don't have to lie anymore and (p) so it's good...

Charlee's story demonstrates that once her disturbed eating behaviours were entrenched, she would go to great lengths to protect her behaviour. Moreover, because her behaviour was well established, the opportunity for early intervention was lost. Therefore, the risk is that health professionals may miss an opportunity to pick up on disturbed eating behaviour, particularly in the early stages. The behaviours may only become apparent when they have seriously impacted on metabolic control, by which stage they are also likely to be entrenched.

Summary.

The health professionals describe the ways in which they attempt to “soften” the focus on disease monitoring activities by, for example, limiting the use of pejorative language, such as “good” and “bad.” However, whilst they acknowledge that young people with T1D face many difficulties and they work to accommodate adolescent behaviours, their focus is on disease-monitoring activities. This focus may reflect the nature of diabetes management. For example, health professionals attempt to normalise eating for diabetes as healthy eating. However, the reality is that eating for diabetes was perceived by most of the young women as restrictive and difficult. The focus may also reflect time constraints mentioned by some of the health professionals. The stories of the young women suggest that they perceive the clinical experience as biomedically oriented. Some young women related that the ways in which some interactions were conducted, for example, talking about unstable metabolic control or asking about insulin omission, were alienating for them. Talking about weight was a sensitive issue, and the stories of the health professionals and the young women suggest that conversations about weight, if conducted at all, were often limited to medical facts. This meant that weight gain that was not medically exceptional was not always addressed. Talking about weight gain can introduce or

exacerbate body image problems, a known antecedent for disturbed eating behaviour. However, not talking about weight gain potentially leaves dissatisfaction with body image unaddressed. Similarly, whilst the health professionals were asking about disturbed eating behaviours including insulin omission if they suspected that these were occurring, they were not routinely screening for these behaviours. Because disturbed eating behaviour may not be apparent, this means that the behaviours may become entrenched before the health professional suspects that the young person is engaging in them.

Chapter 9 - Shaping the Stories

Chapter Overview

The stories of the young women and the health professionals do not exist in isolation, but rather reflect the social, political, cultural and historical milieu that the narrators live within. The stories are shaped by dominant narratives, or public narratives, that are socially available. Public narratives are an “overarching story told by a culture” (Smith & Dougherty, 2012, p. 454) that “reflects the values of the dominant culture and set the standard for normative behaviour” (Bergen, 2010, p. 47). In this way, the contextual nature of the stories of diabetes can be understood.

The themes that emerged in the *Lived Experience of Diabetes* stories are informed by several public narratives. Some of these narratives, labelled “being normal,” “the diabetes diet,” and “self responsibility,” influence the young women’s stories of their health behaviours, including compliance and eating. The *Lived Experience* stories, as well as the *Clinical Experience of Diabetes* stories are also informed by other public narratives that define clinical relationships, specifically the “health professional as expert,” and the “health professional as partner.” The analysis shows that these public narratives define the roles of health professionals and patients, and shape the young women’s expectations for their clinical relationships. Also influencing the stories of the young women’s health behaviours and clinical relationships are the public narratives related to weight and body image, namely “the thin ideal,” “overweight people are lazy and undisciplined,” and the medical public narrative, “the healthy weight.” The narratives are inter-related, and the analysis shows the ways in which they interact, the ways in which they are in conflict, and the ways in which they are resisted.

Public Narratives that Influence Health Behaviours

Being normal. The stories of the young women made numerous references to wishing to be “normal.” That “being normal” constitutes a public narrative, especially during the adolescent and young adult developmental stages, is supported by a body of literature. Young people strive to belong to and not stand out from their social group (Wills, 2005). This is congruent with findings from narratives of young people with depression who, above all else,

desired to “be normal, to be and behave like others, and to be accepted” (Danielsson, Samuelsson, & Johansson, 2011, p. P615). What constitutes “normal” is not an absolute, but rather is defined by the observations young people make of their social groups and wider social contexts (Lloyd & Moreau, 2011), for example, the media (Danielsson et al., 2011). Moreover, as Lloyd and Moreau (2011) concluded from the narratives of young people with depression and social phobia, being “normal” may be an “idealized, other state” (p. 593). The importance of this striving to be “normal” and to belong for health professionals is that young people may engage in seemingly irrational health-damaging behaviours, underpinned by a need to conform to the peer group (Stead, McDermott, MacKintosh & Adamson, 2011). Congruent with these findings, HP3 comments on the pressures that she perceives face young people with diabetes:

HP 3 (Nurse): Well, it's a reality. Not just eating chocolate and fish and chips. Going and having a drink on a Saturday night. You know this is normal life for a young person. For people in their young adult years, and so all of those things will impact on it. And so, ummm (p) mmmm, that's where I think there's a lot of pressures on young people. And young women, and I think young men as well, that they have to fit into a certain sort of thing. And you put diabetes into it, and it does the parents heads in, and if it's doing the parents head in, then it's going to play havoc with young people. You know, just working out where they fit in.

HP 3 reflects on the “*havoc*” that may occur when “normal” life meets diabetes management. Not only are “*eating chocolate and fish and chips*” and “*having a drink*” pleasurable pastimes, but they also provide a social currency for conforming to the group. Most of the stories of the young women told of their difficulties in accommodating these “normal” behaviours within their diabetes regimen.

Some of the young women’s stories describe the problems associated with drinking alcohol. For example, Laura comments:

Laura (25 years): When I turned 18, there was a lot of drinking (laugh). When I was at the pub, my blood sugars were high – but then half way thru next day, down to about 2. So I always found that. Yeh it was quite hard when all my friends were going to parties, ‘cos if I didn’t have my insulin, I couldn’t be at someone’s house and just stay the night. So I used to get quite annoyed.

Laura's story implies that "a lot of drinking" is "normal" for a young person to engage in. That binge-drinking in New Zealand is a part of adolescent culture is high-lighted in the New Zealand Law Commission report on Sale and Supply of Liquor (2010) findings that alcohol-related harm was a significant problem amongst this group. Moreover, it has been posited that youth with T1D often drink alcohol to fit in with peers (Balfe, 2007b; Miller-Hagan & Janas, 2008; Wills, 2005). That drinking alcohol, and even that binge drinking, is, at least in part, influenced by conforming with the group, is supported by the findings in a study of drinking stories amongst Danish youth. The popularity and ubiquity of drinking stories, and the enthusiasm with which they were told led Tutenges and Rod (2009) to conclude that drinking stories may comprise an "epic genre of their own," and that, in part, youth tell drinking stories, even "seemingly vulgar stories" to "constitute narrative identity" (p. 355). Intoxication has been described as an integral aspect of youth culture (Gundelach & Jarvinen, 2006, cited in Tutenges & Rod, 2009, p. 355). The stories of the health professionals suggest that they are aware of the pressure to conform by drinking alcohol. For example:

HP4 (Dietician): But also being really frank with your questioning. And I know [the doctor] is very good at that. He talks about, particularly the drugs and alcohol thing. He's like "I know you'll be drinking, so tell me how much."

HP4 implies that, whilst drinking alcohol can cause unstable sugars with highs followed by potentially dangerous hypoglycaemia, it is more useful to normalise drinking, and provide advice on drinking safely than promote abstinence. In this way, congruent with the stories of eating, the health professionals' stories suggest that they are trying to accommodate "normal" life within the diabetes regimen, rather than lecturing young people about what they should and should not do.

Many of the young women told of their temptation to eat fatty or sugary foods that they have been advised to avoid. For example, Ruth comments:

Ruth (16 years): 'Cos controlling the sugar is very hard. 'Cos young as I am I still want to eat more things that I am not allowed to, 'cos of what I see at school some times. Sometimes, you just have to tell people "I'm diabetic." 'Cos some people, they just don't understand it.

In her story, Ruth describes her predilection for sugary foods as a result of her sweet tooth. However, she also implies that what she is “*allowed*” to eat differs from what others at school eat, and that there may be some coercion from others to eat what others are eating. Her story suggests that she must explain why she chooses not to eat these foods. Therefore, not only does Ruth have to contain her own temptation, but her willpower is further challenged by social pressure and the wide availability of unhealthy foods. In contrast, Lexi comments on the censure she has faced if she chooses to eat unhealthy foods:

Lexi (18 years): And you just go “stuff the healthy food – bring on the junk food.” People go “how can you do that to yourself?” And then they always bring it back to your diabetes. And, wow, it’s just like can you just treat me as a normal person? (p) Wow, if my levels are going to react to it, they’re going to react to it.

Lexi’s story suggests that, at times, she wants to behave in a “normal” way as if she does not have diabetes. Having made that decision for herself, Lexi relates that she faces censure from others as they step in to police her diet. That they do so indicates that medical discourse relating to a “diabetes diet,” with stringent rules relating to, in particular, sugary and fatty foods, has pervaded lay discourse, and hence has become a public narrative. Lexi’s experience suggests that this narrative defines what people with diabetes should and should not eat. Paradoxically, as Lexi’s story suggests, helpful policing may not always be conducive to compliance.

Diabetes diet. HP3 comments on the pervasiveness of the narrative relating to the “diabetes diet”:

HP 3 (Nurse): And there is a popular belief that the food you eat has to be strictly controlled. And that, it used to be through the health sector. And it’s a popular belief now, ‘cos people used to say “you must eat these things. You must not eat these things.” You know people told me that. And the parents, they say “I’ve cut out all the sugar in his diet.” And I say, “well, that’s not – well look at him, he’s skinny.” (laugh) “We don’t want him to lose weight. We want him to put on weight.” So I think the emphasis on blood sugars, on keeping good control, that you do this by looking at what you’re eating, adjusting your insulin, testing all the time – it’s a ripe field for obsession to come into play. And keeping it normal is kinda really important.

HP 3 indicates that medical advice relating to what people with diabetes should and should not eat influences the ways in which people expect individuals with diabetes to behave. As HP3 suggests, this pervasive narrative is not always helpful, and, further, is not always accurate. As HP3 indicates and HP4 elaborates on, this public narrative is based on outdated medical advice:

HP 4 (Dietician): Diets were prescribed, but the ways of eating changed over decades and we have become more relaxed about it, we are not prescribing. But in saying that we do carbohydrate counting. But in saying that, it is not to restrict or manage how much they eat, but to increase their ability to manage, to give them flexibility. And that's how we sell it. It allows you to live normally. So that if you do want to have that ice-cream in an afternoon, don't worry about it, you can. What we are saying is how many carbs in that, and take the insulin you need for that. Some people think "oh carb counting, sounds like a diet." Connotations like that. But it's not a restricted pattern or plan written down – it's nothing like that. As much as we are trying to promote healthy eating for your life, it's not just about diabetes. It's just normal. It's how we should all be eating. But unfortunately society throws a lot of messages out there, and we're doing a lot of silly things.

Whilst fundamentally food is fuel, in the Western world it is also associated with social activity, comfort and pleasure. HP4 describes the way in which food was medicalised for those with diabetes by referring to diets that were “*prescribed*.” HP 4 claims that the focus on food and insulin has changed over the decades from being a prescribed diet to more of a template for healthy eating. In this way, like HP3, she attempts to normalize eating for diabetes. Their comments suggest that they are mindful of the pressures that young people face, and that they attempt to work with the young women using newer regimens, for example, carbohydrate counting, to maximize the flexibility of eating for diabetes. However, whilst the health professionals attempt to frame the diabetes lifestyle as “*healthy eating for your life*,” the stories of the young women suggest that they have struggled at times to stabilize their metabolic control, and that the technical nature of the regimen, particularly when adjusting for exercise, creates barriers to being “normal.”

HP 4 alludes to the “*messages*” that young people are bombarded with, so that a healthy diet is not necessarily synonymous with a normal diet, especially in this age group. The prevalence of unhealthy food in the Western adolescent diet means that young people construe

eating junk food as “normal” behaviour. A skewed view of a normal diet means that despite this new flexibility, compared to their peers, young people with diabetes may still feel as if they are on a diet, which compromises their ability to conform to the group. That the eating behaviours of young people are influenced by the need to conform has been demonstrated in the literature. For example, Wills (2005) showed that changing peer groups was related to the adoption of new eating habits, and that young people tended to adapt their behaviour when socialising with particular groups. Further, in their qualitative research identifying barriers to healthy eating, Stead et al. (2011) found that it was a social risk to choose to eat healthy food, and that such choices carry the risk of being marginalised from the group. Therefore, Stead et al. conclude that promoting healthy eating is not only about accessibility, but must also acknowledge the pressures that arise from the need to conform. For those interested in promoting healthy eating, for example diabetes health professionals, these could be worrying findings, particularly since young people in general may be more likely than others to consume more junk food (Henderson, Gregory & Swann, 2002, cited in Wills, 2005, p. 98).

Diabetes is a hard taskmaster, and most of the young women told of times of poor control, despite their best efforts. The young women’s stories suggest that sometimes risky behaviours were motivated by their view of a “normal” life, which in the face of the day to day grind in managing diabetes lead to a state of weariness of diabetes management. Most of the young women told of times when they knew that they engaging in behaviours likely to compromise their diabetes management, but, as demonstrated in the thematic analysis of *Fear for the Future*, fear of complications did not always motivate the young women toward compliance, as Jess’ story demonstrates:

Jess (24 years): Well that’s the thing. I can’t remember the last time it was below 9%. And they want it around the 7%. So I think it was definitely around that through high school. But maybe it was ‘cos Mum was keeping a closer eye on me (laugh). And now I’ve got the freedom, I’m just letting it slip a bit. Yeh, I don’t, overall I don’t feel ill. But then I don’t know how I’m ‘sposed to feel if my HbA1c is under control. It might be that I would have a lot more energy, but I just don’t know.

Interviewer: How have they talked about complications with you?

Jess: Just kidneys and eyes really. I see the eye specialist once every year I think. But they do notice that there is something wrong in my left eye, but it's marginal, so it's not. If it gets worse, then they will think about lasering it or something.

Interviewer: When you consider that, how do you feel?

Jess: It's hard to say, because there's an issue there, but you wouldn't know. I mean I don't know, I can see out of my eye perfectly fine. But who knows, 2 years down the track, if I start losing my sight, then that Just would be horrible. That's a bit daunting, (p) yeh.

Jess' story, like many of the young women's stories, points to a complex relationship between fear of complications and compliance. Her story suggests that many of the complications of diabetes are insidious. Whilst Jess is concerned about the effects of her lack of control on her eyesight, her talk, "I'm just letting it slip a bit" implies that this protracted fear does not guarantee compliance on a day to day basis.

Self-responsibility. Oftentimes comments about unhealthy behaviours or not worrying about complications were interspersed with contradictory statements. For example, Lucy comments:

Lucy (16 years): I'm not really into healthy eating, so that's kinda off the list. I'm into exercise. I walk to school every day over the hill. So that's about 25 min each way. And I go to the gym 3 or 4 times a week.

Lucy's claim to exercise, a healthy behaviour, serves to offset her stories about eating junk food. This claim implies that she takes a degree of responsibility for her health. That there is a moral virtue in taking care of one's health informed many of the stories of the young women, and reflects the "self-responsibility" public narrative. Brown and Duncan (2002), Broom and Whittaker (2004), and Stephens (2011) suggest that there is virtue in taking steps to avoid ill-health, reflecting the 'responsible citizenship' tenet promulgated by neo-liberal forms of government (Howson, 1998, cited in Brown & Duncan, 2002, p. 366).

The “self-responsibility” public narrative is in conflict with the being “normal” public narrative in two ways. Firstly, being responsible for the self behooves a young person to look beyond the “personal fable” (Elkind, 1967, cited in France, 2000, p. 319) that “it won’t happen to me” by weighing up the likelihood of potential consequences. Secondly, as a result of this weighing up, the likelihood of engaging in risky behaviours is eroded, even if this means standing out from the group. This conflict manifests frequently in the stories of the young women, and they engage in rhetorical work to mitigate the conflict. Firstly, as in the example of Lucy above, many of the women introduced claims to healthy behaviours to mitigate the unhealthy, irresponsible behaviours. Secondly, the women also defended themselves by outlining the restrictive and challenging nature of diabetes. For example, Laura comments:

Laura (25 years): It has its ups and downs. Sometimes I have good control, sometimes it's about 10 or 11. But since I have been diagnosed, I haven't had a lot of routine. Like with studying and training, then I'm not studying and training. I work, then I won't be working. So it's hard to work it all out. 'Cos they say you get used to it and work out your meals. But it's been hard, you know classes at different times, every day, and you're like exercising around that, so everything is just going to be different.

By explaining the ways in which diabetes makes living her life more difficult, Laura seeks the understanding of the interviewer. She implies that diabetes is not fair. In doing so, she resists the “self-responsibility” narrative, asking not to be judged by the same standards as non-diabetic young people, who do not face the same challenges.

That a narrative of “self-responsibility” manifests in the stories of young people, members of group which are often less concerned with the long-term consequences of their behaviour, is perhaps a little unexpected. However, it is congruent with the theme that emerged in the study by Huus and Enskar (2007) that young people with T1D value taking care of themselves. The influence of this narrative in the young women’s stories may reflect their exposure to medical discourses and also their first-hand experience of the short term consequences of risky health behaviours, the sequela of which may not manifest for decades, if at all, for their non-diabetic peers. Dovey-Pearce et al. (2007) describe this as a “coming to terms with risk and mortality” (p. 75) as a result of having diabetes.

In summary, the public narratives that influence health behaviours create a crucible of competing tensions for the young women. Their stories suggest that having T1D introduces barriers to being “normal.” These barriers may be exacerbated by the medical public narrative of the “diabetes diet,” which may encourage unhelpful interference from lay people, and the prevailing culture amongst young people, in which eating junk food and drinking alcohol are the norm. The young women’s work of being “normal” is carried out under the influence of the competing public narrative, the “self-responsibility” narrative, which introduces an imperative for individuals to take care of their health. The resulting tension manifests in the stories of many of the young women, as they talk of being frustrated with, or even overwhelmed by, the restrictions foisted on them by diabetes.

The Clinical Relationship Public Narratives

Health professional as expert v health professional as partner. The stories of the young women suggest that they have had significant exposure to medical discourses, which manifests in their talk, for example, they talk of “highs,” “lows” and “complications.” Talk of this nature is informed by a scientific approach to disease management, namely the Biomedical Model, which informs the “health professional as expert” public narrative. The biomedical model “assumes disease to be fully accounted for by deviations from the norm of measurable (somatic) variables. It leaves no room within its framework for the social, psychological, and behavioural dimensions of illness” (Engels, 1977, cited in Kontos, 2011, p. 509). The biomedical model defines the roles that participants in the clinical relationship should play; the health professional is the expert or the authority figure who dispenses wisdom that the patient should unquestioningly follow. Lupton (2012) relates, how at the turn of the 20th century, the views of the patient had ceased to be relevant, and the responsibility for disease management had become the preserve of the physician. This model for clinical relationships has persisted into the 21st century. For example, Kinsella and Garland (2008) state that the general expectation of individuals receiving healthcare is that they will assume a passive role and that the clinician will solve their problems. Similarly, a qualitative study by Wilson, Brooks, Proctor and Kendall (2012) demonstrated that patients’ expectations in chronic disease management were shaped by a biomedical discourse, and that the patients were more comfortable when they perceived their health professional as “diagnostician, prescriber and medical manager of their condition” (p. 2).

However, Lupton (2012) relates that there came a time of transition, as doctors were exhorted to take note of the social context of illness. As Western health systems moved to a more patient-centred, collaborative model of care, Lupton notes that patients' "obedience to medical advice could no longer be assumed" (p. 85). Accordingly, this can be viewed as resistance to the "health professional as expert" public narrative, in the form of a public narrative relating to the "health professional as partner." For example Pilnick and Dingwall (2011) refer to the reform of medical practice that has taken place in Western countries over the past four decades, from relationships that were dominated by physicians to more patient-centred practices. Moreover, whilst some adolescents with chronic diseases stated a preference for a passive role, others have begun to talk about, and expect a relationship with health professionals that is based on a partnership model, which allows them to participate in treatment decisions (Jedeloo, van Staa, Latour, & van Exel, 2010; Knopf, Hornung, Slap, DeVellis, & Britto, 2008).

The two different roles of health professionals can be identified in the stories of the clinical relationships. For example, Lexi's experience of two different services exemplifies the roles defined by the "health professional as expert" and "health professional as partner" public narratives. Lexi talked of a time when she was engaged in a dysfunctional clinical relationship, where her perception of the health professionals was:

Lexi (18 years): "We know what's best.""We know better than you."

In Lexi's story, a change in diabetes service providers brought about a change in perception of her clinical relationship. For example, Lexi states:

Lexi: I think that's [trust] really important too. I mean, I have to be able to trust them and they have to be able to trust me. And you know, it's really hard for them, 'cos they don't know exactly how I feel. I can only tell them. They can only get sort of an idea, and um, it must be so difficult to work out exactly where to go and what to do. Whereas, I'm sitting there going "this works for me and this works for me" and they're going "well that does not work for everybody else" and I'm going "well I'm not everybody else." Yeh, and um (p) you know, I will try their suggestions, I will try. But if it does not work then I won't do it.

Lexi implies that when she describes how she feels to health professionals, some of her message may get lost in translation. Lupton (2012) refers to the effort required to understand the young person's experience as "cultural brokerage" (p. 87). However, despite the effort required, Lexi refers to her current clinical relationship as being based on "trust," and she implies that, compared to a time when she perceived that she was told what to do, she is more comfortable in her clinical relationship. Her story suggests that as she moved to diabetes services that she perceived as more collaborative, her relationship with the health professionals improved, and so did her metabolic control. Lexi's story is congruent with the literature cited by Robertson, Mori, Skelton, Dowell, and Cowan (2011) which suggests that individuals undergoing health treatments want to be offered choices, and that collaboration is positively correlated with health outcomes.

As part of promoting good diabetes management whilst maintaining a functional clinical relationship, the health professional must gauge the most helpful way to discuss compliance, metabolic control and diabetic complications. The stories explored in the thematic analysis, *Focus on Disease Monitoring Activities*, are informed by the biomedical model public narrative, but the influence of the "health professional as partner" public narrative is demonstrable, as oftentimes the health professionals use more collaborative language to convey their message. For example, the analysis suggests that, congruent with a biomedical model, the health professionals feel it is their duty to discuss the consequences of poor metabolic control. However, mindful that young people may not heed information about long-term consequences, their stories suggest that they tailor their message in a way that they consider may be more likely to improve compliance by talking in terms of complications that were immediately relevant, for example, going low at a party, than kidney failure. Moreover, their stories suggest that they take a similar approach to talking about laboratory results:

HP3 (Nurse): I've got a little – we've got them in all the clinic rooms – and it's a sort of a rainbow thing – green at one end and as the HbA1c increases it goes over to the red. And I use that with lots of people, 'cos numbers don't necessarily mean anything..... So I show them the colour thing, and I put a pin there, wherever you are. Then ask "where do you want to be? What do you think that means?" Especially if it is in the red or yellow. Ummm. So, if you had a house in Christchurch, and it was in that zone, what would you think? You know, because it's topical. But usually I talk about the fire

danger. So I use that as a way of talking about, sort of a tool that gets away from the number and looks at where they want to be and where they are now.

HP3 implies that, whilst it is important to inform the young person that their HbA1c is not within a recommended range, she attempts to convey the message in a way that is not confrontational. She describes a Socratic style, using questions that invite the young person to draw their own conclusions. This way of delivering the message is perhaps less likely to be perceived as admonishment and as HP3 imposing her agenda for metabolic control on the young person. In this way, she is working in a more collaborative way. Similarly, HP2 describes his approach:

Interviewer: How do you talk about complications with them?

HP2 (Endocrinologist): (laugh) Ummm it depends. So sometimes, umm, it depends on whether I get the sense that they have – sometimes my way of managing my patients – our aim is not to manage their diabetes for them. If someone comes to clinic 4 times per year, that's 4 hours a year. So if we're managing their diabetes, that's 4 hours a year out of all the other thousands of hours in a year. So our aim is always to move people into a position where they are comfortable managing their own diabetes. So sometimes if I am having trouble engaging people with that notion, I will remind them the reason we worry about diabetes is because a) it can make people sick now, but also because we are trying to avoid complications later, and I will go through those – problems with the eyes, problems with the kidneys.... And the only thing they can do to modify their risk is to – well blood pressure control, but also glucose control. But foot care, if someone is really taking care of their feet and groom them, they're looking after them, they are wearing comfortable shoes, I'll make a point of mentioning that and tell them that is a good way to prevent problems in the future as a way of reinforcing that. And again, if someone tells me they are doing more exercise, then I'll reinforce that as a way of bringing down their blood pressure and cholesterol and so on. Exercise in general is good. So I'll think about the complications, mentally, in order, and if further work needs to be done, we might need to have a discussion around that. But also, where they are doing really well, we'll have a discussion around that.

HP 2's story suggests that he promotes a partnership approach by providing information and encouragement. However, it is not clear whether he does so because he believes this will culminate in improved outcomes, or whether it arises from necessity, as he is only able to engage with his patients a few times per year. His story suggests that he gauges his approach on his perception of what is likely to achieve the outcome that he desires medically, that is, compliance. He implies that if he senses that the young person may not engage with the partnership approach, he falls back on biomedical principles that poor control will result in complications, a kind of "carrot and stick" approach. In this way, his story suggests that his approach represents a blend between a biomedical and a patient-centred model.

In summary. The stories of the health professionals and the young women suggest that the two public narratives that define the clinical relationship, the "health professional as expert" and the "health professional as partner" exist in a state of flux. The young women's stories suggest that they resist the "health professional as expert" public narrative. Similarly, the stories of the health professionals suggest that, whilst they are aware of biomedical model imperatives, including the bottom line of metabolic control, they are mindful of the impetus to involve individuals in decision-making. However, their stories also reflect that there are limitations to a partnership approach. Accordingly the health professionals' stories of the clinical relationships are informed by both the biomedical and partnership public narratives, with the prevailing approach resembling a hybrid of a biomedical model infused with partnership principles.

The Weight and Body Image Related Public Narratives

The thin ideal. The stories of the young women and of the health professionals relating to body image and weight reflect the biomedical/partnership dialectic, potentiated by the powerful body image and weight public narratives. The stories of the young women often refer to being thinner, or being unhappy about weight gain, reflecting the "Thin Ideal" public narrative. That the "Thin Ideal" constitutes a public narrative is supported by the literature. For example, Ridolfi and van der Wal (2008) refer to a "sociocultural pressure for thinness" (p. 429), and Salk and Engeln-Maddox (2011) discuss the ubiquity of disparaging talk about the size and shape of their bodies amongst college women in the United States, referred to as "fat talk," which the authors claim is immediately recognizable to anyone who spends time with young women in Western cultures. The thematic analysis of *Diabetes, Body Image and Weight*

demonstrated that most of the young women were concerned about their body image, even if they were under or at a medically acceptable weight. For example, Sian comments:

Sian (16 years): Yeh, 'cos before I knew I had diabetes, I was actually happy 'cos I lost a lot of weight. And I always wanted to be skinny. And then I found out that I was actually sick, and I had to eat more. And then I put on weight again and I wasn't happy.

Sian's preference for being "skinny" reflects not only the western ideal for an attractive slim body, but that a body type that young people view as attractive and slim may actually be thin. This is congruent with the findings of a qualitative study of attitudes toward the "thin ideal" that whilst young women disparaged the "ultrathinness" (p. 73) of leading fashion models, their view of a "normal" attractive weight was of a sample with a Body Mass Index of 20, which is at the lower end of the normal weight range (Ahern et al., 2011). Burns and Gavey (2004) concur, arguing that cultural representations of what is aesthetically pleasing render the majority of female bodies as "overweight."

Healthy weight. The "thin ideal" public narrative is congruent with the "self-responsibility" and "healthy weight" public narratives. As Burrows, Wright and Jungersen-Smith (2002) acknowledge, "a slim toned body has come to signify self-regulation and worth, the sign of moral standing" (p. 41). Lupton (1996) concurs, referring to a "food/health/body triplex," in which outward appearance embodies the "inner worthiness" (p. 137) of its owner. It has been argued that the body dissatisfaction culminating from young women comparing their bodies to a "thin ideal" can be a contributing factor to disordered eating, but Burns and Gavey (2004) also argue that a discourse of a healthy weight "provides the cultural conditions that support, rationalise, and to some extent normalise, practices that are considered bulimic" (p. 561). They argue that whilst they accept that there are health benefits to good nutrition and fitness and that there can be health risks related to obesity, absolutely linking weight status to health can have a damaging effect. The stories of the health professionals suggest that they recommend that the young women maintain a healthy weight:

HP1 (Paediatrician): Of course if you put on weight that increases insulin resistance, so that makes controlling diabetes harder. So you don't want people to pack on the weight. It's bad for your cholesterol, bad for your blood pressure, it's not great for your

diabetes control. But it's probably a lesser problem for me than girls focusing on their weight and unfortunately diabetes sets you up to have to focus on your eating, detailing what you eat, so it makes it extra hard. I mean, I almost don't want to weigh the girls every time. I mean girls who are very conscious about their weight, will obsess about it "oh I have put on an extra kg" when it's probably the kilt that she's wearing, or she hasn't emptied her bladder or something like that.

.....

HP5: We address it if it's relevant to their needs. Because often we try and focus on their long term health. So, if they are significantly overweight, then that becomes is a part of it. But if they are just a little bit chubby or something like that, then that is not a major for their physical health. It might be for their mental health. So I tend to shy away from it, because I just worry too much that there is a focus on that than what matters more for their long term health. I mean if it is a question, then let's see what you do weigh to get a starting point and adjust our diet. Then I would refer them to the dietician, and we might weigh them to get a starting point to get some objectivity to it.

Their stories suggest that whilst they would recommend maintaining a healthy weight, they are mindful of the potential problems associated with a focus on weight. Their stories suggest that they might not introduce weight gain as an issue unless the young person's weight had exceeded what they would consider a healthy range.

The medical public narrative of a "healthy weight" has shaped societal attitudes to equate being overweight with being unhealthy. For example, headlines in a Norwegian newspaper read "Norwegians fear fat more than anything else," reporting on a public survey that identified obesity as the leading health problem, ahead of care for the elderly, cancer, psychiatry, and cardiovascular disease (Malterud & Ulriksen, 2010). Burns and Gavey (2004) refer to this as the "pathologization of the non-slender body" (p. 550). However, Danesky, Higgs and Morgan (2010) argue that the linkage between disease and obesity rests on a weak evidence base. Burns and Gavey concur, contending that public health messages construct obesity as a health problem of epidemic proportions and cite the literature that suggests that the relationship between obesity and ill health is putative. Therefore, the congruence between the "thin ideal," the "healthy weight" and the "self responsibility" public narratives may reflect a conflation between health and thinness. For example, Lupton (1995, cited in Burns & Gavey, 2004, p. 551) states that "a biomedical construction of fatness as unhealthy therefore feeds into existing cultural

values about the maintenance of health and the avoidance of illness as personal and moral responsibilities.”

Overweight people are lazy and undisciplined. The “thin ideal” and “healthy weight” narratives thrive in a climate of increasing obesity, as lifestyle changes, for example plentiful, calorie rich food and increasingly sedentary lifestyles, create an environment which Gracia-Arnaiz (2010) describes as “lipophobic and obesogenic” (p. 224). Schwartz (1986) concurs, noting that the same magazines that publish articles promoting diet and exercise also have pages with recipes for double-chocolate, double-layer cakes with icing. Despite this obesogenic environment, the overweight body has come to represent “laziness, weakness, unrestrained desire and deviance” (Burns & Gavey, 2004, p. 551). For example, in the New Zealand Herald, journalist and former Member of Parliament, Deborah Coddington (2012, January 29, NZ Herald) opines:

And I’m no academic, but here’s a simple question on choice. If fat people can say “no” to a brisk walk and a salad at lunchtime, then surely they can give the same answer to an invitation to Burger King?

Evidence for a complementary public narrative relating to stereotypes about overweight people, that “overweight people are lazy and undisciplined,” can also be found in the literature. For example, Robinson, Bacon and O’Reilly (1993) cite the continued documentation of negative attitudes toward overweight people in research studies, Crandall (1994) demonstrates an “ideology of blame” (p. 882) in attitudes toward overweight people, and that “fatism” has less “negative social desirability” (p. 882) than racism, and Schwartz, Vartanian, Nosek and Brownell (2006) found that whilst all weight groups demonstrated an anti-fat bias, people who were not overweight were also likely to attribute laziness and a lack of motivation to overweight people. Lupton (1996) concludes that there is a “cultural distaste” (p.137) for overweight people.

The “overweight people are lazy and undisciplined” public narrative was reflected in the stories of the young women. For example, Lexi shares her views on overweight people with diabetes:

Lexi (18 years): ‘Cos you know, this is going to sound horrible, you notice that, when you are in the diabetes waiting room, you know, they’re quite big(p). I sit there and

think “woooo, you know, what’s going on here?” (p) I try not to judge, but sometimes it’s difficult (p). I’ve been quite lucky so fingers crossed it stays that way.

Lexi prefaces her comments with “this is going to sound horrible” precluding her from being positioned as judgmental. She further mitigates the judgmental nature of her talk by referring to her own body shape as “lucky.” Her story suggests that she considers that overweight people have not made an effort to take care of themselves. Similarly, Sue comments:

Sue (16 years): I have personally never worried about my weight. But I do know some girls with diabetes that are bigger. But I don’t know, it reflects what they do. One girl I know of, she’s always in the 20s. And she does not do her injections when she should. And they have to reflect on themselves a bit. And I think people like that should have the hard – be reminded of what could happen to them. I think there needs to be a strong message “you’ve got to do that to avoid that.”

A strong thread of self-discipline runs through Sue’s story. She implies that weight problems are not inherent in having diabetes, but reflect a person’s behaviour, about which they make choices. Sue draws on the “self responsibility” public narrative, implying that self-discipline and taking care of oneself are moral behaviours. In this way, she positions herself as responsible and moral, and those who do not take care of themselves as irresponsible and immoral. This is congruent with the conclusion drawn from the findings of a qualitative analysis of Norwegian newspaper entries that obese people “who have only themselves to blame, are taking resources from innocent people who have behaved well” (Malterud & Ulriksen, 2010, p. 50).

Whilst Type 2 diabetes (T2D) results from a combination of insufficient insulin and insulin resistance, some of which may have a genetic component, a perfect storm of factors in the Western world, insufficient exercise, obesity, and a fatty, sugar-laden diet, have lead to an “epidemic” of T2D amongst young people. This has lead to a public perception that T2D is often associated with excess weight, lack of exercise and unhealthy diet. Such epidemics lead to the debate around obesity taking on the status of “moral panic” (Cohen, 2002, cited in Daneski, Higgs & Morgan, 2010, p. 739), as obesity threatens both the self, in terms of health outcomes, and society, in terms of cost to health services, and the pervasive “moral laxity” (Daneski et al., 2010, p. 739). The societal “moral panic” is reflected in the stories of some of the young women. For example, Sian comments:

Sian (16 years): Yeh, it's just like with all the publicity about type 2 diabetes, and how you can get it by eating heaps, being overweight and not exercising. Well, people just lump it all together. And when you say you have diabetes, people think it is because you haven't taken care of yourself, and that you are really lazy, and eaten lots of lollies. And it's not true.

Sian notes the conflation around the term “diabetes.” Whilst the aetiology of T2D can include lifestyle factors, there is no evidence that this is the case for T1D. Sian’s story is informed by the “self-responsibility” public narrative, as she resists being positioned as an overweight, lazy, overeater, and as at fault for contracting diabetes. Young women with T1D interviewed by Rasmussen et al. (2007) also commented on the public confusion between T1D and T2D, relating that they had feelings of frustration, anger, and of being judged as a result of the misconception.

In summary. The women’s stories describe the ways in which diabetes introduces challenges for them in terms of a predisposition to weight gain, altered eating patterns, and the complexity of integrating exercise into a diabetic regimen. This rhetorical work, which is often careful to position the young women as “normal,” at the same time positions them as having to work harder than non-diabetic young women. In this way, they are almost asking for an amendment to the public narratives around eating, body image and weight, acknowledging that conforming to such ideals is more difficult for them. Moreover, these young women are also buffeted by public narratives relating to “self-responsibility” and “healthy weight,” which are likely to be potentiated in this group by their frequent interactions with health professionals. Their stories, which include poor body image, insulin omission and internet diet pills, are congruent with the findings that young women may feel a need to identify as the subject in the “thin ideal” narrative. This may lead to complex feelings around weight and body image that can manifest as disturbed eating behaviours (Ahern et al., 2011; Juarascio et al., 2011). Moreover, Burns and Gavey (2004) contend that body dissatisfaction and eating disorders reflect the “glorification of slenderness” (p. 554) and the weight loss messages that young women are inundated with.

Chapter Overview

The functioning of public narratives can be thought of as a feedback loop; they are shaped by the culture that they exist within and they also shape the stories of individuals that live in that culture. Accordingly, not only do the stories of the health professionals and the young women reflect prevailing public narratives, they also serve to augment or resist them, and so shaping them for the future. The analysis identified the influence of three groups of public narratives, namely those that influence health behaviours, weight and body image related narratives, and narratives of the medical model.

The stories of the young women suggest that having diabetes with its concomitant regimen constitutes a barrier to being “normal,” which conflicts with their developmental task of adolescence and early adulthood of conforming to their peer group. Being “normal” is further undermined as the young people face censure, which is oftentimes misinformed, from lay people policing what they should and should not eat arising from the “diabetes diet” public narrative. The analysis suggests that the conflict between diabetes and being “normal” can become become wearisome; some of the young women engaged in behaviours that compromised their metabolic control, and two of the young women became so overwhelmed that they abandoned their regimen completely. In one case, this triggered a spiral into dangerous disturbed eating behaviour. However, many stories of non-compliance were juxtaposed with talk of healthy behaviours, reflecting the “self-responsibility” public narrative. The young women’s task of being “normal” was exacerbated by the prevailing weight and body image-related public narratives. Young non-diabetic women face pressure from competing motivations to enjoy their lifestyle and to be slim and attractive. This pressure is exacerbated by the prevailing interpretation of slim and attractive, which is to be thin. The public narrative of the “thin ideal” is conflated by congruent public narratives of the “healthy weight” and that “overweight people are lazy and undisciplined.” Like their peers, young women with T1D diabetes are influenced by these health behaviour and weight and body image related public narratives, which may culminate in body dissatisfaction.

With the exception of the diabetes diet, these public narratives operate to influence other young people. However, the influence of these narratives may be potentiated by their having a chronic illness which threatens their health and even their lives and by their increased exposure to medical discourses via their clinical relationships with health professionals. The expectations

that the young women have for their relationships with health professionals are fashioned by the state of flux between two competing medical model public narratives, “health professional as expert” and “health professionals as partner.” The stories of the young women suggest that they preferred relationships that were more collaborative, and the stories of the health professionals suggest that they understood this preference. However, whilst the stories of the health professionals suggests that they shape their messages in a collaborative way, oftentimes the message reflects the tenets of the biomedical model, positioning them as “experts.”

Chapter 10 – Discussion

Exploring the lived and clinical experiences of T1D, the stories of the young women suggest that T1D introduces a layer of challenges that their non-diabetic peers do not face. In particular, these challenges include fear for the future, struggling to be normal, and issues related to eating, body image and weight. Some of the young women successfully navigated these challenges, and others had more difficulties. The findings are congruent with the body of literature that associates living with diabetes with psychological and psychosocial stressors (see for example, Davidson et al., 2004; Hillege et al., 2011; Huus & Enskar, 2007; Kyngas & Barlow, 1995), which are often discordant with living a “normal” life. This discordance can be significant clinically. For example, behavioural and psychosocial management of young people with chronic conditions has been shown to be at least as important as medical management (Tielen, van Staa, Jedeloo, van Exel & Weimar, 2008). Some of the young women struggled with depression, and two of the women admitted to attempting to take their own life. Two of the young women’s stories told of their insulin omitting disturbed eating behaviour, and most of the young women had issues with eating, weight and body image.

A diagnosis of T1D is concomitant with the possibility of long-term complications associated with unstable metabolic control, including nephropathy, retinopathy, and neuropathy. The stories of the young women describe the unrelenting conflict between living in a way that is conducive to minimising the threat of complications and living a “normal” life. Most of the women had experienced unstable metabolic control, at least at some time, and many found this an ongoing struggle. Their stories of unstable control formed a continuum between compliance and non-compliance. Some of the young women were obeying the rules, and were frustrated and bewildered with the elusive nature of stable metabolic control. At the other end of the continuum, two young women had experienced a time when they were completely overwhelmed by living with diabetes, and abandoned their regimen completely. Both of these women needed corrective surgery to restore their eyesight after their insulin omission caused blindness, and one young woman nearly lost her life. However, the majority of the young women were generally following medical advice, but were engaging in regular lapses. Some young women were modifying their regimen to achieve balance in their lifestyle, congruent with the strategic non-compliance behaviours described by Campbell et al. (2003), and others were engaged in sporadic acts of rebellion against the restrictions that their diagnosis imposes on their lifestyle.

The young women who were engaging in lapses from their regimen could articulate the role that their choices had in their up and down glucose levels. Moreover, many of them indicated in their stories that they are cognisant that their behaviour might not seem rational to someone with little understanding of what living with diabetes entails. This may be important clinically, as young people may sometimes behave in ways that seem irrational to health professionals. As Crossley (2000) explains, mainstream approaches to health psychology are focussed on rational behaviours, and tend to underestimate the importance of other forces and emotions that may drive decisions about health-related behaviours. The factors underpinning compliance-related behaviours may be many and varied. For example, after forgetting, the next most common reason for not taking medication for HIV infected youth was not feeling like taking it and/or needing a break (MacDonell, Naar-King, Huszti & Belzer, 2013). Moreover, MacDonell et al. (2013) concluded that a higher number of barriers to adherence were associated with higher psychological distress. In the case of dietary lapses, Crossley suggests that they may not be about food, but represent an act of rebellion. In this study, the rhetorical work of the women when talking about their lapses tended to oscillate over three themes. Their unstable control was often linked to their concern for their future, with some young women noting that they have early indications of renal or eye damage. That young people engage in lapses despite the threat of serious complications perhaps reflects that many of the complications associated with diabetes are insidious. This may mean that in the context of the unrelenting nature of a diabetes regimen, the threat of complications may not seem as relevant as day to day concerns. This distant threat may mean that young people are more able to believe that “it won’t happen to me,” at least for some of the time. Their talk of fear of complications was often juxtaposed with stories of living with the hard taskmaster that is diabetes, which served to defend their choices and mitigate the risk that they be viewed as irresponsible. However, by engaging in negative talk about diabetes, the young women risked positioning themselves as “other.” This position would be in conflict with being “normal,” and the young women mitigated this risk by blending the diabetes is hard talk with diabetes is not so bad talk, reflecting the comments of Goffman (1990) “the chronically ill must bear their burden in ways that do not imply either that this burden is too heavy for them, or that bearing it makes them markedly different from the healthy” (p. 147).

The finding that many of the young women engaged in behaviours that might threaten their health despite being aware of the possible consequences is congruent with the literature on adolescent risk-taking. Steinberg (2008) describes risk taking in adolescence as a public health

problem, and notes that increasing health education measures have not resulted in a concomitant decrease in risk-taking behaviour in this group. Similarly, other authors suggest that increased knowledge about risks and consequences does not necessarily curb risk taking behaviour (Bishop, 2011; Schechter & Francis, 2010). Steinberg considers the neuroscientific research related to risk taking amongst young people, and notes that, whilst young people engage in these behaviours more often than their elders, they are at least as knowledgeable, logical, reality-based and accurate as their elders. What is different in the younger group, concludes Steinberg, is that puberty is associated with an increase in sensation-seeking combined with an increased attention to social information, which means that young people are more inclined to take risks, especially when in the presence of their peers. Steinberg concludes that, because risk –taking has a neurobiological basis, the most effective way of reducing adolescent risk taking is to reduce the opportunity for exposure to risk. Accordingly, he makes some practical suggestions, for example, increasing the price of cigarettes and alcohol, and increasing the driving age. However, it is not clear how reducing exposure to risk could be translated into promoting healthy behaviours amongst young people with T1D, as the increasing autonomy in this age-group means that they are moving away from the controls of their parents at the same time as the influence of peers is increasing. Accordingly, their exposure to risk is likely to be increasing. Moreover, having a chronic illness such as T1D may increase the likelihood of engaging in risky behaviours (Erickson et al., 2005). Adolescent risk-taking has been shown to be associated with depression (Huang, Lanza, Murphy & Hser, 2012), and there is evidence to suggest that young people with T1D may be at increased risk for depression (see for example Fay, 2012; Ferreiro et al., 2012; Jacobi et al., 2011). Erickson et al. (2005) suggest that, given the prevalence of emotional and behavioural problems amongst young people with chronic health conditions, access to and utilization of mental health services should be improved for this group. Similarly, Ross, Malthus, Berrett and Harvey (2009) note the greater risk of mental health issues and risk taking behaviours amongst young people with chronic health conditions, and describe the positive role that psychotherapy can play in the management of these conditions. Although accessing psychological services was outside the parameters of this study, some of the young women indicated that they would have liked help of this nature, and this is congruent with suggestions from the diabetes literature (see for example, Snoek, 2006).

Whilst many of the young women had not experienced significant weight gain associated with their diagnosis, many of their stories suggest that they are dissatisfied with their bodies, and/or perceive that eating for diabetes and managing insulin make weight control more of a

challenge for them than for their non-diabetic peers. Their talk reflected the maelstrom of a three-way struggle, comprising healthy eating for optimal management of diabetes, living a “normal” life, and eating and exercise for the thin ideal. These findings are congruent with the findings of Balfe (2008), who suggested that college students with T1D were engaged in “body projects,” and that the pursuit of one body project tends to undermine the work towards another. In this study, the analysis showed that the difficulty in balancing the struggle is underpinned by the overlapping, but mutually exclusive nature of the three goals. For example, eating for diabetes can undermine the pursuit of both a “normal” life and the thin ideal. Eating for diabetes may invoke feelings of being different in young people, because “healthy eating” for diabetes may not be synonymous with normal eating in this age group, and young people with diabetes may often be faced with the choice between compliance and eating foods that they perceive as part of a “normal” diet. Moreover, healthy food may not only be unappealing to this age group, but it is also a risk factor for marginalisation (Stead et al., 2011). Therefore, eating for optimal diabetes management may compromise being “normal” in two ways. Firstly, fitting in with the group may be more difficult if young people are required to restrict certain foods, limit alcohol, and eat at prescribed times. Engaging in behaviours that conflict with medical advice can be understood in the context that it may be rational for young people to behave in ways that consolidate one’s image with the group, even if those behaviours may be health-damaging (Stead et al., 2011). Secondly, choosing between compliance and restricting food perceived as part of an everyday diet may foster feelings of resentment toward diabetes, and a desire to be “normal.” For two of the young women, their resentment toward their diagnosis and regimen contributed to them being overwhelmed by diabetes, and invoked a trajectory of non-compliant behaviours that culminated in serious health complications.

Eating for diabetes may compromise eating and exercise for weight control, as regulating blood sugar levels may require consuming extra food, particularly when blood glucose is low or exercise is undertaken. Moreover the pursuit of the thin ideal may be futile for young women, diabetic and non-diabetic, because the perception of thin for aesthetic purposes is often at the lower end of the healthy range for body mass index (Ahern et al., 2011), rendering the thin ideal unrealistic for the majority of women. The societal interpretation of the ideal may be even more unobtainable for young women with T1D, who, on average have a higher body mass index than their non-diabetic peers (Bryden et al., 1999; Jones et al., 2000; Steel et al., 1989). The analysis identified public narratives that shape the stories that are told. In particular, the analysis identified a number of weight and body image related public narratives, namely the thin ideal,

the healthy weight, and overweight people are lazy and undisciplined. These public narratives overlap and interact, and may serve to intensify weight and body image issues for young women. The pursuit of the thin ideal might result in temptation to engage in unhealthy weight control practices (Howe et al., 2008; Neumark-Sztainer et al., 2006), and the ubiquity of some unhealthy weight control behaviours has led to them being described as normative amongst a non-diabetic population (Rodin et al., 1985). These issues may be particularly pertinent for young women with T1D, in whom several diabetes-related factors may predispose them to disturbed eating behaviour (Surgenor et al., 2002). Moreover, unhealthy weight control behaviours, for example, restriction and bingeing and purging, carry more risk for young women with T1D than their non-diabetic peers, placing pursuit of the thin ideal on a potential collision course with optimal health outcomes. Many of the young women were engaged in weight control behaviours that are considered healthy, for example exercise. However, they talked of the ways that diabetes made this harder or affected their metabolic control adversely. At the extreme end of weight control behaviours, two young women engaged in disturbed eating behaviours using insulin omission, and others engaged in other weight control behaviours that are potentially dangerous. For example, one young woman, who did not identify as overweight, bought “diet pills” over the internet, despite having read that they were contraindicated in diabetes. Interestingly, there were a small number of women, who did not identify as overweight, who were taking less insulin than they should or eating less often than they should, ostensibly for reasons other than weight control. Their motivation for these behaviours might be as stated, as, for example, avoiding hypoglycaemia has been noted as a powerful motivator for taking less insulin (Stotland, 2005). However, it is notable that the rhetorical work of these young women suggests that they were invested in being thin.

The clinical experience of T1D forms the interface between everyday life and the medical management of T1D. The young person’s perception of this interface is thought to permeate everyday life in terms of self-care (see for example, Kyngas et al., 1998). A body of literature is critical of the biomedical model, with its role of the health professional as expert, and focus on disease monitoring activities, suggesting that it does not suit the management of a chronic disease such as T1D (Davidson et al., 2004; Hernandez, 1995; Hillege, 2005; Murphy et al., 2011; Rasmussen et al., 2007; Wikblad, 1991). In this study, the stories of the health professionals suggest that they are mindful of the shortcomings of this model, and reflect their understanding that living with diabetes is hard for a young person. When working with young people, the health professionals indicate that they may modify messages about complications to

those that may be more relevant to the age group, they try to avoid pejorative language associated with metabolic control, and they attempt to negotiate goals with young people rather than simply interpreting results, issuing instructions and dispensing prescriptions. In this way, their stories reflect the concepts of dignity in healthcare and shared decision making, important tenets of a patient-centred care model (Robb & Seddon, 2006). However, the stories of some of the young women suggest that they perceive their clinical consultations to be biomedically oriented. For example, some of the young women told of times that the focus was on their metabolic control, and that they had felt chastised for raised HbA1c laboratory results. As a result, some young women reported feeling uncomfortable in their clinical relationships, with some relationships deteriorating to the point of dysfunction. Moreover, the stories of the health professionals indicate that their approach, whilst reflecting some of the principles of patient-centred care, represents a blended approach or a softening of the biomedical approach. The clinical experience public narratives, namely health professional as expert and health professional as partner are demonstrably in a state of flux for dominance. The findings reflect that, whilst especially for chronic care, a patient-centred model may culminate in enhanced patient satisfaction, and therefore improved outcomes, there are time constraints, as mentioned by some of the health professionals. These time constraints, coupled with the nature of diabetes management, which is complex, technical, and crucial for optimal health outcomes, means that there is a large amount of expert knowledge to be shared in a short period of time.

The blended model, or softening of the biomedical approach identified in the stories of the health professionals in this study is congruent with the suggestions in the literature that, whilst the patient-centred model might be considered ideal, the nature and structure of medicine might mean that aspects of the biomedical model are likely to pervade many clinical interactions. For example, it has been suggested that the nature of doctor-patient relationships is inherently asymmetrical (Pilnick & Dingwall, 2011), and therefore some argue that a patient-centred model remains an idealistic notion (Agledahl et al., 2010). For example, Agledahl et al. (2010) maintain that the ideal of patient autonomy is unrealistic as, in reality, patients' choices have already been whittled down by doctors to those that fit with health structures and other considerations. Elwyn, Gwyn, and Edwards (1999) concur, suggesting that shared decisions can only be made from a situation of "equipoise" (p. 437), that is, when options really *are* options, a situation which may be rare in clinical interactions. Congruent with the findings of Agledahl et al. and Elwyn et al., Robertson et al. (2011) suggest that whilst shared decision making might be considered ideal, in practice, it may be less collaborative than it seems. The discourse analysis of

interactions between Scottish general practitioners and their patients suggests that currently, shared decision making serves to maintain a biomedical, GP as expert approach. For example, they found that the doctor's talk relied on "persuasive rhetorical devices" (p. 85) such as pronoun deployment, joint remembering and three-part listing, which Robertson et al. describe as a "passing resemblance" (p. 91) to shared decision making. These findings are congruent with the stories of the health professionals. Their stories suggest that they work hard to involve the young people in their diabetes management. However, their interactions with young people are underpinned by their bottom line of achieving stable metabolic control. This may mean that, whilst they strive to accommodate the individual, their interactions are informed by a clear agenda. In this way, their approach resembles a hybrid model, incorporating tenets of both the biomedical and partnership models. However, some of the young women in this study do not describe their relationships with health professionals in this way. Their stories suggest that some of them had worked with health professionals that seemed authoritarian and patriarchal to them, reducing them to a submissive role in the relationship. Some of the situations that they describe are congruent with the suggestion that some health professionals resist information sharing (Cooper et al., 2003), maintaining the expert approach.

Talking about weight can be a sensitive issue, and this was evident in the stories of both the health professionals and the young women. Whilst the stories of some of the health professionals suggest that they ask scoping questions, such as "are you concerned about anything?" the stories from both groups suggest that weight, if talked about at all, tended to be talked about in a factual, medical way, rather than in terms of a discussion relating to body (dis)satisfaction. The conundrum facing the health professional is to consider whether to address weight gain if it occurs but is still within a healthy weight zone. Their stories suggest that they are mindful that talking about weight gain can be perceived as admonishment, and may introduce or exacerbate a risk for disturbed eating behaviour. However, by not addressing body dissatisfaction or weight gain health professionals risk missing an opportunity to mitigate the predisposing factors for disturbed eating behaviour. Notably, there is evidence to suggest that weight and shape concerns in females are associated with the onset of disturbed eating behaviour (Bryden et al., 1999; Olmsted et al., 2008), or unhealthy weight control behaviours (Howe et al., 2008; Neumark-Sztainer et al., 2002), and that weight gain and being overweight have been identified as predictive factors amongst the pathways of risk for disturbed eating behaviour in young women with T1D (Colton et al., 2009). The sensitivity identified around talking about weight and body image may reflect that health professionals believe that young

people might be reluctant to talk about their weight. This concern may be valid. However, in a study with adolescents in the general population, Cohen, Tanofsky-Kraff, Young-Hyman, and Yanovski (2005) found that 79% of overweight adolescents noted that their health professionals had discussed their weight with them, and 41% of overweight adolescents desired to discuss their weight. The authors conclude that health professionals and some adolescents may be willing to talk about weight, but a significant proportion of young people with weight problems may not be receptive. Accordingly, Cohen et al. suggest that health professionals may require more training regarding effective ways to talk about weight with teens.

The stories of both the young women and the health professionals suggest that health professionals, whilst being alert for signs of disturbed eating behaviour, only tend to investigate the possibility of disturbed eating behaviour if they are suspicious. A United Kingdom study by Tierney et al. (2008) found that the health professionals in their study were reluctant to initiate discussions about disturbed eating behaviour including insulin omission because (a) it might suggest insulin omission as a weight loss behaviour, (b) it might undermine rapport, (c) people might choose not to attend clinic, and (d) they felt young women were likely to deny the behaviours anyway. Unpacking these findings with the health professionals in this study, they share some, but not all of these concerns. Their responses suggest that when metabolic control is poor and they suspect insulin omission, they are confident to directly ask about it. The health professionals had little concern that by asking about the behaviour they might suggest the behaviour. They generally felt that young people are likely to discover the utility of manipulating insulin for weight control for themselves. However, they expressed concern that asking about insulin omission might damage rapport. That this can be a risk associated with asking was evident in the stories three of the young women, who told of their experience of feeling persecuted by these questions from their health professionals when they were not omitting insulin for weight loss. This is congruent with a story told to Hillege et al. (2011) by a young woman who was maintaining her insulin regimen and felt accused when she discovered that her endocrinologist had advised her paediatrician that she was not taking her insulin. As a result, she experienced a loss of trust in her endocrinologist. The health professionals in this study were also cognisant that asking about insulin omission might result in denial or a disengagement with medical services, concerns which are borne out in the story of Charlee, who engaged in elaborate evasive behaviours and disengaged with the diabetes service for years. However, unlike their UK counterparts, the health professionals in this study indicated that they have little compunction in asking if the young person is omitting insulin if they are suspicious.

None of the health professionals were utilising a screening test or routinely asking about insulin omission, and, whilst some acknowledged potential advantages in screening for disturbed eating behaviour, most had reservations. Generally, the health professionals indicated that they preferred an ad hoc approach, feeling their way, and initiating a discussion if they suspected disturbed eating behaviour. Basing whether or not to ask about disturbed eating behaviour only on the suspicion of disturbed eating behaviour raises two potential problems. Firstly, the signs of disturbed eating behaviour may be subtle, especially because metabolic control can be unstable in this age group in general (Engstrom et al., 1999; Grylli et al., 2004). These findings are congruent with the stories in this study that most of the young women had experienced unstable metabolic control, at least at some time. Secondly, disturbed eating behaviour may be ego-syntonic, and therefore not likely to be raised by the young person as a concern. Amongst the barriers to help seeking in women with Bulimia nervosa Hepworth and Paxton (2007) identified that shame, a low perception of need and a fear of change were important contributing factors. Notably, the women in the Hepworth and Paxton study demonstrated a lack of awareness that treatment may be available for their behaviours, and/or did not seek help for fear of weight gain that would be likely to be concomitant with successful treatment. The ego-syntonic nature of disturbed eating behaviour was evident in Charlee's story. Charlee denied and protected her disturbed eating behaviours in her pursuit of her goal of thinness, and she told of going to great lengths to foil the efforts of health professionals to find her out. She lied to and deceived health professionals, such was the importance of being thin to her at that time. What is not clear from her story is what may have transpired if her weight gain of 12 kilograms was addressed before her obsession took hold, and Charlee herself was unable to answer that hypothetical question. It is also not clear from Charlee's story when she was first asked about insulin omission, and whether she would have denied the behaviour if asked about it before it became entrenched. Because eating and weight issues may not be addressed until a medical problem becomes apparent, it has been recommended that health professionals should be both vigilant and pro-active in identifying eating disorders (Striegel-Moore & Franko, 2003). It is likely that this recommendation should extend to those working with a diabetic population (Colton et al., 2007; Goebel-Fabbri et al., 2008; Nash & Skinner, 2005; Olmsted et al., 2008).

By not addressing weight, the health professional fails to mitigate the risk associated with a raised body mass index (Colton et al., 2007). Howe et al. (2008) concur, but suggest that the risk of disturbed eating behaviour is present not just with raised body mass index but with a

perception of being overweight and/or body dissatisfaction. Because young women with these concerns are most at risk for unhealthy weight control behaviours, Howe et al. (2008) suggest that all children and adolescents with T1D should be asked about weight perception and weight satisfaction. If body image and weight concerns are not talked about and/or behaviours associated with the onset of disturbed eating behaviour are not identified, there is a window of opportunity to intervene before such behaviours become entrenched that is lost. This window of opportunity may be particularly important as the literature suggests that, whilst there is a dearth of research in the area of early intervention for eating disorders (Currin & Schmidt, 2005), there is some evidence to suggest that early intervention may improve outcomes in the general population (Deter & Herzog, 1994), and it is likely that this may also be true for young women with T1D and disturbed eating behaviour (d'Emden et al., 2012). In the general population, because individuals are not likely to seek help for eating-related problems, health professionals should screen for eating- and weight- related problems in youth with a wide variety of presentations (Wilfley, Vannucci, & White, 2010). There may be more opportunity for identification and intervention with a diabetic population, as this group may interact with health professionals on a regular basis, compared to their non-diabetic peers, who may only seek medical advice if they are unwell.

Limitations

There were several limitations of this study. As is often the case with qualitative research, this was a small study. The potential pool of participants was small (58 young women and 12 health professionals) and of this only 22.4% of the young women and 42.9% of health professionals invited to participate took up the opportunity. There is no information available about those young women with T1D who declined to participate, nor about young women who are not attending diabetes clinics, and were therefore not even part of the potential pool of participants. However, whilst it is unclear how representative the participants are of young women with T1D, a range of eating weight and body image issues was identified; some participants had few concerns, others were struggling with weight control or were unhappy with their bodies, and two young women presented with a history of insulin omitting disturbed eating behaviours. Amongst the health professionals, there were three doctors, one nurse and a dietician. Therefore, whilst the study was small and the participation rate limited, a diverse range of voices has been represented.

The data for analysis was obtained from semi-structured interviews. The broad nature of the questions was intended to invite the participant to tell of their experience with minimal intervention from the interviewer. Therefore, the responses to the broad questions often included information that related to other questions, and, as related areas emerged, detours were taken from the semi-structured interview. Conducting an interview in this way is likely to have contributed to the richness of the data obtained. However, there are always unanswered questions that emerge that could have been pursued at the time. For example, one of the findings in this research was that medically acceptable weight gain might not be talked about by some health professionals, and that weight tended to be talked about in medical terms. However, in retrospect, asking the health professionals more directly if they ever asked about body dissatisfaction and the barriers to (if any) and advantages of (if any) starting conversations of this nature even when there is no suspicion of eating pathology or weight gain would have been helpful. However, this only became apparent during the analysis when reviewing the transcripts for the ways in which the health professionals related that they talked about weight.

The data for analysis was based on self-report. Therefore these findings should be considered in the context that there are external and internal factors influencing the ways in which the young women and the health professionals told their stories. In this way, the stories should be viewed as possible narratives (Hyden, 1997). This means that, for example, there may be parts of stories left untold and the narrators may have positioned themselves in a particular way in their story. Whilst not made explicit in the analysis, the interpersonal influence on the analysis should be acknowledged. The analysis should be viewed in the context of the reflexive statement in Chapter 7. Qualitative analysis is not an objective exercise, and therefore cannot be value-free. The personal experience and views of the researcher provide a lens through which the experiences of the women and the health professionals are viewed. The choice of questions in the semi-structured interview, and the choices made by the interviewer to pursue some themes and not others directed the scope of the stories told. For example, the sensitivity of the researcher to issues relating to body image and weight control meant that she was not judgemental of those that struggled with discipline in their eating. In a subtle way, this shared experience may have encouraged those that engaged in this struggle to be more forthcoming and will have imbued this perspective into the research at every level, from the research questions to the analysis. Moreover, the attributes of the interviewer, including, age, sex, appearance and personal style, and her verbal and non-verbal responses are likely to have shaped the ways the

stories were told. Notably, two of the young women were interviewed with their mothers. Their presence is likely to have influenced the stories told in two ways. Firstly, it was noted that their mothers often answered questions for these young women, and the young women's stories then became a blend between the personal and the involved onlooker. Secondly, it is possible that their presence may have stifled some information that the young women may otherwise have shared.

Implications for Future Research

The findings in this research suggest that living with diabetes presents a range of psychological, psychosocial, and eating, weight and body image challenges for young women. The health professionals' stories indicate that they are mindful that living with diabetes is difficult for young women and they relate the ways in which they engage in clinical consultations in a collaborative manner, a softening of the biomedical model. However, reflecting the nature of diabetes management, their interactions are underpinned by the bottom line of helping the young person to achieve stable metabolic control, a goal which can be discordant with other areas of the young person's life. This bottom line was reflected in the stories of some of the young women, who described clinical relationships that they perceived were dominated by these biomedical goals. For a small group of young women, these perceptions lead to deterioration in their clinical relationships. Stable metabolic control is fundamental for optimal health outcomes in this group. However the findings of this research suggest that, for some young women at least, Wolpert and Anderson's (2001a) comment that the message can be "lost in translation" (p. 1301) remains pertinent. The challenge for future research is to consider ways that health professionals can engage with young people in a manner that is helpful in making diabetes a more comfortable fit with the rest of their lives. Some of the health professionals referred to time constraints that they faced. Therefore, it is unclear whether some of the difficulties reflect the wide gamut of issues that must be considered and discussed within a short consultation, or a discord that might be mitigated by further training of health professionals. However, some of the issues may relate to adjusting to a difficult and chronic condition, which may be beyond the scope of practice for diabetes clinicians. Accordingly, these findings add resonance to the literature suggesting that psychological services be integrated into diabetes care (Erickson et al., 2005; Ross et al., 2007; Snoek, 2006).

Some of the clinical relationships did not effectively manage issues relating to eating. For example, some of the young women chose not to disclose times when they may have eaten junk food. Seemingly, this may be to avoid the admonishment that they imagined might accompany such a disclosure. This may mean that, whilst health professionals indicated that they attempted to convey an accepting and non-judgmental style, the reality is that within the confines of promoting good metabolic control, the paradigms of eating in real life for young women and eating for stable metabolic control are not overlapping for many young women. Future research could consider the ways in which clinical relationships might manage this disconnect.

Perhaps reflecting the emphasis that health professionals place on rapport and the risk of introducing unhealthy cognitions about weight, some health professionals may not always address weight gain or talk about weight if it is within medically acceptable limits. The stories of the health professionals and the young women suggest that if weight was discussed, it was talked about in medical terms, rather than in terms of body (dis)satisfaction. Also perceived as a sensitive issue, the question of disturbed eating behaviour is not usually raised unless the health professional notes markers of these behaviours, usually unstable metabolic control or weight loss. Because unstable metabolic control is common amongst this age-group, this means that disturbed eating behaviour might remain undetected until these behaviours become more entrenched, compromising the opportunity for early detection and intervention. Accordingly, the analysis identified two areas of intervention, namely talking about weight gain and body dis(satisfaction), and talking about disturbed eating behaviour even when it is not suspected clinically.

However, it is not yet clear whether these interventions may be included in a positive way. The analysis of the women's stories suggest that these are two sensitive areas, and there is the potential that raising these topics within a relationship perceived as authoritarian may damage rapport. Many of the young women's stories suggest that they found being weighed or talking about weight uncomfortable. Moreover, for some of the young women, a focus on weight may have fuelled existing body image issues. The ways in which health professionals could choose to talk about weight gain and body (dis)satisfaction as part of a routine consultation are many and varied, and accordingly, an important avenue for future research is to consider the ways in which health professionals might start the conversation that minimise the risk to rapport and of introducing or exacerbating body image issues. This may include using a psycho-educational approach to talk about the possible impact of diabetes on weight and body image as

a way to provide an opening for young woman to talk about body (dis)satisfaction. Further, asking questions relating to body image and body satisfaction might present a softer less provocative approach, and conversations of this nature might unveil emerging eating pathology.

The analysis of the stories of both the health professionals and the young women suggests that asking about disturbed eating behaviours can be fraught with problems. In particular, the health professionals indicated that they consider good rapport to be important before asking such questions. The health professionals' concern that asking about insulin omission may undermine rapport was borne out in the stories of three of the young women, who felt accused when asked if they were engaging in this practice. However, two of these women described their clinical relationships with these health professionals as dysfunctional in general. Their stories suggest that their perception of the manner of these health professionals was patriarchal. Therefore, it remains unclear whether their aversion to being asked about insulin omission stemmed from the question itself, or whether it was underpinned by their perception of the inequality in the relationship. Other questions remain relating to what influence on the clinical relationship poor compliance and/or unstable metabolic control may exert. It was noted in a study of the relationship between self-care and the adolescents' perception of their health professionals, that the majority of those with good compliance described their physician as motivating, and the majority of those who described their physicians as routine/negligent had poor compliance (Kyngas et al., 1998). However, the directionality of these findings is not known. It may be that a positive perception of health professionals is motivating, or, conversely, that poor motivation engenders a negative perception of health professionals. Similarly, it is not clear from this study whether the young women who were upset when questioned about insulin omission and perceived their health professionals in a negative way, for example as "*pestering*" or "*we know what's best,*" were perhaps already frustrated or discouraged by the capricious nature of their metabolic control or struggling with compliance, and were therefore overly defensive or sensitive. Therefore, whilst the findings suggest that asking about insulin omission may present risks to rapport, it is not clear whether, if young women perceived that disturbed eating behaviours were screened for routinely in the context of good rapport, rather than because they were being accused of such behaviours, such questions might be perceived as less threatening and culminate in the disclosure of unhealthy weight control practices.

Accordingly, future research could consider the ways in which eating, weight, and body image might be talked about in clinical consultations. This may be by the use of direct screening

questions, the use of screening tools, or introducing conversations about body dissatisfaction.. As discussed above, the findings of this study were that asking directly about insulin omission could be problematic, suggesting that direct questioning may not be helpful clinically. The use of screening tools was discussed with health professionals and the young women. However, because screening tools were not being used, the participants could not draw on their experience to inform the discussion, and the hypothetical nature of these conversations meant that no conclusions could be made. Future research could pilot the introduction of screening tools to determine their clinical utility and the reactions of young women presented with a screening tool during a clinic visit. The largely untapped question emerging from this research is talking about body dissatisfaction. Body dissatisfaction is commonly associated with eating problems but it is not clear whether identifying body dissatisfaction might be useful in identifying emerging eating problems in a clinical setting. Future research could consider whether or not introducing these conversations is deleterious to clinical rapport and explore the nature of any disclosures. Specifically, it would be helpful to ascertain whether the young woman might have broached the issue as an area of concern for her had the health professional had not asked these questions, and whether their dissatisfaction was associated with weight control measures. In this way, it could be ascertained whether routinely talking about body dissatisfaction is clinically useful in identifying disturbed eating behaviours.

Conclusion

The findings from the analysis of the lived experience stories are congruent with the findings in the literature that having T1D may introduce or exacerbate a range of psychological, psychosocial, and eating, weight and body image issues for female adolescents and young women. Moreover, comparing the stories of the young women and the health professionals a paradigm clash was identified between the two partners in the clinical relationship, notably when talking about eating and metabolic control. Whilst health professionals describe the ways in which they attempt to move away from a biomedical model of diabetes care to one based on partnership, the analysis suggests that, for some young women, there is discordance between the messages that the young women are hearing and the ways in which they choose to live their lives. The implication for clinical practice is that this discordance may pervade the clinical relationship and potentially undermine self-care. This discordance may reflect the ways in which health professionals engage with young people, but it may also reflect that, irrespective of the

approach taken by the health professional, optimal diabetes management often conflicts with the tasks of being a young woman.

The analysis of the stories of both the health professionals and the young women established that there is a window of opportunity that could be exploited to identify potential antecedents of disturbed eating behaviours, namely weight gain and body dissatisfaction. By not routinely screening for disturbed eating behaviours, either by direct questioning or the use of a screening tool, there are two lost opportunities. Firstly, although the current literature is largely silent in this area, it may be that the likelihood of denial is less before the behaviours are entrenched. Secondly, early intervention may lead to improved outcomes and culminate in decreasing the risk of serious health complications associated with the behaviours. Starting the conversation about weight gain and body (dis)satisfaction may help to identify those at risk for disturbed eating behaviour, and by routinely screening for disturbed eating behaviour, there is potential to identify and treat such behaviours before they become entrenched.

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Appendix A

AN INVITATION TO PARTICIPATE IN A RESEARCH STUDY

Starting the Conversation about Eating and Body Image: The Clinical Experience of Young Women with Type 1 Diabetes.

If you are a 16-25 year old young woman with Type 1 Diabetes, I would like to invite you to participate in a study about your experience of Diabetes – in particular, eating, body image, weight, and your experience of talking about Diabetes-related issues with Health Professionals.

My name is Raewyn Barry, and I am conducting a study on what it is like to be a young woman with Type 1 Diabetes, and how that might relate to thoughts and feelings around eating, body image, and weight. The aim of the study is to investigate how health professionals and young women with Type 1 Diabetes can more easily begin the conversation about eating, body image and weight.

If you wish to take part in this study, you will be asked to attend an interview with me, which will take about an hour. At the end of the study, you can request a summary of the results.

An information sheet with more details about the study is included with this letter. If you would like to participate in the study, or have any questions, please complete the enclosed form and return it in the stamped, addressed envelope provided, and I will contact you to discuss any questions you may have. If you agree to participate, an interview will be arranged for a time that suits you.

A cell-phone top-up voucher (or equivalent gift) will be provided after your interview to thank you for your valuable input and time.

If you would like to participate in the study, or to find out more about it, please fill out the enclosed form and return it to me in the stamped, addressed envelope provided.

**Starting the Conversation about Eating and Body Image: The Clinical Experience of Young
Women with Type 1 Diabetes.
Female Adolescent.**

I am considering volunteering to participate in your study. I would like you to contact me to discuss it further

Name _____

Address

Contact Phone Number _____

Cell Phone Number _____

Appendix B

AN INVITATION TO PARTICIPATE IN A RESEARCH STUDY **Starting the Conversation about Eating and Body Image: The Clinical Experience of Young Women with Type 1 Diabetes.**

If you are a health professional working in Diabetes Care, I would like to invite you to participate in a study about your experience of working with young women with Type 1 Diabetes.

My name is Raewyn Barry, and I am conducting a study on the experience of health professionals working with young women with Type 1 Diabetes to achieve good health outcomes. The aim of the study is to investigate how health professionals and young women with Type 1 Diabetes can more easily begin the conversation about eating, body image and weight.

If you wish to take part in this study, you will be asked to attend an interview with me which will take about an hour. At the end of the study, you can request a summary of the results.

An information sheet with more details about the study is included with this letter. If you would like to participate in the study, or have any questions, please complete the enclosed form and return it in the stamped, addressed envelope provided, and I will contact you to discuss any questions you may have. If you agree to participate, an interview will be arranged for a time that suits you.

A cell-phone top-up voucher (or equivalent gift) will be provided after your interview to thank you for your valuable input and time.

If you would like to participate in the study, or to find out more about it, please fill out the enclosed form below and return it in the stamped, addressed envelope provided.

**Starting the Conversation about Eating and Body Image: The Clinical Experience of Young
Women with Type 1 Diabetes.
Health Professional**

I am considering volunteering and participating in your study. I would like you to contact me to discuss it further

Name _____

Address

Contact Phone Number _____

Cell Phone Number _____

Appendix C

Starting the Conversation about Eating and Body Image: The Clinical Experience of Young Women with Type 1 Diabetes.

Dear participant

Thank you for taking the time to consider this invitation to take part in this research project. My name is Raewyn Barry, and I am completing a Doctorate of Clinical Psychology at Massey University. As part of the requirements for this, I am completing a research project, investigating the experiences of eating, body-image, and weight, of young women, aged 16-20 years with Type 1 Diabetes, and their experiences with diabetes health professionals.

Currently, it is recommended that nurses, doctors, dieticians and patients should discuss healthy lifestyle factors for people with Type 1 Diabetes during visits to a diabetes clinic. However, health professionals are often reluctant to ask about body-image issues and weight management, and young women with Type 1 Diabetes are often reluctant to talk about them. This study aims to understand why this might be so, and how clinicians and patients can more easily start the conversation about body image and weight.

To take part in the study, you need to be female, aged 16-25 years, with Type 1 Diabetes. You also need to be a client of the Diabetes Lifestyle Centre.

If you decide to take part in the study, you will participate in an interview about your experiences of Type 1 Diabetes. The interview will be conducted at the Massey University Psychology Clinic, the Diabetes Lifestyle Centre, or one of the Diabetes Lifestyle Centre Outreach Clinics, at a time that is convenient for you. Family or whānau are welcome to attend with you. It will last approximately one hour, and will be digitally recorded so the interview can be transcribed. The questions will relate to eating, body-image, weight, and your experiences with Diabetes Health Professionals. You may choose not to answer any question, or to have the recorder turned off at any time. If you experience any emotional distress or discomfort as a result of our discussions, you may wish to contact the organisation listed on the following page.

A cell-phone top-up voucher (or equivalent gift) will be provided at the completion of your interview to thank you for your valuable input and time.

The interview will be transcribed by me, and you will be sent a copy of the transcript so you can edit it before the analysis begins. Transcripts can then be returned to me in the postage paid envelope supplied.

If the transcript is not returned within 3 weeks, I will assume that you are happy with it, and will proceed to analyse the data. At the end of the study, you will receive a summary of the findings.

All personal details including your name will remain confidential and stored separately from your interview data. Your identity will be known only to me. You can choose a pseudonym to use if you wish. All information will be kept on a password protected computer which is available only to my supervisors and myself. Data will be collated and analysed to identify themes and patterns.

Signed consent forms, recordings, and transcripts will be retained for a minimum of five years from the completion of the research, and will then be destroyed.

Rights of Participants:

There is no obligation to accept this invitation to participate. If you decide to participate, you have the right to:

- Decline to answer any particular question.
- Withdraw from the study at any time. You do not have to give a reason for withdrawal.
- Ask any questions about the study at any time, during and after participation.
- Provide information on the understanding that your name will not be used.
- Be given a summary of the project findings when it is concluded.
- Ask for the audio recorder to be turned off at any time during the interview.

If you have any questions about the research project, please contact me or my primary supervisors, Joanne Taylor and Christine Stephens.

If you experience any distress as a result of the questions in the interview, or if issues arise that you wish to talk further about, you can contact :

Helen Snell, Diabetes Service Nurse Leader.

Diabetes Lifestyle Centre, Midcentral Health,

Ph 06 350 8114,

Helen is available for help and advice, and, if needed, can refer you to the Health Conditions Service at Massey University Psychology Clinic.

This research project has received ethical approval from the National Health and Disability Ethics Committee (Central):

Central Regional Ethics Committee

C/- Ministry of Health

2nd Floor, 1-3 The Terrace

PO Box 5013

Wellington

central_ethicscommittee@moh.govt.nz

If you have any queries about your rights should you decide to participate in this research project, you are able to contact the Health and Disability Advocate : Ph 0800 42 36 38 (4ADNET)

I appreciate you taking the time to consider your participation in this research project.

Yours sincerely

Raewyn Barry

Principal Researcher

Contact number : 06 845 0123

Supervisor: Joanne Taylor

Contact number: 06 356 9099 extn 2065

Supervisor: Christine Stephens

Contact number: 06 356 9099 extn 2081

Supervisor: Cheryl Woolley

Contact number: 06 356 9099 extn 2076

Supervisor: Maria Berrett

Contact number: 06 356 9099 extn 5196

Appendix D

Starting the Conversation about Eating and Body Image: The Clinical Experience of Young Women with Type 1 Diabetes.

Dear participant

Thank you for taking the time to consider this invitation to take part in this research project. My name is Raewyn Barry, and I am completing a Doctorate of Clinical Psychology at Massey University. As part of the requirements for this, I am completing a research project, investigating the clinical experience of young women, aged 16-20 years with Type 1 Diabetes and how that may relate to talking about eating, body-image and weight.

Currently it is recommended that nurses, doctors, dieticians and patients discuss healthy lifestyle factors for people with Type 1 Diabetes. However, health professionals are often be reluctant to ask about body-image issues and weight management, and young women with Type 1 Diabetes are often reluctant to talk about them. This study aims to understand why this might be so, and how clinicians and patients can more easily begin the conversation about body image and weight.

To take part in the study, you need to be a health professional working at the Diabetes Lifestyle Centre, Midcentral Health.

If you decide to take part in the study you will participate in an interview about your experiences of talking to young women with Type 1 Diabetes. The interview will be conducted in a private room at the Massey University Psychology Clinic, the Diabetes Lifestyle Centre, or at a Diabetes Lifestyle Centre Outreach Clinic. It will last approximately one hour, and will be digitally recorded so the interview can be transcribed. The questions asked will be related to your experiences of, and thoughts on, talking to young women with Type 1 Diabetes about body-image and weight. You may choose not to answer any question, or to have the recorder turned off at any time.

A cell-phone top-up voucher (or equivalent gift) will be provided after your interview to thank you for your valuable input and time.

The interview will be transcribed by me, and you will be sent a copy of the transcript so you can edit it before the analysis begins. Transcripts can then be returned to me in the postage paid envelope supplied. If the transcripts are not returned to me within 3 weeks, I will assume that you are happy with it, and will proceed to analyse the data. At the end of the study, you will receive a summary of the findings.

All personal details including your name will remain confidential and stored separately from your interview data. Your identity will be known only to me. You can choose a pseudonym to use if you wish. All information will be kept on a password protected computer which is available only to my supervisors and myself. Data will be collated and analysed to identify themes and patterns.

Signed consent forms, recordings, and transcripts will be retained for a minimum of five years from the completion of the research, and will then be destroyed.

Rights of Participants:

There is no obligation to accept this invitation to participate. If you decide to participate, you have the right to:

- Decline to answer any particular question.
- Withdraw from the study at any time. You do not have to give a reason for withdrawal.
- Ask any questions about the study at any time, during and after participation.
- Provide information on the understanding that your name will not be used.
- Be given a summary of the project findings when it is concluded.
- Ask for the audio recorder to be turned off at any time during the interview.

If you have any questions about the research project, please contact me or my primary supervisors, Joanne Taylor and Christine Stephens.

This research project has received ethical approval from the National Health and Disability Ethics Committee (Central):

Central Regional Ethics Committee

C/- Ministry of Health

2nd Floor, 1-3 The Terrace

PO Box 5013

Wellington

central_ethicscommittee@moh.govt.nz

If you have any queries about your rights should you decide to participate in this research project, you are able to contact the Health and Disability Advocate : Ph 0800 42 36 38 (4ADNET)

I appreciate you taking the time to consider your participation in this research project.

Yours sincerely

Raewyn Barry
Principal Researcher
Contact number : 06 845 0123

Supervisor: Joanne Taylor
Contact number: 06 356 9099 extn 0065

Supervisor: Christine Stephens
Contact number: 06 356 9099 extn 2081

Supervisor: Cheryl Woolley
Contact number: 06 356 9099 extn 2076

Supervisor: Maria Berrett
Contact number: 06 356 9099 extn 5196

Appendix E

Starting the conversation about Body Image issues: The Clinical Experience of Young Women with Type 1 Diabetes. Participant Consent Form.

I have read the Information Sheet, and had the details of the study explained to me. My questions have been answered to my satisfaction, and I understand that I may ask further questions at any time.

I agree/do not agree to the interview being sound recorded.

I wish/do not wish to have a summary of findings sent to me at the end of the study.

I agree to participate in this study under the conditions set out in the Information Sheet.

Signature: _____ Date: _____

Full Name – printed: _____

Appendix F

Starting the conversation about Body Image issues: The Clinical Experience of Young Women with Type 1 Diabetes.

Dear

Thank you for agreeing to participate in my research. I have enclosed a transcript of the interview, and a voucher for a cell phone top-up to compensate you for your time. Can you please return this form in the freepost envelope, so that I can be sure that you have received the transcript and cell phone voucher.

The interview will be used to analyse any themes, or ideas that that come out of the research. Any reference to the interview in the final write-up will be made using a pseudonym, so that you cannot be identified.

I confirm that I have had the opportunity to read and amend the transcript of the interview conducted with me.

I agree that the edited transcript and extracts from this may be used in reports and publications arising from the research.

Signature: _____ Date: _____

Full Name – printed: _____

Appendix G

Interview Schedule – young women with T1D.

Tell me what having diabetes is like for you

- How long have you had diabetes?

What does diabetes mean for you in terms of your weight and body shape?

What kinds of things can young women with diabetes do to control their weight?

- Have you ever done any of these?
- How did you find out about them?

Tell me what happens when you visit the diabetes clinic.

- What is that like for you?
 - Are you weighed? When you think about that, how do you feel?
 - How are lab results like HbA1c reported to you? When you consider that how do you feel?
- How would you describe your relationship with your Doctor/Nurse/Dietician?

Have you ever been asked about eating problems and weight control as part of your clinic visit?

How did the Health Professional ask you?

- When you think about that, how do you feel?
- If you think about being asked to fill in a screening questionnaire about eating problems – DEPS – how do you think you would respond?
- If you consider a health professional warning about the long-term consequences of eating problems – how do you think you would react to that?
- A health professional might ask you how you feel about your weight and shape. If you consider that, do you think that would be likely to help you talk about any eating problems?
- Under what circumstances might you talk about eating problems?
- How would you advise a health professional to start the conversation about eating problems and weight control?

Can you please give me some feedback on this interview? Is there anything else I should have asked you?

Appendix H

Health professional Interview Schedule

Tell me about your experience of working with adolescent females with T1D?

In your experience, what impact does T1D have on the lives of these girls?

What impact does T1D have on weight?

What impact does T1D have on body image?

What impact does T1D have on their eating?

Tell me how you talk about weight in your appointments with female adolescents with T1D?

Tell me how you talk about lab results?

What comes to mind when I ask about Disturbed Eating Behaviours?

What do you estimate the prevalence of DEB to be amongst female adolescents with T1D that you see?

Tell me what you believe the impact of DEB is on the long term health of these girls?

Is DEB something you ask about with your clients? What might prompt you to ask?

How do you ask?

What barriers are there to asking?

Should DEB be routinely screened for as part of a clinic visit for female adolescents?

Do you think screening might result in some girls avoiding their clinic appointments?

Do you think it would adversely affect rapport?

Do you think the girls would disclose DEB?

Do you worry that asking about insulin omission might suggest the weight control method to them?

There are different ways of beginning a conversation about DEB. Tell me what you think of the use of a screening questionnaire – DEPS

Are there other ways of asking about DEB that you have thought about or tried?

Is there anything I haven't asked you?